WOLF HIRSCHHORN SYNDROME TRUST

Spring 2017 Newsletter

Hello again, I hope that most of you have had a relatively healthy winter.

It is, however, with sadness, that as some of you may already know that Naomi Price and Gemma Langham sadly passed away in the later part of last year. Our thoughts and prayers go out to both families.

It's only in the last couple of weeks that my family succumbed to suffering bad colds. I thought I had managed to escape its clutches but was I wrong. Poor Adam though spent 4 days in bed, asleep most of the time. At least we didn't have to worry about locking the cupboards for a while as he completely lost his appetite. We moved house 2 weeks ago so all this cold business came at the wrong time. Adam though was looking forward to moving and getting himself a larger bedroom where hopefully he has more room to play on his Wii.

There are a couple of dates coming up to put in your diaries. Firstly is 16th April which is Wolf Hirschhorn Awareness Day. Make the most of this day to raise awareness and also raise funds. Secondly at the end of April is the National Meeting. I am hoping that we get a good turnout for this event. We will be holding an AGM on the Saturday as we wish to discuss the way forward for the Trust. The Trustees are always looking for people to join the committee or even offer their talents be it an accountant, web user, newsletter editor or whatever.

For any Chelsea fans out there we will hopefully be running an online silent auction of a signed football. It will be signed by not one, but 23 of the players including John Terry, Fabregas and Eduardo. More information on this will follow.

I recently attended a Genetic Leadership Symposium run by GenticDisordersUK. It was an interesting meeting with a good mix of speakers and gave a lot to think about. One interesting piece of information, that I came away with, was to do with Jeans for Genes Day. At the National meeting I will be able to say more but what I can say is that it could benefit our charity for the years to come. However it all depends on your ability to fundraise.

A question to you all. Do you ever look at the WHST website? If so, it would be interesting to hear if your views on it. Please email me. My email address can be found on the back page of this newsletter. It will however be changing over the next month or so but the website will be updated.

Stephen

National Meeting:
28 – 30 April 2017

Staverton Park Hotel,
Daventry, NN11 6JT

Calling all Superhero WHS families - the national meeting 2017 is nearly here!

We have an exciting weekend planned with massages, 3D superhero film-making workshops, superhero workshops, bowling, dinner and disco and a family fun day full of fun and games. This years' raffle has some amazing prizes, 2 nights away in a holiday cottage, Ambassador Theatre Group theatre vouchers, and a Denbies winery experience to name just a few!

For all you Superheroes joining us at this years' national meeting, we can't wait to see your fancy dress outfits (that applies to adults as well by the way - there's a prize for the best costume for adults too so please don't just leave it to the kids!).

And if you can, please bring donations for the tombola (toys, bottles, sweets), equipment for the nearly new sale and a cake for the cake stall (nothing that requires refrigeration please!).

If you haven't booked your space at this event and still want to join us for this fantastic weekend please contact Sarah Fleming at sarah_abra@hotmail.com.

TREASURERS POINT OF VIEW

My role as treasurer continues to keep me busy, particularly as our National Meeting is fast approaching. There are numerous cheques to pay in and invoices to settle, as well as letters of thanks and certificates of appreciation to send out, bank reconciliation statements to prepare and the regular updating of the day to day cash book.

At our last committee meeting at the end of February, I was pleased to report that during this financial year we have received donations in excess of £9,000 and subscriptions totalling over £400. The balance on our current and investment accounts now totals a healthy £24,000.

Our thanks go to all our fundraisers who have remembered us at Golden Wedding celebrations, and held fundraising events such as tea parties, coffee mornings, Christmas fayres and concerts. Thanks also to everyone who has bought or sold our Christmas cards. Sales of our cards amounted to £949.

On behalf of the trustees I would like to send our thanks in advance to 3 sets of fundraisers. David Keen and 10 of his friends who are calling themselves ‘Dignity Lads’, are participating in the London to Brighton Cycle Ride on 18th June, and are raising funds through Virgin MoneyGiving which will be split between WHST and MS Society. Alexander Ferguson is also using Virgin MoneyGiving to raise funds for WHST. Together with his friend Jim Barrett, the ‘Xrunner Mad Men’ are running a 10k wild mud run in Derbyshire on 1st April which will include 60 obstacles featuring mud such as vertical drops, climbs, tunnels, a fire pit and open water swims. They must be mad!

