

# AUTISM OUTLOOK

NEWS AND INFORMATION FROM THE KELBERMAN CENTER

Autism Services Across the Lifespan

VOLUME 1 ISSUE 2

FEBRUARY 2006

## Upstate Cerebral Palsy's Promise Program Selected as Research Site

The STAART Center of the University of Rochester has expanded its list of participating sites in a multi-year research project examining the effectiveness of ABA (applied behavior analysis) as an intervention strategy for young children diagnosed with autism. The **Promise Program** of Upstate Cerebral Palsy will join Summit Educational Resources, Monroe BOCES and the University of Rochester as one of four sites that will participate in the study which is funded by a grant through the National Institute of Mental Health.

Dr. Tristram Smith, Dr. Rafael Klorman and Dr. Daniel Mruzek are heading the research team that recently spent a day in Utica meeting with administrators and staff of the Promise Program in preparation for the program's involvement. Children between the ages of 3-5 years who have a diagnosis of autism and are participants in an ABA based educational program are the target population for the study. Selected participants will be followed for up to two years and will be assessed in multiple developmental areas during their participation. Nancy Seller, Division Director for Early Childhood Services at Upstate Cerebral Palsy and Dr. Thomas Curnow, Division Director for Quality Development and Support, will coordinate Upstate Cerebral Palsy's participation in the project.

Now in its eighth year of operation, the Promise Program was established in 1997 as an ABA based special education program for young children with autism spectrum disorders and related learning challenges. Dedicated to use of evidence based practices as a foundation of its educational approach, the Promise Program, in association with The Kelberman Center for autism services, is pleased to collaborate with the University of Rochester on this important study of ABA as an effective intervention for young children with autism.

## moe. Benefit Concert

A benefit concert by the upstate New York rock band moe. raised more than \$35,000 to benefit The Kelberman Center. The concert was held on Sunday, January 22, 2006 at the Landmark Theatre in Syracuse, New York.



*Pictured: Al and Ayla Schnier at a moe. concert.*

**moe.** guitarist Al Schnier from New Hartford is a parent of a child with autism. His daughter was a student at the Promise Program at Upstate Cerebral Palsy and Al, along with his fellow band members, performed a special concert in part to acknowledge the advances that Ayla made while in the Promise Program and in part to ensure that future families continue to have the necessary resources that can change the lives of children and adults with autism spectrum disorder. "The Promise Program is one of the leading resources for preschoolers with autism spectrum disorders in the country. I was amazed and gratified to learn that one of the most highly regarded programs is right here in our community. As we learn more about autism and as our kids grow older, we are finding a need to provide that same sort of high quality, progressive resource for our children and their families as they grow up. The Kelberman Center is fulfilling that need", said Schnier.

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## Mission Statement

**The Kelberman Center at Upstate Cerebral Palsy** is a regional center for excellence for individuals with autism spectrum disorders and related learning challenges. We are dedicated to excellence in service through: Prompt evaluation and diagnosis; individualized education and services; social and life skills enhancement; innovative practices, training and research. We believe in the power of individuals, family, and community working together to maximize our collective potential.

**The Kelberman Center**  
Autism Services  
Across the Lifespan

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Building C  
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[www.kelbermancenter.org](http://www.kelbermancenter.org)

# Message From Dr. Michael Kelberman Board President, The Kelberman Center

Did you know?

- One in every 166 children born in the United States has autism.
- 1.77 million individuals in the United States have autism.
- A new case of autism is diagnosed in the US every 20 minutes.
- The economic impact of autism is nearly \$90 billion annually and expected to double in the next decade.
- Autism receives less than 5% of research funding of the major prevalent childhood disorders and diseases.



Compare the incidence numbers and funding dollars for other childhood disorders and diseases:

Leukemia	1 in 25,000	Funding \$300 Million
Muscular Dystrophy	1 in 20,000	Funding \$160 Million
Cystic Fibrosis	1 in 5,000	Funding \$75 Million
Juvenile Diabetes	1 in 500	Funding \$140 Million
Autism	1 in 166	Funding \$15 Million

Why should you care?

If you are the parent of a child diagnosed with autism spectrum disorder, the answer is obvious. The future of your child depends on funding research that may one day unlock the puzzle that is autism. If you are a taxpayer, every dollar spent for research and early intervention may lessen the amount necessary to support the individual with autism throughout the lifespan. Autism spectrum disorder continues to be the fastest growing developmental disorder and its impact on society will be felt for generations to come.

