CHARGE FAMILY SUPPORT GROUP
Registered Charity No.1042953

February 2013

Hi everyone

A date for your diary 6-8th September at least for young adults with CHARGE. Having just had our first meeting I am excited about this weekend. Sorry for the long delay in a newsletter but quite simply I have not had the time to write and compile one. As some of you are aware Jess went to Secondary school in September and right up to when she started we were still dealing with the local authority regarding her school. I have also changed my work days because Jess is residential and now have less time than before.

At home we receive a number of newsletters from different organisations and there are a number I wonder why they are sent out. They contain so little information. I try to ensure that the newsletter is interesting and contains informative pieces, with contributions it is easy to put together a newsletter and not particularly time consuming. When I have to write a substantial amount of the newsletter it takes alot of time because I do not find writing from scratch particularly easy. This maybe of surprise to many of you.

Writing the piece about the Para Olympic flamelighting ceremony I remembered how much I enjoy writing and preparing the newsletter and do not wish to give it up. I have had offers to help but what I need is for you to write articles etc without me directly asking individuals. This would also mean that it is you influencing what goes in the newsletter rather than me deciding what is interesting. Many thanks though to those of you who I opportunistically ask to contribute and agree.

I am looking for contributions not just from parents or children/adults born with CHARGE but grandparents and siblings. Below is an unsolicited contribution from Elly with her take on what CHARGE stands for in respect of her sister and other children with CHARGE she has met.

Simon

NEWS

Young Adults CHARGE Weekend 6th-8th September 2013

The CHARGE Family Support Group is funding a weekend for up to 12 young adults with CHARGE in September 2013 most likely the 6th-8th. It is being supported by Sense and being organised by 3 young adults with CHARGE. We have just had our first meeting which was very successful. One of the first decisions made by the adults is that it is aimed at the 18 to 30's. Although Sense is not taking applications yet it would be useful to know who is interested in attending so please let me know. Parents – I do not have email/contact details for many of your adult offspring so please let them know. Please see the accompanying flyer made by the young women involved.

Travel insurance

Periodically questions come up about travel insurance. There are a number of insurance policies out there for children and adults with disabilities. However these can still be hit or miss, for example we were declined cover by one company for Jess 2 years ago yet when she was younger and closer to her operations and issues there was no problem. The last time we went to the States we used Fish who we have also used for employer liability insurance when we employed someone using Direct Payments.

There is a new policy on behalf of the Family Fund aimed at families with children with disabilities. The feedback I have had is that it is very simple and more importantly cheap.

CHARGE Syndrome Foundation conference

11th International CHARGE Syndrome conference is to be held in Scottsdale Arizona from 25th-28th July. I shall be going and I know that Steve Rose from Sense and Jeremy Kirk are presenting. Here is the link to the conference page http://chargesyndrome.org/conference-2013.asp.

CHARGE by Elly Howard (aged 10)

Creative minds
Happy all the time
Amazing at what they do
Radiating fantastic things
Greatness destined to be
Excellent people

Family Days

Since the last newsletter there have been 2 further family days. If I am honest numbers wise they were a mixed success. For Bristol where Sense had arranged two workshops only 6 families were in attendance unfortunately another 6 were unable to attend at the last minute. There were a similar number at the Northern Day.

We have just had a committee meeting and there will be a series of family days again this year. The next London family day will be 4th May but please check out the website for dates as we finalise days. However we are looking at more workshops/presentations, maybe a family day including a subsidised overnight stay (so families can spend more time with each other) and further links with Sense. In addition we are hoping to organise our first Scottish and Welsh family days.

In addition I have had a couple of conversations with other parents about financially supporting local family get togethers. The group is happy to support these so if there are a few families in any area that wish to meet up please let me you.

Charge Family Days London – Abi Roman

I have been asked to write a little about my family's experiences of the London Charge Family Days. Our Charger, Jake, is nearly five and we have been attending Family Days at the Ann Wall Centre in Barnet since he before he was one and the only way to describe them is as a much looked forward to family reunion – albeit a pretty unusual family with mass tube feedings, parachutes, arts and crafts, swimming and much more.

