SOFT UK
Winter Newsletter

Welcome to our Winter Newsletter
From Jan Fowler, Chair of SOFT UK

Hello everyone and welcome to the Winter SOFT UK Newsletter.

And it is certainly starting to feel a bit wintery now the clocks have gone back and it is getting dark earlier.

It has been another strange year with many things we have not been able to do but still lots of great achievements despite all the continued restrictions. You will read in these pages news of the podcast series developed; the 'You're Not Alone' project; the work with NHS Digital; the virtual 30th Anniversary weekend, the expanded virtual family calls and much more.

None of this could be done without the support of our families, so 'Thank you' for your contributions and being willing to share your experience. We know that your stories are so helpful to families who are just beginning their trisomy journey.

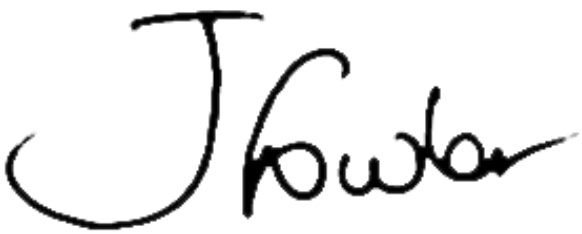
We are trying to capture experiences from across our community of families, whether you are caring for a child affected by Trisomy, are bereaved, or have taken the difficult decision to end your pregnancy. So, if you are willing to contribute to the range of family stories, we would love to hear from you.

As we move into the New year, we have lots of other exciting developments planned, so keep an eye out on our social media channels and website for updates.

Finally, a quick thank you to two of our Trustees, Alison Pearson and Becky Wirth, who have recently given presentations to groups of NHS staff about their lived experiences. Both very well received and, together with the resources we have from our various films and podcasts, we hope to deliver more of this impactful training to more healthcare professionals next year.

Enjoy the rest of the newsletter and do keep letting us know your feedback and ideas for future editions.

Wishing you a wonderful and peaceful Christmas.



SOFT UK News

Podcast - ‘Against All Odds’

Recently, SOFT UK launched a new series of podcasts, ‘Against All Odds’, focusing on incredible stories from incredible people.

This podcast series is focused on those who have faced a Trisomy journey and come out stronger, making a change that has a positive impact on so many people’s lives.

We’ve got interviews with people from around the world, with different and unique stories to tell, but they all have one thing in common, hope and making a change.

Available on iTunes Spotify YouTube

By telling these stories we hope to inspire and change the narrative. We are giving people a voice and helping them to be heard, and together with their strength and mission, we are stronger.

Some examples of the people we will be talking with throughout this series are, an author of a children’s book for siblings aimed at helping them understand what Trisomy 13 and 18 are, a mother of 8 who faced a diagnosis of Trisomy 18 and fought the odds and now supports so many others in the USA, and so many more stories.

We hope you enjoy listening to these stories, and if you’d like to share your own, please get in contact with us at contact@soft.org.uk.

You can find the podcast here: https://anchor.fm/softuk

SOFT UK News

30th Anniversary Weekend

The 30th Anniversary Virtual Weekend took place on 17, 18 and 19 September. The Introduction to Weekend Events saw many of the trustees, volunteers, and staff introduce themselves, to put a face to a name and we kicked everything off with a relaxed family call.

Saturday morning saw the premier of the 'You're not Alone' project by 'Same but Different', together with Illumina. Being collaborators on the project, we got a sneak preview of these real stories behind Edwards' and Patau's diagnoses before it launched fully in October. There was also an interesting chat with Ceridwen Hughes, the photographer and film maker, and two of the Mums- Sharon and Jody, who featured on the videos, hosted by Shirlene Badger, from Illumina, to take a behind the scenes look at the creation of the project.

After an emotional start to the day, we then heard from our panel of experts in the afternoon. Dr. Una MacFadyen, a retired paediatrician who has been involved with SOFT UK since its inception, delivered a talk on 'Experiences with Children with Exceptional Healthcare needs'. Next up was a talk from Neonatologist, Dr. Martin McCaffrey, from the US highlighting a professional's point of view on Trisomy entitled 'Compatible With Life... and Love'. Our final talk for the day was by Dr. Deborah Bruns, a SOFT UK Adviser, who spoke about the 'Tracking Rare Incidence Syndromes (TRIS) Project', with insights into how it works, and how things are progressing. Finally, we held a Trisomy 13/18 Clinic where Dr MacFayden and Dr Bruns joined us to answer questions submitted to our speakers.

Sunday's theme was 'Family Stories and Remembrance'. We heard from Erica Brown, to get a sibling's perspective, Larry Crofton, to give a Dad's perspective, and Bereavement Midwife, Ali Brett, about coping with loss during a pregnancy. The day culminated in a Remembrance Event where we came together to remember all the babies and children we have lost.

