

Organization for Autism Research



The First Ten Years
Using research to change lives...

Jim Sack, Chairman of the Board of Directors



I take pride in having helped to found OAR and establish it as a viable, well run, non-profit organization. OAR has a clear sense of mission in that it is not pursuing biomedical research, but rather focusing exclusively on applied research which has direct relevance to those individuals and families dealing with the employment, housing, education, respite care, etc. issues that affect all individuals with autism.

Because of this clarity of mission, OAR is doing valuable work now which has direct impact on the lives of my two children with autism, Dana (age 25) and James (age 23).

What makes me most proud of OAR's first ten years is what makes me confident in its promise for the next ten. OAR has built a foundation on excellence in its research and resources. It is mission-centric rather than bound to the personas of its founders. It incorporates self-examination as standard business practice, spends each charitable dollar with great care, and understands that all accomplishments aside, there is much left to do. Finally, it is an organization devoid of ego or complacency and, thus, built to contribute to the cause well beyond my days as chairman.

Dr. Peter Gerhardt, Chairman of the Scientific Council



When we started OAR, we spoke in the future tense and acted on our good intentions. Today, we have a 10-year body of work that at once describes us and hints strongly at our evolving mission and purposes.

- Support and maintain excellence,
- Embrace and lead change for the greater good, and
- Continue to change lives one child, one family, one person at a time.

OAR's information programs are critical as a bridge from research to practice that has not existed before. Too often before OAR came along, the information that resulted from research studies sat on shelves getting dusty and never made it into the hands of people who could have used it. Today, thanks to OAR, that is not true.

The diversity that is autism is going to require the kind of research OAR funds to continue. In fact, I think that biomedical research will complement what OAR is doing as it finds different types of autism. Ideally, in the future OAR will be able to target interventions, and direct our funding, to better identify which subset of individuals on the spectrum best responds to which interventions. In other words, an important collaboration between biomedical research and OAR's applied research will be the identification of responders versus nonresponders to intervention.

OAR is the best-kept secret in autism and getting the word out will enable OAR to make a much bigger difference.



Introduction

The Organization for Autism Research was founded in December 2001 by seven individuals whose lives and families had been directly impacted by autism. Together the founders shared a common vision and set out on a singular mission – to apply science to answer the daily questions and challenges that autism presents to individuals with autism, their families, teachers, and caregivers. As OAR celebrates ten years and sets forth on the next decade, OAR takes pride in its many contributions and accomplishments while maintaining a focus on excellence in research and evidence-based practice. OAR envisions a future in which the collaborative efforts of many individuals lead to a global understanding of autism and a future for persons with autism that emphasizes abilities and possibilities over disabilities.

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There are many organizations dedicated to autism. What makes OAR unique is its focus on applied research—studies that examine issues related to living with autism—and resources grounded in research and best practices. As OAR’s founders recognized, biomedical research simply does not address the daily challenges of autism. The studies OAR funds and the informational resources it provides have meaning in the day-to-day lives of persons with autism and their families. Rather than fund research relative to cause and cure, OAR funds pilot studies on topics of more every day relevance such as education, parent and teacher training, communication, self-care, social skills, employment, behavior and adult and community issues. In pursuing its efforts to change lives, OAR’s ultimate focus is quality of life.

Introduction

Since 2002, OAR has funded 134 studies totaling almost \$2.5 million. OAR's mission is far more than just funding research. Sharing findings from research and providing evidence-based information in readily consumable form have been standing objectives from OAR's inception. OAR accomplishes this through its educational forums, Web site, newsletter, *Life Journey through Autism* publications and Operation Autism, a Web site that provides information about autism and a resource directory with a military families focus.

OAR's most direct form of support takes the form of scholarships for persons with autism pursuing post-secondary education. Since 2008, 55 persons with autism have received over \$178,500 in scholarships to pursue vocational training or college degrees.

OAR takes great care in minimizing its overhead and insuring that donated dollars go directly to OAR's programs. In 2009, OAR received a 4-star rating from Charity Navigator, the highest rating possible, and OAR has consistently maintained that high rating since. Charity Navigator is an independent organization that evaluates nonprofit organizations based on fund usage and leadership practices. Only one in four charities examined by Charity Navigator receives 4-stars.

Since its creation in 2001, OAR has been unique among autism organizations in its singular focus on applied research and its emphasis on providing evidence-based resources in usable form. The mission of OAR's founders endures today as OAR funds research to seek findings and information that help change lives.






Who we are

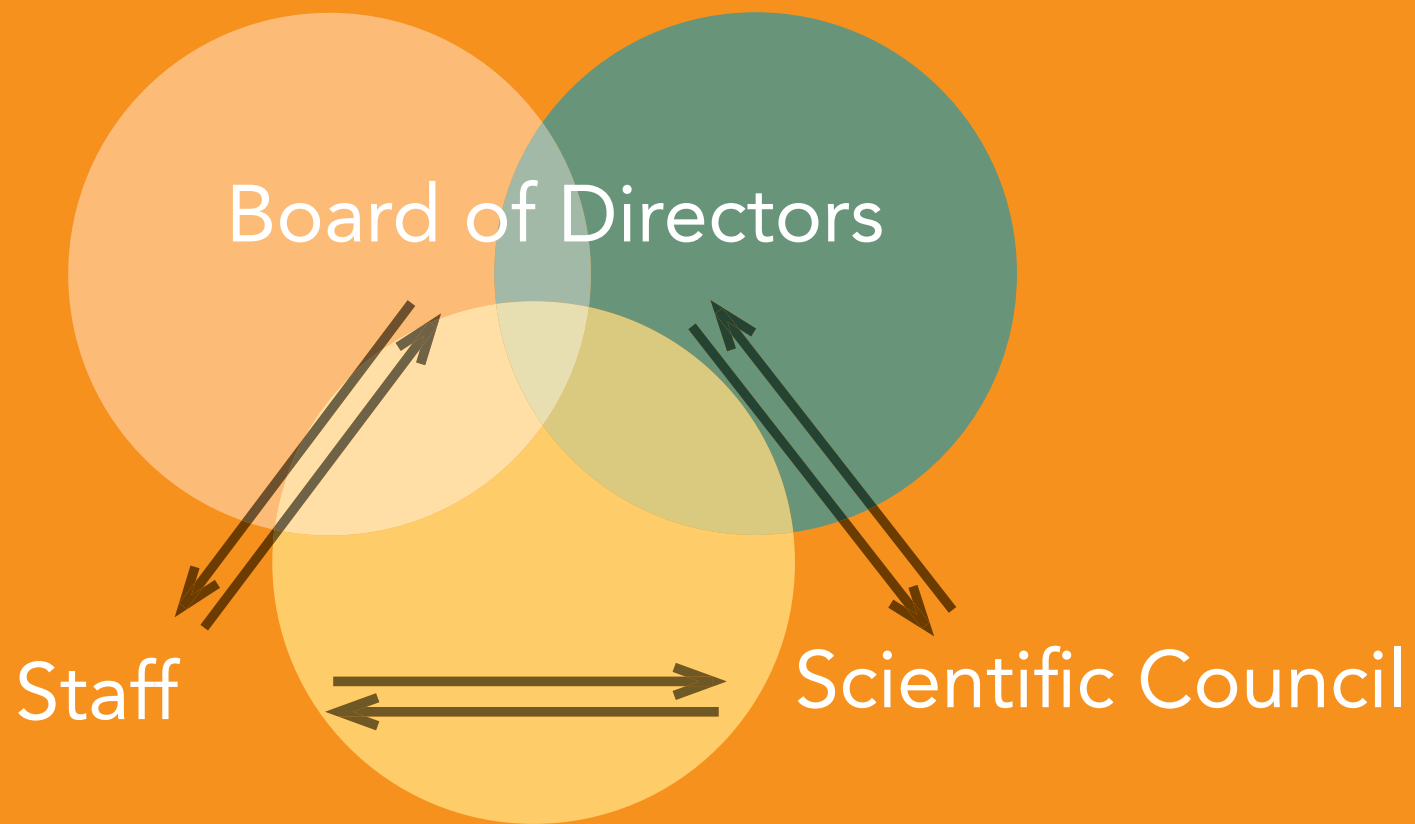
OAR's Board of Directors is comprised of parents, relatives of individuals with autism, and the autism professional that serves as Chairman of the Scientific Council. Combined, they represent more than 200 years of autism experience. Their family members with autism include sons, daughters, and siblings across the spectrum that range in age from very young to almost 50. In addition to their life experiences with autism, the members of the Board bring diverse backgrounds in business and civic arenas to OAR.

