



Organization for Autism Research

ANNUAL REPORT FOR 2021

June 30, 2021

Chairman's Message:

This was the year of the COVID-19 pandemic. It put unprecedented demands on us as an organization. It challenged the autism community and the country too. I am pleased to report that we continued full operations and research and programs support throughout the year thanks to a staff that did not miss a beat despite moving to remote work, the leadership of our Board, and some timely major gifts.

As soon as the full impact of the pandemic became clear, we immediately reviewed every aspect of our annual plan: research studies, programs, fundraising, staffing, meeting schedules, and more. Fundraising was a particular concern given that one of OAR's principal revenue sources is the *RUN FOR AUTISM*, a charity running program built around people running major distance races like the New York City and London Marathons while raising money for autism research. COVID-19 literally shut the big races down.

In response, we adapted, rapidly shifting to virtual running events to help offset some of the lost revenues. At the same time, OAR's Board of Directors stepped up to pledge \$90,000 as a matching challenge for the annual end-of-year campaign. The response was immediate and impactful as we raised an all-time high of more than \$325,000 in the 2020 end-of year campaign.

Thanks to the creativity and adaptability of our staff and Board team, it didn't take us long to regain full confidence in our ability to navigate the COVID-19 challenges without cutting program outreach and support. In fact, we were able to fund six new research grants and surpass \$4.2 million in total funds committed to autism research. I am as proud to share this report as any in our 20-year history. We met the challenge. OAR today is stronger, more versatile, and more capable today than ever before.

In closing, I'd be remiss in not mentioning that we don't do anything 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 fund new research, inform and educate self-advocates, parents, and educators, and extend our Hire Autism employment initiative from coast to coast. We look forward to the challenge of the year to come and 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 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 self-advocates, 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.

Despite the impact of COVID-19 and its impact on fundraising and general operations, OAR continued to grow and build upon previous successes throughout the course of its 19th year of operation. As this report chronicles, OAR met its goals for this period and managed to launch its Hire Autism employment initiative nationally following a two-year demonstration project in Northern Virginia.

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, continue to offer long term benefit and impact.

FY 2021 Program Objectives

OAR's key program objectives for the 2021 fiscal year included:

Research

- Award twelve graduate students conducting applied research in the field of autism (July 2020)
- Conduct the annual meeting of the Scientific Council and complete the annual Applied Research Competition (November 2020)
- Award six applied autism research grants (January 2021)
- Identify winners for the 2021 Graduate Research Grants Program (May 2021)

Information

- Provide current information on autism research and evidence-based resources to the autism community through a variety of means: website, newsletter, resources, and more.
- Support military families impacted by autism 24/7 through the *Operation Autism* website and its 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 by distributing *Life Journey through Autism* guides and “Autism in the Schoolhouse” resources and hosting webinars on topics of high interest
- Release new friendship tip sheets to expand the *Kit for Kids* peer education program (December 2020)

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 33 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
- Award five Autism Education Grants to expand the use of OAR’s Kit for Kids resources and increase autism acceptance in schools across the U.S. (September 2020)
- Establish the Hire Autism employment initiative as a national program.

Research Programs. OAR funds new research through the annual Applied Research Competition and the Graduate Research Grants Program. In July 2020, OAR awarded 12 Graduate Research Grants, totaling \$18,186 to Master’s and doctoral students selected from a field of 45 applicants. In October 2020, OAR opened the 18th annual Graduate Research Grants Program. It received 40 proposals by the closing date in February. The review was completed in May 2021 with 10 grant recipients selected to receive grants in July 2021.

The 2020 Applied Research Competition cycle opened in December 2019, and concluded in November 2020, 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 6 studies from an initial group of 195 pre-proposals. The grants were in amounts up to \$40,000 for each of the studies. The total awarded in FY 2021 was \$240,000 bringing OAR’s 19-year total of research funded through the annual competition and the Graduate Research Grant program to more than \$4.2 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, read the weekly blog, find information on autism support groups and service providers in their area, and read about upcoming OAR outreach initiatives or events.

The OARacle monthly e-newsletter keeps its more than 6,000 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.

In December 2020, OAR published a series of Friendship Tip Sheets that expand the *Kit for Kids* peer education program in an effort to encourage understanding and companionship among peers in grades K-8. The tip sheets use engaging visuals, activities, and reflection questions to capture children's attention and promote discussion around communication barriers, sensory differences, misunderstandings, and more. Since their release, the tip sheets have been used by more than 5,820 students.

Education Programs. OAR introduced the OAR Webinar Series In 2017. In FY 2021, OAR held four webinars on topics to include: skilled trades, mental health priorities and suicide prevention, health and health care in autistic children and adults, and improving healthcare for autistic adults, that attracted a total of 258 live attendees and 1,991 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 \$103,000 to 33 students with autism pursuing post-secondary, undergraduate education in this FY. This brings OAR's scholarships totals to 289 autistic students supported and \$1,170,000 in scholarship awards since 2007.

