

January - February 2003

AUTISM

ASPERGERS

DIGEST MAGAZINE

Outstanding Selections from Around the World

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**AUTISM &
BASEBALL**

New Jersey's Adam Jones

Survival Tactics For Raising A Special Needs Child

Autism & BASEBALL

Out of the Darkness

On to the Mound

An amazing and incredibly uplifting story is unfolding in the suburban town of Toms River, New Jersey. Adam Jones, a six year-old autistic child, is preparing to join his typical peers in Little League this Spring.

New Jersey's Adam Jones

Adam was born on December 20, 1996, the sixth child of Larry and Joni Jones. In January 1999, shortly after Adam's second birthday, two separate neurologists diagnosed Adam with autism. He had over 20 of the identifying characteristics including lack of speech, frequent head-banging, no pain sensation or temperature response, limited food intake, isolation and hand-flapping. He made no eye contact with other people, and exploded into violent rages with head-banging behavior so severe that he had to wear a special helmet to protect his skull from his own outbursts. (He still has marks on his head to this day) One prominent neurologist told Adam's parents that Adam was in all likelihood mentally retarded, and would never live independently. At the age of two, his future held little hope, and Adam seemed destined for a life locked in the darkness of his autistic world.

Adam's mother Joni recalled, "When we first received the diagnosis, we were overwhelmed. We had no experience with autism or how to deal with it. Our own family pediatrician told us he knew nothing about autism and hoped to learn from Adam's case. We decided very early on to educate ourselves by purchasing books, reading articles, obtaining information off the internet, and traveling to other states to attend autism conferences and meet with other parents of autistic children. We concentrated on finding autism success stories where parents were able to achieve significant progress for their young autistic children."

Adam's father Larry added, "During our research, we discovered two points which became the foundation of Adam's program over the next three years. First, studies showed that some autistic children made significant progress when they received an early diagnosis, followed by intense and consistent early intervention, including 30-40 hours a week in one-on-one behavioral therapy, as well as additional speech therapy and occupational therapy. Second, the risks of failing to intervene before school age are very serious. You cannot wait to see if a child will 'outgrow' autism.

The younger a child is when therapy begins, the better the chance of achieving meaningful progress."

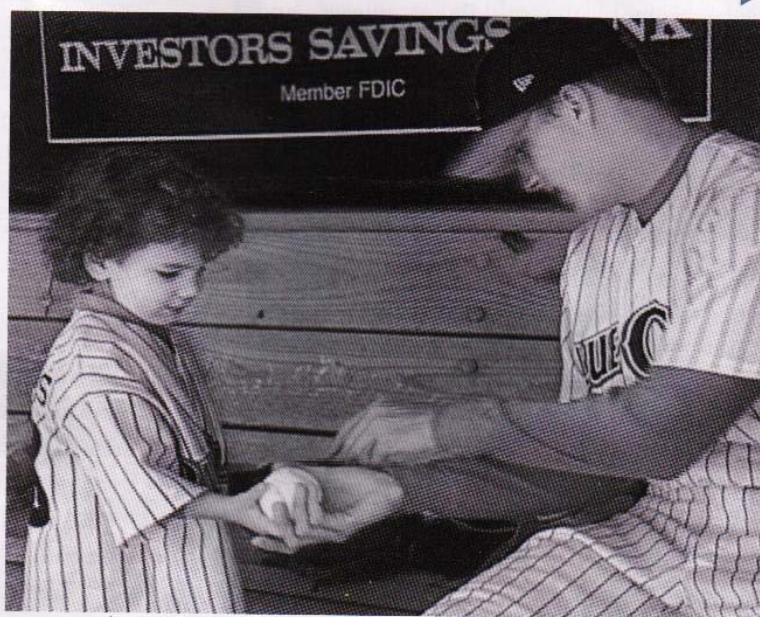
After accumulating information and meeting with other parents who had experienced success, Larry and Joni developed a game plan. Adam had the benefit of a very early diagnosis; his brain was still developing. His parents decided to invest all of their available time and money into as much early intervention as possible. They set up a schedule of intense behavioral therapy, speech therapy, and occupational therapy. They hired three different therapists to come into the home at different hours, seven days a week, to maximize Adam's exposure to therapy. Adam's older brothers and sisters were trained in very basic theories of autism therapy as well. Adam was bombarded with therapy all day long. He underwent AIT hearing therapy, an expensive program that required significant travel. The Jones family viewed it as an investment in Adam's future.

