

## Frequently Asked Questions about Trisomy 13 and 18: for Families

Parents often ask the following questions when facing a diagnosis of Trisomy 13 or 18 during their pregnancy or in their child:

### *What choices will I have during pregnancy?*

Some families choose to continue the pregnancy. Families in consultation with their obstetric providers have many options for developing a tailored plan for prenatal care visits, monitoring of fetal growth and development during the pregnancy, monitoring of the fetal heart rate during labor, and, in some cases, palliative care. Some options can support a parents' goal to hold a living baby. Some women choose to terminate the pregnancy. With the help of their obstetric providers they also develop a plan that consistent with this choice. Your OB or Maternal-Fetal Medicine doctor will discuss those choices with you.

### *Will my baby be born alive?*

There is a wide range of outcomes for pregnancies involving a diagnosis of Trisomy 13 or 18. For women who choose to continue their pregnancies, some pregnancies end early with a fetal death before labor. Some babies do not survive labor or the birth process and are stillborn. Others are born alive but have such severe medical problems that they cannot survive very long. Some infants have significant medical problems that may respond to therapies. Other babies remain clinically stable with little or no medical intervention and can spend time with the family after birth.

### *What choices will I have in the delivery room?*

Some families value private time with their infant – holding, skin-to-skin bonding and breast feeding – and choose to not begin medical treatments even if there are life-threatening problems, so that death is peaceful. Other families choose to have brief or gentle medical interventions if needed. Still others choose a trial of intensive care to see if their infant will improve, even if it means separation from their baby. These decisions are highly individualized and are based on a family's values, the kinds of medical problems their infant will face, and what is medically possible to offer for the baby.

### *What choices will I have after my baby is born? Will I get to take my baby home?*

Your doctor will try to help you understand what to expect in the first few days of life, but doctors cannot always predict accurately how long a baby with Trisomy 13 or 18 will live or what medical needs a baby may have after birth. In some cases, if interventions may be appropriate, parents will need to decide if minor or major medical interventions (such as surgery) are best given the risks and benefits for their baby and the family's goals for their baby.

For some families whose infants face life-threatening problems, working with hospice to provide support and guidance is a good choice. Other families of infants with these problems choose medical interventions in the hope of prolonging life. Many families' decision making changes and evolves after

learning more about their child's unique challenges and strengths. The Supportive Care Team is available as a support to families making these decisions.

*What choices will I have if my baby is discharged?*

It is important to make a plan for the first few days and weeks at home with your pediatrician as families may be faced with difficult decisions after discharge. Families may change their minds about what is best for their child after living with their child and learning more about the challenges and joys they face. It is important to understand that some babies survive for weeks, months or even years with ongoing medical care, so flexibility is often a key part of planning. Families need to be prepared for how to respond if their infant begins to get sick or has a medical emergency. These include questions such as: When do you choose to go to your physician or the emergency room? When is hospitalization needed? Families also need to prepare for a time when further interventions to extend life are not possible or do not align with what is best for the baby. In these circumstances the questions may be: How will we know that it might be time to decide not to pursue interventions that are intended to extend life? How can we support, and be supported, in a setting that allows for our baby's comfort and a peaceful death?

*What about my child's development? Can my child learn to speak or walk?*

Children with Trisomy 13 or 18 who survive into childhood can recognize family members, smile, and laugh. Others can feed themselves, play independently, understand simple words and phrases, point at objects and follow commands. A few can say "mama" or "papa" and some can learn to use a sign board. Many children can sit without assistance, some children can crawl and some can learn to walk with a walker.

*What resources are available for families?*

See "Resources for Families".