



**FAMILY SUPPORT GROUP**

Registered Charity No. 1042953

Supporting families for 20 years

January 2009

Greetings everyone & a Happy New Year.

It is a positive start to the New Year here, well CHARGEwise anyway. With contributions from 3 parents this newsletter is big, the family day at the end of November was a resounding success with largest gathering of parents in this country to date and Sense have set up a working group dedicated to CHARGE the first and second meetings of which I recently attended.

Lydia Howarth the chair designate has prepared a short questionnaire that is enclosed/attached (depending on means of delivery) seeking your views on what you want from the group. Please complete it and return it to her. Without your replies we cannot support you as you want.

This is a bit of a bumper edition that hopefully makes up for the previous short newsletter. There are 2 articles by parents regarding education and the problems they have encountered. Rob & Trina Henderson have had some real problems with their daughter Hannah's education and having found a solution Rob felt the need to write about it. At the same time there was a discussion on the CHARGE listserv about statementing to which Alexis Wolfe contributed. She and Neil were going through this process with their son Jacob. Her input was so good that I asked her to pull it together for the newsletter. Flo and I have recently gone through some issues regarding Jessica with our local authority so I have added my tuppenneth. In addition there is a pen portrait that from the educational view point is very positive as well as socially.

Although the issues considered by Alexis and Rob are in respect of primary school education they are just as applicable throughout the entire education of a child. Having said that, transitioning from school would be a good subject to cover so if there are any parents of young adults that would like to share their experience I would be happy to print it.

I must apologise to both Alexis and Rob who gave me their pieces over the Christmas period. This newsletter has been 95% complete for nearly 6 weeks, unfortunately changes in work combined with building works have left the Howard/Njeru household in chaos.

However, it is that time of year again when I ask you all to reflect on those born with CHARGE who are no longer with us. I know of a couple of children in the States that have not survived the year and here Rayyan who celebrated his first birthday in January only

survived another week, so please take a moment to reflect, think positive thoughts or pray - whatever you feel is appropriate.

Simon

## NEWS

### London Family Day

Just a brief note given the size of the newsletter but as I said this was the best attended family day ever. Age of people with CHARGE attending ranged from a few months to early 20's, even one of Sense's volunteers was born with CHARGE.

Gail Deuce a consultant MSI teacher with Sense, Steve Rose assistant director and head of the Family Education and Advisory Service in the South East (and a Speech and Language Therapist) and Jeremy Kirk the chief medical advisor to the group all came, mingled, chatted and gave advice where wanted.

As usual there was the sensory room, music room, art room, gym and hydrotherapy pool available all with support from volunteers. The pool and trampoline were very popular, whilst the family room doubled as a creche due to number of babies with CHARGE there.

From a personal point of view with Jessica's favourite former school 1:1 there as a volunteer and a set of grandparents attending I could forget about my girls (including Flo!!) and wander around just chatting to other parents as well as Jeremy, Gail and Steve. There is so much to pick up from other parents (and of course the professionals).

Many thanks for such a successful day must go Frances Concannon (our new secretary) who organised it from the group's side, Gemma Blackie from Sense's (Voluntary Service's Team) VST - the family day was her parting shot before going on maternity leave, the volunteers without whom such days cannot be successful. This family day now is part of the VST's calendar of events. I must also thank Sense for the use of the Anne Wall Centre and congratulations to Gemma on the birth of her 5<sup>th</sup> child.

### Novel involving CHARGE Syndrome

Tim Hartshone forwarded me the press release from the author regarding her novel, which is set out below. In addition I have set out first his comments:

'I am excited to pass on the word that a novel has been (or is about to be) published that includes the birth of a child with CHARGE. I read a pre-publication version of the book, and really enjoyed it. If you go to the authors website (listed below) you will find my comments about the book. I offered Shaila to send out information about the book. It is going to be launched on Amazon.com on February 3<sup>rd</sup>. There will be discounts and other offers then.'

'My name is Shaila Abdullah and I am a Pakistani-American author and designer, residing in Austin Texas. My literary novel, Saffron Dreams is due to be released next month. Hailed as "eloquently written, a must-read for any one interested in exploring the lived experiences of Muslim women in the United States" by Harvard professor of Indo-Muslim Languages and Cultures Ali Asani, Saffron Dreams explores the post 9/11 world for Muslims and a culture in shock. The novel's subplot is about the life of a child with CHARGE syndrome and the way in which his mother, a widow copes with the situation. Please read an excerpt at [http://shailaabdullah.com/SD\\_excerpt-charge.html](http://shailaabdullah.com/SD_excerpt-charge.html). This is my second book. My first one was a collection of short stories called Beyond the Cayenne Wall that won many awards and accolades.

