

thebulletin

The official magazine of The British Polio Fellowship

WINTER 2018



Christmas cards going down a snow-storm.



Lady Massie honoured.



Twenty Minutes With Colin Powell, Rotary Liaison Ambassador.

... and much, much more!



dorset
orthopaedic

**“I love
adventures.
I want to see
the world.”**

Christin, Incomplete Paraplegia

Introducing C-Brace®: an innovative system that gives you the freedom to participate in daily activities and walk with confidence.

For Christin, it has proved life-changing.

Dorset Orthopaedic is proud to provide a full range of orthotic solutions.

www.dorset-ortho.com/orthotics

0800 433 2239



STRIVE FOR BETTER.

Partner of Clinical Services Network

ottobock.

The British Polio Fellowship

The British Polio Fellowship, The Xchange, Wilmington Close
Watford. WD18 0FQ
Freephone: 0800 043 1935
Email: info@britishpolio.org.uk
Website: www.britishpolio.org.uk

National Officers

Chairman: David Mitchell
Vice Chairman: Gwenda Cope
Treasurer: Aidan Linton-Smith

Trustees

Bosik Gharapetian;
Andy Mack; Archie Leyden;
Andy Gilliland; Christine Lumb

Patrons

Dr Moira Anderson OBE
Michael Cassidy CBE
Hannah Gordon
Baroness Fookes of Plymouth,
DBE, DL
Julian P Harriss, BSc, MSc,
MD, FRCP (Can)
Rehman Chishti MP
Alex Neil MSP

Lionel Blair
Dr Robin Luff, MBBS, FRCP, FRCS, BSc
Joe Fisher MBE
Professor Steve Sturman, MCh,
FRCP, UBH
The Countess of Verulam
Jonathan Cavendish
Richard Scudamore
Mark Isherwood AM

Ambassadors

James Crisp; Julia Roberts; Anne Wafula-Strike MBE; Professor
Gareth Williams; Rotary Liaison Ambassador, Colin Powell.

**Content, Design and
Production:** BeyondPR.co.uk

Editor: Jon Gardner

Head of Content: Spencer Bailey

Contributors: Jane Sherwin; Julie Woodhouse

Email: thebulletin@beyondpr.co.uk

beyondpr®

Publisher: The British Polio Fellowship

AN INVITATION TO JOIN US. It costs just £40 to become a life member of The Fellowship. As a member you receive *the bulletin* five times a year and can join your local Branch or Group. If you would like to know more about us before making up your mind please contact Central Office (details above).

EDITORIAL POLICY. Apologies if your article has not appeared in this edition, has been edited or shortened. Pressure of space and competing priorities means we cannot always publish everything that is supplied; however we do endeavour to let people know if their submission is not published for any reason. (See below for full editorial policy.)

The British Polio Fellowship is a registered charity in England and Wales (1108335) and in Scotland (SC038863). A company limited by guarantee and registered in England and Wales No 5294321. The Fellowship reserves the right to edit articles and letters submitted. The views expressed in *the bulletin* are not necessarily those of The Fellowship.

Publication of an advertisement does not imply that approval has been given to goods and services.

the bulletin, which comes out five times a year, is the official magazine of The British Polio Fellowship, and distributed free to members (circ. 9,000). Cost for non-members is £2.50 (annual subscription £15.00). Please send cheque/postal orders to Central Office at above address.

Articles, letters, news items, photographs are welcome and will be published at the discretion of the editor. The publishers, authors and printers cannot accept liability for errors or omissions. Any transparencies, prints or artwork will be accepted at owner's risk. All rights reserved. No part of this publication may be reported in any form without written permission of the copyright holder and publisher.

CONTACTS:

**Acting Operations Manager
Marketing and Campaigns;
Website; National Indoor Games**
Kripen Dhrona. Tel: 01923 281 099
kripen@britishpolio.org.uk

**Support Services Team
Disability Benefits; Information and Advice;
all membership issues and enquiries**
Zahida Osman and Vijitha Nathan
Tel: 0800 043 1935
info@britishpolio.org.uk

Trusts/Fundraising
Diane Ware. Tel: 01923 281 091
diane@britishpolio.org.uk

**Fundraising Administration, In Memoriam,
Donations and Merchandise**
Linda Davis. Tel: 01923 281 091
linda@britishpolio.org.uk

Finance and Office Manager
Dawn Grafetsberger. Tel: 01923 281 092
dawn@britishpolio.org.uk

Online Forum Members & Guests
forum.britishpolio.org.uk

**BPF Trading Ltd.
Manager**
Ahmad Butt. Tel: 01923 281 093
ahmad@britishpolio.org.uk

Central Office

Telephone lines open for
member enquiries
Monday – Friday 10.00am – 3.00pm

STOP PRESS

Copies of the Annual Report for 2017
are available now from Central Office.
Contact Kripen Dhrona for details.

The British Polio Fellowship would like to offer special thanks to The Premier League, whose Charitable Fund kindly supports the significant ongoing production costs of *the bulletin*.



Supported by
**Premier
League**

Contents

News from Central Office	P4
Fundraising news	P36
Support Services	P39
International news	P43
Mobility Matters	P44
Members' letters and views	P46
Branch and Regional news	P52
My Way	P68
History Corner	P70

Message from the National Chairman



Welcome to the Winter issue of *the bulletin*. It is literally just a few weeks since I wrote the message for the last issue and here we are in early November looking at the reality of Christmas on the horizon. The deadlines come thick and fast. If you do have news to share, send it into thebulletin@beyondpr.co.uk as soon as you can. There is even more than usual to share with members in this issue, including the comprehensive AGM report; another Twenty Minutes With; plus the Heating Grant information. So let's make a start!

AGM

I am writing this fresh back from a very lively and well attended meeting at Ellesmere Port in September. On behalf of my fellow Trustees, I would like to thank all those members who made the effort to come along. We were delighted to welcome Lady Maureen Massie to accept the Barbara Wood Award on behalf of her late husband, Sir Bert Massie. 2018 has been a year of change in many respects, so this was an important AGM for the charity and indeed the wider membership. I will say no more here, but the full roundup starts on page eight.

STOP PRESS

Many thanks to all who have already purchased our wonderful Christmas cards. These are going down so well that we've had to re-stock. Hence it's not too late to order/place another order and you will be helping the Fellowship enormously by using our Christmas cards.

PLEASE FIND ENCLOSED YOUR RAFFLE TICKETS – YOU'VE GOT TO BE IN IT TO WIN IT!

Christmas cards

The festive season is now fast approaching, so this is your last chance to secure some of our superb Christmas cards. The Trustees are doing all they can to promote the Christmas cards and we thank all those who bought them at the Ellesmere Port AGM. Full details and the order form can be found on page nine.

Heating Grant

Following Andy Mack's Winter Warmth Appeal in the Autumn issue, anyone wishing to apply for a Heating Grant can find the form on pages 39 – 40. If you are planning to apply, please remember that completed application forms must be received by Central Office no later than Friday 7 December, or they may not be considered.

There has been an exceptional response to the appeal this year (over £8,000 and counting!) and there is still time to donate. If you wish to do so, please complete the form on page 36 of the Autumn issue. Thank you to everyone who has contributed and for all your wonderful support.

Travel, parking and pavement problems for people with disabilities

A growing campaign (backed by a letter to The Times from 20 leading disability charities), has been launched. It asks the Government to take immediate action to extend the ban on pavement parking (London only), to the rest of the UK. There has also been much activity regarding the abuse of the 'Blue Badge' scheme. There has been much pressure on large retailers to enforce the 'Baywatch' campaign, and more shocking details have emerged of further problems with rail travel; this has all added fuel to the debate.

I recently witnessed frantic attempts, at Warrington Central Station, to try to get a mobility scooter onto a packed train to Manchester. Good sense and quick thinking prevailed however, as station staff managed to arrange (and pay) for specialised transport – a remarkable result. If you, our members, experience difficulties, go on the offensive and publicise your treatment. Remember that some of our colleagues are still working and use buses and trains to get to their places of work.

Indoor Games update

By the time you receive this copy of *the bulletin*, most of the Branch and Regional heats will have been held,

involving over 1,000 members. Congratulations to all who have qualified, I look forward to welcoming you to the Leicester Marriott from 15 – 16 March 2019.

I wish you all the very best of luck. To those who were not so successful, commiserations, but thank you for taking part and supporting the Games Committee's sterling efforts.

A valid and welcome question was asked at the AGM as to what value the Indoor Games brought to the members and The British Polio Fellowship. The passionate answers from the room were overwhelming.

80 Years of The British Polio Fellowship

On Tuesday 29 January, The British Polio Fellowship will be 80 years old. We came into being on the cusp of significant changes in Europe, and indeed on the eve of World War II. As we reach 80 years old, we are preparing to exit the European Union; it is almost as if things have come full circle. In some ways, things do not seem to have changed. See pages 24 – 25.

Richard Flint Awards

As reported in the Autumn issue, we received a good number of high standard entries this year and it is always nice to involve members who are perhaps housebound. Prizes totalling £1,425 were paid out to winners from the award fund. Details of all the winners are on page eight. How about having a go next year – it can be fun (and rewarding!).

And finally ...

We will do this all again when *the bulletin* returns for the New Year Issue 2019. The copy deadline has been extended to Monday 17 December 2018. The New Year issue is due to be posted to members in early February.

During these difficult times, I would thank all members and Regional, Branch and Group officers for their wonderful efforts in the field.

On behalf of my fellow Trustees and all the staff at Central Office, I would like to wish all our members a very happy Christmas and an even happier and healthier New Year as we approach our 80th birthday celebrations in January.

Yours in true Fellowship

David Mitchell
National Chairman

AGM's Port of call



The British Polio Fellowship's 2018 AGM held at the Holiday Inn, Ellesmere Port, Cheshire, was a lively affair; attended by 69 members (including six Trustees), three staff and four guests.

National Chairman, David Mitchell, paid tribute to all who had managed to attend and we remembered all those who are ill, housebound, elderly and perhaps lonely. Some magnificent work is carried out by Branches and Regions in contacting their local members and giving comfort and friendship.

Poor social care is a ticking time bomb threatening us all (the average of the membership is now 76), and to set up a national system of outreach workers would just cost a fortune; we simply don't have the funds. We now have 7,132 members, 10 Regions (including Northern Ireland), 35 Branches and 10 Groups – all kept going by volunteers – bless you.

Tribute was paid to our current staff who have been magnificent whilst the Trustees have dealt with the huge problems we are experiencing. An update on staffing can be found on page 35. These were alluded to in the Summer and Autumn **bulletins** and highlighted at the AGM by National Treasurer, Aidan Linton-Smith. We must have a guaranteed income stream and Trustees are considering an annual membership subscription. This issue was voted for at the AGM with a resounding majority (7:1). Our Fundraising Officer has a list of over 600 Trusts on her database; despite her valiant efforts, our applications are being constantly rejected.

We valued suggestions from the floor, but many were impractical. The Trustees are operating under the scrutiny of the Charity Commission to ensure stability and of The British Polio Fellowship. The big news, that created some of the stormy proceedings, was that our Central Office in Watford had just been put on the market the week prior to the AGM. Its purchase in 2015 had always caused adverse comment, but with our much-reduced income (mainly legacies), and our diminished staffing levels, we can no longer afford it. Members were reminded that we do not receive any Government funding whatsoever. It is you, the members, who are keeping us going with your voluntary donations; fundraising; the raffle; our Christmas cards; the heating appeal; the holiday fund; in memoriam; sponsored events and a host of other activities – you are stars.

A question was asked as to the value of the Indoor Games. The gentleman who asked was left in no doubt as to the feeling of the room but, again, it was emphasised that any event must cover its cost.

The fate and future of the Burnham bungalow is contentious. Vice Chair, Gwenda Cope (a very experienced housing association specialist), referred to recent professional reports commissioned by the Board. These suggest that a combination of repairs and refurbishments to both make the building structurally sound - and bring it in line with health and safety law - could amount to as much as £70,000 excluding VAT. Questions came about a printing error in the accounts. There is now an amendment sheet. The accounts on Companies House stay as they are (submitted by the auditors), but those sent to the Charity

Commission, OSCR and HMRC are correct. If anyone reading this requires a copy of the Annual Report (sponsored by Charles Stanley & Co, our Investment Managers), please contact Kripen at Central Office. Those present were dismayed to learn of the dire finances of The British Polio Fellowship and the report of the National Treasurer explains the situation.

Report from National Treasurer, AGM September 2018

Friends and fellow members of The British Polio Fellowship:

This is the seventh report I have presented to you as your National Treasurer, and my first, since returning to the Board in 2016. In preparing for this presentation, I looked over my notes from previous years. In so many ways, the world has changed. In September 2010, I reported that our total income for the year was £1.3m, of which legacies amounted to the major share, at over £800,000. I also reported that Central Office spending for the year was £900,000. I expressed some disappointment at the declining level of legacies and emphasised the need to tighten our belts. Eight years on, I am afraid to report that we live in a very different, much starker financial climate. Austerity has reduced the funding and support we and other charities get from Government. A number of our members have also seen their welfare benefits reduce. As our membership gradually and gracefully grows older, the demand for our services increases. And yet, legacy funding, at one time our mainstay, has reduced year on year on year.

In 2017, we received a total legacy income of £325,000, a reduction of £260,000 on the previous year, and some half a million pounds less than we received in 2009. The much anticipated BBC broadcast, whilst a highly professional piece of work, did not generate anything like the return we had hoped. Neither did the publicity from the wonderful film *Breathe*. In overall terms, income was over £300,000 lower than the year before. Balances have reduced from £2.7m to £2.2m. Sadly, this trend looks set to continue in 2018. We can all speculate as to why income is reducing. The poor publicity generated by Oxfam and other international scandals, along with the terrible reputation of Charity Muggers (aka Chuggers) must be a part of this. The British Polio Fellowship has never, and will never, engage in these activities. But there is more. As National Treasurer, I have to say to you that as a Fellowship, we have made mistakes in

past years. We did not make difficult decisions when they were necessary, and we did not see the looming crisis in terms of our reduced level of income. Some in the Fellowship may have felt that, like Mr Micawber in Dickens' classic, *David Copperfield*, "Something will turn up". I have to tell you now, that is no way to plan for a future. As you can imagine, this has been a difficult year to be National Treasurer, and indeed a difficult year for all the Trustees. We have now however recognised the need to act. Unpalatable decisions have to be made, and this process is already well underway. You may be aware of the changes that we have made to the structure of the organisation over the last nine months, and indeed, David has said more about this in his speech. We are also in the process of renegotiating all our major contracts and looking again at how we can most effectively use our property base. We decided, after looking long and hard at the stark choices that face us, to put our own Central Office at Watford on the market the week prior to the AGM. We have already had a potential buyer looking at our premises with the estate agent. We are also seeking to generate new sources of income, including through the new wholly owned Trading Company, and to reduce all unnecessary expenditure. We will continue to keep you updated as these plans progress. [▶](#)



AGM's Port of call ... continued

By the start of 2019, The British Polio Fellowship will look very different to what it did 12 months ago. Our staffing complement will have reduced by over half. Our focus will have moved away from awareness raising of PPS and towards direct support for you, our members. Our small core of remaining staff is a superb group. As David has already done, I should like to offer my thanks to them all. In particular, as Treasurer, the support which Dawn, as Finance Manager, has given me is immense. We are truly fortunate to have such a wonderful group of remaining employees. In conclusion, this has been one of the toughest years for The British Polio Fellowship that I can ever remember. And believe me; I have been in The British Polio Fellowship for a long time! The road ahead may continue to be rocky, but we now have a plan in place which we are already delivering. The restructure has taken place, new contracts are ready to be negotiated and the sale of our property is underway. This will take time, but I look forward to the day when I can report to you on our return to financial health. I should like to thank you, our loyal members, for all your support. As David would say, we proceed together, in Fellowship.

Aidan Linton-Smith
National Treasurer

Richard Flint and Barbara Wood Awards

A very pleasant part of the proceedings was the awards presentations. Full details of the Richard Flint winners are given below. Paul Oulton of the Merseyside Branch was on hand to receive his photography award and he also kindly took photos of the day for us. As always, the 1st prize winners walked away with £250, while £150 went to those in 2nd place and our 3rd place winners claimed £75. Congratulations and thanks to all who took part. There were 60 entries received for which we thank you. The usual varied, interesting and high standard of submissions reflects the skills, talents and ideas of our members; this is an annual feature, which may in fact favour those who are limited in their mobility. The full list of winners is as follows above right:

Poetry

- 1st** Kathryn Hobson, 'Bodywise' (Stockton on Tees)
2nd Janet Jones, 'Poem' (Rose Green) (Bognor Regis)
3rd Diana Marshall, 'Revelation' (Ferring, West Sussex)

Photography

- 1st** Violet Roe (Crieff)
2nd Beverly Gull, 'Where shall I run' (Oxfordshire)
3rd Paul Oulton, 'Christmas Truce Football' (Liverpool)

Art

- 1st** Diana Marshall, 'Painting' (Ferring, West Sussex)
2nd Betty Brown, 'Painting' (Scratby, Norfolk)
3rd Beverley Gull, 'Teapot' Barge Art (Oxfordshire) ▶



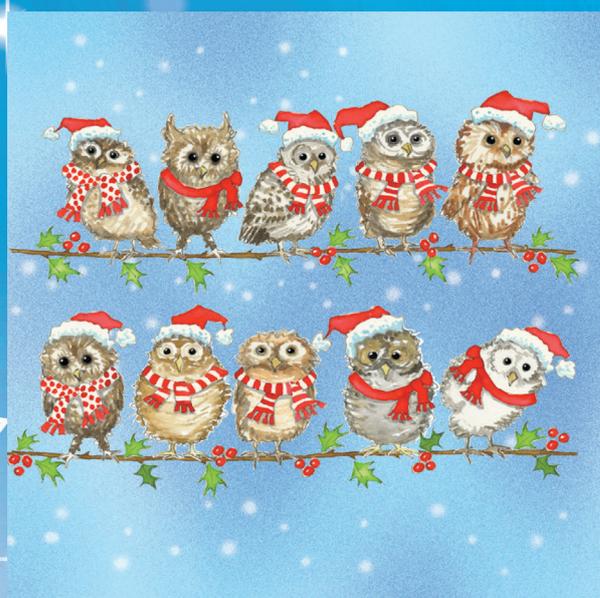
Christmas Cards 2018

Pack of 10 cards single design. Size 128mm square – £4.15 per pack.



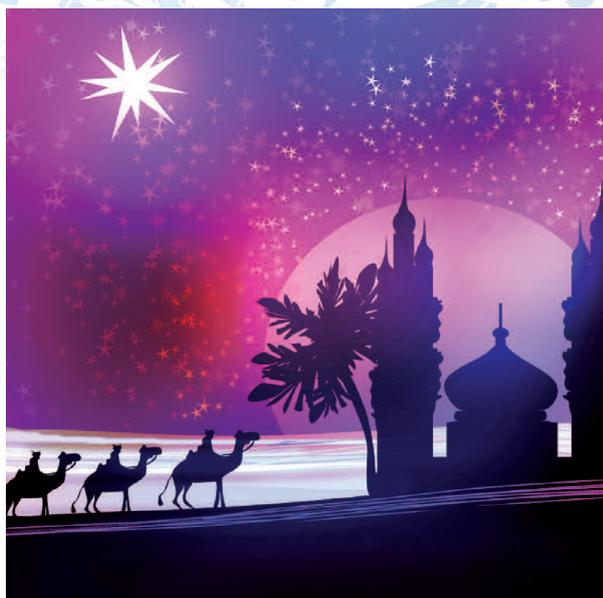
All Spruced Up

Greeting is: With Best Wishes for Christmas and the New Year.



Christmas Hoot

Greeting is: Season's Greetings.



Shining Star

Greeting is: Season's Greetings.



Snowy Robin

Greeting is: Merry Christmas and a Happy New Year.

AGM's Port of call ... continued



Pictured: (L-R) Andy Gilliland; Lady Maureen Massie; Gwenda Cope; and David Mitchell.

Barbara Wood Award

The next award was in honour of the late Barbara Wood and it was fitting that the two nominated recipients were both from the North West. The 'non-Polio' award went to Steve McCarthy, who – inspired by his late wife Lin, organised the local Regional games team (national winners for the last two years). The 'Polio' award was given this year posthumously to the late, great, Sir Bert Massie. A British Polio Fellowship member for countless years, he led a remarkable life and was a long, effective campaigner for Polio survivors and all people with disabilities. He was the author of many reports; chair of national committees; the scourge of bureaucracy; admired and valued by all who met him (in his customary wheelchair); and honoured as Deputy Lord Lieutenant of Merseyside. Trustee, Andy Gilliland, a friend of Sir Bert since childhood, paid a moving tribute to him, and Lady Maureen Massie, accompanied by her niece, gave a very graceful speech of acceptance. After lunch, the afternoon sessions began.

