

Become an Informed Consumer of Information

As you to learn about autism and evaluate treatment options and claims, you will have to put a great deal of time and effort into becoming a knowledgeable consumer of information. General information on autism can be full of false hope, anecdotal information, and conflicting opinions. One of the greatest challenges for parents of children just diagnosed with autism will be sifting through the vast array of information about the disorder available across many different resources, and distinguishing between reputable and questionable sources of information.

You are the primary advocate for your child, so it is important for you to be able to evaluate your child's needs with research that supports various interventions for autism. To make informed treatment decisions for your child, you will have to gather information from a variety of sources, including the Internet, mass media, professional journals, and reports from conferences, workshops and educational providers.

This article is an abbreviated excerpt from OAR's [*Life Journey Through Autism: A Parent's Guide to Research*](#). See the full guidebook for a basic understanding of the purpose of research, how it is conducted, and the criteria upon which to judge its value, as well as guidance on where and how to search for resources on autism and autism research.

Finding the Research

Important reminders when searching for research:

- *Beware of those who claim to have a cure.* Your hopes for your child may leave you vulnerable to those marketing a variety of educational, medical, and other alternative treatments for autism. Although many promoters of various treatments truly believe in their products or services, few of these fads or miracle cures hold up when scientifically tested.
- Most news organizations report scientific research "second hand" in a brief "cliff-notes" style, so many of the details of the research may be left out.
- For the most part, journalists do a good job reporting the research, but it is important to remember that there is no scientific review process to make sure that what journalists report is accurate.

- To be sure that the research cited or discussed is interpreted and reported accurately, it is best to get the report “first hand” from the source, the person or persons who conducted the research.
- Professional journals are the best source for reports on current research by the scientists who conduct the studies, in part because of the “peer review” process. During a peer review, other researchers read and comment on the quality of the research based on whether it adheres to the ethical and quality standards of the profession.
- There is a great deal of competition to publish, so the articles that appear in journals are the best of the research being done.

Web Sites

Many Web sites cover the topic of autism. Unfortunately, not all are good sources of information. Without some experience or training in searching the Internet, it can be very difficult to discriminate among these many Web sites and sources of information. Keep in mind that reputable, reliable sites often:

- Provide links to other major autism organizations, academic research institutions, and professional research articles;
- Are hosted by government agencies or other non-profit organizations; and
- Clearly cite sources of information.

A list of reputable websites can be found on OAR’s *Operation Autism* website.

Searchable Online Databases

Searchable online databases are very good sources of information about autism and autism research. Some databases are for members only and only accessible to the general public through university libraries.

As a starting point, two high-quality searchable databases available to the general public are:

PubMed is maintained by the National Library of Medicine at the National Institutes of Health and contains an extensive collection of medical and psychological literature.

PubMed is located at <http://www.pubmed.gov> on the Internet.

ERIC is supported by the U.S. Department of Education, Office of Educational Research and Improvement, and the National Library of Medicine. It contains an extensive collection of literature in the field of education and is an excellent source of school-based research. OAR's *Life Journey Through Autism* series of publications have just been added to ERIC's database.

ERIC is located at <http://www.eric.ed.gov> on the Internet.

The challenge to new users of online databases is learning to narrow a search so that only articles of interest are displayed. This will usually require some "trial-and-error" before you master the use of these databases. See *A Parent's Guide to Research* for tips on narrowing an online search.

Medical and University Libraries

Medical and university libraries contain a wealth of autism research, both in print and online journals. Those who are fortunate enough to live within commuting distance of one of these libraries can conduct online searches using databases that these libraries have purchased. These databases are usually more comprehensive than those accessible from home computers. The reference librarian is your best source of help for locating journals and resources.

Contacting Individual Researchers

Once you begin reading research reports, you may discover that a particular researcher has published articles in an area of interest to you. Most autism researchers are approachable and often are more than happy to provide reprints of their articles to interested parents.