

# S.O.F.T. IRELAND Winter 2012

Winter 2012 Newsletter No.41

## Supporting each other

The support organisation for  
families of children born  
with Trisomy 13/18



Support Organisation For Trisomy 13/18 (Patau's/Edwards' Syndrome)



# *S.O.F.T. Ireland*

## *General Committee 2012/13*

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# Greetings from the chair : Fiona Hennessy



My name is Fiona Hennessy, Chairperson for 2012/2013. We lost our little girl Leah in November 2005 she had Edward's syndrome. Leah was our only daughter and she lived for just 6 weeks. It was a great privilege to be asked to become Chairperson as I have worked in different positions on the committee for the last 4 years. S.O.F.T has been wonderful to me and my family and I have made some great friends within the organisation.

I would like to thank Lorraine and Derek Thornton and John Lambert once again for all their hard work in producing another newsletter. We only produce one newsletter now every year and it is your newsletter so as members please share your stories, if it's about your special child a family occasion or a big birthday we would love to hear from you.

I would like to tell a little of what's been happening in S.O.F.T since I took over from Terry Mathews in October of 2011. We have a wonderful committee on board, we have had 7 committee meetings since last October to now. We attended a training course in conjunction with Feileacain who are the still birth and neonatal death association and 11 of the committee went to Cork for the day, learning a bit more on how to work with new families and phone calls coming into the organisation. I never realised how difficult it could be to take a phone call from a new family until the training. I was then saddened to hear that the Conroys were stepping down from their role as contact co-ordinators. Adrian and Anionette have been doing such a fantastic job for the past 2 years, I thank you both for all your hard work, time and dedication to the job, you have made such a difference to so many new families.

The biggest highlight for me so far has been the fantastic new Website. We instructed a new company to produce a new web page for S.O.F.T, I am sure you have all seen it by now. We are delighted with the pictures and the stories we have put up so far, but we need your help as members of S.O.F.T to forward us more pictures and stories and fundraising events. We would also like to put your babies' picture up on the moving video if you feel this is something you would like to do please contact Debbie Murphy our secretary who is doing a wonderful job in keeping the website updated with the latest news.

We plan to put up a rainbow and put all our special childrens names with their dates of birth and date of their passing on the rainbow. We would love to get some feedback from you, our members, on the website so please let us know what you think.

I know it has been a tough year for everyone, being in the thick of this awful recession and fund raising has been slower than previous years but there has been some great fundraising events in recent months throughout the country and with the SOFT fundraising week in June it has made you, the members more aware of how important it is to fundraise to keep the organisation running, so I thank you all for the great efforts you make as we all know the hard work that goes into organising these events.

This year we had our spring break in Killaloe Co. Clare which is set in a beautiful location on the banks of the river Shannon, with great attendance and a wonderful weekend had by all. Our younger members painted and decorated flowerpots with the name of their special child. I would like to thank all the committee and especially Eileen Cronin, Teresa Meehan, Debbie Murphy and Alma Stanley. Alma, we loved the beautiful Easter eggs with the name of our special children to hang on the tree. And I thank the rest of the committee for their great efforts in organising such a fantastic weekend and making it a great success.

On signing off I want to take this opportunity in wishing Jamie Cronin a very happy 21st Birthday, which was on the 24th of September. Jamie is one of our special children and such a loveable one.

OUR WEBSITE : [www.softireland.com](http://www.softireland.com)

# Rolling back the years



**Marie O'Conghaile**  
Chairperson 1991-1995

- Founding member
- 1st Chairperson 1991
- Sent 1st cheque £100
- Daughter Aine O'Conghaile (1986 - 1994)
- Attended 1st Conference of S.O.F.T. UK

**21 years of  
S.O.F.T.  
Ireland  
(1991 - 2012)**

**Geraldine Dodd**  
Chairperson 1995 -1998



- Respite Grants Civil Service
- Grant Links with Carmichael
- House Links with SOFT UK
- Launch of "Why My Baby" book

**Angela Lambert**  
Chairperson 1998 - 2000



- 1st S.O.F.T. website set up 1999
- 1st Spring Break
- People in Need Grant £2500 for Newsletter 1999

**Dessie Boylan**  
Chairperson 2000 - 2003



- 2001 link with Jack & Jill Foundation
- S.O.F.T. Home Support Service
- Raised £40,000 from Beach Walks etc.

**Geraldine Matthews**  
Chairperson 2003 - 2004



- Various committee positions over the years
- Letter seeking new stories for Handbook
- Daughter Ellen longest surviving Edward's child

**Martina O'Reilly**  
Chairperson 2004 - 2007



- Increase in new family contacts
- Gathered stories for "Why Our Baby"
- Celebrated 21st birthdays of Elaine and Denise

**Patrick Farrelly**  
Chairperson 2007 - 2009



- Review of S.O.F.T. Policies & Constitution
- Launch of "Why Our Baby" book
- New S.O.F.T. Website
- Great entertainer – Elvis and Tina Turner !



### **Carmel Reilly**

Chairperson 2009 - 2010



- Committee Members' Handbook
- S.O.F.T. Logo updated
- Bumper issue of Newsletter

### **Terry Mathews**

Chairperson 2010 - 2011

Vice Chair- Fiona Hennessy

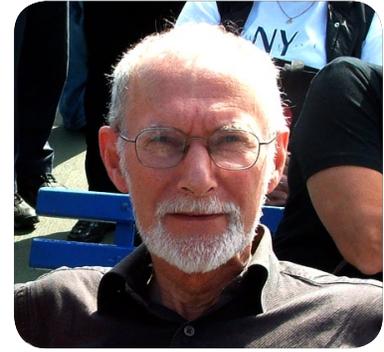


- Valentine Ball Fundraisers in Darver Castle
- Parental Leaflet October 2010
- Plans for 20th Anniversary Celebration

### **Hugh Lambert**

Newsletter editor

1997 - 2005



- Professional Newsletter every Season
- Photographer for countless occasions
- Whizz kid at all quizzes!
- Sorely missed by all at S.O.F.T.

### **First meeting**

Prince of Wales Hotel, Athlone, 15TH Sept 1991.



### **Mothers & Trisomy Children**

AGM, 2002.



### **DESSIE BOYLAN**

Dessie Boylan SOFT Cycle, 1994.



### **Lourdes**

with SOFT jackets, 2005.

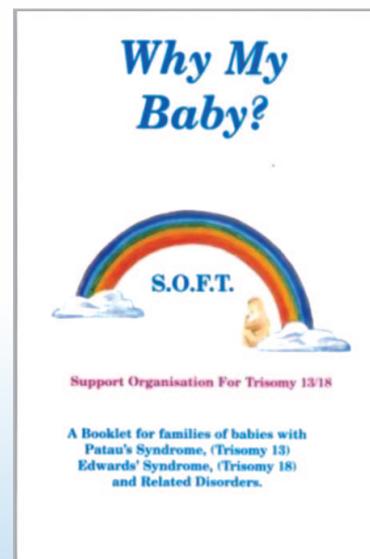




First newsletter 1991



First Colour Newsletter 1998



**SOFT Booklet**  
"Why My Baby" 1996

**Why Our Baby book**

SOFT Book Launch "Why Our Baby" 2008



*Denise O'Brien*  
1986 - 2008



*Elaine Fagan* 1986 - 2011

# Our Journey with Zakk

by Denise and Marcus Devlin

On April 15th 2009 we went to hospital for a 22 week scan to ensure all was well with our baby. This took so long that we both knew something was wrong and when we were told there appeared to be a hernia we thought it wasn't very good but we had no idea how serious it really was.

