

*Celebrating 25 Years of Think Tanks*

research.  
support.  
empowerment.



**2018 annual report**



**AUTISM RESEARCH INSTITUTE**  
*Autism is Treatable*



**1 in 59** identified with ASD this year

Statistics from the Centers for Disease Control and Prevention (CDC) announced in 2018 underscore the need for autism research funding.\*

## 2018 Accomplishments

### Research

ARI awarded more than \$200,000 in grants to scientists whose work will have a direct impact on the lives of those on the autism spectrum.

We continue to publish our quarterly science newsletter, *Autism Research Review International* (ARRI), summarizing current medical, sensory, and educational research.

We sponsored a major think tank, attended by researchers and medical clinicians. In order to make progress in the field, ARI knows it is critical for scientists and experienced clinicians to meet and discuss issues related to causes and treatment.

ARI helps fund two tissue banks, including a brain tissue bank for the National Institute of Child Health and Human Development at the University of Maryland, and a gastrointestinal tissue bank at the Digestive Function Laboratory Repository at Massachusetts General Hospital in Boston.

We support an active dialogue among researchers and clinicians in a private internet discussion group limited to those with advanced science degrees and extensive clinical experience.

We published an online report on aging in autism, an important but understudied issue, covering a variety of topics including co-occurring medical conditions, the need for longitudinal studies, and issues related to sensory and cognitive abilities.

### Continuing Medical Education

ARI offers, in joint providership with the Cleveland Clinic, complimentary *AMA PRA Category 1 Credit™* to physicians and the general public. In 2017, we premiered talks on anxiety and immunology. Informing physicians on appropriate standards of care is crucial to understanding the medical nature of the disorder.

### Online Learning

Our YouTube channel offers free access to experts with up-to-date webcasts on medical support, nutritional guidance, and education, as well as selected talks from past conferences.

ARI hosts live webinars featuring top researchers and treatment professionals in partnership with The Johnson Center for Child Health and Development. The topics include ABA, adult issues, assessment, diet, educational therapies, nutrition, research updates, and much more. Participants can receive a free Certificate of Attendance for most webinars.

### Outreach in the U.S.

ARI offers a hotline for parents and professionals, who can reach a live person for information and support.

ARI publishes a bimonthly e-newsletter, *Clinical Research in Autism*, for obstetricians, pediatricians, and nurses who want to keep up to date with research relevant to their practice.

### International Outreach

ARI is an NGO (non-governmental organization) of the United Nations.

We co-sponsored a major international autism conference in Moscow for the sixth straight year.

We are in regular communication with autism researchers and network groups in Brazil, Canada, France, Italy, Russia, Ukraine, United Kingdom, and Venezuela.

\*Source: Centers for Disease Control and Prevention [cdc.gov/features/new-autism-data](https://www.cdc.gov/features/new-autism-data)



## Our Mission

The mission of the Autism Research Institute is to support the health and well-being of people affected by autism through innovative, impactful research and education.

### Message from our Executive Director and Chairman of the Board

Dear ARI supporters,

Today, as much as ever, we need insightful scientists, passionate clinicians, tireless advocates, and knowledgeable supporters who understand the many opportunities as well as challenges associated with autism. Throughout our 52-year history, the Autism Research Institute (ARI) has provided guidance and support to representatives as well as individual members within the autism and medical communities.

Since the day ARI was established, we have always looked beyond the present, aiming for optimal treatments and services for everyone affected by autism. We can assure you that we will always keep our focus on this mission.

Our deepest thanks to those who have supported our efforts as we continue to find solutions to many of the pressing issues faced by those on the autism spectrum and their family members. Working together, we can continue to make a difference in the lives of persons and families living with autism.

Sincerely,

A handwritten signature in black ink that reads "Stephen M. Edelson". The signature is fluid and cursive.

Stephen M. Edelson, PhD  
*Executive Director*  
*Autism Research Institute*

A handwritten signature in black ink that reads "Marvin Natowicz". The signature is bold and cursive.

Marvin Natowicz, MD, PhD  
*Cleveland Clinic*  
*2018-19 Chairman of the Board, ARI*

# How ARI Touches Lives

ARI receives feedback from families and individuals year round, as they share their personal experiences about autism — including diagnosis, challenges, treatment, progress, and more. We are grateful for this information, as it is vital to our mission and goals.

We thank all who submitted their photos and stories during our Autism Awareness Month event. Those featured here, as well as additional photos used throughout this report, were selected from this group. Photo contributors include Michelle Aulet, Mark Rimland, Wendy Ringel, and Lisa Saldin.

## His smile and optimism keep us moving forward...

“Ben has defied many of the stereotypical traits of ASD. Through so much hard work and persistence, Ben is tremendously resilient and happy. Ben will chat anyone up, is quick to try and make friends, and seeks others to be included. Ben is very sensitive, empathic and cares deeply for those close to him. Through this continuous journey, his smile and optimism keep us moving forward. My hero.”

