



July 2011

Hi everyone

This is the first newsletter since Sense's CHARGE conference in March and let me be very professional - all I can say is Wow! I know that I had been involved in the conference from before its inception (if that makes sense) but it was everything I was hoping for and more. There were over 50 families for the family part of conference, many more than Sense had originally budgeted for. I must thank Sense for this commitment, financial as much as anything, because the conference cost much more than originally budgeted for to put on with this number of families attending. Indeed I must thank Sense for the conference, they have set a standard. I know that the question on everyone's lips whether parents, presenters and dare I say Sense employees is when is the next one?

I'm off to the States next week to the US Conference which appears to be bigger than ever and am looking forward to catching up with friends from the States and other countries that may be there as well as seeing what I can bring back for the group. It will be an interesting contrast to the Sense conference.

Finally, sorry for the delay in this newsletter, I have just not found the time to write it.

Simon

Sense's CHARGE Conference - 21st Century CHARGE

The first CHARGE only conference in the UK happened in March put on by Sense in Reading.

There was a Friday professional's conference followed by a weekend conference for families. The professional's conference in essence was a concentrated version of the weekend. Over 100 people attended this and listened to presenters such as Tim Hartshone and Martha Majors from the States, Andrea Scheele from Germany and Gail Deuce, Jeremy Kirk and Steve Rose from the UK. I have already noticed the impact of this conference in talking to both professionals and new parents to the group.

During Friday the hotel slowly filled up with families. The hotel as with many De Vere hotels is also a golfing hotel. I am sure those guys away for a golfing weekend must have appreciated our takeover of the hotel. The conference itself there is no point in me trying to go through the presentations since Sense is due to make available the papers from the conference. By this stage it was great just being a parent.

One really positive element of the conference was the interaction between the many siblings, some of whom did know each other previously. This is a very important element of a conference the fact that siblings can meet and have fun, which on the Saturday

evening they certainly did with little parental supervision and much to the dismay of the hotel staff!

I asked Bradley Reed to write a report on the conference. This is set out below, but before Bradley sent this to me I read a blog by Esther Freeman which is also included below. On receiving Bradley's piece I was struck by the similarity of them. I had written the following about her blog but it applies to both of them – it captures the essence and importance of such conferences as well as that discovery of a group of people who you would not necessarily meet or have anything in common with but they understand you and your children and often become friends.

21st Century CHARGE Conference – One Parent's Thoughts

An oasis. That's what it felt like - an oasis. Not an oasis of calm, it was anything but calm, but rather an oasis of safety and belonging. The moment that I walked through the front doors of the venue it felt very much like those movies, usually on a street in New York, where the main character (in this case me) moved in slow motion through some sort of time warp while the world around buzzed with activity.

There are always the usual insecurities of arriving into such an environment be it a business seminar or convention of some kind where you feel just a little bit unsettled not really knowing where you're supposed to be going or what to expect. The 21st Century CHARGE Conference was instantly different. The registration table was a wealth of information. There were plenty of helpful people all smiling and eager to help despite having a million things a minute asked of them. It was easy to get a handle on what the various workshops were about and how to get your own name on the list to attend whichever you wanted. Even with the early change of room, we all knew where to go and when.

The subject matter of the workshops was relevant and meaningful. The presenters clearly knew what they were talking about and presented their material in a way that gave us an understanding of the topic while at the same time showing empathy and understanding of us the parents.

The social evening was fun and everyone went out of their way to ensure that a good time was had by all. Even the hotel staff went to great effort to help make a bed out of chairs with a tablecloth blanket for Harrison when he fell asleep half way through dinner. The festivities were a great pressure release valve which helped to clear minds and allow us to have a good rest in preparation for Sunday.