We were taken aside to wait for a Doctor who would come and explain what a congenital diaphragmatic hernia (CDH) was and what would happen now that it had been detected.

The doctor told us babies with this condition had a 40% chance of survival providing life saving surgery was carried out, normally within 48 hours of birth, and that we would be referred to the Royal Victoria Hospital (RVH) in Belfast to have the diagnosis confirmed and arrange special care and treatment for our baby after the birth.

He also told us the hospital would want to carry out further tests to ensure nothing else was wrong, probably amniocentesis and we would have to wait a few weeks to be called for an appointment and possibly a few weeks after that for results.

We left devastated and in tears but we were hopeful nothing else could be wrong and that our baby would be one of the lucky ones who would survive the surgery if the diagnosis was confirmed. We had no idea then what really lay ahead.

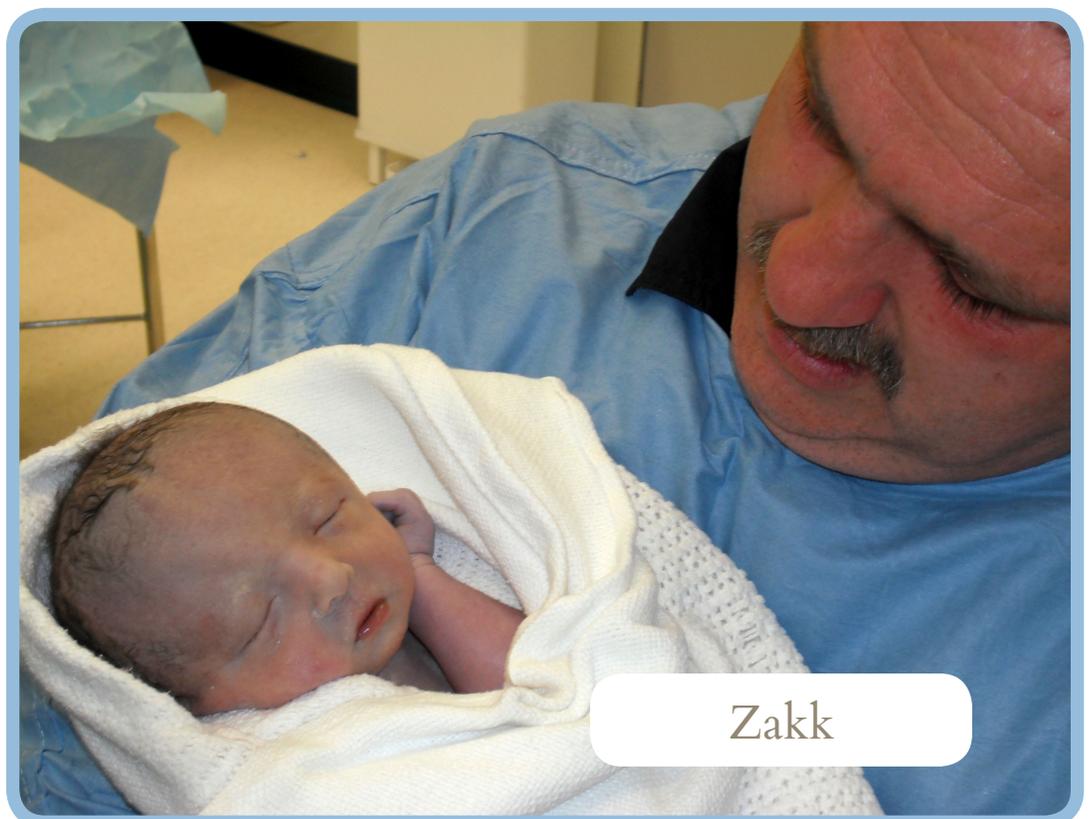
From that point every waking minute was consumed by this awful news and there was nothing we could do except wait. I began that night to research the CDH and while it was much worse than we had initially thought it was something we knew could be treated and our baby could survive to live a long, happy and full life.

On 17th April a letter arrived with an appointment at RVH the following Thursday 23rd. This set me off worrying even more as it had come so quickly. I decided we needed to stay positive and that night we decided on two names for our baby, Zakk if it was a boy. We tried to keep busy and get on with things for the next week. Marcus went to work and I spent hours on the internet learning as much as I could about CDH.

On 23rd April we headed to the RVH for our appointment. The Doctor confirmed the CDH and was very keen to carry out amnio as she put it, to rule out any other issues and ensure they had all the information possible to be well prepared and do the best they could for our baby. We agreed and it was done there and then. We were reassured as everything else looked OK although they thought the baby could have a clenched fist, but again we were reassured this was a minor thing and could be corrected.

We also met a geneticist who asked us questions and discussed possibilities with us but again from our scans she too felt any other problems were unlikely. We were booked back for a further appointment the next week and a heart scan a few weeks later, and we went home feeling anxious but hopeful that all would be well and hoping the results of the amnio would be back soon and would give us some peace of mind.

The next day I was again very anxious but resisted the temptation to research any possible genetic conditions as I felt I did not want to know and did not want to increase my worry unless I really had to know. I still naively thought the worst possible outcome would be Downs Syndrome but that I would cross that bridge if I had to and deal with it as best I could then, taking whatever child God sent me. I still had every hope my baby would live and be OK. Our daughter Cerys was just 20 months and had to go to my parents for the day so I could rest after the amnio as advised. That afternoon at 3.30 the phone rang and it was the geneticist. The call was a surprise as I had not expected to hear from her for a while. She explained the results were conclusive and our baby had Trisomy 18 (Edwards's syndrome) and there was no hope as nothing could be done, our baby would die. She confirmed he was a little boy and he could be born alive if we were very lucky but would die soon afterwards as it was in every cell. There was a high risk that he would arrive early and be still born as many babies with T18 are.



Zakk

I was so shocked I could not speak and could barely breathe. I hung up the phone and called Marcus who I could barely speak to either, I just told him to come home between sobs and gasps for breath. He left work and was home a while later. It was less than an hour but felt like several. We will never forget the devastation.

Our hearts were broken and I had never been so sad before that day. I had the ominous feeling that this was just the beginning of our heart ache. From then on Zakk was in my every thought. I was consumed by grief and my baby boy was 4 months from being born. I did the only thing I could, and went back to the computer and began to research trisomy 18. I begged God to let Zakk live long enough to let us hold him just for a little while and to get him Christened, but I had lost all hope. During our second visit to RVH we were told Zakk could not live and they confirmed no-one would do anything to repair his hernia because he had T18. It is the view of all the medical professionals I have met that T18 is not "compatible with life" as they put it and they will not intervene in any way to help a baby like ours. The Doctor advised me I could return to my local hospital to deliver the baby if I wanted as nothing would be done anyway and it would make no difference to the outcome where the baby was delivered.

We were devastated beyond belief, and every hospital visit after that just brought more bad news when we thought things could get no worse. The baby was very small, his heart had an atrioventricular septal defect with a ventricular imbalance (AVSD), no surgery would be done for this or the CDH as he was "not compatible with life". I got so sick of hearing this from doctors I wanted to shout at them all "who are you to tell me my child doesn't deserve to live", and yet I was intimidated by their expertise and while I later questioned many things, initially I accepted what I was told and felt hopeless.

We were advised to consider a termination which I could not even think about as this was my baby and Zakk was already as much a part of the family as my other children. I could not let him go or play any part in ending his life earlier than God intended.



I cried day and night but I kept on looking at the internet and came across Pre-natal Partners for life and a few other web sites where I saw children alive and doing well despite having T18 or other serious chromosome disorders. I contacted some of these web sites and found other parents who understood the dark place we found ourselves in as parents of a child with a very negative pre-natal diagnosis. From this sprang hope that all was not lost and from this hope we both began to pick ourselves up as we realised Doctors don't know everything, babies just like ours can and do survive, and sometimes even miracles can happen.