Community Impact Programs. OAR launched its first Community Impact initiative, *Autism in the School House*, in 2012. The intent was 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. In the intervening years, OAR has added more supporting modules and activities to enhance the depth and scope of the program. OAR has distributed more than 145,000 copies in the U.S., the booklet has been translated for use in Vietnam, Georgia, 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 had used special events as a major component of community outreach prior to COVID-19. With our traditional outreach activities curtailed, OAR quickly adopted virtual events for both its *RUN FOR AUTISM* program and programs outreach and delivery.

In summary, OAR's major program accomplishments through June 30, 2021, included:

- Funded 6 new research studies through the annual Applied Research Competition (\$240,000 in total grant awards). The 2021 competition is underway.
- Funded 12 grants (\$18,186 in total grants) to Master's and doctoral students through the 2020 Graduate Research Grants Competition. The 2021 competition is now underway.

- Distributed more than 12,000 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 22,000 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.

Meeting of the Board of Directors in Fiscal Year 2021:

During the period of July 1, 2020 until June 30, 2021, OAR’s Board conducted its annual meeting on November 2, 2020, and a mid-year meeting on April 14, 2021.

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 Johnson
Herndon, VA

Secretary

Michael Maloney
Burke, VA

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Peter Gerhardt
New Milford, NJ

Roberto Datorre
Elizabethtown, PA

Lisa Hussman
Ellicott City, MD

William Donlon
Hicksville, NY

Stephen Shore
Brookline, MA

Cathy Farmer
Berkeley, CA

Gregory Smith
Lorton, VA

Anthony Ferrera
Flemington, NJ

Joseph Thomas
Naperville, IL



Organization for Autism Research

Staff

Michael Maloney
Executive Director

Kristen Essex
Deputy Executive Director

Kimberly Ha
Director, Research & Programs

Amanda Rioux
Director, Hire Autism

Courtney Carroll
Hire Autism Associate

Sean Flynn
Director, *RUN FOR AUTISM*

Sarah Culver
Senior Coordinator
RUN FOR AUTISM

Rachel Luizza
Manager
Development and Marketing

Statement of Financial Position as of June 30, 2021

Assets

	June 30, 2021	June 30, 2020
<u>Current Assets</u>		
Cash and cash equivalents	\$ 2,230,862	\$ 1,867,049
Investments	16,876	8,625
Contributions receivable	61,095	53,974
Prepaid Expenses	245,001	227,251
Right of Use asset	96,885	-
Other Current Assets	<u>75,855</u>	<u>83,599</u>
Total Current Assets	<u>2,726,574</u>	<u>2,240,498</u>
<u>Fixed Assets</u>		
Furniture	22,515	22,515
Computer equipment and software	10,715	10,715
Website development	<u>192,961</u>	<u>192,961</u>
	226,191	226,191
Less: Accumulated depreciation and amortization	<u>(208,325)</u>	<u>(199,589)</u>
Net fixed assets	<u>17,866</u>	<u>26,602</u>
Other assets	22,288	32,849
Right of use asset	<u>528,412</u>	<u>717,383</u>
Total Assets	<u>\$ 3,295,140</u>	<u>\$ 3,017,332</u>

Liabilities and Net Assets

<u>Current Liabilities</u>		
Note Payable	\$ 133,249	\$ 134,995
Accounts Payable and accrued liabilities	21,721	12,236
Accrued Expenses	20,892	18,854
Lease liability	<u>100,336</u>	<u>-</u>
Total Current Liabilities	<u>276,198</u>	<u>166,085</u>
<u>Long-Term Liabilities</u>		
Lease liability, net of current	<u>590,086</u>	<u>782,754</u>
Total Liabilities	866,284	948,839
<u>Net Assets</u>		
Without donor restrictions	1,856,254	1,426,083
With donor restrictions	<u>572,602</u>	<u>642,410</u>
Total Net Assets	<u>2,428,856</u>	<u>2,068,493</u>
Total Liabilities and Net Assets	<u>\$ 3,295,140</u>	<u>\$ 3,017,332</u>

Statement of Activities and Changes in Net Assets
Years Ended June 30, 2021 and 2020

	<u>Year Ended</u> <u>June 30, 2021</u>	<u>Year Ended</u> <u>June 30, 2020</u>
<u>Unrestricted Net Assets</u>		
Contributions and grants	\$ 1,272,448	\$ 1,129,953
Special events	295,948	501,262
Donated services	12,399	16,000
Interest income	13,125	12,854
Other income	<u>15,417</u>	<u>12,838</u>
Total support and revenue	\$ <u>1,609,337</u>	\$ <u>1,660,053</u>
Expenses		
Program Services		
Research	342,638	481,274
Information	489,126	553,623
Education	<u>194,811</u>	<u>196,753</u>
Total program services	\$ <u>1,026,575</u>	\$ <u>1,231,650</u>
Supporting Services		
Management	130,924	152,140
Fundraising	<u>226,470</u>	<u>239,323</u>
Total supporting services	357,394	391,463
Total expenses	\$ <u>1,383,969</u>	\$ <u>1,623,113</u>
Change in Net Assets before other item	<u>225,368</u>	<u>36,940</u>
Other item		
Extinguishment of debt	134,995	
Change in net assets	360,363	36,940
Net Assets, beginning of year	\$ <u>2,068,493</u>	\$ <u>2,031,553</u>
Net Assets, end of year	<u>\$ 2,428,856</u>	<u>\$ 2,068,493</u>