

# The Autism New Jersey Fund

## The Cooper Family

December 2018

Dear Autism New Jersey Family & Friends,

In an instant, Lucas was on the floor, barefoot and bloody, rubbing glass shards all over his body, oblivious to the pain. He had just pulled the clock off the wall and threw it on the floor. There was glass everywhere. This is our family's autism reality.

When Autism New Jersey asked if we would share our story, we recognized that our situation is unique and very intense. Autism is all-consuming in our household. Oftentimes suffocating. Many days, unfortunately bleak. Like being trapped in a cave. Amidst the difficult and dark times, we acknowledge, and are grateful for, the assistance and support we've received from Autism New Jersey and their commitment to shedding light on the struggles of families like ours and for improving our lives.

While our story may sound extreme, it's a reality experienced by far too many families.

Like many other autism families, we feel frustration and despair when confronted with the lack of adequate services. Many days, we feel isolated, alone and exhausted. We fear what will happen when we are no longer here. Who will love our son like we do and fight for what he needs?

From the beginning, we knew that we needed to become a voice for our son. We would have to fight on his behalf as if his life depended on it – because it does. Unfortunately, throughout our journey, we have experienced obstacles, roadblocks and misinformation at every turn. It quickly became apparent that to navigate the world of autism, we needed a team of experts who had his best interests at heart. From our first phone call with them, we knew Autism New Jersey had the compassion and expertise to help us.

Our beautiful son, Lucas, now 6 years old, was diagnosed with severe autism at 18 months. We quickly realized that most people do not understand the challenges Lucas and our family face. Well-intentioned friends and family would say things like "Why don't you guys come out for dinner this weekend?" or, "Bring the family over" or, "Just relax and take the day to yourself" or, "Watch 'The Good Doctor' or 'Atypical' – That should make you feel better." Little do they realize that we are faced with a very different actuality than what is depicted on television.

Over the years Lucas has suffered from many maladaptive, aggressive, and self-injurious behaviors as part of his autism. These include uncontrollable screaming and laughing for no apparent reason, hitting himself, hand flapping, scratching himself to the point of drawing blood, running in circles, jumping, eye gazing (including staring into bright light or the sun), eye poking, and stripping. He is virtually non-verbal and has no concept of danger or pain. If he hurts himself, he will do it again because he does not understand that his actions are the cause of the pain.

Lucas also engages in pica (the routine ingestion of non-edible materials such as paper, soap, cloth, metal, pebbles, floor grout, carpet fibers, etc.). Our lives are consumed with constant fear. Will he choke to death? Will we have to give him the Heimlich maneuver ... again? Will he crack his head open diving off one of the two pieces of furniture we are able to have in our sparsely furnished home? Will he somehow escape from the house and get run over or drown in a neighbor's pool? These are just a few of the fears that are part of our daily existence.

We also have a neurotypical 10-year-old daughter, Lynnsey, who is very loving and caring. She is involved with Lucas' therapy and daily routines. She gets extremely upset when she hears anyone say anything negative about Lucas or when she is watching a show that depicts a negative situation involving anyone with disabilities. She is his greatest defender and only friend.



(Continued on back)



**Autism**<sup>TM</sup>  
NEW JERSEY

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Sleep, or lack thereof, is a major issue. Lucas typically wakes up in the middle of the night. He'll run screaming down the hall turning lights on and off and engaging in high rates of vocal and physical stereotypy. Oftentimes, he hurts himself by banging his head against the wall, thrashing his body back and forth, repetitively poking himself in the eye, or scratching himself to the point where he draws blood. Sometimes, we are able to get him back to sleep within a few hours, but more than half of the time he remains awake. By the time 7:30 am rolls around, it's time to get Lucas and Lynnsey ready for the day. As a result, we all go through another day completely sleep-deprived and exhausted.



Last year, things got so bad that we needed to find an in-patient facility to help us deal with his self-injurious and aggressive behaviors. Unfortunately, there were no facilities in NJ that would accept Lucas. After much searching, we heard about the Neurobehavioral Unit at Kennedy Krieger Institute (KKI) in Baltimore, Maryland. Unfortunately, due to demand, it usually takes upward of two years to get admitted. Enter our "ray of light," Autism New Jersey. When they heard our situation they immediately got involved, helping to get Lucas admitted within a matter of weeks. They were incredible.

After months of highly specialized assessment and in-patient treatment services, Lucas' behaviors were stabilized, but they still present significant challenges. Autism New Jersey continued to support us as we struggled to find appropriate services closer to home, a task that hasn't been easy due to the lack of adequate services and limited qualified professionals. Along with our incredible attorney, Autism New Jersey helped identify schools, advised us on how to navigate our conversations with them, and pinpointed for us what to look for in an appropriate setting. When we left KKI, we were fortunate that Lucas began participating in a high-quality Applied Behavior Analysis treatment program at North Jersey Behavioral Health Services in Caldwell, NJ.

Autism New Jersey's clinical expertise and perseverance gave us practical advice and emotional strength when we needed it most. They have, and continue to be, an incredible lifeline of reliable information and compassionate support for all families. They are also constantly advocating for the rights of our special children by promoting social awareness, education, and public policy initiatives.

We hope that you and your family will never experience the dark, trying times that we endure. But, tragically, many families do, and they need Autism New Jersey. Your support and donations will



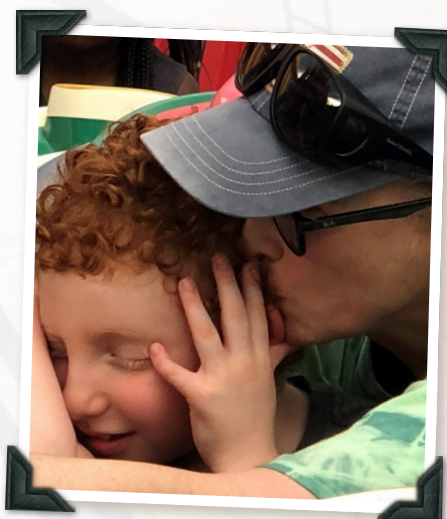
ensure that Autism New Jersey can help countless families through their darkest times and be their "ray of light."

Thank you,

*Michele & Justin Cooper*

Michele & Justin Cooper

Autism New Jersey serves as a collective and influential voice for the community, and systematically and compassionately improves the lives of individuals with autism every day through our four core service pillars: Information Services, Education & Training, Public Policy, and Awareness.



We're proud to have been serving the autism community in New Jersey since 1965. Autism New Jersey provides assistance at all stages of an individual's life, from diagnosis to early intervention to school programs to transition strategies for teens and options for adults. Our Annual Fund Drive provides valuable support for our efforts on behalf of families like the Coopers.

To learn more about Autism New Jersey's efforts, visit [www.autismnj.org](http://www.autismnj.org)

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