— John Sears, Merion Station, PA



## He now craves social experiences...

“Jack, who is 22, preferred a solitary existence for many years, but with behavioral, therapeutic and medical support, he now craves social experiences. After having lost most of his language, he has recovered his speech and engages students, friends and family in dialogue and tours of zoos and animal care facilities, sharing amazing details. He volunteers at a local library, and is a talented artist.”

— Maria Nagy, Coronado CA

## We have learned so much...

“We have learned so much thanks to ARI! We have built on small tasks to accomplish big goals. My son has fantastic eye contact and he can dress himself, point to pictures to communicate and go on the swings. He will sit down to play with Legos, cars and us!”

— Angela Klingler, South Jordan, UT



### 1956

The Rimlands' son Mark is born. As an infant, he displays unusual behaviors. Several pediatricians are unable to help. After reading an old college textbook describing autism, Dr. Rimland realizes that parents, especially the mother, are blamed for causing autism in the child.

### 1964

Dr. Rimland publishes *Infantile Autism: The Syndrome and Its Implications for a Neural Theory of Behavior*, in which he argues convincingly that autism is biologically based and not a result of emotional trauma due to poor parenting.

### 1965

Dr. Rimland establishes the Autism Society of America to network parents of children on the spectrum and to promote the use of behavioral techniques, known today as Applied Behavioral Analysis (ABA). Dr. Rimland was a strong supporter of Dr. Ivar Lovaas, who pioneered ABA.

## For the first time, she was looking at her daddy...

“Tatiana was diagnosed at 11 months. We recognized the early symptoms of autism. Her lack of eye contact was our main concern. This is why this picture means a lot to us. For the first time, she was looking at her daddy. She was totally engaged. Having fun. Having that non-verbal communication. We treasure this picture as the beginning of our journey. We have done ABA, and tried all kinds of treatments. I am doing research and started a Facebook page to gather more families around the world. This is my life... protecting my daughter, making her happy and teaching her, and encouraging her to be the best in all she wants to do.”

— Lehyla Calero, New York, NY



## ARI provided resources and trainings to help our family understand...

“It was really noisy for Lewis that day at the restaurant, and we had forgotten his headphones. Before getting the information and resources on the noise-canceling headphones, we would never go out to restaurants because Lewis would become overwhelmed and it would be a disaster. ARI provided many different resources and trainings to help our family understand sensory overload and how to handle it.”

— Dyshum Robinson, Monroe, GA

## Wonderful seeing them interact...

“I took this photo at the park with my two kids, Vincent and Julianna. Vincent is on the autism spectrum and wasn't able to connect with his big sister. However, after months of early intervention, little by little, now you can't keep these two apart. It's been wonderful seeing them interact, share, play, laugh and even argue together. Julianna has also become Vincent's protector and biggest cheerleader and this photo captures it all for us.”

— Jessica Hurtado, Norwalk, CA



### 1967

The Institute for Child Behavior Research (renamed in the mid 1980s to ARI) is established as a 501(c)3 non-profit with the aim to conduct, encourage, and fund research as well as network scientists with one another and with parents.

### 1968

Dr. Rimland produces the documentary *The Invisible Wall*. In the film, Dr. Rimland discusses his thoughts on autism and suggests a genetic-environmental connection. To view the film, see <http://bit.ly/theinvisiblewall>.

### 1969

Dr. Leo Kanner, the psychiatrist who first described infantile autism in 1943, speaks at the first National Society for Autistic Children Conference and states that parenting does not cause autism. Having once blamed parents, he changed his thinking primarily after reading *Infantile Autism*.

# How We Help

## Advocate for Research That Makes a Difference

Our focus at ARI is to support innovative autism research while providing the latest science-based information for people of all ages on the autism spectrum. We do this through our annual and regional think tanks, in-person and online educational events and courses, free webinars, and by funding the studies that hold the most promise for making a difference in the lives of people with autism.

While the causes of ASD remain unclear, recent scientific advances challenge the traditional view of autism as an untreatable disease — as one that is genetically hardwired. These developments support the position that ARI has always maintained: *autism is treatable*. ARI continues to pioneer research, outreach, and cooperative efforts with other organizations worldwide.



**Support from ARI has helped us make breakthroughs in research** into immune issues and gastrointestinal dysfunction in autism. The pilot grant program has allowed us to explore these areas that are not among the traditional topics investigated in autism. It has truly helped my work in many transformative ways. Without ARI's support, I am not sure my laboratory could continue studying autism. It is that important."

— PAUL ASHWOOD, PhD  
University of California, Davis  
M.I.N.D. Institute

## ARI continues to play a significant role in supporting research

and continues to work toward expanding our understanding of this complex disorder. Although we have made considerable progress, there is still much work that remains to be done. Dr. Bernard Rimland's life-long impact lives on as reflected by the efforts that ARI continues to pursue and support."

— MARGARET BAUMAN, MD  
Boston University Medical Center



### 1970

Dr. Rimland moves his home office to a store front and begins to write about the importance of nutrition and restricted diets (e.g., caveman diet). Parents around the world volunteer to translate Dr. Rimland's diagnostic checklist.