Jake always enjoys the days as he feels very comfortable getting around Ann Wall and knows the volunteers and the different activity areas very well now plus he has made lots of friends throughout the years.

For Nick and me, the benefits have been enormous. I can still remember going to our first Family Day in 2008 and back then feeling like the parents of the only Charger in the world. Suddenly we were in a building full of them and they came in all different shapes and sizes, some talked, some walked, some ate, some didn't. But they were all amazing, happy individuals and for the first time we could see a future for Jake that didn't seem so bad.

We are so grateful to the Family Days for providing us with a ready supply of wonderful friends who understand our world completely. Plus, we get to meet them in really relaxing surroundings with an abundant supply of tea, coffee, good food, amazing volunteers and well organised activities for all the children so that we can have a bit of time off. I think that the ability to reach out to other families and share experiences is the best thing about the Family Days and I now try to make the effort to speak to new families who have that same look of nervousness and apprehension that we once had.

Jake has two older sisters who also look forward to the Family Days just as much as I do. They have made great friends who share their experience of having a sibling with special needs and can play and relax safe in the knowledge that no one will ask 'why does he look like that' or 'why does make those sounds' etc.

The volunteers are really fantastic and work so hard to make everyone's day perfect and they return year after year which is brilliant for building relationships with the kids. The level of arts and crafts is really great and all the children make such lovely things. They get to use the sensory room, do trampolining, play with musical instruments, sing songs, go swimming in a hydrotherapy pool and much more in a warm, safe and friendly environment.

There is nothing more we could ask for really – here are a couple of the girls' own thoughts.

Mia age 10 says "I like meeting other children with Charge siblings. I really like doing trampolining and swimming with my family. I like meeting other older Chargers and seeing what kinds of things Jake could do when he grows up."

Ruby age 6 says "I like it because we do lots of art and go swimming sometimes. We do loads of songs and play games too and I play games with my friends. I also love to do trampolining and make nice things and get my face painted too."

There are so many good points about Charge Family Days (and no bad ones) that I could go on and on. But I'd like to end by saying that the cup of tea I had made for me by a Charger at the last Family Day was the best one I've ever had. I would like to think that in ten years or so how wonderful it would be if Jake could also be a volunteer and perhaps make you a lovely cup of tea too.

Abi

Bristol Family Day – Simon Howard

Having held our first family day at Sense's Woodside centre in Bristol in 2012 we held another in September 2013. It was also our first family day where Sense held workshops for the parents.

Jenny Fletcher did an introduction to CHARGE which given the age of most of the families there was very useful. Gail Deuce and Pam Todd MSI teacher with Surrey did one on multisensory impairments. Parents were given a series of sensory exercises that challenged us. For example a series of clear plastic glasses were placed on the floor and we had to walk round them looking through the wrong end of binoculars. This made the glasses disappear so made the exercise very difficult. There was also a balance exercise which with my years of karate training I could cheat at as I did at the CHARGE conference with a similar exercise! These exercises though are good to help parents try to understand some of the difficulties our children have to overcome.

For the usual health reasons we unfortunately ended up with only half the families that said they were coming which was a real shame given the workshops. It is fair to say though that the parents there enjoyed and got much benefit out of the workshops.

One interesting feature of the workshops was the confidence of parents to chip in with their experiences and advice. This added to the workshops and it's a credit that those leading the workshops were not just comfortable but also encouraged these interjections. More importantly, though there was another great musical workshop for the children.

There was even a bit of pet therapy. As mentioned in my Para Olympic story our family had just acquired a puppy (Pixel) and a couple of weeks after the family day we were attending Sense's members day. Friends in Wiltshire had agreed to look after him so I had stayed the Friday night with them to introduce Pixel not just to them but also their dog.

I brought him in to the family day and found that William Concannon had had a bad experience with dogs so was scared of them. No one could be scared of this little fluffball so William was introduced to him.

Look at the difference in his confidence in the 2 photos here.

Para Olympic Flame Lighting ceremony at Stoke Mandeville – Simon Howard

With the success of the Olympics and Para Olympics in the summer I thought I would share with you our Para Olympic story.

