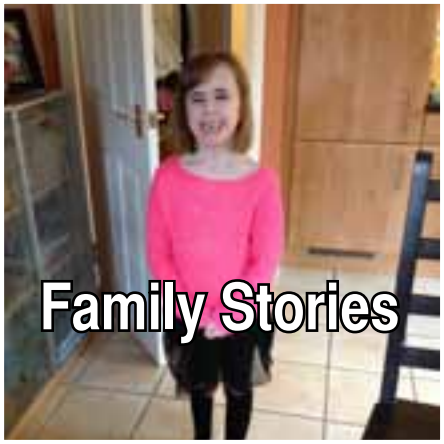
Issue 45 Autumn Winter 2013/14 Magazine

SOFT UK

Support Organisation for Trisomy 13/18

£3.50
Free to SOFT UK Members










The 2013 SOFT UK Family Day took place at the Village Hotel in Solihull on Saturday 29th June.

Turn to page 18 for the full report.





Charity Administrator
Kirsty Bassett
administrator@soft.org.uk

Enquiries
Online **www.soft.org.uk**
Email **enquiries@soft.org.uk**
Telephone **0121 351 3122**

Membership
Register online at our website
www.soft.org.uk/Membership

Registered Address
SOFT UK
48 Froggatts Ride
Walmley
Sutton Coldfield
West Midlands
B76 2TQ

Newsletter
All submissions can be sent to
newsletter@soft.org.uk

Online
www.soft.org.uk
www.facebook.com/SOFTUK

SOFT UK
Founded in 1991 by Jenny Robbins and Christine Rose. SOFT UK provides information and support to families affected by Trisomy 13 (Patau's syndrome) and Trisomy 18 (Edwards' syndrome), and related disorders.

SOFT UK is a registered charity
No. 1002918 (England and Wales)
No. SC043341 (Scotland)

Editor's Letter
Autumn Winter 2013/14

Welcome to our magazine.

I hope that everyone got a chance to enjoy a little bit of the sun over the Summer.

In this issue we have many personal stories from SOFT UK members. Thank you so much to the families who chose to share their experiences - the Watts family, the Cockburns, the Babatundes, the Fitzgeralds and the Edwards family. Thanks also to Corinne Hills, a SOFT member whose daughter Maple was born with T18 at 13 weeks. Corinne writes about her current pregnancy on her blog **motherhoodjourneys.com**. With Corinne's permission we have reproduced a blog post about her current pregnancy that may resonate with many of you.

We've also been able to print excerpts from Sands leaflet *About the other children,* which deals with issues around sibling grief - it perfectly complements SOFT's own information. If you have found information from another charity to be particularly useful, please do let us know as we may be able to include it in a future newsletter.

Thank you to everyone who had a chance to fill in the newsletter survey form. It was helpful to hear about what you liked and disliked about the last issue of the SOFT members' magazine. And for anyone who was concerned - we're certainly not thinking of stopping the newsletter. I hope you'll find that this issue has a good variety of news and information for you as a member, no matter what your own experiences. On page 10 I've published a summary of the feedback so far. If you would like to contact with any further suggestions I'd be delighted to hear from you.

Finally special thanks to Linda Powell and Stephen Scott for their help with this issue of the newsletter. Very much appreciated!

Best wishes,
Kirsty

Kirsty Bassett
Administrator@soft.org.uk

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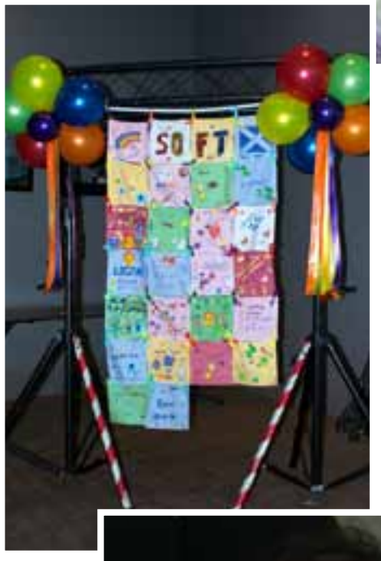


The SOFT UK Magazine is free to all SOFT UK members. To become a member and make sure that you don't miss out on the next issue sign up online

www.soft.org.uk/Membership

From the Chair

Dear All,

You will be reading this as the summer comes to an end and we begin to look toward autumnal days and the evenings drawing in. How quickly this year is going!

A lot has happened in SOFT during 2013. You will see later in the Newsletter that we have had some changes in Trustees, with John Capper and David Delargy coming on board and Demi Powell and Jim Fergus standing down. Our thanks go to both Jim and Demi for the support they have given to SOFT. In particular, I would like to give my personal thanks to Demi, who did an amazing amount of work for SOFT and, thankfully will continue in a volunteer role, to support us.

We have had two great conference / family days over the summer – the English Conference in June and the Northern Ireland day in August. Both are covered later, with plenty of pics so you can see what went on. The Scottish day is taking place in September, so more of that in subsequent Newsletter editions. These family days are so important to enable families to meet each other, share their experiences and gain support in an informal setting. We continue to seek your views on how we can ensure they are meeting YOUR needs, so do drop us an email if you have any ideas for the future. Better still, get involved and help us organise them, it is great fun and you'd be really welcome.

The other major development which will come to fruition this year is the volunteer training. As you know SOFT support is provided entirely by parents who have been through the experience of a child diagnosed with Trisomy. This bespoke volunteer training programme, developed in collaboration between SOFT and Erica Brown, Vice President of Acorns Children's Hospice, and accredited by Coventry University, will run for the first time in November. We recognise that it is so important to support those who come forward to volunteer for SOFT, so they in turn are equipped to support the families who come to us.

I hope you enjoy this Newsletter and find it informative and inspiring, in equal measure! Thank you to everyone who has contributed, without you there would be no Newsletter, and thank you to those who have worked so hard to pull it together.

Jan Fowler
Chair SOFT UK

SOFT UK Volunteer Training Day
This will be taking place on Saturday 16th November at the Village Hotel Cheadle (SK8 1HW). It will be a long day of learning and sharing and should be a great chance for volunteers to meet others. It will also be an opportunity for volunteers to learn more about the new SOFT training course, developed by Coventry University, Erica Brown and SOFT.

If you are interested in becoming a support volunteer please contact Laura **prenatalchoices@soft.org.uk**.

SOFT UK Trustee Training
This is scheduled to take place on 19th October to coincide with the next Trustees' meeting. The Training will be run by Myles Kunzli of the National Council for Voluntary Organisations (NCVO). This training day will give new Trustees an insight into the responsibilities of Trusteeship, and provide long-standing Trustees with the opportunity to undertake a review of current practice and share experience.

Trustees in, Trustees out
First a huge "thank you" to Demi Powell who stepped down as a Trustee in July. Demi has made an enormously valuable contribution to SOFT over the years and will continue to help out as a volunteer.

Thanks also to Jim Fergus who stepped down as Treasurer and Trustee in June. Jim has done a huge amount of work for SOFT, helping to build a secure financial base for the charity. We are very grateful for all of Jim's hard work. Following Jim's resignation, Laura Petrie has been appointed as honorary Treasurer. Laura will be supported by a part-time book keeper, Cynthia Crawshaw.

Welcome to John Capper and David Delargy who both join the Board as Trustees. Many of you will already know John and his lovely family - Louise, Charlotte, Harry and Jack. The Capper family lost Jack to Edwards' syndrome at 31 days old. You may also have had the pleasure of meeting David at the Family Days in Scotland and Northern Ireland or at this year's UK conference. Read more about them in the next issue of the newsletter.

Sadie's Star

Drew and Samara Collins' first-born child Sadie was born will full Trisomy 18. When Samara was 4 months pregnant with her son Patrick, Sadie died at the age of 8 and a half months.

Whilst grieving and anticipating Pat's birth, Samara decided to write a book for Pat about his sister. She did this so that when he began to ask questions, Samara and her husband Drew would have something tangible to help him.

Samara worked with Erica Brown, Rachel Walker, Amy Townsend and the design team at Ultimate Creative Communications to really bring the book to life. *Sadie's Star* reflect's Samara's belief that Sadie is in Heaven and remains very real her loved ones.

SOFT UK and other charities will be benefitting from the sale of this book. To buy a signed copy for £4.99 + P&P email **Samara.Collins@btinternet.com**.

You can read *Sadie's Star* online at **http://sadiecollins.yolasite.com/**

Dr John Carey
Dr John C. Carey is the 2013 Rare Champion of Hope Medical Caregiver. Dr Carey is a geneticist and paediatrician who co-founded SOFT USA and serves as its medical adviser.

According to Nicole Boice, President & Founder of Global Genes, Dr Carey was awarded this for his "commitment to excellence, compassion, and innovation for those families affected by Trisomy 18, 13 and related disorders."

www.globalgenes.org
https://www.facebook.com/globalgenesproject/info

Do you live in Scotland? Are you caring for a child with a disability? For Scotland's Disabled Children (fSDC) is a coalition of almost fifty disability and children's organisations. fSDC is working on a project with Children in Scotland, the national network organisation for the children's sector in Scotland, The project is funded by the Scottish Government with the objective of improving both the level of participation of, and the extent of influence on policy on, parents of children with disabilities.

The Project has been asked to gather specific evidence regarding the impact of welfare reform on families of disabled children in Scotland.

If you would like to share your views please complete the survey at **http://www.surveymonkey.com/s/fsdcwr**

SOFT UK Update

Together for Short Lives

SOFT UK is a member of Together for Short Lives, the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. It supports families, professionals and services

As the authoritative voice for children's palliative care Together for Short Lives works to influence policy across the UK. Helping children and families get the best possible care and support.

As a member, SOFT UK is kept up to date by the regular newsletter *Policy Matters*. Here are two policy issues that featured in the August 2013 issue.

Proposed new standards for independent health providers in Northern Ireland

The Department for Health, Social Services and Public Safety is consulting on minimum care standards for independent healthcare establishments. To view the document online visit **bit.ly/1c8t9Pq**.

