Who are we?

The UT Mitochondrial Center of Excellence is a multidisciplinary team of physicians, along with 2 nurses, social worker, 3 research coordinators, patient liaison/special programs coordinator, and administrative coordinator that provide care to adult and pediatric patients with neurometabolic and primary mitochondrial diseases. We provide comprehensive services to aid in diagnosis and management of neurometabolic and mitochondrial disorders. We consult with patients, their primary care physician or pediatrician, and subspecialists to develop a long-term treatment and management plan that is individually suited to each patient. We also perform research in the field of neurometabolic and mitochondrial disorders and investigate novel treatment approaches in these devastating diseases.

The UT Mitochondrial Center of Excellence operates under the direction of Dr. Mary Kay Koenig, Associate Professor of Pediatrics and Neurology at the University of Texas-Houston Medical School.

All patients are seen by Dr. Koenig and other subspecialists on the team, according to their medical concerns. The center hosts weekly multidisciplinary meetings to improve continuity of medical care across subspecialties. Patients are followed inpatient at Memorial Hermann Hospital and outpatient through UT Physicians.

Our mission is to provide cutting edge medical care to individuals affected by neurometabolic and mitochondrial disorders, to perform both clinical and basic science research to provide treatment options for patients with mitochondrial disease, and to educate medical professionals and the community about mitochondrial disease.

Our Team:

Dr. Ebony Beaudoin, Pediatrics & Chronic Care
Dr. Rita Swinford, Nephrology
Dr. Susan Pacheco, Allergy & Immunology
Dr. Cindy Jan, Pulmonary & Sleep
Dr. Marc Rhoads, Pedi Gastroenterology
Dr. Ricardo Mosquera, Pulmonary
Dr. Suur Bicicler, Neurology
Dr. Maria Matuszczak, Anesthesiology
Dr. Jael Carbajal, Anesthesiology
Kristie Cullum—Chronic & Palliative Care
Dr. Soham Roy, ENT
Dr. Robert Lapus, Pedi Emergency Medicine
Dr. Ankur Kamdar, Rheumatology
Dr. Mohammed Numan, Cardiology
Dr. Erin Furr-Stimming Neurology
Dr. Ikram Haque, Pediatric ICU
Dr. Eliana Bonfante, Neuroradiology
Dr. Deborah Brown, Hematology
Glenda McDonald, Chaplain
Eugenia Mileykovskaya, Basic Science Research

Director:
Mary Kay Koenig, MD
Clinic Coordinator:
LaKeesha Minor, RN
Clinic nurse:
Shamonica Williams, LVN
Coordinator of Special Projects:
Melissa Knight
Social Work:
Grace O’Toole Waiz, LMSW
Research Coordinators:
Rahmat Adejumo, MBBS, MPH
Vinu Perijelil, MBBS
Noemy Contreras, BS
Administrative Coordinator:
Alexis Aguilar
**Team Hudson Fundraiser**

Hudson Schaper is a charming little guy that has captured the hearts of an entire community. For the fourth year in a row, the town of Brenham, TX, has rallied together to raise money in support of Hudson and his fight with mitochondrial disease. The Schaper family chose to donate the proceeds of the event to the UT Mitochondrial Center of Excellence. The event was a first-class country party, complete with live music, dancing, food auction items, and even an appearance from Superman! The auction was full of fun and interesting items, including a golf cart and a goat that passed out when it was startled! We are so grateful to the Schaper family, friends, and the entire town of Brenham, TX, for their amazing support.

This fun-filled event raised over $30,000!

**Ladybug Party**


Carole joined many of our families for a grand Ladybug celebration, complete with crafts, snacks, and face painting by Rawr Party! Carole read “The Gift of the Ladybug” and gave each child a signed copy of the book.

As part of her multi-city book tour, Ms. Amber also selected a “ladybug” to honor with a special afternoon. Katie joined Carol on an outing to one of her favorite places, The American Girl Store. Katie was treated to a first class lunch at the store restaurant and then to a shopping spree that filled her heart’s desires.

Katie even joined Ms. Amber the following morning in an interview with Channel 2 News.

Katie says, “I felt amazing on Ladybug Day, like I was the president of the United States! It is one of my favorite holidays, like Christmas and my birthday. It was the best day of my life!” -Katie
Multidisciplinary Meeting

At the heart of the success of the UT Mitochondrial Center of Excellence is possibly the weekly multidisciplinary meetings. It is not uncommon for mitochondrial disease patients to see multiple sub-specialists. It can be a challenge for families to keep each doctor updated on their medical concerns. In order to provide a more comprehensive treatment plan, the UT Mitochondrial Center of Excellence hosts weekly meetings with sub-specialists on our team to discuss the medical concerns and treatment options of our patients. The team approach helps encourage communication between physicians and the formulation of the best possible treatment plan for each individual patient.