I got a phone call from Sense asking would you like to take part in the Para Olympics flame lighting ceremony at Stoke Mandeville and oh, you need to make your own lanterns.

Both girls in different ways were excited by these events. Jess for example had already been to the Olympic Stadium twice with her school and she loved the opening ceremony on tv while Elly failed the 'Tebbit test' by cheering on Kenyan competitors as much as British ones. Elly and I also went to see Team GB ladies vs Brazil at Wembley which was a really good football match helped by England - sorry GB winning (I really struggled with this GB concept in football). Her first trip to a decent stadium – she regularly comes to watch Crystal Palace with me!

Typically we realised that having just got a puppy we couldn't all go so Flo sacrificed herself and stayed at home with this little furball, so Jess, Elly and I sat down the weekend and made big lanterns for each of us (there were specific instructions as to size and colour).

Not really knowing what was happening on arrival I found we had to queue to deposit our lanterns and register. This was all a bit tedious particularly with a child desperate for the toilet. Eventually having done and collected our T shirts and instructions we were free to go and enjoy the entertainment. It was a rare sunny evening so we had a picnic and positioned ourselves on the grass in front of the VIP seating to look at the big screen showing what was happening on the stage. After about 15 minutes a steward wandered across and said ‘You can’t sit there’, so I explained that my daughter was visually impaired and she could not see the screen. Unsurprisingly given the event we were at we remained sitting in front of the screen!

We had gone not really knowing what was going to happen. It transpired that we were to be guards of honour for the 4 flames and we were to be part of the one for Scotland, a first for me honouring Scotland!! Apparently we were to walk round the athletics track following our flame. We waited and then a little bit more, Jess was starting to get impatient, not fully understanding what was going on so there were a few little kicks and pushes.

Finally we started up the athletics track which had a small bank to the outside. This bank for its 100 metres length was full of people with cameras, flashes going off and people on all sides cheering. The transformation in Jess was astounding since now there were big grins, the girl certainly knows how to perform for the camera/crowd. I have performed onstage both in a band and acting (both very badly) but I would agree with her that to hear the cheering and to see all the flashes walking along the track was quite something.

It may not have been the opening ceremony in the main stadium for either the Olympics or the Para Olympics, but the 2012 Para Olympics were the best ever. There are many children in the UK for whom there is no difference between Olympic and Para Olympic ‘heroes’, Elly included.

I was very proud to have taken part.

Simon

Tribute to Peggy Freeman

Many of us use or have used Sense’s services in different ways over the years, earlier this year the co founder of Sense Peggy Freeman MBE died aged 94. It’s amazing to remember that Sense started as a parent run organisation so I thought I should reprint Sense’s tribute to her.

Peggy Freeman

Peggy Freeman MBE sadly passed away aged 94 in a Nottingham hospital on 15 September 2012, following a short illness. Peggy was one of the parents who co-founded the National Deafblind and Rubella Association in 1955, the organisation which later became Sense.

Born Peggy Hill in Sutton Coldfield, she is survived by her four children, sons Ian and Robin, and daughters Ann, who lives in Australia, and Bunty, who is deafblind and lives in a Sense residential home in Birmingham.

In her early working life Peggy was a senior civil servant during the war (a senior secretary in the War Office). She married Peter Freeman on 15 December 1941 in London where Peggy continued working for some years.

Peggy received an MBE in 1967 for services to deafblind people for her role in co-founding Sense. The group began with ten founder families and assets of just £2.5s.0d (£2.25). Today, Sense is the UK's largest voluntary-sector provider of services to people with both sight and hearing difficulties. It employs over 3,000 staff and meets the needs of thousands of dual-sensory impaired people from babyhood to old age.


Talking Sense

Season's Greetings to all our Readers

Opening Time

The Next Five Years

The Van Dijk Approach

Teacher Training

Sense The eyes and ears of deaf-blind people.

