



# Every Life Counts

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## SUBMISSION to the CITIZENS' ASSEMBLY FROM PARENTS WHOSE BABIES HAVE BEEN DIAGNOSED WITH LIFE-LIMITING CONDITIONS

"We spent time gathering memories that would have to last us a lifetime; photographs, footprints, handprints, a lock of hair. We talked and sang to him and planned his beautiful funeral. Our greatest comfort now in what was undeniably a tragedy, is that we didn't hurt him and he didn't hurt us."

Carmel Uí Churraoin on her son Marc

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**SUBMITTED ON FRIDAY 16 December 2016**

## WHO WE ARE

We are families whose babies were diagnosed with life-limiting conditions such as anencephaly or Trisomy 18. For some of us, our babies' lives were all-too-brief, and we have experienced the terrible loss and pain of the death of a child. However, we have also experienced the tremendous love and pride that comes with carrying and holding our children, and we know how that shared time brings love and joy and healing after loss and pain.

We work to provide a forum for families to share their experiences and stories, and to create public awareness of life-limiting conditions and of the value of every child's life. We also seek better care and support for families who receive the devastating diagnosis that their baby may not live for long after birth.

It is our view that better support and compassionate care – called perinatal hospice care - - best serve families and baby, and that abortion is not a pathway to healing.



## THESE ARE BABIES WITH A SEVERE DISABILITY

- These are babies with a severe disability, who are alive and kicking in the womb, but who have been diagnosed with a condition which means they may not live for long after birth. They are not a 'fatal, foetal abnormality' and the use of hurtful, misleading and offensive language has not served families, or this current debate, well.
- There is no agreed category of medical conditions which can be described as 'fatal' or 'lethal, since for all of these conditions, research shows that children have lived beyond birth, sometimes for years. (1)

⇒ In fact, even with the most severe disorders, such as anencephaly, studies show that most babies do, in fact, live after birth and that parents will have time to make memories with their children.

⇒ Research shows that 72% of babies with anencephaly live after birth, even briefly, while babies with Trisomy 13 or 18 have lived for weeks, months and years after birth. Parents should not be deprived of the love and joy that comes from this precious time. (2,3)

⇒ These babies are not 'incompatible with life'. No baby is. This label, and ugly and misleading phrases like 'fatal, foetal abnormality', are used to dehumanise these babies – and to justify ending their lives because of their disability. These phrases are NOT a medical diagnosis and misinform parents when they are vulnerable and fearful for their baby.

⇒ The Royal College of Obstetricians and Gynaecologists have pointed out that the term 'fatal, foetal abnormality' is not to be found in any medical textbook.

⇒ The HSE, in revising its *Standards National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death* decided to use the more correct term 'life-limiting condition'. (4)

1. Wilkinson, D.J.C., Thiele, P., Watkins, A., and De Crespigny, L. Fatally flawed? A review and ethical analysis of lethal congenital malformations. *Br J Obstet Gynaecol.* 2012; 119: 1302–1307
2. Jaquier M, Klein A, Boltshauser E. 'Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly.' *British Journal of Obstetrics and Gynaecology* 2006; 113:951–953
3. Nelson KE, Rosella LC, Mahant S, Guttmann A. Survival and surgical interventions for children with
4. trisomy 13 and 18. *JAMA.* doi:10.1001/jama.2016.9819.
5. HSE National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death.

## THE EXPERIENCE OF PARENTS

- We know that the time we have with our babies, however short, brings love and joy, and is a pathway to healing. Our babies lives are of infinite value, they matter because every child matters.
- We want better services to be made available so that parents have the support they need to pour a lifetime of love into the time they have with their child. Making memories, holding your baby, making sure they knew nothing but love, are all enormously important achievements when baby's life is too short.
- A recent study from Cork University Maternity Hospital found that up to 96% of parents continued with the pregnancy after a diagnosis of Trisomy 13 or 18. (1).

1. Houlihan OA, O'Donoghue K. The natural history of pregnancies with a diagnosis of trisomy 18 or trisomy 13; a retrospective case series. BMC Pregnancy Childbirth. 2013;13:209. doi: 10.1186/1471-2393-13-20



"I was told that she wouldn't live after birth, but she did, for 6 days. When you're told you're going to get nothing, to get 6 days is just a miracle. I'm so proud of her that she lived for 6 days."

