

Hope in Turmoil

A Guide for Decision-Making
After Receiving A
Difficult Prenatal Diagnosis
Regarding Your Baby



Written and Compiled By
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www.morninglightministry.org/hopeinturmoil.html

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A special thank you to all of the parents and others who have contributed their personal and often very intimate and painful stories. I will always appreciate their generosity of heart.

Thank you to all who helped with the revised (2014) *HOPE IN TURMOIL: A Guide For Decision-Making After Receiving A Difficult Prenatal Diagnosis Regarding Your Baby*.

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Thank you to everyone who contributed to the making and distributing of this non-profit resource.

Morning Light Ministry is a volunteer, grassroots ministry that relies on donations for its work with bereaved parents, parents carrying their baby to term despite a difficult diagnosis and those couples with fertility challenges. There is no cost to the parents for this help. Any donations are very appreciated. To make a donation or to order MLM prayer/meditation cards, please visit our website for more information.

Hope in Turmoil

Dear Parent In Turmoil

It is my hope that this resource will be given to you at the time when you receive the difficult prenatal diagnosis regarding your baby.

It is also my hope that in your confusion, your fear, your feeling of helplessness, you will know that there are people out there who care deeply about you, your spouse, your baby, your other children. The people in HOPE IN TURMOIL have “been there”.

Choosing to carry your baby to term despite a difficult diagnosis is a decision that can lead to a very positive and healthy experience for you, your spouse and your family.

To understand how this journey of carrying your baby to term can be a positive journey please read the many stories of parents who have lived that journey with their babies. Here is a link to one family's story of being in turmoil, but who, with a different perspective, turned the situation into an enjoyment of the gift of their baby's life. They built a relationship with their baby in the womb in many ways. [Please see the Resource Section for other suggested videos].

Please read this resource and search out the groups/organizations listed for information and support. If your baby has been diagnosed with a life-limiting condition, please contact Morning Light Ministry (See Resource List) before the birth of your precious baby. We can offer you support in addition to the other groups mentioned in the Resource List. Sometimes all you may need is a “listening heart”.

There is “Hope In Turmoil”.

With warm regards,

Bernadette Zambri

ABOUT THE AUTHOR:

Bernadette Zambri lives with her husband and family in Mississauga, Ontario. With her second child she experienced the death of her daughter Stéphanie from a full-term stillbirth in 1992. With her pastor she started MORNING LIGHT MINISTRY which offers information and support to bereaved parents, parents carrying their child to term despite a difficult diagnosis and those couples experiencing fertility challenges. Bernadette also experiences the daily joys and challenges of raising a son with severe special needs.

INTRODUCTION

My daughter Stéphanie was stillborn as a full-term baby in August 1992. The cause of her death was due to a problem with the umbilical cord. Since that time of total despair and feeling God had abandoned me, I have travelled the grief journey with the help of God, family, friends and resources. My grief journey will continue into the Afterlife when I will be reunited with my daughter Stéphanie.

In 1996, I started **Morning Light Ministry** with my new pastor, Father Keith Wallace. Since that time we have helped many families. I consider myself as a resource person and a “listening heart” to bereaved mothers, bereaved fathers and their families. Presently, Father Neil McMillan is my pastor. He is very supportive of all the works of **Morning Light Ministry** and serves as our spiritual director.

Since 1996, I have listened to the pain, anguish and heartache of parents whose children have died through ectopic pregnancy, miscarriage, stillbirth, infant death and older child death. In my experience of helping parents whose babies have received a difficult prenatal diagnosis or whose babies have died before or after birth, these parents experience a different kind of grief. It is neither better nor worse than any other bereaved parent but simply different.

They ask such questions as, “Why did God allow my baby to be formed with these defects?” along with all of the common questions and feelings any bereaved parent experiences: “I feel very angry at God.” “God has deserted me.” “Is God punishing me?” “Why has God done this to my baby and to me?”

These questions and feelings are explored in a non-profit book, **Morning Light: Miscarriage, Stillbirth and Early Infant Death from a Catholic Perspective**, written by myself and many bereaved parents, excerpts of which are included in the book you are now reading.

The healing journeys of bereaved parents who have brought their babies to term with genetic/medical conditions and the healing journeys of bereaved parents who have terminated their pregnancies for genetic/medical reasons are very different. It is for this reason that I decided to write this resource, **“Hope in Turmoil: A Guide For Decision-Making After Receiving A Difficult Prenatal Diagnosis.”**

Hope in Turmoil

Morning Light Ministry offers to parents carrying their baby to term with an life-limiting or challenging prenatal diagnosis (at no cost to the parent) the following:

- a. HOPE IN TURMOIL mini-book
- b. Special prayers of blessing for your child in the womb that you can pray daily with your family or as an individual
- c. Specific suggestions for a detailed birth plan for your baby to discuss with your doctor before your child comes to term. You can decide what you would like the medical staff to do or not to do. You can decide what to include in the sacred time after your baby is born, whether your child has survived or not.
- d. Telephone support
- e. Email: mlmhopeinturmoil@rogers.com

Our webpage (<http://www.morninglightministry.org/hopeinturmoil.html>)

Facebook (<https://www.facebook.com/pages/Hope-In-Turmoil-Morning-Light-Ministry/643841615626738>)

I have listened to bereaved parents who brought their babies to term with life-limiting conditions who told me, “I wish I could have been talking with you or a support group who could have helped me through my pregnancy with information and support.”, “I felt so alone.”, “My doctor (or genetic

counsellor) didn't seem to want to answer my questions.", "I was so confused.", "I felt so helpless.", "I experienced such a loss of control. I didn't know how to get it back!"

I have listened to bereaved parents who terminated their pregnancy through abortion or early induction of labour. Sometimes their babies had a condition commonly associated with death in utero or death shortly after birth. Sometimes their babies had a condition not generally considered to be life-limiting such as Down syndrome or Spina Bifida. These bereaved parents had very similar comments as mentioned in the preceding paragraph. However, there was a common thread in their additional comments:

- "We were told we had to decide by 20 weeks. That meant we had 48 hours to decide."
- "When I asked my doctor questions he said too much information would be too confusing for me."
- "We were not told there was a possibility of false positives for the Maternal Serum Screening tests."
- "I asked for support groups but they didn't know of any."
- "We were not told that these tests can't tell the degree of the deformity."
- "I wanted to talk with someone who has a child with this condition, but they didn't know of anyone."
- "We weren't told that our child could be born alive and live for a short time after birth after a termination."
- "I wanted to be in control again."
- "We felt such pressure to terminate and we were given no hope of any kind."
- "They used words like fetus, abnormal, deformed, no point in continuing, risk to me. They made us feel like our baby was an "it", a "thing", a "monster"...until we saw our baby after the induction. Then it was too late."

As a response to the pain and anguish of these parents, I decided in 1998 to write a resource with stories of parents who continued their pregnancies after a prenatal diagnosis that was either life-limiting or disabling. I also wanted to include an International Resource List of groups and organizations who will offer information and support to carry their baby to full-term. It took me about 3 months to compile this Resource List. Most parents have only days or weeks to find this information and support.

As I update HOPE IN TURMOIL in 2013, I see positive changes and I see negative changes in the whole area of prenatal diagnosis of difficult conditions since 1998. The changes include:

- 1) the explosion of information of these different conditions on the internet
 - the positive aspect is that parents now have instant information and support regarding their baby's condition
 - the negative aspect is that there is so much information, it is difficult for the parent to distinguish the most useful information and support for their pre-born child, themselves and their family
- 2) the vast number of support groups for parents
 - the positive aspect is that parents receive support from other parents who have gone through or are presently going through a similar situation
 - the negative aspect is that there is very little "filtering" of information, experiences and decisions made about the life of their babies. Often, every experience and every decision is equally as accepted, equally as valid, equally perceived as the "truth".
- 3) the growing numbers of parents of faith who are choosing to terminate the lives of their babies with any kind (fatal and non-fatal) of difficult prenatal diagnosis. Unfortunately, some clergy and moral theologians have advised parents that termination is permissible which is not the truth. [see articles written on Catholic Church Teaching in regards to terminations at <http://morninglightministry.org>] There are no positives but many negatives to this situation:

- the baby's life is ended
- the baby's life is devalued
- the short term and long term emotional health as well as the physical, psychological and spiritual health of the parents and their families are endangered

In reading the words of Pope Francis [Encyclical Letter Lumen Fidei "The Light of Faith", June 29, 2013] I was reminded of these changes in the area of difficult prenatal diagnosis. I would like to share several quotations from Pope Francis regarding universal Truth vs. individual, subjective truth, common ground with other religions, authentic love as well as the essence of faith. (See Appendix A)

Moreover, the main faiths in our world have common ground in relation to supporting babies in the womb. (See Appendix B).

"...the heart is the core of the human person, where all his or her different dimensions intersect: body and spirit, interiority and openness to the world and to others, intellect, will and affectivity. If the heart is capable of holding all these dimensions together, it is because it is where we become open to truth and love, where we let them touch us and deeply transform us. Faith transforms the whole person precisely to the extent that he or she becomes open to love. Through this blending of faith and love we come to see the kind of knowledge which faith entails, its power to convince and its ability to illumine our steps. Faith knows because it is tied to love, because love itself brings enlightenment. Faith's understanding is born when we receive the immense love of God which transforms us inwardly and enables us to see reality with new eyes."

[Lumen Fidei #26]

It is my hope that doctors, nurses, genetic counsellors, clergy, family or friends will make this resource available to parents at the time they receive the difficult prenatal diagnosis regarding their baby.

The people in this resource have "been there". Please encourage the parents to read this resource and search out the groups/organizations listed for information and support.

Parents need to hear the message that there is "Hope In Turmoil".

-Bernadette Zambri

Please note: Morning Light Ministry meets parents who have received a difficult prenatal diagnosis regarding their baby from their own unique perspective. This ministry welcomes parents of other Christian denominations, parents of other faiths, parents of no religious affiliation who are struggling with the very notion of faith and parents who may have no belief in God.

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Respecting Every Baby Inside and Outside of the Womb

Each baby is a fully human person with a soul from conception. God has a special relationship with each human being inside and outside of the womb. Sometimes a baby is diagnosed with an abnormal genetic/medical condition while in the womb.

With new technologies such as Non-Invasive Prenatal Testing (NIPT) (a blood test can detect chromosomal problems as early as 10 weeks gestation without the risk of amniocentesis) parents will be under greater pressure to "terminate the pregnancy".

Some genetic/medical conditions are life-limiting such as Anencephaly, Trisomy 13 and Trisomy 18. However, there are babies who have survived for weeks or months and sometimes longer. Other genetic/medical conditions are not generally considered to be life-limiting but rather life-altering such as Down syndrome, Spina Bifida and Hydrocephalus.

When the parents are given the news that their baby has a genetic/medical condition such as the ones previously mentioned, often they are strongly encouraged to "terminate the pregnancy" by induced abortion or early induction of labour. Catholics do not condone terminating the baby's life.

“ Prenatal diagnosis is morally licit, if it respects the life and integrity of the embryo/baby and the human fetus/baby and is directed toward his/her safeguarding or healing as an individual. It is gravely opposed to the moral law when this is done with the thought of possibly inducing an abortion, depending upon the results: a diagnosis must not be the equivalent of a death sentence.

#2274 Catechism of the Catholic Church



Faith



Camryn



Hope in Turmoil



Many parents whose babies are diagnosed with genetic/medical conditions that are commonly associated with death in utero or shortly after birth are pressured into ending the life of their baby through induced abortion or early induction of labour. They are in great need of support and caring from medical staff and their faith community in their decision to carry their baby to term.

Unfortunately, instead of support and caring they hear very non-supportive and uncaring comments such as:

- ...Go ahead. Get an abortion. It's not really a baby. They don't have a soul yet."
- ...They're not really a person. They're just a vegetable. So an abortion makes sense.
- ...What are you doing to yourself? There's no point in carrying the fetus to term.

One parent whose baby was diagnosed in the womb with Trisomy 13 shares some comments that were said to her by fellow Catholics:

- ...Have you talked to the right people about this?" (implying that we were making the wrong decision)
- ...I know what my wife/husband and I would do if it were us..." (implying that we were making the wrong decision)
- ...I've seen babies with this condition; they're not a pretty sight." (implying that since our baby wasn't "perfect" to look at we should terminate our baby's life)

One father experienced people making these comments while his baby was alive in the womb and also in the months following his baby's death. Several mothers heard these comments from their doctors, nurses, co-workers, family and also from fellow Catholics.

Mia



Kayden



Bristol



Peter

Hope in Turmoil

Many parents have found the following quotations comforting and helpful in guiding them on the journey with their baby:



Whoever welcomes this child in my name, welcomes the one who sent me. For he who is least among you all is the greatest.

Lk. 9:48



Human life is sacred because from its beginning it involves the creative action of God and it remains for ever in a special relationship with the Creator who is its sole end.

#2258 Catechism of the Catholic Church



Human life must be respected and protected absolutely from the moment of conception. From the first moment of his/her existence, a human being must be recognized as having the rights of a person - among which is the inviolable right of every innocent being to life.

#2270 Catechism of the Catholic Church



Before I formed you in the womb I knew you, and before you were born I consecrated you.

Jer. 1:5



My frame was not hidden from you, when I was being made in secret, intricately wrought in the depths of the earth.

Ps 139:15 " #2270 Catechism of the Catholic Church

We need to offer love, comfort and support to these parents in their decision to carry their babies to term. We need to respect their babies as fully human persons who have a right to life until their natural death with no termination by the medical community.

Lois' Son Daniel

It was extremely difficult to get through those 21 weeks knowing our baby would not survive from the condition of anencephaly. Unfortunately, we received many negative comments from many people.

After our son Daniel was stillborn I was devastated and grief-stricken but I was grateful that I had freedom from guilt because we caused no harm to our baby boy. After losing Daniel, whose life was not valued by anyone, I felt like I was travelling on a very lonely road. Then, one day in September, 1996, I got a phone call from Bernadette at MORNING LIGHT MINISTRY. She immediately expressed that she valued my son's life. What a blessing it was to know that Bernadette and other parents at the monthly support group and the Series could better understand my loss because they all had experienced the loss of their babies who are all now in heaven. - **Lois**

Richard's Son Daniel

I knew what we were doing was right but I was really worried about my wife during those months. Once our son was born at full term I was really glad that we had not had an abortion (what many people said we should do because our son had a condition called anencephaly). - **Richard**



Anne's Daughter Emma

Anne, a bereaved mother, shares the story of her baby who was diagnosed prenatally with anencephaly, a life-limiting condition.

The results of our pregnancy test were inconclusive at first. David just went back to check and make sure that the initial negative was still there. He came flying back into the kitchen to tell me it was positive.

My initial feeling was 'overwhelmed'...both excited for the new baby, but exhausted from a difficult year with Hannah, who was at this time 9 months old and still nursing. My pregnancies are never easy and our lifestyle is pretty demanding. David was thrilled.

I almost immediately got sick and continued being sick all the time. I lost several pounds in the first few weeks from constant morning sickness. One particularly bad night I just slept in the bathroom, and stayed there all night long, getting sick enough times to hospitalize me the next day for dehydration. David was out of town in Maine and had to be called back on a chaotic midnight flight.

While I was hospitalized, my doctor decided to have routine ultrasounds done. So here I was at about 10 weeks of pregnancy lying on the ultrasound table. There were a lot of films being taken-a lot of silence. Finally when the technician was done, the radiologist came in, and I immediately asked him if my baby had a brain. He looked at me sharply and I asked again,

"Does it have anencephaly?" He answered that he couldn't be sure, things were preliminary, etc., and told me they were looking for placenta previa. I can see now that they were very unnerved by my questions and were trying to buy some time before they told me what they were really looking for.

So it was not a shock to me when my doctor came in and told us that the results of my ultrasound were bad and that our 'product of conception had a condition that was incompatible with survivability'. What? You mean my baby will die? It was as if I was watching this scene play out while I was above it-just watching.

I was told that the standard medical therapy for this condition was 'early delivery'. [*another phrase is early induction of labour] I would have a laminaria tent placed inside my cervix and would be smeared with a prostaglandin gel. This would start my labour and could take 24-72 hours to complete, and would give me a fever, vomiting, diarrhea, and the shakes. I would deliver a small fetus that I could hold and bury if I wished.

My doctor was asking as he could be under the circumstances, but I felt that he did not want me to have this child. Earlier we had discussed me doing I.V. fluids for the baby after birth, at home with a nurse, but now he said, "Well the fluids won't be necessary now." (Since the baby was going to die anyway, why do any treatment?)

We debated for about 5 minutes - I confess it seemed like we should go ahead and 'induce' because the child would die anyway. Why go through a difficult pregnancy with two small toddlers at home when we knew that the outcome was certain death? I was ambivalent about being pregnant, but then I realized that this was my child, growing within me, and she deserved just as much love as my other two. Why would I turn my back on her just because she was missing an organ? If my other two lost a limb, or an organ, I wouldn't love them any less. Thankfully, David felt supportive of not terminating. What if they were wrong? There was no going back if we induced labour and then found out that our child was indeed perfect, how could we live with ourselves? Plus, we believe that God can heal any infirmity and although He might not choose to, if we terminated then there was no chance at all that she could be healed. We decided to wait two weeks and have a repeat sonogram.

That test showed the same results. This sonographer told us a great deal about anencephaly. He said that she would probably not survive labour, she could die any time in the uterus. If she did live through delivery she would be as if she were comatose. She would have no reactions, wouldn't open her eyes, wouldn't know we were around, nothing. We should really consider that if we were going to carry this fetus to term, (he really could not understand our decision), then we should know that she was the perfect candidate for organ donation.

