

Fall Newsletter | 2021

Specialized Services & Support

We Found Easterseals

Meg Navolio grew up within five miles of Easterseals, but had never heard of the organization until the summer of 2020. This is her story:

On June 29, 2020, our son, Nolan was born. Right away we knew something was special about Nolan. Two weeks into his NICU stay we got an answer to what was causing the low muscle tone, sleepiness and feeding issues - Prader Willi Syndrome. Prader Willi Syndrome is a rare disease affecting 1 in 15,000 births. Prader Willi Syndrome includes symptoms such as low muscle tone, developmental delays and later on hyperphagia – the feeling of always being hungry.

"...he's come so far, and his team at Easterseals has been there each step of the way, coaching, encouraging, supporting him and our family." This diagnosis brought grief for many expectations and hopes we had for our son and our family. It also brought some answers, many more questions and the support of communities we previously never knew existed. From the first evaluation meeting at Easterseals, I felt like this place was special. The pictures of other beautiful, smiling, unique children decorated the walls*, Celine and Connie, our physical therapist and speech therapist, spoke with such expertise and the parent liaison, Sharon, offered comfort as someone who had been on this journey with her now grown daughter.

In the months that followed, Connie continued to help us navigate life with a feeding tube and worked towards a life without it. Celine used her capable hands to help Nolan get stronger and also served as emotional support to this often overwhelmed and stressed out mom. Our team shared their knowledge with us and they were open to the information we shared about Prader Willi Syndrome.

We reflected back on all Nolan has already accomplished in the past year getting rid of a heart and sleep apnea monitor, getting his g-tube removed, having corrective eye surgery, doing great at tummy time, rolling over, sitting up and working on table foods. He still has a long way to go, but he's come so far, and his team at Easterseals has been there each step of the way, coaching, encouraging, supporting him and our family.

This is a special place for special kids. This is a community that has given us hope. So to all those on this challenging, unique journey – look around at these beautiful babies, kids, young adults and know there will be HOPE and there will be JOY!



Nolan Navolio served as the 18th Annual Run for the Kids ambassador at the October 2 event. His mom, Meg, captained their team, "Nolan's Champions" and shared their experience (excerpted here) with those who came out to run, walk, roll and volunteer that day.



*Nolan's photo was unveiled as part of the 22nd Annual Photography Exhibition in partnership with College of DuPage's Photography Department. Eighteen new photos were revealed virtually and at a small reception at Elmhurst Art Museum. These photos reflect the personality and spirit of the children we serve, and line the halls at each of our Easterseals centers.



More than one in 37 children under the age of five, and more than one in five children with a chronic disease experience severe pediatric feeding disorders (PFD) in the United States each year.

The Feeding Clinic at Easterseals DuPage & Fox Valley is equipped to help children and their families overcome feeding challenges.



© Rich Howe Photography

Jill Zmaczynski shares, "My daughter, Sarah, relies on her wheelchair to get around. We received her current power chair through the seating clinic at Easterseals. Now Sarah can chase her brother and play freeze tag with kids in the neighborhood."

Expanding Social Services

Joining our team is Licensed Clinical Social Worker, Brittany Wilke, as Director of Social Services, and bilingual Psychologist, Citlaly Gonzalez. Our commitment to social work services has only increased during the pandemic as has the need for counseling and support for families.

Brittany's interests in Trauma-Informed Care and the Developmental, Individual Difference, Relationship-based (DIR) model, along with Citlaly's expertise in developmental disabilities, particularly autism, add to our comprehensive social services for children and their families.

Welcome to our new team members! Contact them at socialservices@eastersealsdfvr.org.





Citlaly Gonzalez

Specialized Clinics Keep Kids Healthy

Sharing Feeding Expertise

For more than 22 years, our multidisciplinary Feeding Clinic has been a valuable community resource for thousands of children. Now collaborating with pediatric gastroenterologists, Dr. Timothy Sentongo and Dr. Ritu Verma from the University of Chicago Medicine, the clinic has weekly opportunities for medical and therapeutic focused feeding interventions. The doctors join a team of Easterseals therapists made up of a Pediatric Licensed Dietitian/Nutritionist, Speech-Language Pathologist and Occupational Therapist.

For many children with disabilities, Pediatric Feeding Disorder (PFD) is a common diagnosis. It is more complex than "picky eating" behaviors and requires clinical care and specialized knowledge that can be found through the Easterseals Feeding Clinic. The team has been evaluating medical, nutrition, feeding skills and psychosocial needs for decades.