By the end of Sunday you could see that everyone was exhausted, emotionally and physically. As the closing presentation wrapped up and the exhausted but energized organisers, participants and families started to prepare themselves for the drive home I was able to wander through the group and get some comments from others. "Really good", "Fantastic" and "When's the next one?" was the common consensus. I also heard of feelings of isolation before the conference and an expression of relief that there was an entire family of amazing people out there to reach out to. It is always fantastic to meet

others in the "CHARGE family" and as one mum put it, "You can't choose your family" but I would agree with her that this is a truly great family to have been destined to become part of.

I have purposefully not mentioned any names. The very structure of the conference meant that I wasn't able to witness the workshops by every presenter. I am sure that they were all as meaningful and brilliant as the ones I was able to be a part of. It wouldn't be fair to not mention them nor would it be fair to say how great they were when I hadn't been there - it would have taken something away from the meaningfulness of the article.

Indeed, it wasn't only the presenters and organizers who made the weekend special. Like me, I'm sure that everyone attending will have met someone who had a substantial impact on their lives even if it only appeared to be in a small way.

It seems like a lifetime since the conference and parts of it are fading into memory behind the events of daily life. I will, however, always remember and cherish the experience and feel proud to be part of a group like this. The conference has helped me to make little, and big changes in the way that I relate with Harrison. Not everything works for every child but I would be certain the every parent was able to take something away with them that helped them in their own unique way.

I want to thank everyone who made such an effort to have such an impact on the lives of so many others. It takes a lot of work just to get the kids ready to come along to attend – the amount of work that goes into setting it all up is an order of magnitude greater. It takes everyone from the organisers and the families to the presenters and the amazing people who looked after the kids so well to make such a successful and meaningful event.

When's the next one?

Bradley Reed

This blog is by Esther Freeman who attended the conference

WE WENT A CONFERENCING...



My brother took this picture. He called it 'and the fog rolled back'. Ten days ago, Pete, Smiling Flower and I attended the first ever UK CHARGE conference. We drove there feeling nervous and tired. We drove home feeling challenged, equipped, fired up, reassured, emotional, amazed at those we met... and more tired! Overall, for me, it felt like some of the fog that has surrounded CHARGE rolled back.

There had been a day for professionals before we arrived. One of the speakers told us what the professionals had said about our children - they are bossy, determined, unique, funny, sleepless, stubborn and inventive in

making the world work for them... Apparently, children with CHARGE have similar personality characteristics and the observations of the British professionals reflect the CHARGE behavioural phenotype.

As she talked, I sat in my seat, breathed out and relaxed. They were describing Smiling Flower. We belonged here.

There were nearly 60 children at the conference. Each one we met and talked to was unique. No two children had a similar presentation. Some had very severe difficulties, some functioned very highly, but they were all sparky. I had been worried that we wouldn't fit in as I was aware before attending that Smiling Flower had less physical problems than some of the kids. But the whole atmosphere was of acceptance, inclusivity and encouragement to see the potential in every child.

A particularly helpful seminar was by Tim Hartshorne, a Professor in Psychology at Michigan University who has a son with severely affected by CHARGE syndrome. He talked about the experience of being a parent and gave me permission to feel all the stuff I push down trying not to feel. My favourite phrases - 'normal is a setting on a washing machine' and 'courage is not denial but can look like denial to other people.' He said it would help to live this as a marathon because we wouldn't last if we tried to sprint this race, that the biggest thing we could give Smiling Flower was encouragement. He was very understanding, tender and compassionate. A great role model.

I found myself reflecting on the phrase 'you can choose your friends but not your family'. At the conference I felt I had met my CHARGE family. I didn't choose for CHARGE to be in my life. I wish Smiling Flower didn't have to overcome its complexities. But the CHARGE family I met were inspirational and I am very grateful to have met a group of people who will instinctively understand and walk this road with us.

NEWS

Sheila Draper

As I mentioned in the last newsletter Sheila Draper who founded the support group died. This happened so close to the newsletter going out that there was no time for a proper appreciation of her. At the Sense CHARGE conference her husband Nick gave a very touching eulogy/reminiscence of Sheila and her role in the CFSG.