Was that what God would have us to do with this child? Could her entire life's purpose be in organ donation? We were unsettled by this information but were trying to keep an open mind.

I then learned that everything that the sonographer told us was untrue. Organ donation is not even allowed with anencephalic babies because, although they do not have the top part of their brain, they do have a brain stem which keeps them alive. They would never require artificial life support. It is against the law to remove organs from anyone with a functioning brain stem. I was told this by a representative from Life Bank, the organ donation organization. I also learned, with relief, that in order to donate organs, all donors have to be alive physically but with a total ending of brain stem function. Originally, I had thought if we were going to do this, we could hold her until she died, and then they would take her, but I have since learned that organ donation only occurs when your body is still alive although your brain does need to stop functioning. So, organ donation for her meant that she would have been taken from me at birth, and the surgery to 'harvest' her organs would have been done while she was still alive. She would die on the operating table after the removal of her organs. I knew that I wouldn't do that to my child. So it was a big boulder off my shoulders when I found out that it was against the law. (Incidentally, this law is being challenged in several states. There are some people who want to use their

organs anyway and are trying to get an exception to the brain death criteria. I feel that this is an abomination and I am working very hard to oppose this idea. Please contact me if you would like to know more about this.)

I think that my doctor was upset and scared by our decision to carry our baby to term.

I think that my doctor was upset and scared by our decision to carry our baby to term. I know that he had never dealt with this before and was feeling frightened and not completely on top of this. I also think he lacked any emotional skills to help me carry this child to term, and felt that it would be easier on everyone if we would just terminate. To that end, he tried hard to scare me by telling me all the horrible things that would happen to me during this pregnancy, namely, that I would develop polyhydramnios, where I would develop an excess of amniotic fluid 'and would blow up like a woman with triplets'. Also, that I would not be able to properly labour because of the baby's lack of a skull, and consequently, the lack of pressure available to help my cervix dilate during labour. I would probably need him to cut open my cervix or need a cesarean, and 'did I really want to deal with a C-section on top of a funeral?' Although I was shaken by this information, I still felt that I could recover from a

C-section eventually but that I would never have another chance to hold my baby, even if it were just for minutes.

I decided to research the information he gave me and found it to be basically false. Although polyhydramnios is a possibility, there are also simple ways to treat it. I also found no examples of anencephalic births needing C-sections. I confronted him with this information, and he replied that 'it would have been a lot easier for him if I did not know so much'. Then and there I decided I would not have this baby with him. The moral of this part of my story is that you have to find out the truth about what you are being told and realize that everyone who advises you has their own fears and inadequacies. It is likely that those fears will surface in their advice to you. Realize that only you and your family have to live with your decisions. Make one that you feel you can live with now and for the rest of your life.

Thus we began our long wait. She was diagnosed at 10.5 weeks gestation...7 months of heartache had begun. I was surprised at the lack of outright support for our decision, even from our fundamentalist church. It seemed that everyone thought that most babies had a right-to-life, but maybe not this one. I did not find in the Bible, any references to God making mistakes that He expected us to remedy. The Bible says that all children are formed with God's knowledge and love. 'Less than perfect' is a man-made category, not a spiritual one.

For future reference, the friends that helped me the most were the ones who helped me with my house cleaning and caring for my other children. I see now that I was deeply grieving this loss, and that grief takes an enormous toll on your ability to cope with even the most mundane things. I also had absolutely no tolerance for anybody's well-intentioned but heartless remarks, like, 'Well, at least this is a girl you are losing and not a boy, since you have two girls already.' or 'I'm praising God that you will at least have more space between your children, three in 4 years really is too much.' I came to dread any remarks that began with 'At least...'. I knew I would be hurt by whatever came next.

Labour finally began 3 weeks after her due date. I have since learned that it is very normal for an anencephalic pregnancy to go way overdue. It was a long and difficult labour but I had many great friends and a wonderful midwife all supporting me. I really believe that their support was crucial-both in their belief that Emma was a baby deserving of their love and their confidence that I could finish this birth alone. I chose a home birth because I wanted Emma to be surrounded by people who loved her. I didn't feel that I could control that in a hospital setting, and if she was only going to live a few minutes, I wanted them to be wonderful minutes.

I was overjoyed when, at the moment of birth, she let out the normal cry. It was a miracle that she was still alive after the birth. David caught her and just began to weep. I think he still hoped that this would not

be true, that Emma would not have anencephaly, that this was all a big mistake.. But when she was born, there was no hiding from the reality. She had anencephaly, but she was just beautiful. There was a grouping of tissue where her skull would have been, making her head size smaller, but everything else was just perfect. You could barely tell there was anything different about her.

**We were with
her all the time,
protecting her,
defending her, and
cherishing her.**

Overjoyed by her healthy heartbeat and great colour, I decided to try and nurse her. Imagine my surprise when Emma latched on hungrily and proceeded to nurse for twenty minutes!. She nursed a few more times after that and each one felt like a gift.

Emma lived for five wonderful days in which she was held, loved, snuggled, bathed, sung to, and adored. Our two children, Bethany (3) and Hannah (19 months) just couldn't get enough of her. They held her, stroked her, kissed her, and generally behaved the way you would expect them to treat a new baby-with fascination and wonder. I believe it was easy for them to accept Emma's 'broken head' because we did. We were not afraid of her and I think that was apparent to our children. Children come into situations like this without a bias, and they learn their responses from us.

Emma was fully welcomed at home and they fully loved her. Emma would hold their fingers tightly-we told the girls that if the baby holds your fingers, it means she loves you. So they were always trying to hold her hand, and still talk about how much Baby Emma loved them. There was a lot of sadness which we also did not hide from them. They were involved with her funeral and said their good-byes. It was difficult for us to continue to nurture them too, being so wiped out ourselves, but somehow we all survived intact.

My greatest comfort right now is that we never ran away from loving Emma. We were with her all the time, protecting her, defending her, and cherishing her. I believe that living with the pain of her dying is hard enough, but I am grateful that we have no guilt, or regrets. There is a Bible verse that says, 'There is no fear in love, as perfect love drives our fear...the one who fears is not made perfect in love.' I think that the love we possess for our children can allow us to be fearless in loving them, even when we hurt so much. May you be blessed by her story as we were by her life.

- Anne

Maria's Daughter Kristina

Another bereaved mother, Maria shares her story about her baby who also was diagnosed with anencephaly and describes how receiving information and emotional support are so important.

I had just been told that my unborn baby had anencephaly—a rare and serious birth defect that meant she was alive but had no upper brain. I cried as the doctor patted my hand and tried to explain what had happened. The baby's neural-tube (spine) had not closed completely at the top which it was supposed to do 21-28 days after conception. Depending on how severe the anomaly (defect) was the baby could be stillborn or live only a short time after birth.

Soon after my husband, Dave, and I had married...we had three healthy children close together: Laura, Susan and Andrew (Drew). We decided to wait and see if we wanted to plan for more. I found out you can't always plan your life.

What had caused this serious defect I wondered? Was it me? Was it something I did or didn't do as she was forming in the womb? I learned later that doctors don't know what causes anencephaly. [*Folic acid, a 'B' vitamin, is encouraged to be taken on a daily basis to help prevent neural tube defects. Ask your doctor about the daily recommended dosage. Research indicates that other reasons may be the cause in other incidences.] It has existed as far back as ancient Egyptian times. My husband wondered if he had caused the baby's condition.



We drove to a hospital in Salt Lake City to confirm the diagnosis. Friends took care of our children: Laura (5), Susan (4), Drew (2). During the long drive I planned the baby's funeral. I wanted to talk about it but Dave couldn't.

The doctor looked at the previous sonogram pictures and then at the kicking fetus on the screen. He said, 'Yes, it is anencephaly. How can we help you?' I asked what our options were and the risks with each option. Since I was only 14 weeks along we had three options: abortion, induce early or go to term. I already knew in my heart that I would carry this child to term. I just didn't know how I was going to do it. We were told not many women choose to continue this type of pregnancy. I asked him if he knew of any support group for us but he didn't.

Afterwards we talked to a perinatal loss counselor. I asked the counselor for a picture of an anencephalic baby but she couldn't find one. I asked if she knew anyone who had been through what we were experiencing. Again—nothing. I felt so alone.

As we left the building I saw babies everywhere. I cried. I wanted to hold a newborn so much. We went back to our hotel, held each other and cried. I remember saying, 'I just want my baby back.' Spiritually and emotionally I had lost my child. Physically I was now my baby's intensive care unit for the next 6 months. My due date was set for May 8, the day before Mother's Day.

One month after we discovered our baby's defect, we were approached by a younger couple. Kathleen and Dave were pregnant with their second child. Kathleen said there was something wrong with their baby's heart. Reed David, their unborn son, had a Hypoplastic Left Heart. His heart had not developed properly and would be too small to sustain him once he was born. The doctors gave him three days to three weeks to live. Now there was someone else who was facing the same thing as me.

Kathleen and I called each other often. She was due before me. They had decided to bring Reed home and to love him for as long as they could. Reed was born in February. He was a beautiful baby. He died six days later.

When our baby was 19 weeks we discovered by sonogram that we had a girl. We named her Kristina Marie; the name I had chosen before her conception. I was referred to the local support group for parents who have lost a child. Unfortunately, I was politely informed that I didn't fit their group's criteria because my child wasn't physically dead yet. I was devastated. I had four

more months to go. I questioned God's plan. I still had Kathleen but I needed someone who had already taken an anencephalic baby to term to show me how it could be done.

It wasn't until my brother sent me a book that a woman had told him to send me that I found that person. The book listed pregnancy loss support groups. I immediately told him to find her again which he did. I called her and we talked for hours. I'll never forget what she said about her daughter who died named Rachel Marie, 'If telling you about her helps you then it helps me feel that her life was not in vain.'

I wrote to the support groups listed in the book. The support group, the genetic counsellor at a hospital in Helena, Montana, and prayer became my lifeline. There was a toll-free number to the hospital that I could call anytime to talk, cry or request information on anencephaly.

I felt an urgency to take control of whatever I could - collecting pictures of anencephalic babies, planning the birth, the funeral-anything to make me feel in control of this totally out-of-control situation.

Word spread fast in our town. I was amazed at the number of people who would ask me when I was due or what number child this was. Sometimes I would answer and move on. Other times I would explain my situation to them whether they wanted to hear it or not. Dave and I wanted to run away but we knew there was no place to hide.

My friends helped me with cheerful notes and my Bible Study even cleaned my house for me. Others would come over and prepare lunch for my kids so I could put my feet up and rest a while. Secret Pals left gifts on our doorstep. A 'casserole shower' was given in Kristina's honour. (Friends each brought a casserole dinner for us to freeze and eat later.) I'll never forget all the special support we received. Just before Kristina's birth, Dave's Mom, Grandma Jo, died of lung disease. Before she died she told us that God had chosen her to go first-to take care of the baby.

I felt an urgency to take control of whatever I could-collecting pictures of anencephalic babies, planning the birth, the funeral-anything to make me feel in control of this totally out-of-control situation.

We buried her on May 4th. We felt Grandma's presence in the delivery room the following week when at 8:30 p.m. Kristina Marie was born at forty weeks and two days.

I wanted to see her but was nervous to at the same time. I started to cry as my husband placed her in my arms. I couldn't give this baby any more life. I wanted so much more for her. She was beautiful with all of her facial features, ears and hair. She gave no respiratory effort and died nine minutes later in our arms. It was the day after Mother's Day.

I wanted the community to acknowledge my daughter. I believed she had a right to an obituary, public funeral and to as much life as she could take. I had planned everything as well as I could and felt I, her mother, had done as much as I could for her.

When I was first diagnosed, I received a newsletter with stories from parents who had terminated. At that time it was very upsetting to me.

Through the support group, I was able to find other parents who had taken a child with anencephaly to term. Kelly from Bakersfield, California, wrote to me. Missy from Chambersburg, Pennsylvania, wrote to me. These women (as well as Kathleen with Reed) helped me through my pregnancy with Kristina.

All of the women mentioned have gone on to have healthy babies. Kathleen and I are working with parents and friends to make sure no one else feels as lonely as we did on our journeys to know and meet our children."

- Maria

January's Brother Daniel

The following are excerpts from a high school English assignment written in 1998 by January S. who was 15 years old at the time:

...I have personally had the experience of witnessing my own mother lose a child when I was thirteen. However, our family's crisis was somewhat different because we were prepared for the death. We were informed a few months into the pregnancy that my brother Daniel had a condition called anencephaly. This left us with the option to go through with the birth to full term, or abortion. Our family held on to hope leaving Daniel with any chance of survival that he had the right to. Unfortunately, on Aug.2, 1996 Daniel was stillborn.

I believe he went on to a place where he was needed more. This brought our family together to support one another through the disaster.

The most difficult part of the whole experience was holding my brother, dead in my arms. Seeing my mother, who by far suffered the most, was the next most difficult obstacle. But she received a tremendous amount of support, love and care by the people closest to her and by the community. The two churches who offered great support were St. Mary Star Of The Sea and St. Dominic's (both located in Port Credit, Mississauga). Each institution provided support and counselling individually and in groups through the Morning Light

Ministry and the Parish Social Ministry...Social justice is the answer. We as a society need to answer these cries in whatever way we can.

No matter what religion or background a mother or father belongs to, losing a baby in such circumstances needs the love, prayers and support that is humanly possible. This needs to be brought to everyone's attention and cannot be forgotten...May the parents receive the proper foundations for healing for each day, week, month or however long it takes to heal.

- January



The following excerpts are from **MORNING LIGHT: MISCARRIAGE, STILLBIRTH AND EARLY INFANT DEATH FROM A CATHOLIC PERSPECTIVE**. (*See **RESOURCE LIST** under **MORNING LIGHT MINISTRY** to borrow or purchase this non-profit book.)

Michele's Daughter Gabriela

Michele, a bereaved mother, shares her story of her daughter's death due to Potter Syndrome (Renal Agenesis):

I am dedicating my story to my daughter, Gabriela Lael, who died shortly after birth on October 8, 1999 from a condition called 'Potter's Syndrome'. Renal Agenesis is the more technical term. It basically means that Gabriela was conceived without kidneys and survived her nine months in my womb without any amniotic fluid. Potter Syndrome is very rare and the chances of a baby being born with Potter's is 1 in 4000. There is very little information about Potter Syndrome and very little research has been done.

Despite knowing the outcome was terminal I decided to carry Gabriela full term and let God take care of her. I approached this part of my life with the love for my daughter and the support and love from my family and friends. I did not shy away from people who asked questions about my pregnancy, rather I faced them head-on and explained that my baby had Potter's and without a miracle her birth would be her death.

I remember when the doctor told me about Gabriela and asked me if I wanted to induce labour at 22 weeks. I felt so much anguish and pain in thinking of ending this pregnancy. I was so tormented that I would have to say that this was the most difficult part of the whole pregnancy, even more than delivering her and letting her go. I remember that when I made the decision to accept what was to be and to let God take care of her life, that I felt so much inner peace, I knew then that what I was doing was the right thing to do.

I honestly believe in my heart that because of this decision, God took care of me during my labour and delivery. It was a wonderful experience for me, and I would do it all over again. I remember thinking right after I delivered that I could get pregnant again right away. I felt such joy in carrying God's miracle and the beauty in seeing what the

love between my husband and I created, I can say this honestly...I was a gestational diabetic and was taking four insulin shots a day during my pregnancy and I did not regret one shot for the chance to be with my baby for one more day.

Many people acknowledged and agreed with the continuation of my pregnancy. Let me assure you that carrying a terminally ill child to full-term is not easy, but if you have faith and love for your child you will welcome each day as a blessing. Each kick of my baby reminded me of her life and brought tears of sadness and joy to my eyes.

My pregnancy itself was filled with various pregnancy complications, but I would be willing to go through all of them again if only I could carry my daughter for a little while longer. Many people ask me how I could continue a pregnancy that I knew was 'terminal' and how I can be so strong as I am through all that has happened. I can only answer one thing to you and that is 'FAITH'. God is my light and my strength. This pregnancy has led me back to God and I feel blessed to have found my way back to Him. I read an interesting quote the other day in a book that simply said, 'Faith is not meant to carry us around our problems, rather it is to carry us through them.' I know now that is true!

I never regretted carrying Gabriela Lael to full-term. I was given the choice to terminate the pregnancy at 5 months. I decided in the interest of my conscience and faith that I had to continue, put my faith in God and let Him take care of what was to be. How could I be the one to stop the strong heartbeat of my little girl? At each appointment it became apparent that she was a fighter and not going to give up, so how could I as her mother give up on her too?

From 5 months onward I relished each kick that she made and each pound that I gained. I used to lie in my bed each evening and say prayers for Gabriela Lael, and she used to respond to the prayers by kicking her feet. It seemed as though she could feel my love for her and knew that my prayers were meant for her. I felt such joy

in watching her little feet pushing my stomach outwards to let me know she was there. (At this point mind you I honestly thought she was a boy.) Her heartbeat was strong right up until the point that I delivered her. I had never felt her kicks more strongly than I did right before I delivered her. I think she was letting me know that she was still there and fighting.

When Gabriela Lael was finally born and baptised they put her into my arms. I remember seeing her chain breathing and thinking 'poor sweet dear, how can I let her suffer'. Gabriela was born unconscious and did not open her eyes or cry, so I just looked at her and whispered, 'It is OK angel, go in peace to heaven,' and she just let go. It was probably the hardest thing I have ever had to do in my life, but I just knew it was right.