It was this hope we needed to help us through each day, greatly aided by the support and prayers of others. From then on my days were filled with lots of research, I thought if I could find the right Doctor he could help us save Zakk. I was upset that no-one I spoke too would agree to help keep Zakk alive and this for me was the hardest thing to accept. I knew my child's life would never be like my other children. He would probably not communicate as they did or be as able bodied but I could not accept that he didn't deserve to live, or that no-one was prepared to help us keep him alive when that was the only thing I wanted.

When I went back to my local hospital we were asked to attend a meeting where we were formally advised nothing would be done to assist our baby live, and what would happen when he died. We were told about the mortician and asked to think about what we wanted regarding taking our baby home and where we would bury him. We were told there was no rush in making these decisions until the time came, but we needed to "bear them in mind"... I think part of the hospitals motivation was to also try and re-assure us that we would not be put in the post natal ward with other babies, and they would do their best to give us privacy in our grief, but I was distraught by the whole thing. Our precious son was being written off by Doctors months before he was even born and no-one could understand the shock of hearing these things unless they too have been in the same situation. Instead of looking for a new pram we were now deciding where we wanted to bury our baby son and feeling under pressure to make such awful decisions in-case he arrived early as predicted.

Never before had it even occurred to me despite years of life experience that anyone ever carried their unborn child for months with such a heavy burden. I even knew family members who had lost babies and still it had not registered with me that anyone could know so far in advance and go through months of anxious waiting and hoping. (continued on next page) >



I have always struggled to accept no-one could help Zakk, but I could find no-one within my reach who said they would or thought there would be any point. Everyone I spoke to felt that with his combination of problems it would only cause him unnecessary suffering to artificially prolong his life by attaching him to machines, nor did anyone feel he would be able to survive surgery. I just feel that if I had unlimited resources or lived somewhere else maybe he would still be here with us now. Or maybe I just didn't try hard enough to find a more sympathetic Doctor. Knowing I was treated within the policy guidelines of the National Health Service in the UK does not console me in any way. I continue to struggle with accepting these decisions even now, and can only pray that some day I will be at peace with them. Although I can't help feeling these policies are wrong and a parent should have a right to choose to ask for more aggressive measures to be taken in an attempt to save their child if at all possible rather than be forced down a route of comfort care if it is not what they want.

We had a number of family birthdays between May and August and we lived through all these events in an almost auto pilot fashion. We went through the motions, celebrated the birthdays and tried our best to act as normally as we could, while all the time hoping and praying Zakk would by some miracle be born alive and be OK. I had trouble sleeping not helped by the usual pregnancy issues as I got bigger. Everywhere I went it seemed like the world was pregnant and I was the only one whose baby was going to die. I got really cross when I saw pregnant women smoking or worse, drinking alcohol and sometimes I wondered what I had done to upset God so much. I had been so careful to stay as healthy as I could and have a proper diet and this was what I got for all my careful care of my unborn child. I felt guilty for thinking previously Downs Syndrome would be so terrible and wished that Zakk had this instead as at least he could live. I bitterly regretted allowing the Doctor to carry out the amnio test as I felt they would still be planning for surgery and doing all they could to help Zakk had they not known for certain he had T18. Realistically I know that they would have soon figured it out after he was born, but I still feel we would have got more time with him as they would have helped him even for a little while in the absence of this information. The next few months were filled with hopeful anticipation as we approached the birth of this very special child, coupled with dreading the day as I knew Zakk was safer where he was. I didn't want him to be born, knowing he would face such a great struggle to live and I would not be able to help him, nor could I find any Doctor willing to do anything except agree to give him a little oxygen if he was born alive and struggling to breath.

Every day I carried Zakk was a blessing. Every move and kick was a great joy, much more than with any normal pregnancy as my little boy was reassuring me he was alive and well and getting stronger. I had been told I would not feel much as he would be weak and very small, so when I felt Zakk it was wonderful. Doctors don't know everything.

Zakk moved well and did not feel weak or small and with every movement my hope strengthened. Many others helped us through this journey. One very bad day my sister sent me a text message containing a little prayer:

*May God grant you the strength and faith to count your blessing, not your crosses, count your gains, not your losses, count your joys, not your woes, count your friends, not your foes, count your smiles, not your tears, count your courage, not your fears.*

Gradually my mood changed as the time went on and Zakk continued to defy the odds and live. My hope grew with the help of people who were there for us when we needed support, my family and close friends and those in the Trisomy family who have also been down this road. Just knowing that others remembered us and many people we were unlikely to ever even meet in person kept us in their prayers brought great comfort and strength and helped us face each day with hope rather than hopelessness. I read a lovely poem on the Prenatal partners for life web site, "God sent to me an Angel", and it has helped me through many dark days then and now.

To me my baby was perfect and special and I loved him. I prayed for minutes, I wished for hours and I hoped God would grant us the miracle of days. Every single movement Zakk made each day made up for all the worry and upset we went through. Every second I carried him really was precious and I only wish now I could turn back time and feel him move once more. I went to the Doctor or Midwife weekly to check he was alive and had a heart beat and Zakk kept reassuring me he was OK. The appointments with the Midwife were OK as I only saw one of two midwives and they were both great, very encouraging and supportive, but I hated the Doctors appointments as I was waiting in a room full of other pregnant women and I so wanted to be just like them with their healthy babies.

Life is full of unexpected twists and turns. I had always feared having a child with a serious disability and wondered irrationally if this was my punishment. I knew the risk increased as I got older I just always thought I could never cope and now I found myself having just such a child and hoping and praying he would stay with me and not die. I just wanted Zakk to live and not be suffering or in pain. I didn't mind what he could or couldn't do, I just wanted him with me and I promised God I would look after and cherish him no matter what. It is a strange thing to wish if only your child could have had a less serious chromosome disorder such as Trisomy 21 as at least it would not be as the Doctors described T18 a "lethal Trisomy".





Zakk did not come early, and the week before my due date I was persuaded that to give him the best possible chance and avoid putting him through the trauma of a natural birth I should have a caesarean section as his heart coupled with the CDH and T18 left the situation very dire. We were booked in for 11th August and suddenly Zakk's birth was upon us far too soon.

So many times before he was born I wondered what would happen. I hoped and prayed for a miracle, and I wondered how I would get through if my miracle didn't come.

Zakk came into the world on 11th August 2009 at 12.10pm weighing 5 lb and looking just like the perfect and beautiful Angel he is. He was given a little oxygen as promised to help him breath, and was Christened straight away as we had wanted. After a few minutes a paediatrician came to speak to us and advised us the oxygen was not helping and he would only live another minute or two and we were asked if we were happy they stopped and gave him to us otherwise we would not get to hold him alive.

We didn't want to waste his last few minutes and we wanted to hold him in our arms so he was handed to his Daddy at which point he opened his left eye to the Doctors surprise. When I took him in my arms a few minutes later I just talked to him and begged him to be strong and hold on for us as long as he could. I was so desperate he would live but I knew in my heart he was very weak and it was a great struggle for his little lungs to breath and his little heart to keep beating.

Despite everything and to the amazement of the paediatrician our brave and precious son lived on for 70 minutes and got to meet his big brother and sister and his Granny, Granda and Aunt. He fought as hard as he could to live, and passed away peacefully in his Daddy's arms surrounded by those who loved him most in the world. My prayers had been answered.

I could not have asked God for any greater gift than being Zakk's Mummy. It was the greatest honour and privilege of my life to carry him and hold him in my arms. I know I will have to live a lifetime on the precious but all too short time I had with him. I know somehow I will get through my grief and life will go on. I know too that there is a reason why we were blessed with such a special and inspirational child, and while his time with us was very short, he has forever changed our lives and the lives of those closest to us.

