

# Portia Iversen

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## A BRIEF HISTORY

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In 1995, soon after our son Dov was diagnosed with autism, my husband Jonathan Shestack and I co-founded the Cure Autism Now foundation (CAN). The foundation soon became a driving force in growing the field autism research and a leader in raising awareness and funding. Soon after founding CAN, we established the Autism Genetics Resource Exchange (AGRE), an autism gene bank that was the first to provide open access to the entire scientific community and soon grew to become the world's largest. I established CAN's Scientific Review Council (SRC), an advisory council modeled after the NIMH Advisory Council, whose members were made up of scientists and clinicians most of whom were also parents of autistic children. The SRC was responsible for ensuring that the research which CAN funded was relevant and reflected the urgency of those affected by the disorder. In 2007 CAN merged with Autism Speaks. I am now serving on the NIMH, National Advisory Mental Health Council through 2012.

I've served on a number of public and private research boards including as an NIMH grant reviewer, I've co-authored a number of research papers and have studied molecular biology and neuroscience in a variety of courses. I continue to participate in workshops and attend scientific meetings such as the International Meeting For Autism Research (IMFAR - which I founded several years ago), the Keystone Symposium on Autism, the Cold Spring Harbor workshop on Autism and the annual Society For Neuroscience meeting. I continue to give lectures and workshops both in the community and at academic institutions. I've been honored to receive a number of community awards in recognition of my role as an advocate for the advancement of autism.

My current advocacy efforts are focused on the long-neglected, nonverbal segment of the autism population. I initiated the 'NIH Workshop on Nonverbal School-Aged Children with Autism', held April 2010, Co-sponsored by the National Institute of Deafness and Communication Disorders and NIMH. For a summary see: <http://www.nidcd.nih.gov/funding/programs/10autism/detail>  
The recommendations generated by this workshop lead to the announcement of an RFA in August 2010: "*NIDCD and NIMH Announce Availability of Funds for Competitive Revision Applications for Targeted Research on Non-Verbal School-Aged Children with Autism (R01, R34 and P50) (NOT-DC-11-001)*" <http://grants.nih.gov/grants/guide/notice-files/NOT-DC-11-001.html>

I published my first book: 'Strange Son' (Riverhead) in 2007, which chronicles my experience with my son Dov who has autism and is nonverbal, focusing on the story of how he began to communicate for the first time at the age of nine.

I earned my BFA at the University of Illinois and went on to become an art director and writer for film and television; my entertainment career culminated with the winning of an Emmy Award in 1989, after which I married and had three children. I currently live in Los Angeles with my husband Jon Shestack and our children, Dov, Miriam and Gabriel. My eldest child, Billy Rich, now an adult, also lives and works in Los Angeles.

For more specific information about me please visit: [www.portiaiversen.com](http://www.portiaiversen.com)

## ACCOMPLISHMENTS

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Appointed to the NIMH National Advisory Mental Health Council (NAMHC), 2008 - 2012

Founder of the Descartes Institute Online Community, 2007

An online community providing information, resources, support and hope for families and professionals caring for nonverbal children with ASD. The Descartes Institute online community now serves nearly 3000 members.

[www.Descartesinstitute.org](http://www.Descartesinstitute.org).

Founder and Director of The Descartes Institute, "I Think Therefore I am", 2004 – present.

The Descartes Institute is a nonprofit foundation whose mission is to improve the quality of life for nonverbal and low-communicating individuals by raising awareness and funds to support research, development, documentation and dissemination of interventions focusing on communication, education and medical treatments for this long-neglected population.

Author of the book: 'Strange Son' (Riverhead Books), 2007

This book tells the story of how my son who has autism and is nonverbal, began to communicate for the first time at the age of nine.

[www.strangeson.com](http://www.strangeson.com)

Founder of the Innovative Technology for Autism (ITA) initiative at CAN, 2002 -2009

Founder of the International Meeting For Autism Research (IMFAR), 2000 - present

Co-founder of the Autism Genetic Resource Exchange (AGRE), 1997 - present

AGRE is the first open resource gene bank for autism, making biological materials and clinical data available to the entire scientific community. AGRE is now the world's largest resource for DNA and clinical data from families with more than one member with autism.

[www.agre.org](http://www.agre.org)

Co-founder of the Cure Autism Now Foundation (CAN), 1995 - 2007

CAN, a nonprofit advocacy organization, raised ten million dollars annually for autism research until February 2007, when the foundation merged with Autism Speaks.

[www.autismspeaks.org](http://www.autismspeaks.org)

## PUBLIC SERVICE

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Member NIMH National Advisory Mental Health Council (NAMHC)

2008 - 2012

Member Review Panel, RAND Systematic review of treatments for children with ASD

2008 - 2010

Stanley Nelson autism genetics project UCLA, Community Advisor

2008 – 2009

Autism Speaks, 'High Risk/High Impact' committee member, Founder and Chair of the "Characterizing cognition in nonverbal individuals with ASD" (CCNIA) Initiative

2007 - 2009

Department of Defense - Autism research grants reviewer

2007

Autism Speaks, Scientific Advisory Committee (SAC)

2007 – 2008

ESCRO Committee (Embryonic Stem Cell Research Oversight)  
California Institute of Technology, Pasadena, California  
2006

Autism Genome Project, External Advisory Board  
Genome Canada Project, Hospital for Sick Children, Ontario, Canada  
2004 – 2008

CPEA/STAART Scientific Advisory Board, National Institute of Mental Health  
2004 – 2007

Public Participant Grant Reviewer, National Institute of Mental Health  
2000 – 2004

Co-Chair of the Scientific Review Committee (SRC), The Cure Autism Now Foundation  
1999 – January 2007

The SRC was established in 1999 to compliment the CAN Scientific Advisory Board. Composed of family members who are directly affected by autism and who also have a background in science or medicine, the SRC determined the relevance of grant applications while the SAB determined their scientific merit. The SRC was modeled after the NIMH Advisory Council.

