



## Organization for Autism Research

### ANNUAL REPORT FOR 2016

June 30, 2016

#### Chairman's Message:

There are an estimated 2.5 million people with autism in the United States. Most will live a normal lifespan. It is this generation living with autism that is the focus of OAR's mission. As the father of two adult children with autism, I appreciate the need for research to identify the causes of this disorder. This work is vital, yet its promise is long term. It offers little for my son and daughter today, or even in their lifetime. The research studies that OAR funds and the programs and resources OAR offers do.

OAR's leadership team is built around a dedicated Board of Directors, a Scientific Council whose professional work is uniquely tied to OAR's mission, and a staff that delivers amazing results. Together we recognize that individuals with autism, their families, caregivers, teachers, and service providers need better answers to a variety of pressing questions, and we strive to provide those answers.

OAR's mission is "to apply research to the challenges of autism." That implies three basic objectives: Raise money. Fund research. Change lives. It's that simple, and the ultimate goal – making a lasting impact on the lives of children and adults with autism – compels us to raise the bar each year. This is our report card for Fiscal Year 2016, July 1, 2015 to June 30, 2016.

Through our annual research competition, we fund pilot studies that address issues such as diagnosis, early intervention, social communication, community living and employment, and family support. In just under 15 years, we have committed more than \$3.4 million to 214 applied research studies by scholars and graduate students pursuing degrees in fields related to autism across the U.S. and abroad. With the grants we make later this year, our total funding will surpass \$3.6 million.

We haven't done this on our own. We engage the autism community in everything we do, and we will need its support as never before as we launch our Hire Autism employment initiative in an effort to improve employment opportunities for adults with autism. We laid the groundwork by building the jobs portal this year. The year to come is where it will be put to the first test. We look forward to the challenge and then reporting our success to you at this time next year. Thank you.

Sincerely,

James M. Sack  
Chairman

## Introduction

Founded in 2001, the Organization for Autism Research (OAR) is a non-profit organization dedicated to the advancement of applied autism research. Specifically, OAR's mission is to apply science to the daily challenges of autism, addressing the social, educational, and treatment concerns of parents, autism professionals, and caregivers. Implicit in this mission is the requirement to fund research and deliver programs and resources that enhance quality of life for as many individuals with autism possible.

Throughout its 14th year of operation, OAR continued to grow and build upon previous successes. OAR's goals for this period included: fund six to eight new professional research studies and six to ten graduate research projects, continue to support the *Conference-on-the-Road* Program and military families through the *Operation Autism* site ([www.operationautismonline.org](http://www.operationautismonline.org)) and *A Guide for Military Families*, further expand the "Autism in the Schoolhouse" initiative, revamp OAR's main website, [www.researchautism.org](http://www.researchautism.org), build the [Hire Autism](#) jobs portal, and raise autism awareness and program funding through special events.

OAR categorizes its programs into four mission areas: research, information, education, and community impact.

**Research** encompasses the work of OAR's Scientific Council as it pertains to the direction and selection of OAR-funded research studies, funding research, and general oversight of the research program.

**Information** revolves around the website, which is updated with the most current information regarding research findings and available resources. It also extends to OAR's array of electronic and printed resources: the *Life Journey through Autism* guide series, several "Autism in the Schoolhouse" resources (e.g. *Kit for Kids* peer education materials, *Understanding Autism: A Guide for Secondary School Teachers* curriculum on DVD), the *Understanding Asperger Syndrome: A Professor's Guide* DVD, resources for military families, *The OARacle* monthly e-newsletter, blog, and social media outlets.

**Education** encompasses all outreach through the Conference-on-the-Road program. These include formal, structured educational forums and formats, such as conferences, seminars, and workshops on a specific topic or theme hosted by partner autism organizations and web-based or printed materials designed along the same lines. Education also includes the OAR Scholarship program, which provides funding for students with autism to pursue post-secondary undergraduate education, trade and vocational training, and cooperative life skills programs.