We spent the next two days with Zakk in hospital by our side, and then we took him home to meet the rest of our family and friends. He stayed with us until the 15th August, his original due date, when we had a very moving funeral service for him at home with a mass in his honour and later we laid his little body to rest.

Nothing could be so precious as the brief time we held Zakk in our arms while he fought for life, but every minute we spent with Zakk over those four days was also precious to us and we will always treasure this time. We got to say goodbye properly to our little boy and he has left behind everlasting memories.

I cannot begin to explain how devastated we are by his passing, but nor would we have missed this journey for the world. He is our inspiration and reason to go on. I know that we will eventually learn to live with this great loss, and until then we will remember how brave he was and how hard he fought to stay with us and these thoughts of him will help us through.

I will never be the person I used to be, Zakk has forever changed me for the better and I believe this change will continue to happen for as long as I live. This journey has renewed my faith in human nature as I have been overwhelmed by the support of all those who travelled this path with us, and he has renewed my faith in God as I know for certain Zakk's spirit lives on and he is with us always Our precious Angel.

For this child I prayed and the Lord has given me what I asked of him, so now I give him to the Lord...(Samuel 1:27-28)

*by Denise and Marcus Devlin*

\* You can see a slide show of our precious sons journey if you type "Zakk Our Angel" into Youtube.

Very unexpectedly in late 2010 we discovered we were to be blessed with another baby. I cant say the pregnancy was easy as I was very stressed and worried for most of it. Though I took some comfort from his size on scans I refused to have any tests done as I could not put another baby in a position where doctors could refuse to treat him because of a prenatal diagnosis.

Jake Brody was born on 23rd May 2011 and weighed 8lb 9oz. He is the most wonderful little boy, a little miracle. He is a happy and contented baby and I look at him everyday and feel that he is a beautiful gift from his big brother Zakk.



Jake Brody



# SPRING BREAK 2012

## in The Lakeside Hotel, Killaloe

The Spring Break this year took place in the lovely Lakeside Hotel in Killaloe, Co. Clare in March 2012. A wonderful morning was spent painting plant pots with our special babies and children's names on, which we all took home along with sunflower seeds to do our own planting in our special pots. A relaxing afternoon was spent swimming and walking around the beautiful village of Killaloe.

Arts & Crafts morning



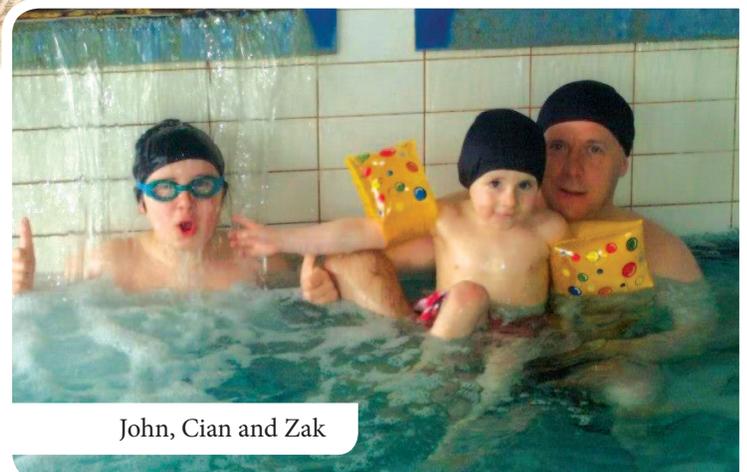
Joanne Mellows



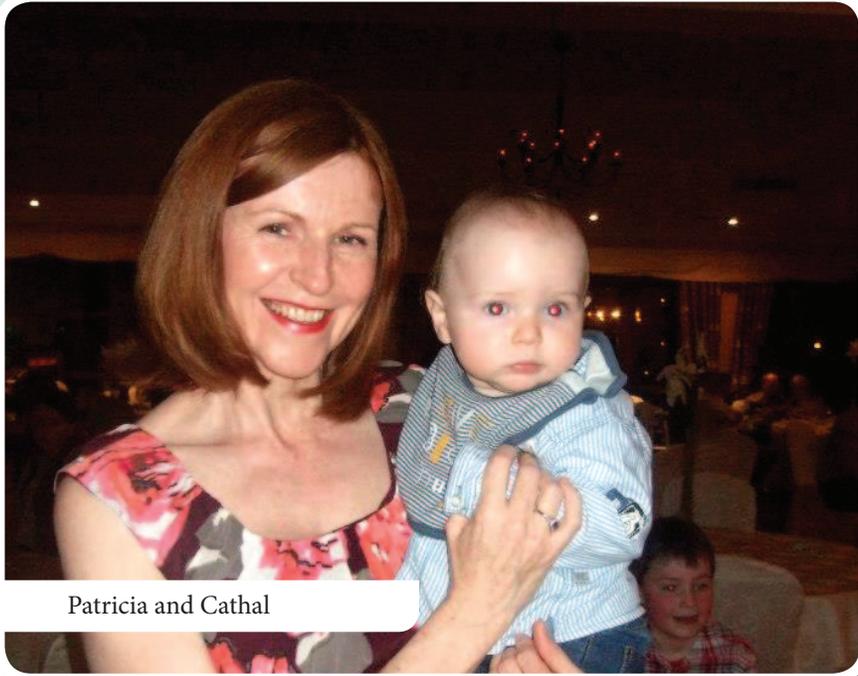
Vanessa



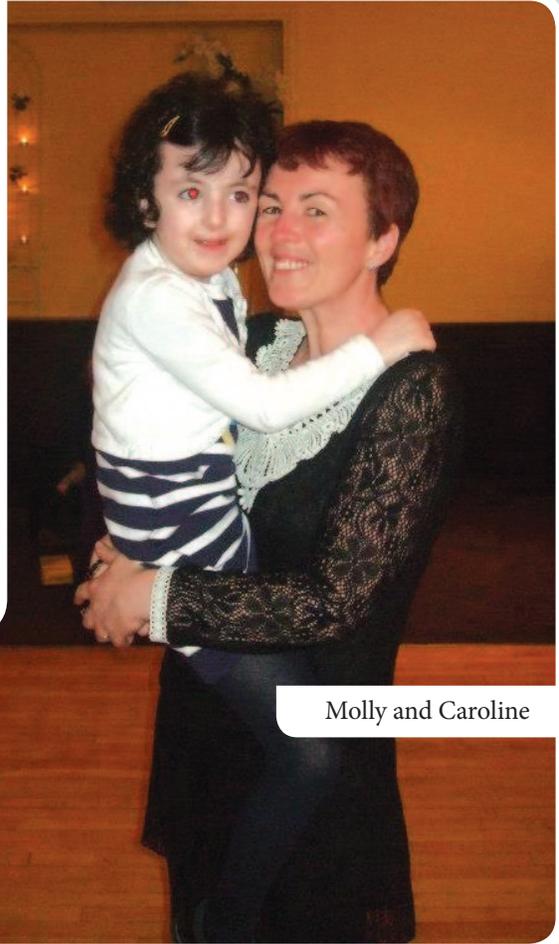
Debbie and Rebecca



John, Cian and Zak



Patricia and Cathal



Molly and Caroline

In the evening we all had dinner together and we had a special birthday to celebrate too - Terry Matthews 50th!! On Sunday, it was time to say goodbye and prepare our balloons for our special children to all let go off together.



Alma Stanley

**Happy Birthday Terry!**



(From left) Danny, Aoife, Niamh with Terry & Geraldine.