Energy for Life Walk

The UT Mitochondrial Center of Excellence participated in the 4th annual Energy for Life Walk to raise funds for the United Mitochondrial Disease Foundation (UMDF). The 5K walk is held the first weekend in February at Sam Houston Park and is always a fun event.

Brownie Troop Book Donation

In July 2014, Brownie Troop #110024 donated over 1,000 book to Children’s Memorial Hermann Hospital and UT Physicians! Marabelle knows what it is like to spend a lot of time in waiting rooms and in the hospital. She says, “Sometimes kids, like me, have to wait a long time for the doctor to come in. And it gets boring sometimes. So now there will be lots of books to read so the kids will have something to do when they’re waiting.” Marabelle’s mother, Caralou, adds “Unfortunately, we spend a lot of time in the doctor’s office, and it can be hard to keep a child occupied during the wait times. On several occasions, Marabelle stated that she wished there were books for her to read in the examination rooms. When the opportunity arose to think of a community project that would benefit children, this need came to mind. We were both very happy with how successful the book drive was. I’m glad so many children will get to enjoy these books.” Marabelle and her brownie troop collected books from their friends and schools for over a month. Their hard work will be putting smiles on children’s faces for years to come.
People Against Leigh’s Syndrome

People Against Leigh’s Syndrome (PALS) is an organization seeking to build awareness of Leigh syndrome and support efforts that would lead to discovery of a treatment or a cure.

PALS is working in partnership with Children’s Memorial Hermann Hospital, UT Mitochondrial Center of Excellence and the Memorial Hermann Foundation. Dr. Mary Kay Koenig and Melissa Knight, of the UT Mitochondrial Center of Excellence both serve on the advisory council for PALS.

In May 2014, PALS hosted its second annual fundraising event at Saint Arnold’s Brewery, raising $100,000. Lori Martin, board member of PALS says, “This year’s PALS event was an amazing time, but what really what made the night so special is knowing we would be able to make a real difference in the lives of those living with Leigh syndrome.”

This year’s guest speaker was Elizabeth Baker. She explained to the audience how Leigh syndrome has affected her son, Grayson. Elizabeth says, “Our family is so grateful for the opportunity and honor to participate with PALS. Although Grayson’s diagnosis is devastating, it brings us joy and hope that there are many people who care enough to donate to an organization dedicated to finding new treatments for our kids, and hopefully one day a cure. It’s so comforting to know that although raising a child with this illness is challenging and heartbreaking at times, we are not alone.”

The UT Mitochondrial Center of Excellence has amassed a large Leigh syndrome population and hosts the only functioning Leigh syndrome clinic. The funds raised by PALS have been put to great use with the hire of a full time research coordinator that solely researches Leigh syndrome with the UT Mitochondrial Center of Excellence. Vinu Perinjelil began her work with us in June 2014. For more information about PALS, visit their website at www.peopleagainstleighs.org.

Raising Awareness

Mitochondrial Disease Awareness Week

Each September, we celebrate mitochondrial disease awareness week. LaKeesha Minor, UT Mitochondrial Center of Excellence nurse coordinator, organized an awareness booth at Memorial Hermann Hospital. Upsher-Smith and Supernus each sponsored a portion of the event. Ken Furman, owner of Oak Leaf Printers, donated “Mito Awareness” T-shirts. The UT Mitochondrial Center of Excellence staff handed out snacks, Mito Mike turtles, t-shirts, information brochures, and other goodies, as well as answered questions about mitochondrial disease to hospital employees and families.

Rare Disease Day

February 28, 2014, was declared Rare Disease Day. The UT Mitochondrial Center of Excellence joined in support of those suffering from rare genetic disorders by participating in the “Jeans for Genes Day”. 
Publications

The UT Mitochondrial Center of Excellence published several research papers this year.


Luminate 5K

In October, the UT Mitochondrial Center of Excellence was selected to be the beneficiary of the Luminate 5K race in Houston. It was a beautiful night outside of Minute Maid Park for the Eastern themed race. Hundreds of runners, lit up with glow sticks and glow in the dark paint, warmed up with an energizing cardio hop routine and danced to the music of DJ K-Touch before taking to the streets for a great race. UT Mitochondrial Center of Excellence hosted a tent to distribute information and held a raffle. Seven year old patient, Rebecca, said, “I liked the run because everyone was wearing glow sticks and it was pretty. I liked selling raffle tickets because it was fun to talk to all the people. The music for the dancing was great, too.”

We look forward to more events with Luminate 5K!

