new start
The Transplant Centre

InTouch Newsletter

Winter 2014 Issue 23

Chairman's Report

I am writing the winter addition of the Newsletter when it's still relatively warm but Christmas card orders are beginning to arrive so it must be that time.

As many of you may be aware Sean Bell, who was a double lung recipient and had served as a trustee since March 2010, passed away in August. Sean was "a lovely man" and his willingness to support and organise a number of New Start's activities, his wise counsel and his calm manner will be sorely missed by his wide circle of family, friends and colleagues.

We have recently seen a change in the charity's office and are very pleased to welcome Lynda Ellis, who joined us in August as our administrator in succession to Janice Taylor. Janice, who had worked for the charity since 2006, had decided to move from the area and we are grateful to her for all her work with patients and supporters which made a real contribution to the operation and profile of the charity.

On the sporting front the Transplant Games in Bolton were our best year yet. Our team brought home 12 Gold, 9 Silver and 4 Bronze medals. Well done to all the participants and particularly the medal winners. (See overleaf for further details)

Our 1000th Transplant Celebrations went ahead at Lancashire County Cricket Club last Month and it was fantastic to see so many of our recipients, supporters, family and friends there enjoying themselves and participating in a live TV feed with Look North..

Our transplant numbers are up on the previous year, the LVAD programme is running smoothly, the lab continues to flourish and our supporters continue to raise funds for us – a number of which are highlighted overleaf. As a result, the current financial position of the charity is healthy and we continue to identify and fund projects to benefit both current and future recipients and the unit as a whole. On this note, I would like to thank you for your support in 2014 and wish you all the very best for the forthcoming festive season

Richard Dyson
Chairman

A Heart on the Day of Hearts

On 14th February 2014, a Heart Transplant Patient, Neil Eadie, received the news he had been waiting for, for a long, long time. He had suffered from heart failure for some time but in January 2013, he entered the final stages of the condition and reached the point where a "Do not Resuscitate Order" was signed. However, with perseverance and a great deal of help and support from his family and the brilliant expertise of the staff at UHSM, he finally got his transplant last Valentine's Day.

As anyone who has undergone transplant surgery will be aware, the journey can be somewhat arduous but the level of support advice and standard of treatment he received were second to none and the ultimate goal was achieved. One question bothered him. How did he repay the debt he felt he owed to such wonderful people?

He decided to write a book about his journey through transplant primarily to raise funds for the New Start Charity but also to help other post and pre transplant patients by giving them an insight as to what may happen and to understand that they need not feel isolated.

The book 'A Change of Heart' is now in print and is available from the Transplant Reception and Charity office for a suggested donation of £5.

With continued support from UHSM, Neil's health is improving and he has applied to work as a volunteer for the UHSM Trust.

Family Affair

Michael Taylor had his transplant a month before the Transplant Games. His family decided to run in the Annual Donor Run at the games and raised over **£3000** whilst Michael who had only been released from Hospital that week cheered them on. Well done Team Taylor!

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Just search for NewStartCharity**

twitter

British Transplant Games
Bolton 2014 – **Paul Ashberry**

Bolton 2014 may not have the same prestigious ring as London 2012. Danny Boyle had no involvement in the opening ceremony and the chances of receiving a knighthood off the back of competing are pretty slim.

But for me and the eight hundred other athletes who take part in the annual British Transplant Games it is a culmination of as much hard work as any Olympic athlete has undergone.

The hard work was in seemingly endless days spent fighting for breath, for energy and for life. For the eight hundred at Bolton, the British Transplant Games marks the passing of most of that hard work. To be a part of a group so determined to commemorate this shared second chance is certainly an experience to revel in.

I had a double lung transplant nearly three years ago. Bolton was my second Games: Sheffield last year my first try. On meeting the rest of the Wythenshawe team and, Janice, the manager, I was made to feel a part of the team. Not just because we'd shared similar times and had the scars to prove it, but because they turned out to be a good combination of loud, eccentric, funny, kind and competitive people.