### 1971

Dr. Rimland co-authors one of the first biochemical studies on autism with Dr. Mary Coleman and finds a correlation between serotonin levels in blood platelets and his diagnostic checklist. "The Rimland School" for children with autism opens in Evanston, IL.

### 1973

ARI publishes a large-scale study on autism involving 190 children using a placebo-controlled research design to evaluate the efficacy of several vitamins. Dr. Rimland concludes that vitamin B6 may be beneficial to people on the autism spectrum.



**ARI provides a unique platform for scientists and clinicians** to present new findings, discuss treatments and brainstorm. My first experience as a participant in these meetings has been inspiring and informative. The organization, through its support for innovative ideas and exploratory research, has provided valuable support to researchers.”

— EDWARD V. QUADROS, PhD  
 Research Professor, Department of Medicine  
 SUNY Downstate Medical Center, NY

HOW WE HELP

**Convene Scientists and Clinicians Face-to-Face**

Since 1995, the Autism Research Institute has brought together experts at its annual scientific think tank meetings to address novel questions and discuss issues related to promising interventions. ARI also funds and sponsors consensus meetings to facilitate ongoing discussion about the latest findings and approaches to understand and treat medical and behavioral symptoms associated with autism spectrum disorders.

We have always been committed to asking the tough questions. For over 50 years our work has influenced how researchers approach investigating the cause of and effective treatments for autism spectrum disorders.

**Our purpose is clear:**

*Advance research by following the science wherever it leads.*



**Is it  
Autism?**



**Medical,  
Sensory &  
Behavioral  
Symptoms**



**Screening &  
Assessment**



**Treatment**

**1976**

Dr. Rimland co-edits the book *Modern Therapies*.  
 Sylvester Stallone establishes the Stallone Fund for autism research, to which he donates the proceeds from several *Rocky* movie premieres. As treasurer, Dr. Rimland awards grants primarily for studies of brain tissue.

**1978**

Dr. Rimland publishes an article titled “The Autistic Savant” in *Psychology Today*. He argues that the original term used to describe someone with an unlearned skill, “idiot savant,” should be replaced with the term “autistic savant.”

**1979**

Dr. Rimland and Dr. Lovaas are featured in a story in *Rolling Stone* magazine. The publicity brings much attention to their work.  
 Dr. Lovaas introduces Stephen M. Edelson, PhD to Dr. Rimland, and Dr. Edelson offers to volunteer with ARI.

## Read about the investigations we funded in 2018

In 2018, ARI awarded more than \$200,000 in grants to scientists whose work will have a direct impact on the lives of those on the autism spectrum. The funds supported research in immune, gastrointestinal, metabolic, neurologic, and sensory issues. A sampling:

### Maternal dysbiosis at birth as a model for increased risk of autism

**Paul Ashwood, Ph.D.**

**Dept. of Medical Microbiology and Immunology  
UC Davis School of Medicine**

Assess whether the alteration of maternal microbiota will result in long-term changes in microbiota composition in the offspring, altered local intestinal barrier function, increased neuroinflammation and altered behavioral outcomes.

### Mitochondrial Dysfunction Associated with Autism: Clinical Signals and Treatment Outcomes

**Margaret Bauman, M.D.**

**Boston University School of Medicine**

Review the medical records of 12 ASD patients with biopsy proven mitochondrial dysfunction, ages 6-25 years of age, followed by the Integrated Center for Child Development (ICCD) (Bauman) and by the Cleveland Clinic Foundation (Natowicz) with regard to their clinical presentation, laboratory studies including blood, genetic and histopathologic findings and with regard to their developmental and medical outcomes as the result of having received the mitochondrial cocktail and carnitine.

### Enhancement of tissue procurement from individuals with ASD

**Thomas Blanchard, Ph.D.**

**University of Maryland Brain and Tissue Bank**

This 3-year proposal from the Maryland Brain and Tissue Bank is to identify additional medical examiners at national and state association meetings and to educate the public and medical examiners about the critical importance of tissue donations from individuals with ASD and matching controls for continued research into the etiology of autism.

### Joint Hypermobility & Hypermobility Spectrum Disorders in Mothers of Children with Autism & ADHD

**Emily Casanova, Ph.D.**

**University of South Carolina**

Survey mothers of children with autism who are assessed by our clinic, which diagnoses and treats many hundreds of ASD children each year.

### Study of Pyramidal Cells and Interneurons in the Cerebral Cortex of Patients with Autism Spectrum Disorders

**Manuel F. Casanova, M.D.**

**Endowed Chair in Translational Neurotherapeutics  
University of South Carolina**

**Greenville, South Carolina**

Identify and help quantitate inhibitory neurons in the brains of individuals on the autism spectrum. If present, the presence of such an inhibitory deficit may help justify and guide future therapeutic interventions, such as transcranial magnetic stimulation.