CNS Conference

The Child Neurology Society hosted their annual conference in Columbus, OH this October. UT Mitochondrial Center of Excellence nurses LaKeesha Minor and Shamonica Williams traveled to Ohio to join other nurses from all over the world. They attended sessions on a broad spectrum of neurological disorders that impact children. They also participated in discussions with other nurses and physicians to learn about new tests and treatments. LaKeesha and Shamonica believe that it is important to continually gain new medical knowledge that they can utilize at the UT Mitochondrial Center of Excellence to ensure that all patients receive the best possible care.
Putt an End to Mito Golf Tournament

The fourth annual Putt an End to Mito Golf Tournament was held in September at Stephen F. Austin State Park. The friends and family of Trace Wehring hosted another great event. The golfers enjoyed a day of friendly competition and contests on a great golf course. Following the tournament, players were treated to a nice dinner reception with awards and auction items.

Trace’s mother, Laurie says, “We choose to host Putt an End to Mito to raise funds for the UT Mitochondrial Center of Excellence along with awareness of mitochondrial disease. We see a more direct impact raising the funds for the Center where Trace and so many other affected children are treated. Not only do we raise funds to benefit the care the children receive, it also is an amazing way to raise awareness of mitochondrial disease. We had never heard those words before Trace was diagnosed. It is really important to us, our family & friends to continue to raise awareness. Raising awareness & funds is key to the future of every person battling Mitochondrial Disease.”

The Wehring family and their generous donors are a big part of the continued success of the UT Mitochondrial Center of Excellence. We are so grateful to all of those that worked so hard to make this event successful.

The Putt an End to Mito golf tournament raised over $25,000 for the UT Mitochondrial Center of Excellence.

UMDF Symposium

Each June, the UT Mitochondrial Center of Excellence enjoys a week with the United Mitochondrial Disease Foundation at the national symposium. This year, the group travelled to Pittsburgh, PA, to share our research and to learn from other top mitochondrial disease physicians and researchers. Dr. Mary Kay Koenig sat on a panel with two other doctors for an “Ask the Mito Doc” session. She also met with many families individually for “Ask the Mito Doc” sessions.

Melissa Knight, LaKeesha Minor, Grace O’Toole, and Shamonica Williams also led a workshop on “Getting Organized” and provided medical binders to participants. They each also moderated round table discussions in the “Parent to Parent Mentoring Workshop” and “Adult Patient Mentoring Workshop” sessions.

We had four research abstracts that were invited to participate in the poster presentations. Dr. Claudia Soler-Alfonso and Dr. Mary Kay Koenig presented their poster, “Identification of HIBCH gene mutation causing autosomal recessive Leigh syndrome: A gene involved in valine metabolism.” Dr. Mary Kay Koenig and Dr. Eliana Bonfante presented their poster, “Neuroimaging of Leigh Syndrome Revisited in the Era of Genetics”. Dr. Nada Memon, Dr. Mohammed Numan, and Dr. Mary Kay Koenig presented their poster, “QTc Interval Prolongation Is Associated With Mitochondrial Disorders”. Dr. Susan Pacheco, Dr. Cindy Jon, Dr. Ricardo Mosquera, and Dr. Mary Kay Koenig presented their poster, “Etiology, management and clinical outcomes of patients with Leigh syndrome and febrile episodes treated at the UT Mitochondrial Center of Excellence.”
Fantasy Flight to the North Pole

Once again, patients of the UT Mitochondrial Center of Excellence were invited to join the Fantasy Flight to the North Pole. United Airlines hosted an amazing day for families of children with chronic health conditions. The families boarded an airplane and took off from Houston International Airport and a short hour later, landed in the frigid North Pole where they visited with Santa Claus, ate sweets, and loaded up on goodies.

Anna Beth and her sister, Camille, were excited to make the trip this year. Their mother, Laura, says the most enjoyable moment for her was seeing the joy on their faces when the pilot announced they were landing at the North Pole. Camille was most impressed with seeing the real Santa Clause.

We have been privileged to invite new families to participate in this once in a lifetime opportunity for the past 3 years!

Supplement Assistance Fund

Caring for a loved one with mitochondrial disease brings about many challenges. Often one of the greatest challenge is the financial struggle that families find themselves in. Families are often forced to operate on a single income while one parent is the primary care giver to an ill child. Families may spend hundreds of dollars a year to park in the medical center’s parking garages. Hospital stays can be long and eating meals from the hospital cafeteria can be quite expensive. There are many hidden costs in dealing with chronic health care issues beyond insurance deductibles and co-pays. However, mitochondrial disease can present one more obstacle for families.

