

Weap: The People

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A-maze-ing Maize

By Justin Sallows

Wisconsin Early Autism Project



On October 3rd and 4th, Treinen Farm hosted the A-Maze-ing Days of Autism. Visitors enjoyed a vast corn maze cut in the image of a mermaid and underwater environment.

Alan Treinen is the third generation to farm the Treinen Farm just five miles west of Lodi, Wisconsin. The eighth of ten children, Alan relies on the help of his close extended family to farm the 200 acres. The farm produces hay, corn, soybeans, free-range chickens, beef, pork, and of course the popular corn maze and pumpkin patch.

Alan and his wife Angie have two sons, Patrick (age 7) and Thomas (age 11). Thomas has been diagnosed with Aspergers.

Like all parents, the Treinens were getting to know the person their child was going to develop into, so at first they didn't recognize Thomas' behaviors as being out of the ordinary. Angie elaborates "Thomas spoke very early and precociously. He was lecturing people about the correct pronunciation of words and about the technical aspects

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How Health Care Reform Affects Autism Insurance

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Autism Speaks was founded in February 2005 by Bob and Suzanne Wright, grandparents of a child with autism. Bob Wright is also the former Chairman and CEO of NBC. Bob recently spoke of this journey towards the coverage of autism services by insurance.

Autism Speaks has grown into the nation's largest autism science and advocacy organization. They are dedicated to funding research into the causes, prevention, treatments and a cure for autism. Their goals are also to increase awareness of autism spectrum disorders and advocate for the needs of individuals with autism and their families.

Bob is alarmed by the recent rise in autism rates. "We've got new numbers now", he explains. "The new numbers are basically 1%, 1 in 100 children have autism. 1 in 58 boys. We're in territory here we never expected to be in, even when I got involved in this. We're going to be down to the common cold here pretty soon, the prevalence level is so high."

One theory for how these numbers have exploded is that the definition of autism has opened up to

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of all construction equipment known to man by the time he was 3." Over time they began to suspect something was different. "Thomas had somewhat unusual speech. He spoke very precisely and with a slightly choppy pattern. A few other things that we recognized in hindsight were his lack of facial expression much of the time compared to his younger brother, his intense special interests, one-sided conversation and minimal eye contact."

The Treinen's began to realize that something was out of the ordinary and this caused them severe stress as the time to register for school loomed. "I literally started having panic attacks over planning for Thomas to enter kindergarten.", Angie says. "Several acquaintances independently mentioned to us that we should consider having him screened for autism."

The Treinens began researching Autism and discovered that the list of characteristics matched Thomas' behavior almost exactly. Subsequently they were referred to a Psychologist by their family Pediatrician and Thomas was diagnosed just before he turned 6.

Having identified the problem, the Treinens set about treating it. Angie says their local school district has been an immense help to her son. "Thomas began receiving services through the Lodi Schools in kindergarten, and the school district has been very supportive and helpful. We have tried many strategies to keep him engaged in the classroom and functioning independently at home and school." At one point they received a revelation. "Thomas was re-evaluated by Neuropsychologist Nancy Viscovich, and she felt that he also had symptoms of Attention Deficit Disorder. At first, I was extremely skeptical, but when we did a medication trial, the difference in his functioning at school was incredible."

The Treinens continue to work with the school to develop strategies for keeping up with the class and learning to function more independently. With the help of an educational assistant for most academic subjects, Thomas is doing grade level work. Angie continues, "We are working specifically on organizational skills, techniques to stay on task and motivated, as well as providing accommodations such as a laptop so he can type rather than write, sensory breaks, and lots of flexibility in the classroom." When Thomas' IEP is due, he is also seen by Autism Consultant Glenis Benson for more insight and opinion. "She has been a terrific help", declares Angie.

The Treinens also work with Thomas at home. "Sometimes we'll have "Speech Class" where everyone role plays social situations." Angie has found that Thomas isn't the only one that benefits from such experience. "It's made me realize that we can all use a little practice in listening, greeting people, conversational skills, etc."

Thomas has developed friendships with peers at school and through Cub Scouts. Angie explains, "Since we live in the country, we have to make a point to schedule times for someone to come over, but we do that every now and then."

Anyone who has visited the Treinen farm can see that Thomas has a wonderful, large and close-knit family. "Thomas' cousins Joe (age 8), and Jake (age 11) spend lots of time at our farm, so it's almost like having two extra brothers. This also provides opportunities to practice social skills."

Angie says that Thomas is able to connect with his peers with little problem. "His special interests tend to be pretty age appropriate and he can talk at length about Star Wars, Pokémon, or Bakugan."

