

ETHICS & MEDICS

A Commentary of The National Catholic Bioethics Center on Health Care and the Life Sciences

HOPE AFTER POOR PRENATAL DIAGNOSIS

Parents who receive news that their unborn child has a serious birth defect, genetic syndrome, or other medical complication are often left to sort out their responses on their own. As co-founders of the network Be Not Afraid, for almost ten years, we have had the privilege of supporting parents who carry their babies to term after a poor prenatal diagnosis. BNA provides this support both online and through the development of local services in several communities.¹

Neither of us is a medical professional. We are Catholic lay women (mothers and wives) who are simply unwilling to leave parents with complicated pregnancies unsupported. Over time, our team has been immersed in the technical aspects of these pregnancies and has learned a great deal about many complex maternal-fetal situations and a wide variety of prenatally diagnosable conditions. For example, most recently, we assisted parents in planning for the births of their babies in cases such as that of conjoined twin girls; a boy who had a combination of defects, including encephalocele, hydrocephalus, and gastroschisis; and a boy with osteogenesis imperfecta type 2. We also consulted with a colleague in Washington, D.C., who offered in-person support concerning the birth of a boy with a very rare chromosomal deletion. These were all extremely difficult and challenging cases.

We have also had the opportunity to attend key conferences regarding advocacy, such as the 2011 national SOFT (Support Organization for Trisomy 18, 13, and Related Disorders) conference in Chicago. Conferences such as this raise technical questions about treatment options for babies born with trisomy 13 and 18. The issue of basic care is especially important to us, because it is sometimes difficult to secure such care for infants who are not expected to survive.

We came to this work either because we stumbled into the topic involuntarily through personal experience, such as a poor prenatal diagnosis of our own or because we discovered that the unique needs of parents with complicated pregnancies were not always addressed through traditional crisis pregnancy outreach, bereavement ministry, or pastoral care.

The teachings of the Catholic Church regarding the dignity of human life are intended not only to inform

parents who are at risk of choosing to abort after receiving a poor prenatal diagnosis but also to guide the response of our faith communities toward these unborn babies who are most vulnerable. It is the responsibility of the Church to provide pastoral care and works of mercy to those in crisis, and from personal experience, we can assert that a poor prenatal diagnosis is a devastating crisis.

Crisis upon Diagnosis

Unlike the typical scenarios that present at crisis pregnancy centers, which are essentially crises of decision, the scenarios of poor prenatal diagnoses often involve actual medical crises that must be addressed. The news is nearly always experienced as being “out of the blue,” leaving parents to feel as though they have been hit by a train. After all, when parents agree to an ultrasound, often what they want is just to see their baby in utero and to bring home an image to hang on their refrigerator.

While there are parents who consent to testing with the mindset that they will abort if an anomaly is detected, most are simply engaged in a rapidly moving clinical process that ushers them along without requiring them to make any definitive decisions about what they will do if test results are poor. In addition, the process of informed consent for screening and diagnostic procedures is sometimes inadequate, particularly with ultrasound imaging, which is widespread, and with early nuchal translucency screening.

Dori’s story of her baby Mathilda Hope, who was diagnosed with cystic hygroma, dramatically illustrates how quickly an ultrasound can lead to an unexpected and unrequested test procedure: “The doctor came in so matter of factly. ‘Your baby has a large cystic hygroma and hydrops. Hygromas are fluid filled sacs usually in the back of the neck and hydrops occurs when that fluid spreads to other areas of the body. It is not compatible with life; I would recommend termination so that it is easier on you.’ He recommended an amniocentesis, and within seconds a needle was inserted. I was given no time to process anything that was going on. I was truly in

OCTOBER 2011 VOLUME 36, NUMBER 10

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A CATHOLIC RESPONSE

Monica Rafie and Tracy Winsor

shock." Confirmation of the diagnosis left Dori confused and feeling lost. Medical personnel were not able to provide her with adequate information about the risks of the tests, let alone concern themselves with meeting her emotional needs.

Although most expectant parents who enter into the process of testing say they will not abort, most who receive a poor prenatal diagnosis actually do. The pressure to act quickly when abortion is offered, often in isolation from family and from a supportive community, can effectively knock parents out of their usual moral decision-making parameters. Eighty percent of parents who are told that their unborn baby has a severe congenital anomaly decide to abort.

