

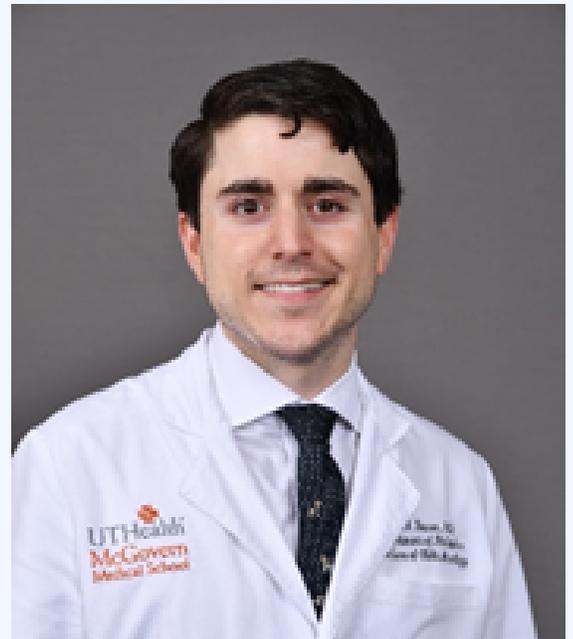
FIRST ANNUAL NEWSLETTER



The Center for the Treatment of Pediatric Neurodegenerative Disease (CTPND), formerly UT Mitochondrial Center of Excellence, received its official Center designation in the Fall of 2020. Since the establishment of UT Mitochondrial Center of Excellence in 2007, the program has grown to include other subspecialties, including Movement Disorders, and our Clinical Research Program has undergone exponential expansion. CTPND is the umbrella descriptor for all that we do, including, but not limited to: Leigh clinic, Mitochondrial Disease Clinic, Ataxia-Telangiectasia Clinic, and Clinical Research.

WELCOME DR. S. NICK RUSSO

This year, the most notable change in staffing was the addition of Dr. S. Nick Russo to our faculty in July 2021. One of our former Chief Residents of the Child & Adolescent Neurology Residency Program at UTHealth, Dr. Russo began shadowing/studying in our Center a year prior to his graduation. He is a Texas Medical Board-approved (Faculty) Fellow in Neurometabolics and Neurogenetics, a newly-established fellowship intended to aid in the expansion of treating these complex disorders from a neurological standpoint. He hit the ground running, with heavy clinical commitments, rotations on our consult service for the hospital, and a thirst for clinical research. (He serves as Principal Investigator, “PI”, of 4 studies.)



DEVELOPMENT OF A DIVISION RESEARCH INITIATIVE

OPPORTUNITIES TAKEN BY OUR STAFF

Dr. Koenig met with Dr. Von Allmen, Division Chief of Child & Adolescent Neurology, to discuss the development of a Division Research initiative. As Director of Research for the Division, Dr. Koenig is encouraging research amongst our academic child neurologists, by offering support of CTPND staff to advance their efforts. Our Center has supported clinical research studies from five new PIs over the past year!

In March of 2021, CTPND research nurse, Lindsey B. Miller, LVN, received a communication regarding an opportunity from the National Multiple Sclerosis Society. In support of National MS Awareness Week, and backed by the KPMG Family for Literacy, a fund of the KPMG U.S. Foundation, CTPND was sent an e-gift certificate for \$300 to purchase books for our clinical and research patients. These books are provided to patients while they are waiting to see the doctors in clinic, or while awaiting treatment in our Research Center. Thank you to Lindsey for coordinating this opportunity, for our patients!

In November 2021, CTPND Social Worker, Patricia Arnold, LCSW, MSW, in collaboration with Antionnette Bowers-Whitaker, LMSW for CHOSEN clinic, submitted a proposal for the 2022 Anne R. Wilford Endowment funding cycle. Awards will be announced beginning December 31, 2021. Good luck Patricia!

Anyone wanting to support these or other CTPND efforts can do so by clicking on

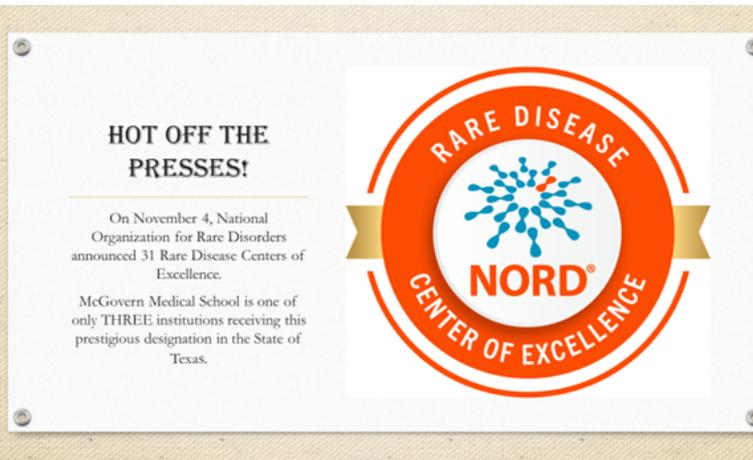
[Donate to CTPND](#)

