

Web Resource Reviews & Local Resources MPHP 439 Health Management and Policy Class Spring 2008

Compiled by: Hillary Melchiors

Table of Contents

Author	Topic	pages
Leslie Cofie	Anthrax	2-3
Carla Conroy	Bipolar Disorder	4-5
Kate Conway	Anorexia Nervosa	6-7
Kavi Devulapalli	Schizophrenia	8-9
Dena Fisher (Bartko)	Juvenile Rheumatoid Arthritis	10-12
Anne Gifford	Arthritis	13-14
Obehi Irumudomon	Rett Syndrome	15-16
Isabelle Lane	Diabetes	17
Yamini Levitzky	Bicuspid Aortic Valve	18-19
Ilya Litvak	Mitral Valve Prolapse	20-21
Melinda Davenport Martin	Sickle Cell Anemia	22-23
Lauren Meredith	Parkinson's Disease	24-25
Jonathan Metcalfe	HIV/STDs	26-28
Aggrey Mukose	Tuberculosis	29-30
Emma Nochomovitz	Crohn's Disease	31-32
Tonya Passarelli	Fibromyalgia	33-34
Ileana L. Piña, MD	Heart Failure	35-38
David Rebhan	Stroke	39-40
Thomas Rehman	Diabetes Mellitus Type 1	41-42
Andreea Seicean	Attention Deficit Hyperactivity Disorder	43-44
Julie Stephenson	Alzheimer's disease	45-46
Krystel Tossone	Still's Disease	47-48

LESLIE COFIE
MPHP 439
1/29/07
Website Review

Disease: Anthrax

Anthrax is an acute infectious disease caused by the spore-forming bacterium *Bacillus anthracis*. It occurs in wild and domestic herbivores and lower vertebrates such as sheep, goats, and cattle. Humans can also be infected when exposed to infected animals or anthrax spore from infected animal tissues and products. Infection can possibly occur through inhalation, skin, or gastrointestinal. Transmission of *Bacillus anthracis* spores is very effective because they can lay dormant and live in soil for many years. Symptoms usually occur within 7 days. Skin infection begins with an itchy bump and develops into a painless ulcer. Inhalation symptoms may progress from a common cold to severe breathing problems; it can be fatal. Manifestation of nausea, loss of appetite, vomiting of blood, and severe diarrhea, are characteristic of inflammation of the intestine. Anthrax can be effectively treated with antibiotics, if diagnosis and treatment are initiated early. Also anthrax vaccines, with 93% effectiveness, can protect against infection. Anthrax became prominent national health issue post 9/11, amidst growing concerns of bioterrorism.

The following websites are links from a google search, which are rated based on their overall usefulness. Ratings of these websites are based on comprehensiveness, relevance, organization, and presentation.

Excellent *****
Very Good ****
Good ***
Fair **
Poor *

<http://en.wikipedia.org/wiki/Anthrax>

Wikipedia provides very comprehensive information about anthrax. The website provides an overview of the disease, a detailed description of the bacterium, mode of infection, treatment and prevention, as well as available vaccines. The page layout makes the site very easy to navigate; there is an outline of topics covered on the site. Additionally, the site provides a historical account of the disease, as well as current issues related to biowarfare and bioterrorism. Another useful tool on the page is its external links section and its references. People with little knowledge of anthrax will find this site a very good starting point in learning about the disease.
Rating: *****

<http://www.bt.cdc.gov/agent/anthrax/>

The Center for Disease and Control and Prevention's page is designed to appeal to the public. It is very comprehensive, providing all the necessary information one would need to know about anthrax. The website features a frequently asked section, which provides all the basic information about anthrax. The only useful external link and phone number are recommended for service men/women. This well focused website is limited in focus, and has not been update since 2005.

Rating: ***

<http://www.nlm.nih.gov/medlineplus/anthrax.html>

Medline Plus has an interactive and easy to use site on anthrax. The pages contains an interactive tutorial section, a basic information section, a question and answer section, and more importantly a link to the information in other languages (including Spanish, Chinese, Korean, and French). Also, the website contains information for children, teenagers, and women. Related issues related to anthrax, such as bioterrorism are covered. Research on the disease conducted by organizations like the CDC and the NIH are covered. This site's relevance is the depth of information it offers to the public. Although the information provided is very comprehensive, it is not made too simplistic. The most useful section on the site is that it provides useful information on local services and providers across the United States. Lastly, the website is regularly updated (last updated Jan, 2008), which contributes to the overall usefulness of the page.

Rating: *****

<http://www.fda.gov/cber/vaccine/anthrax.htm>

The US Food and Drug Administration's website provides brief information about anthrax. It has a number of links to references that provide some detailed information about the disease. This sight is primarily beneficial in providing information about anthrax vaccines. It is a good way of learning more about the efficacy and benefits of the vaccine, as well as who should get the inoculated and when.

Rating: ***

<http://www.clevelandclinic.org/health/health-info/docs/3000/3090.asp?index=10853>

The Cleveland Clinic has a page on anthrax. It provides all the necessary information that one needs to familiarize one's self with anthrax. It provides a toll free number and a link to the CDC website, if for more information about the disease. The Website Clearly outlines who should consider getting vaccinated. It explains that infection can be effectively treated, if one seeks early treatment. The Clinic's page provides a local number for people to contact the health information center or local health provider.

Rating: ***

Website Review

The disease I chose to research on the internet was Bipolar Disorder. Bipolar Disorder is a mental disorder characterized by periods of extreme lows (depression) lasting weeks or months at a time, in addition to periods of extreme highs (mania) lasting days or weeks at a time. The duration and severity of a persons manic symptoms is what determines if they have Bipolar I (manic symptoms last at least a week and cause significant impairment, or have resulted in hospitalization) or Bipolar II (manic symptoms last 3-4 days at a time and cause some impairment).

There are a number of websites dedicated to Bipolar Disorder and mental illness in general. One such website is for The Depression and Bipolar Support Alliance (DBSA - <http://www.dbsalliance.org/>). This website is a valuable resource because it provides information for people with bipolar disorder and offers help to friends and loved ones of those suffering from bipolar disorder. The DBSA has chapters all over the country, including here in Cleveland. Another site dedicated to bipolar disorder is Pendulum.org (<http://www.pendulum.org/>). This site contains information on the disease, as well as news, support and education resources. It also includes a forum where people can share their personal stories, thoughts and treatments they have tried. A resource for people here in Cuyahoga County is The Cuyahoga County Mental Health Board (CCCMHB - <http://www.cccmhb.org/>). This website provides information on agencies in Cuyahoga County that provide treatment for those with mental illness. These are agencies in the community that work to provide care to all Cuyahoga County residents, including those without health insurance.

For people with insurance needing outpatient services in the Cleveland area, the psychiatric departments of University Hospitals (<http://www.case.edu/med/psychiatry/>) and The Cleveland Clinic (<http://www.clevelandclinic.org/psychiatry/>) both have doctors who specialize in the treatment of Bipolar Disorder. For those requiring inpatient services, Laurelwood Hospital (<http://www.laurelwoodhospital.com/>) and Lutheran Hospital (<http://www.lutheranhospital.org/body.cfm?id=195>) are excellent local choices.

Those without insurance who live on the east side can go to Murtis Taylor Multi-Service Center (<http://www.murtistaylor.org/home/default.aspx>), which provides diagnostic assessments, medication services, counseling, support groups, partial hospitalization services and residential treatment services. On the west side those with mental illness can receive services from Bridgeway, Inc. (<http://www.bridgewayinc.org/>). Bridgeway offers crisis stabilization, outpatient counseling, residential treatment and employment services.

Kate Conway
MPHP 439
1/29/08

Website Review: Anorexia Nervosa

A general internet search led to multiple pages of “hits” when “anorexia” is entered into the search criteria. Using some of the provided criteria for judging good websites, the following are highly recommended with the following rating system:

Excellent: *****
Good: ****
Average: ***

1) **Medline Plus:** <http://www.nlm.nih.gov/medlineplus/eatingdisorders.html>:

This link will bring you to a general site for “Eating Disorders”. It is basically a hub of further internet links on specific topics under the umbrella of “eating disorders”. The topics are broken into the categories of “Overviews, Latest News, Diagnosis/Symptoms, Treatment, Prevention/Screening, Coping, Specific Conditions, Related Issues, Financial Issues, Clinical Trials, Research, Dictionaries/Glossaries, Directories, Organizations, Children, Teenagers, Men, Women”. Navigation in and out of the site is very easy. The breadth and depth of topics covered via the various links are outstanding. The links appear updated and provide full spectrum information including links to treatment resources. The site was last updated 1/23/08 and topic last reviewed 11/7/07.

2) **National Eating Disorders Association:** www.nationaleatingdisorders.org:

This link is the ultimate resource not only for anorexia but for all eating disorders. In one site you can find general background information, specific diagnosis information, treatment options and resources, financial considerations, and how to get involved and participate in networking. My favorite part of the site is the fact that it also is translated into Spanish. The website is easy to navigate and appears updated though it is not explicitly stated. The Medline Plus website previously reviewed has many of its links set to this website.

3) **American Academy of Family Physicians; Patient information:**
www.familydoctor.org: ****

This website can be used to search any medical topic for patient-accessible-easy-to-read information. For Anorexia there is a brief, general overview and definition of the condition with a few links to further, more specific information.

Where to seek quality care:

Upon further investigation, one local place appears to offer a very good extensive treatment and evaluation program that has been recommended to me in the past:

Child and Adolescent Psychiatry Services: Department of Psychiatry and Psychology at the Cleveland Clinic

- Offers a comprehensive spectrum of mental health services for children from infancy through age 18, designed to meet the special needs of children, teens, and their families in times of adjustment or crisis. They offer outpatient hospital-based and consultative care with a multi-disciplinary team approach for evaluation and treatment which is an essential component for successful treatment of eating disorders.
- Adolescents with anorexia or bulimia are evaluated by a child and adolescent psychiatrist, clinical social worker and registered dietitian. Laboratory tests are performed and medical assessment by a Cleveland Clinic pediatrician is provided as indicated.
- Following the evaluation, an individualized treatment plan is developed, encompassing dietary and weight goals; individual, group, and family therapy; and drug therapy as indicated. A six week intensive outpatient eating disorder program is available for more serious clinical situations.

Kavi Devulapalli
MPHP 439
January 29, 2008

Schizophrenia

Schizophrenia is a mental illness characterized by impairments in one's perception of reality. Symptoms primarily characterizing the disease include auditory and visual hallucinations, paranoid or bizarre delusions as well as disorganized thoughts and speech. In order for the diagnosis of schizophrenia to be made, an individual with such symptoms must experience significant social and/or occupational dysfunction. Approximately one percent of the entire population is affected. The onset of symptoms is generally does not occur until late adolescence and early adulthood. There is no cure for schizophrenia, and scientists are still unaware of the exact causes; however, research does suggest that early recognition and treatment of symptoms can reduce the severity of future symptomatic episodes.

Website Reviews

The following websites were rated based on the ease of navigation, source of information, disease description, information regarding treatment options, and links to medical and community resources for support and treatment. The rating scale is as follows: ***** Excellent, **** Very Good, *** Good, ** Fair, and * Poor.