### To Determine the Minicolumnar Morphometry of Autistic, 15q dup and various Shank3 Mutant Mouse Models as Compared to Those in Control Tissue

**Manuel F. Casanova, M.D.**

**Endowed Chair in Translational Neurotherapeutics  
University of South Carolina**

**Greenville, South Carolina**

Examine differences in minicolumnar morphometry between the brains of 7 autistic individuals, 7 patients with 15q dup, 7 controls, all matched for age and sex (already obtained from the Autism Tissue Program), and the brains of various Shank3 mutant mice and wild type (n=15 total).

### Role of Environmental Factors in Autism Spectrum Disorder

**Ved Chauhan, Ph.D. and Abha Chauhan, Ph.D.**

**The Research Foundation of Mental Hygiene**

Evaluate the effects of three environmental chemicals, i.e., bisphenol A (BPA), methylmercury (MeHg) and alcohol, alone and in combination, on development and behavior of *Drosophila* (fruit fly) larvae, along with behavior of flies.

### Analysis of Common Factors in Genetic and Non-Genetic ASD Models

**Andreas Grabrucker, Ph.D. and Kieran McGourty, Ph.D.**

**University of Limerick**

Use proteomic analysis of 4 brain regions to identify common biochemical pathways that are dysregulated in both genetic and non-genetic causes of ASD.

## 1984

Dr. Rimland retires from the Navy and devotes all of his time to autism. Dr. Edelson finishes his graduate training on the same day. Soon after, they start a twenty-year collaboration.

## 1985

Dr. Edelson begins teaching at the Claremont Colleges. He organizes a yearly seminar on autism and invites leaders in the field to speak, including Drs. Rimland, Temple Grandin, and Laurence Becker. Parents of children on the autism spectrum are also invited and share their stories with the students.

## 1986

Temple Grandin publishes her first book, *Emergence Labeled Autistic*. Dr. Rimland edits the book and writes the forward.



As the scientific community began to understand more about the impact of medical conditions on behavior, ARI has supported research that enables clinicians to better care for their patients.

We are all grateful for the ongoing support of the Autism Research Institute.”

— HARLAND WINTER, MD  
Harvard Medical School  
Massachusetts General Hospital

**Metabolomics Analysis of Young Children with Autism Spectrum Disorders and Their Mothers Compared to Neurotypical Controls**

**Haiwei Gu, Ph.D. and James Adams, Ph.D.**  
**Arizona State University**

Simultaneously analyze and compare urine samples from children with ASD and their mothers compared to NT controls using metabolomics technology.

**Elevation of methionine sulfoxide in children with autism**

**Jill James, Ph.D. and Stepan Melnyk, Ph.D.**  
**University of Arkansas for Medical Sciences**

The oxidized form of methionine, methionine sulfoxide was found to be elevated in children with autism relative to their siblings and unrelated controls. This proposal will extend and confirm this finding with plasma previously collected from 50 ASD/sibling/control trios and determine the extent to which this marker of oxidative stress is related to other markers of protein damage. Positive results will provide a convenient marker for antioxidant treatment efficacy for protein damage.

**Gender Dimorphism: Microbiome Analysis in Autistic Boys and Girls**

**Rafail Kushak, Ph.D., Dr. Sc.**  
**Massachusetts General Hospital**  
**Harvard Medical School**

Test a new hypothesis suggesting that differences in the intestinal microbiota may underlie the well-established male preponderance in ASD.

**Proteomic Analyses of Autistic Brain**

**Marvin Natowicz, M.D., Ph.D.**  
**Pathology & Laboratory Medicine, Genomic Medicine, Neurological and Pediatrics Institutes**  
**Cleveland Clinic, Cleveland, OH**

This study, the first proteomic analysis of ASD brains, deepens our understanding of the brain biology in autism. Confirm earlier hypothesized dysregulated biological processes that were proposed on the basis of molecular genetic investigations such as disturbances of synapse biology. Provide new insights regarding the biology of ASD including, for example, insights regarding the dysregulation of key differentially expressed brain biochemical networks.

**To study CREB and Akt after zinc therapy**

**A.J. Russo, Ph.D.**  
**Hartwick College, Oneonta, New York**

The PI has previously demonstrated that the transcription factor CREB and the protein kinase Akt are low in children with autism. In this proposal, the PI will determine whether or not zinc therapy in children with autism will significantly raise both Akt and CREB levels in plasma and whether this increase will be associated with improved autism symptom severity in 50 children with autism and 50 age/gender matched neurotypical children.

**To Study the Effect of Zinc Therapy on ERK Levels in Individuals with Autism**

**A.J. Russo, Ph.D.**  
**Drew University**

Measure plasma ERK levels and zinc levels before and after zinc supplementation in 50 ASD and 50 control subjects to determine whether there is an association between plasma zinc and ERK levels and whether supplementation affects severity of autism symptoms.

**Determination of Exosomal Biomarker Candidates in ASD**

**Judy Van de Water, Ph.D.**  
**UC Davis, MIND Institute**

Perform an unprecedented proof-of-principle study analyzing the exosomal RNA and protein cargo associated with autism spectrum disorder (ASD) aiming to identify potential biomarkers and to inform as to CNS status.