The days following have been hard but I have been given the strength to deal with it all and I know that my baby girl is in heaven watching over me. If given the chance to carry an 'angel', please don't let go of this chance. Grab it, enjoy it and love your little one as long as you can!

- Michele

Jackie's Son Aaron

A bereaved mother, Jackie, wrote her story a few weeks after her son Aaron's birth and death as a result of Potter Syndrome:

On September 1st, 1999, my husband Dave and I received some rather heart breaking news. A second ultrasound of our unborn child revealed a rare genetic disorder affecting primarily the kidneys and then ultimately, his lung development. This condition is known as Potter Syndrome. We were told our child would not survive his birth. He was safe inside the womb (alive and kicking literally!), but once he was born, he would not live long. Needless to say we were devastated. Our doctor suggested he induce me as soon as possible, but this was simply not an option for us. My doctor said that he didn't consider this an abortion; in fact he said he didn't do abortions, but that this was different. We still said no. My doctor seemed uncomfortable and explained that the baby would go full term and that the baby could be large; I might even have to have a C-section. He wanted me to think

of all these things. He then told us that we could induce at 26 weeks, that the baby would then be viable. We told him we needed to talk to a priest, but that for the time being, we wanted everything to continue as normal.

Once he saw our decision was firm, he was very respectful and told us he would do whatever we wanted. If we wanted further ultrasounds or tests to re-confirm the diagnosis, we could have those. He would see me regularly, just like any other patient. We told only family and a few close friends. We did this mainly because I wanted to have as normal a pregnancy as possible, both for the baby's sake and my own. I didn't want people avoiding me or walking on eggshells around me for months on end. I felt that the baby could feel and sense my anxiety and I did not want him to feel anxious or afraid I will always be grateful for the fact that I was able to enjoy being pregnant. For me this was a blessing in itself.

Within a week of our diagnosis we were in contact with a support group. A family member was able to search the Internet and found the National Potter Syndrome Support Group in Texas. We called the number and I found myself talking to Evy Wright, a wonderful woman who started this group when she lost her son to Potter Syndrome in 1995. She sent us a package of medical information that she had researched and compiled over the years as a way of helping other parents who were faced with the same diagnosis. We quickly learned that our doctor was right; all of the studies showed the same conclusion: 'Prognosis; inevitably fatal'. As heart wrenching as it was to read those words, we will always be grateful for having the knowledge and information that Evy sent us. It gave us knowledge of what was to come in the months ahead and abated our fears. We no longer felt alone.

Our doctor continued to be supportive. He called us the day after we received our news to see how we were doing and referred us to a counselor who was a former hospital chaplain. We never did end up seeing this person, but it was nice to know our doctor cared. At every visit, he was very patient with us and answered all of our questions; at times the appointments went 30-45 minutes. He never rushed us. Our doctor was not Catholic, but told us that his wife was Catholic. Several times he asked

us questions about the Church's views on the moral and ethical issues surrounding our situation. It comforted us to know he was thinking of us outside of the exam room. For the next four months we lived day to day and although we prayed for a miracle, we also accepted the reality that our child would likely not live beyond his birthday.

As my due date approached, the topic of early inducement continued to rear its ugly head. My doctor was concerned about the size of the baby. Without the amniotic fluid, there was no way to accurately gage how big the baby was without doing another ultrasound. For us, the only advantage to inducing early was ensuring our doctor would be there. I wanted the hospital staff to know our situation and didn't want to suffer insensitive questions or comments. After consulting with two different priests, on two separate occasions, we decided to have me induced on January 2nd, 13 days prior to my due date. Even though I knew that medically the baby would be considered full term (38 weeks) and both priests said there was nothing wrong with inducing this close to our due date, I still felt uncomfortable. Choosing your child's birth date is one thing, choosing his death date was a decision, I felt, belonged to God. I began to pray, with fervour, that I would go into labour.

My prayers were heard. I began having contractions on the 19th of December. They were slow and, although painful at times, never seemed to increase in frequency or intensity. The week of December 26th through to New Year's Eve they got worse. Most days they would stop by morning, and I would go back to bed to get a few hours rest. I was quickly becoming extremely exhausted. On New Year's Eve my contractions started at 7 p.m., quite a bit earlier than usual, and increased in intensity until we went to the hospital at 5:30 am. I was given an epidural and was able to relax for the first time in weeks. The delivery was incredible. I was in no pain whatsoever. I was amazed when I saw our baby's head appear, and then suddenly we were holding him. Aaron Joseph Flynn arrived at 4:18 p.m. on New Year's Day: our millennium baby.

He was squirming and cried a little so we could hear his tiny voice. He was only 5 lbs. 7 oz. and 18 inches long, but he was perfect. David and I both

cried. We had never seen such a beautiful baby. I knew from the look on the doctor's face, we did not have much time. David baptized Aaron right away with holy water from Fatima that my mom had given us. The priest from our parish arrived a few minutes later and anointed Aaron and said some prayers. We took a bunch of pictures and then called my mom and Dave's dad in to the room. They were both able to see Aaron and hold him a short time. He died peacefully, in my arms, a short while later. Aaron lived only 57 minutes, but it was the best hour of our lives.

For some people, Aaron's death meant that a miracle didn't happen. But for us, it did. The miracle was Aaron himself. It is amazing how someone so small, who lived such a short life, could have such a profound effect on our lives. The hour we were given with him was one of absolute joy and wonder. Although the miracle some were hoping for didn't happen, I believe that all of my prayers were answered. I prayed that I would not have to choose a date on which to be induced and by the grace of God, Aaron came on his own. He was born on the Feast of Mary, Mother of God; I can think of no day more appropriate. He was born alive and we got to hold him and take pictures. I got to bathe him and dress him and I rocked him in the rocking chair until we had to give him up. I wanted him to know that even though I was only given a brief opportunity, I was still a good mom. This was what I had prayed for.

We had arranged to donate Aaron's heart valve and corneal tissue through the M.O.R.E. programme. When the nurse came and asked us if the surgeon from The Hospital For Sick Children could come at 7:15 p.m. we agreed. Once again, a difficult decision had been made for us. Saying goodbye to Aaron was the hardest thing either of us has ever had to do, but we know he is with God and will be for eternity. (*Each family situation is different but generally the family would have up to 12 hours after the death of the baby for heart valve and corneal tissue donation.)

One reason Aaron's birth experience was so wonderful was due to the hospital staff. This was partly due to some pre-planning. Our prenatal instructor had agreed to see us privately when we shared with her our child's diagnosis. As part of her instruction, she gave us a hospital tour a few weeks before my due date. She made sure the Nursing

Director knew of our situation and made several recommendations that proved to be of great help. We were able to meet the director herself and she explained that all the nurses would be advised of our diagnosis. Many of the nurses were familiar with Potter Syndrome, but sadly few had ever known anyone to bring their baby to term. All of the nurses were wonderful. Immediately after Aaron was born, one nurse came to me, kissed me and said, 'Congratulations'. I was so touched. Everyone in that room knew he would not live, but that did not prevent her from acknowledging Aaron's birth and the fact that we still had had a baby. It was a kindness I will never forget.

The director also suggested that rather than being moved to the surgery ward after the birth, I might consider staying on the Birthing Suite Ward. At the time didn't think this was a good idea, but she reminded me that would have the same nurses. This made a huge difference. After Aaron was gone, I stayed on the same floor that night. They moved me to a quieter room away from the nursing station and a little removed from the other birthing suites. It was very private and even had its own shower. Every nurse who came in the room was so obviously aware of what we had just been through, it was wonderful. There was just that extra bit of compassion and gentleness in everything they said and did. Before they discharged me, our

doctor came to see us. We spent some time telling him about our birth experience and reflecting on the past few months. We were pleasantly surprised when he commented, 'I learned something from the way you've handled this.'

On the Monday night we had a private wake, just Dave and I. The funeral was also private and was held on Tuesday, January 4th. We did not want to face a large crowd. A priest, who is a friend of the family, said a Mass of the Angels, a funeral especially for infants; it was simple but beautiful. Aaron was buried with David's mom and brother in Peterborough. We wanted to know he was cradled in the arms of the Grandmother who didn't get to hold him in this world. Dave and I both wrote letters to Aaron telling him all of the things we would never get the chance to say. We included these in the urn casket, as well as Rosary beads and the St. Gerard medal I wore every day I was pregnant.

These are tough days still, but we both have a sense of peace. There is no guilt and no regret and there are so many blessings to count. We try to focus on the joyful aspects of Aaron's birth and the happiness he brought us in that short hour. We have each other and our faith, as well as the support of wonderful friends and family.

- Jackie



David's Son Aaron

David, Jackie's husband and father of Aaron, wrote the following story:

After we received the diagnosis which told us that our unborn child's condition was incompatible with life, we were devastated. We were informed that our baby suffered from a rare kidney disorder called Potter Syndrome. We cried for our child and for ourselves. During the first few days after the diagnosis (in my wife's fifth month of pregnancy), we grieved our loss deeply. All seemed hopeless. After we received the sad news, we took a couple of days off work to go away and talk. Upon reflection, however, we reminded ourselves that we were our baby's parents and as such we had a responsibility to remain strong for our son. We knew that our job as parents was to protect and honour our son's life from conception to death and we began to devise strategies to survive the remaining months of the pregnancy.

We decided to tell our families and some close friends right away; we needed the support and we wanted to avert any baby showers. We tried to return to work with a positive attitude. Trying to figure out the answer to 'why?' just wasn't worth it. We relied on faith and on our trust in God. The remaining months of the pregnancy were difficult, but we attempted to see the many positive things around us rather than live in a place of pain. Being

called as parents even to one who will go home to God so early in life, is an honour. We focused on the blessings of pregnancy and found joy in choosing a special name and in establishing ways to honour our son's life.

I should admit that when we first received the news I didn't know how to pray because I felt angry. Upon reflection, I decided to pray that our little son would not suffer and that he would always know that his parents love him. I also prayed for my wife, whose courage and strength amazed me. I could only imagine the kind of emotion that she carried; it would only intensify after our baby was born.

On the Feast of Mary, January 1, 2000, our baby son Aaron was born. He lived for an hour and died peacefully in his mother's arms. He is our first child, and in spite of the situation, we were excited by the experience of meeting him. Even today, I feel the thrill of his birth when I proudly show the picture of our baby Aaron.

The grace of God is very apparent to my wife and me. We have seen the best in people; they have been most supportive and kind. While we miss our child terribly, we realize that we are part of God's plan, a plan we may not understand, and one whose purpose cannot be estimated. We look to the future with hope and thanksgiving.

- David

Mary Beth's Daughter Molly

One bereaved mother, Mary Beth, shares her story regarding her baby who was diagnosed at 17 weeks, with Trisomy 13, a life-limiting condition:

After the initial ultrasound we returned to the doctor's office where we received some very heart-breaking news. I felt like our world had fallen in...Several attempts were made to induce labour around 26 weeks and after three days, it was evident that my body was just not ready for labour. We decided that I would carry Molly to term, or until I felt I could no longer continue in light of my emotional and physical health...

I saw the O.B. for a prenatal visit. I advised him that since Molly would be born at or close to full-term, we would insist that her heartbeat be monitored at the time of labour (they had told us at 26 weeks at the time of the attempted induction that

Molly's heartbeat would not be monitored during labour as the O.B. was not prepared to take any extraordinary measures if distress was indicated) and a Cesarean section be performed if distress was indicated. The doctor expressed his strong concern against such a practice and reiterated the medical facts surrounding the issue. With reluctance, he agreed to note our request on my hospital chart.

I can remember saying to my husband that I wished I could remain pregnant with Molly forever, because as long as she was in the womb, she was alive! She was so active. I thought this was a good sign, until my doctor explained that because of her condition, she would just flail about aimlessly. (I preferred to think of her as jumping and skipping happily inside of my womb.) I grew to an enormous size while pregnant with Molly. Again, a good sign, I thought.

However, I had developed a condition called polyhydramnios whereby, again because of her condition Molly had no swallow reflex and thus, as she continued to produce urine, she could not 'recycle' the fluid by swallowing and thus I filled with fluid. Molly was in fact, a very tiny baby. Again, it was wishful thinking (and desperation) on my part. Oh, how I prayed and longed for a miracle, in the form of a baby who would live.

I must be honest and say I felt cheated when she died. Only years later could my husband and I recognize the many miracles of Molly's birth (my other three children, all born within four years after Molly-to mention a few.)

My water broke at home and I was admitted to the hospital. I immediately insisted that the fetal monitor be in place. It was soon evident that Molly was in distress with the onset of each contraction and that she would certainly not survive the continued labour or vaginal delivery.

We had, and would continue to do all that was in our power to give Molly a chance for life. We felt that Molly was just as worthy of rescue from her distress, as any other baby, healthy or not. We were not prepared to let others give up on her when we could do something for our baby.

With the O.B. and a nurse in the room, we were adamant in our insistence that a Cesarean section be performed. We were once again aware of the O.B.'s objections, but clearly, he was respecting our rights as parents and as advocates for our daughter.

Molly was born. She was baptized by our parish priest, in the delivery room and we spent the most joyous moments with our daughter for the one hour that she was alive, outside of the womb.

Molly met both sets of grandparents and an aunt and an uncle shortly before another doctor pronounced her dead. We spent at least two more hours holding and loving our baby in the privacy of our room.

We have but one regret today, and that is that our daughter didn't live longer (deformities and all). Looking back, we would do nothing differently if given the chance to advocate again on our daughter's behalf. It is easy for people to say that performing a C-section was too serious a measure

taken for a baby who only lived for an hour. Would there be any such question if Molly were still alive today?

We were, of course, really sad when she was born and died but I have to say there was some relief too because it had been such a struggle the final 17 weeks of my pregnancy and our time with her. Sometimes we didn't think we were going to get through it and so when that aspect of it was over, it was a relief for us...

People continued to be really supportive for the most part. It wasn't until our doctor called us to say that he was really receiving a lot of flack from the hospital staff that we really became embittered that we had to defend the fact that we had tried to save our baby...So we put in writing our feelings and we also went before the Board of Ethics at the hospital and again stated our case in defense of the position we took and that of our doctor and his actions. We made it really clear that if we had to re-live the whole thing we would certainly choose to go the route that we had and do everything in our power to save our baby...

I always speak of Molly's birth rather than 'Molly's death'. It's always been this way. I am uplifted by the thought of Molly being born and of course, so saddened by her death, so, I never say it. I love it when people talk about Molly especially when they call her by name or remember details like her birthday, her weight etc...

My parents display large photographs of their grandchildren on a special wall in the living room of their home. There, right in the middle, is Molly's picture (defects and all) in a frame subtly different from all the rest. It is so obvious how much they love her. Her memory is such a part of our extended families.

Within our immediate family a day rarely goes by that we don't speak of Molly to each other or to our other children.

- Mary Beth

Todd's Daughter Molly

Mary Beth's husband and father of Molly wrote the following:

At 2:49 a.m. today, Molly was presented into our world. 'Mom' and 'Dad' were joyful to finally meet their daughter in person. I saw a beautiful ivory-skin girl. She weighed 3 lbs. 8 oz. and measured 17.5 inches.

She was so gentle and soft. A perfect little angel. Her body seemed so strong and powerful. She had her mother's arms and legs and chin and my frown and lips (maybe Gramma Konecny's frown). She surprised us with her hair. It was light brown with a tinge of blonde and, surprise-red!

As I placed my daughter on top of her mother I saw a devoted, caring, perfect mother (as I often think our mothers are). I knew Molly loved her mother as her lips pressed against Mary Beth's cheek...if time could stand still.

It was a joy to see Molly with her grandparents as they proudly displayed her in their own special way. It was a joy to know that the entire family was with Molly today. Our friends' caring thoughts will always be remembered.

Molly was playful and strong, yet graceful and soft. She is our first, and will be with us always...

- Todd

Barb Farlow's Daughter Annie



My daughter Annie was predicted via ultrasound to have trisomy 13 and the most severe heart condition called Hypoplastic Left Heart Syndrome. (We refused amnio). However, after she was born, there was no sign of the heart condition. Annie also did not have the common, fatal brain condition associated with trisomy 13.

Annie's life ended tragically shortly after arrival at hospital at the age of 80 days. The medical care she received was, in the words of the Coroner's Paediatric Committee, "inappropriate." It seems that the doctors failed to treat her as a child and instead, considered her as a genetic label with a fixed outcome. In fact, 5-10% of babies with trisomy 13 and 18 do survive beyond one year.

As a result of the manner of Annie's death, I undertook research with two wonderful physicians. Ours was the first study in which the parents were given a voice about their experience of having a baby with trisomy 13 or 18. Prior to our work, everyone assumed that it is best to abort or for the baby to die as soon as possible after birth to lessen the burden on everyone. Our research, published in the best paediatric journal in the world, revealed that almost all parents who continue pregnancy have a positive experience with no regrets, regardless of the baby's life span. Surviving children were described as happy, despite their disabilities and parents say they enrich the family's life.

I've been blessed to know hundreds of parents who continued pregnancy after a diagnosis of trisomy 13 and 18 and each is a special love story. These children are the greatest teachers of what is important in life.

- Barb

Link to Annie's video: <http://www.youtube.com/watch?v=UqFkxT9BUJA>

Annie's story: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2532897/>

Link to published research: <http://pediatrics.aappublications.org/content/early/2012/07/18/peds.2012-0151.full.pdf+html>

Cris' Daughter Sara

Cris, a bereaved mother, shares the story of her baby who had a condition called Trisomy 13, a life-limiting condition. Sara was given Palliative Care in the hospital and in her home:

Sara was born on April 15, 1997. She was diagnosed with a rare chromosomal disorder called Trisomy 13 Syndrome. Sara had many life-threatening birth defects which unfortunately also included congenital heart defects. As a result of these anomalies, we were informed that Sara would not survive.

