Cystic Fibrosis Information for Parents

What is Cystic Fibrosis?

- Cystic Fibrosis (CF) causes problems with how well the lungs work.
- CF is passed down in our genes from parents to children. Usually the parents do not have CF but can carry it in their genes.

How do we know that my child has Cystic Fibrosis?

- Pennsylvania has a newborn screening program that screens for many different medical conditions.
- A very small amount of your baby's blood was collected at the hospital in the first few days of life.
- Your baby's newborn screen showed us that the CF level was high. It needs to be repeated.
- 90% of babies who have a high CF level on the newborn screen will NOT have CF on the repeat test.

What do we do now?

- Based on how high the level is, we may take blood again when your baby is 2 weeks old.
- Sometimes we will send the baby to see a pulmonologist (a lung doctor) in order to get a special test done called a chloride sweat test when the baby is 4 weeks old.