

## Action In Autism

Thomas P. McCool, Ed.D.

President/CEO Eden Autism Services

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#### **Testimony**

#### **Eden Background Information**

The mission of Eden Autism Services is to improve the lives of children and adults with autism and their families by providing a range of community-based services to meet specific needs throughout the lifespan.

Eden was founded as a private school in Princeton in 1975 by Dr. David Holmes and 14 families, and opened adult services programs in the early 1980's. Eden Outreach was established to provide consultation and support to families who needed services but could not be accommodated in Eden education and adult programs.

Currently Eden serves 60 children in the New Jersey School; 43 children in two Southwest Florida schools; 100 adults in three New Jersey adult employment centers; 75 adults in New Jersey residential programs (group homes and apartments) 10 adults in residential and employment services in Southwest Florida; and more than 2000 individuals and organizations across the country and beyond through Eden Outreach. Recently Eden has expanded its direct impact on autism classroom teachers via edWeb.

## **International Activities**

In November 2006, Eden Autism Services participated in the World Congress Autism Conference held in Cape Town, South Africa and launched its web-based autism training program for teachers and families, and highlighted the Eden Curriculum as an essential element of a comprehensive autism education program.

From time to time Eden Autism Services sponsors internship programs at the request of organizations around the world including: an 18 month internship program in adult services for 8 interns from the Philippines; other intern programs have been provided to students from Singapore and Canada.

Eden Outreach Services has conducted evaluations of individuals with autism from Bahrain and Abu Dhabi, and the Eden Curriculum is being used in Singapore, Philippines, Canada, Israel (and is in the process of being translated to Hebrew) and South Africa.

## **Eden Autism Services Partnerships**

- National Association of Private Special Education Centers association of schools serving children with disabilities
- Autism Society of America advocacy and information sharing; presentations at annual conferences held across the US.
- Autism Speaks advocacy and information sharing; awareness. Eden is working with AS on its Advancing the Future of Adults With Autism
- National Association of Residential Providers for Adults with Autism shared expertise among providers of direct care services nationally and internationally. Fall conference in England is being planned.
- Autism Europe Member information sharing

- Eden Innovative Learning partnership with Innovative Learning, a technology company that has developed competency based testing protocols for web based learning.
- Florida Gulf Coast University cosponsor of annual autism conference "Promising Pathways" since 2008.
- CARF (Commission on Accreditation of Rehabilitation Facilities) assisted in developing autism specific standards for this international accreditation organization.
- Princeton University Since 1995 Eden and Princeton University have sponsored an
  annual lecture series on autism research. Since its inception, the Series has featured
  globally recognized scientists, researchers, educators and administrators. Attached is a
  listing of the autism experts who have participated in the Eden-Princeton University
  Lecture Series. Summary

#### **Summary:**

Our goal is to share the knowledge and experience Eden Autism Services has gained over the past 36 years to improve the quality of life of children, adults, and families impacted by autism. The information is available; the technology is available. Only with a united and focused effort will we be able to achieve this goal.

## edWeb

Eden Autism Services is working with edWeb.net to create online communities of practice to support educators serving students with special needs, particularly autism and engage educators who are working within an organization, across organizations, or anywhere in the world. edWeb.net is a professional social network for the education community that makes it easy to connect with peers, share information and best practices, spread innovative ideas, and create professional learning communities.

The U. S. Department of Education recently issued a draft report – *Connect and Inspire: Online Communities of Practice in Education* – that makes the case for "broadening educators' access to and participation in online communities of practice, which show strong potential to support professional learning and collaboration." See http://edcocp.org.

Eden Autism Services has two online communities of practice for educators on edWeb.net:

Teaching Students with Autism: Effective Strategies for Grades preK-5 Teaching Students with Autism: Effective Strategies for Grades 6 - 12

The program uses a combination of interactive live webinars and online discussion forums so that educators can connect on an ongoing basis to receive support from the Eden staff and from each other. The online community is used to archive all of the webinars and supporting resources. Tools like a blog, discussion forum, shared calendar, documents library, wiki, polling tool, and shared links – support the creation of an active and engaged collaborative community of educators.

Webinars are held weekly, and each week, members of the community receive a free lesson plan from Eden. The structured, ongoing activity is the key to active engagement. Community

members also receive a CEU certificate for attending the webinar, or watching a recording and taking a quiz.

