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VIEWPOINT

Why Autism Awareness?

By Leslee Melamed
April 2 is World Autism Awareness Day, and April is Autism Awareness Month. One would be hard-pressed to go through the other 11 months of the year without hearing a lot about this rapidly growing epidemic. But it is empowering for those of us whose lives it touches to have an official recognition of the need for national awareness about it for an entire month.

Autism is a complex neurobiological disorder. It is the point at the top of the umbrella of a group of diagnoses known as Autism Spectrum Disorders (ASD). There are varying degrees of its disabling effects, and there is no telling what a person with it may or may not be capable of as he matures into adulthood.

Autism usually lasts throughout a person's lifetime, and it impairs a person's ability to communicate, relate to others, and, sometimes, to make sense of the world. One in 150 people, usually children under the age of 3, are diagnosed with autism, making it more common than pediatric cancer, diabetes, and AIDS combined. Autism strikes four times as many boys than girls; currently, 1 in 95 boys will be diagnosed with an ASD.

Much is still unknown about autism, such as who gets it, and why, and who will do well in spite of it. Sadly, to date there is no known cure or preventative therapy for autism, and no known medical intervention that has proven to be effective against it.

Why is autism awareness important? Because one of the things

that really does work is behavioral intervention, and the earlier it is started and more comprehensive it is, the better chance it has of really helping someone with autism. But it is costly, and often difficult for families to obtain in sufficient amounts to be effective—even from school districts.

I am one of the moms who has a child with autism. But in my case there are two, fraternal twin boys who are now 6 years old. I represent a rapidly growing number of parents who face the harsh reality of having more than one child with autism. My sons were diagnosed at the young age of 16 months (autism spectrum disorders can typically be diagnosed by age 3).

When my children were diagnosed, the odds for a diagnosis of autism was 1 in 166. Now, only a few years later, it is 1 in 150 for all children, 1 in 95 for boys. Take a moment to think about this: At the height of the infamous polio epidemic of 1952, which terrified everybody, the odds of a child's diagnosis were about 1 in 4,000. Compare that with today's 1-in-150 rate for ASD.

How do you know if your child is showing signs of autism? Parents are usually the first to notice unusual behaviors in their child, or their child's failure to reach appropriate developmental milestones. When parents suspect something is wrong with their child, they are often correct. If you have concerns about your child's development, do not wait—speak to your pediatrician about getting

your child screened immediately.

There are some pediatricians who adopt a passive, "let's wait and see" attitude about testing, because of the fear stigmatizing a child with a serious diagnosis. Experience has shown that this usually does more harm than good. I recommend going to autismspeaks.org to learn the signs of autism.

Federal law mandates that all children, including those with autism, are entitled to a free, appropriate public education. As a parent, you have an important voice in the decision-making process about what services your child should receive. Parents or legal guardians facing these daunting decisions should educate themselves in order to make the best possible choices for their children.

There are many not-for-profit advocacy groups and service agencies that are specifically designed to assist you in navigating the special education world. Many are made up of parents who have also entered the special needs arena out of necessity, and they will often be able to attend planning meetings with you. There is nothing like a compassionate, helping hand that can identify with you, someone to make the journey a little less scary.

We as parents and guardians must do what we can to advocate for our children with autism and raise awareness on a local and national level. Bea Huste-Petersen from East Islip, also a mom with two children on the autism spectrum, founded a non-profit group

called The E.J. Autism Foundation.

On May 16 and 17, an event called Real-Aid for Autism, organized by this foundation, will be taking place all along the South Shore of Long Island on Montauk Highway. It is a two-day, non-competitive relay through every school district along the route from East Islip and ending at the Montauk Lighthouse. A baton will be passed through each community and each leg of the walk will be between 1 and 2.5 miles. Each group of walkers in their community will have a VIP, someone affected by autism in some way, holding the baton to pass to the VIP in the next town.

The proceeds from the event will be divided among autism-related organizations in four townships (Islip, Brookhaven, Southampton and East Hampton). Locally, the two charities to be beneficiaries are the Long Island Community of Practice, a group that organizes activities for entire families that have a member with special needs, and The Child Development Center of the Hamptons (CDCH) Charter School in Wainscott.

For information about the E.J. Autism Foundation or Real-Aid you can go to ejautismfoundation.org, for the Long Island Communities of Practice you can contact Lisa@LICoP.org, and for CDCH you can go to cdch.org or call (631) 324-0207.

Knowledge is empowerment.

Leslee Melamed is a resident of Montauk and will participate in Real-Aid for Autism.