Summer 2009

Issue 33

Syndrome Support Group

Providing support, information and friendship for families, carers and professionals

Dear Supporter

Firstly, and on behalf of all on the committee, I would offer our sincere apologies for not being able to finance a full weekend conference this year. Unfortunately the credit crunch is hitting all areas of our lives and major sponsorship for such events is proving difficult to attain.

Self-supporting fundraising becomes even more important and we are very grateful for those hardy souls who have been climbing mountains and running marathons on our behalf. Perhaps your family or friends are planning such an event, hopefully they will nominate Cri Du Chat as the charity to receive sponsorship.

Enclosed in the newsletter is a booking form for our one- day event and I do hope you will wish and be able to join us. I am sure you will agree that the once a year opportunity to meet other families involved with the Syndrome should not be missed. The full programme is featured on page 7 and this year our speakers include Dr Chris Oliver, Kevin Mann and Rebecca Lewis, a senior Occupational Therapist, who will be focusing on strategies for parents and health care professionals when dealing with self injurious behavior.

I must now relate some disappointing news, namely the resignations from the committee of Angie Stokes and Steve Gregory. Both have been long standing members, even before my time, and have both contributed so much to the development of the support group over more than fifteen years. Steve was more recently the membership secretary and we will miss his dry Yorkshire humour. Angie will be known to many of you as the new family coordinator and the organiser of the many Conferences at Earl Shilton. We understand that ever-changing commitments preclude them from continuing and we wish them well but they will both be very sorely missed.

The launch of Rare Disease UK. took place at the Houses of Parliament at Westminster. The Support Group was represented by the Chairman and members of our Committee.

We believe it is important to be involved and committed to such initiatives. All families will be aware of the many difficulties we face in obtaining acceptable services and, hopefully, you will wish to add your MP to the political process by writing to him/her as requested by the newly formed Rare Disease UK on page 2.

Damian Haywood, Ray Clarke, Billericay MP John Baron and Caspar Hull

Lucy Tetlow, administrator

I would like to give a big welcome to our new members – five families this year so far – and hope that you all enjoy this newsletter. We have a lot of content this issue so you will see that it is bigger than usual – and hopefully this is something we can keep up in the future. As always we welcome contributions from members so if you have some knowledge to share, a good story to tell or just want to introduce yourselves please do let me know.

You may also notice that I have changed my name. My husband will be pleased to know that this isn't my way of 'surprising' him with a divorce but after two years of marriage I have just not been able to get into the habit of my new name and have driven Ray crazy with going by the two names, sometimes simultaneously. So time to put Ray out of his misery and go back to Tetlow.

I also wanted to take the time to thank the members of the Committee who have worked so hard over the last year to develop the group. Our new Clinical Advisory Group, headed by Caspar Hull, has been a great success and they have answered many queries from families all over the world. We are about to launch our brand new website including (eventually) a much requested parents and carers forum. If there is anything you would like to see on our website please do let us know so we can ensure that that the new design takes into account the needs of all our members and supporters.

You will also see that once again our family stories recommend Makaton. If you do wish to find out more about Makaton please visit their website www.makaton.org or contact our office to buy our remaining copies of the series 'Something Special' (please see page 3 for more details).

The Keystone Project: A Research Update

For those of you who aren't yet aware of the Keystone Project, this is a research project that is being carried out by a specialised team of researchers at the Cerebra Centre for Neurodevelopmental Disorders at the University of Birmingham. Postgraduate researchers Laurie Powis and Jane Appleby run the project, which is supervised by Professor Chris Oliver. The project also has input from two developmental psychologists, Dr. Sarah Beck and Dr. Ian Apperly and has links with Great Ormond Street Hospital. The Project aims to understand the brain processes that underpin impulsive behaviours and social understanding in people with CDC syndrome.

The Projects Progress to Date

Last October, Laurie and Jane started to visit families with children with CDC syndrome in order to run a variety of assessments and to talk to parents about their experiences.