## The webinar topics are:

- Understanding the Unique Needs of Students with Autism
- Effective Strategies for Paraprofessionals
- Goal Selection for Students with Autism
- Positive Behavior Support Strategies
- Effective Transition from the Classroom to Adulthood
- Establishing Play and Leisure Skills for Students with Autism
- Toilet Training Students with Autism
- Generalization: Why Is It So Critical?
- Facilitating Language and Communication in the Classroom Environment
- Troubleshooting: What is it, and How do you do it?
- Utilizing the Principles of Reinforcement in a Classroom Environment
- Meeting the Needs of Students with Asperger's in the Classroom Environment

The program launched in March 2011 and already has over 900 educators participating.



# EDEN AUTISM SERVICES FOUNDATION, PRINCETON UNIVERSITY ANNOUNCE $17^{\mathrm{TH}}$ ANNUAL LECTURE SERIES ON ADVANCEMENTS IN AUTISM

**PRINCETON, NJ** Eden Autism Services, a New Jersey-based nonprofit organization serving individuals with autism, and Princeton University's Department of Physics is proud to announce its lineup of world-renowned guest lecturers for the seventeenth annual day-long Lecture Series for families and professionals on Friday, June 3, 2011, at the University's Reynolds Auditorium. Entitled, *Autism: A Journey in Optimism and Opportunity*, the event will conclude with a question and answer panel discussion comprised of many experts in the field.

"We are delighted to again bring together an impressive group of leaders in the field of autism who will explore and explain new and positive actions being taken to enhance the quality of life for those with autism. We hope those who attend will be able to view the future with far greater optimism than previously possible," says Dr. Thomas McCool, Chief Executive Officer of Eden Autism Services.

Supported in part by the Puzio Family Charitable Trust and the Asch Foundation for Funding Education and Research in Autism, the event will feature keynote addresses from three noted leaders in the field who have made outstanding contributions to autism services and research:

## ■ Sarah Spence, M.D., Ph.D.

Board certified pediatric neurologist at Children's Hospital Boston (Harvard) with research training in cognitive neuropsychology, Dr. Spence has clinical expertise in the treatment of both childhood seizure and autism spectrum disorders. Previously she was medical director of UCLA's autism evaluation clinic and of the Autism Genetic Resource Exchange.

#### Ami Klin, Ph.D.

The author of over 180 publications on autism and related conditions, Dr. Klin is the Harris Professor of Child Psychology and Psychiatry at Yale University School of Medicine's Child Study Center where he directs its Autism Program. With a primary focus on the aspects of autism from infancy through adulthood, Dr. Klin's studies include such novel techniques as eye-tracking laboratories that allow researchers to see the world through the eyes of those with autism, techniques now used in the screening of babies at risk for autism at the Simons Laboratory of Social Neuroscience in Infancy.

## Lynn Kern Koegel, Ph.D.

Director of Autism Services in the University of California, Santa Barbara Autism Research Center, Dr. Koegel is active in developing programs to improve communication in children with autism, including the development of first words, grammatical structures, and pragmatics. She is published in the areas of communication, language development,

## EDEN - PRINCETON UNIVERSITY LECTURE SERIES GUEST LECTURERS

#### 2010

## Randi J. Hagerman, M.D.

UC Davis M.I.N.D. Institute, Medical Director

Fragile X: Leading the Way to Targeted Treatments in Autism

## Brian A. Iwata, Ph.D.

University of Florida; Florida Center for Self-Injury; Prader-Willi Syndrome Program Experimental Approaches to Behavioral Assessment

## Kathryn McFadden, M.D.

University of Pittsburgh, Division of Neuropathology

Neuropathology and Genetics of Connectivity: Altered Axonal Pathfinding in ASD

#### 2009

## Timothy Roberts, Ph.D.

Children's Hospital of Philadelphia

Electrophysiological Signatures of Language Impairment in Autism

## Christopher A. Walsh, M.D., Ph.D.

Children's Hospital Boston

Genome Wide and World Wide Searches for Autism Genes

## Peter C. Mundy, Ph.D.

UC Davis M.I.N.D. Institute

Linking Neurodevelopment, Social Symptoms, and Early Intervention in Autism

## 2008

#### Paul Ashwood, Ph.D.

M.I.N.D. Institute, University of California at Davis

Evidence of Dysregulated Immune Responses in Autism

#### Joseph D. Buxbaum, Ph.D.

Autism Genome Project, Mount Sinai School of Medicine

The Genetic Architecture of Autism

#### Laura Schreibman, Ph.D.

Autism Laboratory, University of California at San Diego

The Science and Fiction of Autism

## 2007

## Martha R. Hertbert, M.D., Ph.D.

Autism: A Brain Disorder or a Disorder Affecting the Brain?

