

Asda Community Scheme

- We recently received a cheque from Wythenshawe Asda from their green token community scheme.
- Did you know you can nominate New Start at your local Asda store? Just ask at customer services or nominate online.
- Waitrose also run a similar scheme.



Horwich New Heart Club

After 27 years in existence Horwich New Heart Club has finally disbanded. During that time they have raised an amazing £193,880.74

Their activities have included sponsored walks, bowling tournaments, brass band concerts and supermarket collections. From everyone connected with the Charity, we'd like to say a big thank you to all members both past and present who helped in any capacity in this fantastic achievement.



Did you know that whenever you buy anything online - from your weekly shop to your annual holiday - you could be raising a free donation for New Start Transplant Charity?

easyfundraising
.org.uk

There are nearly 3,000 retailers on board ready to make a donation, including Amazon, John Lewis, Aviva, thetrainline and Sainsbury's – it doesn't cost you a penny extra!



It's really simple, all you have to do is:

- 1. Join** Head to <http://www.easyfundraising.org.uk/find-a-cause/> and sign up for free.
- 2. Shop** Every time you shop online, go to easyfundraising first, pick the retailer you want and start shopping.
- 3. Raise** After you've checked out, that retailer will make a donation to your good cause for **no extra cost whatsoever!**

There are no catches or hidden charges and **New Start Transplant Charity** will be really grateful for your donations.

For any donations or contributions to the next edition of the Newsletter please contact:



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www.newstartcharity.org



News Start



The Wythenshawe Hospital Transplant Fund Newsletter

2016

A word from the Chairman

A Happy New Year to you all. Welcome to our new look Newsletter. We now have so much to fit in our Newsletters we have decided to double the size so we can include more articles and stories.



2016 sees the Charity celebrate its 30th year and we are currently deciding how best to celebrate the fantastic achievements made in those years. As soon as it is decided we will let you know. This year will also see our first Heart Transplant using a new system funded by New Start which allows use of non – beating organs. The team here are very excited to be only the third Hospital in the UK to use the system.

"I am always overwhelmed by the generosity and enthusiasm of our supporters"

We have had people running, parachuting, doing obstacles courses, dancing, and acting to raise money for us. There is also a boxing event taking place in March that recipient Joe Jackson has kindly organised for us.

The bungalow refurbishment is now complete and I am sure anyone who has made use of them will agree they are much improved. Whilst we don't charge for their use, many people who use them kindly make a donation, which is always gratefully received.

Enclosed with this Newsletter is some information on our new fundraising incentive – the 200 Club - please have a think about joining as it will be great fundraiser for us and you never know, you could be a winner!

We already have a database with email addresses but if you don't already receive communications direct from us, it would very helpful if you could supply the office (lyndaellis@newstartcharity.org) with a current email address if you have one.

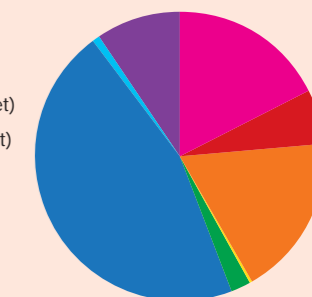
Richard Dyson
Chairman of the Trustees

Projects we have funded in 2015

Providing free TV for patients awaiting transplant on CCU	£2.5k
Purchase of 2 ECMO machines for CTCCU	£60k
Purchase of new lockers for Jim Quick ward	£4.8k
Purchase of a guest bed for relatives on CCU	£1.3k
Refurbishment of the Bungalows	£61k
Purchase of surgical equipment for use during the insertion of LVADS	£13.5k
Diet and Lifestyle Research Projects	£40k
Purchase of new Biopsy Lab equipment	£55k
Grants given to recipients taking part in the British and World Transplant Games	£12k
Funding an Innovative Organ Care System which should allow us to undertake more Heart transplants thus reducing waiting list	£125k
Total	£375.1k

Sources of average annual income (2006-2015)

- General Donations
- In Memory Donations
- Fundraising Events (Net)
- Charitable Trading (Net)
- Gift Aid
- Legacies
- Support Groups
- Investment Income



Research News

Ann-Marie, the Transplant Dietitian, has completed her Master's degree on Clinical Research Methods. The New Start Charity supported her study into improving knowledge on diabetes and pre-diabetes in heart and lung transplant recipients using continuous glucose monitoring. She would like to thank everyone who took part in the study.

