



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.

Eventually 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

### XMAS FUNDRAISER & FAMILY FUN EVENING (7th December)



The night was a great success & £595 was raised.



Emma Pearcey took part in the NUTS challenge, on 1st March, & has raised £1670.

## CONTACT

### MOTS

General  
Enquiries

Fundraising &  
Donations

Emma Abdullah

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Find us, like  
us, add us,  
share us on  
FACEBOOK &

TWITTER-  
WEBSITE:

www.mots2012.  
org.uk

## UPCOMING FUNDRAISING EVENTS

- ◆ A group will be doing the Edinburgh Marathon in May
- ◆ The Cardiff Half Marathon in October
- ◆ Bag Packing Slots in Asda throughout the year



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



## A Tribute to Dawn Carter from her brother Larry

### DONATIONS

- \* The late Dorothy Carter, mum of Dawn Carter, joint co-founder of MOTS, donated £300.
- \* Two ladies from Australia, Isobel Richardson and Alison McEneny, kindly donated £100 and £40 of their xmas money.

*Thankyou so much*

### Leaving as MOTS Secretary.

When I was introduced to Emma & MOTS, by a mutual Facebook friend within the transplant community, we got chatting, quite excitedly, about all sorts. What MOTS was hoping to provide and which direction it was heading in. Emma threw me a bolt from the blue when she asked me if I would like to take on the position of secretary for MOTS. I was flattered, excited as well as a little daunted, I had never taken on such a responsibility before. I do have Transplant Kids website & it's Facebook support but it's not a charity, not answerable to any other body, just wittle ole me & the amazing members who have grown through the years, plodding on, all sharing experiences & offering support to each other it doesn't require much of my time.



So I decided to accept & take on the role, setting to work enthusiastically on my duties - contacting companies for potential support & donations, I continued the work on the 'launch edition' newsletter Dawn Carter began & sourced a couple of beneficial resources for charitable contributions via online shopping 'click' and 'In Kind Direct' which are now supporting MOTS with supplies for the hospital packs.

I then became busier than ever with things within my own life, as well as the usual ongoing mayhem of a home life & 2 teen lads, one of whom requires care & support from myself due to his transplant as well as his learning & behavioral difficulties.

Life was good but I realized I had taken on more than I could reasonably cope with, my time was becoming more & more stretched to the max, with that came the added stress of time management & discovering I really was spreading myself way too thin, too much in too little time.

So towards the end of last year I made the choice to prioritize, what to keep & concentrate on & what I must give up and I felt I wasn't doing justice to the work required for MOTS. Therefore I will be relinquishing the secretary position, passing it onto someone who can offer it their full attention.

I am sad to be leaving so soon but I am happy to carry on as a committee member, I will always be supportive of MOTS, it is a much needed charity through which my son will undoubtedly benefit from in the future.

I wish Rachael all the very best in her future endeavors as MOTS secretary.

Catriona Hamilton

## **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. We now have our own community bank account and our aim is to get a 5K turnover this year so we can become a registered charity. We have now registered with the HMRC and have been recognised as an official charity, so we can claim gift aid.

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 already have over 814 followers, over 153 members in the support group & over 346 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 have more bag packing slots booked for 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 the green token scheme in his local Asda, which raised £25 for MOTS.

We have been busy contacting companies for donations. MOTS have secured two sponsors from the South Wales area: MascotsRUs and The Spiritual You. The Spiritual You are helping to fund our hospital packs, from IN KIND, where we can get products at a reduced price by registering as a charity.

Emma went up to Cambridge on 20th January, for a few days. She took DVD players for each dayroom and all the DVDs people donated as well as 3 portable DVD players for patients to use rather than paying for hospital TV and lots of hospital packs for inpatients. This was all possible because of all your generosity thank you.

Alex is in the process of updating the MOTS website. He has added a number of new sections already, including an information leaflet and the previous newsletter as well as members stories. 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.

## **MOTS MERCHANDISE**



**T-shirts adults £5, Kids £3.50**



**Pens and wristbands £1 each.**

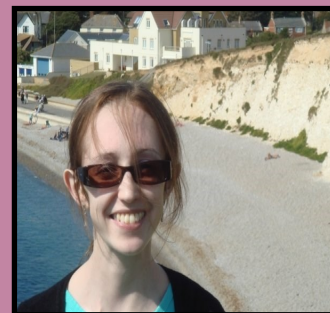
Hello, my name is Rachael Green and I am 28 years old. I had my stomach, small bowel, large bowel and pancreas transplant on March 19th 2013 at Addenbrookes, Cambridge. I live in Surrey with my younger brother and parents.

I heard about MOTS whilst on the waiting listing and after having the transplant I met Emma and was keen to become more involved.

I have now been home for about 6 months and am still recovering from the transplant and adapting to my new life. I have already experienced many ups and downs and feel that the work MOTS do is vital in helping people through their journeys.