**The role of the intestinal microbiome in children**

**Harland Winter, M.D.**  
**Rafail Kushak, Ph.D.**  
**Tim Buie, M.D.**  
**Harvard Medical School**

**and Massachusetts General Hospital**  
This grant supports the continued enrollment of children with autism and neurotypical controls into the Harvard/MassGeneral Hospital's biorepository of blood and gastrointestinal tissue samples. Samples will be used for their own research and shared with other researchers who are pursuing novel and creative approaches to understand causes of autism and potential treatment options.

**1987**

Dr. Rimland publishes a printed science newsletter on autism, the *Autism Research Review International*. The first year was supported by a grant from Hasbro toys. It is still published today for thousands of subscribers.

**1988**

Because of his publications on savant abilities, the producer of the movie *Rain Man* asks Dr. Rimland to be the head consultant. He suggests that Raymond, the lead character played by Dustin Hoffman, have autism rather than an intellectual impairment.

**1989**

Dr. Edelson opens the Center for the Study of Autism (CSA) in Oregon, a research laboratory for ARI. The center conducts research on sensory related interventions and offers services. Families worldwide travel there to participate and learn how to help their children.



**We are grateful to ARI for the support** that has made it possible to serve as the scientific community’s only source of brain tissue from autistic donors in recent years. ARI has been instrumental in our outreach efforts with medical examiners to expand the number of cases available to investigators throughout the country.”

— THOMAS BLANCHARD, PhD  
Associate Professor  
Pediatrics  
University of Maryland

## HOW WE HELP

### Collaborate to Support Tissue Donation

Research on brain tissue is needed to understand the underlying causes of autism. The neural configuration may also provide us with clues regarding appropriate treatment. For the past several years, ARI has supported the University of Maryland’s Brain Tissue Bank. We can assure our donors that this storage facility has extensive, built-in safeguards; an important issue to address given the news of recent losses at another autism tissue bank. Besides the brain, another organ important to understanding autism is the bowel; ARI supports the gastrointestinal depository at Massachusetts General in Boston.

## HOW WE HELP

### Compile Precious Data

Since the mid-1960s, ARI has been collecting data regarding developmental history and symptoms. A recent analysis of over 40,000 cases revealed ten to twelve subtypes of autism. Follow-up research is needed to replicate these findings. ARI is involved in data collection for several major research projects.

## HOW WE HELP

### Facilitate Expert Consensus Reports

ARI is collaborating with top researchers to write summary reports on known findings as well as areas requiring further investigation in their particular field of study (e.g., gastrointestinal, genetics, immunology, metabolism, nutrition, neurology, neuropathology, and sleep).

## 1993

Dr. Rimland consults on *Frontline’s* “Prisoners of Silence,” and the movie *House of Cards*.

Dr. Rimland guides Catherine Maurice and promotes her book *Let Me Hear Your Voice: A Family’s Triumph Over Autism*, which brings widespread awareness of ABA.

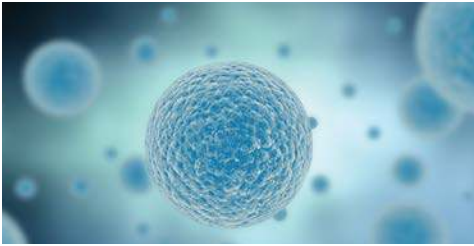
## 1994

The Society of Auditory Integration Training (SAIT), co-sponsored by ARI and CSA, holds its first meeting.

Drs. Rimland and Edelson publish the first research paper examining the efficacy of auditory integration training (AIT).

## 1995

ARI convenes its first international think tank consisting of more than 50 researchers and expert physicians, focusing on medical co-morbidities associated with autism. This was the first recorded time that a group of professionals discussed GI issues associated with autism.



## HOW WE HELP Conduct International Surveys

### Large-Scale Subtype Survey

If there are valid subtypes of autism, researchers will be in a much better position to study the underlying cause and the most effective treatments for each type of autism.

### Senior Survey

We are conducting an online survey of seniors to collect data about autism through the entire lifespan. We anticipate that this study will inspire others as well as better inform the autism community, government agencies, and other welfare and health-related organizations about such aging issues. We hope the results will provide insight about the needs and challenges faced by seniors with autism (ages 50 years) and their support providers.



“The Autism Research Institute fills a unique place in national and international autism organizations. ARI supports unique approaches to understanding and treating autism spectrum disorder (ASD) **leaving no stone unturned while supporting good science;** helps families understand the potential etiologies of ASD and consider the evidence for all treatments; and provides education for all who are interested in understanding and evaluating a wide variety of often inadequately understood approaches.”

— ROBERT L. HENDREN, DO  
Professor of Psychiatry  
University of California, San Francisco

## 1995

Think tank participants Sidney Baker, MD and Jon Pangborn, PhD agree to work closely with Dr. Rimland on this project. Later, Dr. Rimland uses the Defeat Autism Now! or DAN! protocol to describe this approach to GI issues associated with autism.