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The Board's responsibilities include: governing OAR, setting OAR's research direction, approving all plans for funding research and operating OAR, raising funds to support OAR's programs and activities, and ensuring that OAR's business and fiscal practices are sound and well managed. All members of the Board are volunteers and receive no compensation for their service.

OAR's Scientific Council is comprised of leading autism and medical professionals serving together as an expert information resource for all OAR matters concerning issues of research. In that regard, the Council assists OAR's Board of Directors in developing its research strategy, near term priorities, and long-range research objectives. The Council also provides program guidance and oversight for OAR's research competition and plays a central role in ensuring the highest quality reviews for prospective OAR research studies.





OAR's Board of Directors leads by providing sound governance, focus, fiscal oversight, and project direction with expert guidance from the Scientific Council on research issues. OAR's staff executes the day-to-day operations putting projects and ideas into action.

Fund research

While many organizations fund autism research, OAR is unique in that it exclusively funds applied autism research. Applied research is research conducted to solve practical problems or develop therapies with the purpose of helping people in their daily lives. OAR funds research that is concerned with applying the knowledge gained through basic research to practical, everyday problems. OAR lives in the present. Rather than focus on cause and cure, OAR's research efforts strive to improve the lives of individuals on the autism spectrum today.

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OAR funds "seed grants" or pilot studies of up to two years in amounts up to \$30,000 for each study through its annual Applied Research Competition. OAR also awards small grants to graduate students conducting autism research through its Graduate Research Grant Program. These studies allow researchers to test hypotheses, develop studies, and collect data that are needed to conduct more in-depth research and be approved for larger grants. OAR's grants support studies that are stepping stones to more comprehensive studies.

Since its creation in 2001, OAR has awarded 134 grants totaling almost \$2.5 million to researchers and graduate students at some of the most prestigious universities in the U.S. and abroad. OAR selected each of the studies funded based on its potential to offer meaningful outcomes or, in other words, provide information that can be used immediately. The following pages list research studies OAR has funded.



Early Intervention

Researcher(s)	Institute	Topic	Year Selected
Rebecca MacDonald, PhD, BCBA, and William Ahearn, PhD	The New England Center for Children	<i>Using a Direct Observation Assessment Battery to Assess Outcome of Early Intensive Behavioral Interval</i>	2011
Laurie Vismara, PhD	University of California, Davis, M.I.N.D. Institute	<i>Expanding the Reach of Toddler Treatment in Autism Spectrum Disorders</i>	2010
Jennifer Durocher, PhD, BCBA-D	University of Miami, Center for Autism and Related Disabilities	<i>Identifying Socially-Based Reinforcers for Young Children with ASD</i>	2010
Connie Wong, PhD. and Samuel Odom, PhD	The University of North Carolina at Chapel Hill	<i>Outcomes of a Community Center-Based Program for Toddlers with Autism Spectrum Disorders (ASD)</i>	2010
Jon Campbell, PhD	University of Georgia Department of Educational Psychology and Instructional Technology	<i>University of Georgia-Carolina Autism Resource and Evaluation Center (UGA-CARES): A Collaborative Autism Screening Project Utilizing Web-based Technology</i>	2009
Rebecca MacDonald, PhD BCBA	The New England Center for Children	<i>Using a Direct Observation Assessment Battery to Assess Outcome of Early Intensive Behavioral Intervention for Children with Autism</i>	2009
Jennifer Durocher, PhD	University of Miami Center for Autism and Related Disorders	<i>A Clinical Randomized Control Trial of Joint Attention Intervention in Young Children with ASD</i>	2007
Connie Kassari, PhD	University of California, Los Angeles	<i>Joint Attention Intervention for Nonverbal Children with Autism</i>	2007
Phil Himeline, PhD, and Saul Axelrod, PhD	Temple University	<i>Evaluating Intensive Behavioral Interventions in Autism</i>	2007
Brian Lopez, PhD, and Dina Hill, PhD	University of New Mexico School of Medicine	<i>The Identification of Early, Mutli-systemic Factors Influencing Treatment Initiation for Children with ASD</i>	2006
Phil Himeline, PhD, and Saul Axelrod, PhD	Temple University	<i>Evaluating intensive behavioral interventions for autism: "Discrete trial" and "Applied Verbal Behavior"</i>	2006
Emily Jones, PhD, and Kathleen Feeley, PhD	Long Island University	<i>Joint Attention Intervention for Children with Autism</i>	2005
Karen Pierce, PhD, and Eric Courchesne, PhD	University of California, San Diego	<i>Early Identification of Autism: Warning Signs from Brain and Behavior</i>	2004
Brooke Ingersoll, PhD	Autism Treatment & Research Program – Hearing & Speech Institute	<i>Teaching the Imitation and Spontaneous Use of Gestures Using a Naturalistic Behavioral Intervention in Young Children with Autism</i>	2003
Robert Stromer, PhD	University of Massachusetts Medical School	<i>Teaching Social Communication Using Picture Activity Schedules</i>	2002

Identifying At Risk Infants

The first step to helping young children with autism is identifying at risk infants. In a study funded by OAR in 2004, **Dr. Karen Pierce** and **Dr. Eric Courchesne** both from the University of California, San Diego developed a new screening technique to be included as part of the one year well-baby check-up. This seed grant led to further research in which Dr. Pierce taught the check list approach to pediatricians in the San Diego region who then administered the check-up to patients. 75% of the infants identified using the check list were later diagnosed with true developmental delays including autism. This research points out that a risk of autism can be identified in infants as young as one. It also shows the easiness of using a check list as part of a regular check up to screen for autism. As a result of this research by Dr. Pierce and Dr. Courchesne, more physicians are screening for autism and more infants are being identified to receive early intervention services.

