



Welcome to our winter edition of MOTS News. Our aim is to support patients and their families who are waiting for or have undergone multi organ transplants. We all know how demanding this surgery is on our lives and we hope to provide practical help as well as telephone support, newsletters and information leaflets.

We also hope to benefit people through providing equipment and help with accommodation for when you are in hospital.

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

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Find us, like us, share us on FACEBOOK & TWITTER-WEBSITE:

www.mots2012.org.uk



Jill Carter raised £519.58 for MOTS in her event Make Every Colour Count.

FUNDRAISING



£308.53 raised bag packing at ASDA on Sat 22nd Nov



Sam raised £400 in the Cardiff Half.



Rachel, Andy & George Rouse (friends of Rach) raised over £200 in the Wildman 10K.run.

MOTS AT THE MOMENT

Setting up a new charity takes time and a lot of hard work from members and volunteers but since our last newsletter we have made big strides. On 15th October we had our second AGM and from that we have now made some significant changes to our constitution. It has been decided that we will now provide support to all 4 transplant centres, Addenbrookes, Oxford, Birmingham and Kings, including support to the under 16's.

We are pleased to welcome some new committee members to our charity structure. These include Molly Smith, Gary Palmer and Kim Hughes. They will all be a great asset to MOTS and help us achieve our aims, including supporting patients through the transition phase from child to adult services and offering support to the under 16's.

As we are carrying out our expansion we are always looking for people who could offer their time to help. Could this be you? If you would like to get involved please contact us.

We continue to have a Facebook page – please “like” us, we now have over 1200 followers. There are over 242 members in the support group and over 573 followers on Twitter. Many of which have offered financial assistance and to hold events to benefit us.

We have had great support from Asda in South Wales and recently had a bag packing slot on 22nd November. They are a great way to raise money. We were also nominated for the green tokens scheme at ASDA Pill for November. If anyone wants to get their local Asda involved please get in touch and we can tell you how to go about it. You could also try other supermarkets in your local area, such as Tesco. If you do not think you could bag pack yourself, why not get the local scouts involved?

Freespirit travel insurance, sponsors of our awareness week this year and next, put up a dedicated page to travel for those with organ transplants. This is a significant step in increasing awareness about organ transplants.

Thanks to Gary Palmer & The New Sussex Hotel who allowed our leaflets in their bar and collected £149.19 from a collection box. If you can think of somewhere where you could put a collecting tin in your local area please get in touch. Gary also sold a football shirt on a bid site for £80 and did a raffle.

We are in the process of revamping the MOTS website. It will look more modern and contain additional features such as an online shop. Elly Jay, friend of Rachael Green (our secretary) has kindly offered her services for this process with no charge to MOTS, We are looking forward to being able to show you all the finished product.

We introduced an 80 day challenge in the run up to Christmas to encourage people to get involved in fundraising for MOTS. The idea was that people would sign up for a day (80 down to 1) and think of a fundraising idea to raise that amount in pounds. We have had good support with people doing various activities including runs, bag packing, a dress down day, a fundraising lunch as well as a Make Every Colour Count event in Cambourne and our Christmas Family Night which will be held at Bettws Rugby Club on 6th December.

Steria Accounts have been raising money for MOTS during the months September, October & December. So far they have done a treasure hunt, which they raised £120 (£150 including gift aid). Through October/November a few smaller events & cake sales have taken place, so to date they have raised about £200. Jane (Fleming) is currently organised their final event, a Christmas quiz night for mid December.

We have lots of plans in the pipeline, to extend the support we offer to our members. We sent out a Yes/No email to members to see interest in some patient events. The results were very positive with the vast majority being in favour of such events. We are planning on making our first event an informal chat style format.



Sponsorship and Donations



We are delighted to announce after submitting a letter and then a more detailed proposal we have successfully received a grant for £6,000 from Takeda.



Frespirit Travel Insurance donated £20.23 for their commission.

Joan Maslen - £50

Linda & Gary Palmer-£375

Nicola McClellan-£100



PERSONAL STORIES

Gary Palmer

I was first diagnosed with Crohn's disease in 1989 when I was 24. Up until then I had always been fit and healthy. I started to get ill and lost lots of weight. I was 18 stones at my heaviest. In 1991 I had an operation, a right hemicolectomy, then in the next few years I had another 21 operations for strictureplasties. In 2001 I had an ileostomy and I ended up on Total Parental Nutrition. I had to infuse 6 litres a day and went down to less than 9 stones.