These families were recruited through the syndrome group and many families expressed a strong interest in taking part in the study after meeting Laurie and Jane at the last CDC family conference in Stratford Upon Avon. Parent response to Laurie and Jane's recruitment campaign has been good so far and both researchers can't thank the families enough for their warm and open interest in the project. Laurie and Jane are still very keen to get new families involved in the project and in order to make the project as worthwhile as possible Laurie and Jane need to see between two to three families per week over the next couple of months. Although it's a busy life for the researchers both agree that meeting families is one of the most rewarding parts of their research.

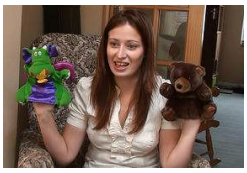
Impulsive Behaviours in CDC Syndrome

Jane decided to focus her research on impulsive behaviours in CDC syndrome because many parents have reported that their children often have difficulty controlling their behaviour in certain situations. Jane is addressing the possibility that impulsive behaviours are underpinned by problems with a particular area of the brain that is associated with a set of processes called the executive functions. The executive functions are related to the control and regulation of behaviour.

As part of the assessment Jane runs a number of executive function tasks with each participant and compares the results of these individual assessments to one another in order to uncover an individuals executive strengths and weaknesses. So far the tests have been working well with individuals with CDC syndrome and the researchers have been working to constantly adapt and improve the assessments along the way.

What's next?

Parents are reporting to Laurie and Jane that they have found the day of the research visit interesting and that it was enjoyable for the person they care for. It will be several more months before all the results are in and Laurie and Jane can start processing their data to draw their final conclusions. Laurie and Jane will keep us posted!



Jane and her dragon/bear assessment

CDCSSG supports Rare Disease UK in achieving its goal of 150 signatures to our Early Day Motion.

We have been asked to highlight this campaign by Rare Disease UK. Please can you contact your MP and ask them to sign the Rare Disease Day Early Day Motion number 914, tabled by Dr Evan Harris MP.

It's very easy. Please go to www.theyworkforyou.com where you can put in your postcode and find your MP. You can then email them directly from this site.

A personal message is always best but if you would like to use the sample message please do:

"I am writing to ask for your support for EDM 914 which acknowledges Rare Disease Day 2009 which was held on 28th February (www.rarediseaseday.org) This EDM has kindly been tabled by Dr Evan Harris MP.

Rare Diseases affect over 3.5 million people in the UK and I personally have an interest in the improvement of services and support for patients and families affected by the over 6000 conditions that have currently been identified. The families often struggle to find appropriate health services support, and research is also often hindered by lack of funds although experience tells us that understanding a rare disease - such as a rare, familial cancer - often provides a vital clue to understanding, and treating, the more common diseases which affect millions.

As your constituent I would be very grateful for your support."

Thanks a lot, and do let Melissa (melissa@raredisease.org.uk) and Stephanie at Rare Disease (info@raredisease.org.uk) know if you get a response.

Fundraising activities

Thank you to all our members and supporters who have donated or organized events on our behalf.

Kevin Riley	£2109.35	Marató Barcelone
Rob Metcalf	£1970.54	Mt Kilimanjaro
Research Team	£1169.11	Robin Hood Half marathon

We are delighted to announce that your subscriptions are now Gift Aidable – allowing us to claim back money on each payment you make. In order to allow us to do this please complete and return the form enclosed in this mailing. We will be planning on doing a claim in the next few weeks so the sooner you are able to return the more money we can claim!

JustGiving is a wonderful website where those who want to do some sponsorship can register and create their own fundraising page on behalf of the CDC Support Group. Registration is easy (and free!) and really does make it easy to raise money on behalf of the group.

www.justgiving.com/criduchat/raisemoney

CURRENT FUNDRAISERS

Mary Pearson, sponsored slim, donate at www.justgiving.com:80/marypearson1

Stephen Taylor, running in the Swindon half marathon October 2009, donate at www.justgiving.com:80/stephentaylor75

Uncle Kevin Riley kindly ran the Barcelona Marathon on behalf of the CDC support group. For those who do not run marathons in their spare time the *Marató Barcelone* has been in existence since 1978 and starts and finishes below the green hills of Montjuic Park in front of the Magic Fountain. The 42km course takes in Camp Nou (home base of the soccer team, FC Barcelona), Gaudi's magnificent La Pedrera and the UNESCO site, Hospital de Sant Pau.

