dhg
down's heart group

Newsletter
Spring 2014

Issue 49

INSIDE

Member Stories
Latest Information

Plus lots more!

Chair's Report

Welcome to the New Year edition of our newsletter.

I hope everyone enjoyed their Christmas and you are looking forward to 2014. By this time I suspect that I will be a grandmother again so life will be busy!

This year we will be holding our AGM in the Spring. Our normal format for this a small open meeting but we rarely have more than a few people attending, so I would like suggestions from the membership as to an area of the country that would be more accessible and would give us a greater presence of members. Please email your preferences to Penny or Sarah and we will look at finding a suitable venue.

21st March will see World Down Syndrome Day being celebrated with socks! Please wear as bright a pair as you can to celebrate and raise awareness and maybe even arrange a fundraising event.

My best wishes to everyone and I look forward to seeing a few more faces at the AGM, the details of which will be announced in our next newsletter.

Kind Regards

Chris Stringfellow

Contents

The New Congenital Heart Disease Review

On 12th June 2013 the Secretary of State announced acceptance of the advice of the Independent Reconfiguration Panel, that the Safe and Sustainable proposals could not go ahead as they stood. He went on to say that the process of ensuring that a world class congenital heart service was available to everyone in England should continue, albeit in a different way and tasked NHS England with moving things forward on the basis of the clear recommendations that had emerged.

NHS England have stated they want a comprehensive and inclusive debate to include a range of groups, with various views, national and local and they won't assume that the only experts are those people who lead their organisations. They will make a particular effort to reach out to minority groups and those who are not always sufficiently heard, including children and young people with CHD, to give individuals, as well as organisations, a voice. And that they will conduct the review with rigour, honesty and transparency.

They have advised that there is no agreed number of units, that they may at the end of the process have determined that they want a specific number, but that is not where they are starting from. Instead they are commissioning a national service against national standards for the whole population, which must be consistently high quality and it must be sustainable, which requires them to look at the latest data and best projections, to use the evidence and to make judgements and of course they are looking at adult and childrens services together, which is a big change from the last review.

John Holden, NHS Director of System Policy, is writing a fortnightly blog on the NHS England website that has updates on all meetings held and links to agendas, reports and presentations. This also provides an opportunity for anyone to register any comments they have directly on the website.

www.england.nhs.uk/category/publications/blogs/john-holden

They want to engage with as many stakeholders as possible: patients, parents, families, clinicians, local and national groups. This is your opportunity to have your views and experiences considered as part of the process that will shape the future of the service, so watch out for announcements about specific meetings etc. or use the contact details below to get in touch with them and voice your comments and concerns.

england.congenitalheart@nhs.net

0207 932 9128

New congenital heart disease review, NHS England, Southside,
105 Victoria Street, London SW1E 6QT

Annie's Removed Thymus

Annie and Ella

Annie was born in September 1993 and underwent heart surgery to repair a VSD at GOSH the following April after suffering pneumonia at Christmas. The surgery was a success and we no longer had to worry about her going blue or getting bad chest infections.

Roll on to January 2013, a visit to our new adult cardiologist in Norfolk & Norwich Hospital highlighted that at the time of surgery Annie's thymus gland was removed, a standard procedure with heart babies, should she be referred for immunity testing? We didn't have a clue what all this meant; we were urged to get this checked so agreed.

At the time of surgery Annie's thymus gland was removed

I researched as much as I could, I contacted the DSA and also Down's Heart Group; there was hardly any information available. I found on the internet that the thymus gland is the immunity gland, it produces T cells and T-lymphocytes. I also learned that if a thymus needed to be removed if someone is suffering from thymus cancer it is quite difficult to remove all of the thymus gland. This gave me hope that maybe some of the thymus remained in Annie and was still doing some good. Annie had a CT scan, tests for reflux and many blood tests. After a very long six months we went to Papworth to get the results of all these tests.

We were told that Annie is producing some T cells, she has some immunity albeit very low, iron was low and it was recommended she have a pneumonia immunisation.