We were thrilled with how many people watched the various talks and interacted with the content and speakers. It is thanks to the support from you, our community, that events like these are a success.

If you didn't get the chance to catch it all live, or you'd like to replay any of the presentations, then head to our YouTube channel to watch it here: https://www.youtube.com/c/SOFTUK or it can be viewed on our Facebook page here: https://www.facebook.com/SOFTUK/videos/?ref=page_internal

We welcome any feedback you may have on the event so please be in touch if you'd like to share anything with us.

SOFT UK News

NHS Digital Project Update

Work is underway with NHS Digital and the Down's Syndrome Association on two films that will help families affected by Trisomy 13 and 18. These films will be available on the NHS website when someone searches Trisomy 13/18, and the NHS and SOFT UK will be widely distributing them to our audiences.

They are hugely important in helping families at an uncertain and emotional time of their lives. Filming is now complete, and the editing process is underway. Thank you to everyone who came forward to share your experience, all the feedback has been heard and will be used in changing things for the better for other families going through the same thing.

The intention is to help support families during the early stages of learning about the condition, to share the support available, and to communicate the options open to them. Both SOFT UK and the NHS are determined to offer information and support to families in the future, by sharing a range of experiences and outcomes. We will keep you informed about when these films are launched.

Same But Different Exhibition Launch

As part of Baby Loss Awareness Week (BLAW), from 9 to 15 October, the 'Same but Different' Exhibition was launched in collaboration with SOFT UK and Illumina.

'You're not Alone' was created, in conjunction with SOFT UK, to provide insight into the experiences of families following a Trisomy 13/18 diagnosis and to show that you are never alone, no matter what choices you make. Photographer Ceridwen Hughes has captured some of these experiences through a short film and conversations with families. The stories can be watched here https://www.samebutdifferentcic.org.uk/yourenotalone

We are extremely proud of our involvement in the project and thank all the families who shared their stories.

SOFT UK News

SOFT UK Supporting PHE Scotland with CARDISS

SOFT UK have been asked to support PHE Scotland to develop their congenital anomaly register. Our Chair, Jan Fowler, will be attending a meeting in November to help establish a register which will bring them into line with England (NCARDRS), Wales (CARIS) and link in with other registers in countries across Europe.

CARDRISS is part of a wider programme of work to improve information on individuals affected by rare diseases, and hence ultimately improve their outcomes. We are proud to be part of making this change happen.

Termination for Medical Reasons (TMFR) Results

ARC (Antenatal Results and Choices) together with Tommys and Petals charity, conducted a survey to find out more about the experience of TFMR on families. More than 1300 people took part to share their experiences, thoughts, and feelings.

“I felt like I didn't deserve to grieve because I had chosen to terminate, and that my loss didn't matter as much’’

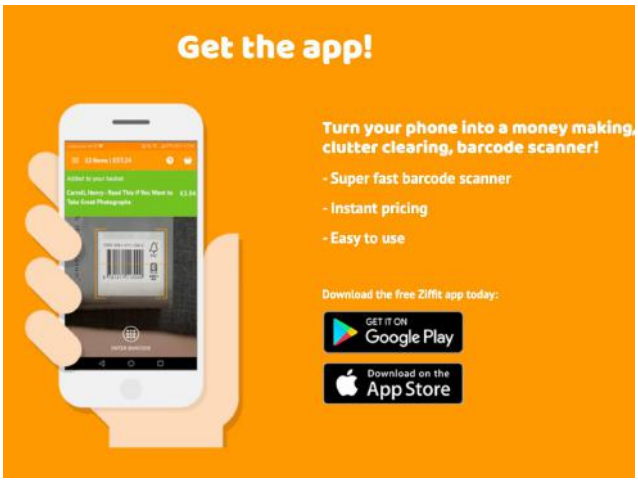
The aim of this work is to break the silence around TFMR and help lift the taboo. The results are available to read on their website here: https://www.arc-uk.org/for-parents/break-the-silence-around-tfmr/tfmr-survey

Fundraising

Ziffit

With Ziffiti.com it's easy to donate money to SOFT UK. Go from clutter to donations in 4 easy steps:

1. Download the Ziffit app, scan the barcodes of your products and get an instant value.
2. Select your chosen charity at checkout and pack up your unwanted goods.
3. Use Ziffit's free courier or drop-off service to send your items, of free of charge.
4. The value of your items will then be donated to SOFT UK.



To find out more go to:
https://www.ziffit.com/en-gb/donate-my-stuff

Pay Slip Giving

Do you know that you could give to SOFT UK through your wages?

The Payroll Giving scheme enables you to donate regularly from your gross pay to a charity of your choice. The donations are taken from your pay before income tax is applied, making it a tax-effective way to give. Ask if your company offers this and help make a difference to a cause you care about.

