



Organization for Autism Research

ANNUAL REPORT FOR 2015

June 30, 2015

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 2015, July 1, 2014 to June 30, 2015.

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 14 years, we have committed more than \$3.3 million to 184 applied research studies by scholars and graduate students pursuing degrees in field related to autism across the U.S. and abroad. With the grants we make later this year, our total funding will surpass \$3.5 million.

We haven't done this on our own. We engage the autism community in everything we do, and it has paid dividends. The input we received from parents and professionals immeasurably contributed to the quality of the three resources for siblings OAR published last August and *A Guide to Safety*, the 8th guidebooks in OAR's *Life Journey through Autism* series, released in December. In addition, the financial support the community provides allows OAR to provide its resources at no cost to parents, teachers, and other front-line service providers who serve our children, teens, and adults. 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 13th 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, introduce resources for siblings and *Life Journey through Autism: A Guide to Safety*, begin planning an adult employment initiative, 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 Web site, 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 adult employment initiative under development offer long term benefit and impact.

FY 2015 Program Objectives

OAR's key program objectives for the 2015 fiscal year included:

Research

- Select six to eight applied autism research studies to receive funding in January 2015 and issue a new Request for Proposals for the 2016 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 2014 and identify winners for the 2015 Graduate Research Grants Program

Information

- Maintain 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* resource guides to the autism community, at the request of individuals and through partnerships with local support organizations
- Publish and distribute new resources for siblings and *A Guide to Safety*, the 8th guide in the *Life Journey through Autism* series
- Support military families affected by autism 24/7 through the *Operation Autism* Web site 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
- Increase the number of scholarships for individuals with autism 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
- Begin work on 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 begins in January 2013 with the release of the Request for Proposals (RFP, and concludes in October when the Scientific Council meets to conduct the final review, then presents the most deserving proposals to OAR’s Board of Directors for funding consideration. In October 2014, the Board approved 7 studies from an initial group of 84 pre-proposals. The grants were in amounts up to \$30,000 for each of the studies. The total awarded in FY 2014 was \$210,000 bringing OAR’s 13-year total of research funded through the annual competition and the Graduate Research Grant program to just over \$3.3 million.

In July 2014, OAR awarded ten Graduate Research Grants, totaling \$17,312 to Master’s and doctoral students selected from a field of 27 applicants. In October 2014, OAR opened the 12th annual Graduate Research Grants Program with the release of the new RFP and received a record 29 proposals by the

closing date in February. The review was completed and 10 grant recipients were selected to receive grants in July 2015.

In addition to OAR's research grant activities, the Scientific Council convened its 13th general meeting in October 2014. 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 Web site remains the primary communications platform through which OAR communicates with the global autism community. The 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 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 Web site 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 2015, OAR continued its successful *Conference-on-the-Road* program through three existing partnerships: Commonwealth Autism Services (VA), Autism Society of Wisconsin, and Milestones (OH) and opened the door to a new partnership with the Current Trends in Autism Conference to be held in November 2015.

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 \$117,000 to 39 students with autism pursuing post-secondary, undergraduate education.

Community Impact Programs. It's been three 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. For example, more than 10,000 people accessed the *Understanding Autism: A Guide for Secondary Teachers* video modules in the first three months it was available.

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 2015FY 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 since, 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 \$700,000 for new research and information programs in FY 2015. 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, 2015, included:

- Funded 7 new research studies through the 13th annual Applied Research Competition (\$210,000 in total grant awards). The 2015 competition is underway.
- Funded 10 grants (\$17,312 in total grants) to Master's and doctoral students through the Graduate Research Grants Competition. The 2015 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 four *Conference-on-the-Road* sites: Commonwealth Autism Service (Richmond, VA) in March, 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 \$700,000 in the 14th annual *RUN FOR AUTISM*, engaging more than 800 participants.
- Published three new resources for siblings and *A Guide for Safety*.

Meetings of the Board of Directors in Fiscal Year 2015:

During the period of July 1, 2014 until June 30, 2015, OAR's Board conducted its annual meeting on October 20, 2014 and a teleconference meeting on May 5, 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

Samantha Millard
Assistant Director of Development

Wendy McKinnon
Programs & Outreach Associate

Emily Branham
RUN FOR AUTISM Coordinator

Katherine Ginda
RUN FOR AUTISM Coordinator

Statement of Financial Position as of June 30, 2015

Assets

| | |
|---|---------------------|
| <u>Current Assets</u> | \$ |
| Cash and cash equivalents | 1,281,101 |
| Contributions receivable | 89,533 |
| Prepaid Expenses | 59,994 |
| Other Current Assets | <u>38,445</u> |
| Total Current Assets | <u>\$ 1,469,073</u> |
| Office equipment, net of accumulated depreciation | 71,989 |
| Other assets | <u>9,674</u> |
| Total Assets | <u>\$ 1,550,736</u> |

Liabilities and Net Assets

| | |
|----------------------------------|---------------------|
| <u>Current Liabilities</u> | |
| Accounts Payable | 69,357 |
| Accrued Expenses | 2,487 |
| Deferred Rent | 5,101 |
| Total Current Liabilities | <u>\$ 76,945</u> |
| Long-Term Liabilities | 35,730 |
| Total Liabilities | <u>112,675</u> |
| <u>Net Assets</u> | |
| Unrestricted | 903,540 |
| Temporarily Restricted | <u>534,521</u> |
| Total Net Assets | <u>\$ 1,483,061</u> |
| Total Liabilities and Net Assets | <u>\$1,550,736</u> |

Statement of Activities and Changes in Net Assets
Years Ended June 30, 2015 and 2014

| | <u>Year Ended</u> <u>June 30, 2015</u> | <u>Year Ended</u> <u>June 30, 2014</u> |
|--------------------------------|---|---|
| <u>Unrestricted Net Assets</u> | | |
| Contributions and grants | \$ 931,763 | \$ 563,806 |
| Special Events | 645,959 | 532,493 |
| Donated Services | 9,888 | 14,109 |
| Other income | <u>2,313</u> | <u>2,080</u> |
| Total support and revenue | <u>1,589,923</u> | <u>1,112,488</u> |
| Expenses | | |
| Program Services | | |
| Research | 415,658 | 417,567 |
| Information | 338,573 | 315,545 |
| Education | <u>202,066</u> | <u>182,409</u> |
| Total Program Services | <u>956,297</u> | <u>915,521</u> |
| Supporting Services | | |
| Management | 49,442 | 59,129 |
| Fundraising | <u>160,065</u> | <u>146,246</u> |
| Total expenses | <u>1,165,804</u> | <u>1,120,896</u> |
| Change in Net Assets | <u>429,119</u> | <u>(8,408)</u> |
| Net Assets, beginning of year | <u>1,013,942</u> | <u>1,022,350</u> |
| Net Assets, end of year | <u>\$ 1,438,061</u> | <u>\$ 1,013,942</u> |