<http://www.schizophrenia.com>

Rating: ****

Schizophrenia.com: A Non-profit source of information-support-education

Schizophrenia.com provides useful and easy to read information regarding the overview of schizophrenia. One of the challenges websites outlining schizophrenia face is the complexity of new research and describing new, relevant breakthroughs in a logical and simple manner. Schizophrenia.com does an excellent job of describing the results of new research studies and how that might impact patients and families with regards to new treatments. The website also does a commendable job in describing the hallmark symptoms of schizophrenia through videos that can be accessed online at the site. Perhaps the best part of the site is the support provided for patients and the family/friends of patients through success stories and an extensive list of discussion forums. I decided to not give schizophrenia.com an excellent rating because the website design is very antiquated, thus rendering it somewhat difficult to navigate. Nevertheless, the website provides solid information (National Institute of Mental Health is the primary source), along with information regarding where to seek treatment and community support.

<http://www.nimh.nih.gov/health/topics/schizophrenia/index.shtml>

Rating: *****

National Institute of Mental Health (NIMH)

The NIMH website provides succinct and easy to read information regarding the overview of schizophrenia, information regarding treatment, where to receive treatment and support. The greatest asset the website can claim, is its ease of navigation and relevancy of website content. The organization of the website is four-fold and laid out in a very logical manner: What is Schizophrenia, Signs and Symptoms, Treatment, Locating Services. The information first provided is very basic, however additional links are provided for users seeking more in-depth information. While it does not provide forums

for patients or families to discuss questions and concerns, the list of resource links provided lead to credible organizations whose aim is to properly assist those suffering from schizophrenia. The website layout and simplicity, but yet relevancy of content, make this website an ideal first stop for anybody seeking information regarding schizophrenia and its treatment.

<http://www.mentalhealth.com/dis/p20-ps01.html>

Rating: ***

Internet Mental Health

The Internet Mental Health website focuses its content to the symptoms and clinical overview of schizophrenia; however, little content is devoted to treatment and resources for seeking treatment and support. Links are provided for additional information regarding treatment, but accessing this information would require linking to different sites and undergoing additional browsing. Furthermore, the website layout does not utilize frames or links to topic areas, making it difficult for a user to easily access information they might be seeking. The website is nonetheless a good source for individuals seeking in-depth clinical information regarding the symptoms and diagnosis of schizophrenia.

http://www.nami.org/Template.cfm?Section=By_Illness&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=54&ContentID=23036

Rating: ***

National Alliance on Mental Illness (NAMI)

The NAMI website provides an extensive overview of schizophrenia, research regarding its etiology and treatment options. While the content is solid, and comes from a reliable source, it is not easy to read and may not be directly relevant for an individual seeking practical and succinct information. Like the *Internet Mental Health* website, information regarding where to seek treatment requires additional browsing through clicking on links on the NAMI website which will lead a user to different websites on the internet.

Local Treatment Facilities

<http://mentalhealth.samhsa.gov/databases/>

Mental Health Services Locator

Schizophrenia can be handled in an outpatient psychiatric setting. Provided the disease has not progressed to such an extent that hospitalization is necessary, I would suggest that my neighbor use his primary care physician (PCP) in order to be referred to a psychiatrist. If my neighbor does not have a PCP, he/she can locate a psychiatrist using the *National Mental Health Information Center's* Mental Health Services Locator. If an outpatient physician feels hospitalization is necessary, my neighbor will be properly referred to an appropriate long-term care facility.

If my neighbors are interested in learning more about the quality of potential physicians, they can purchase additional information regarding their background and qualities through <http://www.healthgrades.com>

Dena Fisher (Bartko)
MPHP 439
January 29, 2008

Juvenile Rheumatoid Arthritis: Website Reviews

Medline Plus defines Juvenile Rheumatoid Arthritis (JRA) as a type of arthritis that affects children age 16 or younger. It causes joint swelling, stiffness, and sometimes reduced motion. It can affect any joint and may also affect internal organs as well. Symptoms may come and go but one that is most common is limping in the morning. Some children have just one or two flare ups; others have symptoms that never go away. JRA causes growth problems in some children.

No one knows the exact cause of JRA, however it is a known auto immune disorder, which means your immune system attacks your body's own tissue. Medicines and physical therapy are methods used to reduce pain and swelling in children with JRA.

Rating System: 1=Poor, 2=Fair, 3=Good, 4=Outstanding

Kids Health for Parents

<http://www.kidshealth.org/parent/medical/arthritis/jra.html>

This is a terrific site to begin searching for information if you are a lay person simply searching for general information pertaining to JRA. It is specifically designed for parents so it provides an easy to read, easy to navigate site that informs parents with reliable and trustworthy information provided by physicians and other health professionals. One of the most appealing points of this site is a side tab bar on each page to the right of the article that allows visitors to view related articles as well as additional resources, many of which I chose to also review. The article for JRA provides information regarding the three types of JRA, symptomology, diagnostic tests to confirm JRA, and treatment modalities complete and on one page-this makes navigating through the piece easy. Kids Health is not exclusive to adults, it also provides information for kids and teens at an appropriate level at which they are able to understand.

4 Outstanding site with a terrific page of additional credible resources.

Arthritis Foundation

<http://www.arthritis.org/index.php>

The arthritis foundation does not meet many of the criteria that Longcar and colleagues define as a "good" site. While it is a national foundation that supports research and provides support to those looking for general information on arthritis-related diseases, it does not contain an opportunity for email, bulletin boards for posting questions or comments, support group information, or pictures—many components necessary to build a quality site for consumers. However, where it lacks in virtual communication support resources it makes up for in its description of the disease and ways it is best managed as well as provides a search box on the home page for zip code searches to link the visitor to regional chapters of the foundation. Additionally it provides a "what we suggest" page

that offers some emotional support tips and information regarding federal laws and financial information.

3 Good site with links to regional resources and a newsletter titled: “Kids get Arthritis Too”

The Mayo Clinic

<http://www.mayoclinic.com/>

The Mayo Clinic is a world renowned health services organization that treats several diseases. While their site is full of useful information for lay persons, it does not provide extensive information on JRA, perhaps this is because JRA is not treated at the Mayo Clinic. While the site does not offer more than basic disease related information, it does provide a tool called, “Ask a Specialist”. Visitors will find a host of questions and answers to disease-specific questions and if none exist for the disease in question, guests are encouraged to submit a question or concern free of charge and without membership obligations. For anyone searching for cancer specific diseases, the Mayo Clinic offers a plethora of resources, however JRA gains little attention and may not be a useful resource for anyone searching for advanced help or information regarding available local resources.

2 This site is rated as “fair” simply because it does not provide more than a summary of information related to JRA

National Institute of Arthritis and Musculoskeletal and Skin Diseases

(National Institute of Health, Department of Health and Human Services)

<http://www.niams.nih.gov/default.asp>

This is a research site that provides a wealth of information to scientists and researchers in the field; however it does little to speak to JRA and would not be recommended to people who are simply searching for answers and sources of clinical and personal support. This site provides links to research related articles and funding opportunities for anyone who might be interested in advancing the knowledge of arthritis and musculoskeletal diseases.

2 This site is rated as “fair” simply because it does not help patients directly with providing information or resources specific to JRA

WebMD

www.webmd.com

While WebMD seems to move to the forefront of informational health websites for patients, it seems to live up to its name and justify its catchy television advertisements. This site proved to be an excellent resource for people interested in just about any disease, especially JRA. It provides all of the disease-specific information found on most of the previous sites but also includes photos to further illustrate the text. For example, healthy joints versus swollen and inflamed joints are colorfully captured in additional windows by simply clicking on a photo icon. Another aspect of the site that may be useful is a page that suggests “when to call the doctor” and “who to see while there”

depending upon your immediate concerns. Moreover, much like the Kid's Health site it offered "Home Treatment Tips" but with additional information that explained and illustrated range of motion exercises and balance and rest activities. WebMD also provides a long list of frequently asked questions conveniently categorized to address JRA specifically. Another section provided help to "make the most of your appointment" with downloadable intake forms the doctor's office may require at initial and follow-up visits. (While these forms may not be universal in nature, they offer an idea of what to expect.) One last component worth mentioning in the site is a link to a comprehensive list of clinicians across the US who specializes in treating and managing Juvenile Rheumatoid Arthritis.

4 Outstanding site, though it lacks the capability to find local resources using a basic zip code search

The Cleveland Clinic Children's Hospital

<http://cms.clevelandclinic.org/childrenshospital/default.cfm?oTopID=538>

This local resource offers the expertise of The Department of Rheumatic and Immunology, rated among the "10 Best" programs in Rheumatology in the United States. The site itself does not provide extensive information, pictures, additional web resources, or JRA support group information; however it does offer a telephone number with a direct extension so that prospective patients might schedule a consultation. It also includes information as to what to bring to the first appointment as well as guidelines for referring physicians.

3 Good site for those living in Cleveland looking to seek help from a specialist, although insurance and financial information is not mentioned

Rainbow Babies & Children's Hospital

<http://www.uhhospitals.org/Default.aspx?alias=www.uhhospitals.org/rainbowchildren>

Rainbow Babies & Children's Hospital also specializes in pediatric rheumatology, although services offered are not as specific as the Clinic and there is little information available as to how to obtain a consult from one of the UH specialists serving Rainbow. The site does offer a more precise overview of JRA in their "Health Encyclopedia" page for parents. One aspect of this site is that you are able to click on key words or specific tests in order to gain further insight into a disease specific problem or symptom. This site does offer a page that lists all acceptable insurance plans as well, which often times, guides decision-making.

3 Again, good site for a local resource but lacks information on how to reach pediatric rheumatology directly

ARTHRITIS

Arthritis is a term under which many diseases and conditions fall, most of which are characterized by aching, pain and/or inflammation of joints, connective tissues and muscles. Among the most common forms of arthritis are: osteoarthritis, fibromyalgia, rheumatoid arthritis, and lupus. Generally speaking, there is no cure for most forms of arthritis, so “treatment” may consist of pain management therapies, lifestyle changes and general disease management strategies. Some of the commonly prescribed therapies for arthritic conditions include pharmaceutical therapies, physical therapy and stretching exercises, surgery, and preventative measures such as reducing painful movements. The websites reviewed were all found by a Google search of the terms “arthritis” and “arthritis management.” They are rated on a scale of 1-5 (5 being the best).

Medline Plus --- <http://www.nlm.nih.gov/medlineplus/arthritis.html> 4.5 out of 5

This NIH-supported website presents very comprehensive, thorough and patient-friendly information on the many forms of arthritis. One main benefit to this site is that they use links to other sites such as the Arthritis Foundation, American Academy of Orthopaedic Surgeons, American College of Rheumatology, American Physical Therapy Association, American Medical Association and others for specific information written by experts in the field. The site has a broad overview of disease definitions, treatment options, preventative strategies and information on general health as it relates to arthritis (e.g. “Diet and Your Arthritis”). This site is useful to many people at various different stages of arthritis care. This is the only site where I found that information was well referenced and pages were noted with a “last updated” notice.

The Arthritis Foundation --- <http://www.arthritis.org/> 4.0 out of 5

A Google search for “arthritis” produces quite a few commercial websites, but I chose to review the first non-profit organization that appeared. The Arthritis Foundation is one of the biggest and most frequently referenced sites on the web on the subject. The site is fairly user-friendly, and the information provided is easy to understand and thoroughly explained. Additionally, this site seemed to be one of the best for patients who haven’t been diagnosed and are just beginning to pursue medical evaluation for joint pain. There is also a Spanish language version of the site. Being members a non-profit foundation, the authors of this site make frequent reference to donation options and local social events, but the site provides a nice message board, which allows people to connect and share their experiences and troubles. This was the most comprehensive and patient-focused site that I reviewed.

