Diagnosis of antiphospholipid syndrome is increasing. Here’s how to recognize and treat it.

>> By Graham R.V. Hughes, MD

Since its clinical description in 1983, antiphospholipid syndrome (APS or Hughes Syndrome) has become the domain not only of rheumatologists and obstetricians, but of neurologists, cardiologists, psychiatrists, otolaryngologists, and orthopedists. Like lupus, APS embraces all clinical specialties.

continued on page 20

This is part two of a four-part series on the 2006 Rheumatology Workforce Study. See part one on p. 1 of the January issue.

In 2005, when the ACR commissioned its first workforce study in 10 years, it suspected—correctly—that the demand for rheumatology services would increasingly exceed supply over the next several years. In fact, rheumatologists are keenly aware that patients are already waiting longer to see a specialist. “The problem is not specific to rheumatology; it really involves all healthcare delivery in this country,” says Timothy Harrington, Jr., MD, head of the rheumatology section at the University of Wisconsin in Madison.

continued on page 15

Clinician Call to Action

Use teamwork, screening, and scheduling to improve efficiency—and patient care

>> By Terry Hartnett

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The ACR has a long history of strategic planning. At its inception, a strategic plan was created to set goals for the organization. This plan has been modified over the years as the ACR has grown and changed, but the basic principles remain the same. In recent years, the ACR’s strategic plan has been used as a road map for guiding the work of ACR committees and ensuring that the organization continues to support its mission to advance the rheumatology subspecialty through programs of education, research, advocacy, and practice support. The ACR monitors progress on the strategic plan annually; however, every few years we take a look at the external environment and make necessary revisions to the plan in order to adjust strategies to coincide with changes to the environment that will have an affect on the rheumatology landscape.

On February 21, 2007, prior to the ACR Board of Directors meeting, the board, standing committee chairs, and several invited guests met to review critical issues and strategies in the current strategic plan and revise those strategies to most effectively address the needs of members over the next two years. This planning session had two prevailing themes: develop strategies to maximize the ACR’s value for its members and find ways to effectively communicate the ACR’s many initiatives to its members.

Volunteer Your Thoughts and Your Time
The College exists primarily for the benefit of its rheumatologist and allied rheumatic health professional members, so the main focus of the strategic planning session was to define and focus on how we can add the most value to ACR membership. Be on the lookout later this year for a membership survey soliciting feedback on what ACR programs and services you value and what additional benefits you would like the ACR to provide. Please take the time to complete the survey when you receive the questionnaire. The best way for you to ensure that the College is growing and expanding into areas that you value is to tell us about your wants, needs, and concerns.

Strategic planning session participants emphasized the need for members to be involved in the organization. The ACR is always looking for new volunteers. The number of committees and subcommittees has grown, and there are many new ways to get involved. Notable new opportunities this year include a Drug Safety Subcommittee and a Political Action Committee. Volunteering for the ACR benefits the organization, but it also provides you with unique networking opportunities and allows you to make a positive impact on the rheumatology subspecialty. This month, “From the College” talks with Mary K. Crow, MD, chair of the Committee on Nominations and Appointments, about applying for a volunteer position. (See “Call for Volunteers,” p. 8.) Because there are often more volunteers than positions, you may not be selected for a committee in a given year, but you will be considered the next year. You can also contact Dr. Crow or the chair of the committee on which you would like to serve about opportunities to serve in an ad hoc function or on a subcommittee.

**A Renewed Sense of Purpose**

**ACR’s success depends on its members**

**By Neal S. Birnbaum, MD**

*“A goal without a plan is just a wish.”—Antoine de Saint-Exupéry, French writer*

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Commitment to Communication

Another important decision during the strategic planning session was how to improve communications to members about the ACR’s many initiatives. The ACR’s initiatives focus on many areas that are pertinent to rheumatologists. Through the work of its committees, the ACR engages in continuous dialogue with the government and insurers on behalf of the rheumatology community, promotes educational- and research opportunities for rheumatologists, and develops strategies to ensure the sustainability of the rheumatology workforce. The College’s leadership is committed to keeping members involved in the ACR’s efforts and communication is a vital component of that effort.

Ultimately, communication should run both ways. I encourage you to contact me directly with any questions, ideas, or suggestions. You can reach me at Birnbaum@rheumatology.org. The ACR heard any questions, ideas, or suggestions. You can reach me directly with

Dr. Birnbaum is president of ACR. Contact him via e-mail at birnbaum@rheumatology.org.
Sniff 101 and Other Lessons
Sometimes doctors don’t speak the same language

>> By David S. Pisetsky, MD, PhD

Each year, I spend one month as the attending on the general medicine service. While I am active clinically as a rheumatologist, it has been more than 30 years since I was a house officer and served on the front lines to treat pancreatitis, cirrhosis, or lung cancer. I may be a Duke Marine, but when it comes to inpatient work, my status is more appropriately inactive reserve.

I always have a great time as attending; any anxiety about clinical rustiness is far outweighed by the excitement and satisfaction that comes from caring for the very sick. I also relish team camaraderie. The practice of medicine always involves a team, but the ward team is unique. It unites novices and experts, students and teachers, young and old. While the ward team members are the age of my children, they will as likely teach me as I will them.

The current pace of medical advance is fast if not frantic and, in the year that will pass between my stints as ward attending, there will be a torrent of new drugs, imaging studies, and treatment approaches. There is no way that anyone can keep up with the pace of innovation and I long ago learned that it is better to admit ignorance than to bluff your way through rounds.

This year on rounds, I was blindsided by a term I never heard before. The term is “sniff.”

