



Welcome to our spring 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.

FUNDRAISING



Andrew Proctor raised £581.50 from the Edinburgh Marathon.



Terry Faber organized a charity comedy & music night raising £322.83



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Find us, like us, share us on

FACEBOOK &

TWITTER-WEBSITE:

www.mots2012.org.uk

UPCOMING FUNDRAISING EVENTS

- ◆ MOTS members will be packing bags in ASDA, Newport, raising money for MOTS on 12th July.
- ◆ Sam Duncan, Sam Williams and David Abdullah will be running the Cardiff Half Marathon on 5th October.
- ◆ Steria Accounts will be raising money for MOTS throughout the months of September, October and December.



Swim

Silence

Run

Skydive

Cycle

Walk

Car Boot

Could you or someone you know help fundraise for MOTS?

Bake

An Auction

A Raffle

A Ball

A coffee morning

MOTS AT THE MOMENT

Setting up a new charity takes time and a lot of hard work from members and volunteers but so far we have made a great start. On 14th April MOTS became a registered charity, registered charity number 1156562. MOTS are now registered with Just Giving, for all future fundraisers to take advantage of. Just Giving has also replaced Paypal for the donate button found on the website. MOTS held their first AGM on 3rd March, minutes of the meeting can be found on the website.

We have a hardworking team at MOTS consisting of Emma Abdullah (Founder/Chair), Sam Williams (Treasurer/Trustee), Alex Geiger (Media Manager) and Rachael Green (Secretary) with Jan Barnett, Jenny Pinkstone, Bev Size, Terry Faber, Alison Jones Mooney and Catriona Hamilton as Committee Members. We are still looking for people to join who could bring something extra to MOTS. Could this be you?

We have a Facebook page – please “like” us, we now have over 1000 followers, with a little help from a t-shirt incentive for the 1000th liker, well done Liam John Millar! There are over 194 members in the support group & over 507 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 a bag packing slot will be taking place in Newport on 12th July this year. If anyone wants to get their local Asda involved please get in touch and we can tell you how to go about it.

Terry Faber, committee member, from Essex, organized an evening of comedy and music, held at the Essex Skipper, which raised £ 322.83 for MOTS.

Alex is in the process of updating the MOTS website. He has added a number of new sections already. There is also a links page to charities/companies that can offer help or advise patients. The website will keep everyone informed of events and information, including news on medical advances & procedures, stoma care & supplies, members benefit form, links directly to each benefit, organ donation sign up button, how to fundraise for us etc. There will be a MOTS merchandise shop where you can purchase the marvellous MOTS t-shirts, pens and wristbands. There are also ideas about selling other products such as key rings, cups/mugs, trolley coins, umbrellas, badges, bumper stickers, fridge magnets and lanyards.

MOTS have also introduced a membership system. This is available to anyone aged 16 or over who has had a small bowel or multi-visceral transplant or for the parents of children who have had these transplants. There is a detailed explanation of membership on the mots website including the application process with downloadable forms. Members will receive membership cards as well as a thank you card for joining, sponsor form, grants form, information leaflets, access to discounts from companies, the newsletter, birthday, transplant anniversary and Christmas cards, invitations to events and the eligibility to apply for a grant.

DONATIONS

- * Larry and Sue Carter donated part of their wedding collection and Dot’s family and friends donated to MOTS at her funeral. This amazing family has raised £891.60.
- * **Mr and Mrs Ratu collected £87.50 for MOTS by asking for donations instead of wedding presents., at their marriage on 21st May.**
- * Kirsteen’s family and friends generously donated £956.40 at her memorial collection on 23rd May.
- * **Bettws community fund donated £300 on 6th June.**
- * Emma Abdullah’s brother and mum have started a flower garden at Bettws allotment. They have had their first collection with what they have sold over the last two months and it came to £78.94.



Thankyou so much



PERSONAL STORIES

Alison Mooney

Hi, I want to share my transplant story with you in the hope that you might find some inspiration or encouragement from it.