This scenario described by Tiff, who recalls when she and her husband were given their child Gracie's prenatal diagnosis of Dandy Walker malformation, exemplifies what all too many parents experience:

A few days later I received a call from my OB, who stated that a Dandy Walker malformation and choroids cyst were seen in the ultrasound. She sent us in for further testing. Naively, we figured they would tell us that everything was okay and send us on our way. In the hours that followed, we were left exhausted, terrified, and unsure of what was to come. Our baby was diagnosed with a Dandy-Walker variant with normal chromosome analysis. We were also told that no anomalies besides the Dandy Walker malformation were identified, but that other abnormalities could be present but unable to be seen in an early second trimester ultrasound.

The doctors, nurses, and genetic counselors then promptly all urged us to terminate our pregnancy that day. They told us that we were young and not ready for what this baby would bring and not financially prepared for the hardship and, that if we were good parents, we would spare this baby from a life suffering and pain, what little life she would probably have. They explained we would be in this for life, taking care of an adult child with the mental capacity of possibly a three or four year old at best. Then they proceeded to give us a long list of all the worst case scenarios.

We were shocked that their first option for helping our baby was termination, especially when all they knew about this malformation was from the textbook they had just opened and a few articles they found. We then asked if we could seek out doctors who knew more about this condition. They explained that we didn't have time. We needed to terminate now as we were already at the twenty-week mark. We continually had to fight for our baby's life that day. Termination was never a choice for us. In the end, the doctors basically told us we were making the wrong choice and had a few days to change it before it was too late. We left so emotionally drained, in shock from the whole ordeal, and mostly sad that our baby was just a number to these doctors and not a life worth keeping. I remember that in those darkest days after we were given her condition and outlook all I needed was a little glimmer of hope.

While Gracie's diagnosis had indeed been correct, the prognosis she was given was far off the mark. Since

that time, Gracie has developed and progressed typically, sometimes even exceeding the abilities of her schoolmates and peers. Far from the life of suffering and pain that some medical professionals predicted, Tiff reports that Gracie has an active life full of activities she enjoys, such as gymnastics and running.

The Testing Process

The American College of Obstetricians and Gynecologists (ACOG) recommends prenatal screening for all expectant women. The ability to identify fetal anomalies is rapidly increasing. Currently, technicians are able to identify up to 150 genetic syndromes or conditions and numerous structural defects prenatally, and additional tests are continually being developed. In the past, parents might have accepted noninvasive screening procedures but declined invasive procedures like chorionic villus sampling and amniocentesis. Now, however, less invasive diagnostic tests are being developed, which parents find more acceptable. For example, standard delivery of a noninvasive diagnostic test for Down syndrome is likely in the near future, with the promise of the same for trisomy 18 and trisomy 13 right around the corner. These new tests, which use maternal plasma DNA, will require only a blood draw, prompting many women to agree to diagnostic testing.

Increasingly, the delivery of a healthy baby is perceived less as a blessing from God and more as an entitlement, a modern benefit associated with ever-progressing medical technology. As a result, when there is a poor prenatal diagnosis, the medical focus shifts away from the baby's condition to the pregnancy itself as the medical problem. There are no treatments or cures for babies diagnosed with anencephaly or genetic syndromes, for example; thus from the clinical perspective, the pregnancy is the condition requiring intervention.

Abortion is routinely offered for fetal defects incompatible with life, as well as for virtually all disabling conditions, including complex heart defects, spina bifida, Turner syndrome, and Down syndrome. In a survey conducted by ACOG, 90 percent of the doctors who responded considered abortion a "justifiable treatment option" for fatal fetal anomalies, and 63 percent considered it justifiable for nonfatal anomalies. This finding was surprising even to the officials at ACOG.² Abortion is likely to be presented as the best available option by a medical provider who personally thinks that there is no reason to continue a pregnancy when the baby's prognosis is uncertain or poor.

