



MAY 2016

PARENT NEWSLETTER

From the Autism Spectrum Disorder Department at Easterseals Joliet Region

Visit our [website](#) or find us on [Facebook](#)

What's Going On At Easter Seals....

Chat with a Therapist

Each month Easterseals features a topic of interest on our [Facebook page](#). This is a great opportunity for parents and community members to log on and get information, ask questions and connect with Easterseals' staff and clients. The therapist is available for a scheduled hour where they will provide some basic information, but will mostly focus on answering questions. You can leave questions ahead of time if you aren't able to log on during the scheduled chat session, or go back and read what was said after the chat session is over.

On **Friday May 20th**, from **12:30-1:30pm**, Lisa Meyer, a physical therapist, will be discussing Aquatic Therapy. This summer therapy program can be particularly beneficial to children who are working on certain goals in physical and/or occupational therapy that can also be addressed in the aquatic environment. Lisa will explain what type of goals are best met through aquatic therapy and why it can be a great supplement to traditional physical and occupational therapy.

Parents Raising Children with ASDs

Our parent support group continues to meet the **second Wednesday of every month from 6:00 – 7:30** at our Regional Pediatric Center at 212 Barney Drive in Joliet. This program is very well attended and it is a wonderful way to meet other parents, get information and get connected to resources in your community. This month we will meet on **Wednesday, May 11th**. As always, childcare will be provided for those who sign up ahead of time by Easter Seals staff. Both the group and childcare are **FREE** of charge. Please call Laura with any questions or to register for childcare at 815-927-5466.

Thank you for a successful Telethon!



WATCH TELETHON HERE

The Regional Celebration of Giving Telethon held Saturday, April 16, exceeded \$200,000! The money raised provides services to over 3,272 children and adults with disabilities that Easterseals Joliet Region serves annually.

Summer Therapy Groups

Every year Easterseals offers a wide range of therapy groups over the summer that offer a wonderful supplement to traditional one on one therapy. Whether your child is 2 years old or 20 years old we have something for you! Here is a list of all of the exciting groups we are offering this year. See the flyer attached to this email for more information or call 815-725-2194.

Blooming Buddies Play Group
Golf For Kids with Special Needs
All Kids Yoga
Preschool Language Group
The Alert Program
Handwriting Without Tears
Soccer Shots
Animal Action
Fit, Fun & Fabulous

CORE Movement
Job Seeking Skills
Gardening Group
ZONES of Regulation
Aquatics
PlayPals
Feeding Group
Sibshops
Fit, Fun & Fierce

Ladies from Bethel Yard Sale

Please join us on **Saturday May 28th from 8:00 a.m. to 1:00 p.m.** for a yard sale hosted by some of our adult residential clients. The ladies will be having the sale to earn funds for recreational outings this summer. The sale will be at our Social Services office at 991 Essington Rd in Joliet. Donations are currently being accepted and can be dropped off during business hours.

Our Fresh New Brand!

Easterseals is redefining disabilities



For nearly [100 years](#), Easterseals has been changing the way the world defines and views disabilities. We make profound, positive differences in people's lives every day.

Now more than ever, the challenges in the disability community are more complex and the definition of disability is broad, going beyond physical conditions to include invisible, emotional, social and educational challenges.

To respond to these important shifts and re-introduce our organization to the public in a clear, more modern way, we embarked on a brand renaissance ... and we are so excited to show you, our closest friends, our new look online on May 3, 2016!

The new look is in the form of a brighter logo, a new spin on our established name, Easterseals, and a refined brand voice that will further energize our long-time supporters and inspire a new generation of friends. We also have a new tagline, "Taking on disability together," which speaks to our collaborative work across our affiliates, within our communities, alongside the people we serve and with you, our loyal supporters.

One thing we aren't changing is who we help ... or how we make a difference. We remain the vital resource for people living with disabilities, veterans, caregivers and families.

So get ready. You will see our fresh new brand take hold over the next year on our website, communications and our local centers, whom we have been working with closely on this new initiative.

