Biofeedback 104 - November 2014

Welcome to the 104th issue of Biofeedback!

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**Director's Notes**

After working in the USA Biomedical Library for 25 years, I have announced my retirement effective 12/31/14. I have thoroughly enjoyed working with the health sciences faculty and staff on projects involving research and curriculum. The challenges presented have helped me to grow professionally. Also, I am very thankful for the support provided to help me develop my professional skills.

I will be leaving the Biomedical Library in the very capable hands of Geneva Staggs, who will be appointed Interim Director. She along with the wonderful faculty and staff of the Biomedical Library will continue to provide you with the value added service to which you have become accustomed.

I feel very blessed for the opportunities I have had in the years I have worked at USA and look forward to seeing the University continue to expand and improve.

Judy Burnham
USA Biomedical Library Hosts the Southern Chapter/Medical Library Association

The USA Biomedical Library hosted the 64th Annual Meeting of the Southern Chapter/Medical Library Association at the Battle House Hotel the last week in October. Faculty and staff from the Biomedical Library planned the meeting that included over 100 health science librarians from throughout Alabama, Florida, Georgia, Mississippi, South Carolina, Tennessee and Puerto Rico. There were also 17 exhibitors present. The Welcome Reception included an introduction to Mobile Mardi Gras, and the banquet was held at the 5 Rivers Delta complex. Dr. Sam Strada, Dean of the College of Medicine, delivered a welcome on behalf of the University. Speakers included Dr. Sheri Fink, author of Five Days at Memorial: Life in a Storm Ravaged Hospital. Because Dr. Fink was in Liberia covering the Ebola crisis for the New York Times, her presentation was given via Skype. Dr. Elaine Martin, Director of Library Services, Lamar Soutter Library, and Director, National Network of Libraries of Medicine, New England Region, at the University of Massachusetts Medical School, Worcester, also gave a presentation entitled "Reshaping the Health Science Librarian." She discussed emerging new roles for health science librarians. Ray Weinshenker, a graduate of USA in Recreational Therapy, concluded the keynote addresses with a laugh therapy session.


Also at the meeting Judy Burnham was award the T. Mark Hodges Outstanding Service Award. The Award is given for dedicated and continuing service to Southern Chapter in the form of elected or appointed office, committee participation, and/or presenting papers or posters at the Chapter meetings.

AccessMedicine App

AccessMedicine now has a mobile app that features four clinical reference titles. To use the app, first sign up for a MyAccess Personal Account by visiting AccessMedicine, clicking the "University of South Alabama" drop down in the top, right corner of the screen, then choosing "Login or Create a Free Personal Account." The AccessMedicine app is available for iOS and Android.

- Quick Medical Dx & Rx - quick outlines for clinical reference
- Fitzpatrick's Color Atlas of Clinical Dermatology - visual atlas with color images to facilitate diagnosis
- Differential Diagnosis Tool - browse this reference by symptom, disease, or organ system
MedGen

MedGen is an information portal that combines knowledge from all over NCBI resources to provide genetic and clinical information about phenotypes and medical disorders with genetic components. MedGen records define and collect disorders with multiple names into single concept pages that provide descriptions, causative genetic variants, medical findings, access to a registry of available tests and the facilities that provide them, applicable clinical trials, evidence-based guidelines, patient information, molecular resources, and more. MedGen aggregates information from Online Mendelian Inheritance in Man, ClinVar, GeneReviews, PubMed Health, Genetics Home Reference, the Genetic Testing Registry, ClinicalTrials.gov and other NCBI tools.

Hb SS disease
MedGen UID: 287 • Concept ID: C0002885 • Disease or Syndrome

Synonyms:
- Anemia, Sickle Cell; HbS disease; Hemoglobin S Disease; Hemoglobin S; Sickle cell anemia; Sickle cell disease; Sickle cell disorders; Sickling disorder due to hemoglobin S

Modes of inheritance:

- Autosomal recessive inheritance
- SNOMED CT:
  - Sickle cell disease (127040003); Hemoglobin S-S disease (127040003); Hb SS disease (127040003); Sickle cell anemia (127040003); Hemoglobin S-S disease (127040003); Hb S disease (127040003); HbS disease (127040003); HbS disease (127040003); HbS disease (127040003); HbS disease (127040003)

