



The Infant in My Womb Leaped For Joy

PETER'S STORY: DISCOVERING HOPE AND LOVE AFTER AN ADVERSE PRENATAL DIAGNOSIS By *Mary Kellett*

“You need to have amniocentesis. These markers indicate there could be a chromosomal disorder ... one that’s incompatible with life. We need to find out for sure, and soon, so you have more choices.”

These were the words of the specialist at my nineteen-week ultrasound.

“Do you mean abortion?” I asked. “We’d never consider that. As for amnio, isn’t there a risk of miscarriage?”

“Yes, there’s a small risk,” the doctor conceded. “But I highly recommend it, so you know what you’re dealing with. These markers indicate trisomy 18. If the baby makes it to birth, it won’t survive beyond two weeks.”

“Well, we won’t take the chance of hurting the baby. We’ll love this little boy no matter what he has,” I said through tears.

So began the journey with our son, whom we named Peter. We knew he’d need a strong name if he had the condition the doctors thought he had. We had 10 healthy children and knew that this child would be loved by all of us, for however long God allowed.

Peter was born at 34 weeks by emergency Caesarean section. He was immediately baptized by the hospital chaplain, who also confirmed him two days later.

After we learned that Peter had full trisomy 18, some recommended that we wrap him in a blanket and let him die. They said he’d never have any “quality of life” or be able to contribute to society. He’d never recognize us or interact with us. But Peter is now a giggling, smiling 2 1/2 -year-old who, though physically limited, brings joy to his family every day.

In the year after Peter’s birth, I thought often of the mothers and dads who receive adverse prenatal diagnoses, followed by grim descriptions of the genetic condition and assessments of the baby’s prospects that are inaccurate, incomplete and even outright lies.

Overwhelmed with sorrow over their baby’s health problems, fearing that he may suffer, and given only negative information about his life prospects, it is no wonder so many parents feel pressured to abort their child. I asked God how I could encourage these parents to make a life-affirming choice, one that would bring them peace, joy and more love than they’d ever thought possible. His answer was for me to start a support group for these parents called Prenatal Partners for Life.

Prenatal Partners for Life matches families who’ve recently received an adverse prenatal diagnosis with families who’ve given birth to a child with a similar condition. The experienced parents offer accurate information, support and encouragement—through e-mails, phone calls, letters or personal visits—for as long as the other couple needs help.¹ We are faithful to the Catholic Church and have two wonderful priests as advisors. In the eighteen months since Prenatal Partners for Life was founded, we have given support, information, and encouragement to hundreds of families worldwide.

Many parents who contact us for information and support describe the pressure exerted on them to “induce labor early” (i.e., abort their baby) after they received an adverse diagnosis. Doctors and other medical personnel use a variety of euphemisms to disguise the fact that they are recommending killing an innocent child because he has a disability: Early Induction, Therapeutic Abortion, Medical Termination, Genetic Termination, Interruption of Pregnancy and Saying Good-Bye Early. These parents are sometimes made to feel guilty for wanting to carry their baby to term and to seek treatment for him after birth. With a false sense of compassion, abortion is sometimes urged on them as a moral obligation and the most loving choice for a child who may have special needs. Very often, medical personnel discuss only the negative aspects of having a child with disabilities; no hope or resources are offered.² Frightened and vulnerable parents, given no offer of support, may make the tragic, life-altering decision to abort, and then live the rest of their lives with questions and regret.

Pam had an abortion over a decade ago.³ In her own words she relates: “I had a ‘therapeutic’ abortion when I was four and a half months pregnant with my only son, a Down’s syndrome baby—James Kent. Well-meaning professionals impressed upon my husband and me how we were rescuing our son—and ourselves—from a life of needless pain and suffering. Our family doctor told us James Kent would be our shadow for the rest of our lives in choosing to birth him. We didn’t realize my son would be our shadow for the rest of our lives in choosing to abort him.”

Dina shares her story of aborting her daughter who had a chromosomal disorder: “Looking back I can see what was missing from the conversation in the doctors’ office. They never mentioned anything remotely positive. Surely there was something they could have told us that wasn’t bleak and morbid, like the fact that we could love our daughter no matter what her physical/mental condition. ... I wish they would have explained to us that all life is precious and we should do whatever it took to make our daughter’s time here comfortable. I wish the priest we sought counsel from would have advised us on how to find the joy in our daughter’s life, because it surely would have been a joy to be her mother. No one explained the guilt and shame that will follow us forever. Nor did they tell us what to tell our son and other children that followed.”