Kevin writes
I came back late last night and straight back into work this morning, still aching in most places - it was quite a come down! I spent a few more days after the run taking in the sights; it was my first trip to Barcelona so I thought I'd best make the most of it.

I think I'll leave the running for a week or so now but I won't be stopping all together, I'll keep on top of my fitness then maybe look to do another when I have the appetite for it again? It was an amazing experience and I am really glad I did it, something I would definitely like to experience again.

GLAM GIRLS 2010

We are pleased to announce that the CDC Syndrome Support Group has been chosen as a supported charity by Alba Model Information who are launching a free to enter charity competition celebrating women of all ages, backgrounds and sizes.

Described as a GOK-like experience without having to get naked this competition is a fun uplifting and empowering event about women and glamour that aims to raise funds from the profits of sale of the glossy 'GLAM GIRLS 2010' calendar, bringing iconic film poses into the 21st Century, in full Hollywood Glitz style glamour.

This competition is going to be filmed for a TV Network as a documentary and not only is this a wonderful opportunity for fundraising but we will also be able to use the whole experience as a way of increasing awareness of the syndrome.

Other supported charities are Macmillan Cancer Support, Stroke Care, NAT, the International Otter Survival Fund, Marine Connection and Mr Testicles.com

For more information visit www.glamourgirloftheyear.org

Kevin in less back breaking times with his cousin Amy Elston

FOR SALE

We still have copies of Something Special left at the very special price of £11.00 (plus £0.80 per item for P&P). We have negotiated with the BBC to be able to acquire these DVDs at a much reduced cost which we are passing on this saving to families.

Something Special helps children with learning and language difficulties communicate. It is specially designed to be inclusive, teaching a signing system called Makaton, which will allow children of all abilities to join in the fun.

Contact the office for more information.

Perhaps you have knowledge of similar events being undertaken, could you obtain sponsorship for the group?

Family Stories

Sasha and Andy Arnoux write:

Hi - Our son, William who is now 3 3/4 years old has CDC. He was born on 23 July 2005 in Geraldton, WA, Australia. (Will's mum was from the UK and his dad is from South Australia). We are currently living on Cocos (Keeling) Islands in the middle of the Indian Ocean, but are shortly moving back to Geraldton. William has twin sisters, Molly and Evie who were born on 29 May 2007 (both free of CDC).

William has started walking over the last year; he still loses his balance alot but really loves chasing his sisters around the house and pushing their pink prams!! He is using Makaton to sign, especially 'biscuit' and has recently started to sign for 'hungry' which makes life alot easier. Just this week he has started to try and say the ‘c’ of ‘coconut’ and ‘car’ which is very exciting!

He really enjoys biting his sister Molly and pulling her hair but Evie will fight back so he doesn't try it on her so much. Health-wise he is good, especially in the warm climate where we live; he has a lazy eye and bangs his head with frustration (we think) and bangs his top front teeth on anything and everything.

Therapy-wise he has a therapy assistant visit daily which is provided by the local health service on the island. When we move back to the mainland this will only be once a week so he also has private OT and speech regularly.

Generally, he is a happy little fella!

If any other families have any advice on the head banging and behavioural issues, or would just like to be in touch, please email sashaarnoux@westnet.com.au

Jenny Sorbie writes:

We may already have mentioned that we have been incredibly lucky in the support we received from diagnosis onwards with Holly and that is probably the reason we haven't been in touch before now. We live in a suburb of Glasgow and are very fortunate to have the fantastic Yorkhill Children's Hospital on our doorstep. I was interested to see the warning in your recent newsletter about misinformation on the internet. Our Consultant warned us about this on the day he broke the news to us. He was absolutely fantastic! A shining example of true professionalism. One of the best pieces of advice we were given at the early stages by our Doctors was to treat Holly as exactly as we treated our other two girls and that is what we have done. The hospital put us in touch with the other family who had a little girl with Cri Du Chat. We see each other when we can and the other little girl is about to start attending the school where Holly goes to nursery.