Aileen, mother to Lilly Ann, born with anencephaly.

Seán Hynes was diagnosed with Trisomy 18, caused by an extra chromosome, and he lived for two days after birth.

His mother, Sarah, says:  
"So we wrapped him in love for those two days, two wonderful days we will never forget. Seán has made us the proudest parents in the world. He has made us better people, and for that we are forever grateful."



Kathleen Rose Markin has now reached her 9<sup>th</sup> birthday, living with Trisomy 13 - a condition often wrongly often described by the media as a 'fatal abnormality'.

Her mother Tracy says: "Children like Kathleen teach us how to love. It upsets me that parents are pushed towards abortion."

"I look back knowing I did everything I could possibly do to make sure she got here and knew that she was so loved."

Baby Lilly Joy Sharp with her mam, Grace



*"Maya lived for one hour and thirteen minutes after she was born, and those minutes will last in my mind, heart and soul for a lifetime. Maya was alive and kicking in my womb and she was a determined little fighter who was adamant she would meet her Mammy and Daddy."*

Mam Clara Conroy on her little baby, Maya Rose



*"I was so proud that my body was Carragh's safe haven for those 38 weeks - it was her home. She knew nothing but love in our time together."*

Carragh O'Neill Fox with her mam, Mandy O'Neill

*"Muireann was born, two fists in fighting position... ready to take on the world. And fight she did, for six whole weeks. She was an amazing little girl who made a huge impact on us all."*

Baby Muireann Dunne who lived for six weeks after birth with Trisomy 13



*"Her imperfections are beautiful to me. I am blessed to have seen her beautiful face and touched her tiny hands. I wanted to give her every chance."*

Tanya Coonan on her daughter, Lillie

## WHEN 'CHOICE' BECOMES AN EXPECTATION

Parents say that the negative language and misinformation used in Irish hospitals, as well as by abortion campaigners, can push parents towards abortion, and to a lifetime of regret.

- Researchers at Cork University Maternity Hospital found that negative attitudes – from doctors and others – was unhelpful (1). “The doctor said the baby would not have any emotion or personality so what was the point?” reported one mother, while another added “I felt that he considered continuing my pregnancy with Talia a waste of resources and a waste of his time”.
- Parents also said that “If abortions had been legal in Ireland I would have done it so I am glad it wasn’t” and that “The media campaign for termination of pregnancy made me feel like I had something to hide”
- A recent Parliamentary inquiry in Britain, the Bruce Inquiry (2), showed that parents came under pressure to abort if the baby had a disability and that parents felt they did not receive adequate information about other options, including palliative care after birth.
- Research by Janvier *et al* showed that 93% of families of babies with Trisomy 13 and 18 had been told their baby’s condition was ‘lethal’ or ‘incompatible with life’ and more than two-thirds felt under pressure to abort. (3)

1. Preparing for Stillbirth in Cases of Prenatal Lethal Diagnosis, Orla O’Connell, Cork University Maternity Hospital
2. <http://www.abortionanddisability.org/> – The Bruce Inquiry
3. Janvier, A., Farlow, B., and Wilfond, B.S. The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*. 2012; 130: 293–29

## CONTRASTING OUTCOMES

- In drafting its revised National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death, the HSE's consultation document said that "It is acknowledged that women, who for whatever reason opt to have a termination of pregnancy, experience more intense emotional distress in the short and long term as compared with women after preterm birth or normal birth (Kersting et al., 2009)."
- A new (2015) study from Duke University by Cope *et al* has found that mothers who undergo an abortion after a diagnosis of anencephaly are significantly more likely to suffer depression and despair than those who continued with their pregnancy(1).
- In contrast, recent research has found that almost 90% of parents who continued with their pregnancy following a diagnosis of Trisomy 13 or 18 said that their overall experience was positive, while 98% of parents described surviving children as happy and as having an enriching influence on their lives, and on their families (2,3).
- Parents are being horribly misinformed and pushed towards abortion at a time when they are very vulnerable. Parents need the right support – perinatal hospice care – to give them time with their baby. That time brings great joy, and healing after the pain of loss.

