COVER: Denver Educational Seminar Highlights Need for Early AS Diagnosis

Electronic Medical Records: Numbering the Days of the Paper-Based System

Symptoms and Social Security Disability Benefits: Are They Enough to Prove Disability?
ON POINT

SAA is, first and foremost, a volunteer organization and so I greatly appreciate the unique qualities that each volunteer brings to the table. Consequently, every two years when the SAA Board of Directors seeks a candidate from within to assume the role of Board Chair for the upcoming term, the utmost diligence is exercised to assess each volunteer board member’s strengths and match them to the organization’s current needs.

This year, I am honored to introduce our new Chair, Michael J. Supancich, M.D. I have had the pleasure of working with Michael during the past several years and I cannot think of any candidate better suited at this time to assume this tremendous responsibility.

Dr. Supancich is a retired General Ophthalmologist from Carlsbad, California, with a fifty year history of Ankylosing Spondylitis. In addition to his board service, he has been leading a highly proactive Educational Support Group in San Diego for six years. He is known by many for his calm and caring demeanor, high intelligence and acute sense of humor.

As we welcome Mike, it is with deep appreciation that we acknowledge the fine work done by our two-term outgoing Chair, Dr. David Hallegua. We are grateful that David will continue to serve on the board during the upcoming term. During the past four years, David has provided outstanding leadership to SAA -- supporting our vision and motivating, inspiring and energizing people at every level of the organization to be their very best.

In this fiscal year, with the help of many volunteers -- friends both old and new -- SAA’s programs and services will expand in number as well as scope. New programs include a peer mentor program, informational podcasts and webinars and a new website that will include the SAA Interactive Screening Tool for AS.

Another program that I am very proud to announce is the development and implementation of an education and awareness campaign in collaboration with the National Association of Emergency Medical Technicians (NAEMT) to address the needs of spondylitis patients during a medical emergency. One reason that I am so proud of this initiative is that it was driven by you -- our members. You told us of the need to address this critical issue and we listened. This initiative would not be underway if not for you and I thank you for that as well as for your continued support. The program, which will include a video reenactment, will be made available to the more than 800,000 emergency medical technicians and paramedics in the United States.

I look forward to sharing additional information about these and other programs throughout the upcoming year.

Laurie M. Savage
Executive Director
SWIFT (Spondylitis Web Info For Teens)
I don’t know how long SWIFT has been around, but thank you! I’m a grown up now...30 (yikes)! Nothing like this existed when I was a teen. I had so many questions and I felt so alone. I was originally diagnosed with JRA after a bad car wreck in the 3rd grade. (Now diagnosed as AS) I continued to stay active, even through the pain, most of my life. When I was younger I was told to stay away from too much physical activity. Now my doctor has said that the activity is the only thing that has kept me from being in a wheelchair. I can relate to these teens in many ways and I want to encourage them that it is possible to have a normal life. People may not understand you or your physical limitations but don’t let it stop you from being all that you can be. Try new things, learn all you can about the world and don’t let any one tell you that you can’t do something. With AS we can do everything that others can, just in a different way.

Once again, thank you for this site! I’m sure that it has comforted many to know that they are not alone.

CHRISTINA ASHFORTH, Chicago, IL

Remicade?
I have AS with a fused neck, no chest expansion and little lower back movement but very little pain. About 3 months ago my rheumatologist suggested we try Remicade by infusion. After determining that I had no side effects I now receive infusions every 8 weeks. Results have been great with considerably more flexibility than I’ve had in years. I haven’t seen Remicade discussed in your literature and wondered why. If it works on someone in their 70s I would think it would do even more with younger people.

ART PEHRSON, Hilton Head Island, SC

Editor’s Note: Dear Art, thanks for the note. Remicade is one of the medications called “TNF-a Inhibitors” also known as “biologic” medications. We refer to it as Infliximab, which is its generic drug name. The other two in this class that are FDA approved for AS at this time are Enbrel (generic name Etanercept) and Humira (generic name Adalimumab). We currently have information on this class of medications on our website, in our brochures, and in our books “Your Guide to Living with Ankylosing Spondylitis” and “Straight Talk on Spondylitis”.

Denver Educational Seminar
I just wanted to thank you and the organization for the wonderful seminar in Denver. I enjoyed and found both speakers very educational and thought how wonderful it would have been 27 years ago when I first was diagnosed with AS to have had this type of opportunity and help. It is great to have an organization to share and gather info. As you know, our support group in Denver is just getting off the ground and I am sure that some of the people at the seminar will show up to our next meeting and we can grow and contribute. As a long time member I would just like to express my thanks for all the things SAA has done and continues to do.

PETE PETERSON, Denver, CO

Letters to the Editor
Dear Readers: We want to hear from you, whether it be informative, uplifting or a concern you need to express. Include your full name, address and daytime phone number.

We reserve the right to edit for space and clarity.