The Workshops

After a delicious lunch the afternoon sessions were kicked off by Delia Ray from Motability. She spoke at length about Motability and, in particular, the impact of PIP assessments on the scheme, as well as how Motability guide and assist members in the event

of a change in circumstance. Mike Jackson from Northampton Branch followed this with an interesting and insightful talk about how Northampton Branch introduced a programme of hydrotherapy and how they made this happen through the support of the local Branch of Rotary, who helped not only with financial assistance, but with volunteers to assist at the hydrotherapy sessions. Following a quick break, Philip Taylor (The Cordwainer) spoke about solving problems with NHS footwear, the difficulty of getting adequate orthopaedic footwear through the NHS and the challenges members face in finding adequate footwear to suit their needs. The workshops were rounded up by Mike Griffiths (ably assisted by Gillian Griffiths), with useful tips on setting a social calendar for a Region. His talk focused on the highlight of the Region's social year, the race day and how they went about making the event successful.

"I am delighted to say the workshops were very well received this year and I would like to thank all contributors for helping us make the day informative and useful for members," said Acting Operations Manager, Kripen Dhrona. "I would also like to thank Fish Insurance for their generous sponsorship of the workshop sessions." Many members took the opportunity to speak to Fish Insurance's Scott Moody during the day. **b**

Twenty Minutes With Colin Powell JP, FCCA



Colin Powell, Rotary Liaison Ambassador.

Twenty Minutes With aims to give readers an insight into the people who have and continue to help and shape the world of The British Polio Fellowship. In this issue, we talk to Colin Powell JP, FCCA, who, in addition to being a member for many years, has taken the charity's message far and wide and maintained and developed our relationship with Rotary. In having a truly inspirational life story to tell, Colin shares much in common with many members. What sets Colin apart is the way he has lived not just his own life to the full, but encouraged others both with and without Polio and without to do the same.

the bulletin: Colin, thank you for taking the time to talk to **the bulletin** today. For those readers who don't know, could you tell us a bit about how you first contracted Polio and how it affected you?

CP: You are welcome. I was born in 1949 and when I was just six months old, my parents took me to the doctor, concerned I was unwell. The doctor told them I was teething, but mum noticed soon after that I couldn't lift my legs. I returned to the doctor and Polio was diagnosed. At this point, I was transferred to an isolation hospital in Essex, then to Rush Green Isolation Hospital, where I was to remain for four years.

the bulletin: Do you remember (or have you been told) about your treatment in these early years?

CP: I was transferred to Great Ormond Street. The impact of Polio was high levels of paralysis and respiratory problems. I was far too small for an iron lung to be used, so other methods had to be found. Polio was at epidemic levels at the time and the NHS had only been going a year, so it was all new territory for everyone. I had blond, curly hair at the time, so when it was announced the Queen Mother would be visiting the hospital, I was in prime position to meet her, until that is, I poured porridge all over my head! At this point, the nurses panicked as they couldn't get the porridge out fast enough, so they placed me in an airing cupboard out of the way. After Her Majesty had safely left, people started to ask, where is Colin? It took a while before someone could remember where I had been left. It was warm in there and I was happy enough!

the bulletin: It sounds like this was the start of a long stay in hospital?

CP: I was laid on a bed for four years and wound up with a spinal curvature – a scoliosis. I went back for surgery on many occasions, including at Great Ormond Street and ultimately had a spinal fusion at Royal London Hospital. This meant I was encased in plaster for a year, from my forehead to my knees. To carry out surgery, a square was cut in the plaster and done through a hole. At one point, to make the bed, I was moved onto a sideboard and when a nurse tried to carry me back to bed, she couldn't. She dropped me and basically undid all the surgery that had been done to that point.

the bulletin: That couldn't have helped with your recovery. Did you receive further treatment as a consequence and how did that go?

CP: At age eight I had to go to the Robert Jones and Agnes Hunt Hospital in Shropshire and undergo another procedure for eight months. They removed half of my ribcage on the left this time and it was implanted in my spine for support. A Harrington rod is used today but those things weren't around back then but they did their best.

the bulletin: This must have had a terrible impact on you and your family at the time

CP: Yes, indeed. As many members will know, you were put in isolation. I was young to begin with, but I should say through all these procedures and years, I was 200 miles away from home. My parents did their best and had to drive all that way (before motorways) every Sunday to have a couple of hours with me and then drive all the way home again without me. It was a strange experience and throughout; you do get used to being on your own.

the bulletin: Were you able to attend school?

CP: At age 11, it was announced there was nothing more that they could do for me. I was to be thrown on the scrapheap. I would never walk, I was a vegetable and would just have to make the best of it. Back in those days, there was simply no distinction made between physical and mental disability and everyone was thrown together as group failures. The local education authority had me sent to a 'special school', where we were taught needlework, painting and other practical skills but nothing academic. There was to be no academic achievement for us as far as they were concerned.

the bulletin: This is unimaginable in this day and age. You are known for not letting Polio hold you back. How did you go about confronting this situation?

CP: My parents realised I was very unhappy and knew that they had to get me out of there. But that would mean moving home to live in a more 'enlightened' area; somewhere where they might look at the person and not the disability, so we moved from Newham to Waltham Forest and I attended a regular secondary school.

the bulletin: That sounds like an improvement. How did that work out? What do you remember of the experience?

CP: I couldn't climb stairs of course and was transported each day so there was no interaction with my fellow school pupils, which was difficult and of course made it very hard to make friends. This was a big deal. As it happened, I had joined The British Polio Fellowship (IPF then) very early and the local Branch was under the direction of Mr and Mrs Dubber. It was good because it gave you that interaction with people I was missing and all the camaraderie of a club. When our family moved to Hackney, I joined the Highbury Branch at that point.

We formed a tenpin bowling team and played every Saturday. We were sponsored by the Daily Mirror as we were called the Andy Caps, which was great! When I ultimately left school, it was with just one old fashioned O level on the British Constitution! I knew I needed to do more and already had my plan in place.

the bulletin: This sounds like a momentous decision was taken?

CP: Education was a key issue and I remember as a 14 year old being sat in the library while the others all did PE. I decided there and then that what mattered was in my head and I should make use of my brain if I could decide what to be. I felt that being a doctor was out; I had spent enough time in hospital even by that stage to last several lifetimes and I didn't see myself as a solicitor. I decided at that point accountancy would be my best bet, so I set my mind towards achieving that aim. I went onto technical college and took another six O levels for starters.

the bulletin: It's amazing that you were making such big life decisions on your own at just 14 years of age?

CP: It is an odd thing, but having spent so much time alone and having faced so much misfortune, I grew up very, very quickly. You had to. I wasn't an adult, but when faced with what were simple decisions, you simply had to make them. It is surprising what you can achieve if you set your mind to it and refuse to take no for an answer. And this was a first early lesson.

the bulletin: Accountancy is not exactly known for taking a chance on people, and discrimination was rife at the time. How did you manage to get your foot in the door?

CP: Despite not having the grades for the course, I asked the head of the accountancy if I could sit in on his lectures and he said yes. As an external student, I took the A level accountancy exam and (to my surprise) I passed with a grade 'A'. There was no money at home, so I worked for £7.50 a week at an accountancy firm, and studied evenings and weekends by a correspondence course, to get all the necessary qualifications I knew I needed. It took five and a half years, but at the end of it I qualified as a chartered certified accountant. Not too bad for someone dismissed as a vegetable!

As an aside, I should say that aged 16, I got some transport in the form of a ministry of health invalid carriage! Only a few days ago, I was approached by the BBC to do a shoot on the history of this vehicle. They came to see me having actually secured one in working order! I sat in it and did a six hour filming shoot for them. It is due to be transmitted on the BBC World Service shortly.

Apparently, the BBC had seen me in a YouTube link that had been sent to them of a Rotary District Conference I had attended in 2017, so it does show that such links can be seen and have an impact in perhaps unexpected ways. 

Twenty Minutes With Colin Powell JP, FCCA



the bulletin: That is some achievement but how did you translate this into the world of work?

CP: Well, to go back to my story, having qualified, I naturally wanted experience with a large accountancy firm, but that proved difficult. Members reading this will not need me to tell them discrimination abounded. Let's face it; I was never going to conform to the stereotypical image of the accountant in his pinstripe suit and bowler hat!

It was another one of those times to make a big decision, and I decided if they wouldn't take me, I would simply set up on my own. I gave myself two years initially and told myself I could always go back to where I was if it failed. Well, 45 years later and here I am.

the bulletin: That must have taken real guts and determination to succeed. Was this something you always had, or did Polio spur you on, do you think?

CP: I always had real drive. Whether Polio gave me that or not, coupled with all the isolation and being forced to make my own decisions from an early age, I don't know. But, I never believed the state owed me anything or would give me anything. In truth, I probably wanted much, much more than they thought I should have. In my mind, I had to have control over my own destiny and that's the way I have always approached my life.

the bulletin: This kind of drive usually filters into other parts of people's lives. Was that the same for you too?

CP: Well, ten years in, I took a number of unemployed people off the dole queue and gave them gainful, useful employment in home insulation and installation of security products. It proved to be a big success and on the back of this, I was nominated to become a magistrate. I was approached; I accepted and was appointed a Justice of the Peace in May 1987. I've now sat as a Chairman in Adult Criminal Courts for 32 years, although I face mandatory retirement next year.

the bulletin: You must have seen a lot in that time. What have you taken away from your time as a JP?

CP: I have indeed seen a lot in my time as a JP. You can see wasted opportunities in people's formative years and it is always very sad to see. However, what I would say is, even if you had a bad start, you can succeed, if the willingness is there. I'm living proof of that.

the bulletin: Your life has been one of strength and determination in overcoming adversity. There are clear high points and low points, but are the highs and lows for you what people would expect?

CP: For me, the undoubted high point was meeting my wife, Anne. She made such a big difference in my life. When I met her, I had the feeling I had finally arrived in society. We have two stepchildren and four grandchildren. The eldest is 22 and a medical student, who was motivated to go into medicine from my influence, which is nice. Sadly, I lost Anne last year to terminal cancer which was devastating. Life has sent me several challenges over the years but losing Anne was the biggest.

the bulletin: How do you manage day to day and has PPS played its part?

CP: I survive today with a team of trusted carers and with their help I can function and retain my independence. I am fortunate to have a small care company; the owner is a qualified doctor from Mauritius, who was driven to become a doctor as his dad was an amputee. We have formed a strong bond and I have a lot of trust in him, which means we interact very well.

PPS started to run me down ten years ago and at that point, I got involved with Rotary and its efforts to eradicate Polio globally. Rotary asked me to speak at an event and I spoke about my job but it was my life they were interested in. When I finished speaking – silence followed. I think it made an impression, as I was invited to speak again and at bigger and bigger gatherings, from district conferences to founder's lunches, that sort of thing and for the Rotary Foundation too in connection with Polio eradication.

the bulletin: What have you taken away from speaking to Rotary over the years and what do you think they have learnt from you about Polio, PPS and The British Polio Fellowship?

CP: The biggest void I discovered was the lack of knowledge – there was no knowledge or plan in Rotary to support Polio survivors and I wanted very much to motivate them to include that ethos. I think it is fair to say that has been a hard struggle, but the tide has now turned. I think Rotary now accept a degree of responsibility for Polio survivors. In 2016, I became The British Polio Fellowship Rotary Liaison Ambassador and also this year one of eight ‘Purple for Polio’ Ambassadors for Rotary, so I have used these joint roles to try and bring both organisations closer together.

the bulletin: Where do you see these relationships now and what progress do you think has been made?

CP: The culmination of all this, is that I have finally been invited to speak at the 2019 Rotary National Conference in Nottingham next May. This is the big one, with a two and a half hour Polio showcase, including a talk about my life, followed by a question and answer session.

To speak at this event has been an aim and ambition of mine for some considerable time now and it has involved a lot of favours, talking to the right people and pulling strings to get to this point, so I have high hopes for what we can achieve. It is the perfect platform to talk about The British Polio Fellowship and I will be attending the World Polio Day event in the grounds of Stoke Mandeville, too.

the bulletin: That’s great news. You have worked on a number of joint initiatives over the years?

CP: I worked on the Bill and Melinda Gates Foundation’s One Last Push campaign and took part in a short video, which is still used today. The producer and I had a long talk and three fellow British Polio members were filmed individually, we then did the voiceover at a sound studio in Central London.

The point of all this, is I have a foot in each camp and can use that to hopefully bring both organisations closer together. We are also in discussions about another project.

the bulletin: How have you found the impact of PPS in recent years? Have you taken any steps to alleviate the symptoms and do you have any advice for other members?

CP: In 2010, I contracted a chest infection and was hospitalised. I felt ready to leave and the team there were out of their depth and insisted I went home with oxygen to use 15 hours a day. That is the worst treatment for someone with a respiratory condition, as it can increase

the amount of carbon dioxide. I was able to get on to my own long-term team who got me on a sleep study and I now use VPAP (Variable Positive Airway Pressure) machine – a non-invasive ventilator for eight hours a day. This helps get rid of the carbon dioxide.

I have also attended the PPS rehabilitation course at St Thomas’ Hospital Lane Fox Unit. This tries to give lifestyle guidance and advice on good quality of life. I would say this is a superb course – if you have a positive attitude and can accept that you can live well with what you have. Not everyone can accept that – or is ready to.

Currently, I am offering my support to a fellow Polio survivor, who simply cannot come to terms with the impact of PPS. Many of us can be at different stages of this journey and it is hard. For my part, I try to encourage and tell her, that although you cannot do what you did before, this does not mean that your life is over – far from it. I would say again, it is amazing what we can achieve if we set our minds to it.

the bulletin: This has been a period of change for The British Polio Fellowship. What do you see as the future of the charity and what should we be doing more of?

CP: Our charity, by definition is one that has a limited life. Thankfully, the impact of Polio in this country has diminished, which has affected the number of people joining us, as Polio is here no longer. However, the support The British Polio Fellowship offers members is invaluable and should continue, in my opinion, for as long as possible. I think many of us who have been members for a very long time share that view. However, we may have to accept the charity does not remain in its current form but it would be a shame for our knowledge and experiences to be lost – when I think we can offer so much more to others, particularly those living or coming to terms with living with neurological conditions with similar symptoms.

The British Polio Fellowship team has done and continues to do amazing work we can all be proud of, but nothing is forever. To be blunt, we need to establish a new role and identity. We will be too small as we are and perhaps a merger with a neurological charity with like-minded aims may be the best option. We know there are many out there and would have to choose the best fit for all concerned. We still have a substantial percentage of members for now – but for how much longer?

I have lived a very full and active life but I still have a great deal of empathy for members not as successful. I hope my experience (and our experiences as Polio survivors) can offer some hope to others. 

Twenty Minutes With Colin Powell JP, FCCA



the bulletin: In addition to running your own business and lecturing on Polio and PPS, you have travelled the world. Where have you been and what advice would you give to those living with similar disabilities who would like to follow in your footsteps?

CP: I think I have indicated, I have always had no intention of disability holding me back. I have travelled just about everywhere in the world at one time or another – Australia, New Zealand, China, Japan, Polynesia, South America, North America, Europe, you name it, I've been there, so it can be done. My advice would be twofold:

- 1) Plan any trip like a military operation – leave nothing to chance and be as specific as you can. Plan well in advance.
- 2) Don't take 'no' for an answer – from anyone!

I'm not saying this means travelling is easy – it's not. But everything is possible. In 2017, I took the inaugural flight from Heathrow to Santiago, which was 14 hours non-stop. I needed my ventilator attached to the oxygen supply in the aircraft to do it. It all had to be arranged and wasn't easy, but we managed it. There are hand controlled cars available in the US and New Zealand, so I have been able to use those. The thing I would say is, there are always going to be issues, but if you approach people in a polite but firm way and keep your cool and try and foster a team spirit, things can be resolved.

I always have a lot of equipment to carry with me – which must be in hand luggage and not in the hold – and this has caused problems. Despite best efforts, there was a breakdown in communication when trying to travel from London to Lima in Peru and I was denied boarding. What followed was a stand off that lasted four hours! This is why you must plan everything as I do. I had all the paperwork to hand, plus all the emails confirming the arrangements. These showed they had been told in advance and that I was right. They had to eat their words and let me on the plane in the end and get it sorted. They had told me to, "Come back tomorrow" but I refused to leave. The trick is to remain unfailingly polite, but firm and assertive. If you blow a gasket, you are in trouble, but a calm approach in my experience yields the best results.

the bulletin: What's next for Colin Powell? The forthcoming flight from Heathrow to Sydney perhaps? Is there anything you would like to add?

CP: The 14 hour flight to Chile was enough for me for now! I will be speaking for Rotary on World Polio Day in October. The 2019 Rotary National Conference is a major, major platform to reach 3,000 delegates with our message and will be the largest audience I have addressed to date. I don't visit individual clubs these days, as I find it takes too much out of me, but there are other means to reach people. So called e-clubs have now been established and I have done online presentations to Rotarians around the world. We 'meet' weekly online and you can be chatting away to a global audience or to someone in New Zealand who is still in their pyjamas having got up at 7.00am to hear you speak. It is another exciting avenue to get the message out.

the bulletin: Thank you for talking to us today, Colin.

CP: It is my pleasure. I will never forget my affinity to The British Polio Fellowship, after 65 years our charity will always be a cause that is close to my heart and anything I can do to help I am very glad to do.

If any member with Rotary connections wishes to suggest that I speak at their District Conference or at a British Polio Foundation fund raising event, they can contact me through Central Office by emailing colin@britishpolio.org.uk **b**



Colin Powell on the BBC shoot.

Chairman's Corner



This has been difficult article to write for this issue of *the bulletin*. Major events have not only moved at a rapid pace, but most ongoing problems and issues seem to have come to a head together.

A good thing in one

way, as we need these outcomes to move forward, but the sudden conclusion of many issues have put intense strain on the Trustees (some of whom still work full time) and on the reduced staff at Central Office (staffing update in the AGM report on page six and in the article on page 34).

Everything that the Board does is always with the future of The British Polio Fellowship at heart, but we can only plan ahead with a regular income stream and could break every rule in the book by taking risks. I have often explained about the current financial crisis in the charitable sector and as a small organisation we have been badly affected. You only have to look around at the retail sector; banking; manufacturing; local government; health; education; the Police; (and the Brexit situation), to see uncertainty; austerity; redundancy; meltdown; and fear, everywhere!

This situation has hit hard at our cash flow and sadly, Polio is way down the list of people's priorities and perceptions, (as the BBC Appeal proved). We are no longer even recognised. It is in many ways you, the stalwart members, who give us heart, hope and the desire to carry on. Your volunteer efforts and your fundraising is superb but unfortunately, you are let down by some members who are giving The British Polio Fellowship a bad, bad name, which could rebound on our future existence.

Enough negativity for now! We must look to our future, working together, which has always been the ethos and backbone of The British Polio Fellowship. I think that I have said enough about the challenges we face – in this issue and the past three 2018 *bulletins*.

The Trustees have been hurt by some ill-judged remarks but we still soldier on with hope and your support!

Every day brings donations from around the British Isles, the Heating Fund is going great guns, we had to order more Christmas cards and we have great expectations for the annual raffle. Anyone can win – I did! The Trustees and our staff welcome any good ideas for fundraising, which will be properly evaluated. As said elsewhere, we have great hopes for sales revenue from the two wheelchairs – which you have enthusiastically supported already.

We are looking at the Annual Membership fee, as we must have a regular income base. Voluntary donations are most welcome and we sincerely thank those who do this generous act already. Just a couple of weeks ago, there was great joy and celebration at Central Office when a cheque for £5,000 came from a lady member who we had only spoken to (and helped) the day before! What a superb gesture for the Fellowship, our hard working staff and the National Treasurer! Unexpected amounts come to remember a past supporter, In Memoriam collections are heart-warming and your personal and Branch fundraising gives us heart – you are stars!

Since the last *bulletin*, we have held three Board meetings, two finance committees and a host of teleconferences. You can guess most of the content: cash flow; property; running costs; staffing; contracts; the AGM; legacies; fundraising; the Annual Report; our three-year financial plan; the growing importance of our trading company; the link with the European Polio Union; Branch and Group activities and problems; and a huge amount of proper contact from members and the overwhelming workload for Support Services etc.

I realise genuine, long-term stalwart members are worried about The British Polio Fellowship. Be 100 per cent assured, so are the Board. Once again, thank you for all you do for your fellow members - bless you.

Never give up on us please, as we enter our 80th year.

Yours in Fellowship

David Mitchell
National Chairman

Staying safe on the internet



Following concerns raised by several members, what follows is a brief introduction to phishing and what people should look out for. This is not a comprehensive look at what is a complex subject but is offered as a basic guide to some of the most common ways that phishing can be used to obtain sensitive information by fraudulent means.

Phishing has been used as a way for criminal hackers to gain personal data since the 1990s. Its aim is to trick its victims into sending passwords and bank details etc or to click on malicious links and the evidence is it remains a highly successful ruse. The truth is, phishing is becoming more sophisticated than ever at impersonating well-known brands, and even people you know, such as friends and work colleagues. The goal is to trick people into believing an email is important and convince them to click on a malicious link/attachment, or to provide highly sensitive details such as bank accounts; dates of birth; or requests to forward funds.

In 2017, over 48 per cent of such emails were opened by recipients, that's an increase of 12 per cent on the previous year. That scammers can still achieve such a high success rate shows that phishing has evolved and can be very convincing.

Why don't we do something about it?