Theresa Forthofer, President and CEO of Easterseals DuPage & Fox Valley in Illinois, was among those who provided important feedback on our rebranding effort. A mother of three, she has two sons, ages 22 and 16, who have autism and myotonic muscular dystrophy (MMD), a genetic muscle disease.

As both a mom and CEO, she's excited about our "refreshed brand," saying it better reflects "the amazing and innovative work happening at Easterseals right now in our communities."

"I love that it's fresh, young, energetic and positive," she says. "That's who we are, and I want more parents and loved ones to know, so that they get the support they need – just like our family did."

Every day, Easterseals breaks down barriers, dispels stereotypes, overcomes obstacles, and challenges attitudes and perceptions about people with disabilities and their potential. But we can't do it alone. It takes a team. Thank you for being part of our team!

What's Going On In Your Community...

Workshops & Resource Fairs

Early Childhood Mental Health Conference

Will County's AOK Early Childhood Network is presenting their annual mental health training at Lewis University on **Friday May 20th from 9:00am – 3:00**. The training is completely **FREE** and covers a wide range of issues that face early childhood families. Different speaker options are offered throughout the day including: Taking a Bite out of Challenging Behaviors: Strategies for young Children, A Practical Understanding how Attachment and Separation Issues Affect Young Children, and Social-Emotional Learning in the Preschool Years. CEU's and EI credit are available for a small fee. Contact Rebecca Deang at 815-774-7328. Visit their website and register for more information <http://events.r20.constantcontact.com/register/event?oeidk=a07ec8k3jdn682e3be6&llr=cklyw4jab>

Milestone Markers for Toddlers

Join us for All Our Kids (AOK) Early Childhood Network of Will County's Workshop called "Milestone Markers for Toddlers". This workshop focuses on what toddlers are and are not capable of doing (sharing, taking turns, compromising). Children are welcome to attend; there will be toddler friendly activities provided simultaneously. This **FREE** event takes place on **May 10th at 9:30-10:30am** at the Shorewood library.

Online Course

The Autism Society offers a **FREE** online course for users to increase their knowledge of autism in general, as well as courses on specific topics related to autism. They take approximately 30 minutes to complete and participants can download a certificate of completion when finished. To take this **FREE** course, go to <http://50.116.70.15/living-with-autism/how-the-autism-society-can-help/online-courses-and-tutorials/#autism101>

Recreational & Social Opportunities

Dancing on the Spectrum

Dance with Flair, LLC hosts a class that is designed for a child on the spectrum, although any special needs child and parent may attend the class. The class will be structured with a picture schedule to help students to understand what comes next. Steps, will be broken down in order for students to understand how to execute them. Parents will assist students at their own levels. The cost is \$40 per session and takes places in Oswego, IL. For upcoming dates and times, contact Angela Flaherty at (630) 201-4305

Remember your SRA this summer!

If you are looking for recreational opportunity for your child this summer, check out your local Special Recreation Association (SRA). Each park district is associated with an SRA, with the goal of bringing traditional activities to children with special needs. SRA staff have more training and interest in

assisting individuals with special needs. They also have a higher staff to child ratio and adaptive ideas for programming. If you don't know which SRA you belong to, call your park district today to find out!

Autism Speaks Walk

The Autism Speaks Walk is an inspirational and impactful opportunity to raise money and awareness to help change the future for all those who struggle with autism. Participating in Autism Speaks Walk empowers you to make a difference and provides you with an opportunity to honor someone with autism. Everyone is touched by autism in a different way. The walk takes place at Soldier Field in Chicago on **Thursday 5/14/16**. The walker registration is **FREE** and if you raise \$150, you will get a T-shirt.

https://www.kintera.org/faf/reg_new/registerPre.asp?ievent=1150524&lis=1&kntae1150524=838FF8C0237C42E084A49EE63F954D52&teamAction=none