Please send letters to: laurie.savage@spondylitis.org
Letters to the Editor/SAA
P.O. Box 5872, Sherman Oaks, CA 91413
Nearly a year ago, researchers identified two genes, ARTS1 and IL23R, which increase the risk of developing ankylosing spondylitis. People carrying variants of these two genes, along with the genetic variant HLA-B27, are expected to have a one in four chance of developing spondylitis.

Speaking to a packed audience at a Spondylitis Association of America educational seminar in Denver in June, Dr. Michael Weisman, a Los Angeles rheumatologist who specializes in spondylitis, said the identification of these two genes should make early diagnosis of the disease easier for clinicians. Early diagnosis is important in terms of beginning appropriate therapies and preventing potentially debilitating deformities.

These two new genes, in addition to HLA-B27, a powerful predisposing gene identified nearly 38 years ago, and inflammatory back pain, “will almost make the diagnosis of ankylosing spondylitis. The answer is, yes, these new genes are going to be helpful,” said Dr. Weisman, Director of the Division of Rheumatology at Cedars-Sinai Medical Center and Professor of Medicine at the David Geffen School of Medicine at UCLA.

Early diagnosis tricky but essential

The many different forms of the disease and our limitations in understanding how and when the disease begins make diagnosing spondylitis difficult. Dr. Weisman said a proper diagnosis typically includes classification (a set of criteria used to identify spondylitis patients unequivocally), genetic epidemiology, and symptomology.

The New York Classification Criteria for Ankylosing Spondylitis, developed in 1966, is the most widely used set of criteria for determining who has spondylitis. This system classifies the disease based on both clinical and radiological components. But, says Dr. Weisman, the system has limitations, primarily because it identifies only people who have late-stage disease or disease that has progressed beyond a certain point.

“When you classify patients,” he said, “they have to absolutely have the disease, but that doesn’t mean that people who have the disease may not make those criteria when you diagnose them. They may not be severe enough. It may not be fully manifest.”

Clinicians can, he added, diagnose a patient before they meet classification criteria, so these criteria are not necessarily, in and of themselves, diagnostic.

“If you use classification criteria to diagnose patients, you’re going to miss people, a whole lot of them who have not fully developed the features to be classified as having the disease,” he said. “This is an extremely important issue because classification criteria have been misused as diagnostic criteria.”
Susceptibility to AS is largely genetically determined. If one identical twin has AS, the other twin has a 63 percent chance of developing the disease. This compares to a 23 percent chance in fraternal twins (twins who are not genetically identical). The risk of AS in a sibling of someone who has the disease and is HLA-B27 positive is considerably higher than it is in an HLA-B27 individual in the community.

Although not yet commercially available, genetic testing, says Dr. Weisman, can help to identify individuals who are at risk of developing AS; however, there are limits to this, as well. The discovery of the ARTS1 and IL23R genes makes genetic testing much more accurate than simply testing for the genetic variant of HLA-B27.

“The key to making a diagnosis of AS is understanding what constitutes inflammatory back pain.”

“Now if you screen patients and find a population that has inflammatory back pain—let’s say 10 percent; let’s say you screen patients and with that screening tool, you come up with a 10 percent prevalence—if you apply just B27, the prevalence will be 50 percent. If you add the other two genes, the prevalence goes up to 90 percent. So these two new genes, if you add it to an inflammatory-backpain population, you will almost make the diagnosis of ankylosing spondylitis,” said Dr. Weisman.

Inflammatory back pain is key to diagnosis

The key to making a diagnosis of AS, however, is understanding what constitutes inflammatory back pain. Inflammatory back pain, said Dr. Weisman, is back pain that awakens you in the middle of the night, improves with exercise and walking throughout the day, is worse in the morning and is associated with morning stiffness, and sometimes alternates from buttock to buttock. Mechanical back pain, on the other hand, usually does not awaken you and typically worsens during the day.

In an attempt to develop a diagnostic algorithm for AS, a European study conducted several years ago examined inflammatory back pain in both AS patients with back pain and non-AS patients with back pain. Using criteria such as morning stiffness, improvement with exercise, awakening in the second half of the night, and alternating buttock pain, the researchers found that inflammatory back pain was present in a large majority of the AS patients compared to the control group of non-AS patients.

“Inflammatory back pain is a pretty good way of telling the difference between AS and non-AS back pain.” The recognition of inflammatory back pain will lead to a diagnostic algorithm for early diagnosis of AS, he added.

Another tool for diagnosing spondylitis is radiographic testing, or X-rays. But, says Dr. Weisman, what kind of X-rays should be used? Who should do them? Who should interpret them?

MRI, or magnetic resonance imaging, uses a magnetic field and pulses of radio wave energy to make pictures of organs and structures in the body. This type of imaging gives different information than a standard X-ray and may show problems that cannot be seen with other imaging studies.