The competitive aspect varied; with the Transplant Games everybody always says – it's not about the medals, it's about being alive and taking part. And they are right, after everything it took to get there just turning up is enough.

At Bolton I felt a bit more like a Games veteran, and not just because I'm knocking on in years. The first time was exciting; a chance to test out the new lungs, but the sheer scale of the event was surprising and it might seem daunting for some transplant recipients. But the camaraderie and sheer joy of being involved will quickly take over and banish any apprehension. And despite the competitive nature some of us bring to the event, many more just want to try different sports, not worry about how long it takes or where they finish. After a couple of days, I usually arrive at the realisation that this taking-part attitude is where the real spirit of the Games lies. It's a spirit impossible to define; it just exists in the air as you take in different events and visit the various venues.

In the build up to the Bolton Games I agreed to do some media interviews to promote the event. On the first day I was to be filmed on a squash court for the local news. But after realising I'd brought along a broken racket for my squash debut on the box, a more sedate, almost casual style of squash was on show. It certainly wouldn't have struck fear into any watching opponents. With an intact racket, later in the day, I managed to obtain a silver medal and an injured back to boot, causing me to sweat on further participation in the Games.

The next event was football. A bit of advice for anyone who attends the Games and suffers an injury – see the physiotherapists. Their treatments are the equivalent of someone taking a double shot of whisky before going on stage just to get through a performance. A quick session with these healing hands and I felt able to give it a go. Wythenshawe don't have enough footballers to make up a team, so for the last couple of years myself and another Wythenshawe lad, Andy, have slotted into the Harefield team. For the second year in a row, we won the gold medal.

I had a guilty moment during our march to the final when we handed out a bit of a hammering to the Freeman Hospital team. Despite being a proud member of the Wythenshawe team and receiving my outpatient care there, I had my transplant done at the Freeman Hospital in Newcastle. Beating this great hospital at football felt like some weird case of biting the hand that has fed me.

The final day of the Games is when the big Track and Field events take place.

I arrived at the Bolton arena where I soon realised the impact the bad weather was having. I'd anticipated a bit of a soaking, I'd even predicted some of the field portions of the 'track and field' might fall casualty to the conditions. But it never occurred to me that the timings of each event might be brought forward. I was informed I'd already missed my first event, the 100m, and my second, the 200m, was about to start on the other side of the track. I jogged over to find my particular age group had already run. I tagged onto a miscellaneous group of other ragged late arrivals still to run and after comparisons of finishing times for my age group had been done I was given a bronze medal.

So that was my Bolton Games - a lot of fun, highs and lows, and some moments of personal triumph. I've not even mentioned the socialising and partying that goes on at each Transplant Games, but you could easily give out medals in this for the more hardcore.

Paying it forward: with science from the heart

A few years ago, The New Start Charity awarded me with the life changing opportunity of pursuing a PhD at The University of Manchester. I am happy to share the news: I have completed my programme.

I would like to give special thanks to: Douglas Graham, Richard Dyson and the members of the charity board for their amazing support, the patients and their family members for their trust and contribution, the clinical staff at the Transplant Centre for their help in a truly altruistic and outstanding manner (regardless of how busy clinics were!), colleagues in the lab and special thanks to my supervisors: Dr. James Fildes and Prof. Nizar Yonan for their guidance and support throughout. Far from being finished, we continue the hard work in collaboration with the Transplant and the Heart Failure teams to better understand how the immune system manages to resolve inflammation and injury. Thank you all for your help to make this project a success!

Dr. Mary Gieschen-Krische

AMEND-IT **Diet Study Update**

The AMEND-IT diet study is currently well underway and the first group of pioneers are now half way in. A huge thank you must go to all those taking part and to family members or close friends that not only accompanied you on the training day, but who encourage you on a daily basis. Changing our eating pattern requires a lifestyle change, but more importantly, a new way of thinking and acting.