WebMD --- <http://arthritis.webmd.com/default.htm> 3.0 out of 5

I chose to look at this site because WebMD is a frequently advertised and popular general medical information site. The site is almost too big, and while there is a useful information, it is often difficult to navigate and find exactly what information pertains to one individual. The benefit to this site is that the authors describe in detail what to expect

from your physician and from yourself at various stages: early symptomology, diagnostics, treatment and long-term pain management. Information was generally not cited or referenced and it is hard to tell what is reliable. Overall, the information is not easy to follow, and I would not highly recommend it. Oddly enough, the website MedicineNet.com (<http://www.medicinenet.com/arthritis/focus.htm>), which is owned and operated by WebMD, is a much more user-friendly, better-referenced and better organized site, providing much more thorough information. Nevertheless, its association with WebMD makes me question the site's authenticity.

Centers for Disease Control and Prevention --- <http://www.cdc.gov/arthritis/index.htm>
1.5 out of 5

This site has good epidemiological data for health professionals, but is simply not patient-friendly. The surveillance data on prevalence, incidence, hospitalization rates, mortality rates and impacts of concurrent morbidity are readily available, but are neither understandable nor useful for lay persons looking for more diagnostic information or resources. This site is clearly intended for health professionals and researchers and really provides little patient-specific information at all.

Where to find treatment around Cleveland, OH:

A Google search of "arthritis treatment Cleveland OH" produces several links to local foundation offices, such as local offices for the Arthritis Foundation, that provide information and advocacy, but few sites actually discuss local treatment options. Generally, nearly all of the websites mentioning treatment options referenced the Cleveland Clinic. One link to the Cleveland Clinic's Department of Rheumatic and Immunologic Diseases was particularly promising. <http://www.clevelandclinic.org/arthritis/>. The site provides background disease and treatment information, biographies of the department physicians, and instructions on how to make appointments at the clinic. However, the information is presented assuming patients already know their specific diagnoses and can click links to specific arthritic conditions, rather than being geared toward a patient who is just beginning to seek care for unspecified arthritis pain.

Another interesting site that comes up on the same Google search is a link to a medical doctor in Cleveland who specializes in acupuncture and Chinese herbal medicine, for those seeking alternative therapies. Alternative therapies for pain management have become highly sought after, especially as traditional arthritis treatments may require frequent physician visits, surgery or highly regimented drug therapies. The physician featured on the website <http://www.drgrotte.com/SpecialApplications.shtml#arthritis> is a CWRU medical professor who seems to run a legitimate operation, with a somewhat informative website. The information on the site mostly focuses on the benefits of eastern medicine, rather than arthritis-specific information, but based on what was presented, I would be interested in pursuing that option.

Obehi Irumudomon
MPHP 439 Public Health Management & Policy
January 24, 2008

Rett Syndrome

Rett syndrome is a neurodevelopmental disorder that primarily affects females. The stem of the disorder is genetic, with the mutation occurring on the X chromosome. Due to the mutation location females are more likely to present with this disorder, while males with this mutation do not survive to term. The disorder is usually seen in children ranging in age from six to 18 months. The children will develop normally until the symptoms appear at which time they either stop brain development or they will regress. The regression will be seen as a loss of purposeful hand movements, breathing irregularities and the head will also stop growing. These children also seem to exhibit autistic like behaviors. There is no cure for Rett syndrome but symptoms may be managed, and these individual may live for up to 40 years. There is a lot of physical and occupational therapy involved in order to make these more independent but only so much can be done. Therefore, this genetic disorder will affect the entire family, and really understanding what it means to have this disorder and finding support is important to how the family will function together.

In searching websites I was looking for places that had information about the disorder, and sites that showed local resources for families. I found it very difficult to find websites that did well with bout of these aspects.

WeMove

This website belongs to the non-profit organization by the same name and is dedicated to the “Worldwide Education and Awareness for Movement Disorders”. I found this website to be a great tool, that had sections for 22 different movement disorders, and in the case for Rett, really laid out the facts from a general overview to the pathophysiology and genetics of Rett. They were also good about listing references so people could find more information, and also providing a list of supporting organizations all over the world. Another cool feature was the discussion board; it is a way for parents of children with movement disorders to connect with one another. While there were discussion boards for each of the disorders, I found that the most active boards were the general boards where parents of children with varying disorders were supporting one another. While the site in all was very good, it still lacked the local resources that people may need, and while the information was great, it would not be understood by the average parent. They did try to separate the information for caregivers and medical professionals, but when I checked both links they were basically the sample information.

www.wemove.org/rett/

International Rett Syndrome Research Foundation

This website was very good in that it provided a lot of information to caregivers with specific sections dedicated to what Rett syndrome was, parent resources such as “dealing

with Rett”, current research being done, and also national events going on. This site was definitely caregiver friendly in that none of the information was too overwhelming, and there were a lot of pictures of families so that the site visitor could put a face to the disorder. There were also encouraging letters and pictures from parents of children with Rett as well as a list of online support groups. Once again the site listed various worldwide organizations for individuals with Rett syndrome, with four locations in the US. There was also a parental guide that one could sign up to receive in the mail that included contact information of parents in your area that could help direct you to more resources. While I do not know how extensive the contact list is, the idea behind it is great. This was overall a great site for parents finding out their child has Rett syndrome. www.rsrf.org

The National Institute of Neurological Disorders and Stroke

This website was one of the first site that pop up on a search for Rett syndrome, and at first glance it seems too official and cold. The general appearance would probably be off-putting to the average person wanting to find information. But after going through the site, the information is actually laid out in an easy manner. It is in a Frequently Asked Questions style with the questions being in a Table of content and being linked to the answers. The answers were also very readable, without going into too much detail. There was also a link to a Spanish version, which was also something that was not an option on the other sites. The list of resources was also a little more extensive of the US but most of the locations were in Maryland. There were a list of clinical trials, and their activity status “recruiting/completed” which is a good option for some people. The only thing that was a little too much was the literature section linking right to PubMed. While PubMed is a great source of information, it is not very user-friendly for people who are not familiar with it.

http://www.ninds.nih.gov/disorders/rett/detail_rett.htm

While there is a lot of information on the Internet about Rett syndrome, it may still be difficult for caregivers to find local support online and would probably have to resort to asking their physicians for guidance. But despite the lack of local support, there seems to be overwhelming support nationally and globally for these individuals. WeMove is the best example I found with an active discussion board on which people can connect nationally, or even find others in their communities.

Isabelle Lane
MPHP 439
January 29, 2008
Website Review

Website: www.MyDiabetesCentral.com

I found this website via Google after typing in "Top Diabetes Websites." This was the first hit listed and after browsing through, I think it is a very informative website. There are many resourceful items on this web-site and the aspects I thought were most helpful to the public were up-to-date information about diabetes, drug information, and advice on how to live with the disease.

The up-to-date section includes recent summaries from articles of renowned journals such as the *Journal of the American Medical Association*, *Diabetes Care*, and the *Journal of the American College of Cardiology*. They summarize the articles and offer links to the entire newspaper article making it easier for patients to navigate through topics they are interested in. The topics are very informative and discuss the most recent updates regarding Diabetes.

The section for drug information appears to be very instructive as well. It offers a quick overview of what each medication is used for including how it works, the importance of glucose control and what class the drug belongs to. Additionally, there is a link to learn more about each individual drug. The link offers information on how to use the drug, what potential adverse reactions may occur and how to store the medication. This type of section may ease patients' anxiety about taking new medications especially for those who tend not to trust the pharmaceutical companies.

The last section that I felt would be useful for patients is the areas that offer patients information on how to live with Diabetes. There are many links to this which point to diet, exercise, and recipes patients can enjoy. This is a section that makes living with diabetes very practical as it may be very overwhelming to be diagnosed with the disease.

Overall, this seems to be a user-friendly website that is easy to navigate and is extremely resourceful for patients. There are numerous links that patients can be directed to and there is even the opportunity to receive articles on weekly updates via e-mail if desired. As a physician, I will definitely direct my patients to this very informative and seemingly trustworthy website.

For the treatment of diabetes, I found the Joslin Diabetes Center at St. Vincent Charity Hospital in Cleveland. After researching their website, it appears that it the center is affiliated with Harvard Medical School and is one the world's largest and cutting edge center for diabetes care, education and research. It is convenient and local for patients who have difficulty with transportation. They offer educational classes taught by certified diabetes educators recognized by the American Diabetes Association. They also teach self-management skills, the importance of glucose control, and give dietary advice.

Website Review: Bicuspid Aortic Valve

A bicuspid aortic valve is the most common congenital anomaly involving the aortic valve, with an incidence of approximately 1-2%. It has been found to be a heritable trait, and may occur in up to 10% of affected family members.¹ The condition is usually asymptomatic until middle age, when repeated folding and creasing of the abnormal valve leaflets results in aortic stenosis, regurgitation, or a combination of stenosis and regurgitation.² Replacement or repair of the valve apparatus should be considered when the patient develops symptoms thought to be related to the damaged valve, or when they meet echocardiographic criteria for intervention.

The following is a brief review of resources available online for patients diagnosed with the condition. Websites were selected from the first page of hits from a Google search of “bicuspid aortic valve,” and represent an array of sources ranging from medical schools and scientific journals to websites intended for laypersons.

1) Medical school source:

http://med.yale.edu/intmed/cardio/echo_atlas/entities/aortic_stenosis_bicuspid.html

This site is listed as an atlas of echocardiography, and its page on bicuspid aortic valve is limited. It presents an excellent anatomical diagram of the valve anomaly, and offers several links to echocardiographic clips which illustrate the case. It is an excellent resource for medical personnel looking for pictorial examples of the bicuspid aortic valve who do not need information on the basic epidemiology, clinical manifestation, or treatment of the disorder.

Overall assessment: Excellent resource for medical professionals. Not very helpful for patients seeking information on the diagnosis and treatment of this condition.

2) Layperson website: <http://bicuspidfoundation.com/>

This site bills itself as a website by families and medical professionals written for families and medical professionals. They are supported by an impressive scientific advisory panel comprised of multi-disciplinary physicians (cardiology, cardiothoracic surgery, internal medicine, etc) from across the world. Financial sponsorship for the Foundation and hence, the website, comes from a combination of corporate support and private donations, which are fully disclosed. For a patient seeing information on the condition, there are multiple vignettes of actual patients and outcomes, basic background information, and perhaps most importantly, a list of risk factors and treatments which the patient could employ to minimize risk of complications. This enables patients to be more informed when seeing their physicians, and to prepare any questions they might have regarding their specific cases. For medical professionals, there is a link to medical references which cover both important historical advancements related to

diagnosis and treatment, as well as links to recent publications, presentations, and conferences.

Overall assessment: Excellent resource for patients, reasonably good for medical professionals.

- 3) Medical journal: <http://circ.ahajournals.org/cgi/content/full/106/8/900>

While this is a scientific publication in a well-respected cardiology journal, it begins with a case presentation of a 34-year old patient with a newly diagnosed bicuspid aortic valve. The article is formatted as a question/answer session, which makes it appropriate for a layperson seeking information, though it is listed as a “Clinician Update”. While it does touch on more technical aspects of the disease entity, such as genetics and histology, it is still comprehensible by a well-read patient. The paper concludes with recommendations of the primary cardiologist to the patient regarding management and follow up.