I would like to reach out to the CHARGE community and see if they would be interested in spreading the word about this novel and build some awareness about the syndrome and the unique role parents have to play in the lives of their special children. I am open to ideas and suggestions. Please feel free to contact me and share your thoughts.'

### **Notes on our Statementing process - Alexis Wolfe**

Our son Jacob, age 5 recently started at the ICAN Meath School and Simon asked me to write a few notes on our experience of getting Jacob's Statement of Special Educational Needs (SEN) to share with other parents who might not have got that far yet. So set out below is some of what we learnt along the way....it is quite difficult to remember everything in retrospect therefore we are more than happy to talk to anyone about it in more detail - feel free to email me at [alexis\\_wolfe@yahoo.co.uk](mailto:alexis_wolfe@yahoo.co.uk) if you have any questions.

Jacob has CHARGE - the main issues for him are: severe speech and language delay/disorder, severely sight impaired, severely balance impaired although he is walking independently, tube fed and mild fluctuating hearing loss due to glue ear.

We first requested a statement when Jacob was 3 and already attending pre school 2 sessions a week with 1:1 support. We were lucky that the nursery put in 1:1 support using some Early Years funding and that he was visited at home or in the placement fortnightly by his Teacher of the Visually Impaired (VI Teacher). Therefore we did not need to get a statement earlier. If, however we had wanted Jacob to attend the full 5 half day sessions (to which he was entitled) we would have needed to start the statementing process sooner. When we started the process we had visited several schools, but we had not yet decided between mainstream or special schools and we had not found the school we wanted Jacob to attend.

Our VI Teacher initiated the statementing process for us although it is possible for parents to do this themselves. The Independent Panel for Special Education Advice (IPSEA - [www.ipsea.co.uk](http://www.ipsea.co.uk)) has some standard letters which can be used to write to the Local Authority to request they make a statutory assessment of your child. There is a short form you need to fill in when you request a statement setting out why you feel your child should be

assessed. We did not provide much information on this initial form as it clearly said we would be given a further opportunity to express our views, also we were very confident that a request for Jacob to have a statement would not be refused and the council would proceed to a full assessment given his complex needs. So on this first form I just listed briefly Jacob's main issues due to CHARGE, the support we had accessed already such as Portage and the VI Teacher and said Jacob will need a range of support in place in order to access the curriculum at school. We then wrote that we would submit a full parental report detailing all Jacob's needs in full when the decision to proceed to statementing is confirmed and assessment reports are gathered from all professionals.

Then when we got the letter saying the authority has decided to make an assessment in order to produce a Statement we were ready to send in a full report saying exactly what we felt Jacob would need. We sent this after we had seen all the other reports which were being provided by all the professionals involved with Jacob. Our report re-emphasised some of the needs they had expressed and also gave our perspective and additional information about Charge which was lacking from the reports the professionals had provided. We also attached the report we had from Sense after our recent assessment by them.

I divided our Parental report up into sections covering his different needs, it was several pages long and much of it was used in the final statement particularly in Part 2 which is the section which details the child's needs. Your report and those of the professionals should be read by the local authority's statementing officer and then a detailed description of the child's needs for Part Two is written. Part Three of the statement should then detail the appropriate provision and adaptations which will be made to meet those needs. And that is where the fun starts...

I would strongly recommend all parents get a copy of the SEN Code of Practise and also the SEN Toolkit which accompanies the code - details are here <http://www.teachernet.gov.uk/wholeschool/sen/sencodeintro/> these were very useful.

One of the first problems we had was that professionals such as the speech therapist and OT wrote very vague reports which did not detail Jacob's needs sufficiently and did not give clear instruction on the specific provisions which would be required to meet these needs. This meant that we were at risk of getting an inadequate statement which would in turn fail to get any school to provide what Jacob really needed. We insisted that all professionals sent their reports to us first before sending them to the council and I would recommend you ensure that happens. We decided our main priorities were getting Jacob a 1:1 Learning Support Assistant (LSA) and getting him an adequate amount of speech therapy. So getting them to improve their reports was our first challenge and we cajoled, pleaded and pressured for improved reports.