We can now strive forward in keeping our daughter healthy

Halleluiah some pleasing answers! I wanted to know if they thought there was a small amount of thymus in there to which the reply was 'probably yes'. We can now strive forward in keeping our daughter healthy. She has always had a daily vitamin supplement and I think this has helped along the way. She needs to eat iron rich foods too. Gone are the yoghurts she chooses for breakfast and replaced with vitamin packed cereals.

I did contact GOSH to ask why we were never told about the procedure. I also asked where my daughter's thymus is (as there were body part scandals in the media with regard to pharmaceutical companies around the time of surgery). I asked why wasn't the thymus re-implanted back after surgery as it would have started working again? I posed the situation of 'there are many children who undergo heart surgery who know nothing about this procedure and their child's immunity'. GOSH's reply wasn't very fulfilling and didn't answer my questions. They did however recommend that my daughter undergo immunity testing !! Bit late for that as she is now approaching 20, perhaps 19 years ago would have been useful.

'There are many children who undergo heart surgery who know nothing about this procedure and their child's immunity'

When Annie was 7 I discussed the flu vaccination with 3 health professionals before accepting it, but it resulted or coincided with a seriously bad chest infection and shadows on her lungs. 7 years later, with me thinking she has grown now and her immunity has probably improved, we tried the vaccination again but it makes her very ill, with last winter being particularly bad, so this year we are going to not have the injection and test the waters with her health. We now buy a vitamin supplement which has folic acid and zinc in and will be looking at her diet to help keep her healthy and boost immunity.

I would like parents to be aware that their child's immunity could be affected if a thymectomy has been carried out

Whilst not wanting to cause panic, I would like parents to be aware that their child's immunity could be affected if a thymectomy has been carried out. A healthy diet is quite vital if so and you can then choose to help boost their immunity. I also know that many hospitals are not informing parents of this procedure and think this needs to change as we have the right to know and be able to look after our children's health positively.

If anyone has had a similar experience or knowledge surrounding our situation I would be very happy to hear from you.

Amanda Smy

DHG and Amanda would be really grateful for any feedback or information on this topic. Please send any replies to

sarah@dhg.org.uk

family portrait

Brittany

We have been members of Down's Heart Group since Brittany was born 24 years ago and have shared stories of her progress in previous newsletters. We've now reached the next chapter in Brittany's life and would like to share it with you, especially with parents who are anxious about the future.

Brittany outside her house

Brittany's AVSD was diagnosed at 8 weeks and she underwent open heart surgery at 11 weeks. She made a full recovery and despite bouts of ill health in her early years (many pneumonia and blood transfusions and an operation on her oesophagus), once she reached 7 or 8 her health problems seemed to be behind her.

Brittany attended Quince Tree Special School then completed 3 residential years at Derwen College in Oswestry. Britt had a blast at college but, there was very little for her to return to in our local area - no appropriate independent/supported accommodation, no suitable employment, very few eligible college courses - just a local authority building based day service or the private sector.

With the help of our excellent social worker, we found exceptional Personal Assistants (PAs) for Brittany, and worked out a schedule of some local authority day service, some independent day service and some activity with PAs. This served Brittany well for a couple of years but the independence skills she had gained at college were being eroded and we knew that we needed to support Brittany to move on to the next phase of her life.

In 2012, some friends also had young adults about leave Derwen College and were looking for independent/supported living accommodation. Another friend's son was already living independently but was looking for a change of accommodation. A suitable property became available, and one by one, the young people moved in, supported by the same PAs that Brittany has employed for the past 3 years.

Brittany has settled quickly and is very happy

Brittany has settled quickly and is very happy. Three live in a modern 4 bedroom house, which also accommodates sleep-in support, and there is a self-contained flat for the fourth who has been independent for several years. He can access the rest of the house and is loving the interaction, whilst maintaining his independence.

All the house mates have developed and continue to develop their independence skills, speech skills and interaction with each other, and we are delighted with their progress.

