



Organization for Autism Research

ANNUAL REPORT FOR 2018

June 30, 2018

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 2018, July 1, 2017, to June 30, 2018.

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 17 years, we have committed more than \$3.6 million to 237 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 continue to develop our Hire Autism employment initiative to improve employment opportunities for adults with autism. We laid the groundwork by opening the jobs portal last year. The year to come is where we will complete its 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

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. This extends to 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 16th year of operation, OAR continued to grow and build upon previous successes to include receiving a 4-Star rating from Charity Navigator for the third year in a row. 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 military families through the *Operation Autism* site (www.operationautismonline.org) and *A Guide for Military Families*, further expand the "Autism in the Schoolhouse" initiative, initiate the [Hire Autism](#) demonstration project in Northern Virginia, 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 provides the most current information regarding OAR's research findings and available resources. It also provides access 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*: resources for siblings and military families, *The OARacle* monthly e-newsletter, blog, and social media outlets.

Education encompasses all outreach activities, most prominently the OAR Webinar Series successfully introduced in April 2017. 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, launched in April 2017, offer long term benefit and impact.

FY 2018 Program Objectives

OAR's key program objectives for the 2018 fiscal year included:

Research

- Select six to eight applied autism research studies for funding in January 2018
- 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 2018 and identify winners for the 2019 Graduate Research Grants Program

Information

- Publish *Life Journey through Autism: An Educator's Guide to ASD (Level One Supports)*
- 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 newly introduced OAR Webinar Series to inform and educate the autism community on topics of high interest to individuals with autism and their families
- Award 40 scholarships for post-secondary, undergraduate education to individuals with autism through the OAR Scholarship Program

Community Impact

- Maintain the "Autism in the Schoolhouse" initiative by educating typically developing school peers, enhancing teacher knowledge of autism, and helping parents become better advocates
- Continue the Hire Autism demonstration project to test the jobs portal, develop a local model for future replication, and help adults with autism find meaningful work in No. Virginia

Research Programs. OAR's research programs include the annual Applied Research Competition and the Graduate Research Grants Program. In July 2017, OAR awarded 11 Graduate Research Grants, totaling \$20,619 to Master's and doctoral students selected from a field of 26 applicants. In October 2017, OAR opened the 15th annual Graduate Research Grants Program with the release of the new Request for Proposals (RFP) and received 42 proposals, a record high, by the closing date in February. The review was completed and 11 grant recipients were selected to receive grants in July 2018.

The Applied Research Competition cycle began in December 2016 with the release of its RFP, and concluded in October 2017, when the Scientific Council met for its 16th annual meeting to conduct the final review and make its recommendations for new grants to OAR's Board of Directors. The Board approved 7 studies from an initial group of 150 pre-proposals. The grants were in amounts up to \$30,000 for each of the studies. The total awarded in FY 2018 was \$206,555 bringing OAR's 16-year total of research funded through the annual competition and the Graduate Research Grant program to more than \$3.6 million.

Information Programs. As OAR continues to grow and expand its reach each year, the website remains the primary platform through which OAR communicates with the global autism community. To that end, the fully responsive main site, upgraded in December 2016, 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.

In 2003, OAR introduced its *OAR's Life Journey through Autism* series with its first publication, *A Parent's Guide to Research*. In December 2017, it released *An Educator's Guide to ASD (Level One Supports)*, as the 9th 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*, and *A Guide to Safety*. The *Military Families* guide has a companion website called *Operation Autism* (www.operationautism.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. In January 2018, OAR released *Finding Your Way: A College Guide for Self-Advocates* and its companion microsite, *College Central*. *These resources guide young adults with autism on the expectations of college living, and discuss a range of topics such as financial aid, executive functioning skills, social relationships, and safety.*

The OARacle monthly e-newsletter keeps its more than 5,000 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 replaced its *Conference-on-the-Road* program with the OAR Webinar Series. The first webinar featured OAR Scientific Council Chairman, Dr. Peter Gerhardt, speaking on the Transition to Adulthood. More than 700 people registered for the webinar.

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 \$120,000 to 40 students with autism pursuing post-secondary, undergraduate education in this FY.

Community Impact Programs. It's been six years since OAR launched its *Autism in the School House* Initiative, an effort to better inform typical peers, parents, and teachers and help effect positive learning environments in schools across the U.S. The most widely-used 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. OAR has distributed more than 118,000 copies in the U.S., the booklet has been translated into Vietnamese, Georgian, and Spanish.

The other component is the *Curriculum-in-a-Box*, which focused on educating teachers and includes *Understanding Autism: A Guide for Secondary Teachers*, a one-hour curriculum on DVD, along with more supporting materials.

