CF CAREGIVERS SUPPORT GROUP

The CF Caregivers Support Group will be held every other month on a Saturday at the Potpourri House at 3320 Troup Hwy Ste. 300, Tyler, TX, from 11:30am-1:30pm. When dates are determined, you will be notified by email, mail, or text message if we have your permission and email address or phone number. Lunch is provided at no cost to you, so please come and fellowship with us and other caregivers.

THERAPEUTIC DEVELOPMENT NETWORK

This year we were accepted into the Therapeutic Development Network (TDN) which is a subset of the CF Foundation. TDN is the largest CF clinical trials network in the world, bringing together experts from across the country to evaluate the safety and effectiveness of new CF therapies through clinical studies. We are very excited to be included in this network which opens us up to many more clinical trials!

UPDATE:

ORKAMBI Now Approved for Patients Age 6 and Older

ORKAMBI is a prescription medicine used for the treatment of cystic fibrosis (CF) in patients age 6 years and older who have two copies of the F508del mutation (F508del/ F508del) in their CFTR gene.

ORKAMBI is made up of lumacaftor and ivacaftor:

- Lumacaftor helps to move F508del-CFTR proteins to the cell surface
- Ivacaftor helps the CFTR proteins at the cell surface work better

As a result, ORKAMBI allows more chloride ions pass into or out the cells. This may keep a balance of salt and water in certain organs, such as the lungs.

For more information visit: www.ORKAMBI.com or ask your healthcare professional.

UPCOMING EVENTS

May is CF Awareness Month

Tyler Great Strides CF Walk

- September 23rd
- Check-in 8am
- Walk-9am
- Chapter-Northeast Texas
  Tyler Event Location-TBA

NEWS:

CLINICAL RESEARCH STUDIES

Current Enrolling Studies:

- Novartis CTBM100C2407: Observational study with Pseudomonas aeruginosa
- Cystic Fibrosis Patient Registry: CF Foundation Registry for all CF Patients
- Abbott CF-FC: Observational study for Fibrosing Colonopathy

Please visit https://www.cff.org/Trials/finder or for more information on clinical trials please contact Lilly Garza, Clinical Research Coordinator at (903) 877-5435.
ADHERENCE PROGRAMS:

BEADS OF HOPE & D.Y.S. (Do-Your-Stuff)

The Beads of Hope Program is an incentive program for pediatric patients ages 3-13 years old to receive beads for completing therapies, treatments, clinic visits, etc., regarding their health. Once a patient reaches the age of 13, your CF Team believes it is time to branch off from the Beads of Hope Program. The patient will then begin the new incentive program, D.Y.S. (Do-Your-Stuff) Program.

This program is a continuation of the Beads of Hope Program for teenagers and adults ages 13-40 years old. The D.Y.S. program entails accumulating points in order to receive a gift/prize of the patient’s choice from any level depending on the amount of points they received for being adherent to treatment, therapies, etc. The incentive rewards include gift cards from various restaurants and shopping retailers. You are not obligated to participate in these programs, but we feel both programs provide great incentives for “doing your stuff.”

PRESCRIPTION REFILL REMINDERS

Please call your pharmacy five working days before you take your last dose of medication. Always call the pharmacy before picking up your medication to ensure your prescription has been filled. Reminder: Mail-in prescriptions require additional time to process. Some mail-in pharmacy services require up to 10 working days to process refills. Please call your pharmacy at least 7-10 working days before your last dose to request refills.

PLEASE WELCOME

Our Newest CF Care Staff Members

Melanie Dangerfield
LMSW and Mental Health Coordinator

Melanie is a Licensed Master Social Worker (LMSW). She received her Bachelor of Social Work and Master of Social Work degrees from Texas A&M University in Commerce, Texas. She has worked with the CF Team since January 2017. As your CF social worker, Melanie will help you and your family members cope effectively with the inevitable stress of having CF by offering emotional support, counseling, advocacy, education, and identification of resources in and out of your community. As the Mental Health Coordinator, Melanie will administer depression and anxiety screenings yearly for all patients ages 12 years and older, and caregivers of pediatric patients.

Billy (Joe) Sartor

Joe moved to Tyler in 1982 after a layoff from the steel industry. Joe graduated from UT Austin in 1973 with a Bachelor of Science in Pharmacy and from Texas Tech in 2002 with a Doctor of Pharmacy. He was a pharmacist at Mother Frances Hospital until 2002, after which he joined UT Health. His primary areas of practice are geriatrics, ambulatory care, infectious disease and cystic fibrosis. Joe has worked with CF patients in the past, helping with dosing of antibiotics during inpatient and home care. He is proud to be a member of the CF clinic team, helping with all medication needs.

Caryn Vorsas
Physical Therapist

Caryn received her Bachelor of Science in Rehabilitation Medicine (OT/PT) from the University of British Columbia, Vancouver, BC, in 1985 and her Master of Science in Interdisciplinary Studies from the University of Texas at Tyler in 1993. She has worked in acute care for most of her career and took over the directorship of Rehabilitation Medicine at UT Health Northeast in 2006. She has retired from UT Health, but came back to work on the CF grant to provide exercise education to our patients. She has worked in Canada and the West Indies, and has worked with cystic fibrosis patients both in the hospital and the outpatient clinic. She is a 28 year member of the American Physical Association and has held the position of education chair for the East Texas District of the TPTA.

Ida Rodriguez (Sabina)
Certified Medical Assistant (CMA)/Medical Interpreter

Sabina began working in the medical field in 2002 and started at UT Health Northeast two years ago working with the adult pulmonary and sleep patients. She worked in the CF Clinic on an as needed basis until she accepted her current position in December. She is fluent in Spanish and assists with Spanish speaking patients in the CF clinic as well as hospital wide. She is responsible for the administrative needs of the clinic and assisting physicians and nurses with clinical care as needed. Sabina has experience working in home health, mental health for acute, chronic and forensic patients. Most recently, she worked with adults with a dual diagnosis of intellectual disabilities and mental health.

Beads of Hope Program

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