We are excited to announce our partnership with the University of Rochester, which allows The Kelberman Center to access the most current research and refine our programs to maximize its effectiveness and impact. Founded in 1997, the Autism Spectrum Disorders Program at the University of Rochester is a multifaceted program that provides service and training to families, schools, and developmental agencies. The program also conducts research on effective treatments, evaluation of educational models, and the psychometrics of diagnostic and assessment instruments. The program is an integral part of the Studies to Advance Autism Research and Treatment (STAART) center.

Already a national leader in autism research due to the late-1990s discovery of a critical genetic link, the University of Rochester Medical Center is among eight institutions in the United States selected to study treatments for this early childhood neurological disorder. As we begin a new year, The Kelberman Center will continue to fulfill its mission of providing excellence in service to individuals and their families with autism spectrum disorder. With the support of our partners and founders, the strides we make in 2006 will impact generations of children to come.

*Michael Kelberman*

## Moments at Risk Training First Responders



*Pictured: Police Chief Gregg DeLuca, Helen Stepowany, Executive Director, The Kelberman Center and Dennis Debbaudt.*

For parents of an individual diagnosed on the autism spectrum, there is always a fear that their child may at some point be at risk and be attended to by first responders such as police, fire, or emergency personnel. The reason for the fear – people with autism, both children and adults, often exhibit behaviors that are not typical and may in fact be misinterpreted by the responder. “Increasing the sensitivity of community resources to the special needs of individuals with autism spectrum disorders will likely lead to more successful encounters,” says Helen Stepowany, Executive Director of The Kelberman Center.

For this reason, in collaboration with the Herkimer County Department of Mental Health, The Kelberman Center recently presented a workshop entitled “Autism & Law Enforcement: Recognition, Response and Risk Management.” Dennis Debbaudt, a law enforcement trainer and parent of a child with autism, presented the workshop to two different audiences: first, to law enforcement personnel and other first responders, and then presented a complimentary

training to parents and persons with autism spectrum disorders.

In his presentation, Mr. Debbaudt provides an overview of autism, relates some of his own personal experiences as a parent, and provides tools for use by community resource personnel on interacting with individuals with autism spectrum disorders. To set the stage, Mr. Debbaudt referenced research that has shown that people with developmental disabilities, including autism, will have up to seven times more contact with police than a member of the general public. “When I first heard that statistic, I knew that as a law enforcement trainer and parent, I had to broaden the knowledge base for police, fire and other personnel whom I knew would approach given situations differently, if they had only known.”

The Autism & Law Enforcement program is just one of the ongoing community education programs offered by The Kelberman Center. To view more education opportunities visit the Kelberman Center website at [www.kelbermancenter.org](http://www.kelbermancenter.org).

## Speaker Series to Feature Film Screening

Mark your calendar and plan to attend the special presentation and film screening for “Keeper of the Kohn”, an award winning documentary featuring an adult with autism. Scheduled for **April 9, 2005 at 7:30 pm at the Radisson Hotel** and sponsored by First Source Federal Credit Union, “David Gaynes: Keeper of the Kohn” helps viewers better understand the subtleties of human relationships, and not just those of people with developmental disabilities.

The term “Keeper of the Kohn” refers to a unique relationship between lacrosse players from Middlebury College and Peter Kohn, a beloved field manager for the team. Every year a new “Keeper” is entrusted with the responsibility to make sure that Peter’s basic needs are met and that he has a companion when the team travels. And in that way, the role of “Keeper of the Kohn” becomes a metaphor for all the relationships in the film. As a film about relationships, Keeper sheds light on universal human experiences and helps viewers understand them in greater depth.

David Gaynes and Peter Kohn will be available at the screening to answer questions and to discuss the film. The film recently won the Jury Award for Best Documentary at the 2005 Vail International Film Festival and won the Audience Award for Best Documentary at the Palm Beach International Film Festival. To register, call Denise Dawes at (315) 798-4006 ext. 284.

# The Community Foundation of Herkimer and Oneida Counties, Inc.

## Awards a Founding Grant to The Kelberman Center

A \$100,000 grant from The Community Foundation of Herkimer and Oneida Counties, Inc. has provided a strong and positive boost to The Kelberman Center's expanding services to children with autism spectrum disorders and related learning challenges.

