



Organization for Autism Research

ANNUAL REPORT FOR 2019

June 30, 2019

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 2019, July 1, 2018, to June 30, 2019.

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 18 years, we have committed more than \$4 million to 250 autism studies by researchers, including 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 \$4.3 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 17th 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 military families through the *Operation Autism* site (www.operationautismonline.org) and *A Guide for Military Families*, further expand the "Autism in the Schoolhouse" initiative, complete 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, the "Autism in the Schoolhouse" resources for students and teachers, 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 2019 Program Objectives

OAR's key program objectives for the 2019 fiscal year included:

Research

- Award six to ten graduate students conducting applied research in the field of autism (July 2018)
- Conduct the annual meeting of the Scientific Council to complete the annual research competition (October 2018)
- Award six to eight applied autism research grants (January 2019)
- Identify winners for the 2019 Graduate Research Grants Program (May 2019)

Information

- Publish *Sex Ed. for Self-Advocates*, a first of its kind sex education resource for individuals on the spectrum
- 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 **newly launched** *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 OAR Webinar Series to inform and educate the autism community on topics of high interest to individuals with autism and their families
- Award 50 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
- Complete the Hire Autism demonstration project to test the jobs portal 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 2018, OAR awarded 11 Graduate Research Grants, totaling \$20,619 to Master’s and doctoral students selected from a field of 42 applicants. In October 2018, OAR opened the 16th annual Graduate Research Grants Program with the release of the new RFP and received 42 proposals by the closing date in February. The review was completed in May 2019 with 11 grant recipients selected to receive grants in July 2019.

The Applied Research Competition cycle began in December 2017 with the release of the Request for Proposals (RFP), and concluded in October 2018, when the Scientific Council met to conduct the final review and make its recommendations for new grants to OAR’s Board of Directors. The Board approved 8 studies from an initial group of 152 pre-proposals. The grants were in amounts up to \$30,000 for each of the studies. The total awarded in FY 2019 was \$206,555 bringing OAR’s 17-year total of research funded through the annual competition and the Graduate Research Grant program to more than \$4 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 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 January 2019, it launched *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 April 2019, it also released *Sex Ed. for Self-Advocates*, a one-of-a-kind online resource that contains videos, quizzes, and visuals to help individuals with autism learn about sexuality and sex education.

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 introduced the OAR Webinar Series. The first webinar featured OAR Scientific Council Chairman, Dr. Peter Gerhardt, speaking on the Transition to Adulthood. In FY 2019, OAR held three webinars for a total of 971 live attendees and 5,488 post-event viewers.

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 \$147,000 to 49 students with autism pursuing post-secondary, undergraduate education in this FY.

Community Impact Programs. It's been seven 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 135,000 copies in the U.S., the booklet has been translated for use in Vietnam, Poland, and Bulgaria.

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 2019 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 \$700,000 for new research and information programs in FY 2019. 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, 2019, included:

- Funded 7 new research studies through the annual Applied Research Competition (\$206,555 in total grant awards). The 2019 competition is underway.
- Funded 11 grants (\$20,619 in total grants) to Master’s and doctoral students through the Graduate Research Grants Competition. The 2019 competition is also underway.
- Distributed more than 10,000 copies of *Life Journey through Autism* guides free of charge to families, teachers, service professionals;
- Continued the “Autism in the Schoolhouse” initiative by supporting the peer education of 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 \$700,000 through the annual *RUN FOR AUTISM* program, engaging more than 600 participants across the U.S.

Meeting of the Board of Directors in Fiscal Year 2019:

During the period of July 1, 2018 until June 30, 2019, OAR’s Board conducted its annual meeting on October 16, 2018.

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

Marie Kish
Vienna, VA

Secretary

Michael Maloney
Burke, VA

Directors

William Donlon
Hicksville, NY

Peter Gerhardt
New York, NY

Cathy Farmer
Berkeley, CA

Lisa Hussman
Ellicott City, MD

Anthony Ferrera
Hillsborough, NJ

Gregory Smith
Lorton, VA

Staff

Michael Maloney
Executive Director

Kristen Essex
Deputy Executive Director

Programs and Research

Kimberly Ha
Director, Research & Programs

Hire Autism

Amanda Rioux
Manager, Hire Autism

Naina Chernoff
Hire Autism Associate

RUN FOR AUTISM

Sean Flynn
Director, *RUN FOR AUTISM*

Sarah Rodis
Senior Coordinator, *RUN FOR AUTISM*

Rachel Edrich
Senior Coordinator, *RUN FOR AUTISM*

Statement of Financial Position as of June 30, 2019

Assets

	June 30, 2019	June 30, 2018
<u>Current Assets</u>	\$	\$
Cash and cash equivalents	1,713,420	1,768,299
Investments	6,749	3,852
Contributions receivable	92,266	58,206
Prepaid Expenses	148,871	182,997
Other Current Assets	<u>59,373</u>	<u>69,370</u>
Total Current Assets	<u>\$2,020,679</u>	<u>\$2,082,724</u>
Office equipment, net of accumulated depreciation	19,714	73,206
Other assets	51,918	9,674
Total Assets	<u>\$2,092,311</u>	<u>\$2,165,604</u>

Liabilities and Net Assets

Current Liabilities

Accounts Payable	44,098	32,403
Accrued Expenses	13,799	10,344
Deferred Rent	2,861	13,963
Total Current Liabilities	<u>\$60,758</u>	<u>\$56,710</u>

Long-Term Liabilities	-	2,861
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Total Liabilities	<u>\$60,758</u>	<u>\$59,571</u>
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Net Assets

Unrestricted	1,271,373	1,129,586
Temporarily Restricted	<u>760,180</u>	<u>976,447</u>

Total Net Assets	<u>\$2,031,553</u>	<u>\$2,106,033</u>
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**Statement of Activities and Changes in Net Assets
Years Ended June 30, 2019 and 2018**

	Year Ended <u>June 30, 2019</u>	Year Ended <u>June 30, 2018</u>
<u>Unrestricted Net Assets</u>		
Contributions and grants	1,008,680	1,036,293
Special Events	626,789	573,919
Donated Services	12,847	13,429
Other income	<u>16,495</u>	<u>12,906</u>
Total support and revenue	<u>\$1,664,811</u>	<u>\$1,636,547</u>
Expenses		
Program Services		
Research	555,986	408,402
Information	611,535	553,635
Education	<u>248,986</u>	227,900
Total program		
services	<u>\$1,416,507</u>	<u>\$1,189,937</u>
Supporting Services		
Management	56,857	59,747
Fundraising	<u>265,927</u>	<u>212,086</u>
Total expenses	<u>\$1,739,291</u>	<u>\$1,461,770</u>
Change in Net Assets	(74,480)	174,777
Net Assets, beginning of year	<u>\$2,106,033</u>	<u>\$1,931,256</u>
Net Assets, end of year	<u>\$2,031,553</u>	<u>\$2,106,033</u>