

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.

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Find us, like us, add us, share us on FACEBOOK & TWITTER-WEBSITE: www.mots2012. org.uk **FUNDRAISING**



Top Left, Kim & Rocco (Pre Transplant). Right, Kim & Rocco,. Bottom left, Kim, 4 stone lighter with 10llbs to go, with Olivia.

Kim Fraia, is raising money by slimming for MOTS. So far she has raised £135.



Laura Sturdee ran the Surrey Half Marathon, & raised £445.



Sally Ann Hart has lots of great fundraising ideas to raise money for MOTS. On 11th April is her Mobility Scooter Ride & Walk round the Great Orme. To date she has raised £1,031.25. On 2nd May is her Grand Raffle Draw. She has managed to get some great prizes, and Christina Trevanion, from "Bargain Hunt", "Put your money where your mouth is" and "The Great Antiques Road Trip" will draw the winning tickets.

MOTS AT THE MOMENT

Setting up and running a charity takes time and a lot of hard work from members and volunteers. In the last 12 months we have made big strides. We are now an officially registered charity able to provide emotional and financial support to many.

We now have our own coded "organ donation sign up forms." This will enable us to keep track on how many people we will get to join the organ donation register during our fundraising events. Thank you NHSBT.

Jodie Morgan (JM Events) have decided to support MOTS throughout the year. Jodie has built her business from scratch and continues to arrange an excellent variety of sold out events in the South Wales area. JM Events will help us by organising raffles and collections at their various events throughout the year.

We were delighted with the support we received for our 80 day Christmas challenge, with funds coming from many sources. An incredible total of £4813.48 was raised, so thank you so much to everyone who supported this.

We are now able to officially provide support both emotional and financial to all 4 centres, Addenbrookes, Oxford, Birmingham & Kings. This means our helping hand grant is now also open to all those under 16.

As we are carrying out our expansion we are always looking for people who could offer their time to help. Could this be you? If you would like to get involved please contact us.

We continue to have a Facebook page – please "like" us, we now have over 1290 followers. There are over 275 members in the support group and over 562 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. We won £50 from the green token scheme in ASDA Pill. If anyone wants to get their local Asda involved please get in touch and we can tell you how to go about it. You could also try other supermarkets in your local area, such as Tesco. If you do not think you could bag pack yourself, why not get the local scouts involved?

We have lots of plans in the pipeline, to extend the support we offer. We are currently arranging installation of drinks machines both at Addenbrookes and at the Churchill, Oxford, to provide good value hot drinks for patients and their families whilst they are in hospital.

Our website is making good progress. The new website will have an online shop which will give us the opportunity to sell our merchandise. We will be adding some MOTS jackets to our existing range. We also plan to sell our Christmas cards online. As this is our first year of selling Christmas Cards we want to do everything we can to make it a success. If you have any marketing or sales ideas to sell the cards or think you may be able to sell some in your local area, e.g. a local shop please get in contact.



CHRISTMAS CARD COMPETITION

PLEASE SUBMIT YOUR DESIGNS BY JUNE, SQUARE & IN JPEG FORMAT OR A PIECE OF ARTWORK (PICTURE/PAINTING/PHOTO). WE PLAN ON HAVING 6 DESIGNS, (3 ADULT & 3 CHILD)







Jonny Owen's Story

When I was 15/16 and still at school I was diagnosed with IBS. At the time I didn't know much about it and the symptoms e.t.c, but all I knew was that I could tell the difference more and more each day. Luckily for me I was almost leaving school so rushing to the toilet didn't happen much!

Once I left school, at 16, it was then I started to really notice the difference. It was over the next few years the trouble started with the flare ups of my stomach. Age 19 onwards was the point in my life where I had to make sensible decisions, as I basically lived on the toilet and had to be close to one all the time! Taking tablets became a big part of my life and I was constantly in hospital with infections and flare ups. I could be in hospital for at least 3/4 weeks at a time. During all this, I was also working full time, which was really stressful for me, trying to earn money and keep myself as healthy as possible.

Aged 21, my oesophagus burst, causing me to get rushed into hospital as I more or less lost all my blood and that's where all the fun began! They told me about my Crohn's Disease, PSC, oesophageal varices, deep portal mesenteric thrombosis, pancreatitis, anaemia and other little bits and bats I had going on like asthma.

Aged 22-26 were the hardest years of my life because without fail I was in hospital twice a fortnight with complications due to all my problems, such as losing weight, fluid build up, lack of iron, no appetite and so on. During 5 of these years I was in a relationship. It killed me watching how upset my partner was, and yet there was nothing I could do about it apart from lay in bed helpless.

At the start of 2014, I was listed for a multi-visceral transplant, a pancreas, colon, small intestine and liver. They advised me to keep an overnight bag with me at all times, as at any point I could get the call to go down for my transplant which could or not go ahead and then as well there were precautions e.t.c. I did have one call, a few months after being listed but 5 mins later it got cancelled as the donors heart beat was unstable.

It was October 31st 2014, I received the phone call which was going to change my life. It was all legit and they were ready for me, so transport came to pick me up and got me down there and then the op went ahead. I spent just 6 weeks in hospital recovering. This is unheard of, they said it should have taken 6-12 months, so my recovery was rapid. To this day the doctors have no idea how or why I recovered so fast!!!

In February 2015, I started back at work and am still going strong with no problems what so ever. My heart, respect and thoughts go to my donor and his family as I can wake up each morning knowing I've been given a chance!



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.

Members Area

Molly Smith has kindly provided us with a yummy recipe for *Blueberry fairy muffins*. We hope you all enjoy trying them.

Makes aprox 18-20 **Ingredients** 150 g margarine 150 g caster sugar 3 eggs











150g self raising flour (+ tsp baking powder) 100g blueberries

Method

- Preheat oven to gas mark 5/190 degrees Celsius. 1)
- 2) Put bun cases into trays.
- 3) Cream margarine & sugar together with a wooden spoon until light & fluffy.
- 4) Whisk the eggs together in a jug then add half to a tsp of the flour. Repeat with the rest of the eggs.
- Sieve half the remaining flour & fold in lightly with a metal spoon. Repeat with the rest of the flour. 5)
- 6) Stir in the blueberries.
- 7) Spoon the mixture into the bun cases.
- 8) Bake for 15-20 minutes about 1/3 of the way down the oven. Keep a close eye on them!
- 9) Cool on a wire tray.

Donations

Fruits of the World: £42.89

N McLellan: £100.00

PJ Hayman: £20.23

Kristina Francis, from the Medium-ship evening: £50.19

PM Wade: £50.00

Steria Accounts: £756.16







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

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