One strongly worded email to the Ed Psych got us a report with slightly more clarity on the need for 1:1 assistance, but they were still reluctant to make a concrete recommendation on staffing levels for Jacob ..... you may find none of the professionals actually want to be the ONE who states the (blooming obvious!) need for additional staff ..... we also had a long

process of trying to extract a decent report from the NHS Speech therapy department.

Our speech therapist gave us an excuse about being told by her manager she was not allowed to specify the provision needed! Talking to other parents we knew it was common for SLT's to play down a child's needs because they knew the limited resources within the borough and so avoided recommending more than they knew they would be able to provide, so we became firmer, we questioned each and every vague point and gave examples of how they should amend the report, whilst pointing out the requirements in the SEN code of practice.

Eventually the resulting report contained much more clarity and specificity regarding the speech therapy required. Sadly at this point it also became clear to us that the "One block of a minimum of 5 therapy sessions per term" they were willing to recommend was no where near the volume both us and the independent speech therapist (we had hired for extra therapy) felt Jacob would need once he got to school. It was at this point I began to look at the ICAN schools as they focus on speech and communication issues.

Anyway, I think you are probably getting the gist of how things went, reports came we batted them back once or twice and slightly improved reports were finally submitted. We had to compromise in some cases as it was clear that some people would never make a categorically clear statement of our child's needs no matter how much you twisted their arms...

We ended up funding one private report in the end - for Occupational Therapy - and got an accurate detailed report from an OT who was accepted as an expert by our local authority. Without this Jacob would not have got any OT provision in his statement so we saw it as money well spent. Had we not found ICAN 's ([www.ican.org.uk](http://www.ican.org.uk)) Meath School (where a speech therapist is full time in each class) we would also have needed to obtain an independent speech therapy report to contradict the one from the local SLT team and recommend a realistic amount of speech therapy input ..... otherwise Jacob would have been left with completely inadequate input.

Another point worth mentioning is that it certainly helps if you have an idea of the type of school you want since you can then emphasise what the child needs with the focus on the bits which will be difficult to meet in other setting eg we wanted a Sign Supported English environment for Jacob so made sure that all the reports mentioned this.

Throughout this stage we were still visiting schools and talking to other parents for ideas - we were fluctuating between choosing mainstream or a more specialised school setting and that is a whole other article...! *(yes please - Simon)*

One of the other good things we did was to borrow some statements from other kids so we knew how they looked and could get an idea of what to expect Jacob's to look like. We were fortunate that another Charge Family offered to lend us their daughter's statement which they had battled to achieve and it was very detailed and this gave me a good idea of what was possible.

So after a while the proposed statement was issued - and it came through the post. We asked them to email it to us as well. This made life easier because it meant we could make some amendments to it in another colour and email our suggestions back to them without having to type the whole thing out. The other benefit of receiving it in email form is that it can be emailed to other people for comments and advice. There then began a process of toing and froing with the department to make them write the statement in the way we wanted it.

The thing that helped me most in this situation was joining [www.specialkidsintheuk.org](http://www.specialkidsintheuk.org) as they have a forum and there is an education bit with many experienced parents on there. Do join!

Other mums at Special Kids helped me pick out the meaningless terms the LEA were trying to include like 'Jacob would benefit from' or 'Jacob needs regular' - these mean nothing on a statement - Santa Claus is regular - he comes once a year...

As we discussed recently on the Charge Listserv, the devil is in the details when it comes to statements and it is all about the specific wording ..... if it states a child 'must have' staff trained to deliver her tube feeds .. or have the provision of nursing staff/a communication device' it would mean he/she definitely gets that .. but if it says 'must have access to regular speech therapy' or 'must have input from OT' then that is not so good as "access to" and "input from" are virtually meaningless in a statement - it could mean you end up with annual or termly access/input when in reality you need weekly input or a therapy programme carried out daily, it could be interpreted to give insufficient services even though it is prefaced with "must have".

Ideally when you are detailing services from therapists who will be visiting the school setting you need to state what therapist, how often they will see the child and what they are going to deliver...everything needs to be specified and quantified eg Jacob will have termly assessments by a trained OT who will provide a therapy programme and targets which will be delivered in the class via the LSA on a weekly basis ..... or Jacob will have a weekly 45min speech therapy session with a qualified speech therapist who will also devise a therapy programme to be carried out on a daily basis by an LSA.