The Mysterious Sniff
I learned about “sniff” on my first day attending as I reviewed patients with the admitting teams. We were sitting in a crowded and messy workroom—similar to the one I toiled in as an intern except it has five flat-screen computers and an espresso machine. Even working just 80 hours a week, house officers apparently need caffeine to keep them going.

Ward teams are usually named by color; let’s call this group Orange 1. It was a typical team—a quiet and earnest medical student, an overworked but cheerful intern, and a junior assistant resident with the swagger that the rite of internship can bring. As I talked with Orange 1, the ward 2 group worked at their computers, the air filled with a barrage of clicking as they banged on keyboards with blazing speed.

The resident on Orange 1 was “running” the patient list, redacting each person to two or three sentences so that I could make a recommendation or eradicate comment. When we got to a patient we can call Mr. Jones, the resident issued a staccato summary: “72-year-old man with recent stroke, MI, and GI bleed. We are trying to get him a ‘sniff.’ ”

I startled. I had never before heard the term “sniff.” Although my hospital has discouraged abbreviations and acronyms, they nevertheless persist and, if anything, proliferate at a furious rate. Everyone is too pressed for time to spell out diabetes mellitus rather than popping in DM with two quick keystrokes. Who has the luxury of time to say “an ST elevation myocardial infarction” rather than more familiar and benign sounding “STEMI”? STEMI sounds like a cute name for a girl rather than a catastrophic life-threatening event.

When you round with a new team, it is always good to start off with a winner, a case where—as the attending—you can show your stuff. The best circumstance is to have a case within your clinical bailiwick. With lupus, I could shine, lecturing on recent articles and asking the house staff questions for which I know the answer. But I did not know what a sniff was and being flummoxed is no way to start as the attending.

I wrecked my brain to see if I had ever heard of a sniff. Was it a class of drugs like an ARB (angiotensin receptor blocker)? Or was it type of diagnostic test like a cath or a therapeutic intervention like TIPS (transjugular intrahepatic portosystemic shunt)?

My silence was uneasy as I conjured possibilities for sniff. Maybe it was a sinus node fragmentator or frumtanator or something like. Alas, I could not come up with anything that corresponded to sniff.

Ten minutes into my attending work, I was ready to go down in defeat, stumped by an acronym the preciousness of time had forced into use.

My face desolate, shaking my head, I asked, “What is a ‘sniff’?”

“Oh,” the resident said, smiling in a kind but indulgent way, “a ‘sniff’ is a skilled nursing facility.” I felt a light went off in my head as I put two and two together. It was clear that sniff was for a pronunciation of SNF.

I was tempted to expiate on the importance of clear communication in medicine and the hazards of using abbreviations. I decided to accept a small setback, however, and not act like an old curmudgeon.

“The sniff is a good idea,” I said, sitting upright, and then added with just a little swagger in my voice, “Make sure the BUN and hematocrit are ready to go down in defeat, stumped by an acronym the preciousness of time had forced into use.”

Alphabet Soup
I did well for about another 10 minutes when I had to ask what “HOCUM” was. That was an entity that I used to call IHSS (idiopathic hypertrophic subaortic stenosis); its new moniker is hypertrophic obstructive cardiomyopathy.

I got annoyed, embarrassed, and asked by my ignorance of so many aspects of today’s medicine. As they say, you could fill a textbook with what I don’t know. As a matter of fact, you could fill two. One is called Cecil Textbook of Medicine and other is called Harrison’s Manual of Medicine. While my foibles on rounds can be amusing, there’s a serious side to what I do. In admitting ignorance, I’m trying to teach the house staff some lessons. Most important: if you don’t know something, ask for help. Others include don’t be proud, act with understanding, and be honest in the face of change.

The inpatient ward is a special environment that exists at the extreme edge of medical practice. Education starts there because it is best place to learn. The stakes are high, indeed, they are matters of life and death. Because the consequences are dire, mistakes are remembered, the recollection of serious error a spur to maturity.

The month on the ward gives me a reality check on what we, as physicians, know and what we don’t know. In looking at some recent events affecting rheumatology, I worry that some physicians are not heeding the lessons learned on the ward and are disregarding the limits on their knowledge.

In future issues, I will discuss this matter further and give you my own take on situations where asking for help could go a long way.

Dr. Pisetsky is physician editor of The Rheumatologist and professor of medicine and immunology at Duke University Medical Center in Durham, N.C.
Rheum’s Role in the New NHS
What the United States can learn from the U.K. system

By Alan J. Silman, MD

T he National Health Service (NHS) is still, some 60 years after its founding, considered one of my country’s greatest strengths. It promises health care “free at the point of delivery,” funded from general taxation and providing access to necessary services for everyone, independent of income and means. There is a continuing attachment to this notion across the political spectrum and the relative credence given to promises to maintain this concept has been similar among political parties at every general election.

NHS Today
Reading the tabloid press, one would be forgiven for believing that the basic tenets underlying the NHS are under severe threat. In truth, they are not—but there are seismic changes in the way healthcare will be delivered in the future. History will judge whether reforms will deliver the quality and efficiency politicians desire. What is certain is that these changes will affect U.K. rheumatologists; their concerns and anxiety are palpable at all levels. Some see nothing but doom and gloom (and early retirement as leading to some form of salvation), while there are the entrepreneurs who see the opportunities to deliver a level of service to which they have always aspired.

What is the nature of this revolution? Since its inception, the NHS has been both purchaser and provider of both primary and secondary healthcare. Whereas hospital doctors were salaried full-time employees, primary care physicians (or general practitioners—GPs) secured themselves “independent contractor” status. The GPs provided primary care within the NHS, but as a delivery and business model they had some freedom to develop. Access to hospitals was channeled via GP gatekeepers. A geographically devolved system decided what secondary care was needed and aimed to ensure that there were services to meet these demands. In comparison with their GP colleagues, hospital consultants had nationally fixed salaries that were (apart from various extra merit award schemes) independent of performance. In this model, the salaries of hospital consultants mirrored the situation of U.K. hospitals as institutions because their funding was determined from a historical baseline and incentives to improve were limited.

