

# 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, 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.

I have also served on a number of public and private research boards including serving as an NIMH grant reviewer, I have 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 conferences such as the International Meeting For Autism Research (IMFAR - which I founded seven years ago). Recently I was a lecturer and participant at Cold Spring Harbor's first autism workshop. I've been honored to receive a number of community awards in recognition of my role as an advocate for the advancement of autism research and I have given talks about autism throughout the world. I published my first book: 'Strange Son' (Riverhead) in 2007, chronicling my experience with my son Dov who has autism and is nonverbal, when 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 a set decorator and art director and later a writer for film and television; my entertainment career culminated with the winning of an Emmy Award in 1989, after which I married and started a family. Today I live in Los Angeles with my husband Jon Shestack and our son Dov; we have three other grown children. I continue my work as an autism advocate as well as an artist and writer. For more information about me please visit: [www.portiaiversen.com](http://www.portiaiversen.com)

## ACCOMPLISHMENTS

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

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.

2007

Founder of the Innovative Technology For Autism (ITA) program at CAN  
2002

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

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

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)

1997

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

CAN, a nonprofit autism research organization, raised ten million dollars annually for autism research and lobbied successfully for major increases in federal autism research funding. The foundation merged with Autism Speaks in 2007. [www.autismspeaks.org](http://www.autismspeaks.org)

1995 - 2007

## PUBLIC SERVICE

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National Institute of Mental Health Advisory Council member  
2008 - 2012

Autism Speaks, 'High Risk/High Impact' committee member  
2007 – 2010

Chair (and instigator) of the "Characterizing cognition in nonverbal individuals with ASD" Initiative  
April, 2007

Department of Defense - Autism research grants reviewer  
November, 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  
1999 – 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.

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## AWARDS & HONORS

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Etta Israel Community Leadership Award

2016

<https://etta.org/>

<https://jewishhomela.com/2016/12/29/what-the-world-needs-now-is-a-little-more-etta/>

International Society for Autism Research (formerly IMFAR) Advocate Award

2011

The Rick Weiss Humanitarian Award

April, 2006

Cure Autism Now Tenth Anniversary Gala Founders Honorary Award

2005

The California Psychiatric Association Exemplary Family& Patient Award

For Exceptional Advocacy on Behalf of the Mentally Ill

2002

Emmy Award Nomination

For Art Direction on 'Carole' (The New Carole Burnett Show)

1990

Emmy Award

For Art Direction/Set Decorating on 'The Tracey Ullman Show'

1989

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## SELECTED LIST OF PRESENTATIONS

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UCLA, Current Perspectives on the Autism Spectrum and Neurodiversity (class)

'Taking Another Look at Nonverbal Autism'

2015, 2016, 2017

Cold Spring Harbor Laboratories - Autism Workshop

Presentation on Non-verbal Autism

June, 2007, 2013, 2015

Interagency Autism Coordinating Committee (IACC), National Institute of Mental Health (NIMH)

'Nonverbal Autism: Rethinking the Model'

July 2013

United Nations Autism Awareness Day

'Nonverbal Autism: the Forgotten Half of the Spectrum'

April 2012

University of Southern California, Engineering and Autism: A National Workshop on Autism and Technology

Expert Panel member  
September 2012

Tel Aviv, Israel

‘The Forgotten Half of the Spectrum: Nonverbal and Low-Communicating Individuals with Autism’  
March, 2011

Los Angeles, Community Presentation, sponsored by Rob Rome (educational psychologist)

‘Nonverbal and Low-communicating individuals: The need to update our model’  
March, 2010

Split, Croatia, Nonverbal Individuals with Autism

‘Rethinking the cognitive potential of so-called “low-functioning” or non-verbal individuals with autism’  
October, 2010

Taiwan Autism Society

‘Characterizing Cognition in Nonverbal Individuals with Autism’  
July, 2009

Annual Academy of Neurology Meeting

‘Autism Spectrum Disorders’  
April, 2008

Billings and Bozman, Montana, PLUK and Parent group

‘Informative Pointing Method” workshop’  
April, 2008

UCLA, Department of Anthropology (class)

June, 2007

Society For Neuroscience

‘Nonverbal Autism Research: Need for a New Approach’  
October, 2006

University of Gotenberg, Sweden

‘Autism Advocacy and Research’  
September, 2002

Many other presentations at advocacy and research meetings and educational (classroom) presentations.

## PUBLICATIONS

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### Books:

**Strange Son: Two Mothers, Two Sons, and the Quest to Unlock the Hidden World of Autism**

Portia Iversen  
*Penguin, Riverhead Press, 2007*

(Published in English, French, German, Italian, Finnish, Korean, Mandarin, Dutch, Hebrew, Swedish, Japanese)

Nonverbal and Low-communicating Autism: the Forgotten Half of the Spectrum

Portia Iversen

*Healing Magazine*, Vol. 14, No. 2, 2009 ([healingmagazine.org](http://healingmagazine.org))

**Journals Articles:**

Nonmedical Interventions for Children With ASD: Recommended Guidelines and Further Research Needs

Margaret Maglione, MPP,<sup>a</sup> Daphna Gans, PhD,<sup>a</sup> Lopamudra Das, MPH,<sup>a</sup> Justin Timbie, PhD,<sup>a</sup> Connie Kasari, PhD,<sup>b</sup> HRSA Autism Intervention Research – Behavioral (AIR-B) Network, Technical Expert Panel: Anshu Batra, MD, Tony Charman, PhD, Janet Grillo, Parent, Patricia Howlin, PhD, Brooke Ingersoll, PhD, Portia Iversen, Parent, Cofounder - Cure Autism Now Clara Lajonchere, PhD, Susan Levy, MD, Catherine Lord, PhD, Brian King, MD, Marsha Mailick Seltzer, Ann Neumeyer, MD, Ricki Robinson, MD, Lawrence Scahill, PhD, Laura Schreibman, PhD, Ilene Schwartz, PhD, Tristam Smith, PhD, Aubyn Stahmer, PhD, Wendy Stone, PhD  
*PEDIATRICS* Volume 130, Supplement 2, November 2012

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.* 2009 May 16

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*, April, 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.  
2001

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.

Autism: what does the future hold; what can we learn from the past; and what can we do right now?  
Iversen, PE  
*California Pediatrician* Fall 2000

**Abstracts:**

Universal Features of Language and Communication in Autism  
International Meeting For Autism Research (IMFAR)  
Spence, Iversen, Yuan JY, Alarcon M, Fedele, AGRE consortium, Cantor RM  
2003

## **EDUCATION**

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

## **CONTINUING EDUCATION**

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Cold Spring Harbor Autism Workshop (2007, 2013, 2015)

Keystone Symposium on Autism, (2007)

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 Neuro-immunology, UCLA, (1997-1999)

## **PERSONAL INFORMATION**

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I was born in Chicago Illinois and I 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. I currently reside in the Korea Town area with my husband and our son Dov.

## **CONTACT INFO**

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Portia Iversen  
Tel: (213) 706-3862  
e-mail: [Portiaiversen@gmail.com](mailto:Portiaiversen@gmail.com)