When they found out their daughter Gemma had trisomy 13, Courtney and Terry knew they would never consider abortion.⁵ This is what they experienced: “Our precious Gem was born at 12:38 P.M. and lived for 52 amazing minutes. She weighed 5 lbs., 6 ounces and was 16 inches long. She was held by family and friends and knew only love. ... Although our time with her was short, our lives will never be the same. We are only beginning to comprehend how such a little being can have such a profound impact on our lives and the lives of others. Our little Gemma has taught us how to love deeper, experience gratitude, and treasure all of the gifts we have been given, especially the precious minutes we had together with our little Gem in our arms and the 8 1/2 months we had with her living inside me. God is good. He knows our hearts desires and He does answer prayers.”

Elizabeth describes her experience and how the right attitude can make all the difference.⁶ “Never has a pregnancy given me more joy, more fatigue, or more worry than when I was expecting Lily. At 18 weeks, I had a Level II ultrasound, which revealed four ‘soft markers’ for Down

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syndrome. The doctors and nurses couldn't have been more gloomy and 'sorry' although the results of this test are far from conclusive. They recommended an immediate amniocentesis, which I refused due to the risks involved for our baby. Two weeks later I had another ultrasound ... [and] the doctor found what he believed to be severe heart defects. ... The doctors could not have been more discouraging. It was only when my sister, a doctor herself, recommended that I get a second opinion that things began to change. From the moment my husband and I walked into the new doctor's office, the clouds lifted. Instead of pushing dangerous tests and informing us about the option of abortion, we felt that our child's life was valued and that the doctor would do everything he could for our baby. His office and staff were cheerful, and when they performed an ultrasound, the nurses kept telling me how cute she was, and they laughed when Lily insisted upon keeping her gender a secret. I remember later telling my husband that if we were to lose this child, I wanted to lose her while this new doctor was caring for us.”

How Priests and Pastors Can Support Families

God has given to priests and pastors the gift to touch people's lives in ways the rest of us cannot. They stand as a moral compass, giving direction, love and compassion to those in need. Priests and pastors play a crucial role in ministering to a family facing an adverse diagnosis. Loving, compassionate, life affirming support is what parents need most at such a time.⁷ In light of pressure from many in the medical community to abort babies with adverse conditions, it is all the more critical that pastors and priests stand strong in the defense of life. Sadly, there is sometimes a misguided sense of compassion, a desire to avoid “judging” the decision of parents who have been told that their child's life may bring hardship and suffering and that the only solution is an abortion.

From a Catholic viewpoint, early induction of labor performed simply for the reason that the child has a lethal anomaly is direct abortion.⁸ Catholic parents have a right to know this. In addition, parents have shared with us many statements by priests and pastors which they found tremendously helpful in deciding to follow God's will for their child's life. We offer these suggestions for anyone whose advice is sought at such a difficult time.

- God will give you every grace you need.
- Every life is created by God and has a purpose.
- God has chosen you to be the mother of this special child.
- Name your baby, talk to your baby, and love your baby like any mother would.
- I hear your pain. God hears your pain. He loves you and calls you, and all of his children, to embrace the sanctity of human life from conception to natural death. He will be with you and never leave your side.
- Go to our Blessed Mother. She knows your pain and will wrap you in her mantle.
- No matter how long your baby lives, he will be your child for all eternity.
- Create wonderful memories of this special time while he is still alive and protected in your womb.
- Remember that God can and does perform miracles. Don't be afraid to ask, and don't be afraid to hope.
- These special babies bring with them many spiritual gifts and graces.
- You are united to Christ through suffering.
- If your baby doesn't survive through birth, there is baptism by desire.

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Here are some suggestions on what *not* to say because these statements could lead to confusion and perhaps a decision to end the child's life:

- Only you know what is best for you and your family.
- This is between you and God.
- You need to keep your own health in mind.
- This has got to be hard on your body.
- What do you think is the right thing to do?
- This is a complicated matter.
- Follow your own conscience.
- I'm worried about your mental health.
- Listen to the doctors and do what you think your heart tells you to do.
- If your choice is made with love, it can't be wrong.
- In this case, it is okay to say good-bye early.

In our journey with Peter, my family was blessed by the support of a faithful pastor and associate pastors, caring religious, our extended family, many wonderful families from our parish and surrounding parishes, and a holy hospital chaplain. Their continued love and support still sustain us. They were and are a living sign of Christ's love, and we are incredibly grateful.

Above all, we are grateful for Peter, whom we call our "little teacher." Even though he may never speak a word, he has taught us many important lessons about love, sacrifice, compassion, patience, hope and faith. He has transformed the way we look at life and has broadened our view on the deeper meaning of the sacredness of all human life made in the image of our loving God. Peter is teaching us what Jesus taught, and he is a tremendous source of grace. He is a sweet, happy little boy who knows and loves his family. In many ways he is my easiest child out of the eleven.

There is a place in the world for children with special needs. We all are differently-abled, with flaws and gifts. These children are teachers of our souls, and society desperately needs the lessons and blessings they bring.

Mary Kellett is the Founder and Director of Prenatal Partners for Life.