EVOLUTION OF THE CENTER

by: Lindsey Miller, LVN

I recently entered my third year of working with Dr. Koenig as a research nurse. When I started out, we were simply known as the "Mitochondrial Center of Excellence." We took up 5 offices on the 7th floor of UT Professional Building and had to conduct research visits in a single room in the 5th floor clinic. Now, we are an entire Center dedicated to the clinical care and research of patients with neurodegenerative diseases. (Try saying that 3 times-fast!) With our upgraded Center designation, we have also moved into our own office suite with 3 dedicated research treatment rooms for patient visits.

Three years ago, we had maybe a handful of clinical research studies. To date, we have approximately 25 active research studies, with another handful in the works. We have gone from having one Principal Investigator (Dr. Koenig), to adding another, Dr. Russo, as well as assisting four other PIs by providing Center space and research personnel. In the month of October 2021, we conducted 20 research visits in our Center. With the new year, we are looking to average the same number of visits per month.



In a medical team like ours, that is engaged in clinical practice, provides consult service to a hospital system, and runs clinical research trials, work in our office has light moments, but also has some very intense moments as well. In November, all of our members (with exception of our valued research nurse, Lindsey) gathered for a light-hearted gathering outside of work, our first since 2018. Thankful for this team, who brings their best to the table each and every day, to help our patients and advance medical science.

#CTPND #UTHEALTH

HOW TELEMEDICINE HAS CHANGED CLINICAL PRACTICE: A NURSE'S PERSPECTIVE

PHYSICAL THERAPIST IN THE LEIGH CLINIC

by: *Lakeesha Minor, RN, BSN*

Everyone who knows me knows that I love my patients and that I am a “touchy feely” kind of nurse. Seeing patients in person in clinic, hugging and touching them is always the joy of my day. During the COVID-19 pandemic, the use of telehealth became a global necessity, and although its overall benefits, in terms of access, convenience, and cost, are undeniable, an overlooked downside of the growing reliance on telehealth caused a change in nurse care. So much of clinic nursing is done by phone, and integrating telehealth into practice has had the potential to change the type of patient care clinical nurses provide.

I have always felt that TOUCH is crucial. It brings humanity and compassion to nursing care, improving the patient care experience. So much of clinic nursing and what I do is now conducted by phone. With the integration of telehealth into practice, I believe that some of the therapeutic connections with my patients, which are primarily accomplished during in-person clinical visits, may have been lost. As regular visits slowly increase, and the pandemic continues to evolve, I look forward to a time when I can safely hug my patients again.



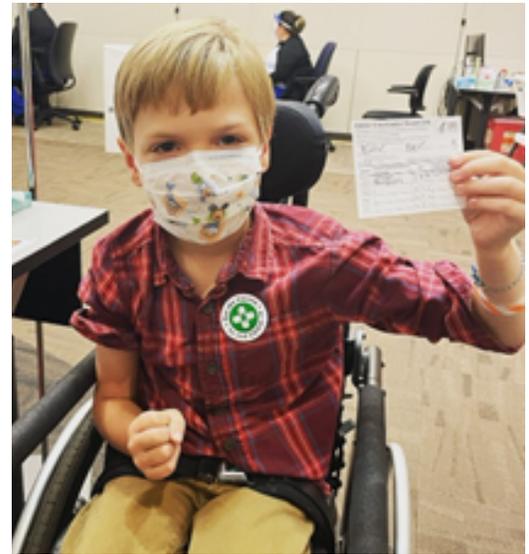
The second quarter of 2021 came the introduction of a Board-certified Clinical Specialist in Pediatric Physical Therapy to the Leigh Clinic, which was made possible by a philanthropic donation from PALS (People Against Leigh Syndrome).

Dr. Emily Furl described a first-time physical therapy consultation at Leigh Clinic: "A first-time physical therapy consultation in the Leigh Clinic typically starts with introducing myself and my consultative role to patients and their families. Typically, I proceed by asking if the child is receiving therapy services. If the child does not receive therapy services I brainstorm with parents to determine options that would allow them to obtain therapy services. I then provide a recommendation to the patient/family and Dr. Koenig. Furthermore, if a patient is utilizing a wheelchair, I am able to assess the fit of the wheelchair and make recommendations for referral to DME company for wheelchair growth or referral to wheelchair clinic for modification and/or new seating as needed. I also discuss other equipment and bracing needs with the patient/family and make recommendations for referrals as indicated."