JoAnne found little support from her medical providers when she chose to carry her baby boy Gabriel to term after his being given a diagnosis of a lethal skeletal dysplasia:

We told my doctor that we would not terminate the pregnancy, and he insisted that I speak to a counselor. He gave me a phone number, which I called. I figured the more people I talked to and the more information

I gathered, the better prepared I would be. I called the number and began to tell my story to a counselor named Patty. I had no idea that Patty was a counselor for an abortion clinic. After hearing my story, she explained to me that, because I was already twenty-one-weeks pregnant, I had to make an appointment quickly—I only had up to twenty-four weeks to terminate. She then explained that because I was so far along, they would have to do a procedure in which the baby would not be “intact” after removal. I cannot begin to explain the feelings that I had at that moment. It was a combination of sheer horror and complete peace—horror at the thought of killing my baby and peace at the knowledge that my decision to keep the baby was confirmed. We were having this baby, and we would love this baby. We would hold him and kiss him and hug him for as long as God would allow us.

My husband and I felt very strongly about our decision. We felt that we had signed on to be parents to this baby right from the beginning, and if being his parents meant that our only job was to see him through his short life and make sure that he went with peace, dignity, and love, then we have done our job as parents. We also began to feel that this was a very special baby with a very special reason for coming, although we did not know what that reason was. We did, however, know that God had picked us to be his parents and for that we were honored. We knew that we had a very big job to do, and we were going to make sure we did it right. We started by choosing a name for him. We picked Gabriel, meaning “angel of God,” because we knew that he would always be our special little angel looking out for us. For his middle name, we chose Jonathan—a name that my Godmother had begun calling him when she prayed for him. Jonathan means “God’s most precious gift,” and we felt that was appropriate.

We switched doctors because my original doctor was uncomfortable with my continuing the pregnancy. He felt it was too risky and so would not deliver the baby. The hospital where I had planned to deliver felt the same way. So at five months pregnant, I began searching for a new doctor and a new hospital. We were amazed at how difficult a task this was. Some doctors agreed to deliver the baby, but it was quite obvious by their comments and attitude that they felt we were wasting their time. After much searching and many consultations, we were so lucky to find a wonderful group from St. Peter’s Hospital, which is Catholic, in New Brunswick, New Jersey. They had maternal–fetal specialists who fully respected our beliefs and our desire to have this baby. The staff at their office and at the hospital helped to turn a difficult pregnancy into a beautiful experience. This was unfamiliar territory for all of us, and we had to learn day by day how to survive it gracefully.

The Catholic response to pregnancies that involve a poor prenatal diagnosis is to affirm the dignity of the unborn child, regardless of the complications and corresponding prognosis, as well as to encourage the mother and father to parent the life entrusted to them to the best of their abilities. Despite the high incidence of abortion after poor prenatal diagnoses, it turns out that, as with JoAnne above, these Catholic principles resonate with the desires of most parents. Research indicates that

80 percent of parents choose to carry their babies to term when they are offered services that provide comprehensive support throughout the pregnancy.³

A Community of Support

Parents who carry a problematic pregnancy to term present with unique needs, which can be met in a collaborative effort among lay persons, clergy, and medical professionals with an eye toward the basic principles of Catholic pastoral health care. We have the ability, if not the obligation, to work together to create and contribute to a community of care for parents who have received a poor prenatal diagnosis.

The Be Not Afraid model of care addresses five areas of support most commonly needed by parents who carry to term a baby with a poor prenatal diagnosis. (1) We support parents as they come to terms with the reality of their baby’s prognosis, with may involve significant grieving. (2) We work with parents who may feel they are traveling an uncharted path by offering them practical guidance and (3) by creating a community of care that recognizes how crucial relationships are at this time.⁴ (4) We also assist parents in reframing the circumstances by stressing the importance of preparing them to parent the baby God is sending, and (5) we recognize the importance of preparing a birth plan as an essential element of that parenting. Despite the emotional pain involved in receiving a poor prenatal diagnosis and, in many cases, the heartache associated with the loss of a newborn baby, parents receiving BNA support report a positive experience of carrying their child to term and would encourage others to do the same.