The intense intervention began to work. Slowly, Adam's aggressive behaviors decreased, and he

began to develop language and comprehension. His therapists then began to discover that Adam possessed advanced intelligence. At the age of three, he began to grasp concepts of math and reading. Adam was IQ tested at Rutgers University, and found to be highly gifted in abstract reasoning. With these results, the therapists intensified Adam's academic programming and developed with Adam's

parents a program of "community therapy," where Adam would be taken out into the world to learn how to interact with typical children in public environments such as libraries and playgrounds. Adam's progress continued to increase at a phenomenal rate.

Dr. Jan Handleman, one of New Jersey's leading experts on autism, has personally studied Adam's case history. Said Dr. Handleman, **"In the short span of two years, Adam has been transformed from a little boy who could not talk or interact with people into a precocious, captivating little boy.** While Adam still deals with the challenges of his autism, the self-injury of years past has been replaced with many strengths; all wonderful evidence that



when given the opportunity and appropriate tools for success, children with autism can maximize whatever their potentials might be.”

BASEBALL

Adam began taking an interest in baseball at the age of four, when his parents began using a ball with him as part of his occupational therapy.

Said Joni, “We started Adam with a bigger ball, throwing and catching to improve his hand-eye coordination and revising the size of the ball as Adam’s skills began to improve. The living room became his first playing field. Adam enjoyed our praises of his accomplishments, jumping up and down. As we increased distance, Adam began developing an accuracy in throwing the ball.”

One day, Larry took Adam outside to try having him throw against a black metal pitchback they had kept in their garage. “The pitchback had a square in the middle representing the strike zone,” recalls Larry. “I was very surprised when he started throwing strikes into the square. He just got better and better, **throwing 10 strikes in a row and then 20.** After that, baseball started becoming a regular part of his routine. I would come home from work every night in the middle of winter, and he would be standing there asking to go into the garage to pitch the baseball into the pitchback. He would wear an oversized winter coat with an old dusty baseball cap on his head and a mitt on his hand. Then his older siblings got involved and wanted to play too, everyone in winter coats and mitts. We switched to batting with a hard foam bat. Almost overnight a winter baseball league of sorts had formed in the middle of our garage, and Adam was the first one ready to play every evening.”

Adam began practicing throwing from a pitcher’s mound. “We would go to the local high school in Toms River on Sunday mornings,” recalls Larry. “The field was always

empty because it was still the off-season. Adam would be the pitcher, the umpire and the announcer. He basically called every pitch he threw a strike and would protest whenever I disagreed. Every time he finished pitching, he insisted on running victory laps around the entire baseball field while I waited to go home. It was difficult at times to keep up with his energy.”

During the winter of 2001, a local magazine had run a feature story on success in autism, spotlighting Adam and his gains from early diagnosis and intervention. The story was read by the front office of the Lakewood BlueClaws, the Class A minor league affiliate of the Philadelphia Phillies baseball team. The team contacted Adam’s parents and invited Adam to throw out the ceremonial first pitch at a baseball game the following year.

