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CHARGE FAMILY SUPPORT GROUP
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Note from the editor:

As I write this I am told by the meteorologists that it is officially summer time. The rain is moving sideways across the garden and the wind is howling. I am wondering if it is reasonable to turn the heating on in June… Still, I am also told that a heatwave is on its way, and summer months often bring a welcome relief from infections. Summer also means that the 2nd newsletter is coming together…

As promised, this edition will include information on issues surrounding transition. I have written an article which pulls together some information and there is also a list of useful resources. In addition – if you have ever wondered who the man is behind some of the good advice on the facebook page – read the inspiring interview I had with David Brown via Skype. Finally, as well as the usual sections on fundraising and CHARGE syndrome news, I have tried to get the ball rolling on pen portraits and there is a poetry corner which is well worth a read if you would like to connect with the writings of a poet who is inspired by her daughter with CHARGE syndrome ;o)

Please let me know your feedback and ideas for future editions via my personal email (estbu@hotmail.com) or the Facebook page. I am currently thinking of having an education focus in the autumn edition so let me know if you want anything particular included…

Transition.

Each stage of our children's lives presents enormous challenges – from the first days following birth and the vast amount of information we have to take on board, through the celebration of milestones that are unique to each individual. From finding the right educational setting – through to seeing a young adult emerge, some with the opportunity to enjoy independence and new skills in a way that, initially, we may have found unimaginable. So much to celebrate and yet so much to worry about!

Thankfully, there is help out there… Hot off the multisensory press (only published in May 2015) is a new pack from SENSE entitled **'Getting a Result'**. It is aimed at young people ages 14-25 and their carers / parents / professionals. It includes **person centred planning tools** that young people can use to plan their future, and **factsheets** covering education, healthcare, benefits and financial trusts, living arrangements and employment. Also helpful is a year by year guide to the **key milestones** in the transition process (starting in year 9 at school) and **checklists for transition meetings**. I have read most of it and the information is clear, comprehensive and thought provoking. Thinking about the complex range of abilities that young people with CHARGE syndrome have, I think the best way to use the pack is to set aside a couple of hours (there are 139 pages in all!) and download, print or file the aspects that are most helpful for you to use, at this stage of your transition. The pack is full of inspiring stories from young people and parents so it is an engaging read.

You can download your copy from www.sense.org.uk/content/getting-a-result-project or request a copy from info@sense.org.uk or phone /textphone 0300 330 9256.

The Law, Transition and EHC plans.

Understanding legislation can be mind boggling and intimidating. The good news is that current legislation including The Care Act of 2014 and The Children and Families Act of 2014 do ensure that there should be no 'cliff edges' in the care and support you receive as you look towards transition.

In a nutshell, the Care Act 2014 is all about social care and ensures that children's social care must continue until adult social care provision is in place. The Children and Families Act 2014 ensures that all children with a Statement of Special Educational Needs will be transferred to an **EHCP** (education, health and care plan) which can be used up to the age of 25. The EHC plan should include provision for assisting in preparation for adulthood from year 9 at school. Again, SENSE have created a simple and informative factsheet which can be seen here: www.sense.org.uk/content/education-health-and-care-plans

Another brief, succinct and informative guide to EHC's can be found at IPSEA (Independent Parental Special Education Advice): www.ipsea.org.uk/what-you-need-to-know-/ehc-plans It confirms that the Local Authority have a legal duty to ensure the educational provision specified in the plan is secured and delivered. In addition the local health care provider has a legal duty to arrange any health care specified in the plan and ensure it is delivered. Interestingly, IPSEA confirm that a particular therapy can be included in the EHC plan even if it is not available from the local health service. This may be relevant to many of us who are requesting MSI support, given that it is not widely available and may need to be 'bought in' from organisations such as Sense. You must just ensure that it is clearly identified as a need in section B of the EHC plan. So, in conclusion to this piece, my understanding is that the responsibility for a parent appears to rest initially on ensuring that everything that a child needs is put into the EHC plan in the first instance. Following that, yearly reviews should alert us to what we need to do in terms of planning towards transition.

