

# 2019 annual report



**Together, We Can Make a Difference.**



**research.  
support.  
empowerment.**



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



**1 in 54** identified with ASD this year

Statistics from the Centers for Disease Control and Prevention (CDC) announced in March 2020 underscore the need for autism research funding.

## 2019 Accomplishments

### RESEARCH

*ARI takes an active role in all phases of autism research*

We awarded more than \$287,000 in grants to fund exciting and innovative research that holds realistic promise to impacting the lives of individuals with autism spectrum disorder (ASD).

We expanded our **Scientific Advisory Board**, which consists of leading researchers in all areas related to the understanding of the underlying biology of autism.

We sponsored forums, such as **national and regional think tanks and an online discussion group**, to engage scientists and practitioners in in-depth dialogues about current and upcoming research. In these settings, scientists have opportunities to share their thoughts and findings directly with clinicians. In so doing, the researchers receive practical information from practitioners and the clinicians become informed about major research developments.

We continued to provide researchers with **advice and guidance** on how to optimize their experimental designs. We also helped them recruit participants for their studies.

ARI provided funding support for two major tissue banks, including a brain tissue bank for the National Institute of Child Health and Human Development at the University of Maryland and a gastro-intestinal tissue bank at the Digestive Function Laboratory Repository at Massachusetts General Hospital in Boston.

We continued to publish our quarterly science newsletter, *Autism Research Review International (ARRI)*, where we reported on current medical, sensory, and educational research.

We completed a multidisciplinary book—set to be published in 2020—on **understanding and treating anxiety co-occurring with ASD**. Contributors include leading experts in challenging behaviors, medicine, neurology, nutrition, and sensory processing.

### CONTINUING MEDICAL EDUCATION

*ARI continues to inform the medical community about best-practice treatments.*

ARI offered, in joint providership with the Cleveland Clinic, complimentary **AMA PRA Category 1 Credit™** to physicians and the general public. Connecting physicians to improved standards of care is crucial to amplifying understanding of the medical nature of autism. New talks on psychiatry, psychopharmacology, and genetics were released in the Fall 2019—view online at [ARI-CME.org](http://ARI-CME.org).

### ONLINE LEARNING

*ARI has an active online presence.*

During Autism Awareness Month 2019, we released a new website, [www.Autism.org](http://www.Autism.org), integrating our online presentations, updated content, and diagnostic and assessment tools for all members of the autism community.

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

ARI continued to host live webinars featuring top researchers and treatment professionals. Topics included research updates, diet, nutrition, ABA, assessment, educational therapies, and adult issues.

Our YouTube channel continued to provide free access to expert presentations with up-to-date webcasts on medical support and educational videos, social stories, and talks from past conferences. Users have tuned in for more than half a million viewings.

### OUTREACH IN THE U.S.

*ARI offers personal support to parents and professionals.*

ARI continued to sponsor a telephone support line for parents and care providers seeking information.

We continued to provide an opportunity for viewers of our live webinars to ask questions directly to the presenters.

### INTERNATIONAL OUTREACH

*ARI embraces the global autism community.*

ARI is an NGO (non-governmental organization) of the United Nations, which enables the organization to further awareness of autism research around the world.

ARI continued to translate many of our key articles, as well as our Autism Treatment Evaluation Checklist (ATEC), into different languages. Now available in 22 languages, ARI's ATEC is completed by more than 150 users per day.

We continued to work directly with network groups and clinicians worldwide, especially in regions where awareness and support are still emerging, including areas of Eastern Europe and South America.



## 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

It's not unusual to look for a sense of reassurance during a time of so much uncertainty. You can count on ARI to continue its mission in the months and years to come.

Throughout our 52-year history, ARI has provided guidance and support to individuals with autism, families, and professionals. With meetings cancelled and facilities closed due to the COVID-19 pandemic, we are leveraging technology to continue these efforts, networking with insightful scientists, passionate clinicians, tireless advocates, and knowledgeable supporters who understand the challenges associated with autism.

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.

Finally, we want to express our sincere appreciation for the healthcare workers, first responders, essential workers, and families who have worked tirelessly to support our communities in this unprecedented time.

Stay safe and well,

A handwritten signature in black ink that reads "Stephen M. Edelson".

