

Dispelling the ‘fear of the unknown’

Ministry reaches out to families of babies with Down syndrome

by KATIE MOORE

staff writer

CHARLOTTE — A local chapter of a support group for women and families who are dealing with difficult pregnancies is expanding their program to reach out to mothers of unborn babies who are diagnosed with Down syndrome.

Elizabeth Ministry is an international outreach designed to support women and their families during the joys and sorrows of the childbearing years.

In the past, one of the primary services of Elizabeth Ministry has been providing perinatal hospice for mothers who carry their babies to term despite receiving a poor prenatal diagnosis.

“Perinatal hospice provides a great service for many moms,” said Tracy Winsor, a parishioner at St. Peter Church in Charlotte and regional perinatal bereavement coordinator.

But, she said, the problem is that “Down syndrome parents never get referred.”

This new service “is part of our effort to support moms who are carrying to term,” said Winsor. “We want to have a very specific service dedicated to Down syndrome because that population is largely underserved.”

According to Winsor, the abortion rate for parents who are informed their unborn children have Down syndrome is 90 percent.

She attributes the high termination rate to a lack of information and understanding of Down syndrome within the medical community.

“As an issue of public health, we need to do a better job of providing information and supporting” parents who receive these diagnoses, said Winsor.

There are other options, “even if a family feels that they can’t raise a child with Down syndrome,” she said.

One of the things most people don’t realize is that “there are actually waiting lists associated with families who want to adopt a child with Down syndrome,” said Winsor.

Winsor recently held a training session for peer ministers or counselors who will work specifically with Down syndrome cases.

Kristin Pettler, a parishioner at St. Matthew Church in Charlotte and mother of three children, attended the training. Pettler’s 3-year-old daughter Kaitlin has Down syndrome.

“It hurts my heart when I find out that other parents don’t fully understand what they are doing,” said Pettler of her reason for getting involved.

As a mother of a child with Down syndrome, Pettler wants to be able to help other families by sharing her experience.

“I want to let them know the future is still bright,” she said.

The biggest challenge the group faces now is getting the word out about its ministry.

“We know that these women exist in the community,” said Winsor.

The problem is getting referrals from the medical community.

“Doctors can unknowingly pressure women,” said Pettler, referring to the vulnerable state of most women at the time of their diagnosis.

“At that point they don’t understand the full ramifications and they are pressured to make a decision within 24 to 48 hours,” she said.

As far as the negative connotation that comes with receiving a diagnosis of Down syndrome, Pettler said she thinks it is the “fear of the unknown.”

“There is such pressure for everything to be perfect in our society,” she said, but “when you stop and think about it we never know the future because it’s always in God’s hands.”

“As a community of faith and society, we have to struggle with making certain that we are extremely welcoming and supportive of these families,” said Winsor referring to the ultimate goal of Elizabeth Ministry.

Pettler hopes to do her part.

“We are all different,” she said. When it comes to children with Down syndrome, she said “the difference is just a little bit more obvious on the outside.”

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WANT MORE INFO?

Three churches in the Diocese of Charlotte currently have Elizabeth Ministry support groups — St. Mark Church in Huntersville, St. Matthew Church in Charlotte and Sacred Heart Church in Salisbury.

For more information about Elizabeth Ministry, go online to www.elizabethministry.com.