Thanks also to Danielle Swain who is fundraising through JustGiving and is seeking sponsorship for the Great Yorkshire Bike Ride on 17th June. Thank you to all our supporters and good luck for all the training you will need to do!

If anyone would like to raise funds in aid of WHST a fundraising pack is available which includes a sponsorship form, donation form, guidelines on fundraising and ideas for fundraising events.

As most of you know we lost our beautiful princess Naomi in October. She was and still is a huge part of our life and things will never be the same without her. She was sent to us at a dark time in our lives when we thought we wouldn't be happy again.. in 2010 we lost her sister Chardelle who also had WHS she was 17 months. Then found out we were expecting another baby in 2012 we were bless with Naomi who Brought so much happiness to our family, 15th February 2012 was the day we got our sunshine back in our lives and a bounce in our step. Don't get me wrong it was emotional roller-coaster lots of ups and downs and scared we would lose her once she passed the 17th month mark I guess I started to relax. Naomi was my right hand little lady everything we done we done for Naomi or with Naomi she was and always will be my best friend our world and our life. We will NEVER get over her loss or forget who she was. Our hearts will always be broken.. There isn't a second she's isn't thought about. She was and always will be loved by some many people she touch so many hearts.

So a little insight to Naomi..
Naomi was so cheeky, she knew what she wanted and when she wanted it. She met some of her mile stones which to your average family wouldn't thing was a big deal but to us was a huge deal. Like she learnt how to roller and she was superfast at that, escape the room and follow you in to the kitchen, she would find her dummy in the mix of her toys roll to get it and put it in her own mouth she started weight bearing on her little legs. Would finger feed herself, hold her own bottle, drink from a straw, sit up by herself and shout to get you attention. Everything she did made us so proud.

She would always get excited about a big fuss. She loved attention. Cuddles.. She was just always so happy.

I could talk about all the things my little pricey done for ever. You kind of got an insight to her. Anyone who knew Naomi was touched by her she had a way of gripping people's hearts.

Naomi has a page on Facebook with is called princess priceys progress page. Feel free to add it. I still upload it with photos.

She has left a massive hole in our lives.
Her big sister Rochelle misses her more than anything but I'm proud of the way she has dealt with what this cruel life has thrown at her to deal with.

❤

Shelly

Gemma Lanham

It is with great sadness that we have to advise that our beautiful and much loved daughter and sister, Gemma, died unexpectedly at the end of last year, aged 22. Those of you who have been to the National Meetings may have met her and remember her for her blonde plaits and pink wheelchair!

Our first contact with the WHS community was when we were given Gemma's official diagnosis when she was just 3 days old. We were given Chris Hilder's phone number by a Doctor at the hospital and rang her almost immediately. Gemma was born on the weekend of one of the 1st national meetings of the WHS group and Chris was full of stories of the children and families she had met and of the antics and achievements of her son Steven. We will always remember Chris's positivity during that phone call which was just what we needed as we embarked on a journey which was very different from the one we had been expecting.

We like to think that Gemma lived a full and happy life. She was very much at the heart of our family and a big part of the community in which she lived. She attended a nursery at a Specialist School from the age of 2 ½ and later moved on into the main school where she remained until she left school at the age of 19. Gemma was happy and content at school and formed a close bond with many of the staff. She loved taking part in hydrotherapy sessions and the freedom that they gave her from her wheelchair. She also enjoyed the great outdoors and having the wind in her hair, especially on the many canal boat trips she went on, on the canals of Shropshire and Mid Wales. Gemma was able to go to a fantastic Children's Hospice for respite and loved to go down to the lake there to feed the ducks. When she moved on into adulthood, she attended a Day Opportunity Programme. Being in a rural area, there is a limited (but thankfully excellent) choice of provision which meant that Gemma remained with people she had been at school with, so friendships could be maintained.

When we look back on Gemma's life, we reflect on what a huge part she has played in the lives of so many people. In spite of (or because of) her limitations, the little girl who never spoke a word has taught people to be more sensitive and understanding of others. She has inspired people to try new things, she has brought a whole host of new friendships to our family which will always be treasured and above all, she has made people realise that EVERYONE has a place and contribution to make in Society. We miss her dreadfully.

Anne, Matthew and Ben Lanham.

23/10/94 – 7/12/16

Tryb4uFly

For those who fly with your WHS children/young adults this may be of interest to you.

