Replacing the hospital water cooler

Despite what you may have seen on Grey’s Anatomy or ER, physicians have many other things to do at the hospital besides socializing with colleagues over who’s dating whom. In fact, the doctors’ lounge—in addition to being an oxymoron—is quickly becoming a thing of the past. Unfortunately, without trusted colleagues to turn to, many questions go unanswered and, perhaps more important, individual observations go unshared. So where do busy physicians go when they need a sounding board?

Now that social networking Web sites such as MySpace, Facebook, and Xanga have become household words, startup companies have formed with the sole purpose of serving the healthcare industry by providing physicians with online communities that allow them to make contacts that they would not have ordinarily made on their own. Yes, the typically technology-wary healthcare industry has followed suit on the social networking trend.

From drug potency to warts

“Where I use it most is as a sounding board,” says Cliff Geertz, MD, an office and ambulatory surgery–based physician who accesses the online community via Cambridge, MA–based Sermo (www.sermo.com). In fact, he was one of Sermo’s first members. Sermo completed alpha testing in summer 2006 and went to full, general availability in September. Site members post observations, create discussions, and write multiple choice survey questions based on a topic. Physicians can comment or vote on the question and even propose alternative answers to it. As doctors vote, they also raise the credibility of the observation based on how many other physicians corroborate it.

The system keeps track of the survey results, which allows doctors to return to the site to find out how the vote turned out and whether they share the consensus opinion.

“Sometimes I’ll get a strange case that’s not in the textbooks, or I don’t agree with what the textbooks have to say and I want to hear what other people think about it,” says Geertz.

In the past, Geertz has turned to Sermo to post messages about drugs his patients have used that he felt lacked potency to find out whether other physicians had similar experiences. And when his patients started complaining about the
effectiveness of a generic drug over its brand-name version, he again turned to Sermo.

“I wanted to see if anybody else was encountering the same problems,” says Geertz. “The [U.S. Food and Drug Administration] has MedWatch, and the problem is that that’s going to take months and years for anybody to really compile enough data. Here, I can acquire [information from] 10 other docs fairly quickly and I’ll hear what they think. You post your questions, and usually you’re going to get an answer within 24 to 72 hours.”

Sermo means “conversation” in Latin, and there certainly is no lack of conversations on the site. They can be serious, surprising, and sometimes a bit irreverent, as the tool lets physicians make any observations they want—which sometimes leads to some pretty interesting discussions.

“We’ve never removed a single thing on the site,” says Daniel Palestrant, MD, Sermo’s founder and CEO. “What we rely on is the wisdom of the crowds—the power of the physicians to decide what they see value in and what they don’t see value in.”

The community’s response to an observation made by a pediatrician in a small community recently surprised Palestrant. The pediatrician initiated a conversation about when to switch children from 2% to whole milk. Many physicians joined in on the heated debate, with those in family practice saying that whole milk predisposes children to obesity, and pediatricians saying that children need whole milk for growth.

“Sure enough, that has been one of the hottest topics on the site right now,” says Palestrant. “That’s clearly something that doctors are very interested in. JAMA [the Journal of the American Medical Association] is not going to publish an article on that, but clearly, it’s a very hot and relevant topic for physicians.”

Palestrant believes that physicians are beginning to believe that mainstream publications aren’t reflecting real world issues. “The things that I read about—while interesting and scientifically relevant and critical—aren’t what I’m dealing with on a day-to-day basis.”

Another conversation that generated a lot of interest was a running joke within the company, says Palestrant. It’s an ongoing debate about the use of duct tape to kill warts, and it has become a perennial hot topic, with one physician even speculating whether the treatment is billable.

**Conversation starter**

Palestrant was well on his way to starting this online community a year ago when he was a surgical resident in Boston. He was having back problems and decided to leave surgery. At the same time, he had been toying around with the idea of creating a social networking site for physicians.

He says that after he and his colleagues would read medical articles in The Wall Street Journal or JAMA, they would often remark to one another that they had known about the problem being reported on for a long time, or that it was something that had come up during grand rounds. It was then that Palestrant founded Sermo with its “Know more, know earlier” philosophy.

“We’re trying to tap into the power of individual observation,” says Palestrant. “We have come up with a technology where we can capture the types of clinical observations that clinicians are making all the time—at the bedside in the clinic, late at night, early in the morning. And we put this into a format where it becomes very potent information for improving patient care.”

**It’s a small (virtual) world after all**

Interestingly enough, Geertz doesn’t think of Sermo as social networking, but rather a substitute for the sidewalk consultations that physicians used to have at the hospital water cooler or the doctor’s lounge.

“Because more and more people are moving out of the hospital into private offices and surgery centers, there’s a need to replace the office water cooler,” says Geertz. “This substitutes for that. There is no other water cooler on the Web like this for docs.”

Geertz also appreciates that the tools can allow him to
communicate with other physicians regardless of their geographic location in the United States. “It will be a nationwide sampling,” says Geertz. “If you’re in a small community hospital, it’s not going to be the local chief of service answer. You’re going to get a very wide spectrum of answers from places like [Los Angeles], Portland, [OR], and New Orleans.”

“It’s sort of like the cross section of American physician zeitgeist,” says Palestrant. “It’s just an amazing look at what doctors are talking about.” Recently, Sermo conducted a survey of its members. It was surprised when it discovered that its heaviest users were physicians who had several years of career experience. After a few more surveys, it became clear that doctors were experiencing a sense of isolation resulting from a push toward outpatient medicine. “So, the usual points of discussion where doctors would talk with one another have evaporated,” says Palestrant. He speculates that younger physicians are more likely to be in urban environments and are still in a social circle with their friends from medical school. However, as physicians’ careers progress, they lose touch with these friends and replace them with others from the parent-teacher association or local fitness club. “They don’t have those normal opportunities to talk medicine,” says Palestrant. “That’s why I think older physicians seem to be particularly excited about Sermo.”

**Paying the bills with a new business model**

Palestrant says that Sermo uses an entirely new business model, which is what makes the site so unique. Sermo’s customers fall into three categories: financial institutions, industry, and government research. Their customers pay the company for the information the system generates.

The site, which does not charge physicians, also does not contain advertising, which can turn off physicians, Palestrant says. Sermo reimburses physicians for the information they provide, but doesn’t tell them what information is eligible for reimbursement in advance. At presstime, Sermo had 6,000 physician members, making it the largest online physician community, says Palestrant. He says that anywhere from four to 600 physicians join Sermo each week. A survey of one week’s worth of activity on the site revealed that physicians had spent over 800 hours on Sermo. Word of mouth, positive press coverage, their physician referral program, and e-mails containing interesting system content have helped boost the site’s popularity. There’s just one thing that Geertz is waiting for the Cantabrigians over at Sermo to do. “I wish these guys would go [initial public offering],” he says.