Overall assessment: Excellent resource for a patient seeking an “online” medical opinion regarding a new diagnosis of bicuspid aortic valve, and probably the best resource of clinicians of the websites reviewed. The only caveat is that the recommendations for care and follow up of patients with valve disease were updated in 2006, and some of the minor recommendations in the paper may be outdated.

- 4) Wikipedia: http://en.wikipedia.org/wiki/Bicuspid_aortic_valve

Surprisingly, Wikipedia has a very short page on this condition, citing only 4 references. The additional downside of Wikipedia is that one is not certain who is writing. While what is written is accurate and corroborates multiple other sites as well as the published literature, there is a dearth of information on clinical presentation, diagnosis, and treatment.

Overall assessment: Minimally helpful.

Best local treatment option: Of the three major academic medical centers in Cleveland (Cleveland Clinic, University Hospitals, and MetroHealth System), all three offer excellent care. The Cleveland Clinic cardiothoracic surgical program has consistently been rated among the top in the country, which would probably make it the first choice for a patient *with health insurance*. For a patient *without health insurance*, MetroHealth offers the same surgical options performed by Cleveland Clinic surgeons, with an excellent website detailing the disease, treatment options, and surgical procedure here: <http://www.metrohealth.org/body.cfm?id=1328>

Reference List

- (1) Fedak PW, Verma S, David TE, Leask RL, Weisel RD, Butany J. Clinical and pathophysiological implications of a bicuspid aortic valve. *Circulation*. 2002;106:900-904.
- (2) Aboulhosn J, Child JS. Left ventricular outflow obstruction: subaortic stenosis, bicuspid aortic valve, supraaortic stenosis, and coarctation of the aorta. *Circulation*. 2006;114:2412-2422.

Ilya Litvak
MPHP 439
01/29/2008

Website Review: Mitral Valve Prolapse (MVP)

Introduction

Mitral valve prolapse (MVP) or click-murmur syndrome is a heart disease characterized by the thickened mitral valve into the left atrium during systole. Mitral valve opens to pressure from the superior surface of the valve, allowing blood to flow into the left ventricle during systole, and closes at the end of atrial contraction to prevent blood from back flowing into the atria during left ventricle systole. In a normal cycle, the atria contracts first, filling the ventricle. At the end of ventricular diastole, the bicuspid valve shuts, and prevents backflow as the ventricle begins its systolic phase. MVP is diagnosed when backflow occurs. Treatment may include prescription of beta blockers (prepranalol) and blood thinners (asparin or warfarin). In severe cases a patient may require surgical replacement of the mitral valve. Mitral valve prolapse affects about 2% of US population.

Rating System

The websites were rated on the scale of Excellent-Poor. All websites were checked for credibility and accuracy.

Website Reviews

<http://www.mayoclinic.com/health/mitral-valve-prolapse/DS00504/DSECTION=1>

Excellent

This website is part of the Mayo Clinic cardiology department. It outlines in a simple form causes, symptoms, diagnoses and prevention tips. The website can be useful for people looking to get accurate information with simple jargon. In addition to providing the information on MVP, this website outlines various centers around the country which specialize in severe form of MVP, which require surgical care.

http://www.nhlbi.nih.gov/health/dci/Diseases/mvp/mvp_treatments.html

Good

This website is hosted by National Heart Lung and Blood Institute. It produces valuable information on MVP, but fails to deliver any suggestions on finding professional care. It does, however, establish a good overview of Mitral Valve Prolapse. Website provides the visitor with major causes, treatment and prevention options. It offers good information on valve replacement and repair. The user can navigate the menu to the latest research in the field, involving a procedure of repairing leaky valves with the catheter. It also outlines potential side effects associated with the illness.

<http://mvprolapse.com/treatment.html>

Good

Website is hosted by The Autonomic Disorders and Mitral Valve Prolapse Center. The on-line page is geared toward prevention and care. The visitor is given an advice on the

diet and exercise. In addition, the website provides the support groups throughout the country for people with the MVP. The site, however, lacks an advice on local health care providers and current on-going research in the field. Overall, the page is useful for individuals seeking prevention tips.

<http://familydoctor.org/online/famdocen/home/articles/598.html>

Fair

FamilyDoctor.org was launched by American Academy of Family Physicians as a quick reference website for individuals seeking to explore different types of illnesses. It provides short, but valuable description of MVP, lists major causes with graphical presentation and has a section on treatment possibilities. The amount of information is inadequate. It lacks any prevention advice or suggestions on local health care providers or nationwide centers, which treat MVP.

<http://www.texasheart.org/HIC/Topics/Cond/mvp.cfm>

Poor

Texas Heart Institute is a branch of National Heart Association and is based out of St. Luke's Episcopal Hospital. The website provides minimum information needed to get familiar with MVP. It does not have any links to available healthcare providers in the area or on-going research in the field. The website lacks extensive information on the illness and has almost no graphics to support verbal statements. The site is acceptable for individuals looking to get quick information, easy to understand, information on MVP.

Local Care

<http://www.clevelandclinic.org/heartcenter/pub/guide/disease/valve/mitralvalveprolapse.htm>

Excellent

This website is hosted by Cleveland Clinic Heart and Vascular Institute. In addition to giving the visitors an excellent overview and prevention tips on MVP, webpage allows you to quickly navigate the menu to find an extensive list of Cardiologists who specialize in treatment of MVP. By clicking on the name of each specialist a patient can learn the specialty of such doctor and overview performed procedures. The site also allows a visitor to chat on-line with the representative from Cleveland Clinic Heart and Vascular Institute and schedule an appointment on-line. The webpage accomplishes two main objectives- it serves as an educational tool for visitors as well as a resource for individuals seeking care in North-East Ohio.

Sickle Cell Anemia Website Reviews

Sickle cell anemia is a genetic disorder in which red blood cells, due to defective hemoglobin, form the shape of a sickle upon deoxygenation. These sickle-shaped erythrocytes cannot pass through blood vessels, causing blockages which result in moderate to severe pain. Patients are in sickle cell crisis at this point, and need immediate medical attention. This is a list of some websites providing information that would be helpful to someone who has just become aware of the presence of sickle cell disease (SCD) in their family; whether they are a patient with the disease, or a carrier of the trait that can cause the disease in his or her offspring.

1. Sickle Cell Information Center (scinfo.org)

This website is maintained by several entities, including Morehouse School of Medicine, the Sickle Cell Foundation of Georgia, Inc., and Emory University School of Medicine/Department of Pediatrics. It has many links from the home page connecting to the definition of SCD, pharmaceutical clinical research, other websites related to the disease, and books and other media. One positive comment of the website is that it has questions submitted by real people under the FAQ link. Many of these questions pertain to specific experiences, such as pain in an elderly SCD patient, the risk of two parents carrying the sickle cell trait having more children, and limiting one's active lifestyle. The website also has an interactive link for children to learn more about the disease, what the signs of crisis are, and when to tell an adult when they feel these symptoms. A complaint about the website is that it caters to both physicians and patients. For example, there are several questions in the FAQ link asked and answered by doctors; the answers can be complicated for a patient to interpret. This website would be recommended for information to supplement one's previously acquired knowledge of the disease.

2. The American Sickle Cell Anemia Association (ascaa.org)

This association is a United Way Agency. It is based in Cleveland, OH, and provides links to reputable hospitals in the area for treatment. The website has a very organized layout, and it caters well to patients. It defines the disease, gives

information about support groups, has a link for Spanish speakers, and has a FAQ link. Few negatives were found on this site; it would be recommended for anyone with no previous knowledge of SCD to get great information.

3. WebMD (webmd.com)

When “sickle cell anemia” was entered into WebMD’s search engine, many entries followed. Its overview of SCD was brief, but still informative. Other entries included a general overview of other types of anemia, prevention of the pain associated with SCD, and the pros and cons of transfusion to correct anemia in an SCD patient. This website is excellent for an introduction to one who has no prior knowledge for SCD, and would like to read different articles pertaining to breaking news in treatment.

4. University Hospitals (uhhospitals.org)

When “sickle cell anemia” was typed into the website’s search engine, the profiles of three physicians followed. The profiles listed their specialties (which include SCD), their training, and their contact information. These profiles would be helpful for a patient searching for someone who specializes in innovative treatment for SCD.

5. Black Health Care.com (blackhealthcare.com/BHC/SickleCell/Description.asp)

This website discusses in great detail common ailments among African-Americans. The SCD category includes information such as a definition of SCD, its global epidemiology, treatment, clinical trials, and causes of death in SCD patients. While the information is thorough in detail, it is not difficult for a patient to comprehend. This website is excellent for patients who would like an in-depth source of information about SCD.

Parkinson's Disease

By Lauren Meredith

Background:

Parkinson Disease is a disorder that occurs when the neurons in the brain that produce dopamine begin to deteriorate. Dopamine is a chemical in the body that helps the muscles move in a smooth, coordinated fashion. It is when approximately 80% of these cells become impaired that the signs of Parkinson Disease become apparent. Symptoms include tremors, stiffness, and a general lack of control of the body's muscular functions. The symptoms associated with Parkinson Disease become progressively worse as more and more of the neurons become impaired. According to the National Parkinson Foundation, approximately 1% of those over the age of 60 are affected by this disease with about 60,000 new cases being diagnosed each year.

Website Review:

The following websites have been reviewed and rated based on quality of content, navigational ease, and usefulness to those seeking treatment.

* poor ** fair *** good **** excellent

National Parkinson Foundation ****

www.parkinson.org

This website is an excellent resource. The home page is very easy to navigate and the link to "About Parkinson Disease" provides a brief description that seems to be targeted to the general public as well as a section entitled "A Primer on Parkinson Disease" that offers more detailed information for those in the medical field. The site also contains information about treatments, living with Parkinson Disease and maintaining wellness. The home page also offers a quick way to search for support resources in any part of the country. A search for support groups in Cleveland provided contact information for a number of places that currently offer support including the Cleveland Clinic Foundation. Overall this website is an excellent resource for anyone seeking information or support for Parkinson Disease

National Institute of Neurological Disorders and Stroke ****

www.ninds.nih.gov/disorders/parkinsons_disease/parkinsons_disease.htm

This website for the NINDS (part of the NIH) also offers a comprehensive overview of Parkinson's symptoms and treatments. In addition to this information, the website contains contact information for many organizations that are currently funding research, seeking new treatments, and/or offering support to those who are currently living with Parkinson disease. The site also posts recent publications about Parkinson's research which is very helpful.

Cleveland Clinic Neurological Institute ***

cms.clevelandclinic.org/neuroscience/

This is a really good local resource for Clevelanders. The only problem is actually getting to the information about Parkinson Disease, but once you're there the information is very helpful. In order to navigate to the specifics on Parkinson Disease,

you must first click on the link to the Center for Neurological Restoration and on the right of that page you will see a box that says “More Information” and you will find the link to Parkinson’s Disease there. This site gives you detailed information about symptoms, medicines, and other treatments including Deep Brain Stimulation. At the bottom of the site is a link to the Cleveland Clinic Parkinson’s Disease fact sheet which contains much of the same information but also offers a phone number to call in order to schedule an appointment with a Parkinson’s Disease Specialist.