Holly has come a long way. Recently she has made great progress with her makaton signing and it is lovely to see her begin to let us know what she wants. Her "little pointy finger" helps too. I would encourage any parent to find out about makaton ASAP after seeing recent results with Holly. Walking is still a long way off but at least Holly can get around a bit in her walking frame as well as shuffling at the speed of light on her bottom.

Holly attends the nursery at our local special needs school X4 mornings per week. She receives her speech and physiotherapy there so it cuts down some of the appointments. In addition to this Holly recently started attending our nursery at our local mainstream primary one afternoon per week. The staff have been fab in the efforts they have made to accommodate Holly one afternoon a week in the nursery. Both her sisters attend this school making this extra special. If anyone had said to us three years ago that the little frail baby we held would be able to attend a mainstream nursery even for an afternoon a week we would never have believed them! All those involved with Holly comment on her happy disposition and her determination despite all her difficulties.

William Arnoux at the beach

Holly Sorbie and her sister Hayley

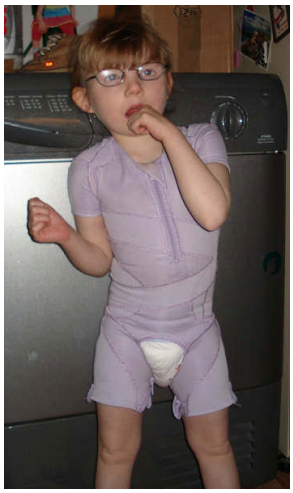
Focus on Lycra

Lisa Bowden on her daughter Evie

Evie is now four and a half years old, and was diagnosed with Cri Du Chat syndrome at seven months old. At around her second birthday we began to notice that her posture was poor; her spine looked crooked and her shoulders were slumped forwards. This gradually got worse until a paediatrician referred her to Great Ormond Street Spinal Clinic in April 2008.

Evie's scoliosis quickly progressed from 23' to 42' over the space of five months, and the consultant was just about ready to have her fitted with a hard body brace, to be worn 23 hours per day. I had read the literature, and spoken to other parents, and knew that infants and young children with fast developing curves tend not to respond well to such jackets, and generally end up requiring invasive and dangerous spinal surgery. As Evie cannot yet walk, I also worried that this jacket would limit her ability to crawl, disabling her further.

Luckily in June 2008 we attended the Cri Du Chat conference in Stratford Upon Avon, and Evie had an osteopathic consultation with Louise Hull. As well as treating Evie and finding a local cranial osteopath, Louise also urged us to investigate lycra pressure garments. Previously our local trust had stated they did not supply these garments, but on Louise' advice I again approached the trust who happened to be setting up a new lycra clinic. With a bit of campaigning I managed to get Evie into the first clinic. A gentleman from an orthotics company came and assessed Evie, looked at her x-rays, agreed she was appropriate for lycra, then measured her very carefully to get the right fit (these garments must be very tight to give the correct support)



Evie

The lycra garment arrived in December, and Evie has worn it for about 12 hours per day ever since. The difference is phenomenal. Within a couple of weeks her back and spine were looking straighter, her left ribs no longer stuck out, and her shoulders were much less slumped her head off of her chest, and stretch her arms up into the air to reach an interesting object, and her sitting posture is improved. Evie also seems much more confident when climbing, clambering and cruising, and has even started attempting to climb the stairs, something she would never do before.

Although Evie won't be x-rayed again until March, when I guess we will really know what effect the lycra has had, everybody who knows Evie, including her physio's, have commented on the improvement since December.

Evie's lycra garment has already had a very positive impact on her life, and will hopefully prevent further deformity, and the possibility of invasive and uncomfortable treatments. It also appears to be helping Evie to gain greater control and confidence in her body and how she moves. I believe lycra garments are a treatment option that could be beneficial to many children with Cri Du Chat, and I thank Louise Hull whole heartedly for giving me the confidence to pursue this with my local health trust.

A member writes:

I was at a regional meeting of the Angelman group on Saturday and have a couple of potentially useful things to pass on.

