



WELCOME

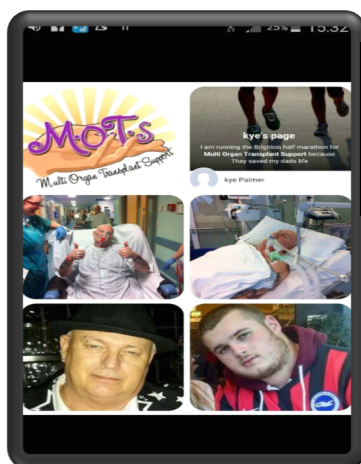
February
2016

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 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.

WINTER EDITION

UPCOMING FUNDRAISING



Kye Palmer, Gaz Palmer's son, will be running the Brighton Half Marathon, for MOTS, on 28/02/16. To sponsor him go to <https://www.justgiving.com/kye-palmer/>



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General enquiries,
fundraising and
donations

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Find us, like us,
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Some recent donations

£930 – Funeral Directors

£365.69- Dignity Funeral Home (Anonymous Donor)

£210 – Gary & Linda Palmer

£250 –easyjet

£196 – Anonymous donation

£132.11 FreeSpirit

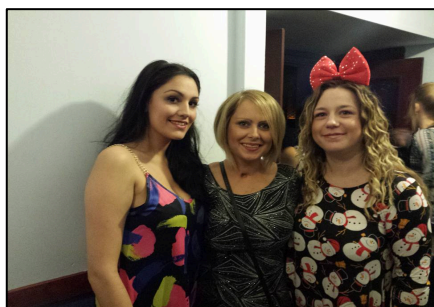
£106.79 – Tess Aitken's daughter.

Thank you to everyone else for all your other donations. We are very grateful for all the donations we receive.

MOTS AT THE MOMENT

Transplant week was later last year, than the previous one. The week is an opportunity to spread awareness around the important issues of organ transplantation and donation. Last years slogan was, '7 days to say yes I donate' a key purpose was to encourage people to have the conversation about organ donation. Among other things, we carried out a social media campaign on Facebook. Each day we shared a member story. This was a great success and each post reached many thousands of people.

For the first time this year, we produced and sold Christmas cards. Our members created the designs and we then had these printed professionally. Whilst we recouped our costs and a small number of us sold our hearts out, sadly there was less support from the membership as a whole, so this is probably not a venture we will repeat. Committee member, Cat Hamilton, put her creative flair to good use and produced some beautiful Christmas items. She raised £75 and made all the items out of recycled materials to tie in with the idea of organ donation. Among the items were some lovely rag wreaths, made from coat hangers and cloth as well as snow globes from recycled jam jars. Cat started by selling the items in local fairs and then from November on a Facebook page she created for the purpose.



Emma and Sam, organised their Christmas Family Fun evening in South Wales. This has become a popular event especially for local children, and raises some money for MOTS at the same time and £1,021.20 profit was made from the event, more than previous years.



An AGM is scheduled for the end of February, and there will be a lot to discuss, including new members to join the committee. Over the last year we have said goodbye to a number of committee members and some trustees too. We are always looking for volunteers keen to play an active part in MOTS' future, and if you think this could be you, maybe you could have a think which areas of MOTS would appeal to you and where your skills would be best placed, and then please do get in touch.



One latest venture is the 'hug in a box.' The idea is to send items in a gift bag/ box tailored to the needs of the person. This may be a patient who is pre or post transplant or family. Either way, it will aim to bring a smile to the face of people going through tough times. To fund this venture we have set up a JustGiving page specifically for this purpose. If you would like to help bring a smile to someone's face and show that we care please consider donating, and encourage your friends and family to as well. The JustGiving link is <https://campaign.justgiving.com/charity/mots/huginabox>

Since June last year, MOTS have helped 7 members, totalling £1,012.80 with accommodation or helping hand grants, courtesy of the £6,000 grant from Takeda donated for this purpose.

Please do continue to follow us on our social media medias, to get involved in supporting one another in the support group and following our activities on our charity Facebook page. We are always looking for people willing to do some fundraising and for donations, or us so if you think you could help in any way please get in touch!

Personal Story

My name is Helen Walters, and I am 30 years old. My story starts when I was 7 and lost my dad to bowel cancer. Therefore, my brother and I were tested at 15 with an endoscopy to check for polyps. As the oldest, I got my mum to check me the day after my 15th birthday. We saw my GP, who booked us in our local hospital. I went for the test, and the results showed 7 benign polyps. At this point it was confirmed I had F.A.P (Familial adenomatous polyposis). They took them all out while I was in there, but as I was only 15 they weren't expecting to find any till I was 20/21, so I was checked every 6 months until I got to 18 when I decided I wanted my colon out, I did not want to wait until I was planning my wedding for the polyps to turn active. I had a gut instinct that one day they would turn active and my colon would have to come out. My consultant suggested I spoke to my family. They supported my decision although they didn't agree so; my consultant suggested one more scope before we made a final decision. The scope showed the polyps were active so I was booked in for a j-pouch and colon removal. A stoma would be made and reversed 6 months later. This all went smoothly and was a success. For 11 years I had a j-pouch that worked better than most, 3-5 times a day. I used the toilet like any other person from the back passage.