WebMD Parkinson Disease **

www.webmd.com/content/Article/46/1833_50733.htm

I found this website while performing a Google search for “Cleveland Parkinson disease.” There is a lot of information here and WebMD actually partnered with the Cleveland Clinic Foundation to put the site together. The links will take you to WebMD’s Parkinson’s Disease Health Center site. From there you cannot navigate to other links that are listed on the original site, you have to go back, choose the link you want, and then the information will come up. While the information is all very good and helpful, it is too much trouble to be worth the time. I was able to find another useful resource for those living in Cleveland from the link to resources on the original site. The first resource that is listed by WebMD is the American Parkinson Disease Association Information and Referral Center which is located at the Cleveland Clinic. That organization does not have a website of its own, but the contact information would give anyone seeking care a good place to start.

Parkinson’s Resource Organization *

www.parkinsonsresource.org/

This website contained very little information regarding the signs, symptoms, and treatments for Parkinson Disease. It did offer links to recent news articles related to Parkinson Disease research. I found the organization of the website to be poor and support group events are only offered in southern California where I assume the organization is based. Overall this is not the best resource for someone living in Cleveland or anywhere outside of Los Angeles for that matter.

Jonathan Metcalfe
MPHP 439
Website Reviews
29 January 2008

HIV (STD's) Website Reviews

A friend of mine recently got out of a serious relationship. His way of coping with the breakup was to meet as many new women as he could. At first he was careful to use a condom every time he had sex with one of these new friends but after a few months he became more apathetic about his risk for STD's and stopped using condoms. He knows that he is putting himself at risk by not using a condom each time he has sex but perhaps he does not realize just how serious a risk he is at. I am putting together this list of websites that provide information on HIV (and other STD's) with the presumption that if he had more information about his risks he would change his behavior and start using condoms again. I am also including information about locations where he can get tested and receive treatment if he wants/needs it.

HIV InSite (<http://hivinsite.ucsf.edu/InSite>)

This is an excellent site to find information about HIV. It is run by the University of California, San Francisco and has a wide range of information and data about HIV. The information ranges from the basics of HIV to scholarly scientific articles. Another tremendous resource is the HIV InSite Knowledge Base (HKB). HKB is an online textbook of more than 100 chapters and resource pages covering an array of HIV clinical topics such as the diagnosis and management of HIV, opportunistic infections, and AIDS-related malignancies as well as HIV transmission, prevention, and public policy. The website is easy to navigate, and whether you are a high school student or a physician there is information that everyone would find useful.

Rating: *****

Centers for Disease Control and Prevention (<http://www.cdc.gov/hiv/>)

This site, run by the United States Department of Health and Human Services, Centers for Disease Control and Prevention, is another excellent source of information. It provides basic information as well as fact sheets and data from the United States and also international data. They also have a large amount of information available in Spanish. One other neat feature is the availability of email updates. You can sign up to receive updates on HIV/AIDS information through email as it becomes available. The topics available are not expansive; however there are a good variety of updates available. The website is fairly easy to navigate however since there is so much information it can be easy to get lost in the different pages.

Rating: ****

National Library of Medicine (<http://sis.nlm.nih.gov/hiv.html>)

This site is run by the United States National Library of Medicine, National Institutes of Health. The site itself does not have information on HIV but rather provides links to other websites with information. The links are organized in a logical manner in a way

that makes it easy to find resources for the public, researchers, health professionals, and students.

Rating: *****

The Johns Hopkins HIV Guide (<http://www.hopkins-hivguide.org/>)

This site is run by The Johns Hopkins University and appears to have a lot of information on HIV transmission, drugs, and research. This site is focused mainly at an audience of researchers and health professionals and would probably not be the most useful for the public. The website is not very user-friendly. There are problems with the pages loading properly on the screen. Another negative feature is the fact that you must register in order to use the site. This might be a deterrent for users that wish to remain anonymous. The home page even has a FAQ section in which one of the questions is “Why do I have to register to use the site?” Unfortunately, you have to register in order to read the answer.

Rating: *

World Health Organization (http://www.who.int/topics/hiv_infections/en/)

The World Health Organization’s (WHO) website on HIV has a lot of information however it is presented in a broader manner. The target audience seems to be researchers and health professionals and not the general public. There is an expansive library of data from virtually every country around the world. The information that an individual who is concerned about his/her HIV status is sparse however. The site also contains a link to the Joint United Nations Programme on HIV/AIDS (UNAIDS), (<http://www.unaids.org/en/>), which focus entirely on HIV/AIDS around the world.

Rating: ***

HIV Testing and Treatment

National HIV Testing Resource (<http://www.hivtest.org/>)

This website allows users to search for HIV testing centers nearby. The site is very user-friendly. The homepage allows you to search for testing centers by ZIP code in a radius ranging from 10 to 35 miles. For example, the search provided 29 centers within 10 miles of ZIP code 44106. The site also provides answers to common questions that people might have about HIV and what to do before and after you go to get tested.

Rating: *****

Best Care

Mount Sinai (Manhattan, New York)

(<http://www.mountsinai.org/Patient%20Care/Service%20Areas/AIDS%20HIV>)

Mount Sinai has 24 physicians specializing in HIV/AIDS care in specialties from infectious disease, adolescent medicine, OBGYN, and pediatrics.

Stanford Hospital (Northern California)

(<http://www.stanfordhospital.com/clinicsmedServices/clinics/positiveCare/positiveCare>)

The Positive Care Clinic at Stanford Hospital treats patients with HIV infection, Acquired Immunodeficiency Syndrome, and related opportunistic infections such as Kaposi's sarcoma, pneumocystis carinii pneumonia (PCP), cytomegalovirus disease, disseminated MAC, and wasting syndrome. Physicians provide interdisciplinary approach to care with social worker, psychiatrist, and nutritionist available on site. The clinic also provides primary care management to adult, non-HIV gay and lesbian patients.

Yale-New Haven Hospital (Connecticut)

(http://www.ynhh.org/patients/aids_care_program.html)

The AIDS Care Program was established in 1984 in response to the increasing number of individuals being treated for HIV/AIDS at Yale-New Haven Hospital. The program provides comprehensive care to adults, adolescents and children living with HIV/AIDS and their families and significant others. The scope of services includes outreach, testing, counseling, outpatient and inpatient clinical care, clinical research trials and community support. The AIDS Care Program is staffed by a multidisciplinary team of physicians, nurses, HIV counselors, social workers and clinical researchers.

San Francisco General Hospital (Northern California) (<http://www.sfghf.net/aids.php>)

For over twenty years, the Positive Health Program has been an international model of compassionate health care for HIV/AIDS patients. San Francisco General Hospital is also part of the Bay Area Perinatal AIDS Center, which provides comprehensive preconception counseling and prenatal care to women and families infected and affected by HIV. This is part of UCSF's Positive Health Program.

Aggrey Mukose

MPHP 439- Public Health Management & Policy

Website Reviews

Due January 29, 2008

TUBERCULOSIS

Tuberculosis (TB) is an infectious bacterial disease that is caused by a germ called mycobacterium tuberculosis. It usually attacks the lungs, but can attack almost any part of the body. Tuberculosis is spread from person to person through the air, when a person with TB of the lungs or throat coughs, sneezes or talks. One is more likely to get TB if their immunity is low.

There were 8.8 million new Tb cases in 2005 and 1.6 million people died from TB in the same year, equal to an estimated 4400 deaths a day world wide.

The symptoms of tuberculosis include: cough that lasts three weeks or longer, weight loss, coughing up blood or mucous stained with blood, excessive night sweats, loss of appetite, evening fevers or chills, body weakness or malaise

Active tuberculosis can be cured by taking appropriate drugs for the recommended time. People with latent TB can take appropriate medicine to prevent them from developing active TB.

If not treated, each person with active TB infects on average 10 to 15 people every year. 1 in 10 people infected with TB bacilli will become sick with active TB in their lifetime. In the United States, a total of 13,779 cases of tuberculosis were reported in 2006 (a rate of 4.6 cases per 100,000 persons).

Website Reviews

The following websites provide very useful information on Tuberculosis.

1. World Health Organization (WHO)

<http://www.who.int/mediacentre/factsheets/fs104/en/> and

<http://www.who.int/topics/tuberculosis/en/>

Rating: **Very good**

These are World Health Organization (WHO) websites and give very good information on Tuberculosis on both a worldwide and country basis. They give facts on tuberculosis including; the causes, symptoms, statistics and treatment guidelines.

2. Center for Disease Control and Prevention: Division of Tuberculosis Elimination

<http://www.cdc.gov/tb/default.htm> and

http://www.cdc.gov/tb/pubs/tbfactsheets/prevention_eng.htm

Rating: **Very good**

These are Center for Disease Control websites that give very good information on tuberculosis. The information includes; United States statistics, definition, general information on causes, symptoms, prevention and treatment.

3. Medline plus

<http://www.nlm.nih.gov/medlineplus/tuberculosis.html>

Rating: **Good**

This is another good website with very good patient information on tuberculosis. It is a service of the U.S national Library of Medicine and the National Institute of Health. The information is very simple, clear yet very important.

4. *American Lung association.*

<http://www.lungusa.org/site/pp.asp?c=dvLUK9O0E&b=35778>

Rating: **Very good**

This website has very good information on tuberculosis and many other lung diseases. The information is simple and well written to be understood. It even has a Lung Help Line.

5. *World Lung Foundation*

<http://www.worldlungfoundation.org/tuberculosis.html>

Rating: **Excellent**

This is an excellent website with up-to-date information on tuberculosis and other lung conditions. It has links to very good websites like; World Health Organization, TB news, information and Resources, International Union Against Tuberculosis and Lung disease, US Centers for disease Control, Global Fund to fight AIDS, TB and Malaria, tbvt.org (an organization for TB patients), TB alliance and Kaiser Global Health reporting with basic information about TB geared for an audience without medical expertise.

6. *Tuberculosis information and consumer guides*

U.S Department of Health and Human Services

<http://www.healthfinder.gov/>

Rating: **Excellent**

This is a guide to excellent and reliable information with many links. It is sponsored by the Office of Disease Prevention and Health Promotion. It has excellent links to different diseases under the health library. It has a link to locating a good facility for care across the United States at the link below:

<http://www.cdcnpin.org/scripts/locates/LocateOrg.asp?SearchType=Advanced>

Some of the TB treatment providers on the link leading to a good facility include:

1. <http://www.cdcnpin.com/scripts/display/OrgDisplay.asp?OrgNbr=14598> : METRO HEALTH MEDICAL CENTER TUBERCULOSIS CONTROL CLINIC. RATING: **EXCELLENT**

2. <http://www.cdcnpin.com/scripts/display/OrgDisplay.asp?OrgNbr=5540> : University Hospitals of Cleveland, Case Western Reserve University, Infectious Disease Division John T Carey Special Immunology Unit (UHC CWRU SIU)

Rating: **Very good**

3. <http://www.cdcnpin.com/scripts/display/OrgDisplay.asp?OrgNbr=14597> Hamilton County Department of Job and Family Services Health Care Services Tuberculosis Control Clinic (HCJFS)

Rating: **Very good**

4. <http://www.cdcnpin.com/scripts/display/OrgDisplay.asp?OrgNbr=3148>

GEAUGA COUNTY COMBINED HEALTH DISTRICT

Rating: **Very good**

Emma Nochomovitz
MPHP 439
Spring 2008

Crohn's Disease

Crohn's disease, a form of inflammatory bowel disease, is a chronic illness for which no real cure exists. Crohn's causes inflammation of the digestive or gastrointestinal tracts and most commonly affects the colon and/or the small intestine. The disease also notably affects the body's immune system, leading to bowel injury, ulcers within the digestive tract and nutritional deficiencies. Crohn's disease is most commonly found among adolescents and young adults, as well as individuals of Jewish descent.