The rate at which physicians have embraced Sermo has staggered Palestrant. “Two or three years ago, my guess is that Sermo probably wouldn’t be as successful as it is now,” he says. “We really have caught this trend of social media exactly at the right time.”
A U.S. District Court sentenced Yvon Lafaye Hennings, 47, of Seattle to four months in prison for conspiracy to commit access device fraud and wire fraud, according to an Associated Press article.

Hennings had admitted to stealing credit card information from the medical billing firm at which she worked. The information was from patients who had recently seen physicians at a hospital emergency room.

**FDA investigating testing of wireless defibrillator**

A spokesperson for Minneapolis-based Medtronic, Inc., said the company “thoroughly investigated” allegations made by a former employee that the company didn’t test its wireless heart defibrillator properly before it was used on patients.

According to a *Star Tribune* article, the U.S. Food and Drug Administration (FDA) is investigating allegations made by Christopher Fuller, a former Medtronic employee, who made the claims about the company’s Concerto CRT-D device.

The FDA approved the device in May 2006. The device sends electrical impulses to the heart to resynchronize contractions of the lower chambers. It also transmits a patient’s data to physicians using wireless telemetry.

According to Medtronic, more than 75,000 patients had been treated with the device as of May 2006. The FDA is investigating patient injuries that are related to the device.

**Defendant guilty in identity theft case**

On January 24, a jury convicted Fernando Ferrer Jr. of an eight-count indictment, charging that he committed identity theft, wrongfully disclosed personal health information, and defrauded the United States government, according to a release from the U.S. Department of Justice.

Ferrer’s cousin, Isis Machado, has already pleaded guilty to one count of conspiracy to commit computer fraud, identity theft, and wrongful disclosure of individual health information in connection with her involvement in the case.

According to prosecutors, Machado used her position at the Cleveland Clinic to download the information of more than 1,000 patients from May 2005 to June 2006. She then sold the data to Ferrer, who used the stolen Social Security numbers, names, dates of birth, and Medicare numbers to submit approximately $7 million in false Medicare claims.

Ferrer faces a maximum of 30 years in prison. District Judge James Cohn will sentence him on April 27.

**AAFP encourages family physicians to use free e-prescribing software**

The American Academy of Family Physicians (AAFP) is encouraging family physicians to use free electronic prescribing software offered by the National ePrescribing Patient Safety Initiative (NEPSI). NEPSI is a coalition of technology and health benefits companies, academic medical centers, and healthcare delivery organizations.

A Web-based product called eRx NOW is available to any healthcare professional with legal authority to prescribe medications. It does not require download or new hardware and only requires minimal training. It was designed with solo physicians and small practices in mind.

A July 2006 Institute of Medicine (IOM) report attributed 1.5 million patient injuries each year to medication errors. The IOM has asked physicians in the United States to adopt e-prescribing by 2010.

For more information, visit www.nationalerx.com.
11,000 devices have been implanted, and no “adverse events” have been reported.

**Senate reintroduces drug safety legislation**

The Senate Health, Education, Labor, and Pensions Committee reintroduced the Enhancing Drug Safety and Innovation Act, which was first introduced in August 2006. The act would require drug makers and the U.S. Food and Drug Administration (FDA) to engage in better safety planning before a drug is approved for release to the public, while improving the FDA’s response to risks identified after a drug is on the market.

A key provision of the bill involves establishing a publicly available database of clinical trials. The database would enhance patient enrollment in clinical trials of drugs, provide a mechanism to track the trials, and ensure that the results are made public and that patients, doctors, and pharmacists have the most up-to-date information.

Senators Edward Kennedy (D–MA) and Mike Enzi (R–WY) both hope to have the legislation approved before the August recess.

**Healthcare company funds development of Dossia**

Cardinal Health of Dublin, OH, a provider of healthcare products and services, announced that it has become the sixth member of the Dossia Founders Group. Dossia is an organization that funds an independent nonprofit institute to develop “Dossia,” a Web-based framework in which U.S. employees, dependents, and retirees can maintain personal health records.

The Omnimedix Institute is the nonprofit organization responsible for developing Dossia. The system hopes to improve population health by facilitating preventive health measures and improving consumer communication with healthcare professionals.

The system also hopes to improve the efficiency and effectiveness of the U.S. healthcare system by reducing waste and duplication of efforts.

Cardinal Health is the first healthcare company to join Dossia, which was first announced in December 2006.

Other members include Applied Materials, BP America, Inc., Intel Corporation, Pitney Bowes, Inc., and Wal-Mart.

More than 2.5 million U.S. employees, dependents, and retirees of Cardinal Health, as well as fellow members of the Dossia Founders Group, will receive initial access to Dossia when it is launched. The launch is slated for mid-2007.

**Hawaii receives grant to develop EHRs**

The Hawaii Department of Human Services received a $3.18 million federal grant to develop an electronic healthcare records (EHR) system for rural clinics across the state, according to an article appearing in the Pacific Business News.

The two-year grant from the U.S. Department of Health and Human Services will be used to train community health clinics and doctors on how to use EHRs.

The University of Hawaii Telecommunications and Information Policy group will develop and operate the EHR system. Doctors will be able to use the system to access health records, preven-
tive care reminders, and medication information for patients using the Internet. The system will also allow doctors to e-prescribe.

The grant targets clinics that serve native Hawaiians and those on Medicaid. Four clinics on Oahu and two clinics on Kauai will be the first to use the system.

**McKesson acquires Per-Se Technologies, Inc.**

McKesson Corporation of San Francisco announced that it has successfully completed the previously announced acquisition of Per-Se Technologies, Inc., in an all-cash transaction. The acquisition adds nearly 6,000 employees and a customer base that includes 100,000 physicians in small practices, 17,000 hospital-affiliated physicians, 3,000 hospitals, and 50,000 retail and institutional pharmacies.

The acquisition gives McKesson the opportunity to combine the connectivity assets from both companies into a new business, known as RelayHealth. RelayHealth expands on McKesson’s physician-patient communications business with a focus on decreasing administrative costs and improving care by connecting physicians and other providers, pharmacies, payers, and consumers.

McKesson Corporation is ranked 16th on the Fortune 500.

**Hunterdon Medical Center to implement order set from Thomson Healthcare**

Thomson Healthcare of Greenwood Village, CO, announced that Hunterdon Medical Center, a 176-bed facility in Flemington, NJ, is implementing its order set solution.

The order set application helps a hospital’s performance management in the medication care delivery and disease management process by providing evidence-based recommendations.

The solution consists of an evidence-based library of order sets covering the most frequent hospital and emergency department diagnoses and procedures. The order set templates link to disease, lab, and drug referential information from Thomson Healthcare.