I asked Sally Ferguson who is mother to 20something Mark and was around in the early days of the group to write an appreciation of Sheila. She very kindly obliged and her thoughts are set out below:

It was with great sadness that we heard of Sheila Draper's death earlier in the year.

Our first contact with Sheila and her husband, Nick, was when she approached us with the suggestion that we meet up as we both had boys who had been born with CHARGE. At that time in 1987 the boys, Gregory and Mark, were aged 2 and CHARGE was a relatively newly defined syndrome. There was little information available to us as parents, or indeed the medics, so Sheila was anxious to find other parents in a similar situation so we could share our experiences. And so the CHARGE Family Support Group was born!

From the very beginning Sheila and Nick were the driving force behind the group. They organised a regular newsletter, which provided much needed information from various professionals as well as other parents, and the mailing list grew apace.

The first family day was held at SENSE in Ealing in 1989 and a great time was had by all! Sheila managed to arrange a whole army of helpers so the parents could have contact time whilst the kids were being entertained. Sheila's Mum and other members of her church provided tea and coffee on request throughout the day.

The family days continued apace and soon branched out to other locations, but invariably Sheila was involved in the organisation. How can we ever forget dancing in the park in Fulham whilst local residents looked on in amazement? Everyone who attended any of these meetings will tell you what a wonderful and uplifting experience they were. We all came away feeling revitalised and ready to deal with the next problem. And then there were the party bags!!

Sheila was undoubtedly the central point of contact for any new families and was fantastic at offering parents support, encouragement and reassurance. She would encourage them to come along to the family days if they felt up to it but failing that she made sure they received the newsletter and could contact her or other members of the group whenever they needed a chat or a bit of advice.

This all took an enormous amount of Sheila's time but she never gave you the impression that she wasn't delighted to hear from you and didn't have time regardless of what was going on in her own life. She and Nick successfully juggled the numerous hospital appointments, surgery and schooling issues with Gregory as well as bringing up Anthony and Caroline. And she always did it with a smile on her face!

We'll leave you with perhaps our abiding memory of Sheila, letting her hair down jiving for all it was worth to a rock and roll track at one of her birthday parties. Whatever was going on in her life she always chose to live it to the full and it is an absolute pleasure to have known her. And a quick look here www.justgiving.com/sheiladraper shows everyone felt the same!

The Ferguson family

Jeremy Kirk – British CHARGE Paediatric Survey

As mentioned in the last newsletter the Draper's set up a Just Giving page in memory of Sheila with the money raised going towards the funding of the Paediatric survey. Over £4,200 was raised which is sufficient to fund the survey for a year. What a way for Sheila to be remembered. On the strength of this, Jeremy Kirk has applied to start the survey with the intention of finding additional funding so that the survey lasts for three years.

The purpose of the survey is to monitor the number of births of children diagnosed with CHARGE in England & Wales. Paediatricians are obliged to participate in this survey. This will enable us to know approximately the number of babies born with CHARGE each year in the UK. 2 smaller surveys have been carried out in Australia and Canada so this will be the largest yet.

It will also enable us to consider whether the current birth ratio one in 9/10,000 is right.

Family Days

A reminder that there is a family day on 9th October in Bristol at Sense's Woodside Centre. This is the first time we have held a family day in the South West. Please contact Frances Concannon if you to go. Unfortunately the Northern day was postponed due to lack of interest. This was the first Northern family day for 3 years yet only 5 families were interested in attending.

On a more positive note this last Sunday was the Midlands family day which again was held at SNAP in Cannock. Steve Dawson who organised it said " I am delighted to report that the Family Day was a real success! We had as many as 70 people in attendance from 12 families. This consisted of adults, our children and their siblings.