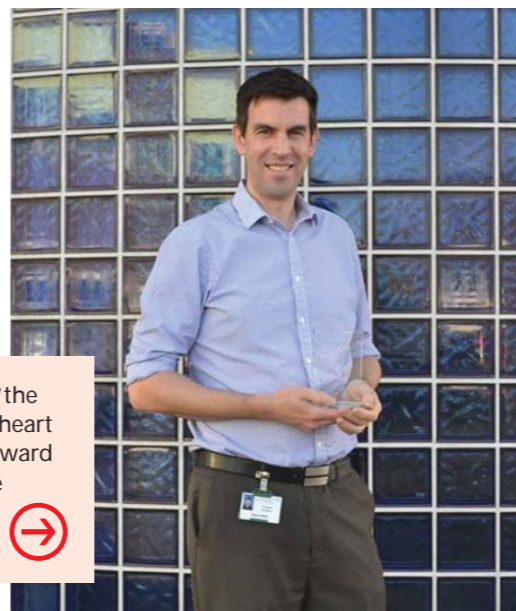


Results of the study found 25% of participants had impaired glucose tolerance (pre-diabetes) that had previously been undetected. In addition blood sugars were significantly higher in the afternoon than morning. Unfortunately most glucose tests are undertaken in the morning and therefore may underestimate blood sugar levels. In addition, a new standard test for diabetes, being HbA1c or glycated haemoglobin, did not detect any cases of diabetes or pre-diabetes.

To help reduce your risk of developing diabetes and pre-diabetes you should try to maintain a healthy weight for your height and keep active. If you are overweight then achieving a 10% weight loss can reduce your risk of developing diabetes by a huge 50%. If you would like support with losing weight please ask your GP or Transplant nurse to refer you to either local weight management services or the dietitians here at the Transplant Unit.

So what does this mean? Although this was only a small pilot study, the findings suggest standard tests for diabetes may lead to delays in diagnosing and treating diabetes. This, in turn, may lead to symptoms such as tiredness, thirst, increased frequency urinating, as well as increasing the risk of complications such as infections, poor circulation, strokes, and worsening kidney function.

Our very own Dr Steve Shaw recently won: "the Pumping Marvellous Foundation", a leading heart failure charity's 'You're Simply Marvellous' award for outstanding patient care. Judging by the high number of comments we had on our Facebook page, you are all in agreement!



LVAD Open Day

On the 30th September UHSM was delighted to host our first Left Ventricular Assist Device (LVAD) open day for patients and their relatives. The day was organised by the LVAD team, including our social worker Jan Withington, occupational therapist Suzanne Butterworth, dietician Ann-Marie Nixon, physiotherapist Laura McGarrigle and psychologist Katy Silverman, and the LVAD coordinator nursing team.



The LVAD Team. (From left to right), Jan, Suzanne, Ann-Marie, Laura and Katy

Little is known in the community about LVADs as they are a relatively new piece of medical equipment, first provided for patients by UHSM in 2010. The implanted left ventricular assist device is a small battery operated pump, which is used to support patients with failing hearts who are awaiting heart transplant. They are suitable for only a few select patients but can provide life-saving support.

The open day provided an opportunity for these patients and their relatives to share experiences and gain further information from the LVAD team. Attendees discussed topics such as travel, clinic appointments, medications and health support outside UHSM.

The open forum provoked honest comments and useful practical everyday tips. One patient commented: "meeting other LVAD patients and sharing our experiences was invaluable"

A family member expressed that the "group discussions allowed my husband to compare symptoms and effects of his LVAD and experiences of living with it"

Not only was this forum an excellent learning experience for the patients but it also provided the LVAD team with insight into real life experiences, helping us to continue to improve our care and service for present and future patients.

Many thanks to all those who attended and we hope to run a further open day in 2016, so we will keep you posted.