**Intel to create at-home health technologies for seniors in Ireland**

Intel Corporation of Santa Clara, CA, will set up a Technology Research for Independent Living (TRIL) Center in Ireland. The center, supported by the Industrial Development Agency of Ireland, will involve significant research capabilities to address the challenges of independent living for older people in Ireland.

Approximately $30 million will be invested in the center over a period of three years. Intel will collaborate with several Irish universities to create one of the largest research efforts of this type in the world.

Experts at the center will invent and test new technologies with older people and their families to support them in continuing to live independently. TRIL will focus on three key areas: improving social health and community engagement, detecting and preventing falls in the home, and helping those with memory loss to maintain their independence.

**Parco completes civilian RFID-enabled location tracking system installation**

Parco Wireless Corporation of Portland, ME, announced that it has completed the largest civilian ultra-wideband radio frequency identification
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New on the net

A laptop computer containing the personal information of more than 1,000 patients is missing from Salina (KS) Regional Health Center, according to an Associated Press article. The laptop contains patient names, Social Security numbers, and medical history.

The computer, other equipment, and a small amount of prescription drugs were stolen in early January. Hospital officials are offering a $2,000 reward for the return of the laptop. Meanwhile, they have sent letters to patients whose data are on the missing computer, advising them to let their financial institutions know about the threat and to be on alert for false charges.

The laptop was off when it was stolen, and the patients’ data are double-password protected, according to a hospital representative.

Cleveland Clinic demonstrates virtual visit during Arab Health

The Cleveland Clinic demonstrated its new Virtual Visit teleconsultation service for the first time during Arab Health 2007, a global healthcare exhibition in Dubai. The clinic already has an Internet-based second opinion service called eCleveland Clinic My Consult, which is made available to patients worldwide. The new teleconsultation service will allow real-time patient examinations using interactive live video technology, supported by its existing eCleveland Clinic Services.

New Web site offers consumers guidance on health supplements

PogoHealth, Inc., of Durham, NC, announced its first comprehensive online service offering consumers independent, individualized guidance on health supplements. The site includes tools such as personalized shopping lists, reports for personal physicians, and advisories on supplement interactions with prescription drugs. PogoHealth.com offers services for healthcare professionals and consumers.

PogoHealth offers a free basic report, a one-time purchase of personalized reports, and continuous subscription services. The free service includes nutritional evaluations and recommendations of essential nutrients on selected personal characteristics, such as gender.

The one-time report costs $19.95. Monthly subscriptions are $29.95, semiannual subscriptions are $59.95, and annual subscriptions are $69.95.

States receive $103 million in HHS grants

U.S. Department of Health and Human Services (HHS) Secretary Mike Leavitt awarded $103 million to 27 states to fund implementation of new ways to improve Medicaid efficiency, economy, and quality of care. The states will use the funds to implement innovative systems to get more value out of the money they spend providing healthcare to their low-income elderly, children, and disabled citizens.

The funds will support more widespread use of electronic health records that can be accessed by treatment teams.

No matching funds are required for these special grants.

Wisconsin governor includes EMR adoption in budget proposal

Wisconsin Governor Jim Doyle announced that his budget will include $30 million to increase the use of electronic medical records (EMR) systems, reducing medical errors, improving safety, and decreasing healthcare costs.

The proposal will include $20 million for the creation of an eHealth grant program, $10 million in tax credits for businesses that implement eHealth initiatives, and funding for the Wisconsin eHealth Care Quality and Patient Safety Board.

Pennsylvania hospital installs electronic medication administration system

Mercy Hospital of Philadelphia is installing a $1 million electronic (RFID)–enabled location tracking installation in the world at Washington Hospital Center in Washington, DC. The system covers 2.5 million square feet at the 926-bed facility.

The RFID project addresses the daily tracking and location needs of a major tertiary medical center, enhances the hospital’s emergency response capabilities, and explores innovative analysis and application of the collected information.

Parco has installed its patient and asset tracking systems throughout the entire hospital. When operational, the system will provide subroom accuracy and realtime reporting facilitywide.
medication administration system in March, according to an article in The Times Tribune of Scranton, PA.

The move will put the hospital in early compliance with Pennsylvania Governor Ed Rendell’s “Prescription for Pennsylvania.” Among the anticipated mandates in the healthcare reform package is the adoption of quality management and error-reduction systems.

Mercy representative John Howells said the hospital’s new computerized system would help ensure that hospital personnel are “giving the right medication to the right patient in the right dosage at the right time.”

The system starts working when a doctor orders medication for a patient. The pharmacy enters the information into the system, validates the order, and fills it. From there, the medication goes into the medication cart for delivery.

Then, a nurse scans a bar code on the package to ensure that it is the correct medication in the correct dosage for the patient. A final check happens when the nurse scans the bar code on the patient’s wristband. The system flags any problems.

### Hospital reports lost data

St. Mary’s Hospital in Leonard-town, MD, has notified up to 130,000 former and current patients that a laptop with personal information was stolen from the facility.

According to an article in The Baltimore Sun, the information was stolen in December 2006.

The computer contained the names, Social Security numbers, and birth dates of patients treated by the hospital as long ago as 1989.

The data, which were not encrypted, did not include medical or financial information.

The laptop was used to register patients as they arrived for treatment. It was taken from a treatment area accessible to the public.

The hospital is working with a firm specializing in identity theft cases to help patients keep track of their personal information, such as credit card usage and patterns. The service will be free to patients.

### Man sentenced to six years for identity theft

U.S. District Judge Ricardo Martinez sentenced admitted heroin addict James Leroy Henderson, 62, to more than six years in prison for stealing the identities of patients at Virginia Mason Medical Center in Seattle.

According to an article in the Seattle Post-Intelligencer, the judge also ordered Henderson to pay $120,125 in restitution.

Henderson had pled guilty in October 2006 to bank fraud and aggravated identity theft. Authorities caught up with Henderson when he was arrested at gunpoint in 2006 after attempting to steal $6,000 from a Washington Mutual branch office in Ballard, WA.

It was then that investigators discovered that the Des Moines man had stolen the identities of 12 customers at five banks.
Social psychologists create a circle of friends

More often than not, physician entrepreneurs are the founders of the healthcare startup companies featured in Medicine on the ‘Net, but that’s not true in the case of Lansdale, PA–based MyMedwork (www.mymedwork.com). Three social psychologists trained to examine people’s interactions with others, as well as with the social environment, founded the online social networking company for physicians and researchers.

“I think the fact that they have real research experience and knowledge in this area helps fine-tune the site,” says Luo. “I think having that background is an advantage.”

I’ve got people

The site’s major theme is that of connectivity: Getting people connected to people to get the information they need and, more important, finding that information from the people who they know and trust.

“You use your network of people you know as a filter to keep out bad information and bring in good information,” says Markus.