Firstly, a few parents were discussing the fact that their children were constantly chewing plastic items and one parent recommended a company called Kapitex. They are specialists in Laryngectomy, Tracheostomy, Dysphagia and Airway Management but this parent mentioned items called 'chewy tubes' that were designed to be chewed. The website lists them as being useful for improving chewing skills and have other items around difficulties with chewing and swallowing which I thought might be helpful for some individuals, particularly those with feeding tubes and swallowing problems?

Chewy Tubes are innovative oral motor devices designed to provide a resilient, non-food, chewable surface for practicing biting and chewing skills. Chewy Tubes have been designed to be used with the new Jaw Rehabilitation Program, a patented methodology offered by Speech Pathology Associates, LLC to develop jaw motion for biting and chewing skills. Chewy Tubes should always be used with supervision. Assessment of the jaw is recommended prior to biting on Chewy Tubes. Patients should follow the recommendations of their therapist or caregiver when using Chewy Tubes.

www.kapitex.com for more information.

Do you have experience of using lycra pressure garments or chewy tubes? If so please let us know as we would like to follow up these tips in the next edition.

Perhaps you have another product that you have found useful and would like to share it with our families? All tips and contributions are welcomed for the Winter 2009 edition which will be published in November.

Resources and Recommendations

We have been contacted by Mencap who are running a series of free wills and trust seminars in the Eastern region in May 2009. The wills and trusts team at Mencap advises over 3,000 people each year on how best to make a will and set up a trust and the 'Planning for the Future' seminar is delivered by a qualified local solicitor who provides advice on how to leave a legacy to a loved one with a learning difficulty.

Full details of these events and other regional sessions can be found by contacting Gina Collins (Wills & Trusts Team, Freepost WD3537, London, EC1B 1AA), call 020 7696 6925 or email willsandtrusts@mencap.org.uk

Mencap also have a number of helpful guides and booklets that give valuable information about writing wills, setting up trusts and leaving gifts and for more information on this please have a look at their website www.mencap.org.uk or contact their helpline 0808 808 1111.

A new DVD "*Challenging Behaviour – Supporting Change*" is now available from the Challenging Behaviour Foundation. *'Challenging Behaviour – Supporting Change' shows how a functional assessment may be used to understand challenging behaviour and identify ways of supporting behaviour change in individuals with severe learning disabilities.*

In this 2-disc DVD set meet Oliver, Dougie and Dominic and hear Mark Addison (Psychologist) explain the functional assessment process. Interviews with family carers highlight the range of causes of challenging behaviour, and how a functional assessment can help put in place appropriate behaviour management strategies for individuals with severe learning disabilities.

To view a clip of the 'Challenging Behaviour – Supporting Change' DVD visit the Challenging Behaviour Foundation website: www.challengingbehaviour.org.uk

"As soon as Dominic pulled somebody's hair it meant that he was either removed from the room or a person was removed from the room. So actually what Dominic was getting was an outcome for that hair pulling. He was indicating to us that he was uncomfortable, but he was having to pull hair to achieve that."

Produced primarily for family carers, this resource also provides a useful introduction and refresher for professionals. The families' stories demonstrate the importance of a functional assessment and provide insight into positive ways to support families.

Running time 70 minutes (approx). Organisations/professionals: £63.00; Registered charities: £33.00; Family carers: Free of charge, *donations welcome*

All prices include p&p within the UK. A resource order form can be downloaded from the Challenging Behaviour Foundation website: www.challengingbehaviour.org.uk

For further information contact the Challenging Behaviour Foundation:

Tel: 01634 838739 E-mail: info@thecbf.org.uk website: www.challengingbehaviour.org.uk

We are often asked about Genetic testing, the many reasons for families' enquiring varying as to individual concerns. It is difficult to be specific in reply but the professionals are consistent in recommending that all benefits and risks are fully considered before proceeding.

The following extract has been taken from the Eurogentest paper "What is a Genetic Test? Information for Patients and Families" page at http://www.eurogentest.org/web/info/public/unit6/patients.xhtml. It is available in several languages, please visit the website for the full transcript.

