

Autumn 2013

MULTI ORGAN TRANSPLANT SUPPORT

LAUNCH EDITION



Welcome to our first edition of MOTS News and the launch of our new charity. 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 we 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.

Just some of our Fabulous Fundraisers

Billy Edmondson did a 200mile bike ride from Hull to Liverpool!



Our MOTS bag packers in ASDA collected £463!



G5 staff on transplant unit walked mount Snowdonia, so far they have raised £375 with more still coming in!



A charity evening held by Charley Macauley in Southampton raised £600!



CONTACT

MOTS

General enquires

Fundraising & donations

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Find us, like us, add us ,share us on

FACEBOOK

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Website :

www.mots2012.org.uk

THANK YOU ONE & ALL! (details of other donations inside)

Dawn Carter (In Memoriam)

Sadly Dawn passed away earlier this year, she will be greatly missed but the work of MOTS, which she helped begin will continue to grow into a respected national charity.

I'd just like to say hello to you all. My name is Dawn Carter and I had a multi organ transplant at Addenbrookes Hospital in Cambridge just over a year ago. In fact I had 6 organs in total so the past year has been a bit of a challenge.

I live in North Yorkshire with my partner Martin and our 3 black spaniels in my previous life was a staff nurse in a busy Intensive Care Unit. In 2010 I finished a BSc (Hons) in Social Policy and now work as Volunteer Centre Manager. I absolutely love my work and was pleased to return to it 11 months after my transplant, although only on a part time basis.

Since having my transplant I've been doing some publicity to raise the profile of this type of surgery and the photo on the right shows me appearing on This Morning on ITV—an amazing appearance.

I am also a trained telephone support listener so please call if you want a listening ear when things get rough. I'm really pleased about being asked to get this group off the ground.



MOTS AT THE MOMENT

Setting up a new charity takes time and lots of hard work from members & volunteers but so far we have made a great start. We now have our own Community Bank account and our aim is to get to 5k turnover this year so we can become a registered charity.

We still need to recruit an additional trustee and also some more management team members— could this be you? We have established a Facebook page—please 'like' us, we already have over 600 followers, over 100 members in the Facebook support group & over 80 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 area, we won £250 from green tokens. If anyone wants to get their local Asda involved please get in touch and we can tell you how to go about it. We have been busy contacting companies for donations and we have even had an offer of help from Charlotte Church!

MOTS website is in the process of being constructed at the moment to keep everybody informed of events and information, including news on new medical advances & procedures, stoma care & supply's, member's benefit form, links directly to each benefit, organ donor sign up button, how to fundraise for us etc. There will be a MOTS merchandise shop on the site where you can purchase the marvelous MOTS T-shirts, pens & wrist bands.

We have also had a chance to promote our charity through articles which have appeared in The Mail on Sunday and in ITV regional programmes. Emma did an interview for Wales this Week and Dawn appeared on Yorkshire TV's Calendar programme.

Its been a busy time, we are making great progress and with more members, more offers of support then we are certain we can achieve much much more.

Think Positive Quote

Friendship is born
at that moment
when one person
says to another,
"What! You too? I
thought I was the
only one."
C.S. Lewis

FB/Treasured Sentiments©

TRAVEL INSURANCE

We all deserve a holiday but when we have a serious medical condition the insurance can end up costing us almost as much as the holiday. It is important to obtain travel insurance and not travel against the advice of your medical team but several companies charge on perceived risk and not on the actual risk of individuals. There are several insurance companies who are willing to insure those of us with medical conditions at a competitive rate and on the persons individual health and requirements. We have a list of insurers some of our members have had comprehensive cover at a reasonable cost from, this list can be emailed to you send a request to mots2012@hotmail.co.uk

The rate charged will never be as cheap as for someone who is fit and healthy but they will look at each individual risk and insure you appropriately.

If you are travelling in the European Union then its useful to register for an EHIC card, you can do this via www.europeanhealthcard.org.uk

However, this won't cover expenses if you need to be flown home.

We would also like to hear from you if you can recommend any insurance companies that you have found useful.



Introducing some of the MOTS team

Emma



Hi

My name is Emma Abdullah, I am the founder/trustee of MOTS.

I started my charity and support group with another multi visc patient Dawn Carter, who was an amazing friend ,we became close as no one understood us the way we did.

Dawn sadly passed away in march 2013. Before my friend passed away we agreed to set up MOTS as there was no support for us nor our families after we had received our transplants,.

I am 29yrs old, I have a 4yr old little girl, a loving husband,we have been together 13yrs and a loving, caring Mum & family. We had just started our little family when in 2011 I had my four organ multi visceral transplant ,small bowel, liver, stomach & pancreas, also having my spleen and gall bladder removed at the same time. After I had my transplant, once I was stable enough, I intended to start something like mots, this is my time to give something back for all the hardwork by medical staff and for the generous gift I've been given.