I really wanted to help MOTS, and a friend offered to do the NUTS challenge for MOTS. This is a tough army style assault course over 7km and with obstacles and liquid mud often in very cold temperatures. Together we have been collecting sponsorship and have raised lots of money for MOTS.

During this time Emma said she had a proposition for me and asked me if I would like to take on the position of secretary for MOTS. I accepted the role with enthusiasm and am looking forward to being part of the MOTS team and all the challenges ahead.



*Rachael*



## **PERSONAL STORIES**

*ALEX GEIGER (MEDIA MANAGER)*

### **TPN. Transplant and Triumph**

Hi, I'm Alex, and as I write this, a few months shy of my 6<sup>th</sup> transplant anniversary. It was a multi-visceral transplant of 4 organs: liver, small bowel, stomach and pancreas. I still to do this day find myself at a loss to try and convey the very amazing and surreal experience it is to have undergone this literally life-changing surgery.

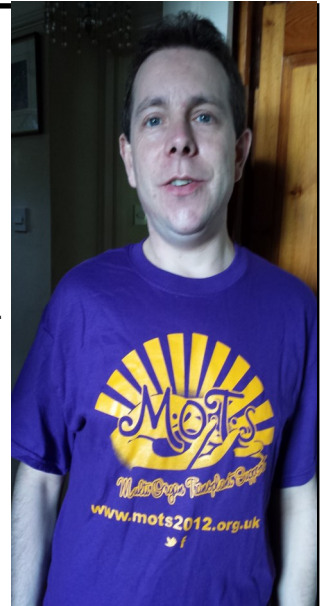
It is a very emotional experience, and of course whilst there is great joy, that not only was the surgery a great success, but it is also tinged with the sadness, that you know the organs were made available to you, because someone else passed away and was generous enough to donate their organs. I did write a letter of thanks after my transplant, but I never received a reply, I can only speculate as to the gamut of emotions that must have been running through their mind. My quiet reflections and silent "thank yous", often seem to be inadequate, but all anyone can ever ask of you is to make the most of the chance you've been given. It is also what spurred me to help out with MOTS, to try and give some of my time and support back to these amazing people who have undergone these journeys.

It is hard to convey or really explain why the surgery has changed my life, without knowing the background, so apologies for delving into medical history, I shall try to make it as brief as possible – but be warned there is a lot of it! Should it not be for you, skip forward 3 paragraphs, I won't be offended.

If we rewind the clock back to my early teenage, it was as if a life of severe illness was a virtual impossibility, but alas I was stricken with Crohn's disease, which presented itself with many unpleasant symptoms, suffice to say most of them can be described by imagining you have some really nasty food bug, except instead of going after a day or two, you have it almost every day. As you can imagine it really was a horrible experience, but as I stumbled from treatment to treatment, dietary supplements, abscesses, and even bowel resections nothing could prevent the most sinister effect it was having on me – the virtually glacial pace of my adolescence. As I approached my 18<sup>th</sup> birthday, it wasn't an anniversary to celebrate in any way: I was 5' 2", a mere 2" more than my height at 11, and I could pass for a 12-yr old – it was utterly soul-destroying to be seen as a child in the eyes of the world when it should be the prime of your life. In the end I made the height of 5'6", a long way short of the 6-footers in my family and the predictions based on my bone scans, had I not become ill. The thing about Crohn's is people can't often see there is anything wrong with you from a glance, but my height was a permanent reminder of all the things the disease had robbed me of. And socially, where once I was confident and outgoing, it made me shy and reclusive – habits to this day I'm struggling with.

The disease became worse, it causes parts of the bowel to become inflamed, but they often don't heal properly and the result is scarring and narrowing – this in turn makes it harder to absorb food, and painful as food passes through the narrowed areas. And it eventually reached a point where I was unable to maintain a reasonable body weight through food alone, and thus I was introduced into a world of parenteral nutrition. It is essentially a sugar solution, sprinkled with vitamins and minerals that is administered intravenously. You have to learn the sterile procedures to safely connect and disconnect it from a central line – essentially a tube plumbed into your blood stream. For a while however, it went well, my weight was maintained, and for once I had high hopes that this treatment would be the answer. But, the parenteral nutrition has known complications, one being that some livers don't tolerate it well, and in my case it was slowly poisoning my liver.

Things came to a head at the end of 2004, when a narrowing in my gut closed completely, and I was rushed into hospital where I passed out. I had a very serious infection, and woke up some weeks later in intensive care, only to find out that I had been on the verge of death – so much so my family had been called as they didn't expect me to make the night at one point. I think you'd agree that it would probably rate in your top 3 worst Christmases, had you undergone a similar experience, and whilst I was out of it, it isn't too hard to imagine what my family were feeling during this extremely difficult time.