1. Cope, H.,Garrett, M. E.,Gregory, S., and Ashley-Koch, A. (2015) Pregnancy continuation and organizational religious activity following prenatal diagnosis of a lethal fetal defect are associated with improved psychological outcome. *Prenat Diagn*, 35: 761–768. doi: 10.1002/pd.4603.
2. Janvier, A., Farlow, B., and Wilfond, B.S. The experience of families with children with trisomy 13 and 18 in social networks. *Pediatrics*. 2012; 130: 293–298
3. Guon, J., Wilfond, B.S., Farlow, B., Brazg, T., and Janvier, A. Our children are not a diagnosis: the experience of parents who continue their pregnancy after a prenatal diagnosis of trisomy 13 or 18.*Am J Med Genet*. 2014;164A: 308–31

## WHAT HELPS PARENTS

Our experience tells us that families need to know that almost all parents who continue pregnancy have reported a positive and enriching experience regardless of the lifespan of their child. They had some time with their baby and that was truly precious.

- Babies with these conditions do not suffer in the womb and parents are being horribly misled in this regard. None of these conditions causes the baby in the womb to suffer pain. Any discomfort after birth will be managed by good palliative care.
- Perinatal hospice care is the way forward to help families in this very difficult time – this support system for families is not expensive to provide and is hugely helpful. It simply means that parents are provided with the gift of time with their child by ensuring that they have the same medical team throughout the pregnancy and that special bereavement counsellors and midwives and photographers help baby and parents through this pregnancy and birth.
- Research shows that, in jurisdictions where abortion was available, when perinatal hospice care services were explained and offered up to 85% of parents availed of them (Calhoun, 2003).

Calhoun BC, Napolitano P, Terry M, Bussey C, Hoeldtke NJ. Perinatal hospice. Comprehensive care for the family of the fetus with a lethal condition. *J Reprod Med.* 2003;48:343–348.

## **THE REALITY – LATE TERM ABORTION**

- These are usually late-term abortions. The baby is either dismembered or given a lethal injection of potassium chloride into the heart, and the mother will then give birth to a dead baby.
- These are not abortions for 'medical' reasons. There is no threat to the life or health of the mother, and abortion certainly brings no benefit to the baby. This is abortion for reasons of disability and we do not believe that abortion should be legalised in Ireland on disability grounds. This would introduce the most lethal form of discrimination possible, and, as the medical literature shows, will not help mother or baby.
- Instead, the gentle, compassionate and life-affirming support of best perinatal care should be made available.

## WHAT IS PERINATAL HOSPICE CARE

Perinatal hospice and palliative care is a new and compassionate model of support that can be offered to parents who find out during pregnancy that their baby has a life-limiting condition. As prenatal testing continues to advance, more families are finding themselves in this heart-breaking situation.

Perinatal means around the time of birth, and hospice incorporates the philosophy and expertise of hospice and palliative care into the care of patients.

When we hear the word hospice, we think of a building, but, as author Amy Kuebelbeck points out, perinatal hospice is not a place, it is more a frame of mind. It's about providing support to families and can easily be incorporated into standard pregnancy and birth care, and be made available in maternity hospitals and units in Ireland.

Indeed, in some centres in Ireland, this kind of care is made available but, right now, that provision is patchy.

**In practical terms, perinatal hospice** care requires that obstetricians, nurses, chaplains, neonatologists, social workers, bereavement counsellors and even photographers work together to ensure that parents are given the gift of time with their children.

## THIS ENSURES:

- Continuity of care, so that the family has a dedicated team who are aware of the baby's diagnosis and they do not have to explain their situation at every appointment – It also ensures that parents are properly informed about their baby's condition – and are not misinformed either by medical staff, or by being told to look things up on google
- That a special, separate room is made available for the family when their baby is born.
- That counselling is available for families throughout the pregnancy and bereavement counselling is available afterwards
- That palliative care ensures that any pain or discomfort the baby may feel is managed and minimised
- That a special photographer helps to make memories for families
- That a chaplain is available to baptise the baby if that is desired

All of this ensures that parents have the gift of time – that they can focus on spending every precious moment with their child, before and after birth.

## APPENDIX

### Life-limiting conditions:

#### ANENCEPHALY

Anencephaly is a serious neural tube defect which causes the baby's brain not to develop properly. A recent study found that 72% of babies with anencephaly lived for a short time after birth. Of those children, 25% lived up to 5 days, while up to 7% lived up to 28 days after birth (1). Two children – Stephanie Keene and Nicholas – lived in excess of two years.