Touch-A-Truck

The New Lenox Park District is hosting an event to explore your favorite vehicles including fire engines, police cars, and construction trucks at Walker Country Estates Park. This **FREE** event takes place on **May 7th, from 10am-12pm**. Visit the New Lenox Park district website for more information.

http://www.newlenoxparks.org/?sc_event=touch-a-truck

Ready, Set, Ride

Located in Plainfield, Illinois, students as young as three come from all over the Chicagoland area. It is the goal of Ready Set Ride to assist these children in achieving the highest quality of life possible through the use of horses and individualized activities focused on the needs of the student. Parents are always welcome and encouraged to participate in therapy sessions. Volunteers are also an integral part of the therapy sessions at Ready Set Ride.

Following Professional Association of Therapeutic Horsemanship (PATH) guidelines, Ready Set Ride bases its program on developmental techniques utilizing the horses as a means of mobility for the children. Certified therapeutic riding instructors guide the students and closely monitor individual needs to encourage consistent improvement. Therapy is conducted in the form of games on horseback which incorporates physical, speech, occupational, developmental, and recreational therapy.

Check Your Library!!

If you are looking for something to do with your kids this summer, don't forget to check your local library! Each library website has a link to events that they host and different activities daily. It's a great way of socializing and the activities range to all ages. Many libraries now host programs that are specifically designed to meet the needs of kids with different abilities, so if you feel your child isn't ready for "typical" library groups yet, call and find out what else they offer!

Recurring Monthly Events

These events are going on every month out in your community. Please contact them directly for more information!

Exploration Station Special Needs Nights

Exploration Station is a wonderful children's museum in Bourbonnais. They host a special needs night

on the **first Thursday of every month from 5:30 – 7:00**. The museum is only open to families with special needs children during this time, which provides a safe and accepting environment. The fee is \$2 for residents and \$3 for non-residents. Exploration Station is located at Perry Farm Park on 459 N Kennedy Drive in Bourbonnais. Call 815-933-9905 ext. 351 for more information or visit them online at www.exploration-station.org.

Sensory Friendly Films at AMC

AMC has EXPANDED their Sensory Friendly Film program to include some evening hours with films geared towards an older crowd! The auditoriums dedicated to the program have their lights up, the sound turned down and audience members are invited to get up and dance, walk, shout or sing! They will now be on the **second and fourth Tuesday at 7pm AND second and fourth Saturday at 10 am every month**. Go to <http://www.amctheatres.com/programs/sensory-friendly-films> for more information and to find a nearby theater that is participating in this great program!



DuPage Children's Museum Special Needs Nights

Did you know that the DuPage Children's Museum has a dedicated night for families of children with special needs? They do! It is the **third Thursday of every month from 5pm-7pm**. It is a time designated for the families of children with special needs to enjoy the museum in an inclusive, typically quieter, less crowded atmosphere. They have a creativity drop-in studio that implements sensory-based activities with a different theme every week along with purposeful play with peers, adaptive equipment, and guides to help parents use the exhibits for therapeutic benefit. Admission is \$11 per person, ages 1-59, and \$10 for anyone over 60. For more information go to their website at <http://dupagechildrens.org/>

Sensory Story Times

The Plainfield Public Library is hosting a **FREE** drop-in Sensory Story time one Saturday per month. After free play, socializing, and tactile activities, gather for a story time designed for children of all abilities. Friends and siblings are welcome. Children ages 3 to 9 must be accompanied by an adult. Drop in event, *No registration is required. Find out more information at* <http://il.evanced.info/plainfield/evanced/eventcalendar.asp>

Fountaindale Public Library (in Bolingbrook on Briarcliff) offers a **FREE** drop-in Sensory Story time on the second Saturday of every month from 10:30 to 11:15 for children from 2 to 6 years old with a caregiver. This story time is geared "especially for children with sensory integration issues". Visit their calendar at <http://host7.evanced.info/fountaindale/evanced/eventcalendar.asp>

Articles of the Month

In honor of Mother's Day, our articles this month are 3 blog posts written by moms of children with special needs. Enjoy!