Sue Ewings
(LVAD Coordinator)



Following on from the first LVAD open day I wanted to talk a little more about exercise after LVAD surgery. "Exercise"... that word strikes fear and dread into many people. Everyone knows how important exercise is for good health in the general population but that doesn't mean we all do it or enjoy it! After having an LVAD fitted, exercise can help prevent weight gain, improve levels of breathlessness, increase energy levels and boost your mood. BUT realistically we know that not all of you will want to lace up your trainers and hit the gym. A big misconception is that for exercise to benefit your health you have to run on a treadmill or lift weights.

I try to talk to individuals I advise about how to improve their "physical activity" levels. It's all about moving more, sitting less and trying to increase the number of steps you take in a day. These low level activities also have a positive effect on health and best of all you don't need any expensive equipment, fancy trainers or hip hugging lycra.

Some research has shown that individuals with an LVAD typically lead sedentary lifestyles. One study showed LVAD recipients take on average 4000 steps per day, and heart transplant recipients take 6000 steps. Both of these are well below the recommended 10,000 steps per day. Starting to make changes to your routine or activities can be daunting so the first thing I'd suggest is have a close look at what you already do. That way you can set some realistic goals and appreciate it if you do manage to make positive changes. The simplest way is to use a small pedometer to count your daily steps. You can buy these cheaply online or you can download a pedometer app if you have a smartphone (often free) that will count steps, calculate distances, show walking routes and even create graphs of daily activity. Once you know what your current levels of activity are you

can set some small goals to increase them. Don't aim to double your steps in the first week, try to be realistic. Also you'll probably find you tire yourself out and then lose motivation.

Small changes that can add up to making a huge difference include....

1. Parking towards the back of the supermarket/hospital car park.
2. Standing up every time an advert comes on the TV. You can progress this to standing/sitting more times or you could walk around until the adverts have finished.
3. Use an upstairs toilet if you usually use one downstairs.
4. Add 5 minutes on to your dog walk route.
5. Get off the bus one stop earlier than usual.

If you find you have managed to increase your steps-per-day you could aim to increase the speed you walk, add in a few inclines/hills or even join a walking club. The NHS choices web page "walking for health" has some good links and ideas for keeping your activity interesting.

Walking is a cheap activity and one that anyone with an LVAD can try. If you have any questions about what exercise/activities are suitable with an LVAD please ask in clinic or feel free to ask for a face-to-face chat with a physiotherapist. You can also email us on transplant.physio@uhsm.nhs.uk We'd love to hear how you are getting on.

Laura McGarrigle

Transplant Outpatients would like to thank everyone for the numerous cards and presents received over the Christmas period it was very much appreciated.



New Members of Staff

A Warm Welcome to Staff Nurse Nicky Collins, Health Care Support Worker Ciara McClosky, Dr Karl Hayes and Transplant Co-Ordinator Ruth Sutcliffe who have all joined the Unit in the last few months.



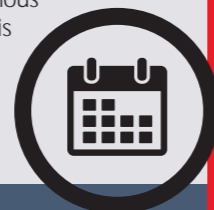
You Are Not Alone

Whether you are pre or post organ transplant, one thing you can be absolutely certain of is that at UHSM you will receive the best possible care and advice from our team of medical professionals and support staff.

However, it may well be the case that you need additional reassurance to help you and your family members deal with any uncertainty you may experience. The University Hospital of South Manchester at Wythenshawe provides a volunteer support group called "The Buddy Scheme." These volunteers have all had organ transplants and are in a unique position to offer valuable insight into what lies ahead.

The "Buddy Scheme" has offered reassurance and support to many patients, who've found the discussions to be of enormous help when dealing with what is undoubtedly a traumatic and emotional time.

ALL patients who have concerns, please collect or request a "Buddy Scheme" leaflet from the Transplant Reception Area, and contact a Buddy of their choice.



The Pre-Transplant Support Group runs every month. Dates as follows:

Thur 4th February 2016 10.15-12.15pm

Thur 17th March 2016 12.00-14.00pm
Easter Lunch at Hare & Hounds, Altrincham

Thur 14th April 2016 10.15-12.15pm

For further details please contact:
Jan or Bev on 0161 291 2695



Meet other people who are having similar experiences to yourself, as well as those who have had a transplant within our service. Family members are welcome too.