# Donations & Fundraisers

As a charity organisation, S.O.F.T. Ireland relies on fundraising and donations to continue to offer support to families. We are extremely grateful for any contributions received – without which we wouldn't be able to continue the work that we do.

## THANK YOU TO...

**Phyllis McCrory and family** in Co. Tyrone who organised fundraising in memory of their daughter Derbhla who was born with Edwards Syndrome. Adrian Leonard, a friend of the family helped with the fundraising by running the Dublin City Marathon

**Carmel Reilly** in Athlone organised a sports day for the children she minds.

**Helena Harcourt, Maggie Reilly, Nicola Harcourt, Marie Collum and Aileen Shaw** took part in The Mayo Mini Marathon in May.

**Lisa O'Riordan** and family took part in The Cork Mini Marathon in memory of baby Roisin.

**Kelly Collins** in Listowel, Co. Kerry a friend of Brian & Ellen Mulvihill ran The Flora Mini Marathon in memory of Darren.

**Carla Quinn** a friend of Alison Fleming ran the Longford Marathon in memory of Baby Matthew.

**Terry Matthews** 50th B-day - No Presents all donations to S.O.F.T. Ireland.

**Geraldine Dodd** took part in the Mini Marathon

**Caroline Dempsey** organised Non-Uniform days in 2 Primary Schools (Ticknevin Natational School, Kildare & St. Conleths, Kildare) & 2 Secondary Schools (Oaklands College & St. Mary's Secondary) also held a Table Quiz in The Community Cabin. > *Continued next page*

## 'Youghal Coffee Morning'



Anne Ria (left) proprietor of La Bella Roma and Fiona Hennessy Chairperson of S.O.F.T Ireland (right).

We had a wonderful coffee morning organised by our Chairperson Fiona Hennessy at the fabulous La Bella Roma restaurant in Youghal on 15th March 2012.



Fiona Hennessy with Staff of La Bella Roma, Youghal, Cork.



Thank you to Students from St Ultan's National School, Navan 6th Class Confirmation Class for their wonderful fundraising.

## AND ALSO TO...

**Fiona Kehoe** who ran the Flora Mini Marathon, Dublin on behalf of her sister Ann and family who had a little boy Christopher with Patau's Syndrome who survived for 5 days.

**Fiona Hennessey** organised a Coffee Morning in Cork.

**Alma Stanley & Joanne Mellows** organised a Coffee Morning in The Black Bull in June in memory of their babies Lily May and Darren who had Edwards Syndrome

**Geraldine Healy** organised a fundraising Race/Walk in Kilmeeady, Co. Limerick on 3rd August 2012

**Mary Rispins** - St. Ultans N.S. gave a donation from the 6th class after they made their Confirmation **Sarah Martin** a transition year student in Loreto Secondary School, Bray along with her friends took part in a project called Mini Company. Her group called The Can, Can, Girls were awarded overall best mini company by the Enterprise Board. As a class, proceeds were donated to S.O.F.T Ireland in memory of Sarah's baby sister Christina who passed away in 1999 with Patau's syndrome.

**Cathy Newman** Aunt of John Newman (Sarah-Janes Dad) organised a Coffee Morning in her local Gym (Energie in Rathfarnham) on 7th Sept to raise funds for S.O.F.T. Ireland.

**Breda Masterson** cousin of Michelle Bell (Sarah-Janes Mum) organised a fundraising event "Showing we care" in The Snug House Pub in Kildalky, Co. Meath on 31st August.

**Michelle and Michael Griffin along with friends and family** climbed Crogh Patrick 22nd Sept in Memory of Ethan.

**Enda Mannion along with his brother and brother in-law** ran the Dublin Marathon 29th October in memory of Baby Lily Ann.

**Marie-Claire Hendricken** ran The Dublin Marathon on 29th October in memory of Baby Christopher Rooney.

**Sam Donohoe**, son of Allison organised a Non-Uniform Day at his school, Scoil Assaim Boys National School in Raheny, Dublin 5 on 16th November. Sam and three of his closest friends, Brian, Liam and Michael made powerpoint presentations in each class and put up posters before the event in order to raise awareness of S.O.F.T Ireland.

Thank you so much to everyone, everywhere who has taken part in fundraising for S.O.F.T Ireland.



Orlaith O'Brien with family and friends.

**Drogheda joint fundraiser**  
with the Jack & Jill Foundation

We also had a joint fundraiser with the Jack & Jill foundation at The Black Bull, Drogheda with Alma Stanley and Joanne Mellows.



Julie, Ann Marie, Suzanne, Jennifer and baby Adam.

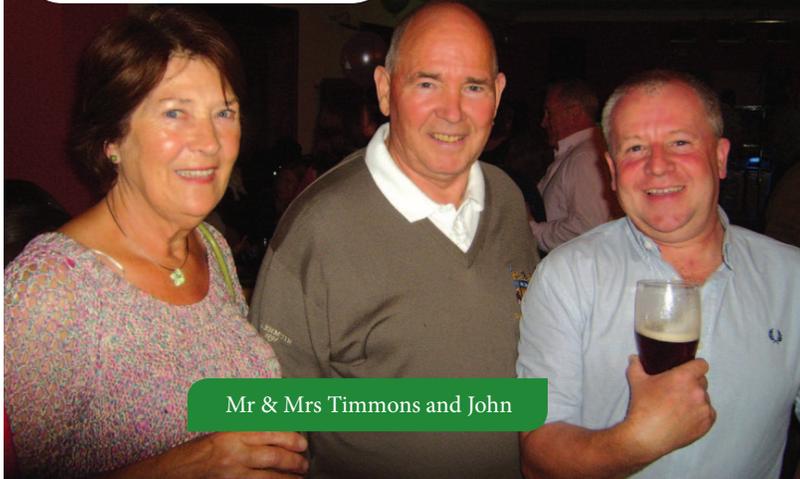
# Rainbows

Rainbows would never be rainbows  
If sunshine had never met rain.  
No one would ever need comfort  
If there were no sadness and pain.  
But life holds both sunshine and showers  
The days aren't all bright and fair.  
So look through the showers for the rainbows  
You'll always find hope shining there.

Breda, Sarah Jane & Assumpta



Katrina & Michelle Bell



Mr & Mrs Timmons and John

## Showing We Care Fundraiser

The Snug Pub, Kildalkey, Co. Meath

“Showing We Care Fundraiser was held in The Snug Pub, Kildalkey, Co. Meath on 31st August 2012.

The event was organised by family and friends in particular, Breda Masterson and her mam Assumpta who are cousin and Auntie to Michelle Bell. Michelle and John are mammy and daddy to Sarah-Jane who is now 8 months old and Sean.

A big thank you to local musicians who entertained for free on the night. Local and not so local businesses who donated raffle prizes and items for auction. Also many thanks to The Snug Pub, family and friends who supplied food and thank you to everyone, everywhere who helped make this fundraiser such a success.”

# Rebecca's poem

My brother Jake, he was not well.  
We've known it for a while,  
but still my brother Jake arrived,  
and blessed us with his smile.  
So angels up above I pray,  
that you will gather round,  
and welcome up my brother Jake,  
into your cool play-ground.

Even the smallest of feet have  
the power to leave everlasting  
footprints upon this world.



Written by Rebecca Murphy for her brother Jake.

