

6 Gardiner Place, Dublin 1, Ireland. www.thelifeinstitute.net E: info@thelifeinstitute.net T: 00 353 1 8730465

To all Members of the
UN Committee on Economic, Social and Cultural Rights
Human Rights Treaties Division
Office of the United Nations High Commissioner for Human Rights
Palais Wilson
52, Rue des Paquis
CH - 1201 GENEVA
Switzerland

15 October 2014

Dear Members of the Committee on Economic, Social and Cultural Rights,

We hope you will find this submission from the Life Institute useful as you compile a List of Issues for the periodic review of Ireland's compliance with the International Covenant on Economic, Social and Cultural Rights.

The Life Institute is one of Ireland's best-known organisations seeking to protect human life and the dignity of every person.

Should you have any questions please don't hesitate to contact us.

Yours sincerely,

Niamh Uí Bhriain

ARTICLE 5

We note that the Committee has received several submissions from abortion campaigners, including two from the Center for Reproductive Rights, which is not an Irish organisation, and one from the Irish Family Planning Association, which is an affiliate of the global abortion business, Planned Parenthood.

We would like to remind the Committee that no right to abortion exists under international law, nor does any United Nation's treaty recognise a right to abortion.

The right to life of every human being, on the other hand, is well established and protected under the Universal Declaration of Human Rights, International Covenant on Civil and Political Rights, and other international instruments.

Article 5 of the International Covenant on Economic, Social and Cultural Rights states that:

"No restriction upon or derogation from any of the fundamental human rights recognized or existing in any country in virtue of law, conventions, regulations or custom shall be admitted on the pretext that the present Covenant does not recognize such rights or that it recognizes them to a lesser extent."

Attempts by abortion campaigners to restrict the fundamental human right to life under the false pretext that the Covenant supports a right to abortion should be rejected by the Committee.

Similarly, attempts to classify abortion as a form of healthcare should also be rejected.

ABORTION IS NOT REQUIRED TO SAVE WOMEN'S LIVES

Attempts by the Centre for Reproductive Rights to exploit the tragic death of Savita Halappanavar to push an abortion agenda is distasteful but not surprising, given the CRR's mission of making abortion on demand available in every country. Their submission to the Committee contains statements that are misleading.

The CRR writes that Ireland's abortion laws "may result in maternal deaths due to the chilling effect the law has on health care professionals preventing them from providing the necessary health care to women until it is too late. A shocking example of this was the death of Savita Halappanavar in October 2012. She died at a Galway hospital of septic shock after being denied an abortion even in the face of an inevitable miscarriage most likely caused by an infection.

The medical staff refused to perform an abortion, claiming that "[u]nder Irish law, if there's no evidence of risk to the life of the mother, our hands are tied so long as there's a fetal heart beat. The investigation into her death revealed that "concerns about the law . . . impacted on the exercise of clinical professional judgment" and that the lack of clear clinical guidelines materially contributed to her death."

As a matter of fact, the report referenced by the CRR does not list Ireland's laws on abortion as a Key Causal Factor in Ms. Halappanavar's death, and it acknowledges that terminations of pregnancy to save the life of the mother had taken place in Ireland, not-withstanding the previous ban on abortion, because these terminations, where due care was also given to the life of the child, were permissible under Irish law.

Two further inquiries also found that mismanagement of sepsis in pregnancy had led to the loss of Ms. Halappanavar's life, compounded by the virulence of the bacteria infecting the patient, E.coli ESBL.

The final official report, from the Health, Information and Quality Authority, concluded that there were a total of 13 missed opportunities to have intervened in the case of Ms Halappanavar's infection, and those interventions could have potentially changed the outcome of her care. The report does not identify Ireland's protection of human life as a barrier to treatment, precisely because there has never been a barrier to life-saving treatment caused by Ireland's previous ban on abortion. In fact, Ireland, without abortion, was recognised by the UN as one of the safest places in the world for a woman to have a baby.

ARTICLE 12

Article 12 of the Covenant states that the Irish State recognises the "right of everyone to the enjoyment of the highest attainable standard of physical and mental health," and must provide for "the healthy development of the child".

Yet the Irish government recently passed legislation which has caused a child to be deliberately born prematurely at just 24 weeks, with all the health complications that that is likely to bring.

PROTECTION OF LIFE IN PREGNANCY ACT 2013

Most recently, the Irish government passed into law the Protection of Life in Pregnancy Act, which sought to approve abortion as a treatment for suicidality arising in pregnancy.