Fundraising

My Fundraising in Memory of Grace Emily Born Asleep 04.05.2000

Our story begins in Pattaya, Thailand where we had recently relocated with Mark's job when I discovered I was pregnant with our third child. It's fair to say that I wasn't at all thrilled with this news to begin with as I was pretty much alone in a foreign country with two boys, Matt aged 3 years and Josh aged 9 months, Mark working long hours and no extended family to reach out to for support. I could only imagine how difficult this was going to be for me. However, after a visit home to see my Mum and a few weeks to come to terms with things I sorted out a Nanny to take some of the burden and started to look forward to meeting our new arrival. When I visited the hospital at 15 weeks for the Triple Test and dating scan, I was delighted to learn that all was well with our new bundle and that we were expecting another BOY.

Having fallen in love with our expected new addition, I spent the next few weeks starting to buy everything we would need on many trips to Pattaya and Bangkok. At 21 weeks I returned to the hospital to get my test results. I had no concerns until I was kept waiting for two hours. Eventually I was approached by a British midwife who advised that my baby was 'high risk' for Downs Syndrome at 1:250. I was offered an amniocentesis at the IVF clinic in Bangkok but decided against it as Matt had also been high risk at 1:200 and after the amnio I had worried about miscarriage until he was born. I was eventually seen by the Consultant to discuss matters further and it was at this point that I noticed a high-lighted result on the paper but as she was ignoring it, I assumed it was nothing to worry about. How wrong could I be?

I left the hospital feeling happy and looking forward to my new baby BOY. This was to change dramatically in a phone call from the Consultant only one hour later. She had spoken with the IVF Consultant in Bangkok who had advised her that the high-lighted result was extremely serious and required immediate investigation. The result read T18 1:3. I returned to the hospital to be shown photos in a medical book of babies born with T18 by a Consultant with no knowledge of the condition. I was frozen in horror and knew that at that point in time my life was to change irreversibly. On returning home I called a trusted Midwife at my former NHS employer to ask her more about T18 but the more she told me the worse I felt. She referred me to the website of an organisation who gave advice on antenatal results and choices, and I was crushed to read the words 'if your baby has this condition it will not survive'. How could my precious baby, who we planned to call Lewis, not be given the chance to live the life he deserved.

Fundraising

Two days later after many tears and very little sleep we headed to Bangkok to the IVF clinic for more tests. I was clutching at straws and praying that a 1:3 result still gave my baby a 2:3 chance of being born free of T18. The first sentence spoken by the Consultant crushed even that tiny spark of hope. The highest risk he had seen for T18 before this was 1:10 and that baby had it so he was certain that our baby would too. My heart was shattered and for the first time Mark, who until then had an 'everything will be fine' attitude, finally had to accept what was becoming the inevitability of our situation. After a detailed coloured scan watching our baby move on screen and an amniocentesis to confirm the results, the Consultant listed the 'defects' he had identified in our baby which all pointed to a diagnosis of T18. Low set ears, tiny pelvis, clenched fists, hole in the heart, hernia and rocker bottom feet. My head knew I had to accept what the future was going to hold but my heart desperately wanted to find a way for my SON to have the life he so deserved.

The next 10 days past in a blur as we waited for the amnio results to come in. Mark's Mum flew out to Thailand to help with Matt and Josh and provide some much-needed family support to us all. On the day the results came in I took a call from the Consultant who told me, in the most direct way imaginable, that my baby had Full T18 and invited me to the hospital to discuss 'my options'. Two hours later sitting opposite the Consultant I heard for the first time the two phrases that I truly believe ought to be eradicated from childbirth terminology: my baby was 'not compatible with life' and I should undergo a 'therapeutic abortion'. I could barely comprehend what I was hearing but that my devastation was to intensify when I read the upside down results in front of me: 47XX+18. My baby had T18 for sure but not the baby boy we had named Lewis, I was expecting a GIRL. When I asked the Consultant to clarify this, she confirmed it with a big smile on her face in a tone that almost said congratulations. She then suggested that I should abort my baby that day. I had no strength left in my body or mind, but I knew I had to keep my baby inside of me until I could get her safely back to the UK for a second opinion and more information on the choices available.

We flew home as a family two weeks later and after seeing a GP and being assessed by a Community Midwife at 28 weeks gestation I found myself once again sat in front of a Consultant, this time in Foetal Medicine, discussing the fate of our unborn baby girl, who we had named Grace Emily, and with her the fate of a huge part of my heart. Another scan had discovered she was also missing the base of her brain so without my body for life support she could not survive. The Consultant was uncomfortable with my decision not to allow him to stop her heart with an injection prior to him inducing her birth but, after everything I had endured to get her to this point, I desperately wanted to have the chance to hold my baby girl and see her open her beautiful eyes so that when she grew her wings she would do so knowing how much her Mummy loved her.