Brittany lives a very full life - Boxercise, Zumba, ballroom dancing, horse riding, swimming and trampolining. She enjoys going to rangers, SPIN youth club and Saturday Leisure Club. She still attends Briars Barn day service twice a week where she looks after chickens and horses, and she volunteers at 2 senior citizen luncheon clubs, preparing food and serving the lunches where she is a valued and popular member of staff.

Children with Down's Syndrome and CHD have the potential to live full, amazing lives.

I won't pretend it's been an easy process, dealing with the local authority has been challenging to say the least but we were all committed to the project and the best interests of our children.

Children with Down's Syndrome and CHD have the potential to live full, amazing lives.

Brittany and her house mates

Lynne Holden

Milo's Story

Milo in hospital

Milo had his complete AVSD and PDA repaired at 4 months old. He'd been very poorly up to this point and was transferred to Alder Hey on the urgent list in January following a particularly nasty bout of influenza B. We knew his surgery would be high risk due to his pulmonary hypertension oxygen dependency.

We were aware that the reason that they'd held off for so long in performing his surgery whilst he struggled with heart failure was because of the difficulties in making the new valves that are needed when an AVSD is complete. The surgeon informed us that the difference of an extra month can mean the difference between the valves being as thin as paper, clear and soft as butter to something much tougher that could hold the stitches in place.

Milo Continued

The consent forms and false starts meant the build-up to surgery was very intense and difficult. All I wanted to do was run away with my baby but I knew that decision would be fatal whereas to operate would give him a chance at life.

Milo struggled following his surgery with complication after complication. I was very impressed by the dedication and expertise of the staff. Milo was cooled down using a water filled cooling jacket which also increased his blood pressure and improved his urine output. By day 5 he was off the ventilator but was placed back on it the next day.

The following week was very difficult as Milo was very poorly, he had necrotising enterocolitis, suffered a massive pulmonary haemorrhage and by day 10 he was in severe heart failure due to his valves failing him. We were prepared for the worst.

We were touched that friends, family and strangers worldwide thought of and prayed for Milo and sent us love and strength. After a bedside vigil lasting many days, on day 16 Milo was taken back to theatre where the damage was identified as being caused by early stage endocarditis. Because replacement valves are not available for such a tiny baby, repair may not have been possible but to our massive relief the surgeons managed to repair Milo's valves using bovine pericardium.

Going home!

Making sure he ticked off another few complications along the way seemed to be Milo's style of recovery but we didn't mind. Unfortunately he had to have another chest drain which revealed a chylothorax - leakage of lymphatic fluid into the pleural cavity. Amazingly though, I continued to give Milo his precious breast milk during this time (treatment used to be to stop all fat in the diet to help the lymphatic system heal quicker).

After 6 long weeks at Alder Hey and many months being in hospital I finally took my little boy home where we worked on getting rid of his naso gastric tube that he'd had since he was 2 weeks old. He has continued to suffer from chest infections but not to the extent that he did before. He's been left with leaky valves but it is impossible to predict if or when he might need them replaced again in the future.

We keep a close eye on Milo as his journey has taught us how extra special he is and we love life with our precious boy!

Laura Dempsey

Easy Read Page

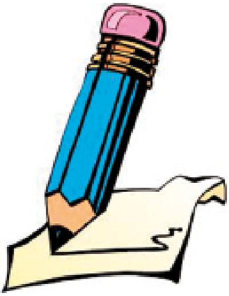
We hope you enjoyed Christmas and that you liked your presents

Did you stay up for New Year?

Or were you in bed asleep?

We would love you to tell us

What you like doing



You can write

Or send drawings and photos

Feedback Required

DOWN'S HEART GROUP NEWSLETTER

Spring '89

Welcome

Hooray!

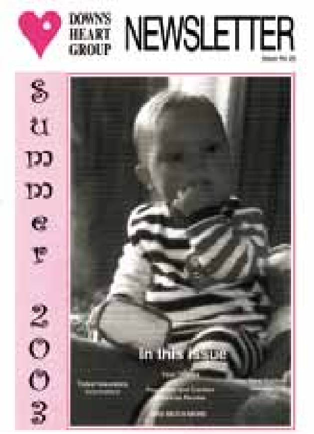
Down's Heart Group has experienced many changes over the years as it has adapted to meet the needs of our members, but to do this we rely on feedback from our members, fundraisers and supporters to enable us to understand what families and professionals want from us. We also use this information when we apply to grant funders in order to demonstrate the need and demand for our services and how they impact our users.