The Irish government held Parliamentary hearings where medical experts agreed that abortion was <u>not</u> a treatment for suicidality in pregnancy.

They told the Parliamentary hearings that:

1. Abortion was not a treatment for suicidality

"There is no evidence either in literature or from the work of St Patrick's University Hospital that indicates that termination of pregnancy is an effective treatment for any mental health disorder or difficulty". *Prof James Lucey, St Patrick's University Hospital*

"On the suicide issue, we need to become very focused on the fact there are other treatments for suicide. If a male patient pitched up in accident and emergency tonight and said he wanted

to kill himself, there would be medical treatments, drugs and therapies, and these would be reviewed in a couple of weeks. That is the first-line treatment, and cases are reviewed after a couple of weeks." Dr. Mary McCaffrey, OB/GYN, Kerry General Hospital

"All appropriate mental health supports need to be made available for women who are at risk of suicide, have threatened to commit suicide, or have suicidal ideation. The committee can ask the psychiatrists, but most people would agree that the termination of pregnancy is not a treatment in this regard." *Dr Sam Coulter Smith, Master of the Rotunda Hospital*

"On the issue of suicide, nobody is suggesting that termination of pregnancy is a cure for mental anguish or the disorders associated with suicide ideation." *Dr. Rhona Mahony, Master of National Maternity Hospital, Holles Street*

"..there is no evidence that abortion reduces suicide risk in pregnant women, and there is some evidence that it may have a negative effect in some instances." *Professor Patricia Casey, Mater Hospital and UCD*

2. None knew of a case where abortion was the only treatment for a woman who was suicidal

"However, we have not had the experience of seeing any women who were suicidal where the appropriate treatment for their suicidal feelings would have been a termination of pregnancy." *Dr Anthony McCarthy, College of Psychiatry*

"Although we have discussed this among the group [of 12 Obstetricians and Gynaecologists], I personally have no knowledge of ever having cared for a woman who wanted to end her life specifically because of a pregnancy, and in my pursuit of information over the past week or so, I have been unable to identify any other consultant who did know of such a woman, which backs up the information we already have - i.e., that this is an extremely rare situation.

That was their opinion having practised abroad. In all of their clinical experience and practise they had not met a woman citing suicidal intent or ideation purely because she was pregnant. That was the view of the 12 consultants involved." *Dr. Mary McCaffrey, OB/GYN, Kerry General Hospital*

"I was asked if we have ever had to perform a termination of pregnancy because of risk of suicide; not in my experience." *Dr Sam Coulter Smith, Master of the Rotunda Hospital*

"I refer to Deputy Terence Flanagan's question on whether we, as perinatal psychiatrists, have ever seen a situation in which termination of pregnancy has been the treatment for a suicidal woman. To reiterate our statement, with more than 40 years of clinical experience between us, we have not seen one clinical situation in which this is the case." *Dr. John Sheehan, Consultant Perinatal Psychiatrist, the Rotunda Hospital*

"However, one must remember that it is absolutely individual and for us, with our 40 years of experience, we have never assessed a woman for whom our management would be to advise a

termination and for the legislators, this must be taken into consideration." *Dr Joanne Fenton, Consultant Perinatal Psychiatrist, the Coombe Women's Hospital*

"In my work as a psychiatrist, I run the attempted suicide service in the Mater Hospital in which we see and assess more than 400 attempted suicides in women per year. I have never seen a pregnant woman who was suicidal for whom an abortion was the only answer." *Prof Patricia Casey, Mater Hospital and UCD*

3. None knew of a case where a woman had died by suicide because abortion was not available

"I am not aware of any death from suicide because a termination was declined." *Dr. Mary McCaffrey, OB/GYN, Kerry General Hospital*

"As regards mental health issues in pregnancy and following pregnancy, it was stated earlier that the incidence of mental health issues in pregnancy is approximately 10% to 15%. The risk of suicide in pregnancy is extraordinarily low. We all know that women can suffer from postnatal depression and that the risk of suicide remains following pregnancy. It is my belief that the risk of suicide can increase a little post-natally. However, that is an issue which the committee can explore later in more detail with our psychiatric colleagues." *Dr Sam Coulter Smith, Master of the Rotunda Hospital*

4. Senior psychiatrists testified that abortion would be an inappropriate treatment in respect of a person who is extremely suicidal

