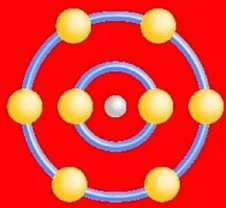


Sussex MS Centre



Sussex MS Centre

Small charity, big impact

01273 594484

Southwick Recreation Ground

Croft Avenue

Southwick

West Sussex

BN42 4AB

www.mssussex.com



Issue No 78

Spring 2017

Small Charity - Big Impact



Read all about Krissie's amazing feat inside.

Charity Number: 801075

Company Registered in England 2319928



Give More with [Gift Aid](#)

Are you a UK taxpayer?

If you have an income of over £11,000 per year, you probably pay income tax in the UK. Gift Aid is a government scheme that allows us to claim back the basic rate of tax on your donations to the Centre, giving us an extra 25p for every pound you donate.

Donations for treatments and classes at the Centre are not eligible for Gift Aid as they are considered to be payments for services. We can claim Gift Aid if you sponsor someone or give us a donation towards our costs. If you are eligible, the process is really simple; all you need to do is fill out a Gift Aid Declaration form at the Centre. Your donations won't qualify for Gift Aid if they are more than four times what you've paid in tax that tax year. If you stop paying enough tax at any point, you must let us know.

CHANGES TO BLUE BADGE [PARKING IN ADUR](#)

Disabled parking in car parks

Customers displaying a valid disabled persons badge (Blue Badge permit) when parking in either a designated disabled bay, or in a non-designated disabled bay, must

PURCHASE A PAY AND DISPLAY TICKET

when parking in Adur Car Parks - the car park standard charges apply.



Manager's Comment

We have a lot useful tips and information in this edition and some great photos of some of our wonderful fundraisers. As a self-funding charity, we really do appreciate members and their families and friends supporting the Centre with a variety of fundraising events. It enables us to keep the Centre running and to provide low cost therapies, treatments and classes.

We often post Centre news, therapy sessions available and photos on our Sussex MS Centre Facebook page so it is useful to keep an eye on this to keep up to date with what is happening at the Centre.

Fingers crossed the weather will get a bit warmer and we get to enjoy a good summer.

Best wishes

Penny

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Classes

Pilates

Monday
1.15pm

Thursday
10.30am

Keep Fit

Tuesday
10.30am & 6pm

Thursday
2.30pm

Yoga

Wednesday
10.30am

Seated, Thursday
12 midday

Voiceworks

Friday 11am

Physio Gym

Friday 1pm

These are drop in classes, so please call reception if you were thinking of coming for the first time. 01273 594484

My Vitality Brighton Half

Marathon Journey

Centre Member Krissie Ransom was instrumental in persuading the [Brighton Half Marathon](#) organisers to accept competitors who use wheelchairs.

“On the 26th February, I completed the inaugural Vitality Brighton Wheelchair Half Marathon. It was an incredible experience. The atmosphere was amazing, the volunteers went above and beyond the call of duty.

My husband Graham ran the Brighton half marathon in 2015 and I wanted to be able to do it too. I was really disappointed to find that most half marathons don't allow wheelchair users and for those that do, you have to be an Elite Wheelchair Racer. I spoke to race organisers in Brighton and persuaded them to look into allowing it for 2017 and in December 2016 they agreed to there being a wheelchair race as part of the Brighton Half Marathon. I called the organisers, [Sussex Beacon](#), and their excitement was catching and I signed up.

Since 2015 I have been dabbling in wheelchair racing. Due to commitments with work, family and wheelchair basketball with the [SWBC Tigers](#) I have been unable to take up wheelchair racing regularly. I did a charity event half marathon distance around the track at Worthing Leisure Centre in August 2015 which wasn't a recognised half marathon, but I was able to prove to myself that I could do it. Since then I have competed in 1 wheelchair racing event in 100m and 400m distances.

I prepared for the Brighton Half Marathon at Worthing Leisure Centre on their track under the guidance of Julian Stevens who leads the [wheelchair racing](#) program in Worthing. I would go for up to 2 hours one evening a week and endeavoured to follow his training program. This included one long push each week as well as some interval training. In January, I did some long pushes along the seafront from Hove.