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

A handwritten signature in black ink that reads "Marvin Natowicz".

Marvin Natowicz, MD, PhD  
*Cleveland Clinic  
2018-21 Chairman of the Board, ARI*

# How ARI Touches Lives

Year round, ARI receives feedback from families and individuals, who share their personal experiences with 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. Those featured here, as well as on the cover and throughout this report, were selected from this group. Photo contributors include the Barbu, Guinn, Hart, Hughes, Lehman, and Perdomo families.



“**Though it was all very overwhelming at first, ARI was a reliable source I could count on.**”

ARI was one of my first resources in the beginning of our journey. The website listed what to look for, and I learned exactly what autism is. This helped confirm that what I was seeing were signs that Evan was on the autism spectrum.

Evan started early intervention soon after. Today, Evan is 8 years old. He is a wonderful student and an amazing son. I can't wait to see him progress and accomplish anything he sets his mind to.”

— Jennifer Rosenthal, Vineland, NJ

“**Sion is my hero because he has taught me what hard work and determination look like.**”

Sion was nonverbal at 5 years of age. Now, at 8, he is academically above his level and has taught me so much about what it means to be loved unconditionally.”

— Shannon Kennedy, Topeka, KS



“**Thank you, ARI. She is doing so well!**”

The information I received from ARI has helped me to stay current with the latest findings on autism. I found that hearing the encouraging journeys of other autism parents provided hope. My daughter has also benefitted from eating a healthy and organic diet.”

— Mary Amoah, Accra, Ghana

**“ In the beginning, I wondered how he would ever fit in the world. Would he ever have someone he could call a friend and would he be able to communicate his needs within the world around him?”**

Hunter’s autism journey started when he was 18 months old. Once we obtained a diagnosis, obtaining evidence-based information to help formulate a game plan was our number one priority. It would prove to be the only way for Hunter to be successful in the long run.

We used ARI articles and webinars as our gold standard when making decisions for Hunter related to his autism diagnosis. As a parent, I was learning right alongside him and to have that proven place to go to and learn from gave me the peace of mind to be a better parent knowing the decisions I have chosen for him were going to offer him the best opportunities at success any child with autism, could hope for.”

— Lynn Dalton, Stony Point, NY



**“ Maylee handles the ups and downs of autism in our home with love and grace.**

When her brother has a meltdown, she keeps her cool and lovingly attempts to comfort him and offer him solutions. She is sweet and goofy and has a genuine desire to keep our family happy and calm. Through ABA therapy, her brother has come a long way. He is often able to use techniques to calm himself or appropriately escape a situation before it escalates. Maylee has also learned what helps her brother and can often offer him suggestions.

— Amber Gordon, Cedar Falls, IA

**“ Always believe in your child first, no matter what others say. Embrace their strengths. Celebrate their uniqueness.**

With love, hard work, determination and discipline, people with autism can achieve great things. It took non-stop work and the dedication of a team of amazing human beings — Victor’s horse trainer, piano teacher, ABA analyst, speech therapist, and great teachers of general education classes that welcomed him and included him in all the activities as any other child. Victor is my Hero. I am a better person because of him.”

— Carmen Garcia, Miami, FL

Man With Autism Learns to Code at Miami-Based Coding School  
[www.nbcmiami.com/news/local/Man-With-Autism-Learns-to-Code-at-Miami-Based-Coding-School-508517141.html?akmobile=0](http://www.nbcmiami.com/news/local/Man-With-Autism-Learns-to-Code-at-Miami-Based-Coding-School-508517141.html?akmobile=0)



NBCMIAMI.COM  
Man With Autism Learns to Code at Miami-Based Coding School

# 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.



Is it  
Autism?



Medical, Sensory  
& Behavioral  
Symptoms



Screening &  
Assessment



Treatment

### 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.***

### 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.org](http://ARI-CME.org).



### FROM THE ARI CHAIRMAN OF THE BOARD OF DIRECTORS



**I am honored to work on behalf of persons and families touched by autism** by serving on the board of directors of ARI, and in doing so, supporting research and education.”

— MARVIN NATOWICZ, MD, PhD  
Cleveland Clinic  
Case Western Reserve University School of Medicine

#### 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. ARI is involved in data collection for several major research projects.