During the 1980s and 1990s the conservative governments of Margaret Thatcher and subsequent prime ministers attempted to stimulate improvement by making the difference between purchasers and providers of secondary care. They achieved this goal by putting GPs in a pivotal position to purchase healthcare for their patients from the available secondary care providers. As a result, patients found themselves having their hip replacements performed at the other end of the country as hospitals began to compete on price and waiting time.

Despite the hype, the effect on healthcare was only modest because acute care was excluded and GPs predominately purchased care from their traditional, geographically based hospitals. Waiting times for the first outpatient appointment (ambulatory care) following GP referral and for admission to hospital rose. Election campaigns focused on a few high-profile and probably totally atypical cases such as “Jennifer’s ear,” where a young girl whose grommet surgery had been unreasonably delayed was wheeled out to the media to highlight the inadequacies of the NHS. Spending on healthcare was historically low compared with our European comparators.

Increased Funding—and Performance Targets
In 1997 the return of the Labour Party with Tony Blair brought new hopes and a vast increase in spending with an almost two-fold increase of the proportion of GDP devoted to healthcare. Salaries at all levels increased with an expansion in all groups of health professionals (including a 30% to 40% increase in the number of rheumatologists). There was also a massive hospital-building program, funded by public-private partnerships. The fact that such initiatives will be paid for by future generations is ignored, but for politicians seeking a quick fix, the sight of giant cranes in every major hospital in the land showed “something was happening.”

The creed of Blair’s “New Labour” was that there had to be “delivery.” The problem was how to measure it. In the past 10 years, we have been faced with an ever-growing list of targets for performance, with published league tables of the good guys and the bad guys (whether it is waiting times for cataracts or response times to dealing with complaints). The job security and rewards for the new breed of hospital chief executives depended on their meeting the latest bunch of targets. Professional activity started being managed to meet these targets in the teeth of great opposition and some incentives.

One new feature of this landscape was the waiting-list initiatives. In order to meet targets of specific waiting times for new (but not follow-up) outpatient appointments, hospital managers required extra evening or weekend clinics, paid for at premium rates. The incentive to see extra patients during the working day declined and paradoxically (though predictably) waiting times for new patients rose as many providers had to increase the number of slots for the follow-ups of these extra referrals.

The crude data for the past 10 years are clear: massive expansion in funding, many new hospitals, reduction in waiting times, and increases in salaries. The problem is that everyone is unhappy. The government’s solution has been to relinquish control of the hospitals, freeing them to become independent businesses (but remaining within the NHS) and encouraging those responsible in primary care for the purchase of secondary care to choose from a range of providers—both within and without the NHS.

Americanization of Healthcare
“Patient choice” has become the slogan of New Labour, and automatic referral to your local hospital confined to previous generations. As a consequence, some hospitals with established reputations are losing money and face a downward spiral of staff loss, low morale, and decline in service. These self-governing hospitals are starving bankruptcy in the face and may wither despite the political fallout even if alternative providers can fill the gap. A Mayo Clinic in London or a Scripps Clinic in Manchester could provide the NHS-funded healthcare of the future. This “Americanization” of healthcare in theory should not lead to a two-tier service. The goal is to ensure uniform quality and, possibly in contrast to the U.S. situation, British public opinion across the social divide still supports equality of access to the best care. Surgical colleagues are leaving NHS management in droves and establishing groups of independent contractors to provide the operations the NHS needs at a price and quality all accept as being an improvement. Interestingly, the consequence of this situation is that the parallel system of private healthcare funded by the wealthier middle classes is in decline, as the private providers see higher profits and greater business opportunities in satisfying the NHS.

Of Rheumatology and Research
Where does this leave rheumatology? Primary care purchasers of rheumatology services are looking for other models of healthcare provision. Intermediate and referral centers are being established where GPs with a Special Interest in rheumatology (GyPsIles) screen referrals from GP colleagues and undertake the necessary investigations (including MRIs) before either referring the patients back to primary care or selecting the few for specialist referral. Inflammatory joint disease will still be managed in hospitals, but by a possibly reduced number of fully trained specialists. Further, if independent providers can give the quality of care demanded, then the sky is the limit. Groups of rheumatologists could establish plans for the long-term multi-disciplinary management of RA, for example. Redundancy from traditional employers in NHS-run institutions looms for many colleagues.

The NHS has been a vital tool for clinical research, and access to its patients and their records have provided the backdrop for the strong legacy of academic activity in the United Kingdom. Traditionally, undertaking investigator-initiated clinical trials in the United Kingdom has been much easier than in the United States, where there is a much greater reliance on industry to fund interventional research. The U.K. government, in the strategy document “Best Research for Best Practice,” recognized the synergy between the provision of high-quality research opportunities and excellence in clinical care and is directing NHS funds toward this goal. With increasing amounts of care being undertaken outside the NHS, however, gathering whole population experience may be constrained in the future.

For my generation, a consultant job was a job for life. Today there is no guarantee for the future visibility of the hospitals where we work, so we need to justify our continued employment in our specialty. The U.K. rheumatologists, with an eye to mortgage repayments and other family responsibilities, are anxious about the future and worry about the protection from the harsh external world cannot continue.

In the waiting area of my clinic last week, I saw hordes of patients waiting an hour for their 10-minute follow-up as the agency staff employed to provide para-nursing support worked arduously, stress engraved on their faces. The “utopia” managing our own service, employing our own staff, and setting our own standards for “sale” to the NHS suddenly seemed very attractive. The NHS will continue into the foreseeable future. The question is whether the care will look more like Main Street, U.S.A., than High Street, U.K.