About 5 years ago I went to St Marks. I had the ileostomy changed to a colostomy. As a result of having a Hickman line I had well over 100 infections each time spending up to 3 weeks in hospital on IV antibiotics.

In the end my specialists at my local hospital in Brighton and St Marks hospital had run out of ideas also I had no good veins to use in my chest, so they sent me to Cambridge where a possible transplant was discussed.

Last December I had an appointment at Cambridge, which I attended with my girlfriend and one of the nurses from my local hospital. I saw the surgeons at Cambridge and was put on the transplant waiting list. Within a week, on 13th of December, I was called up there but when I got to Cambridge I was told the match wasn't right so I was sent home again.

I got another call on the 14th January, again I got there to be told it wasn't a match, so I came home yet again. Then a few days later on the Sunday, the 19th January, I had just got home from a day out, opened a can of lager and my phone went. It was Cambridge telling me they were sure they had got a complete match. So I went back up, I got there about 9pm and was told the match was perfect.

I then remember waking up which I assumed was the morning after and it was Wednesday. My transplant of small bowel, colon and pancreas had all been done. Unfortunately the following day I had internal bleeding, so was taken back to theatre, but woke up on the Friday and all was good.

I was told I would be in hospital 6-8 months after, but I was allowed a weekend home after 34 days and home for good after 38 days. During my stay in hospital, on Valentines Day, I proposed to my girlfriend and got married on July 5th this year. I'm now 15 and half stone and feeling the best I have felt in years. I would love to tell you more but I'm just on my way to watch Brighton play up at Spurs, in the cup, lol.



WELCOME TO OUR NEW COMMITTEE MEMBERS

Hello, my name is Molly. I'm 24 & I live in Cambridgeshire. Towards the end of 2006 I received a small bowel, liver & pancreas transplant at Birmingham Children's Hospital but am now under the care of Addenbrookes Hospital in Cambridge.

The last 8 years haven't been plain sailing & I know I will always face challenges with my health but things are good at the moment & I'm optimistic about the future.

I like listening to music, attending pop concerts, browsing carboot sales & charity shops for bargains, spending time in London, reading & dogs, especially my miniature schnauzer puppy, Toto.

I had quite a difficult transition from paediatric to adult health services so have joined MOTS in the hope of being able to help other young people through the process. I also want to use my experiences to support others through transplants and life afterwards because at some points during my transplant & the recovery I felt like I was the only one going through it.



Hi I'm Gary Palmer. I'm 51 & I live in Brighton. I had a small bowel, large bowel & pancreas transplant on 20th January 2014, at Addenbrookes Hospital, Cambridge.

My hobbies are football, Brighton, Hove, Albion & Horse and Greyhound racing.

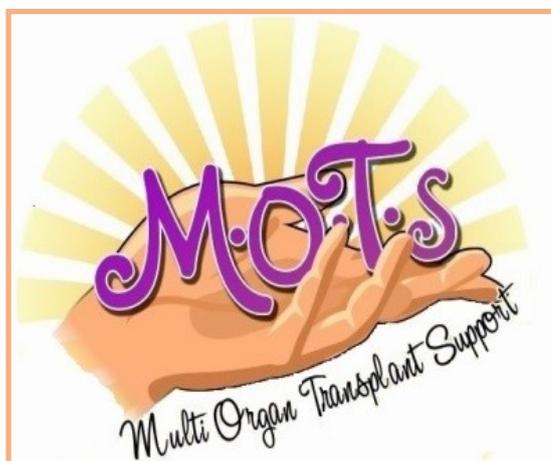
I joined MOTS as I had heard about it from Cambridge during one of my stays there. I found everybody friendly and got answers in a way that was easy to understand not drs lingo!



Hi I'm Kim, 32 years old from Lancashire, mum to Poppy, almost 8 years old, multivisceral transplant recipient. Poppy had a small bowel, liver, pancreas, colon & stomach at Kings College Hospital on September 5th 2014.

I'm a family girl at heart so I love to spend time together at the beach, park or days out with my partner and daughter Coral (6). I love to read a good book & watch films.

I joined MOTS as committee member as MOTS has just expanded to now help paediatrics awaiting or post bowel/multi organ transplant. I feel we can make a huge difference to parents in supporting them, it's a rollercoaster of emotions and I hope with time we will just keep growing.



MOTS ACTIVELY PROMOTES ORGAN DONOR AWARENESS



Visit our website www.mots2012.org.uk Registered charity number:1156562

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