OAR also continued to make a greater impact by distributing its *Life Journey through Autism* guides and resources to thousands of families – whether directly or through local partner organizations, like support groups, school districts, military installations, and independent practitioners.

OAR uses special events as a major component of community outreach. They serve to heighten the public awareness of autism as well as OAR programming initiatives. The 2018 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 Marathon, and international expansion to marathons in London and Berlin, OAR has been able to place the autism cause in the national and international spotlight. Through the efforts of its dedicated runners, OAR raised more than \$750,000 for new research and information programs in FY 2018. 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, 2018, included:

- Funded 7 new research studies through the 15th annual Applied Research Competition (\$206,555 in total grant awards). The 2018 competition is underway.
- Funded 11 grants (\$20,619 in total grants) to Master’s and doctoral students through the Graduate Research Grants Competition. The 2018 competition is also underway.
- Distributed more than 10,000 copies of *Life Journey through Autism* guides free of charge to families, teachers, service professionals;
- Successfully launched the OAR Webinar Series in April 2018
- 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 \$750,000 in the 16th annual *RUN FOR AUTISM*, engaging more than 690 participants.

Meeting of the Board of Directors in Fiscal Year 2018:

During the period of July 1, 2017 until June 30, 2018, OAR’s Board conducted its annual meeting on October 12, 2017.

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
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Hicksville, NY

Cathy Farmer
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Anthony Ferrera
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New York, NY

Lisa Hussman
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Marie Kish
Vienna, VA

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Christine Searight
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Crystal Lake, IL

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Staff

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Kimberly Ha
Director, Research & Programs

Amanda Rioux
Manager, Hire Autism

Sean Flynn
Director, *RUN FOR AUTISM*

Rachel Edrich
RUN FOR AUTISM Coordinator

Kristen Essex
Business Manager

Saman Kamgar-Parsi
Programs & Outreach Associate

Naina Chernoff
Hire Autism Associate

Sarah Rodis
RUN FOR AUTISM Coordinator

Statement of Financial Position as of June 30, 2018

Assets		
	June 30, 2018	June 30, 2017
<u>Current Assets</u>	\$	\$
Cash and cash equivalents	1,768,299	1,467,932
Investments	3,852	-
Contributions receivable	58,206	147,360
Prepaid Expenses	135,972	178,049
Other Current Assets	<u>69,370</u>	<u>74,915</u>
Total Current Assets	<u>\$ 2,035,699</u>	<u>\$ 1,868,311</u>
Office equipment, net of accumulated depreciation	73,206	129,240
Other assets	<u>9,674</u>	9,674
Total Assets	<u>\$ 2,118,579</u>	<u>\$ 2,007,225</u>
 Liabilities and Net Assets 		
<u>Current Liabilities</u>		
Accounts Payable	32,403	42,113
Accrued Expenses	10,344	6,188
Deferred Rent	13,963	10,844
Total Current Liabilities	<u>\$ 56,710</u>	<u>\$ 59,145</u>
Long-Term Liabilities	2,861	16,824
Total Liabilities	<u>\$ 59,571</u>	<u>75,969</u>
<u>Net Assets</u>		
Unrestricted	1,082,561	950,556
Temporarily Restricted	<u>976,447</u>	<u>980,700</u>
Total Net Assets	<u>\$ 2,059,008</u>	<u>\$ 1,931,256</u>
Total Liabilities and Net Assets	<u>\$ 2,118,579</u>	<u>\$ 2,007,225</u>

**Statement of Activities and Changes in Net Assets
Years Ended June 30, 2018 and 2017**

	<u>Year Ended June 30, 2018</u>	<u>Year Ended June 30, 2017</u>
<u>Unrestricted Net Assets</u>		
Contributions and grants	\$ 1,036,293	\$ 941,460
Special Events	526,894	519,568
Donated Services	13,429	15,111
Other income	<u>12,906</u>	<u>11,990</u>
Total support and revenue	\$ <u>1,589,522</u>	<u>1,488,129</u>
Expenses		
Program Services		
Research	408,402	447,064
Information	553,635	425,438
Education	<u>227,900</u>	<u>212,463</u>
Total Program Services	\$ <u>1,189,937</u>	<u>1,084,965</u>
Supporting Services		
Management	59,747	79,222
Fundraising	<u>212,086</u>	<u>184,720</u>
Total expenses	\$ <u>1,461,770</u>	<u>1,348,907</u>
Change in Net Assets	<u>127,752</u>	<u>116,722</u>
Net Assets, beginning of year	<u>1,931,256</u>	<u>1,814,534</u>
Net Assets, end of year	<u>\$ 2,059,008</u>	<u>\$ 1,931,256</u>