I was told by my consultant about ten years ago that I had serious problems with my kidneys and that I would need a transplant. At the time it didn't seem to bother me too much, but looking back, that period of my life didn't really feel real, so I just got on with things. I went to see a transplant surgeon who told me that I could either have (and although I'm paraphrasing, this is pretty much how he said it) just a kidney transplant, which is a pretty safe and common procedure in relation to other transplants. I could have a kidney and then in time consider having a pancreas, this would cure my diabetes, but the organs probably wouldn't last as long and wouldn't work as well together. Or I could have a kidney and pancreas transplant together but the chances of me dying would be significantly increased! He then asked for my decision, which I didn't give him. I went away and thought about it over night and spoke to my fiancé and family about it. After a while I decided I owed it to whoever was going to be my donor, to give the organs the best possible chance, so although it was the most dangerous of the options I went for the SPK. I forgot all about it, it still didn't feel real, until my kidneys started getting a lot worse. On 14th January 2008 I had my first dialysis session whilst being in hospital, with pretty bad pneumonia. Being on dialysis is a dreadful experience but I know that compared to others on my unit I had it pretty easy. I tried my best to live a normal life and I even got married on 3rd May 2008.

Two and a half years later on 10th July 2010 I got my call! So my husband, my dad all got into the car and off we went. I got my call at 1:40 am and didn't actually go to theatre till 3:00 pm and even now that feels like the longest day of my life, but because of my amazing family we even had some laughs during that day. I remember silly things that might seem insignificant to other people, one of them was that I woke up at 05.00 and a nurse was fiddling with a venflon in my arm. I asked her what she was doing and she said she was testing my blood sugars. I asked for the result and when she told me I asked her if it was one of the many drips surrounding me that was controlling my sugars. I burst into tears when she told me that my new pancreas was doing the job! I also remember scaring my mum half to death ringing her at 07:00 to say "Hi." After the operation I was pretty sick with CMV (a low immunity illness) and spent many months travelling backwards and forwards to Manchester and being admitted for long periods.



But here we are almost four years later, both of my organs are doing really well. I've been able to come off a lot of medications, I've posed in my underwear to show my scars off in the Daily Mail and on 1st November last year all of my dreams came true when I gave birth to my perfect little boy, Alexander. Transplantation is a long hard trek and I know that many people post transplant still have their problems, but it has given me the chance to meet some fantastic people. I've done things that I would never have done beforehand and although there were some complications towards the end of my pregnancy, my son is the most amazing thing to come out of my transplant.

Alison

If you are willing to receive an organ , you should be prepared to donate....

Become an organ donor- register today

[Www.LLTGL.org.uk/nhsbt](http://www.LLTGL.org.uk/nhsbt)

My Holiday Experience....

I was looking for holiday insurance and I did it the way most people would by going on the internet, I looked at a few companies and put in that I had had a multi-organ transplant. From the few companies that then let me carry on quoted me about £500.00 for a two week holiday.

I then thought it would be a good idea to contact MOTS for some advice and they recommended a company called Free Spirit Travel Insurance who were very helpful with the whole process and their final quote was £45.00. I would recommend them to anyone who has a medical condition as they are very helpful and friendly.



Alyesha Nichols



This is our First awareness week, working with NHSBT promoting the importance of organ donation.

MOTS have a Just Giving text code. Text MOTS2012 £2, £5 or £10 to 70070 to donate.

Throughout the week MOTS members will be holding stalls in hospitals up and down the country with targets for organ donation sign ups. We will be at the following hospitals on these dates:

St Marks hospital, Harrow/Spinney surgery St Ives, Cambridge & Specsavers, Newport- Monday 7th July

University of Wales hospital Cardiff & Churchill Hospital, Oxford - Tuesday 8th July

Addenbrookes hospital Cambridge- Wednesday 9th July

Fazakerley hospital Liverpool- Thursday 10th July

Spinney surgery St Ives Cambridge & Specsavers, Newport- Friday 11th July

Altnagelvin area hospital Derry and at Duffryn Asda for bag packing on Saturday 12th July.

All week Spinney surgery St Ives Cambridge and Specsavers in Newport South Wales will be helping us by promoting our awareness week. They will be collecting for us and also donating all money that is paid for repairs on glasses for that week, really appreciate you helping us raise awareness and promoting organ donation xxx



HINTS AND TIPS

Asda's own make sunscreen SPF 50 has 5 stars and is £10 for a multi pack of three and one after sun.

Over the warmer weather carry a 1litre sports bottle to combat dehydration.

Drinking water can also help with acid reflux.



MOTS ACTIVELY PROMOTES ORGAN DONOR AWARENESS



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

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