The weather was glorious. We commenced at 12:00 and the final families drifted away at 5 o'clock. We had four new families in attendance including a young girl who has a four year old boy who was only diagnosed 6 weeks ago and thought she was the only Charge parent in the area until she contacted Simon. On the day we received an extremely generous donation of £200, which was raised by the grandmother of Joseph, Barbara Ray. The funds were raised by a sponsored slim at Barbara's slimming club.



Steve Dawson with Joseph

We enjoyed the support of Jenny Fletcher and Sense volunteers. We put on a buffet and drinks which was very well received. I was very impressed and heartened this year to see

the families recognise each other and renew acquaintances. There was a lot of socialising going on."

Website

The new website is up and running and we are already looking to update it. We had a number of positive comments about the site but any observation is welcome so that we can continue to improve it.

Sense/CFSG Children's Questionnaire

At the CHARGE conference Gail Deuce gave a presentation on some of the results from this questionnaire. It may seem that it is taking a long time for the results of this to be published, but it is fair to say that the amount of information we have obtained is such that 3 separate papers (and articles) will be needed to cover it all. This takes time given research and writing articles does not form part of any our roles. I hope though that over the course of the next year this information will be published, here and in Talking Sense (Sense's magazine).

UK CHARGE forum

This forum was set up by a parent, Vicky Dibba, for all families in the UK and Ireland so just a quick reminder that this forum is for you, if you post a question it goes straight through to the email addresses of other members rather than waiting for people to access the forum. Here is the link <http://uk.groups.yahoo.com/group/ukchargesupport/>. There are about 50 members currently.

FUNDRAISING

I think this story is lovely and it touched me. It is from Lisa Joyce nee Keyte "My brother, Nicholas Keyte was born with CHARGE Syndrome, he spent most of his short life in Great Ormond Street and only came home for one night. When he did come home he slept in the same cot that our elder sister and younger brother slept in and also the same cot two of my children slept in. We decided the best thing we could do would be to sell the cot and any money raised we would like to give to the CHARGE organisation. We raised £60.00 and hope it can contribute in some way."

As I have said previously it doesn't matter whether you raise £10 or a £1,000 each pound is the same and just as important. You will have read above about the money raised by a slimming group. Here are a few other stories.

I would also like to thank Kate Sanders aunt to Sofia who ran the Milton Keynes ½ marathon (the weekend of the conference) and raised over £1,500 for the group and in a different way Mary Lee the grandmother of Sara Wiles who sadly died on the Sunday of the conference. She requested that rather than flowers, donations be given and split between the CFSG and the Pituitary Association. We received just over £600.

Buy gifts online and support us

Group Secretary, Frances Concannon makes and sells jewellery and gifts. Visit her Folksy shop at www.folksy.com/shops/dappledesigns. Throughout 2011 she will be donating 10% of the value of everything purchased online (excl. p&p) to the Group.

Frances said "Giving time to the Group is one thing, but this year I wanted to see if I could also raise some funds. Most of my pieces look great teamed with a t shirt and jeans, others are a little more showy and will help glam up that little black dress or evening outfit. I do my best to keep my prices affordable and I am always happy to adapt or make pieces to order. My bookmarks and keyrings/bag charms make lovely, inexpensive gifts for family, friends and teachers." Why not treat yourself or buy for family and friends and support our work at the same time.

Fundraising pack

There are members and friends who are prepared to raise funds for the group. We need to put together a fundraising pack that we can give out to anyone who wants to raise money for the group. Can any of you help create a pack?

Have a look at the charity giving of whoever you bank or save with. Many of them run schemes that without much effort from you can provide us with much useful funds.

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.

PEN PORTRAITS

We have not had any for a long time so please let me have a pen portrait of your child or grandchild or if you have CHARGE then of yourself. These are very popular with other families.

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.chargesyndrome.org. There is available to download free a CHARGE Manual aimed at both parents and professionals.

CONTACT DETAILS – Please note additions/changes below

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

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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
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