Friday 26th February 2016 **LVAD** 10.00am-12.30pm
Wednesday 9th March 2016 **HEART** 9.30am-12.30pm
Thursday 10th March 2016 **LUNG** 9.30am-12.30pm

Venue: Transplant Unit Seminar Room



A Big Thank-you

As a Charity we rely on donations and fundraisers to be able to continue to assist in keeping our Transplant Programme at the forefront of excellence. There are too many to mention but we would like to thank everyone who has contributed in the past months, whether it was by holding a fundraising event, by donation or "in memory of"..

Elizabeth Abbott	Siobhan Duffy	Graham Lamb	Kashmir Singh
Khalil Ahmed	Ian and Betty Ferrier	Wendy Lomas	Anne Stuart
David Ayre	Jay Jay Gallery	Leyland Masonic Fellowship	Angela Smith
Beaverbrooks Charitable Trusts	Yvonne Garrett	Lynda Macklin	Stephen Smith
Sir Jacob Behrens	Mr Hanrahan	Frank Mc Donald	Gary Teare
David and Sue Brydges	Charles Hanson	Patricia Moore	The Village Quilters
Hammond Buckley	Edward Hayes	Carol North	Barry Waddington
Simon Cadenhead	George Hayton	North West Ambulance Service	Meryl Washington
Lyndon Caffrey	D Hodgkinson	Mr and Mrs Olive	Rob Weatherall
Harold Carter	Bill and Jackie Jones	Geraldine Orme	John Williams
Marie Cosgrove	John Jones	Chris Randall	Dilys Wright
Dorothy Daniels	Paul Jones	Diane Thomas	
Bolton Duathlon	Alison Knapper	Vicky Shelley	



Joe Jackson

I became ill in October 2014 at age 23. It was a hard time for me and my family and close ones. My heart failure wasn't diagnosed until weeks after I became an inpatient at Bolton Royal. I was then transferred to Wythenshawe hospital, as it's a specialist heart Hospital. After being told on December the 12th I was on the emergency heart transplant list,

I spent Christmas and New Year in hospital, as well as my girlfriend and Dad's birthdays. I underwent surgery on January 26th after a match was found. I was released from hospital two weeks after the transplant and I am now back to full health and looking to compete in next year's transplant games in Liverpool.

I take part in football five-a-side matches and I box 3 times a week at my old boxing gym. I have recently organised my second charity event to raise money for New Start, after they did so much for me. I'm holding a boxing event at my football club Bolton Wanderers, and I also organised a parachute jump in the summer that raised **£7000**.



Adrenalin Rush

We were lucky enough to have 2 teams taking part in the Adrenalin Rush. The first were a team of friends of recipient, Leaf Petrides, and they raised over **£3000**. The other team was made up of staff members Laura, Ruth, Sue and Dawn.



Suzanne Dagers

Suzanne Dagers celebrated her 21st Birthday in style by holding a Ball in memory of her Auntie Eileen Smith, raising over **£1600**.



Dynamic School of Dance

Dynamic School of Dance in Barrow raised nearly **£2000** at their Annual Dance Show. Simone and Erin Bradbury whose late Mum Lorraine was a patient at the unit collected the cheque in her memory.



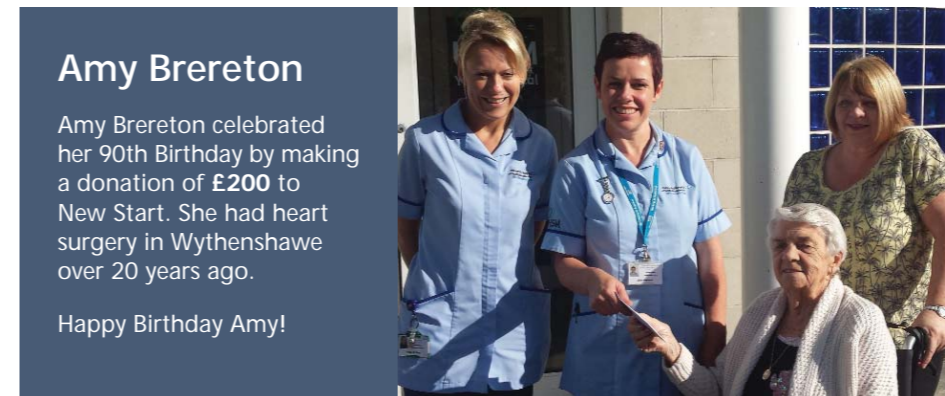
Dave Morris

Dave Morris celebrated his one year anniversary in style and held a fundraising party, which raised over **£1200**.