The David Brown Interview…

David Brown is an education specialist in deaf-blindness with a particular interest in CHARGE syndrome. He is now retired, although you wouldn't know it, and regularly pops up on the CHARGE syndrome UK Facebook page to answer our questions particularly around multi-sensory impairment and education. A few evenings ago, I poured myself a glass of wine, whilst he had his morning coffee in California, and we chatted over Skype in fact, he was very chatty so apologies that the interview runs into 5 pages!

So David, what took you out to California?

I worked for Sense for 18 years, when I joined we had no children's services. My colleague and I created the children and family service. We had a multidisciplinary team, teachers, an internationally known feeding therapist, a wonderful physio. Families came to the centre and stayed there and we were also travelling teachers visiting schools and homes all over SE England. It was my dream job. The organisation grew very rapidly, nationally.

I'd been to two American CHARGE conferences where I'd met a couple from San Francisco who had a daughter with CHARGE. I got friendly with the couple – Jackie, the mother, worked for California Deaf-blind Services, and I told her I was looking to move on from SENSE. Jackie sent a Christmas card and explained they were having trouble at work because their full time teacher left and they couldn't fill the post. I couldn't sleep… but it was in California and I didn't know if they would let me in and I had a house in London. The next day I wrote a letter to her (I'd never used a computer in 1999!) so we exchanged letters and then her boss called me. He thought the university might get me a work visa. So I came strictly for 2 years, and then it became another year, and another year for 9 years! Eventually I became a permanent resident.

What did the young David do? What happened after school?

I started as an academic, a history student and they offered me a scholarship to do a Masters and I had a great two years doing that, and then they got me a scholarship to do a PhD but by then I had had enough of academia. I didn't like that world and I ran away to Italy. I got a job teaching English in Italy. I just got on a train and went to Italy and then wrote to my supervisor at Swansea University and said 'I am now living in Italy and won't be doing a PhD! And then I came back to the UK and got my PGCE teaching qualification and became a history teacher, but I was a disaster at it and only did it for 1 year.

How did you first get involved in MSI and deafblind issues? What sparked your interest initially?

I went to an Autumn fair at a holiday centre for children with disabilities. I'd never met anyone with a disability before, except elderly people. There were children there with Downs syndrome and a boy with cerebral palsy and I just loved these kids and played football with them and games and painting, and the guy who ran the holiday centre said why don't you come as a volunteer? So I used to go every weekend and volunteer and eventually I moved sideways into residential child care for social services. Then I got headhunted by a charity in London called KIDS who sent up a home visiting service for infants and families with all sorts of developmental problems and I worked there for about 6 years. The woman who had been my boss there left and joined Sense and they asked her to create a children's service and she approached me and asked 'will you help me' so I joined their working party for 9 months and then applied for a teaching job with them, which got me into deafblindness. I remember being very anxious the night before I started because I thought ‘I don’t know anything about deafblindness’ but I quickly realised that quite a lot of the children I had already been working with were deafblind but no-one had used those words. The chief exec came to see me on my first day in the job at Sense. I told him that I always changed jobs about every 3 years and he told me I wouldn’t move on now because once you work with children with deafblindness they grab you and they won’t let you go. And he was right. I did move to America but I have basically had just two jobs in deafblindness for 33 yrs.

What is it about children with CHARGE syndrome that keeps you so enthusiastic?

I think children with deafblindness are the most challenging and the most interesting, and within that population the children with CHARGE are by far the most interesting and the most challenging. I think most people with CHARGE are probably the most adaptable and most determined of all of us. These children inspire me endlessly. I go on the CHARGE Facebook pages a lot, and sometimes people say ‘you are so good going on Facebook’, but it’s quite selfish in a way, because it interests me so much, and it’s quite inspiring when you see what these children do.

And it angers me when these children are judged and criticised for being so smart, for being so adaptive, for working so hard. So often when they are criticised it is because they are working hard and doing their best but everyone thinks they are doing their worst. In fact I see them as exemplary. So there is a kind of missionary zeal…

I went to a Welsh Baptist Sunday school and our pastor was all hellfire and damnation, old fashioned, thumping the pulpit, and there is part of that in me - when I get up and present I can almost hear him being channelled through me, especially when I start thumping the podium to make my points about the children!

