WHO ARE WE

The UT Mitochondrial Center of Excellence is a multidisciplinary team of physicians, along with nurses, social workers, researchers, a patient liaison and special programs coordinator, and an administrative and accounting team. We provide comprehensive services to aid in the diagnosis and management of neurometabolic and mitochondrial disorders in both adult and pediatric patients. We consult with patients, their primary care physician or pediatricians, and subspecialists to develop an individualized long-term treatment and management plan. 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 Health Science Center at Houston, McGovern 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.

CONTACT US

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Our Team 2016

UT Mitochondrial Center of Excellence

Dr. Mary Kay Koenig, Director
Lakeesha Minor, RN, Clinic Coordinator
Rosie Godfrey, LVN
Grace Smith, LMSW
Melissa Knight, Patient Liaison/Special Projects
Alexis Aguilar, Accountant and Budget Analyst
Margaret "Meg" Smith, Senior Support Assistant
Rahmat Adejumo, Research Director
Noemy Contreras, Research Coordinator
Parisa Mehrzad, Research Coordinator
Sree Dasgupta, Research Coordinator

Multi-Disciplinary Team

Dr. Ebony Beaudoin, Pediatrics & Chronic Care
Dr. Suur Bilciler, Neurology
Dr. Eliana Bonfante, Neuroradiology
Dr. Deborah Brown, Hematology
Dr. Jael Carabajal, Anesthesiology
Kristie Cullum – Chronic & Palliative Care
Dr. Kimberly Earle, Palliative Care
Dr. Erin Furr – Stimming Neurology
Traci Gonzales, NP – Pedi High Risk Clinic
Pam Griggs, Dietitian
Dr. Ikram Haque, Pediatric ICU
Dr. Cindy Jon, Pulmonary & Sleep
Dr. Ankur Kamdar, Rheumatology
Dr. Robert Lapus, Pedi Emergency Medicine
Dr. Maria Matusczak, Anesthesiology
Glenda McDonald, Chaplain
Dr. Ricardo Mosquera, Pulmonary
Dr. Mohammed Numan, Cardiology
Dr. Susan Pacheco, Allergy & Immunology

Dr. Marc Rhoads, Pedi Gastroenterology
Dr. David Rodriguez, Genetics
Dr. Soham Roy, ENT
Heather Saavedra, Dietitian
Dr. Rita Swinford, Nephrology
NEW TEAM MEMBERS

Rosie Godfrey, LVN, joined the UT Mitochondrial Center of Excellence in February 2016. Rosie is crucial member of our team as she is on the front lines of our clinic, providing nursing care for our patients. When she is finished with her work day, Rosie enjoys movies, shopping, and anything and everything basketball. In fact, she is a basketball coach in her free time. Rosie is a delight to be around and her loving and compassionate heart is what makes her such a perfect addition to our team.

Grace Smith, LMSW, joined the team as a social worker in October 2015, where she fiercely advocates for every patient. She attended Texas A&M University for her undergraduate and the University of Houston for graduate school where she earned a Masters in Social Work. Grace is dedicated to ensuring that our patients have access to all the services and assistance necessary. During her free time, Grace enjoys baking and cake decorating. Grace’s passion for people makes her an essential asset to our team.

Sreejeta Dasgupta joined the UT Mitochondrial Center of Excellence’s research team in early 2016. Sree graduated from the University of North Texas with a Master’s in Biomedical Sciences. She is vital in the coordination of many clinical trials, patient communication, and study organization. During her free time, Sree enjoys spending time with her family both at home and on the road. Sree is a great addition to the UT Mitochondrial Center and we are happy she is a part of our team.

Parisa Mehrzad joined the research team in March. Since then, Parisa has been an integral part of the UT Mitochondrial Center of Excellence team. As a research coordinator, Parisa focuses her efforts on Leigh syndrome research. She graduated from the University of Houston with a Bachelor of Science in Biomedical Engineering. Originally from Iran, Parisa now lives with her husband and two children and enjoys baking and reading novels in her free time. Parisa’s drive for excellence challenges the entire team, keeping us motivated and progressive.