## 1996

ARI publishes a 41-page booklet, *Clinical Assessment Options for Children with Autism and Related Disorders: A Biomedical Approach*, written by Drs. Baker and Pangborn. Five editions were published over a ten-year period.

## 1997

ARI begins to sponsor conferences highlighting medical and biomedical issues. Researchers, physicians, nutritionists, individuals with autism, and parents attend. Dr. Edelson is invited to Taiwan to help establish an autism society for parents and professionals.

## HOW WE HELP

# Democratize Learning Through Online Webinars

At the Autism Research Institute, we make an effort to provide presentations that are unbiased and broad-reaching, and to assist families and professionals in making informed treatment decisions. We also strive to provide professional education that gives innovative clinicians the means to offer appropriate support. We are grateful to the Johnson Center for Child Health & Development for working in partnership to offer many of these presentations.

**Thousands register for free ARI webinars each year and more than 425,000 viewers have watched ARI's free, expert webinars.**



I am very grateful to the Autism Research Institute for introducing me to **a parent-centric view of autism**. The community of researchers, united under the umbrella of ARI, is focusing on careful analysis of scientific leads that can culminate with practical steps to help the affected kids and their parents.”

— ANDREY RZHETSKY, PhD  
University of Chicago

## HOW WE HELP

# Translate Resources

ARI offers translations of a variety of resources online at Autism.org. Along with content pages and selected on-demand videos, the Autism Treatment Evaluation Checklist (ATEC) is available to users in 20 different languages.

### 1999

Drs. Edelson and Rimland release the Autism Treatment Evaluation Checklist (ATEC) to help researchers, therapists, and parents assess treatment efficacy. Parents also rely on the ATEC to monitor their children's progress over time. As of 2018, over a half million ATECs have been completed.

### 2003

Drs. Edelson and Rimland co-edit a book titled *Treating Autism: Parent Stories of Hope and Success*. A second, revised edition titled *Recovering Autistic Children* is published in 2006. This is one of the first books that discussed the possibility of recovery.

### 2004

ARI funds gastrointestinal (GI) research (\$100K) at Harvard/Mass General. These funds were used as “seed money” to start the Autism Treatment Network.



## HOW WE HELP

# Create Free Online Continuing Education on Autism for Physicians and Other Healthcare Providers

ARI works in partnership with leading experts to provide professional education that gives thoughtful, inquisitive clinicians the means to offer support that is safe and effective.

Informing physicians about appropriate standards of care is crucial to our mission — in joint providership with the Cleveland Clinic we continue to offer complimentary CME-certified online education to amplify understanding of the medical nature of the disorder.

All Internet users can view the *Autism Spectrum Disorders: Research and Medical Treatment Implications* webcast series for free online. Learn more at [ARI-CME.com](http://ARI-CME.com).



I am thankful to the Autism Research Institute for inviting me to speak at their meeting and present on their webinar series this past year. **The webinars provide a remarkable opportunity for a broad spectrum of interested parties to learn what is going on directly from the researchers, and the meeting allows face-to-face interactions between researchers and clinicians in a small group setting. This type of communication is critical for moving forward.**

— DAVID BEVERSDORF, MD  
University of Missouri School of Medicine

## 2005

The last edition of the *Clinical Assessment Options for Children with Autism and Related Disorders* booklet is published. This edition by Drs. Pangborn and Baker, titled *Autism: Effective Biomedical Treatments, Have We Done Everything We Can for this Child?*, contains 328 pages.

## 2006

Dr. Rimland passes away in November and leaves a monumental legacy of commitment and dedication to the autism community. The Board selects Dr. Edelson to become executive director of ARI.

## 2007

ARI launches a monthly e-newsletter. ARI collaborates with Unlocking Autism to sponsor a toll-free resource center. ARI begins a Rural Outreach Pilot Project to provide needed information to various regions in the U.S.

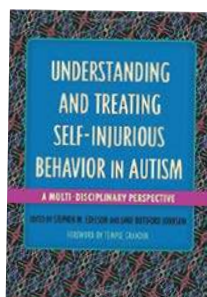
## HOW WE HELP

# Publish Articles and Books on Critical Topics



### **Autism Research Review International**

From early days, ARI updated the autism community about research in the areas of behavioral, education, genetic, medical, and sensory issues. To that end, our founder began publishing a quarterly science newsletter, the *Autism Research Review International*, starting in 1987. Besides reporting on the most current and relevant research findings, the newsletter includes editorials on important insights and perspectives about the field. For many people, this newsletter, now also accessible online, is their main source of trusted information about science and autism.



### **Understanding and Treating Self-Injurious Behavior in Autism**

Our latest book, *Understanding and Treating Self-Injurious Behavior in Autism* (2016), is a comprehensive analysis of this poorly understood and often devastating behavior in people with ASD or related developmental disabilities. Various treatment methods are also described in the book. A second book in this series, *Understanding and Treating Anxiety in Autism*, is scheduled to be published later in 2019.

