Pediatric Epilepsy Support Group presents:

2018 Pediatric Epilepsy Surgery Family Reunion:

And Life Goes On!

The Seventh Biennial Reunion for Cleveland Clinic’s Patients and Families

July 27–28, 2018
Embassy Suites Cleveland – Rockside, Independence, Ohio
A Message from the Reunion Directors

It is time for our 7th Biennial Pediatric Epilepsy Reunion, taking place July 27-28, 2018. Following our tradition to gather during the summer school break, we hope that many of you are able to join us to celebrate the successes and accomplishments of the patients and their family members of our surgery program.

As always, the Reunion is a chance to share many accomplishments:

- Our pediatric epilepsy surgery program continues to improve the lives of many children who suffer from epilepsy and the lives of their relatives. But we could not do that without the contribution of many, including the parent ambassadors who are always there to support the families in the hospital and during the complex epilepsy surgery decision making process. THANK YOU to our Parent Ambassadors for all the good work and support given so generously to our patients.

- This year we are adding two exciting workshops to our program. One is dedicated to patients who have had a vagus nerve stimulation (VNS) implanted for the control of the seizures. This program will provide the unique opportunity for the caregivers of children with VNS to share their experience with a team of neuro-stimulation experts. The second workshop will be dedicated to young adults who experienced epilepsy surgery as a child. This workshop will be led by the new generation of epileptologists at the Cleveland Clinic Epilepsy Center. Discussion topics include life as young adults after epilepsy surgery and the challenges surrounding education, employment, dating, and transitioning into adulthood.

- In 2018, Cleveland Clinic welcomed a new President and CEO, Dr. Tomislav Mihaljevic. A moving video of the Sakai family’s epilepsy journey was shown during his first State-of-the-Clinic Address on February 28, 2018. The video highlights their struggle in trying to control seizures that led to a successful epilepsy surgery. The video also highlights teamwork. Cleveland Clinic caregivers, led by Dr. Elaine Wyllie and Dr. William Bingaman, confirm that “it takes a village” to improve the lives of our children with any chronic medical condition.
• Cleveland Clinic has 40 years of experience in treating the most difficult pediatric epilepsy cases. The medical program, led by Dr. Ajay Gupta, treats patients from all over the world. But we cannot accomplish the goal of providing care for the children in need without the collaboration of the surgeons:

• Dr. William Bingaman continues to lead our surgical program, having treated adult and pediatric epilepsy surgery patients for 21 years; performing over 1800 pediatric surgeries. He remains one of the busiest epilepsy surgeons in the world. He is well known for his expertise in the surgical treatment of hemispheric epilepsy. He is annually recognized as a Best Doctor and one of America's Top Surgeons.

• In 2017, the Epilepsy Association awarded the Legacy Award to one of our own, Dr. Jorge Gonzalez-Martinez, who has been at the Cleveland Clinic since 2008. He has touched the lives of many children with his innovative approach to neurosurgery.

• For those who are not candidates for epilepsy surgery, the pediatric epilepsy physicians offer alternative treatments such as the ketogenic diet. The ketogenic diet clinic, led by Dr. Ahsan Naduvil, has provided treatment to more than 30 children with epilepsy. Also, we continue to offer specialized care to children with Tuberous Sclerosis and CDKL5 gene deficiency.

• Educating those who treat patients is one of the four pillars of the Cleveland Clinic. Dr. Ajay Gupta will again lead the “Cleveland Clinic Epilepsy Update and Review” course taking place from September 22-24, 2018, in Cleveland. Year after year, this annual course attracts over 100 physicians from around the world. Dr. Elaine Wyllie, who has been working with epilepsy patients since 1985, is working on the 6th Edition of her book The Treatment of Epilepsy, long considered the “go-to” book for epileptologists.
2016 Reunion Highlights

In July 2016, 30 families from across the United States gathered in Cleveland to share their life experiences after epilepsy surgery.

Some of them were a few months out from surgery while others had years of journey behind them. They all brought a cheerful outlook for the future while remembering sobering moments from their previous challenges with seizures. The wealth of personal experiences set the stage for a remarkable learning experience for the attendees. Just like every reunion, the faculty of physicians and other experts facilitated stimulating discussions and a rehabilitation exposition for the families. The young attendees had fun engaging in age-specific supervised activities.

We have put considerable thought behind an exciting program for 2018. It brings back the new format for the morning session based on our experience with six memorable reunions of the past and valuable feedback from the participants.

www.ccfcme.org/epilepsyreunion18
Rehab Expo and Community Support

Following epilepsy surgery, a patient faces numerous challenges which may require additional support such as therapy or psychological services. The rehabilitation expo will allow families and friends of those individuals to listen and interact with professionals in various fields to support the process of regaining life outside of the hospital. Multiple topics, including the school re-entry process, orthotics and splints, behavior management, constraint-induced movement therapy and other pertinent topics will be addressed. Community service representatives from the Epilepsy Association, Make-A-Wish, and Empowering Epilepsy will be present to discuss with you ways in which the community help children with epilepsy and their families to achieve the best quality of life.