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"I started doing autism research at the age of 19 at Stony Brook University as an undergraduate student and have never stopped since. Autism is fascinating and I love doing this research because I hope that my findings will have direct, immediate benefit to children and families," Dr. Pierce explains. "OAR is on the front lines of research that supports people with autism, families, clinicians, and educators. It has a huge impact in the autism community."

Education and School Aged Children

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Researcher(s)	Institute	Topic	Year Selected
Robert Koegel, PhD, and Lynn Kern Koegel, PhD	Koegel Autism Center at University of California, Santa Barbara	<i>Training Paraprofessionals to Provide Appropriate Social Opportunities for Children with ASD</i>	2011
Marcus Thomeer, PhD and Christopher Lopata, Psy.D.	Canisius College, Institute for Autism Research	<i>Randomized Clinical Trail of Mind Reading and In Vivo Rehearsal for Children with HFASDs</i>	2010
Kelly Whalon, PhD	The College of William and Mary, The School of Education	<i>The Effects of a Reciprocal Questioning Intervention of the Reading Comprehension and Social Communication of Students with Autism Spectrum Disorder</i>	2009
Audrey Blakeley-Smith, PhD and Susan Hepburn, PhD	University of Colorado Denver, Departments of Psychiatry and Pediatrics	<i>Peer-mediated Intervention for Elementary School Students with Autism Spectrum Disorders</i>	2009
Kristi Asaro-Saddler, PhD	State University of New York at Albany	<i>Writing Instruction for Children with Autism Spectrum Disorders: A Study of Self-regulation and Strategy Use</i>	2009
Jeffrey J. Wood, PhD, and Marilyn Van Dyke, MA, CCC-SLP	University of California, Los Angeles, and The Help Group	<i>Transporting Evidence-Based Practices from the Academy to the Community: School Based Cognitive Behavioral Therapy for Children with Autism Spectrum Disorders</i>	2008
Dennis H. Reid, PhD, BCBA	Carolina Behavior Analysis and Support Center, Ltd.	<i>Training Paraprofessional Staff to Provide Proactive Support for Individuals with Severe Autism in Inclusive Settings</i>	2008
Rebecca MacDonald, PhD, BCBA, and William Ahearn, PhD, BCBA	New England Center for Children	<i>Examination of Prerequisite Skills for Learning Using Video Modeling</i>	2008
Maureen Conroy, PhD	Virginia Commonwealth University School of Education	<i>An Examination of the Effectiveness of Manipulative Letter Instruction on the Decoding Skills of Young Children with Autism Spectrum Disorders</i>	2007
Laura Anthony, PhD, and Lauren Kenworthy, PhD	Children's National Medical Center	<i>Development of an Executive Function-based Intervention for Autism Spectrum Disorders</i>	2007
Kevin Klatt, PhD	University of Wisconsin	<i>A Comparison of Simultaneous Prompt and Constant Prompt Delay Procedures on Teaching Skills to Young Children with Autism</i>	2005
Jonathan Campbell, PhD	University of Georgia	<i>The New Friendship Study, Part III: The Influence of Information on Middle School Students' Attitudes and Behavioral Intentions towards a Peer with Autism</i>	2003
Richard M. Kubina, Jr., PhD	The Pennsylvania State University	<i>Fluency Research for Children with Autism</i>	2002

Teaching Flexibility

A key deficit for students with autism is the inability to be flexible. Students often have a difficult time when the unexpected happens. To address this issue, **Dr. Laura Anthony** and **Dr. Lauren Kenworthy** both at Children's National Medical Center developed a guide for teaching flexibility to school aged students with autism. OAR provided a grant in 2007 to get this study off the ground. The results were so positive and the intervention so effective that Dr. Anthony and Dr. Kenworthy went on to receive a grant of \$775,000 from National Institutes of Health. The researchers also published the guide in *Unstuck and On Target! An Executive Function Curriculum to Improve Flexibility for Children with Autism Spectrum Disorders*. This easy to use guide presents usable curriculum for teachers to teach flexibility to students with autism and it has its roots in OAR funded research.

When OAR selects a study for a research grant, it has three goals. The first is to select well-designed studies that will yield meaningful outcomes for the autism community. The second goal is that the study will produce results or data that will lead to subsequent grants and greater funding for the study. The third goal is that the research produces tangible practical resources for those in the autism community. The study by Dr. Anthony and Dr. Kenworthy successfully met all three goals.

Employment, Transition, and Adults

Researcher(s)	Institute	Topic	Year Selected
Robert LaRue, PhD, Lara M. Delmolino, PhD, Kate E. Fiske Massey, PhD, and Kimberly N. Sloman, PhD	The Douglass Developmental Disabilities Center at Rutgers University	<i>Increasing Functional Vocational Skills in Adolescents and Adults with Autism Using Behavioral Economics</i>	2011
Hsu-Min Chiang, Ph.D.	Teacher's College at Columbia University	<i>Predictive Factors of Participation in Employment for High School Leavers with Autism</i>	2011
Patrick Szary, PhD	Rutgers, The State University of New Jersey	<i>Development of a Transportation Skills Assessment Tool (TSAT) for Individuals with Autistic Spectrum Disorder to Aid in Finding Safe and Accessible Community Transportation Service</i>	2010
Kara Hume, PhD	University of North Carolina at Chapel Hill	<i>Increasing Independence and Task Completion in Adolescents and Adults with ASD using Independent Work Systems</i>	2010
Paul T. Shattuck, PhD	Washington University in St. Louis	<i>Transition to Adulthood: Service Utilization and Determinants of Functional Outcomes</i>	2008
Jan Graetz, PhD	Oakland University School of Education and Human Services	<i>Identifying the Supports that Promote Success of College Students with Asperger Syndrome</i>	2007
Paul Wehman, PhD	Virginia Commonwealth University	<i>Efficacy of Community-based Instruction and Supported Employment on the Competitive Employment Outcomes of Transition-age Youth with Autism</i>	2007
Carla Mazefsky, PhD	Children's Hospital of Pittsburgh	<i>Comorbid Psychiatric Disorders in Adolescents and Young Adults with Asperger's Disorder</i>	2006
Marlene Cohen, EdD	Rutgers, The State University of New Jersey	<i>The Effects of Precision Teaching with Frequency Building of Language Component Skills on the Performance of Language Composite Skills in Adolescents and Adults with Autism</i>	2006
Marlene Cohen, EdD	Rutgers, The State University of New Jersey	<i>The Effects of Precision Teaching with Frequency Building of Fine Motor Skills on the Performance of Functional Life Skills in Adolescents and Adults with Autism</i>	2005
John Burke, PhD and Richard Hudson, PhD	University of Louisville	<i>Removal of Social Barriers to Employment for Persons with Autism Spectrum Disorders</i>	2003

Increasing Work Independence

As a doctoral student in the school of education at Indiana University, **Dr. Kara Hume** studied the use of individual work systems to increase independent work skills in children. Individualized work systems are part of the TEACCH method and consist of visual prompts to allow children or adults to move through work or play sequences independently. Dr. Hume's findings were subsequently published in multiple peer-reviewed journals including *Preventing School Failure*, *TEACHING Exceptional Children*, and *Journal of Autism and Developmental Disabilities*.

