



WELCOME



May
2016

Welcome to our summer edition of MOTS news. Our aim is to support patients and their families, who are waiting for or have undergone multi-organ transplants. We know how demanding this is on our lives, and we hope to provide practical help as well as emotional support.

This is your newsletter, and we would love to hear from you. If you are willing to share your story, or have any other hints or tips, any suggestions, recommendations or anything else you think may benefit others, then please get in touch.

SUMMER EDITION

RECENT FUNDRAISING

Elaine Williams & team took part in Bridgenorth walk on 30th May. They raised over £1,300 for us. 'Thank you so much Elaine for doing this for us. We really do appreciate your hard work and dedication, it means a lot to us.'



Thank you **Ian Swain** and **Louise Hine** for putting us forward for this.'

<https://www.justgiving.com/fundraising/E-WILLIAMS4>

CONTACT MOTS

General enquiries,
fundraising and
donations

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Find us, like us,
add us & share us
on Facebook and
Twitter.

WEBSITE:
www.mots2012.
org.uk

SOME RECENT DONATIONS

Give as you live - £4.93

Acorn Bakery (Bettws) from 5p carrier bag charge - £35.95

Paul Fleming - £50

Graham & Carole Plumstead Wedding collection - £250

Freespirit - £8.69

High beauty definition (Bettws) - £11.18

Total from Kye Palmer - £540.63

JustGiving Hug in a Box campaign- £170



MOTS AT THE MOMENT

On 23rd February, MOTS held its AGM. This year it was held at 'The four Horseshoes', Basingstoke. It was a productive meeting. We welcomed Helen Walters to the committee and discussed appointing Amanda Watts to the position of secretary and trustee. All committee members agreed to Amanda's appointment, and felt having a healthy individual to help keep the clogs of the administration side of MOTS running would be a great advantage.

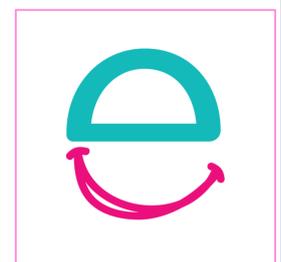


Since Amanda's appointment she has enthusiastically given her time to MOTS. She has already set about updating members' details, and updating various forms. We are now asking members to indicate if they would like the transplant coordinators to inform us when in hospital and if they would like to be considered for a 'Hug in a box' when going through tough times. She has also sent out the applications for the summer packs. This is something we offer each year, to give members a few summer essentials, like sun cream. She is also looking into potential accommodation at Addenbrooke's Hospital. This is something we would all love to be able to help provide, and have wanted to help with since MOTS was formed, but sadly we are limited due to our existing funds and the practicalities of property upkeep.

The 'Hug in a box' campaign has really taken off. Here is a collage of some of the 'Hugs' members and their families have received so far. Each one was different and made for the individual receiving it. The feedback we have received for the boxes has been unanimous gratitude and joy, and we really feel this is a way we can demonstrate to our members we care. Our next challenge is to keep the campaign going and continue to raise funds to make this venture a continuing success.



One way for us all to raise money for MOTS is through easyfundraising. As the name suggests, there really is no easier way to fundraise. All you need to do is sign up, which takes minutes. Then download the tool reminder, so that when ever you shop online at a participating retailer you simply click 'activate donations' and the participating retailer will donate to mots. Although the amounts per purchase may be small, it all adds up and the more people we get to sign up the more money can be raised. We are really not making the most of this at the moment; so if you have not already signed up then please go to www.easyfundraising.org.uk and sign up today!



We have recently welcomes back an old committee member, Alex Geiger. We are thrilled he has decided to re-join team MOTS, and his skills will be a real asset. Among other things he has already set to work producing some easyfundraising posters, looking at ways to promote the charity as well as getting a survey underway. We will be sending this out to you all by post, so keep a look out for it. It's a chance for you all to tell us what you want to receive from us, so please do take the opportunity to fill it in!

Personal Story

Aaron Gray & his mum, Catriona Hamilton

Recently, on the 30th May, I celebrated my 16th transplant anniversary. I was only 3 when I was fortunate enough to have received a combined liver & small bowel transplant at Birmingham Children's Hospital, I don't remember much about that time, nor my life spent in hospital prior to that but with the help of my Mum this is my story...