"Someone who is intensely suicidal often needs admission to hospital. It is exactly the opposite to the medical intervention and, consequently, even the notion of carrying out an emergency termination is completely obsolete in respect of a person who is extremely suicidal. I reiterate that in our practice, we see people who are profoundly depressed, who feel hopeless, worthless or utterly helpless to deal with situations. In such situations, one can see clearly the intervention usually is to admit such people into hospital, day hospital or home care but the intention is to support and help them through the crisis they are in. It is not to make a decision that is permanent and irrevocable." *Dr. John Sheehan, Consultant Perinatal Psychiatrist, the Rotunda Hospital*

"If the woman is profoundly depressed and mentally ill, she would be advised not to take any major life decision at that time, and frequently admission to hospital might be advised. Ongoing review and monitoring would typically be required." *Dr Anthony McCarthy, College of Psychiatry*

Nontheless, the Irish government pressed ahead against the medical evidence, and, despite huge public opposition to the proposal, legalised abortion on suicide grounds.

This year, the first reported use of the Act caused a baby boy to be deliberately delivered prematurely in an Irish hospital because the child's mother said she was suicidal and her unborn child was 24 weeks gestation - past the point of viability.

The child was left struggling for life in an Irish NICU, with a high risk of long term complications to the little boy's health, including blindness and brain damage. Neither was his mother best served by the abortion law, which attempts to circumvent best medical practise and evidence-based medicine and force doctors to prescribe abortion as a treatment for suicidality.

The law is unworkable, cruel and has caused a horrific outcome. It should be repealed.

ARTICLE 12 (2) - THE RIGHT TO LIFE OF CHILDREN WITH PROFOUND DISABILITY

Article 12 also states that the State Parties must provide for:

"The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child" and "The creation of conditions which would assure to all medical service and medical attention in the event of sickness".

The Committee may be aware from other submissions that pressure is being brought to bear on the Irish government to legalise abortion where unborn children have a profound disability.

A child's disability should not, in any way, diminish that child's right to life.

Most Irish parents facing a diagnosis of anencephaly or Trisomy 13 or 18 or any other life-limiting condition continue with their pregnancy.

It is estimated that less than 10% of Irish parents - in only 34 cases in 2011 for example - go to Britain for an abortion because their baby had a serious or fatal anomaly.

Research by Lalor et al in Trinity College and the Rotunda found that some 700 such cases arise in Ireland each year. At least 90% of Irish parents choose to continue with the pregnancy and to spend every moment they can with their child.

We know this because the records kept by the British Department of Health not only record all Ground E abortions (abortion on disability grounds) performed on Irish women, but also record the condition diagnosed, and separate out conditions such as anencephaly, Trisomy 18 (Edwards Syndrome), Trisomy 13 (Patau Syndrome) etc.

As you can see from the Table released by the British Department of Health in Appendix 1, in 2011 a total of 51 abortions were carried out on Irish women for reasons of disability - including Down Syndrome and Spina Bifida, which are not fatal abnormalities at all.

When we narrow it down to life limiting disorders, then we see that the total is 34 abortions in 2011. (The Committee should note that our collation of those disorders which may be described as 'fatal abnormalities' adopts a very prudent approach, since in at least three categories - Q06-07, Q86-89, and Q92-Q99 - there is not sufficient information to ascertain whether these conditions may, in fact, cause a severely limited life or might prove fatal within the womb, but those categories have been included in the total of life-limiting disorders so that if there is an error, it is on the side of prudence, and the collation cannot be said to underestimate the total.)

In 2011, for example, 8 babies with anencephaly being carried by Irish women were aborted, 7 babies with Edwards Syndrome were aborted, while 7 babies with Patau's Syndrome also had their lives ended. In 2010, the numbers were slightly higher; in 2009, they were slightly lower.

We've now obtained the 2012 figures and the number of babies with life-limiting disorders who were aborted under Ground E is at 42 for 2012 - so the figure flexes from 41 in 2010 to 34 in 2011 to 42 in 2012.

The increase in the <u>total numbers</u> of Ground E abortions (i.e. all abortions carried out on Irish women in Britain for reasons of disability) are largely being driven by an increase in abortion of babies with Down Syndrome - 28 in 2012 - a shocking and very sad increase of 460% since 2008. This may be due to the increasingly negative reporting in the media on disabilities detected in pregnancy.

NOTE: These British DoH figures record all Ground abortions in \underline{all} hospitals and clinics in England and Wales. See Table in Appendix 1

BETTER CARE FOR CHILDREN WITH PROFOUND DISABILITIES

What really helps parents in very sad situations is perinatal hospice care. This gives parents the gift of time and they can ensure that their children knew nothing but love for their brief time on this earth, and that is an extraordinary achievement.