“In an MRI is a completely different modality [than an X-ray],” said Dr. Weisman. “An MRI is actually using a magnetic field to measure inflammation of the molecules. An X-ray only shows you bones. An MRI shows you soft tissues and tendons and ligaments and fluid.”

Further, he said, an accurate diagnosis may not be possible because subtle disease changes over time cannot be detected using conventional X-rays. While results may be ambiguous early in the disease process, MRI is better suited, over the long haul, to identify these changes.

Yesterday and Today

Advances in diagnostic techniques have created an old-world vs. new-world view of AS. The old-world view said that there was a long period of back pain and then, at some point, X-ray changes took place and an individual was diagnosed with spondylitis. Dr. Weisman said this really was not a diagnosis of spondylitis, but actually radiographic sacroiliitis. This is inflammation of one or both of the sacroiliac joints, which connect the lower spine to the pelvis, that shows up on an X-ray and is a prognostic factor for AS.

“The new-fashioned way of looking at the disease,” he said, “is that there’s a genetic predisposition, there’s an environmental trigger—and we don’t know what it is—and there’s the onset of symptoms that take place for a long period of time before patients get X-ray changes. This is our new paradigm of the disease over time.”

This new way of thinking about AS and the resulting changes in treatment, however, leads to several questions: do anti-TNF therapies alter the natural history of the disease and improve prognosis? Even with the identification of IL23R and ARTS1, do we completely understand the genetic risk for the disease?
Anti-TNF therapies have been proven to reduce inflammation, said Dr. Weisman, which can be measured with MRI and blood tests, but do they have an impact on fusion over time? These therapies are drugs that block the action of tumor necrosis factor (TNF), which causes the inflammation associated with AS and other autoimmune disorders.

“In studies that have been done so far, the measuring tools that have been used have not shown that anti-TNF drugs have had an impact on the rate of change, of bony change,” he said. Two potential reasons exist: one, the fusion that takes place in AS is independent of any anti-TNF action (that is, these drugs do not control the process of bone change that leads to fusion) and two, other pathologic mechanisms are causing bone changes that are not affected by anti-TNF drugs.

While these drugs do treat inflammation but not bone changes, Dr. Weisman considers them to be a “boon to patients with ankylosing spondylitis.”

**What is SAA doing?**

The Spondylitis Association of America is actively involved in helping physicians make early diagnoses of AS through a research study to develop a screening tool that identifies people at risk for the disease.

In this case, the tool is actually a questionnaire that will help to differentiate back pain caused by AS from other causes of back pain. At the conclusion of the three-year study, which began in 2005, the questionnaire will be available on the Internet for those searching for the cause of their pain.

An individual will answer the questionnaire and a score will be generated in real time that states the likelihood of that person having AS. Information on the disease and instructions on where to seek help will also be provided. Individuals with high-risk scores can see their physicians and obtain further testing, such as genetic testing for the HLA-B27, IL23R and ARTS1 variants and MRI.

“Ultimately, the screening tool will help to identify new cases, greatly improve early diagnosis, encourage care-seeking among patients who learn that they are at risk for AS, provide useful information to patients and physicians, and help raise awareness about AS,” said Dr. Weisman, who is the study’s principal investigator.

**“Shining a light” on early diagnosis**

Ankylosing spondylitis is often diagnosed late and under-treated, with traditional therapies providing only symptomatic relief. An earlier diagnosis of the disease based on inflammatory back pain, imaging features, and genetic testing should, said Dr. Weisman, provide a “window of opportunity” to make therapy more definitive. Early diagnosis is important in terms of being able to identify patients before they develop the changes that occur in the spine that limit activity. Diagnosing patients when they fulfill classification criteria is too late, he added, because their joints have already been damaged.

“Early diagnosis [of AS] is close to being made with the development of assessment for inflammatory back pain and the new genes,” Dr. Weisman said. “At the very least, it’s going to bring people out of the wilderness into a place where you can shine a light on it and treat it and, hopefully, treat it effectively.”

_The Denver Spondylitis Educational Seminar was supported by an educational grant from Amgen & Wyeth._
In 1985, SAA produced Straight Talk on Spondylitis, the first comprehensive publication in the United States developed for patients and their families to help them understand and manage spondylitis. The publication received rave reviews from rheumatologists and others in the medical community, including the Journal of Rheumatology and the Journal of the American Physical Therapy Association.

Complimentary copies were distributed to every rheumatologist in the country and the book was even translated for distribution to physicians throughout Japan.

Today, SAA has released an updated version of this groundbreaking book, which provides patients with a straightforward look at the nature of the disease and important tools to manage it successfully including information on therapies and treatments, activities and exercise programs, and tips for coping with the psychological challenges of living with a chronic illness. Included with the book is a free pull-out exercise poster to help you maintain an effective fitness program to ensure continued mobility and flexibility.

Newly expanded and updated sections include:

- Spondylitis in Women
- Medications and Treatment
- Employment Issues
- Childcare
- Health Insurance

Straight Talk on Spondylitis remains the most comprehensive self-management book geared to the spondylitis patient.

