CHARGE FAMILY SUPPORT GROUP
Registered Charity No.1042953
March 2015

Note from the editor:

Welcome to the first newsletter of 2015! I would like to begin this Spring edition by saying a huge thank you to Simon for his past and continued support in creating and publishing the CHARGE newsletter. I have found it to be invaluable in the early years of my daughter’s life as we came to terms with her CHARGE syndrome diagnosis. It helped us understand her and to feel less isolated. I hope this will continue to provide a base of support, knowledge and encouragement to all who are involved in and affected by CHARGE syndrome.

We are aiming to publish three newsletters a year; roughly coinciding with February half term, June half term and October half term. Apologies for the late first edition – life hasn’t run as smoothly as I’d hoped the last 5 weeks! Hopefully the next two will be out on time this year.

The summer newsletter will be focusing on the transition into young adulthood, EHC – what you need to know, and may also include an interview with David Brown who has a vast amount of knowledge and experience in the CHARGE syndrome world. Please let me know your feedback and ideas for future editions via my personal email (estbu@hotmail.com) or the facebook page.

Charge Syndrome Family Support Group won the Peggy Freeman Award for Exceptional Contribution to Sense!

On the 8th December last year, the Sense Awards took place in London. Dr Dawn Harper, star of Channel 4’s ‘Embarrassing Bodies presented the awards.

The Peggy Freeman Award for Exceptional Contribution to Sense was awarded to the CHARGE Family Support Group – a real honour. Simon and Lydia attended to receive the award on behalf of the group. This is what Sense wrote about the group on their website in describing the award:

“This very special award this year honours the CFSG, a group who have made a positive and enduring impact on the lives of deafblind people and their families, particularly those with CHARGE Syndrome.

The CHARGE Family Support Group is made up of families, individuals, and professionals with the aim to create a positive supportive network; to share ideas, experiences and information. In the last few years they have run two conferences, persuading leading international leading speakers on CHARGE Syndrome to talk in kind. They have run a host of ever more popular family days, a weekend for young adults with CHARGE, and have contributed to the CHARGE Syndrome Information Pack – the first UK detailed guidance for professionals. They have affected hundreds of families over the years – giving them friendship, knowledge, and hope.”

We should all be very proud of this award, but, particular thanks has to go to the committee for continuously working hard on all of our behalf to provide support and information as well as raising the profile of the group at a national and international level.

JEANS FOR GENES®

Helping children with genetic disorders

Early this year we heard that CFSG had been successful in applying for a ‘Jeans for Genes’ grant. Jeans for Genes raise money through encouraging school children and adults to wear their jeans on a specific day whilst donating money to the charity. They have donated £4999 which will be put towards the next UK Charge weekend in 2016. A huge thanks goes to **Frances Concannon** for all the thought and form filling that went into this application. Without this level of commitment to our group such weekends would just not be possible.

Frances Concannon, Secretary of The CFSG committee said: “We had been discussing the possibility of applying to the charity behind Jeans for Genes Day for a little while. I, perhaps stupidly, volunteered to look into it. I simply registered with the charity and then they sent me a grant application form when the time came. There were different levels of grant we could apply for but we decided to stick to one that wouldn’t involve having to make a presentation to the decision making panel – one of the pitfalls of being a charity run by volunteers, all of us busy people, scattered across the UK. The grant application process wasn’t too hard really. I had lots of support from my fellow Committee Members and Genetic Disorders UK. Their guidance was invaluable. From the outset it was clear we were just the sort of charity that they are there to support. It was all about finding something tangible the money could be used for – something that would make a real difference to the largest number of people. I guess the clue is in our name; we are a family support group and that is what we try and do. With Genetic Disorders UK’s help we will continue to do that with another Family Weekend in 2016. Watch this space!”

If anyone in the Group has the experience of and/or the time to research and perhaps apply for other sources of grant funding the Committee would love to hear from them.

The CHARGE syndrome Family Support Weekend.

In October 2014 we had a weekend at the Hilton in Coventry. It was a wonderful opportunity to mix with other families and learn more about various issues that impact those with CHARGE syndrome. Over 40 families attended and SENSE did a wonderful job of looking after our children on the Saturday whilst we attended seminars. Options were Advocacy, Statements and EHC changes, Executive Function, and Growth and Puberty.

In the evening families came together for an evening meal. A huge thank you must go to the siblings who attended, as they spent a lot of the weekend fundraising for the CFSG by fleecing hotel people! Clearly a confident group of entrepreneurs! Thank you too to parents who bought raffle tickets, and people who bought Christmas cards. Together with the silent auction and Martin Stevens our fundraising co-ordinator who went sober for October - £420 was raised in all which was a wonderful result.

