

# NEUROLOGY AND RHEUMATOLOGY COMBINE TO OFFER UNIFIED CARE PLANS

## Creative Collaboration Improves Care for Rare Diseases

In 2012, a patient presented at Children's Mercy Kansas City with CNS sarcoidosis, a rare autoimmune disease seen primarily in adults. Her rheumatologist noted changes in the patient's spinal cord, so she contacted one of the neurologists at Children's Mercy. Together they met with the patient and devised a care plan that covered both the rheumatological and neurological aspects of the disease. This close collaboration created the genesis of the Neurology-Rheumatology Combined Clinic at Children's Mercy, which has since expanded to having 84 patient visits per year in a clinic that meets monthly.

### IMPROVING CARE THROUGH REAL-TIME COLLABORATION

The Neurology-Rheumatology Combined Clinic now includes three physicians: Tyler Allison, MD, neurologist; Cara Hoffart, DO, rheumatologist; and Julia Harris, MD, rheumatologist. Together they see a highly complex patient population with autoimmune conditions that affect the central nervous system (neuroimmune disease). With these rare pediatric diseases, the team is faced with a lack of data and trials to guide treatment plans. They often must extrapolate information from the adult literature and case reports and series. The team members combine their knowledge and provide care based on the most current evidence-based guidelines from each subspecialty.

On clinic days, patients are seen concurrently by a neurologist and rheumatologist. Each performs a thorough physical exam, and together they listen

to input from the patient. By the end of the visit, the team creates a unified plan of care. The parents and patients appreciate the combined visits, which minimize time and transport for the families. More importantly, the patients feel confident in the plan of care, having heard it from both the neurologist and rheumatologist at the same time. They also better understand the treatment rationale and are more engaged in the management of their own illnesses.

### SOME CONDITIONS TREATED IN THE CLINIC:

- Adenosine deaminase 2 (ADA2) deficiency
- Autoimmune ataxia
- Autoimmune encephalopathies/encephalitides including anti-NMDA receptor encephalitis
- Chronic inflammatory demyelinating polyneuropathy (CIDP)
- CNS lupus
- CNS sarcoidosis
- CNS vasculitis
- MOG-IgG-associated inflammatory disease
- Myasthenia gravis
- Neuromyelitis optica ± spectrum disorder
- Opsoclonus-myooclonus syndrome

### POOLING DATA ON RARE CONDITIONS VIA BRAINWORKS

BrainWorks, an international repository created at The Hospital for Sick Children, was established to improve the understanding of inflammatory diseases of the brain and spinal cord. This multisite consortium of

## POOLING DATA ON RARE CONDITIONS VIA BRAINWORKS

Continued from page 1 ▶

neuroimmunology patients provides an avenue for pediatric centers to pool data on rare diseases as a way to develop the most effective diagnostic and treatment approaches using evidence-based medicine.

Dr. Allison is the site principal investigator for BrainWorks for Children's Mercy. The team is a significant contributor to the registry due to the large volume of patients who meet criteria for inclusion in the database. The data they contribute will eventually help foster research that will lead to new guidelines and protocols for diagnosing and treating pediatric patients instead of extrapolating from adult patient data and case reports.

*the first stroke in a short period of time, but even after a significant work-up, the team was unable to find the underlying reason. A month later, the patient had a second stroke, which led to a brain biopsy diagnosis of primary CNS vasculitis. Dr. Harris and Dr. Allison worked together in the Neurology-Rheumatology Clinic to provide the patient with the best evidence-based treatments available, based on BrainWorks protocols. After several months of treatment, the patient relapsed, suffering a third stroke. While scant medical evidence existed to specify the next step in therapy, the team's ongoing collaboration in the Neurology-Rheumatology Clinic led to treatment options that have managed this rare disease for the past two to three years without any signs of relapse.*

## INCREASING CLINIC CAPACITY AND CAPABILITIES

For the first four years, clinic capacity was 24 visits per year. Today the clinic handles approximately 84 patient visits per year. Due to increased demand, plans are in place to expand appointment availability to be able to handle more than 120 patient visits per year. The team is also making plans to expand capabilities. For example, approximately 80% of clinic patients are living with a chronic illness, which can be difficult to process. Psychologists will soon be integrated into the clinic to provide mental health support, and discussions are underway to determine ways to provide strong psychosocial support to families.

## LEADERSHIP



**Tyler Allison, MD**  
Director,  
Neurology-Rheumatology Clinic  
tallison@cmh.edu  
(816) 302-3331



**Julia Harris, MD**  
jgharris@cmh.edu  
(816) 302-3686



**Cara Hoffart, DO**  
cmhoffart@cmh.edu  
(816) 302-3686

© Copyright 2020 The Children's Mercy Hospital

## PATIENT STORY

*When an 8-year-old child presented to Children's Mercy for a stroke, the care team was focused on identifying the underlying cause. The patient recovered well from*

*In academic affiliation with*



LEARN MORE ABOUT THE NEUROLOGY-RHEUMATOLOGY COMBINED CLINIC AT CHILDREN'S MERCY.  
[transformpediatrics.childrensmercy.org](http://transformpediatrics.childrensmercy.org)

For transport, admissions or consults, call:  
1 (800) GO MERCY / 1 (800) 466-3729



Summer 2020