## AWARDS

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The Rick Weiss Humanitarian Award  
April, 2006

The California Psychiatric Association 2002 Exemplary Family & Patient Award  
For Exceptional Advocacy on Behalf of the Mentally Ill

Emmy Award  
For Art Direction on ‘The Tracey Ullman Show’  
1989

Emmy Award Nomination  
For Art Direction on ‘Carole’ (The New Carole Burnett Show)  
1990

## SELECTED LIST OF PRESENTATIONS

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NIH Workshop on Nonverbal School-Aged Children with Autism, Co-sponsored by the National Institute of Deafness and Communication Disorders and the National Institute of Mental Health  
April 2010

UCLA, Current Issues in Applied Linguistics, ‘Communicative Capacity of Low-Communicating/Non-Verbal Children with Autism Spectrum Disorders’  
Spring Quarter 2010

Touro College, Bureau of Jewish Education, Los Angeles  
March 2010

University of Southern California, Viterbi School of Engineering Technology for Autism Spectrum Disorders Course  
February 2010

University of Taiwan, Taipei  
July 2009

Cold Spring Harbor Autism Workshop  
June, 2007 and 2009

Annual Academy of Neurology Meeting  
April 2008

UCLA, Department of Anthropology  
June, 2007

Society For Neuroscience  
October, 2006

IMFAR  
May, 2006

University of Gotenberg, Sweden  
September, 2002

Many other presentations at advocacy and research meetings.

## **PUBLICATIONS**

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### **Journals Articles:**

Autism overflows with syntheses.

Belmonte MK, Bonneh YS, Adini Y, Iversen PE, Akshoomoff NA, Kenet T, Moore CI, Simon HJ, Houde JF, Merzenich MM.  
*Neuropsychol Rev*, June, 2009.

Cross-modal extinction in a boy with severely autistic behavior and high verbal intelligence

Bonneh, Y, Ashmookoff, N, Belmonte, M, Iversen, P, Hirstein, W, Kenet, T, Pei, F, Simon, E, Houde, J, Merzenich, M  
*Cognitive Neuropsychology*, July, 2008.

Nicotinic receptor abnormalities in the cerebellar cortex in autism

Lee M, Martin-Ruiz C, Graham A, Court J, Jaros E, Perry R, Iversen P, Bauman M, Perry E.  
*Brain*. 2002 Jul;125(Pt 7):1483-95.

Autonomic responses of autistic children to people and objects

Hirstein W, Iversen P, Ramachandran VS.  
*Proc R Soc Lond B Biol Sci*. 2001 Sep 22;268(1479):1883-8.

The autism genetic resource exchange: a resource for the study of autism and related neuropsychiatric conditions.

Geschwind DH, Sowinski J, Lord C, Iversen P, Shestack J, Jones P, Ducat L, Spence SJ.  
*Am J Hum Genet*. 2001 Aug;69(2):463-6.

A genomewide screen for autism susceptibility loci.

Liu J, Nyholt DR, Magnussen P, Parano E, Pavone P, Geschwind D, Lord C, Iversen P, Hoh J, Ott J, Gilliam TC.  
*Am J Hum Genet*. 2001 Aug;69(2):327-40.

Cholinergic activity in autism: abnormalities in the cerebral cortex and basal forebrain.

Perry EK, Lee ML, Martin-Ruiz CM, Court JA, Volsen SG, Merrit J, Folly E, Iversen PE, Bauman ML, Perry RH, Wenk GL.  
*Am J Psychiatry.* 2001 Jul;158(7):1058-66.

California Pediatrician Fall 2000

Iversen PE

‘Autism: What does the future hold; what can we learn from the past; and what can we do right now?’

**Abstracts:**

Universal features of language and communication in autism.

International Meeting For Autism Research (IMFAR) 2003

Spence, Iversen, Yuan JY, Alarcon M, Fedele, AGRE consortium, Cantor RM

## EDUCATION

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Bachelor Degree, Fine and Applied Arts  
University of Illinois, Circle Campus, Chicago, Illinois

## CONTINUING EDUCATION

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Keystone Symposium on Autism, (2007)

Cold Spring Harbor Autism Workshop (2007 and 2009)

Visiting Scholar - Bioinformatics Tutorial, Columbia University, New York City, N.Y. (2000)

Short Course in Genetics, Jackson Labs, Bar Harbor, Maine, (1999)

Visiting Scholar - Bioinformatics Training, National Center for Biotechnology Information (NCBI), (1999)

Course(s) in Molecular Cell Biology, Neuroanatomy and Neuroimmunology, UCLA, (1997-1999)

## PERSONAL INFORMATION

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I was born in Chicago Illinois and have lived in Los Angeles since 1981. I am married to Jonathan Shestack and we have four children, one of whom is affected by autism. We currently reside in the Korea Town area with our three younger children, Dov, Miriam, and Gabriel. My oldest child Billy, lives and works in Los Angeles.

## CONTACT INFO

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