Three of the 67 standards relate specifically to children's palliative care and include:
Assessing and Caring for Children and Young People in Hospices, which calls for the special needs of children to be addressed;
Qualifications and Training for Staff Caring for Children in Hospices, which specifies that children and young people should be cared for by a multi-professional team with expertise and training in providing palliative care for children;
and Hospice Environment for Care of Children and Young People, which calls for children's special needs to be addressed by the facilities provided.

Together for Short Lives will respond to the consultation in partnership with the sector in Northern Ireland.

Independent Liverpool Care Pathway review

In July 2013 the Government published the report of the independent Neuberger review of the Liverpool Care Pathway (LCP) (**bit.ly/15wJTL8**).

Care Minister Norman Lamb responded to the report by committing to a full system-wide response in the Autumn. The Government also stated that the Care Quality Commission will be undertaking thematic work on end of life care.

The Scottish Government has issued a separate response (**bit.ly/UimPxe**). The Wales End of Life Care Board, chaired by Professor the Baroness Finlay of Llandaff, has also published a response (**bit.ly/13KuWXE**).

In response, Together for Short Lives says that it
- supports the review's recognition that it is important to listed and learn from the experiences of patients and their families.
- will seek to be recognised as a stakeholder in developing the full system-wide
- will engage with Government to ensure that children's palliative care is reflected in the proposed end of life assessments and personalised care plans.

Policy work updates

You can follow James Cooper, Together for Short Lives' Public Affairs and Policy Officer, on Twitter **www.twitter.com/james_tfsl**

or visit **http://www.togetherforshortlives.org.uk/about/our_policy_work**.

Would you like to take part in research on stress? Cerbera and Swansea Metropolitan University are carrying out research on stress in grandparents and siblings of children with neuro-developmental conditions and disorders. The purpose of this study is to explore your day to day life with your grandchild/sibling. It will include reading statements and then rating how stressful you find these scenarios: for example explaining your grandchild/sibling's condition to others. If you decide that you would be happy to be interviewed, the study also aims to explore the ways in which you may have coped. The results of this study will be used to create an advice guide for other grandparents and siblings, and inform us on effective support mechanisms.

Participation in the study is entirely voluntary and you are free to withdraw at any time without giving a reason.
If you are interested in taking part in the interviews or completing the questionnaire please contact **vicki.hardy@smu.ac.uk**.
For more information about Cerbera visit **www.cerebra.org.uk/**.

Genetic Alliance UK

SOFT UK is a member of Genetic Alliance UK, a national alliance of 150 charities that support children, families and individuals affected by genetic disorders.

The Shire rare disease report

In April 2013 Shire Human Genetic Therapies produced a report *Rare Disease Impact Report: Insights from patients and the medical community.* The survey that informed this report included responses from families affected by Trisomy 18.

The report highlights the issues faced by patients affected by rare diseases and by the families who care for them. It includes comparisons of the experiences of health professionals and patients in both the UK and the USA.

Alastair Kent, Director, Genetic Alliance UK states that "[t]his new report from Shire highlights and confirms the issues faced by patients affected by rare diseases. The inclusion and comparison of clinicians', payors' and patients' experiences demonstrate the importance of working together, as a community, to tackle the issues faced by patients. It also highlights the importance of working with the international rare disease community in order to share best practices and information for all those affected."

The Shire report can be downloaded as a pdf from **http://www.geneticalliance.org.uk/latest-news.htm**

Working with Rare Disease UK in Wales

The current focus of Genetic Alliance UK in Wales includes campaigning with Rare Disease UK (RDUK) for a UK strategy for equitable access to effective services.

In 2012 Rare Disease UK produced a ground-breaking report *'Experiences of Rare Diseases: Patients and Families in Wales'*. The report highlights significant issues with access to services, information and support for the 175,000 people affected by rare diseases in Wales. It includes suggestions on ways to improve the experiences of patients and families.

These suggestions include:

- more effective use of resources so patients can access specialised care (within or outside Wales)
- improvements in diagnosis
- better coordination of care
- improved access to allied health professionals (eg physiotherapists) and social care professionals
- increased levels of funding
- improvements to the transition between paediatric and adult care and a reduction in the disparity between the two.
- an end to the postcode lottery of care - patients should receive appropriate care and management of their condition regardless of where they live.

The RDUK report can be downloaded as a pdf from **www.raredisease.org.uk/living-with-a-rare-disease.htm**

Does an emphasis on "rare diseases" help or hinder a campaign for improved services for patients with T13 or T18 and their families?

Both reports featured today talk of "rare disease". The UK Department of Health ran a rare diseases consultation from February to May 2012 with the definition that a rare disease is one that affects fewer than 5 in every 10,000 of the population.

If we look at birth rates for England and Wales (2009) we can see that births of babies with Patau's or Edwards' make up a tiny proportion of the 706,248 babies born that year - at 18 and 37 respectively. Thus they fit into the definition of rare diseases.

However when speaking of Trisomy 18, Dr John Carey (Medical Founder of SOFT USA) explains that while it is a "rare" condition it is relatively common. He estimates the overall frequency of a family experiencing the pregnancy and/or birth of a baby with trisomy 18 as 1 in 2,500 in the USA (from a 2008 Center for Disease Control report). This figure includes both live born babies and those who were lost during pregnancy. For this reason, Dr Carey prefers the phrase "relatively common chromosome condition"for Trisomy 18.

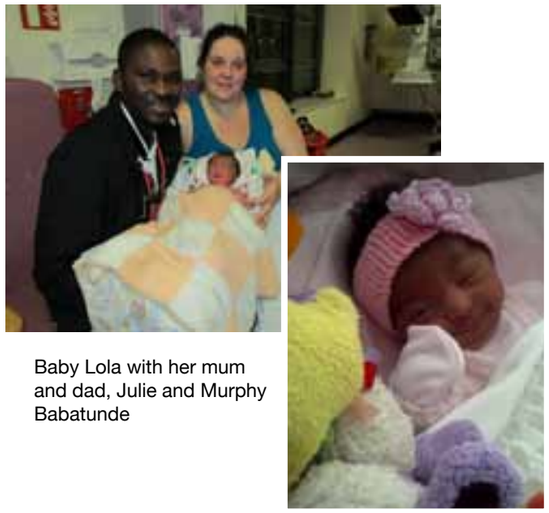
Although SOFT UK is not a campaigning organisation, we do aim to build awareness among clinicians and other professionals. So we are acutely aware of the importance in choosing the most appropriate language when talking of these conditions. What do you think? Are we getting it right?

For more information see:
http://soft.org.uk/Trisomy13-18/Research/2008-09-Medical-Data

http://www.ons.gov.uk/ons/rel/vsob1/birth-cohort-tables--england-and-wales/2009/stb-bct-2009.html

http://trisomy.org/what-does-rare-disorder-mean/

Damilola



Baby Lola with her mum and dad, Julie and Murphy Babatunde

My pregnancy went quite well, except I was very accident prone, but all scans and bloods were all normal and everything was fine. 20 weeks came and went - dopplers were done constantly and nothing was unusual at all. Limbs fine, organs all fine and everything seemed normal.

Then I moved and slipped one day but I went to work. Then a couple of days later I went for a check up and they decided to give me a quick scan to reassure me. They noticed (at 34 weeks) a large umbilical cyst, which were rare and had never been seen at this hospital. Also they could only see 1 kidney which was strange as they said they had seen 2 normal ones previously. They consulted St Michaels hospital in Bristol and they said to deliver at 38 weeks to prevent anything rupturing.

On the 22nd October 2012 my angel was born at 11.36am. We were told that she would go to Bristol that evening and I would follow the next day. They spent around 10 minutes resuscitating her then took her to the neonatal unit. The following day in Bristol she had a blood test for genetics as they said there appeared to be more problems and wondered if they were related in some way. It turned out she did have 2 kidneys, one being in the pelvic area, which annoyed me as the previous scan at 20 weeks showed 2 normal.

Lola was having apnoea attacks and then needed an operation for the cord cyst. She sailed through the operation, remained strong, breathing fine, and only needed oxygen on a couple of occasions. An MRI scan showed that she had a hole in the heart and a cyst in the brain.

A few days later I was told she had Edwards' syndrome. To me that meant nothing; I had never heard of it and was under the impression that it meant she would be physically disabled. I felt I could deal with this eventually, but then when I was told there was no life expectancy I just shut down. I said "I don't need to know any more, I know that she is a miracle, she shouldn't be here, nor have made it past birth". The next few days were crucial.

After around 5 days she had a severe lapse in breathing and we had to decide about CPR. I said she should not have it as I would not want her suffering. I felt cruel, but you have to be in that position to know though.

When I heard other mothers saying their children had to have an operation on this or the other, I thought "You know what, I would rather that, to just have to worry about an operation in order for survival". For us this was not the case; there is no cure and there would be an end at some point.

There were so many tests, prodding and poking, even tests done for meningitis in the back; she tolerated it all and never winced at all. She become so strong and used to it. Then they said to me the only reason they had been holding her at Bristol was for surgery, and now that had been done she could leave and return with us to Exeter.

We returned to the neonatal unit for more observational purposes, and for us as her parents to learn to adjust and get our heads around what would happen when we took her home. They advised us to take her off monitors for her oxygen and heart as when we got home there would be none of that, and we had to try to adjust to what we had to face.

Lola was nearly 3 weeks old when we were allowed to take her home, which initially was scary but it was lovely having her in her surroundings with us. We have up to now had some blips - apnoea and poor feeding - but she was holding down her feeds given by a NG tube. She required 24 hour care but we wouldn't have changed anything for the world.

She is our angel and she fought from day 1. In fact prior to that, in her journey via pregnancy, birth and operations, and even now. We want to thank all those for their support so far.

Julie Babatunde
December 2012

Sadly at 3 months on January 8th, Damilola passed away peacefully, having caught the RSV virus.