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In a perfect example of graduate students being encouraged to study applied autism research through OAR's graduate grant programs, Dr. Hume became an investigator at Frank Porter Graham Child Development Institute at University of North Carolina, Chapel Hill. She went on to receive a grant in OAR's 2010 Applied Research Competition to expand her research regarding independent work systems to adolescents and adults.

Families

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Researcher(s)	Institute	Topic	Year Selected
Marcie Desrochers, PhD, BCBA-D, and Erin DiCesare	The College at Brockport-SUNY and the Mary Cariola Children's Center	<i>Evaluation of Synchronous Online Parent Skill Training</i>	2011
Ericka Wodka, PhD	Hugo W. Moser Research Institute at Kennedy Krieger	<i>A Preliminary Investigation of the Neurobehavioral Basis of Sensory Behavior in Autism</i>	2011
Daniel Openden, PhD, BCBA, and Christopher Smith, PhD	Southwest Autism Research and Resource Center	<i>Measuring the Effects of Training Parents to Provide Intervention via the Arizona Telemedicine Program</i>	2008
William G. Sharp, PhD, and David Jacquess, PhD	The Marcus Autism Center	<i>Feeding Problems among Children with Autism: The Impact of Parent Education in Modifying Aberrant Eating Habits</i>	2008
Susan Mayes, PhD	Penn State College of Medicine	<i>Sleep Disturbance and Daytime Functioning in Children with Autism</i>	2007
Shana Nichols, PhD	Fay J. Lindner Center for Autism/NS-LIJ Health System	<i>Growing Up on the Autism Spectrum: A Parent Education and Skill Building Curriculum</i>	2006
Beth Malow, MD	Vanderbilt Kennedy Center for Research on Human Development	<i>Parental Sleep Education Program for Children with Autism Spectrum Disorder</i>	2006
Judy Reaven, PhD and Susan Hepburn, PhD	The University of Colorado	<i>Family-Focused Cognitive-Behavioral Intervention for Anxiety Symptoms in Children with High-Functioning Autism or Asperger Syndrome</i>	2005
Eric Butter, PhD	The Ohio State University, The Columbus Children's Hospital Autism Center	<i>Demonstration of a Parent Mediated Generalization Program to Enhance Outcomes During EIBI for Children with Autism Spectrum Disorders: PEPING Up EIBI</i>	2005
Judy Reaven, PhD, and Susan Hepburn, PhD	University of Colorado Denver, Departments of Psychiatry and Pediatrics	<i>Family-Focused Cognitive-Behavioral Intervention for Anxiety Symptoms in Children with High-Functioning Autism or Asperger Syndrome</i>	2004
Edward Carr, PhD	State University of New York at Stony Brook	<i>Problem Behavior: The Development of a Contextual Assessment Inventory for Use by Families</i>	2003



Social Skills

Researcher(s)	Institute	Topic	Year Selected
Elizabeth Laugeson, PsyD	Jane & Terry Semel Institute for Neuroscience & Human Behavior, University of California, Los Angeles	<i>Effectiveness of a Virtual Coach Application in Social Skills Training for Teens with ASD</i>	2011
Carolyn Hughes, PhD	Vanderbilt University, Peabody College	<i>High School Inclusion Program for Students with Autism Spectrum Disorders</i>	2009
Alexander Gantman, PsyD	Jane & Terry Semel Institute for Neuroscience & Human Behavior, University of California, Los Angeles	<i>Social Skills Training for Young Adults with Autism Spectrum Disorders</i>	2009
Scott Bellini, PhD	Indiana Resource Center for Autism	<i>Increasing Social Engagement in Young Children with Autism Spectrum Disorders Using Video Self-modeling and Peer Training</i>	2007
Isabel Dziobek, PhD	Max Planck Institute for Human Development, Germany	<i>Evaluating the Effectiveness of the Social Cognition Training Tool (SCOTT) in ASD on Behavioral, Oculomotor, and Neuronal Levels</i>	2007
Raymond Romanczyk, PhD	State University of New York at Binghamton	<i>A Multi-method Assessment and treatment of Social Skills Core Deficit in ASD</i>	2006
Jonathan Tarbox, PhD	Center for Autism and Related Disorders	<i>Electronic Data Collection for Intensive Behavioral Intervention for Young Children with Autism: An Analysis and Comparison of mTrial to Traditional Pen and Paper Methods of Data Collection</i>	2005
Raymond Romanczyk, PhD, and Jennifer Gillis, MA, BCBA	State University of New York at Binghamton	<i>A Multi-Method Assessment and Treatment of the Social Skills Core Deficit in ASD</i>	2005
Brenda Myles, PhD	University of Kansas	<i>Assessment of Characteristics of Students with Asperger Syndrome and the Evaluation of the Mind Reading Computer Software on the Emotion Recognition Ability of Students with Asperger Syndrome</i>	2005
Kathleen Koenig, MSN	Yale Child Study, Yale University	<i>Development of an Instrument for Measuring Change in Social Behavior for Children with Autism Spectrum Conditions: The Social Reciprocity Observation Measure</i>	2005
Brenda Smith Myles, PhD	University of Kansas	<i>Assessment of Characteristics of Students with Asperger Syndrome and the Evaluation of the Mind Reading Computer Software on the Emotion Recognition Ability of Students with Asperger Syndrome</i>	2004
Kevin Ayres, MA	University of Georgia	<i>Improving Social Skills Using Computer-Based Interventions</i>	2004
Lawrence Scahill, MSN, PhD, and Kathleen Koenig, MSN	Yale Child Study Center	<i>Social Skills Development in Children with Autism Spectrum Disorders</i>	2003

Graduate Research Studies

OAR recognizes the importance of encouraging up and coming researchers to enter the field of autism research. With this in mind, OAR offers grants of \$1,000 to \$2,000 for graduate students conducting studies related to autism in support of their pursuit of their advanced degree. As with the Applied Research Competition, OAR looks for studies that offer to provide meaningful outcomes and practical information for families, professionals, and individuals with autism.