#### HOW WE HELP

### Facilitate Expert Consensus Reports

ARI is facilitating the collaboration among distinguished researchers and clinicians to write summary reports on known findings as well as areas requiring further investigation regarding diverse aspects of autism, including, gastrointestinal, genetic issues, immunology, metabolism, nutrition, neurology, neuropathology, and sleep.

#### HOW WE HELP

### Conduct International Surveys

#### 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 aging issues. We hope the results will provide insight about the needs and challenges faced by seniors with autism (aged 50 years or more) and their support providers.

## Read about the investigations we funded in 2019

In 2019, ARI awarded more than \$287,000 in grants to scientists whose work will have a direct impact on the lives of individuals diagnosed with ASD. The funds supported research in immune, gastrointestinal, metabolic, neurologic, and sensory issues.

Below is a sampling of research studies funded wholly or in part by ARI.

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### Identifying Metabolic Differences During Pregnancies in Mothers of Children Later Diagnosed with ASD

**James B. Adams, David Haas, Haiwei Gu, and Juergen Hahn, Arizona State University**

Prenatal supplements with folate are known to reduce the risk of neurological birth defects, and also seem to significantly reduce the risk of a child developing ASD. Our recent research on mothers of children with autism suggests that they have many metabolic differences from mothers of typically-developing children, and suggests that certain nutritional supplements including folate could be important. We propose to investigate levels of those metabolites in blood samples from 10,000 women, and compare the metabolite levels during pregnancy in those whose children developed ASD vs. those who developed typically. Our hope is that this study will lead to the discovery of other nutrients that may improve the mother's metabolism and reduce the risk and/or severity of ASD in their children, as well as symptoms including seizures, intellectual disability, gastrointestinal problems, and sensory sensitivities.

### The Domino-Drosophila Ensemble for the Functional Validation of New ASD Genes

**Alexandros Kanellopoulos, University of Lausanne, Switzerland**

ASDs are characterized by significant limitations in both intellectual functioning and adaptive behavior. Despite substantially different clinical phenotypes and genetic contributions, there seems to be a convergence on common cellular pathways, which ultimately affect brain wiring, function and behavior. A large list of potential ASDs risk genes has been compiled through analysis of copy number variants (CNVs) or single-nucleotide polymorphisms (SNPs). We plan to identify and experimentally validate new genes for Autism. Specifically, our approach is based on a machine-learning algorithm which predicts which genes may harbor autosomal-dominant mutations. We have currently extracted 141 de-novo mutations from a public database that possibly cause ASDs, and 7 of these are novel putative genes. The validation will be performed using the fruit fly *Drosophila melanogaster*, a valuable animal model for a medium-throughput screening.

### Single Session Intervention for Comorbid Internalizing Symptoms in ASD

**Matthew Lerner, Stony Brook University**

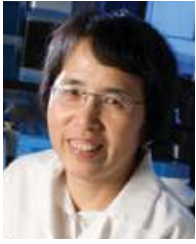
Teens with ASD experience substantial internalizing (anxiety and depression) symptoms, as well as considerable social challenges. Existing interventions for these symptoms are resource-intensive, with variable effects. Growth mindset single-session interventions (GM SSI) represent a promising, new, scalable approach to addressing these symptoms, which can be delivered via computer in just 30 minutes. GM SSIs have been shown to reduce internalizing symptoms in youth without ASD. This project is the first to examine a GM SSI in teens with ASD; it employs a randomized controlled design with a well-matched attention control (a supportive therapy [ST] SSI). This project will evaluate effects of GM SSI on internalizing symptoms and core social and executive functioning outcomes.

### Using Zebrafish to Help Identify Which Environmental Toxicants Could Increase Autism Risk

**Edward Levin, Duke University**

In the proposed project, we will use the zebrafish model to investigate the behavioral consequences of environmental toxicants affecting retinoic acid receptors (RARs) during early neural development. We will study RAR acting compounds because RAR signaling plays a critical role in proper formation of the neural tube/plate. Disruption of RAR signaling such as with the anticonvulsant drug valproic acid (VPA) has been shown to increase risk of ASD. We anticipate that even modest disruptions in RAR signaling will not result in dramatic alteration in neural organization until a later stage of neurodevelopment when the brainstem nuclei project rostrally to help organize later more rostral neurodevelopment.

