At the helm of a nonprofit organization that strives to increase access to effective autism treatments, Nancy Alspaugh-Jackson’s activism stems from firsthand experience with her son Wyatt, who was diagnosed with autism at the age of 3.

"OUR ONCE PERFECT BABY BOY" became a whirling dervish at two, banging his head, biting and having tantrums so severe he put his head through the kitchen window twice," recalled Alspaugh-Jackson, the executive director of Autism Care and Treatment Today! — also known as ACT Today!

An early talker, Wyatt became silent and appeared deaf. "It turns out that he did have autism, but what made that reality even more devastating was the year it took to get a proper diagnosis and then the two more years it took to get the proper treatment," she said. "I knew things must change. If it was this hard for me, a former television producer and author, how were other less fortunate families able to cope?"

Alspaugh-Jackson now helps families get the funding and information they need to give their children a chance to succeed in this life. "And incidentally, Wyatt is going into second grade next year and thriving due to a combination of behavior therapy and biomedical interventions," she said. "We still have a long way to go, but we have seen so much improvement."
ACT Today! is the brainchild of several parents with autistic children and professionals who saw significant progress with their children with certain types of treatment, primarily applied behavior analysts — more commonly known as ABA. Together, the group led by Dr. Doreen Granpeesheh — the pre-eminent expert in the world on ABA — launched the nonprofit to do just as the name implies: take action to make proven treatments more accessible to all families affected by autism.

“We make funds available immediately to the provider of services that the family needs for their child or children,” Alsipough-Jackson said. “Medical treatments for autism are not covered by insurance in most states. In addition, laws vary from state to state in regards to state funding for schools and behavior therapy.”

Autism is a complex developmental disability that typically appears during the first three years of life and affects a person’s ability to communicate and interact with others, according to the Autism Society of America. Autism is defined by a certain set of behaviors and is considered a “spectrum disorder” that affects individuals differently and to varying degrees.

“The biggest misunderstanding is that an autistic individual is mentally retarded, when in fact most autistics are of either average or above-average intelligence. They simply have deficits in communication and social skills,” Alsipough-Jackson said. Another illusion is that there is no hope for recovery. “And that is not true, as many children have been diagnosed and lose the diagnosis with early intervention and treatment. This is known as recovery rather than a cure.”

Yet another myth is that autistic children are all savants — brilliant in one particular area, such as music or mathematics. “Savants are in fact relatively rare.”

“One of the most effective treatments for autism is ABA, which is the only treatment that has had controlled studies that show a proven success rate,” said Alsipough-Jackson, noting that Dr. Granpeesheh has recovered many autistic children using this method and has produced a documentary on the subject. “Other treatments include occupational therapy, sensory integration therapy and speech therapy.”

While many autism nonprofits focus on research and autism awareness, ACT Today! does not, Alsipough-Jackson said. “We DO provide grants to families that cannot afford or access the treatment their autistic children need to achieve their full potential. Our impact is immediate, as there is an urgent need to help these families NOW, not in the future.”

Also, because the nonprofit is such a small organization with very low overhead, the funds go directly to the families. “We have only one full-time employee, several part-time; all the rest are volunteers,” Alsipough-Jackson said. “We don’t have the advertising and promotion costs that many national organizations require in order to survive. So instead of paying for an expensive ad campaign or nice offices, our donors’ money goes to helping these families get services, like behavior and occupational therapy, effective schooling, and medical treatments.”

Cyndi Burns of Louisville, Kentucky, discovered ACT Today! while seeking assistance to help pay for ABA services for her son who is not only autistic, but also has Down’s syndrome. “Insurance would not pay for ABA services,” Burns said. “ACT Today! called to tell me that my son had won the grant … this enabled us to have an ABA therapist work with him and improve his cognition, attitude and education.”

She further praised the organization for providing help based on the child’s specific needs. “Our son would not be on the road to improvement if not for ACT Today!” Burns said. “ACT … helped us help our son be the best person he can be. He has a voice and a right to be heard, but without ACT’s help none of this would have been possible.”

The organization also opened a world of possibilities for the son of Jammi Collier. “My income was low and I needed assistance getting my son the therapies that he needed,” said Collier, who lives in St. Louis, Missouri. “What makes ACT Today! so unique is that they are willing to give grants for ABA therapy, which in St. Louis is not covered by insurance companies. ACT Today has allowed us to provide ABA therapy for my son.” As a result, he has made great progress, “and ABA has been the reason for the progress that he has made,” Collier said. “ABA is a very expensive therapy that is a fully out-of-pocket expense for our family.”

Elizabeth Obrey of Springfield, Missouri, discovered the organization after a parent brought the information to her son’s school, the Rivendale Institute of Learning, which serves traditional students as well as students with learning disabilities, including autism.

“When we made the move to Springfield to be close to extended family, my husband’s practice failed and we have been struggling ever since,” Obrey said. “I spend a significant amount of time raising the funds for my son’s tuition. I am constantly looking at organizations that may be able to assist in tuition payments.” ACT Today! is the single most significant source of non-household funds for her child’s needs, Obrey emphasized.

“There are very few grant and scholarship opportunities for families with children with autism. ACT Today! has the least restrictions on what you can request funds for,” she said. “Each family’s needs are different and ACT Today! does not try to cookie-cutter our needs. They also are very respectful to our situation and make me feel like I am helping them by allowing their organization to be part of my family’s life.”

Organizations like ACT Today! are vital for families like hers, Obrey added. “Currently health insurance does not cover treatments … and schools are only required to provide appropriate education … which leaves families to fund their child’s treatments and therapies,” she said. “With the economy and the extreme expense that is required for the care of our children’s needs, many families are left to fight this battle on their own.”

Debra Ilray Merchant’s son attends a private specialized school for autism treatment, and its cost can total up to $60,000 per year out of pocket with no coverage from insurance. “Without grants, scholarships or donations, the majority of children with autism would not be able to receive these very helpful therapies that are out there for our children,” said Merchant, who lives in Ruffin, North Carolina. “I am very grateful to ACT for their support … they donated to my son’s school which helped to extend his stay there for several more months for the summer session. These therapies have been very helpful to progress my son.”

Most likely everyone today knows someone who has autism. Alsipough-Jackson said, “Autism is going to significantly affect our society as we need to educate and care for rising numbers of individuals with autism spectrum disorders. We are all going to be affected by this epidemic, and we all need to help in whatever way we can, whether we have an affected family member or not.”

For more information, visit www.act-today.org. yhc