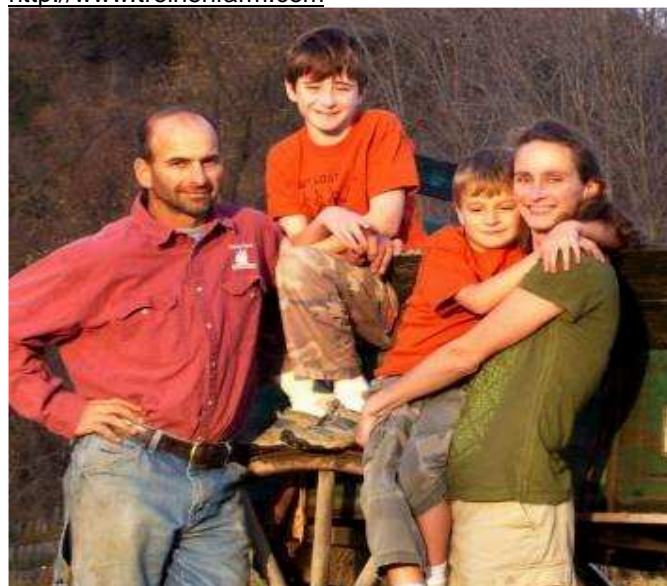
According to Angie, Thomas is still a bit shy around the general population. "He prefers to help behind-the-scenes at the farm, so he'll help me in the office or help take care of the baby chicks, etc."

The Treinens know they aren't out of the woods yet. "Thomas will be in middle school next year, and I'm apprehensive about that." says Angie, "Partly because of the more complex social milieu in the middle grades, but also because of the greater need for independent functioning."

One thing is for sure; Thomas Treinen couldn't ask for a better support network than his lovely family.

The Treinen Family Farm is located five miles west of Lodi on Highway 60. The pumpkin patch is available through Halloween while the corn maze and other attractions operate through November 15th. See website for details, pricing and directions.

<http://www.treinenfarm.com>



The Treinen family. From left to right: Alan, Thomas, Patrick and Angie.

encapsulate more people. Bob has an answer for that. "There has been no expansion of the definition of autism in the last 15-18 years. There's also been no change in the diagnosis procedure. So that sounds like something that's reasonable to say but it's just not true. Now I think that there is a certain percentage of children that are probably given earlier diagnoses but they're going to be in there anyway. These studies don't deal with 1-year-olds, they deal with 7 to 8-year-olds. Autism fully presents itself by the time you're 3. What has happened is that there's more awareness of it. There is a willingness for people to go out and seek a diagnosis, but there is an unexplained level of increase."

Bob is very hopeful about the future of autism research and therapy. "We have a great supporter in President Obama. It's very fortuitous. He happens to know a great deal about it [and is] very forthright. One of his campaign pledges, as a matter of fact, was that he was going to help increase the funding for autism at the Government level up to 1 billion dollars a year by the time his first term was over (W:TP Vol.2, Is.5). So that started us very big. He has made it one of his three priorities, along with heart and cancer. He's allocated almost 90 million dollars of stimulus money to the NIH for autism research."

Two years ago, Autism Speaks launched the Autism Votes initiative to help direct grassroots activity for passage of autism insurance reform legislation in the states.

This initiative has been very successful. "We've got 15 states to pass insurance bills to make sure that autism is covered. We have 51% of the population in states now covered by insurance."

Autism Speaks also launched a campaign consisting of both print and television advertising calling on the community to contact congressional leaders and urge their support for the autism insurance reform amendments in the Federal health reform bills now moving through Congress. (You can see and watch these ads at www.autismvotes.org)

This campaign has tapped into the power and dedication of the autism community. Parents and advocates have been incredibly committed and involved every step of the way in getting amendments into the current health care reform bills.

These supporters have had to answer an oft repeated accusation that it will raise costs across the board. "It's inconsequential, the cost to do this.", Bob says, "And there's a real benefit to the state too. It gives a chance for these kids to matriculate into a public school at or near age level. If you are diagnosed in 1st grade, your chances of matriculating through that school system are very, very slim. Schools are catching up to this. They're putting pressure on it."

Hard work paid off and we now have amendments prohibiting discrimination of benefits for people with autism that have been included in both the House and Senate bills to reform health care. Behavioral health treatments are now part of the essential benefits package that has been added to the House Energy and Commerce Committee bill, the America's Affordable Health Choices Act (HR 3200) by Congressman Mike Doyle (D-PA) and the Senate Finance Committee bill, the America's Healthy Future Act (S 1796), by Senator Robert Menendez (D-NJ).

"Both the house and the Senate have a basic, fundamental view of insurance, which has a series of essential benefits in it.", Bob explains. "There's a lot of conversation about pre-existing difficulty or causes. That's in there (Federal Health Reform bills). You can't block people from having [health insurance]. There's a lot of blocks in state insurance laws from many years back. This federal law undoes those blocks. So we are a beneficiary with autism because first of all it says that you cannot deny a person with autism. Right off the bat the discrimination is gone. And secondly it recognizes behavioral therapies. It allows parents to get reimbursed for speech therapy, and occupational [therapy], which go on forever."

Bob concludes, "This is going to be a big change. It doesn't unfortunately take effect until 2013, but we're moving. The states are taking effect right now."♦



States with Autism insurance coverage: Arizona, Colorado, Connecticut, Florida, Illinois, Indiana, Louisiana, Montana, Nevada, New Jersey, New Mexico, Pennsylvania, South Carolina, Texas, Wisconsin

Madison Lost & Found

If you are missing any items, please feel free to check the "Lost and Found" in the Madison clinical reception area. We have several items that have been found over time. Please feel free to call Andrea Gugel, Madison Scheduling Coordinator, at (608) 288-9040 if you feel that you may have left an item behind at a recent appointment.