See page 21 for details of "Lola's Little Gifts", raising funds for SOFT UK in memory of Damilola.

http://lolaslittlegifts.webs.com/

http://damilola.babatunde.muchloved.com/

Thank you so much to everyone who had a chance to fill in the newsletter survey. We had a very useful range of feedback - from new and long-standing members alike.

- Most respondents found the newsletter to be useful, reading it for between 30 and 60 minutes.
- They particularly enjoyed reading about babies who had survived (and thrived).
- Most respondents hoped that we would continue to produce the newsletter.
- They would be content to see minor changes to ensure that SOFT funds are spent wisely. These were changes to the paper quality, reduction in size to A5 (thus saving on postage), and the inclusion of paid-for advertising.

The Board of Trustees will consider this feedback and make improvements accordingly. So you may see some changes over the next few issues.

We also had some very specific issues raised about the Spring/Summer issue including:

A Week in the Life should be about a family caring for their child rather than about a member of the SOFT team.

The SOFT newsletter serves a number of purposes. Many affected families are apprehensive about coming along to SOFT family events and accessing support. We hope that by putting faces to names SOFT as a charity will become less intimidating and more welcoming to new families.

We also know that members appreciate hearing about other families with similar experiences. This latest issue includes stories from families with a range of different experiences. If you are interested in writing a family story for the next issue please do get in touch - we'd love to hear from you. The cutoff date for submissions for the Spring/Summer 2014 issue is 20 January 2014. Family Stories usually have a word count of 500 to 1000 words with photos. Email **Newsletter@soft.org.uk**.

SOFT UK has received many donations recently - why are we considering stopping the newsletter?

It is true that SOFT has many generous supporters and we are in a healthy financial position. However as a charity we cannot be complacent. Indeed it is the legal responsibility of the Board of Trustees that donations be spent in a responsible way.

It was useful for us to canvass opinion about the support that members and other affected families actually need so we don't spend money unnecessarily.

Freeing up funds from the newsletter - less expensive printing, for example - would give us more to spend on other forms of support. Rest assured the newsletter will not be disappearing any time soon!

Remember that the newsletter is dependent on SOFT families for its content. We're always delighted to hear from people willing to write for it. Email Kirsty at **Newsletter@soft.org.uk** *if you would like to help out.*

Would you like to volunteer for SOFT?

We already have a fantastic team of volunteers - the family support team of Laura, Neil, Mandy and Annamarie; Liz and Stephanie who keep the generous donations coming in; John, Louise and Fliss who organise the annual Family Day; Stephen who keeps our website and database up to date; Emily (of whom you can read more later); Linda who fixes all the mistakes in the newsletter; and all the Trustees. But we could always do with more help!

Family support: We are looking for suitable volunteers to provide email and telephone support to families affected by T13/18, and related conditions. If you have personal experience, and can spare some time on a regular basis then we would love to hear from you. All support volunteers are given full bereavement training before commencing the post.

Trustees: Trusteeship gives you an opportunity to actively shape the future of SOFT UK. Experience in the charitable sector would be helpful but is not essential.

Admin: We always need more help with the administration of the charity - making sure that our donors, supporters and members are well looked after.

Please note: All SOFT volunteers are unpaid, although authorised out-of-pocket expenses will be met. Also, in order to ensure that all applicants are fully ready for the volunteer role, we ask that you wait 12 months following a bereavement before you apply.

If you are interested in any of the above, please email us, including a land line phone number, and someone will call you for a chat - **enquiries@soft.org.uk**.

Chloe

Chloe's story and amazing life started on the 23rd April 2011. During my pregnancy we were told we were having a healthy baby and after an emergency section, that is where our world fell apart. When Chloe was born the doctors rushed her off and resuscitated her and when we saw her in incubator, they broke the news, suspecting that she was T18. To make matter worse the doctors actually said – that if he had know that she had T18 he would have never resuscitated her !!!! She spent 4 weeks on low flow oxygen and tube feeding in NPCIU, which was a nightmare in itself, trying to cope with the hand we were dealt plus the machines bleeping and not knowing what was going on. When the blood results came back we were given the option to take her home or move her to a children's ward. No way – my baby was coming home with me, no matter what horror stories we were told at the hospital and what we found on the internet regarding T18 babies. We got all the oxygen we required and learnt to change the feeding tube and she was set to come home at only 1.2 kgs.

For the first 6 months we were walking on egg shells, so nervous of every breath or not that she took. It was a dreadful time for everyone and we were all exhausted but I think the worst feeling was never knowing if the moment would be the last. At 7 months or so, we changed our outlook and started living each day to the max. So we started to push the boundaries and started to treat her like a normal baby rather than a sick one. At 8 or 9 months we started taking the oxygen off to bath her and there was no negative reaction and therefore I thought my baby does not need this oxygen and I removed it gradually during the day, without telling the doctors, we knew what our baby needed. Chloe was a fighter !!!

The next step was the nasal gastric feeding tube. During the previous months with oxygen we tried the feeding bottle and slowly but surely she started to drink from it. That was another sign –she has a sucking reflex, (which we were told she was not going to have). The nasal gastric tube came out!!!! We knew how to replace it, so we just gave her the chance and she took it!!!! Chloe is now 2 yrs and 4 months and has not had any sort of medical intervention. She has been off the oxygen for 1 yr 6 months and she drinks from the bottle (125ml) at a time and eats 2-3 jars puree foods a day. She has also started physiotherapy – which took us 2 yrs to get for her!

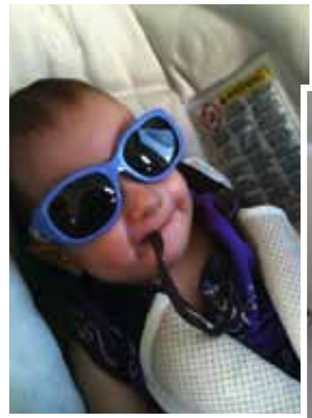
Chloe has developed such a fun and happy character. She is a little tease too moving away from you when you go to kiss her. She is a lot cleverer than what the doctors expected and/or told us. They said she would be close to a vegetative state, but that is so far from the truth. She identifies all the family members and has different and special smiles for everyone. She reaches and grabs the toys she is in the mood to play with and walks aided. She loves playing with her toys and books and loves a swim. She watches DVDs and Baby TV and smiles and makes noises at the characters she likes. When Chloe sees a bottle she opens her mouth immediately to drink and she knows how to alternate between eating her food and drinking from a cup and/or bottle. She is now picking up her bottle and drinking by herself, when she feels like it !!!

She is living proof that miracles can happen, even if only for a short time, but they happen and she has made us so much stronger.

Chloe is my little Mediterranean Gem and according to the latest statistics she is the only one alive here in Malta.

Have strength and faith mummies and daddies – my moto with Chloe has always been – She is a fighter and as long as she is fighting I will never give up or doubt her strength. She is here to stay!!!!

Paula Fitzgerald
August 2013



Cerys

Cerys Watts 19.01.12 – 15.05.12

We were ecstatic when we found out that Caroline was pregnant. We had been trying unsuccessfully for several years. Our baby was very much wanted, and we were over the moon.

The pregnancy initially seemed to go smoothly. Aside from being very tired at first, Caroline suffered no morning sickness and little discomfort. However, at 28 weeks pregnant, Caroline was diagnosed with gestational diabetes and told that she was at risk of having a very large baby. The doctors decided that she should be induced early (between 38-39 weeks), and she was sent for two additional scans to check on the baby's size.

At 31 weeks pregnant, the first of these scans took place and everything went well. The second scan took place at 34 weeks. Despite being a few weeks away from giving birth, and having been told 3 weeks earlier that everything was OK, the midwives suddenly detected a heart defect. We were shocked and deeply upset.

An appointment with a Cardiologist was scheduled, and it was confirmed that as well as having a hole in the heart, the baby also had some other very serious heart abnormalities. We were told that the baby would probably need open heart surgery almost as soon as it was born, and that it would probably spend 2-3 weeks in intensive care at the Children's Hospital in Bristol. Needless to say we were devastated. However, we were repeatedly told that although it was major surgery, the baby would probably make a full recovery and live a full and normal life afterwards.

At 1.41 am on Thursday 19th January we were told that we had a daughter and the most beautiful little girl in the world was placed in our arms. We named her Cerys Megan. After a few minutes with her, and as we had expected, Cerys was placed in an incubator and taken down to the Neo Natal Intensive Care Ward (NICU).

Thursday was a wonderful day. Although our daughter was in NICU, she seemed to be doing OK, and we were both completely smitten with her. A feeling of complete contentment struck us that day that we had never experienced before.

As Thursday turned to Friday, things seemed to be taking a strange turn. A few comments had been made here and there about some of Cerys' physical attributes, and the word 'genetics' kept cropping into conversations. A geneticist came to Caroline's bedside in the maternity ward. She explained that tests were being run on Cerys and explained a little about chromosomal abnormalities. She never said 'Edwards' Syndrome', but when she left real fear began to set in. Something was wrong, and we were terrified.

The following day, Saturday, our world was blown apart. The lead consultant in NICU along with some of his colleagues called us into a room, and told us the devastating news that Cerys had Edwards' Syndrome, and that her life expectancy was no more than a few months. As we both struggled to grasp what exactly was going on, we just couldn't comprehend how the world could be so cruel. There lying in the room opposite was the most beautiful little girl we had ever seen. How on earth could this be happening?

On the Monday it was agreed to transfer Cerys to the Cardiac ward of the Bristol Children's Hospital. In some respects things improved for us. Cerys was no longer in an incubator, we could pick her up whenever we wanted and visiting hours were not restricted. However, the week we spent in the Children's Hospital was also one of the most stressful weeks of our lives as the medical team refused to operate on her heart. At no point did anyone explain why they wouldn't operate. They told us that Cerys would have no quality of life. We will always dispute this fact. Cerys was full of personality and character. We came to understand her limitations as we got to know her, but she enjoyed life and to the very end she fought hard to stay.