The parents on Special Kids advised me ..... don't let Part 3 of the statement where provision is specified be about the child's needs (that should all be detailed in Part 2), don't let it say what they would require or benefit from ..... make sure it says what they are going to actually get given.....so make sure Part 3 is about the appropriate PROVISION, QUANTIFIED and SPECIFIED to meet those needs.

We found it worked to our advantage to remain undecided about what type of school we wanted so that the statement they wrote had to be full enough to cover potentially putting Jacob in a mainstream setting - we knew they had been told by our local mainstream that he would need a large support package in order to attend the school so we got as much of that in there (despite the fact we were now leaning towards a smaller specialised school). You

receive the Proposed Final statement issued with Part 4 (which names the school) initially blank so you have the chance to name the school you want the child to attend and they will either agree or disagree and name a different school. Anyway, our first Final statement was actually issued with no school name as we still hadn't decided and were waiting for an assessment at Meath School so they agreed to issue it blank and revise it 6 months later after the assessment.

On the advice of other parents, in all our communications with the council we put everything in writing (by email) even if they called us to discuss by telephone we sent a follow up email stating what had been discussed for the record. Also useful was showing your proposed statement to others - we got Sense to look at ours ..... you only have 15 days to act on the Proposed Statement so you need be quick! Calling/writing with feedback or requesting a meeting to discuss lengthens the time frame so we did that and waited for a date for a meeting.

All along we indicated that we wanted to WORK WITH the authority and ideally avoid having to end up at a SEN Tribunal (your route of appeal if you are not satisfied with the Final Statement) to get the necessary provision. However I think ending some of our emails about changes that were needed with wording along the lines of "I hope we can resolve this matter to our mutual satisfaction without the need to proceed to Tribunal" made it clear that we would exercise that option if the statement was inadequate.

Our final aim was that although they agreed verbally to us and the school to provide a 1:1, we wanted the specific details of the LSA provision to be included in Jacob's statement. We complained that our statement does not make clear that an LSA will be provided, doesn't detail the number of hours that will be allocated to support Jacob or give details of the training that the LSA will receive. We advised them that we understood from IPSEA and the Code of Practice that unless LSA support is clearly specified and quantified in the statement, then the school would have no obligation to provide this and the 1:1 could be diverted to assist other children despite them funding it to specifically support Jacob. It was also crucial that Jacob's current requirement for 1:1 support is clearly documented in his statement in case we were to change boroughs in the future.

In the end our meeting with the head of the SEN department went really well and we got the phrases concerning the 1:1 support written in the way we needed them. By now we knew Jacob had been offered a place at Meath and the council had agreed to fund it (maybe in part because they knew our alternative choice was the local mainstream and an even more expensive support package). However I would also like to think it was because we had battled to get such a thorough description of his needs initially documented so they had a clear "picture of Jacob" and agreed it was a placement which would meet all his needs whereas their local special school would not. I found this quote from the IPSEA website that I tried to keep in mind throughout the process:

"There is no question of Parliament having placed the local education authority under an obligation to provide a child with the best possible education ... or to educate him or her to

his or her maximum potential."

This is an important judgement to bear in mind if you are arguing for a place in a specialist independent school for your child. You must not rest your case on proving how good the school is or how well it will meet your child's needs. Both the LEA and the Tribunal may agree with you that the independent school is the best possible option for your child, but they may still decide that one of the LEA's school can meet his needs. So, your task is to present as much evidence as you can which shows that the school the LEA is offering, or any other school it could offer, cannot meet your child's needs as these are described in the statement. It helps if you have a full and detailed part 2. " - IPSEA website.

If you get stuck in battle with your LEA then IPSEA are the people to call for advice on what is legal, what the authority has to do, what they might be trying to do instead etc ..... they are also the experts when it comes to tribunals. Tribunals are an option for parents but it is expensive and stressful. Other parents advised do not be disheartened when the LEA tell you that you are talking rubbish and they never ever do Statements with that much detail or give children that much support. Another parent told me she would also only give them one opportunity to get it right, then accept the next draft/proposed and then when you have the Final draft go and lodge an appeal at SENDIST, otherwise they will keep you discussing it forever. For some authorities that might be the case but we felt that ours were open to negotiation and we had plenty of time before Jacob was due to start school so we kept on talking to them.

In the end we are reasonably happy with Jacob's final draft and we are glad we kept the lines of communication open and didn't need to go to Tribunal. It is not the perfect Statement but we are hoping it will be good enough.

