Cystic Fibrosis

What is Cystic Fibrosis (CF)?

- CF is a genetic disease passed from parents to child; two defective genes are needed (one from each parent) in order for the disease to be present
- People with CF have thick, sticky mucus which clogs some organs in the body, mainly lungs, pancreas and liver
- Mucus build up in the lungs allows bacteria to get stuck in the airways, causing infections and inflammation, which can lead to lung damage over time
- Mucus build up in the pancreas and liver prevents the intestine from absorbing certain nutrients from food

How is Cystic Fibrosis Diagnosed?

- Oregon and Washington test for CF on newborn screen
- A sweat test detects high chloride on the skin which determines the diagnosis for CF
- A blood test identifies which two genes are defective on the CF gene

What are signs and symptoms of Cystic Fibrosis?

- Salty tasting skin
- Not growing or gaining weight normally, difficulty maintaining weight
- Lung infections
- Persistent coughing sometimes with mucus
- Greasy, foul smelling bowel movements that may float in the toilet bowl
- Belly pain, diarrhea or constipation
- Nasal polyps – small growths in the nose

How is Cystic Fibrosis Treated?

- Because there is no cure for CF at this time, goals of treatment are to reduce symptoms and slow the progression of your disease.

Treatments to help the **lungs** include:

- Medicines to thin the mucus in the lungs (Pulmozyme™, sodium chloride 7%)
- Inhaled antibiotics fight bacteria that cause infections (TOBI™, Cayston™)
- Chest physiotherapy (CPT) – therapy to break up and loosen mucus in lungs

Treatments to help the **digestive tract** include:

- Enzymes (Creon®, Zenpep®) taken at every meal and with snacks to help break down food in the intestines
- Specific vitamins that are not absorbed

New Treatments:

- Ask your doctor if you are eligible for new medications
- For information about new treatments, visit the CF Foundation website: www.cff.org/treatments/pipeline

Points to Remember:

- Make sure your vaccinations are up to date
- Maintain a smoke-free environment, including your home and car
- Schedule regular appointments with your CF care provider

For Additional Information:

- Cystic Fibrosis Foundation: 1-800-FIGHT-CF, www.cff.org
- Boomer Esiason Foundation: 1-516-746-0077, www.esiason.org