Then, the full phenotypic expression of the early neurotoxic injury may manifest in behavioral dysfunction. Here we propose that exposure to environmental toxicants affecting RAR signaling contribute to the increasing rates of ASD.



“Support from ARI has been a great help for studying complex interactions between the brain and other organ systems. This is appreciated given the high frequency of co-morbid conditions in ASD subjects, which is not well elucidated. ARI helped advance scientific research of autism as a systemic disease(s) involving multiple organs and possible denominating factors underlying variable clinical features of ASD.”

— HARUMI JYONOUCHI, MD  
Saint Peters University Hospital;  
Robert Wood Johnson University Hospital;  
Rutgers New Jersey Medical School

### **Corneal Confocal Microscopy: A Surrogate Marker for Neurodegeneration in Autism**

**Rayaz Malik,**  
Weill Cornell Medicine, Qatar

Major challenges in managing people with ASD include its heterogeneity, poor knowledge of disease trajectories and an inability to accurately identify the extent and progression of underlying neurodegeneration. Neuro-imaging studies confirm altered neural connectivity and trajectories for normal brain development, but lack precision. Whilst the focus of these studies has been on central brain pathology, recent studies show altered tactile discrimination and allodynia on the face, mouth, hands and feet of subjects with autism, indicating defects in peripheral somatosensory neurons. Indeed, a reduction in lower limb intraepidermal nerve fibre density has been reported in children with autism. We have pioneered the technique of corneal confocal microscopy (CCM) to rapidly image corneal nerve fibres and established it as a biomarker for peripheral and central neurodegenerative disease. In our pilot study of eight children with ASD, we show a significant reduction in the corneal nerve fiber length ( $P < 0.01$ ) and branch density ( $P < 0.01$ ) compared to healthy controls. We propose to assess if CCM can act as a rapid and reliable non-invasive biomarker of neurodegeneration in people with ASD.

### **Examining the Impact of the Very Early Treatment of ASD Between 12-17 Months**

**Karen Pierce,**  
University of California San Diego

Evidence is striking that ASD begins in the womb, likely at around 20 weeks gestation. Yet, according to the CDC, most children do not receive a diagnosis and treatment until around age 4 years. Given the enormous plasticity of the human brain during the first years of life, the time delay between the disorder's fetal onset and eventual treatment is likely a missed opportunity. Leveraging our pediatrician network in San Diego and our Get SET Early ASD detection program that has been shown to detect ASD as young as 12 months we propose to examine the impact of very early, high intensity, treatment of ASD. Our treatment will combine pivotal response training with a social enhancement module, parent training, gaze contingent eye tracking, and sensory motor training for a

total of 24 hours per week for 6 months. A small sample of toddlers will start intensive treatment at very young ages (between 12-17 months) in comparison to toddlers that either started at an equally young age but did not receive intensive treatment, or started at a much later age. At baseline and outcome 6 months later, all toddlers will participate in a series of standardized tests. Creating synergy with existing NIMH grants, toddlers will also participate in novel tests of visual social attention and neural functional activation patterns. To examine the impact of very early treatment, changes in standardized test scores, free play behaviors, eye tracking, and neural functional activation maps will be compared between the 3 groups of toddlers. Our overall goal is to collect pilot data aimed at testing the hypothesis that the timing and intensity of treatment engagement is the key to maximizing change in symptoms for toddlers with ASD.

### **Assessing Novel Impacts of RASopathies on Cortical GABAergic Neurons**

**Daniel Vogt,**  
Michigan State University

ASD may be caused by multiple factors, including environmental impacts and gene mutations. There are several monogenetic syndromes with high rates of ASD that may be the low hanging fruit that could uncover which biological mechanisms are altered, and in turn, may be targeted, to alleviate ASD symptoms. The RASopathies are syndromes caused by mutations in genes regulating the RAS/MAPK pathway, which is associated with high rates of ASD. While much work has uncovered genetic causes of these syndromes, their contribution to ASD symptoms are poorly understood. We deleted the RASopathy gene, *Nf1*, in GABAergic interneurons, and uncovered a drastic loss of a key GABAergic control gene and loss of a specific types of interneuron, i.e. those expressing parvalbumin (PV). Since GABAergic neurons are the primary driver of brain inhibition, this discovery may uncover some mechanisms underlying the neuropsychiatric changes in ASD. This proposal will be the first to assess the core GABAergic molecular program in RASopathy models with low to high rates of ASD diagnoses as well as correlate our findings with rates of ASD diagnoses.