Gene:
- HBB

Cytogenetic location:
- 11p15.4

OMIM®:
- 603903

Orphanet:
- ORPHA232

Disease characteristics

Excerpted from the GeneReview: Sickle Cell Disease
Sickle cell disease (SCD) is characterized by intermittent vaso-occlusive events and chronic hemolytic anemia. Vaso-occlusive events result in tissue ischemia leading to acute and chronic pain as well as organ damage that can affect any organ in the body, including the bones, lungs, liver, kidneys, brain, eyes, and joints. Dactylitis (pain and/or swelling of the hands or feet) in infants and young children is often the earliest manifestation of sickle cell disease. In children the spleen can become engorged with blood cells in a ‘spleenic sequestration’. The spleen is particularly subject to infection and the majority of individuals with SCD are functionally asplenic in early childhood, increasing their risk for certain types of bacterial infections. Chronic hemolysis can result in varying degrees of anemia, jaundice, cholelithiasis, and delayed growth and sexual maturation. Individuals with the highest rates of hemolysis are predisposed to pulmonary artery hypertension, priapism, and leg scleroses but may be relatively protected from vaso-occlusive pain. [from GeneReviews]

From OMIM
Sickle cell anemia is a multisystem disease associated with episodes of acute illness and progressive organ damage. Hemoglobin polymerization, leading to erythrocyte rigidity and vasoocclusion, is central to the pathophysiology of the disease, but the importance of chronic anemia, hemolysis, and vasocapathia has been established. The most common cause of sickle cell anemia is the HbS variant (141900.0243), with hemoglobin SS disease being most prevalent in Africans (review by Rees et al., 2010). http://www.omim.org/entry/603903

Additional descriptions

View full author information

Genetics Home Reference
Genetic Alliance
NCATS Office of Rare Diseases Research (GARD)
MedlinePlus
From GHR
Sickle cell disease (SCD) is a group of disorders that affects hemoglobin, the molecule in red blood cells that delivers oxygen to cells throughout the body. People with this disorder have hemoglobin molecules called hemoglobin S, which can distort red blood cells into sickle, or crescent, shape. Signs and symptoms of sickle cell disease usually begin in early childhood. Characteristic features of this disorder include a low number of red blood cells (anemia), repeated infections, and periodic episodes of pain. The severity of symptoms varies from person to person. Some people have mild symptoms, while others are frequently hospitalized for more serious complications. The signs and symptoms of sickle cell disease are caused by the sickling of red blood cells. When red blood cells sickle, they break down prematurely, which can lead to anemia. Anemia can cause shortness of breath, fatigue, and delayed growth and development in children. The rapid breakdown of red blood cells may also cause yellowing of the skin, which are signs of jaundice. Painful episodes can occur when sickled red blood cells, which are stiff and inflexible, get stuck in small blood vessels. These episodes deprive tissues and organs of oxygen-rich blood and can lead to organ damage, especially in the lungs, kidneys, spleen, and brain. A particularly serious complication of sickle cell disease is high blood pressure in the blood vessels that supply the lungs (pulmonary hypertension). Pulmonary hypertension occurs in about one-third of adults with sickle cell disease and can lead to heart failure. http://ghr.nlm.nih.gov/condition/sickle-cell-disease

Clinical features

Abnormality of blood and blood-forming tissues
Abnormality of metabolism/homeostasis
Abnormality of the abdomen
- Cholelithiasis
- Hepatomegaly
- Jaundice
- Splenomegaly
Abnormality of the cardiovascular system
- Cardiomegaly
Abnormality of the eye
Abnormality of the genitourinary system
Abnormality of the immune system
Abnormality of the integument

Term Hierarchy

Clinical test, Research tests, OMIM, GeneReviews
Hemoglobinopathy
- Hb SS disease
  - Sickle cell-beta-thalassemia
  - Sickle cell-hemoglobin C disease
  - Sickle cell-hemoglobin D disease
  - Sickle cell-Hemoglobin 0 Arab disease
- Thalassemia
Mendeley

Mendeley is a free reference manager and academic social networking tool. With Mendeley, you can read and annotate PDF articles either by highlighting or with sticky notes, tag them with your own keywords and make your own fully-searchable library in seconds. You can share your notes and collaborate with others by creating a public or private group. You can see comments others add as well as what others add to the group. Public groups allow users to see who is working on the same type of research and perhaps find collaborators for a project. You can follow individuals in whose research you are interested. Mendeley works with a variety of devices.