"A genetic test can help identify if there is a change in a particular gene or chromosome. It is usually a blood or tissue test. There are a number of reasons why a person might take a genetic test.

It will not always be necessary for the doctor or health professional to do a genetic test. They may be able to diagnose a genetic condition through a clinical examination, or tell you about your risk by looking at a detailed family history.

The decision about whether to take a genetic test can be a difficult one. Taking a genetic test is your choice. Therefore it is important that you have discussed and understood all the information that you have been given to help you make your own decision. It is also important that you have the opportunity to discuss with the doctor any questions or worries that you may have."

Cri Du Chat Syndrome Support Group AGM 2009

From the Chairman, Ray Clarke

As already mentioned we have had to change the date and format of our conference this year to a one day event held in Milton Keynes. Despite it only lasting for one day we are planning on having a full day with lots of information, research findings and clinics which will be suitable for all families. If you have never been before, perhaps because you were concerned about spending the whole weekend away, we do hope that you will take this opportunity to join us.

Our venue this year is in Milton Keynes. We have been holding our committee meetings there for the last year in a very central and convenient location with plenty of parking. The format of the day is quite informal and there is the opportunity to attend as many of the lectures/clinics as you wish.

We have not yet arranged for any activities for the children but, if there is enough demand, we may be able to arrange a visit to a nearby attraction. Please let us know if you wish to take part in this.

As we appreciate a one day event can be quite tiring we have arranged a special group rate at a nearby Holiday Inn. On the Saturday night we will also be having dinner in nearby restaurant (to be confirmed) but again this is completely optional.

I do hope you and your family are able to attend and if you do wish to come to this day please see enclosed booking form.

You are hereby given notice of and are invited to attend and participate in the Group's AGM which has been allocated time during this year's Conference on 18th July 2009.

As a registered charity it is essential that the Group is conducted in line with the constitution and the committee would welcome your involvement. Ideally you will wish to serve on the committee to ensure that your expectations are being met. If so please contact me beforehand so your details are ready for advise to the meeting.

The proposed agenda is as follows;

1. Chairman's welcome.
2. Apologies.
3. Minutes of the 2008 Annual General Meeting.
4. Administrators report.
5. Membership Secretary's report.
6. Treasurer's report and Accounts.
7. Election of Officers – Treasurer
8. Any other business. – End of year accounts, Change to the Constitution

Programme (subject to change)

Saturday 18th July
10.30am Registration and Coffee

11.00 am Welcome by Ray Clarke, Chairman
AGM, including re-election of officers

Start of "First time families counselling clinics"

11.45am
Professor Chris Oliver, Centre for Neurodevelopmental Disorders, University of Birmingham

12.30 am
Kevin Mann, Use and Benefits of Orthotics

1.00 - 2.00 Lunch

Start of Chris Oliver Clinics

2.00
Rebecca Lewis – Sensory Integration and Self Injurious behaviours

Start of Kevin Mann Clinics

2.45
Tea and Biscuits and social time

3.30
Conference feedback and close

7.00pm
Optional evening meal and stay over at Holiday Inn

Our Speakers

Rebecca Lewis, Senior Occupational Therapist
Rebecca Lewis is an Occupational Therapist specialising in children's and adolescent mental health. She trained at Canterbury Christ Church University and qualified in 2001. Rebecca is currently working as a primary mental health specialist with children and adolescents in primary mental health care setting. She is exploring sensory approaches within this setting and its application in education. Although Rebecca's work is focused on individuals with mental health issues her work is also applicable to individuals with special needs.

Kevin Mann, Senior Orthotists, The Bristol Royal Hospital for Children
Kevin Mann qualified in 1983 and is now a clinical specialist. During the last 12 years he has exclusively dealt with paediatric orthotics and is based 4 days a week at BRHC. His long-term interest is spinal orthotics and is part of the Scoliosis team based at BRHC, which is regarded as the regional centre for non-invasive treatment of Scoliosis. This team has been in existence since the early 1980s and over the years has seen 400+ children with various spinal problems.