If you do end up thinking that you might need to go to Tribunal then IPSEA would be first port of call. Also I noticed on the SENDIST website [www.sendist.gov.uk](http://www.sendist.gov.uk) you can read through the rulings and outcomes of previous tribunals, each one has a report stating what the appeal was about, what evidence was presented/discussed and how the panel came to a decision. This gave me a good idea of points families were successfully able to appeal and what made the panel decide in their favour. Searches can be done by age of child, disability, type of school etc so that might be useful.

Hope some of this helps ..... there are very strict guidelines on how an Authority carries out an assessment and issues a statement - all this and more can be found in the SEN Code of Practice and Toolkit, so I would say that should be the starting point for everyone. Each council also has "Parent Partnership" officers to assist Parents in this process but they are employed by the council so there are some concerns about how independent they really are. I think that it is fine to get advice from them, but do it in conjunction with talking to other parents. IN addition use the internet, IPSEA and of course our wonderful CHARGE Listserv for more advice.

## Hannah's Education - A Journey by Rob Henderson

Our 10 year old daughter, Hannah has CHARGE and recently started at a new school - this is an account of the journey we have undertaken to make this change of school possible. Although all parents of children with CHARGE face similar challenges finding an 'appropriate' educational setting for their child, we have made some discoveries in the last year which may be useful or of interest to others.

Hannah was born in Oxford in 1998 and diagnosed with CHARGE at 2 years old. She was considered to be developmentally 'age appropriate' at 2 years old and in the early years we had good support from a Teacher of the Deaf and a Pre School Teacher Counsellor. Hannah attended a local nursery (with 1:1 support) but by the time she was 4 it was clear that she would need a Statement of Special Educational Needs before starting school. We were hopeful that Hannah would be able to attend a local mainstream school and once the Statement was in place (it specified her need for 1:1 support) we looked at various alternative schools.

The headteacher at the school we chose was very positive about making Hannah's placement at the school work and committed to find the right person to work with Hannah as a 1:1 Learning Support Assistant (LSA). The first couple of terms in the nursery class went quite well, but we were disappointed to discover in the summer term that the headteacher would be retiring that term. We were even more disappointed the next term when we met the new, young headteacher who, being on a mission to push the school up the results league tables, quickly decided that Hannah was in the wrong school.

The new headteacher had definite, but rather surprising views on 'inclusion' for example "what's the point of inclusion if the child can't participate fully in everything that is going on in the class?" Our assumption was that with Hannah's Statement we had the funding in place for a package of support which could make inclusion work for her at the school. We therefore spent about a year attempting to resist the changes that the new headteacher made to Hannah's provision - including replacing the one good LSA working with Hannah with a weekly rota of 5 different (untrained) LSAs. In retrospect we probably wasted this year fighting a battle that we could not win. We learnt from this that if you are not in complete agreement with the headteacher about what your child's needs are and how they should be met, then you are probably better off moving schools rather than attempting to achieve a level or type of support that the headteacher is opposed to.

Once we had become reconciled to the fact that 'inclusion' couldn't work in practice for Hannah at her school, we started to look at SEN schools in our local Oxfordshire area. The one we chose for Hannah was in a village just a few miles outside of Oxford where we were impressed by the caring environment in the school and the supportive attitude of the staff (they were actually quite enthusiastic about Hannah moving to their school!). We were also encouraged by the fact that the school had been a pioneering school for fully integrating a SEN school within a mainstream school setting - they shared facilities with and were adjacent to a mainstream primary school site. Some pupils have the opportunity to spend

time in both settings. This seemed to be a positive advantage for this school given that we felt that our decision to move Hannah out of mainstream education was (at least at the time) a marginal decision.

Hannah's first 2½ years at her first SEN school were fairly uneventful - she appeared to be much more happy. Although administratively the school was somewhat disorganised (we were not invited to an annual review meeting for the first 18 months) we were content that her teachers were positive about the progress that Hannah was making. Overall we felt greatly relieved that we had made the decision to move Hannah into a SEN school as it did seem to be a more appropriate setting for her. In her second full year at the school Hannah's behaviours began to become more challenging (eg self-harming), but we ascribed this more to anxiety at home (where we were living through the upheaval of a major house extension project) than anything that might be happening at school.

At the start of Hannah's third full year at the school she was unexpectedly moved up into a different class in year 5. The school had planned her transition into another class the previous term, but informed us of the change just before term started - apparently due to an unexpected change in numbers on the school roll. Sense had been providing advice to us at various points (mainly prior to her move into a SEN school) so we decided to ask them to visit Hannah in her new class in year 5 to see how they thought she was progressing.