**Community Impact** includes programs that are long term and whose goals are to effect significant positive change. The "Autism in the Schoolhouse" initiative, begun in 2012, and the Hire Autism adult employment initiative offer long term benefit and impact.

## FY 2016 Program Objectives

OAR's key program objectives for the 2016 fiscal year included:

### Research

- Select six to eight applied autism research studies to receive funding in January 2016 and issue a new Request for Proposals for the 2017 funding cycle

- Conduct the annual meeting of the Scientific Council to complete the annual research competition and discuss possible directions for future OAR-funded research initiatives
- Make awards to six to ten graduate students conducting applied research in the field of autism in July 2015 and identify winners for the 2016 Graduate Research Grants Program

### **Information**

- Update and completely revamp the OAR Web site; ensure its ease of accessibility and functionality as a user-friendly resource for updated autism content
- Distribute *Life Journey through Autism* guides and other OAR resources to the autism community, at the request of individuals and through partnerships with local support organizations
- Support military families affected by autism 24/7 through the *Operation Autism* website and a companion guide, *Life Journey through Autism: A Guide for Military Families*
- Continue to publish *The OARacle* monthly e-newsletter, including featured articles from Scientific Council members, “How To” features for parents and caregivers, news from the community, and summaries of the latest autism research
- Increase public awareness of autism through existing OAR programs by publicizing findings from funded research, distributing *Life Journey through Autism* guides and “Autism in the Schoolhouse” resources, attending conferences, and hosting other special events

### **Education**

- Continue the successful *Conference-on-the-Road* Program to more broadly inform the autism community on the latest applied research in the field and how it can be used to improve the lives of individuals with autism
- Maintain the number of scholarships for individuals with autism (40) through the OAR Scholarship Program

### **Community Impact**

- Expand the “Autism in the Schoolhouse” initiative by educating typically developing school peers, enhancing teacher knowledge of autism, and helping parents become better advocates
- Develop, test, and launch Hire Autism, a jobs portal, as the centerpiece of an adult employment initiative to help adults with autism find meaningful work

**Research Programs.** OAR’s research programs include the annual Applied Research Competition and the Graduate Research Grants Program. The Applied Research Competition began in December 2014 with the release of the Request for Proposals (RFP), and concluded in November 2015, when the Scientific Council met to conduct the final review and present the most deserving proposals to OAR’s Board of Directors for funding consideration. The Board approved 9 studies from an initial group of 142 pre-proposals. The grants were in amounts up to \$30,000 for each of the studies. The total awarded in FY 2016 was \$230,000 bringing OAR’s 14-year total of research funded through the annual competition and the Graduate Research Grant program to just over \$3.4 million.

In July 2015, OAR awarded ten Graduate Research Grants, totaling \$17,849 to Master’s and doctoral students selected from a field of 26 applicants. In October 2015, OAR opened the 13th annual Graduate Research Grants Program with the release of the new RFP and received a record 34 proposals by the

closing date in February. The review was completed and 11 grant recipients were selected to receive grants in July 2016.

In addition to OAR's research grant activities, the Scientific Council convened its 14th general meeting in November 2015. The Council met to discuss the future directions of OAR's research funding, as well as to identify the most outstanding proposals submitted through the annual Applied Research Competition.

**Information Programs.** As OAR continues to grow and expand its reach each year, the website remains the primary communications platform through which OAR communicates with the global autism community. To that end, OAR began the project to fully upgrade and modernize its main site in 2016. At the end of the FY, the project was fully underway. The present site offers visitors information on the current state of applied autism research, as well as updates regarding OAR resources and events. Visitors can sign up to receive *The OARacle* monthly e-newsletter, find information on autism support groups and service providers in their area, and read about upcoming OAR outreach initiatives or events. The new site will make all the information and resources more accessible and be fully responsive for mobile applications.