## HOW WE HELP

## International Outreach; Translating Resources

ARI is a Non-Governmental Organization (NGO) of the United Nations providing educational resources and tools for users around the globe. Our Autism Treatment Evaluation Checklist (ATEC) is offered for free, online, in 22 languages – more than 150 users per day use this free tool. International outreach includes targeted efforts in Eastern Europe and South America.

“ARI has given us tools to better understand ASD by providing a more humane and effective science-based approach. This has allowed us to change the paradigm we knew, and give a better quality of life and hope to our patients and their families. We are forever thankful to Dr. Bernard Rimland and Dr. Stephen Edelson, who always responded promptly to our questions, laying the scientific foundations of our 40-year-old institution.”

— MARÍA RUSSO, President  
Sociedad Venezolana para Niños y Adultos Autistas  
Venezuela

“ARI has made a profound impact in my practice. The Institute not only widened my vision and perspectives for a more thorough approach to ASD but also helped me to interact with a network of key experienced researches. ARI has given me and my country much more than I ever expected.”

— MAURO F CARDOSO LINS  
Brazil

“ARI provides valuable resources for families as well as professionals in need of quality information and education. Our charity frequently directs our beneficiaries to ARI’s online materials, as we know they will be in good hands — the standards and the quality of ARI’s webinars and publications are always very high. The research into biomedical causes and treatment that ARI has pioneered, promoted and funded has had wide-ranging ripple effects, providing great hope as well as real, practical answers to countless families. Their work has had a large effect in moving the field forward and improving lives all over the world, including the UK. We are grateful to ARI for paving the way and for continuing to shine a light.”

— NATASA BLAGOJEVIC-STOKIC  
ThinkingAutism.org.uk  
United Kingdom

## HOW WE HELP

# Democratize Learning Through Online Webinars

ARI makes 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.

More than half a million viewers have watched ARI's free, expert webinars.



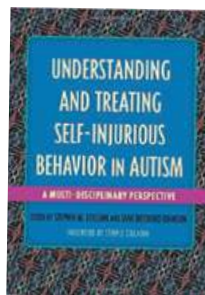
## HOW WE HELP

# 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 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 2020.

*ARI publications are available on Amazon.com.*

## Past Books





## HOW WE HELP

### Offer Free Online Screening Tools

#### Autism Treatment Evaluation 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 Evaluation 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.” We post information on a daily basis to Facebook, Twitter, Instagram, FlipBoard, 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.



I always teach my students that Dr. Bernard Rimland — founder of ARI and a parent of a son with autism — was the first to assert that autism was caused by biological/biochemical factors. **ARI has been passionately upholding Dr. Rimland’s legacy through resources, information, and support.** Through its free expert webinars, ARI provides the amazing opportunity for parents and professionals to learn from top researchers and clinicians. ARI also supports researchers by funding innovative, exploratory studies and hosting think tanks that allow for the presentation of findings and brainstorming in a small group.

— LAUREN MOSKOWITZ, PhD  
St. John’s University

# Financial Summary



Bernard Rimland, PhD



**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  
University of South Carolina's  
School of Medicine at Greenville

## 2019 Financial Overview

### FUNDING

Donations and Grants \$1,078,068

### PROGRAMS

Grants for Research \$ 287,091

Online Education and Resources \$ 80,885  
Webinars/Website/  
Physicians' Training-CME