After one week of immense highs and lows at the Children's Hospital, we finally were able to take Cerys home. As we had no idea about when we might lose Cerys, we decided she was never to be left on her own. Sean would stay up through the night with her and sleep in the day, and Caroline would do the opposite. Cerys was fitted with a naso gastric feeding tube before we left the hospital. We had heard that Edwards' babies are prone to feeding difficulties, so we had one fitted and we were shown how to use it. It was very straightforward and initially Cerys took to it well.

Those first few weeks at home were non-stop. We had Midwives & Health Visitors calling in, as well as meetings with the Community Paediatrician, our GP and the Community Nurses. On top of that family and friends would visit. Our feet barely touched the ground at times.

Cerys was fitted with an apnoea monitor, we were supplied with Morphine for her, should we need it, and we were given a suction machine in case she choked. The signs of deterioration were explained to us and there were a lot of very heavy conversations about death.

We made our first visit to Children's Hospice South West in Wraxall in February. Initially we didn't want to be there. The thought that our only child was in hospice care broke our hearts, and we thought that it would be a sad place. How wrong we were. The Hospice was amazing with Cerys, and with us, and we came to rely on them and their support heavily.

We also took a trip home to Mid Wales to visit Caroline's parents. Cerys sparkled when she was there and everyone who met her there was bewitched by her charms.

After a second trip to the hospice, it was noticed that Cerys had a strong suck, and step by step we managed to get her taking her feeds entirely from the bottle. We therefore made the decision to remove her feeding tube. The feeding tube had started to become difficult for us anyway, as Cerys kept pulling it out. We had had several trips to A & E to get it put back in, such that Sean had been taught how to insert a new feeding tube himself.

Cerys' feeding went very well for about 3-4 weeks. Caroline was able to take her out to the local shopping centre for the first time, and she went to 'Music with Mummy' classes. People would stare at Cerys as she was small (at 8 weeks old she was only just over 5 lbs). Although Cerys seemed normal to us, the way other people looked at her brought home how small she was. Gradually her feeding started to deteriorate. We had started her on expressed milk, but eventually moved her to Infatrini, a high calorie formula milk. When this seemed to make no difference, with help from the hospice we weaned her a little. She loved all the sweet stuff, but still when it came to her milk she would scream and reject it. Once we even put Crusha in her milk to see if that might help. It didn't.

Her weight gain was slight, although with each week that passed, despite the feeding difficulties we were having, she seemed to be putting a few ounces on.
On one trip to the hospice we managed to get Cerys in their pool. It was wonderful, and is a moment neither of us will forget. For a few stolen moments we were just a family having a swim, and she looked so cute in her swimming nappy!!

With Cerys still not feeding well, we eventually tried putting the feeding tube back in. However, Cerys had other ideas! For some reason she no longer seemed able to tolerate it. She would scream continuously until we eventually took it out again. We never found out why it hurt her so much.

We had our first real scare with Cerys in April. We were on a scheduled visit to the hospice, and she became quite ill whilst we were there. On one morning, we were even woken to be told that we should say our goodbyes. Once again Cerys had other ideas!. She may have been small, but she had real strength. She battled hard over 4 days, and to the amazement of everyone we got to take our amazing girl home again.

Her illness had hit her hard though. By this point, we were syringe feeding her, and every drop of milk we placed in her mouth made her scream. We received no help from the community dieticians, we just had to get on with things.

In early May we took her to the SOFT UK conference. For the first time, it felt as if we had found a place where we belonged. Cerys shone that day again (she knew how to turn the charm on!!). It struck us how amazing all these children and their families were. How dare anyone say there was no quality of life to be had.

Out of the blue about 2 weeks later Cerys struggled to sleep one night. Initially Caroline wasn't too concerned, but as night turned into day, and she still hadn't settled, Caroline decided to call the GP. We were told that she thought Cerys might be going into heart failure, so we decided to take her to the only place we knew where people had truly cared about her, the hospice. They continued to help us find solutions for her feeding, but the following night Cerys failed to settle again, and it started to become clear that things were looking bleak. It had been Caroline's wish that Cerys got to try chocolate whilst she was alive. That day she tasted it and our reward was a smile. Cerys had never smiled throughout her life, but she smiled that day, as if to say thank you. Our daughter was amazing, and we will always be so very proud of her, and how hard she fought to stay with us. At 9.15 pm on Tuesday 15th May, Cerys our beautiful girl took her final breath and passed away in the arms of her Mummy and Daddy.

Caroline and Sean Watts

Visit **www.ceryswatts.co.uk** *to read Sean and Caroline's very personal account of their experiences.*

Sands
Stillbirth & neonatal death charity

Supporting anyone affected by the death of a baby and promoting research to reduce the loss of babies' lives

Sands is a national charity established in 1981 by bereaved parents to offer support to anyone affected by the death of a baby.

Sands produces an information pack for parents, available free of charge from **www.uk-sands.org**.

With Sands' permission we are able to feature excerpts from their publication *About the other children*.

Children of different ages perceive death in different ways. The quality and degree of their understanding may be quite unrelated to age. Depending on the child's past experience, each child will have an individual way of coping.

It is best if parents can be open and honest with their children. When children sense that something is being hidden or kept back, the 'something' can be exaggerated in their minds and become far worse than it actually is.

Children do not need very complicated explanations; simple ideas like - "The baby died because she didn't grow properly. Mummy and Daddy are very sad, but will feel less sad as time goes on", often will do. Allow them to ask questions when they feel ready.

Some parents feel unable to mention their baby at all on their return from the hospital. They go in to have the baby and come home empty handed, and, because of their emotional distress don't feel able to explain why. Do try and talk to your children about your baby that died.

Where possible include the children. There is no reason why they should not see and even hold their dead brother or sister, or attend the funeral, and visit the grave or garden of remembrance.

After their baby dies, some parents feel that the world is unsafe and that something terrible may happen to their other children; this may lead to them becoming over-protective. It is also common to react by resenting their living children's demands when they feel the need to give time to thinking about their dead baby.

Most children, however young they may be, feel guilty after the baby dies, and blame themselves, thinking that jealous, angry thoughts or actions could have killed the baby. It is important that parents bring the matter up by saying something like, "it was nobody's fault" and indicating that guilt is normal, and they too have it even through they were not responsible.

Children will grieve in their own way and at their own pace. It is healthier if they can express their grief quite soon after the baby dies. Often a talk about what happened, allowing the child to use toys to play out the events, can make all concerned feel more in control.

Children, like adults, may use jokes or giggling to hide or avoid an overwhelming anxiety or sadness on hearing of their baby brother's or sister's death. This can be bewildering to parents, who are not expecting such a reaction. Children can upset adults by asking pregnant women or couples with small babies when their baby is going to die. You can help by having a discussion that enables them to see that not all babies die.

If your child is at school it is important that the school knows of the tragedy that has occurred. Very often your child's concentration at school will be affected.

Some children have found themselves being jeered at in the playground because of the baby's death. This adds to their distress, but it's something they do not always feel able to discuss at home because it may increase your distress. You can help them to understand that it is often fear that something as frightening may happen to them that leads children to behave in that way.

The next pregnancy can be an anxious time for your child. Their experience will have taught them that in their family, pregnancy can end in death. It is not uncommon for children to start bedwetting and soiling again. Parents cannot promise that everything will be all right; they can explain that not all babies die, and they too are anxious about the outcome.

Often parents are surprised by their child's reaction when the next baby is born. Many become over responsible towards the baby, and may be extremely anxious if the baby becomes ill. Often these reactions develop because children feel that their feelings of jealousy are so destructive that they may have killed the last baby. By talking about it you can help them to learn to tolerate their jealousy by understanding that these are normal feelings.

Erica Brown has worked with SOFT to produce information on siblings. ***www.soft.org.uk/Bereavement***

You can also download a copy of the SOFT sibling support booklet (Trisomy 13/18 for Siblings) from the Support section of our website.

contact a family
for families with disabled children

Over the past year we have seen a number of changes to the social security system - a consequence of the introduction of the Welfare Reform Act 2012.

These changes apply to England, Scotland and Wales. Subject to approval by the Northern Ireland Assembly and the Northern Ireland Executive these changes will also apply to people living in Northern Ireland.

In **April 2013** council tax benefits were scrapped and replaced with local schemes. In England each local authority has introduced its own scheme. In Scotland and Wales the new schemes mirror the previous council benefit tax rules.

April 2013 also saw the introduction of the 'bedroom tax', which sees council tenants and housing association tenants facing a housing benefit cut if they are deemed to be living in a home with too many bedrooms for the number of occupants. Although most children are expected to share a bedroom, families will not be penalised if a child cannot share with a sibling because of a disability (government guidance issued on 12 March 2013).

Community care grants and crisis loans were scrapped in **April 2013**. Instead of applying through Jobcentre Plus, you must now apply to your local council for help with one-off costs. New schemes have been introduced in Scotland and Wales.

In **June 2013** personal independence payments (PIP) replaced disability living allowance (DLA) for those aged 16 or above. PIP will have two types of payment - a mobility component and a daily living component. The eligibility rules will be different to those for the old DLA.

Summer 2013 saw the introduction of the 'benefit cap' for out of work families. The new cap for out of work families will be £500 per week. However this cap will not apply to families if any member receives disability living allowance. It will not apply if you work sufficient hours to be eligible for working tax credit (regardless of whether this is actually paid or not). Further details, including the list of exemptions, are available at **http://www.dwp.gov.uk/docs/benefit-cap-factsheet.pdf**.

In **October 2013** all new claimants of working age who apply for means tested benefits and tax credits will receive the new universal credit. Claimants in receipt of existing means tested benefits will be moved onto the new credit at some point between 2014 and 2017. More detailed information about all of these welfare reforms is available in *Benefits are changing - a guide for families with disabled children*, available free from the Contact a Family helpline on **0808 808 3555** or by email at **helpline@cafamily.org.uk**.