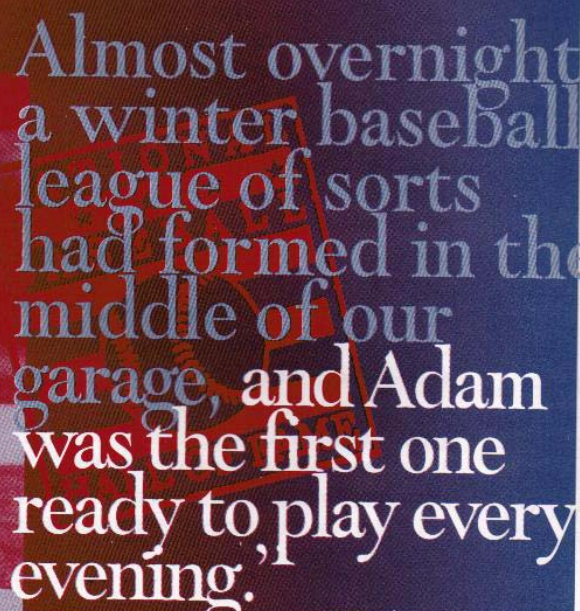
“On Adam’s behalf, my husband and I accepted the invitation and met with the BlueClaws’ management,” said Joni. “We suggested that the team develop an entire *Autism Awareness Day* as a public event for the entire autistic community.”

The team embraced the Jones’ suggestion and suddenly, the ball was in motion for professional baseball’s first-ever *Autism Awareness Day*. By game day, April 27, 2002, it had developed into the largest autism awareness event ever held in New Jersey. Over 6,000 fans were in attendance, including 800 autistic children and their families. Adam threw out the first pitch from the mound, tossing a strike to the BlueClaws’ catcher as the crowd cheered. Several autism organizations, including the Autism Society of America and Cure Autism Now, participated by distributing educational information to people in attendance. U.S. Senator Jon Corzine addressed the crowd and met with families of autistic children. The National Baseball Hall of Fame of Cooperstown, New York, presented a plaque

honoring baseball's first *Autism Awareness Day*, and formally recognizing Adam for having inspired the event. A class of autistic pre-school children came on the field to sing "Take me out to the Ballgame." The event received substantial press coverage, including an 8-minute TV news segment which was broadcast to over four million people in the New York metropolitan area.

With Adam's high interest and skill with baseball, and the natural teaching environment it provided for socialization and other people-connecting skills, the Jones family registered Adam for a summer baseball camp in Toms River. Said Larry, "We signed Adam up for baseball camp to see how he could function in an environment with all typical children. We planned to watch him carefully and have his longtime therapists observe him as well at the ball field, to monitor his conduct and interactions with the other children."

Added Joni, "Adam was a boy who had spent much of his life sheltered by the world of special education. While we had worked long and hard in taking mini-steps towards mainstreaming, it was important to finally test the water and see how Adam could handle himself in the real world without a safety net." (See Sidebar) Despite some difficulties,



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Standing on the Sidelines isn't always easy

During their search for information on autism, Joni Jones related that she discovered many options for treating the symptoms of autism when characteristics present more intensely. However, as Adam started developing and improving, going back to these sources she found very few options for programming when children are successfully overcoming the detriments of the disorder. What she did realize is the important role that parents play. "It is absolutely necessary for the primary caregiver to take an active role in formulating a plan of care that is not only very specific, but also very creative. It needs to be focused on your child, his strengths and weaknesses, and no book is going to lay it out for you."

As Adam progressed, the Jones family entered into another dimension, another tier in their management of autism. It required that they remain very observant and active in designing Adam's continued care plan. Joni adds, "What does become most frustrating are the obstacles that arise that can negate almost everything we strove for in those earlier years. When a child no longer presents with severe symptoms people tend to lose respect for the diagnosis. Some become non-supportive in their own comparisons, and we found that some educators didn't understand the continued need for special services."

"The biggest surprise was how difficult the social world would be. Adam was soon to enter baseball camp and was so excited. He was usually the 'top' of his class, always well liked and always supported and respected by his peers. He attended an integrated pre-school program and was viewed as the 'social butterfly.' We too, were excited as this was Adam's first adventure to a setting that consisted of all 'typical' boys. It was a rude awakening."

"What we didn't fully realize was the impact that being sheltered by the world of special education would have on Adam, and on us. We did not realize how active and vivacious little boys are upon entering the "real" world. Yes, we had done all the mini-steps toward mainstreaming, but this was baseball camp, with lots of healthy, active little boys, with no care in the world beyond their moment of camp. We quickly realized that Adam's accomplishments would mean very little in this new setting."