Fundraising

On the day my precious girl was to be born in to and sadly leave this world I was admitted to a home from home room at Newcastle RVI Hospital, joined by Mark, my Mum and Mark's Mum. It had been agreed that if Grace was born alive she would be left with me for the first ten minutes. If after ten minutes she was still breathing she would be given a painkilling injection then left with me for a further two hours. Only after two hours would a full team by ready to intervene and give her life support. Sadly none of these plans were needed as, at 10.50pm on Friday 4th May 2000, Grace Emily Wilson was born asleep, weighing less than 2lbs and badly bruised after my stomach had gone in to a tight contraction for three hours before she was born. The wonderful Midwife who had been at my side all day and night confirmed her stillbirth to us but still handed my precious bundle to me. To this day I can still feel her warm tiny body against mine and will hold on to that feeling forever. After weighing and measuring my beautiful girl the Midwife dressed her carefully in a tiny outfit after taking ink impressions of her hands and feet for a keepsake and handed her to my Mum for Nana cuddles. We spent the evening holding, kissing and talking to our precious baby girl and the Midwife took many photos as memories of our short time together.

Grace stayed with me safely in my arms in a tiny bassinet throughout the night. I took in every minute detail of her beautiful face and fascinated at how much she looked like her brother Matt with her thick set brow and wispy black hair. By 6am I felt the time was right to say my goodbyes to my precious bundle and I handed her to a Midwife with one final kiss. Before leaving the hospital I was visited by the Bereavement Officer, Julie Bailey, who became a firm friend at a time when I really needed someone to help me through the dark days ahead. It was Julie who made sure my baby girl existed by registering her, not as a 'therapeutic abortion' but as a stillbirth, meaning I have a Stillbirth Certificate acknowledging legally that my angel touched this world in a brief but special way. Julie also looked up organisations that could provide much needed support and along with SANDS she introduced me to a support organisation that has remained a part of my life to this day. Julie introduced me to SOFT UK.

After two days out of hospital and away from my baby girl I knew I had to see her again. I was completely broken and the GP felt it was important I go back to see Grace one last time. Julie Bailey organised my visit and I returned to the room where Grace had been born. The Midwife who delivered her brought her back in the tiny bassinet but when I looked at her I felt complete horror as she looked different. I remember screaming that it wasn't my baby and crying hysterically. The Midwife very calmly rearranged how Grace was lying and handed her to me again explaining that it was my baby girl but with no muscle tone she just needed more support. As I calmed down I took in her tiny face and as my tears fell I began a two-hour conversation with my beautiful girl. I told her all about her brothers, her Daddy, her Nanas and Grandads, Uncles, Aunties and Cousins. I described our house in Thailand and the life she should have had. I promised her she would always be a part of our lives and that we would love her endlessly forever. I kissed every part of her and took in her smell. I held her hands and imagined how beautiful her eyes would be and how sweet it would have been to hear her cry. This time when I let her go I knew it was the right time and I was doing it having made precious memories to last a lifetime.

On 12th May Grace was buried in Hebburn Cemetery with her Great Great Grandparents and soon after a Teddy Bear headstone was erected in memory of our beautiful girl born asleep. Soon after the funeral I returned to Thailand but couldn't settle and quickly realised that I needed to be near my angel. As a family we returned to the UK in July 2000 eventually setting up home in Scunthorpe, only a 2-hour drive from Grace's final resting place.

Fundraising

On our return to the UK I contacted SOFT UK for the first time and spoke at length to a lovely lady called Christine Rose about my feelings of guilt, the intense emptiness, the endless question of why me and my inability to even begin to accept our loss. She listened without comment to my guilt, anger and intense sadness and slowly helped me make sense of my world once again. She helped me find a way to move forward with my grief and one year later I welcomed into the world my first rainbow baby, the baby boy we had expected the year before, Lewis joined our family. He couldn't have looked more different to Grace with his blonde locks, and he certainly made life interesting with his cheeky personality but of all her siblings Lewis is the one with the closest bond to our angel. Its almost as if she sent him to us with a part of her inside him. Five years later we were blessed with a second rainbow child. Libby is as different again to the others with her beautiful red hair and quirky personality. Her love of Musical Theatre certainly keeps me busy.

Over the years I looked forward to receiving the SOFT UK Newsletter every month. I read with sadness the stories of all the other families grieving the loss of their much wanted and loved angel babies and with inspiration the stories of those families learning to live with their awesome T18 and T13 warriors. I knew in the background that SOFT UK was also a huge support to all these families too so decided very early on that we as a family would do our best to pay back the support the amazing people at SOFT were giving to us.