We don't just support families and produce information, we work with medical staff and provide representation on various groups and committees so that members specialised needs are not overlooked.

Every two years we hold a conference and family weekend. This is a big undertaking in time and money, so we'd like to understand why more members don't come. Perhaps it's too costly, the content doesn't interest you or maybe you didn't even realise it's happening – please let us know your thoughts so that we can consider them as we plan for 2015. Of course there's a lot more too.

We need your feedback, interaction and support to keep DHG running

It requires time and effort from our dedicated team of staff, trustees and volunteers to ensure that DHG continues to be available to families when they need us, but we cannot do it without YOUR INPUT!



DOWNS HEART GROUP NEWSLETTER

Summer 2003

In this issue

If you've got time to help us in some way, organise a fundraiser, tell your local hospital about us, ask your employer to support us financially – that would be great. But even if you haven't, on the next page there are some ways you can assist that won't take long or cost you money.

- Let us have your email address so we can pass on details of events that miss the newsletter. Consider reading the newsletter online to save on print and postage.

- Ask if you need some information that's not on our website, we'll try to find it for you and we'll know that it's something we need to look at providing in the future.

- Tell us about things you'd like in the newsletter, send us your stories and articles for inclusion. If you've held a fundraiser, send us a write-up with photos.


DOWNS HEART GROUP
NEWSLETTER
(Issue No 18)
Spring / Summer 1998

- Sign up to a website that donates to DHG when you shop online at no cost to you. If your company buys online, perhaps they could do it too?

- When you are looking for car and travel insurance, check out the links on our website, you might get a better deal and help DHG too.

- If your company makes charitable donations, please consider approaching them on our behalf. Or if your employer has a grant giving trust, let us know as many only accept applications supported by an employee.

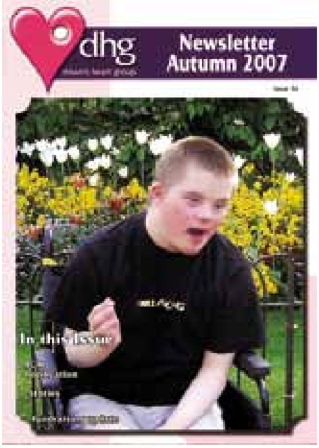
- If you've got some skills we may be able to use and you can spare a few hours a month, get in touch so we can discuss how you can help.

- If we've helped you in some way, even a long time ago, please let us know. It's not just a boost for the team, but a great way of showing funders that what we do really does matter and demonstrate why we need funds to continue our work.

Send us your feedback by email to
info@dhg.org.uk

via our Facebook page (Down's Heart Group),
tweet us @DownsHeartGroup or

write to us at Down's Heart Group, PO Box 4260,
Dunstable, LU6 2ZT


dhg
Newsletter
Autumn 2007
In this issue

Ellie's Charity Hair Cut

Kind DHG member, Ellie Myers, decided to help two charities by having her waist length hair cut into a short bob.

The hair cut was a sponsored event and Ellie raised a fabulous £800 for DHG. Ellie's hair has been sent to the Little Princess Trust, a children's cancer charity which supplies real hair wigs to children suffering from cancer or alopecia.

Ellie before

What a way to celebrate her 10th birthday.

Ellie raised £800

Well done Ellie!

Ellie after

Jennifer's Fundraising

Jennifer wrote a letter about her fund raising birthday

Dear Penny,
I want to support your charity.
I want to say *"thank you"* for my life!
You are very precious to me.
You are raising money always for people like me.
I want to say thank you.

I was born in Pakistan, had heart surgery as a baby and more recent heart monitoring because I collapse.

