



WOLF HIRSCHHORN SYNDROME TRUST

Autumn 2016 Newsletter

Hello again,

It only seems like last month that I sat here typing out an introduction to the newsletter. A lot has happened over the last few months, well for me anyway. Adam turned 25 at the beginning of September. You would think it would get easier but it doesn't, particularly as we are now getting older. Sara would love to have a peaceful nights' sleep where Adam doesn't go foraging for food and drink.

Little and often I think his motto is.

In case some of you forgot, we are no longer printing the newsletter unless it is specifically asked for. Instead we are making the most of the technology that is now available to us and emailing it to those who have given us their email addresses. For those people that haven't it will be on the website.

There have been a number of changes on the committee lately. Alasdair, Carol, Ted and Val have retired after a number of years. Ted's input and commitment to the trust was invaluable. It is now, when we are faced with the task of taking over his duties we realise exactly what he did. We also need two new regional co-ordinators to take over from Carol and Val.

With the loss of key members the remaining committee have taken over on their responsibilities. Mine, attempting to produce the newsletter amongst other things. Elaine is now the Treasurer and Margaret is Secretary. So if there is anyone out there (hopefully reading this) we are looking for volunteers to come forward and make themselves available to the Trust and help keep the momentum going. As you will appreciate the current committee cannot keep going on forever.

Stephen



AFTERNOON TEA FOR WOLF-HIRSCHHORN SUPPORT GROUP

On Saturday 23rd August a dedicated group of people again gathered to raise funds for Our WHS Support group. They did this by providing Afternoon Tea, with delicious cakes and sandwiches, in the local St Mary's Church of Ireland Parish Hall in Dungarvin, Co Waterford.

Over the course of the afternoon nearly 1000 Euro was raised which will be passed on to our Treasurer Elaine very soon. Many families and friends attended and people's generosity was really appreciated.

Many thanks to Jenny, Liam and Kate, Winston and Myna for all their help on the day.



HIDDEN HERO

Recently I was nominated secretly, as a Hidden Hero, by my family. I was totally taken by surprise by this. Part of the reason for nominating me was my involvement as Co-Chair of WHS Trust and my advocacy work on behalf of families with disabilities. I am involved in a lot of Community Groups and services, but I could not do this without the support and encouragement of my family. They are the true heroes, not me, but I am deeply indebted to them for their thoughtfulness in nominating me.

Thanks also to Hidden Hearing for sponsoring the opportunity to honour all the nominated Hidden Heroes.

Damien, Co-Chair



On 1st June, the start of our financial year, I took over as treasurer from Alasdair Millar who had worked tirelessly in the role for over 14 years. Huge thanks to Alasdair for his commitment to WHST during this time.

I am a solicitor by profession, not an accountant, so my role is to maintain the books, settle invoices, reimburse committee members for necessary expenses, pay in donation cheques and report to my fellow trustees and committee members at trustee meetings. At the end of the year we will be instructing an accountant to prepare the end of year accounts. If any of our members are qualified accountants and would be interested in helping the WHST with its finances, perhaps you could get in touch with either of our co-chairs Stephen D'Allenger- Bradshaw or Damien Douglas.

I am pleased to report that in the first 3 months of the financial year the Trust has received **£4554.10** in donations and subscriptions. Thanks to all our families, friends and supporters who have fundraised on behalf of the Trust by holding concerts, dress down days, and raffles, participated in the Great North Run, sold cards and paid their subscriptions. As always 100% of funds received is used to support our families, as all trustees and committee members give their time voluntarily.

If anyone is not already paying their subscription and would like to, please arrange to contact your bank to set up a standing order in favour of the Trust. The bank details are:

Account name: Wolf Hirschhorn Syndrome

Sort code: 82-11-07

A/c no: 60509784

The tax man can give us an additional 25% on top of all subscriptions and donations through Gift Aid, so long as donors are tax payers. As the rules have changed, new Gift Aid Declaration forms need to be signed. These were sent out to all families with the National Meeting pack recently, but if anyone needs another form, please contact me by phone or email (details at the back of the newsletter).

Many thanks for continuing to support WHST.

Elaine
Treasurer

thank
you!

**National Meeting:
28 – 30 April 2017**

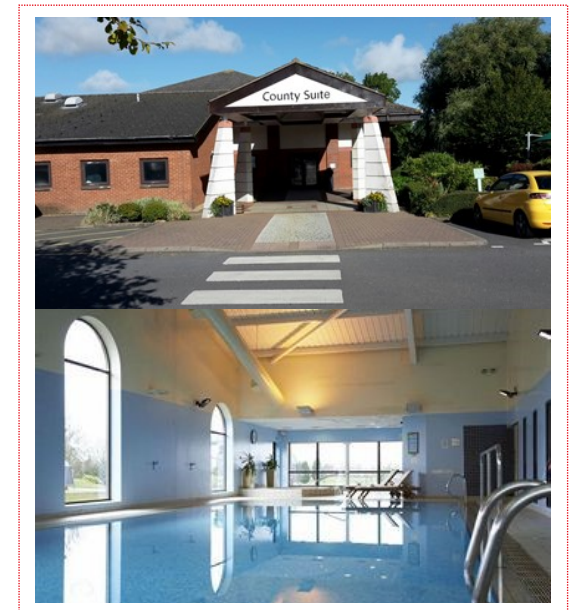


**Staverton Park Hotel,
Daventry, NN11 6JT**



NATIONAL MEETING 2017

All of you will by now have received your invite to the National Meeting next year. Our thanks go to Sarah for all the hard work in managing the new location and format without too many problems. Details will be posted on the website as soon as I can find out how it's done. If there is anyone out there with website experience please do let me know.