¹ Support available at www.prenatalpartnersforlife.org

² Skotko, B., "Prenatally diagnosed Down syndrome: Mothers who continued their pregnancies evaluate their health care providers," *American Journal of Obstetrics & Gynecology*, 192(3): 670-677, March 2005.

³ http://www.prenatalpartnersforlife.org/Second%20Thoughts/StoriesSecondThoughts_Pam.htm.

⁴ <http://www.prenatalpartnersforlife.org/Second%20Thoughts/SecondThoughtsMyDarkestHour.htm>.

⁵ http://www.prenatalpartnersforlife.org/Stories/StoriesTrisomy13_Gemma.htm.

⁶ http://www.prenatalpartnersforlife.org/Stories/StoriesDowns_Lily.htm

⁷ <http://www.prenatalpartnersforlife.org/priests.htm>.

⁸ <http://www.ncbcenter.org/04-03-11-EarlyInduction.asp>.

Programs for Parishes

- Include a prayer for children born with special needs and their families, and for the families of children who were miscarried, stillborn, aborted or died in infancy, in the Sunday Mass intercessions on a regular basis.
- On the April 13 feast day of Blessed Margaret of Castello (who was born blind, lame and physically "deformed"), have a special Mass to honor children with special needs and their families, followed by refreshments and a brief program to applaud and encourage families for their witness to the sanctity of all life, and to acquaint them with parish and local support services. Advertise this event in the bulletins of neighboring churches.
- Invite the mother or father of a child with special needs (living or deceased) to speak after all Masses. The remarks should briefly tell their story, explain how their child's life blessed their family and encourage others who receive an adverse prenatal diagnosis to love and care for their child according to God's plan.
- Ask your pastor to identify families with children with special needs. Invite these families to consider being a resource your pastor can offer to families whose child has recently been diagnosed with a similar condition. When meeting with these families, learn what concrete help other parishioners can give them. Recruit volunteers from the parish willing to offer assistance, for example, providing a few hours of respite care each week to parents needing a little break.
- Donate "Beautiful Faces" calendars to teachers in your parish's school for their classroom use. Each month has a beautiful photograph of a child with Down syndrome. Calendars are available from www.bandofangels.com (\$15) and would make a lovely Christmas gift for your child's teacher. Display a "Beautiful Faces" calendar in the vestibule or stock them in your pamphlet rack late in the year when the demand for calendars is high.
- Invite parents and siblings of a child with special needs to speak to school and CCD classes about the joys and challenges (including the prejudice they've experienced) of raising a child with special needs.

Resources

Organizations and Support Groups

- Be Not Afraid
www.benotafraid.com
Stories, articles, resources and community message boards for families who've been given an adverse prenatal diagnosis
- Morning Light Ministry
www.morninglightministry.com
Catholic ministry for bereaved parents of a deceased child and those who've received an adverse prenatal diagnosis
- Perinatal Hospice
www.perinatalhospice.org
Resources and hospice locations for parents whose child received a terminal prenatal diagnosis
- Elizabeth Ministry
www.elizabethministry.com
Parish-based ministry offering peer support, mentoring, spiritual nourishment, educational and inspirational resources to women during their child-bearing years. Includes support and resources for mothers who've received an adverse prenatal diagnosis. Booklets include: "Our Unborn Baby Has a Problem," "Prenatal Testing" (discussing its risks and realities), and "Mourning a Miscarriage: Prayer for a Couple Grieving the Death of their Unborn Child."
- American Assn. of Pro-Life Obstetricians and Gynecologists
www.aaplog.org
Database of pro-life ob-gyns and more
- A Place to Remember
www.aplacetoremember.com
Support and resources for anyone touched by pregnancy complications or the death of a baby
- Adoption of Special Needs Children
www.chask.org
- NATHHAN
www.nathhan.com
Resources for home-schooling children with special needs

Anencephaly Support Foundation
www.asfhelp.com/asf/home

National Down Syndrome Society
www.ndss.org

National Down Syndrome Congress
www.ndsccenter.org

Little Hearts, Inc.
www.littlehearts.net
Support for families with children who have congenital heart defects

Support Organization for Families of Trisomy (SOFT)
www.trisomy.org

Information and Family Support—Trisomy
www.livingwithtrisomy.org

Information and Family Support—Trisomy 13
www.livingwithtrisomy13.org

Books

Martha Beck. *Expecting Adam*. New York: Berkley Publishing Group, 2000.

Bruce Carroll. *Sometimes Miracles Hide*. West Monroe, La.: Howard Publ. Co., 1999.

Christopher De Vinck. *The Power of the Powerless*. New York: Crossroad Publ. Co., 2002.

Melinda Tankard Reist. *Defiant Birth: Women Who Resist Medical Eugenics*. Melbourne, Australia: Spinifex Press, 2006.

Judy Winter. *Breakthrough Parenting for Children with Special Needs*. San Francisco: Jossey-Bass, 2006.