



ASGC Newsletter

From The President's Desk

Dear Members,

Right now is a critical time for the ASGC, the ASA and anyone affected by autism.

By now you most likely know that we have outgrown our old location at St. Basil's Church and will move to our new home at the Cuyahoga Valley Career Center in January, with no meeting in December.

Sadly, we have just learned of the passing of our parent organization's founder, autism pioneer Dr. Bernard Rimland, of cancer on November 21 at the age of 78.

Just prior to his death, the two organizations he began, the Autism Society of America and the Autism Research Institute announced a new partnership that will have nation-wide implications on autism treatment and information distribution. We will keep you informed.

Recently autism has been the cover story of the most circulated national news magazines and special reports with the topic of autism have run on cable and broadcast news networks.

ASGC Meeting Time and Place

The ASGC now meets at 6:30 P.M. the first *Tuesday* of every month at the Cuyahoga Valley Career Center on 8001 Brecksville Rd. Our next meeting will be Tuesday, January 2. There is no December meeting. Anyone who is affected by, has a loved one affected by, or just wishes to learn more about autism or autism spectrum disorders is welcome to attend.

**For more information, please call:
(216)556-4937**

All this while a local couple takes their fight to represent their autistic son all the way to the Supreme Court.

In these days where autism awareness is increasing and the nature of the entities that lead us are rapidly changing, it is more important than ever to underscore our role as the local support organization that looks to be the source that binds other local autism organizations together. We act as a non-biased clearing house of information on autism and autism spectrum disorders. We believe that much more often than not, the parents of an autistic child are the preeminent experts on that child. Mostly we believe that there is hope, more than ever before, that autistic children can grow up to be happy and productive autistic adults.

As we near the end of our eight-month strategic planning process, we feel our vision for the future comes at a crucial time. We are energized and emboldened by that vision originally authored by our President, Rory McLean and now refined in a clear set of objectives by our future board members and our most able facilitator, Mr. Tom Romito.

We have too many people to thank and too little space to do it with, but you all know who you are. If you would like to join us, become a member of the ASGC by sending a check of only \$5 to the address on the back of this newsletter. Join us today and together we will change lives.

Sincere thanks-
Gus Gallucci, Vice President

Autism Society of
Greater Cleveland

November/
December 2006

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Autism Society of
Greater Cleveland
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We can be reached
at:
(216)556-4937

Autism Society of America mourns loss of Dr. Bernard Rimland

Dr. Bernard Rimland, ASA founder and pioneer in autism research and support, to be honored by community he founded

The Autism Society of America (ASA) announces with profound sympathy today the death of its founder, Dr. Bernard Rimland.

A pioneer in the area of autism diagnosis and treatment, Dr. Rimland transformed the prevailing pessimistic view of autism in the medical and scientific community and built the largest parent support organization in the United States.

Along the way, he inspired hundreds of thousands of parents, advocates and professionals to treat individuals with autism with respect, dignity and care.

"Bernie Rimland was among the first to realize the importance of combining a focus on medical interventions with treatments, supports and services," stated Dr. Cathy Pratt, ASA Board Chairperson. "There is not one parent or professional who has not been impacted by the knowledge, dreams and thinking of Bernie Rimland."

Dr. Rimland's 1964 book, "Infantile Autism: The Syndrome and its Implications for a Neural Theory of Behavior," was responsible for challenging and changing the long-held belief that autism was an emotional disorder caused by poor mothering. Autism is now recognized as a biomedical disorder.

Rimland devoted himself tirelessly to conducting and disseminating the results of research on methods of diagnosing and treating the full spectrum of autism. These treatment modalities, once considered radical, are now gaining wide acceptance as the news spreads about formerly autistic children who have been reclassified as normal.

Dr. Rimland's determination was spawned by his own son's diagnosis of autism, at age two, in 1958.

"Dr. Rimland was a hero to the autism community and his legacy will live on through the work of the Autism Research Institute, the Autism Society of America and the good work of others," said Lee Grossman, President and CEO of ASA. "No one has done more for Autism

than our founder, Bernie, and all in the autism community have been positively touched and have benefited through his decades of passion and dedication to our cause."

A private funeral will be held in San Diego, California.

See <http://www.signonsandiego.com/uniontrib> for a fine article on Dr. Rimland by Jack Williams in the November 22 edition.