The key aim of this study is to encourage you to think about food in a different way by explaining why these changes are beneficial, and providing information to make it practical. Special thanks must go to Matthew Pohl for taking time out from his daily chef duties at the transplant centre in Sweden. Matt gave his personal account of how he overcame the challenges of dietary change and the positive effects he has experienced. He helped provide practical advice of how to put the information into action by preparing tasty, healthy foods. Matt will return later in October for the second arm of the study to welcome a new group of budding chefs who are about to start the program.

In addition, we are currently in the process of setting up an online 'blog' site for those involved in the study. The aim is to create a support community incorporating the latest interesting food research, recipe ideas and testimonials from people who are benefiting from these changes.

We would like to welcome 3 new starters to the research laboratory. Niamh Shepherd, Zaheeda Begum and Daniel Brownbill will be with us for the next 12 months as part of their BSc degrees. Their help has already been invaluable for all the various research projects that are currently underway.

Tim Entwistle and Research Team

Fundraisers

Thank you to **Lancashire County Ladies Bowling**. They raised **£1300** organising a bowling competition. Mavis Hancock organised the event in August. Her brother Michael underwent a transplant here at Wythenshawe.

Alan Pugh and team took part in the Manchester – Blackpool Bike ride and raised **£450**

Louise and Matthew Lord - took part in the Great North swim in Lake Windermere (Brrrrrr!) in June and raised over **£300**

David and Susan Brydges celebrated their Wedding Anniversary in style and raised **£1000**

Sam and Mandy Fisher had a big party in June to celebrate their Birthdays and Anniversary and raised a whopping **£1770**

Stephen Schofield raised **£345** by organising a Charity Football match in memory of his Dad

Helen Owens took on a grueling 2 marathons in 2 weeks and raised a fantastic **£335**

Callum Wood and his Dad Graham planned to take part in a run, kayak, and cycle challenge in September but unfortunately due to a rugby injury Callum had to pull out. They still have raised nearly **£600** to date

Tesco Express in Fulwood raised **£120** having a cake sale

Transplant Games 2015

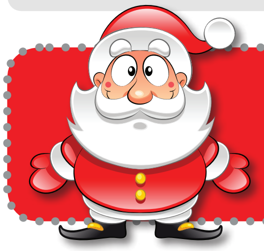
Next years' games take place in Newcastle from 30th July -2nd August. For those that haven't been before please don't be put off thinking you need to be able to run like Usain Bolt! There are sports to suit everyone such as Cycling, Fishing, Snooker, Archery, Ten pin Bowls. If you are interested in taking part please ring the office and let us know. For more details on events available please see **http://www.britishtransplantgames.co.uk**

Party Party

The 1000th Transplant Celebrations took place on September 18th at Lancashire Cricket Club. Over 180 Recipients, family members, staff and supporters attended for what was a fabulous evening. Mr Rahman who carried out the first transplant at Wythenshawe was one of the speakers.

Grandads' New Airbags!

Megan and Mollie Walker are well on their way to raising their target of £500 after holding a cake stall. They are fundraising for "the Hospital that gave Grandad Bob his new airbags". Well done girls!



Christmas Cards

Are now on sale in the Charity office and online at www.christmas-cards.org.uk/newstart/

Please be assured 100% of the profit comes to New Start

Patient **Information**

Car Parking

Parking for all transplant and disabled patients is now free. Please speak to reception regarding your parking permit

Clinic Times

Monday, Wednesday and Friday Mornings are post–heart transplant clinics

Tuesday, Thursday mornings and **Wednesday 12-2pm** are post lung transplant clinics. (Lung Function is open from 8.30)

Routine Bloods every 6-8 weeks.

Echos, ECGs and X-Rays every 6 months. Please make sure you always have an appointment

We have Echo Slots on:
Monday: 10.00, 10.20, 10.40 and 11.00
Wednesday: 10.00, 10.40 and 11.40
Friday: 10.00 x 2, 10.40 and 11.00

If you are unable to keep your echo appointment, please let us know well in advance so the slot can be reallocated. When attending clinic please could you bring a list of your medication with you.