*ARI publications are available on Amazon.com.*

## Past Books



The Autism Research Institute has been a pioneer in both the understanding and treatment of autism. Bernard Rimland was definitely ahead of his time.”

— TEMPLE GRANDIN  
Author of *Thinking in Pictures*  
and *The Autistic Brain*



## 2007

ARI enters an agreement with the National Institute for Child Health and Human Development and the University of Maryland to co-sponsor a tissue bank.

ARI begins a collaboration with the Autism Network for Hearing and Visually Impaired Persons.

## 2008

Dr. Rimland's book, *Dyslogic Syndrome*, is published.

ARI converts a store front office into an art gallery. Dr. Rimland's son, Mark, is the resident artist, and proceeds from the sales are used to fund research.

## 2010

ARI begins publishing a quarterly e-newsletter focused on topics related to adults on the spectrum. The editor is an adult on the spectrum, and the majority of the articles are written by people also on the spectrum.



## HOW WE HELP

### Offer Free Online Screening Tools

#### Autism Treatment Effectiveness Checklist (ATEC)

Although researchers have published thousands of studies attempting to evaluate different biomedical and psycho-educational interventions intended to benefit those with autism, a major obstacle has been the lack of valid assessment tools designed to measure treatment effectiveness. The Autism Treatment Effectiveness Checklist was developed by Dr. Rimland and Dr. Edelson to fill this need. Since its inception hundreds of thousands of ATEC forms have been completed.

## HOW WE HELP

### Provide Resources and Support

#### Autism.org

The advent of the Internet changed the autism community dramatically in the mid-1990s, and ARI has led the way since the “early days.” Today, ARI sponsors a Yahoo discussion group that gives parents the opportunity to ask questions and share information with one another. We also post information on a daily basis to Facebook, Twitter, FlipBoard, Google+ and Pinterest. These daily posts include descriptions of recent research studies and other important autism-related news.

#### Toll-free Telephone Hotline

ARI offers a free hotline for parents and professionals, who can reach a live person for information and support.

#### Special Support

ARI publishes a bimonthly e-newsletter titled *Clinical Research in Autism* for obstetricians, pediatricians, and nurses to keep them well-informed of research relevant to their practice.

## 2012

ARI begins to sponsor online webinars.  
ARI premieres a bimonthly e-newsletter for obstetricians, pediatricians, and nurses titled *Clinical Research in Autism*.  
ARI receives NGO status from the U.N.

## 2013

ARI begins co-sponsoring a think tank with Massachusetts General Hospital.  
Two discussion panels at the United Nations on Autism Awareness Day are sponsored by ARI.  
Dr. Edelson speaks in Russia and Ukraine.

## 2013

ARI co-sponsors a half-day conference on immunological factors, genes, and environment at the MIND Institute.  
Dr. Edelson is a featured speaker in Russia and Ukraine and shares ARI resources with these countries.

# Stewardship

It's important our donors trust that we're using our funding wisely to accomplish our mission of improving the health and well-being of people on the autism spectrum. We accomplish this by sponsoring autism research while educating professionals, those who are affected, and their families.



Only one out of four non-profit organizations earns a Charity Navigator 4-star rating.

The Autism Research Institute's sound fiscal management practices and commitment to accountability and transparency have earned it another 4-star rating from Charity Navigator, America's largest independent charity evaluator. Using objective, data-driven analyses, Charity Navigator awards 4-star ratings to only the most fiscally responsible organizations.

"The Autism Research Institute's coveted four star rating puts it in a very select group of high-performing charities," according to Michael Thatcher, President & CEO of Charity Navigator. "Out of the thousands of nonprofits Charity Navigator evaluates, only one out of four earns 4 stars – a rating that demands rigor, responsibility and commitment to openness. The Autism Research Institute's supporters should feel much more confident that their hard-earned dollars are being used efficiently and responsibly when it acquires such a high rating."



**This is a purpose driven organization that exudes social responsibility, patient engagement, and personal values as expressed in their work and achievements.** Throughout the last five decades the Autism Research Institute has been the one-stop center that provided answers and support to the autism community."

— MANUEL F. CASANOVA, MD  
SmartState Endowed Chair in Childhood Neurotherapeutics  
Professor of Biomedical Sciences  
Departments of Pediatrics and Biomedical Sciences  
University of South Carolina School of Medicine Greenville Campus

*The Autism Research Institute is a non-profit 501(c)3 organization focused on conducting and sponsoring research aimed at improving the quality of life for today's generation of children and adults with autism spectrum disorders. Contributions are tax deductible as allowable by law. Fed ID No. 95-2548452.*

## 2014

ARI is instrumental in the release of the 50th anniversary edition of Dr. Rimland's seminal book, *Infantile Autism*.

ARI co-sponsors a medical/biomedical think tank in Toronto with Autism Canada.

## 2014

ARI begins offering complimentary CME to physicians in joint-providership with the Cleveland Clinic Foundation.