Since 2004, when OAR introduced the Graduate Research Grants Program, OAR has awarded \$126,000 in grants to 28 students at the following universities:

Ball State University
Center for Psychological Studies at
Nova Southeastern University
Emory University
George Mason University
Georgia Institute of Technology
Indiana University
Long Island University
Michigan State University
The Ohio State University
The Pennsylvania State University
Rutgers University
St. John's University

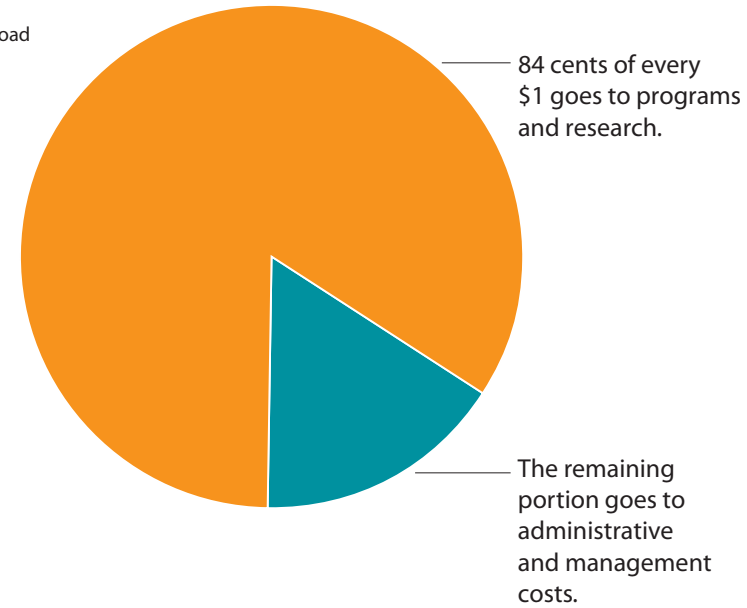
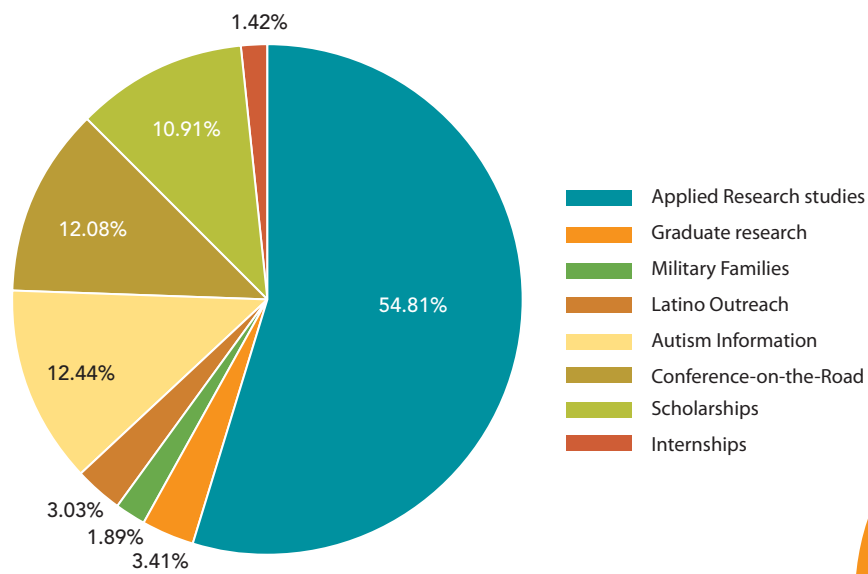
Texas Tech University
University of Alabama
University of Arizona
University of California
University of Central Florida
University of Florida
University of Georgia
University of Kentucky
University of Massachusetts
University of Missouri
University of Nevada
University of North Carolina
University of Phoenix

University of Queensland, Australia
University of Rhode Island
University of Vermont
University of Washington
University of Witwatersrand,
Johannesburg, South Africa
Vanderbilt University
Virginia Commonwealth University
Virginia Polytechnic Institute and State
University
Wayne State University
West Virginia University
Yale University

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OAR is a good steward of the charitable dollars it receives, keeping overhead expenses low and committing the majority of funds directly to programs and research.



Information and Resources

OAR's mission does not stop at funding research. It extends to informing and educating the autism community and general public about autism, evidence-based practice, and current research. To do that, OAR has focused significant efforts on providing practical and competent resources to the autism community through its Web site, monthly e-newsletter, publications, conferences, scholarships, and work within the military community.

Life Journey through Autism Series



OAR published its first resource guidebook, *Life Journey through Autism: A Parent's Guide to Research* in 2003, and with that launched what has become a series of targeted, informative, and practical guidebooks that transform applied research in a given area into everyday use. These guidebooks assist parents, professionals and caregivers on specific issues they face. Since publishing *A Parent's Guide to Research*, OAR has produced six more guidebooks and delivered more than 50,000 copies free of charge to families nationwide and military families at posts abroad.

All of these publications are available free of charge as a download from OAR's Web site or in hard copy.

A Parent's Guide to Research

A Parent's Guide to Assessment

A Guide for Military Families

An Educator's Guide to Autism

An Educator's Guide to Asperger Syndrome

A Guide for Transition to Adulthood

Navigating the Special Education System

The Best of The OARacle

“As an autism specialist, I rely on OAR to help me to stay current with cutting edge research and evidence-based practices in my field. OAR does a fabulous job of funding needed research on autism and dissemination of that information through their publications.”

–Deborah, teacher

Schwallie Family Scholarship Program

In 2007, thanks to the interest, vision, and generosity of OAR Board member, Ed Schwallie and his family, OAR introduced the Schwallie Family Scholarship Program to support individuals with autism or Asperger Syndrome pursuing post-secondary education. The program offers one-time scholarships of \$3,000 to students attending four-year undergraduate colleges, two-year undergraduate colleges, and trade, technical, or vocational schools based solely on merit. In five years, OAR has awarded \$178,500 in scholarships to 55 students from across the United States.

In the first year of the program, OAR received 85 applications and awarded three scholarships. Since then, the number of applicants has grown each year with a record-breaking 415 applicants and 22 scholarships awarded in 2011. The continuing increase in applicants underscores the need for the scholarship program and serves as vivid testimony of the results of early intervention and the educational progress made by individuals on the autism spectrum in the last 15-20 years.

In addition to the sustained support of the Schwallie family, Board member and now Scholarship Committee Chairwoman, Lisa Hussman, and the The Lisa Higgins-Hussman Foundation have contributed generously to the scholarship fund in the last three years.

“The opportunity to attend college is a dream come true. When I was 9, the chance that someone with Asperger’s Syndrome would succeed was 1 in 10. Now nearly a decade later, I can say I have a job, I own my own car and pay insurance and now I will be going to college.”

–2011 scholarship recipient, CJ

“Thank you for choosing me to receive one of this year’s scholarships. It has truly made it possible for me to survive financially while attending college full-time. I am so very grateful to you all for believing in me and my dreams for the future.”

–2008 scholarship recipient, Hillora.



Military Families Initiatives

Operation Autism

Operation Autism is a web-based resource specifically designed and created to support military families that have children with autism. It provides detailed information and serves as a companion resource to *Life Journey through Autism: A Guide for Military Families*.

OAR's resources for military families:

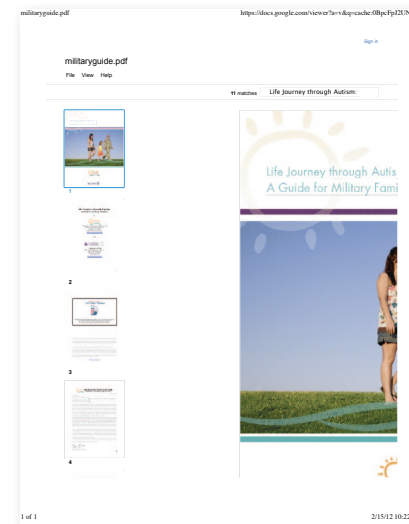
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- Provide military families touched by autism with access to quality, evidence-based information about the disorder;
- Identify sources of treatment and support on and off base;
- Offer tips for addressing some of the unique challenges military life poses for military dependent children with autism and their families; and
- Inform parents about their child's educational rights and offer some practical strategies for success in the classroom.