Aides sought for Local Parish

The Autism Society of Greater Cleveland is looking for in-class aides for autistic children. While we have an ongoing need for volunteers in special education programs, this is an example of a more immediate need:

The children we need aides for attend PSR at St. Basil's church in Brecksville. They are second graders. They go 2-3 Sundays a month from 10:30 to 11:50, so we would be looking at 10:15 to Noon for anyone who could help.

They have been disruptive in class due to behaviors typical for a child with moderate autism (noises and self-stimulating behavior or "stimming"). They are just good little guys that need some in-class direction.

We would be happy to provide an "Autism 101" for any interested individual, and are ready to start immediately. We are all volunteers and provide our services at no charge. We are looking for a bright, compassionate individual with an interest in special education who would do likewise. A student of special education is preferred.

If this does not work with your schedule, we have other students that need your help as well.

Thank you on behalf of St. Basil's and the ASGC. Anyone interested can reach us via: support@asgc.org, at 216-556-4937 or Mary Ann Webb directly at St Basil's: 440-526-3520.

Local Parents take Autism Case to High Court

WASHINGTON (AP) Oct 27- The Supreme Court agreed Friday to consider an appeal from an autistic child and his parents, who want to sue over his school accommodations without hiring a lawyer.

Jeff and Sandee Winkelman say they cannot afford an attorney to argue their court case against the Parma, Ohio, school district over the education of their son, Jacob.

The 6th U.S. Circuit Court of Appeals ruled that the parents had to find a lawyer, although other federal courts have ruled differently in cases under the Individuals with Disabilities in Education Act.

The Bush administration urged justices to take the case, saying Congress clearly intended parents to be able to represent their children in such court proceedings.

The Winkelmans contested Parma's plan to educate Jacob at a public school. They wanted the district to pay for his \$56,000 yearly enrollment in a private school that specializes in educating autistic children.

Whether Jacob should have private schooling at public expense is not before the Supreme Court, only his parents' right to go into federal court without a lawyer.

The Winkelmans have spent about \$30,000 in legal fees since first contesting Jacob's treatment in 2003. Jeff Winkelman has taken a second job while his wife has researched previous court rulings and written her own filings.

The case number is Jacob Winkelman v. Parma City School District, 05-983

This landmark case with local parents has connections to a recent case with an Akron area family.

The following is from May 6, 2006:

Non-Lawyer Father Wins His Suit Over Education, and the Bar Is Upset

By ADAM LIPTAK, NY TIMES

Several years ago, Brian Woods sued the school board in Akron, Ohio, on behalf of his autistic son Daniel. Mr. Woods wanted to make sure that Daniel received an appropriate education, and he won several concessions and about \$160,000. "I soundly defeated a team of lawyers," Mr. Woods, an adjunct professor at Cuyahoga Community College, said yesterday.

When the Cleveland Bar Association got wind of Mr. Woods's victory recently, it also went to court - to sue Mr. Woods.

The bar association said he had engaged in the unauthorized practice of law. It sought a \$10,000 fine, lawyers' fees and a promise that he would not continue to assist other parents seeking to represent their own children in court.

The Ohio Supreme Court was not impressed. On April 20, it ordered the bar association to produce evidence by next week in support of its complaint, saying the available facts suggest that Mr. Woods "has not engaged in the unauthorized practice of law."

With that deadline looming and after reports on the controversy in The Plain Dealer in Cleveland, the bar association backed down. Sort of.

In a statement on Wednesday, its president, P. Kelly Tompkins, said the complaint against Mr. Woods "had a legitimate, technical basis." Mr. Woods did, after all, represent someone else in court - his son - without being a lawyer.

The filing of the complaint was nonetheless a mistake, Mr. Tompkins said, withdrawing it and apologizing to the Woods family. The association should not have considered filing the complaint, he said, until after the United States Supreme Court acted in a case it might decide to hear this month.

That case involves two other Ohio parents, Jeff and Sandee Winkelman. In November, the federal appeals court in Cincinnati gave the Winkelmans, who had been representing their autistic son Jacob in a suit against the

Continued on page 4

Parma, Ohio, school district, 30 days to find a lawyer or have their case dismissed. Justice John Paul Stevens issued a stay of that order in December.

Federal courts around the country are divided over the circumstances in which parents who are not lawyers may represent their children in federal court under the Individuals With Disabilities Education Act.

Ms. Winkelman said the ruling of the appeals court effectively barred the courthouse doors to her son. Her family, she said, simply could not afford a lawyer.