The site works similar to LinkedIn (www.linkedin.com). Colleagues, institution associations, or alumni groups can invite new members to join. Then, each physician or researcher can begin building his or her own community. Currently, the company is building its base by working with healthcare centers and large physician groups.

“Within a healthcare institution with 1,800 physicians, most physicians and researchers only know the colleagues who they see on a day-to-day basis,” says Markus. People can only manage about 150 relationships, he says, but with technology such as MyMedwork, people have the potential to manage many more.

Luo is in the process of persuading the large UCLA healthcare system to use the tool. “I've actually spoken to a lot of doctors at the UCLA main campus, but I've never met them,” he says. “I think this is one thing that could help make an impact at creating a social presence.”

The site can also be helpful to small organizations, Luo adds. They can use the tool to create a forum to communicate with members and eliminate communication methods such as listservs or bulk e-mails.

In addition to building a strong referral network, members also increase their visibility and the opportunities that they may find through their colleagues, says Markus.

“For me, if I want to network, it gets difficult,” says Luo, who is interested in medical informatics. “Using professional sites like MyMedwork enables me to reach out and connect to other people in my field who are not necessarily psychiatrists.”

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Another area in which members have used the tool effectively is within the research community. Markus says the site helps researchers highlight their work with others. Clinical researchers can use the site to find other primary investigators and patients who can participate in their clinical trials.

“We’re using the community and tools that we can provide to get the word out to find people who meet certain criteria,” says Markus.

The company’s current business model is to charge healthcare systems with large physician and research groups subscription or yearly fees. The company charges per user or group. Markus says the amount is relatively small, but that it covers the company’s cost of operating the site. It has both basic and premium features that are in development.

Markus says that the trend toward niche social networking sites is likely to continue. “It’s a good thing,” he says. “The best information is found through people we know and trust or through our colleagues.”

In the future, MyMedwork plans to integrate with third-party applications, such as billing and electronic medical records systems, to provide members with one fluid system.

Luo, a self-described geek who is addicted to gadgets, says he has to prompt his wary colleagues to check out the site by educating them on what it has the power to accomplish.

He says physicians may be hesitant to use social networking sites because they don’t know how they are going to use it or why they need it. The negative media coverage of popular sites such as MySpace and Facebook hasn’t improved his sales pitch, either.

“MyMedwork is growing larger, but it’s an organic process, and it’s still a question of time,” says Luo. “My hope is that more and more physicians will use it and be less reluctant to resist adopting technology.”

Test driving the social search engine

The site contains what Markus calls a “social search engine” for healthcare professionals. It lets members search for information within their own interpersonal network. Markus says that whereas search engines such as Google return the same search results regardless of who is searching, MyMedwork allows members to have a personalized search experience.

“If I log in to MyMedwork as a physician or researcher and type in ‘ovarian cancer,’ the information that comes back is based on my unique perspective in the network based on the people I know and the people they know for each person,” says Markus. “All of us have personalized search results. We’re reorganizing healthcare information no matter where it exists.”

Building a social network with staying power

S.M.A.R.T. Link Medical, Inc., which owns MyMedwork, is a portfolio company of BioEnterprise, a nonprofit business accelerator chartered by the Cleveland Clinic, Case-Western Reserve University in Cleveland, University Hospitals, and Summa Health Care.

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SITE OF THE MONTH

Organization for Autism Research
www.researchautism.org

Created in 2001 by parents and grandparents of children and adults with autism, the Organization for Autism Research (OAR) of Arlington, VA, uses science to answer questions that parents, families, individuals with autism, teachers, and caregivers commonly ask. The organization focuses exclusively on applied research.

At first glance, the site itself is visually appealing and well-organized. Users will have no problem at all navigating through its rich contents.

It also has separate areas for family and friends, educators, service providers, and professionals.

Let’s take a moment to look at the features it has to offer.

Within the Family & Friends section of the site, you’ll find an abundance of both basic and in-depth information about the disorder, the diagnostic process, the intervention process, research, and resources for family members.

And, if you find something worth sharing, you can even print and e-mail pages to others.

The Educators & Service Providers page contains valuable information to help teachers and service providers assimilate those with autism spectrum disorders into the classroom while, at the same time, balancing the needs of the student.

Similar to the Family & Friends section, this section also contains information about understanding autism aimed at educators.

Educators can use the site’s guide to help prepare for the entrance of a child with autism into the classroom. Another guide helps educators prepare for the entrance of a child with Asperger’s Syndrome.

Parents and educators alike will be interested in this section’s Individualized Education Programs content, which discusses how to implement a program for a student.

Another handy resource is the Worksheets section, which contains useful forms and worksheets, including an individual education plan calendar, questions to ask parents, transition considerations, and parent-teacher communications.

The Professionals page contains information about funded studies, research grants, and the organization’s research convocation topics.

Users can also post their own research announcements on the Web site.

Other features on the site include a Resources section and a News & Events section.

The Resources section is particularly helpful. It contains an autism forum, a searchable database of autism organizations, a newsletter archive, a list of recommended reading, and links to external sites.

The News & Events section contains information about OAR programs, fundraising events, and community events. It also contains press releases about the organization’s events and findings.

The site is free, but it does accept online donations. Users can click on the Subscribe to E-News link on the Home Page to receive updates about research and events.

Questions? Comments? Ideas?
Contact Managing Editor Maureen Larkin

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Focus: Autism spectrum disorder resources

Before the 1960s, physicians thought that those living with autism were schizophrenic or that they were the result of poor parenting.

In fact, it wasn’t until the 1960s that people began understanding the disorder and identifying its symptoms and treatments effectively. Researchers still have much to learn about this puzzling disorder. But, luckily, many organizations, foundations, and others have published sites aimed at raising awareness about the disorder and connecting people to appropriate resources.

According to recently released Centers for Disease Control and Prevention statistics, the average prevalence rates for autism spectrum disorders was 6.7 per 1,000 for eight-year-olds in 2000 and 6.6 per 1,000 eight-year-olds in 2002 in several areas of the United States. That is about one in every 150 children in these communities. Many sites allow parents and caregivers to connect with one another in online support communities. Autism Pervasive Developmental Disorders Support Network (www.autism-pdd.net) is one such site that provides this service. It houses both support forums and message boards on which users can post questions and connect with others.

If you are looking for research information about the disorder, visit the Autism Research Institute site (www.autismwebsite.com), which contains information about research studies on topics such as thimerosal and mumps, measles, and rubella vaccinations. This site also has a handy Microsoft Excel spreadsheet that parents can use to track the progress of their autistic child.

For a reading list of autism books, look no further than the Autism Resources site (www.autism-resources.com). Its Book Information section contains an exhaustive list of autism-related books categorized by nonfiction, fiction, books for children, and books of interest.

If you’d rather sit back and watch to gain information about autism, visit Autism TV (www.up-to-date.com/autism.tv/index.html). It contains links to television channels containing information about the disorder. The site includes links to audio channels as well.