GREATEST PRIZE POOL EVER.....

Well, that's what we're hoping for anyway. With more activities and competitions at next year's National Meeting we are in need of more prizes. So if you know anyone who would be willing to donate or can approach those local to you who work for a company who may be willing to donate something, please approach them. Think of all the lovely things you'd like to win!

We are after fancy dress competition prizes for kids and adults, raffle prizes, tombola prizes, as well as prizes for the family fun day activities where you may be in with a chance of winning if you say, hook a duck, guess what's in the boxes, splat the rat, hoop on hoopla, find all the treasure, or hit the tipping target.

So far we are lucky enough to have been given a short break, a Surrey cricket shirt signed by Gary Wilson (Irish captain) and the Surrey cricket team, and an ATG theatre gift voucher. If you can help add to this bounty please email details to Sarah Fleming on sarah_abra@hotmail.com

If you have a contact and would prefer Sarah to contact them instead please let her know and she will be happy to do this.

Thanks
Sarah

REGIONAL MEETING

In July we had our regional get together in Horsham for families in the South East. We had a couple of hours together over lunch, catching up with families we haven't seen for a while.

It was really useful for the two new families travelling from London and Kent who came for the first time. It gave them the opportunity to meet other families.

As we know, it can be a little daunting when you have young children to see a glimpse of the future but of course it also provides support and the experience of the members of our exclusive club.

We'll look forward to hopefully seeing more families at the national conference next year.

Pauline (Theo's mum)

REGION 6

Pauline Nixon (London & South East England)
(BH,BN,BR,CR,CT,DA,GU,KT,ME,PO,RH,SM,SO,SP,SW,TN,TW)
nixonp@btinternet.com



FUNDRAISING

Well, in and amongst all the hospital appointments, stays and various development sessions your fundraising team have been trying to get a little bit of fundraising action up and off the floor. Paula and I have had a few catch up sessions to bounce a few ideas about to see how we could begin to raise some funds to benefit our community and the longevity of our trust.

We are introducing a 'Whacky H Day' within the Kirklees SEN Schools. The idea is that the schools will host a fund raising day, where they may charge £1 for students to participate. The 'H' could be anything; Hair, Hoodies, Harry Potter. We are hoping the days could also include the usual cake stalls etc. I have digital posters in which I can insert a picture of your WHS child. If anyone feels they have a good relationship with their child's school/community group and would kindly ask them if they would like to become involved and host a 'Whacky H' event please get in touch.

In addition to this, we now have a number of cash containers that are placed in local, trust worthy venues. Generally businesses run by family and friends, if anyone has this kind of connection with any businesses and can spare 20 minutes a month to collect any monies and transfer any monies received to the trust this would be very much appreciated.

I am really proud to have hosted a 'coffee and shop' morning on the 16th April this year which was a HUGE success, and so very easy to organise. This event raised over £700 with the

main money raiser being the raffle, (each prize was brand new and unused) £1 a ticket or £5 for 7, EVERYONE loves freebies and two free tickets encouraged people to spend more than the £1/£2 they usually would spend... So there is a top tip for you if ever you're doing a raffle!! I'm hosting a Christmas shopping morning too in November, so if anyone has anything they would like to donate as a raffle prize It would greatly be received.

We all have some wonderful people in our lives, many of which would love to help raise the profile of Wolf Hirschhorn Syndrome. Since taking on this 'fund raising roll' it has given more conversation to my usual introducing Oliver and WHS. Most of the people I've spoken to recently have never heard of WHS, and from conversation they have offered to support us. Amazing, huh? A Ten Minute conversation resulted In £X monies raised through my local Longwood Sing event. £50 raised by Oliver's Great Gran and her friends at their local bowling club and not to mention a huge £2500+ raised by Oliver's Godmother, Katie Lowe from sponsorship for participating in the Great North Run. All this, just for chatting and spreading awareness of Wolf Hirschhorn Syndrome, just from one little family in West Yorkshire. Imagine what services we could provide, what research could be done and how many lives we could change if our whole community had that ten minute conversation.

If anyone has any ideas, or would like to get involved in developing our fundraising please contact me, Laura on 07731356755 Paula on 07811653509 or Stephen on 07860446502

Thanks Laura

If any of you employ carers you will be affected by the new Pensions Regulations. Below is an extract from Disability Rights UK which you may find of interest.



Disability Rights UK with support from The Pensions Regulator are putting on a series of seminars for care sector professionals around the UK. These sessions are free to attend and, in addition to hearing a presentation on automatic enrolment from the regulator, you will have plenty of opportunity to ask The Pensions Regulator questions and talk with other professionals working in the same area.

The events are being held between 1:30pm-3.30pm on:

- 13th October - The Space, Roundtree Way, **Norwich**, NR7 8SQ
- 26th October - Friends' Meeting House, Ship St, **Brighton** BN1 1AF
- 1st November - In association with Spinal Injury Association (SIA) **Milton Keynes**
Christian Centre, Strudwick Drive, Oldbrook, Milton Keynes, MK6 2TG
- 23rd November - Plymouth University, Drake Circus, **Plymouth**, Devon, PL4 8AA
- 29th November - The Circle, 33 Rockingham Lane, **Sheffield**, S1 4FW
- 30th November - BVSC building, 138 Digbeth, **Birmingham**, B5 6DR

For further information, please visit our Events webpage.

If you would like to attend any of these, please email Nick Ash at events@disabilityrightsuk.org

All venues are accessible, however please let us know any access needs you may have in advance.

CONTACTS

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REGION 4

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