For a limited time only, when you purchase *Straight Talk on Spondylitis* along with the companion “Back in Action” exercise DVD, you will receive a free copy of SAA’s Spondylitis Educational Seminar CD. This 50-minute CD features Michael Weisman, MD leading an interactive discussion about the Medical Management of Spondylitis.

*Book, DVD, CD, Poster -- Your comprehensive toolkit for the successful management of spondylitis!*  

To order today, and receive your free gifts, go to spondylitis.org/store or call Helene Hart at 800-777-8189, ext. 229.
You can play a principal role in ensuring that the Spondylitis Association of America (SAA) can continue to fund research, produce educational programs and advocate on behalf of the spondylitis community by leaving a planned gift to SAA.

Whether you want to leave a legacy through a bequest, charitable trust, life insurance or other planned giving options, your gift should ensure financial security for you and your loved ones, while allowing you to make a meaningful gift to future generations living with spondylitis. There are a variety of planned giving options that can be tailored to your individual financial and charitable goals.

**Bequest**
Designating SAA as a beneficiary in your will is the simplest way to create a legacy gift to SAA without affecting your current financial situation. After providing for your family, you can remember SAA in your will for a specific dollar amount or a percentage of your estate.

**Charitable Trusts**
Setting up a trust that provides you with current income for life for yourself and/or loved ones is another way to leave a legacy gift to SAA. You will receive favorable tax benefits and SAA will receive what is remaining in the trust.

**Life Insurance**
Another opportunity to make a significant gift to SAA is with life insurance. You can transfer an existing policy that is not longer needed by your family to SAA or you can make SAA the beneficiary of a new policy.

**Other Planned Giving Options**
There are many other planned giving options available. Planned gifts have many benefits including the possibility of increasing your income while avoiding capital gains taxes and reducing estate taxes.

**Quest Legacy Society**
SAA has established the Quest Legacy Society to commemorate the generosity of those supporters who have remembered SAA in their estate plans. If you have already made a financial provision for SAA in your estate plans, please let us know so we may honor you as a charter member of the Quest Legacy Society.

If you are interested in learning more about the Quest Legacy Society or how to leave a planned gift to SAA, please complete and mail the enclosed reply envelope or contact Susan Jones at 800 777-8189, ext. 231 or susan.jones@spondylitis.org.

The Spondylitis Association of America would like to thank Robert and Raye Werner for their generous leadership gift. Through their generosity, they enable SAA to develop new strategic initiatives that will serve the spondylitis community while continuing to provide the programs and services that are the hallmark of SAA’s mission. We are very grateful for their investment in the future of the Spondylitis Association of America.
A Capitol Idea

We’re pleased to announce that the Spondylitis Association of America has been selected to participate in the Combined Federal Campaign (CFC), the annual fundraising drive conducted by federal employees, postal workers and military personnel.

Each year federal employees and retirees are given the opportunity to support the charities they care about by designating a portion of their earnings to a specific cause. If you receive a paycheck, or a pension, from the Federal government, you can choose to support SAA through the Combined Federal Campaign. Our CFC number is 89466.

CFC is the world’s largest and most successful annual workplace charity campaign, with more than 300 CFC campaigns throughout the country and internationally that help raise millions of dollars each year. Pledges made by Federal civilian, postal and military donors during the campaign season (September 1st to December 15th) support eligible nonprofit organizations that provide health and human service benefits throughout the world.

This year, SAA can benefit from your thoughtfulness and generosity. A few minutes of your time today can make the difference in the fight to cure spondylitis and make the world a better place for those affected.

Payroll deductions make it convenient for you to give by allowing you to spread your contribution across the entire year. Last year, more than 90% of all CFC funds raised were given through payroll deduction.

To make a donation through this campaign, simply enter CFC code #89466 on your pledge card during your agency’s fund drive or contact your Human Resources Department or the Office of Personnel Management (www.opm.gov).

Get Smart

Not a Federal employee? You can still spread your SAA contribution out over the year by becoming a member of the Spondylitis Monthly Automatic Rewards Team (S.M.A.R.T.). By becoming a S.M.A.R.T. Giver, you can designate an amount to be charged to your credit or debit card each month.

As a Charter Member of S.M.A.R.T. your support will help sustain SAA’s worldwide leadership role in promoting early diagnosis and effective treatment of AS and related diseases.

Here’s how the program works:

- Just specify a monthly amount and SAA will automatically deduct the contribution from your debit or credit card.
- Then, each month thereafter, your generous contribution will be put to work immediately – helping to hasten the day when all of us, working together, find a cure for spondylitis.
- At the end of the year, we’ll send you a summary of your giving and a tax receipt.

Your dependable monthly gift of $100, $50, $25, $15 or even $10 will boost the impact of your SAA membership many times over. It’s easy, convenient and your monthly donation will be put to work right away -- providing the programs and services you’ve come to rely upon. Sign up online at spondylitis.org/smart or by calling Helene Hart at 800-777-8189 x229.