"At times, camp was difficult for Adam. He was a stranger to the other boys; some began to pick on him, calling him 'girl' because of his curly hair. Another boy pushed and shoved him. At first he tried to advocate verbally for himself, saying 'Oh yeah, well you don't know negative numbers!' Although

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Adam made it through baseball camp and graduated with his typical peers, proudly receiving his diploma at the camp graduation.

Adam's baseball skills continued to develop, and his parents created a small makeshift field in their backyard where Adam and other children could practice and play.

"We picked up some bases, rubber-coated practice baseballs, and used mitts from a second-hand sporting goods store," said Larry. "We set up the field in the backyard. Almost every day in the summer, Adam was outside pitching or hitting. Sometimes he would play outside with his therapists' children of the same age range and actually try to teach them how to hit or throw."

What's next on the horizon for Adam? He's eligible for Toms River Little League T-ball in the spring of 2003, when he is six years old. While Larry and Joni are unaware of any other autistic children in the traditional Little League program, this does not change their plans in any respect.

"There's a first time for everything," says Joni. "Yes, there will be challenges and obstacles along the way. But he wants to play and we will do everything to give him that opportunity. Everything Adam has accomplished to date has been the product of discipline and consistency. Adam loves to practice baseball, and we will be practicing with him throughout the winter at an indoor batting cage. He has an amazing ability to focus, and will be ready on Little League's Opening Day to represent the autistic community on the playing field."

Editor's Note:

This piece is a sequel to the back cover segment on Adam Jones, featured in our July-August 2002 issue of the magazine. It's a testament to the powerful results of intensive early intervention and using a child's innate abilities and strong interests as a natural teaching environment, one that can be highly self-motivating.

If you have a success story you'd like to share with our readers, email it to submissions@autismdigest.com or send it to the magazine at PO Box 337, Little Falls, NY 13365. Submission guidelines are available on our website, www.autismdigest.com

inappropriate, it was nice to see the puzzled look of confusion on the bully's face. When the pushing and shoving started, Adam just covered his face and looked down. He never was a physically aggressive child, so closing his eyes to make everything go away was probably an age appropriate thing to do."

"Nevertheless, I shadowed by the sidelines and was not going to intervene. My son depended on us to teach him, and being protective and sheltering were not always optimal initial responses. Adam is autistic, and therefore does not learn things that typical children might grasp more incidentally. I needed to learn his strengths and his weaknesses if I was going to help him long-term."

"I also was able to observe my son's lack of understanding how the game is actually played. It was an important lesson for me and Larry. We never guessed that kids at camp could be so unforgiving of Adam's challenges. We should have taught Adam the basic skills of the game prior to placing him in a situation with this level of social demands. For example, Adam was positioned in right field. When the ball came into right field he just watched it go by. I verbally prompted him to run after the ball. Well guess what? When the ball was hit to 3rd base, Adam ran to 3rd base. Of course, I immediately realized his literal translation of what I said and broke it down further. I gave him his designated space. Everything was going along fine until another little boy left his position on the field and went into Adam's space. Tears broke out at that point."

"I took the time to mention all of this because it reinforces our need to be involved and to be keen detectives about the world around our children. Observing Adam in camp allowed us to take information back to his program coordinator and write up problem solving programs. My husband took him to the backyard and worked on developing his needed skills. I can't even express the excitement on this little boy's face of how proud he is of his achievements now. Proud - I can remember when we were using picture cards teaching him what proud meant. Now I see that he can actually feel it."

"If I had to sum everything up, I guess I would say never, ever set expectations low. Our kids can achieve things that many people, including autism 'professionals' may think unachievable. Adam is the perfect example of this. So much of what we need to know about how to teach them is right here, sitting at our fingertips. It just takes a little ingenuity and a lot of effort."

"For Adam, baseball is just not a game; it's an experience - one that can 'put it all together' and not limit him to four walls or the confines of a table or classroom setting. Find whatever it is that does that for your child. It's there; you just need to look hard enough and long enough to find it. But when you do, your life, and your child's will never be the same."