Hi all,

I am Catriona Hamilton, I am the secretary for MOTS.

I live in the Scottish Borders with my two teen lads. My eldest son got off to a rocky start in life, he was born with a congenital heart disorder but unfortunately he got NEC (necrotising enterocolitis) post heart surgery when he was just 6 days old, 3/4 of his small bowel had to be removed, on TPN & enteral feed till he was 3 yrs old. After corrective open heart surgery he was listed for transplant, eventually receiving a combined liver & small bowel transplant at Birmingham Children's Hospital in 2000. He's now 17 and attending college.

I have a website called Transplant Kids, providing child friendly information about organ transplant. I have been active in creating organ donor awareness & fundraising for various charities over the past few years.

I look forward to being a part of MOTS, knowing the support it offers is needed as well as appreciated & watching it grow from strength to strength.

Catriona

Catriona



Sam



Hello Everyone,

My name is Sam Williams and I am the treasurer and a committee member of MOTS.

I have worked in the healthcare industry most of my adult life and have seen first hand how patients need support and I would like to continue to provide support, empathy and help to others. MOTS is a worthwhile and much needed charity and I am honoured to be part of it. Emma is not only my sister in law, but also my best friend and I came near to losing her and I have been there before, during and after her transplant and understand how scary the experience of having multiple transplants can be.

I have also met some amazing people who have undergone transplants or awaiting the procedure. I am very proud to be helping this charity as it is close to my heart and I will always be there to help and support MOTS

Sam

Molly's story

My name is Molly and I'm 22. My life was saved by an organ donor 6 years ago.



I was born healthy but when I was just 6 months old my small intestine telescoped in on itself which cut off the blood supply. As a result the majority of it died and had to be removed in a series of operations. I was left with just 30cm of small intestine which wasn't enough to absorb the nutrients from food, so I had to be fed a special liquid called TPN directly into my heart through a central line. I couldn't eat anything orally.

When I was two and a half, blood clots formed on the end of my plastic central line in my heart so I had to have open heart surgery to remove them.

As I grew up I attended mainstream school full time and apart from never eating and having the odd days off for hospital appointments, I did all the same things as my peers - even taking part in sports & going on residential school trips.

When I was about 14 I began to be teased at school for being 'green'. As time went on my jaundice (skin having a yellow tinge due to problems with the liver or gall bladder) progressed and I became increasingly lethargic. I also suffered from profuse nosebleeds leading to me needing blood transfusions. After various tests and referrals to different hospitals it was discovered that my liver was failing due to me being fed via TPN. Just before my 16th birthday I was told that my liver was too damaged to repair itself and I needed a multi organ transplant to survive - liver to replace my damaged one, small bowel so I could come off TPN so the liver failure wouldn't reoccur and I was told pancreas was just part of the package and would make the plumbing easier!



I was put on the transplant waiting list and sent home to wait for the call. Several weeks later I returned to hospital for a check up and was told there was a national shortage of organs so I could be in for a long wait. But time was running out and I only had a matter of months to live.

Luckily I received my call just a few days later so we rushed to the hospital. I was in theatre for 12 hours, in intensive care for a few days and in hospital for a total of 12 weeks. While in hospital I had complication after complication resulting in several more trips to theatre but once I got home I went from strength to strength.

After my transplant I was able to sit my GCSEs and then go on to sixth form, which I completed.

I've had to take some time out from my studies/work due to other health problems but things are looking brighter every day. I'm now 6 years post transplant - I'm learning to drive, doing some voluntary work and enjoying my life. I've travelled outside Europe and am looking forward to seeing more of the world. And I'm now able to eat completely normally, without any kind of tube feeds.

I feel privileged to have been in contact with and met my donor family because if it wasn't for them I wouldn't be here now.



WE WOULD LOVE TO HEAR FROM YOU WITH YOUR OWN PERSONAL STORIES - SEND THEM TO OUR EMAIL.

HINTS AND TIPS

- ◆ We all need to take our medication but have you found this stains your teeth? Some of our members have reported this and told us that Smokers toothpaste really helps remove these stains
- ◆ Doesn't work for everyone but for some marshmallows really help thicken up your stoma output.

Please send us your own hints & tips.

MOTS ACTIVELY PROMOTES ORGAN DONOR AWARENESS



Our thanks also go to an anonymous transplant patient from Addenbrookes ,a cheque given via staff. To all those who contributed to the collection at Dawn's funeral, To Elaine Gwilym who is kindly giving a monthly donation.

If you would like to help us in anyway however small ,it may be via monetary donations, donations for raffles etc or by organizing an event, by doing some kind of fundraising or sponsored challenges, Emma can provide ideas and sponsor forms.

PLEASE contact Emma

Email: mots2012@hotmail.co.uk



Visit our website www.mots2012.org.uk

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