One of the things that parents hope for is that with the loss and the sorrow can also come joy and love and comfort, and that means improving the services available for families so that they can have time with their babies and take photos and make memories.

THE SITUATION IN IRELAND

Those services have certainly improved in Ireland - great work is being done in the Coombe for example - but the improvement is patchy. Right now, getting the right kind of support and understanding from the medical system is really the luck of the draw, it can depend on where you live and who you meet, and that is not acceptable.

More worryingly, some attitudes have changed, not for the better but for worse, in that parents are being pressured to go for abortion once a diagnosis of a life-limiting condition has been made.

This is hugely distressing for parents, yet we are not hearing from those parents at the moment, instead we are repeatedly being told that the law in Ireland must change to allow children with a profound disability to be aborted here.

Mothers who have joined initiatives such as the Every Life Counts program in Ireland have reported that they've experienced some or all of the following during their pregnancy:

- Negative attitudes from medical staff towards their pregnancy
- Repeated suggestions of abortion
- Surprise expressed that they had continued with their pregnancy
- A lack of empathy and respect for the dignity of their child
- Use of terms and words that are incorrect, unsympathetic and cause hurt for parents involved, including the phrase 'incompatible with life'.

This reflects the experience of parents in other jurisdictions, although, since abortion ends the life of up to 95% of children with a range of disabilities in other countries, that experience is likely to have been even more negative.

A 2013 paper published in the American Journal of Medical Genetics found that 94% of parents given a diagnosis of Trisomy 13 or 18 were told their baby would not live after birth, although, as we will see, that is not the case with these conditions. 61% of parents said they came under pressure to abort, 55% were told that their child would be a vegetable, 28% that their baby would destroy their family or their marriage. Others had more positive experiences, but, and this must have been enormously upsetting, some parents were told that their Obstetrician would refuse to continue seeing them if they did not abort.

It should be pointed out that these attitudes often arise because of a lack of understanding, and the adoption of phrases which are medically meaningless such as "incompatible with life".

A 2012 paper entitled 'Fatally Flawed?' published in the *British Journal of Obstetrics and Gynaecology* (BJOG) similarly found that the term 'lethal anomaly' is not a medical prognosis and should not be used in counselling parents facing a diagnosis of severe malformation for their unborn child.

The authors, who work in the field of newborn intensive care and in counselling, said that the term hindered clear communication, and should be avoided in counselling.

Crucially, they pointed out that "prenatally diagnosed abnormalities that are associated with death in the newborn period are often referred to as 'lethal malformations'. Yet, for many of the commonly described lethal malformations long-term survival is possible if supportive interventions are provided."

In an interesting discussion entitled 'the language of lethality', the authors examine the use of the term 'lethal', and consider the published literature, accounts of parents, and their own experience and conclude that "a significant proportion of practitioners do use this or related terminology."

They then ask why the term is used, and identify several reasons:

- 1. Practitioners may mistakenly believe that conditions [such as Trisomy 18] are not compatible with survival beyond the newborn period.
- 2. A second potential reason is a discomfort with uncertainty, or a desire to make decision-making simpler. The authors write "It is potentially easier for women to come to terms with termination of pregnancy or with palliative care if they are told that survival is impossible, and it may be easier for professionals to make and rationalise such decisions."
- 3. A third possibility is that practitioners are aware that death is not inevitable but believe that the survivors will not have a life that is worth living.

The third possibility – that doctors make a judgment call on the 'quality of life' of another person – has certainly been the experience relayed to us by parents who have faced a diagnosis of a severe abnormality. Parents and their babies deserve better than judgment and a nudge towards abortion.

The paper was published just weeks after new research by Dr Anne Janvier of the University of Montreal found that almost all families of children with Trisomy 13 and 18 reported that their time together was happy and rewarding overall. The research, published in the peer-reviewed journal, *Paediatrics*, found that over 97% of the parents interviewed considered that their child was happy and its presence enriched the life of their family and their life as a couple regardless of longevity. This finding is hugely significant to the current debate on perinatal care in Ireland and elsewhere.

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 heartbreaking 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.

Sometimes we can think that the word hospice means that we have given up hope - but that's not the case. Hospice is a special concept of care designed to provide comfort and support to patients and their families, and staff offer a specialised knowledge of medical care, including pain management.