“We use this Web site all the time! At Madigan, we make 3-4 new diagnoses of autism spectrum disorder every week! This is better than anything out there. I especially like the attention paid to transition. Thank you again for your excellence and diligence.”

– COL Beth Ellen Davis, USA, M.D., Board certified in Developmental and Behavioral Pediatrics



Community Education

Like other autism organizations, OAR set out to fulfill its educational mission through a conference. Beginning in 2003, and thanks to a grant from the Doug Flutie Jr. Foundation for Autism, OAR held its first Applied Autism Research and Intervention Conference in Arlington, VA, just outside Washington, DC. Built around the theme *Education and Intervention across the Life Span*, OAR continued to host the conference annually focusing on the latest findings in applied research and evidence-based practice until 2010.

After the 2010 conference, OAR partnered with established autism conferences around the country and thus was born OAR's Conference-on-the-Road. In 2011, OAR partnered with Milestones for the Milestones Autism/Asperger's conference in Cleveland, OH, and Autism New Jersey for its 29th annual conference in Atlantic City, NJ. Both tests were successful. OAR was able to provide quality speakers in a Research to Practice track for each conference, provide research based information to ten times as many people than before, and do it at 40 percent of the cost. Based on the enthusiastic response of its partners and conference attendees, OAR intends to continue this program with at least two annually.



Research and Programs Timeline: 2001- 2012



OAR founded
2001

Scientific Council established
2002

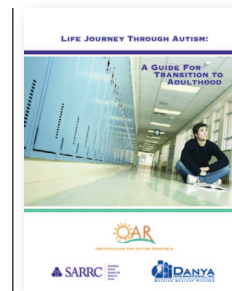
Life Journey through Autism: A Parent's Guide to Research
2003



Life Journey through Autism: An Educator's Guide
2004



Life Journey through Autism: A Guide for Transition to Adulthood
2006



2002
www.researchautism.org

2002
The OARacle
THE OARACLE

2002
Applied Research Competition

2003
Graduate Research Grants Program

2003
Applied Autism Research and Intervention Conference



2005
Life Journey through Autism: An Educator's Guide to Asperger Syndrome

2006
Autism Research Convocation - Evidence-based Interventions in Support of Adolescents and Adults with Autism

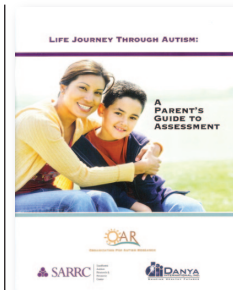
The Best of The OARacle
2007



2007
Schwallie Family
Scholarship
Program

2007
Latino Outreach,
Promotoras
Training Program

Life Journey
through Autism: A
Parent's Guide to
Assessment
2008

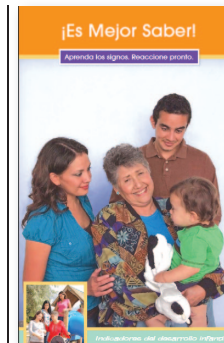


2008
Understanding
Asperger
Syndrome: A
Professor's Guide



2008
Autism Research
Convocation -
Evidence-based
Interventions in
Support of Social
Skills and Adaptive
Behaviors

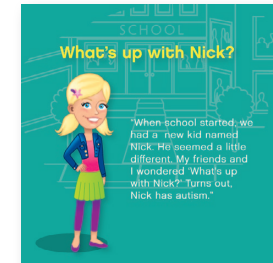
It's Better to Know
fotonovela
2011



2010
Life Journey through
Autism: A Guide for
Military Families

2011
OAR Conference-on-the-Road

What's Up
with Nick?
2012



2012
Life Journey through
Autism: Navigating
the Special Education
System

Fundraising

OAR depends on donations from the general public and grants for funding. Over the past ten years, OAR has received contributions large and small from people across the U.S., and both unrestricted gifts and grants from other autism organizations, foundations, corporations, and the federal government. OAR's growth and increased capacity is largely due to the success of three events: the *RUN FOR AUTISM*, the Combined Federal Campaign and state, municipal, and corporate workplace campaigns each year, and the annual Chairman's Dinner hosted by OAR Chairman, Jim Sack.

RUN FOR AUTISM. OAR was the first autism organization to establish a national charity running program. The *RUN FOR AUTISM* program helped catapult OAR from its status as a small, unknown research foundation to a nationally recognized autism organization. Launched in Washington, DC in 2003 through a charity partnership with the Marine Corps Marathon™ in Washington, DC, it now involves charity partnerships with major races in New York City, Chicago, Washington, DC, Cleveland, Houston, and more and is OAR's signature fundraising effort. Since 2003, more than 4,500 people from across the U.S. and abroad have run as part of OAR's team and raised over \$3.6 million for autism research.

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“My wife and I have twin granddaughters that were both diagnosed with autism. The people involved in *RUN FOR AUTISM* are like me- parents and family members or even friends of people with autism. Trying to make a difference. Trying to answer the questions.”

—Pete, Marine Corps Marathon Finisher and Autism Grandfather

Combined Federal Campaign and Workplace Giving. OAR has also been successful in raising funds from workplace charitable campaigns: the Combined Federal Campaign (CFC), the annual charity drive for federal employees and military service members, similar drives at the state and municipal level, and selected United Way and private workplace campaigns. Among those, the CFC has enjoyed considerable success. OAR participated first in 2003 as a local agency in selected CFC drives in the National Capital area, which includes the District of Columbia, Maryland, and Virginia. Since 2004, OAR has participated as a national charity as a member of the Health and Medical Research Charities of America federation. Since 2003, the CFC and other workplace campaigns combined have raised \$1,900,000 for OAR's research and information programs.

Chairman's Dinner. In 2002, Founding Chairman, Jim Sack, hosted a benefit dinner for his friends and business associates that raised \$35,500. He has continued each year since with the 2011 dinner surpassing the \$100,000 mark. Thanks to the Chairman's leadership and his friends' generosity, the 10-year total for the Chairman's Dinner is over \$700,000.



Thank You to OAR's Supporters

OAR's work through ten years has been the work of many hands. OAR's devotion to its mission and to changing lives through research and evidence-based practice is matched only by its gratitude to all the people, organizations, and businesses that comprise the mosaic that is OAR today. To each of you, whether leader, self-advocate, researcher, parent, donor, runner, volunteer, or friend, your contribution has made the difference and enabled OAR to fulfill its mission in support of children and adults with autism, their families and the autism community through its first decade of service. With your continued interest, support, and participation, each day will bring us one step closer to a world that offers children and adults with autism the opportunity to the highest quality of life. Thank you for partnering with OAR.