Does Mother's Day make you sad? You're not the only one

Posted on May 2nd, 2016 by Beth Finke at www.easterseals.com

For years after our son Gus was born, I begged my husband Mike not to get me a gift for Mother's Day. "I'm not your mother!" I told him.

Our son Gus has severe mental and physical disabilities — he doesn't understand what Mother's Day is. Gus wouldn't be making me a card. He wouldn't be presenting me with dandelions picked especially for me. I knew that. But I was determined not to let any of that bother me. I knew I was a good mother, and I knew my son loved me in his own special way.

And then one year — Gus must have been 5 or 6 — I burst into tears on Mother's Day. "I'll never get to celebrate like all the other mothers do!" I wailed. Poor Mike didn't know what to do.

This article about [Parental Grief and Adjustment to a Child with a Disability](#) reassured me I am not alone when it comes to feeling a bit of sadness on Mother's Day — in fact, Mother's Day is one of the more common occasions of stress for families of a child with a disability. Ditto Father's Day.

Ever since that outburst of mine, we've gone out of our way to celebrate Mother's Day, and not always in traditional ways. This Sunday we're heading to a White Sox game — it's Family Sunday at White Sox Park. We're proud of Gus, and I'm proud to be his mom. We'll order hot dogs, clink our plastic cups at Sunday's game, say "cheers" to Gus and hope for another White Sox win. —

Dear Autism: Mom's letter shares her anguish, hope

Apr. 21, 2016 at 3:21 PM

Carrie Cariello

TODAY Parenting Team

I almost lost my marriage because of you.

It was the year my son named Jack was born, and you were born right along with him.

At first, we had no idea. He was just a squirming chubby baby who didn't sleep too well and hated to be swaddled and cried a little more than we expected.

Slowly, you made your presence known.

The sleep got worse.

The cries got louder.

The quiet got quieter.

He was sick all the time; reflux and ear infections and a deep, barking cough.

Then eighteen months later, on a gray day in early November, an official diagnosis of autism spectrum disorder.

Courtesy of Carrie Cariello



The Cariello siblings. Jack, wearing green sweatshirt second from right, was diagnosed with autism at 18 months old.

I charged full-steam ahead. I wanted to read about you and research your symptoms and figure out the best plan for speech and occupational therapy and maybe some sign language and then integrated preschool



and if we had time we should do music class because everyone knows music is great for kids who don't talk a lot.

My husband, Joe, took the wait-and-see approach. He wanted to slow down, and understand you. He wanted to be thorough before we jumped into anything.

I was right, he was wrong. He was right, I was wrong.

I was frantic.

He was methodical.

I was raw.

He was angry.

Because of you, we were both lost.

Oh sure, we never fought about you specifically. Instead, we fought over who got more sleep and who spent more money and who did more housework; all while a wolf knocked quietly at the door—an interloper in the dark of the night.

Inside every marriage is a secret language, a private code of nicknames and jokes and memories. Some days are full of a thousand tiny hurts, followed by a million small recoveries.

Once you bared your long, yellow teeth in our house, the jokes ebbed. Our nicknames faded, and our attempts at recovery were dwarfed by the hurt. Most of our spousal dramas played out on our big tan couch, with one of us rocking and patting a fussing Jack.

I said I would look into—

Why can't you just calm down?

Calm down? Calm down? Something is really wrong with him. You know it's true.

I always hated that couch.

Because of you, our young marital ground was sliding beneath us, and separately we each battled the nagging feeling that the landscape of our little family was shifting for good. We were a statistic, a number, a plot line on the spectrum's sloping bell curve.

Ever since November 3, 2006, you and I have been like two boxers in a ring, circling and jabbing, trying to gain whatever ground we can against each other.

We are brother and sister at the end of a long, hot car ride, poking and needling and annoying and griping.

We are the quintessential cat-and-mouse, and we take our turns chasing and hiding, hiding and chasing.