Phishing is worth millions (if not billions), which motivates criminals to develop ever better lures to draw in the unwary. Sadly, no matter how many security defences banks and charities like The British Polio Fellowship put

in place, no email filtering technology can hope to be 100 per cent successful, which leaves it up to individuals to identify and delete phishing emails. Human nature is the biggest asset in the criminals' locker. The good news is, no matter how much better these emails become, they are not perfect and there are various things you can look out for to help you spot them. The first rule is, if in any doubt at all, do not open it. Below are our top five ways to foil the phishermen:

1. The email is sent from a public email address

Check the email address carefully. This can give the scammers away and is the first clue all is not as it should be. They might use a public address (like gmail.com, rather than britishpolio.org.uk for example) and if you hover over the address and it is different to the one displayed, that is a warning sign. Scammers often change the name to make it look more authentic. This is known as 'spoofing' and there is usually a bizarre email address hiding behind what might look like a genuine name. If the person concerned's email has been hacked, it could be a genuine address, so you still need to be on your guard.

Greetings can also look odd. Scammers want to use our names to try and make it personal but they can get this wrong. Some emails just say 'Hi' – so think – is this likely to be from someone I know? If you have been saying 'Hello Mike' in emails for years, would you suddenly switch to just 'Hi' or 'Hi Michael Smith'? Changes from what is normal are often a clue. To get round this, some phishing emails try to strike an official tone and rather overdo it. You are very unlikely in a real official email (for example) to find them shouting about how 'official' it all is. Is the message trying a bit too hard? If so, it is likely to be a scam.

2. Strange information and attachments

If you get an unexpected email asking you to open an attachment – don't. They can contain malware that can harm your computer and capture personal data. If in doubt, delete them. Scammers love to include branding and logos, as this makes the emails look so much more plausible and genuine. Check the quality and if logos look fuzzy, or an older logo is being used that doesn't match the current logo on what you know is the genuine website, that's another clue that all may not be as it should be. [▶](#)

Donate your old car to charity



If you have an old car that you no longer need, why not put it to good use? We will collect it from you free of charge and either auction or scrap it, giving the proceeds to the British Polio Fellowship.

With over 8,000 vehicles recycled through the Giveacar service, we have raised over £1 million for charities across the UK!

0207 736 4242

www.giveacar.co.uk

- ✓ FREE COLLECTION
- ✓ ANY CAR
- ✓ COUNTRYWIDE

£1 million raised for charity



Making a difference, one car at a time

www.giveacar.co.uk Giveacar is a non-profit social enterprise supported by over 1,000 UK charities. Giveacar Ltd, Riverbank House, 1 Putney Bridge Approach, London SW6 3JD. Registered as a Company Limited by Guarantee in England and Wales, No. 7128365.



Head 2 Toe Orthotics

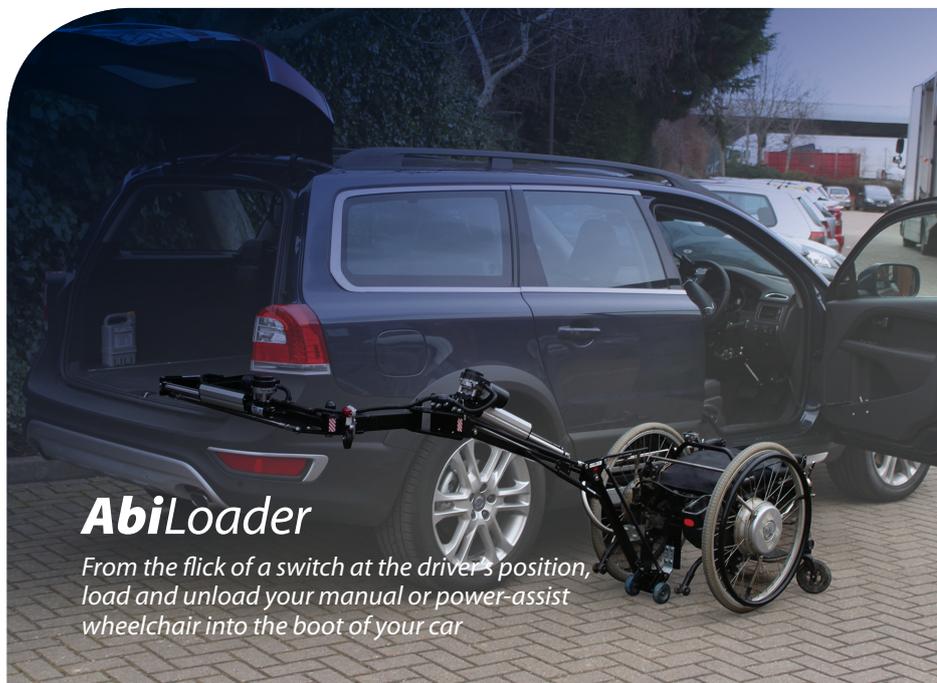
Specialist in the full range of orthotics at very competitive prices.

Products Include:

- Callipers – lightweight, traditional or state of the art
- AFOs – carbon, plastic and metal
- We can also offer footwear adaptations at low prices with quick turn around times
- Our lead orthotist has over 40 years experience. All our technicians are extremely high skilled
- Why wait months for your orthotics through your local NHS Trust when you can have the best quality at the best price

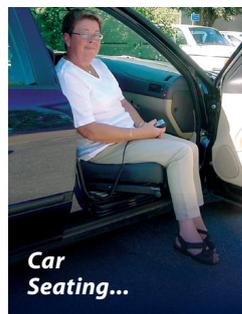


Tel: 0114 2584639 www.head2toeorthotics.co.uk
sales@head2toeorthotics.co.uk



AbiLoader

From the flick of a switch at the driver's position, load and unload your manual or power-assist wheelchair into the boot of your car



Car Seating...



Vehicle Controls & PAS Lightening...



Power-Assist Wheelchairs...



& Crash-tested Power Chairs

01442 212918

enquiries@steeringdevelopments.co.uk

www.steeringdevelopments.co.uk

MOBILITY SPECIALISTS • HEMEL HEMPSTEAD



Staying safe on the internet ... *continued*

3. A false sense of urgency

Phishing emails often contain a false dilemma. This is a classic tactic of salesmen for generations. You don't want to miss this offer, so you must buy now! If you don't act now, there will be a penalty of some kind.

This is done to create a sense of urgency. Don't fall for it. Take a step back and think. Never be rushed. How likely is this request? Would you really receive such a demand for money/information out of the blue with no warning?

Another firm favourite is 'your account has experienced suspicious activity and needs to be reset, just click the link' or someone you know needs urgent help, which is usually in the form of a request for money.

These can contain a direct or implied threat in order to scare you – the police will get you if you don't; HMRC will fine you if not paid immediately etc. Don't fall for it. A bank will never ask you to give details in such a way nor will the tax man. Don't do it. If you are in any doubt, look up the number of the organisation and call them; do not use any number or contact details in the suspicious email!

As a rule of thumb, an email out of the blue, unexpectedly asking you to send money or update your personal or bank details is always a scam. No reputable company will ever ask you for information in this way. Don't be rushed. Take your time and make the checks you need to.

Never assume that because an email comes in a name you recognise that it must be ok. It is always as well to double check. If it is genuine – no harm done. It is much better to miss out on a genuine deal than to ever risk compromising your personal details, your money or that of the charity.

Some members have asked in the past why The British Polio Fellowship does not ask members to transfer funds, preferring to ask for donations and payment via cheque or credit card instead. One of the reasons is to protect members from phishing. Payment via a credit card is very safe, very secure and leaves a clear trace. Payments can also be refunded in some cases if you have been a victim of fraud. On the other hand, bank transfers do not contain such security and they are more open to phishing and scam abuse. We can and do accept payments this

way, but by having to organise this over the phone first, members know (we hope) that they will never receive email requests for money from us. If you do get bizarre or unexpected requests, you are welcome to check with Central Office first; you will not offend anyone by double checking any approach is a legitimate one.

4. Links to sites or URLs that misspell familiar domain names

Phishing emails are getting much better at this, but by hovering over the link, you can see the true URL without clicking on it. These are often incorrect, spelt wrong or completely different to what you would expect given the contents of the email and who it claims to be from. This is good practice anyway. Always, always double check any link before you click on it.

If the email is claiming to be from the bank, never click any links. Banks will only ever send you links to information pages, so contact the bank first. Log into your internet banking in the usual way, via the official site, if there is no message there then you know the email is from a scammer. Some banks ask you to report such activity, so let them know.

5. Poor spelling, style and grammar

Criminals are getting much, much better at this, but you can often detect a phishing email by the way it is written, the style and punctuation. Many of us (and most organisations) have a style of writing and if you know the sender well, does the email use their style and form of words and the sign offs they are fond of?

The more words, the easier this is to spot, which is why scammers keep it concise. But if the email is from someone who usually sends long text-heavy emails and you suddenly get one with just three words, that's a concern. As many originate overseas, they can also have a poor grasp of written English – something you will not find from your bank.

These are just a few guidelines and are not intended as a definitive list. The best advice is if you receive an email of concern, don't open it, but do what you can to check its legitimacy first. If it's a concern about an email claiming to be from The British Polio Fellowship, don't hesitate to contact the team at Central Office. **b**

Irton House Farm The Lake District

Fully accessible, spacious 4 star self catering accommodation

Stunning views over lake & mountains in National Park

Cottages sleeping 2-6, all with wet rooms

Ideal for exploring the beautiful North Lakes

Open all year, friendly owners in residence



Call 017687 76380 www.irtonhousefarm.com

Cornwall. Near Truro

"Truly accessible self catering accommodation"

Free use of all mobility equipment



Two specially converted detached cottages on a small sheep farm in mid Cornwall.

- Ensuite wetrooms
- Electric profiling beds
- Air/pressure mattresses
- Hoists
- Shower chairs
- Riser/recline chairs
- Care available locally
- Free WiFi

We are only 15 mins from Truro and 30 mins from the Eden Project, making Treworgans the ideal place to explore this beautiful county.



01726 883240 / 07762 173860
www.treworgans.co.uk



Treworgans

ACCESSIBLE HOLIDAY COTTAGES IN CORNWALL



Two specially converted and detached cottages - both level access with wheel in shower. We can provide free use of electric profiling beds, air mattresses, hoists, shower chairs, riser recliner chairs plus a wide range of extra equipment to make your stay easier and more comfortable. Care is available locally. We are only 15 mins from Truro and 30 mins from the Eden Project, making Treworgans the ideal place to explore this beautiful county.



01726 883240 / 07762 173860
www.treworgans.co.uk



Beautiful Cumbria...

Fancy an escape to the countryside?

Situated in the Yorkshire Dales National Park and just a stone's throw away from the beautiful English Lake District, The Fat Lamb is the perfect base for a peaceful getaway.



The Fat Lamb is fully accessible and has facilities for guests with disabilities. Please discuss any requirements you may have with our booking team to ensure a comfortable stay.

Two nights dinner*, bed and breakfast prices from: £240 for two people or £140 for single occupancy

*The dinner included is a £20 allowance per person per night to use against our food menu
Bank holidays are excluded from this offer



The Fat Lamb Hotel
Ravenstonedale
Cumbria
CA17 4LL



Tel. 015396 23242

www.fatlamb.co.uk

enquiries@fatlamb.co.uk

Give immobility the stick



How to get hiking

Arising from *the bulletin* survey this year, a number of people asked us to cover more issues surrounding those with disabilities and PPS. A number of comments were centred on outdoor activities, such as hiking, with requests for details on walking aids and technology. In a recent issue we covered hiking using a wheelchair or a scooter, and while this was well received, some have rightly pointed out that not everyone with Polio and PPS uses a wheelchair or a scooter. So, in this issue, we are looking at helping those who are a bit more mobile and have investigated walking sticks and trekking poles as aids to mobility.

There is very little UK based advice on trekking poles, and while they can look a bit odd around town, they can help with general mobility and not just for those traversing mountains. Prior to PPS,

many who had Polio managed quite well, with many members remaining active. The onset of PPS, therefore, can come as a bit of a shock for those keen to retain an often hard won mobility for as long as possible.

All of this can change following a first bout of PPS, depending on the severity of the symptoms. After the sudden shock of an unanticipated and unexpected debilitation, it is natural that some find themselves almost subconsciously withdrawing from their old life. There can be that fear, what happens if I have a fall, or struggle to carry on?

This can lead many to give up on the walking and rambling they once enjoyed. There may be no need for this to happen with the range of aids currently available. Despite this, some do not choose to make use of them. Why? Pride can be one reason. Many of us see the use of a stick (or even glasses

when we are young) as an image we do not want to portray, or we don't want to be seen as 'giving in' to disability or are concerned about what others might think. It is almost as if using a walking aid is a public admission of disability. This is not always helped by what can be a very 'medical' looking range of NHS sticks and walking canes. They are cold and grim, let's be honest about it. Not all of us are ready to embrace this look just yet.

However, it doesn't have to be this way. There are a host of companies offering a range of walking sticks, trekking poles and seats at very affordable prices that don't look like they came straight out of A&E. Using a stick or trekking poles for the first time may make you feel vulnerable, but with the sheer array of types and styles out there, choosing something to suit you and make your own can make a big difference.

Trekking poles can be a big help. They are cheap, adjustable and widely available in a range of styles and designs. What's more, they are regularly used by people both with and without disabilities, so you don't look out of place or different, which is an important consideration for some. True, you might get some joker asking when you are leaving for base camp, but people tend to think you are perhaps on your way to a hike or in training. It's all about perceptions, and with such aids, disability is not the first thing that springs to mind.

It all depends on your unique situation. You should always consult your GP or specialist before trying something new, but the use of two trekking poles can really help with mobility and give your confidence a much needed boost. The advantage of two poles, as skiers and hikers alike realise, is balance. They keep you stable and allow you to take advantage of upper body strength to aid walking if your legs are weak. It is also much easier to catch yourself from falling with the help of two sticks rather than one, as anyone who has done a lot of hiking will be able to attest to. This is why the majority of professional backpacks come with storage on the sides for two trekking poles and not just one. They also help you to get up should you fall.

Two sticks can also help improve mobility. With a weak back, there is a tendency to lean over on one stick and this can cause poor posture. Two sticks encourage an upright bearing and distribute the

weight evenly. This also applies to those who may have weak wrists; two sticks distribute the weight and avoids putting all the pressure in just one place.

The shock absorbers built into many trekking poles also make them less tiring to use than the rigid stick variety. Two sticks also help with momentum, which is why so many professional walkers and hikers use them. If you struggle with knee joints, it can be more of a problem going downhill than up, and the steadying effect of two trekking poles on a decent is a real help.

What type? Telescopic poles help when you need to pack them away – but a word of caution – not all poles are created equal and you do get what you pay for. Better quality ones will give you a stick that locks properly and stays locked. The last thing you need is a locking system prone to failure.

One foot to ferrule them all?

The British Polio Fellowship has worked closely with Flexyfoot; their unique ferrule helps absorb shock and keeps the 'foot' in contact with the ground, which gives that all-important grip on wet and shiny surfaces. However, it is as well to consider other 'feet' – depending on the situation – so you will find there are 'ice boot' ferrules also available.

Wandering not so lonely as a cloud?

It may be that there is a mix of people in your party, with some able to walk and others using a combination of sticks and scooters. What do you do then? Well, as we have seen in previous issues of *the bulletin*, there are places opening up everywhere that allow people using a wheelchair to get out and about in the countryside. Canal paths are a great example because they were designed to have horses walk alongside pulling a barge. The paths are relatively flat and wide, so they are possible to negotiate in either a wheelchair or walking and are located in some of the UK's most beautiful countryside.

This is not intended as an advertisement and there are many suppliers of walking sticks and trekking poles. The best advice is to take a look online and find some local stores. Try out a few different types until you find something to suit you. It may be you end up with different types for different situations. **b**

British Polio Fellowship 80th anniversary 2019



Oak planting

You might recall our aim to plant 80 hundred (8,000) oak saplings around the country, as part of our 80th Anniversary in 2019. Well, we are now approaching autumn and nearing the time when acorns will be falling from their parent trees. The Merseyside Branch is embracing the scheme and has already begun to gather acorns and plant them. Pictured are some members with saplings planted last year and acorns being planted for the celebrations next year.

While we have been promised support from The Woodland Trust; The National Trust; and Rotary, Epsom, we still haven't been able to establish specific sites to plant our acorns and saplings. So, we are

appealing to you again for your help in identifying sites for us to plant our trees. We are also appealing to you to help us to plant acorns or saplings across the country.

As you can see in the picture, it's amazing to think that a tiny acorn can grow into a huge tree that can live for hundreds of years and be so beneficial to our environment.

If you are interested in joining our initiative, or can offer any help, support or advice then please contact me or Kripen at Central Office.

andygilliland@hotmail.co.uk

Andy Gilliland
Trustee

That was the year that was!

Not all of us can recall the last 80 years, but we can all reflect on the changing world that The British Polio Fellowship has witnessed during that time. This experience gives the charity and our members a unique insight into so many things.

Back in 1939, it was a very different world. In one DC Comic, a Superhero called Superman made his debut in a daily newspaper comic strip (he first appeared in Action Comics in 1938, before moving to DC). The Irish poet W B Yeats died on Saturday 28 January and Germaine Greer was born on the same Sunday The British Polio Fellowship was born – 29 January.

Two days later on Tuesday 31 January, President FD Roosevelt took several senators into his confidence over fears concerning Adolf Hitler, remarking even then that Hitler was intent on dominating Europe and if he did so, it would imperil the safety of the United States, saying:

“The safety of the Rhine frontier does necessarily interest us”. When asked if he meant the Rhine frontier to be America’s frontier, the president said he did not, but “Practically speaking, if the Rhine frontiers are threatened the rest of the world is too”.

Here in the UK, fear of war dominated the agenda and Neville Chamberlain was prime minister and George VI was king. The coming of war on Sunday 3 September and the lead up to it of course, overshadowed everything else in 1939, and much social history of 30s Britain is eclipsed by it.

This was also a time when football games had the kind of attendance that we can only dream of today. The all-time highest attendance at a British football league game was set on 2 January, where an incredible 118,567 people watched Rangers beat Celtic at Ibrox. [b](#)

Forum update

Only a couple of weeks between receiving the Autumn *bulletin* and the deadline for articles for the Winter *bulletin*, Chris, Jilly and I have come up with some thoughts, so here goes:

I want to talk about the issue of Forum use by Trustees, Regions and Branches. If our Trustees, and every Region and Branch had one Forum member to represent them on our pages, then communication would be easy, quick and private. Everyone could be kept up to date on all that goes on and the membership would be less likely to indulge in unnecessary speculation. Instead of hearing rumours that certain staff had left us, we would know the true story.

The *bulletin* is a five times a year publication and as with any publication, submitted articles can be out of date by the time it is read by the membership. Unless the Forum is used to its full potential, and until the next ***bulletin*** appears, I suppose we can amuse ourselves speculating on any number of issues.

Some interesting topics have appeared on the Forum recently. Sadly, several concern medical matters such

as cancer and the effects different treatments have on us Polio survivors as well as sleep problems, especially for those who must use a BIPAP (Bilevel Positive Airway Pressure) or CPAP (Continuous Positive Airway Pressure). Advice has been sought on joint replacements; orthoses; accessibility including the use of wheelchairs in everyday life such as shopping; driving; and parking. Much of this can be helpful and reassuring. On the happy side of life, we have quite a lot of reports and information about holidays. Some within the UK, others in much more exotic destinations and accompanied by photos.

For those, like me, who do not use Facebook or Twitter, we are kept fully informed by a regular update on what has appeared in and on different social media. All kindly provided by BeyondPR.

I hope some of this encourages more of you to look in on us and join in if you wish. Also, we hope a Trustee or two may put in an appearance, together with the committees of Regions and Branches and use our pages to inform and learn. We are all in this together and must support one another in whatever way we can. [b](#)

Managing PPS Symptoms: survey results

Part two By Dr Ruth Bridgens, medical sociologist



Dr Ruth Bridgens.

As 70 per cent of the PPS management survey sample felt they were deteriorating more than they would have expected from ageing, it seemed important to look closely at the strategies they were using to try and halt the deterioration, and why, in many cases, they were not working well. As PPS is thought to be due to overuse, activity levels are important, but too little or too much activity depends on the amount of weakness and fatigability. PPS research has shown many times that actual muscle strength does not correlate with developing PPS or having PPS muscle pain and fatigue. Pain does not even relate directly to activity level. According to

Klein et al (2004) it is higher strain, perceived exertion and intensity level of activity that determines pain levels. Those with the most severe weakness do not necessarily have the most pain and fatigue, and muscle fatiguability is a crucial factor.

Almost everyone in the survey knew the advice that they should pace and modify activities in order to diminish overuse symptoms, and some had taken part in the Lane Fox PPS rehabilitation course. But many were confused by what they saw as conflicting advice – on the one hand to keep active and on the other to pace, take rests, and if necessary do less in order to minimise the pain and fatigue. Besides the confusing advice, it is difficult for people who had Polio to forget the messages they had received in the past about not giving in, not asking for help, and pushing as hard as possible in order to strengthen their muscles and lead a normal life. It is also the general view of health professionals and the public that exercise, irrespective of pain and fatigue, is good for everyone, as they see the symptoms as disuse rather than overuse, so these views tend to predominate. Polio patients hear ‘use it or lose it’ far more often than the Post Polio advice ‘conserve to preserve’. Much PPS advice varies and is confusing.

