



New Jersey Center for Tourette Syndrome
AND ASSOCIATED DISORDERS

*Collaborative Partnerships
for the Tourette Syndrome Community*

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Humanistic Medicine Symposium gets glimpse into NJCTS' patient-centered training program

Dr. Stuart Green and a New Jersey family affected by TS informed more than 100 healthcare professionals about the program

SUMMIT – When Dr. Stuart Green helped the New Jersey Center for Tourette Syndrome & Associated Disorders (NJCTS) develop its patient-centered training program two years ago, the idea was to provide a setting where physicians could deepen their understanding of the perspectives, stresses and needs of families living with Tourette Syndrome.

The program has been presented six times at five separate New Jersey hospitals and medical centers, and qualifies as a rousing success. And that was the reaction of the more than 100 doctors, physicians, nurses, social workers and other healthcare professionals who gathered May 3 at Overlook Medical Center for the third annual Atlantic Health Medicine Symposium.

Patient-centered training was in focus during the “Empowered Patient: Patient as Expert, Educator and Advocate” portion of the symposium and was led by Marc Brummer and Suzanne Klar, who are the parents of two sons with Tourette Syndrome.

In the patient-centered training approach, physicians play an active role in the learning process. A professional – in this case Dr. Green – with expertise in the recognition and treatment of Tourette facilitates the training. This professional works in collaboration with a teaching team consisting of TS patients and their families.



Photo by NJCTS

Suzanne Klar and Marc Brummer inform the more than 100 healthcare professionals at the third annual Atlantic Health Humanistic Medicine Symposium about their family's battle with Tourette Syndrome in a NJCTS patient-centered training presentation.

This team describes their personal experiences with Tourette Syndrome, focusing on initial diagnosis, quality of life and encounters with physicians and the health-care system. This patient-led process engages physicians to deepen their understanding and appreciation for the experiences of TS patients and their families. By sharing their perspectives, patients feel empowered and understood.

“It is just this approach that helped us to shepherd our sons from an especially rocky childhood to become the caring successful adults that they are today,” said Marc Brummer, who along with his wife, Suzanne, described the conditions their family has faced at home, school and within the community – focusing on initial diagnosis, quality of life in school, and encounters with physicians and the healthcare system.

Brummer and Klar’s oldest son, David, also has participated in the patient-centered training program – giving the program’s very first presentation almost two years ago at Overlook. The couple shared David’s story, which features bouts with learning difficulties, social anxiety, OCD, bullying and more.

“We were able to impress that TS is much more than just visual and audible tics. It can have an educational and psychological component,” said Brummer, who instructed the physicians present to “Pay attention to the patient and the family that this a disorder that truly affects the entire family. The more the medical community understands the medical and the personal aspects, the better the treatment will be.”

The ultimate goal in dealing with TS – especially with children going through their formative years, according to Klar – is to get them through with their self-esteem and confidence intact, in addition to getting them help for their symptoms. Dr. Green, who believes that in order for that to happen, patients need to take control of their care – with education being a key step in that process – echoed those sentiments.

“With patient-centered care, we envision a future where patients have an ownership stake in their health care. We’re not there yet,” he said. “Most of the work in managing care needs to be done by patients when they are not in our facilities, and I believe that as professionals, our only chance of reaching the heights we aspire to reach lies in meeting the rising expectations of patients.”

More information about the patient-centered training program – which also has taken place at Saint Peter’s University Hospital in New Brunswick, Jersey Shore Medical Center in Neptune, Robert Wood Johnson University Hospital in New Brunswick and Goryeb Children’s Hospital in Morristown – is available by visiting www.njcts.org or by calling 908-575-7350.

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