

Prenatal Diagnosis

By Megan Wedwick, co-Director of Apostolate for Persons with Disabilities – Diocese of Madison

I'd like to introduce you to Omar. Omar is a 7 year old boy in first grade. He enjoys music, has a beautiful smile, grows, learns, and lives with a diagnosis of Trisomy 13, also known as Patau syndrome. Early on in Omar's life, specifically after his 11 week ultrasound, his parents learned that he was developing abnormally and that they would need to get further testing done. This was the start of countless appointments and tests for Omar and his mother, Monica.

Before continuing with Omar's story, let's learn a little bit about Trisomy 13. This diagnosis refers to individuals who have abnormal replication of their 13th chromosome, so rather than the typical pair, they have an extra 13th chromosome. The cause of this replication is unknown. A majority of babies who receive a diagnosis of Trisomy 13 have significant life limiting health issues. Notice the use of the term "life limiting" here, it is a term that Monica shared with me and it has opened my mind to a better understanding of the value of life, as well as the importance of how we talk about life. Before meeting Monica, I had also never heard of the term that was used when she was first learning of Omar's Trisomy 13 diagnosis, which was "incompatible with life".

When looking at pictures of Omar that Monica shared with us and hearing her talk about her son, it's clear to see that he is in fact very alive and that he is compatible with the life he is living, so where does the term "incompatible with life" come from? Medical professionals work with odds. The odds of Omar surviving birth, or even more than a few hours after birth were very low. God does not work with odds, God creates and loves against all odds. As Catholics, we believe that life starts at conception, so even the concept of a baby in utero being incompatible with life should not make any sense to us. Someone who is alive already cannot simultaneously be incompatible with life.

When a child is medically "incompatible with life" there are pressures from others to end the pregnancy. During birth, when the baby typically would be monitored throughout, professionals will instead only monitor the mother for life threatening concerns. Monica had to advocate for Omar throughout the majority of her pregnancy and after his birth. From birth plan to getting referrals to specialists, many things were not common practice and required her advocacy. She recommends that anyone whose child receives a prenatal diagnosis advocates to give birth at a hospital with a level IV NICU.

Advocacy needs to be approached from many different sides for babies who receive a prenatal diagnosis of a disability. One of these is in legislature. There is currently a bill in Wisconsin that the Wisconsin Catholic Conference is in opposition of stating "The bill also legalizes abortion in any circumstance in which the fetus has no chance of survival. This language is unduly vague and will lead to the destruction of children with fetal abnormalities. When the death of a newborn is imminent, perinatal hospice and palliative care provide families with a nonviolent

way to care for their child and grieve a premature death. Wisconsin currently has five hospitals offering such assistance and more are needed.”

Advocating in the medical community is also important. Prenatal testing has come a long way, but the results can still be interpreted incorrectly. Researching and understanding what the diagnosis means and preparing for the best and worst possible outcomes are both important parts of being able to advocate for what a family needs during this time. Babies have a right to life saving medical treatment when needed, so it is important for the parents to know what options they have. Despite medical advancements, the reality is that not all babies with a prenatal diagnosis live a long life, still we praise God for the life no matter how long the length. Parents have the option at some hospitals in Wisconsin, listed below, for their child to receive perinatal hospice and palliative care (also referred to as comfort care), both which treat the child with dignity and are responses to the natural imminence of death and respond to the need for grief support for the entire family. Ministries around the country such as, Behold Your Child, Redbird Ministries, and Now I Lay Me Down to Sleep, and Jerome’s Hope all exist to aid families during these times of immense sadness and grief that comes with the loss of a child. Some also help with planning after receiving a prenatal diagnosis. In all of these ministries, the dignity of human life is upheld and recognized.

We need to start talking more about this topic so that if parents receive a prenatal diagnosis, they will know that they have options. We also need to address the stigma of disability. I encourage everyone to seek out opportunities to spend time with people with disabilities. Receiving the news that your baby has a disabilities and what he or she’s prognosis is will most likely lead parents into a time of a lot of fear, sadness, and being scared of the unknown in what the future holds. There will be sacrifice and difficulties in having a child with a disability, there will also be joys and triumphs. As Monica reflected, “Though this has not been an easy journey, it is one I would pick a million times over, just to meet our sweet boy.” People with disabilities contribute to the world in ways that too often go unrecognized. Families need support of those around them to be able to see this goodness in their lives, they need people to walk with them and let them know that they don’t have to do all the hard parts alone.

If you or someone you know receives a prenatal diagnosis of disability, you can contact the Apostolate for Persons with Disabilities for resources additional to those listed above.

Programs and groups listed below may vary in their scope of support and services. Most of the programs listed below are based in hospitals and are integrated into pregnancy and birth care; some are hospice-based; and a few are faith-based or independent. This list, begun in 2006, is compiled free of charge and is not necessarily exhaustive; if you need this support and your hospital is not listed, your hospital might already be providing this care or be willing to learn with you. If your organization provides formal or informal perinatal hospice & palliative care support and you would like to be added to this list, please contact the editor of this site. From: www.perinatalhospice.org/list-of-programs

Ascension NE Wisconsin St. Elizabeth campus Perinatal CARE Program. Contact: Sherah Sroka MSW, (920) 738-2094. Appleton, Wisconsin

Beyond the Rain, doula services and peer support in Janesville, Wisconsin

Children's Hospital of Wisconsin Perinatal Palliative Care. Milwaukee, Wisconsin

Gundersen Health System perinatal palliative care. Contact: Bereavement specialist Marie A. Walter MS RN C-EFM CPLC, (608) 775-3796 or (800) 362-9567 ext. 53796. La Crosse, Wisconsin

HSHS St. Vincent Hospital pregnancy and infant loss support. Contact: Perinatal palliative care and bereavement coordinators Lana Reinke RN CPLC (NICU) or genetic counselor Theresa Shuck MS MA CGC CPLC. Green Bay, Wisconsin

UnityPoint Health Meriter Hospital Perinatal Palliative Care. Madison, Wisconsin