"One quoted \$60,000," Ms. Winkelman said. "She wanted \$2,600, biweekly. I was in tears. I decided to go on my own. We had no money, and we had nowhere to send Jacob to school. When you're in a do-or-die situation, you do what you have to do."

Christina H. Peer, a lawyer for the Parma district, said there were good reasons for requiring that only lawyers might handle such cases. "People who are not attorneys cannot represent the interests of another in a court of law," Ms. Peer said. Where disabled minors are involved, she added, courts should be even more reluctant to let others, even parents, speak on the minors' behalf. "Do they have the skills," Ms. Peer asked, "to adequately represent the rights of their children?"

A lawyer for Susan Woods, Daniel's mother, said he was furious that the bar association had pursued charges of unauthorized practice of law against her and her husband. "I'm very angry about it," the lawyer, Allan M. Michelson, said. "I'm upset that my fellow attorneys should spend their time like this."

In an interview, Mr. Tompkins of the bar association sounded conciliatory. "Our board had not approved this filing," he said. "We had a breakdown internally on this."

But he refused to rule out the possibility of further action after the Supreme Court acted in the Winkelman case. "We'll stand down until it's resolved," Mr. Tompkins said.

Mr. Woods said he suspected that the peace might be temporary.

"The issue is," he said, "to shut me up so that I can't beat them again."

OCECD may be a valuable resource for children with disabilities, their parents and associated professionals and groups

The OCECD is an organization that strives to be a valuable resource for both individual parents, professionals and groups. OCECD is a statewide, non-profit organization dedicated to advancing the educational interests of children with disabilities. OCECD's staff, many of whom have children or other family members with disabilities, are available to assist individuals or groups with such areas as:

- Public policy and school reform
- Identification of disabilities
- Early intervention for infants and preschoolers
- Family support systems
- Special education
- Community based services
- Information, referral and networking services
- Transition from high school to employment/college in the community
- Resources for professionals
- Team work between persons with disabilities, their families and service providers

Tools used by OCECD to provide assistance include:

- One-on-one consultation
- Group presentations and training sessions
- Numerous published materials, including a bi-monthly newsletter

OCECD also collaborates with local parent support organizations to offer information, training and support to parents of children with disabilities. They are also responsible for coordinating the Parent Mentor Program.

You can check out their publications, training schedule (which is quite extensive and runs all over the state), and more information at their website www.ocecd.org. You can also get more information on the Parent Mentor Program and a directory of Parent Mentors at <http://thelinkto.com/parentmentor/>.

Ohio Coalition for the Education of Children with Disabilities

Marion, OH 43302-3741

Phone: (740) 382-5452 or (800) 374-2806 (in Ohio)

Fax: (740) 383-6421

E-mail: ocecd@gte.net

OCECD-Cleveland Office:

440-617-9544 - Office

440-617-9547 - Fax

Autism Society of America and Autism Research Institute Announce Partnership To Address Epidemic

The following was published by the ASA just before Dr. Rimland's passing. We hope to keep you updated on the progress of this new partnership.

Two organizations founded by Dr. Bernard Rimland join together to promote cutting-edge research and service delivery in the autism community.

The Autism Society of America (ASA) and the Autism Research Institute (ARI) today announced a strategic partnership to collaborate on conferences, publications and services that will improve the lives of all those affected by autism in the United States.

By joining forces, ASA and ARI aim to continue the important stewardship of their founder, Dr. Bernard Rimland. A pioneer in the area of autism diagnosis and treatment, Dr. Rimland transformed the prevailing pessimistic view of autism in the medical and scientific community and built the largest parent support organization in the United States.

"Bernie Rimland was among the first to realize the importance of combining a focus on medical interventions with treatments, supports and services," stated Dr. Cathy Pratt, ASA Board Chairperson.

"There is not one parent or professional who has not been impacted by the knowledge, dreams and thinking of Bernie Rimland. The ASA/ARI partnership is our way of ensuring that Bernie's vision will continue to guide the autism community for the long-term."

A major purpose of the ASA/ARI partnership is to promote awareness that autism must be treated as a whole body condition. Projects in 2007 will include biomarker conferences, distribution of scientific journals and collaborative efforts to serve over 100,000 members and supporters of these two organizations.

"I founded ASA in 1965 as a parent advocacy organization to work on behalf of autistic children and their families at local, state, and national levels," said Dr. Rimland.