Meg Smith is the newest addition to the UT Mitochondrial Center of Excellence. Meg graduated from the University of Houston, Downtown with a Bachelor of Arts in Health Communication. She supports and organizes the day-to-day operations of the Center. Meg is a native Texan. Her favorite season is fall, and she enjoys cooking and traveling on her time off. We are so excited to have her as a part of our team.
MULTIDISCIPLINARY MEETINGS

At the heart of the success of the UT Mitochondrial Center of Excellence is the weekly multidisciplinary meetings. It is not uncommon for mitochondrial disease patients to see multiple subspecialists. 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 subspecialists on our team to discuss the medical concerns and treatment options of our patients. The team approach helps facilitate communication and encourages the formation of a comprehensive treatment plan for each individual patient.

CLINICAL TRIALS

We are pleased to be a host site for two clinical trials this year.

Reata Pharmaceuticals, Inc. is sponsoring the study, “RTA 408 Capsules in Patients with Mitochondrial Myopathies—MOTOR”. Available data suggests that RTA 408 can potentially improve muscle function, oxidative phosphorylation, antioxidant capacity, and mitochondrial biogenesis in patients with mitochondrial myopathies. We began enrolling patients at our site in 2015.

Ultragenyx Pharmaceuticals, Inc is sponsoring the study, “Phase 2 Study of Triheptanoin (UX007) for the Treatment of Glucose Transporter Type 1 Deficiency Syndrome (Glut 1 DS)”. Glut 1 is a neurometabolic disease that often causes seizures and other neurological concerns. We enrolled our last patient and completed this study this past year.

The UT Mitochondrial Center of Excellence has also teamed with Dr. Peter McGuire, from the National Institutes of Health, to enroll patients with inborn errors of metabolism in “The NIH MINI Study: Metabolism, Infection and Immunity in Inborn Errors of Metabolism”. This study aims to better understand how these disorders affect immune system function.

UT Mitochondrial Center of Excellence will have a big year in 2017. In addition to the trials listed here, we have many trials that are in the final stages of initiation. We are excited to share our research with you and to begin enrolling soon!
PUBLICATIONS

The UT Mitochondrial Center of Excellence works collaboratively with physicians and researchers around the world to publish information about mitochondrial disease. This year we have been involved in the publication of the following articles.


Mary Kay Koenig, MD; Lisa Emrick, MD; Amel Karaa, MD; Mark Korson, MD; Fernando Scaglia, MD; Sumit Parikh, MD; Amy Goldstein, MD. Recommendations for the Management of Stokelike Episodes in Patients with Mitochondrial Encephalomyopathy, Lactic Acidosis, and Stokelike Episodes. JAMA Neurology, May 2016.


Yu–Hsin Chao1, Laurie A. Robak, Fan Xia, Mary K. Koenig, Adekunle Adesina, Carlos A. Bacino, Fernando Scaglia, Hugo J. Benel, and Michael F. Wangler. Missense variants in the middle domain of DNM1L in cases of infantile encephalopathy alter peroxisomes and mitochondria when assayed in Drosophila. Human Molecular Genetics, May 2016.
The PALS Leigh Syndrome Registry is an international database of patients with Leigh syndrome. This project was developed by the UT Mitochondrial Center of Excellence, with the assistance and support of People Against Leigh Syndrome (PALS), the United Mitochondrial Disease Foundation (UMDF), and the Mitochondrial Medicine Society (MMS).

The registry launched in the summer of 2015 and has received overwhelming support from the mitochondrial community.

There are over 20 mitochondrial disease specialists and support organizations assisting with information dissemination and international recruitment. Support organizations include: People Against Leigh Syndrome (PALS), the United Mitochondrial Disease Foundation (UMDF), MitoAction, and the Mitochondrial Medicine Society (MMS). We have patients enrolled throughout the US, Japan, Canada, Europe, and Australia and our registry continuous to expand!

In uniting the medical and patient communities of Leigh syndrome, we gain vital information needed to develop a cure. Each participant who registers allows us to gather meaningful data which connects patients to clinical trials, distributes information to physicians, and brings awareness to Leigh syndrome.

As more individuals are diagnosed with Leigh syndrome, it is vital for clinicians and patients to promote global research.

The registry can be accessed from the People Against Leigh Syndrome website:

www.peopleagainstleighs.org

KADEN

Kaden is 4 years old and has a primary diagnosis of PIGN (multiple congenital anomalies, hypotonia, seizures) syndrome and secondary diagnosis of Leigh syndrome.