It Doesn’t Matter How You Do It...

However you decide to support SAA, you can be confident that your donations will be used wisely, responsibly and effectively to respond to the stated needs of supporters like you. From our Educational Seminars and Support Group Network to Podcasts, First Responder Training and MedicAlert membership discounts, all of SAA’s programs and services are undertaken in direct response to the concerns raised by our members.

Your ongoing support is what enables us to continue to respond to those needs and we Thank You!
IN FOCUS: ELECTRONIC MEDICAL RECORDS

ELECTRONIC MEDICAL RECORDS: Numbering the Days of the Paper-Based System

by Scott P. Edwards | July 30, 2008

More than 120 years before electronic medical records (EMR) were even imagined, Florence Nightingale, the pioneer of modern nursing, lamented its paper brethren. “In attempting to arrive at the truth,” she said in 1863, “I have applied everywhere for information, but in scarcely an instance have I been able to obtain hospital records fit for any purpose of comparison.”

For hundreds of years, doctors, nurses and other health-care providers have relied on a paper-based records system to learn about their patients and share information with other caregivers. Patient medical records are typically maintained in large binders, called charts that contain a patient’s medical history, list of medical encounters, test results, medications, hospitalizations, surgeries, clinical notes, and other pertinent information. Many health-care providers agree that this is a less-than-adequate system. These charts, maintained for a patient at each physician’s office, clinic or hospital at which they are treated, are at the whim of often illegibly handwritten doctor notes, potential transcription errors, missing pages, or notes entered in the wrong order.

Today, the electronic medical record, or EMR, represents the lynchpin in the effort to ensure that critical information is accurately entered into a patient’s chart and accurately transferred from one facility to another so that appropriate, cost-effective medical treatment can be provided. Electronic medical records are a digital version of the old paper system of patient information. EMR proponents say these digital records decrease medical errors, reduce costs, and allow physicians and others to communicate and share patient information more accurately, effectively and consistently—especially in emergency situations—than they can with paper records. Opponents of electronic medical records question the privacy protection of electronic records, as well as technology limitations and social and institutional barriers to using such a system.

Early history of EMR

In the late 1960s, Dr. Lawrence L. Weed, a Vermont physician, reinvented the patient medical record as the Patient-Oriented Medical Record, or POMR, and developed one of the first systems for computer-based records. Weed, whose research primarily focused on information gathering in medicine (he also spent considerable time researching nucleic acids), said the core problem in health care is that the human brain cannot process the volume of information that is required to properly care for patients in the short time that a doctor has to see them. From the late 1960s to the early 1980s, Weed spent his time developing the POMR and then launched a company, PKC Corporation, that develops computerized “knowledge coupling” tools that help health-care consumers and providers “make well-informed choices.”

Following Weed, a number of early EMR systems started up in the late 1960s and early 1970s, including:

- COSTAR, the Computer-Stored Ambulatory Record, the first completely computer-stored medical records system, which aimed to improve patient care by increasing the availability, accessibility, timeliness and organization of patient medical information. By 1973, nearly 30,000 people enrolled in the Harvard Pilgrim Health Care plan were managed by COSTAR; however, use of the system was discontinued in the late 1980s.

- HELP, Health Evaluation Through Logical Processing, developed by LDS Hospital in Utah. This system provides computer-aided decision support programs that allow doctors to directly order antibiotics at bedside terminals, resulting in improved drug selection and a reduction in adverse drug events.

- Regenstrief Medical Record System, developed by the Regenstrief Institute, an internationally recognized informatics and health-care research organization in Indianapolis. The Regenstrief system stores more than 30 years of patient data from emergency room visits, hospital stays, clinic visits, lab results, and imaging studies. It also generates reminders and captures physician orders. The program is still in use.

- Clinical Computing System, developed by Drs. Warner V. Slack and Howard L. Bleich of Boston’s Beth Israel Hospital in the mid-1970s. This hospital-wide clinical computing system provides results of diagnostic tests upon request, offers access to medical literature, gives advice consultation, alerts and reminders, and assists in day-to-day medical practice. Studies have shown that systems like these help clinicians improve patient care.
Giants enter the field

While fewer than 10 percent of hospitals have implemented EMR systems (as of 2006), including electronic prescribing systems called Computerized Physician Order Entry (CPOE), a number of technology and health-care giants are entering the field of personalized electronic health records.

In 2007, Microsoft became the first to offer an online health management program for consumers. Microsoft HealthVault is a network of websites, personal health devices, and other services that can help consumers manage their health. Microsoft says HealthVault is designed to “put you in control of your health information.” The program allows consumers to store health information in one central place on the Web, creating an emergency list of documents, including medical history, medications, allergies, immunizations, care providers, and more. The consumer controls what information is stored, and decides who can view it, change it or help manage it. In addition, the information can be shared with family members and health-care providers.

