GENERAL

EurekAlert! is an online, global news service operated by the American Association for the Advancement of Science (AAAS), the publisher of <u>Science</u>. The service provides a central place for universities, medical centers, journals, government agencies, corporations and other organizations engaged in research to bring news to the media. EurekAlert! also offers its news, resources, and archives to the public at <u>http://www.eurekalert.org/</u> where news and resources focused on all areas of science, medicine and technology are featured. Users can look up information by clicking on any topic under News by Subject or by typing specific information into a search window.

MedlinePlus at <u>http://medlineplus.gov/</u> provides information to help answer health questions. The service brings together authoritative information from the National Library of Medicine (NLM), the National Institutes of Health (NIH), and other government agencies and health-related organizations. Preformulated MEDLINE searches give easy access to medical journal articles. The site also includes extensive information about drugs, an illustrated medical encyclopedia, interactive patient tutorials, and the latest health news.

The National Institute of Neurological Disorders and Stroke (NINDS), one of the research centers of the National Institutes of Health (NIH), conducts and supports research on brain and nervous system disorders. NINDS overviews each of a large number of neurological disorders in their website at http://www.ninds.nih.gov/

ASPERGER SYNDROME / AUTISM

Autism and Asperger Research Reports is a website from Stanford University Child and Adolescent Psychiatry at <u>http://aarr.stanford.edu/</u> that provides abstracts of selected published research studies from the medical literature on autism and Asperger syndrome useful for both families and professionals.

Autism Research Centre (ARC) at Cambridge University seeks to understand the biomedical causes of autism spectrum conditions, to develop new and validated methods for assessment and intervention, and to foster research collaboration among scientists. Their website at http://www.autismresearchcentre.com/ includes ARC publications, such as tests available for download, journal articles, and lists of books.

OASIS @ MAAP: The Online Asperger Syndrome Information and Support (OASIS) center has joined with MAAP Services for Autism and Asperger Syndrome to create a single resource for families, individuals, and medical professionals. Their website at <u>http://www.aspergersyndrome.org/</u> lists a range of resources, including links to locate professionals, parent groups, camps and day programs, articles, research, and a newsletter. Find them on Facebook at <u>www.facebook.com/pages/AspergerSyndromeorg-OASIS-MAAP/270607908455</u>

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DEMENTIA

ADEAR, the Alzheimer's Disease Education & Referral Center, has a website at <u>http://www.nia.nih.gov/Alzheimers/</u> designed to provide current, comprehensive Alzheimer's disease information and resources from the National Institute on Aging (NIA).

The national **Alzheimer's Association** website at <u>http://www.alz.org/</u> provides comprehensive information on the disease, resources, services, research, and advocacy.

The Association for Frontotemporal Degeneration (AFTD), a national non-profit, promotes and funds research, provides information, education, and support to people with FTD and their families, and educates physicians and allied health professionals. Their website at http://www.ftd-picks.org/ includes resources for both professionals and families.

The **Lewy Body Dementia Association (LBDA)** is a nonprofit dedicated to raising awareness of the Lewy body dementias, supporting people with DLB, their families and caregivers, and promoting scientific advances. Their website at <u>http://www.lewybodydementia.org/</u> offers comprehensive information on DLB, including the full text of selected articles.

The **Michigan Dementia Coalition**, a collaborative group of consumers, community groups, universities, and state agencies, is focused on improving the quality of life of Michigan people with dementia and their families. Their website at http://www.dementiacoalition.org/ provides a range of resources and links of interest to both professionals and families. Additionally, they have established a new website at http://worriedaboutmemoryloss.com/ to provide information and support for parents, spouses, and people with dementia.

DEVELOPMENTAL DISABILITIES

The Association of University Centers on Disabilities (AUCD) is a non-profit that promotes and supports the national network of university centers on disabilities. They provide coordination of federal funding for programs, technical assistance to Congress, information exchange among members, and educational activities. Their website at http://www.aucd.org/ includes training materials and legislative updates.