One of the hardest aspects of training was sitting in the racing chair. My legs kept spasming and bruising. Fatigue management was also a massive component of my training. I would have to plan my training around rest periods.

On the day, I was a bundle of nerves. I had set myself a target of finishing in less than 2 hours. I hoped this would be an achievable goal based on the training I did. The “gentle incline” on the course worried me greatly. Being surrounded by so many people was also a worry. This was my first official half marathon that is properly timed and recognised. Once I started off, all the nerves and stress was worth it. It was absolutely incredible! The runners were helpful, friendly and supportive. At mile 10 I figured I had missed my 2 hour goal, as I went without a watch. Upon coming up to the finish line, seeing the timer and realising I had made it in less than 2 hours I was ecstatic! It was overwhelming and surreal.

I did it!”

Krissie



On the internet? Got a  page?

If so, don't forget to seek out our page, Sussex MS Centre and become a follower. It helps to keep you in touch with what's going on at the Centre and spread the word about what a great place this is amongst your friends and the wider community.

There is also a FB group for you to join that allows you to communicate with other Centre members, sharing ideas, activities , tips and tricks to help us all.

HBOT in Canada

Like most Oxygen Therapy users I do miss my dives when I go on holiday, particularly when I go abroad and have the added fatigue complications of extended travel time.

I've typically got extra dives in before going away, and taken short trips (2 or 3 weeks), or just lived with the fact that I won't be able to fully enjoy the latter stages of the holiday as much as at the beginning.

Recently I went to Toronto, in Canada, for 5, yes 5, weeks, particularly to see my 3 Grandchildren. I hardly missed a beat.

Before going, my son found and I contacted 2 HBOT Centres in the Toronto area. One of them particularly appealed, as their website mentioned the UK ARMS setup (which was the forerunner of our MS Centres).

The ontariohbot.ca website gives a good idea of what to expect, but the reality of visiting surpassed my expectations. There are clear differences: it's HBOT only, and that's in individual mono-chamber compartments, where you don't wear a mask and you wear cotton scrubs clothing.

I dived at 2.4 Atmospheres (47 feet/14Metres), for 90 minutes each time. I'm planning to use them again: Laurie-Anne Fayle is the Director, and her family members occupy key positions e.g. her son Dave is Chief Operator. It's fair to say that there's a resultant "family" feel to this place, and there's a waiting room for friends/family/carers to relax in and chat.



I must just point out that this is a North American business, with all the healthcare red tape you'd expect: regulations, etc. and a session costs \$200 (Canadian), more or less. Quite a hike from our UK charity, unregulated operations, set up, with a suggested donation of £10(MS) - £23 (Sports injury) for an hour or so.

However, I spent less on my HBOT that I did on flight tickets for myself, and am delighted at how my holiday was transformed: No "Grandad can't take you to the beach/swing park, as he's too tired", after only 2 or 3 weeks. I was fine right up to getting back on the plane home 5 weeks later. Well worth it.

I'd be delighted to hear if anyone else has found similar facilities abroad, that might make extended holidays abroad possible for me/others with MS.

Derek Aitken

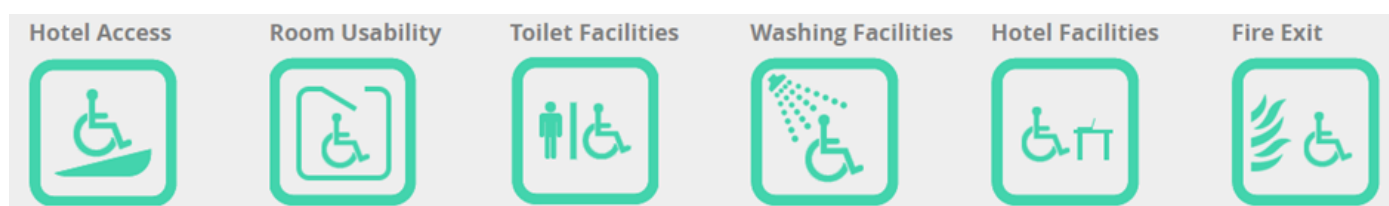


If you are going to Gibraltar there is actually an MS Centre there offering HBOT. The prices at the [Gibraltar MS Therapy Centre](#) are very impressive and a nice place to spend a little holiday in the sun and have HBOT although it might be difficult with a scooter but clearly disabled people go there.