Gillian Morbey CEO, Sense and Sense International and President of Deafblind International, said: ‘Although small in stature, Peggy was huge in courage and determination. At a time when people thought deafblind children couldn’t be educated or live full lives Peggy battled, not only for her own daughter, but what has become the whole Sense family. Peggy made a deep impression on everyone she met and many deafblind people and their families owe Peggy a huge debt of gratitude. She is our last great ‘trouper’ from the early days of Sense and will be sadly missed.’

Peggy Freeman contracted rubella in 1952 just before becoming pregnant with her fourth child, Bunty who was born on 29 January 1953 in Gravesend. Doctors assured her that her baby would be alright but Bunty was born deaf, blind and with heart problems. Peggy had no one to turn to for help until a teacher of deaf children introduced her to other parents of deafblind children.

Peggy met another parent, Margaret Brock MBE, whose son was similarly born with Congenital Rubella Syndrome (CRS), and together they formally set up the first parents’ Rubella Group in 1955. Peggy was the group’s very first secretary. At the time, those with dual disabilities were neither recognised or provided for. The group fought for the provision of all deafblind children and pioneered Sense homes – places where deafblind people are supported with ongoing education, vocational training and leisure skills, allowing them to lead a full and meaningful life.

Up until recent years, Peggy was a regular speaker on matters of deafblindness, not just here in the UK, but also on the international stage. Even at 85 years old, Peggy flew to

Canada to support Deafblind International at a conference.

"It is difficult to believe that a minute virus so small it can only be seen with a microscope of great magnitude, could cause impairments to the vision and hearing of a child even before it is born. It is also unbelievable that when a few families with rubella got together in 1955 they should start an association that in time would grow to become as successful in all fields concerned with the care of deafblind people as Sense is today.

"These years have seen many changes in society and these are reflected in the changes at Sense. Changing attitudes followed a growing awareness and understanding of the needs of people with disabilities."

Paying tribute to her, Sense Trustee Gini Bartlett said: "I simply don't know what mothers like me would have done without Peggy. I first knew her over 45 years ago when I needed support for my son Ian who was deafblind following my contracting rubella during my pregnancy. From the very beginning I was so impressed by how supportive she was. She was truly kind and happy to share her knowledge with me personally. I am truly indebted to her as are so many thousands of deafblind people who have received support from Sense. Peggy continued to be amazed at the growth of Sense and the awareness of deafblindness throughout the world. It is an incredible legacy she leaves behind and she will be sadly missed."

In 1996, four years after the passing of her beloved husband, Peggy authored "Good Sense" a history of the charity. She wrote in the foreword: "I wish to thank Peter who was still with me when I began writing this history of Sense and who shared all those years with me. Also the members of Sense who have worked with such dedication. Above all my thanks go to Bunty and all deafblind people. To serve them has given a purpose to my life."

Professional Footballer being kind!

All too often professional footballers get bad press, usually deservedly so. There are however it is good to be able to give an example of a player demonstrating behaviour contrary to this especially when it relates to CHARGE. The report below below is taken from 'Thisisstaffordshire.co.uk' website although Leanne had posted about it on the facebook group.

CHANCE MEETING: Danyl with parents Leanne and James. Picture: Malcolm Hart

A TODDLER battling a rare disorder will be given special clinical equipment – after a Premier League footballer offered him a surprise gift. Brave two-year-old Danyl Brough will soon be able to watch his favourite cartoons in comfort after his family's chance meeting with Sunderland star Craig Gardner.

Little Danyl, of Sneyd Green, has CHARGE syndrome, a rare genetic disorder which leads to a number of serious health problems. It means the youngster has a weak heart, is completely deaf, cannot eat solid food and suffers mobility problems.

But thanks to midfielder Craig, his family will be able to buy a special chair that will allow Danyl to sit up straight like a normal child. The former Aston Villa and Birmingham City player insisted on paying the £500 cost after meeting the family one lunchtime in Birmingham. They were eating in Selfridges restaurant, shortly after one of Danyl's regular appointments at Birmingham Children's Hospital.