Dr. Silman is director of the Arthritis Research Campaign’s epidemiology unit at University of Manchester in the United Kingdom.
From the COLLEGE

NEWS FROM THE ACR AND THE ARHP

CIMING ALERTS

NPI System Becomes Mandatory Next Month

On May 23 it will be mandatory to use your National Provider Identifier (NPI) number when billing the Centers for Medicare & Medicaid Services (CMS). Currently, you can use your PIN alone, your PIN and the new NPI, or the NPI alone—but as of May 23, only the NPI number will be accepted.

Physicians are advised to try billing using their NPI number before May 23 to ensure that there aren’t any problems with the number before its use becomes mandatory. You can apply for an NPI on the CMS Web site, https://nppes.cms.hhs.gov, or by calling (800) 465-3203 to request a paper application.

MEDICARE TIPS

ASP Pricing Reduced Part B Spending

The Medicare Payment Advisory Commission (MedPAC) reported to Congress in January that Medicare’s switch to a payment method known as ASP, or Average Sale Price, has reduced spending on drugs in the Medicare Part B program. This system reflects actual market spending, rather than wholesale prices.

MedPAC reported that Medicare spending on Part B drugs fell by $800 million—from $10.9 billion in 2004 to $10.1 billion in 2005. Although there is evidence that drug use overall declined between 2004 and 2005, the year the ASP system was implemented, MedPAC found that much of the decreased spending occurred because of lower drug prices.

For rheumatologists, average drug spending decreased only 1%, as compared with a 52% decline for urologists, for example. These results suggest that rheumatologists were paying market prices before the new system was implemented.

The ASP system was created under the Medicare Modernization Act of 2003 because Congress was concerned that Medicare was losing billions of dollars in drug payments under the old system. At the time, there was physician opposition to the ASP system because physicians believed quality of care and drug access could be in jeopardy. Another physician concern was that the higher costs of drugs helped cover the cost of administering the drug. The MedPAC study found no evidence that patient quality of care has been affected under ASP, or that patients have trouble accessing Part B drugs.

MedPAC suggested that the decline in drug use might be from physicians treating cancer with surgery instead of using drugs that produced unproven benefits or harmful side effects, among other things.

In December, MedPAC recommended that the Department of Health and Human Services clarify how average sale prices are reported for bundle products. The ACR will continue to update members as the situation evolves.

Drug Denials? Write Part D on Your Scripts

Many prescription drug providers (PDPs) still require prior authorization for Part D drugs. The ACR has been working diligently with Robert Bennett, the Physician Regulatory Issues Team (PRIT) at PRIT@cms.hhs.gov to resolve these denial problems in 2007. Rheumatologists should write “for Part D” along with the diagnosis on relevant prescriptions so that PDPs can waive the need for a new prior authorization. PDPs need verification that the drugs are for Part D diagnoses and should not be paid under Part B. Questions or concerns? Contact the ACR’s practice advocacy department at (404) 633-3777 or PRIT at PRIT@cms.hhs.gov.

CALL FOR VOLUNTEERS

Now’s Your Chance to Join an ACR Committee

Volunteers who serve on the ACR’s committees and subcommittees are a vital component of the organization’s ability to respond to the rheumatology landscape for the benefit of members. There are many complex issues facing the subspecialty of rheumatology, it is those dedicated members who choose to become involved who drive the organization’s achievements in advocacy, training, recruitment, education, practice support, and the development of professional standards.

“The ACR recognizes that success in responding to the many challenges facing rheumatology depends on the effort of a diverse group of dedicated volunteers representing all member constituencies and [having] expertise in areas relevant to key goals,” says Dr. Peggy Crow, MD, chair of the Committee on Nominations and Appointments.

Dr. Crow suggests that interested volunteers prepare and submit key information in support of their application. “The Committee on Nominations and Appointments encourages all interested members who are willing to participate in the work of the College to provide us with the information we will need to consider how you might fit in to our committee and subcommittee structure. It is very helpful for the committee to receive a statement of the areas in which a volunteer might be interested in working, along with a detailed description of relevant experience. Supporting letters from colleagues confirming or further describing the contributions and expertise of the member are often helpful to the committee. All potential volunteers are carefully considered by the committee. Final decisions on nominations for committee positions are informed by current needs for particular skills, as well as consideration of demographic balance among committee members.”

In addition to the traditional committees, there are several new opportunities to serve this year, including a Political Action Committee and a Drug Safety Subcommittee. The deadline to nominate yourself or a colleague to serve on an ACR committee is June 1, 2007.

Job Search

New Tools for Job Seekers on Career/Connection

Career/Connection, the official online job bank of the ACR, has launched several exciting new features for job seekers that will improve job search efficiency and quality with state-of-the-art tools and technology. Features are free to job seekers and easy to use, with simple instructions and templates.

New design and improved usability: The registration process, job search, and conference connection features have been streamlined, allowing job seekers to register quickly and easily with minimal information.

Resume builder: In addition to redesigning the site, we’ve added a resume builder that allows job seekers to create a new resume or upload an existing resume in Microsoft Word or Adobe PDF format. Uploaded resumes will retain their previous formatting, saving job seekers time and increasing efficiency.

The resume builder offers variety of design and formatting options, including customizable fonts and color schemes. It offers a list of standard sections generally included in a professional resume and allows job seekers to select the specific sections they wish to include, reorder sections, and add information to the established template for each section. Additionally, job seekers can now save multiple resumes—and choose which versions are searchable by employers and which versions to post to their personal Web site.