Art Therapy and Mural “Life After Epilepsy Surgery”

A special art therapy session will be dedicated to create a mural with the topic “Life After Epilepsy Surgery.” Children who had epilepsy surgery, their siblings and caregivers are all invited to participate and share their experience via art creation, a form of expression that will also help you to release stress.
2018 Program Session Descriptions

Based on the overwhelmingly positive feedback from the 2016 reunion, parallel workshops will be offered again, with each being repeated during the second half of the morning session. The informal, yet stimulating, sessions offer a platform for vital information exchange for parents and other family members.

Workshop #1:
Parents Decision Making/ Rehabilitation and Back to School
In this workshop, our panel of experts will discuss postsurgical issues such as medications after epilepsy, seizures recurrence and short-term and long-term expectations including motor weakness, sensory rehabilitation and schooling.

Workshop #2:
Hemispherectomy & Focal Resection: Mental Health in Children with Epilepsy
Our team of neurosurgeons, child psychiatrists, psychologists, social workers and parents of our support group will discuss the diagnosis and management of important medical comorbidities such as anxiety, depression, ADHD and various socialization problems including autism. They will also answer your questions about treatment alternatives of behavioral problems and ways to involve the entire family.

Workshop #3:
Vagus Nerve Stimulator: Life After Neurostimulation – The Family Experience
This session is for family members of patients that have had a vagus nerve stimulator (VNS) implanted to control seizures. It is a unique opportunity for caregivers to share their experience with a team of neuro-stimulation experts.

Workshop #4:
Life After Childhood Epilepsy Surgery: The Experience of Young Adults and Teenagers
This session is for young adults who experienced epilepsy surgery as a child. The workshop will be led by the epileptologists from the Cleveland Clinic Epilepsy Center. Discussion topics include life as young adults after epilepsy surgery and the challenges surrounding education, employment, dating and transitioning into adulthood.

Youth Group Session for Siblings
When a brother or sister has epilepsy, siblings may experience many unique and different feelings. Our youth group sessions for siblings have been extremely well received at each reunion. This session will engage siblings from age 11 years and older.
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Friday, July 27, 2018

4:00-6:00 pm  Registration
6:00-8:00 pm  Welcome Dinner/Reception – Ajay Gupta and Elaine Wyllie
7:30-8:00 pm  Testimonial from patients and families who have had epilepsy surgery
   Moderators: Prakash Kotagal, William Bingaman and Jorge Gonzalez-Martinez

Saturday, July 28, 2018

7:45-8:30 am  Breakfast
8:30-9:00 am  Opening Remarks – Prakash Kotagal, Deepak Lachhwani
9:00-12:30 pm  Kids Activities: Dance, Yoga, Bubble Creations
   Workshops with Panel Discussions (Each Workshop Offered Twice)

   Workshop #1: Parents Decision Making/Rehabilitation and Back to School
   Moderators: Deepak Lachhwani, Ahsan Moosa Naduvil Valappil, Lara Jehi,
   Doug Henry, Patricia Klaas, and Marie DeLord

   Workshop #2: Hemispherectomy & Focal Resection: Mental Health in Children with Epilepsy
   Moderators: Tatiana Falcone and Team IMPACTT, William Bingaman,
   Ajay Gupta, Elaine Wyllie and PESG Ambassadors

   Workshop #3: Vagus Nerve Stimulator: Life After Neurostimulation – The Family Experience
   Moderators: Prakash Kotagal and Dileep Nair

   Workshop #4: Life After Childhood Epilepsy Surgery: The Experience of Young Adults and Teenagers
   Moderators: Jessica Fesler and Vineet Punia

10:30-11:00 am  Break
11:00 am-12:30 pm  Youth Group Sessions For Siblings – Samantha Juhn and Elia Pestana Knight
11:00 am-12:30 pm  Games and Art Therapy for Teenagers and Young Adults
   Moderator: Tamara Shella (Sponsored by the Art and Medicine Institute and Child Life)
12:30-2:00 pm  Lunch
2:00-4:00 pm  Rehab and Community Support Expo, Art Therapy and Mural Exhibit Tables
   • School re-entry
   • Vision/Behavioral Optometry
   • Orthotics
   • Augmentative Communication
   • Equine Therapy
   • Constraint Induced Movement Therapy
   • Adapted Aquatics