I woke up with a naso-gastric tube (a tube inserted into your nose, then down the throat which then enters your stomach) to drain the fluid from my stomach that couldn't escape due to the blockage, I had my TPN lines, and when they finally wheeled me out of intensive care onto a ward, it was then the murmurings started about a liver transplant. As if I hadn't been through enough, I had this on top to deal with? I mean come on, give a person a break! So, still rather weary and weak, I was sent to Addenbrookes Hospital, back when the transplant ward was on C9, and the very patient and caring staff who had the dubious pleasure of my company, and the generally bleak mood I was in to be prodded and poked a bit more. I can still remember "the Friday" when I was told they were discussing my case and the same afternoon Mr Jamieson told me that they wanted me to have a liver and bowel transplant, and they wanted me to consent as soon as possible. I refused, fought tooth and nail to come home, and did my utmost to stay out of hospitals. My life at this point had been reduced to a mere existence. I was hooked up to a pump nearly 24 hours a day, the naso-gastric tube rarely came out, and drained litres of fluid a day, and unsurprisingly, with all that I slowly slipped into a depressive state. I held out 3 years before consenting – I was so mentally drained from that frightful experience in hospital I couldn't bear the thought of spending any length of time back in, but in the end my liver was really on its last legs. I had become severely jaundiced, and starting to suffer things like horrendous nosebleeds, and at my two weekly check-up, I still remember them saying, "if you don't consent now, there's a good chance you might not get the transplant in time". I read the consent form, and one word stood out in my mind, "complications: .... Death". I think, it may seem silly now, but I'm trying convey a sense of the sort of things that 20 years of illness with very little respite can do to your mind, but part of me was hoping for that outcome. I'm almost ashamed to admit it, but I suppose this was my crunch point – the very literal in my mind "do or die" moment.

It must have felt right, for soon after consenting the call came – and the rest as they say is history. I woke up feeling amazing with the wonderful Dr Woodward beaming at me, telling me how well everything was going. I had this overwhelming sense that I felt better – even though I had someone else's organs in me. To this day it is one of those things I can't explain, or even get my head round, and why I started this off saying how surreal this is all can seem at times – but I can with no doubt in mind state it was literally life-changing and for the better. There were some tough points along the way but I made a very good recovery, and I am doing well now. I can live a near normal life – and am in a position where it seems as if my previous illness was nothing but a bad dream. I can't thank Addenbrookes' and St.Mark's Hospitals, and their staff for the amazing care they'd given me up to this point – they never gave up on me (and I'm aware I can be a difficult patient at times!), because as much as illness is a physical battle, it is a mental one as well, and they were always so encouraging and provided me the counselling I needed to get through this difficult period in my life. And to my donor, thank you, for none of it would have been possible without you.

Thank you for reading.

## HINTS AND TIPS

Some foods that thicken output include jelly babies, marshmallows, bananas, mashed potatoes, baked potatoes, pasta, peanut butter and rice.

Arnica and witch hazel are useful to apply to bruises.

Use a high protection sunscreen with an SPF of at least 30 which also has a high UVA protection, 4 or 5 stars, and make sure you apply it generously and frequently whilst in the sun.

To remove stains, first wash in cool water then add a stain remover like vanish or bi-carbonate of soda before placing in washing machine.

On 5th February 2014, Dot Carter (nee Wade) sadly passed away. She was our Co founder Dawn Carter's mum. She passed away peacefully at the age of 80, after a period of illness, with her loving family by her side. She was a loving mum, auntie, godmother, friend, loved by so many people. She was a very brave, wonderful, caring lady who always went out of her way to help others. She will be missed dearly by everyone especially her loving family. Her funeral service was held at Darlington crematorium and donations were in aid of Multi Organ Transplant - MOTS.



**TRAVEL INSURANCE:** Freespirit travel insurance have agreed to offer all MOTS members a 10% discount.

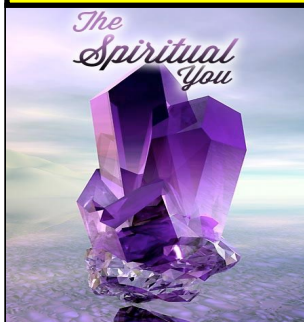
Contact MOTS via facebook or email to become a member.

Telephone number: 08455 201075 Website: [www.freespirittravelinsurance.com](http://www.freespirittravelinsurance.com)

All the links and details will be on our website [mots2012.org.uk](http://mots2012.org.uk)



## OUR SPONSORS



Have agreed to give 10% of their weekly earnings.



Have agreed to provide mascots for events in the South Wales area.



Will donate 10% of their commission earned per member policy.



MOTS ACTIVELY PROMOTES ORGAN DONOR AWARENESS



Visit our website [www.mots2012.org.uk](http://www.mots2012.org.uk)

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