The British Polio Fellowship booklet, ‘Pacing for activity and exercise’ which advises first finding a baseline is clearer than many. In the section on non-fatiguing exercise they say: Conditioning exercises or any repetitive activity, including walking, which causes pain or a sense of excessive muscle fatigue and increased weakness should be stopped (for that exercise session). Symptoms that last longer may mean muscle overwork and possible injury. If this occurs, the exercise or activity should be reduced or stopped... Any exercise that causes additional weakness, unusual muscle twitching, or inability to perform a task that you can normally do without help should be stopped. It is important to respect these symptoms in order to avoid doing permanent harm to your muscles.

When I asked people why they thought they were deteriorating, the answers fell into three main categories. They either related to past beliefs from childhood and

growing up, current beliefs about the causes of PPS, or their interpretation of their particular situation and symptoms, including the effects of other illnesses. But it was the beliefs from the past that predominated and often influenced the other two groups. Some felt it was a sign of failure to stop doing anything they had always done. Others said they could not ask for help. Some mentioned guilt about stopping to rest or doing less because of pain or fatigue, often because they felt that maintaining their exercises would 'keep them going' and doing less would lead to a downward spiral. Trying to do slightly less to see if it helped symptoms was sometimes inconceivable because of the tendency to think in terms of black and white, making it difficult to see a middle ground between working flat-out and doing nothing. The fear that doing a little less would increase weakness sometimes led to a perseverance with walking, however painful and difficult, and not using a wheelchair, even occasionally. However, if a wheelchair eliminated overuse pain and fatigue, it might stop further weakness and deterioration. Many, of course, knew they were doing too much but found it hard to change.

The current beliefs about PPS, which affected people's management, were generally a redefining of terms, so that they could carry on the activities they felt uncomfortable modifying or giving up. A few said that they believed deterioration was inevitable, so change was not necessary. Some felt that moderate pain was normal and they would only begin to pace activities and take some rests if the pain was extreme. Some with fatigue said that they did not need to modify their activities because they didn't have pain, and others with pain would say that it was only fatigue that meant they were overdoing things.

The symptoms themselves caused various problems in trying to work out the best management. Some people had quite severe pain and fatigue after activity, which disappeared quickly when they stopped, so did not seem important. Others did not get symptoms until the next day, so were not sure what had caused them. Some people had conflicting reasons about how much exercise to do for different conditions like heart disease or arthritis. A few mentioned becoming stiff or getting cramps when they sat down after being active, so they returned to the activity. This could be due to many reasons and probably both the activity and the seating need to be looked at. Others were so used to having pain and fatigue all their lives that they had learnt to ignore it and now found it very difficult to recognise it at all. Some people did not have

warning symptoms or only very mild symptoms even though their weakness was increasing.

The medical advice about exercise for new weakness, if a person does not experience pain or fatigue, is ambiguous as no long-term exercise studies have been done. The new weakness of PPS is probably due to overuse of enlarged motor neurons, but it is thought that non-fatiguing (less intense) exercise might be helpful. In one study, involving 22 weeks of endurance training, in which the patients were all under 50 and all but one capable of walking without assistive devices, two out of 12 had a decrease in muscle strength, so care must be taken (Ernstoff et al 1996). Of course, if one group of muscles are weakening, it might be possible to strengthen others for support. Exercise made a few people feel good, probably from both psychological and physical changes, even though they felt weak and tired afterwards, and for them, possibly because they know exercise is good for one's health and strengthened their muscles in childhood, the good outweighed the symptoms afterwards. Two people became permanently weaker after one or two episodes of overuse, so became particularly wary of how much they pushed their muscles.

There were, of course, the 20 per cent of the survey sample who had generally managed to stabilise most symptoms. About half this group did some form of exercise, though often quite gentle. Some of this group had quite mild PPS or had not had it very long and could balance quite an active life, including exercise, with a certain amount of pacing and resting. Everyone talked about finding a balance between activity and rest.

Exercise was monitored quite closely and often included some swimming, Pilates or yoga. Stretching and massage were very common and were all that some could manage, along with pacing, heat and rest. Others did a certain amount of activity in the morning and then restful occupations in the afternoon and evening.

Several researchers have suggested that, in order to make lifestyle changes acceptable to people who have had Polio, they need to be phrased differently in words that do not bring back the fears of not succeeding from childhood. In an interview study about managing everyday life in PPS patients, the authors suggest that the term 'setting priorities' is more positive than 'giving up occupations' (Thoren-Jonsson et al 1999). This concept was stated more clearly by anthropologists Scheer and Luborsky (1991) who noted the incredible work ethic of Polio patients and suggested that the work ethic itself needed to be turned towards managing PPS. 

Managing PPS Symptoms: survey results ... *continued*

Managing PPS becomes the job at hand and the work involved is setting new priorities, reducing some activities, having rest breaks and using the determination and problem-solving used to recover from Polio to manage PPS. Scheer and Luborsky also mention the pride many Polio patients have in the way they have pushed themselves beyond their limits to become stronger and succeed in life, and maybe this pride now needs to be channelled towards having the strength to change, move on, listen to one's body, and be flexible. At the same time health professionals should realise that Polio patients are generally as active as possible and working hard because of limited strength, so their advice should emphasise that first a baseline needs to be found where muscle pain and fatigue are eliminated, before any exercise regime is started.

If you would like to take part in a small survey looking specifically at the little-researched PPS overuse symptoms, muscle fatigue, muscle pain after exercise

and general fatigue, whether you took part in the previous survey or not, contact Ruth Bridgens: ruthbridgens@btinternet.com or go to the survey website: <https://hiddenpolio.wordpress.com/>

References

Ernstoff B, Wetterqvist H, Kvist H, Grimby G. Endurance training effect on individual with Postpoliomyelitis. *Arch Phys Med Rehabil.* 1996 Sep;77(9):843-8

Klein MG, Keenan MA, Esquenazi A, Costello R, Polansky M. Musculoskeletal pain in Polio survivors and strength-matched controls. *Arch Phys Med Rehabil.* 2004 October; 85: 1679-83

Scheer J and Luborsky ML. The cultural context of Polio biographies. *Orthopedics* 1991; 14 (11): 1173-81

Thoren-Jonsson A-L, Moller A, Grimby G. Managing occupations in everyday life to achieve adaptation. *American Journal of Occupational Therapy* 1999; 53:353-62 **b**



10 Years of Polio Australia

As The British Polio Fellowship marks 80 years in January 2019, we wanted to take this opportunity to recognise an important landmark recently achieved by our opposite number down under, Polio Australia. It marked its own tenth anniversary in August this year. On behalf of all at *the bulletin* and indeed British Polio Fellowship, we wish everyone involved with Polio Australia (and its excellent regular newsletter, thank you!) a healthy and prosperous 2019. Here's to the next 10 successful years of Polio Australia.

Readers will not be surprised to learn that many of our concerns regarding everything from PPS to orthotics and accessibility are shared by our friends down under. One key difference is Polio Australia supports those younger, migrant Polio survivors and others born after 1975 – the so called 'next generation' of Polio survivors.

Just as we have discovered how hard it can be to connect with people who have Polio and PPS, who may not be aware of our help, Polio Australia has encountered similar problems with young survivors not connecting with Polio Australia or State Polio networks, and hence lack the level of support and information on how best to manage their condition and PPS in the future.

Our approach has been to keep up a presence in local and Regional press (with letters from David Mitchell and others) as a means to communicate with fellow Polio survivors, who may be unaware we are still here. Others have put up leaflets in village halls, post offices and doctors' surgeries. We all have a part to play in spreading the message of The British Polio Fellowship. If you have suggestions on how either organisation might better communicate with potential new members, let us know at the usual address: thebulletin@beyondpr.co.uk 

FOR EVERY RESULTING SALE THROUGH THIS ADVERTISEMENT, **ACORN STAIRLIFTS** WILL DONATE **20% OF THE SALE PRICE** TO THE BRITISH POLIO FELLOWSHIP.



Acorn Stairlifts

Regain the freedom of your home

Simple, safe and stylish, Acorn Stairlifts give people the chance to enjoy their own homes once again.

- Next day installation available
- Buy direct from a British manufacturer
- 365-day local service and support
- Local surveyors, local engineers
- Safe and reliable
- Open 7 days
- Rent or buy
- New or reconditioned

What to look for in a stairlift:

All Acorn Stairlifts include:

- ✓ Easy to use controls
- ✓ Easy-read digital display
- ✓ Smooth start/stop action
- ✓ Fold-up seat and footrest
- ✓ Safety cut-out sensors
- ✓ Safety seatbelt

"Many people with limited mobility simply find themselves living downstairs, with the upstairs practically out-of-bounds. But there is an answer... a stairlift."

Dr. Hilary Jones

Medical Advisor to Acorn Stairlifts



CALL NOW ON FREEPHONE
0800 016 9301
for your free DVD and information pack



ADVERTISING

PUZZLE

Page

	9		8				5	7
		6			1		2	
3				7				
5			9		6		3	8
	3			1				
2		8				5	1	
6				9				3
	1						9	
		7	6		5	8		

Sudoku

Enter the numbers into the blank spaces so that each row column and 3 x 3 box contains the numbers 1 to 9



Quiz – for this issue we have taken a look back to *bulletins* of old, to see how good your memory is!

1) Which of these well-known brands used to advertise in **the bulletin** – Lucozade; Guinness; BSM or British Gas?

Answer is:

2) Who made the Good Cause Appeal for The British Polio Fellowship on Sunday November 20 1966 (52 years ago) at 7.55pm on the BBC Home Service?

Answer is:

3) Who was National Chairman of the Fellowship in December 1966?

Answer is:

4) What year were the first two Branches at Reading and Mansfield formed?

Answer is:

5) How many Branches were there ten years later?

Answer is:

6) Which two sports stars presented trophies in 1974 at the Stoke Mandeville Sports Day?

Answer is:

7) Which British actress was on hand to present the raffle prizes at the Silverwood Ball on 24 October 1975?

Answer is:

8) Which British actor joined boxer Joe Bugner at the Royal Albert Hall on 30 October 1975 to present awards at the Dance Championships in aid of the Fellowship? Clue – “schhh...You know who”!

Answer is:

Answers on page 45

The Hedgehog

A small, lightweight and user-friendly powered wheelchair offering unrivaled value in its class.



- Easy to use
- Easy to fold
- Easy to transport

Price
£1850

If you are looking for a modern powered wheelchair that fits easily in your car boot, the Hedgehog is for you. One simple pull of a cord and it folds into a compact unit in just five seconds.

A strong aluminium construction and two lightweight 1.5 kg lithium battery packs with a great range, make it a perfect everyday travelling companion.

This comfortable and reliable wheelchair is being offered by The British Polio Fellowship at the best possible price with the mobility needs of people suffering from muscular degenerative neurological conditions at its heart.

Specification

Warranty <i>(Includes Supplementary Warranty)</i>	2 years
Max speed	3.7 mph
Weight capacity	18.9 stone (120 kg)
Range	7.5 - 9.3 miles / battery
Product weight without batteries	21.5 kg
Overall size	87cm x 57cm x 84cm
Folded size	57cm x 29cm x 69cm
Batteries	2 x lithium 24V7.8ah
Charging time	5 hours
Model	SQPC - 07A



Call us now on
0800 0431935
or email
info@bpftrading.co.uk



Virginia's golden account of great Guy's



Virginia Olds.

In August this year, Northamptonshire Branch member Virginia Olds was referred to the Post Polio Syndrome (PPS) Rehabilitation programme at Guy's and St Thomas' NHS Foundation Trust in London.

It is believed that Virginia's account of the programme, which took place on six days over two weeks during August, is of interest to Polio survivors throughout the UK, and as such, is being reproduced for the benefit of readers of *the bulletin* below.

Since joining the Northamptonshire Branch in 2014, Virginia has been aware of the benefits that Polio survivors have gained by attending the rehabilitation programme. However, for many members, it has proved difficult to gain a referral from their GP to an experienced consultant with a background in the treatment of Polio and Post Polio Syndrome.

With the support of the Branch, Virginia was able to gain a referral to Professor Sturman at the Queen Elizabeth Hospital, Birmingham. Professor Sturman is recognised as a leading UK consultant in the treatment of Polio and PPS.

At her consultation with Professor Sturman and following a number of tests, he recommended that she attend the rehabilitation programme at St Thomas' Hospital. Before being accepted on the programme, patients have to go for an assessment at St Thomas' Hospital, carried out by both a senior physiotherapist and an occupational therapist. Virginia was accepted for the programme and wrote her account which is attached.

Feedback from those in our Branch who have already attended the programme is highly complementary, as it improves the understanding of PPS and how to manage the condition, which in turn significantly improves the 'wellbeing' of the person. Hopefully, this article will encourage more Polio survivors to seek help in the management of both Polio and PPS.

Post Polio Syndrome (PPS) Rehabilitation Programme at Guy's and St Thomas' NHS Foundation Trust in London

This takes place for three days in the first week, followed by three days in the second week. The programme is aimed at the self-management of symptoms associated with PPS mainly fatigue, new weakness and loss of function and endurance. It is run by Alex Curtis the physiotherapist and Jeong Su the occupational therapist.

It is not possible to cure or resolve all problems, but the idea is to improve lifestyle balance and reduce peaks and troughs of activity. The overall aim is to give those attending information to aid them in managing their symptoms. I attended this course at the end of July, staying in the hotel which is within the hospital grounds. There were five of us on the course, one other lady and three men, all with varying but similar problems. We had to be in 'class' from 9.00am until 4.00pm with a good break for lunch, which was provided (as were all meals) in the hotel.

Day 1 covered a test paper on our knowledge of PPS; most of us knew quite a bit but it was still interesting. ABC – Activating an event, what happened? Belief of thought, what was going through your head? Consequence, emotions, how did you feel? What did you do?

Vivian a psychologist talked about thinking patterns. This was complicated but re-reading the paperwork brought some understanding. After an hour and a half lunch back at the hotel, we were given a verbal introduction to exercise and then individually assessed. We were also interviewed privately, asking us five things we like to do with our time.

Day 2 began with fatigue with Jeong Su the occupational therapist. This covered both physical and mental fatigue which can be caused by illnesses other than Polio. Roughly half of Polio survivors experience fatigue. Then we saw Dr Steer, who explained how Polio affects the central nervous system and talked about sleep apnoea and the respiratory causes. We also covered joints and posture.

Day 3 we looked at fatigue management with Jeong Su followed by an individual physical assessment – in my case walking round and round cones in the gym, which I couldn't complete. Later we were back with Vivian for part two of thinking styles with some written exercises. After lunch in the café, for which we were given vouchers, it was back to the meeting room for a final session on lifestyle management.

Finally, after the first week, we all went our separate ways, with homework which entailed keeping a diary of our energy levels, depending on what activities we partook in, until we were due to return on Sunday evening. So, then we were free for the long weekend. I have relatives not too far away so decided to go and stay with them, making it my summer holiday!

Sunday evening we were back at the hotel for dinner, ready to start again next morning. This commenced with a review and discussion of the energy diary we had all completed, followed by pain mechanisms, pain control, and goal setting.

After lunch, we learnt about falling and recovery – I was not willing to throw myself on the floor to demonstrate! Then we should have done relaxation, lying on the beds in the gym, but unfortunately the builders were working on the floor above banging hard, so it just made us laugh. But we did have a short session the next day. On the second Tuesday, we were taught about nutrition with the dietician Angela, followed by communication with Jeong Su. Then, in the afternoon it was hydrotherapy. Margarita and I went in together – she turned out to be a great swimmer – I'm jealous!

On the final day we had a question and answer session with Dr Shaw who is studying PPS – we could bring our partners if we wished. Some more on exercise and repeated the knowledge test— we improved slightly. At the end of the course, we all set goals for the coming six months based on what we had learnt and our personal priorities. An individual exercise programme was provided by Alex, and we were told that they would contact us by phone in three months and invite us back for an update at the end of six months. It is quite a demanding course, but I really did enjoy myself. We all got on so well and I believe it will be very beneficial – if I can stick to my goals!

Virginia Olds

New Central Office staff structure

Many of you will have read in *the bulletin* or heard about changes in the Central Office staff team. Some members have told us that they are not sure of the staff structure at Central Office, so this page outlines the new staff structure.

In September, we were sad to see Yvonne Wright leave The British Polio Fellowship as she moved on to a new role. Likewise, Shakari Chapman our apprentice, had come to the end of her course and found employment elsewhere. We wish them both all the best for the future. In July, Ahmad Butt chose to move over to BPF Trading full time, to enable him to concentrate on developing the trading arm to its full potential.

Shān Nicholas also stepped down from her role as Interim CEO at the end of September. Shān came in with the objective of steering The British Polio Fellowship through a turbulent period of financial uncertainty. She has done a fantastic job over the last six months and we also wish her well for the future.

Kripen Dhrona, has been promoted to Acting Operations Manager, and together with Dawn Grafetsberger (Finance and Office Manager) will form the senior leadership team at Central Office. As you can see from the chart, both Kripen and Dawn will be reporting to the Board of Trustees. In April, The Board



Pictured: (L-R) The Trustees: Archie Leyden; David Mitchell; Gwenda Cope; Aidan Linton-Smith; Andy Mack; Andy Gilliland; Bosik Gharapetian and front: Christine Lumb.

of Trustees determined that the following priorities/objectives of The British Polio Fellowship were:

- To be a support organisation for members, social welfare information and advice
- To be a provider of grants/funds eg: heating, holidays etc
- To be a campaigner raising awareness of PPS, by ourselves, or in partnership with others eg: education of the medical profession via the Expert Panel
- To be a campaigner promoting accessibility for travel, by ourselves, or in partnership with others

Kripen and Dawn will work closely together towards achieving these objectives, with the primary focus on providing much needed support to the membership.

We are lucky to have two very knowledgeable and experienced Support Services Advisors, Zahida Osman and Vijitha Nathan. They will continue to take the lead on all membership and Branch issues and will provide members with support on a wide range of problems that members face daily. These issues often cover a multitude of subjects including help with diagnosis, getting more information on PPS, advice on benefits and mental health and wellbeing, amongst many other things.

Diane Ware continues to manage fundraising and does a fantastic job in securing funds from a wide variety of trusts and foundations. She also raises much needed funds through our annual winter raffle. Diane also provides vital support to events and legacies.

Linda Davis provides administrative support for fundraising matters, including processing payments, handling collection tins, thank you letters and managing the ordering and sales of Christmas cards. Linda also provides valuable support for events.

We have also advertised for a new apprentice to provide administrative support to all departments and we are looking at a programme of student volunteers to also support this function. [b](#)

CO Staff Organisation Chart

Board of Trustees



Finance and Office Manager
Dawn Grafetsberger
Full time



Acting Operations Manager (including marketing)
Kripen Dhrona
Full time



Apprentice NTC
Full time



Trusts and Fundraising
Diane Ware
Part Time



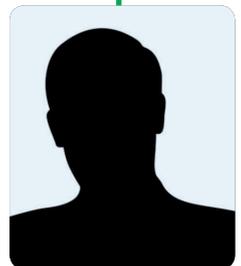
Fundraising and Finance Administrator
Linda Davis
Part Time



Support Services Advisor
Vijitha Nathan
Part Time



Support Services Advisor
Zahida Osman
Part Time



Student Volunteers
TBC

Please contact Kripen at Central Office if you have any questions on 01923 281 099 or email kripen@britishpolio.org.uk

Erewash half marathon



A timely reminder alerted me to send you the following for *the bulletin*.

After a couple of false starts, Peter's friend Mark ran in the Erewash half marathon on Saturday 18 August, for the Notts and Derby Branch of The British Polio Fellowship. We had an athletic shirt made for him complete with The British Polio Fellowship logo. He has raised approximately £450 (still counting).

A big thank you to Mark and all those who sponsored him.

Regards

Barbara Worrall
Notts and Derby Branch

STOP PRESS
Congratulations to Patricia Eames – she is our £1,000 lottery prize winner. Well done Patricia; we're all jealous!

Giving By Text

You can always make a donation to The British Polio Fellowship from your mobile phone, just follow these simple steps:

Text: BRPF39 £ (amount you wish to donate), maximum amount of £10.

To: 70070 It's as simple as that! The amount you have donated will then be charged to your mobile phone account. **b**

Give As You Live

As The British Polio Fellowship is registered with Everyclick, when you do your online shopping at selected stores, around 3-4 per cent of the cost of your total shop will be donated to The British Polio Fellowship.

In some cases this could be more as the amount is dependent on the discount that has been agreed with the supplier. There are over 3,000 stores participating in this scheme, such as John Lewis, Waitrose, M&S, Amazon, Debenhams and many, many more.

All you have to do is visit the website www.giveasyoulive.com and start shopping. But don't forget to nominate The British Polio Fellowship as your preferred charity. **b**

Grand Winter Raffle 2018

Second prize: £250

First prize: £1,000

Third prize: £100



Two FREE tickets to a Watford Premier League home game of your choice (from the remaining fixtures this season), courtesy of our new Charity Partner, Watford FC.

Many more fantastic prizes to be won! These include Gift Vouchers; Weekend Break away; Overnight Stay at Marriott Hotel; Tomy toys; and jewellery just to mention a few. The draw will be done by the Mayor of Watford on 12 December.

A BIG THANK YOU to all who have kindly supported this raffle by donating the cash and prizes. Inside your *bulletin* you will find a book of 20 raffle tickets (unless you have requested not to receive them). It would be greatly appreciated if you are able to sell them all and please do contact Diane on 01923 281 091 or email: diane@britishpolio.org.uk if you would like more tickets!