Last, the newly launched Healing Thresholds site (http://autism.healingthresholds.com) connects parents to scientific and health information about autism. The majority of the sites offer content free of charge, with only a few sites reserved for members only. A number of sites provide information in a variety of languages.

Several autism spectrum disorder resource sites are described and reviewed in the following pages, as listed in the index below, using the five-star system to rate each on content, interface, and style.

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American Academy of Pediatrics: Autism
www.aap.org/healthtopics/autism.cfm

Ratings: Content: **** Interface: **** Style: ****

This is the go-to site if you want to find out how an organization of 60,000 pediatricians addresses autism spectrum disorders. You can find the topic within the site’s Children’s Health Topics section. The site contains a definition of autism, as well as the following features:

- Guidelines adapted from American Academy of Pediatrics (AAP) and American Academy of Neurology policy statements
- Fact sheets
- Developmental, autism, and audiological screening guidelines
- Publications marketed to healthcare professionals, such as the “First Signs Screening Kit”
- Links to archived symposiums and Webcasts
- A Microsoft PowerPoint presentation titled “Autism Spectrum Disorders: Communication and Language”
- AAP Council on Children with Disabilities reports

Other resources on the site include information about Autism Awareness Month, public awareness campaigns, and links to external sites.

Unique elements: Under the AAP Policy heading, users will find a policy statement and a technical report on the role of the pediatrician in the diagnosis and management of autistic spectrum disorder in children.

Comments: Users can purchase academy publications, including Understanding Autism Spectrum Disorders and Is Your One-Year Old Communicating with You, on the site.

Cost: Free. However, some of the publications can only be viewed if purchased.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, American Academy of Pediatrics, AAP.

Autism and PDD Support Network
www.autism-pdd.net

Ratings: Content: **** Interface: **** Style: ****

The Autism PDD (pervasive developmental disorders) Support Network is an information and resource site aimed at the parents and caregivers of children with autism.

The organization describes itself as an “online support community.”

The Home Page contains information about autism as a disorder, such as what it is and how physicians diagnose children. Along the left-hand side of the page, users will find links to information about the history of the disorder, other spectrum disorders, research, and recommended books.

Click on the What is Autism? link for information about symptoms, causes, research information, and other disorders on the spectrum.

The Diagnosing Autism link takes users to information about the characteristics listed in the Diagnostic and Statistical Manual of Mental Disorders that healthcare professionals use to diagnose the disorder.

The Autism Resources section of the site is quite com-
prehensives. It categorizes links to resources, such as legal resources, school and college assistance, financial planning, state resources, disability resources, and more.

What truly makes this site an “online support community” are the support forums and message boards. Users typically post questions on the message boards to make friends with others. The services are free.

Unique elements: The Tell Your Autism Story Here section of the site is another tool that lets users reach out to others by sharing their experiences with the community.

Comments: The site posts information about upcoming autism conferences, workshops, and events.

Cost: Free.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, pervasive developmental disorders, PDD, AutismInfo.

**AutismInfo**

**www.autisminfo.com**

**Ratings:** Content: ***** Interface: *** Style: ***

Founded in November 1998, Merrit Island, FL–based AutismInfo.com is “dedicated to providing current and useful information on autism.” The goal of the organization is to provide parents, especially those of newly diagnosed children, with information about the disorder.

The site itself contains a lot of text and links, but if you can get beyond its visual appearance, you’ll find a plenitude of information. The best place to begin navigating the site is through the links at the top of the page. The Home Page also contains links to important external resources running along the left-hand side of the page. For those looking for information about the disorder, click on the What is Autism? and the Quick Facts About Autism links. They will provide you with an abundance of basic and in-depth information on the disorder, including highlighting some of the disorder’s markers such as odd behaviors and sensory dysfunction.

If you are looking for information about how nutrition and diet can help treat autism, click on the Diet and Autism link. It contains information about the various approaches used to treat the disorder through diet restriction and supplements. You’ll also find helpful links to articles and sites with related information.

A must-visit section of this site is the Action Plan for Parents with Newly Diagnosed Kids. It is a step-by-step list of action items aimed at parents. Sample items from the action plan include autism testing, therapy, and education.

This site contains an abundance of resources, including an alphabetized resource list, a state-by-state resource, and another containing links to applied behavioral analysis resources. Other resources on the site include a news archive, newsletter and catalog information, and a list of upcoming conferences, to name a few.

Unique elements: Click on the Booklist link to view the site’s Top 10 list of autism books, including *Thinking in Pictures* by Temple Grandin and *The Out-of-Sync Child* by Carol Stock Kranowitz. The site also categorizes other books, such as those containing therapy-related information.

Comments: Users can translate the site into Chinese, Spanish, French, Portuguese, German, Japanese, Italian, or Korean.

Cost: Free.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, AutismInfo.
working with autistic children—to resources, support, and research information. Starting with the Home Page, the site has featured products that it promotes, such as videos and educational materials. From the Home Page, users can select from seven tabs to find out more about the organization and the site’s content. The What is Autism? link contains an overview containing facts and links to helpful booklets published by the likes of the National Institutes of Mental Health. This area also contains an interesting twist on an overview by including a section called What Autism is Not, which serves to debunk myths about the disorder. Users can also learn more about how healthcare professionals diagnose autism, including the diagnostic criteria for autism, and the autism in toddlers checklist.

The site contains a handy conference search engine that lets users search for conferences based on date and location. Lastly, users will want to check out the list of resources on the site, which includes links to both international and domestic organizations. And, for those still looking for more, check out the Research tab to read about recently published research on the disorder.

Unique elements: The Products tab on the site contains the majority of what users would flock to this site for—links to books, videos, software, teaching aids, and much more.

Comments: The site promotes the fact that it contains products that are available in a variety of languages, such as Spanish, Turkish, Arabic, and Korean. The site also contains information about autism in a variety of languages.

Cost: Free.

RSS XML Link: None.

Keywords: autism, autism products, autism spectrum disorders, Autism Online, AO.

**Autism Research Institute**

www.autismwebsite.com

**Ratings:**

- **Content:** *****
- **Interface:** ***
- **Style:** ***

Established in 1967, the San Diego–based Autism Research Institute is part of a movement that believes that healthcare professionals can treat autism and related disorders through intensive behavior modification and individualized biomedical treatments. The recently deceased director of the institute, Bernard Rimland, PhD, is considered by many to be the “father of modern autism research.” The institute provides free and low-cost information to parents and healthcare professionals by mail and on its Web site.