Calling all travellers!

Dan Humphrey's father had an accident in 2005 which left him a paraplegic. Over the years he and his mother tried to go on holiday with him, or to take him to places when an overnight stay was needed. Many hotels suggested that they were fully geared up to accommodate his father's needs, but on arrival they were still met with frustrations.

Dan searched the internet for a useful website but found nothing, so he knuckled down and launched one himself. The site offers disabled travellers the chance to score all aspects of a hotel's suitability.



It's a new site, so Dan is calling for your help. If you have stayed in any hotels recently and would like to help others find suitable accommodation, please visit www.tripable.org

Changing from DLA to PIP?

How to get support with your assessment.

Filling out the forms from the DWP can be very stressful. We have a small and dedicated team of volunteers who have been offering support to many of us as we are transferred from Disabled Living Allowance (DLA) to Personal Independence Payment (PIP), or applying for support for the first time.

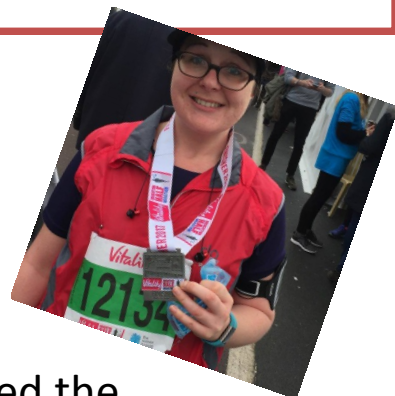
The current target for the Department of Work and Pensions is to assess everyone still receiving DLA by the end of 2017. This has led to a surge in demand for advice and our small team is struggling to cope.

Please contact the Centre if you are in need of advice and we will be able to let you know how quickly we can assist, and if not, direct you to other sources of support. Please do not contact our advice volunteers directly.

On April 20th, as a result of a petition and campaigning the government announced that those with mobility cars who fail the criteria when transferred to PIP, will be able to keep their cars pending appeal.

Centre Member Does the Double!

Cat Young achieved her goal of completing the Brighton Half Marathon in February, but not content with that she went on to run the whole one too!



Cat was diagnosed with MS about 10 years ago and joined the Centre in 2014. She had intended to do the full [marathon](#) with her sister in 2011 but her MS put a stop to it on that occasion. Cat has been on what she calls 'hardcore disease modifying drugs' and has been coming to the Centre for Pilates which, with a bit of 'gritty determination' got her to a place where she was ready to take this on. She set about fundraising with great enthusiasm too—which is often just as difficult as the event itself (though she may beg to differ). Just to add to the challenge it was a hot day - so CONGRATULATIONS Cat on a remarkable achievement!



Forthcoming Socials at the Centre

The QUIZ!

With Fish and Chips

Friday 26th May

Doors open at 6.30pm

Both events:

£5 Members, £9 Member plus carer



Back by popular demand....

The Sizzling Summer

Sunday 25th June

at 1.30pm



Please note that for safety reasons (moving furniture and hot food) we are only able to open the doors half an hour before each social function.

Farewell to Mike

We first met Mike when he came along to the MS Centre in January 2003. Like so many people there his life had been turned upside down by Multiple Sclerosis and he was struggling to cope.



Mike's enthusiasm, skills and expertise were quickly put to good use and he soon became a much valued member. He volunteered as Webmaster, produced the newsletter and then set about developing and improving all our IT systems, and especially our databases.