The case of Shulena, who was supported by BNA Charlotte, shows what can happen when a mother has this kind of strong moral support. Shulena learned in her first trimester that she was pregnant with mono-amniotic twins and that her pregnancy would be complicated. Mono-amniotic twins are connected to a single placenta and develop in the same amniotic sac, resulting in disproportionate development of the children. At her eighteen-week checkup, Shulena learned that the twins also had twin-to-twin transfusion syndrome, in which blood moves from one twin to the other, and prenatal surgery was recommended: “Wanting to give them the best possible chance, I traveled to Cincinnati where I had surgery on November 2. It was on my return from that trip that I was referred to BNA. After the procedure, Addison was given a 60 percent chance of survival and Layla 40 percent. For several weeks, it appeared that the surgery had worked and the girls grew to be the same size.”

At her twenty-three-week check-up, Shulena was told that Layla no longer had a heartbeat: “Imagine my surprise to get this news when at my last appointment, just a week before, both my little girls were fine. It was terrible. One of the first people I called to share the news was my BNA contact. She called me back right away, and I remember the comforting words she shared that rainy afternoon.”



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VOLUME 36, NUMBER 10
OCTOBER 2011

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Four weeks after learning of Layla's death in the womb, Shulena was hospitalized because of premature rupture of the membranes:

I went from the doctor's office to the hospital, where I remained for seven weeks while we waited for Addison to grow so that both girls could be safely delivered. I was so grief-stricken in the loss of Layla, and anxious about the safety and wellness of Addison. And because I couldn't be home, I experienced a sense of alienation that no one really understood.

Honestly, I don't know what I would have done without BNA support. They connected me to other moms who had lost a twin, even another mom whose pregnancy continued like mine beyond the loss of the first baby. There were weekly visits and encouraging phone calls, assistance in preparing for the birth, and referral for maternity pictures to capture images of my big belly and the too-short time both my girls would be with me. There were pints of ice cream and special remembrances of Layla, hugs and tears, and often laughter from my hospital room that compelled nurses on staff to see what was going on.

Both girls were delivered by cesarean section on a cold, rainy February morning. Addison Grace was a healthy, squalling six-pound newborn, and Layla Rose was smaller, still, and quiet. Both were wrapped in handmade blankets and welcomed by their family, along with two BNA peer ministers who attended this special birth as support for Shulena: "My two primary BNA contacts were there the day I gave birth welcoming Addison and holding Layla. Nothing could be changed about the stress of this pregnancy, but when people asked how it was that I was doing so well, I would always say it was the support I was receiving from BNA. It is amazing what you can do with a little company."

The bittersweet outcome of Shulena's pregnancy provides an instructive example of the virtue of our Catholic perspective on prenatal diagnosis. A baby who will not survive and a baby who will survive both share the same dignity before God. The primary challenge we face with a poor prenatal diagnosis is not about the "end of the story" or about the outcomes, disabilities, or even capabilities associated with any particular condition. Ultimately, our challenge is to continue to bear witness, by our words and actions, to the fact that a poor prenatal diagnosis does not affect the inherent dignity, the unique and unrepeatable human reality, of a baby.

Monica Rafie
Tracy Winsor

Monica Rafie, from Chicago, Illinois, founded the Web site outreach www.benotafraid.net. Tracy Winsor, from Charlotte, North Carolina, co-founded Be Not Afraid Ministry, the first of the Be Not Afraid local service projects. BNA is hosting a free conference for those interested in providing support to parents in their own community. More information can be obtained at benotafraidnc@live.com.

¹BNA services are currently available in Charlotte, North Carolina, and in the dioceses of Charleston, South Carolina, and Richmond, Virginia. We are in the process of developing services at this time in Austin, Texas; Providence, Rhode Island; and St. Petersburg, Florida.

²Denis Cavanagh et al., "Changing Attitudes of American Ob/Gyns on Legal Abortion," *The Female Patient* 20 (May 1995).

³Michelle D'Almeida et al., "Perinatal Hospice: Family-Centered Care of the Fetus with a Lethal Condition," *Journal of American Physicians and Surgeons* 11.2 (Summer 2006).

⁴Melissa L. Horning and Carie A. Braun, "The Lived Experience of Families Who Are Told Their Child Will Die at or Shortly after Birth," <http://juns.nursing.arizona.edu/articles/Fall%202006/horning.htm>.