Our first fundraising venture was to be undertaken by Mark and his workmates who trained for and took on the Three Peaks 24 Hour Challenge. This involved them climbing Ben Nevis then Scafell Pike then Snowdon within a 24-hour period. The challenge was completed with the help of both of Grace's Grandads as drivers and my Dad even took on Snowdon at the end, all in her memory.
The next family member to fundraise was my Mum who gave all donations in lieu of gifts at her wedding to Harry to SOFT. Libby and I were bridesmaids and when they were signing the register a small white feather fluttered down. I guess Grace was making her presence known that day.
Grace's eldest brother Matthew was next to take on the fundraising gauntlet. He nominated SOFT UK as the charity when taking part in the National Citizenship Service awards. He and a group of friends took on Service awards. They and a group of friends also took on open water swimming, hiking and cycling with Paralympians in Scotland before returning to Stafford to organise their fundraising event. They raised money at a cake sale in the local market followed by a disco and awards ceremony the same evening. I was so proud of Matthew for all his hard work and determination in memory of his sister.

Up to this point I hadn't been directly involved in any fundraising myself but that was to change when I challenged my friend to take on Couch to 5K with me. It was not going to be easy as at the age of 49 I had never been a runner, but with determination I completed the eight weeks and soon after joined Beaconside Runners, a beginners running group. With two incredibly inspiring coaches and some fabulous running buddies I was soon running 10k, completing my first organised run in June 2019, and had a place to run the Great North Run in September 2019. This was the start of my own fundraising journey. Although I was running on a charity place, as soon as I reached my target I switched my donations to Wonderful.org and started raising money for SOFT.

Fundraising

Within days of me completing the Great North Run I found out I had a public place in the London Landmarks Half Marathon so I ordered my SOFT UK running vest and started planning every way to raise as much money as I could. I organised an Afternoon Tea with musical theatre entertainment provided by Libby and her super talented friends. It was a huge success raising over £700 only days before Covid changed our world. Unfortunately, London Landmarks was postponed due to lockdown but as part of my daily exercise I took on the Local Landmarks challenge to claim my medal and justify my fundraising. The next year was a difficult one for fundraising but we did take part in Sing for SOFT, putting together a fabulous online mini concert featuring Libby and her theatre friends and manged to raise £100. In addition, I started to make small items such as cushion covers, carrier bag holders and peg bags using my Facebook page LibbyGrace Crafts to advertise them with all proceeds going to Soft. I also set up a Facebook birthday fundraiser and was astonished to raise £230.

Sadly, my Mums husband passed away in October last year and as requested by him the donations in lieu of flowers were shared between his hospice and SOFT UK.

As the world started to open again the delayed London Landmarks was rescheduled for August 2021. I kickstarted my fundraising with a 24-hour run/walk challenge. This involved me selling 30-minute slots over a 24 hour period to friends and family for a donation of their choice to SOFT UK. They then ran or walked their slot and sent me photographic evidence. I completed 10 hours myself including a 10k run, a half marathon and a three-hour dog walk. Most impressively were the slots taken between midnight and 5am by my son's friend and some running buddies. Everybody knows how much SOFT means to me and so many people wanted to be involved in the event that I had some slots covered several times. The run itself was on a hot humid day in August and was by no means easy. Thinking about Grace and all the other SOFT families and the reason I was doing it kept me going and got me across the line although it was certainly a very emotional day. Before during and after the race my Virgin Giving page sent me messages to tell me I had been sponsored. I was truly humbled by the support from all my friends and family.

Next was the Stafford Half Marathon where I was joined on the start line by Grace's brother Josh and his team mates from Stafford Town FC, all raising money for SOFT UK. To say I felt proud of them all is an understatement. Another unexpectedly hot day with very little water enroute made for a very difficult run but once again Grace's memory and the incredible support from friends and family got me across the line.

As a culmination of my fundraising this year I hosted an 80s Fancy Dress Charity Disco on 23rd October. Over 90 people bought tickets and several friends and extremely generous local businesses donated raffle and auction prizes not forgetting fantastic merchandise direct from 80's artists Siouxie and the Banshees and Erasure. It was an awesome night. All of Grace's family were there and I couldn't have been prouder of them all: Matthew, Joshua, Lewis and Libby you are my world and Grace is your guardian angel. You ask why I fundraise… that is your answer. I class myself as so incredibly lucky to have four perfect, healthy children despite my grief at the loss of Grace 21 years ago, and I want to do all I can to support anybody else on that journey who needs it, both now and in the future.

So what next in 2022…

I just booked the Rugeley 10 miler in February then the London Landmarks in April. Got an Afternoon Tea in March and later in the year the Great North Run. That will do for starters.

Family Stories

Anouk's Story

We are Mark and Claire Bergeron. I'm from France and Mark is from Dorset. We live in Bristol. In February 2015, we found out that we were expecting a baby, a little girl.