4:00 pm  Adjourn
General Information

- When families check in on July 27 at the Reunion Registration Desk, they will receive a folder with details of all the activities taking place on July 27 & 28, including handouts from the guest speakers and Rehabilitation Resources Exposition.
- Child care and sponsored activities for our young guests and participants will only be provided during the morning conference sessions. Drop off begins at 8:30am on Saturday, July 28.
- In the event of a medical emergency, a designated family member will be called out of the conference. Please have any personal medications available to be used if needed.
- Sponsored meals include: Welcome Dinner Reception (July 27), Breakfast, Lunch and Breaks (July 28).
- Expected personal expenses will include registration fees, hotel room charges and taxes at applicable discounted rates, meals outside the conference, and additional travel expenses as per personal preference.
- To ensure safety, access to the hotel pool will be prohibited during the reunion.
- Coordinated post-operative appointments will be offered Wednesday through Friday prior to the event, and Monday through Wednesday afterward. Appointments may be made upon individual request, but certain time and scheduling limitations will apply.

Contact Us

For more information about the reunion, please contact us by phone at 216.445.6739 or email at pediatricepilepsysupport@ccf.org.

Learning Objectives

1. Discuss the various circumstances that require the continuation of medication after surgery
2. Review long-term post surgical complications
3. Describe potential physical and sensory challenges after surgery
4. Discuss life changes after surgery for the patient and family members

Registration

Pre-registration is required. Pre-registrations are accepted until 5:00 pm ET, Tuesday, July 24, 2018. After Tuesday, July 24, please contact Shana Spade at 216.444.9380 or spades@ccf.org.
Co-Directors

Elia Pestana Knight, MD  
Staff, Pediatric Epilepsy

William Bingaman, MD  
Vice Chairman, Neurological Institute

Jorge Gonzalez-Martinez, MD  
Neurosurgeon, Epilepsy Center

Deepak Lachhwani, MD  
Staff, Pediatric Epilepsy

Cleveland Clinic Faculty

Marie DeLord  
PESG Patient Ambassador

Tatiana Falcone, MD  
Child and Adolescent Psychiatry  
Staff, Epilepsy Center

Jessica Fesler, MD  
Staff, Epilepsy Center

Nancy Geschke  
PESG Parent Ambassador

Ajay Gupta, MD  
Staff, Epilepsy Center

Doug Henry, MD  
Director of Therapy Services at Children’s Hospital  
Children’s Rehabilitation

Lara Jehi, MD  
Staff, Epilepsy Center

Samantha Juhn, LSW  
Epilepsy Center

Patricia Klaas, PhD  
Pediatric Neuropsychology

Prakash Kotagal, MD  
Staff, Pediatric Epilepsy

Dileep Nair, MD  
Staff, Epilepsy Center

Dana Osborne  
PESG Parent Ambassador

Vineet Punia, MD  
Staff, Epilepsy Center

Tammy Shella, MA, ATR-BC  
Art Therapy Manager  
Arts & Medicine Institute

Ryan Suder, MS, OTR/L  
Children’s Rehabilitation

Kate Taricska, MA, ATR, LPC  
Art Therapist  
Arts & Medicine Institute

Ahsan Moosa Naduvil Valappil, MD  
Staff, Pediatric Epilepsy

Elaine Wyllie, MD  
Staff, Pediatric Epilepsy

Diane Zemba, BSN  
Research Coordinator, Epilepsy Center
Hotel Accommodations

Embassy Suites Hotel
5800 Rockside Woods Blvd.
Independence, OH 44131
1.216.986.9900

Room details:

• Discounted rate: $115.00 per night plus tax
• Bedroom and living room with pull-out couch, kitchenette with microwave and refrigerator.
• Some handicapped accessible rooms available.

• Room reservations will be the responsibility of each individual family.
• Contact Embassy Suites directly at 216.986.9900 to make your hotel reservation by June 27, to receive the special rate of $115 per night plus tax. Room rate cannot be guaranteed after June 27.
• Early check-in or late check-out is at the hotel’s discretion and must be arranged on an individual basis by each family desiring the request.
• Transportation to and from Cleveland Hopkins Airport is available from the hotel at no additional cost. Please contact the hotel for details and to make arrangements.
• Special accommodations:
  • Complimentary cooked-to-order breakfast in the main lobby
  • Complimentary manager’s cocktail reception after 5 p.m. – snacks and beverage
  • Indoor pool and fitness center. To ensure safety, access to the hotel pool will be prohibited during the reunion.

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Register at: www.ccfcme.org/epilepsyreunion18

Fee includes: Friday dinner, Saturday breakfast, lunch and afternoon refreshment break.

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For additional questions about the reunion, please call 216.445.7501.
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Cleveland Clinic’s Pediatric Epilepsy Support Group (PESG)
Email: pediatricepilepsysupport@ccf.org
Telephone: 216.445.9768/800.223.2273 x59768

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