When we hear the word hospice, we think of a building, but 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 made available in maternity hospitals and units in Ireland.

Indeed, in some centres in Ireland, this kind of care is made available but, as we previously noted, that provision is patchy.

In practical terms, perintal 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.

So the support begins at the time of diagnosis, not just after the baby is born. This approach supports families through the rest of the pregnancy, through decision-making before and after birth, and through their grief. Perinatal hospice also enables families to make meaningful plans for the baby's life, birth, and death, honouring the baby as well as the baby's family.

For a baby who is expected to die, parents' original wishes and dreams for their child's long life are shattered. But their hopes can change direction: for the baby to be treated with dignity, for the baby to be protected until death comes naturally, for the baby's life to be filled with love. Parents who have chosen perinatal hospice have said that this kind of care helped their hopes be fulfilled.

As previously noted, we know from figures released by the British Department of Health that more than 90% of Irish parents faced with a diagnosis of a life-limiting condition continue with the pregnancy. It's a matter of urgency then, that the Minister makes proper care and support available to families.

We can see too from the experience of other countries, that when parents are offered perinatal hospice care the percentage that continue their pregnancies increases dramatically. In a U.S. study, when parents were given the option of perinatal hospice, the number rose to 75 percent. (D'Almeida et al, 2006) And in another U.S. study, the number who chose perinatal hospice was 85 percent. (Calhoun 2003)

GIVING PARENTS REAL INFORMATION

Making this best-standard care available is not expensive, does not require capital expenditure or huge investment, but, rather, requires training and the commitment and goodwill of the Irish Health Service Executive.

These are our most sick and vulnerable children: they are babies with a serious and life-limiting disability. We need to wrap our arms around these families and lift some of the burden of what is otherwise an almost unbearable sadness.

For example, parents are told their baby is 'incompatible with life' - which is a judgement and not a medical opinion. They are told that abortion is a better option because the baby will not make it until birth, and will suffer after birth.

The medical literature contradicts those assertions.

THE MOST COMMON CONDITIONS

A recent study published in the British Journal of Obstetrics and Gynaecology 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. 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 two 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."

Trisomy 18 or Edwards' Syndrome arises because of the presence of an extra chromosome. There is a significant risk of miscarriage before birth, but, quite contrary to recent reporting, studies have found that the average duration of survival for children who lived until birth with Trisomy 18 was 14.5 days; with 39% of babies surviving for more than a month, while 8.4% survived for more than a year. 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.

Research has also found that children with Trisomy 13 or Patau's Syndrome 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. Kathleen Rose Harkin, who lives in Cavan, has defied all doctors' predictions to celebrate her 8th birthday despite having Trisomy 13.

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.

WHAT IS BEST FOR MOTHERS?

Whatever the condition, the time parents can have with their children is hugely rewarding and tremendously important for healing.

In contrast, research suggests that substantial numbers of women who undergo abortion in these circumstances suffer post-traumatic stress. (Korenromp et al, 2005),

A longitudinal study in 2009 in the Netherlands looked at 147 women in Netherlands who had a termination of pregnancy because of foetal anomalies and reviewed psychological outcomes at 4, 8, & 16 months.

- At 4 months 46% women revealed pathological levels of post-traumatic stress symptoms
- At 16 months 21% still had symptoms

Abortion is not a shortcut through grief, and in contrast, parents' responses to perinatal hospice are "overwhelmingly positive" (<u>Calhoun & Hoeldtke 2000</u>), and parents report being emotionally and spiritually prepared for their baby's death and feeling "a sense of gratitude and peace surrounding the brief life of their child" (Sumner 2001).

CONCLUSION

We strongly urge the Committee to:

- Reject the notion that abortion is a human right and affirm that no right to abortion exists in any UN treaty
- Recognise that the right to life is recognised and must be upheld
- Request the Irish government to repeal the Protection of Life in Pregnancy Act which
 forces doctors to ignore best medical practise and evidence-based medicine, and which
 failed a woman in distress, and has caused a baby to be forcibly born prematurely with
 possibly devastating effects on that child's health
- Uphold the right to life of every human person, regardless of their disability
- Request the Irish government to ensure the term 'incompatible with life' is not used within the health services and the maternal healthcare services in particular.
- Request the Irish government to make perinatal hospice care widely available in Ireland

REFERENCES

http://www.hse.ie/eng/services/news/nimtreport50278.pdf

http://www.hiqa.ie/publications/patient-safety-investigation-report-services-university-hospital-galway-uhg-and-reflect

http://www.independent.ie/irish-news/health/baby-delivered-as-woman-refused-abortion-under-law-30512513.html

http://oireachtasdebates.oireachtas.ie/Debates%20Authoring/DebatesWebPack.nsf/committeetakes/HEJ201301 0800001?opendocument

www.everylifecounts.ie

Guon J, Wilfond BS, Farlow B, Brazg T, Janvier A. 2013. 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 Part A 164A:308–318.