Good Luck!

In Memoriam

Name	Region	Member
Mrs Audrey French	Bristol	no
Mr Robert John Cheesman	Norfolk	yes
Mr Tony George Wade	Surrey	yes
Mr Norman Shaw	West Midlands	yes
Mrs Marjory Mary Dench	Essex	yes
Mrs Daisy Ellen Harding	Middlesex	yes
Mrs Dorothy Blackburn	West Midlands	yes
Mr George Wells	not known	no
Mr Leslie Sinclair	not known	no
Ms Monica Grace Blatchly	not known	no
Mrs Sylvia Florence Trautner	London	no



We would like to offer our sincere condolences to the families and friends of the above people.

Thank you to everyone who has contributed in their memory. If you would like to make a donation in memory of a loved one, please contact Linda on 0208 836 3689 or email linda@britishpolio.org.uk

Any unwanted gifts?



Any unwanted gifts that you feel you won't be in need of, or are not using, please do think of The British Polio Fellowship. We would be so grateful to receive them, as we can use them for tombola or raffle prizes.

We would like all gifts to be new and still in their original packaging if possible please. To save the cost of postage, please use our Freepost address:

Freepost, The British Polio Fellowship, The Xchange, Wilmington Close, Watford, WD18 0FQ.

Please contact Diane in Fundraising on 01923 281 091 if you need any further information.

Donations have been received from the following Trusts and Foundations recently:

- Miss W E Lawrence 1973 Charitable Settlement
- Gowling WLG (UK) Charitable Trust
- Maud Elkington Charitable Trust
- MacCabe Family Charitable Trust
- Hospital Saturday Fund
- Traynor Foundation

We would like to say a big thank you to all the trusts and foundations who have kindly supported the work of The British Polio Fellowship so generously.

These funds help the charity continue to provide valuable services to members.

Thank you

BRITISH POLIO FELLOWSHIP - HEATING GRANT APPLICATION FORM 2018

Application for a heating grant for people with Polio/PPS in the UK, living in households NOT eligible for the government Winter Fuel Payment (Only one application per household, even where there is more than one person with Polio/PPS.)

Please complete both sides in BLOCK CAPITALS and return it FREEPOST to Central Office:

FIRST NAME: LAST NAME: (Mr/Mrs/Miss/Ms)

ADDRESS:

POST CODE: TELEPHONE NO:

DATE OF BIRTH: Age now: Age when you contracted Polio:

AGES OF OTHER MEMBERS OF HOUSEHOLD

MEMBERSHIP INFORMATION

Are you a member of the Fellowship? YES/NO If no, we will send you membership details

If yes, give details of which Branch or Central Office:

Are you or a close relative on a Branch, Regional or national committee? If so give details

PAYMENT DETAILS – payments will be made directly into your bank or building society account or that of someone you nominate. Please write your bank details clearly and ensure all sections are completed.

Name of Bank or Building Society:

Your Name (as shown on your account):

Or that of the person you have nominated to receive your payment

Branch Sort Code:

Account Number:

If you do not have access to a bank or building society account, who should we make a cheque payable to?

(Please note it may take longer to receive your payment by cheque)

Data Protection Statement

The information that you provide on this form will be kept in accordance with the Data Protection Act 2018 (GDPR). We will hold only such information as we need to on paper and on computer records. As your application is confidential we will not discuss it with anyone outside The British Fellowship. We do not pass your information on to any other organisations without your consent.

To the best of my knowledge nobody in my household is eligible for the government Winter Fuel Payment 2018 (you should receive the Winter Fuel Payment if you were born on or before 5 November 1953) the information on this form is correct and I am happy for The British Polio Fellowship to hold this information for Heating Grant purposes:

YOUR SIGNATURE DATE

Please complete other side of form.



Section A: INCOME

1. EARNED INCOME:

If you / other people in your household are working OR have other non-benefits income (including pensions) – please put what you / other people in your household earn per year (before tax)

You: £ **Other:** £

2. MEANS-TESTED BENEFITS: (please tick each benefit you / other people in your household receive):

	You ✓	Other ✓
Income Support		
Pension Credit		
Income Based Jobseekers Allowance		
Child Tax Credit or Working Tax Credit		
Housing Benefit		
Council Tax Exemption / Assistance (Not Just Disability / Single Person Reduction)		

3. OTHER BENEFITS: (please tick each benefit received):

	You ✓	Other ✓
Disability Living Allowance (DLA) or Personal Independence Payment (PIP)		
Mobility Component		
DLA Lower Rate or PIP Standard Rate		
DLA Higher Rate or PIP Enhanced Rate		
Care (DLA) / Daily Living (PIP) Component		
DLA Lowest Rate		
DLA Middle Rate or PIP Standard Rate		
DLA Highest Rate or PIP Enhanced Rate		
Incapacity Benefit (IB) or Employment and Support Allowance (ESA)		
Other Benefits (Please Say Which):		

Section B: ABOUT HOW THE COLD AFFECTS YOU, please tell us in the space below how cold affects you and any Polio/PPS related symptoms.

.....

Please return this form to the address below.

If this is your first grant application we will require a doctor’s note to confirm your history of Polio.
 If you are a Branch member we may forward your application to your local Branch.
 If you or a close relative are on a Branch, Regional or national committee, Central Office will need to consider your application, so also post it to the address below.
 We reserve the right to contact you should we need more information to assess your application.

FREEPOST, BRITISH POLIO FELLOWSHIP, The Xchange, Wilmington Close, Watford, WD18 0FQ

No stamp needed but if you use a stamp it will save on our postage costs

Please return this form by Monday 3 December 2018 (late applications may be refused) if your application is successful, payment will be made in February 2019.

Over 30 years of winter warmth



2018 sees more than 30 years of The British Polio Fellowship Heating Grant programme. A remarkable achievement that has enabled us to offer help and support, over three decades, to thousands of members who struggle with the increasing cost of heating during the cold winter months.

The British Polio Fellowship is pleased to be running the popular Heating Grant programme again. The aim of this scheme is to supplement the cost of additional warmth, needed during the winter months for people living with Polio, in households not eligible for the government Winter Fuel Payment.

If you are living in a household in which no one is eligible for the government payment, you are on a low income and have extra need for heat because of your Polio, you should complete the Heating Grant application form in this issue of **the bulletin** and return it to Central Office by Monday 3 December 2018 at the FREEPOST address.

All applications from eligible members will be considered, so please tell us how the cold affects you and your need for heating in the appropriate section on the form.

Branch members' applications may be forwarded on to the Branch to which they belong, but please send all Heating Grant application forms to Central Office in the first instance. If you are unhappy with any decision, you may appeal to Central Office.

All Heating Grants will be considered during November and December. Grants are usually paid at the end of

January/beginning of February. Payments will be made directly into the bank/building society account nominated by the applicant.

Please ensure that you complete ALL sections of the form and that bank details are up to date and correct. If this is the first grant you have applied for, you will need to enclose a note from your GP confirming that you have had Polio.

Do make sure completed application forms arrive before Monday 3 December 2018. Applications that arrive too late may be refused.

Keep warm – save money

Are you paying more than you need for your gas and electricity? If you haven't yet thought about changing your energy supplier, you could do. Energy Best Deal is a quick guide to getting the best deal on your energy supplier by shopping around and making the most of the help available. The guide includes information about comparing prices, government schemes and where to get help and advice about saving energy and money. Free copies are available from your local Citizens Advice Bureau or may be accessed at the following link:

<http://bit.ly/thebulletin18>

The Warm Home Discount Scheme

This winter (2018/19) you may be able to get a £140 discount on your electricity bill through the Warm Home Discount Scheme.

This won't affect your Cold Weather Payment or Winter Fuel Payment. It is a one-off discount on your electricity bill, usually granted between October and March. You may also qualify for the discount if you use a prepay or pay-as-you-go electricity meter. Your electricity supplier will be able to tell you how you'll get the discount if you're eligible.

Who is eligible?

In winter 2018/19, you may qualify for the Warm Home Discount Scheme if on 12 July 2018 (the qualifying date):

- You were receiving the Guarantee Credit element of Pension Credit (even if you get Savings Credit as well)
- Your name (or your partner's) is on the electricity bill
- Your supplier was part of the scheme 

Over 30 years of winter warmth ... *continued*

If you don't qualify

Some energy suppliers can offer the discount to vulnerable people (eg: those on low incomes). Each supplier has their own rules about who else (known as the 'broader group') can get this help. Check with your supplier if you meet their rules for help and how to apply for it.

How to claim the Warm Home Discount

If you qualify

If you qualify for the discount, you'll get a letter this autumn/winter telling you one of the following:

- You don't have to apply for the discount – you'll get it automatically
- You must apply for the discount before the deadline – the letter will tell you how

You will receive your letter by Sunday 23 December 2018 at the latest.

If you don't receive a letter but believe you qualify, you can write to the Warm Home Discount Team:

Warm Home Discount Team

Pink Zone, 1st Floor, Peel Park, Brunel Way, Blackpool FY4 5ES.

If you don't qualify

If you don't qualify for the discount you may be able to apply directly to the energy supplier for help.

More ways to save this winter

As well as switching to a cheaper provider, this checklist includes other ways to cut costs:

Dual fuel (gas and electricity from the same supplier) isn't always the cheapest option

It is a good idea to compare the cost of the cheapest dual fuel supplier with separate cheap gas and cheap electricity suppliers.

Switch to monthly direct debit

Fixed monthly direct debit payments (where you pay a fixed estimate each month) can save you up to eight per cent, as companies are sure you won't default, and they earn interest on any overpayments (which should be refunded at the end of the year).

Do a meter reading every time

Every time you receive a bill, do a meter reading; don't rely on your energy provider's estimate, as these are often way out. If they're under billing, you'll have a big whack to pay at the end of the year, if they're over billing, then they've got your cash unfairly.

Switch to your company's internet tariff

If you have internet access, switch to your company's internet billing. It will usually save you up to ten per cent over the standard tariff, providing you're prepared to be billed online.

Are you on a prepayment meter?

Those on prepayment meters often pay more than everyone else. If possible, you should try to switch to a billed meter. Ebico (call 0800 458 7689 or visit <http://bit.ly/thebulletin22>) has historically been competitive on prepayment tariffs, though some other major suppliers are now starting to cut costs to prepay customers too.

What can your energy supplier offer?

It's always worth checking with your energy supplier to see if they offer grants towards home insulation.

Just use less energy!

Cutting down on your energy consumption is easier than you think. Turn lights off when you leave a room, defrost the fridge and check it isn't on too high; don't leave electrical goods on standby ... Look at local insulation schemes or government heating and home insulation schemes. For more information, contact the Energy Saving Advice Service on 0300 123 1234 (England and Northern Ireland), 0808 808 2282 (Scotland), 0800 512 012 Option 3 (Wales) or visit <http://bit.ly/thebulletin23> 

Polio outbreak in Papua New Guinea

As there have been several worrying developments in the battle to beat Polio on the international stage in recent months, International News makes a return to this edition of *the bulletin*. Year end seemed an appropriate time to bring members up to date on the current state of play ahead of our 80th Anniversary in January. We had hoped to be using the return of International News to declare the final victory over Polio worldwide, but sad developments in Papua New Guinea make it look like this is unlikely to prove the case.

First outbreak in Papua New Guinea in 18 years is a cause for concern

In July, David Mitchell wrote a letter to the press concerning the first confirmed case of Polio in Papua New Guinea (PNG) in 18 years. The hope was this would only be a minor setback in global efforts to eradicate Polio; so news of 12 new confirmed cases is particularly distressing.

That Polio was thought eradicated in PNG in 2000 (last confirmed case 1996), demonstrates the terrible power of Polio to return against the odds and the need to maintain vaccination levels post eradication. When you consider there were only 22 cases worldwide in 2017, these new cases are a blow for all those who hoped to see the world declared Polio free in 2019. The authorities have moved swiftly to containment zones and mass vaccination, but only time will tell if it is enough. Our charity continues to support the WHO and Rotary in their efforts to defeat this blight. We see time and again that complacency has proved as much a problem as Polio. Reducing spend on vaccine at a time when 85 per cent live in remote areas, where water supply and sanitation are almost non-existent, has proved an error with devastating consequences.

This news is a sign we must redouble our efforts to help people worldwide to get the basics right. Infrastructure is needed to put a lid on Polio and keep it there, but this is a warning to all of the importance of vaccination programmes – lest we see other killer diseases thought

vanquished coming back from the past to haunt us. We will be watching events unfolding in PNG closely and hope this is just a blip on the eradication road.

The state of play in the battle to beat Polio

Despite the sad news from PNG, three countries – Afghanistan, Nigeria and Pakistan remain of most concern. This is because they have never been able to halt the transmission of endemic wild Poliovirus. Places like Papua New Guinea are of concern because they were no longer Polio infected, but remain high risk, as the 12 new cases in PNG demonstrate. Closer to home, Ukraine remains classified as ‘at risk’ and is on Europe’s doorstep.

(Onset of paralysis in most recent case is prior to 2017. Figures exclude non-AFP sources. In 2018, cVDPV includes all three serotypes 1, 2 and 3).

For Somalia: 1 cVDPV2 and cVDPV3 isolated from one AFP case.

cVDPV definition: see document “Reporting and classification of vaccine-derived Polioviruses” at: <http://polioeradication.org/polio-today/polio-now/this-week/> **b**

CASE BREAKDOWN BY COUNTRY

Countries	Year-to-date 2018		Year-to-date 2017		Total in 2017	
	WVP	cVDPV	WVP	cVDPV	WVP	cVDPV
Afghanistan	14	0	6	0	14	0
DRC*	0	15	0	9	0	22
Nigeria	0	8	0	0	0	0
Pakistan	4	0	5	0	8	0
Papua New Guinea	0	5	0	0	0	0
Somalia	0	8	0	0	0	0
Syrian Arab Republic	0	0	0	40	0	74

* Democratic Republic Of Congo

Travels with My Wheelchair

Part 23 -Last call for flight ...



Well, summer is now over, the nights are drawing in and, by the time you read this, the shops will be targeting our purses and wallets for Christmas 2018. Lots of people will have enjoyed the lovely summer in this country – an unexpected bonus, with many more travelling abroad and enjoying the weather there as well. The majority of these people having no problem with their travel arrangements as they are all able-bodied. For those of us with mobility issues, it's not always so straightforward.

If you remember back to when I started this series, it involved planning travel to Northern Ireland, with my new (at the time) powerchair, for my niece's wedding. One of the main issues related to various means of transport not being particularly wheelchair accessible. In the interim, there have been some improvements, but while the mostly physical barriers have been addressed, the remaining barriers seem to be of the human variety.

Our National Chairman wrote in the previous issue of the treatment handed out to Steve Smithers over his wheelchair repair kit which could, potentially, be used to 'dismantle the plane' he planned to travel on. I know I shouldn't find it ridiculous, but I'm amused by the picture it conjures up of a gentleman in a wheelchair, attempting to loosen the wheel nuts on an airplane tyre with his wheelchair spanners! It's at times like this I wish I was more of an artist and I could create the cartoon picture which is currently running through my head.

Another tale that emerged this summer caught my attention, as it appeared that someone has 'stolen' my article title. A social media post on Twitter by The British Polio Fellowship caught my eye, and another member also commented on it. Well, I had to investigate. The article, from a Central Scotland local paper, was written by a powerchair user who has muscular dystrophy. She (Emma) was initially commenting on the little boy who was refused travel home because he used a mobility scooter and the family were unable to provide proof of his disability. The family had followed all the airline's procedures – well they must have as they'd travelled OUT to their holiday. This was them trying to fly home. It turned into a dreadful occasion for the young boy and it certainly gets you thinking about the way airlines approach the thorny issue of accepting and transporting mobility equipment on aircraft.

In the Falkirk Herald article, the author goes on to relate the problems she faced when trying to book a trip to Austria. The same airline as the young boy, Jet2, was involved.

Most people don't think twice about things when booking a flight, except perhaps the airline with the best price and whether they want a window or an aisle seat. As I said, Emma has muscular dystrophy and has complex seating needs. She has a backrest which has been specially set to ensure her maximum comfort. Jet2 decided that it was too high to fit in the aircraft hold. Jet2 wanted her to remove, or at least adjust, the backrest to fit. Other airlines, operating the

same planes, accepted Emma's chair without any such adjustments. With reluctance, Emma agreed to address the backrest issue, but required tools to fold down the back. Next issue – Jet2 wouldn't allow her to fly with them if she used tools, either her own or those of airline staff, to dismantle the backrest. This, of course, is the same problem encountered by Steve Smithers who was simply carrying them for use once he had landed and would need to adjust his chair to use the hire car he had booked.

All of this had taken a couple of days and numerous phone calls. The next problem was apparently the weight of the wheelchair. Why suddenly now it was a problem – the delay ensued while the airline decided whether to transport the chair under the Dangerous Goods Act! Do you have a manual chair was the next question. She didn't due to the nature of her disability. What right has Jet2, or indeed any airline, to ask that you travel with a less than suitable mode of transport? What was emerging was that if Emma had been travelling with a manual chair, she would have been cleared to travel on day one.

This was just one traveller's experience in trying to book a flight. It says nothing of the many tales of the damage done to wheelchairs which are transported by airlines, including lost footplates, armrests etc., not to mention damage to the frames which can render them unusable. If this happens at the start of your trip, how do you cope? You don't have access to your usual repairers/suppliers. You may face language barriers in your holiday destination. What about your holiday insurance – does it cover such careless handling by airport/airline staff? How do you prove who exactly is to blame for the damage? One thing is for certain – I doubt whether I shall look to travel abroad, by airline, now I am a powerchair user. I am happy to holiday in the UK, despite the uncertainties of its weather. At least I know what to expect. Good luck to all those wheelchair users amongst our members who travel abroad regularly – rather you than me.

As a footnote I should say that Emma did make her trip to Austria some months later, on another airline, from Manchester airport.

Georgina Hay



<p>Quiz Answers</p> <p>(1) All of them! All featured at one time or another from the 50s onwards.</p> <p>(2) Dame Margot Fonteyn.</p> <p>(3) Tom Rowley (Chair 62-67).</p> <p>(4) 1946.</p> <p>(5) 86 Branches and Groups, with a membership of 16,000.</p>	<p>Sudoku Answers</p> <table border="1"> <tr><td>1</td><td>9</td><td>4</td><td>8</td><td>6</td><td>2</td><td>3</td><td>5</td><td>7</td></tr> <tr><td>8</td><td>7</td><td>6</td><td>3</td><td>5</td><td>1</td><td>9</td><td>2</td><td>4</td></tr> <tr><td>3</td><td>5</td><td>2</td><td>4</td><td>7</td><td>9</td><td>1</td><td>8</td><td>6</td></tr> <tr><td>5</td><td>4</td><td>1</td><td>9</td><td>2</td><td>6</td><td>7</td><td>3</td><td>8</td></tr> <tr><td>7</td><td>3</td><td>9</td><td>5</td><td>1</td><td>8</td><td>4</td><td>6</td><td>2</td></tr> <tr><td>2</td><td>6</td><td>8</td><td>7</td><td>4</td><td>3</td><td>5</td><td>1</td><td>9</td></tr> <tr><td>6</td><td>8</td><td>5</td><td>1</td><td>9</td><td>4</td><td>2</td><td>7</td><td>3</td></tr> <tr><td>4</td><td>1</td><td>3</td><td>2</td><td>8</td><td>7</td><td>6</td><td>9</td><td>5</td></tr> <tr><td>9</td><td>2</td><td>7</td><td>6</td><td>3</td><td>5</td><td>8</td><td>4</td><td>1</td></tr> </table>	1	9	4	8	6	2	3	5	7	8	7	6	3	5	1	9	2	4	3	5	2	4	7	9	1	8	6	5	4	1	9	2	6	7	3	8	7	3	9	5	1	8	4	6	2	2	6	8	7	4	3	5	1	9	6	8	5	1	9	4	2	7	3	4	1	3	2	8	7	6	9	5	9	2	7	6	3	5	8	4	1
1	9	4	8	6	2	3	5	7																																																																										
8	7	6	3	5	1	9	2	4																																																																										
3	5	2	4	7	9	1	8	6																																																																										
5	4	1	9	2	6	7	3	8																																																																										
7	3	9	5	1	8	4	6	2																																																																										
2	6	8	7	4	3	5	1	9																																																																										
6	8	5	1	9	4	2	7	3																																																																										
4	1	3	2	8	7	6	9	5																																																																										
9	2	7	6	3	5	8	4	1																																																																										



Every issue we have a bunch of carnations, courtesy of Le Tourneurs, to send to the writer of one letter, so send your letter now.



Angela

Dear bulletin,

It was with concern that I read the report of this year's Fellowship AGM and hope by now members have had a chance to digest the information.

Whilst it is obvious that some mistakes have been made over the last 2-3 years, I hope that members will focus on the huge amount of work the Fellowship has done for people with Polio for almost 80 years whilst acknowledging there will be challenges ahead. I am sure the Fellowship will meet those challenges and continue to provide support for people who have Polio for many more years to come.

It is of course very sad that we have lost members of staff and that our remaining staff are now having to pull out all the stops to keep supporting members, to raise funds and to assist with various funding and retail programmes. We also have the added burden that up to £70,000 is necessary to refurbish and maintain the Burnham bungalow.