When we received their report (in November 2007) we were alarmed to discover that Hannah was being let down by her school on many counts. She was the only non verbal pupil in a class of 10 pupils - many of whom were autistic and quite boisterous and disruptive. The teacher and his assistants seemed unable to include Hannah in what the class were doing. They had made no attempt to sign to Hannah since the start of term when we were being trained to use Sign Supported English with Hannah at home, were unable to provide her with an appropriate chair (ie one with arms and of a size to allow her feet to touch the ground), further the toileting programme which we had agreed with the school in the summer term had been abandoned in her new class. The Sense report was worded very diplomatically, but made a number of definite recommendations including the suggestion that Hannah needed to be supported by a 1:1 'intervenor' (or sensitive communication partner).

We requested an urgent meeting with the headteacher to discuss the Sense report. Unfortunately we felt she was very defensive about the findings and recommendations in the report. She disagreed with the suggestion that Hannah should have 1:1 support (in case she became too dependent on one person) and further didn't appear to understand what was the role of an 'intervenor'. Whilst she was apologetic about the breakdown in signing, she also displayed a lack of understanding about what multi-sensory impairment means - for example "if Hannah is able to listen to a piece of music and then play the tune on the piano (*one of Hannah's talents*) why can't she speak?" The headteacher also pointed out to us that she had very limited resources with which to award additional support for any one individual pupil.

There then followed a series of further meetings with the headteacher and various others including our Sense advisor, the Local Authority and Hannah's MSI teacher/advisor. Her

class teacher was not involved in any of these meetings. It became clear to us that although some of those involved were aware of how big the gap was between what Hannah needed and the provision available at her school, it would take a very long time before all the training required could make a difference to Hannah. We also realised that the three people who were most likely to be able to make a difference to Hannah's educational provision - her class teacher, her headteacher and her LA MSI teacher/advisor - did not seem to have either the experience or motivation needed to be able to help Hannah.

In the 2007 Christmas holiday I met someone socially who though now retired had been a headteacher at a SEN school in Oxford. He listened to my account of our concerns about Hannah's school and told me that he believed (on the basis of 20 years as a SEN school headteacher) that Oxfordshire - and the city of Oxford in particular - is one of the worst places in the country to attempt to educate a child with special educational needs. Why - a combination of misguided policies at the Local Authority level, low levels of funding and a lack of competence and innovation amongst the headteachers in SEN schools.

With great reluctance (we have two other children who were happily settled into their second year at an Oxford school) we began 2008 considering the possibility that we might have to move Hannah to a new school, but not in Oxfordshire. While discussions were continuing with the Local Authority about improving Hannah's support package we began looking at alternative SEN schools in the neighbouring counties of Buckinghamshire and Berkshire. Assisted by Sense we identified a good specialist SEN school just outside Reading with a Sensory Resource unit within the school equipped to support pupils with MSI related disabilities. The school also has an Autism and Behavioural Support service within the school together with the other support services which Hannah needs (OT, SALT etc) on site. One of the issues in Oxfordshire is that the SEN schools are generally small (about 60 pupils) and support services are provided from central county resources, but there appears to be difficulty in retaining these support professionals. There is therefore a lack of continuity and often extended periods when no support is provided in the schools.

We asked the Reading SEN school what we needed to do to make it possible for Hannah to move to the school. They advised us that we had to start by asking our existing Local Authority if they would be willing to fund Hannah being educated 'out of county'. We prepared a very detailed proposal for the Local Authority explaining why we believed it was necessary for Hannah to move to the Reading school. This included an analysis comparing the level of support available at Hannah's current school together with all the other schools we had visited (both inside and outside of Oxfordshire). The Reading school was so impressed by the proposal that they asked us if they can use it as a template for other people to refer to!

Unfortunately Oxfordshire Local Authority was less impressed. After keeping us waiting for a decision for months, they rejected our proposal stating that they believed that they 'ought' to be able to provide an 'adequate' education for Hannah within Oxfordshire. We discovered at this stage that the level of funding per SEN pupil provided by Berkshire for the Reading school was more than twice the level of funding per SEN pupil provided by

Oxfordshire for Hannah's school. Add to that the cost of transport and we were asking Oxfordshire to pay an additional £40,000 per year for Hannah's education. I'm not sure that the Oxfordshire panel reviewing our proposal ever got past the costs to read the analysis. We were advised by Sense that we had a very good case to take to tribunal, but we were also told that the tribunal process takes at least 4 months and can be a very demoralising and exhausting experience.