Danyl's mum Leanne, aged 29, who lives in Hanley Road with her husband, James, and their children Declan, aged five, Amelia, aged four, and 16-week-old Ethan, said: "We were having lunch in Selfridges in Birmingham and Craig was sitting nearby. I didn't even know who he was at first because I don't watch football. "His little girl was interested in Danyl and we got talking."His wife, Lexie, said how much she'd love to have four children like us. "He asked if there were any charities involved with Danyl's care and we said that there weren't.

"He immediately said he was going to go to the cash point and get the money out there and then. We had to tell him not to at least four times before he would listen." The families exchanged contact details and before long Craig was in touch again. And this time he wouldn't take no for an answer.

Full-time mum Leanne added: "He was wonderful. He was so caring. He meant everything he said. We just feel so incredibly lucky." Danyl's dad James, aged 34, said: "Craig passed on a telephone number and Leanne exchanged a few emails with his wife."Craig also rang my mother-in-law, who was also there when we were having lunch in Birmingham. It's not something you expect to happen to normal families just going about their business."

The £500 from Craig will go towards a special supportive harness, similar to a baby bouncer. Leanne says her son is a huge Mickey Mouse fan, and it will allow him to watch his favourite cartoon character in comfort. Craig said: "We were in the restaurant and my wife and I were both extremely moved by Danyl's plight. They are such a lovely family and I thought if there was anything we could do then we should. "I wish them all the best and hope the equipment will go some way to making Danyl's life a little easier." Danyl was diagnosed with CHARGE at the age of around sixth months. The congenital condition can be life-threatening, but Danyl has been making good progress.

Charities offer financial help to families coping with the condition, but Leanne said she was uncomfortable with the idea of asking for 'handouts'. She said: "We work, so we weren't comfortable with the idea of being asked about our finances. It sometimes seems as though people on benefits get given everything, but we are a working family. When we looked into it, they wanted to know everything about our gas and electric bills and how much we spend on the kids at Christmas. I didn't like the idea of it. But Craig's generous gift has been a huge help."

PEN PORTRAITS

I have not received a pen portrait for a long time. These are something that many parents enjoy reading so please write some.

FUNDRAISING

There are quite a few people raising money for the support group. I would very much like to hear from you so I can let everyone know what you have been doing and acknowledge your efforts. Below is a copy of the blog written by Rachel Goswell about an original fundraising event in Exeter that raised over £1,100 for the group.

The Day Many Lampshades Were Made!

Saturday saw a very special day for me in Exeter at the Hub on the Green. After a few months of planning, Quincy Lampshades came to town to run two workshops with the aim of raising money for the CHARGE Family Support Group. Ruth who *is* Quincy Lampshades sent me a message in autumn of last year and told me that one of her oldest and dearest friends has a young daughter with CHARGE too and she had been wanting to organise a fundraiser for some time for the Support Group. The CHARGE community is quite small and it turned out I knew of her friend and daughter Saffie though we had not yet met.

Of course it was a no brainer to do this and with a few emails back and forth support for Ruth's idea fell into place very quickly and tickets went on sale. We tweeted, facebooked and emailed. So many people retweeted details which was SO heartwarming and both workshops sold out. There were two workshops, with the morning 29 in attendance and the afternoon session had 25. I went to both workshops and had such great fun. I met some truly lovely people and it was fantastic seeing everyone's

lampshades come together.

In the morning I made a lampshade for Jesse's room which has a fab retro robot print on it. It will be a little while before it can go up as his room is in redecoration mode. A lasting memory for me is the laughter coming from Ally's table (Shaldon Bakery). She giggled her way through and it really made me smile. It was lovely seeing so many have such fun and I have to say that her Macaroons are the best I have ever tasted! *They didn't last long!*

There were two other CHARGE mothers in the workshops. Tracy who is local, I have been in contact with for over a year when I knew I would be relocating down here. Our children are quite different in their needs. And Julia, Ruth's close friend who drove down from Wales to attend in the afternoon. Without whom really, this wouldn't have happened! Again our children are quite different. That is the thing with CHARGE as I have written before. It is such a broad spectrum it is unlikely you will meet two children with completely identical issues yet there are naturally common bonds between them. The understanding and ease in which we are able to talk about our children can't be found anywhere else. And I always find it a relief to have the opportunity to talk with other parents. This is why the CHARGE Family Support Group is also so important. It brings families together with Family Days around the country, usually in conjunction with Sense (the Deafblind charity); because many of our children have multi sensory problems. The money that has been raised will go towards these days and is so needed. For that I would like to thank every single person involved. All of the companies who are listed below that gave free of charge their services and every single person that came and made a lampshade. I hope you know that all of you have made a difference.