My Site personal career Web site: The new My Site feature allows job seekers to build a personalized, password-protected Web site with a unique URL that they can provide to potential employers. Job seekers can create a home page and upload a personal photograph or other image of their choice to it. The Site Materials section allows them to upload or link to articles they have written or published, resumes and professional references can be included on this site as well. Finally, job seekers have the option of branding their site to indicate that they are a member of the ACR or ARHP.

My Work Style self-evaluation tool: Perhaps the most exciting new feature, the My Work Style tool allows job seekers to uncover their personal professional style—which helps identify optimal work environments and potential professional obstacles. This is done using a new state-of-the-art self-evaluation tool, the ProStyle survey, which measures 42 professional motives and thinking styles. The unique combinations of these 42 dimensions underlie work-style differences between people—even people within the same profession or specialty. This level of specificity helps people understand their own work style and that of others. Understanding their professional style can help job seekers make important career path decisions and achieve their goals in rheumatology.

After completing the self-evaluation, job seekers will be given a free report ($100 value) that explains:

• Their unique work style;
• Optimal work environments based on this style;
• Potential professional obstacles that they may encounter along their career path; and
• How they can use this information to advance their career.

To learn more about Career/Connection, visit www.rheumatology.org and click on “Career Center.”

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Look for more exciting announcements in future issues of The Rheumatologist.
April coding challenge: Paul, a new patient age 50, comes in with a referral from his primary care physician. Should his visit be coded as a new patient visit (code 99201–99205) or a consultation visit (code 99241–99245)? Look for the answer in May’s “From the College.” Tell us how you would answer the question by e-mailing the ACR coding/practice management list serve. Want to take part in this exercise but haven’t signed up for the list serve? It’s quick and easy to join! Go to http://lists.rheumatology.org/read/all_forums and follow the instructions.

March’s coding answer: During a follow-up visit for a diagnosis of fibromyalgia, the physician performs an examination including a review of symptoms and a history, and makes a medical decision of moderate complexity. The physician performs an appropriate level of an E/M visit. During the visit, the patient complains of pain in the neck trapezius muscle, shoulders, and hips. Because of the severity of the pain, the physician gives the patient three trigger-point injections. What is the proper code for this scenario?

Many coders and billers have coded this scenario incorrectly in one of three ways:

- As 99213-25: Mid-level evaluation and management with modifier -25; significant, separately identifiable evaluation and management service by the same physician on the same day.
- As 20552X3 or 99213-25: Injections; single or multiple trigger points, three or more muscles; or
- As 99213-25, 20552, 20553x2, and 20502: Injections; single or multiple trigger point injections in two muscles.

The correct answer is 99213-25 for the E/M and 20553 for the injections. Trigger-point injections are billed according to number of muscles injected, not how many injections are given. For example, if you gave four injections to two muscles, it would be coded as 20552.

**PATIENT FACT SHEET**

**Hepatitis-C Virus–Associated Arthritis**

Hepatitis-C virus (HCV)-associated arthritis is highlighted this month in our ongoing series on patient education materials.

Physicians need to address HCV and the rheumatic manifestations associated with the disease, according to Kristine M. Lohr, MD, chair of the ACR Patient Education Task Force. “Chronic hepatitis-C virus is the most common cause of chronic liver disease and reason for liver transplantation in the U.S.,” she says. “In one study of chronic HCV infection, more than one-third of patients had clinical extrahepatic manifestations. Arthritis occurs in up to 20% of HCV patients; the majority [of cases mimic] rheumatoid arthritis and the remainder, oligoarthritis. Mixed cryoglobulinemia is seen in about half of chronic HCV Patients with these and other rheumatic complaints, such as Raynaud’s phenomenon and SICCA syndrome, should be screened for HCV to ensure accurate diagnosis and appropriate therapy.”

Points to remember about HCV-associated arthritis from fact sheet author Pierre Miossec, MD:

- Any musculoskeletal syndrome can be the consequence of an HCV infection, even in the absence of hepatitis;
- HCV-associated rheumatic disease may occur before HCV infection diagnosis; and
- Treatments for these manifestations do exist, but are best used in the context of a multidisciplinary interaction between physicians taking care of the patient.

For more detailed information about HCV-associated arthritis or to download the fact sheet, visit www.rheumatology.org/public/factsheets. Coming next month: Paget’s disease.

**CODING CORNER**

**Audioconference Offers Advice on Adolescents’ Low Back Pain**

Tough back pain disables 5.4 million Americans and costs at least $90 billion in medical and non-medical expenses annually, the study and treatment of back pain in children and adolescents is relatively new.

On May 17, Julie Fritz, PhD, PT, ATC, will present a rheumatology audioconference entitled “Evidence-Based Care of Low Back Pain in Children and Adolescents.” She recognizes the importance of spreading what knowledge there is about this patient group. “Although there is a need for research on the etiology and management of the condition in this age group, there are things that we know that can help to guide our management,” she says.

Fritz’s research and practice as a physical therapist focus on patients who experience "non-specific" spinal pain, which is a difficult condition to assess and treat. Her approach has focused on identifying subgroups of patients in this population and “targeting these subgroups for more specific non-operative interventions,” she explains.

Fritz’s focus is children of part is what she calls the increasing recognition of the problem of low back pain in children and adolescents and its ramifications for affected individuals as they move into adulthood. “We have the potential to have a real impact on the quality of life of affected individuals if we are able to prevent or effectively manage low back pain when it occurs in younger individuals,” she says.

Because young people with low back pain are likely to become adults with low back pain, treating them is a particular and important challenge.

While her talk will cover actionable techniques and interventions for these patients, Fritz notes that the field of study is evolving so rapidly that clinicians are well advised to stay abreast of recent research in order to gather more information about treating children with low back pain.