What was it like working in the CHARGE world in the early days?

Well Facebook is breathtaking, I can’t believe what it gives you parents these days. When I look back more than 30 years I had to get trains all over Britain, like when I went and stayed with Elaine in Scotland – Jack was two at the time, and I had two whole days in the home watching him eating, moving, and communicating. But the families back then were generally very isolated; all we had was the telephone and letters, but no network. And then Sheila and Nick Draper created the association. I offered Sheila our Sense Family Centre in Ealing for a CHARGE family picnic in August 1987, and it instantly became an annual event until I moved to the US in 2000.

I got into CHARGE because when I joined Sense my first day was orientation and the next day I went down to South London to meet a 10 month old baby boy who had the diagnosis of CHARGE association. It was 1982 and CHARGE had only just been named – he must have been one of the first children diagnosed in the UK and I saw him every Friday for several years because we didn't have a big caseload at the beginning. Then the caseload expanded and we couldn't do that any more. I'd spend about 4 hours at the home each visit and his mum would make sandwiches for lunch! So for me deafblindness and CHARGE have always been closely linked. I have campaigned endlessly to get deafblindness and CHARGE together in people's minds because they fit and so many of the children with CHARGE are in fact deafblind - they may see a bit or hear a bit but, functionally, they are part of our deafblind population.

So, it was pure luck that the first boy I met in my job with Sense had CHARGE syndrome and then you enter this amazing world. And one of the most amazing things for me is the way the population has changed. We are now working predominately with children who wouldn't have survived 30 years ago, so what we always thought of as immensely complicated has just got more and more complicated.

On Facebook when new parents come along they have no idea what is out there. People don't know you can click on files on the top of the Facebook page and read articles, so the more that we can disseminate the stuff out there the better. It's so powerful when you can take that with you. (Ed note: do check out these files – David has written many helpful articles which are a great resource on all sorts of issues)

What is retirement like?

I still do a lot of teacher training at universities; that expertise comes from many years working with the children, home visits, school visits, hospital visits. I've been retired 4 ½ months and I'm exhausted because I'm still doing so much. I am known here in the US as a good speaker. So in January I went to New Mexico for the first time where a school for the blind put two days on looking at what a child's self-stimulation teaches us. Self-stimulation is seen as a bad thing in educational settings – the minute a child's hands flap everyone wants to stop them doing it - and I’m saying no this is fabulous, what does it mean when she’s doing it, what is it showing you? So I go in and say, let’s just look at what this child is doing, let’s not interfere, let’s find out who they are first.

In March I did that day in three places in Pennsylvania. I’ve done some CHARGE consultations – I’ve done staff training over skype for two hours for a child for was about to attend their preschool. I’m doing a lot of writing and I get a lot of private messages on Facebook, parents asking me about issues / references. And then I have things lined up – like the CHARGE conference in Chicago. I wouldn’t miss it because it is a sensational conference.

It must have been hard to leave England and move to California with its Pacific coastline, Nevada desert and impressive mountain range. What do you miss??

Apart from the obvious (family, friends, and my house) what do I miss most about the UK? The British sense of humour is something I miss a lot, and all the time. It is interesting that most of the Americans I would call friends now are big Anglophiles and love British TV, especially British comedy shows. I miss good public transport here since I don’t drive - arriving in London from California is always a joy because suddenly there are tube trains and buses all over the place. Then I miss stuff which is easy to remedy by shopping and packing my suitcase each time I fly back from London to San Francisco - HP brown sauce, Wright’s Coal Tar soap, Pears Transparent soap, good strong tea bags (so that 2 will make a pot of tea rather than 4 American ones), Tiptree orange marmalade with malt whisky (the true nectar of the gods), Terry’s chocolate oranges, and good Indian herbs and spices which are hard to find here and cost a fortune.

I heard you were a malt whisky lover – what is the best whisky you have tasted?

I prefer the strong dark single malt whiskies from the Scottish coast rather than the milder Highland ones, although I love all of them. My favourite is probably Lagavullin, but a Welsh friend who is a true fanatic has introduced me to very old cask strength whiskies from long gone distilleries, which are splendid but cost a fortune.