The Intro page contains several sections of interest to visitors. The What is Autism? link contains a description of the disorder that includes facts, causal information, and a brief paragraph on the outlook for those living with the disorder. This area also contains an article containing advice for parents of young children. Experts in the field wrote this article, which is the site’s hidden gem. It contains a lengthy explanation of the disorder and discusses key topics such as genetics, speech development, cooccurring conditions, and much more. Lastly, this area contains a diagnostic checklist and research questionnaire. For those who want to understand more about the role that vaccines may or may not play in relation to autism, click on the site’s Vaccines link. It contains articles about vaccinations and heavy metals.

Other resources on the site include audio and video conference presentations, editorials, a newsletter, and more.

**Unique elements:** The site’s Research page contains a compilation of research studies on topics such as thimerosal and measles, mumps, and rubella.

**Comments:** The site contains a Microsoft Excel spreadsheet aimed at helping parents track the progress of their autistic child. Click on the DAN! (Defeat Autism Now!) link and then select the link under the For Parents heading.

Cost: Free. The site accepts online donations and also hosts an online store.
RSS XML Link: None.
Keywords: autism, autism research, autism spectrum disorders, Autism Research Institute, ARI.

**Autism Resources**  
[www.autism-resources.com](http://www.autism-resources.com)

Ratings:  
Content: ***** Interface: **** Style: ****

Created by John Wobus, the father of a child with autism, the Autism Resources site contains links to information about autism and Asperger's Syndrome. The Links section contains an indexed list of links to autism-related Web sites, including links to sites with information about treatment options and those dedicated to Asperger's Syndrome.

Another useful area on this site is the Frequently Asked Questions section. It contains information contributed by users, such as a glossary of terms and acronyms, books, organizations, initiatives, and much more. Parents of the newly diagnosed should visit this site's Advice section. It contains information written by parents who have raised autistic children, and includes information such as helpful lessons learned.

**Unique elements:** Before you head to the library to arm yourself with information, visit this site's Book Information section. It contains a list of autism-related books categorized by nonfiction, fiction, books for children, and books of interest. Users can browse the books by full list, topic, genre, year, author, and much more. Once you find titles of interest, visit the library to check them out.

**Comments:** This site is well-organized and well-categorized for one containing such an abundance of information.

Cost: Free.
Keywords: autism, autism spectrum disorders, autism resources, Autism Resources.

**Autism Speaks**  
[www.autismspeaks.org](http://www.autismspeaks.org)

Ratings:  
Content: ***** Interface: **** Style: ****

After doctors diagnosed their grandson with autism, Suzanne and Bob Wright cofounded the New York City–based Autism Speaks organization to help find a cure for autism by raising funds to help speed up research, raise public awareness of autism, and provide support to those suffering from the disorder.

The Be Informed page is a great place for those looking for basic information about the disorder. This overview also goes beyond the basics to deliver expert interviews, facts, videos, an interactive quiz, and more.

In the How to Cope section, users can find information about coping strategies as well as legal rights. In the How to Grow with It section, users can read about the impact the disorder has on the lives of teens and adults.

Other resources on the site include event listings, news briefs, advocacy information, and a calendar of events.

**Unique elements:** The site contains a video series with news clips on the topic of autism from TV programs such as The Today Show. Sample videos include When Early Intervention Works and What Causes Autism?

**Comments:** The site Resources page contains a helpful list of autism organizations.

Cost: Free. The site accepts online donations and also hosts an online store.
Keywords: autism, autism spectrum disorders, Autism Speaks.

**Autism Today**  
[www.autismtoday.com](http://www.autismtoday.com)

Ratings:  
Content: *** Interface: *** Style: ****

Founded in 1996, the Autism Today Web site bills itself as containing “everything you need to know about autism.” It is an online directory of the programs and services offered by professionals, schools, camps, recreational programs, and others.

By signing up for the site's free membership, you can access the Article Library, which contains an archive of more articles on all aspects of autism.

Keywords: autism, autism spectrum disorders, Autism Today.
than 5,000 articles. The section lists articles chronologically by publication date. Other resources on the site include a list of upcoming conferences and links to external sites.

**Unique elements:** The site hosts an online education series that consists of a series of courses that address autism issues. Courses are up to two and a half hours in length and cost $49.97. Available courses include “Early Intervention for the Autistic Child” and “What’s New in the World of Autism” by Dr. Temple Grandin.

**Comments:** The site contains an Ask the Experts feature.

**Cost:** Free. Membership is free and offers users access to additional features such as a free newsletter. The site also has an online store.

**RSS XML Link:** None.

**Keywords:** autism, autism spectrum disorders, Autism Today.

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**Autism TV**

**www.autism.tv**

**Ratings:** Content: **** Interface: ***** Style: *****

Sponsored by the Autism Research Institute and the Center for the Study of Autism, Autism TV contains links to television and audio channels containing information about the disorder. Following is a sampling of the television channels:

- Foundation for Autism Information and Research, Inc.
- Dan Marino’s Child Nett
- Autism Technology
- Defeat Autism Now! Conference

**Comments:** The directory of television and audio channels alone make this site one of a kind.

**Cost:** Free. Users can submit links to their sites for inclusion on the Autism.tv site.

**RSS XML Link:** None.

**Keywords:** autism, autism spectrum disorders, autism television, autism audio, Autism TV.

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**CDC: Autism Information Center**

**www.cdc.gov/ncbddd/autism/index.htm**

**Ratings:** Content: **** Interface: ***** Style: *****

The Centers for Disease Control and Prevention (CDC) hosts an Autism Information Center. The site provides a wealth of information and resources. It’s a great starting point for anyone looking for autism information on the Internet.

Click on the About Autism link to find out more about autism spectrum disorders (ASD).

Here, users will find basic information as well as content that addresses specific topics, such as the symptoms of ASDs, vaccines, and early detection.
This is a great place to go if you are interested in knowing more about the CDC’s research on vaccines and autism to determine whether experts can link the Measles, Mumps, and Rubella vaccine to the disorder.

The site’s Resources page contains a list of resources for families and researchers alike.

The San Diego–based Center for the Study of Autism provides information about autism to parents and healthcare professionals. The organization also conducts research on the efficacy of various therapeutic interventions. They collaborate with the Autism Research Institute of San Diego—a site also included in this month’s list of site reviews.

What’s great about this site is that it contains information about autism subgroups and related disorders, such as Fragile X Syndrome, Asperger’s Syndrome, and Prader-Willi Syndrome.

Another great feature of this site is the Issues section, which contains content about autism-related issues, such as advice for parents, social behaviors, treating self-injurious behavior, and learning styles to name just a few.

The Interventions section contains a great deal of information about therapies that have worked well for those living with the disorder. Some of the interventions mentioned include Temple Grandin’s Hug Machine, music therapy, exercise, and sensory integration.

Users should take the time to visit the Exclusive Interviews section. It contains interviews with renowned autism experts on topics such as Visual Perceptual Problems and Sensory Integration.

Other resources on the site include links to external sites.

