



Welcome to our summer 2015 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

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org.uk



Sally Anne Hart raised a total of £4221.18 in her 'Walk of Hope' & other fundraising activities.



Kyle raised £275



Grahame Champs Motown night raised £930.

Grahame and
Steve from
Carlsberg



Aaron Munson raised £1406.25 in his triathlon.

MOTS AT THE MOMENT

Setting up and running a charity takes time and a lot of hard work from everyone involved. We are now an officially registered charity providing emotional and financial support to many. Since January this year, we have funded a total of £360 (3) helping hand grants and paid for 25 nights of accommodation for members totalling £600 and helping 6 members. We are also pleased that our membership is consistently growing often following support that they receive.

We are sad to say goodbye to trustee and media manager, Alex Geiger. Alex has played an integral role in MOTS since its formation, and special mention must be attributed to his development of the initial website. He inherited it from its bare bones but turned it into a bright and friendly place full of information. He also participated in the AGM's and got involved in fundraising events, such as bag packing in South Wales and was also involved in last years transplant awareness week. We wish you all the best for the future Alex, in whatever you do!

MOTS have had a busy few months. We have had some incredible fundraisers and special mention must go to Sally Anne Hart, Grahame Champ & Steve from Carlsberg and Aaron Munson. Sally Anne's walk of hope and other fundraising ventures raised an incredible amount of money, remarkable for anyone, especially someone as unwell as Sally. Steve and Grahame's Motown event, was a great event and we look forward to their future plans to get involved in helping MOTS. Our founder, Emma also had the opportunity to speak about MOTS at this event.

Recently we have been fortunate enough to receive money from the fundraising efforts of a number of liver transplant recipient families. As these families and patients will be unable to benefit financially from our grants, we have used the money they have raised on the Transplant unit, where all transplant patients may benefit. We have recently had drinks machines installed on the Transplant Units at Addenbrookes, Cambridge and The Churchill, Oxford. This will not only provide a service of nice drinks, at a very reasonable cost, but also provide a small income for MOTS.

After a number of months of hard work, our new website is near to completion. We must thank Elly Jay for all her hard work in helping us to achieve such a fantastic result, all in her own time, with no expense to MOTS. The website will have among other things the new feature of a shop, where we will be selling our merchandise and for the first year our own Christmas Card range.

A significant amount of work has gone into the Christmas card project, from researching potential publishers to getting our members to create designs. We had a large number of designs submitted and with the help of the committee we have chosen a final 4. Due to minimum orders we have to sell 200 packs (of 10 cards) for each design, so that will be 800 packs. So we really need you all to get behind us and sell your socks off, to make sure this venture is a great success! The cards will be priced at £2.50 for a pack of 10, which I'm sure you will agree is an exceptionally good price for charity Christmas cards and as you can see bellow our designs are fantastic.

Christmas Stars by Riley Neale, age 8 (small bowel transplant recipient)



Mary and Child & Tweeting Robin by Catriona Hamilton (Mum to Aaron Gray, small bowel and liver transplant recipient)



Xmas Donor Tree by Helen Walters (bowel and abdominal wall transplant recipient)



PERSONAL STORY

Hi everyone, for those of you that do not know me I'm Rachael Green, aka Rach, and this is a condensed version of my story.

My health problems started young. Hospitals featured in my life for as long as I can remember. However thanks to my amazing family and especially my mum, for me hospitals and the medical bits did not really dominate my childhood in a large way. Up until I was 16, I stayed with my peers in my year group and achieved excellent results academically. I was also involved in a whole host of extra curriculum activities both in and out of school. I had a passion for drama and dance and I played the flute. I also led an active social life and loved spending time with my friends. People tell me I displayed a real zest for life.



However, at the age of 16, after my GCSE's, things started to change for the worse. The huge number of calories and supplement drinks were no longer working. My pain was out of control and my sickness had become a daily nightmare. I had already been diagnosed with intestinal pseudo obstruction, but in 2001 I was put on TPN for all my nutrition, which I was to stay on for the next 11.5 years.

Initially after a lengthy stay in hospital I was able to resume my education, and attend sixth form. It was not easy, I was not that well and I seemed to spend every holiday in hospital for one reason or another. During the upper sixth these hospital stays and periods of extreme illness began to dominate the school terms too, so although I was offered a place to read physiological sciences at Oxford University, I was too unwell to sit my final A2 exams or take up any offer at any university.

I then transferred from the paediatrics to the adult services at St Marks. My pseudo obstruction symptoms got worse and my central access became more of an issue. I experienced increasing numbers of complications associated with the TPN and my health deteriorated, to a point I really just existed. Finally in 2010, after a transplant assessment at Addenbrookes I was listed for a multi visceral transplant.

As I am so small, I required child organs, so I had to wait 3 long years for my transplant. This meant I was very ill when I finally received my one and only call, my gift of life, a stomach, small bowel, large bowel and pancreas transplant. I was in hospital for a total of 5 months, and my recovery with significantly longer. I had a number of complications and due to the time I spent in ICU and HDU, I lost my hair and most of my muscles. It was about 18 months until I no longer required a wheelchair on a daily basis.

Today, I am experiencing some problems with the transplanted bowel, but the team at Addenbrookes hospital, have started me on some medications to improve the symptoms I am experiencing. As it is, I have much to be thankful for. My life is much better than it was pre transplant. For a start I can eat, and do not require any TPN or tube feeds, granted I do have to follow a restricted diet and require a couple of supplement drinks per day, but in my book that doesn't count! I have recently embarked on a part time degree in psychology, with the Open University, which I am doing mainly for personal fulfilment. Since the start of 2014, I have also been secretary and trustee for MOTS, which I love. I am so honoured Emma asked me to take up the position and enjoy the variety of my role and am so proud of all we have achieved including all the people we support. I very much look forward to playing a part in the bright future I know MOTS will have.

Would you be willing to share your personal story? You could be a pre or post transplant patient or be close to someone who is. We would love it if you would share your experiences with us.

IMPORTANT NOTICE TO ALL MEMBERS.

Please could you or a family member let us know if you are admitted to hospital when you/they have time so that we can support you? If you could text or ring us on 07599 299861. Thanks xxx



easyfundraising
.org.uk

easyfundraising is a great way to raise money for charity just by shopping on line & now also by shopping in-store.

You can now also raise money by shopping on the High Street. You can get donations on purchases you make in-store at your favourite retailers, just go to the easyfundraising website and it only takes a few seconds to register your debit or credit card.

If you think you might forget to shop each time via easyfundraising then the donation reminder is a great free tool, designed to help. It provides a little reminder each time you shop online, and takes just seconds to download. We'd fully recommend this, as we all have a tendency to forget. People who use this tool, raise on average 5 x more.

So what are you waiting for? Please go & register & sign up your debit or credit to start raising money for MOTS today, both online and in-store.

Donations

Susie Bavington kindly donated £1376.25, following the funeral of her husband Dave. Thank you so much & our thoughts are with you.

We have a annual standing order of £25 from a member.

People donated £43.28 to a collecting tin in Emma's sisters shop.

Freespirit have donated £14.86 from people using our code.



HINTS AND TIPS

Do remember to wear factor 50 sunscreen, and also to use a lip protector (there are many with SPF 30 to choose from), also remember to protect your eyes with sunglasses, and wear a hat! Lastly keep up those all important fluids! Some people find it helps to put markers on a bottle, so you know how much to aim to drink each hour! Keep safe & enjoy summer!



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Multi Organ Transplant
Support - MOTS



MOTS ACTIVELY PROMOTES
ORGAN DONOR AWARENESS



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

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