One year later, the Internet search engine giant, Google, started Google Health, a web-based health information management program that allows consumers to store and manage all of their health information in one central place. With Google Health, consumers can build online health profiles, including health conditions, medications, allergies and lab results, and important medical records from hospitals and pharmacies, so that an accurate history of medical conditions, medications, test results and doctors’ notes can be kept in one place. Google says that “saving your medical information in one secure location helps you and your doctors have accurate and up-to-date information about your health when you need it most.”
In the summer of 2005, MedicAlert, the manufacturer of medical identification bracelets and necklaces, launched its E-HealthKey product, a secure, portable personal health record using USB flash drive technology. MedicAlert members can carry their complete medical record on a key drive and upload information to or download it from MedicAlert’s database. E-HealthKey can track recordings like blood pressure or blood glucose levels, store medical images (X-rays, MRIs, EKGs, etc.), and set up appointment and medication reminders.

Nearly a year after E-HealthKey was launched, Kaiser Permanente of Georgia became the first health maintenance organization to move toward online access to medical records. HMO members in Georgia can now e-mail their doctor’s office with questions, request lab results, and review past office visits online. Kaiser Permanente was one of the first HMOs in the country to implement an electronic medical records system, which includes patient online access, for its nearly 8.5 million members in nine states and Washington, D.C. Officials with the HMO say that the EMR system allows doctors to access critical health information about their members, saves time and money, and saves lives by automatically flagging abnormal test results and dangerous drug interactions. Kaiser Permanente’s EMR system was reported to be the first to discover increased heart attack and stroke risk associated with the over-the-counter pain medication Vioxx, helping the drug’s manufacturer, Merck, to pull it from store shelves while it investigated.

While only a small number of hospitals nationwide have fully implemented EMR systems, the electronic medical record is inevitable. There are, however, pros and cons to using such a digital system of patient recordkeeping.

**Outmatching the paper system**

A number of benefits of the EMR cannot be matched by the old paper-based system:

**Patient safety** – Features such as CPOE help to ensure patient safety by intercepting errors at the time tests and medications are ordered. When orders are entered into a computer, they are integrated with other pertinent patient information and then automatically checked for errors. Medication errors, which contribute to nearly 7,000 deaths each year, according to the health-care watchdog organization The Leapfrog Group, are one of the primary safety features addressed by CPOE. In addition, CPOE reduces the risk of errors caused by manual order entry, poor handwriting, and transcription mistakes.

**Ease of communication** – While different versions of EMR software are available, they are interoperable, meaning that different technology platforms and software applications can communicate. This makes sharing information much easier from one health-care institution to another. In addition, all EMR systems follow a standard format so that lab results, radiology reports, and clinical notes are easy to follow and understand.

**Flexibility** – In a traditional written record, clinical notes, test results, lab reports, and other information is entered in a chronological order. A clinician can arrange a patient’s EMR so that it makes more sense. Thus, while a patient may have multiple medical issues, doctors can group them so that information pertaining to, say, a patient’s heart condition remains separate from that of his arthritis.

This format follows Weed’s problem-oriented medical record that divided a patient’s medical condition into a discrete list of issues.

**Automation** – Most EMR programs are equipped with a medical decision making process. For example, EMR programs can detect life-threatening laboratory results and immediately alert clinicians so that the proper action can be taken. They can also correct errors that might result in a patient receiving the wrong drug or an incorrect—and dangerous—dose.

**Quality Assurance** – EMR systems audit patient conditions, diagnoses, lab and radiology results and other information so that unnecessary and often costly tests and procedures are not ordered. This not only spares patients the hassle of having needless tests and procedures, but it controls costs as well.

**Remote access** – Electronic records and online health programs (like Google Health and Microsoft HealthVault) let clinicians and consumers remotely review their medical information. This way, doctors can check on their patients from home, if need be, or if they are transferred from one health-care facility to another. Primary care physicians are also able to participate in the management of their patients by having remote access to the patient’s records while they are hospitalized.
Troubling aspects
While many facets of the electronic medical records make providing quality healthcare easier, there are a number of potential troubling aspects to it:

Privacy and confidentiality – The privacy and confidentiality of patient information is perhaps the most vexing issue for the electronic medical record. The U.S. Department of Health and Human Services estimates that about 150 people have access to a patient’s records during a hospitalization—from doctors and nurses to radiology and lab technicians and billing clerks. Approximately 600,000 payers, providers and companies that convert raw data into billing data also have access to patient records.

Most of the information in medical records is protected under HIPAA, the Health Insurance Portability and Accountability Act of 1996. This is called Protected Health Information (PHI), which is defined as “any information, whether oral or recorded in any form or medium” that is created or received by a health-care provider and relates to the “past, present or future physical or mental health or condition of an individual.” HIPAA covers material created both in paper and electronic formats. The technical solutions that allow banks and corporations to share data can be used in health care to protect PHI; however, that sharing of information by the many public and private entities in the U.S. health-care system remains unregulated.