I had a very enjoyable pregnancy, my first and only one! Practising yoga twice a week, meditation to be mentally prepared for a positive birth, all booked to go in a midwife led birth centre, cycling to work every day until my 34 weeks, only having to stop due to pelvic pain…

At 38 weeks, the midwife told us that my bump was quite small and off the chart. Following a scan few days later, I was advised to have an induction as baby Bergeron (baby B) had a reduced abdominal circumference. This wasn't the plan! We had to forget giving birth in a midwife led centre. It will be in hospital now.

I felt very deeply that baby B was very happy there and declined the induction but requested daily monitoring instead, which was accepted. So, every day I commuted to Southmead hospital in north Bristol to hear that the bump had still not grown, and an induction was advised, but that baby B's heart was strong and regular. At 39 weeks and 6 days I developed signs of light pre-eclampsia (with protein in my urine) a lovely consultant told me that now the induction was needed. I accepted.

Following my daily monitoring, I was admitted on the ward for an induction in the evening. The induction didn't happen until just before midnight... one of those hospital waiting games! I can't remember at what time the contractions started but I breathed through them and had a warm bath. But then they started to be closer and closer, too close and I knew somehow that it wasn't quite right. I called a nurse, I wasn't dilated at all but in real pain. Baby B's heart started dropping steeply. It was time to go for an emergency C section. I wasn't ready for this but drugged up with gas and air. I remember being wheeled down the aisle with a very funny anaesthetist who helped me to relax and made me laugh to stop me crying. It was 6.30am when baby B was born, on her exact due date (she has lived to an exact routine ever since!) She didn't have a name yet, we wanted to wait to meet her first. I had to ask to see her before she was rushed to NICU as she had issues breathing. I couldn't hold her but will always remember her face.

And then it went all very quick and it is still very blurred. I was drugged up with morphine (which was great) and wheeled to NICU to see baby B only in the late afternoon. Mark told me that baby has an extra finger and an extra toe and needs CPAP oxygen to breathe and has very low sugar level. She couldn't be breastfed. I start expressing milk and freezing litres and litres of it (we still joke about it as I'm quite petite but I was producing like a Holstein Friesian on a concentrate diet!)

Mark asked the consultant if extra digits could be a sign of something. It was then decided to do some genetic testing. I started Googling what an extra digit and low sugar could be linked to and found articles about trisomy 13. It just couldn't be that surely, the odds were far too long and we are never that lucky.

Family Stories

Day 3, the NICU consultant met us in a special room and he explained that baby has trisomy 13. We collapsed. That was exactly what I had read the evening before. He handed us a leaflet and told us that she may not make it, may live for few days or weeks, maximum a year.

We went straight back to her room and I kept expressing my milk and focusing on starting to feed baby B orally with a special bottle as she couldn't latch, using her NG tube once she couldn't cope anymore, (normally after about 30 seconds) At day 4, she was diagnosed with full trisomy 13. Anouk Cleo (name finally decided after week 1!) has always been very intuitive and I knew from the start that she was stronger than she looked. She stayed 2 weeks in NICU and we were discharged just before Christmas, Mark having rushed out to get an XL tree that we thought we weren't going to need. Our first Christmas.

Anouk was doing really well. At 2 months, we requested a second genetic testing of her skin cells, it confirmed that she was actually trisomy 13 mosaic. It didn't really change anything but somehow, we felt that we needed to know to be able to fight for her.

One day, I received a letter from the consultant I met when I accepted the induction. She was asking if I wanted to meet her. I will always remember how emotional I became reading her letter. The light pre-eclampsia I had was in fact linked to Anouk's condition but she confirmed that nothing was seen during all scans done during my pregnancy.

She had a gastrostomy at 9 months old which helped so much with her reflux/vomiting. At 9 months, the seizures also started. This was scary. She would stop breathing and turn blue. But she was growing in length mainly as her weight was always out of scale but we "sacked" the nutritionist to avoid having to listen that she needed to put more weight on! She was a very happy little girl who learned to eat orally her puree after months of perseverance and against all expectations. I knew she could do it. She still loves her food and is a light weight but so am I, and I have all the correct number of chromosomes!

We've had few trips to the hospital by ambulance with quite a few status epilepticus. But she always made it through them. The scariest time, when post admission to the Neuro ward she went into a Status Epilepticus again and the RESUS team were buzzed to intubate and transfer her to PICU. But the little girl stopped seizing just as the anaesthetist was preparing the injection to sedate her. She is as stubborn as her mum is (her dad says).

UTIs and seizures are her main problem and the main current discussions are whether or not to operate and de-tether her spinal cord; quite a major operation, and not without severe risks, but a possible solution to the UTIs. The Neurosurgeon is nice enough, but the decision to operate is clearly with us. Whilst we might be the experts on Anouk and her condition, we'd much rather not be the experts and be able to confidently take the advice of a trusted professional.