Sara was placed under Palliative Care (*to palliate means to relieve symptoms). This meant that our goal was to give her warmth, comfort, and love. The only way I knew I could do this was by bringing Sara home. I did not want Sara to die in the hospital. I wanted to take my baby home to die. I wanted God to decide when this was going to happen and how.

Within a week, to the surprise of many doctors and nurses, we were able to provide for our daughter's needs. With all the required legal documents signed, namely, the DNR (Do Not Resuscitate) papers, which enabled her to die with dignity, and ensuring that all the required home support services were in place, the doctors had no alternative but to comply with our wishes. Sara survived miraculously for 26 days. I have no doubt that even though her time on earth was short, her stay at home, surrounded by the love of her family and friends allowed her to live to the fullness of life. Sara passed away on Mother's Day...She moved on to live in her Eternal Home with God where she could live forever in the midst of His warmth, comfort and Love!

- Cris

And now I offer my prayer:

Lord, through Sara, the incarnation of our love, I ask that You show me what to do.

Where do I begin? I have so many thoughts and things I want to do.

Help me to want what You want. Help me to know what You want.

Help me to do what You want. Help me to remain united with You always.

I thank You for the miracle You have given Don and I. The miracle of life through Sara.

I thank You for letting me feel Your presence through the many graces You have given us to take each day as it presented itself then and continues to present itself now.

You made it clear to me that Sara was carved in the palm of Your hand and that You never let her leave Your hand. She came on earth all the while You held her.

You allowed her to return to You in the same manner snuggled dearly in Your embrace.

I loved her dearly too, my sweet Father. I still do and I always will.

I will miss her dearly too, my sweet Father but at least I know she is with You.

The crown of thorns that was around my heart has been transformed to a crown of roses that I know is placed around Sara's head.

Let her precious soul become Your instrument of doing Your will both in heaven and especially on earth.

Let those who pray to You be allowed to experience Your love and peace through her. Amen

John's Son John Diego

John, a bereaved father, shares the story of his son John Diego, who was diagnosed with Trisomy 18. John and his wife made the decision to bring their baby to term. John Diego survived the birth process and lived for three days in the loving arms of his family.

We were very excited when we found out that my wife was pregnant with our 5th child. (We had at that time 3 daughters and one son.) But then, on December 12th, the feast of Our Lady of Guadalupe, we had our 20 week ultrasound, and learned that our baby had abnormal findings that strongly suggested Trisomy 18. Often Trisomy 18 babies don't even survive to birth. We were very sad, but I hoped that Our Lady would intercede for us, especially given that we had received the news on her feast day. We both spent much time in prayer; I started the practice of taking a walk every evening to pray the rosary for our baby, and continued without fail for the entire pregnancy. I hoped that the diagnosis would be wrong, and that even if our baby had some birth defect, it would not be a fatal one.

We decided that my wife would not undergo amniocentesis, since it would increase the risk of a miscarriage, and it would not lead to any helpful treatment.

Our baby stayed viable through eight months of pregnancy. My wife went into labor on April 9th, which happened to be Holy Thursday. We prayed that even if the baby did not live, he or she would at least survive to



John Diego

be baptized. On the evening of Holy Thursday night, our son was born. We named him John Diego, in honor of Our Lady of Guadalupe, and the saint who had revealed her apparition to the world. We had called a priest friend when my wife went in to labor, and the timing worked out in a way that he had finished the Holy Thursday liturgy, and had arrived in time for John Diego's birth. Father administered both the sacraments of baptism and confirmation that night. One of the nurses even happened to be Catholic, and she served as godmother for our son.

John Diego was taken to the Intensive Care Nursery. Though he was on a ventilator, his condition was stable enough so that we could hold him. Many friends visited, and we were even able to have a family picture taken with John Diego, my wife, my four other children, and myself.

My wife was discharged Saturday night, but John Diego started having more problems. We were called during the early hours of Easter Sunday morning, and told to come in right away

because it seemed that he wasn't going to make it. He stabilized before we arrived, and we had a chance to sit with him and spend time with him. When morning came, I went home to pick up my children, but before I returned, he passed away. My wife had stayed at his bedside, and John Diego died in her arms.

Even though God did not answer our prayers in the way we had asked, we could see His hands very clearly in our son's short life. John Diego was born Holy Thursday night, when His son was just entering into His passion. John Diego died Easter Sunday morning, when the Son of God had completed his passion and risen from the dead. It was as if God were saying, *"Even though I am not answering your prayer the way you would like me to, I understand your pain and your sorrow. But take heart, in the end, you will be reunited to John Diego, and the joy that you will have at that time will be even greater than it would have been if he had lived."*

We miss John Diego greatly. I think about him every day. At times I still feel deep pain. If only he had lived! If only my other son could have a brother and a playmate! But, I know that God's plans are always better than our plans. And I know that he is with Jesus and Mary, and that one day, God willing, we will be with him.

- John

Susan's Son Aidan

Susan, a bereaved mother, shares the story of her son, Aidan, who was diagnosed with Trisomy 18. Despite this diagnosis, Susan chose to bring her baby to term. Aidan's photo graces the cover of this book.

We found out we were pregnant with Aidan in January of 2010. He was very much a surprise, but very much a welcome blessing. We fell in love the minute the two pink lines formed on the pregnancy test. I could already picture this new baby. How I would decorate his room (yep, already had that 'boy' feeling), clothes I would buy, and ideas for names (Aidan was at the top of my list).

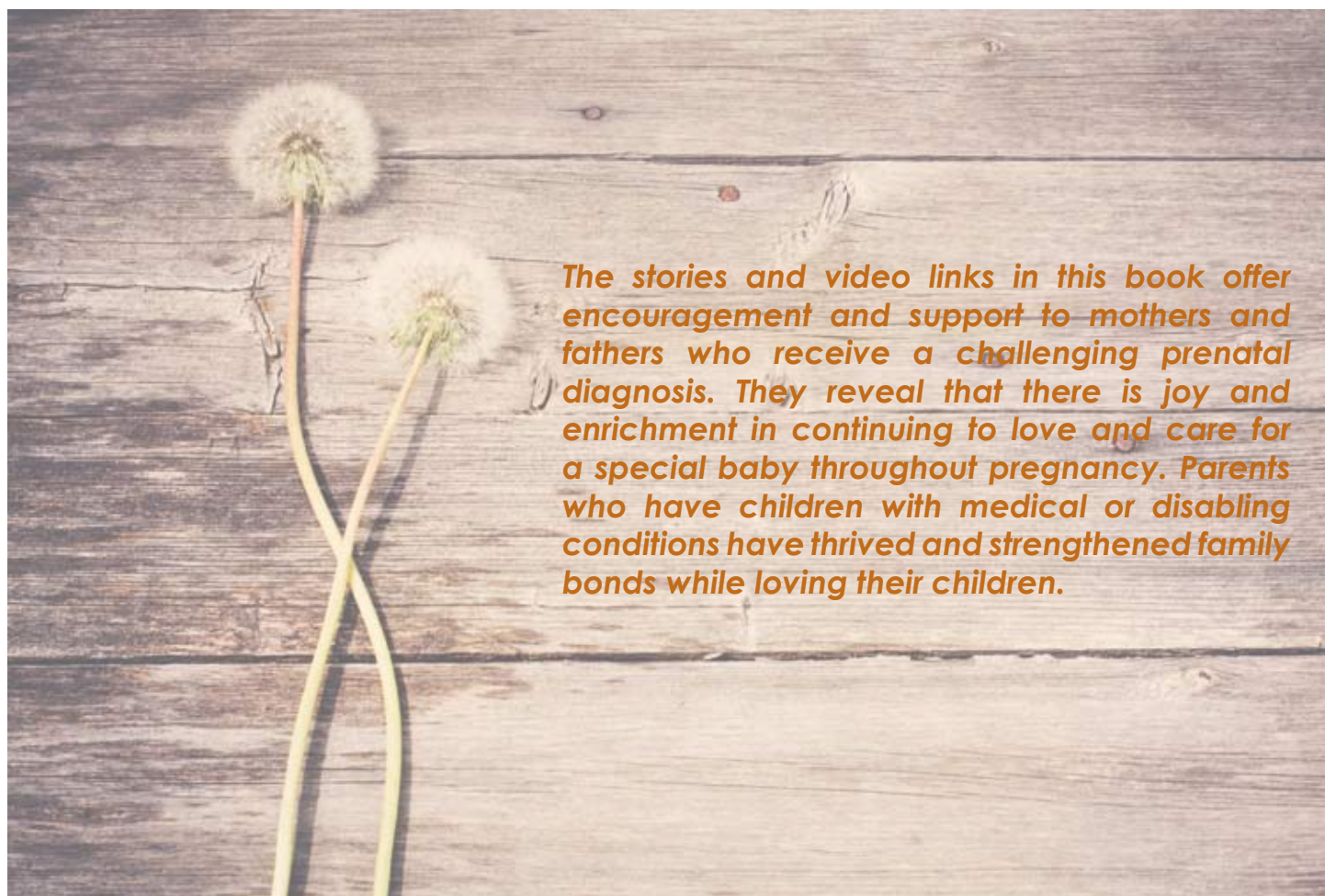
At just 11 weeks into our pregnancy, we learned that our precious son had Trisomy 18. We were told that T18 is "incompatible with life, and that it might be best to terminate the pregnancy, especially because we were so early into it." I couldn't believe what I was hearing. I told the doctors that he is my son, and that I would carry Aidan as long as God allowed. We were broken hearted, and scared, but I leaned on my faith, my family and my friends. With the help and guidance of a wonderful group, we created many special memories with Aidan while he was with us. Memories I would never have if we had chosen to end our pregnancy. Memories that are

more valuable to me than gold. Aidan was born into the arms of Jesus on August 1, 2010. We were able to spend quality time with his earthly body, take pictures, share him with friends and family and create many keepsakes with him.

Aidan Donan Guilfoyle is survived by his loving parents and his two big brothers. We speak Aidan's name daily and love sharing memories of him.

-Susan

[The support group that Susan speaks of in her story is listed in the Resource Section under BeNotAfraid.]



The stories and video links in this book offer encouragement and support to mothers and fathers who receive a challenging prenatal diagnosis. They reveal that there is joy and enrichment in continuing to love and care for a special baby throughout pregnancy. Parents who have children with medical or disabling conditions have thrived and strengthened family bonds while loving their children.

Erika's Daughter, Alessandra Rose

Erika, a bereaved mother, shares the story of her daughter Alessandra Rose who was diagnosed with Trisomy 18. Erika made the decision to carry her daughter to term. After discussions with medical personnel she chose "comfort care" as Alessandra's treatment after her birth.

I remember vividly how frightened I was when I first learned of my very unexpected pregnancy. My life had seemed to have come to a screeching halt. So many questions and emotions clouded my mind, but what I felt more than anything was happiness. I was a mommy from the moment I found out.

The weeks passed slowly until the date of my highly anticipated gender-revealing ultrasound had finally arrived. I couldn't wait! I planned to go straight to Baby Gap after to buy his or her first outfit. I was so excited as the ultrasound technician began and my child's heartbeat filled the small room. Within minutes I was told I was having a baby girl. I already had her name picked out, Alessandra Rose.

While I waited to be seen by my obstetrician, I spread the happy news to my closest family and friends. I had no idea that my world was about to be flipped upside down. I must have been oblivious to how long the technician spent looking at Alessandra's head and heart. But the minute I saw my doctors face, I knew. My heart even skipped a beat. She started telling me there were certain

markers on my ultrasound that indicated a serious problem with my baby. She lost me when she spoke the words that I'll never forget, "incompatible with life". It was the first out-of-body experience I've ever had in my life. It was as though it wasn't happening to me at all. I watched this poor girl as tears streamed down her face, while the doctor talked about blood work and level II ultrasounds needed to confirm this fatal diagnosis, Trisomy 18. A medical termination was offered at this time.

I barely recall walking out of that room or going down the hall to get blood taken. I don't remember driving home. I only remember feeling so empty that I felt as if I might collapse into myself. The tears never stopped. For the first time in my life I knew what true heartbreak felt like.

The very next day, I was sent to a near-by hospital for further testing. A 45-minute ultrasound revealed more devastating news. Alessandra had a confirmed neural tube defect, a serious diagnosis on its own. The doctor "coolly" explained that this alone could mean she may never walk or go to the bathroom on her own. She would require immediate surgery after birth and the extent of the damage wouldn't be known until that time. I was offered an amniocentesis as the doctor explained the spinal defect could be caused by the more serious issue, Trisomy 18. She stoically explained if I planned to terminate with the knowledge I already obtained, that the amnio wasn't necessary.

For the second time in just 24 hours, I was being offered the chance to end my daughter's life. This doctor was offering it just based on a neural tube defect. Simply because she wasn't going to be perfect and could potentially need extra care. I was so horrified that this doctor specializes in bringing life into the world. How awful that she could so easily tell a patient and a mother, that her baby shouldn't live.

I chose to do the amniocentesis that day. Matthew shielded my eyes as the biggest needle I had ever seen was inserted into my abdomen to slowly remove amniotic fluid. It was such a painfully long day waiting to get the call with the results. I prayed nonstop that Alessandra's only problem would be the neural tube defect. But the call came and she was officially diagnosed with full Trisomy 18.

I was devastatingly heartbroken. My doctor invited me to come back in and talk the following Monday to discuss what direction I wanted to go in. There never was any other option for me. I was specially selected to be Alessandra's mommy and there wasn't anything the doctors could tell me that could make me want to opt out of my responsibility to my baby girl. I'm sure I shocked my OB when I told her I would carry my sweet girl until the day God called her home, but she was proud of me for making the choice so many other moms couldn't.

I never once gave up on Alessandra. I always held tight to the promise that God was

always in control. I knew the odds and was painfully aware of the bleak statistics. The medical world and my rational side told me that Alessandra had over a 90% chance of being miscarried, stillborn or passing shortly after birth. Not to mention my doctor had told me that no doctor would preform the surgery that Alessandra required after birth. I refused to believe that.

I took it upon myself to contact neonatal specialists at one of our nations best pediatrics hospitals. I am blessed to live just an hour away. We set up an in-depth ultrasound, echocardiogram, and an MRI. With traffic it was taking us so long to get there and we were so late, that my sister and I got out a half mile away from the hospital and essentially ran the rest of the way there. We were there for almost 10 hours.

When the doctors sat down to discuss Alessandra's medical problems, there were more than we had originally been told. Her neural tube was opened in the lumbar region, which is much more serious. This had caused a chiari II malformation in her brain, which essentially displaces the brain stem. Her brain hadn't formed completely. There was dysgenesis of the corpus collosum and a kink in her brain stem. These were her most serious problems as they could affect her ability to regulate her breathing, heart rate and body temperature. In addition, she had a large ventricular-septal defect (a hole in between chambers in the heart), which would require surgery as well. She had a coarctation of the aorta (a narrowing of the aorta). She also had hypertelorism (space between

the eyes), micrograthia (small jaw), rocker bottom feet and clenched hands.

I felt my heart break all over again. I had officially done everything I could think of to help save my daughter's life. But I knew that I could no longer make the decision to choose life saving measures if she was born alive. Instead, that was the day I decided I would choose comfort care for my little girl. I was so thankful to the doctors that were so compassionate to myself and my unborn baby. It was the first time I felt there were medical professionals that truly cared about her and were willing to do whatever I was comfortable with. It was truly amazing in contrast with the doctors that had diagnosed Alessandra.

I chose to live like Alessandra was already here. Every day was another gift that I was able to spend with my little girl. We traveled to New Hampshire to camp and see a concert. We went on vacation to Miami to bathe in the sun. We made a trip to the Berkshires and New York. I read her bed time stories. I took her for ice cream. I took her to the beach and the lake. I did 2 maternity photo shoots. I brought the entire family to see her on a 3D ultrasound. I talked to her all day long and told her about the things I might never have a chance to. Most importantly, I never missed an opportunity to tell her I loved her. Every day was special.

On September 21st, I had my last OB appointment. For the first time Matthew decided to accompany me to my appointment. I had an

ultrasound scheduled just to check how she was doing. Matthew and I watched her cuddled into the same position she had always slept in with her arms curled up around her neck. Her heart beat sounded through the room. It's always been one of my favorite sounds. Later that night, Matthew felt her move around like crazy. He had always complained that she never moved for him.

The very next I waited all day to feel her move around. By 5 o'clock, I called my OB office and told them I hadn't felt her move all day. They gave me instructions to go get checked at the hospital.

Matthew drove me to the hospital and we waited in a tiny triage room closed in by a curtain. The nurse began to look for her heartbeat, and within seconds of her not finding it, I already knew. Alessandra's heartbeat was always so strong. She excused herself and got the portable ultrasound. She could not find any movement in her heart. The doctor came in next and checked as well. After a few minutes that lasted a life time, he said the words that shattered my heart, "I'm sorry. She no longer has a heartbeat." He left us in that tiny room and we cried for our little girl.

I let my closest family and friends know that Alessandra had been called home and I was to be induced that night. My family came to the hospital and most stayed the entire time. At 8 pm my labor was induced. I was already 3cm dilated. It was slow progress for awhile as the pitocin took effect.

I had the most incredible nurse, Nathalie, who gave us a room at the end of the Labor and Delivery unit. There were no other moms around us. By about 1:30 am, the pain set in and I was given fentanyl and my epidural. Somehow I was able to go into a semi-sleep state. By 3am I knew it was time. I was fully dilated and in just 3 pushes, she was here.

