

MEET THE COMMUNITY

# An Autistic Pianist and the Quest to Communicate

## SPARK



Milosz Gasior created a buzz when he auditioned for the music program at a Florida high school. He arrived with piano music, and a teacher's aide to help him follow directions.

"It was obvious that he was very musically talented, but it was very difficult to communicate with him during the audition," recalls Derek Weston, program director of the Pinellas County Center for the Arts at Gibbs High School, on Florida's Gulf coast. The program had never had a student "who was as far on the autism spectrum as Milosz, and it honestly made everyone nervous." They were not anxious about Milosz, but rather about their lack of experience teaching a student like him, he explains.

Autism occurs along a wide spectrum, and Milosz has a particular mix of strengths and challenges. He speaks in short sentences and struggles to answer questions about his day. At the piano bench, however, he does not miss a note, his fingers gliding effortlessly over the keys.

That audition four years ago landed Milosz a place in the competitive program, which resembles a college-level conservatory for the performing arts. Staff knew they would need to push themselves to help Milosz reach his potential.

### A Sound Sensitive Child

Milosz's parents, Bozena and Marek, could not have foreseen that the little boy who covered his ears to block out sound would one day enjoy playing in a band. He had been a "perfect baby," so calm and happy, his mother recalls. The only clue that something was different about him arose later, when he did not imitate sounds and start talking.

Bozena mentioned her son's speech delay to his pediatrician. But the doctor said the delay may be due to his parents speaking their native language, Polish, at home. That is a common misperception about children in bilingual families.

In 2005, when Milosz was 2, a developmental specialist diagnosed him with moderate to severe autism. "I remember the doctor telling us, 'This is autism, and there is nothing on this planet that can change that.'"

Milosz's parents did everything they could to help him. He had speech therapy to help him talk, occupational therapy to help with motor skills and sensory issues, and autism therapies that focused on behavior, learning, and developing relationships. "Equestrian therapy, assistance dogs – whatever it was, we tried it," Bozena says. Also on the list: music therapy.

Music therapy gave Bozena an idea ...



Scan to read  
more of  
Milosz's story!

MEET THE COMMUNITY

# Debunking Autism Stereotypes: Cami's Story

SPARK 



The Austins suspected that their middle child, Camryn, had autism, but her teachers and doctor did not. Perhaps it was because Camryn did not fit the traditional picture of someone with autism. Camryn is talkative, female, and Black.

Camryn was one of only a handful of Black children in her small, rural school district, says her mother, Kristin Austin. Austin worried that, if she kept pushing the school to evaluate her daughter for autism, it might affect how teachers viewed other Black girls.

The family moved to a larger, more diverse area, where Cami, as she's called, could get the help she needed. Cami's new school diagnosed her with autism in 2021. The desire to help others like Cami led the Austins to SPARK, the largest research study of autism.

Austin is a professor with a doctorate in education. As she learned more about autism, she realized that studies often did not include girls of color. The family joined SPARK to help change that. They provided DNA samples to SPARK researchers, who are looking for more genes that cause autism so we can better understand how the brain works differently in individuals with autism.

## Getting Attention for Cami's Autism

Cami is the second child, and only daughter, of Kristin and Cerick Austin, educators who live in Pennsylvania. From infancy through her toddler years, Cami slept very little, maybe just four hours a night, and usually not in one stretch.

Cami's doctor did not worry because she was a happy child who was seemingly unaffected by lack of sleep. "She has always been an incredibly amicable, loving, and exuberant child," Kristin Austin says. But that did not relieve her worry about Cami's sleep problems: "Brain development at that age takes place during sleep," she says.

As Cami grew, her parents saw that she struggled with social skills, attention, and behavior. Two preschools that she attended also noticed: they each found her behavior to be too disruptive for them. Austin expressed her concerns about Cami's social problems, but Cami's many strengths derailed those conversations.

Cami is smart with an advanced vocabulary and a great memory. At 4 years old, she could recite the periodic table of elements, which most students do not learn until high school chemistry class, her mother recalls.