Jacque Watkinson

Jacque Watkinson cycled the coast-to-coast trail and raised nearly **£600**.



Amy Brereton

Amy Brereton celebrated her 90th Birthday by making a donation of **£200** to New Start. She had heart surgery in Wythenshawe over 20 years ago.

Happy Birthday Amy!

Regular Giving

If you feel you would like to give to the Charity on a regular basis whether it be monthly or quarterly please contact the office and we can send you out a standing order form for you to complete.

Christmas Raffle

Our Annual Christmas Raffle that is run in Outpatients raised **£270**. Many thanks to all who donated prizes. Special Thanks to Pat Derby for making the cake and Harry Gorse for donating the Lamb.

Encore Theatre Group

Encore theatre Group in Castleford, West Yorkshire raised nearly **£800** from their 2015 productions in memory of Craig Walton.

Merridy Shakibai

Merridy Shakibai held a Cheese and Wine evening and raised over **£1000**.

Andy Baird

Andy Baird, 6 months after receiving his new heart, cycled to Blackpool, raising over **£600**.



British Transplant Games - by Paul Ashberry

This year's British Transplant Games in Newcastle/Gateshead undoubtedly set the bar high in terms of all round enjoyment and excellent organisation. The Transplant Games somehow manages to keep growing each year, retaining its aim of spreading awareness and celebrating organ donation and the life that donation gives.



Over 800 athletes take part in the Games with thousands of spectators turning up. This may feel slightly intimidating to first-timers, but each individual event can be condensed into a group of like-minded people getting together and doing something they enjoy. The sheer size of the games comes from adding together the sum of all these different parts.

The facilities this year were great with the Gateshead International Stadium forming a wonderful centrepiece - a venue where not only have 5 world athletic records been set but it's also a place where Jon Bon Jovi has showcased his unique combination of lycra pants and poodle haircut. So with these contrasting images as inspiration such a setting could hardly fail to see competitors reaching new heights of sporting prowess.

As the opening ceremony of athletes, supporters and representatives of the donor families paraded the streets in front of welcoming, enthusiastic locals - and some shop staff thankful for a break - a carnival atmosphere descended on Newcastle; a city which, due to its well documented football failings, is not used to such scenes.

From a personal point of view I went into the games having emerged from a period of poor health. Although The Games can be a means of pushing yourself to new levels of achievement, meticulously training to meet such demands, my own lack of preparation reinforced to me that the games are mainly about hundreds of people getting together, doing their best to inspire, spread the message, try new sports, get better at old ones, make new friends, meet old ones; and all the while celebrate being alive.

Whether it was the adrenaline of competition or my recent poor health hadn't had the negative impact I'd feared, I managed to get through my events without the difficulty anticipated. That is, except for the event that has become the bane of my transplant games experience - the 100m sprint. An event entered twice with tentative seeds of optimism on both occasions, turning up late last year and missing the start of the race was 'bettered' in sheer incompetence this time when I tripped halfway, leading to a less than graceful tumble, and an unanticipated early encounter with the track. I'm not sure what third time lucky would constitute - whether that would be a medal or just finishing the damn thing. There was a time when, like a number of people who've had transplants, being able to run 100m seemed like a dream, so on that score I'll be happy

to cross that finishing line next year and chalk it up as an achievement.

Whatever my future accomplishments, I can honestly say I've found the Transplant Games to be an important part of my recovery from a double lung transplant. I believe exercise, of any level of intensity, is a crucial part of keeping new organs working well. But also on a more abstract, difficult-to-describe level the camaraderie and enjoyment that comes with getting together and competing with people who've endured similar times was a key part of regaining my confidence and helping me come to terms with what I'd been through.