In 2003, OAR introduced its *OAR's Life Journey through Autism* series with its first publication, *A Parent's Guide to Research*. In December 2014, it released *A Guide to Safety*, as the 8<sup>th</sup> in the series joining: *An Educator's Guide to Autism*, *An Educator's Guide to Asperger Syndrome*, *A Guide for Transition to Adulthood*, *A Parent's Guide to Assessment*, *A Guide for Military Families* and *Navigating the Special Education System*. The *Military Families* guide has a companion website called *Operation Autism* ([www.operationautismonline.org](http://www.operationautismonline.org)), which offers general information on autism and evidence-based treatments, but addresses in detail the military healthcare system and tips for raising a child with autism in the military community.

*The OARacle* monthly e-newsletter keeps its nearly 4,000 subscribers up to date on program and outreach initiatives, as well as recent research findings and news from the autism community. Since its inception in 2002, *The OARacle* has featured articles from the Scientific Council as well as guest experts, teachers, and parents on a variety of topics. This resource furthers OAR's mission by bringing research news to the autism community in a simple, straightforward format.

**Education Programs.** In FY 2016, OAR continued its successful *Conference-on-the-Road* program by opening the door to a new partnership with the Current Trends in Autism Conference in Boston, MA, in November 2015, and continuing two existing partnerships with the Autism Society of Wisconsin and Milestones (OH).

OAR offers more scholarship funds for students with autism pursuing post-secondary education than any other organization in the U.S. or abroad. Through its unique scholarship program, OAR awarded \$105,000 to 35 students with autism pursuing post-secondary, undergraduate education.

**Community Impact Programs.** It's been four years since OAR announced the launch of its *Autism in the School House* Initiative, a three-pronged effort to better inform typical peers, parents, and teachers and help effect a positive learning environment. The first component, the *Kit for Kids*, is a peer education package targeting students in grades K-8 built around *What's Up With Nick?*, an engaging informational booklet presented from a typical peer's perspective. The other two components are the *Navigating the*

*Special Education System* guidebook for parents and *Understanding Autism: A Guide for Secondary Teachers*, a one-hour curriculum on DVD, which OAR delivers as its *Curriculum-in-a-Box*.

OAR continued to make an impact by systematically distributing its *Life Journey through Autism* guides and “Autism in the Schoolhouse” resources to thousands of families – whether directly or through local partner organizations, like support groups, school districts, military installations, and independent practitioners.

Special events are included under the Education Program, and are a major component of community outreach. They serve to heighten the public awareness of autism as well as OAR programming initiatives. The 2016 FY saw the continuation of the highly successful *RUN FOR AUTISM* program, which was introduced in 2003. Through continuing partnerships with the Marine Corps Marathon, Bank of America Chicago Marathon, Chevron Houston Marathon, New York City Half Marathon, and more, OAR has been able to place the autism cause in the national spotlight as an official charity partner in these events. Through the efforts of its dedicated runners, OAR raised more than \$550,000 for new research and information programs in FY 2016. Plans for the *RUN FOR AUTISM* fall schedule were underway at the close of the fiscal year. As the program continues to expand, it is introducing OAR to more people across the nation.

In summary, OAR’s major program accomplishments through June 30, 2016, included:

- Funded 9 new research studies through the 14th annual Applied Research Competition (\$230,000 in total grant awards). The 2016 competition is underway.
- Funded 10 grants (\$17,849 in total grants) to Master’s and doctoral students through the Graduate Research Grants Competition. The 2016 competition is also underway.
- Distributed more than 5,000 copies of *Life Journey through Autism* guides free of charge to families, teachers, service professionals;
- Partnered with three *Conference-on-the-Road* sites: Current Trends in Autism (Boston, MA) in November, the Autism Society of Wisconsin in April, and the Milestones Autism Organization (Cleveland, OH) in June.
- Continued the “Autism in the Schoolhouse” initiative by distributing the highly successful *Kit for Kids* peer education resource that was introduced in April 2012, and the *Understanding Autism: A Guide for Secondary Teachers* curriculum on DVD and Curriculum-in-a-Box introduced in January 2014.
- Raised in excess of \$550,000 in the 15th annual *RUN FOR AUTISM*, engaging more than 600 participants.