She also had traits common to autism ...

Scan to read  
more of  
Cami's story!



# Accelerating Research

**291** RESEARCH MATCH STUDIES 

**58,000 families** have been part of nearly **300 studies** through SPARK Research Match, ranging from the study of the neurobiology of atypical language development, to a clinical trial for a specific genetic cause of autism, to repetitive thinking patterns in autistic adults.

**309** SCIENTISTS USED SPARK DATA 

**309 scientists** have used **SPARK data** to further autism research.

**131** SCIENTIFIC PAPERS 

There have been **131 scientific papers published using SPARK data**, covering a range of topics from motor impairments, to mental health, to rare genetic variants.

**500** GENES 

SPARK data has helped researchers discover new autism genes. **There are now more than 500 genes known to play a role in autism and other neurodevelopmental conditions.** Dozens of these genes have been discovered in the past 7 years.

**72** RESEARCH MATCH PAPERS 

There have been **72 scientific papers published using SPARK Research Match** on topics from sleep, to mental health, to understanding other issues autistic people have as they age.

## Thank You!

Thanks to participants like you, we are advancing the understanding of autism to improve lives. With your help, we will advance research that can help inform care and support for generations to come.

"We were excited to be part of the [SPARK] study. Then it became so much more. The research exceeded any expectation we could possibly have had."

Jodie Z., autism mom and SPARK participant

"As an autistic person, [I know that] research can really help someone who's struggling. I hope [SPARK] inspires other people who have questions about being autistic to invite their families to participate in the research, too."

Jada T., autistic adult and SPARK participant

"Even if we're not going to benefit from it, it's really important for other families in the future, for diagnosis or treatment. We've benefited from knowledge that was gained in the past, so this is what we have to do, for the future."

Jennifer S., autism mom and SPARK participant

"I can't imagine a reason not to participate in the SPARK study. There's so much to be learned and nothing at all to lose."

Lynn V., autism mom and SPARK participant

# SPARK by the Numbers

SPARK is a growing community of families, autistic adults, and researchers working to understand autism to improve lives. Together, we're studying autism across the lifespan to better understand what makes each person with autism unique — and how each child, adult, and family can receive the support they need to thrive.

## Building Our Research Community

**30**

CLINICAL SITES



The SPARK clinical site network includes **30 top research centers** and **academic institutions**.

**333,184**

PARTICIPANTS JOINED



Since launching in 2016, over **333,184 people, including 130,000 with autism**, have joined, of which 30,000 are autistic adults.



**153,000**

PARTICIPANTS' DNA SEQUENCED

**DNA from over 153,000 participants**, including over **52,000 people with autism** has been sequenced.

## Giving Back



**220,000** REPORTS RETURNED

More than **220,000 families** have received **reports** from six different screening tools used in SPARK. These reports reflect the individual behavior and development of participants.



**2,200** AUTISTIC PEOPLE WITH GENETIC FINDINGS

SPARK has notified more than **2,200 participants** about a **genetic cause for autism**.



**85** WEBINARS

Over **20,000 people**, including parents, autistic adults, researchers, and service providers **tuned into 85 webinars**.

**187** ORIGINAL STORIES



SPARK has written more than **187 original stories on participants, treatments and therapies**. The most popular are about girls, special interests, and LGBTQIA+ identity.

# Together We Can **Answer** Your Questions About Autism!



I continue to be amazed by the SPARK community's dedication to moving autism research forward. SPARK is now a community of over 330,000 people, including more than 130,000 individuals with autism and their family members. It's truly astounding to see the advances we're able to make toward understanding autism thanks to the participation of so many.

SPARK is committed to supporting autism research for years to come. We will continue researching dozens of topics, including sleep, mental health, heart disease risk, and understanding other challenges autistic people experience at different life stages. Whether you're a "first family" or you're brand new to SPARK, thank you for being here. Together we can answer your questions about autism.