The following websites provide information and/or support for individuals with Crohn's disease. The sites have been reviewed based on a "5 star system" in light of ease of navigation, the manner in which information is presented, availability of useful links to other resources, and the breadth and depth of the content provided. Those sites receiving a larger number of stars are considered the most useful overall.

<http://www.ccfa.org/info/about/crohns> ****

Crohn's and Colitis Foundation of America

This website offers a wealth of information about Crohn's disease and other related diseases. Its content includes a wide array of issues related to Crohn's from its basic etiology to some of the complications someone living with the disease might expect to encounter. While this website is useful because of the varied knowledge it provides, its wide range of topic areas and plentiful link options serve to make navigation of the site more difficult. The content offered is provided in simple terms and easy language that insinuates a sense of encouragement and optimism for those dealing with disease. Among the several links to detailed information about some of the events and services hosted by the Crohn's and Colitis Foundation of America, this site does provide a link to a physician search that allows patients to search for providers associated with the Foundation by state.

<http://digestive.niddk.nih.gov/ddiseases/pubs/crohns/> ***

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) and the National Institute of Health

The NIDDK offers a simple, readable and easy to navigate website on the basics of Crohn's disease, from its symptoms and diagnosis to prognosis and areas of research. The page layout is pleasing to the eye and non-cluttered. The site also offers a basic, but not extensive, list of contact information to other organizations that may offer information or aid to individuals' with Crohn's disease.

<http://www.netwellness.org/ency/article/000249.htm> ****

University of Cincinnati, The Ohio State University, Case Western Reserve University

The content of this website covers a broad spectrum of issue related to Crohn's disease, its symptoms, diagnosis, prognosis and treatment. The site also offers two things that many other sites of this nature do not offer: pictures meant to guide one's understanding of the disease and links to individual definitions of words that a browser may not be

familiar with. Despite the depth and breadth of information presented in an easy to understand way, the site lacks a navigation system that allows browsers to identify specific information in a timely manner.

Specific populations

<http://pages.prodigy.net/mattgreen/> *****

This page was created by an individual with Crohn's disease as a hub for stories about, by and for teenagers coping with this chronic illness. The page includes a large number of links to cooking recipes, stories of individuals' personal experiences with Crohn's and other news or information that individual's with the disease want to share from across the globe. While the website is geared toward teens, all it has to offer is not limited to a teenage audience and may be useful for anyone with or anyone that knows someone with Crohn's disease. The page is somewhat difficult to navigate, given its extensive number of links to other pages, but it is worth putting in the effort to explore what kind of information it may have hidden within it.

Local Links

<http://cms.clevelandclinic.org/digestivedisease/body.cfm?id=91> *****

Cleveland Clinic

This easy-to-navigate page offers basic and easy to understand information about Crohn's disease, its symptoms and treatment. With regard to treatment, this website includes several links directing web-browsers to more specific information about how one may schedule an appointment at the Cleveland Clinic or choose a specialized physician. Furthermore, the site offers links with information about the Cleveland Clinic Digestive Disease Center and the hospital sponsored "Health Talks" that are held monthly at the Cleveland Clinic main campus to educate community members and patients about living with a variety of chronic illnesses. This page is an excellent resource for an individual that knows he/she has Crohn's and would like to schedule an appointment with a physician. Viewers should be warned that while offering services to potential patient's, this site primarily serves as an advertisement for Cleveland Clinic.

Fibromyalgia

Overview

Fibromyalgia is a chronic condition that consists of widespread pain in the muscles, ligaments and tendons that can be debilitating. It also can result in sleep disorders and extreme fatigue. Accurate information in understanding and treating Fibromyalgia is critical as a Fibromyalgia diagnosis can be quite challenging. Fibromyalgia cannot be determined by a laboratory test, blood work or x-rays; physicians must rely on the patients' symptoms for a diagnosis. These symptoms are quite varied and can often result in an incorrect diagnosis. Patients often spend years undergoing tests for conditions as varied as depression to arthritis. Fortunately, there are a number of helpful websites for those with this chronic condition.

National Fibromyalgia Association

www.fmaware.org/site/

The National Fibromyalgia Association (NFA) was founded in 1997 and is the largest nonprofit related to Fibromyalgia and other chronic pain illnesses. It is the most comprehensive website available on the topic. This site was visually appealing, user-friendly and easy to navigate. The site is appropriate for both patients as well as health care providers. Content is extensive and covers many areas including: science (understanding the condition itself), research (latest scientific studies and ongoing clinical trials) and an online support community. The website also did a good job of providing a human interface through patient stories and by providing opportunities for patients to interact with one another. One unique element to this site was a national resource directory by topic for fourteen different topics ranging from insurance to elderly issues.

The site did provide a directory of local health care providers (accessed by zip code). The process to access this information consisted of requesting a referral by email or over the phone at which time the patient would be given the names of providers in the area. Additionally, information regarding local community support groups was also provided. A support group for Cleveland was not listed. The two closest cities with support groups listed were in Columbus and Napoleon:

Columbus - [Fibromyalgia Support Group - Columbus](#)

Napoleon - [Henry County Hospital Fibromyalgia Support Group](#)

American College of Rheumatology

www.rheumatology.org/public/factsheets/fibromya_new.asp

The website for the American College of Rheumatology is another good online resource. It provided a detailed description of the condition. The site was easy to navigate, patient friendly in terms of language and visually acceptable. While information was available for patients and the general public, the emphasis was on providing information to health care professionals including physicians, fellows, residents and students. For the patient, categories included a detailed description of the condition, living with Fibromyalgia, the role of the Rheumatologist, finding a rheumatologist and resources for additional research.

American College of Rheumatology (Cont.)

www.rheumatology.org/public/factsheets/fibromya_new.asp

The site also contained one very potentially helpful resource; it provided a list of patient assistance programs for Rheumatology related drugs. In Cleveland the site listed over thirty rheumatologists in the city of Cleveland in the format below:

Steven J. Spalding, MD

Division of Rheumatology

Cleveland Clinic

9500 Euclid Ave

Cleveland, OH 44195

Ofc: 216-445-1099

Time Spent: Patient Care, Administration, Research-Clinical

Disciplines: Pediatric Rheumatology, Pediatrics

Locations: Practice-Multiple Specialty Group

Member Type: Fellow Member

Fibromyalgia & Fatigue Center of Cleveland

<http://www.fibroandfatigue.com/index.php>

The Fibromyalgia & Fatigue Center of Cleveland specializes in treating Fibromyalgia, chronic fatigue and immune dysfunction syndrome. This site's target audience is primarily the patient and heavily promotes using their own centers (twelve in total) for treatment. One center is located in Cleveland. The website is the visually appealing and directed towards the needs of the patient. The site includes detailed information & descriptions of the condition, symptoms and related topics. While effective in providing an overview of the condition as well as a local resource to visit to get more information, caution must be used in that it is not affiliated with a hospital or another known, reputable institution.

Fibromyalgia & Fatigue Center of Cleveland

18151 Jefferson Park Road, Suite 103

Middleburg Heights, OH 44130

Phone: 440-260-9700

Other General Resources

Mayo Clinic: <http://www.fibroandfatigue.com/index.php>;

Fibromyalgia Network www.fmnetnews.com;

National Institute of Arthritis and Musculoskeletal and Skin Diseases

<http://www.niams.nih.gov/hi/topics/fibromyalgia/fibrofs.htm>

The American Fibromyalgia Syndrome Association, Inc.

www.afsafund.org

Ileana L. Piña, MD
Best web page for lay public. www.abouthf.org

Entering “heart failure” on Google brings up a plethora of sites. The first site that appears to provide education is funded by a company that has a device (not approved) for end-stage disease. Other web sites range from Academic Medical Programs who have special Heart Failure Sections to patient driven “blogs” to holistic and homeopathic remedies. Even Wikipedia is listed as well as Medline and WebMD. The Web MD website is directed to the public but is full of advertising of companies interested in heart failure who will happily have a link. Academic site links, of course, are looking for patients to recruit into their clinic and programs. Caveat emptor! It would be very difficult for someone with no medical knowledge and perhaps ill or with ill family members to recognize the factual sites from those that are trying to “push” their own product, often not even approved by the FDA. In moments of uncertainty, one hopes that the consumer will link into sites of good reputation, such as the American Heart Association. Less well known, but equally accurate and professional is the Heart Failure Society of America. The rest of this paper discusses their lay-public focused web page, abouthf.org.

This webpage is an off-shoot of the main website of the Heart Failure Society of America. The site was developed as part of the “Heart Failure Awareness” campaign to reach the public. Google results return at least 10 web pages of “patient information”. Unfortunately some of those are powered by commercial interests telling patients about expensive devices and making them sound like the panacea of care rather than providing factual information about choices which are fair.

The “aboutHF” web page has been designed by heart failure professionals to offer hope and accurate information to patients and families seeking education about heart failure.



The screenshot shows the website for the Heart Failure Society of America. At the top left is the logo for the Heart Failure Society of America, featuring a heart with a pulse line. To the right is a smaller logo with the letters 'fai' and 'A.W.A.' below it. Below the logos is a navigation menu with links: HOME, EDUCATION MATERIALS, QUESTIONS ABOUT HF, HF AWARENESS WEEK, WHAT'S NEW, and CONTACT US. The main content area has a blue header with the text 'Questions About' and a small image of two elderly people walking. Below the header is a list of links on the left: What is Heart Failure?, Symptoms of Heart Failure, Risks for Heart Failure, Diagnosing Heart Failure, Treating Heart Failure, Stages of Heart Failure, Living with Heart Failure, Impact of Heart Failure, Future of Heart Failure, Educational Video on Heart Failure, Send Me E-Mail Updates, and a back button. The main text area is titled '"What You Should Know About Heart Failure" America's Silent Epidemic'. It contains a paragraph explaining that heart failure affects nearly five million Americans and is responsible for more hospitalizations than all forms of cancer combined. It also mentions that many people are not aware of the condition because symptoms like feeling tired and short of breath are often mistaken for normal signs of aging. A second paragraph states that some common questions and answers are found on the website, emphasizing the importance of early diagnosis and treatment. At the bottom, there is a section for 'Frequent Questions and Answers on Heart Failure:' with three bullet points: 'What is Heart Failure?', 'Symptoms of Heart Failure', and 'Risks for Heart Failure'. On the right side of the main text area, there are three links: 'print p', 'bookmark p', and 'e-mail this'.

In addition, the site provides educational material which can be used by health providers for their own patients.



Education Materials

- [Education Modules on Heart Failure](#)
- [Heart Failure Practice Guidelines](#)
- [Heart Failure Awareness Materials](#)
- [Order Materials](#)
- [Send Me E-Mail Updates](#)
- [← back](#)

Heart Failure Education Materials

The HFSA has produced educational materials to help promote awareness and educate patients, individuals at risk as well as family members about heart failure. These materials represent the collective expertise and best practices by the members of the HFSA for heart failure.

Clinics, hospitals, institutions or individuals that wish to order these educational materials may do so by filling out an [order form](#). All of these materials may be either downloaded and/or viewed on line to help you determine which materials are most appropriate for you.

[print p](#)
[bookmark p](#)
[e-mail this](#)

[Educational Modules on Heart Failure](#)

The HFSA is producing and publishing a series of modules to help patients, their loved ones and individuals at risk work better with their doctor or nurse. These modules are not intended to replace regular medical care.