Currently, the only treatment for mitochondrial disease is an assortment of vitamin supplements that insurance companies will not cover. Most patients with mitochondrial disease are prescribed Coenzyme Q10. The price of this supplement can be several hundred dollars each year. Often, this is more than the family can afford. Through generous donations to the UT Mitochondrial Center of Excellence, we have been able to offer free Coenzyme Q10 to many families in 2014. The supplement assistance fund has now assisted families for the past 3 years. Without this fund, many patients would not be receiving an integral part of their treatment. We are very grateful to the donors that continue to make this possible.
Houston Top Doc Awards

The UT Mitochondrial Center of Excellence was pleased to learn that several of our physicians were named by Houstonia Magazine as Top Docs in Houston for 2014.

Congratulations!

Research Department Growth

The UT Mitochondrial Center of Excellence has experienced great growth in our research department in 2014. Through generous donations from People Against Leigh Syndrome, the center was able to hire a research coordinator dedicated exclusively to researching Leigh syndrome, a specific type of mitochondrial disease. Vinu Parinjelil joined our team in June. Vinu obtained her medical degree from Charles University in Prague and comes to us after working on multiple research projects at MD Anderson.

Vinu currently has 4 research projects underway specific to Leigh Syndrome.

Noemy Contreras also joined our team in June as a research coordinator. Noemy brings years of experience in research from MD Anderson and has been fantastic in developing and facilitating multiple research projects that are underway at the UT Mitochondrial Center of Excellence. Noemy and Rahmat Adejumo are currently working on 11 different research projects on mitochondrial diseases.

We also had the privilege of working with Nadia Haj-Ismael, a medical student, who presented a poster, “The Natural History of Leigh Syndrome”. 
Texas Parent to Parent Conference

UT Mitochondrial Center of Excellence social worker, Grace O’Toole and patient liaison, Melissa Knight attended the annual Texas Parent to Parent Conference in San Marcos, TX.

The Texas Parent to Parent conference is a gathering of parents, advocates, family members, caregivers, and professionals that learn from each other in ways to provide better care for children with disabilities or special health care needs.

Melissa and Grace attended seminars on a broad range of topics, including advocacy, parenting and sibling issues, special education laws, creating a Medical Home, accessing Medicaid Waiver Programs, mental health, behavioral concerns, available resources, and transition to adulthood, plus much more. The two day conference provided them with many opportunities to network with families and professionals and learn new ways to help the families at the UT Mitochondrial Center of Excellence.

To learn more about this great organization, please visit their website.

www.txp2p.org

VSA Playwriting with the Alley Theater

The UT Mitochondrial Center of Excellence is pleased to partnered with the Alley Theatre and several local schools in a project to introduce playwriting to children with disabilities and their siblings. Through a grant funded by The Kennedy Center, UT Mitochondrial Center patients will have the opportunity to work with teaching artists to tell their story in a play.

To kick off this event, families were invited to a showing of A Christmas Carol. Prior to the show, the children participated in activities hosted by the Alley Theatre teaching artists.

The children were also invited to tour the Alley Theatre production studio. They learned how each of the intricate costumes were designed and produced and also participated in fun activities.

Over the next year, the children will continue to learn about theatre while working on creating their own play that will be performed by Alley Theater actors.

Riley, 9 years old, says, “My favorite part so far was seeing the behind the scenes. My favorite workshop was the background shop where they make all the different props. We also got to see a Captain Hook costume really close up and it was cool.”

We are excited to see this program develop.

Comcast Newsmakers

Dr. Mary Kay Koenig had the opportunity to participate with Comcast Newsmakers, once again, to bring about more awareness for mitochondrial disease.

Newscaster, Michael Bybee, interviewed Dr. Koenig about the UT Mitochondrial Center of Excellence and the newly established Leigh Syndrome Clinic.

The interview was played throughout the month of August on Comcast.

We are so grateful to have this opportunity to raise awareness for mitochondrial diseases in our community.
Mitochondria are part of every cell. They are responsible for converting the food we eat into energy our bodies can use. A mitochondrial disease occurs when the mitochondria are unable to function properly. Cells do not have enough energy to perform their functions and organs begin to fail. Mitochondrial disease causes problems with growth, muscle strength, vision, hearing, learning, heart, liver, and kidney function, breathing, diabetes, seizures, strokes, and gastro-intestinal functions. Any part of the body that requires energy to function can be affected by a mitochondrial disease.

Mitochondrial disease affects 1 in 4000 people. This makes it as common as childhood cancer. Mitochondrial diseases contribute to many common ailments like growth failure, diabetes, heart disease, dementia, and stroke.

Mitochondrial disease can be inherited. It can run in families affecting both parents and their children. Many diseases of aging, like Parkinson's and Alzheimer's, have also been found to have defects of mitochondrial function.