Alessandra Rose McKenzie was born on September 23rd, 2012 at 3:15 am. She weighed 2 lbs 13 oz and was 15.5 inches long. She was so beautiful. I was so afraid my entire pregnancy that I would have to say goodbye before I said hello. But here I was in that exact position and I couldn't stop smiling. It was still the happiest moment of my life. I was able to hold and cuddle my little girl. Kiss her cheek. Hold her hand. I was a proud mommy.

The moments were captured through numerous pictures. I was so blessed to have found out about Now I Lay Me Down To Sleep, which is a nonprofit organization that professional photographers donate their time and talent to give mothers like me professional photos of her precious time here on earth. I couldn't have asked for a better and more compassionate photographer. His name was Jeff and he was an absolute blessing to my family. He came in the middle of the night and took hundreds of photos. They are by far my most prized possessions.

Alessandra was with us for 12 hours. The hardest moment of my entire life was making the decision to let my little girl go. I didn't want to have to say



goodbye. But I knew in my heart that it was time. I had just a few minutes of time alone with her to tell her how I was feeling. I just wanted to tell her how much I loved her and to thank her for changing my life for the best. Just after 3pm, my nurse came to take Alessandra away. And for the first time since I got the news that she had been called home, I cried. The tears said all the things that I couldn't.

I was released from the hospital soon after. The week moved so slowly. The flowers, the cards and the outpouring of love from family and friends was outstanding. We had her celebration of life service at the one week mark. It was beautiful. There were pink roses everywhere. My father delivered her service. We followed it by doing a balloon release of 38 balloons to represent the weeks she was here with us. I never imagined doing a balloon release could be so touching. Matthew and I released our special balloons first. Everyone

else followed right after with notes attached for Alessandra. Matthews balloon shot straight up to Heaven. All of the others stuck together and traveled slowly up and disappeared into the hazy sky. My balloon was the last to disappear. It traveled all by itself apart from the rest. The very next day I saw the most brilliant rainbow I had ever seen just outside my house. I like to think it was sent with love from Alessandra as a thank you for all the balloons and notes.

Since she has passed, I have shared her story with as many people as will listen. I've done all I can to share my message that life is precious no matter what. If I had been told the day she was diagnosed that she would say goodbye before I could say hello, I still would've made the choice to carry her. She was a blessing, as every child is. Some are called home far too soon.

But her short life has touched so many people. She continues to touch thousands of lives around the world. I couldn't be prouder to be her mommy. Princess Peanut was my greatest gift in this world. I will always love her and I will always miss her.

- Erika



Barb's Son Paul

Barb, a bereaved mother, shares the story of her son Paul who was diagnosed with anencephaly. Many babies with this condition do not survive the birth process but Baby Paul's story illustrates that some babies do survive for varying periods of time after birth.

We were thrilled to find out we were pregnant with our second baby. Our two and a half year old son Matthew had been asking for a brother or sister for quite some time. We celebrated that day like crazy. The beginning of my pregnancy was just like any, I was always nauseous and very tired. We decided to sign up with a midwife this time. People were saying that they allocate more time when you go for appointments, hence allowing for a more personal experience. Five months into my pregnancy we went for an ultrasound. The technician only kept us for few minutes. She didn't want to talk to us about anything and didn't show us any pictures. When I asked her to print a picture, she

told me that the baby was not cooperating today. We went home with a bit of a concern. The next day, I went to work and I couldn't really share much with my coworkers. They tried to console me that everything would be fine.

When I went home it was still a nice and warm day. I sat on the porch and watched my Matthew playing on the driveway. Then the phone rang. When I picked it up it was my midwife. She asked me if my husband was at home. I told her he will be home later and I asked her if everything was ok. She told me she needed to speak to both of us, so she would call back. However, at that minute I sensed that something was wrong so I persuaded her to tell me everything right away. And she did. She had told me that there was a problem with the baby. I started screaming, 'What does it mean?' She told me that my baby would DIE. I lost it! I grabbed my son and brought him inside. I remember being in such a shock that I started throwing up. I couldn't control

anything anymore. I picked up the phone and called my parents house. My dad picked up and all I could say is my baby is going to die repeatedly. I didn't call my husband because I did not want him to get into an accident on the way home. In a few minutes my parents showed up at my door. They tried to make sense out of all of this. The midwife called me again and spoke to my mom. She tried to apologize for the way she handled the situation, that she told me the news over the phone without an adult with me for support. When my husband came home and I told him he didn't know how to behave. He tried to stay strong for me and tell me that everything would be fine but it was really hard for him. The next day, I called work to take couple of days off, which was granted to me. We were scheduled for an ultrasound and an appointment with the genetic counselor. The genetic counselor explained to us that the baby had anencephaly and that in many cases it is not hereditary. She also said that creating a baby is such a complicated process that it is a miracle that so many babies are born fine. We were given two options in this situation: to abort the baby or to carry it till the end of the pregnancy. She continued, "It is of course your choice, but for sure the baby will not survive." I couldn't believe it. I looked at my husband who basically told me that no matter what I decide he would stand by me. I told the doctor that I would keep the baby and that maybe they had made a mistake and the baby would be fine.

My life after that was like a bad dream. At first I cried a lot and could not face anybody. Later I went into survival mode and started looking for some help. I spoke to a priest who was a great support for the rest of the pregnancy. He tried to explain to me that our life is like a beautiful blanket, which looks great on the top side but has lots of knots on the bottom. Those knots are all the difficult situations that we deal with in order to make our life as great as possible.

The rest of the pregnancy was the hardest time of my life. I lived in a denial. I prayed a lot and hoped that all of this was just a great mistake. My husband and my mom were always there for me. I also met almost every week with three girlfriends who tried their best to help me get through it. If it wasn't for them I would have gone mental. Some of my other friends kept away. I guessed they just didn't know how to behave around me.

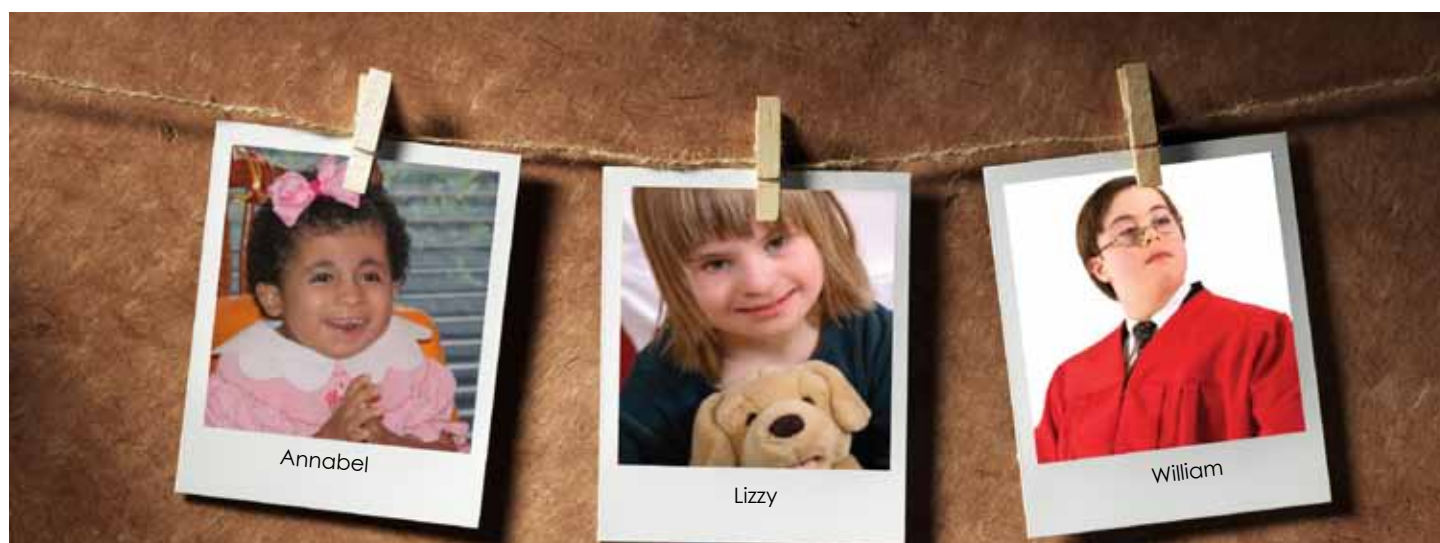
Seven months into the pregnancy I was referred to the high-risk clinic. It was there

where I was attacked by a doctor because I decided to keep the baby. My husband did not come with me so I had nobody to defend me. The doctor basically told me that by keeping this baby I put myself in a great risk of having a lot of things go wrong. He even offered for me to abort that baby at that time. I cried so much when he was telling me this but he did not seem to care. As I was driving home I could not stop crying. How could somebody be so cruel? I couldn't abort this baby. It was a gift from God even if only for a short time. I heard the heartbeat, I felt the movements, how could I just kill an innocent baby?

When I got home I decided to call and complain about the doctor and I asked the hospital to keep him away from me. After that incident it was just frequent checkups. I was still praying a lot for a miracle and just getting ready for the delivery of the baby.

Three weeks before the due date I started having the contractions. It was time. I was

so scared I almost denied that the baby was coming. I knew that the minute I have this baby his life will be over. My mom and my husband went with me to the hospital. Everybody in my family was informed that the baby was coming and they should be on a standby. My mom also informed the priest and even though it was getting late he came to the hospital and waited for the baby to be delivered. The labour was progressing really well. And even though the previous doctor told me that there would be so many complications it was the easiest delivery I have had so far. Dr. Doyle was an attending obstetrician and she handled the situation amazingly. She made me feel good about my decision and she received this amazing baby with such peace and calmness. When the baby came he wasn't breathing so we thought he was dead. The nurses took him away from me and passed him on to my mom who took him straight to the priest. Father P. Dudek was getting ready to baptise him. My mom's girlfriend who brought Father Dudek that night was chosen to be a godmother.



It was the saddest day of my life but the atmosphere in the room was unbelievable. You could feel God's presence and it seemed like everyone who was there and came to visit was transformed.

When Father Dudek baptised the baby, my little boy started breathing and you could see a blood flow to his cheeks. It was a miracle. After that I was able to hold my precious boy and wait for all my visitors to come and greet him. I knew I didn't have much time with him so I held on tight until the end. He lived for 11 hours. My wonderful and strong mother was there with me every step of the way. She and my husband helped me stay sane during that time. All the nurses who came to look after me and the baby were so amazing and understanding. Even a paediatrician who came to look at the baby was so gentle with him. What was also amazing was that this little boy knew that I was his mommy. He only stayed quiet and comfortable in my arms. My little baby boy was a gift from God who came to this

world for only a short time but had received so much love from everybody but also brought so much love and transformed many people's lives.

This journey was the hardest thing I have done in my life so far. However, my faith and the support from the people around me kept me strong so I could face anything. Before this pregnancy I seemed always the one in charge of my life. I learned that we are not in charge but God is in charge and in order to be happy we need to let God's plan take its course and completely trust him. I know that right now I am richer than many people because I have my little "angel" in heaven watching over us. I mean, how many of us have their personal saint so close to God?

Fifteen months after the birth of baby Paul, I delivered my healthy boy Darek. It wasn't easy to be pregnant again but with the help of everybody again I stayed calm during the pregnancy. Matthew who went through this turmoil with

me finally received his brother. Matthew never forgot his brother Paul, even though he didn't really see him. Even till today he talks about him and makes sure that everyone knows that he has another brother.

It's been five and a half years since the birth of baby Paul and our life is still changed. I am expecting my fourth baby soon. I never thought I would have more than two but I guess God has his own plan. The boys are extremely excited and awaiting their baby sister. I was very scared to have more kids after baby Paul but if I allowed fear to take over my life I would never had Darek and this new baby in my arms. To get at least some of my life back to the way it was I needed more kids in my house. There is not one day I don't think about my precious baby Paul and I know I would not have changed anything for the world. He made me a stronger and better person and I'm sure that my journey has made many people look at things differently.

- Barb



Kristi's daughter Sofia

Kristi's daughter Sofia was born 2004 with Trisomy 13, non-mosaic, nondisjunction of chromosome 13.

In emails to friends and family, Kristi shares Sofia's remarkable progress.

January 1, 2008

Dear Friends,

I can't believe more than a year has nearly gone by since our last update. A lot has happened this year that has kept us busy. Sofia is now a proud big sister. God has blessed us with a healthy boy, Daniel Edward born Sept 6, 2007.

Medically, Sofia has been in very good health. She recently had a tongue tie surgery (frenulectomy). This may or may not help her speak or swallow her food but we feel if there is a chance to help her improve then let's see. Over the summer she went through a big growth spurt, in Aug she had about two seizures a week, but her anti-seizure drug Keppra seems to have them in control. The seizures usually happen at night when she is sleeping.



Physically, Sofia is doing very well. She loves her physical therapy. She's been sitting up on her own

for a year now, and even progressing to a kneeling position. She loves spending time in her stander, and is starting to take steps in her gait trainer. She definitely has the will to walk. So if there is a will there is a way. As of Sept we started an outside physical therapy program that includes swim therapy. Sofia still wears glasses, but tends to take them off and chew on them. A headband helps keep them on.

Sofia continues to go to school to a half-day special needs Pre-K programs at our local public school. We are lucky she receives one on one attention in a small class size. As always, she enjoys her music, in particular "If you are happy and you know it", and she loves knocking down block building someone builds for her. She still loves her musical books and she loves to hear the alphabet and numbers sung to her. "Mr. Brown can Moo, can you?" is her all time favorite, thank you Dr. Suess.

October 24, 2008

Dear Friends,

Sofia has had a few big growth spurts this year. She is about 45 lbs and a little over 3 feet tall. It's hard to believe she'll be 5 in Jan. Over the summer she has finally gotten used to her walker and she loves scooting around the classroom in it. She still has seizures about twice a week in her sleep. Please keep her in mind and in your prayers on Nov. 3 she is going to have her tonsils and adenoids out. We hope this surgery will alleviate her snoring and lower her chances for apnea when she sleeps.

January 2010

Dear Friends and Family

Happy 6th Birthday Sofia! In 2009 we had a lot going on and it involved our military move from hot San Antonio to scenic and much cooler Hudson Valley, New York. It is nice to see four seasons again. But, we will miss all of our friends and teachers that we had in San Antonio. Maybe we'll be back again one day.

Sofia overall had a good year. She did have two broken legs this year one in January and again in

October. Her breaks were both in the lower portion of the left femur. One break was a medial buckle and the other lateral buckle. We're told breaks are common in children like Sofie, who have low bone density or osteopenia due lack of physical activity and weight bearing. Besides breaking her leg twice this year, she has made wonderful progress toward walking. First kneeling on her own, bearing weight in her legs and taking many steps while we hold her. Sometimes she even takes a few steps while we hold just her hands. She is definitely strengthening her trunk. At the same time she has also made progress crawling. This past month she takes 2 or 3 solid crawling moves to a favorite toy on a table. As with anything Sofia does, she knows and has a strong will to reach a milestone.

Sofia continues to be very cheery and loving. She still loves her Dora, Lori Berkner, Jack's Big Music Show, and Barney. Even though she doesn't talk, she vocalizes and lets us know what she wants by laughing, giggling, whining and shouting out if she is in the midst of doing something she doesn't want. This year we would like to work on her vocalizing and also improving her fine motor skills. She knows how to push buttons on all of her toys



and most of the time put objects in a container with minimal assistance. Maybe we will find a nice switch toy for her to communicate more with us.

Please keep our family and Sofia in your thoughts and prayers this year that we will have another blessed and healthy year.

- Kristi

Liam, April 2, 2013 - October 4, 2013

A picture story of Liam who was diagnosed with Trisomy 18.



Liam, diagnosed with Trisomy 18, is 2 weeks old and waiting to be baptized.



Liam 3 weeks old, is well loved and, despite what doctors recommend, is worth having all chances for survival.



Liam beats many odds, proves the doctors wrong and makes it home. With God all things are possible.

Siri's daughter Evy Kristine

Siri, a doctor in Norway, brought her baby to term knowing that her baby girl, Evy Kristine had full Trisomy 18. Siri lives 3 hrs from the hospital where she was to deliver and as it was her fourth birth, it was safer to be induced. Siri shares her story of her pregnancy and the three cherished days with Evy Kristine after her birth.

We were expecting our fourth child. Due to my age we were offered the ultrasound/maternal hormone-test by week 12 of the pregnancy. This is common practice in Norway, where we live. The results showed a great chance of Trisomy 13 or 18, so we were offered amniocenteses for confirmation. By week 15 they phoned us with the results - our baby, a girl, had full Trisomy 18. We were devastated!

The geneticist offered us an appointment the next day for termination of the pregnancy. According to the geneticist the disorder was "incompatible with life". Ending the pregnancy was no alternative to us – we wanted to give our daughter a chance to live, and it felt much better to let nature run its course.



We informed our other children about her diagnosis, telling them their baby sister would likely not make it to birth. My oldest son, aged 9, cried and cried, then he wrote her a poem, naming her Kristine. My husband and I added the name Evy, which means life.

Big brother Einar also made this poem the day baby Evy Kristine was diagnosed:

***" Kristine is so beautiful
it is difficult to accept
it is a pity she will not live for long,
but I will keep hugging her,
and she should receive praise and lots of hugs
because praise and hugs make well."***



Translated from Norwegian - he made it rhyme. I just could not translate it to rhyme...

