

AutismUp: How moms led way for a community

Support

Group has championed center opening next year

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When Rachel Rosner's son was diagnosed with Autism Spectrum Disorder 18 years ago, public awareness about the developmental disability was still very limited, and access to information about the diagnosis was the same.

"There was no one," said Rosner. "I really didn't have anyone in my life who had a child with a disability."

Now, Rosner is the director of education and support for AutismUp.

Since its beginning, the nonprofit has served thousands of families of children with autism, helping to guide them through the diagnosis and providing a

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valuable social network for the greater Rochester community — one that Rosner said she didn't have all those years ago.

What's emerged as the leading 501(c)3 autism support organization in the area had its beginnings in a small group of well-intentioned moms, each with a child with autism, each with a palate for coffee, who made a habit of getting together over the beverage starting back in 2004.

The beginning

Although Rosner now holds a leadership position with the organization, she wasn't one of the "originals," and neither was Sarah Milko, although she reckons she was, "probably number 9 or 10."

Milko, who now serves as the executive director for AutismUp, has a 17 year-old son with autism, her second child of three. His diagnosis prompted what's become more than a decade of work to make sure that her son, and other children on the spectrum, are given the same opportunities as everybody else. The group of moms that Milko connected with back in 2005 had gotten in touch with one another through various shared therapists to talk about the gaps in services for their children and work together to educate themselves about ASD. With the internet in its early phases, it wasn't long before that group started to grow.

"For the first few years we just met monthly," said Milko. "When my son was diagnosed I was pregnant with my third child and feeling really overwhelmed, so I was meeting with this group to just get as much information as I could."

In the beginning, they called themselves UNYFEAT, which stood for Upstate New York Families for Effective Autism Treatment, but later on, once they had a greater membership, changed the name to AutismUp.

“We invited guest speakers to come in and talk to us about various interventions, therapies, things that were going on that we could use as parents to help our children,” said Milko. “More and more people started to show up, and we went from meeting at Starbucks to the old conference room over at the Al Sigl Center.”

Soon, the group had 25 to 30 people showing up to each meeting. By 2008 that number had the addition of more than 150 families.

Milko said that by this point, the group had worked to go beyond educational programming to incorporate recreational opportunities.

“I was signing my other children up for summer camp and I realized that my son with autism couldn’t go, and that other parents were facing the same issue. That launched us into a whole new realm as an organization,” said Milko. “We went to the YMCA and developed a program to send our kids with autism to summer camp with the support they needed, but in a very integrated setting with typical kids. So for the first time, kids with autism could go to summer camp with their siblings and neighborhood kids just like everybody else.”

That’s when the mindset began to change.

“We realized that, as a group of moms, we could not just get together and support each other, but that we really had the power to develop programs that didn’t exist in the communi-ty,” said Milko.

And they grew.

The present

Fast-forward a near-decade, and through fundraising and continuous growth, AutismUp has become more than a mom group; it’s become an irreplaceable community with specialized facilities and programs for individuals with autism and their families.

Currently located in Webster, the organization offers opportunities for individuals with autism to build social skills, sensory and readiness skills and engage in recreational activity in a safe space. The organization also offers a variety of programs and events to extend opportunities to children with autism that match those of their neurotypical peers, including cooking and fitness classes, as well as special events.

“Around Christmas they had cookies with Santa,” said Quinn Brady, a member of the group. “A lot of parents can’t take their children to the mall or to different places. I get nervous going out sometimes. This was an opportunity where Robert could do something that all kids do, and sit on Santa’s lap and take a picture in a safe and understanding space.”

The future

What if it was possible to bring all of the best autism support services in Rochester together under one roof?

That’s the question Milko, Rosner and others at AutismUp were asking themselves approximately two years ago when the idea of building a revolutionary center for autism support was planted in their minds by two other community organizations committed to a similar cause.

In partnership with Al Sigl Community of Agencies, and CP Rochester, who reached out to inquire about a collaboration, the potential reach of AutismUp began to expand.

“This was a game-changer as an organization because we had these two very experienced agencies saying we’re going to build a future together for these tens of thousands of families living in the Rochester area who have had no sense of coordinated support,” said Milko.

In April 2017, that vision scored the partnered organizations a meeting with Rochester businessman Thomas Golisano and his board of directors. Thanks to a donation by Golisano and his foundation totaling \$3 million, in 2019, the dream will become a reality.

“We pitched our vision for this autism center, and much to our amazement, he said yes,” Milko said.

“For so long, families had to navigate various systems and really quarterback how all those systems were working together for their own child based on individual needs,” said Milko. “It was so complicated. The fact that all of these services will be under one roof working together, I believe will make this center unlike any other in the nation. It really will catapult our region into a whole different realm in terms of offering collaborative autism services.” Anne Costello, executive director of the Golisano Foundation, said the foundation is proud to support the mission.

“Families currently experience great difficulty connecting with services, which creates stress, and is costly,” said Costello. “The collaborative approach to providing services in the new Golisano Autism Center will greatly improve quality of life across a person’s lifetime, increase effectiveness and efficiency of services, and provide an essential circle of support for individuals with autism and their families.”



Clara Washington and her 7-year-old daughter, Jayla Morrison, play with a tablet and practice recognizing words and symbols. Jayla has autism, and her mother has activities and certain precautions in place around the home to help her daughter. OLIVIA LOPEZ/@OLOPEZ4/STAFF PHOTOGRAPHER



Milko



This sign is posted on the front of Clara Washington's home in Rochester, and on her car as well. OLIVIA LOPEZ/@OLOPEZ4/STAFF PHOTOGRAPHER

To get connected with the free support offered by AutismUp, families should visit the AutismUp website at autismup.org or reach out by phone at (585) 248-9011.