In addition to educational materials which are one on one for patients, materials are also available to health providers who wish to take part in heart failure awareness and distribute them to a larger group of the lay public. This campaign has been widely popular and has served hospitals and clinics as an authoritative source of information that can be trusted by those distributing it.



HF Awareness Materials

- [Heart Failure Awareness Materials](#)
- [2007 HFSA Heart Failure Roundtable](#)
- [2001 Heart Failure Spokesperson](#)
- [Press Releases](#)
- [Educational Video on Heart Failure](#)
- [What is the HFSA?](#)
- [Order Materials](#)
- [Send Me E-Mail Updates](#)
- [← back](#)

Heart Failure Awareness Materials

The Heart Failure Society of America has produced a turnkey kit (updated 11/13/07) and supplemental materials to assist professionals in planning events related to heart failure either during National Heart Failure Awareness Week or at other times during the year.

Some of the materials, for either medical professionals or individuals, may be ordered online. Other information may be downloaded directly.

Materials that can be order online include:

- **What You Should Know About Heart Failure**
A 20 minute DVD for patients with heart failure is designed to help patients and their families understand the disease and treatment options.
- **What You Should Know About Heart Failure: America's Silent Epidemic**
Brochure which lists the causes, symptoms, risk factors and information about living with the disease. The brochure is six pages long and measures 4 x 11 inches.
- **Who Is The Patient With Heart Failure - FACES Card**
A 5 x 7 card which lists the symptoms and risk factors for heart failure.



[print p](#)
[bookmark p](#)
[e-mail this](#)

The main criticism of the web site is that there is a statement of support from various commercial entities. See below:

Support provided by the HFSA
Heart Failure Awareness
Roundtable:

- [Abbott Laboratories](#)
- [GlaxoSmithKline](#)
- [Guidant Foundation](#)
- [Medtronic, Inc.](#)
- [St. Jude Medical](#)

Clicking on the names takes the viewer to the commercial sites of these companies. This small and perhaps often overlooked facet of the page makes the web site take on a more commercial and less desirable aspect.

Stroke

Stroke is one of the leading killers around the world, but it is particularly impactful in the United States. In the U.S., stroke is the leading cause of adult morbidity and the third leading cause of death. A stroke occurs when a blood vessel or artery in the brain is blocked by a blood clot or when a blood vessel or artery ruptures within the brain. When either of these events occurs, blood fails to transmit to vital cells within the brain. If these cells do not receive blood, they will undergo a series of chemical reactions and ultimately die.

When brain cells die, cognitive and motor functions may be impaired. Stroke outcomes vary by the location of the stroke within the brain. While some people may die from their stroke, others may not experience any effects lasting more than 24 hours, and still others may be forever impaired. While the outcomes are uncertain, the majority of stroke victims will experience lasting ill effects.

The overt symptoms of stroke are fairly easy to recognize: sudden weakness on one side of the body, abrupt slurred speech, sudden onset of a powerful headache, abrupt confusion, and sudden numbness. Stroke symptoms are quick to start and often become progressively worse. If you or someone you know is experiencing these symptoms, *immediately* contact emergency services.

The following 4 websites give information regarding stroke and stroke management. Each website is reviewed for usefulness to an individual wishing to learn more about stroke. The websites are each given a subjective rating on a point scale from 1 (worst) to 10 (best).

<http://www.stroke.org>

Rating: 9

National Stroke Association (NSA)

The National Stroke Association's website is extremely valuable. The tool bars are easy to navigate and they provide the most crucial information regarding stroke: stroke description, risk factors, prevention, and recovery. Moreover, the site differentiates between potential visitor demographics, providing targeted information for specific groups such as stroke survivors, family members, African Americans, women, and even children. Perhaps the most valuable tool is the ability to switch the page between English and Spanish. The website is also valuable in providing access to StrokeSmart, an in-depth and knowledgeable publication which can be delivered to anybody, for free. Beyond these features, the website is also user-friendly for the elderly who may not be able to read small print on websites. Located on the bottom left hand corner of the site is a text change tool to provide larger font sizes for those who lack 20/20 vision. The NSA website can also provide information for research and for additional resources such as your nearest Stroke Center (a hospital that has been designated a national leader in stroke care). One thing that could be improved upon in this site is the wasted space at the top of the webpage. Some of the information clustered in the bottom of the page, such as news and research findings, could be transferred to larger text at the top, making public research and knowledge more accessible.

<http://www.strokeassociation.org>

Rating: 7

American Stroke Association (ASA)

The American Stroke Association provides a more basic website which at first glance lacks the information provided by the NSA's website. However, the website does have some upgrades which the NSA website lacked. For instance, the site contains a scrolling news update for crucial research related to stroke treatment. Moreover, ASA's site provides easy access tabs for stroke symptoms and stroke survivors. There are also useful features not found on NSA's site such as a Frequently Asked Questions tab, a media tab which provides statistics and videos, and also a Heart and Stroke Encyclopedia tab which gives a vast list of medical information alphabetized for ease of use. Despite these, the site lacks the user-friendliness of NSA's site.

<http://www.nlm.nih.gov/medlineplus/stroke.html>

Rating: 7

Medicine Plus

Medicine Plus' website contains a section for stroke and is very simply laid out with plenty of access to information necessary for learning of stroke and for recovering from stroke. The site does not bury the definition of stroke or the symptoms of stroke behind a tab, but instead provides these as the first available information for site visitors. Moreover, the site provides links to other sites for additional information, such as the National Institute of Neurological Disorders and Stroke as well as a special site exclusively for senior citizens. Beyond this, the site provides crucial information such as how to prevent strokes through proper nutrition and even tutorials for stroke rehabilitation and surgery. Perhaps the best feature of the site is a "Go Local" tool which allows visitors to enter their location to see the best stroke treatment centers in their area. While this site certainly provides enough information, it is less user friendly than that of either NSA or ASA.

<http://en.wikipedia.org/wiki/Stroke>

Rating: 6

Wikipedia: Stroke

Wikipedia's webpage for stroke provides a wide breadth of primarily research based knowledge which is unavailable or difficult to find on other sites. Nevertheless, this key feature is also what makes this site difficult to navigate. Unless familiar with the find features on your computer, you will be hard pressed to locate the information you are looking for when researching stroke. Moreover, you must already know about stroke in order to enter the correct search terms. Despite this shortfall, for any person seriously interested in investigating the physiology of stroke (including specifically why stroke symptoms occur), the analytical tools used to assess stroke (i.e., MRI and CT scans), the epidemiology of stroke, or even the history of stroke, the information is present and is very thorough. One definite advantage of Wikipedia is the rapidity at which information is updated. If a new and critical study regarding stroke is released, the findings will quickly be posted on Wikipedia. In addition, the site contains external links for further research and learning.

Overview - Diabetes Mellitus Type 1

Diabetes mellitus type 1 is a chronic disease in which the pancreas ceases to produce insulin, a hormone which is necessary to process blood sugar.¹ Individuals with diabetes of this type must artificially supplement their insulin via injection in order to enable normal food digestion, and must also monitor their blood sugar carefully to prevent it from going too high (which can release toxins into the body and cause organ damage) or too low (which can cause coma and death from lack of blood glucose).² However, with management, individuals with diabetes mellitus type 1 can live long and productive lives³.

Each of these websites is given an overall score from one to five stars on the basis of how informative it is, how well organized it is, and how credible it is.

Rating System

- ***** Excellent resource, could be used as a primary source for anyone
- **** Good resource, could be used as a primary source for most people
- *** Fair resource, should only be used with other sources
- ** Poor resource, could potentially confuse most people unless other sources are used
- * Terrible resource, could potentially confuse anyone unless other sources are used

Websites

<http://diabetes.webmd.com/guide/type-1-diabetes>

WebMD has a plethora of information available on nearly every common disease within the United States. Their section on diabetes covers the different forms of diabetes and includes information on potential symptoms of diabetes and how to tell the two versions apart. The layout is easy to navigate, but can seem cluttered. While most computers are coming with larger and larger screens, the site still seems to waste away large tracks of screen space, compressing text into a column in the middle of the screen. Advertising is prominently displayed, and in general, the site seems too crowded and active. Further, as discussed later in this review, loading a page with this much content both slows load times (important to consumers who are on slow internet connections) and potentially confuses users, giving them too much to choose from.

However, this stylistic issue does not detract from the quality of the information provided and the ease of locating specific information within the diabetes section. The language is accessible to the average reader and there are illustrations at critical points. Further, WebMD is produced and maintained by a team of “medicine, journalism, health communication and content creation” specialists who are clearly credible. *****

http://en.wikipedia.org/wiki/Diabetes_mellitus_type_1

Wikipedia is a free encyclopedia which anyone can edit and access. As a result, its credibility is immediately suspect. At the same time, however, the fact that anyone can edit Wikipedia often results in the availability of information there which has been written by experts in the subject matter. There have been extensive debates on the validity of Wikipedia (for instance, see http://en.wikipedia.org/wiki/Criticism_of_Wikipedia), but the core issue is that

¹ <http://diabetes.webmd.com/tc/type-1-diabetes-topic-overview>

² Primary source; the author's significant other is a type I diabetic.

³ <http://diabetes.webmd.com/tc/type-1-diabetes-topic-overview>

anyone can edit a Wikipedia article, which means that they should never be used without another reference. This automatically means that Wikipedia will receive three stars in this review.

Moving away from issues of credibility, the page on diabetes mellitus type 1 is mostly focused on research and questions of the pathophysiology of the disease. This information is not aimed at the general consumer of health information and seems specialized to researchers. In addition, the article appears to be somewhat poorly organized, with sections appearing in a confusing order. There are extensive links throughout the article to other articles within Wikipedia; these links are embedded in the paragraph. This makes it easy to follow the Wikipedia to other pages, though unfortunately some of these seem to be as poor as this one. Overall, this source is not recommended for users without a background in health care and should not be used as a primary source. **

http://www.medicinenet.com/diabetes_mellitus/article.htm

Medicinenet.com (an unfortunate portmanteau of net and com) is another independent website run by physicians, thus giving it excellent credibility. Of particular note on this website is that the author of each article is listed and linked to, allowing you to look at their background and biography if you are interested. While not strictly necessary for the general consumer of information, this feature could be useful for professionals and researchers. Overall, the articles are well-written, but use language which is not suitable for the entire population. The articles are extensive and explain the issues surrounding diabetes well, but the language and structure seems to assume something akin to a high-school education. This is not necessarily a fact against the site, but means that before referring someone to here, a referrer should consider carefully their level of medical and health expertise.

The “Diabetes at a Glance” section of this website is particularly noteworthy, however.⁴ This section offers clear, concise bullet points which a new patient could review prior to reading in depth, giving a quick overview of the disease. However, the section is located at the end of the article, making it unlikely to be read in this pattern. As a referrer, one may consider giving a link to this section first and then a link to the entire article second, in order to get the “At a Glance” portion into the hands of a friend or patient first.