Jennifer and parents in Mexico

I chose to go to Mexico to celebrate my 21st Birthday and have a party on my return in the garden of our home. We raised £256.00.

Best wishes from Jennifer Durman and family.

New Forest Marathon

Alice Croot completed the New Forest Marathon in a time of 5:47:16 on 22nd September. This was her first marathon and she raised an amazing £581 for DHG.

Alice has agreed to join DHG as a fundraising officer on a voluntary basis. Initially she will be taking on some fundraising support, and as she gets the hang of things will be able to support anyone wishing to raise funds. She will be on hand to help with setting up fundraising pages on Virgin Money, providing sponsor forms and generally giving tips and ideas to increase funds raised and help things go as smoothly as possible.

Alice can be contacted on

fundraising@dhg.org.uk

Andy's Run To The Beat

Andy Lawson ran in the *"Run To The Beat"* half marathon on 8th September. The event took place in Greenwich and despite an old knee injury, Andy completed the race in exactly 2 hours.

Andy raised £208.75 for Down's Heart Group.

One Cent Call

One Cent Call's initiative allows anyone with a mobile phone to give small amounts regularly via their phone bill. A subscriber can contribute between 50p and £3.00 per month.

The One Cent Call app is available on both iOS and Android phones. Non-smart phone users can get the service too, by registering via the website. The scheme is available to contract and pay-as-you-go customers on Vodafone, T-Mobile, O2, 3 and Virgin Mobile.

One Cent Call will pass a minimum of 85% of all donations to Down's Heart Group. Please register your interest and tell your friends and family about it.

www.onecentcall.org

Future Events

World Down Syndrome Congress 2015

WDSC2015
12th WORLD DOWN SYNDROME CONGRESS
Let's make an inclusive tomorrow

Down Syndrome International has chosen Chennai, India as the venue for the 2015 World Down Syndrome Congress. It will run from 18th to 21st August 2015 and will involve professionals, support groups and families from around the world.

The theme will be *"The Five Truths"* of Down's Syndrome;

Social awareness and self determination Health
Education and employment Support systems
Rights and the law

To find out more, go to:

www.wdsc2015.com

Scotland to Host WDSC 2018

Down's Syndrome Scotland
helping people realise their potential

Down's Syndrome Scotland and partners have won the bid to hold the World Down Syndrome Congress 2018. It will be held at the Scottish Exhibition and Conference Centre, Glasgow in August 2018.

Pandora Summerfield, Chief Executive of Down's Syndrome Scotland said:

"We look forward to working with Down Syndrome International to ensure that World Down Syndrome Congress 2018 will be a memorable and informative event that benefits all who will attend."

Down's Syndrome Scotland is a Charitable Company Limited by Guarantee, registered in Scotland No. 356717, Scottish Charity No. SC011012

Andrew Macintyre, Sam Ross and Stuart Campbell helped DS Scotland's bid

www.ds-int.org/world-down-syndrome-congress.

World Down Syndrome Day

21st March is the 9th anniversary of World Down Syndrome Day, a day advocating for the rights, inclusion and wellbeing of people with Down's Syndrome. The day is recognised by the United Nations and observed all over the world. The date 21.3 symbolises the triplication of chromosome 21 which is unique to people with Down's Syndrome.

This year's theme *"Health and Wellbeing - Access and Equality for All"* will be highlighted at the WDSD conference, featuring speakers and self advocates from around the world.

The *"Lots of Socks"* initiative is running again on WDSD. People are encouraged to wear brightly coloured, mismatched socks or even 3 socks for 3 chromosomes. Socks matching the "Lots of socks" logo will be available to purchase online from DSi.

Finally, following the success of previous videos for WDSD, DSi will once again be producing a WDSD Global Video Event for 2014.

www.worlddownsyndromeday.org.

Dragon Boats

Children's Heart Federation is the umbrella group for the UK children's heart charities and DHG gives and gains support from CHF. Our members are invited to join in with all CHF events.

