

Panel discusses ways to help pregnant couples facing dire diagnoses

WASHINGTON - When parents receive a prenatal diagnosis that their unborn child has a disability or a potentially lethal illness, they need the support of the church and the community more than ever, said a panel of medical and pastoral experts and several parents who have experienced that sad scenario.

"Parents feel harassed and judged if they even consider bringing into the world a child" with a prenatal diagnosis of a disability or a lethal or even nonlethal condition, said Dr. John Bruchalski, an obstetrician-gynecologist at the Tepeyac Family Care Center in Fairfax, Va.

The pressure to abort such a child is strong and often couched in euphemisms such as "early induction" and "merciful choice," Bruchalski said. As a result, up to 90 percent of children diagnosed with Down syndrome are aborted. But he said screening tests for Down syndrome deliver "false positives" 7 percent to 10 percent of the time.

The diagnosis of an illness or disability often comes unexpectedly after an ultrasound, on a day when parents "hope to come home with a cute ultrasound picture for the refrigerator," said Monica Rafie of Chicago.

Rafie had what she calls her own "D-Day" in 2001, when a doctor told her the child she was carrying was "incompatible with life."

"The defining moment of your pregnancy is no longer the delivery date, but the diagnosis date," Rafie said. "And from that day on, the pregnancy does begin to feel more like a battle than something wonderful."

Rafie and her husband resisted pressures to abort their child diagnosed with complex heart problems. Although she required several surgeries in the first months of her life, their daughter Celine is now 8 and in the third grade.

In 2002, Rafie and other parents and professionals founded BeNotAfraid.net, a resource designed to offer hope and information to others facing a poor prenatal diagnosis. Although the outreach is guided by Catholic principles on decisions related to life and death, it is available to anyone who needs support.

Capuchin Father Dan Mindling, a theologian and academic dean at Mount St. Mary's Seminary in Emmitsburg, said it is important for everyone affected by a situation involving a poor prenatal diagnosis to remember that "the child is alive now, the parents have a relationship with the child now."

"Their very seriously ill child is both their child and a child of God right now," he added. "Every moment should become precious."

Nancy Mayer-Whittington, who lives in the Archdiocese of Washington, said she learned from her daughter Angela that "life can be lived fully and completely in nine months and 10 minutes."

Angela was diagnosed in utero with trisomy 18, a genetic defect that is usually fatal. She died 10 minutes after her birth in 1994.

"I was scared that I would never be the same, that I would never recover," said Mayer-Whittington of her decision to continue the pregnancy after the diagnosis. And that turned out to be true, because Angela "opened my life in ways I had never imagined," she said.

Mayer-Whittington and Cubby LaHood, whose son Francis died shortly after birth, founded Isaiah's Promise nearly two decades ago to help women continue their pregnancies after receiving a poor prenatal diagnosis.

"We hold their hands as they walk the path of a pregnancy that is not as they envisioned," Mayer-Whittington said.

Tracy Winsor, a North Carolina perinatal loss peer counselor, co-founded the BeNotAfraid Ministry of Charlotte in 2008 with Sandy Buck, whose son Casey was diagnosed with trisomy 18 during her pregnancy. Winsor said the free services - primarily offered by volunteers - are "a ministry of presence" that can help parents "move past the diagnosis."

She recalled the comments of a Charlotte nurse who witnessed the help given to one mother. "I didn't realize you were a regular service," she said. "I just thought those parents had the best friends in the world."

The panel discussion with Bruchalski, Father Mindling, Winsor and Rafie was part of an Internet seminar organized by the National Catholic Partnership on Disability. Held before an audience at The Catholic University of America in Washington, the seminar also had online participants in 258 sites around the country.

The seminar was followed at Catholic University by another panel discussion with LaHood and her husband, Dan; Mayer-Whittington; Theresa Bonopartis, whose New York-based organization, Lumina: Hope and Healing After Abortion, offers retreats for women or couples who regret an abortion following a prenatal diagnosis; and Monsignor Charles E. Pope, pastor of Holy Comforter-St. Cyprian Parish in Washington.

The second discussion was designed to move forward local plans for a Catholic pastoral response to unexpected prenatal diagnosis.