As always out of hours please contact the Jim Quick ward on 0161 291 2204

Patient Bloods

Patients' attending clinic for blood tests only are asked to arrive between 9.30 and 11.00. During busy times it may be necessary for patients to go to the phlebotomy clinic in the main hospital to have their bloods taken. Clinic appointments are limited to a manageable number dependant on how many Doctors are available. If you wish to see a Doctor at your visit please phone the clinic prior to your arrival as it may help avoid a long delay.

If you would like your bloods done locally please speak to the clinic staff

Flu Vaccinations

All transplant patients should have their yearly flu jab, However it has come to our attention that children and teenagers are being offered a "live" flu vaccine in the form of a nasal spray. Transplant patients and those living in close contact with immunocompromised Transplant patients should be offered the inactivated (non- live) flu vaccine and NOT the live flu vaccine spray.

Please contact the Transplant Centre if you need further information.

Donations

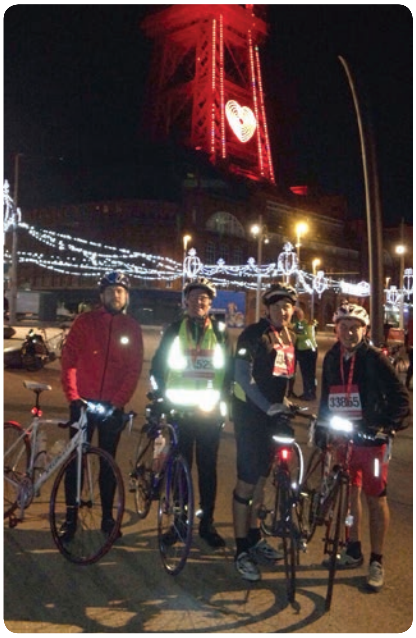
We are overwhelmed by your Generosity, so much so we are unable to list all of you but from the Charity a BIG THANK YOU.

- Simon Cadenhead
- Bill Cawley
- Pat Derby
- A & BM Duffy
- Ian Ferrier
- Andrea France
- Horwich New Heart Group
- Irish Guard Singers
- Life for a Life
- Mrs L Owen
- Patricia Moore
- Ceiran Roberts
- Lynn Rowe
- Pat Selkirk
- Caroline Shelley
- Enid Simpson
- Norman Stoller
- Barry Waddington
- James Wallace
- Dilys Wright

In Memory Donations

- Stanley Aird
- Evelyn Annis
- Kerry Bevan
- Clifford Buxton
- Geoff Crawford
- James Davis
- Delia Egan
- Eileen Hill
- Christina Hunter
- Sheila Huntington
- Phillip Jackson
- Arthur Kahn
- Angela Kingham
- Sheelagh Lamb
- Graham Lovatt
- Alice Needham
- John Phillips
- Joyce Rennie
- Susan Rowland
- David Schofield
- John Scott
- Stanley Seddon
- Kenneth Smith

Fundraisers



Emma Donald took part in a Sky Dive over the summer and raised over **£500**

Adam Stirling and his team raised over **£500** cycling in a night ride to Blackpool and back. It was a bit of an extreme way to see the illuminations lads but Well Done!

IMPORTANT NOTICE

Brand name for **Cyclosporin is NEORAL**

Brand name for **Tacrolimus is PROGRAF** (if it is a twice daily dose) **or ADVOGRAF** (daily dose)

Please be aware of the packaging of your medications. If you are at all concerned about medication you receive from your GP/ Pharmacist. Do not hesitate to contact the Transplant Unit.

Please let reception know any changes in contact details

After clinic appointments please make sure you are contactable for any changes in your medication.

If you do postal bloods please make sure you collect postal when you are in clinic

For any donations or contributions to the next addition of the Newsletter please contact:

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