The website suffers from the same problems as described for WebMD: the content is all arranged into a slender text column in the middle of the page, while to either side there is extraneous data. In some circumstances, it is advertising (a fact which was also in evidence on the WebMD site and which is conspicuously absent from Wikipedia); in other circumstances, it is simply links to other parts of the same site. In either case, the layout is somewhat cluttered and makes load times longer, a fact which may be of some consequence to patients who do not have access to high-speed internet. Also, as stated above, such an “active” interface may confuse or turn off individuals looking for a simple, text-based description of the issue they are facing. Given the slight increase in language difficulty from WebMD, this site is recommended to most users who have some high-school education, but not to those who are less educated. ****

⁴ http://www.medicinenet.com/diabetes_mellitus/page8.htm#glance

Attention-Deficit/Hyperactivity Disorder (ADHD)

Attention-Deficit/Hyperactivity Disorder (ADHD) is a diagnostic label assigned to children who present with symptoms of inattention, impulsivity and hyperactivity. It is a disorder thought to affect anywhere from 3 to 7% of children, with 3 to 5% of all primary school children diagnosed with ADHD. Three different subtypes of ADHD children have been delineated: the inattentive type (ADHD-IA), the hyperactive, impulsive type (ADHD-HI), and the combined type (ADHD-C) based on of the presence of both symptomatology. While population based studies consistently reveal that ADHD-IA is the most prevalent of the ADHD subtypes, clinically admitted children diagnosed with ADHD tend to present with higher rates of ADHD-C (55%) compared to ADHD-IA (27%). The ADHD-C group tend to be rated by parents with higher externalized problems and are more apt to be co-morbidly diagnosed with conduct disorder (24%) and oppositional defiant disorder (68%) compared to the ADHD-IA group (9% conduct disorder; 44% oppositional defiant disorder).

Similar to the patterns observed with other developmental disorders, males tend to be over-represented in the ADHD category, with estimates of 4:1 in the ADHD-C subtype and 2:1 in the ADHD-IA subtype. While consistent gender differences in prevalence rates emerge between subtypes, less is known about how socioeconomic status affects ADHD. Some have argued that ADHD is a middle to upper middle class diagnosis, with higher prevalence rates especially noted for ADHD-IA. Efforts to pinpoint specific subtype differences have met with limited success, with no neuro-anatomical basis for differentiation and limited developmental research in the area.

Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD)

<http://www.chadd.org/>

CHADD is a national organization designed to promote and support and empower people with ADHD and their families. It was founded in 1987 and consists of over 16,000 members. The website is very good, user friendly and well organized. It contains basic information such as defining ADHD subtypes and symptoms and explaining the effects that ADHD has on daily life and school performance of the people affected with it. The website also contains information about ADHD myths and links to ongoing ADHD research studies. I thought the links to the ongoing studies were especially helpful for recruitment for these but also as a source of help for the families needing help that they may not be able to afford, but would receive for free as a member of a trial study. The website is also very good in providing information on finding support. Part of this section involves finding a specialist. You can scroll down to the type of specialists you are interested in, the area that you need help in, and enter your state. A list will be generated!!! The website will also put you in contact with your local branch of the organization for additional support. Very good website.

National Alliance for the Mental Illness (NAMI)

http://www.nami.org/Template.cfm?Section=By_Illness&Template=/TaggedPage/TaggedPageDisplay.cfm&TPLID=54&ContentID=23047

This organization, being that it focuses on mental disorders in the American population in general, is not so specific to ADHD. It does however provide a fact sheet about ADHD. This addresses the different subtypes, causes, treatment, and prevalence in the general population. This website obviously is inferior compared to the CHDD, but is meant as a general overview of ADHD.

Center for Disease Control: Attention-Deficit / Hyperactivity Disorder (ADHD)

<http://www.cdc.gov/ncbddd/adhd/>

The CDC website is also a good place to start when looking for basic information. This includes basic facts such as symptoms and health perspectives, but also provides a research agenda as well as some suggested links to learn more about the disorder. Information sheets are offered as free PDF documents that can be downloaded. I liked the map provided with statistics about ADHD as well as a national report from 2003. The prevalence of ADHD in Ohio children is listed as 8.1-9.0%. The website could use some more information on how to combat ADHD in terms of early diagnosis and treatment strategies.

National Institute of Mental Health

<http://www.nimh.nih.gov/search/index.jsp?q=ADHD>

This website provides 196 hits when searching for ADHD. These articles deal with many different topics from defining the disorder, to treatment and diagnosis procedures, to new findings. One huge downside is the lack of organization of these. Unless your search is very specific on one specific topic, a lot of hits come up and these are not organized in any sort of real fashion, so you just have to glance through them to find what you may be looking for.

US Department of Education

<http://www.ed.gov/searchResults.jhtml>

Searching for ADHD on the Department of Education website produces 288 hits. A lot of these are publications dealing with how to teach / instruct children who have ADHD and how to help them work through this disability. This is the only website that I found which seemed to be directed more towards educators and trying to get them to help. This is a very good idea because with around 10% of US children suffering from ADHD all teachers will have to work with these kids in their classrooms on a regular basis. The articles can be viewed for free and include information coming out from current ADHD studies.

Seeking Care in the Cleveland Area

ADHD Center for Evaluation and Treatment (ACET)

<http://cms.clevelandclinic.org/childrenshospital/body.cfm?id=321>

The Cleveland Clinic is one good place to go for ADHD diagnosis and treatment plan. This center was designed for children suffering from the disorder and works to seek medical and social intervention as modes of treatment while working with families and teachers.

Julie Stephenson
Dr. Neuhauser
MPHP 439
Jan. 28 2008

Web Review

For this project I investigated the resources available to one with Alzheimer's; principally because I walk past a facility for Alzheimer's patients nearly everyday. Furthermore I recall several, okay maybe 10 years ago Alzheimer's made the news and maybe it is just that my perspective has changed, but I rarely hear about any *breakthroughs* or *new treatment options*. CDC faststats names Alzheimer's as the 7th leading cause of death (mortality data from 2004). In Ohio, the Kaiser Family Foundation estimated that the Alzheimer's death rate was 22.4/100,000 in 2004.

Sites Viewed:

<http://www.cdc.gov/nchs/fastats/alzheimr.htm>

<http://www.nia.nih.gov/alzheimers>

<http://www.webmd.com/alzheimers/default.htm>

<http://www.alz.org/cleveland/>

<http://www.statehealthfacts.org/comparemaptable.jsp?ind=63&cat=2&yr=14&typ=3&o=a&sort=n>

In search of information about Alzheimer's I noticed two distinctive venues: federally funded and not-federally funded. The former included, the CDC, the National Institute on Aging both of which had numerous links to NIH studies. In contrast, non-federally funded sites represented Webmd, the Alzheimer's Association and, the ubiquitous Kaiser Family Foundation.

Webmd provided basic information about Alzheimer's for the general public while the Alzheimer's Association took a much more pragmatic approach that also included information about local chapters. Overall these were educational sites offering an efficient overview of symptoms, treatment options, diagnostic criteria as well as links to support services. On a personal note, after drowning in NIH clinical trial reports in JAMA and CDC MMWR it is refreshing to find information that is free of federal-speak (meaning, it does not read like a tax form) as well as relatable to me or my grandmother. In my opinion this is what the CDC and National Institute of Aging lacked- presentation and cohesiveness. For this reason, I recommend that one begin with the user-friendly Webmd et. al. in order to know what to look for on the federally funded sites.

Ultimately, the basics are the same. There are 5 drugs currently on the market to treat the cognitive element of Alzheimer's: Aricept, Exelon, Namem, Razadyne and Cognex. These medications facilitate communication between nerves in the brain damaged by the disease as well as slow the rate of deterioration of healthy nerves. A hallmark of Alzheimer's is the change in personality that patients undergo as the condition progresses. These behavioral changes are particularly difficult for the loved ones of Alzheimer's patients and can be managed with a range of drugs including anti-depressants. Furthermore, it is widely accepted that physical and mental exercise are effective tools that can increase the number of "good days".

Crucial to the treatment of a person with Alzheimer's is the availability and access to service programs. The Alzheimer's Association has a local chapter with 4 offices in northeast Ohio. They offer a wide range of services directed towards Alzheimer's patients and their caregivers including a 24-hour hotline, support groups and a national reporting system for individuals registered with Alzheimer's or another presentation of dementia who may wander from their home. A unique and valuable feature for those of us living in Cleveland is the Clinical Trial Index which identifies clinical trials in your region. Currently there are 16 clinical trials investigating some aspect of Alzheimer's that are in the recruitment stage and seeking volunteers.

Still's Disease

Overview of Still's Disease

Still's Disease is a form of juvenile rheumatoid arthritis (JRA) that can strike both children and adults. In adults it is called Adult Onset Still's Disease (AOSD). AOSD occurs in about 1 out of 100,000 people worldwide. The patterns of disease differ; for some it goes away permanently, some experience remissions, and some experience constant SD.

The cause is unknown, but there are many theories, including it being caused by a microbacterial infection, or being an autoimmune disorder.

The symptoms of AOSD are similar to Lupus and include:

- Spiking, intermittent fevers (Usually about 100° to 104° F)
- Rash
- Joint pain and swelling (Rheumatoid Arthritis)
- Inflammation of organs

There isn't a cure for Still's Disease, although there are treatments available. These include NSAIDS (anti-inflammatory medications), cortosteroids, Cox-2 inhibitors, arthritis medications, and many with Still's Disease use pain medication.

Website Reviews

The following websites were rated mainly on overall appeal of site, ease of navigation, forums/email groups/bulletin boards, support group and doctor contact information, treatment information, and links to other sites.

The rating system is as follows:

- *****Excellent
- ****Very Good
- ***Good
- **Fair
- *Poor

<http://www.stillsdisease.org/>

Rating: ****

International Still's Disease Foundation

The headline of the homepage is "Welcome to Stilligan's Island". This is worth noting and depending on who you are, it might elicit a small laugh or smile. Overall, it gives a decent overview of what the disease is and discusses the different treatment options and a guide to lab tests. It offers a support group, a mailing list, a discussion board, a chat and a form to find a rheumatologist locally. The general information is easy to understand, but the question and answer section (FAQs) is incomplete. It also needs to be edited better. For those that are interested in more information, it offers links to other sites and Still's

Disease information in peer-reviewed journals. It's useful for general information about Still's Disease and treatments.

http://en.wikipedia.org/wiki/Still%27s_disease

Rating: **

Still's Disease Wikipedia Article

This website is a very basic and brief overview of Still's Disease. It offers some of the symptoms, diagnosis, and prognosis. It doesn't give a lot of information, but offers some external links to other sites.

<http://www.mayoclinic.com/health/adult-stills-disease/DS00792>

Rating: ***

Mayo Clinic Adult Still's Disease Information

The layout of Mayo Clinic's website goes in a progression by clicking the next button instead of seeing it all at one time. You have an option to skip sections. The sections are titled "Introduction", "Signs and Symptoms", "Causes", "Risk Factors", "When to Seek Medical Advice", "Screening and Diagnosis", "Complications", "Treatment", "Prevention", "Self-Care". All of these sections are very short but very easy to understand. It's good for someone just learning about Still's Disease. It's also easy to navigate even with having to go into different websites every time for a new section. It also offers a "more on this topic" section that gives links to different articles relating to arthritis. Overall, it's a good website, but it doesn't offer any information about support groups or external links for Still's Disease

<http://www.arthritis.ca/types%20of%20arthritis/Stills/default.asp?s=1>

Rating: *****

Still's Disease from the Arthritis Society of Canada

This webpage is very similar to the Mayo Clinic one where it has sections. These sections are very similar but are in the form of questions, such as: "How Common Is Still's Disease?". It offers similar information, but also offers information about how to contact the Arthritis Society for information on support groups and resources. It also offers links to a self-help program and a forum for support for patients with AOSD. This site is very easy to navigate and gives some in depth information that the other websites haven't covered, such as how frequent and in what percentage of the affected population do certain symptoms occur and how to manage medications safely.