IMPORTANCE OF COVID VACCINE FOR OUR PATIENT POPULATION AND THEIR FAMILIES

by: Dr. Mary Kay Koenig

I highly recommend vaccinations and boosters for all of my eligible patients (anyone over the age of 5 years). For many of my patients, their condition places them at higher risk for complications from COVID than the general population; therefore the risk of any short or long-term complications from the vaccine itself is negligible compared to risk of infection with COVID. The delta variant has hit young people much harder than the original form of the virus, which continues to mutate. Additionally, there remains considerable uncertainty surrounding the impact of the new omicron variant. The vaccine provides protection from hospitalization and need for ICU admission for those who have received it, including high-risk patients and patients who have previously had COVID. Here at the CTPND, we urge all of our patients, along with their family members, to either get vaccinated or receive a booster as soon as they are eligible.



Blair, age 10

CLINICAL RESEARCH DURING A PANDEMIC

by: Lindsey Miller, LVN & Donovan Calvert

The biggest transition, when COVID-19 hit, was changing schedules, to minimize the number of subjects and staff in the office. We also created new standard operating procedures (SOPs) to ensure we were maintaining distance from others, became more strict with safety policies (wearing of personal protective equipment/PPE), and changed how patient visits were conducted. Since we see patients from all over the world, we created a SOP specifically for patients crossing state and international borders, which was also adopted by the Department of Pediatrics.

The most difficult change for the patients was they were no longer able to have any guests with them (other than pediatric and disabled patients). We had to modify research visits, including condensing in-person visits, which were conducted while wearing layers of PPE. While PPE protected all involved, it creates a challenge to read both body language and facial expressions.

A big part of clinical research, especially with kids, is making the experience feel comfortable, while forming a relationship of trust in the researcher. Some visits occurred over the phone, which, unfortunately, can create a bit of a disconnect in even a well-established researcher/patient relationship.

During a months-long period of time, when sponsor/study representatives were not allowed onsite, customary research visits, such as study monitoring visits, site initiation visits, and other study-related activities were performed remotely, placing an undue burden on both site and sponsor.

As the pandemic evolved over the past two years, we now better understand how to protect all parties against COVID in our controlled setting. We see roughly 20 research patients per month, sponsors are now visiting our site again, and we are all adapting to what will be the “new normal” in clinical research.

THE SOCIAL WORK CORNER

by: *Patricia Arnold, MSW, LCSW*

Most of the times I've been delegated to a corner, it has meant I'm in trouble – so I'm thrilled that on this occasion, it means I get to share a bit about myself and what I do!

As the Social Worker here at the CTPND, my role is as varied as our patient population. One way I've found to describe it is to say that my efforts focus on how all the medical 'stuff' works with the rest of 'real' life. When I meet patients in person, I typically explain that I am there to help them and their families feel happy, healthy, and safe by connecting them with things that they need, either within our organization or community. It is my job to understand how and what it is for our patients and their loved ones to live with the multifaceted consequences of neurodegenerative disease, to anticipate and provide solutions for barriers they face, to process the inevitable difficulties inherent to the management of chronic health conditions, and to serve as a safe place for it all to land.

Modern medicine recognizes the trauma of interaction with healthcare systems and the fact that when you or a loved one have a complex healthcare need, you're subjected to the stressors of those systems more than most. For many of our patients, their treatment at the CTPND is only one part of a long, difficult, and confusing diagnostic odyssey. I am here to meet our patients (and their families) wherever they are along their healthcare journey, identify what (if anything) they may want or need to improve their wellbeing, and support them (and their loved ones) with any anything else that comes up on the way. The reality is, no one is supposed to already know how to deal with all that having a rare and/or complex health condition means, and most don't even consider it until they find themselves or someone they love amid that chaos. Quite understandably, most faced with the circumstances of neurodegenerative disease diagnosis do not have the motivation and/or resources to follow through with treatment recommendations, the emotional footing to stand and face mortality, or the confidence to be decisive in a place both demanding of response and lacking in answers; this place of uncertainty is my specialty, and I am trained to help navigate where all the medicine leaves off and the living begins.

If there is any part of life that you need help figuring out how to carry, please reach out to me and let's work through it together. It will never cost you anything but your time to speak with me, and the only limit to our confidentiality is safety. I know that living with the health conditions that bring you to the CTPND is a hard thing, and I also know that we can do hard things. I hope to be of assistance to you and your loved ones as you move forward into 2022.

With Care from the SW Corner,
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