I, for one, would certainly be happy to pay a yearly subscription to remain a member and I know those I

have spoken to in my Branch (South East Kent) would also be willing to do so thereby helping finances and as contributions to the production of **the bulletin**. After all, the Fellowship is one of the most generous charities in existence and there can hardly be many members who have not benefited in some way from being a member, either through Central Office or through their local Branch, so I think a yearly subscription is little enough to ask.

The British Polio Fellowship has the most loyal of members and all of us now need to look to the future.

May I offer my thanks to every single member of staff, the Trustees and volunteers for the work they are doing. Most especially, thanks must go to David Mitchell for all the work he has done over the years and most especially, during this difficult time as we head towards our 80th Anniversary.

What better way to end this letter than to quote from the RAF motto: Per Ardua Ad Astra.

Angela
Chair
South East Kent Branch

Ann Blake

Dear bulletin,

With reference to the article 'Train companies must help disabled more'.

I had Polio in 1948, both legs back and stomach. I am living with Post Polio Syndrome. I am now in a wheelchair. The service I get from my local train station in High Wycombe is excellent. As soon as I arrive the ramp is ready for me and I am helped into the carriage

by a station assistant, they even ring Marylebone station to tell them when I will arrive, so they are there with a ramp.

It is a great pleasure to use the train.

Regards
Ann Blake
High Wycombe, Bucks

Linda Treherne

Dear bulletin,

After a very long and successful career in the insurance industry, I decided to retire last year at 63 and make the most of my life whilst I had a reasonable amount of mobility.

My Polio had affected my left leg since the age of six months and over the last twenty odd years has seen my knee joint deteriorate quite significantly and quite severely recently. Having undergone a few arthroscopic surgeries to clear debris from the joint, I had often been advised that a total knee replacement may not be an option due to the leg muscles not being able to operate it. A possible option could be an arthrodesis, which is to effectively cement the joint straight.

Having recently undergone an arthroscopy on my good knee, the consultant referred me on to the Royal National Orthopaedic at Stanmore to further discuss my Polio leg.

The consultation was long and informative and we discussed a new knee replacement by way of a stem hinge. This is not without its issues but the positives at discussion appeared to outweigh the negatives.

I do not have to make an immediate decision, and have been researching to try and get feedback from other Polio survivors who may have had a knee replaced by the hinge method, or general knee replacement.

If any members have had a knee replaced, I would appreciate hearing about your experiences.

Yours faithfully

Linda Treherne
Hornchurch, Essex

Thank you for your letter, Linda.

the bulletin is always happy to publish member's experiences, particularly if they may help others make decisions about surgery, care or mobility. If anyone has advice to share with Linda (either in public via **the bulletin** or privately) do write to us at the usual address at thebulletin@beyondpr.co.uk

Ed.

Anne Martin

Dear bulletin,

With reference to the many complaints regarding assistance on aircrafts, trains and coaches, I, too, have been 'forgotten' on a few occasions whilst travelling alone on both trains and aircraft. In one instance (East Midlands Trains) Norwich to Liverpool refused to take my electric scooter on board unless I folded it and placed it in the luggage rack – not possible – plus not all scooters are collapsible. My Luggi did not meet their strict gradient requirements for a ramp. I had to take my wheelchair instead which restricted my movements – I did not have a companion to help.

On that journey, Tanyalee Davis joined the train and was appalled at my predicament. She gave me some good travelling tips, so it is serious when a passenger

as astute as her has also come up against bureaucracy. We need, in this country, an overall strategy for electric scooters accessing our rail service – travelling is stressful enough without the worry as described above.

On a better note, I have had mostly excellent help on Greater Anglia Trains. On one occasion my battery failed and I managed to coax it to Ipswich station where help was exemplary – they phoned ahead and a wheelchair was waiting for me – buggy (Luggi) taken to my car. I was so grateful to staff for being proactive.

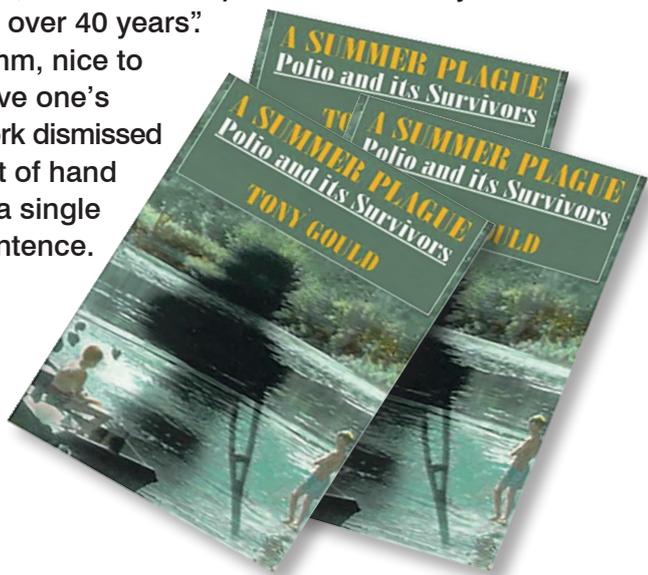
Anne Martin
Norwich

Tony Gould

Dear bulletin,

In the latest issue, you published an interview with the Emeritus Professor, Gareth Williams, who claims that his book *Paralysed with Fear* was, "The first comprehensive history of Polio for over 40 years".

Hmm, nice to have one's work dismissed out of hand in a single sentence.



Until I read this, I had been under the impression that my *A Summer Plague*, published by Yale University Press in 1995, was pretty comprehensive. But no; apparently not. I haven't read the eminent professor's book because it was published more recently than mine and, while I do my best to read everything I can find on any subject I write about before I put pen to paper, I have an aversion to reading books on subjects I've already written about.

But had the professor read my book? Apparently not. I phoned the London Library and asked someone there to check if it was listed in the bibliography, and/or my name in the index. Again, apparently not. But then I am not a medical professional; merely a layperson who contracted Polio when he was 20 and, partly because of that, became a writer.

Sincerely

Tony Gould
Maidstone, Kent

Gareth Williams

Dear bulletin,

I'm sorry that I managed to miss Tony Gould's book while searching the literature to write *Paralysed with Fear: the Story of Polio*. I certainly had no intention of 'dismissing' his work, and apologise for the offence which I have evidently caused him.

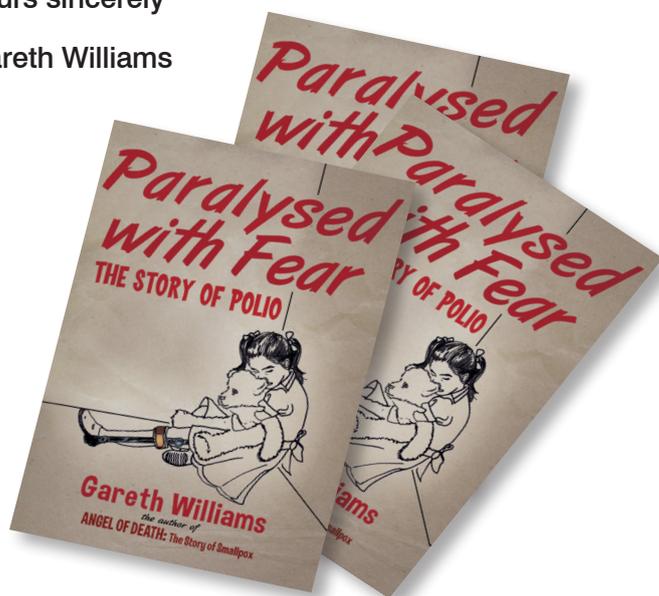
In fact, our two books cover the topic from rather different angles. Mine goes back to the earliest clinical descriptions of what was probably Polio and the scientific debates around its possible causes; Tony's comes in some time after that. The only previous book to cover the history of Polio from its origins (unless I've missed others) was John Paul's *A History of Poliomyelitis* (1971).

Both our books set out to tell the story of Polio (Tony's with the added authority of his own personal experience), to highlight the problems faced in the past, today and in the future by Polio survivors – and to help

with the final push to exterminate this miserable disease. I hope that both books, in their different ways, are succeeding in those aims.

Yours sincerely

Gareth Williams



Alan Hall

Dear bulletin,

We have heard much about travel problems encountered by people with disabilities, but I think bouquets are deserved for my recent journey. I had to travel from King's Lynn, by train/underground, to St Thomas' Hospital Lane Fox Unit, on my buggy.

Pre-travel enquiries at King's Lynn Station secured outbound ramp bookings for King's Lynn and King's Cross. They also gave me a leaflet 'Transport for London – Step-free Tube guide' (also available online at (<http://content.tfl.gov.uk/avoiding-stairs-tube-guide.pdf>)). It suggested using the Circle line to Westminster (nearest for St Thomas' Hospital).

The journey to King's Cross was uneventful, and we found our way to the Circle line. The station guard pointed out the sign for the access point – apparently that particular carriage will line up to the best boarding/alighting point at each accessible station. The journey and subsequent appointment at St Thomas' went without a hitch.

The return was unplanned as we didn't know how long the appointment was. We made our way to Westminster tube station and were joined by Frankie, a tube

customer services employee who saw us arrive and offered to help.

Frankie took us to the platform, parked us at the access point and went forward to inform the driver of our presence. We were dispatched with a cheery wave! At King's Cross a man met us off the tube having been advised by Frankie, and he conducted us to the exit lifts.

On the mainline platform we saw that a train was leaving in two minutes: I asked the gate attendant if there was a chance to catch it. Yes, follow me – as he jogged off to the front of the train where the disabled access was. We boarded with seconds to go. Arriving at King's Lynn the original platform attendant was waiting, with the ramp. No complaints and bouquets all round.

As I have to repeat this journey several more times, I hope this is the service I will come to expect and receive.

The moral of my tale is plan, research and inform. And keep your fingers crossed!

Yours sincerely

Alan Hall
King's Lynn, Norfolk

Steve McCarthy

Dear bulletin,

I received a letter from David Mitchell advising me of my nomination for the Barbara Wood Award at the AGM on Saturday 22 September 2018.

Thank you for this nomination and I am delighted to have been given this award. My late wife Lin talked me into helping out with the Regional and national games over 13 years ago, and I can only say it has been my pleasure and honour to assist and help so many inspiring people with the games.

Lin always thought The British Polio Fellowship brought so much support in friendship and enjoyment to her. We both made so many good friends over the years.

Yours in Fellowship

Steve McCarthy

Thank you for your letter Steve. As Steve was on holiday on the 22 September, he will be presented with the award at his local meeting.

David Mitchell
National Chairman

Gordon Guest



Dear bulletin,

I am writing in reply to the article about wheelchair problems on trains. Where I live in Devon, I am not allowed to take this on any trains out of Tiverton Parkway railway station, nor am I allowed to take it on local buses. Therefore, without my WAV car and scooter I would be pretty stuck.

However, I can tell a different story from Australia. In July this year, we visited relatives in Australia. My wife and I were amazed at how good Australia was for mobility scooters. In Sydney, they have a light railway and a train system. Both take mobility scooters with no problems.

On all railway stations painted on the platform is a large blue disabled sign. If you need assistance (this could also be parents with pushchairs) you go to that spot and wait. In my experience that disabled spot meant when the train pulled in, you were in the carriage immediately behind the train driver. The other

advantage was that the train driver knew where to look for the blue badge to see if there was anyone needing assistance.

The train driver got out of his cab, brought ramps, and got you onto the train. No 24-hour pre-booking, you just turned up and waited on the spot. The driver asked where you were going and when you got there he turned up with ramps to get you off.

What was also impressive was the space. There was enough space for either four scooters or wheelchairs or a combination of scooters and large prams. On one occasion there was a scooter parked beside me and another behind me. One of those scooters is what I would class as an eight mph road scooter in UK. All three of us on one train with no problems getting on or off at different stations. What a difference in comparison to the UK, where you have to book at least 24 hours in advance, and then there is only one small space and if it's booked, another person cannot use that train.

The carriages we went on had similar doors to the London Underground. Double sliding doors opened onto a large standing space. Doors were at both sides. Seating was off to the left or right which meant you drove your scooter into this space, stayed in your scooter and then drove off either in front, or reversing off.

However, you always had to wait for a guard or driver to appear before you got on or off. There never seemed to be a time issue with getting on and off as in the UK. Sometimes in UK you only have two minutes to get your chair on or off the train. However, the operation was so good and efficient they were very quick in getting you on or off.

The most amazing experience we had was coming back out of Sydney late at night. We went to central station on the Quayside in the harbour, found the train we needed, and waited on the blue badge spot. As we were getting on the train, we were asked where we were getting off so the driver could get us off. A few stations down the line a guard / driver appeared and asked me to get off quickly they had brought ramps.

So we did. The train left. We were then told they had received a radio message that the elevator on the platform we were going to was broken. At that time of night, the station was not manned. So, rather than let us go on and face a problem, they got us off to work out what to do. We could either go beyond the station we wanted, then get on another train and come back to the station we wanted and get off at a different platform. Alternatively, go to another station. We decided the easiest option was to go to another station and walk a bit further back to our residence. This we did with no hassle or fuss. I just cannot imagine British Rail and the UK train operators ever being as helpful and proactive as that.

All of this gave us great flexibility and enjoyment of going in and out of Sydney. I just wonder why the UK cannot be as good. Australia really put UK disabled train services to shame. Wherever we went, we found the same great support for wheelchair / scooter users, whether it was disabled toilets, drop kerbs or just attitude in being helpful.

So could the UK improve? Painting a blue badge on all stations is not expensive and could be done easily. Making sure the correct disabled carriage stops by the blue badge could be trickier. Making sure, you have guards / drivers trained and willing to get scooters on and off is an issue. But above all, it's the technology.

The train carriages were actually designed to make it easy for wheelchairs and scooters, whilst in the UK, carriage design really does not take this into account.

On this note, in 2017, we went to Valencia, Spain. We discovered that all the local buses were scooter friendly. They had a single door near the driver, who also took fares just as in the UK. But all the buses had double opening doors located in the middle, with an electric ramp that slid out when needed. The bus driver sat in his chair pressed a button and the ramp came out. Again, as in Australia, there was a very large standing space in the middle of the bus. Big enough for wheelchairs, scooters and large prams. On one trip, we had two scooters and two large prams on the same bus with no problem. So again, it was the technological design of the buses that made this work.

So, if other countries can have wheelchair and scooter easily accessible buses and trains why can't the UK?

Sincerely

Gordon Guest



Pride Go Go scooter parked on train in Sydney. I remained on scooter. Note how easy it is to drive off when the doors open.

Edinburgh Branch

Edinburgh Branch Beetle Drive

At the Edinburgh Branch September 'drop in' we held a Beetle Drive. It was only a small (but select) group who attended. Our depleted numbers were due to clashes with hospital appointments, car servicing and other unavoidable activities.



Joan did an excellent job of researching how to play Beetle (because it was so many decades since any of us had last played). She also supplied dice, shakers, pencils and paper.

After several frenzied games, as you can see, I was so hot I had to take off my jersey. You forget how physical shaking a dice can be, so we were all in need of our tea and coffee at half time.

It was a great laugh and everyone had super fun. Joan was there again to present the winner with the first prize of a packet of sweets and the joint 'booby prize' winners with chocolate animals!

It took us all back to when we were a lot younger. We can recommend it to other Branches as a way to pleasantly pass a rather dreich afternoon.

Alex Spence

Paisley Branch

Paisley visits the Kelpies

This year we've had one of the best summers in a long time. When it came to choosing a venue for our summer outing.

- Let's go visit the Kelpies and the Falkirk Wheel
- We've not been for a while

And so the decision was made. The date was set, the bus booked – all arrangements made. Then the weather collapsed! It wasn't wet, but it was cooler and a bit breezy. We all enjoyed our trip on the wheel. On returning to the visitor centre, we discovered that the only accessible loo had been put out of order. Even on a Branch trip I can't get away from accessible toilets and their issues!

We shortly moved on to the Kelpies and fortunately the accessible toilets there were newer and were well appointed, apart from having a mirror! Not much to complain about but added a Euan's Guide card to ensure that it stayed that way. The Kelpies site is a bit exposed, so our visit was not as long as it might have

been, plus we wanted to make sure that we reached the restaurant for our evening meal on time.

We had a fabulous meal at The Boardwalk, which has a lovely nautical themed decor and an amazing accessible loo, complete with two mirrors (for standing and seated users). We all ended up stuffed – the food was excellent and portions very generous. We look forward to another visit to try more of it – especially the desserts! [b](#)



Yorkshire Region

Members of the Region got together on Sunday 16 September to have tea, chat and make a poppy. Artistic skills came to the fore as members were presented with red and black felt; red net; crepe paper; wool; knitting needles; crochet hooks; and of course a pattern.

There were some very serious faces, as concentration was obvious; but there was plenty of laughter too, when things didn't go quite to plan.

A good afternoon of Fellowship was had by all.

Yorkshire Region Boccia and Kurling

Boccia and Kurling days are always eagerly anticipated and the members had to wait quite some time to play this year. Our original date was before the last National Games and would have been a good practice for the competitors, but the venue had heating problems so the event was rearranged.

As usual it was very competitive but with lots of banter – some helpful and some not so much!

It was really nice to see members who have never played before having a go, and in one case coming second in the competition. Congratulations to all who took part, it was another good afternoon. **b**

Wakefield Branch

The members of Wakefield and District Branch continue to enjoy monthly lunches. If any member of Wakefield would like to attend, please contact Jan Taylor on 07592 045536.

We meet at 12.00 noon:

Thursday 8 November – Turnpike, WF11 0BU.

Thursday 13 December – Christmas party at Rustic Arms, WF7 7EZ.

There are menu choices for this event, so please contact Jan no later than Friday 30 November, if you wish to attend. **b**

North East Lancashire Branch

Some of our members had a four night break to Blackpool staying at the Queens Hotel, which gave us great views of the sea and good access to South and Central Piers and the promenade between. Whilst there, we enjoyed good weather, the 'lights' and of course the opportunity to look around the shops.

Good Fellowship was enjoyed by all and a chance to make lots of fond memories. Thanks go to the 'Ron Scudamore Trust' for financial help with the cost of this Branch holiday.

Regards

John Brear
NE Lancs Treasurer



Merseyside Branch

A big thank you to Gill and Mike Griffiths for all their hard work in organising another successful fundraising event.

The annual 'Race Day' was attended by members from the North West Region who were given the chance to show off their skills in picking a winner from the afternoon race card. At the end of an enjoyable and entertaining afternoon, with a break for an excellent buffet, a lot of members may have gone home a little lighter in the pocket; but overall, everyone was a winner. **b**



Cheshire, Wirral and North Wales Branch



The Cheshire, Wirral and North Wales Branch of The British Polio Fellowship continues to provide Regional members with a programme of activities which take account of the progressive challenges in travel and mobility. Simply getting to a meeting is beyond several members; where possible we maintain contact by phone or post and have spent a lot of time discussing what we can do to ease the burden on these restrictions. These are issues which will resonate throughout The British Polio Fellowship and can only get worse.



Despite these difficulties, we have maintained a programme of monthly meetings punctuated by lunches, cream teas and guest speakers. The Central Office Support Services Team has been really helpful in easing our members through the trauma of PIP forms and interviews. The winter months have become a no-go zone for meeting up, although the general morale and spirit of independence remains a bedrock. A series of bereavements did cause heart searching and the outcome seems to be, that come what may, we should use our resources to ensure members can enjoy time together.

The latest adventure was a trip to the National Waterways Museum at Ellesmere Port in Cheshire, which by coincidence was next door to the Holiday Inn hosting the 2018 AGM. A sparkling clear late summer day did a lot to enhance the sight of the spectacular double locks, which take the narrow boats through the heart of the museum on the Shropshire Union Canal. Access through the various elements of the site was surprisingly good and I think most people felt they had a rewarding afternoon, both proceeded and followed by visits to the museum cafe. For those with a little bit more mobility, there was also an atmospheric row of workers' cottages, which were set out to display what was then comfortable enough accommodation from the early 19th century, through to the 1960s.

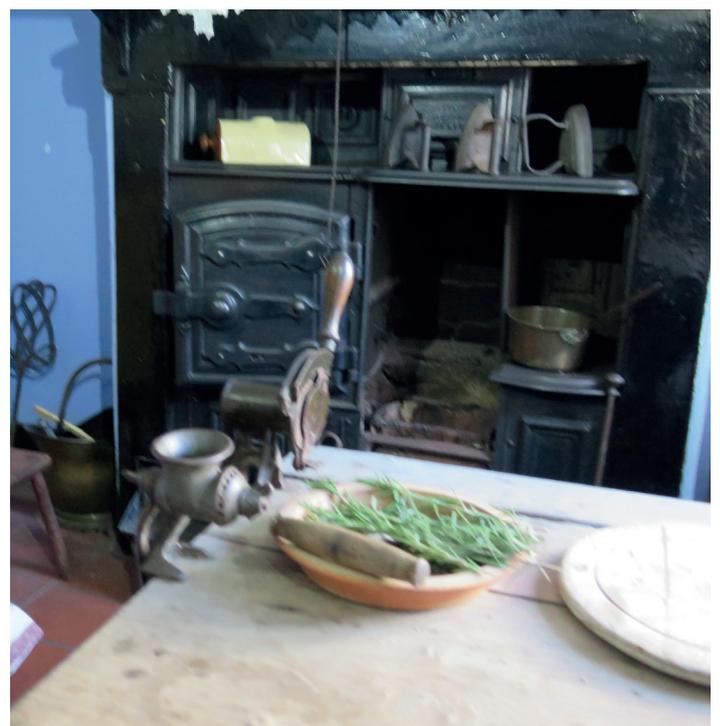
The Branch still engages in supermarket collections, although volunteers are more thinly deployed than ever. It has helped to have leaflets from The British Polio Fellowship which explain Polio and PPS to the public. We still regularly hear of survivors who are unaware of The British Polio Fellowship. We are working on a programme of visits and activities, which we can advertise, and hopefully encourage people to make that little bit of extra effort to enjoy the company of their fellow members.