When Mike joined us we had recently been described by Derek Jamieson in an article in the Argus as a small shed in the corner of a park. In 2007 Mike took over as chairman, overseeing the addition of our wonderful gym and then refurbishment of the rest of the building in 2009. His chairmanship saw a huge increase in Centre usage. In 2010 Mike stood down as chair but continued to be our IT fixer and developer and an active member of our Voicework class which he had helped to start.

He made many friends and his loss will be very deeply felt for a long time.



Building Project Update

We're delighted to say that progress is being made with our plans for an exciting new Centre. The main hurdle we have been working to overcome is ensuring that we have enough room to make significant improvements to our existing services.

Adur and Worthing Council are being hugely supportive in helping us move forward. We hope to have resolved this issue soon and will then be moving on to developing designs. Don't forget there is a book on the reception desk inviting your comments/suggestions/concerns/wishes for a new build which will serve our community way into the future.

Jane is currently leading the project, feel free to speak to her at any time, or email jane.taylor@mssussex.com. We are determined not to change the ambience of the Centre, just improve it!

Just Can't Wait Card



Unfortunately quite a few of us suffer with bladder and/or bowel urgency, which can really restrict our ability to get out and about.

It's a hidden symptom that can be very embarrassing. The Bladder and Bowel Community offer a widely recognised help card for £5. The card:

- Assists with access to your closest toilet
- Helps explain and avoid a potentially embarrassing situation quickly
- Universally recognised symbols – take your card anywhere!
- Durable plastic material – just like your other essential cards
- Simple fee of just £5 – no extra shipping or hidden costs
- Pay online or by post – no membership necessary
- Cards delivered within 5 working days^{**}
- To order and pay online:

<https://www.bladderandbowelfoundation.org/just-cant-wait-card-introduction/>

Patient Steering Group

Hi, my name is Charles Ellis and I have been coming to the MS Centre for about 2 years. I was diagnosed with MS about 20 years ago and it started off as relapsing remitting and has now moved to secondary progressive. I have been asked by the Brighton and Sussex University NHS Trust to be a member of their patient experience panel and I have agreed to do this. I would like to represent members of the MS



treatment centre and would like to hear about any issues, comments - positive and negative that you may have about any aspect of the services provided at the Brighton and Sussex University Hospital. The panel meets regularly and I would take any questions to that panel that you may have. Please feel free to email me any questions. My email address is cdellis14@gmail.com.

I look forward to hearing from you.

Message in a Bottle

[The Lions](#) Message In a Bottle scheme is a simple idea designed to encourage people to keep their personal and medical details on a standard form and in a common location - the fridge. Whilst it is focused on the more vulnerable people in our community, anyone can have an accident at home, so this scheme can benefit anyone, Including you. As a minimum it will save the Emergency Services valuable time identifying you and your emergency contacts. By telling whether you have special medication or allergies or not, it is a potential lifesaver and provides peace of mind to users and their friends and families.



Step 1



Complete the form and put it into the bottle.

Step 2



Place the bottle in the fridge.



Step 3

Place one green sticker on the inside of the front door.



Step 4

Place the other sticker on the outside of the fridge door.



The emergency services are aware of the scheme and will use the information in an emergency.

Where can I get one of these?

We have some of these bottles at the Centre.

They can also be picked up from many Lions clubs.

Please contact us if you would like to know where your nearest Lions club is.

Overcoming Multiple Sclerosis is a charity set up to promote a programme of diet and lifestyle management that has been shown to improve the health and lives of people with MS. Professor George Jelinek, who was diagnosed with MS in 1999, developed the rigorously researched OMS Recovery Program more than 15 years ago.

Many of our members have used advice from OMS to help them manage their MS. Next month's issue will contain an article by Debbie Scrivens describing her personal experience and how the OMS diet has helped her manage her MS.

OMS receives no funding from the pharmaceutical industry. The OMS Recovery Program is based on the pillars of diet, exercise, stress management, sunlight, vitamin D and omega-3 supplementation, and, when needed, medication.

