

LI Life

Sofia Stipanov, of Wantagh, founder of Our Journey support group, with her son Lucas, 9.

Building *a village*

LI mom finds community in the Facebook group she created for parents of neurodiverse kids **E4**

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MORGAN CAMPBELL

Kristin Freilich, of Levittown, helps her son Charlie, 4, during an open swim hosted in November by the support group Our Journey — Long Island Special Needs Families.



Tashana Marinas, left, of Queens, chats with Our Journey founder Sofia Stipanov during an open swim at Saf-T-Swim in Nesconset.

Sharing their JOURNEY

LI mom of autistic boy forms support group on Facebook

BY LIZA N. BURBY
Special to Newsday

When Sofia Stipanov's son, Lucas, was diagnosed with autism at age 2, she said the news "rocked" her world and all her thoughts involved getting him services

he needed. Their apartment in Bayside, Queens, became a revolving door of therapists for Lucas, she said, while she also juggled her twin daughters' schedules as her husband, Anthony Stipanov, worked full time.

Then the isolation set in. "I couldn't leave my house," said Sofia Stipanov, 42. "There was always a therapist. I had no family who could help and my friends became distant because they didn't understand Lucas' behaviors."

In 2020, the family moved to Wantagh, where they could get

in-district services for Lucas, who turns 10 this month. Stipanov said the loneliness persisted because her husband, 40, a high school principal, commutes to Brooklyn and doesn't get home until after 7 p.m. As she learned more about the range of services for Lucas, she said, she realized what was lacking was help for parents like her.

"There's so much support out there for children with special needs, which is amazing," Stipanov said. "But there is a lack of support for parents. By the time Lucas was 4, I said

MORGAN CAMPBELL



From left, Sofia Stipanov, of Wantagh, catches up recently with three regular members of the group: Italia Orellana, Dana Frank and Jennifer Kirsh, all of Plainview. The group hosts monthly lunches and dinners, in addition to Zoom meetings.

RICK KOPSTEIN

said are helpful but that it's typically left to families to access them.

"There is something to be said for in-person groups," said Reicher. "The sharing of experiences for moms is so powerful and can often be more useful than any information or guidance provided by professionals."

That's what Stipanov said is the value of Our Journey — which she emphasized is not just for children with autism, but for all disabilities: It offers parents a judgment-free place to vent and to learn they're not alone.

"There's such a stigma about sharing your child's diagnosis because not everyone understands and that adds to the isolation. I had family members who told me Lucas would just grow out of it," Stipanov said. "What I love about the group is I have met moms whose children are just like my son, but they're 20 and it helps me to see what my future is going to be, so I'm learning from them."

She said, "I've made deep friendships. I could have a day and call one up and they're like, 'Just let it out.' That's the support I needed when I started and the moms have told me that's what they need, too."

TIPS, VENTING AND CONNECTION

Another benefit is sharing resources, like clinicians, schools and activities, information about diagnoses and behavioral issues that might arise. That's what Italia Orellana, a licensed clinical social worker and a single mother, said helped when her son Elias was diagnosed with autism spectrum disorder at age 3 in 2019.

"I didn't know where to turn for support and resources for Elias and for myself," said Orellana, 46, of Levittown. "Our Journey really helped because we're supporting each other. We share the same journey and thanks to Sofia, we're

See COVER STORY on E6



Among family events, Our Journey hosts a sensory-friendly Santa gathering in December. Above, Angela Tso-Bondoc, of Syosset, and her husband, Chris Bondoc, with twin sons Jacob and Ian Bondoc, 3.

DEBBIE EGAN-CHIN

to connect on that level because it's really hard to find."

LACK OF SUPPORT, ESPECIALLY FOR MOMS

Supporting caregivers of children with disabilities impacts the child's development and well-being, but there's a lack of infrastructure for that support, said Debra Reicher, an assistant clinical professor of psychiatry at Stony Brook University School of Medicine.

"It would be great if, upon initial diagnosis, a family could be immediately connected to a support group, or at least other parents of a neurodiverse child," she said, adding that typically the burden of accessing a child's services falls on mothers. "Families are bombarded with a to-do list of services they need to access and get thrown in the world of acronyms. It's very overwhelming."

Reicher, who has run support groups for parents, said there are limited groups available, often associated with a specific program like a preschool. There are also national and local programs like Parent to Parent, as well as Facebook groups, which she

there needs to be something for moms so they can at least talk about what they're going through."

She decided to create that supportive community herself and formed a Facebook group she calls Our Journey — Long Island Special Needs Families.

Stipanov has since organized regular in-person meetups and community-building activities for families, growing Our Journey to over 2,600 members.

"Our Journey is a safe environment to share our personal experiences, joys and struggles

and to uplift each other with friends who understand our journey," Stipanov said. "We're here to help special-needs families build their village. Everybody has a story to tell and it's very difficult. But to meet parents who are on the same journey, I think it's good

'No judgment anywhere'

COVER STORY from E5

able to find that perspective that only another special-needs parent can provide."