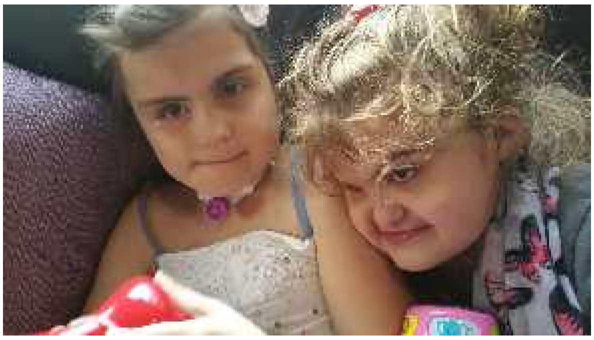
This edition of the newsletter is focusing on transition. Do you have any advice for young people / parents or carers who are experiencing the transition process from childhood to adulthood?

The transition process is always scary, but I have known a surprising number of parents get through it and subsequently say that life is so much easier and more straightforward (and honest) away from the education world! A good resource is on the NCDB website, the Transition section is at https://nationaldb.org/library/list/59

A huge thank you to David for taking time out of his hectic retirement to chat over Skype - I loved ‘meeting’ the man behind the MSI Facebook advice and hope you found it interesting too…

MACS Weekend in Lancashire.

This year a record five families from the CHARGE Syndrome family support group went along and it would seem that lots of fun was had by all… Karen Tilley has kindly given us some pictures of her daughter Josselin and her best friend Amelie and writes the following:



Macs charity supports children born with coloboma, micropthalmia and anopthalmia - which alot of charge children have. They provide local support and events up and down the country and provide grants to children. They also have a family weekend on the first May Bank Holiday each year held in Lancashire from Thurs - Monday. It is alot of fun for the children, their siblings and parents!

Alexis also attended and this is her reflection:

Jacob is 11 now and we have been involved with the MACS charity since his birth, because Charge wasn’t confirmed until he was older but we knew he had micropthalmia and colobomas, MACS was the first charity we contacted. We went to our first MACS weekend whilst he was still a baby and it was such a relief to meet and talk to other families with children with disabilities. The second time we attended we met the Tilley family and since then we have been every few years...and the number of families with kids with Charge has grown. It's a great weekend and in recent years we have gone more for fun rather than for support but also to help Jacob's siblings see that they aren't the only ones with a brother who is different! MACS have also helped our family with a couple of grants for Jacob in the past and we find it the most approachable and helpful charity.

It's still only an Ocean away….

The 12th International CHARGE syndrome Conference took place in Chicago 30th July to 2nd August. I really hope to go to this in the future and would love to read some reflections of those who did make it this year!

CHARGE clinics.

Some of us have benefited from Jeremy Kirk's CHARGE clinics in Birmingham Children's Hospital. He anticipates these will soon be monthly due to demand and he is receiving referrals from all over the UK. A Great Ormond St CHARGE clinic, in London, may be created within two years. If you see a consultant at GOSH please keep mentioning how helpful such a clinic would be. That will help create demand and make it easier to get one going…

Jeremy also informs us that new clinics will also be created soon for those with CHARGE syndrome who are either in a transition process or already accessing adult services. These will be based at University Hospital Birmingham. Lastly, rare diseases centres are also being built at Great Ormond Street Hospital and Birmingham Children's Hospital. These are still in the planning stages but it is hoped they will include will sensory rooms, an area to socialise and consultation / seminar rooms.

Poetry Corner…

I would like to introduce you to an amazing poet – Marina Sanchez. She is of Native-American and Spanish origins, educated in Mexico and Europe and currently lives in North London. She has a 27 yr old daughter with CHARGE syndrome and has written a small book of poetry about her daughter called ‘Dragon Child’. It is such a rare treat, as a lover of poetry myself, to find a collection of poems that is so reflective and so beautifully captures emotions I can identify with. The following poem is kindly reproduced with permission from Marina and Acumen Publications and gives you a taste of her power with words:

Her Neural Pathways

‘All I know is what I have words for’. L Wittgenstein

Looking into her eyes, I ask her a question
again, wondering what her answer might be,

after bumping along the private gravel paths
she’s laboriously tended for years,

but stumbling on the crunch
of syllables, words elude her

and we’re left stranded
in her remote landscapes,

familiar strangers
in indefinite pauses,

she wanting less
of my words,

me, hoping for
more of hers.