In the end we decided we had wasted enough of Hannah's critical time for development in education and needed to simply make this change of school happen by moving house to a place where she could attend the Reading school as a local pupil. We were fortunate in being able to sell our house quickly (before the current financial crisis made the housing market seize up) and find somewhere to move to. We were also lucky in that our employment circumstances meant that we are able to be flexible as to where we live.

It is now 4 months since we moved. Hannah has just finished her first term at her new school. She has not found the change of home and school easy to accept and she is finding the more stimulating environment at her new school very challenging, but we are confident that she will ultimately be much happier supported by people with the specialist skills and experience to help her. We are delighted with the more enlightened and imaginative way in which Hannah's new school supports both her and us as parents.

Since moving and speaking to other parents of SEN children in Berkshire, I have discovered that although the SEN schools in Berkshire are fewer in number, larger and better equipped than the SEN schools in Oxfordshire, the situation in Berkshire is more difficult for children who are on the margins of mainstream/SEN education as the threshold (in terms of level of disability) for acceptance at a SEN school in Berkshire appears to be higher than it is in Oxfordshire. A child with complex or profound disabilities is better served by the educational support system in Berkshire than in Oxfordshire - not least because SEN education in Berkshire continues up to the age of 19 whereas it finishes at age 16 in Oxfordshire.

This whole process leads me to reflect on two things. Firstly, why is it so difficult for us as parents of disabled children to find out about and understand what kind of support is **really** available from SEN schools and whether that support is **genuinely** appropriate for our children? Secondly, is there not a fundamental injustice in an educational system which allows disabled children to become trapped in a school setting that is failing to support their needs? As I mentioned previously, we were relatively lucky in being able to simply move ourselves so that Hannah could change school – most families have other considerations (employment, sibling education) which mean that they are effectively denied choice in SEN education.

### **Recent Educational/Statement Issues - Simon Howard**

Last year we suddenly discovered that our local authority was severing its contract with Sense who were providing it with a Multi Sensory Impairment (MSI) teacher. We found this out from Sense and not the local authority (LA). Jess had had input from Sense since she was 6 months and she was now 7. Her statement had set out that Sense were to provide her

MSI input.

We wrote to the head of SEN stating we were concerned about what they were proposing and reminded them of their legal obligations under Jessica's statement. Compared to other people we were lucky in that the local authority did not dismiss us out of hand and entered into correspondence with us and Sense. Throughout the correspondence we were very clear that unless Sense's input was maintained we were going to Tribunal.

At the same time we also found out that Occupational Therapy (OT) provision had ceased and the sporadic VI input was no more (Jessica is educated out of borough and these services were being provided locally). We thought in for a penny in for a pound and tackled the LA on this as well. Jess' school had observed that since OT had stopped she had regressed with her fine motor skills so we asked the LA what they were proposing to do about these.

It is fair to say that Jessica's school was also in correspondence with the local authority on all 3 points as well.

To our surprise the LA agreed that Sense should provide 16 hours per school year input, they also advised us that they would contact the PCT and LA where Jessica's school was located to contract them to provide OT and VI services. The local PCT agreed to provide 10 sessions a term (ironically this agreement is no longer needed since there are OT's now based at Jess' school). Regarding the VI input the school's LA even with the offer of payment could not provide this service, therefore our LA agreed that a local VI teacher would provide input to the school. This has been incredibly successful. With this teacher involved we have obtained for Jessica (following recommendations from Sense) a laptop and a magnilink to be used at school and home, school has also been provided with a hand held magnifier.

Subsequently we discovered that our local authority has 2 contracts with Sense, one for Jessica and one for other children in the borough - this is despite at least one other child having Sense specifically referred to in their statement.

Yes, we have been very lucky in that we have had a responsive LA, but I think the point I am trying to get across is that although Jessica's educational placement is excellent we have had to be vigilant about secondary issues that in reality complete the educational package.

## **PEN PORTRAITS**

Duncan McCausland

Over the last few years I have had contact with the parents of Duncan and I am grateful that Duncan's mother has now written a pen portrait about him. In some ways it an appropriate portrait for this newsletter in that there is focus on his recent educational

achievements. It was also written in the context of my sleep article. What Lindsey, Duncan's mother doesn't say is that Duncan attended a leading public school in south London and was the only pupil there with a statement of special educational needs. Outside of Duncan's educational achievements I must say that for Duncan to have a group of friends is something that as parent of a child with CHARGE I aspire to.