Contact a Family parents' advisers can provide a full benefits check over the Mon - Fri, 9.30 am to 5 pm. They can also provide confidential debt advice. They can advise on specific questions but cannot help you complete an application form over the phone.

Helpline: 0845 458 1124

fledglings
helping children to spread their wings

Fledglings is a national charity that finds and sells products that can improve the lives of disabled children and their families.

They specialise in finding unusual items, including many specially designed for disabled children with specific needs. The products are simple solutions to complex problems, and if they don't stock a product they can point you in the direction of someone who does.

Products include:

- Raincovers for wheelchair users giving top to toe rain protection
- Sleepsuits which make it difficult for children to take their clothes off
- Backpacks with reins which are useful for children who don't like holding hands
- Age-appropriate bibs and neckerchiefs for children of all ages
- Absorbent pants
- Waterproof sheet and mattress protectors
- Cutlery and crockery which help disabled children eat and drink independently
- Elastic laces which turn lace up shoes into slip ons

Fledglings is a charity (reg no. 1112618) and they price their products to try to make them affordable to anyone who needs them. Many of them are subsidised, or sold at cost price, and any surplus that Fledglings makes is ploughed back into the charity, helping them to help more disabled children and their families.

www.fledglings.org.uk
email: enquiries@fledglings.org.uk,
telephone: 0845-458-1124

Ellie

When Demi asked me if I would like to write an update on Ellie, this prompted me to dig out the article I wrote just “a year or so ago”. Erm, actually that was written 3 and a half years ago – yikes!

So it’s safe to say that a few things have happened in those three and a bit years … but before I go into the news, here’s a little summary of Ellie’s history ...

Ellie was born in May 2003 and weighed 4lbs 5oz. She was whisked into Special Care Baby Unit as she had issues regarding blood sugar and she had very poor sucking capabilities; therefore feeding was a difficulty. I had my suspicions in those early days that she had something “different” about her from “normal” babies – looking at her small, almond-shaped eyes was enough to make me think she had Down’s Syndrome (the only syndrome I was aware existed then). A nurse assured me that the palmar crease testing had been done and she did not have Down’s Syndrome.

Fast-track Ellie’s story on to when she was 15 months old and we sat in the paediatrician’s office while he told us that she has mosaic Trisomy 18. We were provided with fairly scant information in the form of an excerpt from a medical journal which informed us, among a few other details, that mosaic T18s should expect to have an approximately normal length of life. We didn’t even think we would ever have to consider that our daughter wouldn’t have a normal life expectancy.

Ellie’s now 10. She attends two schools on a split placement each week (and has since Primary 1). One school is mainstream and the other is for children with special needs. She loves both schools. She is very popular with the children at both and it is lovely to witness how accepting the children in the mainstream school are of her – they don’t see her as having disabilities – they just see her as “our Ellie”. Ellie has mobility issues (of which, more in a bit) and the classroom is located on the first floor. Ellie and her best friend, Hannah, are first to leave that floor at the end of the school day and I have seen how patient the children behind them are as Ellie slowly makes her way down the stairs! I know most of them are desperate to run down the stairs and fling themselves out of the doors but they understand that Ellie just needs that little bit more time. A lesson for some of them which may last for longer than primary school? We can live in hope…

Ellie’s reading ability has progressed to and she reads at about age 5 level. She doesn’t like sums very much (neither do I!) but she works hard to persevere with all the challenges she’s presented with at school.

The split placement education will continue until she reaches the end of Primary 7 (so in two years’ time) and she will have secondary schooling solely at the special needs school.

As I mentioned earlier, Ellie also has some physical disabilities. She has an inwards-rotated left hip which means that she has an intoed gait on her left foot.

She also has a leg length difference of 2cm – the left leg is longer. This discrepancy is managed by using orthotics in her right shoes. However, she was recently reviewed by her orthopaedic doctor who informed us of an operation whereby the growth on the left leg can be halted to allow the right leg to catch up. We are considering this and are off to Sick Kids Hospital in Edinburgh at the beginning of July to have an x-ray done to kick off the process of deciding if/when this will be right for Ellie.

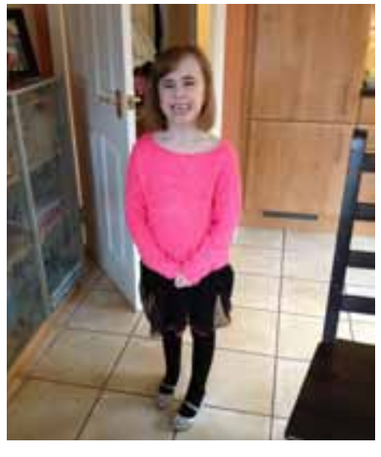
Ellie’s leg length difference has meant that she has developed a 9 degree curvature of her spine. She is reviewed annually by the scoliosis surgeon in Edinburgh and he has stated the importance of having her legs measured regularly since any further discrepancy could mean the development of scoliosis. To monitor the discrepancy we use the services of our local hospital’s orthotics department on a twice-yearly basis to have her legs measured.

She’s got hearing aids in both ears and has had for the last 15 months. She has mild to moderate hearing issues and it’s very obvious when she doesn’t have her aids in – we have to raise our voices and we have to repeat stuff, so these aids have made a massive difference to her both in home and at school. The improvement in her speech alone has made us aware of how important the hearing aids are. She is now constructing sentences and using comprehension in her conversations. It wasn’t that long ago all we ever heard were one word answers from her.

We recently had her assessed for ADD (Attention Deficit Disorder) and while that assessment has come back as not ADD, the team assessing her has agreed that her lack of focus and attention is an issue caused by her learning disability. We have been referred to the Learning Disability Team and await an initial appointment with them. They will also assist us with the many fears and phobias Ellie exhibits – cats, dogs, birds, fingernails, etc.

So yes, that was a quick 3+ years! Wonder what’s next for Ellie?!

Carolyn Cockburn
June 2013



Better prognosis in newborns with trisomy 13 who received intensive treatments

The neonatal intensive care unit (NICU) at the Dokkyo Medical University Hospital (Tochigi, Japan) provides intensive treatments including resuscitation of intratracheal intubation, respiratory support, and some types of surgery for trisomy 13 and 18, if informed consent is obtained from the family after counselling.

A previous study (Kosho et al, 2006) had looked at the prognosis of intensive treatments in 24 Japanese patients with trisomy 18 at the Dokkyo NICU. The 2006 report argued that an improved survival period suggested a better prognosis for patients with trisomy 18 who had been treated at NICU. The data provide helpful guidelines for clinicians by offering the best information on treatment options for families of patients with trisomy 18. However, there remained a lack of precise data concerning the clinical details and prognosis regarding intensive treatments of patient with trisomy 13.

In this new piece of research on trisomy 13, the researchers retrospectively analysed the detailed clinical data of 16 patients with trisomy 13 in order to determine the survival period of patients who received intensive treatment. The data studied relates to patients admitted to NICU at the Dokkyo Medical University Hospital from 1989 to 2010.

Study
Better Prognosis in Newborns with Trisomy 13 Who Received Intensive Treatments: A Retrospective Study of 16 Patients
Keiko Tsukada, George Imataka, Hiroshi Suzumura, and Osamu Arisaka

Cell Biochem Biophys. 2012 July; 63(3): 191–198
Published online 2012 April 10. doi: 10.1007/s12013-012-9355-0

Abstract
Intensive treatment for newborns with trisomy 13 is controversial because of their lethal prognosis. We report the better life prognosis of patients with trisomy 13 who received intensive treatment. At our hospital, we provided an intensive management to such patients including resuscitation and surgical procedures as required. Herein, we present the results of a retrospective study (1989–2010) of 16 trisomy 13 cases who received an intensive treatment. None was diagnosed to have trisomy 13 before birth; 9 were delivered by C-section and oxygen was administered to all patients during postpartum resuscitation. Mechanical ventilation was used in 9 patients after tracheal intubation and tracheotomy was performed in 2 patients when withdrawing of extubation was difficult. Regarding prognosis, 9 patients died, 3 were referred to another hospital, and 4 were discharged from the hospital. Four and 7 patients died within 7 and 30 days after birth, respectively. Nine patients survived for >1 month, 7 for >180 days, and 5 for >3 years. Median survival for 16 patients was 733 days. The patients who received intensive treatments survived longer compared to the previous data. This study provides useful information concerning genetic counselling, especially from an ethical point of view, before providing intensive management to newborns with trisomy 13.

The full article is available to download as a pdf via a link from **http://www.ncbi.nlm.nih.gov/pmc**.

Or you can follow the link from the SOFT USA website **http://trisomy.org/literature-for-professionals-and-families/**

The 2013 SOFT Family Day took place at the Village Hotel, Solihull on a warm Saturday 29th June. It was lovely to see Elisabeth and Philip who were remembering the 20th anniversary of their daughter Anna, and Gail and Mark Breen coming back to the conference, amongst regular families and friends. There was also much cooing over a collection of gorgeous toddlers and babies.

Our thanks go to Nora Shannon and Joan Morris, two of SOFT's professional advisers, who both gave really informative talks and spent time talking with individual families. Joan's talk in particular raised a lot of discussion about future potential research which would be really interesting and valuable to the families of children affected by Trisomy.

It was a really family orientated day, with plenty of time for informal discussions and sharing individual stories. John Capper kicked things off, introducing the day and Chris Rose kept everything running, introducing speakers and the family discussions. Barbara Rosenthal, from CRUSE and a valued friend of SOFT, attended and supported the family discussions. In the afternoon we had the SOFT Annual General Meeting. Not a formal meeting but an opportunity to share with SOFT members the work the charity had done in the past year, its financial position and future plans. It is important that SOFT members are able to see how their charity is working and are able to influence its future. There was some good discussion on future plans, particularly how SOFT can work with healthcare professionals to ensure future families get the information and support they need. Trustees Chris, Jan and Laura spoke to the slides.