The goal of the **Council on Quality and Leadership (CQL)** is to improve the quality of services and supports for people with intellectual disabilities and people with mental illness. They offer person-centered solutions for organizations and systems supporting individuals with disabilities and mental illness by providing accreditation, monitoring, evaluation, training, and consultation services. They currently partner with organizations and providers throughout the USA, Canada, England, Ireland and Australia. Their website at http://www.thecouncil.org/ offers training and resource materials for professionals.

DOWN SYNDROME

The goal of the **National Down Syndrome Society** is to benefit people with Down syndrome and their families through national leadership in education, research and advocacy. Their website at <u>http://www.ndss.org/</u> includes resources of for both families and professionals, including where to find information on Down's and dementia.

The National Down Syndrome Congress seeks to promote opportunities and/or resources to meet individual and family needs, provide leadership in the formation of public policy, encourage research, educate professionals, parents, and community, promote the full participation of people with Down syndrome in all aspects of community life, and provide a network for linking of state and local groups and affiliates. Their website at http://www.ndsccenter.org/ includes resources for parents and legislative updates.

HOARDING

Two experts on hoarding, Randy Frost, PhD, a professor at Smith College, and Gail Steketee, PhD, a professor at Boston University School of Social Work, offer a website at <u>http://www.ocfoundation.org/hoarding/</u> that is designed to provide information and assistance in a comprehensive and efficient way. The site is divided into several sections that cover the definition of hoarding, professional articles on multiple aspects of hoarding, a Research Digest for hoarding-related scientific papers, self-help and support group articles, a hoarding/compulsive buying screening test, and other useful information about this medical disorder.

HUNTINGTON'S DISEASE

The Huntington's Disease Society of America (HDSA), a non-profit dedicated to finding a cure for Huntington's Disease (HD), provides support, information and educational services for those affected by HD and offers resources and guidance for HD families. Their website at <u>http://www.hdsa.org/</u> has resources for professionals and families. The Michigan chapter is located on the web at <u>http://www.hdsa.org/mich/index.html</u>

MENTAL ILLNESS

NAMI, the National Alliance on Mental Illness provides information on mental illness, resources, services, research, and advocacy in their website at http://www.nami.org/

The **National Institute of Mental Health (NIMH)** offers a variety of publications and other educational resources to help people with mental disorders, the general public, mental health and health care practitioners, and researchers gain a better understanding of mental

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illnesses and the research programs of the NIMH. Materials are written by science writers, in collaboration with NIMH scientists and outside reviewers. All materials are free, and some are easy-to-read, as well as written in Spanish. Click on topics of interest in the NIMH homepage at <u>http://www.nimh.nih.gov/index.shtml</u> to download or order.

The Substance Abuse & Mental Health Services Administration (SAMHSA) website at <u>http://www.samhsa.gov/</u> has a wealth of information on substance abuse, mental health, and co-occurring disorders.

MULTIPLE SCLEROSIS

The **Multiple Sclerosis Association of America (MSAA)** provides ongoing support and direct services to people with MS and their families. The MSAA website at http://www.msaa.com/ describes the services they offer.

The National Multiple Sclerosis Society website <u>http://www.nationalmssociety.org/</u> provides information on the disease, resources, services, research, and advocacy.

PARKINSON'S

The American Parkinson Disease Association (APDA) focuses on research, support of people with Parkinson's, education, and raising public awareness. Their website at http://www.apdaparkinson.org/ offers resources for both professionals and families.

The National Parkinson Foundation (NPF) supports research, care of people with Parkinson's, education, training, and outreach. Their website at http://www.parkinson.org/ offers resources in English and Spanish useful to either professionals or families.

TRAUMATIC BRAIN INJURY (TBI)

The **Brain Injury Association of America** acts as a clearinghouse of community service information and resources, participates in legislative advocacy, facilitates prevention awareness, hosts educational programs, and encourages research. Their website at http://www.biausa.org/ has resources for both professionals and families.

The goal of the **Brain Trauma Foundation (BTF)** is to improve the outcome for TBI patients through the use of scientific, evidence-based treatment guidelines, which BTF has developed with medical organizations and physicians with expertise in TBI. The guidelines and other resources are available in their website at <u>http://www.braintrauma.org/</u>