I am always watching you to see what move you'll make next.

And like a stray cat in the dark, you are always waiting for me to give up or get tired.

I will never get tired.

Well, that's not exactly true. Some days I am very, very tired. I am tired because you wake him up at the crack of dawn and told him that he *has* to make pancakes because he made pancakes on this exact day two years ago except this year is a Leap Year so it was different but still he should make them.

But I will never give up. I vow to be as tenacious as you are determined, as resourceful as you are wily, as steadfast as you are slippery.

Because of you, I came *this close*—thumb and forefinger close—to crashing my minivan into an oil truck, after you made 6-year old Jack shriek and scream when he saw an orange cone because he was afraid of anything that was orange that year.

Because of you, I missed the first half of my oldest son's fourth grade play, when you whispered in 9-year old Jack's ear that the auditorium, with its colorful stage and crowded audience, was too loud, too bright, too much.

Because of you, he feels threatened by every single thing around him—a loud noise in the kitchen, or a street light that suddenly goes out, or a different item on the lunch menu. He spends his day in a perpetual state of fight-or-flight, trying to protect himself from an invisible, nameless attack.

Because of you, 11-year old Jack has the hardest time with language, and he communicates with the world around him in his very own dialect. Sometimes it is funny, sometimes it is frustrating, but always it is fascinating.

And how would you like your burger? Medium?

NO! I want it LARGE! I want a LARGE BURGER.

Because of you, I have to watch his inner torment over something as simple as choosing the right clothes to wear; his ceaseless longing to fit in with those around him balanced precariously against his need for order and routine.

Everyone. All the boys. They wear shorts. But I will be too cold. To wear shorts. I think for my turtleneck.

For months now, you have trapped him inside of his own private blizzard—you have cloaked him in fury and tantrums, curse words and depression. He is sad one minute, mad the next.

My son is hurting and I can't reach him and this is all because of you.

Although his diagnosis is clear, his future is as hazy as a morning in springtime. A high school diploma, a driver's license, and an apartment of his own—they all dangle just above his head, like light bulbs burning in a chandelier.

Because of you.

Because of you I had to call our local police department. I worry he will run away from me one day into the street or through the woods or out of the car, and I will need their help to find him.

I want them to know about you—about the wolf that shadows my child and clutches him tightly, even as he thrashes and squirms and begs for release.

Because of you, I worry all the time.

I worry about the f-word in the line at Chipotle because they ran out of guacamole and he really, really wanted guacamole and I worry my about my other four kids and whether their childhood will always be overshadowed by the phrase *your brother has autism* and I worry he eats too many pancakes.

I worry he spends too much time on the computer and what will happen if I die and whether or not I should make him brush his teeth better.

I worry one day my marriage will buckle beneath this tremendous weight, that we are just one meltdown away from complete chaos, because parenting this boy together is so hard.

I want to hate you, autism, but like a child picking petals from a flower, I vacillate between hate and love, loathing and tenderness.

To hate you would be to hate a fundamental piece of my Jack-a-boo, and that is something I can never ever do, no matter which way the silky petals scatter in the wind.

I know you love this boy almost as much as I do. In some ethereal way, I know you chose him—you chose me, and us.

Because if you, I know the kindness of strangers and the devotion of teachers.

Because of you, my children are flexible, and tolerant, and tender, and kind.

Mom, it's no big deal. Nothing really happened in the beginning of the play anyway.

Because of you, this dark-haired man and I found one another again. In the midst of diapers and speech therapy, doctor's visits and long, sleepless nights, we rediscovered our own private language.

He said he wanted a large burger, it was so cute.

He decided on a short-sleeved shirt with cargo pants.

I can't believe you got him in here before the second act, headphones was a good idea.

So today, autism, I'm going to hang up my gloves and stop chasing you. I'm going to try to understand you, and give you the room you need to help this boy blossom.

I only ask one thing. Share him with me. I miss him.