A special mention and thanks must go to Fliss Reading who arranged both a beautiful remembrance room, with soft lighting, remembrance stars, beautiful poems and tribute book. Fliss also organised the balloon release later in the day, with colourful balloons. All of the balloons were completely biodegradable and had small envelopes (also biodegradable) attached containing flower seeds. This meant you could write a message to your loved one on the envelope and when the balloon and envelope landed and degraded, the seeds would plant themselves in the ground. Lovely to think of small patches of poppies and other flowers springing up where the balloons land. What made Fliss's efforts even more amazing is the fact that a few weeks before the conference she not only gave birth to a new baby, but she also moved house a week later and still managed to do all the work for SOFT. She also taught us all a new technique, which she called shooshing ! This involved a nifty way of removing the balloon ribbon immediately before releasing the balloon into the sky, so the ribbons, which were not biodegradable, were not left attached, thus averting possible harm to wildlife.

All of the photographs of the day were taken by Stephen Scott, our photographer extraordinaire. Stephen was snapping photographs all day, so as you can see, we have a great set of pictures from the day.

The children enjoyed a crèche run by Tinies and made some lovely photograph frames. Finally a smaller group had dinner together and enjoyed the entertainment of Andy's Magic Show.

On Saturday 10th August eight families gathered at a lovely hotel in Armagh.

Invited by Annamarie Cartmill to come and share an afternoon; 29 adults and children came to support each other, play with the children, eat a wonderful buffet, share their stories, listen and remember that they are not the only family who have had a baby with Trisomy.

During the afternoon they had the chance to look through the Tribute Book and also add photographs and messages in remembrance of their babies. It was great to see two new families, who having found the SOFT UK website, noted the date and came to learn more from the experience of others. Indeed, as it happens, their stories were very similar.

Trustees Chris Rose and David Delargy flew from England and Scotland respectively to join them. The afternoon was for sharing rather than listening to speakers, but Chris Rose took a few minutes to show the literature SOFT UK provides. She explained that if they could give a booklet (or two or three.....) into a medical professional's hand (rather than post it) then it is likely that it will be used to help other families. Every family took booklets and shared who they would give them to. It was very gratifying to know that two families had been given SOFT UK booklets already from the Royal Belfast Hospital for sick Children and the Daisy Hill Hospital, Newry.

Two parents at the get together expressed a wish to train as volunteers for SOFT UK.

The afternoon ended with a beautiful balloon launch carrying labels with messages for our babies. The sun shone and the sky was blue and everyone could see the trail of balloons over a very long distance.

A big thank you goes to Annamarie for inviting everyone and organising such a friendly and supportive afternoon for SOFT UK in Northern Ireland.

The 2013 SOFT UK Scottish Family Day took place in The Glynhill Hotel and Leisure Club on Sat 7th September. Photos and news from the event will be featured in the next issue of the newsletter. If you can't wait that long, visit the SOFT website for a preview: **www.soft.org.uk/Support/SOFT-Family-Events**.

ST MARY'S PLAYGROUP

St. Mary's playgroup had to close three years ago after over 40 years' service to the local children. Karen and Jim Kirwan's children all went there including their daughter Emma who often used to visit.

The Kirwans made many friends over the years from the playgroup who have always been supportive of SOFT (even during the 21 years since Emma passed away). When the playgroup closed, the manager Deb Reid decided to split what was left of the funds. As Karen was involved with the committee Deb kindly donated the £2,000 to SOFT. Thank you Deb.

NEWBOLD SCHOOL

New SOFT Trustee John Capper recently attended a presentation at Newbold Community School. Jessica Widdowson and friends raised £1500 for SOFT. A huge amount, accepted with many thanks from us all!

SHOP WITH AMAZON

amazon.co.uk

If you use the link on our website SOFT will now receive a percentage of all purchases made on Amazon. Just follow the link from http://soft.org.uk/Fundraising/Easy-Online-Fundraising -

ROBERT TURNBULL

Robert was a Viking in the Jarl Squad January 2013 for Up-Helly-Aa, which is a traditional Viking festival in Shetland held on the last Tuesday in January each year. The highlight is a torch-lit procession and the burning of a replica Viking long ship or galley. This is followed by a night of entertainment.

Robert was dedicated to his role as a Viking and grew his hair for 2 years and his beard for a year. Once he had fulfilled his role as a Viking he then gathered sponsorship for a sponsored head and beard shave. Robert raised £150 for SOFT UK and £150 for the Comfort Funds at Montfield where Robert works as a Social Care Worker. Robert supported SOFT UK in memory of his niece Kate-Lynne van Tonder who was diagnosed with mosaic T18 when she was a week old in December 2009 and sadly passed away at 14 weeks.

You can meet Kate-Lynne's mum Emily on page 24.

SOFT UK is a small charity funded almost entirely by voluntary contributions, and all offers of help are gratefully received. Without generous donations and imaginative fundraising SOFT UK would not be able to offer information and support to the many families who contact us.

Contact us for advice about planning your fundraising event and to order SOFT merchandise:

01213 513122 | enquiries@soft.org.uk

www.soft.org.uk/Fundraising

THANK YOU!

Thank you to these generous donors:

- Clair Nee in memory of Robin
- The Cerys' Cuddles team in memory of Cerys Watts
- Natasha Derrick in memory of Brooke India
- Jonathan Worth in memory of Amelia Rose
- Heidi Bennett in memory of Isabella
- Liam Buckler in memory of Daisy Caroline
- Trinity Church of England School
- Mr and Mrs Kirwan
- Dave Pollard
- Mr and Mrs Reith
- Jonathan Clark
- John Macdonald
- Catherine & Craig Tempero in memory of daughter Angelita
- Hayley Evans in memory of Edythe Delilah
- Nistha Jeram-Dave in memory of Fabien Bear Sweeney
- Rachael Lawler
- Celia Desmond
- Kieron Jordan
- The Maynards in memory of Katie
- Lauren Evans
- Sau Lin Lai on behalf of Eileen Man
- Paul Johnson
- Panjit Rupra in memory of son Ranjit Jr. S. Rupra
- Sheila Maguire in memory of grandson Liam Jay Heseltine
- Ian McColl in memory of Gregor
- Anthony Marshall in memory of Elisabeth Rachel Banfield
- Kim Wrigley
- Geoffrey Ditz
- Anne Scott
- Lisa Johnson & One Health in memory of Jack David Capper
- Stephanie Bain in memory of Kate-Lynne van Tonder
- Owen Roberts
- Tim Lincoln
- Chris Owen in memory of his little nephew or niece
- Marie Norris
- Steven Duncan in memory of Max
- Cameron Millard
- Marita Moxon in memory of Lily-Fay
- The partners of Rawlinson & Hunter in memory of Alice
- PWC UK
- Davison C.E. High School, Worthing
- City of Glasgow College

and to our many anonymous donors - thank you, we couldn't do it without you!

2013 EVENTS

Thank you to everyone who has entered an event to raise money - running, riding, and skydiving so we don't have to!

Katrina Wong, 2013 Blenheim Triathlon (£115)
'Mr The Riverside' (£1523)
Lucy Makina, 10K Dubai (£753)
Amy Fall, sponsored silence (£81)
Tim Donoyou, 2013 Virgin London Marathon (£587)
Polly Hughes, 2013 Bath Half Marathon (£221)
Jonathan Clark, 2013 Paris Marathon (£595)
Glen Cockman, cycling across London (£770)
Natalie McKenna, 2013 Chester Half Marathon (£225)
Steve Pilkington, 2013 Torbay Half Marathon (£610)
Jonathan Gardner, 2013 Rhondda Fun Run (£339)
Adam Ingall and Chris Hammond, 2013 Three Peaks Challenge

And coming up we have...

Neil Hindle running in the 2013 Bupa Great North Run in September
Jason Tomkins riding his bike in memory of his nephew Oliver.
Jenni and Vikki's Golf Day at Leatherhead Golf Club on 19th Sept.
Sean and Caroline Watts in the Bristol Half Marathon in September.

If you would like to support SOFT with an event (and get a T-shirt), let us know.

2012 EVENTS

From the tail end of 2012, thanks to:

Alan Purves, 2012 Speedo Open Air Swim (£321)
'Nice Guys Finish Last and the Convicts', 2012 Men's Health Survival of the Fittest (£1255)
Katharine Foster-Bartlett, 2012 Bupa Great South Run (£185)
Emma James, skydive (£1381)

Any money raised on behalf of SOFT UK should be forwarded as soon as possible so that a receipt can be issued.

Payments can be made in the following ways:

Cheques payable to SOFT UK
c/o Liz Egan, SOFT UK
11 Newlands Road, Uddingston G71 5QP
Email: donations@soft.org.uk

By electronic payment
SOFT UK
HSBC
a/c 21125613 | sort code 40-39-06
32 Gloucester Road, Ross-on-Wye
Herefordshire HR9 5LF

Online via Virgin Money
Follow the links from
www.soft.org.uk

The McKenna family - Shannon's mum Aileen, dad Paul, brother Malachy, and sisters Jodee, Kirsty, Natalie, Narieiosa and Rachael.

THE McKENNA FAMILY

The McKenna family and friends held a coffee morning on the 3rd March 2013 in memory of sister Shannon. They each made some homemade goodies and the youngest sister Rachael, aged 12, set up a tombola table which alone raised £65. There was also a table set up on which they displayed SOFT leaflets a special tribute to their sister with a presentation explaining what Trisomy 18 is.

Everyone was well fed and they still had enough left over to donate evening tea and treats to their local senior nursing home. The coffee morning was well supported by family and friends and raised £555 for SOFT.

Jodee's employers PWC contributed to the fundraising efforts through their matched giving programme - giving an extra £250, thank you very much!

KATE & CHRIS EDGE

Apologies for missing this out of the last issue - On 28th October 2012 Kate and Chris Edge cycled 65 miles in memory of their son Isaac who was diagnosed with T13 and HPE. Isaac was born sleeping on 5th November 2010. £300 was raised for SOFT.