## Fundraising Ideas

### **AUCTION**

Bag packing in your

Local Supermarket

### COFFEE MORNING

### **70's/80's Disco**

### **5 A-side Football**

Head and Beard sponsored Shave

### SPONSORED WAXING

*Table Quiz Night*

### NON UNIFORM DAY

### POKER NIGHT

### **Race Night**

*Social Night* (e.g. 21st, 40th or Anniversary)

### JUMBLE SALE

### **Car Boot Sale**

**Floral or Cookery Demonstration**

*Valentine Ball*

Sponsored walk, cycle or swim

Come dine with me

*Music night (traditional, classical etc.)*

## Would you like to help with Fundraising?

As a charity organisation, S.O.F.T. Ireland relies on fundraising and donations to continue to offer support to families. We are grateful for any contributions received – without which we wouldn't be able to continue the work that we do. We would encourage all members and their families to consider organising a fundraising event, or to make a contribution. Fundraising is also a great way of raising awareness of our organisation within the general public. It is possible for everybody to fundraise and it does not matter how small or large the event is.

If you are interested in organising a fundraising event but are not sure where to start, you can contact a member of our fundraising sub-committee for advice, suggestions and information. We will provide you with sponsorship cards, balloons and t-shirts if required. We will also include details of upcoming fundraising events on our website and in our newsletter and would ask members to support events in their local area, or other members participating in sponsorship events. For some of our nationwide fundraising events it may be possible to have a selection of our merchandise on sale.

All monies received will be put to good use in supporting families. For example your contribution could help us to cover the cost of annual postage to our members, distribute our information booklet 'Why our Baby', develop and maintain our website, publish our newsletter, fund bereavement counselling and respite assistance and to subsidise our two annual family events. (Spring break and Autumn A.G.M. Break).

#### **Fundraising Committee:**

Alma and Chris Stanley - (086) 2606791 (Alma)

Michelle and Michael Griffin - (087) 1489031 (Michelle)

Anna O'Reilly - (087) 6699810

## Tips to get you started in organising your Fundraiser

1. Decide on your fundraising event.
2. Let S.O.F.T. Ireland Website Officer know all the details of your event so he/she can post it onto the website to let everyone know about it.

3. Make a list of the people you would like to invite (family, friends, work colleagues, community etc.)
4. Pass on the invite to these people about your fundraising event asking them to come and join you or sponsor you.
5. Spread the word about your fundraising event verbally, through facebook, texting, displaying posters contacting local newspapers & radio stations. (This also helps to raise awareness of our organisation within the general public).
6. Contact Alma or a member of the fundraising committee in S.O.F.T. Ireland regarding S.O.F.T. Ireland t-shirt, sponsor cards, pull-ups, balloons, posters etc. so you will have them in time for your fundraiser.
7. Always keep track of monies received in and on sponsor cards that you have given out.
8. Approach local businesses for help and support with spot prizes if you are holding a raffle.
9. Remember to talk to your local Gardai regarding holding raffles or selling tickets. A permit may be requested.
10. Always acknowledge a 'Thank you' to everyone who helped and supported your event. It is a good idea to put a piece in your paper to acknowledge how much money you have raised and to show that the money has been forwarded onto S.O.F.T. Ireland. (Whether it's €10, €100, €1000 or €10,000 EVERY LITTLE HELPS.)

# Rainbow Day

## S.O.F.T. Ireland Fundraising Week

30th September 2013 - 4th October 2013

Like many charitable organisations S.O.F.T. Ireland relies so much on money raised through fundraising. With this in mind we have come up with an idea of holding a S.O.F.T. Ireland Rainbow Day. The idea would be that we get as many families as possible in S.O.F.T. to approach their Local Primary Schools or Secondary Schools and ask them would they like to take part in our Rainbow Day to help highlight and make more people aware of Trisomy 13 (Patau's Syndrome) and Trisomy 18 (Edwards' Syndrome).

The idea would be to get as many schools around Ireland to hold a Rainbow day. In which each child would be able to either wear a t-shirt in one of the colours of the rainbow and bring in €1 to participate in this event.

We have dedicated the week of 30th September 2013 to 4th October 2013 as the week when we will all hold Rainbow Days throughout the country.

A standard letter to the Principal/Schools will be drafted closer to the end of this year.

Contact Alma Stanley (086) 2606791 or email: [droghedastanleys@gmail.com](mailto:droghedastanleys@gmail.com) if you would like to get involved.





The Roches

# AGM ATHLONE 2012

The AGM this year was at The Athlone Springs Hotel in Athlone Town in October 2012. This year we have purchased a SOFT Tree where we can attach leaves with our special children's name on and this will be something that we can bring each year. The children got involved in arts and crafts and painted their hands on canvases which was a lovely idea and each family got to take these home. The AGM went very well and new committee members have come on board, which is so important and helpful.

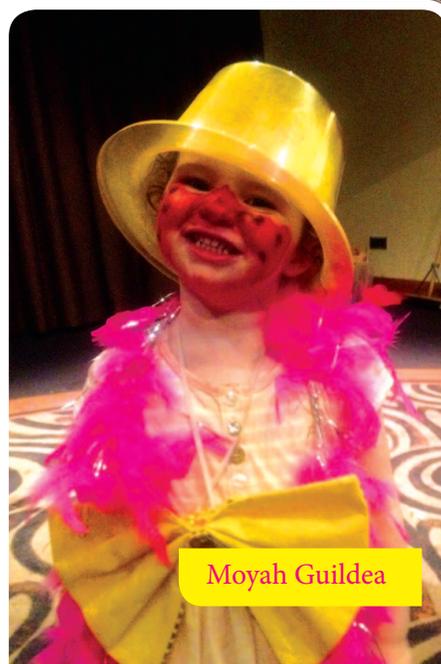


John Newman

Sarah Jane



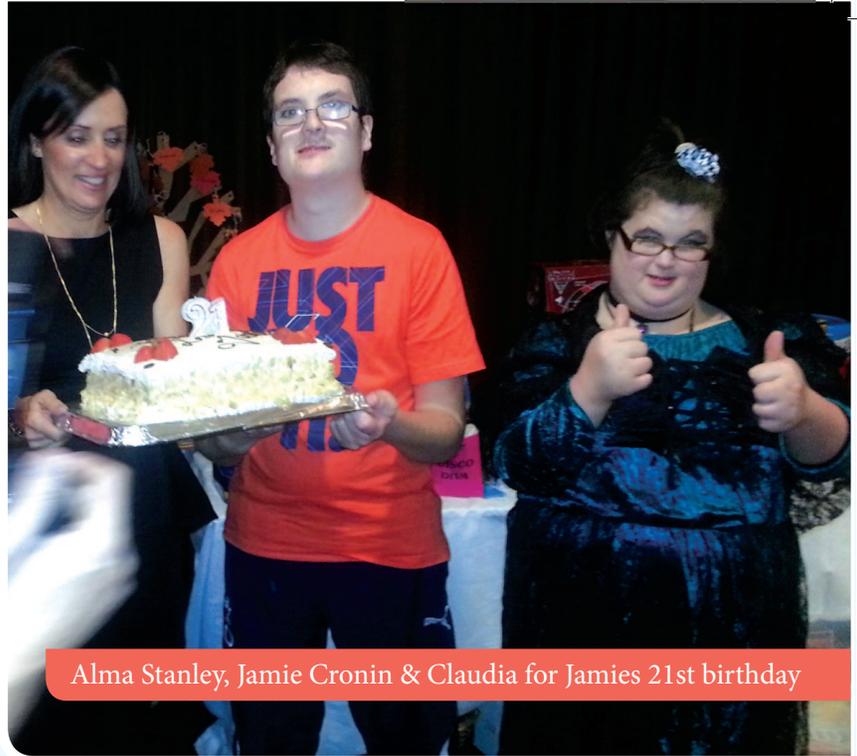
Matthew Mannion, Granny Ann and Chloe Mannion