10 Things Autism Parents Wish You Knew

Posted on www.autismspeaks.org

Kristi Campbell is a semi-lapsed career woman with about 18 years of marketing experience in a variety of national and global technology companies. While she does work part-time, her passion is writing and drawing stupid-looking pictures for her blog [Finding Ninee](http://www.findingninee.com), focused on finding humor and support for her special needs son.

The word autism entered my heart as a whisper. It later entered my brain as a possibility. Later still, it entered my life. I think I knew, long before I knew.



I worried, bought a book on autism, devoured it, and then felt like that must not be what my son has. He was nothing like the boy in the book. Nothing. "Maybe," I thought, "he just has a language delay."

I waited for him to start speaking more. For him to start playing in the way that he was supposed to play. He did play though, unlike the boy in the book, so certainly, his issues were different. Less "severe?"

Never mind that he had an egg-sized bruise on his forehead for six weeks at the age of 18 months from banging his head on the floor. As quickly as that behavior started, it went away. I stopped worrying about it. I mean, it no longer existed. Sure, he ran laps around the house. But only when he was tired. Don't all kids do that? Don't they all twirl their hair, around and around and around, while drinking a bottle?

I've mentioned before that parents and friends assured us that Tucker would catch up, and that his delays were likely due to me being at home with him as a baby.

They were wrong.

I was wrong.

I remember one day, when I looked at my son and with a fearful, time-stopping heart, I wondered whether he was deaf. He wasn't responding to me that day. Then, I gave him a little at-home test, and he responded. I let myself believe that everything was fine. What did I know? I had no other child in the house to compare him to. He loves to snuggle, and, from what I'd read, autistic children do not. He looks at me in the eyes. Deeply. With meaning and intent. I'd already learned from Dr. Google that children with



autism don't make eye contact...

Here. Four years later. Does Tucker look like anything other than a little boy having fun in the snow?

Autism doesn't look like anything but the way it looks. It doesn't look like Rain Man. It doesn't always include hand-flapping, rocking, or issues with language. Sometimes, it does. But, sometimes, it doesn't.


Last night, I reached out to my IRL PAC tribe.

I asked them what they wish the world knew about autism and special needs, and have put the below list together based on their feedback.

10 Things Special Needs and Autism Parents Wish You Knew:

1. People don't need to feel awkward when they're around my son. Yeah, they may need to treat him a little differently, but I wish they wouldn't be weirded out.
2. Not all autism is the same.
3. People seem to think that because my son isn't like the one single other person they know on the spectrum, that he must not be autistic.
4. These kids love. They need love. They are wonderful and bring enormous joy and laughter to those who love them.



5.  Knowing one child with autism doesn't mean anything really – they're all so different. Please don't tell me my son doesn't have it because he looks so different from the other kid you know on the spectrum.
6. Kids with special needs are smart. Talented. Creative, and thoughtful. It may not be obvious all the time – their minds work differently.
7. If my daughter is making strange noises, feel free to look. She's just making them because she's excited. Please don't stand there and gape at us with your mouth hanging open.
8. If you see my son in a grocery store, he may be head nuzzling, chewing on the corner of his shirt, or spinning. He's anxious. I will not scold him, so please do not look at me as if I should. He can't help how his body receives stimuli. He is trying to cope with the way his body is affected by his surroundings.
9. From onlookers who think I am not addressing my child's odd behaviors: I ask for a little empathy. Don't judge. Try to understand that his environment strongly affects him.
10. Please accept our kids the way that you assume we will accept yours.

I think I'm speaking for all of us when I say that what we really want you to know, what we're screaming out loud, is that we, as mothers, are both terrified and brave.

Just like you.

That while our children may act differently from what you're familiar with, they are our normals. That they're full of emotion, fierce love, tender hearts, and hope.

Hope.

Our special needs kids are here, on purpose, and OutLoud.

Even when they're silent.

The Autism Speaks blog features opinions from people throughout the autism community. Each blog represents the point of view of the author and does not necessarily reflect Autism Speaks' beliefs or point of view.