Progress is of course very slow, and she still struggles with head control and sitting unassisted, but has had periods when she makes really good effort to stand assisted. She loves wearing her hearing aids and going to school. The aquarium is a big hit and she has a passion for music, all sort of styles, including regular morning sessions on the piano (feet only) which is a joy for us, but less so for the neighbours!

Anouk will be 6 in November 2021. We love her to pieces!

Anouk

Family Stories

Kate's Blog

We first met Kate Sonley when she joined a family call in June 2021. Following two sad miscarriages, she was expecting her second child, Amber. During the routine 20 week scan, she discovered that Amber had Trisomy 18. But her situation was made even more complex due to her relationship breaking down and where she found herself living- a remote village in the Scottish Highlands. This meant that her care was under multiple hospitals and that she was in touch with different medical teams sometimes at a long distance away.

At first, she struggled with the uncertainty of whether or not to continue the pregnancy. She wasn't sure how a baby with special needs would fit in with her lifestyle, running the village post office and going on long hikes and camping in the mountains. She went back and forth between being certain that she couldn't go ahead with it and then waking up the very next day feeling certain that she couldn't end the pregnancy and wanted to meet her daughter, Amber.

We were with her on this journey as she continued to join the monthly calls and ask us and other families questions and seek advice. We helped advise her with how to go public with her situation and how to talk to friends, families, neighbours and customers.

Kate became a warrior for Amber taking her infamous notebook with her to appointments and never stopping to ask all the questions about Amber's care after birth. She was even in touch with Dr. Martin McCaffrey in the US to get advice and guidance on her birth plan and Amber's treatment post birth.

Her tenacity, love and vulnerability captured so many of us in the community and we have watched with joy, fear and excitement as Amber was born, experienced challenges and improvements along the way and more recently underwent surgery and is making a recovery. To follow her story, please visit our webpage where you can read Kate's blog: **https://www.soft.org.uk/katesblog**

Family Stories

Sharing Your Story

SOFT UK is always looking for your unique and amazing stories to share with our community of families. Expectant parents often tell us that hearing or reading other people's stories helps them to not feel so alone, makes them feel understood and gives them an idea of what their journey may be like.

We are paying particular attention to stories about an ended pregnancy. In the light of all the press TFMR has been getting in recent weeks, it is important to us as a support organisation, that we represent everyone's journey and demonstrate that we respect everyone's choices.

We want to be part of breaking down barriers so that people feel encouraged to speak out. We understand it is often an extremely difficult subject to talk about, but we want to ensure that everyone gets a chance to tell their story. We offer anonymity for anyone for who this would make it easier.

We invite you to get in touch in any way that you wish. You could join us for a podcast conversation, you could submit a written story, you could dedicate a remembrance star on our website.

Please email kate.hart@soft.org.uk to find out more.

Welcome

Welcome to the team!

Kate Hart - Communications Officer (maternity cover)

I'm Kate and I'm looking forward to contributing to the important work that SOFT UK does. It's a charity and a cause close to my heart, so I am excited about being able to give back. I came to SOFT UK in 2020 when I had a beautiful daughter, Hannah, who was diagnosed with Trisomy 18 during pregnancy. She lived for 54 wonderful days, and I am so grateful for the support I got from this community. I look forward to making a difference!

Shaun Dowdall – Operations Manager

I'm Shaun and my journey with SOFT started in 2019 when we found out that there was a high chance of Trisomy in our second pregnancy. After months of research, and positive scans, Emilia was born happy and healthy, showing that every case really is unique.

I joined SOFT UK as their Engagement Officer and now it's my pleasure to work as their Operations Manager.

Events

SOFT Virtual Family Calls

We continue to have a monthly Expectant Families call via Zoom. This is an opportunity for families who have received a prenatal diagnosis or where there is an increased risk of Trisomy 13/ 18, to come together to chat with other families in a similar position. We all have our own experience and story to tell and welcome questions that would help anyone on this journey better navigate what lies ahead.

You're welcome to join us in a non- judgemental, safe space to come together and chat about what you're going through. Everyone is always welcome, and details of the next call can be found by emailing kate.hart@soft.org.uk.

A Call for Dads

Taking part in the recent 'Dads Call' held by SOFT UK was a great opportunity. It's one of those things that you often don't think will have much of an impact until you're actually on it, but once you're there, talking with other fathers, you feel completely differently.

As a dad who faced a Trisomy journey two years ago, I know how easy it is to bottle it all up and not really talk. It can often feel like you have to be the strong one, and I know first hand that isn't healthy.

Getting the chance to talk to other dads about their journey and share my story with them always helps to take a little of the weight off. We all shared how things felt for us, from very different places in our unique, but similar journeys.