The portrait is in 2 parts simply because it is easier to leave it that way.

### **Duncan**

Duncan is now 19 and has left school. He has amazed us all by determinedly dealing with all the challenges of academic and particularly social life at school. To quote his yearbook page he went from being 'the child no one wanted to be with' to being elected a senior school prefect and having (finally) a solid group of friends. It took a long time for people to appreciate just how funny, kind and loyal he is.

He got A levels at A Biology, A Geography and B Physics and has applied for university - UCL, Nottingham, Bristol, York and Sheffield. He wants to read Biology, then do a PGCE and teach in primary school. So far he has offers of a firm place at Nottingham and York; we are waiting on news of the others. Both sent him their disability assessment form with the offer and have said they will gladly meet with him before he starts if he has anything he wants to discuss and have offered a pretty wide range of support. Bristol have sent an assessment form, saying it will not influence their decision to offer a place or not - can't help thinking if it really has no impact then why not send it with the offer if they intend to make one as Nottingham and York did. I'll let you know when we hear from Sheffield and UCL.

Sleep - yes well! Dunc has a pretty mild form of CHARGE, even so he has never got the hang of sleeping. When he was small he took himself downstairs at 4 or 5am and watched TV until we got up. He still gets up by 6 most days however late he goes to bed and we remain a rarity amongst the parents of teenagers - ones who groan through their bedroom door 'try and get some more sleep Duncan'. The side effect of this is not bad for us although sometimes irritating but he is easily fatigued and the combination of fatiguability and inability to sleep properly means he spends a lot of life in a state of exhaustion.

He always nodded off in primary school - we agreed a regime of milk and biscuits to try and recharge him once he woke. Still dozed sometimes at secondary. Now he is an adult perhaps the worst aspect is not being able to last out a late evening like his friends - if they're just chilling at someone's house, Dunc will probably be fast asleep (with his mouth enchantingly wide open due to his hypotonia) in a corner. If they're out and about he survives but is a ratty zombie for a few days. Have given up taking him to any soothing or slow moving theatre/musicals etc because there is a limit to poking him awake! A shame because he loves to act and theatre should be (and is if its active enough) a joy to him.

He got clearance to drive from the DVLA as he has pretty good vision in one eye and eventually passed his test. He clearly though has problems in judging road position and has

not ventured into distance or motorway driving because he is not that confident himself.

He is a great chap, a great son and we are very proud of him and very privileged to have had a part in helping him through so far. Next year he will launch on his own and a whole new lot of issues will no doubt start.

Lindsey McCausland

I received a separate email setting out Duncan's CHARGE issues:

Dunc has bilateral colobomata, malformed middle ear bones and hence both conductive and sensorineural deafness, had swallowing and speech difficulties (but not a TOF), was developmentally delayed, had a large patent ductus arteriosus (PDA) that was operated on, maldeveloped kidneys (15% function in one), hypotonia, balance problems both due to ears and to muscle imbalance, a fit that led to him losing his sight briefly (don't know why the fit), ectopic teeth and poor tooth enamel/tooth position, was very rigid as a child and still is quick to perceive 'unfairness' and to be emotionally vulnerable, somewhat paranoid and inflexible in respect to the outside world.

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.

## **FUNDRAISING**

If anybody is doing any fundraising - big or small let me know and if I am able to publicise it I will. Please remember that we are a self funding group so we need you, family, friends and work to raise money for us. The more active we are the more money we need.

### **Sponsor forms**

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

## **FEEDBACK**

As ever please give me any comments - positive or negative - about the newsletter. I can only improve it if you give me feedback.

## **EMAIL ADDRESSES**

Thanks for the email addresses you are sending me. Please keep them coming.

## **USEFUL INFORMATION**

Sense - is the world's largest deafblind charity who work with children with CHARGE here. They are 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 0060; textphone: 0845 127 0062. Website: [www.sense.org.uk](http://www.sense.org.uk).

CHARGE Syndrome Foundation - US charity that is the main CHARGE charity in the world. Their website is found at [www.chargesyndrome.org](http://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

Please return to Simon Howard, 59 Elmer Road, London SE6 2HA or [si\\_howard@hotmail.com](mailto:si_howard@hotmail.com)