Moyah Guildea



Tom & Jane Stanley

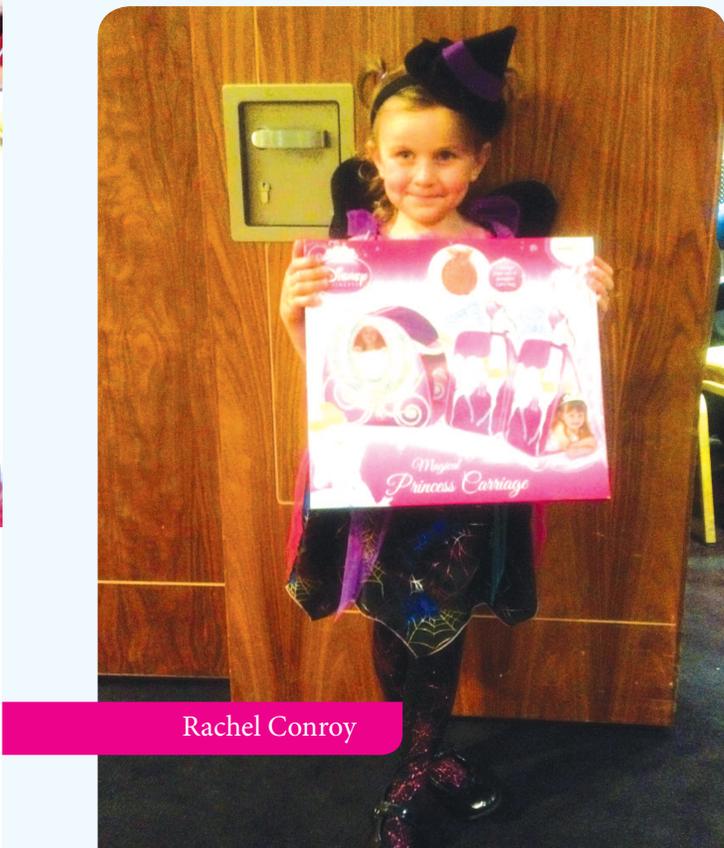


Alma Stanley, Jamie Cronin & Claudia for Jamies 21st birthday

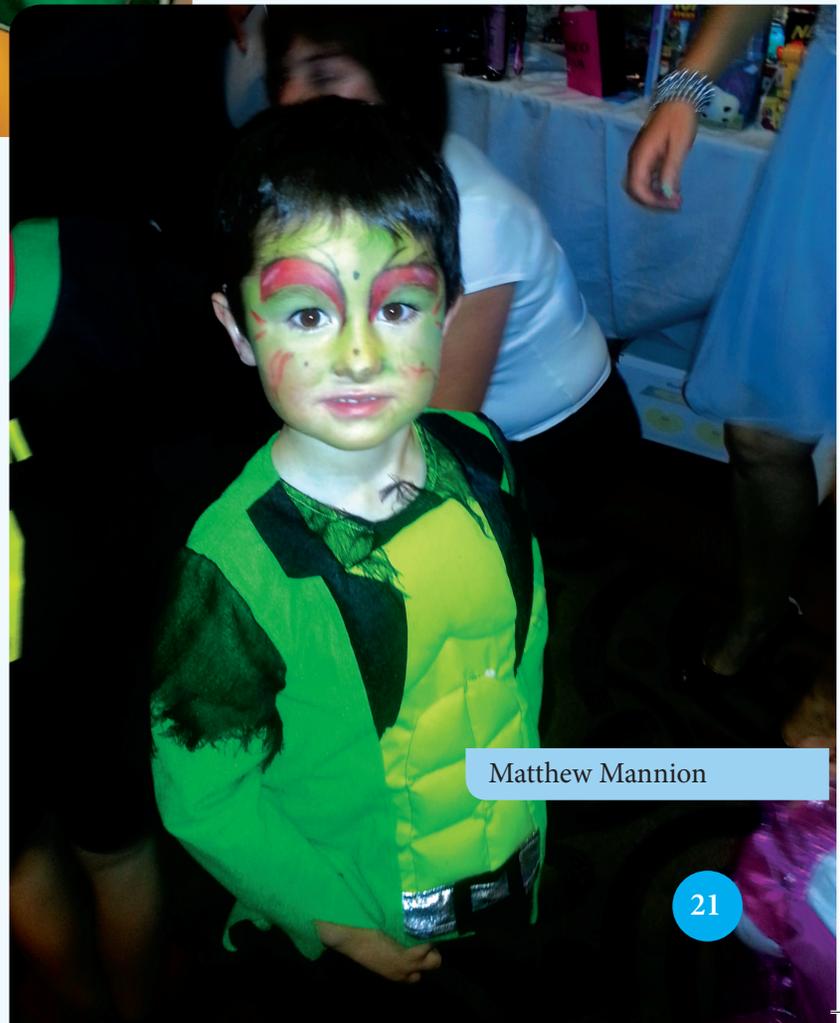


The Casey boys

We all shared in a beautiful dinner and again had a special birthday to celebrate - Jamie's 21st!! Jamie really enjoyed his wonderful cake and all the attention from all the girls. On Sunday, we all got together again to say goodbye and let our balloons go together, as one.



Rachel Conroy



Matthew Mannion

# Lily

Lily is a flower  
With courage and strength  
She kept on fighting  
Till the end  
We cherish the time  
We shared with you  
Although it was short  
The memories will always stay true  
You're in a good place now  
In Heaven above  
You have lots of family there  
To give you their love  
Sleep well little flower  
And we'll meet soon  
Up there in Heaven  
Beneath the stars and the moon.

*For Lily Mannion written  
by her uncle Damian Mannion*



## S.O.F.T. IRELAND TAPESTRY

S.O.F.T. Ireland are putting together in memory of all their special children a Tapestry Wall Hanging that will be displayed at their Spring and Autumn Breaks. If you would like to have your special child's name and date of birth embroidered on their own square with either blue or pink tiny footprints in this tapestry please contact

**Alma Stanley on (086) 2606791.**

# A Poem to our daughter Róisín

Róisín, you were lying in our arms,  
As we tried to say goodbye,  
You fought for every breath you took,  
Never letting go,  
Until one day God made you His,  
Leaving all of us below.

Although you couldn't walk or talk,  
Or even count to ten,  
Your short life had more impact,  
Than a hundred million men.

Gentle Saviour please look down,  
Róisín's by your side,  
A small bewildered three and a half month old,  
That needs you as her guide.

At night when I fall asleep  
She is all I dream of...  
My Little Róisín who's always had my heart,  
My angel from above...  
I want to hold her in my arms,  
and tell her how much we love her.

**Róisín's parents are  
Lisa O'Riordan & Patrick Rowe from Cork.**



Róisín visits Santa Claus



# *Coping with Christmas when you are bereaved*

Christmas can be such a magical time to be shared with family and friends but it can also be a very sad time for those of us that have lost a child, the build up to Christmas can be very difficult to cope with. The following information has been adapted from a leaflet entitled "Coping with Christmas when you are bereaved" which is produced by the 'Bereavement Education & Resource Centre at the Irish Hospice Foundation'.

Few people get through the Christmas season without some sadness, even if they have not been bereaved. There is something about Christmas that tends to make us emotional.

Most of us have strong memories of childhood Christmases – both good and bad – and we recall them each year as Christmas draws near. The first Christmas without our baby or child that has passed away can bring many challenges. This can also be the same for those bereaved for many years. Whatever our particular circumstances, it is important to remember that we are grieving and that we need to pace ourselves and be gentle with ourselves. We need to remind ourselves that it is only one day and we can get through it.

The following points are offered as suggestions, but remember that you are the best person to decide what will work best for you.