**REGISTRATION ONLINE!**

Sign up for the May 17 audioconference by visiting www.rheumatology.org/arhp. The registration fee is $35 for members, and several people can listen in on the toll-free call for one registration fee. CME and certificates of participation will be offered to paid registrants. If you are unable to participate, you can purchase a recording.

**APRIL 2007 III THE RHEUMATOLOGIST 9**
Unexpected Path to a Worthy Destination

AHRP Lifetime Achievement Award winner Robert Richardson reflects on his career.

Robert Richardson, PT, MEd, has a lively voice that conveys his deep enthusiasm for a profession he’s had a hand in shaping—though he became a physical therapist almost by accident. From the College recently spoke with him about the long career that earned him the AHRP Lifetime Achievement Award.

Once an aspiring teacher and coach, Richardson was a collegiate wrestler at the University of Pittsburgh when his trainers encouraged him to explore physical therapy instead. He interviewed with the physical therapy program affiliated with his school and was accepted, and his decision was made.

Nearly 50 years later, with a career that includes service as president of both the American Physical Therapy Association (APTA) and the AHRP, Richardson has no regrets. “When I was interviewed by the school, they admitted me, and I knew that meant I had to show up,” he says. “It was probably one of the greatest things that could have happened to me, and I never felt like I made a mistake.” Happily, his work has led him to an academic practice, and so his career has elements of that original aspiration.

Richardson is committed to rehabilitation at a small rural hospital, Maria Parham Medical Center in Henderson, N.C. He has been executive director of the hospital’s foundation since 1998 and also holds a teaching position at Duke University in Durham, where his wife, Jan, also a past president of the APTA, is director of the physical therapy school.

We all bring to the table our skills to form a comprehensive treatment plan, and that’s essential for meeting the patient’s total needs. It’s an excellent model to deliver quality care.

—Robert Richardson, PT, MEd

A Focused Area of Practice

Richardson says his focus on rheumatology was driven by where he worked for much of his career. St. Margaret Memorial Hospital in Pittsburgh. During his 27 years on staff there, the rheumatology department grew to contain 15 rheumatologists and more than 40 other health-related rehabilitation practitioners. The hospital was able to sustain that growth because it became a tri-state regional referral center. With exposure to rheumatology and orthopedic surgery patients, his interests evolved. “I discovered that the allied health section of the Arthritis Foundation [now the AHRP], that was formed in the late 1960s, had practitioners like me with an interest in the science of the practice, and we were able to work together,” he recalls.

Collaborative treatment in rheumatology care excites Richardson. “We all bring to the table our skills to form a comprehensive treatment plan, and that’s essential for meeting the patient’s total needs,” he says. “It’s an excellent model to deliver quality care. And that’s what keeps me interested in attending the meetings and following the science.”

The Importance of Service

Asked what the recognition for lifetime achievement from the AHRP means to him, Richardson mentions his commitment to service and its early roots. “I was born and raised on a dairy farm in western Pennsylvania—the culture was one of giving to your neighbors and giving back to the community,” he says. “I believe we must serve not only for ourselves, but for the next generation.”

Richardson is committed to passing on his enthusiasm for service to the therapists he trains. “When I teach, I teach that service is essential, and that it is a mark of your professionalism. That’s a core belief,” he says.

“When the light comes on for young therapists and physicians,” he continues, “and they see themselves going beyond the technical or scientific part of what they do, whether it’s a cure or better service or passing the education on to others, that is inspiring. When I see other people who ‘get it’ and demonstrate it in their lifetime, that’s what’s rewarding to me. Watching them grow, develop, and evolve is even more important than teaching.”

continued on page 14.
ARHP Needs You!

I would like to personally invite every ARHP member to consider volunteering for an ARHP committee, task force, or other volunteer opportunity. Volunteer opportunities are available to all ARHP members, including international and associate members. Volunteer opportunities are available to all ARHP members. I have found volunteering in ARHP to be extremely rewarding, both personally and professionally. Volunteering in ARHP is stimulating, rewarding, and a lot of fun!

ARHP is the premier professional organization for rheumatology health professionals primarily because of the talent and energy of its volunteers and staff. ARHP needs both new and experienced volunteers in order to continue our mission, meet new challenges, and grow as an organization. Each and every ARHP member brings unique talents, abilities, and expertise to our organization and we need your participation. I joined ARHP in 1993, and the next year I was appointed to the Practice Subcommittee. It was such a great experience that I have been volunteering in some capacity ever since. I have found volunteering in ARHP to be extremely rewarding, both personally and professionally. Volunteering in various ARHP and ACR committees has helped me to increase my professional knowledge and has given me insights into the perspectives of other disciplines. This, in turn, has helped me to be a better practitioner in providing care to my patients.

Volunteering in ARHP provides you with opportunities to share your knowledge, expertise, and ideas with rheumatology colleagues in a fun and inspiring atmosphere. Some of the benefits of volunteering in ARHP include opportunities for:

- Professional networking and interprofessional collaboration;
- Establishing new friendships;
- Discovering new talents and skills;
- Enhancing your leadership skills; and
- Influencing the practice of rheumatology health professionals and ultimately the quality of care and health outcomes for persons with rheumatic diseases.

I greatly enjoyed your article on the use of the DAS in Clinical Practice—Not Ready For Prime Time Joint counts, DAS [Disease Activity Score], and other numeric measures of RA disease activity are important tools for research, but as currently developed, are not appropriate for clinical practice. There are several reasons, so I’ll start with the most important one first. We live in a complex world where many seemingly good ideas can have unintended consequences. Unfortunately, out in community medicine, managed care companies are using joint counts, sed rates, and CRPs [c-reactive proteins] to restrict the use of biologics. For example, one of my RA patients on methotrexate with two very swollen wrists and erosive disease was recently denied an anti-TNF because the joint count was too low.