There was no scheduled follow-up with the geneticist. He was not used to patients choosing to continue the pregnancy with this type of condition. My gynecologist at our local hospital kept encouraging me to terminate the pregnancy. She told me to think of my other children. She felt that continuing the pregnancy was a waste of time and I wasn't getting any younger. If I truly wanted another baby I would terminate this pregnancy.

We asked for a diagnostic ultrasound at a bigger, specialized hospital, to check for abnormalities common in T18 babies. Our daughter had a VSD – a hole between the ventricles of her heart. Other than that they could find nothing wrong. Her fists were clenched, and her head strawberry-shaped, typical signs of T18.

We were offered ultrasound check-ups twice monthly, but the doctors gave us a feeling we were wasting their time and resources. Are T18 babies not worth caring for? I left the hospital crying every time.

A friend of mine recommended another hospital in a town 400 miles away. A visit there was well worth the long drive. We were well received, we met a gynecologist with experience regarding T18-pregnancies, and who helped us work out a birth plan. A pediatrician who had treated lots of these babies talked us through alternatives of care should Evy Kristine be born alive. She told us she had developed a new respect for T18 babies throughout her career, as these babies seemed content throughout their short lives. We also met with a social worker. I left that hospital in a good mood, not crying this time. I was still saddened by the fact that they refused to monitor babies with Trisomy 18 during birth and refuse to perform C-sections to save babies like Evy Kristine.

Evy Kristine continued to live throughout the pregnancy. I cherished every movement that I felt. She was just as active in my tummy as my other kids had been. I was prouder than ever before of my pregnant belly, proud to be carrying such a special child, proud that she, against all odds, had made it this far.

Our other children were encouraged to join us for the ultrasounds, to touch my tummy, feel her kicking, to make drawings for her and so on. This might be the only way they would know their baby sister. I wanted them to have a memory of her.

As time passed, we grew more and more unhappy with the way our National hospital regarded T18 children. We were lucky, and were allowed to deliver in another hospital in Oslo, where we were received in quite a different way.

We planned for the delivery (at full-term) so that family members could bring our other children to the hospital right after birth. We knew the time with Evy Kristine could be very short, and we wanted her brother and sisters to be able to see her and to hold her. Those memories would be so important to them.

Towards the end of my pregnancy, I felt as I was going to explode, as there was an excess of amniotic fluid, as is common in T18-pregnancies. Friends kept asking me if I wasn't glad it would soon be over, and I felt like screaming back at them "NO"! I was not looking forward to delivery,

because that meant my baby would die, if not right away, then within hours, days or weeks. I wanted to keep her inside me as long as possible.

Labor was induced in the morning of April 15th, 2010. Evy Kristine was born in the evening. She was blue and quiet, so my husband took her away to bag her (to give her air). We are both anesthesiologists, and had discussed this beforehand. We wanted to give her a chance to survive birth by bagging her, then see how strong she was after that. The neonatologist arrived and took over. Soon Evy Kristine was breathing and screaming on her own. What a beautiful sound!

Evy Kristine's brother and sisters arrived at the same time as the minister who performed a baptism while I held her in my arms. It was so wonderful. They all then got to hold her for a while.

After about an hour she got tired and was taken to the NICU for CPAP – to make her breathing easier. We were now so optimistic, believing we would be with her for a while. My husband and I got a few hours of sleep as we were exhausted. In the morning I held Evy Kristine in my lap, skin to skin, and from that moment she was always in someone's arms. After a few hours she suddenly seemed agitated, she turned blue, and we thought we were losing her. I was so scared. We called for her siblings, and just as they walked into the room, Evy Kristine got better.

We were moved to a quiet room, where the whole family could stay with her. Evy Kristine was passed around to all her nearest family members – aunts, grandparents, siblings.

In the evening we celebrated her one-day birthday with a birthday cake.

She had received a nasogastric tube for feeding, and we were so happy. When the tube fell out, the doctors tried to put in another one, this time without luck. This was a strong indication that her esophagus ended blindly, or had a narrow point. It was such a sad turning point. From being so optimistic, we now knew we would not get to keep her for more than a few days, maximum. I later learned that in other countries they insert a PEG in cases of esophageal atresia and even

perform corrective surgery. Sadly they refuse to operate on babies with Trisomy 18 in Norway.

Yet, at the same time, we were so grateful that we got to meet her at all. Our feelings were all mixed up, and every minute with her felt like a gift.

She slept in my lap her second night. She had a few episodes of apnea, and I was terrified we would lose her every time. She was given morphine injections every hour, this helped reduce the number of apneas, and the next morning they put up a continuous infusion for her. She was calm, and seemed content, sometimes dreaming, sometimes looking up at us. It was so wonderful and so sad.

We celebrated her second birthday that evening, and she slept in her father's lap all night.

The next day she was peaceful until noon, when we again thought we were losing her. As her sisters and brother entered the room, she calmed down. She looked changed, though, and her heart rate was slowing. We removed the CPAP, which now seemed to give her discomfort, and I held her

for the next 5 hours, her last five hours on earth. She gradually faded away from us, with her sisters playing on the floor, and with her brother, mother and father singing songs to her and comforting her. We told her to let go, to not struggle for us anymore. She had lived so long for us – three whole days!!!!

But it was so hard, so painful, to let Evy Kristine go!

We took her home, and kept her there until her funeral. Her brother and sisters helped lay her in her casket, filled it with drawings, pictures and stuffed toys.

In hindsight, knowing what I now know about Trisomy 18, I would have fought more for my daughter - fought for a C-section to save her, fought for active interventions, for intensive care. Could things have ended differently? We will never know.

- Siri

“ In our opinion, fragile neonates with short lives can enrich society. We live in a society that is at often centered on goals, excellence, performance and perfection. While these have value they can impoverish if taken to extremes. Many parents report that having a child with a life-threatening condition was difficult, but that it also enriched their lives and had a positive effect on siblings. They learned to love and expect nothing in return, they learned that imperfection does not mean inferior, they learned to not take life for granted, they learned to celebrate every day as if it was the last...we have observed that these short fragile lives morally enhance society by having a positive impact on many individuals.

Annie Janvier, Department of Pediatrics and Clinical Ethics, Neonatology and Clinical Ethics, Sainte-Justine Hospital University of Montreal and Andrew Watkins, Department of Paediatrics, Mercy Hospital for Women, Heidelberg, Melbourne, Vic., Australia.

Medical interventions for children with trisomy 13 and 18: What is the value of a short disabled life?
Source: file:///C:/Users/Win7-user/Downloads/janvier%20watkins%20xyz.pdf

Raising A Child With Special Needs

Many parents whose babies are diagnosed with genetic/medical conditions that are typically not life-limiting such as Down syndrome, Spina Bifida and Hydrocephalus often are not supported in their decision to carry their baby to term.

Comments such as the following are heard by these parents in an effort to pressure them to abort their baby:

...These babies are only a burden on society.

...Your baby may have to endure a lot of tests and procedures in his lifetime. It would be the loving thing to do to terminate his life in the womb.

...She won't be able to fully participate in your family life. Think of how hard it will be on your other children and on your marriage.

JoAnne's Son Joshua

JoAnne shares her story of lack of support that almost led her to abort her child:

In 1990, at the age of 19, I was told that the child who I had been carrying for 16 weeks had a birth defect known as Spina Bifida. I was a single Mom-to-be which was going to be tough enough. I was called into my doctor's office and told that my unborn child had a hole in his back and that he would require surgery after birth. I was then referred to my local hospital where I saw a genetic specialist.

I was told my unborn child would be born deaf, blind and "retarded". He wouldn't even recognize me as his mother. They asked what I pictured my child would be able to do. I responded, "Play baseball." I was then told to forget it because he would spend his life in a wheelchair unable to do such an activity. They told me not to read books on this condition because they would only confuse me. I was told that if he lived I would only watch him suffer. I was also told that I was too young to take on this responsibility and that I had my whole life ahead of me. So I chose to have an abortion. It was a decision that was strongly influenced by everyone that I met.

I was sent home to choose the name that would go on the death certificate, decide whether I wanted him cremated or buried, whether I wanted to hold him and if I wanted a photograph taken.

I went and spoke to the chaplain at the hospital. Because of my Catholic upbringing I was in inner

turmoil. In conversations with the chaplain, he assured me that to abort was okay, "God makes mistakes and this is a mistake that it is okay to fix."

I was then sent to see a gynecologist, to have another ultrasound. The technician commented on the size of his head. What did that mean? I would lay in bed at night and feel my unborn child kick me. Why if he is paralyzed do I feel this?

When I returned to the hospital on the day of the abortion, I asked "Why does my unborn child kick me if he is paralyzed?" They assured me that it wasn't him kicking me and that it was the amniotic fluid that he was in. The doctor then came in and told me, they couldn't perform the abortion in Canada because I was too far along so they would fly me to the States. I responded, "Forget it". They asked me what I was going to do. I told them "If my child is that bad, then I will put him up for adoption". The doctor commented, "Who would adopt a thing like that?" I said a few choice words and left. This was my child that they were talking about.

On May 5, 1991 Joshua Christopher graced the world with his presence. I looked in the incubator before they took Joshua to a specialized children's hospital looking for the child that they said I was to give birth to. Where was he? Joshua had 10 fingers, 10 toes, a doll face. He lay screaming and kicking his legs. Where was the baby that was to be "retarded"? I reached my hand in and touched his hand. It soothed his crying.

Joshua's condition at birth was Spina Bifida and Hydrocephalus. He required operations, one to close the lesion on his back and another to put a shunt in to drain spinal fluid from his brain.

The thought of looking back and remembering all the horrible words that were spoken to me, fills me with great anger. I sometimes think back and wonder what if? What if I had aborted Joshua? What if I listened to them? Here is this beautiful little boy who deserves every right to life as every one else does. They robbed me of the joys of being pregnant, they tormented me like no one should ever be tormented. Is it because of ignorance?

Joshua is now 7 years old. He is the greatest gift I could have ever received. I've always said, "God walked that path with me." He helped me find a strength so deep to follow through with the pregnancy and to make sure I could love Joshua unconditionally in order to carry out His work in caring for him.

I wouldn't trade anything in my life. I am complete and fulfilled by the love that Joshua has brought to me. He has showed me love holds no boundaries, no conditions.

When I watch Joshua doing things that make him whole, I feel so complete. I have done no more or less than what any mother would have done for their child. Joshua plays baseball every Tuesday night. I smile at the fact that I was told he never would play baseball.

I only hope that others will find their hidden miracle in their baby that Joshua is to me and to realize that God sometimes wraps blessing in disguise.

We cannot correct this imperfect world. Our perfect child at birth may tragically encounter a mishap that we may not be prepared for. We can't play God and pick and choose who should live and who should die. Everyone is born for a reason. These children are our future. - **JoAnne**



Jo-Ann's Son Jimmy

The following story is from a mother whose son has a condition called Down syndrome. Jo-Ann calls it "Life with Jimmy:"



Jimmy at 12 days old. Right from the start, Jimmy was a very alert and active child.

What would life be like without Jimmy? Jimmy is our three year old son. He is the youngest of three children and he has Down syndrome.

It all started when my husband, Kevin, and I moved to a house with four bedrooms. We had decided that two children were enough. We had the picture perfect family, one girl, one boy and both healthy. I was thirty-four years old and my husband was fearful that if we tried for a third child, something could go wrong. He wasn't prepared to deal with a child with special needs.

As time went by, it wasn't long before that fourth empty bedroom was nudging us to have a third child. With our fingers crossed, we awaited the birth of our third child.

During my fourth month of pregnancy, I received a phone call from our family doctor. Based on routine blood testing throughout my pregnancy, he informed me that the Maternal Serum Screening Test**indicated that I might be carrying a child with Down syndrome. He urged me to get genetic counselling right away to be informed about our options.

I remember sitting down slowly on the kitchen chair and sobbing. I called my parents right away. They were supportive right from the start.

After the shock of the phone call, and without even knowing whether our child would be born with Down syndrome, my husband's immediate plan of action was to get on the internet. He downloaded pages of medical facts, anecdotes from parents, and presentations from doctors world-wide. The medical facts presented a frightening case. It made us think our child could have all of the listed medical problems associated with Down syndrome.

Fearful and anxious, we met with the genetic counsellor. We learned that we had a 1 in 93 chance of carrying a child with Down syndrome. We were given a hand-out that itemized all the health issues related to Down syndrome. It painted a very negative picture of this condition. I do not recall receiving any information about support groups.

The crux of the conversation seemed to be the counsellor underlining the urgency of making the decision about the amniocentesis because there

would be a two week lag in getting the results. The need to act was imminent, she said, in order for termination to be an option.

Three times, the counsellor urged us to make an appointment for amniocentesis. We turned down the idea because I felt strongly about the life I was carrying, Down syndrome or not. My husband was still uncomfortable with the potential outcome, but when faced with options, he agreed that no matter what, we would keep this child. We were also very aware of the risks to the baby associated with amniocentesis. The counsellor urged us to view a film about amnio so that we could see what a simple procedure it was. She told us we only had the weekend to decide and gave us her phone number so that we could make an appointment should we change our minds. The last thing I remember her saying to us was, 'You do not have to have this child.'

On May 4, 1996, a beautiful blond-haired boy came into our lives. Baptised James Connor, he stole our hearts immediately. Born with a cleft palate, as well as Down syndrome (Trisomy 21), we were quickly immersed into life with a child with special needs. Squeezable bottles and talk of surgery related to the cleft palate, were part of our daily routine.

A doctor at the birth hospital put me in touch with a local family who had a child with Down syndrome. When Jimmy was three weeks old, I took him to this family. I was nervous and emotional. Even though I wanted this child very much, I

had concerns about the road ahead of us.

The mother I met was Linda. I had spoken to her on the phone and she kindly shared with me a realistic picture of what life was like raising a child with Down syndrome. I was about to meet her and her eight year old son, also named Jim, face-to-face.

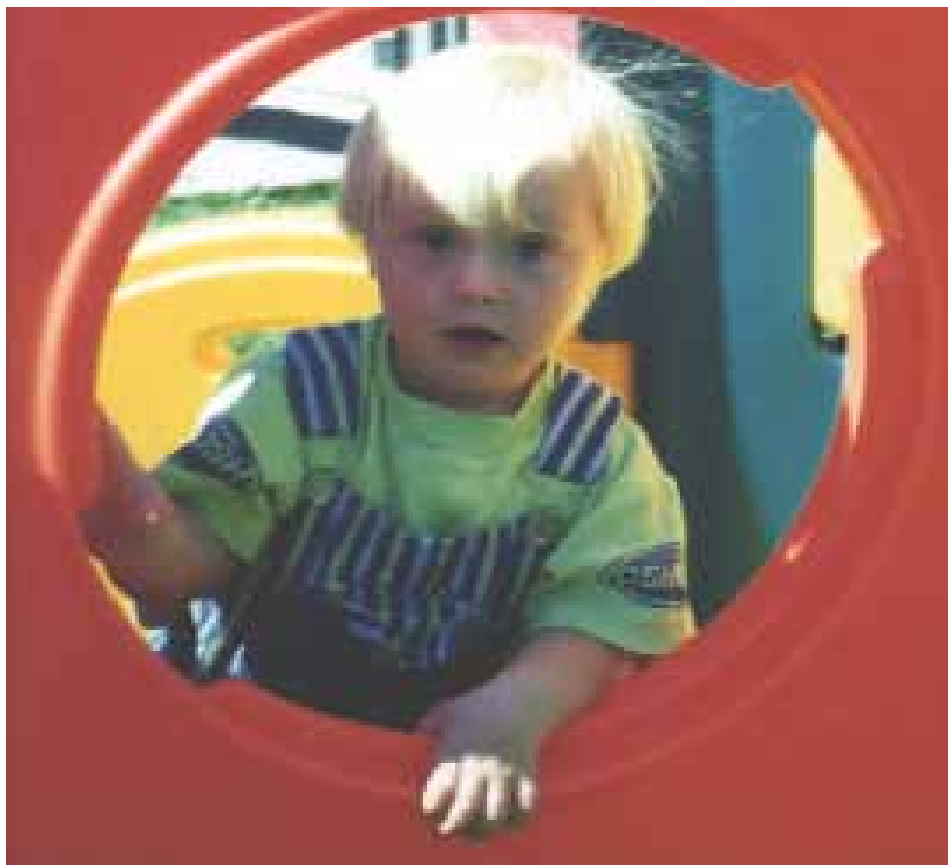
Jim, a handsome blonde-haired boy, gave me a warm hello when we met and asked if he could hold my baby.

Jim, gently rocked my baby and spontaneously broke into song. He sang, 'Twinkle, Twinkle, Little Star' and 'Rock-a-bye Baby' while staring down into Jimmy's face. As I blinked away tears, Jim looked me straight in the eyes and said, 'You have a beautiful baby.'

That clinched it for me. I knew I had entered into a world made more beautiful by genetic imperfection. Jim touched my soul. It wasn't long before my child did as well.



Jimmy at age 1, loves boats and water. Here he is standing up in a canoe at Kelso Park in Milton.



Jimmy at 2, peeking out of a play structure. A physically active child, Jimmy loves to climb and explore.

My husband and I have a wonderful family that has been made more complete by the inclusion of Jimmy. He has brought us immeasurable joy.

Kevin and I are also very active members of the Down syndrome Association of Toronto, and enjoy meeting new parents who have just given birth to a child with Down syndrome. We also offer information and support to parents who are experiencing the dilemma of an adverse prenatal diagnosis. (One of our resources is a brochure called, "See Beyond The Myths/Get The Facts/See The Person" with Jimmy's smiling picture on the front) It is our turn to be supportive to those just starting on that challenging road, which is also sprinkled with unexpected joys.