There are exciting ways for you to stay involved with SPARK. Here are just a few things you can do:



You may have completed some surveys when you joined SPARK, but new surveys may be added to your dashboard – **scan the QR code to log into your SPARK account. Remember to log in to your account regularly to stay up to date on surveys.**



SPARK participants may be invited into new research studies through **SPARK Research Match** – you may have been invited to one (or two...or TEN) already! Some recent studies focus on sleep, diet, depression, and language. More information about SPARK Research Match can be found in this mailer.



**Read the monthly newsletter** to stay up to date on SPARK. Forward to a friend and encourage them to subscribe!



If you consented to the genetic portion of the study, **make sure you return your saliva** if you haven't already! **Need to request a new saliva kit? Email [info@sparkforautism.org](mailto:info@sparkforautism.org).**



**Tell a friend about SPARK!** Let others know that you're a part of the SPARK community – **display your SPARK sticker on a laptop, notebook, or water bottle.**



We are eager and interested to hear from you. If you have any questions, please email us at **[info@SPARKforAutism.org](mailto:info@SPARKforAutism.org)**



*Wendy Chung*

Wendy K. Chung, M.D., Ph.D  
Principal Investigator

Together, we are increasing the understanding of autism.

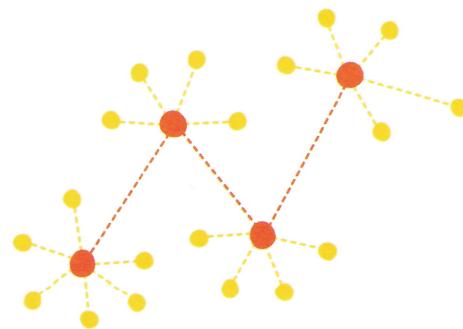
Together, we are making important research possible.

Together, we are making a difference.



@SPARKforAutism

# What is SPARK Research Match?



SPARK Research Match connects members of the SPARK community to autism research studies. Researchers worldwide use Research Match to connect to autistic individuals and families who are willing to volunteer for online or in person studies.

Participants get the chance to be represented in research and hear about studies that are appropriate for them. Some studies even offer a participation incentive. If you decide to participate in a study, you will be told in advance if there is an incentive and when you will receive it.

Researchers are studying a variety of autism topics, including aggression, autism across the lifespan, mental health, and LGBTQIA+ issues. Research Match studies vary in type and time commitment. Some are online and some are in person. Some ask you to complete a survey once, while others may invite you to complete multiple surveys over time.

## How does SPARK Research Match Work?

A researcher with a study approved by their institution applies to recruit participants from SPARK. Their application is then reviewed by a SPARK team. If approved, we look through SPARK data to find participants who qualify. If you qualify, you will receive an email invitation from SPARK that describes the study and how to get started. If you decide to participate, you will work with the study team directly, not SPARK staff. If not, you can always join future studies.



See if your dashboard has any studies for you!



## What do I have to do to be invited to SPARK Research Match studies?

As a SPARK participant, you're eligible for SPARK Research Match! Did you know that completion of your dashboard surveys can increase your eligibility for Research Match studies? So, be sure to complete any outstanding tasks on your SPARK dashboard and send in your saliva kit(s) if you haven't already. Participation is always voluntary.

## What has SPARK Research Match accomplished so far?

- SPARK Research Match has launched 240 studies with another 51 launching soon.
- 58,000 SPARK participants and families have participated in at least one Research Match study.
- Over 122,000 SPARK families and individuals have received invitations for Research Match studies.
- Researchers who have used SPARK Research Match have published 72 articles in scientific journals.



Read more about our Research Match studies!



## Will I learn about the results of the study?

You may receive information about the study from the study team itself. In addition, after a study's findings are published, SPARK will often prepare a Research Match Summary Report and an article about the study.



Need to request a new saliva kit?

Not sure if you already sent it in?

Send an email to [info@SPARKforAutism.org](mailto:info@SPARKforAutism.org)