



Organization for Autism Research

ANNUAL REPORT FOR 2017

June 30, 2017

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 2017, July 1, 2016, to June 30, 2017.

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 16 years, we have committed more than \$3.6 million to 230 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 approach \$3.7 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 it 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 15th 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) and *A Guide for Military Families*, further expand the "Autism in the Schoolhouse" initiative, launch OAR's new, main website, www.researchautism.org, introduce 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* (YouTube), resources for siblings and 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 2017 Program Objectives

OAR's key program objectives for the 2017 fiscal year included:

Research

- Select six to eight applied autism research studies to receive funding in January 2017 and issue a new Request for Proposals for the 2018 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 2016 and identify winners for the 2017 Graduate Research Grants Program

Information

- Complete and launch a fully renovated, responsive OAR main Web site
- 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
- 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 2015 with the release of the Request for Proposals (RFP), and concluded in November 2016, 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 6 studies from an initial group of 148 pre-proposals. The grants were in amounts up to \$30,000 for each of the studies. The total awarded in FY 2017 was \$178,866 bringing OAR’s 15-year total of research funded through the annual competition and the Graduate Research Grant program to more than \$3.6 million.

In July 2016, OAR awarded 11 Graduate Research Grants, totaling \$19,387 to Master’s and doctoral students selected from a field of 34 applicants. In October 2016, OAR opened the 14th annual Graduate Research Grants Program with the release of the new RFP and received a 26 proposals by the closing date in February. The review was completed and 11 grant recipients were selected to receive grants in July 2017.

In addition to OAR's research grant activities, the Scientific Council convened its 15th general meeting in November 2016. 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 launched a fully upgraded main site in December 2016. The new site offers visitors information on the current state of applied autism research, as well as updates regarding OAR resources and events, and is fully responsive. 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 takes all the information and resources from the former site and makes them more accessible through online and 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 8th 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), 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 2017, OAR continued its successful *Conference-on-the-Road* program with a new partnership with the Ohio Center for Autism and Low Incidences (OCALI) in Columbus, OH, and by 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 \$114,000 to 38 students with autism pursuing post-secondary, undergraduate education.

Community Impact Programs. It's been five years since OAR launched 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 2017 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 \$600,000 for new research and information programs in FY 2017. 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, 2017, included:

- Funded 6 new research studies through the 14th annual Applied Research Competition (\$180,000 in total grant awards). The 2017 competition is underway.
- Funded 11 grants (\$19,387 in total grants) to Master’s and doctoral students through the Graduate Research Grants Competition. The 2017 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: OCALI (Columbus, OH) 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 supporting the peer education of more than 15,000 young students through the highly successful *Kit for Kids* peer education resource and the *Understanding Autism: A Guide for Secondary Teachers* curriculum on DVD and Curriculum-in-a-Box.
- Raised in excess of \$600,000 in the 15th annual *RUN FOR AUTISM*, engaging more than 600 participants.

Meeting of the Board of Directors in Fiscal Year 2017:

During the period of July 1, 2016 until June 30, 2017, OAR’s Board conducted its annual meeting on November 16, 2016.

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

Vice Chair

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McLean, VA

Lori Lapin Jones
Great Neck, NY

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Lorton, VA

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Saman Kamgar-Parsi
Programs & Outreach Associate

Sean Flynn
Manager, Endurance Fundraising

Diane Lingenfelter
Manager, Hire Autism Outreach

Rachel Edrich
RUN FOR AUTISM Coordinator

Sarah Rodis
RUN FOR AUTISM Coordinator

Statement of Financial Position as of June 30, 2017

	Assets	
	June 30, 2017	June 30, 2016
<u>Current Assets</u>	\$	\$
Cash and cash equivalents	1,467,932	1,436,844
Contributions receivable	147,360	97,082
Prepaid Expenses	178,049	92,730
Other Current Assets	<u>74,915</u>	<u>60,192</u>
Total Current Assets	<u>\$ 1,868,311</u>	<u>\$ 1,686,848</u>
Office equipment, net of accumulated depreciation	129,240	177,341
Other assets	<u>9,674</u>	<u>9,674</u>
Total Assets	<u>\$2,007,225</u>	<u>\$ 1,873,863</u>
Liabilities and Net Assets		
<u>Current Liabilities</u>		
Accounts Payable	42,113	17,553
Accrued Expenses	6,188	6,046
Deferred Rent	10,844	8,062
Total Current Liabilities	<u>\$ 59,145</u>	<u>\$ 31,661</u>
Long-Term Liabilities	16,824	27,668
Total Liabilities	<u>75,969</u>	<u>59,329</u>
<u>Net Assets</u>		
Unrestricted	950,556	998,616
Temporarily Restricted	<u>980,700</u>	<u>815,918</u>
Total Net Assets	<u>\$ 1,931,256</u>	<u>\$ 1,814,534</u>
Total Liabilities and Net Assets	<u>\$2,007,225</u>	<u>\$ 1,873,863</u>

Statement of Activities and Changes in Net Assets
Years Ended June 30, 2017 and 2016

	<u>Year Ended</u> <u>June 30, 2017</u>	<u>Year Ended</u> <u>June 30, 2016</u>
<u>Unrestricted Net Assets</u>		
Contributions and grants	\$ 941,460	\$ 919,063
Special Events	519,568	604,001
Donated Services	15,111	11,107
Other income	<u>11,110</u>	<u>3,173</u>
Total support and revenue	<u>1,488,129</u>	<u>1,537,344</u>
Expenses		
Program Services		
Research	447,064	456,072
Information	425,438	311,102
Education	<u>212,463</u>	<u>185,224</u>
Total Program Services	<u>1,084,965</u>	<u>952,398</u>
Supporting Services		
Management	79,222	74,956
Fundraising	<u>184,720</u>	<u>133,517</u>
Total expenses	<u>1,348,907</u>	<u>1,160,871</u>
Change in Net Assets	<u>116,722</u>	<u>376,473</u>
Net Assets, beginning of year	<u>1,814,534</u>	<u>1,438,061</u>
Net Assets, end of year	<u>\$ 1,931,256</u>	<u>\$ 1,814,534</u>