



Autumn Newsletter



Jessie May
Children's Hospice at Home.



Hello and welcome

...to our Autumn Newsletter.
We're thrilled to share our latest
Jessie May news, updates and
events for your diary.

I hope you have all had a wonderful summer! We have had a very busy summer, and are hugely thankful to everyone who has supported Jessie May and attended the various fundraising events we have hosted, or been a part of, over the last few months.

Jessie May is now supporting a total of 141 life limited children across our service area, and 47 bereaved families. We are passionate about offering this continuity of care to these families, but inevitably, as a charity, we rely heavily on donations and support to ensure we can continue to do so.

We cannot ignore there is an unmet need for our services, and that there are many life limited children in our service area who are not currently being supported. Our mission is to ensure every voice is heard, every family is helped, and every terminally ill child has the best possible quality of life. We have a growing caseload and are working rigorously to ensure we are raising enough money to welcome each and every child to the Jessie May family.

One way we are working to raise these vital funds is by taking part in the national match-funding campaign The Big Give Christmas Challenge! This is an extremely exciting fundraising campaign which takes place at the end of November – you'll hear more about this later in the newsletter.

You'll also hear from one of the families Jessie May is currently supporting, and Annette, one of our nurses who visits 11 month old Phoenix.

As always, thanks to all our supporters, and if you'd like any information about our charity, please do get in touch.

Chris Roys

Chris Roys
CEO of Jessie May





Phoenix

Phoenix is 11 months old and lives in Swindon with his mum Clare, dad Damien and 9 year old sister Faye.

When Clare was pregnant with Phoenix, she found out during her 20 week scan that something wasn't quite right. During another scan, two days later, doctors confirmed he had Hypoplastic Left Heart Syndrome (HLHS). This means Phoenix would be born with a single ventricle instead of two, and that the left side of his heart would not form correctly. He would suffer from a birth defect which affects normal blood flow through the heart and mean the right side of his heart would have to work twice as hard.

At first, Clare and Damien were told it was unlikely Phoenix would live for very long, but a later prognosis found while he was life limited, he could live much longer than they feared. Phoenix was born through a planned induced labour in hospital and was taken straight to the NICU (Neonatal Intensive Care Unit) where he stayed for the first 6 weeks of his life. He had his first open heart operation at 4 days old, and would later to go on to have 3 more, alongside other operations.

After his first surgery, Phoenix had a heart attack and had to be put on a life machine, where he then suffered from a stroke. While Phoenix recovered and was able to go home for 5 weeks, he then had to spend 6 months in and out of hospital for more open heart surgery. Phoenix is now happy at home with his family but has to take medication 13 times a day, and is pump-fed milk and given oxygen overnight.

Phoenix absolutely loves it when Jessie May come to visit. He recognises them and lights up with a big smile when they come in the room!

Clare was referred to Jessie May in hospital and now has Jessie May nurses visit their home offering respite care twice a month.

Clare said: "We chose the name Phoenix mainly because we just wanted something different that would stand out. That was before we knew about his condition – and it now seems very fitting! It's very optimistic, just like him."

Phoenix's sister Faye likes to help out at home, and always offers to change her brother's nappies! She has had to take on some very important responsibilities since Phoenix was born, and her parents are very proud to see her act as a young carer to help support her younger brother.

Damien said: "When Phoenix was first born, we had some very difficult and traumatic times, when we were frequently told he might not make it through the night. Now we are back home and he's in far better health, although he's got some problems with his lungs, but it's become the norm – with the help of Jessie May. We're taking every day as it comes. The surgery Phoenix has undergone is extremely complicated but relatively new too, so there aren't many recent or accurate statistics to suggest his outlook, but we obviously hope for the best. He's an amazing boy who loves life."

Jessie May Nurse Annette said: "During our visits we have lots of fun! We play with some of Phoenix's favourite toys, go out for walks and have cuddles. This time is gratefully received by the family as it gives Mum a chance to have a break from Phoenix's demanding daily routine of tube feeding, regular medications and the constant supervision he requires due the unpredictability of his health condition which leaves Mum with little opportunity to get on with daily tasks."

"The respite visits are amazing for me too. They give me a chance to have a break, and go shopping, get my nails done and see my mum for a few hours. Even just to have the time to clean the house is a real help."



Annette

Family fun days

Family Fun with Jessie May A roaring success at Avon Valley Adventure and Wildlife Park!

Thanks to the team at Avon Valley Adventure & Wildlife Park for inviting us down for our Jessie May Families' Fun Day! We had an incredible time meeting the animals and exploring the wildlife. Days out like these mean we can bring our families together and create treasured memories with the children we support. Huge thanks to everyone at the park for making it such a special day.



Messy Fun Under the Sea!

Jessie May children came together during two respite days we held at the Woodside Family Centre over the summer. Our theme for the days was 'Under the Sea' and we all had oceans of fun! We got crafty and made jellyfish, hunted for animals on a fun sealife trail, relaxed in the sensory room and ended the days singing songs! Thanks to all our volunteers who came along to help out on the

days including Sophie and Liz from David Wilson Homes, Sandy from Parmenion UK, Tom from CIBC and Karen from Manheim. We all had a whale of a time!