## Michael Wigler, Ph.D.

A Unified Genetic Theory for Sporadic and Inherited Autism

## Fred R. Volkmar, M.D.

New Approaches to Understanding Autism

## 2006

## **Brenda Smith Myles**

Asperger's Syndrome: An Overview

#### **Diane Williams**

Neurocognitive Basis of Language Processing in Autism

## **Eric Hollander**

New Developments in the Neuropsychopharmacology of Autism

#### 2005

## **Nancy Minshew**

University of Pittsburgh

Alterations in Brain Connectivity and Integration of Information in Autism: A New Perspective on Autism

#### **Cathy Pratt**

Crisis Versus Educational Approach to Challenging Behaviors

## **Barry Prizant**

Thirty Years of Learning from Persons with Autism and Their Families

## <u>2004</u>

## **Simon Baron-Cohen**

Is Autism an Extreme of the Male Brain?

#### **Ruth Christ Sullivan**

The Autism Wars: A Report From the Front

## **Bernard Rimland** \* (now deceased)

Autism: Where It's Been and Where I See It Going

## 2003

## Isabelle Rapin

AECM at Yeshiva U

Autism Spectrum Disorders: A Neurological Perspective

## **Edwin Cook** U-Chicago

Genetics of Autism: Current and Future Implications for Autism Services

#### David Amaral

**UC-Davis** 

Amygdala, Autism, and Anxiety

#### 2002

#### Richard Foxx

Penn State

Behavioral Artistry: Change Agent Repertoires that Make a Difference

## **Sandra Harris**

**Rutgers University** 

Siblings Tell Us About Autism: What Does it Mean to a Brother or Sister?

## **Elizabeth Gould**

**Princeton University** 

The Learning Process Through Adulthood: Implications for Autism

## 2001

#### **Ivar Lovaas**

Overview of the UCLA Young Autism Project

#### **Jonathan Cohen**

Princeton Unviersity

Imaging the Human Brain: A Window on the Mind

#### Karin Nelson

National Institutes of Health

Toward a Biology of Autism

#### <u>2000</u>

#### Gary Mesibov, Ph.D.

The TEACCH Approach: Integrating Psychological, Education, and Neurological Theory and Practice

## Patricia M. Rodier, Ph.D.

Embryology of Autism

## Oliver Sacks, M.D.

An Anthropologist on Mars: Some Personal Perspectives on Autism

## 1999

## Margaret Bauman, M.D.

Autism and the Brain: Where Are We Now and Where Do We Go From Here?

## Andy Bondy, Ph.D.

Service Delivery in the New Millennium

## Temple Grandin, Ph.D.

Thinking in Pictures and Learning Language with Autism

#### 1998

## Judith Favell, Ph.D.

Autism Services in the 21<sup>st</sup> Century

### Terrence Deacon, Ph.D.

The Neurobiology of Language: Implications of Autism

#### Joseph Piven, M.D.

Autism: Towards Defining the Phenotype

## <u>1997</u>

## Barry Jacobs, Ph.D.

The Role of Brain Serotonin in Neuropsychiatric Disorders

## Eric Courchesne, Ph.D.

The Developmental Neurobiological Approach to Understanding Autism: From Behavioral Symptoms to Biological Explanations

#### Alan Leslie, Ph.D.

Theory of Mind Impairment in Autism: Its Nature and Significance

#### 1996

#### Martin Kozloff, Ph.D.

Thorns and Dangers

## Marie Bristol, Ph.D.

The State of Science in Autism: A Research Perspective

#### 1995

## Eric Schopler, Ph.D.

Autism Services: Past, Present, and Future

## Bernard Rimland, Ph.D.

Four Decades with Autism: Research and Personal Experience

#### UNITEDNATIONSNATIONSUNIES

THE SECRETARY-GENERAL MESSAGE ON WORLD AUTISM AWARENESS DAY April 2, 2011

The number of children and people with autistic conditions continues to rise – in every nation and in every racial, ethnic and social group. Although the recognition of autistic conditions among the scientific, health and care communities is improving, public awareness remains low.

The annual observance of World Autism Awareness Day thus takes on ever greater importance as an opportunity to mobilize for action and assistance.

Children and persons with autistic conditions face major challenges associated with stigma and discrimination, as well as a lack of access to support. Many struggle with multiple barriers in their daily lives. Far too many suffer terrible discrimination, abuse and isolation, in violation of their fundamental human rights.

Autism is a complex disorder. But in many cases the right treatment early on can bring improvements. That is why it is so important to raise awareness about the signs of autism and provide services as soon as possible.

It is also critical to support parents, create jobs for individuals with autism based on their skills and strengths, and improve public education to better meet the needs of students with autism.

Taking these steps will benefit society as a whole, enriching people with autism, their loved ones and others alike. As the mother of one child with autism said, "Although my daughter has walked a long way, I have walked a longer way."

Together, let us travel this road toward a more caring and inclusive world