Marina’s book can be obtained for the incredible price of £3.50 by emailing Marina: mar.san18jun@gmail.com or go to www.torbaypoetryfestival.co.uk, click on ’Events’ and go to last page, click on buy book. Follow instructions on paying on the screen or enter Dragon Child in Search box.

I am also in the process of obtaining a number of copies that I will send for free to anyone who is willing to submit a pen portrait to the newsletter in return :o)

Pen Portraits.

I thought maybe it would help if I started the ball rolling so here is my pen portrait of our child with CHARGE…Jasmine Ella Hope.

The day I found out I was pregnant a chimney sweep came round, he asked me to go out in the street, look for his brush popping out of the top of the chimney and make a wish. I stood in our quiet street entranced by my unusual day and wished for a baby who was healthy and strong. Six ultrasound scans and an MRI followed over the next 9 months whilst our little one grew in my womb. Anxiety pervaded my pregnancy and Drs who were far too convinced gave dire predictions about the baby soon to be born. I readjusted my framework and hoped simply for a child that could love and know love.

I gave birth at term but after 2 days of struggling to feed, Jasmine was rushed round to special care baby unit and 3 months of tube feeding commenced. Coloboma's were identified in her eyes and she had failed her newborn hearing test but after two weeks we learnt how to use the feeding tube and we went home with no answers. She wore hearing aids for 12 months but when we had a second MRI to assess her for cochlear implants we were referred to genetics for a CHARGE syndrome test as her cochlears were unusual. Her auditory nerve was also missing on both sides so no more hearing aids or implant surgery. She was completely deaf.

Weeks later we were told she had the defective gene CDH7. For me, the hardest news was coming to terms with her deafness. I was so apprehensive about what that would mean for our communication and relationship. The CHARGE diagnosis was actually helpful because it helped us understand her struggles – her delay to sit, her strange way of rolling to get somewhere, her floppiness, her very slow weaning programme etc etc.. It also gave us a community to belong to and before long we found ourselves at the UK CHARGE conference in 2013.

In our early days we were kept busy with physiotherapy, occupational therapy, portage play therapists, speech and language therapists monitoring her swallow and weaning, a wonderful woman from the NDCS who came to our home for ten weeks to teach us the beginnings of sign language before we went on to do level 1&2 at college. Jasmine started ‘walking’ sitting in a regular baby walker. We would drive into town and she would zoom along the pedestrianised street much to the amusement of the locals. We progressed from that to a Kwalker and close to her 3rd birthday we were walking by a canal when I first realised she had simply left the kwalker behind and taken 3 steps without it.

Fast forward to her current age of 5 ¾ and she amazes us every day. She has had far fewer physical problems than many of her peers with CHARGE syndrome which leaves us feeling in awe of those who cope with more. She continues to fall a lot (she has no semi-circular canals or vestibular nerve) and notes are regularly passed between her school nurse to me and me to her teachers about various bruises, scrapes and bumps. She is a sign language professional. She has attended the Royal School for the Deaf in Derby for 3 years and has flourished in that signing environment. Yesterday she asked me how water was made and what colour ‘deaf’ was. I don’t always know how to answer her questions, let alone sign an answer!

She is very much ‘a character’. Bossy, strong willed, loving – without always realising that her hug has turned into a crush and her younger brother is screaming to be released. Sometimes she ‘lets out her wilds’ and school are having to learn how to help her pace herself. She is often exhausted but can’t always stop. She loves sheep (especially Shaun), trampolines, cooking and Charlie and Lola. At home she needs constant supervision due to her unpredictable behaviours. This year she has overcome a massive fear of water (she wouldn’t bath without me holding her steady in 5 inches of water until recently). But now she is going ‘swimming’ with her classmates every week and enjoys it greatly. I think, to sum up, it isn’t always easy to manage the lack of sleep, the different language requirements or the behaviours. But, Jasmine has undoubtedly enriched our lives and we love her to bits :0)

Don’t forget, anyone writing a pen portrait of your child / grandchild qualifies for a free copy of Marina’s Dragon Child poetry book so please do get in touch!