Prof Chris Oliver,
Centre for Neurodevelopmental Disorders, University of Birmingham. Chris Oliver, BSc, MPhil, PhD, AFBPsS, CPsychol is Professor of Clinical Psychology at the University of Birmingham and trained as a clinical psychologist at Edinburgh University before completing a PhD on self-injurious behaviour in people with intellectual disability at the Institute of Psychiatry, London. He is currently researching behaviour disorders in people with autism spectrum disorder and severe intellectual disability, cognitive and behavioural phenotypes in genetic syndromes, neuropsychological and behavioural assessments for people with severe intellectual disability and Alzheimer's disease in adults with Down syndrome.

Dr Mohnish Suri is a Consultant in Clinical Genetics at the Nottingham Clinical Genetics Service. He provides a Cancer Genetics Service to families in Nottinghamshire and Southern Derbyshire and he has a special interest in the genetics of prostate cancer. Dr Suri is also the author of a book on Clinical Genetics and several peer-reviewed articles.

Focus on Drooling

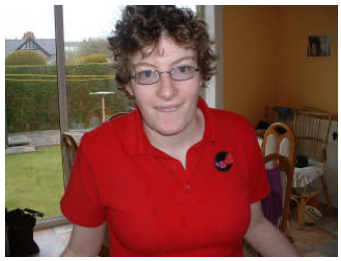
Phillis Simpson on her daughter Laura

My 19 year old daughter has Cri Du Chat Syndrome and has had persistent problems with drooling. Prior to her leaving school at Christmas we had a final consultation with the Speech & Language therapist who suggested Laura might benefit from a swallow reminder. This is a badge, approx 1inch in diameter which emits a beep at a preset interval, which can be controlled as required, to remind the wearer to swallow. It had been used successfully with people who had suffered from strokes and was being introduced to people with other impairments.

3 months on and it has been a great success. At the start everyone involved with Laura was advised to say 'swallow Laura' when they heard the beep and now it is practically an automatic response for her, no reminder required. She also had a small booklet printed by her SALT which had pictures and basic words to tell the story of someone using the swallow reminder which we read to her on a daily basis. Unfortunately adult services wouldn't fund the cost of this item and it had to be returned after 6 weeks but through Winslow (available online via www.winslow-cat.com) we ordered our own. They aren't cheap at £70+ but the fact that she can go out in public and people don't stare at her drooling is worth much more than £70!

I pass this information on in case there are other parents/carers in a similar situation, who are put off by the thought of an operation to re-route the salivary glands, who would welcome an alternative solution.

PS it is fairly robust - even survived a wash cycle in the washing machine!!



Laura

Comment:

For those of us who try and eschew surgical interventions, this is a wonderful training aid to help with the antisocial drooling that 'embarrasses us' carers/parents, notwithstanding the constant changing of clothes and laundry bills.

Like Pavlov's dogs we may find ourselves shout 'swallow' every time we hear a similar beep in other situations and get strange looks from those within earshot.

Some others have found translocation of the salivary duct; a surgical 'cure'. Whilst there are drugs that 'dry up' secretions which can also have other detrimental side effects.

Has anyone else any stories or methods for help with this, because the more methods we can pass on the better the whole group will benefit.

Caspar Hull
CDCSSG Clinical Advisory Group

Information supplied is based on the details acquired. The advice given is from the pooled experiences of the CDCSSG and is clinical advisory group. It does not take the form of full medical advice. Individual medical and care advice should always be sought from your primary care providers e.g. General Practioner (GP). If required the CDCSSG and its clinical advisory group are able to provide further information to practioners and carers.

The swallow reminder is a simply brooch style device that reminds the user to swallow at regular intervals with a beep. The swallow reminder is the result of an idea brought to Bath Institute of Medical Engineering by a local speech therapist who regularly uses them with her clients. The swallow Reminder is powered by an SR44 or equivalent watch style battery that will give 2 months continuous use. The volume and interval of the beeps are adjustable with controls on the back of the Swallow Reminder. The time interval can be adjusted between 15 seconds and 2 minutes. Also included is a backing sheet and instruction manual.

www.winslow-cat.com for more information and for other products

Disclaimer: The view, ideas and comments contained in this newsletter are those of the individual writers and do not necessarily represent the views of the Group

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