Wilkinson D, Thiele P, Watkins A, De Crespigny L. Fatally flawed? A review and ethical analysis of lethal congenital malformations. BJOG 2012;119:1302–1308.

Janvier A, Farlow B, Wilfind BS. 2012. The Experience of Families With Children With Trisomy 13 and 18 in Social Networks. Paediatrics 10.1542/peds.2012-0151

D'Almeida et al. 2006. Journal of American Physicians and Surgeons.http://www.jpands.org/vol11no2/calhoun.pdf

Calhoun BC1, 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 May;48(5):343-8.

Jacquier M, Klein A, Boltshauser E. 'Spontaneous pregnancy outcome after prenatal diagnosis of anencephaly.' British Journal of Obstetrics and Gynaecology 2006; 113:951–953

Mitchel L. Zoler, 'Trisomy 18 survival can exceed 1 year', OB/GYN News, March 1 2003 Trisomy 13 / Patau Syndrome

Rasmussen SA1, Wong LY, Yang Q, May KM, Friedman. Paediatrics. Population-based analyses of mortality in Trisomy 13 and Trisomy 18. 2003 Apr;111(4 Pt 1):777-84.JM. http://www.ncbi.nlm.nih.gov/pubmed/12671111

Korenromp, Marijke José http://dspace.library.uu.nl/handle/1874/9774

Korenromp MJ, Page-Christiaens GCML, van den Bout J, et al. Adjustment to termination of pregnancy for fetal anomaly: a longitudinal study in women at 4, 8, and 16 months. Am J Obstet Gynecol 2009;201:160.e1-7. http://www.ajog.org/article/S0002-9378%2809%2900393-7/abstract

Calhoun BC1, Hoeldtke Nathan, Frontiers in Fetal Health http://www.perinatalhospice.org/uploads/Frontiers_in_Fetal_Health.pdf

APPENDIX 1

by principal medical condition, 2007-2012	Total abortions to women resident in Irish Republic, having abortions under ground E, in England and Wales,

ICD-10 code	Condition	2007	2008	2009	2010	2011	2012
	Total	27	29	42	68	51	93
Q00	anencephaly	2	បា	ယ	10	œ	Οī
Q01	encephalocele	0	0	0	_	0	Ν
Q02	microcephaly	0	0	0	0	0	0
Q03	hydrocephalus	0	0	_	_	0	2
Q04	other malformations of the brain	0	_	N	6	_	2
Q05	spina bifida	4	_	2	2	ω	4
Q06-Q07		20	_	0	4	0	2
Q10-Q18	the eye, ear, face and neck	0	0	0	0	0	0
Q20-Q28	the cardiovascular system	0	_	2	<u> </u>	N	N
Q30-Q34	the respiratory system	0	0	0	0	0	0
Q35-Q37	cleft lip and cleft palate	0	0	0	0	0	0
Q38-Q45	other malformations of the digestive system	0	0	0	0	0	0
Q60-Q64	the urinary system	ω	_	2	2	_	Ŋ
Q65-Q79	the musculoskeletal system	0	ω	Ν	7	0	ω
Q80-Q85 Q86-Q89	the skin, breast integument phakomatoses other	- 1 0	ν О	0 0	0 4	ω 0	ν 0
Q90-Q99	Chromosomal abnormalities total						
Q90 Q910-Q913 Q914-Q917 Q92-Q99	Down's syndrome Edwards' syndrome Patau's syndrome other	0 -1 03 09	<u> </u>	7 7 4 0	16 2 5	6 7 6	28 16 5
	Other conditions total						
P00-P04	fetus affected by maternal factors fetal disorders related to gestation and growth) <u> </u>	0 -	0 20	000	. 0 -	
P05-P08	multiple gestation disorder of the amniotic fluids exposure to communicable disease family history of heritable disorder	0000	000-	0 - 0 -	- 0 N O	000-	- N O O -
P05-P08 O30 O41 Z20-Z22 Z80-Z84							_