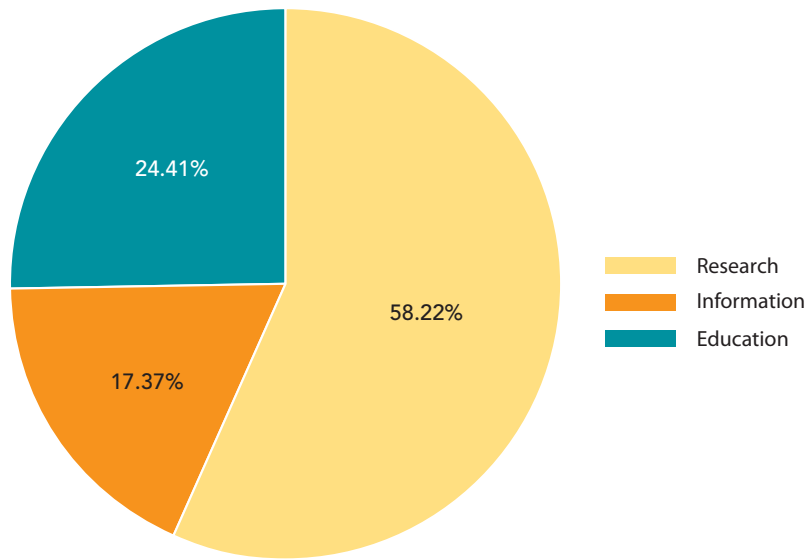
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Mr. and Mrs. Rainer Altmann
American Legion Child Welfare Foundation
Mr. Brian Anderson
Association of the United States Army
Mr. Paul Atanasio
Autism Advocates of Indiana
Autism Coalition for Research and Education
Autism Delaware
Autism Society of Delaware
Autism Society of Southeast Wisconsin
Autism Speaks
Larry and Gert Brennan
Ms. Lillian Cantor
Centers for Disease Control and Prevention
AHEPA, Constantine Cassis Chapter #170
Ms. Sandra Crippen
Ms. Elizabeth Daibes
Danya International, Inc.
Ms. Theresa A. Diulus
DKR Capital Partners, LP
Donald & Shelly Rubin Foundation
Doug Flutie Jr. Foundation for Autism
The Drive for Rebecca, Inc.
Easter Seals
Epic Systems Corporation
ERE Foundation
Mr. Sohail Gabbay
Gibson Overseas, Inc.
Garland and Agnes Taylor Gray Foundation
Mr. Keith Gordon

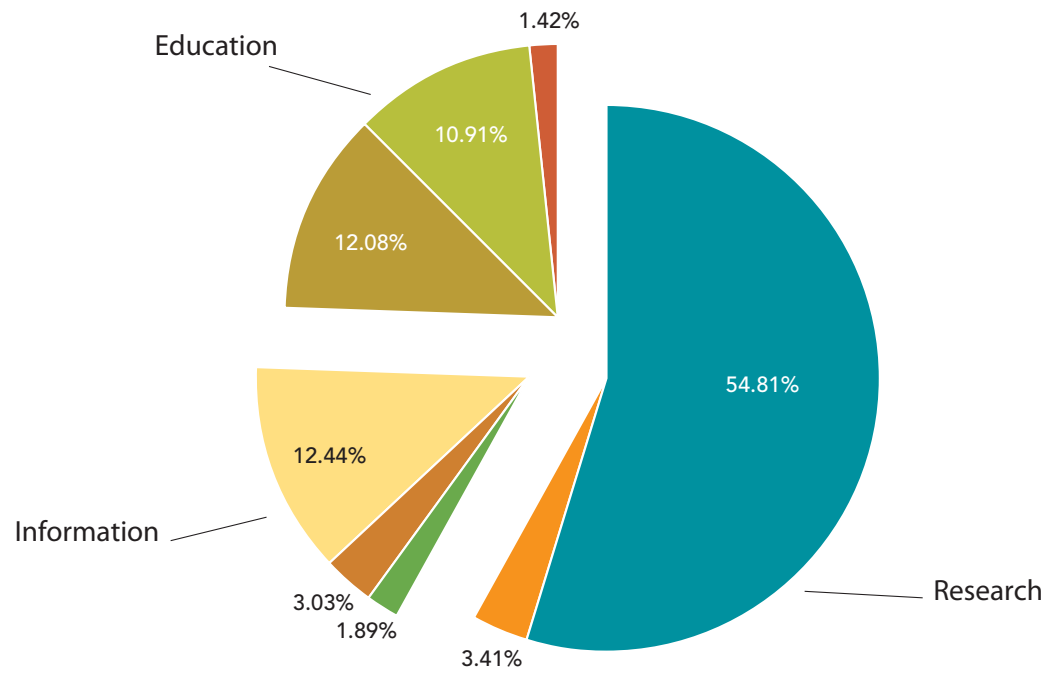
Mr. Hugh J. Gownley
Mr. and Mrs. Guy Gubitosi
Mr. Richard Hausler and Mrs. Lyndon Skelly-Hausler
Mr. William L. Hudson
Jack & Clara Paige Family Fund of the Oregon
Janssen Pharmaceutica, Inc.
Jean Lykes Grace Foundation
Jewish Community Foundation
Lori Lapin Jones PLLC
Mr. and Mrs. Michael P. Kahn
Kaz Brothers, LC
Mr. Victor Kazanjian
KDH Research & Communication, Inc.
Ms. Ingrid Kirkland
Mr. Dean Koocher
Mr. Charles Krockner
Mr. Alexander M. Lankler
Lawrence W. Levine Foundation, Inc.
Mr. Harry Lundy, Jr.
Mr. and Mrs. John Maltby
Manuel Schneider Living Trust
Mr. H. Robert Marcus and Ms. Audrey Flack
Jeffrey M. Mervis, Esq.
Milbank Foundation for Rehabilitation
Madeline and Arthur Millman
Mr. and Mrs. Donald Misner
Mission for Educating Children with Autism
Mueller Investments Inc.
NVR, Inc.
O'Neill Foundation

Pauly's Gift of Love Foundation Inc.
The Peachtree House Foundation
Dr. and Mrs. Gregory Prince
Ms. Judith Reggio
Mr. Michael Rezendes
Mr. Ronald Robichaud
Ryan Homes
Sack & Harris, P.C.
Mrs. Nancy Sack
Schneider Electric
The Schwallie Family Foundation
Shulman, Rogers, Gandal, Pordy & Ecker, P.A.
Siff Exkorn Family
Mr. and Mrs. Joel K. Smith
Southwest Autism Research & Resource Center
Speed Demos Archive
Mr. and Dr. Jeffrey Sporn
Spriggs & Hollingsworth
Mr. Stuart Stafman and Ms. Mary Japour
Mr. and Mrs. Thomas Stanek
Ms. Greta Tessman
The Lisa Higgins-Hussman Foundation
The Horncrest Foundation Inc.
The Brian J. Kelly Family Foundation
Thornton D. and Elizabeth S. Hooper Foundation
Vermont Community Foundation
Ms. Darlene Williams
Mr. Jimmy Ziozis

Areas Funded



- Applied Research studies
- Graduate research
- Military Families
- Latino Outreach
- Autism Information
- Conference-on-the-Road
- Scholarships
- Internships



The Future of OAR

OAR's efforts and accomplishments through its first decade affirm the importance and significance of its mission. They also underscore the fact that OAR's work has just begun. The immediacy of OAR's mission and purpose is undiminished.