Photos taken at the Coventry Family Weekend in November are still on sale. There are some great shots and all the money raised will be used to do a similar event in the future. If you would like some of the pictures please contact Lydia on lydia@howarthonline.net. She will be able to give you the link to the flickr site where the photos can be accessed. We are asking that a donation is made to the group through our Justgiving page. A guide donation is £10 per digital image or £40 for 5. (https://www.justgiving.com/charge-fsg/).

Interview with Steven and Jemma:

It was the first time Steven, Jemma and Eva had attended a CHARGE syndrome event and they have kindly shared their perspectives from the weekend:

- Could you tell us a little bit about Eva - how old is she and when did you find out she had Charge?

Eva is our first and was born on April 13th 2014 at Norfolk and Norwich hospital, so at the time of writing she is nearly 10.5 months old. She was born via emergency caesarean and was in NICU for 3 months, PICU for 1.5 month and then children's ward for another month before we finally took her home at 5.5 months old.

She was 8 weeks old when we received a letter from the geneticist confirming that Eva has a faulty CHD7 gene which confirmed she had CHARGE. However, we were told a couple weeks prior to receiving this official diagnosis that it was very likely she had CHARGE, based on the various features and other tests she had. At the time it felt like the diagnosis process took forever. In hindsight though, having read other people's stories, I do appreciate now we were quite lucky to receive a diagnosis that early.

Eva has got profound sensorineural deafness with missing or severely hypoplastic auditory nerves, absent semi-circular canals, biliateral chorioretinal colobomas and upper airway obstruction requiring a tracheostomy. Eva also suffers from reflux and has been fed via a nasogastric tube since birth but recently had a PEG inserted. Early on we were also told she had a PDA and PFO, but at the last scan they couldn't detect it anymore.

- I think a lot of us were incredibly impressed that you came with such a tiny baby complete with feeding equipment and suction machine! How long did it take you to drive to Coventry and how were you feeling before you arrived?

Prior to the weekend we had not met anyone with CHARGE so overall we were feeling nervous but excited. It took us about 3 hours from Norfolk. We were lucky to go actually, because Eva was quite poorly the week before. It was the first time we had been anywhere in public except for the hospital. Being so far away from home too was scary but we had packed four times as much as we needed just in case - we must have looked like we had packed the entire house! And to top it off, we were quite flustered because just as we parked up, Eva pulled out her NG tube!

- What were your first impressions?

Everything seemed very well organised and it was great to see the weekend so well attended - the atmosphere in the lobby was like a family reunion. After registering we met a really nice man called Lester who kindly made us feel welcome by introducing us to his family and helping to carry our bags.

We arrived late to the introductory talk and immediately felt very self conscious, as we had so many bags with us and had to turn on the noisy suction machine every couple minutes to clear Eva's trachy. As soon as the talk ended though, people came over and said things like 'don't worry, you remind us of how we were years ago.' Everyone was incredibly warm, friendly and welcoming which put us at ease.

- What sessions did you attend and which was the most helpful for you?

We attended Gail Deuce's Executive function talk and also the Advocating for your Child talk. Even though a lot of the content wasn't applicable to Eva yet as she is so young, we found both talks were still interesting and had useful information.

- What would you say was the main thing you 'took home' from the weekend?

The best thing about the weekend was being able to meet other CHARGE families for the first time and share our experiences. It was the first time we felt anyone truly understood what we had gone through.

It was also the first time we felt 'normal' in public - even when we were suctioning every 5 minutes no one stared, everyone just continued their conversation! Receiving the positive encouragement from other families, hearing their stories and especially seeing their little and big children with CHARGE was incredibly inspiring and reassuring.

- What would you say to people who are wondering whether to attend a 'family day' or the next weekend?

Do it! Especially if you are a first timer. Attending the weekend was the best thing we did last year. We left with useful information, new friends and a sense of hope for the future. We can't wait to go again.

We must say thanks also to Simon Howard for telling us about the weekend in the first place.

It's only an Ocean away….

The 12th International CHARGE syndrome Conference is taking place in Chicago 30th July to 2nd August. You can register from March 1st. The American CHARGE website (www.chargesyndrome.org) has brilliant information including hotels, funding guides, and itinerary. I really hope to go to this in the future and would love to read some reflections of those who do make it this year!

Resources.

- **CHARGE Syndrome Foundation**
  This is 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.

- **Webinars** hosted by the American CHARGE syndrome association have been hugely informative over the last year, covering topics such as sensory issues, pain, intellectual assessment, behavioural issues and research. These are many of the issues that pop up frequently on the Facebook site so it may be worth checking out the webinars if you are struggling with a particular issue. They are about 90 minutes long so if you want in depth analysis you will need to make yourself a drink, put your feet up, and go to: www.chargesyndrome.org/resources.asp

- **Facebook Groups:**

- CHARGE Syndrome (UK) supporting each other. 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. If you want to join just search the name on Facebook or use this link http://www.facebook.com/groups/274381645907029/ make a request and an administrator will join you.