Best Wishes

Dave Spencer

Communications Officer

Cheshire, Wirral and North Wales Branch



King's Lynn Group



Following Joella's tea party (probably the only day in July to go below 30 degrees), the entourage moved on to Pensthorpe Nature Park in August.

Pensthorpe was host to BBC Springwatch from 2008 to 2010, featuring Chris Packham; Kate Humble; Martin Hughes-Games; and, of course, wildlife. It is owned by Bill and Deb Jordan (Jordans cereals) and some of the products are grown on arable land attached to Pensthorpe. The site is mainly ponds, shallows and marshes with wildfowl, flora and farmland birds and animals.

After our members enjoyed a subsidised entrance, some went to lunch in the barn, while others set off on the many and adequate accessible trails. About half of the site is boardwalk and therefore wheelchair friendly and larger scooters could manage a lot of the rougher trails. A highly recommended day out for anyone: young; less young; able-bodied; disabled; and especially anyone with sensory problems as there are sights, sounds, smells and tactile experiences abound.

The Motability ONE BIG DAY at Peterborough Arena in September attracted three members.

On arrival we asked for disabled parking, but being Motability, everyone had a Blue Badge! They offered shuttle services from every parking lane.

Featuring 52 static cars, 17 test drives with varied adaptations, adaption companies, wheelchair accessible vehicles and scooters and wheelchairs, it was the one-stop-shop for Motability and mobility. Certainly a good starting point if your Motability renewal is soon.

The 'goody pack' issued on (free) entry even contained a measuring tape – handy for checking bumper heights or boot sizes for wheelchair fit.

Our main event for September was a private visit to see the Queen's racing pigeon lofts at Sandringham. We convened for lunch at the visitor centre, where we also welcomed four prospective new members. Afterwards we went in convoy to the lofts.

Peter, the loft keeper, amazed, amused and entertained us for an hour with an insight into pigeon breeding, training and racing. The recently rebuilt loft currently holds about 250 birds (rising to 300 after breeding). It is the Savoy Hotel of pigeon lofts. The Queen's birds have 'ER' on their rings and for other racers, they are the birds to beat ('ER' birds have 17 first places this year already).

Her Majesty takes quite an interest in the pigeons although, unlike her horses, she doesn't know their individual names!

What do you call a homing pigeon that is lost?*

Three group members have formed A Prickly Sub-Group, having bought a Hedgehog or Porcupine, and all are extremely happy with them. Ahmad Butt from The British Polio Fellowship personally visited, measured and went through the operation of the wheelchairs.

Chris and Alan use hoists in their cars, Christine has a John!

Upcoming events through the autumn are the Regional Indoor Games heats; our PPS Day (lighting the town hall) with dinner after; a lunch in November; and then Christmas lunch. Hydrotherapy restarted in September.

To contact the group please email poliokingslynn@gmail.com

Alan Hall
Group Leader

*A pigeon!

Northamptonshire Branch

The Branch Welfare Officer was invited to give a presentation on the hydrotherapy programme to those attending The British Polio Fellowship AGM at Ellesmere Port, Cheshire this year.

Arrangements were made for Kirsten Good, the Physiotherapist responsible for the hydro programme at Northampton, to visit and meet Alex Curtis, the Senior Physiotherapist at the Lane Fox Unit, St Thomas' Hospital in London during September. Alex works for Guy's and St Thomas' NHS Foundation Trust and has had over seven years' experience of working with patients who have had Polio, through the Lane Fox Unit. Along with the Occupational Therapist, Alex carries out the management of the Post Polio rehabilitation groups twice a year. Kirsten will be briefed on the programme with particular emphasis on both the hydrotherapy and gym exercises.

Since the programme commenced in January 2017, there have been over 70, 30 minute sessions. Members from both the Northamptonshire and Leicestershire Branches take part in the programme, assisted by members of the Branch and the Wellingborough Hatton Branch of Rotary International. The training course for Kirsten is being funded by PoPSyCLE.

Funding for the hydrotherapy programme is an ongoing challenge, with Branch fundraising events such as charity rides, quiz evenings etc. along with the continued and generous financial support from Rotary International and

in particular the Wellingborough Hatton Branch members. Invitations have been extended to the Branch to give hydrotherapy presentations to other Branches of Rotary as well as to the Northampton Lions Branch.

World Polio Day, Wed 24 October

Recognising that there may be many Polio survivors in Northamptonshire, particularly those who have become UK citizens from Asia and Africa, who are not aware of the support available from The British Polio Fellowship, a major publicity campaign for World Polio Day was carried in the county during October, with posters, notices in magazines and village / town newsletters, plus interviews on the local radio. Already two Polio survivors have contacted the group as a result of the publicity and it is hoped that over the coming weeks more will get in touch.

Branch Christmas lunch

Barton Hall near Kettering has been booked for this year's Branch Christmas lunch for members. The venue has been selected for its facilities to effectively accommodate people with disabilities.

Monthly Branch meetings

Monthly Branch meetings are held in the Community Room at Tesco Supermarket:

Victoria Park, Turnells Mill Lane, Wellingborough NN8 2EF.

Next meeting: Wednesday 28 November at 2.00pm. [b](#)



Kirsten Good assisting Virginia Olds and other members during the weekly Branch hydrotherapy programme at the Chris Moody Centre, Moulton College, Northampton.

North Essex and South East Suffolk Group

We are still in our infancy and desperately waiting for the Nat West to sort out our bank account, which seems to have been lost in a time warp, between their HQ and The British Polio Fellowship vaults at Central Office, for over 12 months. We struggle on in the hope we can write a cheque before they disappear from the banking world.

As I said just now, we are in our infancy and for most of us that word doesn't describe us at all; we are all young at heart, but our bodies are like an old steam engine which needs a squirt of oil here and there to keep us going and a bit more liquid in the tank to keep up with the leaks. Thank heavens some of us have carers, partners and friends who keep us topped up and lubricated. Also, thank God for the likes of Gates Foundation and Rotary, as well as others, who have gallantly almost eradicated the beast who got us what I call 'Polibloodyo'.

Our founder and supporter Anne Glynn, Lead Neurology Physiotherapist at Colchester General Hospital, continues to spread the word of PPS throughout the UK at Rotary and other events. I know many of you have benefited from Anne's advice, bless her.

We held an afternoon get-together recently in Colchester, chaired brilliantly by Robbie, where

we discussed openly many of the problems we encounter in life, which was beneficial to all present and generated quite a bit of laughter, especially when Robbie demonstrated his method of getting up after a fall.

Perhaps the main point raised and agreed was that most physios do not understand that Polio victims have vastly different methods for getting out of chairs, climbing the stairs and getting up after a fall. I don't suppose it will ever be added to their training, as in 20 years time our numbers will be greatly reduced, but it would be nice if some of them would listen to the reasons for what we do.

Our next get-together is a demonstration of powered chairs and scooters and aids, as well as tea and chat. It will be over by the time **the bulletin** hits your doormat. We all love reading the other Branch, Group and Regional reports and like all of you, we send 'three cheers' to David Mitchell for taking the helm these past few years.

To borrow Winston's well-known motto 'KBO' (keep bugging on).

Roy Birnie

North West Kent Branch

Transport difficulties

Thank you to **the bulletin** for publishing letters and articles about travel for the disabled. The problem in our Branch is being unable to book transport to get to meetings in the first place.

This has now become a big problem for our Chairman, Marion Webb, who spoke about the difficulties of getting to social meetings. Dial-a-ride can rarely provide a vehicle especially for a return journey, although it is requested at the earliest date and time

allowed for bookings. Occasionally they say they can book for only one way. Community vehicles are also difficult to book at times. Black taxis too are sometimes unable to supply a vehicle suitable for an electric wheelchair occupant.

The Branch has now decided that whole day outings are no longer viable, due to the cost of hiring suitable coaches for the few people who wish to go. As a Branch, without the help of able-bodied members to assist both at outings and socials, we increasingly

have to limit our activities to the few Polios who are still able to drive themselves, have a partner to bring them or can use public transport.

Our socials have dwindling numbers attending and there is now a real threat to our future activities. Appeals for more help have been unsuccessful. PPS has taken its toll on us all, together with age-related problems. Those members still able to get to meetings using their own transport or public transport will be limited to local outings in future.

On the good news side, our newest Polio member Pat Rice is arranging talks and games for our socials. Thank you Pat for all your efforts, we are very grateful you are making the socials more entertaining.

William's visit

On Saturday 1 September the Branch members enjoyed a wonderful visitor to their social afternoon; indeed William was very high in the popularity stakes. As a handsome young fellow, he was made a great fuss of by all the members present, accompanied by Richard.

Who were William and Richard? William was a beautiful Labrador puppy accompanied by Richard, a puppy walker, from Kent Association for the Blind. Richard gave a fascinating talk about his voluntary work, not just about walking William, but caring for him until he is ready to be sent for training by the Association. Richard must abide by the rules of the charity and is regularly monitored by them to ensure the puppy is properly cared for at all times. The dog must not be left alone for more than four hours and the volunteer gives basic obedience training, all done by giving him rewards; everything is done in the kindest way to encourage the puppy to enjoy life while he is learning. The puppies have regular exercise and fun with their walkers.

Richard talked about the work he did with William, who happily slept at his feet. Afterwards, the dog made a great impression as he went round the delighted members who were allowed to stroke him. Richard pointed out that a dog which has been trained, and is working with a blind person, should never be touched without the permission of that person. **b**



South East Kent Branch



Pictured: (L-R) Viv; Shirley; and Sue.

During one of our monthly lunches in July, and on one of the hottest days of the year (just a memory by the time you read this), we had 22 of our members enjoying an air-conditioned room at The Plough, just outside Dover. We spent a lovely afternoon, cooling off with good food and company. Of course, we all know those cheeky ones who make every meeting a joy and full of laughter and today was no exception: from left to right, we have Viv; Shirley; and Sue, just to show what wise little monkeys they are to be members of our Branch.

Our annual Medway cruise was cancelled earlier this year due to high water, so we rebooked for August when, after a lazy lunch at the Wateringbury Inn, we all auditioned for 'Chorus Line' posing by cars and boats whilst waiting for the Kingfisher craft to arrive.

Once aboard, Sue, John and Mark (pictured) were able to take the tiller and we passed peaceful hedgerows and very choosy swans who are now fed with pellets rather than loaves. There was lots of waving and blowing kisses to passing boats and fishermen but sadly we didn't spot a kingfisher during the trip. The boat has a wheelchair lift, so everyone can get in and out of the boat in comfort.

Our Branch covers the areas of Sittingbourne; Medway; Romney; Canterbury; Maidstone; Hythe, Dover; Sandwich; Herne Bay; and all the Cinque Ports. It's 'have fun will travel' (see what I did there, if you're old enough). So, next summer we are planning to link our monthly lunches with visits to gardens and

stately homes, take rail trips and go to other tantalising attractions. We have all become firm friends and regularly welcome returning members and newbies. If you fancy a new lease of life and the friendliest mob you could imagine, come and join us. We meet every month throughout the year on the fourth Thursday (except in December).

Our next lunches planned for the rest of the year are:

Thursday 22 November – Table Table, Dover seafront.

Tuesday 11 December – Christmas lunch at Farthingloe, Dover.

(All events start at 12.00 noon).

For more information, please email Angela or phone The British Polio Fellowship on 0800 043 1935. [b](#)



North London Branch



Pictured: (L-R) Jenny Wootten and Mike Egan.

Branch member Jenny Wootten's South African adventure 2018

I would normally spend my birthday, drinking afternoon tea.

But this year for a change, I thought I'll go to the Kalahari!

It's a long way to go for a cuppa, but the wild life is there all around.

There are big cats, wild cats and meerkats, which live in a hole in the ground.

What with the bee-eaters, chanters, and bulbuls, boubous and weaver birds too.

To work out what you're seeing is really quite hard to do!

And if you should go there via Cape Town, there are flowers a plenty to see,

And even you know, a penguin or two, which is just perfect for me!

Jenny Wootten

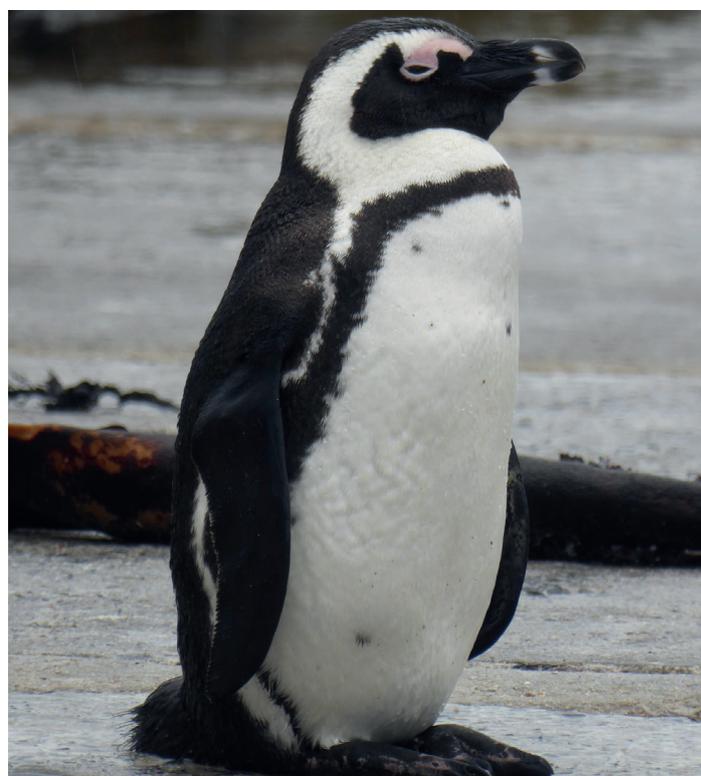
Jenny is our President as well as Branch Treasurer and this year, at her first attempt, won a bronze medal in scrabble at the National Games.

Forthcoming events

Saturday 10 November – Fish and Chips plus film show 'Paddington Bear 2' £5 charge.

Saturday 15 December – Lunch/Christmas Party to be held at the Jim Macdonald Centre, Hatfield. 12.30pm arrival time for tea/coffee.

Janet Drinkwater
Social Secretary



Essex and East London Branch



A picture's worth a thousand words

In the spirit of this well-known adage, we offer a pictorial review of a few of our activities this year.

For some of us the long, hot summer was a mixed blessing. However, 30 plus members braved the heat and found sanctuary in the shady walled garden at Link Place where we met for our annual BBQ.

Thanks to treasurer and designated photographer Mark's excellent photos we can see that meetings of the Essex and East London Branch are all about relaxation, fun and friendship. Of course, the BBQ (and to be honest quite a few other meetings) do focus on good food. This year, for the first time, an outside caterer was used to provide the BBQ food. This proved to be an excellent decision, as the quantity and variety of food provided was approved by all. Thank you to Pat, the caterer, for providing fare which was delicious and appropriate for all tastes.

A further big thank you to the volunteer helpers, Shirley Allerhand and Ila Patel, whose work greatly contributed to a thoroughly enjoyable day.

A family that eats together, keeps together

Recently we were able to demonstrate the truth of yet another adage. An excellent afternoon tea, together with live music was enjoyed by all. This event was dedicated to a celebration of the life of one of our

founder members, who passed away during this last year, and we were delighted that members of her family were able to join us.

Of course, the Branch meetings are often devoted to other issues but this year has been especially joyous and celebratory. It has also been a great pleasure to welcome new members.

If you would like to find out more about our Branch, contact our Membership Secretary, Malini, on 020 827 0231. **b**



Worthing and Sussex Branch

Dates for your diary:

Saturday 17 November – Get-together, Durrington, 2.30pm.

Saturday 8 December – Grand Draw, Durrington, 2.30pm.

Saturday 19 January – Get-together, Durrington, 2.30pm.

Chairman's comments

We invited the Berkshire Branch to join us to celebrate our 65th Anniversary at our annual lunch at the Windsor Hotel in Worthing. The 55 guests enjoyed a super three course meal of salmon mousse; roast lamb; apple crumble; coffee, – and struggled to decipher Barbara Stephens' picture quiz and then the huge raffle took £204.40!

We welcomed Ahmad Butt and his wife Asifa as our guests of honour. In his speech, Ahmad explained his new role within The British Polio Fellowship as the BPF Trading Manager, having left his position as Head of Support Services. His aim is to now produce an income stream from the sale of 'our' two fold up electric wheelchairs – Hedgehog and Porcupine.

The afternoon finished with the presentation of a specially designed bone china mug to all our Branch members, celebrating our 65th Anniversary.

I am sorry but yes, it's that time of year again, can it really be so soon, where did the year go to? Jingle Bells – five Christmas draw books enclosed. I am sure I heard someone say, "Goody goody!" This year we do have 20 very special prizes to be won, ranging from a 32" TV; a cream tea at a top hotel; two bottles of wine and one bottle champagne. Amazingly, the draw books still cost a £1 a book, so please return the stubs with your cheque for £5 made out to The British Polio Fellowship. This actually goes some way towards paying for the copies of the newsletter (actual cost with postage is about £10 a year). If you do not agree with raffles, a donation would be most acceptable, and of course if you can sell more tickets, I would be delighted to post them to you. As always any suitable prizes would be very welcome.

The flag day season has now ended. The last one in East Grinstead was £81 up on last year, with the year's total being up £290 to £2021. So, well done and thank you to all the flag day team and especially our driver Steve Jones, having completed two years with us. Sadly, East Grinstead didn't provide the best fish and chips this year, and on reflection perhaps Chichester was the best, enjoyed in the crematorium gardens! Our last outing was a pub lunch at The Coach and Horses on the A27 at Clapham. 25 of us enjoyed a full and varied menu and were very pleased with the service. It must be very difficult to cope with possibly 25 different meals, and there was a nice buzz of conversation and 'contentment' amongst members! 



Celebrating our 65th Anniversary at the annual lunch.



Worthing and Sussex Branch ... *continued*

My allotment rather suffered in the heat this year. The broad beans were hard and empty; the peas a complete waste of time. But I actually got my money back on potatoes and cucumbers. I learnt that if you leave a marrow too long to grow bigger, it also turns into a brick! However, the plums and apples look like being a record harvest this year. We are now looking forward to our winter programme of get-togethers. Our new Entertainments Officer has several ideas to amuse us with. One last plea, I would be delighted to receive any suitable prizes for the Christmas draw. Please just drop them in or bring them to any get-together.

Bob Stephens

Visit to the Royal Pavilion, Wednesday 4 July

After a lovely coastal coach ride, we arrived in Brighton and parked behind the museum and concert hall. After alighting, we all made our way into the grounds where Gill gave us details of the visit. We sat and had our packed lunch with Clare; Maggie; Roger; Peter and Cora. At 12 noon, we met up with Gill and the other members for our tour. As Peter Thwaites and I had our buggies with us, which were not allowed inside, we had to transfer to wheelchairs, no problem, I could relax while Roger pushed.

The Royal Pavilion is a very impressive building, but this was not always so. It was originally a modest house that was purchased by George, Prince of Wales as a seaside retreat for his health. The house was extended in 1787 into a larger building called Marine Pavilion. George loved horses and carriage driving so he built a magnificent stable complex. (This is now the museum and concert hall.) So elaborate was this new building, that it overshadowed the Marine Pavilion. In 1815, George, now Prince Regent, employed architect John Nash who came up with what we know today as The Royal Pavilion. This building took seven years to complete and was designed in an Indian style, hence the minarets and domes on the roof.

The first room we came to was the magnificent banqueting hall. On looking up you could see the huge domed ceiling, made up of hundreds of shell-shaped mother-of-pearl tiles.

From this hung a 30' chandelier, which in itself hung from the claws of a silver dragon. Below, six smaller dragons breath light through Lotus glass. Back then the chandelier would have been lit by oil lamps and candles. In the centre of the banqueting hall was a table with seating for up to 40 guests. The table was set with crystal glass and gold cutlery. All around the room were frescos depicting Chinese domestic scenes. George loved Chinese inspired art; it was very fashionable at the time, and this included wallpaper lacquered furniture and lots of bamboo.

George was obsessed with food and fine dining and would employ the best chefs. At one time, a banquet was held which included 36 main dishes and 32 side dishes. After going along a very long corridor, we emerged into the bedroom of George IV. It was decorated throughout in gold and green. His bed, so we found out, had a mechanism which enabled the bottom of the bed to be lifted up, like our electric ones today. He also had a secret door in the wall that led to his toilet and another which led to a plunge bath.