Kildare mother Aileen Behan's little girl Lilly Ann lived for 6 days. She says "I was told that she wouldn't live after birth, she did for 6 days. When you're told you're going to get nothing, to get 6 days is just a miracle. There were 2 wishes I had for her, one that she would feel the air in her face and one that she would be held and loved by everyone. And she was."

1. Jaquier M, Klein A, Boltshauser E. 'Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly.' *British Journal of Obstetrics and Gynaecology* 2006; 113:951–95

#### POTTER'S SYNDROME, POTTER'S SEQUENCE AND RENAL AGENESIS – A BREAKTHROUGH IN CARE

Some conditions including Potter's Syndrome, Potter's Sequence and Renal Agenesis mean that a lack of kidneys or kidney development causes a decreased amount of amniotic fluid – which can also mean that the baby's lungs fail to develop. It has tended to be associated with a very poor outcome but this is not invariably so, and a new treatment means the outlook may dramatically improve.

US Congresswoman Jamie Herrera Beutler was told that her daughter had Potter's Syndrome and that "It's 100 per cent fatal. She will either be stillborn, you'll miscarry, or she will suffocate in your arms after she's born". But the Beutlers urged doctors to try an experimental treatment – injecting a small amount of saline into the womb to act as a substitute amniotic fluid.

Abigail Beutler, was born in July 2011, and is thriving, sitting up, chattering and playing with her adoring parents. She is awaiting a kidney transplant and her Dad, Dan Beutler, is a match. Abigail's story may now change the treatment protocol for Potter Syndrome.

Bienstock JL1, Birsner ML, Coleman F, Hueppchen NA. 'Successful in utero intervention for bilateral renal agenesis.' *Obstetrics and Gynecology* 2014

## TRISOMY 18

Trisomy 18 or Edwards Syndrome arises because of the presence of an extra chromosome. There is a significant risk of miscarriage but studies have found that, contrary to recent reporting, the average duration of survival for children with Trisomy 18 was 14.5 days; with 38.6% of babies surviving for more than a month, while 8.4% survived for more than a year (1).

A recent editorial in the Journal of the American Medical Association noted that survival rates were increasing and that in a “study by Nelson and et al, 19.8% of infants with trisomy 13 and 12.6% of infants with trisomy 18 lived past their first birthday”. (2,3)

Here in Ireland, Elaine Fagan, given just days to live after birth, spent 25 years with her loving family before her death in 2011, confounding all medical expectations. “She has touched so many people. I now know happiness comes from caring and sharing with others. I wouldn’t have found that out if I didn’t have Elaine. It’s thanks to her that I am seeing a lovely side of human nature,” said her father Micheal.

1. Rasmussen SA, Wong LY, Yang Q, May KM & Friedman JM. (2003). Population-based analyses of mortality in trisomy 13 and trisomy 18. *Pediatrics*..111(4 Part 1):777-84.
2. 6. Nelson KE, Rosella LC, Mahant S, Guttmann A. Survival and surgical interventions for children with trisomy 13 and 18. *JAMA*. doi:10.1001/jama.2016.9819.
3. Dr John Lantos, ‘Trisomy 13 and 18—Treatment Decisions in a Stable Gray Zone’, *JAMA* July 26, 2016 Volume 316, Number 4

## TRISOMY 13

Trisomy 13 or Patau Syndrome also arises when the baby has an additional chromosome. Research has found that children with Trisomy 13 live on average for 7 days after birth, while almost 31% live for more than a month, and almost one in 10 live for more than a year. (3) Kathleen Rose Harkin, who lives in Cavan, has defied all doctors predications to celebrate her ninth birthday despite having Trisomy 13. “They say Trisomy 13 is incompatible with life, but Kathleen Rose is the love of our lives,” says her mother Tracy. “She shows us how to love.”

1. Rasmussen SA, Wong LY, Yang Q, May KM & Friedman JM. (2003). Population-based analyses of mortality in trisomy 13 and trisomy 18. *Pediatrics*..111(4 Part 1):777-84.
2. 6. Nelson KE, Rosella LC, Mahant S, Guttmann A. Survival and surgical interventions for children with trisomy 13 and 18. *JAMA*. doi:10.1001/jama.2016.9819.
3. Dr John Lantos, ‘Trisomy 13 and 18—Treatment Decisions in a Stable Gray Zone’, *JAMA* July 26, 2016 Volume 316, Number 4