- There is also a Facebook group for Ireland which can be found if you go to Facebook and search for CHARGE syndrome Ireland.

- Lastly, there is a Facebook group which is purely for adults with CHARGE syndrome. If you are interested in connecting with people in a similar situation then go to Facebook and search for the group ‘Adults with CHARGE syndrome’.

- **Cerebra**

  Cerebra is a charity that provides support for people with neurological conditions and they include CHARGE syndrome in their remit. Their website is worth checking out (cerebra.org.uk) as you can apply for all sorts of help from family days to holidays to equipment. Cerebra also have a DLA guide which I find very useful and give one to one support if you are really stuck. They also have a lending library where you can borrow a sensory toy for a month free of charge.

- **Sense**

  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 Information Pack for Practitioners & Other Sense Publications (Written by Simon Howard)

Sense's CHARGE Information Pack for Practitioners was launched just over a year ago. The title is slightly deceptive in that it is aimed at all professionals whether doctors, teachers, social workers who work with children and adults with CHARGE. Its design as a series of downloadable factsheets mean people can be selective as to what they download and not be overwhelmed by too much information.

Individual medical issues, behaviour, development, sensory issues as well as guidance for specialised practitioners are covered in the 28 factsheets. Each has been written by an expert in their field.

From a parent's perspective it means a factsheet aimed at an OT, GP or teachers can be thrust at them to help them understand CHARGE.

Within 24 hours of the launch over 400 downloads had taken place. Thanks must go to Gail Deuce and Stephen McCarthy at Sense for getting the pack through to publication. However special thanks must go to Fergus and Sam Kiely who funded the production of the pack in memory of their daughter Isabelle who was born with CHARGE but died of an undiagnosed heart condition despite spending much of her short life in and out of 2 different hospitals.

The pack (or the individual sheets) can be downloaded here:
http://www.sense.org.uk/content/charge-information-pack-practitioners. Printed copies of the pack are available from Sense.

Two other publications that Esther will look at in greater detail in the next issue are the Making it work for you – a guide for families and deafblind young people to the new system of Special Educational Needs and Disabilities. This is a really good guide to the Education, Health and Care Plans (EHCP) that children and young adults will either be transferring over to or being assessed for. Here is the link:
http://www.sense.org.uk/sites/default/files/making_it_work_for_you_send_reform.pdf

The other is new and is called 'Getting a result – helping you people to make a successful transition'. This looks at the transition into adulthood. Here is the link: http://www.sense.org.uk/content/getting-result-information-pack.

As with the CHARGE professional package it is also available in a paper format.

- **MACS charity.**
  MACS are a charity who support children born with underdeveloped eyes, or without eyes. They support children with colobomas which a lot of our children have as part of their CHARGE syndrome. Their website is www.macs.org.uk. They are holding a weekend in May for families who have joined so it would be well worth getting in touch and seeing what they can offer.

An insight to local Support…

People often ask what support is available for children / adults with CHARGE syndrome and their families. Many of us use Sense's services and they will feature regularly in the newsletter. However there are many other organisations and services. In this newsletter we are featuring Elaine Murray Bell and her family who have found support through their local authority and a local charity – PIN (Parents Inclusion Network). This will be an ongoing section of the newsletter so please get in touch if you use any others, for example MACS, Action for Blindness, Mencap or a specific local service.

Elaine Murray Bell – Local Activities

School holidays can often be a daunting prospect for parents of children with additional needs. There is often nothing for them to do and it is so easy to become isolated. We are fortunate in our local area having two main organisations that provide activities for our children to participate in.

During the summer break our local authority run a Summer Activity Scheme for school age children with additional needs. They provide 3 hours support for your child (1:1 or even 2:1) for 8 sessions during a four week period enabling you and their siblings to have a break. The children take part in many different activities including swimming, arts and crafts, pond dipping, visits to fun park etc. Jack has gone to Summer Scheme since he was about 7 and he loves it. He looks forward to going every year and I look forward to it knowing he is safe, well supported and taking part in activities he would not normally be able to do. It also gives me a few hours respite to do what I want.

I used to be able to spend quality time with Jack's sister but for the last 3 years she has worked at the Summer Scheme and this year was Co-ordinator. The other organisation we are involved in is PIN (Parents Inclusion Network) which is a locally run charity providing support and activities for parents and children. Jack had a wonderful time during the summer attending some of the activities they organised and I enjoyed meeting up with other parents and friends. Jack enjoyed going to the Golf Driving Range, the Chocolate Factory, ice cream if Galloway Ice Cream, den building at Kirroughtree Forest and this week he even tried Carriage Driving for the first time.