The spectacular Dragon Boat Challenge is on Sunday 18th May 2014. The event takes place at London's Surrey Docks and will be a fun day out for all the family. Attractions include cultural performances, puppet shows, children's entertainers, plenty of food and refreshments including a licenced bar.

CHF are looking for people to take part in the challenge, either as individuals or teams of 13, 12 rowers and a drummer to keep the rowers in time. All money raised will go to CHF to support children with heart problems and their families.

www.childrens-heart-fed.org.uk

British Gas Energy Trust

Grants are available for those in serious financial hardship from British Gas Energy Trust. The Trust can award grants to individuals and families to help clear gas, energy and other household debts, like rent arrears or council tax debts.

Grants can also be used to purchase essential items like washing machines and cookers, or to provide financial assistance like bankruptcy deposits or funeral expenses.

Applications can be done by writing to

Freepost RRZJ-XBSY-GYRG, British Gas Energy Trust,
PO Box 42, Peterborough, PE3 8XH

or online at

www.britishgasenergytrust.org.uk

Smile For Life

Smile For Life primarily funds grants for children from across the North East of England and Scottish Borders. Their vision is to be approachable and accessible to anyone where support will make a real difference to a child's life.

Smile For Life is a registered charity with an open door policy where any genuine case is considered for our support. They are passionate about grants reaching those with genuine needs.

Whether funding a specific piece of equipment, supporting special activities and events, or assisting a child to realise their dream, Smile For Life is committed to ensuring funds are utilised to benefit children and their families.

Write to: 27 Ashburton Road, Gosforth, Newcastle upon Tyne, NE3 4XN

info@smileforlife.org.uk
0191 284 4166

Energy Grants

If your young person is on Income Related Employment Support Allowance then your home can be assessed for energy efficiency.

Alternatively, if anybody else in the house receives Income Related ESA or you receive Child or Working Tax Credit with income less that £15860, Income Based Job Seekers, or Income Support you may qualify.

www.gov.uk/energy-grants-calculator

Health Unlocked

Down's Heart Group has joined a new, free online community called Health Unlocked. Users can safely and anonymously share any Down's Syndrome related experience with others, ask questions, and receive insights from people in similar situations.

HealthUnlocked

www.healthunlocked.com/dhg

Discreet Swim Wear

Some older boys have continence issues and families may be worried about going swimming in case of *"accidents"* in the pool.

Munchkins and Poppets is a company that supplies many items for younger children, including swim nappies. They also stock board shorts for boys up to 19 years that have a very discreet built in *"nappy"* to retain any leakage.

www.munchkinsandpoppets.co.uk

Pulse Oximetry Campaign

Children's Heart Federation is campaigning for the introduction of Pulse Oximetry screening for all newborn babies in the UK. The test measures the oxygen levels in the blood and is an effective test in detecting three quarters of congenital heart conditions. Only a third of children with congenital heart disease have their conditions detected before birth so it is essential this test is introduced for newborns. The test is non-invasive and inexpensive.

DSMIG (Down Syndrome Medical Interest Group) advises that all babies with Down's Syndrome have all relevant cardiac checks as soon as possible after diagnosis, so that appropriate and sometimes life saving treatment can be given.

A number of hospitals are already using Pulse Oximetry screening but CHF want all hospitals to be using it as part of the national screening programme for newborns.

The UK National Screening Committee are expected to make a decision on whether to advise the Government to implement Pulse Oximetry testing for all newborns early this year.

To support the campaign please write to your MP. A template letter and contact information is available at:

www.chfed.org.uk/campaigns/chf-pulse-oximetry-campaign/mp-letter/

Council For Disabled Children

The Council for Disabled Children (CDC) is a national body that brings together a diverse range of organisations that work with and for disabled children to support the development and implementation of policy and practice. CDC's work impacts on over 800,000 disabled children and their families.

CDC has recently worked with the Department for Education and the Department of Health to write two guides about the Special Educational Needs reforms. They consulted with children and young adults until the New Year and the guides and findings of the consultations are available through the website.

www.ncb.uk/cdc

Communication Aids

Cerebra
Positively Different

Provision of communication aids, iPads and computers for children should be through Health and Education Departments, usually following assessment by speech therapists or educational psychologists.