Scientific Think Tank \$ 37,354

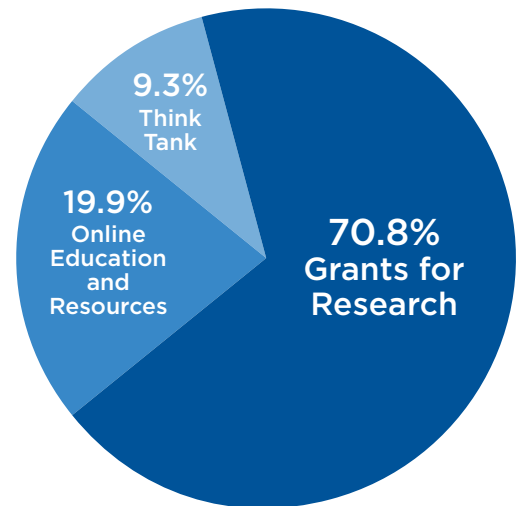
**Total Program Costs** \$ 405,330

### ADMINISTRATION

Management and Support Costs \$ 109,995

### TOTAL NET ASSETS

Total Net Assets as of Dec. 31, 2019 \$ 3,542,345



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

## 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.

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

# Who We Are



AUTISM RESEARCH INSTITUTE  
*Autism is Treatable*

## 2019-2020 Board of Directors



Marvin Natowicz, MD, PhD  
CHAIRMAN OF THE BOARD  
Scientific Advisory Panel Member  
*Cleveland Clinic*  
*Case Western Reserve University School of Medicine*



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*Boston, MA*

## Staff



Stephen M. Edelson, PhD  
*Executive Director*



Denise Fulton  
*Administrative Director*  
*Communications and Online Learning*



Rebecca McKenney  
*Office Manager*

### Finance Committee Members

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*  
Nataliya Ebert  
*Outreach Coordinator*

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Chris Cava Preston  
*Art Direction*  
Melanie Glock  
*Communications Specialist*  
Anthony Morgali  
*Media Producer*  
Nataliya Vasylevskaya  
*International Outreach*  
*Coordinator*

*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.*

## Scientific Advisory Panel



James B. Adams, PhD  
*Arizona State University*



Paul Ashwood, PhD  
*University of California, Davis,  
M.I.N.D. Institute*



Margaret Bauman, MD  
*Boston University School of Medicine*



David Beversdorf, MD  
*University of Missouri*



Emily Casanova, PhD  
*University of South Carolina,  
Greenville Health System*



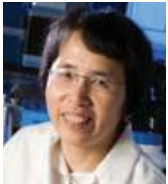
Manuel F. Casanova, MD  
*University of South Carolina's  
School of Medicine at Greenville*



Richard Frye, MD, PhD  
*Arizona Children's Hospital  
in Phoenix;  
Arkansas Children's Hospital*



Juergen Hahn, MS, PhD  
*Rensselaer Polytechnic Institute;  
Texas A&M University;  
University of Texas at Austin,  
Biomedical*



Harumi Jyonouchi, MD  
*Saint Peters University Hospital;  
Robert Wood Johnson University Hospital;  
Rutgers New Jersey Medical School*



Rafail Kushak, ScD, PhD  
*Massachusetts General Hospital;  
Harvard University*



Lauren Moskowitz, PhD  
*St. John's University*



Andrey Rzhetsky, PhD  
*Professor of Medicine  
and Human Genetics,  
The University of Chicago*



Judy Van de Water, PhD  
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### ARI Scientific Advisory Panel Member Dr. Lucy Jane Miller Announces Retirement

Following a 45-year career in the field of research, education, and treatment of Sensory Processing Disorder (SPD), Dr. Lucy Jane Miller announced her retirement from her position as Founder and Executive Director at STAR Institute for Sensory Processing Disorder last October. Dr. Miller's name is synonymous with sensory research, education, and treatment as she and her team have worked towards widespread recognition of SPD.

Due to Dr. Miller's mobilization of the research community, SPD now appears in two diagnostic manuals. Her 14-year process of applying to have SPD included in the Diagnostic and Statistical Manual (DSM-V) 2013 resulted in sensory characteristics being included for children with autism. She has written 10 nationally standardized norm-referenced tests that screen for developmental disorders and provide diagnostic assessment of various domains of function. Dr. Miller founded the first comprehensive SPD research program nationwide and authored two groundbreaking books.

Not pictured:

Mary Coleman, MD  
*Foundation for Autism Research*

June Grodin, PhD  
*Grodin Center in Providence*



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