Reliability – While providers run the risk of losing parts of the paper medical record, EMR systems are at the whim of power outages, system crashes, and programming errors. If the computer system on which a hospital’s EMR runs crashes, there could be potentially life-threatening consequences.

Cost – Many cash-strapped hospitals, especially community hospitals, simply cannot afford the infrastructure—hardware and software—to implement an effective EMR system. While EMR systems may save money in the long run, the initial cost of equipment purchases and training staff to use the EMR can be prohibitive, so many small hospitals remain committed to paper records.

Social and institutional obstacles – Many health-care providers are reluctant to move away from the familiar, traditional paper medical record. Many physicians, especially those used to pen-and-paper records, find the transition to EMR hard (younger doctors, who grew up and were trained on computers, latch on to EMR much more easily). In January 2003, Cedars-Sinai Medical Center in Los Angeles was forced to abandon its experiment with EMR when its physicians, who were uncomfortable with the system, revolted.

Limitations of technology – EMR systems are subject to technical glitches and bugs that can render the systems inoperable. Some systems do not recognize even slight misspellings so that if an error is made, it is rejected by the system. Others issue alerts with a series of questions before orders can be entered, which many doctors find not only irritating, but time-consuming, as well.

Good or bad, it seems that the electronic medical record is here to stay. Despite the early shortcomings of digital records, they are slowly but surely making their way into the healthcare arena and getting better with improved technology and training. And while the paper record that Florence Nightingale lamented some 145 years ago is not yet dead, its days may be numbered.

Patient Perspective

Michael Smith, who works as an office manager/administrative assistant in Manhattan, was diagnosed with spondylitis in 1985, and his neck and spine have been totally fused since 1989. Smith carries an E-Health Key in his pocket at all times.

“I think the opportunity to have all your pertinent data on a device that you carry with you is invaluable,” Smith says. “If, God forbid, I was in an accident or was unconscious and unable to tell an EMS crew my story, then the next best thing would be the E-Health Key, which could at least give them my background and the basics of my health issues, including ICE [in case of emergency] numbers, doctor contact information, and what medications I am taking.”

Smith says he looked at both Google Health and Microsoft’s Health Vault, but has not used either product. He is concerned about access to his entire medical record.

“To me, there is a big difference between having immediate access to pertinent medical information [such as the E-Health Key] and having access to one’s complete medical history,” he says. “Maybe I don’t know all the safety features that have been built in [to Google Health and Health Vault], but I find the possibility for unwanted disclosure too great.”
Symptoms and Social Security Disability Benefits:  
Are They Enough to Prove Disability?  

by Richard I. Feingold 

The chances of becoming disabled are greater than one thinks. Studies have shown that a 20-year-old worker has a 30 percent chance of becoming disabled before reaching retirement age. The Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) programs are the largest federal programs that provide assistance to people with disabilities. SSDI pays benefits to disabled individuals and members of their family if the worker has worked long enough and paid Social Security taxes. SSI pays benefits to disabled individuals based on financial need. 

For individuals suffering from ankylosing spondylitis (AS), symptoms such as fatigue and pain can make daily functioning at work nearly impossible. Unfortunately, these symptoms are difficult to quantify. The Social Security Administration (SSA) considers fatigue and pain to be subjective symptoms, which alone cannot establish disability. This is because the law governing Social Security disability benefits requires that disability be based on the existence of at least one “medically determinable impairment” that can be established by medical evidence, consisting of medical signs, symptoms and laboratory findings. 

According to SSA’s Ankylosing Spondylitis Listing, your disability can be established if there exist findings of unilateral or bilateral sacroiliitis (e.g., erosions or fusions) shown by appropriate medically acceptable imaging such as MRI or CT Scans. You must also have a history of back pain, tenderness and stiffness, and findings on physical examination of ankylosis (fixation) of the dorsolumbar or cervical spine at 45 degrees or more flexion measured from the vertical position (zero degrees). 

Due to the strict criteria set forth in the Ankylosing Spondylitis Listing, it is difficult to establish disability based on this Listing alone. In such circumstances, it becomes necessary to determine your “residual functional capacity,” a measure of activities that can be performed despite the limiting effects of all of your impairments, both physical and mental. Residual functional capacity is considered in evaluating whether or not you can perform past relevant work or any other work. 

SSA recognizes that pain, fatigue and other symptoms may cause functional limitations more severe than the anatomical, physiological or psychological abnormalities alone might indicate. For example, you may have minimal to moderate vertebral fusing that only mildly to moderately limits your ability to perform basic work activities based upon objective medical evidence such as an MRI of the spine. When symptoms such as pain and fatigue are considered, however, the evidence may show that you have more serious limitations than the objective evidence alone would indicate. 