LOLA'S LITTLE GIFTS

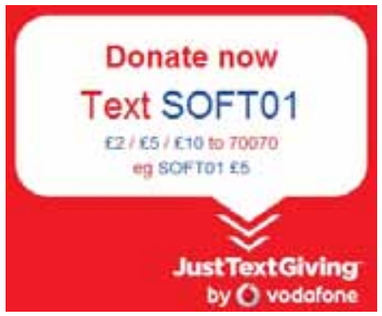
Not knowing she had Edwards until after her birth, Julie and Murphy Babatunde's baby girl Damilola sadly passed away peacefully at home, at 3 months old. Since then Damilola has inspired them to raise funds for SOFT UK through creating beautiful bracelets and charms.

All items can be customized in whatever colour or charms. Items available are mobile phone charms, handbag charms and bracelets. For more information, or to place an order, visit Julie's facebook page via the fundraising section of the SOFT website.

TEXT DONATIONS

We are now signed up to Just Text Giving. SOFT will receive the full amount of any donation, with the donor paying a standard network charge in addition to the sum donated. We have loads of free posters (courtesy of Vodafone) so let us know if you would like some at your next event.

It's simple to do - details are below:



Cerys

If I could have a lifetime wish
a dream that would come true
I'd pray to God with all my heart
for yesterday and you
A thousand words can't bring you back
I know because I've tried
And neither would a million tears
I know because I've cried
You left behind a broken heart
and happy memories too
I never wanted memories
I only wanted you.

Unknown

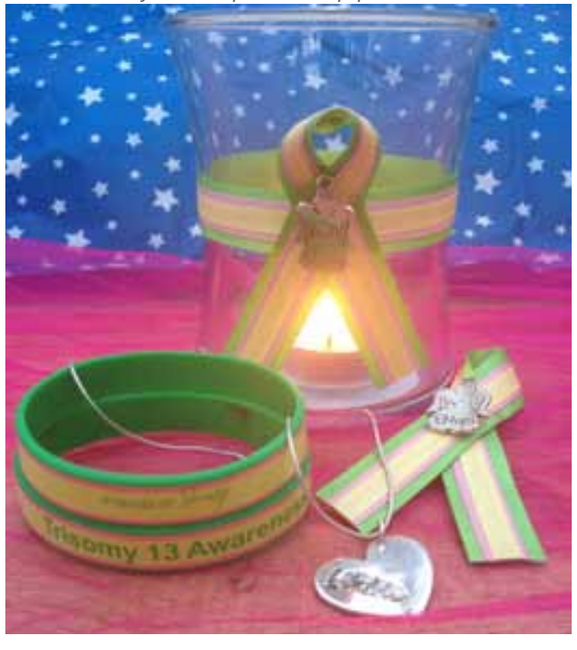
Luke

'Your baby won't sustain its own life'... I will never forget those words spoken to me. Our lives changed from being on the top of the world to heartbreak within seconds. From being sat down on the bed being told there were problems with the baby we were whisked down the back corridors and booked in for an amnio the following day. I was scanned for about 90 minutes and it was then we realised we were having a boy, although we never asked. Three days later we got the call, 'It's a real nasty one. The baby has Patau's syndrome, there's no hope', spoke the midwife. We resisted this news and had meetings at genetics, again being told there was no hope. The syndrome is 'not compatible with life' they told us. A few weeks later I started with pains, it was slow labour. The baby's movements became few, until they stopped. Our baby was gone! I was induced and on the 24th March at 3.32 A.M. Luke was born. I will always remember longing to hear the cry of my baby, but only hearing the silence!

The months have been tough and there isn't a day that goes by where I don't think of Luke. I have strived to do something positive and turn this life changing experience on its head and in Luke's honour 'Friends of Serenity' was founded. The fund has a few aims, T13 awareness and raising money for the suite where women go when they have lost their baby. Over £1200 has been raised to date. I sew my own T13 ribbons and I have sold over 200. We have wristbands too. Both going global and sent to America, Canada and Australia. Different sponsored events by myself and friends have been completed and there is so much more to come, such as balloon races and a day in honour of all the little angels on 13th March, T13 Awareness day. Our presence on social media such as Facebook is growing and we've high hopes of going from strength to strength.

Joanne Edwards
August 2013

To learn more and follow Joanne go to **https://www.facebook.com/hopeserenitytrisomy13awareness**. *Money raised will go to help families at the local hospital where Joanne gave birth to Luke. Joanne has been asked by the hospital to help plan a new suite.*



We arrived and were talked through what would happen. I was asked if I would be willing to talk to some people about the MRI experience for some long term research they were doing. I had to remove my earrings, nose ring, bra and boots but that was all as I'd been careful to wear clothes free of metal.

The MRI tube is shockingly small, it felt like my nose was practically touching the top. I was able to go in feet first which made it less claustrophobic. They asked if I'd like music and what type. I just asked for something classical and it did help me relax. I just tried to concentrate on my breathing while the scan was being done and tried to convey calming thoughts to the baby. The MRI machine was very loud and there were different frequencies of noise which surprised me. It also vibrated; it was a weird experience.

The doctor had told us that she could talk through the results with us straight away and 10 minutes after the scan she called us through. She immediately said the results were concerning and I felt utterly floored. I still can't remember everything she said. Something about the 2 sides of the baby's brain not being properly linked up and something about abnormalities in one side of the baby's brain. She said on a scale of mild to severe disabilities our baby was probably somewhere in the middle. I couldn't stop crying and I couldn't take in what she was saying. After last time it just felt so unfair, I was so sure this baby would be OK. I actually expected the best despite my worries.

We went back to wait while she made an appointment for us to see our consultant. Gareth and I held each other and cried. I realised I wanted to rage against the world, I wanted to smash things and scream that it's not fair that our baby should suffer. I was so angry.

The doctor came back through and told us that our consultant was in clinic that day and had said to go straight round. We arrived and were taken straight into a private room. About 10 minutes later he came in, shook our hands and said he wouldn't ask how we were feeling because it was a stupid question, he knew we must be devastated.

He talked about 'options' and I knew he meant termination. We'd already briefly discussed this and both agreed that it wasn't an option for us. We felt with Maple there wasn't an actual choice, we were acting in her best interests, to stop her suffering. This was completely different.

They don't yet know what sort of learning difficulties this baby will have, they probably won't know until he starts to get older. His development may be slow, he could have autism, he is likely to have seizures or epilepsy. There is no way of knowing until he's here. He mentioned termination again, he said that he didn't want us to feel it wasn't an option at a later date as it still could be because of the nature of the baby's problems.

My baby. My little boy who is perfectly formed in every other way. The baby who kicks me daily to remind me he's still there. There is no way on earth I could end his life.

Explaining it afterwards to close family was really hard. A couple of people suggested the option of a termination (I know out of love for us as a family unit) and asked us to consider the impacts a disabled child could have on our family, the time and energy that we will need to spend, the time and energy that will be taken away from our other boys. Perhaps I am being incredibly selfish towards my other children, perhaps they will have less attention or less time. Maybe it will have a negative impact. But maybe it will make them stronger men, more understanding men, maybe they will see that everyone is different and has different needs in the world. I cannot predict the impact it will have on our family.

I am not so naive as to think that it's not going to be really hard, I have no idea how hard, I can't know because I haven't lived through it. But I also know there is no way I could end this pregnancy and my baby's life.

For now the "why us?" feeling has passed; instead I'm feeling why not us? There's nothing that makes us special to think that we don't deserve this. No one deserves this, our son doesn't deserve this. But we love our family and all our boys. This baby will be loved no less, he's already loved so much. Looking at it clinically from the outside I can see that a person might think for the benefit of the rest of the family a different decision should be made, but as a mother I cannot think that way. I love this baby as much as much as my other babies.

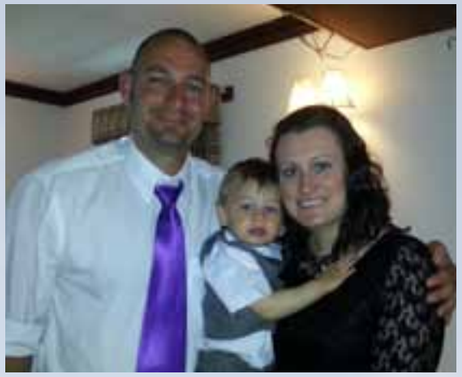
We'll have more MRI scans so they can see how the baby's brain is developing, but we really won't know anything until the baby starts to develop. I was reassured that at birth everything should be 'normal' and there shouldn't be any reason for them to take the baby off for tests. This is important to me, that post birth bonding time matters to me. I don't want to spend the rest of this pregnancy dreading our son's arrival, I want to look forward to meeting him.

That's where we are for now, in shock. My head is thumping and I could happily curl in a ball, cancel all future plans, follow our first instinct to hide from the world. But instead we are going to try and continue as normally as we can, so I will stop here, I need to cook dinner for my boys.

Corinne Hills
May 2013

Corinne and Gareth's daughter Maple was born with T18 on 5th October 2012 at 13 weeks. Corinne is now pregnant with 'Son no. 4', who has agenesis of the corpus collosum (ACC) and is expected to have disabilities. Follow Corinne's journey on **http://motherhoodjourneys.com**.

A week in the life



Emily van Tonder has been SOFT's Administration and Development support volunteer in Scotland since February 2012. Emily became a member of SOFT following the birth of her daughter Kate-Lynne in Dec 2009. Kate-Lynne was diagnosed with mosaic T18 at a week old. She was sadly lost at 14 weeks old.

You can contact Emily via the SOFT email at **enquiries@soft.org.uk**.

Monday

Today is a working day for me. Etienne my husband is not working today, which means he gets up with Dylan our 1 year old son and is looking after him today. I am a Part Time Social Care Worker with the Throughcare and Aftercare team in Shetland for the Local Authority. I work with Looked After Children who are moving on to independence. I really enjoy my job and how every day can be totally different to the next.

After work I come home to teatime which is always fun with a toddler who likes to throw food on the floor; the cheeky grin means we can never be upset about it and really it's just some fun for him. Daddy is in charge of bath time and so it's my job to tidy up and then I head upstairs for bedtime stories.