"I founded the Autism Research Institute in 1967 to conduct and sponsor scientific research on the cause and treatment of autism. ARI, through its Defeat Autism Now! (DAN!) project, has made enormous progress in the past few years.

Hundreds of the DAN! doctors and thousands of parents world-wide have reported bringing dramatic improvement, and sometimes recovery,

of formerly autistic children. It is clearly time for ASA and

ARI to capitalize on the progress that has been made. My colleague, Dr. Steve Edelson, with whom I have worked for 25 years, will play a major role in these efforts." Lee Grossman, President and CEO of ASA, and Edelson, Associate Director of ARI, will oversee this strategic partnership.

ASA is the largest parent-based, autism organization in the U.S., with over 100,000 members and supporters and 200 local chapters. ARI, with over 70,000 supporters nationwide, has pioneered the study of medical problems of individuals with autism and effective treatments.

ASA is dedicated to increasing public awareness about autism and the day-to-day issues faced by individuals with autism, their families and the professionals with whom they interact. For more information on autism or ASA, visit :

<http://www.autism-society.org> .

ASA to Serve as Association Partner for 6th Annual National Inclusive Schools Week, December 4-8, 2006

Week Celebrates Progress of Nation's Schools in Providing Services to Students with Disabilities

National Inclusive Schools Week highlights and celebrates the progress of our nation's schools in providing a supportive and quality education to an increasingly diverse student population, including students with disabilities, those from low socio-economic backgrounds, and English language learners.

The Week also provides an important opportunity for educators, students, and parents to discuss what else needs to be done in order to ensure that their schools continue to improve their ability to successfully educate all children.

ASA will serve as an association partner of this year's National Inclusive Schools Week.

More information on this and other ASA activities can be found at: <http://www.autism-society.org> .

Fathers Make Important Impact on Language Development

In families with two working parents, fathers make important contributions to children's early language skills.

Results from a new study by FPG Child Development Institute show that children whose fathers' vocabulary was more varied when they were two, had greater language skills at age three.

Mother's vocabulary was not found to have a significant impact on children's language skills.

The findings are published in the November/December 2006 issue of the Journal of Applied Developmental Psychology.

Most previous studies on early language development focused on mothers. However, with more women in the workforce and the changing role of men in families, children have greater interactions with their fathers and others in the community. \

The study is the first to consider the father's role to better predict children's expressive language development at 36 months of age. In addition to parent language interactions, the study considered parent education and child care quality.

Parent Language Interactions

Mothers and fathers interact differently with their children. For example, studies show that fathers tend to spend more time playing and being physical with their children, while mothers tend to spend more time talking and giving directions. Little research exists, however, comparing how mothers and fathers talk to their children and what that might mean for the child's language development.

Findings

- Children whose fathers used more varied vocabulary at 24 months had better scores on an expressive language test at 36 months.
- Fathers' vocabulary accounted for 9 percent of the variance above and beyond education level and quality of care.
- A father's vocabulary when the child was 24 months was the only parental language variable to make a significant independent prediction to later child expressive language development. The mother's vocabulary did not make a significant contribution to children's later expressive language development.

- Fathers spoke less frequently to the children in the videotaped play session and used fewer words. They also took fewer total conversational turns.

- Parents asked the same proportion of questions and question types.

- A secondary finding of this study was that high quality child care during the first three years of life was associated with higher scores at 36 months on a test of expressive language development.

To Learn More:

"Mother and father language input to young children: Contributions to later language development?" appears in the November/December 2006 issue of the Journal of Applied Developmental Psychology. Authors are Nadya Pancsofar and Lynne Vernon-Feagans from FPG Child Development

The ARC

The Arc is the national organization of and for people with mental retardation and related

developmental disabilities and their families. It works to promote and improve benefits, supports and services for children and adults with mental retardation and related disabilities so that they can live with their families and in the community.

There are volunteers across the county and staff in Washington, D.C. who work hard to help ensure that families have access to benefits, supports and services.

The Arc has about 1,000 state and local chapters across the U.S and about 140,000 members.

For more information Go to <http://www.thearc.org> and click on the "Locations" button. This will give you the contact for your nearest chapter and a link to its website.

Chapters offer different supports and services, but they all provide basic information or will refer you to other agencies.