Meeting of the Board of Directors in Fiscal Year 2016:

During the period of July 1, 2015 until June 30, 2016, OAR’s Board conducted its annual meeting on November 12, 2015.

### **Board of Directors**

**Terms of Service:** The members of OAR’s Board of Directors serve for one year, to be renewed through majority vote, until his or her earlier resignation or removal. A director may serve for any number of terms, consecutive or otherwise.

**Officers**

**Chairman**

James Sack  
McLean, VA

**Vice Chair**

Lori Lapin Jones  
Great Neck, NY

**Treasurer**

Gregory Smith  
Lorton, VA

**Secretary**

Michael Maloney  
Burke, VA

**Directors**

Christian Bates  
Ashburn, VA

Lisa Hussman  
Ellicott City, MD

William Donlon  
Hicksville, NY

Susan Laredo  
Palmetto Bay, FL

Anthony Ferrera  
Hillsborough, NJ

Christine Searight  
Arlington, VA

Peter Gerhardt  
New York, NY

Thomas Stanek  
Crystal Lake, IL

**Staff**

Michael Maloney  
Executive Director

Kimberly Ha  
Programs & Outreach Associate

Kristen Essex  
Business Manager

Wendy McKinnon  
Programs & Outreach Associate

Emily Branham  
*RUN FOR AUTISM* Coordinator

Morgan Shute  
*RUN FOR AUTISM* Coordinator

**Statement of Financial Position as of June 30, 2016**

**Assets**

<u>Current Assets</u>		₡
Cash and cash equivalents	1,436,844	1,281,101
Contributions receivable	97,082	89,533
Prepaid Expenses	92,730	59,994
Other Current Assets	<u>60,192</u>	<u>38,445</u>
Total Current Assets	<u>\$ 1,686,848</u>	<u>\$ 1,469,073</u>
Office equipment, net of accumulated depreciation	177,341	71,989
Other assets	<u>9,674</u>	<u>9,674</u>
Total Assets	<u>\$ 1,873,863</u>	<u>\$ 1,550,736</u>

**Liabilities and Net Assets**

<u>Current Liabilities</u>		
Accounts Payable	17,553	69,357
Accrued Expenses	6,046	2,487
Deferred Rent	8,062	5,101
Total Current Liabilities	<u>\$ 31,661</u>	<u>\$ 76,945</u>
Long-Term Liabilities	27,668	35,730
Total Liabilities	<u>59,329</u>	<u>112,675</u>
<u>Net Assets</u>		
Unrestricted	998,616	903,540
Temporarily Restricted	<u>815,918</u>	<u>534,521</u>
Total Net Assets	<u>\$ 1,814,534</u>	<u>\$ 1,483,061</u>
Total Liabilities and Net Assets	<u>\$ 1,873,863</u>	<u>\$ 1,550,736</u>

**Statement of Activities and Changes in Net Assets**  
**Years Ended June 30, 2016 and 2015**

	<u>Year Ended</u> <u>June 30, 2016</u>	<u>Year Ended</u> <u>June 30, 2015</u>
<u>Unrestricted Net Assets</u>		
Contributions and grants	\$ 919,063	\$ 931,763
Special Events	604,001	645,959
Donated Services	11,107	9,888
Other income	<u>3,173</u>	<u>2,313</u>
Total support and revenue	<u>1,537,344</u>	<u>1,589,923</u>
Expenses		
Program Services		
Research	456,072	415,658
Information	311,102	338,573
Education	<u>185,224</u>	<u>202,066</u>
Total Program Services	<u>952,398</u>	<u>956,297</u>
Supporting Services		
Management	74,956	49,442
Fundraising	<u>133,517</u>	<u>160,065</u>
Total expenses	<u>1,160,871</u>	<u>1,165,804</u>
Change in Net Assets	<u>376,473</u>	<u>429,119</u>
Net Assets, beginning of year	<u>1,438,061</u>	<u>1,013,942</u>
Net Assets, end of year	<u>\$ 1,814,534</u>	<u>\$ 1,438,061</u>