



Research That Helps Families Today

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“OAR will focus on the children, adults, and families living with autism today.” With that clear purpose, Jim Sack, President of the Organization for Autism Research (OAR) and six other parents or grandparents of children and adults with autism created a new foundation in December 2001. OAR’s mission is to use applied research as the vehicle to answer the questions that parents, families, teachers, individuals with autism, and caregivers ask every day. OAR will attempt to demystify autism and provide practical information by taking on difficult questions like: What are the components of effective education for persons with autism? and How do we best prepare adults with autism to live and work in their communities?

“No one in the autism community, especially parents with loved ones on the autism spectrum, questions the importance of biomedical research. It’s the only research that will tell us what causes autism and then offer a whole new range of treatment possibilities.” said Sack, father of four, two with autism. “Practically speaking, however, biomedical research doesn’t address the issues that we face at home or that our children and their teachers encounter at school. It offers no insights into matters of daily parental concern: socialization, social life, and the potential to enjoy friendship. And, as federal funding for biomedical research has risen, NIH funding for applied research has fallen to the point that in 2001 it failed to fund a single, new behavioral or educational project in autism. We intend to address this collapse of support for applied research by funding studies that will improve the lives of people with autism at every age.

Parents, teachers, and those who treat or work with our kids and adults face challenges daily that relate to the social and behavioral effects of autism. They don’t need theory. They need practical answers to the questions that begin, ‘How do I...?’ as it relates to teaching a child with autism and preparing that person for life’s later challenges. The pursuit and dissemination of this practical knowledge are the essence of OAR’s mission.”

OAR has crafted a research strategy that considers the total population as well as both the social issues and societal effects of autism across the lifespan. Using five areas of focus: diagnosis, treatment, education, work, and housing, OAR’s approach strikes a balance between the importance of early diagnosis, intervention, and treatment for children with autism and the recognition that autism as a life-long challenge presents a different set of social, vocational, and educational issues for those living with autism, their families, and the communities in which they live.

Supported by generous, lead gifts from its Board of Directors, OAR began operating from its office in Arlington, VA, in January. Its priorities in the first six months of 2002 are to introduce OAR to the autism community, establish its Scientific Council, and lay the foundation for a long-term fundraising effort consistent with OAR’s mission and vision. In support of these purposes, OAR will seek broad-based support across America through alliances with other autism organizations and its own network of volunteers committed to autism research. That work has already begun.

The Scientific Council will be a cross-disciplinary group comprised of leading authorities in applied autism research. The Council will assess the State of the Science in applied research, identify gaps, and set OAR's corresponding research priorities and direction. Dr. Peter Gerhardt, formerly at Rutgers University and now Executive Director of the Nassau Suffolk Services for Autism/The Martin C. Barell School in Levittown, NY, has volunteered to serve as chairman of the Scientific Council. "OAR's focus and purpose are unique among parent-led organizations. I expect that OAR will ultimately bring much-needed attention and funds to applied research in the same way that other parent-led organizations like The Autism Coalition, Cure Autism Now, and the National Alliance for Autism Research have successfully done for biomedical research."

OAR's first year program goals include establishing its Research Information Program and funding up to two applied research studies. The information program will include a community-oriented web site, www.researchautism.org, presently in the first stage of development, and the publication of a Parent's Guide to Research later in the year. The site will feature articles of practical interest written in layman's terms and a forum in which leading names in applied autism research respond to questions from the community. The Parent's Guide, is intended as a reliable, first source of information for parents of children just diagnosed.

The studies OAR will fund will focus on lifespan and life care issues identified in part through a Scientific Roundtable drawn from individuals with autism, parents, educators, and caregivers in addition to scientific, health, and medical professionals. The studies ultimately funded will be selected through a phased solicitation and evaluation process conducted under the auspices of the Scientific Council.

OAR will raise funds for its programs through a variety of methods to include donations, special events, and grants. "It's going to take \$250,000 for OAR to accomplish its first year's goals," stated Mike Maloney, OAR's Vice President & Executive Director. "Through commitments from our Board leaders and the events we have planned, we already have that goal in reach. Should we enjoy even greater success, OAR has a contingency plan to increase funding for research and add information modules to the web site."

One of OAR's fundamental objectives is to provide open access to its information programs and resources, and OAR expects to be successful enough in raising funds to do that. While OAR anticipates receiving support from the community, it isn't going to be a traditional membership organization.

"Autism is a lifelong challenge for the individual and the family. That's enough for life membership in OAR. The same goes for those having the commitment to serve the community as a teacher, caregiver, or other supportive manner," said Sack. "OAR isn't going to have a dues structure, membership cards, and annual renewals. That costs money that we can use for programs, and we won't impose a cost barrier that might exclude some. We will ask for support once a year, and let our 'Life Members' place their own value on what OAR does."

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