Webinars with more information about Mendeley can be found at https://www.brighttalk.com/channel/11355.
Copyright Corner: a Practical Guide to Copyright

(In the next several issues of Biofeedback, I will present basic information about copyright principles and copyright law in the United States. If you have questions, please contact me, Trey Lemley, Information Services Librarian at the University of South Alabama Biomedical Library.)

According to Black’s Law Dictionary, copyright is “a right granted by statute to the author or originator of certain literary or artistic productions, whereby he is invested, for a limited period, with the sole and exclusive privilege of multiplying copies of the same and publishing and selling them.” The United States Copyright Office defines copyright as a “form of protection grounded in the U.S. Constitution and granted by law for original works of authorship fixed in a tangible medium of expression.” Copyright is enshrined in American law at various levels: its constitutional basis is found in the U.S. Constitution in Chapter XIV, Article I, §8, Par 8, also known as the “Patent and Copyright Clause:

“The Congress shall have power to promote the progress of science and useful arts, by securing for limited times to authors and inventors the exclusive right to their respective writings and discoveries.”

In addition, the statutory basis for copyright is found in Title 17 of the United States Code, as revised by the U.S. Copyright Act of 1976. Furthermore, the Berne Convention, an international copyright convention to which the United States became a signatory in 1989, granted U.S. authors more rights/advantages in the international arena and created minimum standards for copyright, which altered some rules and regulations pertaining to copyright in the United States.

Two core concepts of copyright law are originality and ownership. According to the United States Copyright Office, copyright is a form of protection provided by the government to authors of original works, including literary, dramatic, musical, artistic works, among others. This originality requirement is one of the building blocks of copyright protection and has been for over 200 years. Likewise, another foundational aspect of copyright is ownership: a copyright can be owned and becomes the property of the author as soon as the work is created, although an author can transfer ownership rights. (But note: if an employee creates a work within the scope of his/her employment, then the work is termed a “work made for hire,” and generally the employer owns the copyright.)

As a concomitant, the copyright owner has numerous exclusive rights, including the right to reproduce the work (1), to prepare derivative works (2), to distribute copies of the work to the public (3), to perform the work publicly (4), and to display the work publicly (5). One important point: according to Circular 1 of the U.S. Copyright Office, mere ownership of a copy of the copyrighted work does not give the possessor the copyright. In other words, simply buying a book does not confer any rights in the copyright.
Copyright protection starts automatically as soon as the work is created/recorded in some concrete form. Or in copyright-speak, to be eligible for copyright, a work must be an original work of authorship fixed in a tangible medium or tangible form of expression in which the expression can be reproduced. The fixation requirement is met if the work can be read or visually perceived directly [i.e., book, manuscript, sheet music] or with the aid of a machine or device [i.e., film, videotape, or microfilm]. In contrast, a thought or idea is not copyrightable; however, if the thought or idea is written down, the writing itself is protected by copyright, because the writing is a tangible medium of expression, in contrast to the thought or idea, which is not tangible and hence not copyrightable. Likewise, words once entered into a computer are a tangible medium of expression, and thus copyrightable. Finally, a work must demonstrate minimal creativity in order to be copyrightable.

What is copyrightable? Copyrightable works include the following (this list is not exhaustive):

- literary works (books, articles), music, dramatic works.
- computer programs, software, websites, e-mail messages.
- pictorial, graphic, and sculptural works.
- motion pictures and other audiovisual works.
- sound recordings.

(An interesting note about websites: copyright infringement can occur whenever copyrighted material is copied from or posted [i.e., "uploaded"] to a website without authorization from the copyright owner, but creating a regular word link to another website's home page does not violate copyright law. See Stanford University Libraries. Transferring Information to and From a Website.)

In contrast, the following items are not copyrightable.

- works not fixed in a tangible form of expression, such as a speech or lecture.
- titles, names, short phrases, slogans.
- familiar symbols or designs.
- variations of typographic ornamentation, lettering, or coloring.
- a simple list of ingredients or contents.
- ideas, procedures, methods, systems, processes, concepts, principles, discoveries, or devices.
- calendars, height and weight charts, tape measures and rulers.
- lists or tables taken from public documents or other common sources.
- works authored or prepared by the U.S. government.