The programme strives to empower people with MS to enjoy a healthy life so the website provides:

- Full details of the lifestyle interventions identified as optimum for embarking on a programme of wellness and maintaining an active, healthy and balanced life
- A community forum for sharing experiences and garnering support with blogs, podcasts, tweets and news on OMS activities
- A summary of scientific information about multiple sclerosis: causes, incidence, genetics, signs, symptoms, diagnosis, prognosis, and the best medical research about the available therapies,
- Updates on new research as it is published and reviewed by our medical research team.

If you would like to know more, visit

<https://overcomingms.org/> or ask at the Centre.





Monthly Nutrition Talks at the Centre with Kathy Kohl

I've had MS since 1985, with various symptoms in the first few years, but pretty stable these days.

I've tried a wide variety of treatments, therapies and diets over the years, and believe that what we eat, how we eat, and what we absorb can make a massive difference to our health and wellbeing. I've studied nutrition with a focus on autoimmune and inflammatory conditions such as MS, and am passionate about enjoying good food and being well!

Each month we'll discuss some of the following burning issues:

- How does digestion work and what can go wrong?
- What foods can help with our condition?
- What foods should we avoid and why?
- What tests can identify Leaky Gut, Candida and nutrient deficiencies?
- What healthy alternatives are there to our problematic favourites?
- ... and pretty much **any** other questions you may have!

Starting Saturday 13th May, 10.30am—12.30pm

Feel free to contact Kathy: kathykohl@rocketmail.com

on Facebook: ['Kathy Kohl Nutrition Group'](#)

or text: 07941563207

We hope to hold regular Nutrition talks at the Centre.
Lookout for information at the Centre and on Facebook.

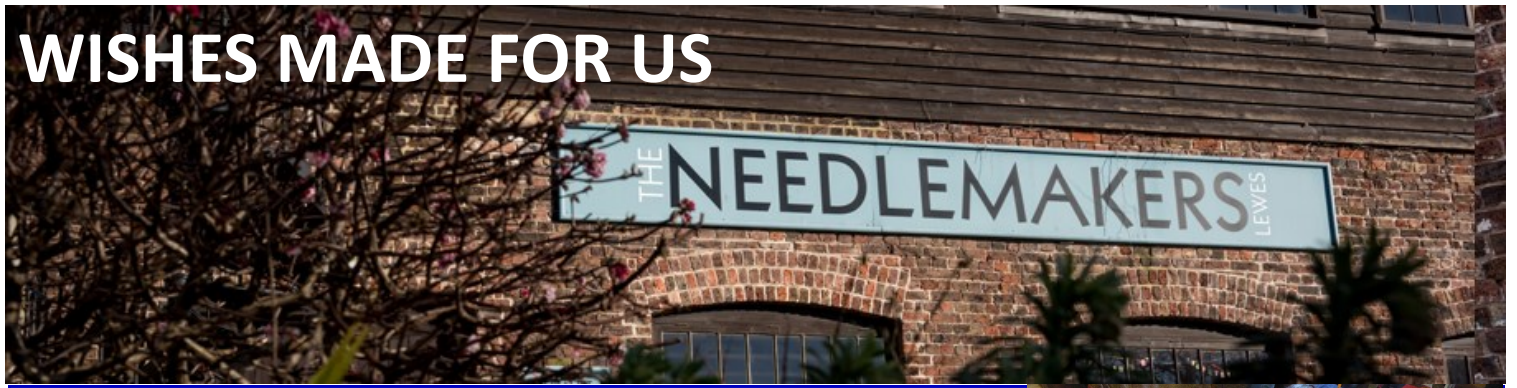
Don't forget! This is YOUR centre.

We are always happy to receive comments to help us improve the Centre. Just jot your thoughts down in the blue book on the reception desk.



This book is reviewed at every meeting of our Board of Trustees. Your thoughts and opinions are taken seriously.

WISHES MADE FOR US



How much do you think £246 weighs in (almost all) pennies? Approximately three quarters of a hundredweight thought our volunteer Bruce when he went to collect it from the wishing well at the [Needlemakers](#) craft centre in Lewes.