"The Community Foundation is pleased to help support the start-up of The Kelberman Center and to have such an institution as this in our community. We are impressed with the dedication of Dr. Kelberman and the staff and volunteers who are making this program a reality and a national model for autism services," said Peggy O'Shea, president and CEO of The Community Foundation.

Raising the necessary funds to ensure The Kelberman Center's long-term viability and expanding services continues into 2006. "Our efforts to find community partners who will invest in the future of

individuals with autism has been successful and we are indeed grateful to the Community Foundation for their grant. The generosity of this community is unparalleled and we are confident that we will continue to raise the funds that will allow us to help individuals with autism across their lifespan," stated Louis B. Tehan, Executive Director of Upstate Cerebral Palsy.

The Community Foundation joins a distinguished group of founders who recognize the critical need for enhanced and expanded services for individuals with autism spectrum disorders and their families. These most generous individuals have made a financial investment of \$10,000 or more in the future of children and adults with autism spectrum disorders across Central New York. The Kelberman Center founders are visionaries who are meeting the challenge of autism and have answered with resounding support. Their leadership and

commitment ensure that everyone on the autism spectrum receives the life-enhancing supports that maximize each person's full potential.

Adirondack Financial Services and Angelo and Angela Nole recently joined the Founders Circle. Their support is gratefully appreciated. For more information on the Founders Circle, please contact Kelly Parsons, Director of Major Gifts and Planned Giving at Upstate Cerebral Palsy at (315) 798-4006 ext. 408.



Please join us for  
**The Faces of Autism Telethon**  
Tuesday, April 11th from  
7:00 pm to 9:00 pm  
on Newschannel 2.



Your pledge will support autism services at  
**The Kelberman Center.**

moe. continued from page 1...

Formed in Buffalo, New York, in 1991, moe.'s tours have taken them from Woodstock '99, to New York's Central Park and to Japan. As one of the finest groups in the jamband movement, **moe.** is also critically acclaimed for its songwriting and studio work; the group's 2001 studio album, "Dither," was awarded four stars by Rolling Stone. **moe.** has released 10 recordings in the last 14 years.



*Pictured: Ayla at a moe. concert.*

## Helen Stepowany Appointed Executive Director of The Kelberman Center

**Helen E. Stepowany** has been appointed to the position of Executive Director of The Kelberman Center as of February 1, 2006. Helen is the Associate Executive Director of Program Services at Upstate Cerebral Palsy, and is the former Executive Director of Finger Lakes United Cerebral Palsy where she was instrumental in the establishment of recognized inclusive early childhood programs for children with and without disabilities. Ms. Stepowany has 28 years in the disabilities field and is a graduate of Niagara University with additional graduate work at the University of Rochester and Rochester Institute of Technology.



Louis Tehan, Executive Director of Upstate Cerebral Palsy stated, "Helen has been leading the development of this new initiative since its inception and it is clear that as we develop more services and establish our identity as a world-class provider of services to individuals across the autism spectrum, Helen's experience and expertise are critical in this journey."

## The Kelberman Center Donors

The Board of Directors gratefully acknowledges the following donors who share our commitment to comprehensive services for individuals with autism spectrum disorders. Gifts received are from September 1, 2005 to February 8, 2006.

### Founder's Circle

G.A. Nole & Son  
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### In Memory of Edith Maidman

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## Key Contacts at The Kelberman Center

For more information regarding The Kelberman Center and Upstate Cerebral Palsy's affiliated programs and services for children and adults with autism spectrum disorders, contact:

- **Education, Training and Consultation Services**

Michelle Williams, Director of Clinical Services  
(315) 797-6241

- **Evaluation and Diagnostic Services**

Michelle Williams, Director of Clinical Services  
(315) 797-6241

- **Early Childhood Services including First Steps and Promise Program**

Nancy Seller, Division Director  
(315) 798-4006 ext. 225

- **Autism Support Group**

Leslie Stephens, Family Services Specialist  
(315) 798-4006 ext. 372

- **School Age Services including the Tradewinds Program**

James Weaver, Division Director  
(315) 533-1150 ext. 231

- **Family Support and Waiver Services**

Dana Guernsey, Family Support Specialist  
(315) 738-0794 ext. 223

- **Recreation and Afterschool Programs**

Dana Guernsey, Family Support Specialist  
(315) 738-0794 ext. 223

- **Administration Office**

Helen Stepowany, Executive Director  
(315) 724-6907 ext. 2266

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