

Angelman Syndrome Clinic At Kennedy Krieger Institute



Here's what's been happening— and what's to come!

Welcome to the inaugural edition of the quarterly Angelman Syndrome Clinic newsletter! We are thrilled to have the opportunity to connect with you through this new platform. It is a true honor for our clinic to be a part of your journey, and we are deeply grateful for the trust you place in us as we work alongside you in the care and support of individuals with Angelman syndrome.

This newsletter is a way for us to stay in touch, share updates and provide resources that can help enrich the lives of individuals and families in our community. As we look ahead, we are excited to launch new initiatives that will make information, education and resources more accessible in a variety of formats, tailored to your preferences and needs. We want to ensure that every family, regardless of circumstances, can easily find the support and guidance they need.

Our clinic is committed to being more than just a place of care. As such, we view this newsletter as a collaborative space for everyone to share insights, challenges and wins. Your feedback is invaluable to us, and we encourage you to share your thoughts and ideas for topics you'd like to see featured in future editions. This is your newsletter, and we want to make sure it serves you in the best way possible.

Thank you, once again, for allowing us to be part of your community. We look forward to continuing this journey together, learning from one another and building an even stronger, more connected support network.

Enjoy this month's newsletter!

With gratitude and excitement,

Wilfreda Lindsey, MD, MS

Medical Director,
Angelman Syndrome Clinic

IN THIS NEWSLETTER YOU CAN EXPECT:

**MEET THE
CLINIC STAFF – 1**

**COMMUNITY
NEWS – 4**

**UPCOMING
EVENTS – 4**

**DR. LINDSEY
SAYS – 5**

RESOURCES – 4

**CALL FOR QUESTIONS
AND FEEDBACK – 5**



MEET THE CLINIC STAFF!



Wilfreda Lindsey, MD

Dr. Lindsey is the clinic's developmental neurologist. She evaluates each new patient for common medical and neurodevelopmental symptoms associated with Angelman syndrome. She also performs a thorough neurological examination of each patient, looking for any subtle deficits. When necessary, she recommends brief developmental, cognitive or academic testing. Following the evaluation, she provides medical referrals and recommendations, as needed. Referrals may be for brain wave tests or EEGs (to look for signs of an increased risk for seizures), brain imaging, sleep studies, heart imaging (to assess heart functioning and structure) and further tests for the patient's primary care doctor to consider. She also provides recommendations for school and therapy, and referrals for a full neuropsychological or psychoeducational evaluation, if appropriate. Generally, Dr. Lindsey sees patients in the clinic on a semiannual-to-annual basis.



Jessica de Curtis Fernandez, MD

Dr. Fernandez is a pediatric physiatrist who specializes in evaluating functional abilities. In the clinic, she works with an interdisciplinary team to create an individualized treatment plan for each patient. She is interested in planning for a patient's medical care throughout their lifespan, and how that care may transition from one provider to another, as well as improving the quality of life and independence of patients of all ages. Treatment plans discussed during the visit may include options to enhance mobility, strength, coordination and overall functioning. This may involve prescribing physical, occupational and speech therapies. She also manages spasticity with medications, injections (e.g., botulinum toxin) or other therapies. She can recommend assistive devices like braces, walkers and wheelchairs. She works with each patient and their family and interdisciplinary team to improve participation in school, community and activities of daily living. Her overall goal is to help patients overcome any challenges they may be facing, and to be a source of support for all of her patients.



Margaret Tunney, PsyD

As the clinic's behavioral psychologist, Dr. Tunney is focused on helping patients achieve developmentally appropriate functioning, participate in therapies, engage in medical regimens, and optimize their quality of life. She conducts evaluations related to mood, behavior, psychosocial functioning, sleep and engagement in related cares and therapies. She also provides referrals and recommendations, as needed, for therapies, behavior management, school engagement and other areas of functioning.

MEET THE CLINIC STAFF!



Sara Rubovits, CGC

As the clinic's genetic counselor, Sara Rubovits gathers family history information, orders genetic testing, interprets the testing results and counsels patients and families on what those results mean. Her primary role is helping patients understand and adapt to the medical, psychological and familial implications of the genetic components of Angelman syndrome. She directs patients and families to supportive resources and provides referrals to other genetics specialties, such as reproductive genetic counseling, if needed. She generally sees all new patients in the Angelman syndrome clinic and follows up with patients as needed.