All of my experiences with friends and neighbours, the medical and social service community, and most especially our own extended families, have been positive and supportive.

Jimmy has inspired us to do more, to care more and to reach out. He's the type of kid who takes advantage of all that life has to offer. His greatest achievement to date, is that he brings out the best in all those he meets.

- Jo-Ann

Some doctors ask permission for the Maternal Serum Screening Test. Other doctors include this test in the routine blood work without the knowledge of the parents.

Sarah's Son

Sarah wrote an open letter to her son, who has a genetic condition, when he was starting school:

We are writing you this letter because you're special. That's a word you will live with all your life and it will come to hold many meanings for you.

The medical profession will use the word "special" to describe your disabilities. What they really mean is you have "some distinguishing characteristics". Sometimes, in their efforts to help you, they will not always see past what is different to see what is the same.

Educators will use the word "special" to describe your needs and programs they will develop to meet those needs. They will rely on the definition "specific in range or purpose, exceptional". In their genuine efforts, they may sometimes forget that as you are learning, you are also teaching. Others will tell Mom and Dad that they are "special"; that God chose them to raise you. This thought, no matter how warmly delivered, misdirects the adjective. We are ordinary parents doing the best we can with an "extra-ordinary" situation. There will be times when we will lose sight of our goals, become tired and frustrated, make incorrect decisions and remain uncertain about the future. No matter how hard we try we do not possess any miraculous source of energy that enables us to cope with everything.

When the adjective "special" focuses more on people's reactions to you, it is closest to the truth. Your twisting body and slow mind will always be what people see first. And for enduring that handicap of your humanity, you are truly blessed. Some people will walk away from your "being different", ignore your needs, not make an effort, because you make them feel uncomfortable. Others will crouch down and try to reach past the disabilities to understand, accept and embrace the person behind. They will be moved into action. In so doing, these people take us all one step closer to recognizing and accepting that which is different in each person we will meet, to understanding and embracing each person's needs and moving us all in a direction to act.

This "special" reaction brings us to the most precious and truest meaning of the word, "beloved". And to the joyful reflection of our heavenly Father looking down on His Son in the Jordan River and calling out into the desert, "This is my Beloved in whom I am well pleased."

So remember when you are told that you are special, what people are really trying to say is that you're loved; you are worth the effort; not just simply because you are you but because you are here. Mind your manners, smile and thank them and leave the rest up to God.

In time and eternity, your loving parents,

Mom and Dad

Sarah recently writes:

After he was born he had been seen by pretty near every medical specialty. The best guess was that he would never walk, never talk and would be mentally retarded.

As with parenting any child, the years that followed his birth were filled with sadness, laughter, disappointment and joy. We were introduced to specialists in pediatric rehabilitation who helped us to help our son. He will be eighteen in October. Our son walks and talks and has a keen sense of humour. He works a room better than any politician I know. Our son was late in doing most benchmarks of growth--but he did make them. Funny, the only thing he did on time was laugh.

- Sarah

Carolanne's Story

Carolanne has an interesting perspective on prenatal diagnosis:

Many health professionals, genetic counsellors, social workers, and others who work in medical facilities are not taught to educate on the special quality of life itself.

I would like to share a story on the lives of three children. My brother, my sister and I took longer to learn than other children but we did learn. When I look at our present-day society, I offer a prayer of thanks to God every day that my parents were loving and faith-filled. Now I pray even more for not having advanced medical technology back in the 1950's.

We are being taught that a "defective" life is no life. Back a few years ago a movie was released called "TWINS", remember it? They took the genes from seven brilliant men and created the "Perfect Man". There was however a flaw. A twin was born. Unlike the "perfect" man, strong and intelligent, the twin was born short and "average". In the movie, he was discarded as "garbage" to an orphanage. When I was asked to write a paragraph for this article, I immediately recalled this movie. I kept thinking, because I was born dyslexic, am I a piece of "garbage"? Now I keep wondering, if they had the medical technology to detect not only physical but brain disorders such as dyslexia and autism, would many of us so-called defective people be here today writing this paragraph?

In all, my parents had five children. We are all married and live happy lives. By the way, three of the five finished high school with a Grade 12 diploma...Guess which three.

- Carolanne

Carolanne included the following with her story:

Bernadette: You asked me to write a paragraph. If I had to write only one, it would be this: 'My life is a paragraph from conception to death and everything in between. I, at least, was given the chance to create my book of paragraphs...others were not...and still...others never will...'

- Carolanne

The Christian community as well as other faith communities need to support these parents (spiritually, physically, emotionally and psychologically) in their decision to carry their baby to term. The parents need to know that there are support groups and their faith community that will support them as they raise their children with special needs. We need to respect their babies as fully human persons who have a right to life until their natural death with no termination by the medical community.

Ellie's Son Michael

A mother whose child has Down syndrome shares:

It was hard to imagine what my life was going to be like raising a child with Down syndrome. Today, Michael is a 12 year old boy with a great sense of humour. He attends a regular classroom in his neighbourhood school. Michael rides a two-wheeler bike, plays soccer, baseball and basketball and has lots of friends. He is more like any other child his age than he is different.

Michael has affected our lives and anyone who has been lucky enough to know him, in a very positive way. The unconditional love that he gives is an example to all of us.

Michael is a contributing member of society who gives far more than he'll ever take. I'm proud to be his Mom.

- Ellie

Owen

A picture story of Owen who was diagnosed with hypoplastic left heart syndrome.



Owen 5 days old, diagnosed with hypoplastic left heart syndrome, recovering well from his first of 4 major heart surgeries.



Owen, a happy, healthy miracle, 4 years after the doctors pushed for abortion, stating that he would be a burden on our lives.

“ For if biological or mental deformity is equated with human deficiency, then everyone is disposable. Regardless of our situation or appearance, everyone’s “life is hidden with Christ in God.” (Colossians 3:3) In light of this truth there is no one, however disfigured now, whom He won’t one day render resplendent and therefore who shouldn’t be cherished now.

The Reverend, Dr. Victor Shepherd, Professor
Tyndale University College & Seminary, Toronto

SUGGESTED VIDEOS TO WATCH

Please share this list with family, friends, co-workers, clergy and medical professionals such as your family doctor and/or obstetrician.

This list may be photocopied for non-profit and educational purposes only.

Carrying Colin (8:03 minutes)

Colin's parents discuss the shock and confusion of learning that their pre-born child had a life-limiting condition called anencephaly. Colin's Dad shares that a perinatal comfort care professional's words "totally changed our thought process". She suggested in the remaining 7 months to enjoy their lives with Colin. Colin's Mom describes the things they did together with their baby still in the womb and says that making memories was "exciting".

<http://vimeo.com/76660126>



Mieko's 1st Year: Trisomy 18 News Story (4:08 min)

Mieko's Mom and Dad describe the joys and challenges of her first year after birth. They also share their feelings while carrying Mieko to term. <http://www.youtube.com/watch?v=cteTcul-xYI>



Our Baby Oliver (3:54 minutes)

This is a lovely video (slideshow) of Baby Oliver's Mom while pregnant as well as at the birth of Oliver. Oliver had a condition called Potters Syndrome. He survived outside of the womb from 7:25 a.m. until 8:37 a.m. The song that accompanies the video is beautiful. <http://www.youtube.com/watch?v=oj0irQ75cvQ>



Annie's Story (4:18 minutes)

This video introduces us to Annie who survived the birth process despite the life-limiting condition of Trisomy 13. Six weeks after her birth she was able to go home and enjoy her life with her family. Unfortunately, 80 days after she was born she developed respiratory problems and she was admitted back into hospital where she passed away. The photos and videos of Annie with her family show how much she was surrounded by love. The song that accompanies the video is wonderful.

<http://www.youtube.com/watch?v=UqFkxT9BUJA>

LIFE-LIMITING CONDITIONS THREE STORIES FROM IRELAND



John Paul-Ours For A Time (6:48 minutes)

Cliona, the mother of John Paul, describes the pregnancy and birth of her son who was diagnosed with anencephaly. John Paul lived for seventeen minutes after birth, surrounded by his family and those who loved him. <http://www.youtube.com/watch?v=PdrLKGmM-pc&list=TLNUOfpvl4PrZyCXWWcRlx54ez3MAkk6T0>



Wishes For Lilly Ann (6:42 minutes)

Aileen, mother of Lilly Ann, shares her pregnancy and birth of her daughter with anencephaly. Lilly Ann lived for 6 days after birth-a time that her family treasured. <http://www.youtube.com/watch?v=UhZda15lvZg&list=TLNUOfpvl4PrZyCXWWcRlx54ez3MAkk6T0>



Mo Leanbh (My baby) (4:16 minutes)

Fiona, mother of Andrew, carried her baby to term with anencephaly. Andrew lived for 27 hours after birth. Fiona shares that time and reflects on the value of her baby's brief life. <http://www.youtube.com/watch?v=kXcvAftCjKU&list=TLNUOfpvl4PrZyCXWWcRlx54ez3MAkk6T0>

LIFE-ALTERING CONDITIONS



Simeon's Story Part 1 (4:53 minutes)

Noel and Anu are the Irish parents of Simeon who was diagnosed in the womb with Hypoplastic Left Heart Syndrome. They were told the baby may die within three days of birth and were given two options: compassionate care (palliative care) or multiple surgeries.

Part 1 (pregnancy and birth of Simeon)

<http://www.youtube.com/watch?v=3xzpewlqzDE&feature=youtu.be>

Part 2 (8:24 minutes) A very honest portrayal of the surgeries, support of the community and an update on Simeon.

<http://www.youtube.com/watch?v=6ND2WeBxQ3E>

<http://www.youtube.com/watch?v=UqFkxT9BUJA>

RESOURCE LIST OF SUPPORT GROUPS

Several of these groups/organizations are Christian-based. Others on this list are secular groups/organizations. When contacting them for support and information please be advised that some groups may have individuals who support the “loving choices” philosophy that maintains that no matter what your choice (carry to term or termination which includes early induction of labour) it is the same “loving choice”. **This “loving choices” philosophy is contrary to the Teachings of The Catholic Church** (see Appendix A regarding universal Truth vs. individual, subjective truth as well as Church teaching on termination at MorningLightMinistry). www.morninglightministry.org

We strongly advise that you ask any group/organization that you may wish to contact the following questions to assure your “choose life” perspective is respected.

1. Will you be able to assure me that the person helping me will share my “choose life” perspective for my baby?
2. Will you be able to assure me that the person helping me will not share the “loving choices” philosophy regarding my baby?

Please share this list with family, friends, co-workers, clergy and medical professionals such as your family doctor and/or obstetrician.

This list may be photocopied for non-profit and educational purposes only.

MORNING LIGHT MINISTRY

c/o St. Mary Star Of The Sea Church
11 Peter St., South, Mississauga, ON L5H 2G1
Phone: 647-781-9300
MorningLightMinistry (www.morninglightministry.org)
Email: morninglightministry@rogers.com
Facebook
Twitter

Morning Light Ministry, started in 1996, offers hope and support to bereaved parents who have experienced the death of their baby through ectopic pregnancy, miscarriage, stillbirth or infant death as well as the death of an older child. This Catholic ministry also welcomes bereaved parents of other Christian denominations, bereaved parents of other faiths and bereaved parents of no religious affiliation who are struggling with the very notion of faith.

PERFECT PRAISE MINISTRY

For those parents who will be raising a child with special needs you can visit our Facebook page regarding a new part of Morning Light Ministry called Perfect Praise Ministry.

Email: perfectpraiseministry@yahoo.ca
Facebook

Morning Light Ministry is a volunteer, grassroots ministry that relies on donations for its work with bereaved parents, parents carrying their baby to term despite a difficult diagnosis and those couples with fertility challenges. There is no cost to the parents for this help.

BE NOT AFRAID (Online pro-life outreach founded by a woman who brought her baby to term with a serious set of heart defects. Her child has undergone several surgeries since her birth and she continues to do very well.)

www.benotafraid.net
Email: info@benotafraid.net

Be Not Afraid is an online outreach to parents who have received a poor or difficult prenatal diagnosis. The family stories, articles and links within this site are presented as a resource for those who may have been asked to choose between terminating a pregnancy or continuing on despite the diagnosis. The benotafraid.net families faced the same decision and chose not to terminate. By sharing our experiences, we hope to offer encouragement to those who maybe afraid to carry their baby to term.

ISAIAH'S PROMISE

www.isaiahspromise.net
E-mail: info@isaiahspromise.net

Providing support for families carrying to term after a severe or fatal diagnosis. Based in Washington, D.C., they are available to answer questions and provide resources to parents. The website provides stories from parents, articles, and videos.

ELIZABETH MINISTRY

Elizabeth Ministry International
120 W. 8th St, Kaukauna, WI 54130
Phone: 920-766-9380
ElizabethMinistry.com (www.elizabethministry.com)
E-mail: info@elizabethministry.com

An international movement to offer hope and healing for women and their families on issues relating to childbearing, sexuality and relationships. Through their Life & Loss Institute, they offer personal visits for those who have experienced miscarriage, stillbirth or child loss. They offer retreats and educational presentations, and also have resources available in the areas of pregnancy and prenatal concerns, and special needs children. There are over 700 Elizabeth Ministry Chapters worldwide. Their origins are Roman Catholic, and their outreach is ecumenical.

PRENATAL PARTNERS FOR LIFE

PO Box 2225, Maple Grove, MN 55311-6745
Phone: 763-772-3868 E-mail: mary@prenatalpartnersforlife.org
www.prenatalpartnersforlife.org

Support information and encouragement for carrying to term with an adverse prenatal diagnosis and support for raising your child with special needs after birth. They offer support and encouragement via phone, e-mail, or in person. The website contains a variety of stories, articles and videos, including perspectives from the siblings of special needs children, and advice for family and friends. They also have information for priests/pastors and medical professionals.

PERINATAL HOSPICE & PALLIATIVE CARE

www.perinatalhospice.org
E-mail: waitingwithgabriel@mac.com

A website by Amy Kuebelbeck, author of *Waiting with Gabriel: A Story of Cherishing a Baby's Brief Life*. Provides a list of perinatal hospice programs around the world, lists of resources for parents and caregivers, and information on perinatal hospice.

EVERY LIFE COUNTS

www.everylifecounts.ie
E-mail: info@everylifecounts.ie

An online outreach where parents of children who were diagnosed with a terminal condition can share their memories, their joy, their pain, and their love. A place to celebrate the lives of much-loved children. Based in Ireland, the group advocates for better perinatal hospice services. The website contains stories from parents and information about anencephaly, Trisomy 18, Trisomy 13, and Potter's Syndrome.

FAITH'S LODGE

4080 West Broadway, Suite 212, Minneapolis, MN 55422
Phone: (612)825-2073
www.faithslodge.org
E-mail: info@faithslodge.org

Faith's Lodge is a retreat centre for parents and families facing the serious illness or loss of a child, and is located in the North Woods of Minnesota. Facilities are handicap-accessible. People must be referred by a healthcare provider, mental health professional, member of the faith community, or an approved support organization, and usually stay from one to five nights. Scholarship assistance is available for those who cannot afford the fee to stay at the lodge.

ROWAN TREE FOUNDATION

PO Box 393, Parker, CO 80134
Phone: (303)378-4300
www.rowantreefoundation.org
E-mail: contact form available on their website.

A volunteer-run program offering support after the death of a child during pregnancy, stillbirth, or infant death. They provide ongoing support and resources for families through online forums, outreach, memorial events, education, and awareness opportunities.

ANENCEPHALY INFO

Monika Jaquier, Route du Vernay 32, 1677 Prez-vers-Siviriez, Switzerland
www.anencephalie-info.org
Email: webmaster@anencephalie-info.org

Monika Jaquier created this website as a resource for parents, after her own experience having a child with anencephaly. The website contains stories from parents, information, statistics and studies. They also offer an "Anencephaly Network," enabling parents to correspond with each other. The website is available in ten languages, including French, Spanish and English.

CDH UK (for Congenital Diaphragmatic Hernia)

CDH UK: The Denes, Lynn Road; Tilney All Saints, Kings Lynn, Norfolk. PE34 4RT. UK
www.cdhuk.co.uk
E-mail: support@cdhuk.org.uk

CANADIAN DOWN SYNDROME SOCIETY

Suite 103 – 2003 14 Street NW, Calgary, AB, T2M 3N4
Phone: 1-800-883-5608 Local calls: 403-270-8500
www.cdss.ca
E-mail: an e-mail form is available on the website

They believe that with early intervention, ongoing preventative medical care, support and understanding, individuals with Down syndrome can grow to reach their full potential. Increasingly, people with Down syndrome are completing high school, gaining job skills, finding meaningful employment, living independently and entering into long-term adult relationships.

They provide a toll free information line, a monthly e-mail newsletter, quarterly magazine, a collection of personal stories, resource catalogue and information booklets. The Society also maintains a national communications network which connects members of parent support groups across the country.

DOWN SYNDROME ASSOCIATION OF TORONTO

40 Wynford Dr, Suite 303, Toronto ON, M3C 1J5
Phone: 416-966-0990
www.dsat.ca
Email: info@dsat.ca

They provide a social and information network for people interested in Down syndrome. They provide a comprehensive parent kit to parents expecting a baby with Down syndrome and to parents whose baby is diagnosed with this condition at birth. This kit is full of information regarding the myths of this condition, parents support groups, parent stories, professional programs for infants and older children with special needs. They also have a newsletter. The website features a comprehensive list of local recreational programs.