Cerebra is a charitable organisation that can provide grants for equipment including communication aids. Their aim is to help children and make lives as easy as possible and will fund many other things, including short breaks in their purpose built holiday home.

www.cerebra.org.uk

Travel Training

Learning independence skills is one of the most liberating feelings our youngsters can achieve. Being able to travel independently is a really useful skill, opening up a world of socialisation, work and leisure.

The Department Of Transport has worked alongside many professionals to put together a guide to help teach independent travel. It has many tips for professionals and parents and shows various schemes and how they work. The brochure is full of great photos which can be used with youngsters to help back up training or even just to fuel an interest and show that it can be achieved.

The training guidelines can be obtained from:

www.gov.uk/government/publications/travel-training-good-practice-guidance

One Size Does Not Fit All!

As a registered dispensing optician in practice, I have to ensure that people are happy and comfortable with their glasses. Children are not always capable of complaining about a poor fit. Instead they lose their spectacles or break them rather than wear them. This is even more the case when we talk about a child with Down's Syndrome.

Fit is a key factor for any child as their small faces are still developing and their facial characteristics are quite different to a mature adult face. As such they require specialist frames -specifically tailored to their needs. Poor fitting frames can mean the glasses slip and the child looks over and not through the lenses. That is an unacceptable situation as children are learning every second of the day and if the world is in poor focus that can only hamper progress.

Half of the 60,000 people with Down's Syndrome in the UK wear spectacles, but 100% have low quality of vision. What's more, people with Down's Syndrome are visual learners. Their vision is key to their everyday activity, making a well-fitting pair of spectacles essential. The petite nose, broader bridge and shorter distance from the ears to the front of the face mean that regular spectacles just do not fit.

A 1993 study at Cardiff University concluded that children with Down's Syndrome cannot be fitted with conventional frames. This is because the facial structure of children with Down's Syndrome do not change with age and rarely coincide with those of other children, either of similar age or younger. As such, a specially designed range makes the job of the dispenser much easier and actually provides the child with spectacles that fit their needs.

Maria Dellapina, a USA Certified Optician has a daughter, Erin, with Down's Syndrome and was faced with this issue when she required a spectacle correction. Maria became frustrated and decided to get a frame manufactured to better fit her little girl's unique features - hence Erin's World Frames came about.

To address the issues, Maria designed a range of frames with the following features:

- A lowered bridge - to make the frame sit higher and more centred
- Custom designed shorter temples lengths to ensure better fitting
- Extra wide frame front to ensure a comfortable fit
- Made of titanium & memory flex-creating a durable frame
- 180 degree spring out flat folding joints to ensure the frame takes life's little mistakes better!

The range of 14 models and 20 colours means that people with Down's Syndrome have a choice of colour, size and style - something we all take for granted when we choose spectacles.

My journey with Erin's World started when I came across a patient with an Erin's World frame. The mother was not happy as the glasses still slipped and out of curiosity I asked her who measured her daughter for the glasses. No-one she said -she took the size on her daughter's existing specs and ordered them from the web. The sizing was too big so this time we measured the little girl's face and ordered new spectacles. The new glasses fitted perfectly thus highlighting the need for proper fitting and assessment for fit and comfort.

When I took over UK distribution of Erin's World and considered how we raise awareness of the product we decided to highlight to both service users and professionals the need to see a qualified eye care professional who can properly measure and adjust your spectacles and provide warranty and back up as needed.

Finding a professional who can give you the time and expertise to provide a customised pair of spectacles for your child, can make a world of difference to you and your child's vision. On recent attendance to a Down's Syndrome event I realised an important fact when I was speaking to a parent. That is, sometimes a child will only want to be seen by their optician, not the stockist down the road. If this is the case, you could get your optician to get in touch instead.

To see who in your local area is a stockist and to find a professional to assist in acquiring Erin's World frames visit our website:

www.specs4us.com/doctorlocations

Jayshree Vasani FBDO
UK Distributor Erin's World Frames

Reproduced from the Autumn 2013 issue of 'Full Potential' the newsletter of DS Scotland.