Kyra Skoog, SLP

Kyra Skoog, the clinic's speech pathologist, assesses patients' communication and feeding skills and makes recommendations for families and caregivers to share with schools and other providers. She determines the most appropriate communication tools to meet each patient's needs while taking into consideration the goals of each family. Kyra works with the clinic team to determine if a patient requires additional referrals to specialty providers, such as assistive technologists, nutritionists and occupational therapists.



Darian Claypool, MSN, RN, CPN and Kim Hollandsworth, BSN, RN

As nurse coordinators for the clinic, Darian Claypool and Kim Hollandsworth facilitate communication between families and clinic providers. They assist with intake procedures before patients' appointments, and they provide each patient and their family members with all of the documentation they need at the end of each visit. They are great resources for locating educational materials on Angelman syndrome and related medications.



Angela Tanner

Clinic coordinator Angela Tanner serves as the first point of contact for new patients and their families, managing appointments, scheduling and gathering necessary documentation and medical records. She plays a key role in coordinating patient care, acting as a liaison between patients and the medical team. She also oversees the daily operations of the clinic, ensuring a smooth workflow to improve patient care and overall clinic efficiency.

COMMUNITY NEWS



The second annual Angelman Syndrome Congressional Advocacy Day occurred on March 4 and 5, 2025, in Washington, D.C. This event was hosted jointly between the Angelman Syndrome Foundation and the Foundation for Angelman Syndrome Therapeutics and was open to parents, caregivers, grandparents and friends of individuals living with Angelman syndrome who seek to inform Congressional leaders and staffers about Angelman syndrome and the importance of Angelman syndrome research.

Participants received advocacy training on the evening of March 4, then met with legislators and their staff members on Capitol Hill the next day, educating them about Angelman syndrome and the effect that an accessible treatment will have. Participants also advocated for support to help bring forth meaningful therapeutics for individuals with Angelman syndrome.



ASF Baltimore City Walk

For over 25 years, Angelman Syndrome Foundation (ASF) walks have united and empowered the Angelman syndrome community, building an incredible network of support. Angelman Strong is a new initiative designed to grow and strengthen support for our loved ones with Angelman syndrome. The details of the Baltimore City Walk are below:

Saturday, May 17, 2025

Canton Waterfront Park
3001 Boston St
Baltimore, MD

Coordinator: Danielle Rigby
asfwalkbaltimore@gmail.com



ASF Research Symposium

The annual research symposium is a chance for leading researchers, scientists and doctors to discuss the latest research in the world of Angelman syndrome.

July 21 - 23, 2025

Sheraton Keystone
8787 Keystone Crossing
Indianapolis, IN

Registration Fees

In-person attendees: \$150
Students: \$100
Virtual attendees: \$75
Fees increase by \$25 on May 3.

DR. LINDSEY SAYS...



Seizures are a common symptom in patients with Angelman syndrome, with a prevalence of about 90%. Seizures typically begin when patients are between 18 and 36 months old. Many times, seizures occur for the first time in the setting of fever or illness.

Though “drop seizures,” also known as atonic seizures or generalized tonic clonic seizures, are often the first seizure type, patients with Angelman syndrome can present with any type of seizure. While a fraction of patients are seen by a specialist with expertise in the disorder, many do not have that privilege.

Here are some key facts to share with any doctors treating your child, including their primary neurologist:

- Levetiracetam (Keppra) or clobazam (Onfi) should be considered as a first-line therapy. The low-glycemic index (LGI) diet can be considered first-line as well.
 - Levetiracetam may cause increased irritability.
 - Higher doses of clobazam may negatively affect alertness, drooling and balance.
- All patients with Angelman syndrome should be provided with a prescription for seizure rescue medications after their first seizure.
- Sodium channel blockers—drugs such as phenytoin, carbamazepine and oxcarbazepine—can worsen seizures.
- There is an increased risk of nonconvulsive status epilepticus in individuals with Angelman syndrome.

We'd Love to Hear from You!

Your thoughts and feedback are important to us. If you have any suggestions on how we can improve, topics you'd like to see covered, or questions you'd like answered, please let us know! Additionally, if you have any experiences, tips or stories you'd like to share, we'd love to feature your contributions in upcoming newsletters.

How to Share Your Feedback or Contributions:

Reply directly to this newsletter.

Contact us via email, phone or fax.

[Join Angelman Strong Baltimore](#) on Facebook.

We look forward to hearing from you!

Thank You For Reading!



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