Even if the available objective medical evidence does not substantiate your symptoms, SSA is not permitted to use that discrepancy alone as a basis to reject your statements about the intensity and persistence of your pain, fatigue or other symptoms, or the effect that those symptoms have on your ability to work. SSA must consider all of your symptoms, including pain and fatigue, and the extent to which those symptoms can reasonably be accepted as consistent with the objective medical evidence and other evidence. “Other evidence” includes statements or reports from your doctors and other sources about your medical history, diagnosis, prescribed treatment, daily activities, efforts to work, and any other evidence showing how your impairments and any related symptoms affect the ability to work. 

The finding that your impairments could reasonably be expected to produce pain and fatigue, however, does not resolve the issue of how intense, persistent or functionally limiting your symptoms are or how they limit your capacity for work. SSA recognizes that symptoms sometimes suggest a greater severity of impairment than can be shown by objective medical evidence alone. Consequently, SSA will consider other factors relevant to your symptoms, including daily activities, the location, duration, frequency, and intensity of pain, fatigue or other symptoms; precipitating and aggravating factors; the type, dosage, effectiveness, and side effects of any medication taken to alleviate the symptoms; treatment, other than medication, for relief of pain, fatigue or other symptoms; any measures used to relieve symptoms, such as taking naps during the day, or lying down to relieve pain; and other factors concerning functional limitations and restrictions. 

As you can see, the evaluation of your symptoms in SSA’s disability analysis is more art than science. Being aware of how SSA evaluates your symptoms emphasizes the importance of having a thoroughly documented case file. You must report your symptoms to your medical providers, and you should present all other supportive sources of information to the Social Security Administration, including the opinions of your treating medical providers. These are some of the steps that you should take to maximize your chances of success in convincing SSA that you are disabled. 

About the author: Richard Feingold, whose law practice concentrates on Social Security disability claims, has been helping disabled adults obtain Social Security disability benefits for more than 20 years. He is a sustaining member of the National Organization of Social Security Claimants’ Representatives, an organization committed to helping people with disabilities. He explains how Social Security disability benefits are determined and what claimants can do to persuade the Social Security Administration that they are disabled.
SAA-Sponsored Educational Support Groups

The people listed below are a vital part of our support system. They have volunteered to lead support groups across the US because they want to help. If you’d like to find out more about support groups and online meetings, pick up the phone or send an email to: elin.aslanyan@spondylitis.org

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*Noel Miles is a temporary contact for Denver, CO

* Teen Athletes with AS located in Orange County - contact WalkerRSM@aol.com
* Support online from NY, NY with Michael T. Smith, spenser23@aol.com

New Program - Network of PEERS (People Educated and Empowered to Rise above Spondylitis)

Have you been recently diagnosed with spondylitis and would like to talk to someone about how they have managed their spondylitis? Or, are you someone who has years of experience in living with spondylitis and would like to offer support to someone who has been newly diagnosed? SAA’s new program, the Network of Peers, may be of interest to you. Visit spondylitis.org/peers or contact Elin Aslanyan, Programs Coordinator, by email at elin.aslanyan@spondylitis.org or by telephone at (800) 777-8189, ext. 222 for info.

New Online Communities

Help us network to educate and spread awareness about spondylitis by joining us on:

Medical and Scientific Advisory Board

Chair:
Robert Colbert, MD, PhD ....... Cincinnati, OH

Bruce Clark, PT ............... Vancouver, BC
Daniel Clegg, MD ............ Salt Lake City, UT
Atul Deodhar, MD ............. Portland, OR
Nortin Hadler, MD, PhD .......... Chapel Hill, NC
Robert Harris, MD ............ Whittier, CA
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Robert Warren, MD, PhD ....... Houston, TX
Michael Weisman, MD ......... Los Angeles, CA
David Yu, MD ................. West LA, CA

www.spondylitis.org
Are you willing to help researchers find the genes involved in ankylosing spondylitis?

How can I help?
If so, you may be interested in participating in our study. To participate you need to be at least 18 years of age, and to have been diagnosed with ankylosing spondylitis. The study is also enrolling non-affected spouses and friends.

Who is conducting the study?
The study is sponsored by the National Institutes of Health. The doctors conducting the study are Principal Investigator John D. Revielle, MD, University of Texas, Houston and colleagues; Michael H. Weisman, MD, Cedars-Sinai Medical Center, Los Angeles.

How can I find out more?
Southern California: Study Coordinator, (310) 423-2422
Houston area: Laura Diekman, (713) 500-6852, laura.diekman@uth.tmc.edu
Spondylitis Association of America Toll Free 1-800-777-8189 x224

SAVE THE DATE!

Banding Together to Beat AS!
Mark your calendars for a 48 hour webathon on BlowUpRadio.com & ThePenguinRocks.com beginning Friday October 17th at 7pm ET, and ending on Sunday October 19th at 7pm ET. The webathon will be featuring performances by over 60 bands and all proceeds will be donated to the Spondylitis Association of America.

LOG IN 24/7
www.spondylitis.org