(But some of these might be covered by other forms of intellectual property, such as patent or trademark law.)

Is notice required? There used to be a notice requirement, but it was eliminated in 1989 when the U.S. joined the Berne Convention. Before 1989, all copyrightable works had to display a notice using the following format: © 2014 John Doe, in which © is the symbol for copyright, 2014 is the year of first publication, and “John Doe” is the name of the copyright owner. Although notice is no longer required, there are advantages to displaying notice: it makes it easier to win a copyright infringement lawsuit, because the infringer cannot claim he/she did not know the material was copyrighted. Also, including a copyright notice might make it easier for a potential infringer to track down a copyright owner and legitimately obtain permission to use the work. (See Stanford University Libraries. Copyright Protection: What It Is, How It Works.)
How Long Does Copyright Protection Last? Works originally created on or after January 1, 1978 are protected from the moment of creation until 70 years after the death of the author. In contrast, for works originally created, published or registered before January 1, 1978, the length of copyright protection was 28 years, renewable once during the 28th year for another 28 year period. When the copyright expires, the work enters the public domain, which means anyone can use the item for free, without obtaining permission of the copyright owner. (For more information on the public domain, see a 2014 article from Biofeedback entitled “Copyright Corner: Public Domain Day.”)

Do I Have To Register My Copyright? Registration is no longer a requirement for copyright protection, but registering a copyright is advantageous in that it establishes a public record of the copyright claim. In addition, in order to file an infringement suit, the author or owner must register [if the work is of U.S. origin]. The registration process is not hard: see the website of the United States Copyright Office at http://www.copyright.gov/. It is possible to register online via the eCO Registration System or by paper forms (available on the Copyright Office’s website). Both methods require a fee and submission of deposit copy (or copies, depending on the class of work). Finally, the copyright owner can register at any time during the life of the copyright.

I think that’s enough for now. In future issues of Biofeedback, I will discuss several topics, including copyright infringement, the rights of the copyright owner, and finally, fair use and the TEACH Act, both of which make it possible to use portions of copyrighted works for educational purposes, including some forms of online instruction, without the permission of the copyright owner.

Trey Lemley, MLIS, JD
Phase 2 of the Healthcare Information for Seniors Project is well underway and seniors in high health disparate zip codes across Mobile are learning to use IPads to locate reliable and accurate health information. During this second instruction session, seniors are guided through four search scenarios as a class, to improve their usability of the IPads and to increase their confidence in using the mobile versions of SeniorHealth.gov and MedlinePlus.gov.

The four search scenarios are as follows:

Using SeniorHealth.gov:
1. A woman explains, “I have high blood cholesterol and my doctor told me I need to eat healthy. I've tried on my own, but I need some help.” She wants more information on anything to help her eat more healthful to lower her high blood cholesterol.

Discussion: For this question, seniors are shown how to use the “Health Topics by First Letter” feature, by selecting “H” for “high blood cholesterol.” Next, seniors are guided through the “In This Topic” section on the left side of the screen, which breaks down the topic of “high blood cholesterol” into small subtopics. Seniors choose the subtopic “Therapeutic Lifestyle Changes (TLC),” where they find suggestions on lifestyle changes to lower LDL, information on the TLC diet, tips on weight management, and a guide to physical activity.

This question introduces the “Health Topics by First Letter” feature and how to use the “In This Topic” section, as two important and easy-to-use methods to research a specific health topic in SeniorHealth.

2. A doctor encourages his patient, a man in his 60’s, to have hip replacement surgery to improve his quality of life. He wants more information on risk factors, the pros and cons of the procedure, and how difficult therapy will be after the surgery. He was also wondering if there were any videos he could watch on this topic.

Discussion: For this question, seniors are instructed on how to use the “Search Box,” located at the very top of the SeniorHealth homepage. Seniors type in “Hip Replacement Surgery” in the search box and click “Go.” This presents a good opportunity to show seniors what happens if you misspell a word in the search box. SeniorHealth is fairly accurate in predicting the intended search terms and seniors are shown how to either click SeniorHealth’s suggested terms or retype their search terms again in the “Search Box.” Seniors examine the choices of articles and choose the one that best answers the scenario question.

From there, seniors are guided to the “Videos A-Z” section at the top of the page because the gentleman in the search scenario wondered if there were any videos on the topic of hip replacement surgery. Seniors locate “Hip Replacement” from the video choices, which are in alphabetical order. Seniors, then choose one of the five choices to watch from their iPad.