Stipanov said it wasn't until the Facebook group started to gain about 500 followers during the COVID-19 pandemic and she saw the postings — moms who were writing that their child just got diagnosed and they don't know what to do or how to feel — that her next step clicked. She started hosting monthly Zoom gatherings.

"I thought we should get these moms together and vent and give each other ideas," she said. "Sometimes you just need to talk it out, and that's healthy because there's only so much you repeat to your spouse or significant other."

Stipanov said the Zoom meetings gave the women a new way to connect with each other that they all looked forward to. So when the pandemic restrictions eased, she scheduled in-person meetups once a month in restaurants, mostly in Nassau. She also varied the price ranges up to \$100. She recently started organizing lunches and some brunches for those who need to meet during the day. But she limits gatherings to 12 "because with more, you can't really connect with every person at the table." Starting this month, she's adding a second dinner because every new meetup gets filled.

Stipanov said she tried to offer meetups for fathers, but none responded. She's looking into a couples' meetup. She also does events for families throughout the year, like an open swim in November and a sensory-friendly Santa gathering in December.

SHARED STRUGGLES

Among the first to join Our Journey was Dana Frank, 41, of Plainview, who said her son Jacob, now 10, was diagnosed at age 6 with level 2 autism.

"I didn't have any friends or family who had children like Jacob and often felt isolated," said Frank, who works part time at a dental office and also has a 6-year-old son she said is neurotypical. "When Jacob was diagnosed, I was depressed



Sofia Stipanov limits the dinners to 12 people to "really connect with every person at the table." From left, Jennifer Kirsh, of Plainview; Stipanov; Dana Frank, of Plainview; and Melissa Theodore, of Huntington.



Stipanov and her husband, Anthony Stipanov, with their son, Lucas, 9. Lucas "has made friends through Sofia's events," Anthony says.

and I posted on all the special-education Facebook groups desperately trying to find support groups for parents of children with autism. That's when I connected with Sofia, who had just started monthly Zooms and welcomed me with open arms."

Frank also looks forward to the dinners every month. "Nobody understands until

they have a special-needs child, and all of us have different situations," she said. "But we're all struggling in the same kind of journey. I post on the Facebook group when I'm having issues or questions. It's good to get opinions and advice from other moms who know you and your son a little bit."

Orellana, who attended her

first dinner with the group two years ago, said she immediately felt comfortable. "A lot of us aren't able to go out to dinner because our kids might not like the lighting, the noise or the food smells, and people judge you," she said. "But there isn't that judgment in this group, so this has given a piece of me back. And at the meetings that we have for the kids, Elias has made friends."

Kristin Freilich, 41, a social worker who lives in Levittown, has two sons who were diagnosed on the spectrum, Jack, 7, and Charlie, 4. She said Jack's diagnosis came during the pandemic when she "dove headfirst into the autism world." That's how, she said, she came across Our Journey on Facebook. When Stipanov started the dinners, Freilich said she was grateful to have a night out with the other moms. "There's so much we're juggling between therapies and school meetings and you start to sort of lose yourself," she said.

Jessica Guadagnino, 47, of Patchogue, said she and her husband, Victor Guadagnino, 53, are both high school teachers so they had a base of knowledge and resources when their 10-year-old daughter, Marissa, was diagnosed with high-functioning autism four years ago. Still, Jessica Guadagnino said it was eye-opening when she learned of Our Journey and started to read the posts from

other parents.

"To see so many other people dealing with the same kinds of challenges and emotions and just being very real about it — like no judgment anywhere, and finding a community where you can connect with people who get it — was so helpful," she said.

BEYOND OUR JOURNEY

Anthony Stipanov said that in addition to the support that his wife has created for others, Our Journey has also helped Lucas. "Through all the things Sofia does, we've learned about a lot of services that Lucas can get, which we didn't know beforehand," he said. "And he's made friends through Sofia's events, too."

Sofia Stipanov said she spends about an hour a day screening the website so that it remains confidential and positive — and to make sure individuals aren't promoting their own businesses.

Stipanov also serves as co-president of both the Wantagh 6-12 Association and Wantagh SEPTA, the special-education PTA. For her advocacy of education and special-needs support, Stipanov was among 18 women in the 5th State Senate District who were honored as 2024 Women of Distinction in September. She said as her 14-year-old daughters, Ava and Olivia, increasingly need her to chauffeur them to their activities, her availability for the Facebook group will change. But she doesn't want to plan the future just yet.

"Obviously, if it grows, I'll just do more meetups. Now we have lunch and brunch, and my husband is teasing me that I'm going out to eat once a week," Stipanov said. "These moms really need the support. But I also love being home with my husband and my children."

Guadagnino said she doesn't know how Stipanov finds the time to organize all that she already does. "I don't think everyone in the group realizes that she's doing this out of pure goodness in her heart," she said. "She doesn't get paid. She's doing this because she saw the need, and she's really helping out so many people. It's been exponential."