Picnic in the Park

Our Swindon and Wiltshire team also hosted a family day at Lydiard Park in Swindon over the summer. Jessie May Families enjoyed a picnic in the sunshine as well as lots of fun and games, including Giant Jenga, bubble machines and badminton!



The EAT BIG

Eat BIG and fork out for
Jessie May and raise money for
terminally ill children in your area

Starter What's 'The Big Eat'?

Jessie May has launched The Big Eat – a big foodie fundraising campaign which everyone, from schools to businesses, can get their teeth stuck in to. The Big Eat brings everyone together, whether you'd like to bake, eat diet or compete!

Main How you can get involved

Bake sales, tuck shops, office 'Bake Offs', dinner parties and sponsored diets, these are just a few ideas! Every cake baked, every calorie lost, will be supporting Jessie May families. The Big Eat is a fantastic excuse for you to EAT BIG and get creative in the kitchen for a worthy cause. From foodie raffles to pizza parties – we have platefuls of ideas for you, your school, workplace, social group, pub, restaurant, friends and family can get involved with.

Dessert Why take part?

And the icing on the cake? Every bite and every calorie will help fund Jessie May nurses, who are supporting local life limited children and their families. If you have an appetite for foodie fundraising, view our full Big Eat Fundraising Pack at

www.jessiemay.org.uk/the-big-eat

Make sure to share your Big Eat photos and recipes online by tagging Jessie May and using

#JessieMaysBigEat

Save the Date!

theBigGive

27th November until 4th December

DOUBLE your Difference with The Big Give!

This November Jessie May is taking part in the Big Give Christmas Challenge, a national match-funding campaign that doubles each donation made to Jessie May!

The Big Give Christmas Challenge will help Jessie May raise the funds needed to accept and set up an additional eleven children onto our caseload this year. Eleven more families that we can provide a much-needed break from their caring responsibilities, help their terminally ill child make the most of their short lives, and support with end of life care. We need to raise our target of £23,100 to do this.



Your donation...

→ theBigGive →



...is doubled by The Big Give...

...meaning we can deliver twice the amount of care

The Big Give Christmas Challenge runs from 12pm Tuesday 27th November until 12pm Tuesday 4th December.

All you need to do is spread the news Jessie May is taking part, and help us raise money during The Big Give week when your donation will be worth double! If we can raise £11,550 during The Big Give – it will automatically be doubled to meet our target!

Supporters must donate to Jessie May through The Big Give website for donations to be match funded. So if you're taking part in The Big Eat – please, if possible donate your funds during The Big Give week to ensure your money is doubled!

To find out more, and process your donations during The Big Give week, visit

www.jessiemay.org.uk/the-big-give



DOUBLE portions with The Big Give!



#TheBigGive

#ChristmasChallenge18

theBigGive.org.uk

helping your donations go further



@jessiemaytrust

@jessiemaycharity



@jessiemaytrust



@the-jessie-may-trust

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In Memory

Jessica May Purrington's parents are the whole reason our charity exists. They set up the charity in 1994 following their daughter's death, to ensure other life limited children are given support in their homes, and the choice to die at home when that time comes.



Precious Memories

We have created a special online book for Jessie May bereaved families, as a place to share and celebrate their memories with their loved ones. Families can share stories through words, photos and videos in **The Memory Book**, and use it as a special place to remember their loved ones. We hope families feel they can use the Memory Book to express their feelings and remember those special moments with the ones they love.



To register to create a tribute space in **The Memory Book** please visit:
www.jessiemay.org.uk/precious-memories

Thank yous



To the wonderful team at Mulberry for letting Jessie May take over the cloakroom at their busy London Sample Sale and receive all donations for entry!



To David Wilson Homes for supporting Jessie May through various fundraising events – including auctioning off a day of their director Gareth Neele's labour for our charity!

To the Morrisons Foundation for funding our two Family Respite Days at Woodside!

To Clifton Down Shopping Centre for helping us host a fantastic launch day to celebrate the centre choosing Jessie May as their charity of the year



To Fig Offices Swindon for their continued support and help organising our Handbag Amnesty Fundraiser

To The Carmela and Ronnie Pignatelli Foundation for choosing to support Jessie May for a second year.



To Great Western Railway for donating all our train tickets to and from London for the Mulberry Sample Sale!

To City West Commercial for their ongoing support and generosity!

To the team at the South Gloucestershire Show for choosing Jessie May as their charity of the year – and also selecting us for next year's show!



We'd like to say a huge thank you to Kbase Connect Ltd for their incredible generosity to our charity. Kbase Connect Ltd have kindly donated us free use of their Policy Central software to further strengthen our charity's data storage and protection. Thanks to the Kbase Connect team for their continued support!

To the Great British Expo's team for giving Jessie May a stand at their Swindon event



To TasteTech for their support and for donating the magnificently BIG and cuddly teddy bear Goliath!