This question introduces the use of the “Search Box” feature as well as introduces seniors on how to locate videos on specific health topics.

Using MedlinePlus.gov:

3. My grandmother wants more information on a prescription her doctor just gave her. The drug is called Restasis.

Discussion: Seniors begin by using the “Drugs and Supplements” section of MedlinePlus. At this point, seniors are asked what they think the next step should be. Since the A-Z feature is similar to SeniorHealth’s, most seniors know to click on the letter “R” for Restasis. Seniors are guided on using their index finger to scroll down to locate Restasis and informed that the drug listings are in alphabetical order. Because Restasis is a brand named product, the word itself is not clickable, but located right next to the word is its alternative name, Cyclosporine Ophthalmic. This presents a good opportunity to inform the class that text that is blue and underlined is clickable, whereas text that it is black and not underlined is not.

From there seniors review the article about the drug Restasis and note the date “Last Revised” at the bottom of the page, which assures them of its currency.
4. A teenage girl says her dad has this problem where he can’t swallow and thinks it could be a sign of Parkinson’s disease? She thinks the doctor called it “dysphasia.”

Discussion: This question is purposeful in nature as the spelling in the question, “dysphasia,” is not a condition of difficulty swallowing. The search begins with a quick look at the “Health Topics” section of MedlinePlus. When the term “dysphasia” is not found, seniors are encouraged not to give up their search. Seniors are advised that because we are unsure of the spelling of this condition and because we could not locate the word in the “Health Topics,” that we should try the “Medical Dictionary” in MedlinePlus. From there, seniors type in the word “dysphasia” in the “Medical Dictionary” search box only to discover that the word has something to do with the inability to understand language as a result of injury or disease. Seniors are again assured that stumbling blocks are a part of becoming a good researcher and encouraged to keep trying. This time, the class uses the “Search MedlinePlus” box from the homepage and instead of guessing the correct spelling of the condition, the class is asked to think of other keywords, which may have been included in the question. Seniors then type the words “difficulty swallowing” in the search box and from those results, discover that the condition is actually spelled “dysphagia.”

This question introduces more advanced search techniques in MedlinePlus, which most seniors are willing to try.

The second phase of the Healthcare Information for Seniors Project has shown that seniors in high health disparate locations in the Mobile seem eager to learn new search strategies and are willing to try new technologies to improve their overall health. The third and final phase of this project will include these same seniors creating updatable, personal health records using an iPad app, and with those records being saved to their own personal flash drive.

This project has been funded in whole or in part with Federal funds from the Department of Health and Human Services, National Institutes of Health, National Library of Medicine, under Contract No. HHSN-276-2011-00004-C, with the University of South Alabama.
USA Biomedical Librarian Earns MLA’s Consumer Health Information Specialization, Level II

Christy Kent, assistant librarian at the USA Biomedical Library, was recently awarded the Level II Consumer Health Information Specialization (CHIS) as offered by the Medical Library Association (MLA). MLA’s CHIS program is a continuing education program to help librarians (medical and public) and allied health professionals keep current in the consumer health information field by providing access to new resources and ideas.

The level II specialization is for those who have gained additional training in consumer health information. Obtaining this more advanced level of specialization requires completion of twenty-four contact hours in at least four courses in separate areas of knowledge.

Christy shares this distinction with other library faculty and staff including, Geneva Bush Staggs, Nancy Pugh, and Heather Hoven.

According to Kent, CHIS membership gives medical librarians with consumer health interests a framework for continuing education and professional development. “As the Outreach Librarian, much of my job involves improving health information services for consumers and creating community partnerships for the delivery of consumer health information,” Kent said. “This certification has not only provided me with the necessary tools to identify and select appropriate consumer health education materials, but also emphasized the importance of networking with community health leaders, organizations, and agencies to facilitate resource sharing and educational opportunities.”

An important goal of the CHIS specialization program is to provide a guide to best practices in providing consumer health information services.


8. Gauthier LV, Mark VW, Taub E, McCullars A, Barghi A, Rickards T, Hicks J, Uswatte G. Motor recovery from constraint induced movement therapy is not constrained by extent of tissue damage following stroke. Restorative Neurology and Neuroscience. 2014 Sep 3; epub ahead of print.