Newcastle/Gateshead was yet another inspirational transplant games - hope to see you at Liverpool.



Volleyball Event - by Lynda Ellis

After attending my first Volleyball event last year in Newcastle as team manager, I decided that with the help of some of the team, there was no reason why Manchester couldn't organise it in 2015.

And once we'd located a venue, and a Hotel that could hold the Gala Dinner, we were halfway there. Now we just had to get some teams and as usual the various centres didn't disappoint, arriving from far and wide to play.

On the Friday night an informal get together was held in the pub for everyone who'd travelled to Manchester. Some of the Freeman team were delighted the 'Boro match was live on television and everyone felt relaxed and ready for the following day. Some of us

retired to bed at a reasonable hour but the Belfast team - having not touched down at the airport until 10pm - decided that as they'd missed out on a few drinks, they needed to keep the bar in profit until the early hours.

Saturday dawned cold but bright (yes the sun does shine in Manchester sometimes) and we all headed to Wright Robinson College (or Wright Robbie as it's known locally) for the volleyball event.

World Transplant Games

Mar del Plata, Argentina - August 2015

As the saying goes 'time flies', so it seems a long time ago that I travelled to Argentina to compete as a member of the Great Britain transplant team, along with 5 other Wythenshawe transplant recipients and one adopted member.

However, I'm reminded that it was only a few months ago that Alan Schofield, Neil McDonald, Andy McGarry, Wayne Lang, Russell Walton and adopted member, Liz Hosford, travelled to Argentina and the city of Mar del Plata where the games were held. Following selection it all sounded a bit exotic, but those feelings soon disappeared when we realised that it was their winter, and shorts and sun cream would not be required.

The World Transplant Games are held bi-annually and the British team is selected following participation in the British Transplant Games, which are held annually. The total membership of the British team in Argentina was just over 200, split almost equally between competitors and supporters.

This was my third World Games, following my heart transplant in 2007, having previously competed in Gothenburg (Sweden) in 2011 and Durban (South Africa) in 2013.

The purpose of the Games is the same as the British Games: to demonstrate the benefits of transplantation, encourage transplant patients to regain fitness, whilst increasing

public awareness of the need for more organ donors, but in a worldwide arena.

Faced with the prospect of a fourteen and a half hour overnight flight to Buenos Aires followed by a six hour transfer by bus to Mar del Plata, I decided to go early with a stopover in Buenos Aires and an internal flight three days later. Whilst Buenos Aires was wonderful a rather turbulent fifty minute flight down to Mar del Plata put me in hospital overnight with labyrinthitis!



Fortunately after 24 hours with drips and jabs I recovered and was able to compete.

My sport is swimming and the swimming competition was held over two days in the middle of the week long games programme. Unlike the British Games, both senior and junior competitions are held together, which is great because we can all support and encourage each other. The other sports are much the same as the British Games which makes for a hectic programme, particularly when venues are spread out, so selecting

events to get the timing right is vital. When not competing we try to support as many of the other team members as we can, but it's not easy, so usually the evening is when we all catch up to find out how everyone has got on. The whole team are always in the same hotel so that makes for a fantastic atmosphere as we meet, eat and socialise together.

The Wythenshawe members of the GB team competed in an array of sports including

swimming, athletics (track & field), golf, volleyball, badminton, tennis, and table tennis. Everyone came away with either medals or personal best performances. Whilst the Wythenshawe members contributed 4 gold, 6 silver and 5 bronze medals to the total team tally of 121 gold, 76 silver and 48 bronze, winning medals is not everything. We compete to celebrate the Gift of Life and for our donors, their families, and loved ones to demonstrate how precious their gift was.

Bill Noble

The results were as follows:

1st - Addenbrookes

2nd - Wythenshawe

3rd - Liverpool and Freeman



The evening Gala Dinner, and Prize Giving, was attended by 75 guests, with Lynne Holt giving out the prizes. A disco followed where most guests made various shapes on the dance floor, some of them in time to the music.



A big thank you goes out to all the Wythenshawe team who helped on the day, and also to the players who helped with the refereeing, not forgetting our official referee Martin Lisowski. Finally, thanks to Neil Macdonald who sorted out all the teams and the order of play.