Health Care Information for Families of Children and Adolescents with Down Syndrome

Child's Age: The Prenatal Period (the time before birth)

☐ Consider testing as desired

- Prenatal screening and (diagnostic) testing for Down syndrome should be offered to all families. Before testing, discuss with your doctor possible tests, and the risks and benefits of each test. Information from this testing can help you make decisions about your pregnancy and best care for the mother and baby.
- Screening tests like ultrasound and blood tests for cell free DNA can tell the chance of having a baby with Down Syndrome. This screening does not give a diagnosis.
- Tests like amniocentesis or CVS (chorionic villus sampling) are diagnostic and can make the diagnosis of Down syndrome.

☐ Counseling

- If a chromosome change that causes Down syndrome is found by prenatal screening and/or testing, you should be referred for genetic counseling to explain the issues and to provide support for the family.
- Your doctor may recommend genetic counseling by a genetic counselor or medical geneticist.
- Ask your doctor or the geneticist to explain the prenatal test results.
- Talk with your doctor about the positive attributes in children with Down syndrome, as well as possible health problems that can occur.
- Ask about organizations that give information and support to families and ask about early intervention services.

Develop a plan for delivery and the best newborn care for the baby with your obstetrician

- A special ultrasound can find gastrointestinal and heart problems that may require care soon after birth.
- Ask your doctor about getting an ultrasound picture of the heart (an echocardiogram). Heart problems are common in people with Down syndrome and getting a prenatal heart ultrasound can help your doctors give the best care to the baby.
- Knowing what is needed for the mother and baby may help you and your doctor decide things like where to deliver the baby.