People that must be thanked are:

Joey (Hub on the Green)
Lyndsey James (Sorbet Design)
David and Paul (Needcraft and Needprint)
Ally (Shaldon Bakery)
Vicky Hammerstein (Hulu Yarns & Fabrics)
Fraser (Ruth's husband)
Ann and Ray (Ruth's mum and step-dad)
Peter and Sarah (Ruth's dad and step-mum)
Jane and Tony (Ruth's sister and bro-in-law)

Left to Right: Ally from Shaldon Bakery, Afternoon workshop

As a result of these workshops, Karen from Cosy Corner Quilts / High View Crafts is making a quilt from all the scraps of fabric that was left. This quilt will be up for auction with all monies going to the CHARGE Family Support Group and I will be posting details up of this when it is ready. Ruth at Quincy Lampshades is also auctioning off her demonstration 'June Song Tea' lampshade that she made during the workshop, details of which are here. Again, all proceeds will go the CHARGE Family Support Group. Everyone paid a minimum donation of £20 for the workshop and the current total is £1153.30 which is fantastic!

Left to Right: Julia, Me, Tracy = the CHARGE mums!

On a final note I *have* to thank Ruth the most. She is an awesome woman. She has worked so tirelessly to make this happen and I feel really blessed to have been a small part of this big process. You can read her thoughts on the day here. I also met a local blogger Jules at the event, who turns out is a friend of Tracy's. Jules will also be writing up about the day over on her blog. I am continually amazed at the serendipity I am experiencing having J in my life. He led us to live in Exeter and far bigger things than I could ever have imagined. I wonder what's around the next corner?!

Just Giving

We have a Just Giving page. This can be found at http://www.justgiving.com/charge-fsg or via the link on our website. This hopefully will make it easier for anyone to raise funds for the group.

Sponsor forms

If anyone is looking to raise funds for the CFSG I have sponsor forms available.

UK ONLINE

Website

We are always looking to improve and update the website, so any comments or suggestions are very welcome.

CHARGE Syndrome (UK) supporting each other (Facebook group)

This Facebook group set up by Lesley Chan (a parent) is the main UK CHARGE presence on Facebook. It is a closed group so that non members cannot access the content. Just search the name on Facebook or use this link
http://www.facebook.com/groups/274381645907029/.

USEFUL INFORMATION

Sense - is the world's largest deafblind charity that works with children with CHARGE here. They are a very useful organisation. On their website are some information sheets on CHARGE. Their contact details are: 101 Pentonville Road, London N1 9LG; tel: 0845 127 0066; textphone: 0845 127 0062. Website: www.sense.org.uk.

CHARGE Syndrome Foundation – the US CHARGE charity. Their website is found at www.chargesydrome.org. There is available to download free a CHARGE Manual aimed at both parents and professionals.

CONTACT DETAILS

CHARGE Family Support Group Website
http://www.chargesyndrome.org.uk

Lydia Howarth (Chair)
Telephone: 020 8932 6824
Email: lydia@howarthonline.net

Simon Howard (Vice Chair)
Telephone: 020 8265 3604
Emails: si_howard@hotmail.com

Any problems with my email please my alternate email address simonthoward@googlemail.com

Frances Concannon (Secretary)
Telephone: 01732 363411
Email: francesmco@aol.com

The views expressed in this newsletter are not necessarily those held by the CHARGE Family Support Group.

INFORMATION SHEET

Name of person with CHARGE

Address

Email address

Telephone No

DoB

Parent's names

Address if different from above

Email address if different from above

Telephone No if different from above

Main Issues

Please return to Simon Howard, 59 Elmer Road, London SE6 2HA or si_howard@hotmail.com