The following year, I discovered a hard mass where my stoma had once been, assuming this was a hernia; I went back to the GP and back to the local hospital. It was determined I had 2 'lumps' one going up my right side starting just below the stoma site, and going up to my bottom rib (roughly), and another going along the bottom of my stomach. These were Desmoid tumours, a growth of tissue caused by scar tissue. They do not attack other organs and aren't cancerous but if they keep growing they can cause damage by causing obstructions. It was discussed how to try and stop them from growing or at best shrink them by using tamoxifen used on breast cancer patients and sulindac an anti-inflammatory. Starting on a low dose the tamoxifen was increased so much that the tumours just seemed to grow faster and get firmer so I was referred to a hospital in Harrow, St Marks where they specialised in desmoids. They decided as the tumours weren't causing any harm to any other organs and they were along the abdominal wall they would remove them both with the muscles attached to them replacing my muscles with mesh.

Whilst recovering from that operation I met my husband. He had found a lot out about me already from mutual friends, which is how we met but they hadn't shared any of my medical. Well as I said he's my husband 5 years later so after explaining everything he wasn't put off and my wedding was in June 2011.

Some time later a tumour was causing trouble with my bowel when it caused my bowel to rupture and a fistula formed. After my local hospital tried to dry it up and drain the fluid off, I was sent to St Marks again where they gave me 3 options. Chemotherapy, bowel transplant, or feed through a Hickman line. My husband was very against the chemo. I didn't want more surgery if I could help it so, the idea was chemo, Hickman then bowel transplant as the last resort. As it happened I ended up getting another fistula so with an open wound chemo was off the table and straight to a Hickman line for feed. At this point I'd lost half a stone already so things moved very quickly.

The Hickman line was put in after trials of build up drinks and 6 weeks in my local hospital. I was set up to manage from home & nurses came in to help. The Hickman line split, so had to come out and be inserted the other side. Meanwhile as the feed was only maintaining a weight of around 6 stone 2, 2 stone less than my normal, I was sent for a bowel transplant assessment. Bad pain was setting in, in my abdomen as well. I was on morphine and buscopan and. In the assessment, they check every organ and your health to assess transplant success and recovery. They found a clot in my heart. It was the size of the chamber it sat in so, in Dec 2013 the performed open heart surgery to remove it. Around this time, I was put on the waiting list for a bowel and abdominal wall transplant.

My Hickman line had come out the vein into a vessel so, again it was removed and placed in the right groin, which lasted a week, before discovering it had caused clotting from my groin to my belly button. The Hickman was removed and it was decided not to have another one placed as I had no access left for it and the clot in my heart and groin were most likely caused because of my blood did not like a foreign body being there.

As a result of having no access, I was moved back to Oxford where it was decided I would have a Hero graft in my left arm. This is a fake vein and the first time to be used for a transplant patient. Nurses can put IV fluids through it & take arterial and vascular blood from it. I also had my feed through it up until and shortly after my transplant.

I had my transplant on 14th July, which finished 25 hours later. I was kept on feed for another week and gradually introduced certain foods. I was able to eat foods I've not had since having my colon out, mushrooms being one of them. My stoma was named Sir fartsalot. After a lot of hard work and determination I was discharged 5 weeks later. Since being home, I've had a few hiccups with my bloods but nothing compared to before the transplant. I had to go on steroids, which I found my hardest journey, due to the physical changes. Walking has been difficult because of issues with vascular problems in my leg. These would have still been there whether I had the transplant or not. I went abroad last year with no problems. I won't be going back to work any time soon but my husband supports me in more ways than one. Without him it would have been a lot more difficult. I've also had the help from MOTS with not just with friendly advice and a listening ear, but also physical help with cleaning packages to start us off, and a summer package to help keep us cool and hydrated.

TEAM NEWS

About two years ago, Emma asked me if I would like to take on the role of Secretary and trustee for MOTS, and since then MOTS have achieved many good things, and I have felt privileged to play a part in some of them. Unfortunately over the last 6 months, I've been struggling with various bowel related issues, which has contributed to my decision, to step down as trustee, as I don't feel I can commit the time and energy that I believe the role deserves. However, I fully intend to continue to play an active role in the committee. Among other things, I've offered to continue to produce the newsletter, and will continue to enjoy being involved in supporting members.

All the best

Rach xxx

Multi Organ Transplant Support - MOTS Rach what can I say I was gutted when you said you were resigning from your position as you have supported members and helped towards the charity no end in every aspect you've been there on the ball.

I am sorry you have had to step down but can totally understand.

Your health is the most important thing Rach and you need to keep focused ...You are an amazing asset to MOTS Team and we are so glad you have chosen to stay on committee.

You are a very caring young woman Rach and it's an honour to still have you as part of our team x

 <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>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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