ARI launches Autism.jobs site.

ARI produces a film on trauma in autism.

## 2015

ARI expands its regional think tanks to include New York.

ARI is instrumental in the publication of several articles on early identification and early intervention in *Pediatrics*.

# Financial Summary

## 2018 Financial Overview

### FUNDING

Donations and Grants \$727,550

### PROGRAMS

Grants for Research \$ 257,923

Online Education and Resources \$ 80,751  
Webinars/Website/  
Physicians' Training-CME

Scientific Think Tank \$ 37,929

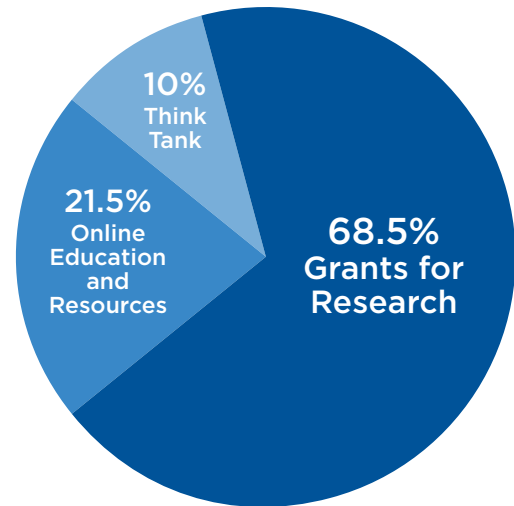
**Total Program Costs** \$ 376,603

### ADMINISTRATION

Management and Support Costs \$ 117,715

### TOTAL NET ASSETS

Total Net Assets as of Dec. 31, 2018 \$2,882,468



To view ARI's comprehensive financial statements, visit [autism.org/donors](http://autism.org/donors)

**Special thanks** to our many generous supporters, including research and education grants from Local 25 Boston Teamsters and *For Autistic Kids Foundation*.

## 2015

ARI launches an online job interview course for adults on the spectrum.

Dr. Edelson and Mark Rimland serve as hosts on stage during a morning session at the 50th Anniversary ASA Conference in Denver, CO.

## 2016

ARI is instrumental in the publication of the book *Understanding and Treating Self-Injurious Behavior in Autism*.

Dr. Edelson co-authors a popular review paper on seizures in autism.

## 2017

Physician webcasts are translated into Spanish and Portuguese.

ARI's YouTube channel offering free online education reaches 225,000 views.

# Who We Are

## 2019-2020 Board of Directors



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*Communications and Online Learning*



Rebecca McKenney  
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Paul Meeks, CFA  
James Walker

### Key Volunteers

Jeff Blair  
*Online Resources*  
Jane Johnson  
*Think Tank Coordinator*

Pelin Bicen, PhD  
*Associate Professor of Marketing*  
*Suffolk University*

### Consultants

Nicole Cacchiotti  
*Marketing Content*  
Chris Cava Preston  
*Art Direction*  
Melanie Glock  
*Communications Specialist*  
Anthony Morgali  
*Media Producer*

### Intern

Charlotte Jegou

## 2018

March - ATEC paper published - Autism Treatment Evaluation Checklist (ATEC) Norms: A "Growth Chart" for ATEC Score Changes as a Function of Age

## 2018

April - international conference in Moscow, Dallas think tank, release of Aging in Autism report

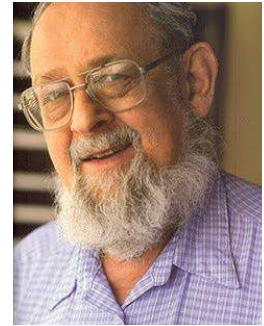
## 2018

Filmed talks on genetic research and ASD featuring Dr. Steve Scherer, Director of the The Centre for Applied Genomics, The Hospital for Sick Children, Toronto

**Autism is now recognized as a neuro-developmental condition.**

**This was not always the case.** One man stood against the prevailing views and, in the end, changed public and medical opinion. This man, Dr. Bernard Rimland, became a one-stop center for parents and patients who needed help and information in regards to autism. Rimland's legacy lives on in The Autism Research Institute. For 50 years, ARI has given a voice to autistic individuals in myriad areas at a global level."

— MANUEL F. CASANOVA, MD



Bernard Rimland, PhD

## Scientific Advisory Board



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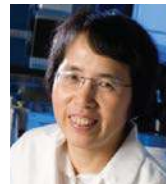
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pictured: Brennan and Oliver Ringel, New Jersey

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funds one webinar that offers free education and support for up to 10,000 viewers in real time.

**\$100/month  
for one year**

funds complimentary continuing medical education programs for 175 medical professionals.

Please use the enclosed donation envelope or visit **Autism.org/donate** to give today.

*Contributions are tax deductible as allowable by law. Fed ID No. 95-2548452.*

*Give with confidence. ARI's sound fiscal management practices and commitment to accountability and transparency have once again earned a 4-star rating from Charity Navigator.*

