

August 2024

Carol & James Herscot Center

NEWSLETTER

A Message from Carol Herscot

Welcome to the 2nd Carol and James Herscot Center for TSC Newsletter! Since our last edition, our new clinic space has opened and was designed with your comfort in mind. When you visit the clinic, you'll notice many butterflies. I love butterflies because they are a symbol for hope. .

Please continue reading to learn what else has been happening at the Herscot Center. Thank you.

Warmly,

Carol Jane Herscot

Carol Jane Herscot

This newsletter includes:

- i. Announcement: TSC fall conference
- ii. A highlight on our Psychiatrist: Dr. Doyle
- iii. An update on ongoing research
- iv. THRIVE Updates
- v. A chat with our Herscot Center Nephrologist: Dr. Paul
- vi. Helpful resources for our Families

Save the Date:

Virtual Fall Conference on TSC

We are very excited to announce that we will be hosting a virtual TSC conference this fall on **Saturday, October 5th from 1:00-3:00 pm.**

The conference will include several speakers from the MGH Herscot Center on the topic of TSC-Associated Neuropsychiatric Disorders, also known as TAND; our featured speaker will be Dr. Robert Doyle, the Herscot Center's Psychiatrist.

Please click on this link to register for this conference:

<https://because.massgeneral.org/event/2024-herscot-center-for-tsc-family-symposium/e591960>

A Highlight on Dr. Robert Doyle

Dr. Doyle has been supporting our Herscot Center families for the last few years. With a long career in psychiatry, he brings a wealth of knowledge and experience to our team. He first became interested in psychiatry while he was practicing general dentistry. The top-down approach to treatment is what drew him to psychiatry, as he noticed a lot of conditions where the body can be remedied by first addressing conditions of the mind. His favorite part of his profession is the reward of seeing a patient break through their psychiatric condition and return to a happy healthy life.

Dr. Doyle has a Masters of Arts in Humanities which he draws from when drafting creative treatments for patients. His diverse interests span various creative fields, including art, interior design, cooking, architecture and fashion.

Dr. Doyle began his psychiatry career primarily treating autism which often overlaps with TSC and epilepsy. Because many of our TSC patients also have autism, Dr. Doyle's prior experience made him a perfect fit with the Herscot Center. We are excited to have him as a member of our team, and looking forward to his talk at the fall conference!



Dr. Robert Doyle

Ongoing Research

In this edition of the newsletter, we will highlight three ongoing studies that feature the use of cannabidiol (CBD) across various indications. We also mention one upcoming study that we are looking forward to starting.

#1 Safety of Epidiolex among patients under 1 year of age (Epidiolex is currently approved for patients over 1 year.)

- This study is analyzing the safety of the use of cannabidiol for seizure control in patients under 1 years of age. This study is an open label add on.
- Once completed, this study will hopefully expand the usage of cannabidiol for newborns to infants with TSC requiring seizure control.

#2 Effect of Epidiolex on TAND

- This study is looking at the effects of cannabidiol on symptoms of TSC-associated neuropsychiatric disorders (TAND) for patients 1 to 65 who have seizures caused by TSC.
- This is the first-ever study utilizing a medication specifically to treat symptoms of TAND.
- If successful, this would be a breakthrough for TAND treatment and would pave the way for similar studies in the future.

#3 Liver function and health of patients who use Epidiolex

- This study is looking at liver function and health during cannabidiol use.
- This is to ensure it remains not only an effective treatment, but a safe one, especially for liver function.

#4 Effect of Low Glycemic Index Treatment (LGIT) on TAND

- This is an upcoming study looking at the effects of the low glycemic index treatment on symptoms of TAND.
- As mentioned in study #2, this will also be one of the first studies aiming to specifically relieve TAND symptoms.

THRIVE would love to hear from you!

THRIVE, Together Helping to Reach Individual Victories in Epilepsy, is as active as ever and working hard to provide support beyond the clinic setting to families that we follow all across New England and the United States and internationally. As you may know, the THRIVE program is an integral part of the Herscot Center and Pediatric Epilepsy Program, focused on promoting the social and emotional well-being of patients and families affected by TSC and epilepsy. THRIVE supports virtual groups for kids, teens, and adults, for example, one of our active groups is a parents of young children group.