Bruce's partner Ruth (our Thursday receptionist) & Mary (Shiatsu therapist) had arranged for the Centre to be the well's charity recipient during last year. The money is collected by Wealden cave & mining society who abseil down to bring it back from the depths.



Bruce soaked the money in coca cola, then washed and dried it out on Ruth's kitchen counter top. Fortunately there were very few pieces of rubbish or foreign coins and a reasonable handful of £1 coins. The following week at the Centre he put it all through the counting machine & bagged it.

Many thanks to Bruce for all his hard work with the money and to Richard of *Revive All* at the Needlemakers, and Andy & Jason from Wealden Cave & Mining society for bringing it up from the depths.

Calling all organisers!

We're in the early stages of planning what we hope will be a massive fun, fundraising day at [Tilgate Park](#) in Crawley. We're looking at a range of events to cater for all abilities. Would you like to be a member of "the creative team" developing the plans for the day and then helping to "put then into practice?" Any assistance will be VERY gratefully received. Contact Hilary at the Centre or email events@mssussex.com

PLEASE DON'T FORGET YOUR 2017 MEMBERSHIP RENEWAL

Your £15 helps keep the Centre open.



BANK TRANSFER

Bank: Lloyds

Account: Sussex MS Centre

Account No. 01813557

Sort code: 30-98-74



If you would like to pay by **standing order** please contact the Centre and we will send you a form.

CARD PAYMENT

In person at the Centre or over the phone.

Donations for HBOT, classes, payment for goods and anything except individual therapists appointments can be made by card or bank transfer. We still accept cheques or cash but other payment methods incur lower bank charges.

A wonderful gift

We were absolutely delighted to receive over £30,000 in February, gifted to us in the will of William Bunce. William was a friend of member Sandra Revett and used to bring her to the Centre. Sandra joined in the very first year of our existence, and was a great supporter. It is heart-warming that William chose to remember us and use a legacy to continue supporting people whose lives have been altered by MS.

We have been offering therapies and support to people with MS for over 30 years now, and have achieved a great deal, but our services will continue to be needed until they finally find a cure.

You can help those who need the Centre in the future by leaving a gift in your will. Making a will is never a pleasant task, but when you do, it is very important that it is drawn up by a properly qualified professional. Please ask your solicitor or will writer for advice.

Fabulous Fundraisers

We've had a lot of support from individuals, local groups and businesses since our last newsletter. Heartfelt thanks go to each and every person who has organised or nominated us for an event, or participated in one, these include.....

Waitrose Hove Branch



Waterhall Seniors Golf Club



Carol's Bridge Afternoon



Harris & Hoole

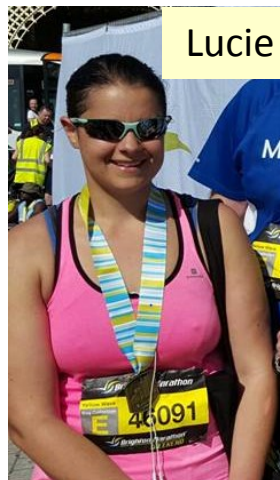


Brighton Half Marathon & full Marathon!