If you get the chance in the future to join a call similar to this, that suits your situation, I'd strongly recommend it. Not only is it a good chance for you to talk about how you are, it's a chance to share something that will help others out there.

Support

New Support Groups

During the month of August, we created a new Facebook group called 'SOFT UK – Support For Families Ending a Pregnancy'. This is a closed group which can be accessed by answering a few membership questions to ensure the safety of our community and safeguard those within the group. It is a safe place to discuss your thoughts, questions and feelings with others in the same position. Please click here to access the page: **https://www.facebook.com/groups/522254565672471**

We want to ensure we offer something for everyone. So, if you have any suggestions for other groups who may benefit from meeting, please get in touch.

The following groups can be accessed here:

SOFT UK - Your Trisomy 13/18 Journey

SOFT UK - Support For Families Ending a Pregnancy

SOFT UK - Grandparents

SOFT UK – Bereaved Parents Support Group

Want To Volunteer?

We're always looking for people who are passionate about our cause to join us as volunteers. If you are interested in helping SOFT UK, and thereby the families we support, then please get in touch by sending an email to kate.hart@soft.org.uk.

The type of things on the go at the moment which you could get involved in include:

- **Furthering fundraising:** we have so many wonderful people doing fundraising for us and we really want to maximise the impact these various campaigns have. This is ideal if you have a passion for raising money or some personal experience of fundraising in the past or even if you're just bursting with ideas!
- **Stepping up social media:** it's an ever changing landscape out there and we know that there is so much more we could be doing on social media. So, if you're an expert or you have an opinion on what more we could be doing, please let us know.
- **Caring for the online community:** as we're opening up more support groups on Facebook, we're looking for people to help moderate and care-take these groups.

To find out more about what's involved or to shape a role based on your talents, please get in touch!

Professionals

Greetings from the TRIS Project

Debbie Bruns, Ph.D., Principal investigator, Southern Illinois University, USA

The Tracking Rare Incidence Syndromes (TRIS) project began in 2007. It seeks to increase the knowledge base on rare incidence trisomy conditions including trisomy 18 and trisomy 13 through longitudinal data collection, corresponding analyses and sharing results with interested audiences through presentations, publications, and online resources. The three forms of the TRIS Survey collect data focusing on common medical conditions, developmental milestones, therapeutic needs, family-related concerns, and demographic data of families with a child (living as well as deceased) with rare trisomy conditions.

Some professional colleagues question my involvement with my “research participants”. I tell them “research participants” is for people you never meet, the people who agree to be part of your project. Parents who participate in the TRIS project often become part of my life with relationships spanning many years! I am truly thankful for the privilege of seeing children grow and progress as well as assist families with decisions never thought possible such as “what type of high school experience should my daughter have?”. This longitudinal focus also gave rise to the TRIS project case studies, which have been shared around the world.

For years, I have received requests for information about the care and treatment of children and adults with rare trisomy conditions. In response, I share TRIS project publications and case studies, links to online information and help connect parents. Yet, there was a need for concise and informative modules for parents and medical professionals with information to raise awareness of the abilities and needs of children diagnosed with a rare trisomy condition. These modules can be found on the TRIS project website at https://tris.siu.edu/modules/ The include recommendations for daily and medical care from TRIS Survey results and anecdotal reports from parents and caregivers.

Finally, the last few years have seen new articles discussing positive outcomes for more aggressive interventions for children with rare trisomy conditions as well encouraging a greater role for parental decision-making. The research cited in these articles, including from the TRIS project, cannot and should not be ignored. It is exciting to witness a shift in conditions often described as “incompatible with life” being viewed as lives with worth and meaning. I thank participants in the TRIS project with helping move this viewpoint forward.

Further information about the TRIS project can be found online:
Project homepage: http://tris.siu.edu
Enrolment page: http://tris.siu.edu/survey/form/PreEnroll.php
If you have any questions, please send an email to the TRIS project at tris@siu.edu or dabruns@siu.edu

Professionals

Working With Professionals

Here at SOFT UK, we are always looking for new and important ways to support you and those who make an impact. We recently begun working on a project to reach out to health professionals, and we would love your help.

Our goal is to put together a pack that will be sent to families as they come through to us for support. This pack will include the information they need to support them and understand some of the more complex parts of their journey, and it will also include important information for the health team they are working with.

To help us make this a reality, we would love to hear your thoughts on what sorts of things you would have found valuable in a pack early in your journey. What would you have liked to have received and what support would you have liked for your medical team to have seen?

With your feedback, we can begin making this a reality, and support families further in the future with more robust support resources. We'll also be able to build connections with health professionals, and support directly.

Thank you for your feedback. We couldn't do this without you.

To contribute, please click the link:
https://forms.gle/pw98cVvBbujfRfr46