Tryb4uFly

QEF

queen elizabeth's foundation for disabled people

achieving goals for life

qef.org.uk

Making it easier for disabled people to fly

Tryb4uFly is a service for disabled children and adults in the UK. We provide cabin assessments, information about flying and hire equipment to make your journey easier

Assessments available in the uk

www.tryb4ufly.org.uk

For more information

QEF registered charity number 251051

Tryb4uFly

QEF

queen elizabeth's foundation for disabled people

achieving goals for life

qef.org.uk

Making it easier for disabled people to fly

Tryb4uFly assessments take place in a realistic aircraft cabin, enabling you to experience what it is like to move down the aisle and use various types of transfer and support equipment.

A trained occupational therapist will guide you through boarding the aircraft, wheelchairs transfer option and support systems available, helping you to plan ahead and increase your confidence.

Equipment can be hired or bought from Tryb4uFly.

Tryb4uFly is available at:

QEF Mobility Services
1 Metcalf Avenue
Carshalton, Surrey
SM5 4AW

Tel: 0208 770 1151
mobility@qef.org.uk

William Merritt Disabled Living Centre and Mobility Service
St. Mary's Hospital
Green Hill Road
Armley, Leeds
LS12 3QE

Tel: 01133 508 989
info@wmdlc.org

Regional Driving Assessment Centre
Unit 11, Network Park
Duddeston Mill Road
Saltley, Birmingham
B8 1AU

Tel: 0121 359 4222
info@rdac.co.uk

www.tryb4ufly.org.uk

For more information

QEF registered charity number 251051

Wolf Hirschhorn Syndrome Trust

Registered Charity Number 1038219

Website address: www.whs4pminus.co.uk

CONTACTS

WHST CHAIRMAN
Stephen D’Allenger-Bradshaw (Trustee)
sw@dalbrad.freeserve.co.uk

WHST CO-CHAIRMAN
Damien Douglas (Trustee)
damiendouglas666@hotmail.com

WHST TREASURER
Elaine Bagg (Trustee)
elainebagg@yahoo.com

WHSSG TREASURER
Stephen D’Allenger Bradshaw (Trustee)
sw@dalbrad.freeserve.co.uk

WHST SECRETARY
Margaret Begent (Trustee)
margaret_begent@hotmail.com

NATIONAL MEETING ORGANISER
Sarah Fleming
sarah_abra@hotmail.com

FUNDRAISING ORGANISERS
Laura Woodhead
laura.woodhead@live.co.uk

SIBLINGS REPRESENTATIVE
Katie Hilder
katie.hilder.25@gmail.com

WEBSITE SHOP
Sara D’Allenger-Bradshaw
sw@dalbrad.freeserve.co.uk

HONORARY COMMITTEE MEMBER
Susan Cooper
suze.cooper@hotmail.co.uk

REGION/COORDINATOR

(EMAIL CONTACT ADDRESS/POSTCODES COVERED)

REGION 1
Madeline Heneghan (Scotland & North East England)
(AB,CA,DD,DG,DH,DL,EH,FK,G,HS,HU,IV,KA,KW,KY,ML,NE,PA,PH,SR,TD,TS,ZE)
maddles78@hotmail.co.uk

REGION 2
Vacant (North West England & North Wales)
(BB,BL,CH,CW,FY,L,LA,LL,M,OL,PR,SK,ST,SY,TF,WA,WN)

REGION 3
Vacant (West Midlands, & East Midlands)
(B,CV,DE,DY,LE,NG,NN,NR,PE,WR,WS,WV)

REGION 4
Vacant (South West England & South Wales)
(BA,BS,CF,DT,EX,GL,HR,LD,NP,PL,SA,SN,TA,TQ,TR)

REGION 5
Margaret Begent (Trustee) (London & South East England)
(AL,CB,CM,CO,E,EC,EN,HA,HP,IG,IP,LU,MK,N,NW,OX,RG,RM,SE,SG,SL,SS,UB,W,WC,WD)
margaret.begent@bhrhospitals.nhs.uk

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

REGION 7
Damien Douglas (Ireland)
(ALL OF IRELAND)
damiendouglas666@hotmail.com

REGION 8
Elizabeth McComish-Rooney (Yorkshire and the Humber)
(BD,DN,HD,HG,HX,LN,LS,S,WF,YO)
lizzier41@yahoo.co.uk