Dr. Theodore Pincus has data showing that 40% of patients on anti-TNFs at Vanderbilt have normal CRPs, yet another one of my patients had an anti-TNF denied because his CRP was <2.0. If we established the physician global score—the modified HAQ [Health Assessment Questionnaire] plus the [Visual Analog Scale] as the “gold standard”—we could circumvent these managed care manipulations. There are also concerns about what we are really measuring. The burden of inflammation in a patient with two hot knees clearly exceeds that of a patient with several swollen [proximal interphalangeal] joints, yet the joint count, and hence the DAS, is lower. DAS and joint counts amplify the significance of small joint disease and can be very misleading in terms of clinical reality. We know that sed rates are “falsely” elevated in patients with high RFs, monoclonal gammapathies, those with liver disease, and the elderly. CRPs are high in the overweight patient and in patients with infections. In populations of patients (i.e., a study), these issues cancel out, and markers of inflammation correlate well with disease activity, but in individuals, they do not. In clinical practice, it is all about the individual patient. I also have practice management concerns. Joint counts add to our already burdensome documentation requirements. A statement like “the [metacarpophalangeal] are slightly swollen and tender, but the left knee still has a large, warm effusion” is perfectly adequate and makes for better reading than a table of 0s and 1s. Let’s make the joint-count table and DAS calculation a separately reimbursable procedure and you’ll see a lot more enthusiasm for their use.

Finally, I’m put off by the implication that rheumatologists only perform joint exams if forced to do so by the exercise of deriving a DAS. Most of us look at and palpate almost every joint at every office visit, we just don’t record a tally. Rheumatologists need to know what a DAS is and how to obtain one. We need to order CRPs and X-rays and MRIs when clinically appropriate. We need to assess our patients’ function and pain. We need to understand that a patient can feel well and look well, but still have synovitis and develop progressive erosions and loss of function over time. But forcing us to “objectify” an exceptionally complex scenario is not in the best interest of the patient or the clinician.

Barry Waters, MD, Coral Springs, Fla.

DAS, HAQ, and EMR

I greatly enjoyed your article on the use of the DAS and HAQ in RA. I am a rheumatologist in eastern North Carolina. For the past five years I have used the DAS-28 in my patients with RA. Although two companies have also given me the DAS calculator you referred to in your article, I have found the DAS Web site in the Netherlands, www.das-score.nl, very simple. My nurses input the data from my DAS data sheet and that number in my EMR [electronic medical record].

Monitoring serial DASs has benefited my patients a great deal. I have also had to use the scores a handful of times to petition insurance companies to pay for a BRM [biological response modifier] in certain patients. My use of and experience with DAS, and now the HAQ, mirrors yours. In late 2005 I started using the Mini-HAQ in my practice. Currently I am trying to set up a touch-screen tablet PC for my patients to directly input their HAQ responses into my EMR. The learning curve has been far steeper for me with the HAQ than the DAS. I am hopeful that using the HAQ in RA and other [connective tissue diseases] will allow me greater flexibility in treating my patients.

Certainly the use of the DAS has allowed me to be more aggressive in the use of BRMs and aggressive combination therapies. In talking to patients about their disease, now “I have a number to throw at them.” At first patients were upset about “another piece of paper for me to fill out,” but now it is commonplace for them to start the forms and it takes me virtually no time to complete the data sheets.

Dave Fraser, MD, New Bern-Jacksonville, N.C.

DAS Forms

I am an office manager for Dr. Jeffrey Mathews. I read your article and am excited to re-implement using DAS in our office. . . . I Googled DAS and didn’t have much luck, and I tried to find it online through ACR, and no luck. What I am looking for is a form that is easy to use at each visit. … If you could direct me I would appreciate it very much.

Lisa Webb, Provo, Utah

TR Responds: You can download DAS calculators in a variety of formats at www.das-core.nl/www.dasscore.nl/index.html. Good luck implementing the DAS! And thank you to all of our readers who wrote in about “Twenty Questions.” We love to hear what you think about TR’s articles. Send us a letter via e-mail to dantolin@wsley.com or psier001@mc.duke.edu.

Karen Kerr is president of the ARHP and a pediatric nurse practitioner at Children’s Hospital of Michigan in Detroit. Contact her via e-mail at arhp@rheumatology.org.
DR. Harrington was a member of the ACR group that spearheaded the workforce study effort, and he has spent the past 10 years redesigning his own rheumatology practice to reduce wait times and deliver higher quality patient care.

The workforce study report suggests practice redesign—for example, implementing patient screening and employing advanced practice nurses and physicians assistants (PAs)—is one way to minimize the effects of the workforce shortage.

“The question that we all must answer is how many rheumatologists are really needed for people with rheumatology disease,” Dr. Harrington says. “We have not defined ‘necessary care’ and the result is a high level of inefficiency.”

Practice Efficiency
The workforce study highlights wait times for patients as a strong indication of excess demand. The current wait time for new rheumatology patients is higher than for general medicine and other specialty referrals, such as cardiology and gastroenterology.

The workforce report notes rheumatologists try their best to see early arthritis patients quickly in order to prevent joint damage, although some practices still have wait times over two months for these patients.

Nearly all (97%) of the rheumatology practices that responded to a survey conducted as part of the workforce study report that they accept new patients. However, nearly half (48%) restrict access by requiring a referral from a primary care physician. Despite this requirement, Dr. Harrington emphasizes that approximately half of all new patients to rheumatology practices show up without medical records and a majority (80%) do not come to the specialist with a written referral. This automatically triggers the need for a follow-up appointment, he says.