Cat

Brighton Marathon



Lucie

Rotary Club of Haywards Heath



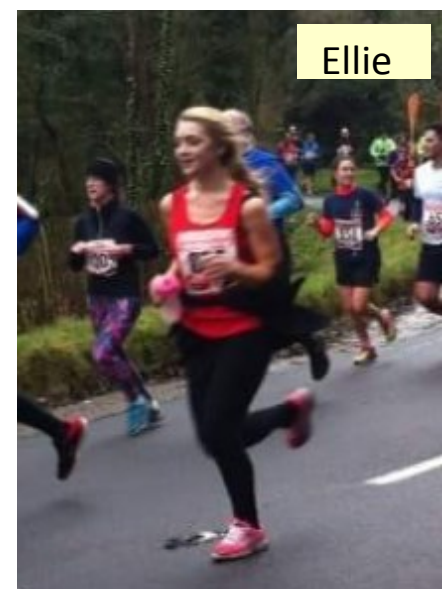
Eastbourne Half Marathon

Brighton Mini mile



India

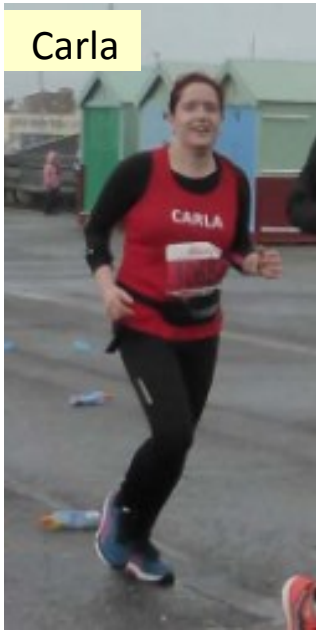
Chris Wing Boxing Challenge



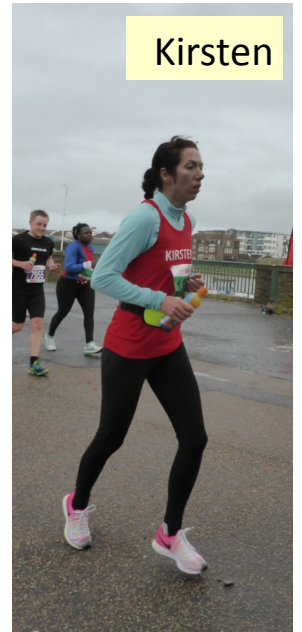
Ellie

Also organised a cake sale at Roedean school

Carla



Kirsten



Liu



Thank you Printech who kindly printed the running vests.



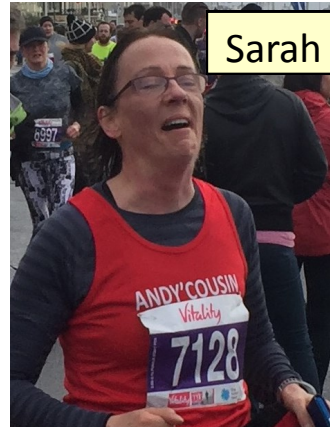
Gaz



Rose



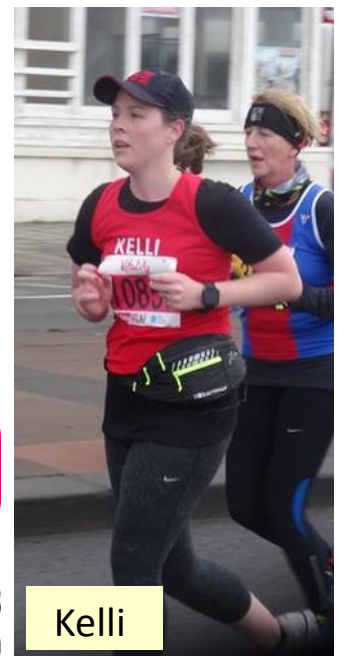
Sarah



Bridget



Kelli



PRINTTECH

Nick Stone | Director

T +44 (0) 1273 411069 M +44 (0) 7778 896238

info@printechprocess.com www.printechprocess.com



Adam Reynolds Memorial Bursary 2016/17



A group of our members took the trip to Margate to view the exhibition of work by Centre Member [Oliver](#) at the [Turner Contemporary](#) in Margate.

The [Adam Reynolds Memorial Bursary](#) is awarded to mid career disabled artists. Oliver has been resident artist there since February and his work was exhibited until 7th May. Everyone thoroughly enjoyed the outing, Judy commented "It was great to see Oliver and his art work and a great lunch with him. The gallery was really interesting". If you would like to be involved with our art group in the future, please let Hilary know. Thanks to Hilary for organising the trip and [Dial a Ride](#) for taking everyone.

Win a Pair of Winning Boots!



Seagulls Striker [Sam Baldock](#) has donated a pair of signed boots for us to raffle. Size 9 if you want to wear them! £1 a ticket. Please contact the Centre if you can help us distribute them to keen fans! Got to be in it to win it!