Once Dylan is settled I spent time on the computer checking emails as I am waiting to hear back from the venue for the Scottish Family Day. No reply yet! I am also on the committee for the local community hall so I send out the reminder for the hall meeting on Thursday before spending some chill out time on the couch watching tv.

Tuesday

Etienne is working today. As he does shift work he will be sleeping at work tonight. This is a day off for me. After dropping Etienne at work Dylan and I go to visit some friends and go for a walk, as the sun is shining so we have to make the most of it in Shetland!

After spending a lovely day with my son and having tea its mammy's turn to bath him which is lots of fun splashing and soaking me.

Once Dylan is all settled I spend some time on the emails. Have heard back from the venue, which is the same as last year as they again gave the best quote. I am working through some of details with them on the final date, the number of rooms we require, equipment, food, and making sure there's disabled access. They seem to be pretty accommodating which helps. I also email Demi to keep her in the loop of what is happening.

Wednesday

Another work day and, as Etienne is working as well, I need to get Dylan organised to go to his Nanny's house.

After work I go and pick Dylan up and take him home where Etienne has tea made - always nice to come home to cooked food! We go through the usual night time routine; daddy is on bath duty, then we spend some time chilling out on the couch watching tv. We have far too much on our Sky Planner!!!! Couch potatoes come to mind ha ha ha. I have a night off the emails.

Thursday

Day off again, so it is Mothers and Toddlers for me and Dylan today. Dylan is up and down the hall crawling and he loves spending time in the toy kitchen – perhaps have a chef in the making.

Then its coffee time - mum's favourite bit - and a chance to try and catch up in between having your biscuit stolen by the bairns. After tidy up its ring a ring a rosies - Dylan's favourite song always brings a big smile - and home time. We head home for lunch and a visit in the afternoon from peerie cousin Lewie who is 6 months old.

Tonight daddy is in charge of bath and bed time as I have the Hall meeting. When I get back I type up the minutes and send them out then check emails and reply to one from the venue.

Friday

Finally Dylan's 6th tooth has arrived, we notice this morning. That'll be what the fountain out his mouth has been this last week; we thought it was never going to get here.

Last day of work for me for the week, a busy day tying up bits and pieces before the weekend.

When I get home from work Dylan, Etienne and my brother are sitting in the garden with some toys. Dylan is loving going in and out his tunnel. We decide to have a bbq and phone around some family to come; this is how we do it in Shetland, taking every opportunity of sun before it disappears.

We are encouraging Dylan to walk and have some fun as he takes a few steps between me and his dad on his own. Big smiles and giggles especially when Dylan turns it into a game where he just falls forward like a fallen tree and get caught by one of us. Good times : I just love love love his laugh.

Saturday

Etienne is working again today so once we have taken him there in the car we go and visit some family out of town.

While I clean the car outside Dylan has a play with his cousin Lewie and big Cousin Peter takes him out to feed the hens and walk around the garden. After a lovely day, well for Dylan (not sure I would call cleaning the car lovely) we head back home for tea.

Once Dylan is in bed I start thinking and making a list of all the things that still have to be done for organising the Scotland Family Day. We need to arrange speakers, the crèche, the booking form, the programme, plan the children's crafts for remembrance and celebration, the coming together time at the end of the day, have someone take photos and write up a piece for the SOFT magazine, and more I have probably not thought of. Lots to think about, discuss, plan and organise with the others in the Family Day committee.

Sunday

Dylan and I pick up Etienne from work in the morning and we have a family day together.

We visit Kate-Lynne to put some flowers down and tidy up around her stone. This is why I want to be involved with SOFT UK because of our baby girl, who will be our forever baby. They gave us the support and information we needed at a time when we were at our most devastated and distraught and continue with that support now. By being involved in this organisation in some way, I feel I am able to honour Kate-Lynne's memory and hopefully give support in some way to others who need it.

Lots still to plan and do for the Scottish Family Day. Hope to see you there.

Saga is perhaps not the first company that springs to mind when seeking information about caring for a disabled child. However, the website contains an excellent article by Marianne Talbot *Essential tips for carers*. Reading it may give you some useful ideas - in the words of the author it could help you "identify what's needed to make you YOU and make damn sure you get it!"

www.saga.co.uk/care/carers-tips/essential-tips-for-carers.aspx

Home-Start is a national family support charity that helps parents to build better lives for their children. Their volunteers provide support to more than 32,000 families every year.

The online postcode finder can help you find your local one of more than 300 Home-Starts.

Tel: 0800 068 63 68 (info line)

www.home-start.org.uk

Gingerbread NI has been supporting lone parents and their children in Northern Ireland since 1978.

They offer free, confidential, impartial and independent advice - online, by email, over the phone or in person at their Belfast or Ballymena offices

Tel: 0808 808 8090
Email: advice@gingerbreadni.org

www.gingerbreadni.org

Sibs is the only UK charity representing the needs of siblings of disabled people. They support siblings of all ages who are growing up with, or who have grown up with, a brother or sister with any disability, long term chronic illness, or a life limiting condition.

www.sibs.org.uk

The **Young Sibs** website is aimed at siblings under 18 years old. They can access support and information and chat to other young siblings via the moderated forum.

www.youngsibs.org.uk

One Parent Families Scotland works to ensure that all families, particularly those headed by a lone parent, have the support, information and confidence needed to play a full part in Scotland's economic and social life.

Tel: 0808 801 0323 (helpline)

www.opfs.org.uk

Together for Short Lives is the leading UK charity for all children with life-threatening and life-limiting conditions and all those who support, love and care for them. It supports families, professionals and services, including children's hospices.

The website includes a comprehensive library of resources for families, family stories, and FAQs.

Tel: 0845 108 2201 (helpline)
or use the online contact form

www.togetherforshortlives.org.uk

Carers UK is a charity set up to help the millions of people who care for family or friends. It provides information and advice about caring alongside practical and emotional support for carers .

They have a very comprehensive website, which now includes a 28pp guide *Looking after someone - a guide to carers' rights and benefits 2012/13*.

Tel: 0808 808 7777 (UK Helpline)
Tel: 028 9043 9843 (NI Adviceline)

www.carersuk.org

Gingerbread is a national charity that provides advice and practical support for single parent families in Wales and England.

The website is informative and you can use their free helpline to speak to an expert adviser.

Tel: 0808 802 0925

www.gingerbread.org.uk

Fledglings is a national charity that finds and sells products that improve the lives of disabled children and their families.

You can download their latest brochure online.

www.fledglings.org.uk

GOV.UK is the new website for finding government services and information (replacing Direct Gov).

Information for disabled people and their carers can be found at

www.gov.uk/browse/disabilities

Kindred is a voluntary organisation that works with parents, carers and young people in Edinburgh, Lothian and Fife, providing information, emotional support and advocacy. Kindred is based at the Royal Hospital for Sick Children

Tel: 0131 536 0583 (helpline)
Fax: 0131 536 0583
kindred.enquiries@gmail.com

www.kindred-scotland.org

SOFT UK is a member of **Genetic Alliance UK**, the national charity of 150 patient organisations, supporting all those affected by genetic conditions.

Its online information centre is very comprehensive, covering topics including genetic testing, life insurance and clinical trials.

Tel: 020 7704 3141
Fax: 020 7359 1447
contactus@geneticalliance.org.uk

www.geneticalliance.org.uk

Cruse is the UK's largest bereavement charity. It promotes the well-being of bereaved people and enables anyone bereaved by death to understand their grief and cope with their loss. As well providing free care to all bereaved people, the charity also offers information, support and training services to those who are looking after them.

Tel: 0844 477 9400 (helpline)
Email: helpline@cruse.org.uk

www.crusebereavementcare.org.uk

Contact a Family is the only national charity that exists to support the families of disabled children whatever their condition or disability. They offer support, information and advice to over 340,000 families each year and campaign for families to receive a better deal.

They run a UK-wide advice service for Special Educational Needs (SEN). As well as providing an online library of information and resources, they provide phone and email support.

Tel: 0808 808 3555 (helpline)
helpline@cafamily.org.uk

www.cafamily.org.uk

This directory contains information about organisations offering information or services that may be of interest to SOFT UK members.

Any commercial enquiries will be considered by the SOFT UK Board of Trustees and only accepted if they conform to SOFT UK's ethical fundraising policy.

For further information please contact us at enquiries@soft.org.uk.

Carers Trust is a new charity formed by the merger of The Princess Royal Trust for Carers and Crossroads Care. In Scotland the name The Princess Royal Trust for Carers will remain.

They aim to ensure that information, advice and practical support are available to all carers across the UK.

www.carers.org

Sand Rose is a charity providing free breaks for families from all local authority areas in England and Wales, who are experiencing a bereavement.

The project base in Marazion, Cornwall, provides a special location needed by those suffering loss and grief. It does not provide a therapeutic or counselling programme but simply the venue for a break.

www.sandrose.org.uk

Many families facing difficult times benefit from seeking professional support to work through their experiences and enable them to adjust to what is happening to them.

The **Counselling Directory** is an online resource, connecting families with qualified counsellors and therapists across the UK.

www.counselling-directory.org.uk

The **Telling Stories** Website from the NHS National Genetics Education and Development Centre is a resource developed to promote understanding among all health professionals of the impact genetics has on real life.

The stories contained deal with all the emotional and practical aspects of living with a genetic condition, but also detail the implications for healthcare practice by sharing the good and bad tales of treatment received.

www.tellingstories.nhs.uk/about_us.asp

Where to go for help

Telephones will be answered by a recorded message. Please leave your name, number and query and we will always return your call. If we do not reply to an email within 24 hours, please re-send the information in case we did not receive it. If you wish to receive newsletters or if you would like a star on the remembrance page of the website, please contact SOFT through the website.

Website
www.soft.org.uk

Email
enquiries@soft.org.uk

Telephone
Contact the SOFT UK support team on 07923 056 132