If you have been bereaved this year, remind yourself that the grief journey takes its own time and that most people experience days when they are coping quite well and other days when they feel ambushed by their grief. Just getting through the day can sometimes be a challenge. It may well be a very sad Christmastime for you, but, even on the most difficult of days, something unexpected may happen that lifts your spirits even for a few moments – it may be carol singers, the sound of excited children laughing or a thoughtful note through the letterbox letting you know that others are thinking of you at this time.

At S.O.F.T Ireland we are all united in our grief at this time, and throughout the year. Knowing that you are not alone at this time and that other families and couples are experiencing similar feelings and thoughts may lighten the load a little.

## *Planning ahead*

Acknowledge that Christmas will now be different and that while we may choose to keep some traditions, others may have to be changed or dropped altogether. Ask yourself which traditions are important to you and what you can reasonably cope with this year.

## *Keeping things simple*

Think about what is meaningful and realistic for you and discuss this with other family members. You might, for example, decide that you want to visit particular close friends or attend a religious service. You might decide against an elaborate dinner or putting up decorations. Each person and each family will have their own preferences and, as much as possible, these preferences should be honoured.

## *Beginning new traditions*

Begin new traditions if you think it might help. Some people begin traditions such as visiting the grave on Christmas Eve and putting a special arrangement there or if they are not near the grave, lighting a candle. Some people choose to make a donation to a charity in the deceased person's name.

## *Being open*

Let the people around you know if you are comfortable talking about your baby or child that has died. If you do not mention their name, others may assume that you don't want them to mention it either.

## *Accepting help*

Accept offers of help, both practical and emotional.

## *Taking your time*

Plan some quiet time for yourself. Grieving is tiring and energy sapping. When you can, lie down or take a short walk. If you accept invitations, give yourself the option of changing your mind or leaving early if you need to.

## *Inclusive planning*

If there are other children in the family, try to include them in the planning. Ask them for their ideas on how to spend the day. Young children may need to be reassured that Santa is still coming and to know that it is OK to enjoy Christmas even if people are sad.



# Small Bump

by Ed Sheeran (Lyrics)

You were just a small bump unborn, four months then brought to life,  
You might be left with my hair, but you'll have your mother's eyes,  
I'll hold your body in my hands be as gentle as I can,  
And now your scan on my unmade plans,  
Small bump four months then brought to life

I'll hold you tightly, I'll give you nothing but truth,  
If you're not inside me, I'll put my future in you

You are my one, and only  
You can wrap your fingers round my thumb and hold me tight  
Oh you are my one, and only  
You can wrap your fingers round my thumb and hold me tight  
And you'll be alright.

You're just a small bump unknown and you'll grow into your skin  
With a smile like hers and a dimple beneath your chin  
(Oh) Finger nails the size of a half grain of rice  
And eyelids closed to be soon opened wide a small bump,  
In four months you'll open your eyes

I'll hold you tightly, I'll give you nothing but truth,  
If you're not inside me, I'll put my future in you

You can lie with me, with your tiny feet when your half asleep,  
I'll leave you be  
Right in front of me for a couple weeks  
So I can keep you safe

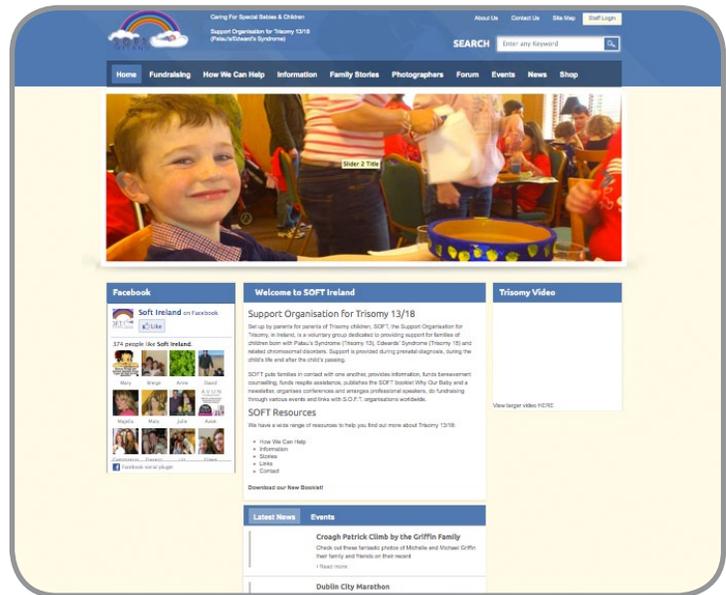
You are my one, and only  
You can wrap your fingers round my thumb and hold me tight  
Oh you are my one, and only  
You can wrap your fingers round my thumb and hold me tight  
And you'll be alright

You're just a small bump unborn just for four months then torn from life  
Maybe you were needed up there but we're still unaware of why

# Our Website

[WWW.SOFTIRELAND.COM](http://WWW.SOFTIRELAND.COM)

Don't forget you can find us online at [www.softireland.com](http://www.softireland.com) which contains comprehensive information about Trisomy, stories from our members, informative articles and much much more. There is also a free download of our 'Why our Baby' book and this newsletter too.



# Your Newsletter needs you

**Don't forget you can download this newsletter from our website**

## Send us your stories & pictures

Please don't forget that this newsletter wouldn't exist without contributions from our wonderful members and that means you. So if you'd like to send on a poem or a child's painting or write us an article or a personal tribute or photographs from any S.O.F.T. related events we would be over the moon to receive them.

## By Email

If possible it would be great if you could double check that your jpgs (photos) are of reasonable size for printing. Middle size is perfect which should be approximately 1mb in size. You can send any photos or written text directly in an email or a word document to

**Email [softnewsletter@gmail.com](mailto:softnewsletter@gmail.com)**

## Mobile Phone Appeal

If you or any of your family or friends have any old mobile phones, we would be much obliged if you could collect as many as you can and bring them to the next AGM where we will collect them from you.

Other ideas may be to send out a group text to friends asking for old phones or even to ask in your local mobile phone shop to see if they have any they don't need. Your help is greatly appreciated as this will help raise funds for S.O.F.T.

## By Post

or if your not too great with computers just pop it in the post to :

**Lorraine Thornton,  
130 Cimin Mor, Cappagh Road,  
Barna, Galway**

# KIDS CORNER

## JOKES

Whats full of T, starts with T and ends with T?  
A teapot

Why should bowling alleys be quiet?  
So you can hear a pin drop.

What do elves learn in school?  
The elf-abet.



What kind of star is dangerous?  
A shooting star

How do fleas travel?  
By itch-hiking.

What colour is a burp?  
Burple.

What kind of tree do fingers grow on?  
A palm tree.

What is Tarzans favourite christmas carol?  
Jungle Bells.

## COOL FACTS



In Tokyo, they sell toupees for dogs



A sneeze travels out your mouth at over 100 m.p.h.

Human teeth are almost as hard as rocks

A dragonfly has a lifespan of 24 hours

A cat has 32 muscles in each ear

Slugs have 4 noses. Reindeer like to eat bananas



$111,111,111 \times 111,111,111 = 12,345,678,987,654,321$

# We're here to help



Support Organisation For Trisomy 13/18 (Patau's/Edwards' Syndrome)

## **S.O.F T. Ireland provides support by:**

- Putting families in contact with one another
- Providing information
- Funding bereavement counselling
- Funding respite assistance
- Publishing the SOFT booklet Why Our Baby and a newsletter
- Organising conferences and arranging professional speakers
- Raising funds through various events
- Linking with S.O.F.T. organisations worldwide

## **S.O.F T. Ireland provides support, assistance and information for:**

- Families with newly diagnosed babies
- Families caring for babies and children with these disorders
- Families experiencing bereavement