Fundraising. (An update from Martin Stevens)

Great news for CHARGE syndrome as members go out of their way to raise money for us. I recently took on the role of helping to fundraise for CHARGE as I wanted to give more to this wonderful extension of my family. I have been amazed already to hear people in Japan are supporting us and someone has even decided to throw themselves out of an aeroplane in order to raise some money. Here are some of the latest efforts made for us:

Steven Ho has announced that his cousin and neighbour are doing some amazing events. My cousin Tuyet and her fiancé Nick are doing the Great Wall of China half marathon on 16th May. They live in Singapore. Their page has raised over £500 so far. Petra, my neighbour, is still on course to do her skydive on 28th May. Will send pictures after the day. I am hoping to raise money from now until the day.

If you or anyone you know of is raising money for us can you let me know martin.stevens.ms@gmail.com and we can send them a thank you letter.

The website **easyfunding.org.uk** is a great way to raise money just by shopping at Amazon John Lewis Expedia and others. Registration is simple and I can send out a prefilled flyer to stick up in the office or anywhere you can so that other people can register and raise even more.

I have also created an A5 poster that everyone can stick on their work notice boards. This is a great way of raising money while shopping online for those essentials like shoes or a new phone that you just happen not to tell the other half about.

Lastly, Steve Dawson recently attended Pete and Jenny Jupe's Arden Bridge Club to receive a cheque for the magnificent sum of £1070. Many, many thanks to Arden bridge club for choosing the CFSG as their annual fundraiser.

Editor: We have a Just Giving page which may help people to raise funds for the group. This can be found at http://www.justgiving.com/charge-fsg or via the link on our website. Martin Stevens as our fundraising co-ordinator and is the first point of contact if you are thinking of fundraising as he can assist. There are also sponsor forms available through Simon or Martin to help with your event.

Raising our Profile.

We are delighted to announce that the **CSFG website** is going to be revamped over the next few months. Any suggestions or comments are very welcome. We would particularly like to add new photos of children, adults and siblings if you would like to donate any. Also a public **CSFG Facebook page** is going to be created by Leanne Howie (this will be in addition to the CHARGE syndrome (UK) ‘supporting each other’ Facebook group.) It will be a less personal page that will educate people who are simply interested in charge syndrome and may include articles, event dates, etc. Again, any comments or suggestions are very welcome. Lastly, Martin Stevens, our treasurer, is created a **LinkedIn page** with invitations to be sent out to CHARGE and Sense contacts – Martin says it will have a corporate platform whilst remaining a closed entry group.

Family Days.

This year saw the first Scottish charge family day. All thanks to Li Gray and Leanne Howie for organising it. 9 families met in Glasgow and it appears to have been a great success. Reflections and photos for the next newsletter please!!

We are hoping that further family days will be organised around the country later in the year – northeast and the midlands are yet to be confirmed but watch this space… In addition we are aiming for a bigger CHARGE event in 2016. Hopefully we will have more information on this for the next newsletter

The next London family day has though been arranged and here is what Frances says about it:

I am delighted to let you know that we will be holding a Family Day in Barnet (North London) on Saturday 17 October 2015.

If you are interested in coming along please email me (francesmconcannon@gmail.com), with your contact details and names of everyone attending.

Sense has some wonderful new facilities in Barnet (in the same location as the Anne Wall Centre) which we will be taking full advantage of and we are hopeful that Sense will be able to provide some of its brilliant volunteers to help support our children during the day. As always we will be providing refreshments and lunch.

The events are for families of children with CHARGE to meet, relax and to take part in fun activities. We would be delighted if any adults with CHARGE or parents of now grown up CHARGE children would like to attend. Everyone's experiences are so valuable and we always receive such positive feedback from attendees about the wonderful opportunity such days provides for sharing information and experiences with others.

The day will run from 10am to 3pm (approx.). In advance of the day we will provide you with directions to the venue and an outline of day. Please note that past family days have proved popular and there may be a maximum number we can accommodate.

Please do not hesitate to get in touch if you have any questions. I look forward to hearing from you and seeing you in October. Frances

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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:

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