We would love to hear back from you as to how we could best support you and your family through various groups. Please help us understand how we can best support you by sharing your thoughts and insights in a brief survey. Simply scan the QR code or click the link below to participate.

Two virtual group ideas we hope to start soon are:

- 1) a group for adults with TSC who are between the ages of 21-35 and are working professionals.
- 2) a group for parents of children with TSC and associated complex medical care needs.

Please scan this QR code or click the the link below to complete a quick survey for THRIVE.

[https://forms.office.com/r/CXRN
VwS60Q](https://forms.office.com/r/CXRNVwS60Q)



Exciting News: Phlebotomy Services Coming Soon to the Herscot Center!

We are thrilled to announce that the Herscot Center is working to provide onsite phlebotomy services. This service will make your visit to the Herscot Center faster and easier.

By bringing phlebotomy services directly to our clinic, we aim to:

- Reduce the need for additional appointments or visits to external laboratories.
- Minimize wait times and streamline the process of obtaining necessary blood work.
- Provide a more comfortable and familiar environment for you or your family member during the blood collection process.

Thank you for entrusting us with your care, and we look forward to offering this onsite service soon. We will keep you informed of this progress!



Pictured left to right is our dietician: Yingyi ‘Wing’ Zhong, PhD, LDN, RD and our nurses: Jan Paolini, RN and Erin Fonseca, RN

Provider Spotlight: Dr. Elahna Paul

The Herscot Center offers coordinated care from more than 46 specialists throughout the hospital to help treat the wide range of symptoms that TSC can cause. In each newsletter, we like to highlight one of our many specialists who serve our patient population.

This year, our Provider Spotlight is on Dr. Elahna Paul. Dr. Paul needs no introduction as many will have already worked with her during their TSC journeys. She is our Herscot Center Director of Kidney Care. Dr. Paul monitors kidney function and determines when medical intervention is necessary. Dr. Paul cares for both pediatric and adult patients, so TSC patients can be assured that they have an expert kidney care physician available to them at any point in their lifetime.

This unique aspect of the clinic allows Dr. Paul to develop strong relationships with patients, and craft unique long term care plans for each patient. Dr. Paul sees 60-80% of our patients at least once in their lifetime. Her favorite part of her job occurs when parents and patients are engaged in her work and she can teach them the science behind it.

In her spare time, Dr. Paul is an avid gardener and loves growing flowers from seed. Just like her patients, she has no favorites and loves them all equally. Recently, in her spare time she and her husband have been working their way through a Steven Spielberg movie marathon. Ask her about it the next time you see her.

We are more than grateful to have Dr. Paul as part of our team, and we hope you can appreciate her as much as we do!



Dr. Elahna Paul

Helpful Resources for Our Readers

Thank you so much for reading this edition of the TSC newsletter! We hope it was a fun, informative read. To finish off this edition, we have a number of resources our readers may find helpful, ranging from information on the transition to adulthood to TSC/epilepsy-friendly summer camps. We hope you will look forward to our next edition!

Summer Activities:

- Camp Triumph: “a therapeutic day camp for children and adolescents in Massachusetts. The camp program offers a supportive, encouraging environment designed to help campers increase their feelings of self-esteem and improve their social, physical, and psychological competence.”
- FCSN: “Federation for Children with Special Needs”
- Very Special Camps: “Summer Camps & Programs For Individuals With Special Needs”

Transitioning Into Adulthood:

- BCIL: “Boston Center for Independent Living”
- Tempo Young Adult Resource Center: “One stop resource center for Young Adults ages 17-24. Focus on achievement, employment, schooling, healthy relationships, and practical skills to reach future goals.”
- Commonwealth Corporation: “a state-funded youth employment program that helps teens and young adults develop the skills and experience needed to find and keep jobs.”

We Want to Hear from YOU!



What would you like to hear about in our next newsletter? Feel free to contact us!



Contact Us

MGH Carol & James Herscot Center for TSC
175 Cambridge St., Suite 340, Boston, MA 02114

Phone: 617-726-6540

Fax: 617-726-0230