The e-petition to ensure all children with Down's Syndrome get help to obtain correctly fitting frames is ongoing until August 2014. Please go to the website below and add your support.

www.simonberry.co.uk

Pop N Grow

Pop 'N' Grow
Here, When You Need Us

Pop 'N' Grow is a national charity supplying free, specially modified baby clothing to those in neonatal ITU, SCBU and paediatric ITU, and clothing to children up to the age of sixteen who require regular medical treatment. All clothing is designed to work around the leads, wires, tubes and machines that are so vital to treatment and recovery.

Clothes can be requested by emailing the team or visiting the Facebook page.

pop.n.grow@gmail.com

Reader's Letter

I am writing in response to an article about Lily Humphrey in the Spring newsletter - yes that's how behind I am with my reading pile!


dhg
Newsletter
Spring 2013

I found it amazing what Lily, like so many of our children, had come through. I was very interested to read that she was diagnosed with ITP as my son Matthew has this condition, too, with very low platelets and he bleeds a lot. I was stunned that Lily is on Warfarin, as well, as it causes bleeding and bruising - what a juggling act!

For many years I was not aware that Matthew had ITP and had thought that his bleeding was a side effect of his heart defect, but it isn't. His blood is thick and sticky yet it does not clot. They are, however, reluctant to give him steroids to thin his blood as it would make his risk of bleeding worse. He is also on Vitamin K.

Angela Weaver

Useful Links

Further information about Down's Syndrome is available from

Down's Syndrome Association
Langdon Down Centre, 2a Langdon Park
Teddington TW11 9PS

0845 230 0372
www.downs-syndrome.org.uk

Down Syndrome Ireland,
Citylink Business Park,
Old Naas Road, Dublin 12

00 3531 426 6500
www.downsyndrome.ie

Down Syndrome Education International
6 Underley Business Centre
Kirkby Lonsdale, Cumbria LA6 2DY

0300 330 0750
www.dseinternational.org

Down's Syndrome Scotland
158 - 160 Balgreen Road
Edinburgh EH11 3AU

0131 313 4225
www.dsscotland.org.uk

Further information about heart related issues is available from

British Heart Foundation
180 Hampstead Road
London NW1 7AW

0300 330 3311
www.bhf.org.uk

The Somerville Foundation
Saracen's House, 25 St Margaret's Green
Ipswich IP4 2BN

0800 854 759
www.thesf,org,uk

Children's Heart Federation
Level One, 2-4 Great Eastern Street
London EC2A 3NW

0808 808 5000
www.childrens-heart-fed.org.uk

PHA UK
Unit 2, Concept Court
Manvers, Rotherham S63 5BD

01709 761450
www.phassociation.uk.com

dhg
down's heart group
charity 1011413

Tel: 0844 288 4800
Email: info@dhg.org.uk
Write: PO Box 4260
Dunstable, LU6 2ZT

Are DSMIG cardiac guidelines being followed effectively in the UK?

"Health and Wellbeing - Access and Equality for All"
is the theme for World Down Syndrome Day, giving DHG the opportunity to highlight that NOT ALL babies born in the UK are being screened for cardiac issues as recommended by the Down Syndrome Medical Interest Group (DSMIG).

In 2013, we ran a pilot survey to investigate whether the recommendations made by DSMIG are being used effectively. The results from this pilot demonstrated that these guidelines are NOT being met. DHG considers it is vital that ALL babies undergo the appropriate screening, not only to quickly identify those babies who may require corrective surgery, but also to reassure the families of those who do not.

To increase the data available to support our campaign for WDSD we need your help. If your child was born after 2007, whether they have a cardiac defect or not and even if you already completed the pilot survey, please complete the brief survey detailing the tests your child underwent. No identifying information is required other than year of birth and county so that any geographical trends can be identified.

Your input could help new babies with heart defects get referred sooner
THANK YOU

http://tinyurl.com/khk2nmc