As we move forward, OAR will maintain and expand its proven programs: funding applied research studies; informing the community through the monthly e-newsletter and Web site; and educating consumers through sponsorship, collaboration, and participation in conferences, seminars, and professional forums sponsored by other autism and disability-related organizations.

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What more will OAR do? Each year as part of their annual meetings OAR's Board of Directors and Scientific Council look to the future and ask:

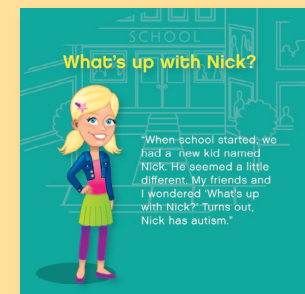
- What are the top three to five issues facing the autism community that relate to OAR's mission?
- What can OAR do to address these issues?
- What are OAR's goals with respect to each of these?

The discussion leads to a consensus that serves as the basis for OAR's plans and programs moving forward. What emerges are a near term plan with specific objectives and a longer term plan that identifies OAR's priority areas and more strategic objectives. Together, these goals chart OAR's future.

OAR's near term (next two years) plan will see OAR combine and target new programs in a themed initiative focused on education and undertake its first research-oriented demonstration project.

Through its *Autism and the Schoolhouse* initiative, launched in 2012, OAR will deliver three unique resources focused on autism and education, each targeting information and awareness gaps for students, parents, and teachers respectively:

- *Navigating the Special Education System*, the seventh guide in the *Life Journey through Autism* series.
- *What's up with Nick?*, a kid-friendly resource to help typical school peers explain autism to their peers.



The Future of OAR

The Immediate Future

- *Understanding Autism: A Guide for Secondary Teachers*, a one-hour instructional DVD on autism and practical strategies for teaching students with autism in middle and high school.

Launching these three related projects within the same year will mark OAR's first attempt to create important synergy and focus within one area of high need within the autism community

Longer term, OAR's leaders have identified the following areas as primary targets for new, major initiatives by OAR and possibilities for collaboration with autism organizations with similar priorities and interests in the next three to five years:

- Housing and residential services and supports
- Employment
- Respite

These plans take OAR closer, but hardly all the way, toward realizing its vision of a future in which OAR leads the way in funding applied autism research and providing practical, evidence-based information to the autism community. That vision demonstrates OAR's intent to see steady growth in fundraising, provide sustained support for applied autism research, and continue to seek the best ways to use scientific methods and results to inform and educate everyone in the autism community. Most of all, OAR's vision is for a future where the collaborative efforts of many quality organizations lead to a global understanding of autism that emphasizes abilities and possibilities over disabilities.



Board of Directors

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Great Falls, Virginia
Adult son and daughter with autism

Lori Lapin Jones

Vice Chairperson
Great Neck, New York
Son with autism

Gregory Smith

Treasurer
Lorton, Virginia
Teenage daughter with autism

Directors

Michael V. Maloney

Executive Director and Secretary
Non-voting
Burke, Virginia

Peter Gerhardt, Ed.D.

Chair, Scientific Council
New York, New York
Autism professional

William Donlon

Hicksville, New York
Son with autism

Anthony Ferrera

Hillsborough, New Jersey
Son with autism

Lisa Hussman

Ellicott City, MD
Son with autism

Edward H. Schwallie

Manasquan, New Jersey
Two adult sons – one with autism,
another with Asperger Syndrome

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Vice Chairperson

Lawrence Brennan

Lewis Grossman

Michael Guarino

James Jacobsohn

Dean Koocher

Sandra Kownacki

Gloria Satriale

Thomas Schirmer



OAR's Scientific Council

OAR's Scientific Council is comprised of leading autism and medical professionals serving together as an expert information resource for all OAR matters concerning issues of research. In that regard, the Council assists OAR's Board of Directors in developing its research strategy, near term priorities, and long-range research objectives. The Council also provides program guidance and oversight for OAR's research competition and plays a central role in ensuring the highest quality reviews for prospective OAR research proposals.

Peter F. Gerhardt, Ed.D.
Founding Chair of the Scientific Council
Director of Education, Upper School
The McCarton School
New York, NY

Shahla Alaí-Rosales, Ph.D., BCBA
Assistant Professor
Department of Behavior Analysis
University of North Texas
Denton, TX

Jonathan M. Campbell, Ph.D.
Professor
Department of Educational, School, and
Counseling Psychology
University of Kentucky
Lexington, KY

Glen Dunlap, Ph.D.
Professor
Department of Child and Family Studies,
University of South Florida
Tampa, FL

Michael Fabrizio, MA, BCBA
Clinical Services Supervisor
Organization for Research and Learning, Inc.
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Executive Director
Eden II Programs
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School for Health Studies
Simmons College
Boston, MA

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Connecticut Center for Child Development
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Michael Londner, M.D., M.P.H., M.B.A.
Inova Health Systems
Falls Church, VA

James A. Mulick, Ph.D.
Professor in the Department of Psychology,
College of Social and Behavioral Sciences
Ohio State University
Columbus, OH

Brenda Myles, Ph.D.
Ziggurat Group
Dallas, TX

Samuel L. Odom, Ph.D.
FPG Child Development Institute
University of North Carolina at Chapel Hill
Chapel Hill, NC

Daniel Openden, Ph.D., BCBA-D
Vice President & Clinical Services Director
Southwest Autism Research &
Resource Center
Phoenix, AZ

Luke Tsai, M.D., FAACAP
Visiting Professor of Education
School of Education and Human Services
Oakland University, Rochester, Michigan
Professor *Emeritus* of Psychiatry and Pediatrics
Research Scientist *Emeritus*
University of Michigan - Ann Arbor

Ann Wagner, Ph.D.
Chief, Neurodevelopmental Disorders
Division of Pediatric Translational
Research and Treatment Development
National Institutes of Mental Health
Bethesda, MD

Mary Jane Weiss, Ph.D., BCBA-D
Professor of Education
Director of Autism and Applied Behavior Analysis
Program
Endicott College
Beverly, MA

Patricia Wright, Ph.D., MPH
National Director, Autism Services
Easter Seals, Inc.
Chicago, IL

Past Members

Michael Alessandri, Ph.D.
Michael Powers, Psy.D
Robert Sprague, Ph.D.



- 10** Years of OAR
- 7** *Life Journey through Autism* Publications
- 8** Spanish resources available
- 103** Issues of *The OARacle* published
- 134** Studies funded
- 55** Scholarship winners
- 4,557** *RUN FOR AUTISM* runners
- 10,000** Guides for Military Families distributed
- 50,000** Guides distributed
- 75,000** Views of *Understanding Asperger Syndrome: A Professor's Guide* YouTube
- \$178,500** Scholarship funds awarded
- \$2,468,000** Grant research funding



... and building for a future where the efforts of many quality organizations, including OAR, lead to a global understanding of autism that recognizes the person above all and emphasizes abilities and possibilities over disabilities.



2000 North 14th Street, Suite 710, Arlington, VA 22201
Phone: 703.243.9710 | Web: www.researchautism.org