An arson attack in 1975 badly damaged the elaborate music room and it was closed for a number of years. Then, in the great storm of 1987, a ball of stone was dislodged from a minaret and crashed through the restored coiving causing more damage, but this was also repaired and the music room is fully restored. I couldn't go up to the next floor but Roger did. 



THE CORDWAINER

Does your footwear reflect your lifestyle?

Does your independence and pride have to take a back seat when it comes to footwear? Is there someone you can go to who understands that the quality, comfort and appearance of your footwear is important?



I am Philip Taylor

- I live with the effects of Polio.
- 30 years in the trade.
- Member of The British Polio Fellowship's Specialist Orthotics Panel.
- I specialise in taking on the most difficult footwear for disabled people.
- Limited home visiting service.

My promise:

- £50 donated to The British Polio Fellowship for each new footwear order. (£25 for returning customers)*
- To support you if you want to have the footwear I make supplied through the National Health Service.

* Applies to all orders 1 month from magazine print date.

Tel: 01433 621623

Email: thecordwainer@hotmail.co.uk

www.thecordwainer.co.uk



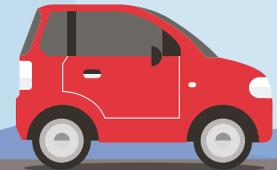
Fish Insurance is proud to be working in partnership with the British Polio Fellowship

Specialist Car Insurance from Fish

KEY BENEFITS AT A GLANCE*

- ✓ Breakdown cover with Home Start included as standard
- ✓ Cover for the repair and replacement of adaptations to your car
- ✓ Free courtesy car or up to £700 mobility allowance if a suitable car is not available
- ✓ If your car is stolen, any settlement will take into account modifications
- ✓ Protection for your wheelchair or other mobility aids carried in your car

A donation will be made to the British Polio Fellowship for every Fish Insurance policy sold



fish
INSURANCE

Call us now on
0333 331 3844
www.fishinsurance.co.uk/bpf

Calls to 0333 numbers are usually chargeable at a local rate from both UK landlines and mobile phones. These calls are usually included within network providers' "free minutes" packages. Lines are open Monday-Friday 9am-5.30pm. Calls may be recorded and monitored for your protection. The British Polio Fellowship is an Appointed Representative of Fish Administration Ltd Trading as Fish Insurance, which is authorised and regulated by the Financial Conduct Authority. Fish Administration Limited is a company registered in England and Wales with company no 4214119. *Limitations and exclusions apply.

Would you like to advertise in *thebulletin*?

For more information please contact **Kripen Dhrona** at Central Office on 0800 043 1935



British Polio Fellowship

THE
ABLE[®]
LABEL

*Stylish clothes,
easier to dress*

Alterations available

No fiddly fastenings

No overhead dressing

Easy free returns



10% off

The Able Label
easy dress clothing!
Use code
BPF1939



NEW RANGE: REQUEST YOUR CATALOGUE

☎ 01622 744242

💻 theablelabel.com

Worthing and Sussex Branch ... *continued*



This consisted of bedrooms, one of which had a bed with quite a number of very thin mattresses on.

While he was up there, I noticed that all the handrails on the stairs were originally made from bamboo. When Roger came down we left via the shop, collected my buggy and made our way to The Lanes. Not at all how I imagined. On our walk we met up with Mogs and Kerry who had driven down. All too soon it was time to get back to the rendezvous spot and wait for our coach home. It was a very nice day.

Janet Jones

Dorset Branch

Greetings from Dorset

We welcomed a good number of Group members to our social on Sunday 12 August for afternoon tea and chat. We played a couple of games of bingo before tea was served and then the chat resumed. It is always lovely to have time to catch up with each other's news.

On Sunday 9 September we had a social entitled 'Let's Talk About Polio'. We discussed PPS with an emphasis on the symptoms and how to manage them. Our group members asked for a follow-up discussion on PPS after our very successful meeting last year. This year, as last year, it was an in-house discussion with no outside speaker. Richard Ashwell and Rhona Benton presented a list of symptoms and taking each one in turn, the group discussed ways to cope and reduce the discomfort. It was very interesting to hear how other people manage their symptoms, and the feedback after the meeting was very positive, with various members saying they had found the discussion very useful. A fuller report of the meeting will be in our Dorset Branch newsletter.

On Wednesday 26 September we enjoyed an afternoon cream tea at Haskins Garden Centre and on Thursday 25 October we celebrated PPS Day with a meal at St Leonard's Hotel.

On Sunday 14 October we had a talk entitled 'Christchurch – A Smuggling Town' at our usual venue and on Sunday 11 November we will watch the film 'Breathe'. It is a biographical film about Polio survivor Robin Cavendish, who was paralysed from the neck down in 1958 aged 28.

Retro Rita joins us on Sunday 2 December to sing and entertain us at our Christmas social. Please note this is the first Sunday of the month.

We hope you are keeping well and look forward to seeing you at our monthly meetings. If you live too far away to get to a meeting but would like to receive a Dorset Branch newsletter, please contact Rhona Benton on 01202 484532 (rhobben@aol.com) or Richard Ashwell on 01202 668329.

Very best wishes

Jose Wood and Rhona Benton

The Ron Scudamore Holiday Programme

The programme originated from a legacy made by our former Chairman, Ron Scudamore. Ron served as our Chairman in the 70s.

At one time Ron used to run the Western Region holidays and he always believed that it was important that members could enjoy affordable and accessible holidays. He wanted his legacy to be used solely for this purpose and so the Holiday Programme was born.

Since the programme began we have helped pledge over £180,000 to help people enjoy a much needed holiday or break.

Grant Applications

How it works

The maximum grant that you can apply for is £350 towards the cost of your holiday or break. You can holiday in this country or abroad and it can be used towards the hotel or flight. To request an application form or for further information please contact Dawn Grafetsberger on 0800 043 1935 or email: dawn@britishpolio.org.uk

Once we have received your application, it is considered at the next Grant Review Panel which meets every two months. Please remember to send your application in well in advance (see box below as to when to submit your application for consideration). After the Grant Review Panel has met you will be notified in writing.

Please note that your holiday departure date needs to be at least six weeks after the relevant panel meeting. Grant pledges are not paid retrospectively.

You can apply for a grant once every two years.

Applications Received	Review Panel Meets	Earliest Grant Payment
1 Nov - 31 Dec 2018	Mid Jan 2019	Mid Feb 2019



Burnham bungalow

Following recent Structural and Health and Safety surveys, it has been determined that the holiday bungalow in Burnham will require substantial investment. The Trustees will need to address

how to manage this in the current financial situation. As we are not sure how this will progress, we are not currently in a position to take bookings for 2019. We apologise for any inconvenience or disappointment.

For further information please contact Dawn Grafetsberger on 0800 043 1935 or email: dawn@britishpolio.org.uk

My Way – D Ivan James



Ivan as a child has a clearly affected right hand, and is already suffering from a scoliosis.

One of my earliest memories is of lying in a hospital bed looking at my mother on the other side of a glass screen and wondering why she was crying. It was the summer of 1932 and at the age of three, I was recovering from Polio in the Royal Gwent Hospital, Newport, Monmouthshire. The large doors at the far end of the ward opened onto a flat roof and on sunny days they wheeled us out into the sunshine. They put blue hats on the boys and pink bonnets on the girls. I was a curly-headed blonde boy and I can remember being very offended because they put a pink bonnet on me.

My recovery was slow but eventually I was taken home in a pushchair, unable to walk. I received no treatment or physiotherapy, only gentle encouragement, and gradually learnt to walk again. I was fortunate in that I recovered the use of all my limbs. Later, I was told that about 60 per cent of my muscles were affected and this left me with a scoliosis, a shortened left leg and a damaged right hand, which affected my writing. In school, a typical staff comment was, "This looks as though you have written it with a six inch nail". At the age of seven, my mother had me taught to play the piano, which greatly improved my dexterity. Later, as a teenager, I was deputy organist to

Mai Jones (the composer of 'We'll keep a welcome in the hillside') playing not only at services but weddings and funerals as well. In recent years, I learnt to play tenor horn with a local brass band.

At the beginning of the war, Alexandra School, which I attended, was requisitioned by the Army. It was arranged that we should attend the nearby Tredegar Wharf School, but since we were classes of forty, and probably they were too, it meant mornings or afternoons in alternate weeks. We were taught arithmetic in between the air raids and following the eleven plus in 1940, I was awarded a scholarship to attend Newport High School. War time education was excellent and by the age of thirteen I was being taught calculus, trigonometry and analytical geometry. In 1947, I was awarded a state scholarship, tenable only at the University College of Swansea, to study physics. It was at Swansea that I met my wife Anne, who studied English. One of the lecturers was Kingsley Amis and Anne's claim to fame is that she once baby sat Martin Amis.

Most of my working life was spent at the Rubber and Plastics Research Association, where I studied the frictional properties of polymers and also trained as an electron microscopist. Later, I was elected Fellow of the Institute of Physics and a Fellow of the Royal Microscopical Society. In the late 1970s I became very ill and was passed from one neurological hospital to another, where I noticed how troublesome the flooring surfaces were to those of us with disabilities. The general opinion of my problem was that it was just the late effects of Polio. Fortunately, Mr RS Cowie, a surgeon at the Robert Jones and Agnes Hunt Hospital, diagnosed correctly that I had had a prolapsed disc for several years. He operated and some months later I was able to return to work, where I resolved to establish tests and standards for flooring and sought co-operation from the Health and Safety Executive, several other research laboratories and members of industry. Eventually, standards and test methods were published which are now internationally recognised, improving safety for all pedestrians, including those of us with disabilities.

D Ivan James FInstP FRMS

Please send your My Way submissions and photographs to thebulletin@beyondpr.co.uk

As space is limited, regrettably we can usually only publish a maximum of 600 words and only one or two images.

Classified For sale



Alpha Powerchair

With charger and manual.
Bought from Betterlife in
August 2017 Never been
used, still in the box.
Cost £1,000, will accept £500.
Tel: 01394 460519.
Suffolk area.

SDL Assist power wheel chair JW 11

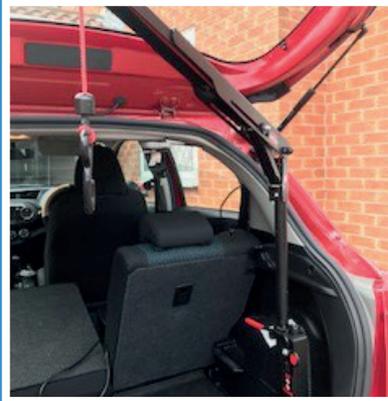
Very good condition. Serviced
annually by SDL, complete with
battery and charger. Owner's
manual included.

£750.
Tel: 01283 790348.
Staffordshire area.



FOR SALE

Hoist previously fitted in a Toyota. £350
Tel: 07825 587655. Collection, Mansfield area.



NURSING HOSPITAL BED WITH RAILS

(Manufactured by days healthcare nursing)

- With manual for assembly and adjustment controls
- No mattress supplied
- Minimum price of £100

Contact 07890 107988 or
Julia.willett9@gmail.com
Bedfordshire area.

Macnish chair raiser

- Black
- Will fit underneath most armchairs and raises the chair up and down with a remote control
- Approx. 10 years old and works perfectly
- Check out the Macnish video on YouTube for more detailed information
- £50

To be collected from East
Grinstead, Sussex area.
email: julie.hillyer@hotmail.co.uk

Good News!

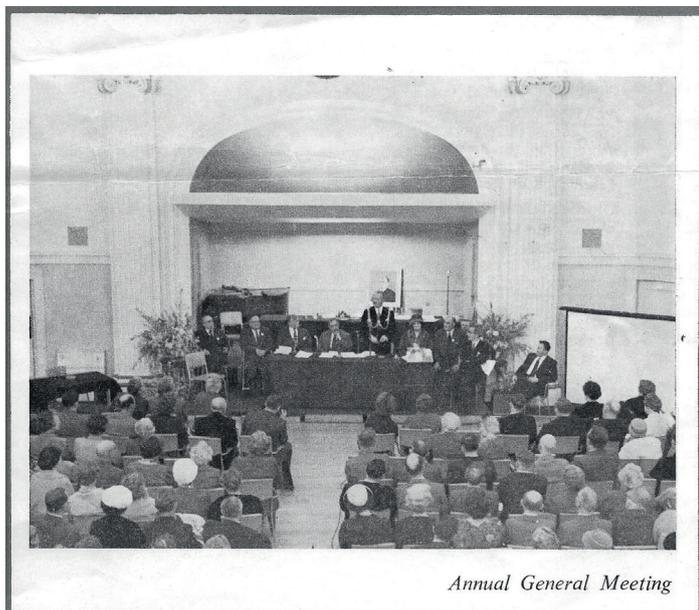
the bulletin deadline extended

In order to allow Regions, Branches, Groups and all members to send in their festive good news, the copy deadline for the New Year edition of *the bulletin* is being extended to **Monday 17 December 2018**. We hope the change is appreciated all round!

Email: thebulletin@beyondpr.co.uk

Many thanks for supplying a photo with this Classified ad, it is really helpful to members. If anyone else wants to send in photos with Classified ads, please do, and we will endeavour to include them. Ed.

History Corner



An old photograph of an Annual General Meeting November 1961.

For the last issue of *the bulletin* of 2018, I am returning to the scrapbook and materials sent by Harry Crews. I think I have held on to them long enough. So, one last article and then they can go home, with my very grateful thanks.

What to write about? Well, as I write this, the AGM of The British Polio Fellowship is only days away, so it seems only right that I try to find something of interest from an AGM of days gone by.

The November 1961 issue has several pages devoted to all the reports and decisions of that year's AGM. I'm going to concentrate on two reports by the then National Chairman, Dr Eric Johnston. The first report related to a biennial conference of the European Association against Poliomyelitis, which had met in Oxford that year. The Association allows medical experts, both clinical and research, to meet, compare notes and discuss the position of the war against Polio. This sounds like a forerunner of the EPU.

Anyway, Dr Johnston comments on the wide variety of papers presented at the conference and the discussions, even arguments, that took place around them. But he was equally impressed with the optimism and "belief in the fundamental sanity of the

peoples of the world". This was at the height of the Cold War between East and West, so quite a startling statement to make, despite being close to a potential nuclear catastrophe, which threatened to engulf many people across the globe. The conference allowed representatives of many of the main protagonists to gather together. Dr Johnston recounts telling a Polish specialist in rehabilitation, about progress being made in the treatment for the ordinary disabled person in the UK. Representatives from both sides of the Iron Curtain were able to talk together about how to conquer the Polio virus, responsible for killing and maiming so many across Europe. This included reports of vaccination programmes in both East and West Germany, so soon after the creation of what was to become the Berlin Wall.

Several papers commented on the extensive use of the live vaccine in Russia and Eastern Europe, and its satisfactory results, leading to the Russian representative forecasting the complete conquest of Polio. A paper presented by the Polish representative, advocated periodic spells of further physiotherapy and exercises throughout life, for those more severely disabled. Dr Johnston was not convinced. Given what we now know about PPS, perhaps Dr Johnston was correct in that repeated exercise would not be beneficial in the long term.

The second report from Dr Johnston, which was what had first caught my eye from this issue, related to 'aqualung swimming'. A practical demonstration of this had been attempted at The British Polio Fellowship's National Swimming Gala, held in Brighton, but this had apparently not been as successful as hoped. This report was an attempt to explain what it was all about. For those of you who have an arm disability, you will be aware of the problems trying to swim, with the exception of swimming on your back. The alternative, as Dr Johnston attempted to demonstrate, was underwater swimming.

Apparently aqualung swimming is not difficult. Anyone used to swimming should be able to get on with it. An unresponsive arm is generally very little bother under the surface. Flippers, even

when attached to a paralysed foot with only weak hip movement, can be of considerable help. Dr Johnston recommended it as a "Grand sport".

Dr Johnston did point out certain potential dangers. It should not be a substitute for learning to swim and was recommended only for those at home in the water. It was hoped that anyone trying aqualung swimming would do so under supervision of a swimming instructor, a member of the Sub-Aqua Club or of the Aqualung Centre, Dartmouth. The swimmer would be using flippers, snorkel tube and face mask.

Due to the complexity and dangers involved, a medical certificate was required before attempting this sport. It was not recommended as an option for those more seriously disabled and certainly not for anyone who had residual breathing problems.

I wonder what interesting items will turn up at the 2018 AGM. As ever, I love to hear your memories and see your pictures to share with all our members.

If you have memories to share, they can be sent to bulletinhistory@outlook.com or to Georgina Hay, 31 Ayr Road, Cumnock, KA18 1DZ. **b**

Book review by Shirley Russell

Stretching the Boundaries – Sideways
The story of a side-saddle champion.

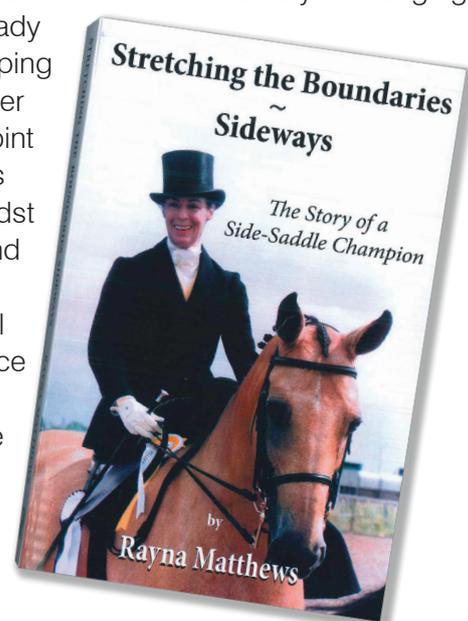
Authored by Rayna Matthews.

As a young woman, Rayna Matthews was severely disabled by Polio, so she could no longer ride the horses she loved without acute discomfort. In a trot, her legs would go into painful spasms. The solution came when she was introduced to Cecily Friar, a founding member of the Side-Saddle Association. From there she never looked back. Training hard to perfect her skills as a horsewoman, she eventually succeeded in qualifying for the national team and represented Britain for many years in international dressage. After retiring from competition, she continued to be involved in the sport as a trainer and judge. Side-saddle has great advantages for people with a variety of disabilities, and Rayna has been one of its most enthusiastic champions, helping to set up TRADISSAR, a charity devoted to training people with disabilities in side-saddle riding.

Below is a review of Rayna's biography by Shirley Russell. The book came out on 25 May priced at £10.95. This book would appeal to those associated with the dressage world and with a love of horses. Many of the names mentioned went over my head. The only thing the author and I have in common was that we both contracted Polio.

Little was mentioned about Rayna's limitations. She was a very determined lady and with the help of her devoted husband, friends, colleagues and the goodwill

of 'the industry' her dreams and ambitions were realised through hard work and perseverance and many times with a twist of fate or leap of blind faith. With that and the connections she had made, she was able to help many other children and adults who would not otherwise have experienced freedom, joy, self-worth and acceptance in a society that can at times be quite harsh and limiting. As she remarked, she knew from experience how an animal can change a person's life. After giving up her competing years, she, along with her husband and army of friends and helpers, set up education programmes supporting young people with a wide spectrum of illnesses, learning difficulties and mobility issues. This was at times very challenging with charities already established in helping disabled riders. Her stamina at one point astounded me, as she was in the midst of this busy life and also working. To this day she is still making a difference by giving joy to those who find life challenging. **b**



Book released 25 May priced £10.95.

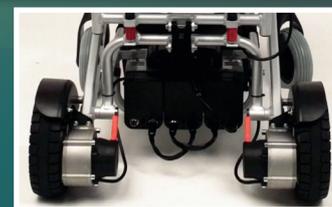
Email: books@ahstockwell.co.uk

Tel: 01271 862557.

The Porcupine

A heavy duty portable and compact folding electric wheelchair - SQPC-08A

Price
£2250



The battery can quickly be released from the frame see the retracting clip under the battery.

- Heavy Duty
- Compact
- Portable

Our second wheelchair product informally named the 'Porcupine' joins our excellent selling 'Hedgehog' from BPF Trading Limited.

At an unbeatable price of £2250.00, the Porcupine comes supplied with 3 batteries and a second year warranty, underwritten by Fish Insurance.

Designed for our larger framed customers with a carrying capacity of 180kg (over 28 stone!) It has wider seat, up to 18" (450mm) and an adjustable backrest. It weighs only 25.3Kgs (55lbs) with 1 battery. (But we will supply every chair with the maximum capacity of three batteries)

The Porcupine is a more heavy duty but still very compact and portable wheelchair.

It can be folded and opened in literally a couple of seconds!

The Porcupine comes with a charger (110V-250V) and international adapter so you can use it with most socket types in the world.

Warranty	2 years - (Includes supplementary warranty)
Seat Width:	450mm
Seat Height:	470mm
Backrest Height:	400mm
Net Weight:	25kgs with one battery
Weight Capacity:	180kgs
Caster:	8"x2" shock absorbing rubber caster
Rear Wheel:	10"x2" width caster or 12"x2" width caster
Motor:	250WX2 Brushless motor
Battery:	Lithium battery, 24V7AH
Max speed:	6kmph
Gradeability:	12degree
Charging period:	5 hours
Endurance:	10km/per battery (Supplied with 3 battery - max capacity)
Overall size:	918 x 603 x 892 mm
Folded size:	668 x 603 x 324 mm

Call us now on
0800 0431935
or email
info@bpftrading.co.uk