Throughout the first few months of Kaden’s life, his doctors and parents kept a close watch on him, as he was having some developmental issues. By the time he was 7 months old, Kaden was diagnosed with Leigh syndrome after a particularly aggressive seizure.

Life after the diagnosis was never the same. The plans that his parents had for him, the life they had dreamed about was severely altered. There was a certain fear that was a reality for his parents more than ever: that they might lose their child.

Currently, Kaden is stable and his household keeps a positive attitude. They take it one day at a time as they prepare for whatever might happen next.

Kaden’s parents want to acknowledge the reality of how full Kaden’s life is. Too many times people see him as a big infant. They wish that people knew how diverse his life experience truly is.

They encourage people to join the registry to help doctors and researchers learn more about the disease, in hopes to find a cure one day.
RECENT EVENTS

MITOCHONDRIAL DISEASE AWARENESS WEEK

Each September, we celebrate mitochondrial disease awareness week. UT Mitochondrial Center of Excellence hosted an awareness booth at Memorial Hermann Hospital. Upsher-Smith and GeneDx each sponsored a portion of the event. The UT Mitochondrial Center of Excellence staff handed out snacks, Mito Mike turtles, t-shirts, information brochures, and other goodies. Hospital employees and families had the opportunity to learn more about mitochondrial disease.

PUTT AN END TO MITO GOLF TOURNAMENT

The sixth annual Putt an End to Mito Golf Tournament was held in September at River Ridge Gold Club. 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 raffle items.

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.

This event has raised over $150,000 for the Center.

ENERGY FOR LIFE WALK

The UT Mitochondrial Center of Excellence participated in the 6th annual Energy for Life Walk to raise funds for the United Mitochondrial Disease Foundation (UMDF). The 5K walk was held in April at Discovery Green.
UMDF NATIONAL 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 traveled to Seattle, WA, to share our research and to learn from other top mitochondrial disease physicians and researchers. Dr. Mary Kay Koenig sat on a panel with the Mitochondrial Medicine Society to get patient input on the development of Mitochondrial Centers of Excellence. She also met with many families in the "Ask the Mito Doc" sessions. During the week, Dr. Koenig gave a presentation titled, "Where does dysautonomia fit in the mitochondrial disease patient?". The UT Mitochondrial Center clinical staff facilitated round table discussions with families.

Additionally, Dr. Nitish Chourasia and Dr. Koenig presented abstract posters:
- "Involvement of the cerebellum in Leigh syndrome"
- "A novel genetic mutation in NDUFS2 causing Idiopathic Parkinsonism/adult onset Leigh syndrome"
- "Organ Transplantation in Mitochondrial Disease: Proceed with Caution".

UMDF CENTRAL REGIONAL SYMPOSIUM

In February, the UT Mitochondrial Center of Excellence, along with Children’s Memorial Hermann Hospital, hosted the UMDF Central Regional Symposium at Hotel Zaaz in Houston, Texas. Together with Dr. Fernando Scaglia from Baylor College of Medicine, Dr. Amel Karray from Massachusetts General Hospital, and Dr. Bruce Cohen from Akron Children’s Hospital, Dr. Mary Kay Koenig led discussions on a variety of topics related to mitochondrial disease. The first day of the two-day event featured clinical sessions to educate medical professionals on the basics of mitochondrial disease. The second day focused on patient and family sessions where they were informed of what to expect with mitochondrial disease and current therapies and treatment options. Towards the end of the event, Dr. Richard Haas from UC San Diego and Dr. Amy Goldstein from Children’s Hospital of Pittsburgh joined the other doctors for an intimate question and answer session with affected families.
UPCOMING EVENTS

FANTASY FLIGHT TO THE NORTH POLE

You are cordially invited to take flight in the annual United Airlines “Fantasy Flight” to the North Pole

December 3, 2016

Please R.S.V.P. to Jody Cope (jody.cope@united.com) Space is limited, serving first 50 patients (+ 2 guests)

Please make sure to read the handout so that you are aware of the details about the event. Deadline is 11/29/16

Please remember that there are only 50 slots available, if your child has already participated, please be considerate to others who have not yet had the chance.

Happy Holidays

From all of us at the UT Mitochondrial Center of Excellence, to you and yours, we hope you have a wonderful and enjoyable holiday season.