I'm Aaron Gray; I live in Peebles, in the Scottish Borders with my wee brother Jamie & my Mum Catriona. I was born via an emergency C-section. The doctors at my local hospital detected a heart murmur, so I was transferred to The Royal Hospital for Sick Kids, & my Mum went to a maternity hospital both in Edinburgh, my Mum & Dad found it really difficult to be separated from their new born baby. I was diagnosed with a congenital heart disorder called Tetralogy of Fallot. I had my 1st heart surgery at 6 days old, all went well but at 4 weeks old I nearly died, I got something called Necrotising Enterocolitis which destroyed $\frac{3}{4}$ of my small intestine, causing short bowel syndrome, I was dependent on TPN & enteral feed to keep me alive. Sadly this impacted on my liver & I developed a liver disease called TPN related cholestasis, so at 8 months old I had my 1st transplant assessment but because my heart required further corrective surgery my parents were told I wouldn't have been strong enough to survive the transplant surgery. I was 13 months old before I got home for the 1st time in my life. As much as it was a happy time for my parents, the terrible reality was I was being allowed home to die; there was nothing more the medical profession could do for me.

Now you know I didn't die as I am sharing my story with you....

Against all the odds I gained weight & my liver recovered, so at 3 years old I was well enough to undergo corrective open heart surgery, but I contracted a nasty fungal infection & my liver disease returned with a vengeance, I had also ran out of venous access, the line I had for my TPN was literally my last lifeline. I was listed for transplant 4 months after surgery. My Mum got 'the call' 4 months later; I was the 16th child in the UK to receive such a transplant. In the early years it was a bumpy journey, I got a cancer called PTLN a year post transplant but since then I have been fit & healthy.



I am 19, I have done so much in my life, and much my parents could never have dared dream possible. I have competed in the British Transplant Games for the past 11 years, I have been snowboarding in the Swiss Alps 3 times, 1st time aged 9, I have travelled to 5 countries, I play football for a local disability sports team, I have a girlfriend & I am about to complete my 3rd year at college.

All this wouldn't have been possible if it weren't for a very special little boy, my donor Wade, a 10-year-old boy from Manchester, who tragically died in an accident. My Mum has had contact with his Mum Maxine for many years, since she replied to a card my Mum sent via my transplant coordinator. 3 years ago an amazing thing happened, we finally met, when she came up to Edinburgh & we spent a wonderful day together with a few emotional tears & lots of hugs.

TEAM NEWS

We are pleased to welcome our recent additions to the committee. Below they tell us in their own words why they wanted to join the team.

Alex Geiger

I rejoined MOTS because like so many of us both pre- and post-transplant, we experience tough times. To my regret, with the benefit of hindsight my emotions got the better of me during a rough time and I made some questionable decisions. With the help of those around me, the fallout from that episode has been repaired and, I wanted to get back to helping others through their tough times by rejoining the committee of MOTS. This whole episode is a perfect reminder of what MOTS is about, that even when you feel all is lost, there are those to help you shoulder your burden.



Amanda Watts

Having known Emma all her life I have been following MOTS from the beginning and have always wondered if there is anything I could do to help, but didn't really know what I could do.

Then when Emma posted at the beginning of this year asking for help with MOTS in general I replied to say I would like to be involved and asked what I could do to help. That's when I found out that MOTS were looking for a new secretary, so here I am.

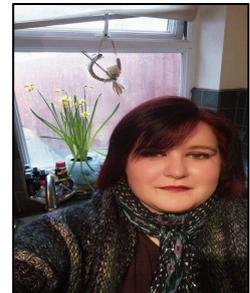


Helen Walters

I have joined the committee in the hope to help other patients in the way MOT's helped me whether that be someone the positions can talk to help get things on the wards or at homes I don't mind.

I haven't been on the committee for long but being in the group has helped me feel apart of something. I was feeling a bit lost before and no one really understood.

I hope in the future we can continue to help patients and provide a support network for transplantees and their families.



<p>Help us help others who Need our vital support</p> <p>Text MOTS12 £2 / £5 / £10 to 70070 to donate now. eg MOTS12 £5</p> <p>JustTextGiving by vodafone</p>		<p>MOTS actively promotes organ donation</p> <hr/>  <p>If you believe in organ donation, prove it. Register now at organdonation.nhs.uk or call 0300 123 23 23</p>
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Visit our website www.mots2012.org.uk. Registered charity number: 1156562

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