THE SPINA BIFIDA AND HYDROCEPHALUS ASSOCIATION OF CANADA

Suite 647-167 Lombard Ave., Winnipeg MB, R3B 0V3
Toll Free: 1-800-565-9488 Local: (204) 925-3650
www.sbhac.ca
E-mail: info@sbhac.ca

This national organization will give you information and support throughout your pregnancy and as you raise your child after his/her birth. They are also able to refer you to a group nearest to you. They also have information regarding preventing neural tube defects in future pregnancies.

S.O.F.T. (for Trisomy 13, Trisomy 18 and other related conditions)

Toll Free in Canada and U.S. 1-800-716-SOFT (7638)
www.trisomy.org

They are a network of families and professionals dedicated to providing support and understanding to families with babies who have Trisomy 13, 18 and related chromosomal disorders. Support is provided during prenatal diagnosis, the child's life and after the child's passing. They have newsletters, resources (such as New Family Packets), local chapters, and an annual conference.

The CDH UK website has common questions and answers compiled with the help of medical professionals. There is also information on diagnosis, what to expect during pregnancy, birth and beyond. They offer support at any of these stages, as well as for those who have lost their baby. For those in the UK, there is a "Home to Hospital" program to assist with the cost of travel to and from the hospital, and related expenses.

PEEL CARING NETWORK FOR CHALLENGED CHILDREN

3837 Oland Drive, Mississauga ON, L5M 6M8

Phone: 905-956-0158 / 905-466-1397 E-mail: lisaverdone@hotmail.com

They are parents connecting to get information, guidance and friendship - the things they need to help them do their jobs as caring parents of children with an intellectual handicap to ensure their children's physical, emotional and intellectual development. They provide a monthly newsletter, a parent support group with regular meetings, and social family events.

TORONTO FAMILY NETWORK

Phone: 416-484-1536 (Janis Jaffe White)

E-mail: torontofamilynetwork@gmail.com

This is a group of parents, siblings and friends who share information and experiences. Parents offer and receive moral and practical support around common issues related to special needs. Parents share knowledge that comes from being a parent, knowledge that cannot be obtained from any source other than "walking in one's shoes".

ONTARIO ASSOCIATION FOR INFANT AND CHILD DEVELOPMENT (OAICD)

c/o Peel Infant Development, 6660 Kennedy Rd., Suite 200, Mississauga, ON L5T 2M9

www.oaicd.ca

There are over 60 locations throughout Ontario. Once your baby has been diagnosed in the womb with one or more areas of delay you may want to contact them to find the centre nearest to you. (Each location has different waiting lists.) They can offer you support and information while your baby is in the womb. Once your baby is born your local centre provides an infant program. Some centres also have pre-school programs available.

CENTENNIAL INFANT AND CHILD CENTRE (An Infant Development Program For Children With Special Needs)

1580 Yonge St., Toronto, Ont. M4T 1Z8

Phone: 416-935-0200

E-mail: contact form available on their website

www.cicc.ca

They provide an Early Intervention program for children with developmental delays (from birth up to five years of age) consisting of home visits at no cost to the parents. They also provide a 1/2 day pre-school program at their centre Monday to Friday, and weekly parent-infant groups, both at a cost to the parents.

EASTER SEALS

40 Holly St, Suite 401, Toronto ON, M4S 3C3

Phone: (416) 932-8382 / (877) 376-6362

www.easterseals.ca

Easter Seals Ontario: easterseals.org Easter Seals (U.S.): easterseals.com

Email: info@easterseals.ca

Easter Seals is dedicated to fully enhancing the quality of life, self-esteem and self-determination of Canadians with disabilities. As Canada's largest local provider of programs, services, issues-leadership and development for the disability community, Easter Seals is dedicated to helping more than 100,000 Canadians with disabilities participate fully in society.

Services include Easter Seals Camps, year-round active living opportunities, as well as the provision of specialized mobility and access equipment such as mobility aids, assistive technology, adaptive

computers, augmentative communication devices and adaptations to homes and vehicles for wheelchair accessibility.

ST. BERNADETTE'S FAMILY RESOURCE CENTRE

Every person has the God-given right to live and actively participate in their community.

128 Ewart Ave., Toronto, ON, M6M 1M9

Phone: 416-654-9810 E-mail: angiecarboni@hotmail.com

www.stbernadettesfrc.org

They provide integrated programs for children, youth and adults. St. Bernadette's programs are designed to bring together children who have special needs with able children and have them participate jointly in all activities, demonstrating that "we can live as one". They foster interaction and support among parents of individuals attending their programs and the community. Their programs include: Day Care and nursery school, Breakfast Club, After School Club, an after-school dance program, Summer Camp, and March Break Camp. St. Bernadette's also initiated the St. Jude's Academy of the Arts, a day program for adults who are developmentally or physically challenged.

HOPEWELL CHILDREN'S HOMES

5651 Wellington Rd #86, RR1, Ariss ON, N0B 1B0

Phone: 519-836-9641 E-mail: info@hopewellchildrenshomes.ca;

hopewellchildrenshomes.ca

Hopewell provides residential, respite and recreational programs for individuals with developmental, physical and mental disabilities. Hopewell Children's Homes provides a total care residence as well as respite care for children and adults with severe developmental and physical disabilities.

Hopewell also runs the PlaySense Activity Centre, a fully accessible play centre for individuals of all ages with developmental disabilities, available on weekdays, afterschool, evening, and Saturdays.

JFJ Hope Centre (previously known as Jewels for Jesus. Private Christian adoption agency licensed by Ontario Ministry of Community & Social Services)

6655 Kitimat Road, Unit 5, Mississauga, ON L5N 6J4

Phone: 905-821-7494 E-mail: helpline@JFJHopeCentre.ca

www.jfjhopecentre.com

Regardless of your situation, we want you to know you're not alone and we are here to help. Why would I choose an adoption plan for my child? If you don't feel you are able to parent this child, you can choose to have your baby raised by a couple who have chosen to take on the challenge of raising a child with special needs.

Today there are thousands of couples who are unable to have children and would welcome your child into their home, just as if the child were their own biologically. They have to go through a rigorous screening process with a registered licensee/agency to adopt and not everyone is approved. You have the option of being involved in choosing a family for your child, including meeting the couple personally.

Would I have further contact with my child? There is more openness in adoption today, than ever before. Most adoptive parents are happy to send letters and pictures to their child's birth parents. It's important to discuss your wish for contact with your adoption worker before you choose your child's parents. When your child is 18 years old, they can register with the "Adoption Disclosure Registry of Ontario" to arrange a reunion with you, if you are willing.

Would I regret my decision? You may always regret that you weren't in a position to parent this child yourself, but knowing that you chose life and a loving family for your child will help comfort you. Adoption involves the loss of the relationship you would have had with your child, but good results come for both you and your child. Our policy is that adopting parents maintain contact, through the agency, with birth parents following placement. Receiving information on the development of the child reassures birth parents that they made the right decision, and allows them to grieve and accept their loss. We provide services throughout Ontario. If you are considering adoption as the best option for your child, we're ready to help. If you want to talk about your adoption options, ask us.

CHRISTIAN HOMES AND SPECIAL KIDS (CHASK)

PO Box 310, Moyie Springs, Idaho, 83845

Phone: 208-267-6246 (1-800-266-9837 for birth families)

www.chask.org

E-mail: info@CHASK.org

Thousands of Christian families believe that life is precious. They desire to put action behind their faith in Jesus Christ, by opening their homes and hearts to one of God's special-little ones.

Loving, Christian families are waiting to adopt special babies if birth moms and dads are not able to parent.

We want parents to hear about life choices. CHASK provides family-to-family support, helping families raise their child with special needs. A matching service connecting adoptive parents to birth parents with special needs children.

CHASK also provides information on adverse pre-natal diagnosis, including a comprehensive list of diagnoses.

ADDITIONAL ADOPTION RESOURCES

If adoption is one of the options you are considering, please contact MORNING LIGHT MINISTRY for a referral to additional agencies who have access to a list of couples who have chosen to take on the challenge of raising a child with special needs.

MY CHILD, MY GIFT: A POSITIVE RESPONSE TO SERIOUS PRENATAL DIAGNOSIS

This book can be purchased online. However, this website has many stories (no cost to read) from parents who have carried their baby to term despite a difficult diagnosis.

<http://www.mychildmygift.com/>

(Resource List originally compiled in July, 1998 by Morning Light Ministry to honour every baby inside and outside of the womb. We particularly remember you, Annie).

[latest revision MLM contact information, 2014]

****PLEASE CONTACT US IF YOU NEED AN UPDATED LIST. WE ASK THAT THE GROUPS LISTED AS A RESOURCE KEEP US UPDATED WITH THEIR INFORMATION.**

APPENDIX A

Excerpts from Pope Francis from *Lumen Fidei* regarding universal Truth vs. individual, subjective truth, common ground with other religions, authentic love as well as the essence of faith.

http://www.vatican.va/holy_father/francesco/encyclicals/documents/papa-francesco_20130629_enciclica-lumen-fidei_en.html

Today more than ever, we need to be reminded of this bond between faith and truth, given the crisis of truth in our age. In contemporary culture, we often tend to consider the only real truth to be that of technology: truth is what we succeed in building and measuring by our scientific know-how, truth is what works and what makes life easier and more comfortable. Nowadays this appears as the only truth that is certain, the only truth that can be shared, the only truth that can serve as a basis for discussion or for common undertakings. Yet at the other end of the scale we are willing to allow for subjective truths of the individual, which consist in fidelity to his or her deepest convictions, yet these are truths valid only for that individual and not capable of being proposed to others in an effort to serve the common good. But Truth itself, the truth which would comprehensively explain our life as individuals and in society, is regarded with suspicion. Surely this kind of truth — we hear it said — is what was claimed by the great totalitarian movements of the last century, a truth that imposed its own world view in order to crush the actual lives of individuals. In the end, what we are left with is relativism, in which the question of universal truth — and ultimately this means the question of God — is no longer relevant. It would be logical, from this point of view, to attempt to sever the bond between religion and truth, because it seems to lie at the root of fanaticism, which proves oppressive for anyone who does not share the same beliefs. In this regard, though, we can speak of a massive amnesia in our contemporary world. The question of truth is really a question of memory, deep memory, for it deals with something prior to ourselves and can succeed in uniting us in a way that transcends our petty and limited individual consciousness. It is a question about the origin of all that is, in whose light we can glimpse the goal and thus the meaning of our common path.

[Lumen Fidei #25]

Faith and the Search for God

The light of faith in Jesus also illumines the path of all those who seek God, and makes a specifically Christian contribution to dialogue with the followers of the different religions. The Letter to the Hebrews speaks of the witness of those just ones who, before the covenant with Abraham, already sought God in faith... Religious man [person] strives to see signs of God in the daily experiences of life, in the cycle of the seasons, in the fruitfulness of the earth and in the movement of the cosmos. God is light and he can be found also by those who seek him with a sincere heart.

[Lumen Fidei #35]

[*Editor Note: See the links in Appendix B with the certain areas of common ground with other Abrahamic faiths as well as other religions in relation to termination of special needs babies or abortion in general.]

In the Bible, the heart is the core of the human person, where all his or her different dimensions intersect: body and spirit, interiority and openness to the world and to others, intellect, will and affectivity. If the heart is capable of holding all these dimensions together, it is because it is where we become open to truth and love, where we let them touch us and deeply transform us. Faith transforms the whole person precisely to the extent that he or she becomes open to love. Through this blending of faith and love we come to see the kind of knowledge which faith entails, its power to convince and its ability to illumine our steps. Faith knows because it is tied to love, because love itself brings enlightenment. Faith's understanding is born when we receive the immense love of God which transforms us inwardly and enables us to see reality with new eyes.

[Lumen Fidei #26]

Faith does not merely grant interior firmness, a steadfast conviction on the part of the believer; it also sheds light on every human relationship because it is born of love and reflects God's own love.

[Lumen Fidei #50]

Faith is not a light which scatters all our darkness, but a lamp which guides our steps in the night and suffices for the journey. To those who suffer, God does not provide arguments which explain everything; rather, his response is that of an accompanying presence, a history of goodness which touches every story of suffering and opens up a ray of light.

[Lumen Fidei #57]

Let us refuse to be robbed of hope, or to allow our hope to be dimmed by facile answers and solutions which block our progress, "fragmenting" time and changing it into space. Time is always much greater than space. Space hardens processes, whereas time propels towards the future and encourages us to go forward in hope.

[Lumen Fidei #57]

APPENDIX B

Excerpts from Pope Francis from Lumen Fidei and other sources from the internet regarding other world religions. http://www.vatican.va/holy_father/francesco/encyclicals/documents/papa-francesco_20130629_enciclica-lumen-fidei_en.html

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[Lumen Fidei #35]

[*Editor Note: See these links with the certain areas of common ground with other Abrahamic faiths as well as other religions in relation to termination of special needs babies or abortion in general.]

<http://virtualmentor.ama-assn.org//2005/05/ccas1-0505.html> : 1st Commentary Catholic view- Patrick D. Guinan, MD/ 2nd Commentary Islamic view- Malika Haque, MD

http://en.wikipedia.org/wiki/Judaism_and_abortion: However the Talmud (Sanhedrin 57b) says that a fetus is included in the Noahide prohibition of bloodshed (distinct from homicide) that is learned from Genesis 9:6 that states (in a direct translation from the Hebrew); He who spills the blood of man in man shall have his blood spilt. The Talmud interprets "the blood of man in man" as to include a fetus, which is the blood of man in man. Things that are prohibited under the Noahide laws are also prohibited to Jews... Some Orthodox law deciders (poskim) forbid abortion to prevent the birth of a severely defective fetus.

http://en.wikipedia.org/wiki/Hinduism_and_abortion: "...traditional Hindu teachings and texts condemn abortion because it is thought to violate the religion's teachings of non-violence. The Vedic texts compare abortion to the killing of one's own parents... The soul enters the womb at the time of conception, and this makes the fetus a living, individual person."

http://en.wikipedia.org/wiki/Buddhism_and_abortion: "...all traditional sources, such as the Buddhist monastic code, hold that life begins at conception and that abortion, which would then involve the deliberate destruction of life, should be rejected."

All who seek to serve, protect and honour the youngest and most vulnerable members of our human family owe a tremendous debt of gratitude to Bernadette Zambri and Morning Light Ministry.

The recently revised Hope in Turmoil is an invaluable resource and “companion” for distraught parents who have experienced a difficult prenatal diagnosis. This unique resource offers mothers and fathers true compassion, real encouragement – and most importantly, the hope that love will prevail, even in times of greatest heartache and turmoil. Hope in Turmoil is a courageous and faithful witness to the Church's clear teaching that prohibits direct abortion – or any choice which discriminates against and denies the right to life of any of God's children, no matter how weak or compromised they may be or how short their precious life might be.

*Dr. Patricia Murphy
Assistant Professor of Moral Theology, St. Augustine's Seminary
Toronto, Canada*

How wonderful that there now exists an exciting new resource for parents, grandparents, siblings, and professionals called Hope in Turmoil that shares how to care for patients and families with a challenging prenatal diagnosis! As one of the pioneers of Perinatal Hospice, I attest that this booklet provides much needed information on practical aspects of assistance to families in need of support. Families with life-limiting conditions or special needs share their experiences, their frustrations, and most of all, their joys. This booklet puts to rest the myths regarding early inductions for life-limiting conditions and children with significant special needs. The powerful message of Hope in Turmoil gives parents the courage to just be parents to their very special children. It is a necessary resource for families, pastors, priests, rabbis, families, medical professionals who deal with obstetrical patients, and hospice programs. It carries my unreserved endorsement!

*Dr. Byron Calhoun
MD, FACOG, FACS, MBA*

This book is invaluable. It confronts readers with congenital defects our society prefers to cover up. It describes the anguish of parents-to-be whom a diagnosis has shocked. It provides genuine comfort and help through the testimonies of parents who carried their child and were able to rejoice in the life, however brief, of their little one. Above all, it reminds a ‘throw-away’ society that everyone, not merely the ‘winners’, is created in the image of God and therefore should be cherished.

*The Reverend, Dr. Victor Shepherd, Professor
Tyndale University College & Seminary, Toronto*

Morning Light Ministry provides this resource that helps anxious parents to cope with difficult or tragic prenatal diagnoses. This guide gives the personal accounts of many families who have lived through the anxiety, pain and suffering that a difficult diagnosis brings or the grief that accompanies the death of a child before or shortly after birth. In this guide, parents can see a reflection of their own circumstance. They will also see the joy and gift that their children who suffer from serious or terminal conditions bring into their families despite their physical limitations or their tragically short time together. This guide helps by providing a list of available resources that parents can access including existing agencies and sources of support. With the Hope in Turmoil Guide, parents will find the strength and encouragement they need as they welcome and love the child to whom with God's grace they gave the gift of life. It truly does provide hope in difficult times.

*+Terrence Prendergast, S.J.
Archbishop of Ottawa*

Hope in Turmoil is a comforting and compassionate sharing of personal stories and resources to help parents through very difficult times. The photos of the babies and children are wonderful. Great listing of resources. I have lost two babies to miscarriage and I have a daughter who was prenatally diagnosed with Down syndrome. I wish I had had a booklet such as this in my hours of turmoil. I craved stories from other mothers who had experienced something similar. The stories of loss and of hope washed over me like an embrace from loving sisters. Thank you!

T.D. (Mother of daughter prenatally diagnosed with Down syndrome)



26 Norfolk Street
Guelph, ON
1 866 LUV BOTH (588-2684)
www.allianceforlife.org