Being able to participate in these activities makes such a difference to all our lives and it's wonderful to see our kids getting involved and having a fantastic time. I now look forward to school holidays as I know there is plenty for us to do rather than be stuck indoors or on our own.

Pen Portraits.

Many parents have enjoyed reading these in the past. If you are willing to write a pen portrait of your child / grandchild please get in touch. The editor is happy to help or simply to receive the finished insight into your life with a child with charge syndrome…

Fundraising.

We are aware that various people up and down the country are fundraising for CHARGE syndrome Family Support Group – from London Marathons to parachute jumps and kilt walks – people are getting involved which is fantastic. 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. Martin Stevens is our fundraising co-ordinator and is the first point of contact if you are thinking of fundraising as he can assist. His email address is martin.stevensms@gmail.com. There are also sponsor forms available through Simon or Steven to help with your event.

On April the 12th, Julie Black is raising money for CHARGE syndrome by walking the Kiltwalk in Glasgow– all 26 miles of it. Below is an interview in which she has kindly given us an insight into the event and why she is doing it: If you are able to donate to this brilliant effort her fundraising page is: http://uk.virginmoneygiving.com/team/jessicainCHARGE

- So you are walking 26 miles for your little girl Jessica who has CHARGE Syndrome, raising money for the CFSG and your local children's hospital? – could you tell us a little bit about Jessica?

Jessica was born 2 may 2010, 6 weeks early, shortly after birth Jessica was diagnosed with CHARGE due to bilateral Choanal Atresia and hole in heart and this was confirmed 6 weeks later by bloods taken by genetics. Jessica spent 7 weeks in hospital and underwent her first operation at 1 week old for her CA. To date Jessica has undergone 5 operations which is a lot less than others so we are very thankful.

I remember the list of things that Jessica had issues with, feeding, hearing, balance etc and this scared me a lot. It was very hard to bond with her at the start of her wee life as I kept thinking I didn't make a CHARGE baby, where was mine?

Lately I read a Meg Hefner post that helped me see the Jessica that WE made and just a wee bit of CHARGE...she is the way she is because of US not CHARGE! Yeah. Jessica is now a walking talking princess. She is soo funny but a very determined little girl who has so much love and affection for others.

- Have you ever walked 26 miles before? Have you been doing any training and how long do you think it will take?

I have never walked 26 miles before, I'm in training with my neighbour and we have been walking for over a year, this year we are trying to build our miles up and so far we have done 10 miles, and looking to increase each time we are out. We do small 5 mile walks 3 times per week and one long walk per week. I think the walk should take us about 7 hours.

- Will anyone be walking with you or will it be you and your Ipod?

We have a team of 6 walking with us, mixture of family and friends... (The fit ones) although my sister is joking that she may take some gin with her to keep her talking for the full 26 miles slough to be fair she doesn't need any help in that area as she doesn't stop talking!

- What will you eat for breakfast on the morning of the walk?

My friend and I have been talking about what we will have for breakfast that morning and I think we both agreed a big bowl of porridge would be a good healthy start...but then we were hoping there would be a burger van on the way around.

- What is your kilt like?? Will there be some ‘outrageous kilts’ along the way?

We asked Jessica what colour kilt we should wear and she chose the red one, my favourite colour.

- The CHARGE Family Support Group clearly means a lot to you as you are willing to endure aching muscles, possible blisters and who knows what Scottish weather! Could you describe what the group has meant to you over the last 4 years?

The support the group has given has been amazing, even if I'm not the one asking questions. It makes me feel part of a family that truly understands what I'm going through...yes Jessica may look ok to others but as her mum it is still hard to come to terms with having a child with additional needs...and this group make you know that it's normal to have these feelings.

- If you hit a 'wall' (because 26 miles is a long way!) what memories or thoughts will you draw on to keep you going?

As I said 26 miles is a loooonng way but I really wanted to give something back to those who have helped me through the last 4 years. I will just keep remembering my wee chicks face and that will be enough to get me through x

Thank you Julie and all the best for your walk – we will be thinking of you! If anyone else would like to be interviewed pre or post fundraising event, please get in touch!

Sponsor forms

If anyone is looking to raise funds for the CFSG Simon Howard has sponsor forms available.

Website

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

Committee Changes.

A big thanks goes to Carol Thomas, the former chair of the Group for many years who worked closely with Simon in running the group. Also to Kirsten Jones who has been keeping the books straight as Treasurer but has now resigned.

A warm welcome to Peter Hughes who is the new Treasurer and to Li Gray and Leanne Howie who have joined the committee and are currently looking at organising the first family day in Scotland.

Contact Details.

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

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

Frances Concannon (Secretary)
Telephone: 01732 363411
Email: francesmconcannon@gmail.com

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