The clinic is known for the collaborative, personalized and compassionate approach to treating feeding challenges. Sudden weight loss or gain, feeding tube transitions, GE reflux, constipation or other issues that can be vexing for families. The team's care and knowledge improves mealtime, nutrition, and gastrointestinal function. Caregivers leave that same day with plans to begin achieving their child's goals with individually-tailored therapy.

To learn more about our Feeding Clinic, contact the clinical admissions coordinator, Mary Beth Scholtes, at mscholtes@eastersealsdfvr.org.

Supporting Proper Mobility & Development

The Positioning and Mobility Clinic team provides evaluation and fittings of adaptive equipment. This comprehensive clinic collaborates with vendors National Seating & Mobility and Numotion to find solutions that meet the needs of each child and family.

Adaptive seating systems were a high priority during the stay-at-home order as children grew and required new mobility needs within home settings. The clinic helps children gain greater independence with the help of wheelchairs, seating systems, standers, adaptive car seats, bath equipment and chairs.

Led by Physical Therapist, Laura Donatello, PT, DPT, a typical visit consists of a thorough consultation and evaluation. The team identifies positioning or mobility needs, communicates with insurance providers, and customizes each device. They excel at integrating assistive technology and making adaptations that incorporate therapists' feedback. The process also involves educating school personnel, physicians and caregivers on the functions and features of the equipment to ensure proper use and support success.

To learn more about our Seating & Mobility Clinic, contact intake coordinator, Michele Tabachka at mtabachka@eastersealsdfvr.org. The clinic meets twice a month at our Villa Park center or over tele-therapy.



SAVE THE DATE #GI≫INGTUESDAY NOVEMBER 30, 2021

DONATIONS WILL BE MATCHED!

Kick off the holiday giving season with us on November 30! Get involved to help us reach our \$115,000 goal. Visit **eastersealsdfvr.org/givingtuesday** for ways to engage in this global day of giving.

Thank you to our matching partners:	Todd & Libby Rieke	KNIGHT
The Tomczak Family	Katten	ante villaria

There's still time to join us as a matching partner. Contact Kelly at kmoreland@eastersealsdfvr.org to learn more. Katten

We are proud to support **Easterseals DuPage & Fox Valley**. Thank you for all you do to improve the lives of those with disabilities and the families who love and care for them.

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Did You Know?

All of our direct services, programs and fundraising efforts are developed in response to the needs of the children and families in our communities. To keep your gifts local, look for Easterseals DuPage & Fox Valley (DFVR) in communications. **Gifts will go directly to DuPage & Fox Valley if submitted:**

By Mail:830 S. Addison Ave. Villa Park, IL 60181Online:eastersealsdfvr.org/donateBy Phone:630.620.4433Through links in email from contacts @eastersealsdfvr.org

Other area fundraising campaigns directed to easterseals.com and local P.O. Box addresses support National Easterseals advocacy and awareness efforts that benefit individuals with disabilities across the country.

Dedicated Father Proves #YESWECAN

In August, Brad Serot channeled his daughter Ava's "Yes I Can" motto to complete an endurance cycling event and raise funds for Easterseals DuPage & Fox Valley and the Epilepsy Foundation of Greater Chicago. Within eight weeks, his vast network had contributed \$367,125 to support the services that make a difference for children with cerebral palsy and epilepsy – like his daughter, Ava. We are deeply grateful to be part of this powerful partnership.

Brad shares, "The Triple Bypass ride was an experience and challenge I will never forget and will always cherish. It was a true test of physical and mental stamina; a feat I was able to accomplish with each of my children in mind the entire time, especially Ava. 8.5 hours, 120 miles and 11,000 feet of elevation later, I crossed the finish line and YES WE CAN turned into YES WE DID."

To learn more about how you can turn a run, ride or social event into a fundraiser for Easterseals, contact Kelly Moreland at kmoreland@eastersealsdfvr.org.





830 S. Addison Avenue Villa Park, IL 60181



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Elizabeth received a new adapted bike as part of the Jonathan Goers Bike Club at our annual Bike for the Kids in August. More than 70 children have received adapted bicycles over the past six years.



Offering individualized services for families, including in-person & tele-therapies

Call 630.282.2022 for evaluations or to schedule an appointment.

Donate

Call 630.261.6240 or visit eastersealsdfvr.org/donate

Volunteering

Call 630.282.2030 for individual, corporate and group opportunities

Villa Park 630.620.4433 Naperville 630.357.9699 Elgin 847.742.3264

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