**Unique elements:** The site has a one-of-a-kind Sibling Center. Here, users will find information on topics such as sibling needs, playtime, and opportunities available to brothers and sisters of those suffering from autism.

The former can locate programs about ASDs, and the latter can find out more about federal funding opportunities.

Another terrific resource on the CDC site is the ability to search the National Center on Birth Defects and Developmental Disabilities database for publications related to autism.

**Unique elements:** The site contains a search engine that lets users look for programs that the CDC funds in individual states.

**Comments:** Click on the CDC activities link to learn more about CDC autism projects. The Other Federal Activities link contains information about other federal activities related to ASDs, such as the Coalition for Autism Research and Education.

**Cost:** Free.

**RSS XML Link:** None.

**Keywords:** autism, autism spectrum disorders, Centers for Disease Control and Prevention, CDC.
Comments: The site provides an overview of the disorder in six different languages.
Cost: Free.
RSS XML Link: None.
Keywords: autism, autism spectrum disorders, Center for the Study of Autism.

Cure Autism Now Foundation
www.cureautismnow.org
Ratings: Content: **** Interface: **** Style: ****

Founded in 1995, Cure Autism Now (CAN) is an organization of parents, clinicians, and scientists working to accelerate the pace of biomedical research in autism by raising money for research projects, education, and outreach.

The Research section contains a list of CAN science programs, such as their Environmental Factors in Autism Initiative and the Biomarker Initiative. Users can click on a program to find out more. This section also contains information aimed at the community, such as a Web-based list of clinical trials, and information aimed at researchers, such as information about how to apply for CAN-sponsored grants.

The Government Affairs section houses the organization’s position statements, bills, news, and updates. The organization also details how users can support their causes.

Other resources on the site include a list of events, local chapter information, and an online store.

Unique elements: The Resources page contains information about online resources and books, as well as a resource directory that lets users locate professionals, services, products, and information related to autism.

Comments: The site contains many publications that users can download on the spot. They are located within the About Us section of the site.
Cost: Free. To join the organization’s mailing list, click the Get eNewsletter link at the top of the Home Page. The site accepts online donations.
RSS XML Link: None.
Keywords: autism, autism spectrum disorders, Cure Autism Now, CAN.

The Dan Marino Foundation
www.danmarinofoundation.org
Ratings: Content: *** Interface: ***** Style: ****

Founded in 1992 by football great Dan Marino and his wife Claire (parents of an autistic son), the Dan Marino Foundation supports medical research, treatment, and outreach programs for children with chronic illnesses and developmental disabilities such as autism. The foundation supports the Marino Autism Research Institute, which works to accelerate the discovery of new strategies to understand, treat, and prevent autism.

This site contains the following features:
» Information about the Miami Children’s Hospital Dan Marino Center, an integrated neurodevelopmental center
» A free Web TV channel called www.Childnett.tv dedicated to autism and other neurodevelopmental disorders
» Funding and grant information
» Event and sponsorship information
Unique elements: Users can view films, including one about the Marino Autism Research Institute.

Comments: To date, the site has raised an impressive $20 million to provide research, treatment programs, and outreach services to children.

Cost: Free. The site accepts online donations.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, autism foundations, The Dan Marino Foundation.

Healing Thresholds
http://autism.healingthresholds.com

Ratings: Content: ***** Interface: ***** Style: *****

Healing Thresholds, a not-for-profit organization, works to connect parents to scientific and health information about autism. Resources on the site include therapy fact sheets, research summaries, news summaries, and a community center. This site is especially visually appealing, containing black and white photographs of autistic children by Thomas Balsamo, a Chicago-based photographer.

To explore the site at a high level, users may opt to click the Tour the Site link located within the About Us section. Following are some of the site’s key features:

- Summarized news articles on autism therapy.
- A Community Center that lets users share stories, learn from other parents, and document their experiences. This area also includes private messaging that lets users know which other members are online at the same time.
- Blogs, forums, stories of hope, and a wiki (technology that lets users create and edit Web page content) on the topic of collective wisdom.

Unique elements: The Collective Wisdom Wiki section lets users contribute to general information, resources, and treatment protocol entries.

Comments: The site includes an FAQ section and a comprehensive, alphabetized glossary of terms.

Cost: Free. Users can sign up through the site to receive new research summaries by e-mail.


Keywords: autism, autism spectrum disorders, autism therapies, HealingThresholds.

International Rett Syndrome Association
www.rettsyndrome.org

Ratings: Content: **** Interface: **** Style: ****

Because children living with Rett Syndrome exhibit autistic-like behaviors, we have chosen to include the International Rett Syndrome Association site for your consideration. The association supports research, increases public awareness of Rett Syndrome, and provides information and emotional support to families and children with Rett syndrome.

The Home Page quick links make this site easy to navigate. Using the quick links, you can read a Rett Syndrome FAQ, find out about diagnostics, and more.

Key features of this site include the following:

- Rett syndrome facts
- A glossary of terms
- A Medical Issues section containing information about diagnostics, general symptoms, seizures and epilepsy, and other topics
- Links to pharmaceutical sites, symptom sites, and government information
- Research opportunities
- An international patient database containing vital statistics about cases of Rett syndrome
- Research findings
Unique elements: The site's Family Support Center contains information aimed at family members of those living with Rett syndrome. It contains information to help those coping with Rett syndrome through every part of life, such as toilet training, bathing, lifting, and puberty.

Comments: The site contains links to services and resources as well as regional representatives.

Cost: Membership rates vary from $30 to $500 (lifetime membership). Member benefits include a quarterly newsletter, discounts, and special conference rates. The site accepts online donations.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, National Institutes of Health, NIH, National Institute of Child Health & Human Development, NICHD.

National Autism Association
www.nationalautismassociation.org

Ratings: Content: **** Interface: **** Style: ****

The Nixa, MO–based National Autism Association works to educate and empower families affected by autism and other neurological disorders.

It is a not-for-profit organization founded by parents of children with autism and related disorders. The association wants to raise awareness about the environmental toxins that they feel are causative factors in neurological damage that results in autism or related diagnoses. The All About Autism area contains an overview, definitions, causes, diagnosis, treatment, autism and safety, and autism myths. It's a great place to start for those who are just beginning to learn more about the disorder. The Causes section provides information on the latest theories, such as vaccines, genetics, and environmental causes.

The Diagnosis section contains the diagnostic criteria that patients must meet to be diagnosed with autism. The Treatments option contains links to information about behavior modification, sensory integration dysfunction, occupational therapy, speech therapy, music therapy, and much more.

Other resources on the site include links to other resources, research information, a Grassroots Center, message boards, event information, and an online gallery of poetry, photos, videos, and articles.

Unique elements: Users can download a Microsoft PowerPoint presentation called “Destroying the Myths of Autism.” You can use the presentation to help raise awareness of Autism and related disorders. You can find the presentation in the All About Autism: Myths of Autism section.