One Woman's Insightful Take on the Winkelman Case

By Susan Senator

Unlike the Winkelmans, the Ohio family that will appear soon before the Supreme Court, I have not yet had to sue my school system over my severely autistic son's education. The Winkelman case is an interesting twist on guilty until proven innocent - or, incompetent until proven able -- and the family will have to prove to the Court that they are capable of legally representing their son.

I am an autism parent, so I already know the answer to this question, even though I have not had cause to fight my district for services. I live in a town which has been willing, over the years, to send my son to different private school programs specializing in autism. I was lucky but I did not feel lucky. For years I struggled with Nat's reluctance to speak, his aggressive behavior, and my inability to understand and connect with my son. We have frequently turned to teachers and therapists for answers. Nat's school follows a behavioral model, which uses positive reinforcement and also redirection of energy and attention as a way of encouraging appropriate behavior. This approach ultimately helped him get his behaviors under control.

But the day when everything changed had nothing to do with pedagogical theory or professional training. Nat was thirteen, and along with occasional flare-ups of pinching and hitting, he had developed a particularly grating behavior: loud, fake laughing. I grew to hate the sound of my son's giggles, and was particularly annoyed by the irony of his middle name: Isaac, which in Hebrew means, "He will laugh."

Nat's teachers urged me to redirect his inappropriate laughter by having him file cards alphabetically every time he did it as a way of channeling his laughing behavior into something quiet and fairly productive. Although the card filing worked - it seemed to stop Nat's laughter cold while he shuffled his cards into order - it made me sad. I realized that what I really wanted was to be able to teach Nat about things that are funny and good, and things that are not; I didn't want simply to block him. But how do you teach something as complex as good laughter, bad laughter?

One evening I was particularly exhausted when the laughing started. I sank into the couch next to Nat and I did not bother reaching for the filing cards. I felt worn down by his efforts to bug me and all I could feel were tired tears forming, and a heavy vulnerability. I looked over at Nat and studied his wide grin, sparkling with silver braces. My heart softened a little, as it does whenever I take a moment and let myself really look at my children's faces. I said, "What is it, Natty? What is so funny?" I poked him and he flinched, but he was smiling.

I started tickling him, giving myself over to our giddy play. He wiggled around and laughed, but now we were both laughing. After a few moments, he stopped laughing and he just looked at me, then away. He was calm.

There are so few moments in parenting when you really know something. But just then, I knew, irrevocably, that Nat had been trying to connect with me with that ridiculous laughing, and that he needed me just as much as I needed him. It changed me forever, how I felt about Nat, and how I dealt with him. It changed us both.

With autism in my life, I have learned to be an expert on my son. Most parents are experts on their kids, but autism parents have to learn how to recognize and analyze some pretty intense problems, and respond competently. After so many years of living with autism, I can say that I have had some pretty rigorous training in problem-solving, by experts and school professionals. However, some of my best responses have come strictly from the heart, simply because as his mother, I yearn for things to be good between us.

I think most parents would agree that the best way to reach a child, autistic or not, is finding just the right mixture of heart and brain. We need the professionals, but we also need to trust our gut. Because of what I know about autism parenting, I would be willing to bet money that if the Winkelmans have come this far, all the way to the Supreme Court, and with autism in their lives, they are more than adequately capable of representing their son without a legal expert. In fact, I'd be willing to bet a whole pile of very valuable filing cards.

Susan Senator is a freelance writer

Autism Society of Greater Cleveland

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"From Diagnosis Through Adulthood"

The ASGC is a 501(c)3 non-profit,
all volunteer organization.

We welcome your support!

To learn more, call us or log on to:
www.asgc.org

The information in this newsletter is for educational purposes only. The Autism Society of greater Cleveland does not endorse or oppose any specific product, method of therapy or organization. Our aim is to provide information that assists our membership to make informed decisions. Thank you for your support!

Upcoming Autism Conferences in Ohio

"Critical Issues for Adolescents on the Autism Spectrum"

[Cleveland, OH ~ January 17-18, 2007](#)

[Holiday Inn Cleveland West](#)

1100 Crocker Rd.
Westlake , OH
(440) 871-6000

A block of rooms has been reserved for \$69+ tax per night. Rooms are limited.

Special Parent Price!

2 Days: \$160 1 Day: \$95

Spectrum Training Systems, Inc.

2024 Jonathon Drive
Appleton , WI 54914

Phone: (920) 749-0332

Fax: (920) 882-0736

Website: www.spectrumtrainingsystemsinc.com