To The Matchroom Foundation for their incredible generosity and decision to renew the support to pay for one of our care team leaders - helping us cope with the growth in demand for our service

theBigGive

To everyone who has pledged to donate to Jessie May through The Big Give

To Wincanton&BQ for making us their charity of the year for Swindon and Wiltshire!

To Brian, Keith and Chris from Ringway for jumping out of a plane for Jessie May - and then Brian and Chris shaving their heads to raise even more money!

To Awards for All – a grant giving programme of the Big Lottery who are supporting our work to support children approaching the age of transition

To Weston-super-Mare Pier for hosting our team for an awareness day.

To The Charlie Froud Foundation – an amazing local family foundation that are supporting Jessie May through funds raised in honour of their son Charlie who sadly died in 2008

To The True Colours Trust for their wonderful support of Jessie May for the last four years and their recent decision to renew this multi-year funding from 2018

To The Kingswood Relief in Sickness Fund for being such a wonderful friend to Jessie May over the years.

To The Burges Salmon Trust who have been an invaluable local supporter of our work for a number of years.

Community Stars

Huge thanks to all our community volunteers and supporters who generously give up their time to help raise money for, and awareness of, Jessie May! We're so touched to see so many communities come together in aid of our charity. Pubs, social groups, WIs, schools – individuals! – and so many more continue to help raise money for the local terminally ill children our nurses support. You are all incredible!

Thank you...



... to our incredible supporter David Bailey who raised money for Jessie May through a sponsored cycle ride from Lands End to John O'Groat with his friend Joe. Unfortunately David suffered an injury during the ride but has still rallied donations for our charity – what a star!

... to Swindon student Jessie May Whitaker for raising money for our charity through a sponsored walk with her boyfriend Toby - what a fitting name for a Jessie May supporter!

... to Bradley and Rivers Care Home for hosting B-Fest in aid of Jessie May.

... to the Swindon Lions who travelled around the town bucket collecting in the rain and the snow to raise money for Jessie May! Thanks to the Lions for supporting us through their Christmas Sleigh.

...to Hawkesbury Farm Tractor Fest for organising a brilliant vintage tractor rally in aid of Jessie May

... to Bromley Heath WI for a fantastic year of support with singing, fetes and fundraising.

... to Bristol City Football Club for letting us collect on game day.

...to Crossways Junior School who held a 'Purple and Yellow Day' fundraiser for Jessie May

... to Worle Lions Club for supporting Jessie May over the summer with their cream tea event

... to The Bank Tavern in Bristol for hosting their Summer Fete in support of Jessie May.

... to Cotham School for all their hard fundraising efforts.

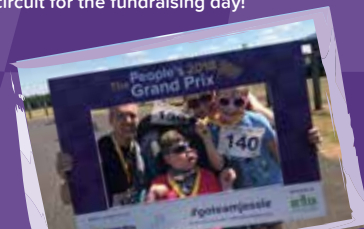


... to all the amazing NCS teams who chose to support us and brought so much energy over the summer, raising awareness of Jessie May and money for our nurses.

Wheelie good fun at The People's Grand Prix!

Last year The People's Grand Prix brought floods of fun – but also rain! This year we were lucky to have beaming sunshine throughout the day instead. Huge thanks to St. James's Place Charitable Foundation who host this annual fun day with Jessie May, and also match-fund every penny made for our charities.

We all had a lovely time making our way around the track at Odd Down Cycle Circuit – some by foot, some by wheel – from wheelchairs to scooters! Thanks also to GLL for letting us take over the cycle circuit for the fundraising day!



The People's Grand Prix 2018



@jessiemaytrust

@jessiemaycharity



@jessiemaytrust



@the-jessie-may-trust

Calendar of events

To find out more about any of our upcoming events, and find out how you can get involved, please visit www.jessiemay.org.uk/events or contact our Fundraising Team!



5 November

Jessie May Firewalk



11 November

The Sodbury Slog

theBigGive

November 27th – December 4th

The Big Give week!



2 December

Saltford Santa Dash



16 December

Portishead Santa Dash



16 December

Weston Christmas Cracker



18 December

Mince Pie Drop-In at Jessie May

Festive Fun –
Save the
Dates!



Jessie May Mince Pie Drop-In

We're inviting everyone to our annual Mince Pie Drop-In to thank all our supporters and celebrate the festivities together! Come along on Tuesday 18th December from 11am to 4pm at our Bristol office at 35 Old School House, Kingswood Estate, Britannia Road, BS15 8DB for scrumptious mince pies, hot drinks and a good natter.



Volunteer this Christmas

We're looking for volunteers to lend a hand – or voice! – during the festive period. If you are part of a choir, or other musical group, and would be able to perform at one of our Christmas events, please do get in touch with the Jessie May Fundraising Team.

Jessie May Christmas Carol Concert

We're inviting everyone to celebrate Christmas with Jessie May at our annual Christmas Carol Concert! Join us for a singalong and a mince pie this December at Holy Trinity Church, High Street, Kingswood, Bristol, BS15 4AD. Our concert date and time will be confirmed shortly – keep an eye on your inbox, our website and social channels for our festive announcement! If you are a choir or singing group and would like to get involved, please contact our Fundraising Team.