Comments: Users can subscribe to the site's mailing list from the Home Page.

Cost: Free. Members receive benefits such as discounted products, e-newsletters, and free merchandise. The site also accepts online donations and has an online store.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, National Autism Association, NAA.

National Dissemination Center for Children with Disabilities
www.nichcy.org/resources/autism.asp

Ratings: Content: **** Interface: *** Style: ***

The National Dissemination Center for Children with Disabilities is a not-for-profit organization that provides information and resources to families, educators, and professionals working with children with disabilities. The site contains a variety of resources, including information on Rett syndrome, along with links to other websites and organizations that deal with disabilities.

Comments: The site is well-organized and easy to use. It contains a wealth of information on Rett syndrome, including descriptions of the syndrome, causes, symptoms, and treatment options. The site also includes links to other websites and organizations that deal with disabilities.

Cost: Free.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, National Dissemination Center for Children with Disabilities.
Disabilities has a health topic dedicated to autism on their Connections page. The Connections page puts users in touch with information on the Internet, making it a type of directory. Users can opt to print out all 11 pages in their entirety, but the site also has a Table of Contents that essentially serves as a list of quick links. The autism page is part of a “suite” of pages on disorders along the autism spectrum.

Unique elements: The site links users to sites that address educational issues, including the individualized education program process.

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**National Institutes of Health: Autism Spectrum Disorders**

www.nichd.nih.gov/health/topics/asd.cfm

Ratings: Content: **** Interface: **** Style: ****

The National Institute of Child & Human Development, a division of the National Institutes of Health, has a section of its site dedicated to autism spectrum disorders as one of the health and human development topics that it tackles.

The site contains a working definition of autism and autism spectrum disorder.

It also contains a list of the main signs and symptoms of the disorder by placing them into the following areas: communication, social, and routines or repetitive behavior.

From there, the site goes on to list some of the treatments that trained professionals have used for autism to minimize symptoms and maximize learning. These treatments include behavioral therapy, school-based therapy, and medication.

Other resources on the site include links to external resources, clinical trials, news releases, and related Web sites.

Comments: The site contains links to the following topics:

**What is Autism?**, Research on Autism, Organizations That Can Help, and more. There are also links available in Spanish.

Cost: Free.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, National Institute of Child & Human Development, NICHD.

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**Online Asperger Syndrome Information & Support**

www.aspergersyndrome.org

Ratings: Content: **** Interface: ** Style: ***

The Online Asperger Syndrome Information and Support (OASIS) organization publishes a popular guide to Asperger Syndrome.

Asperger Syndrome is a neurobiological disorder. Individuals with Asperger Syndrome have deficiencies in social skills, difficulties with transitions or changes, and prefer sameness.
They often have obsessive routines and are interested in particular subjects. Those with Asperger Syndrome often also suffer from sensory dysfunction. Key features of this site include the following:

» Message boards and chat room support forums (registration required).
» Information about Asperger Syndrome written by the Web site founder and coauthor of *The OASIS Guide to Asperger Syndrome*.
» Research papers and descriptions of Asperger Syndrome, some of which have been translated into other languages.
» Information for those involved in the educational aspects of helping children with Asperger Syndrome. This section includes teaching tips, legal information, links to other resources, and more.
» Support group information, both local and international.
» Diagnostic rating scales.
» Information on related disorders, such as nonverbal learning disorders and pervasive developmental disorders.
» Advice for developing social skills, such as how to run a social group.

Other resources on the site include resources for adults with Asperger Syndrome, event information, newsletters, ongoing research projects, and more.

**Unique elements:** The site’s Kid’s Corner contains Web pages developed by children and adolescents about Asperger Syndrome.

**Comments:** The site contains a wealth of information; however, much of it is hard to find because of the site’s cumbersome navigation.

**Cost:** Free. The site contains an online bookstore with recommended resources for Asperger Syndrome and other related diagnoses.

The site also accepts online donations.

**RSS XML Link:** None.

**Keywords:** autism spectrum disorders, Asperger Syndrome, Online Asperger Syndrome Information and Support, OASIS.

**Pathfinders for Autism**

www.pathfindersforautism.org

**Ratings:** Content: ***** Interface: ***** Style: *****

Founded in 2000 by parents of children with autism, Pathfinders for Autism of Baltimore is a nonprofit organization that supports and develops services, raises funds for research, and provides information for families of children with autism. The goal of the organization is to improve awareness, ensure early detection and intervention, provide information and resources, expand the availability of lifespan services, and increase the number of trained professionals.

The About Autism link takes users to information about the disorder, research, public policy, and links to external sites. The Research section contains a list of research studies looking for participants. The Public Policy section highlights the major legislation in the field of autism. The Links section contains links to resources in Maryland, national resources, and regional organizations.

The Resources section includes a Maryland provider search tool, a list of therapies, services in Maryland, articles, a book list, information for the newly diagnosed, and employment and training opportunities. The Therapies section is particularly helpful. It contains a comprehensive list of therapy approaches, such as applied behavioral analysis, pivotal response training, verbal behavior, auditory integration training, occupational therapy, and much more. The site provides a good definition for each method. The Articles section is well organized and presented by category, such as treatment and therapies, education, newly diagnosed, and more.

Other resources on the site include a calendar of events and a list of ways to become involved with the organization.

**Unique elements:** The organization has a toll-free number that users can call to talk to experienced staff members and learn about early intervention, recreation, education, and medical options.
Comments: The book list on the site is quite comprehensive, including references for teachers, publications, and brochures.

Cost: Membership ranges from $10 to $35. Users can join the site’s mailing list. The site accepts online donations.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, autism research, autism therapies, autism articles, autism books, Pathfinders for Autism.

Unlocking Autism
www.unlockingautism.org

Ratings:
Content: **** Interface: **** Style: ***

The purpose of the Unlocking Autism organization is to increase awareness about the disorder. Part of its mission involves educating and assisting parents, raising funds for research and projects, and educating parents about the dangers of mercury to children. The Home Page contains links on the top to the various sections of the site. Must-visit areas include the following:

- A list of the organization’s projects, such as Open Your Eyes—a collection of 58,000 photos of autistic children
- A national and international network of parents and professionals working to help parents of newly diagnosed children find resources and support in their area
- A list of books on the topic of autism and related issues, such as vaccinations

Other resources on the site include event and advocacy information as well as links to external resources.

Unique elements: The organization has a national call center.

Comments: For those interested in vaccine information, the organization has a vaccine statement posted on the site.

Cost: Membership is free. Users can sign up to receive the organization’s mailing list. The site also has an online store containing books, jewelry, clothing, and more. The site also accepts online donations.

RSS XML Link: None.

Keywords: autism, autism spectrum disorders, Unlocking Autism, UnlockingAutism.org