“That almost half of rheumatologists report limiting access based on referral and almost half report wait times for non-urgent patients exceeding four weeks suggests that there is considerable excess demand for rheumatology services,” notes the rheumatology survey final report. “The current supply of rheumatologist visits is not equal to the demand for those visits such that rheumatologists are limiting access through requiring referrals or having long wait times for non-urgent patients.”
wait times for appointments.

The workforce survey also asked practices if they planned to hire now or in the next five years—and the response is another indicator that practice redesign is needed. The survey asked rheumatologists if they planned to hire now or in the future, a rheumatologist, a pediatric rheumatologist, a PA, or a nurse practitioner (NP). The results indicate a strong demand for rheumatology services.

Change Your Practice

In the article “Pre-Appointment Management of New Patient Referrals in Rheumatology: A Key Strategy for Improving Health Care Delivery,” Dr. Harrington and Michael B. Walsh, DO, discuss implementation of a screening process for newly referred patients. This article, profiled in the workforce study report, outlines strategies that have been implemented by many ACR members to respond to the need for practice redesign. It listed three general strategies for improvement:

1. New patient screening;
2. Improved appointment scheduling; and
3. Improved quality of care for chronically ill patients.

Dr. Harrington and others have implemented a screening process for all new patients that follows an algorithm for determining if and when the patient should be seen by the rheumatologist, referred to another specialist or pain center, or referred back to the primary care physician. The rheumatologist reviews each case to make this determination. Some of the patients not seen by the rheumatologist were referred to an orthopedist or spine program. “Others were assured that their treatment through the primary care physician was appropriate,” the report notes. “The review of patient records prior to the first appointment had other benefits … it allowed the rheumatologist more information on the patient prior to the appointment so that they could decide whether a brief or longer visit was needed. Also, with the records on hand, duplicate testing occurred less frequently.”

Dr. Harrington tells The Rheumatologist that he was forced to look at redesigning his own practice when he lost the services of an orthopedic spine specialist and wait times in his practice went from two months to six months.

At that time, he and colleagues decided to take a deeper look at the 120 patients on his six-month waiting list and found that half had either gotten better or seen another physician during the six-month period. “As rheumatologists, we need to enhance clinical practice guidelines,” says Dr. Harrington. “We have to learn to do a better job of pre-appointment assessment and management. For instance, if we get a call from a patient with back pain for three days after lifting, the appropriate clinical assessment would send that patient to the primary care physician.”

The study report highlights one rheumatology practice that tested other strategies to reduce wait time for early arthritis patients with success. “Within several months of implementing this strategy, the wait time for an appointment in the department fell from about 60 to 25 days,” according to the workforce study report. “Nine months after implementation, wait times declined to two days. The department also saw improvements in cancellation rates which fell from about 40% to 20%.”

Similarly, the report cited a chronic care model developed in the 1990s as one that has been used by some rheumatologists. This model suggests that care needs to be changed from episodic to continuous treatment. One idea proposed is to encourage the implementation of the chronic care model into the current medical education curriculum. “Through this implementation, students will learn how the biology of chronic disease evolves and the [effects] of treatment as well as how physicians can efficiently use available treatment and other resources.”

The ACR workforce report suggests that physician specialists can improve their ability to treat patients by creating a multidisciplinary team approach to care management and, as part of this team, should hire a nurse practitioner or a physician assistant to perform routine duties that are now covered by the rheumatologist.

Another factor cited in the study report is the effect of Medicare coverage on practice. Changes in Medicare payment policy and the policies of other insurers for rheumatology services are important considerations. These include a cut in Medicare reimbursement for drugs for on-site infusion services from 95% to 85% of the wholesale price as of January 2004. At the same time, as part of the provisions of the Medicare Modernization Act of 2003, Congress increased reimbursement for practice expenses by 32% in 2004. Beginning in 2005, a formula called the average sales price is used to calculate reimbursement. The report states this new formula increases payment to physicians to 100% of the average sales price.

However, “the change in reimbursement for on-site infusion is likely to result in decreased reimbursement for infusion drugs for rheumatoid arthritis. This may result in rheumatologists needing to reduce the number of sites where a patient can receive infusions as well as the size of the staff at the sites,” the report notes.

Teamwork on Patient Histories

Dr. Harrington notes that one particular area in which rheumatologists can use the NP or PA helps is in taking the patient’s medical history. First, he stresses, patients must bring all of their records—including lab results and X-ray films—with them to the initial appointment. Second, many rheumatologists are still doing their own narrative histories with patients, but having a PA or NP do this can save an average of 10 minutes per patient and close to double the number of patient appointments available in a day.

Dr. Harrington recommends using a standardize history form that uses branching logic. Give the form to patients while they are in the waiting room and have NPs and PAs who have training in the protocols assist the patient and then provide a summary to the rheumatologist before the actual patient time with the doctor. The standard form has a disease activity score that the NP or PA then can use to qualify the patient’s needs. “We need to learn how to function like dentists and use other clinical staff (e.g., the dental hygienist) to share the workload,” says Dr. Harrington.

He also urges rheumatologists to switch to electronic medical records (EMRs). (See “Go Digital” in Dr. Harrington’s 2006 Forum.) Despite their proven ability to enhance practice management and streamline patient care, only 15% of rheumatologists currently use EMRs.

The technological changes like EMRs and changes in practice organization and design provide a backdrop for fundamental workforce supply and demand and for the primary goal of improving patient outcomes.

“All of the things that we have identified as improvements in practice also improve patient outcomes,” says Dr Harrington. He stresses that the ACR workforce study report is just the opening round of the discussion on how to further improve.

Retirement Effects

The workforce study highlighted the need to increase the number of U.S. rheumatologists in order to meet future demand for services. One key factor in whether the supply of specialists in the future will meet the demand is the number of rheumatologists planning to retire in the next five to 10 years. Rates of retirement are not available for rheumatologists specifically, but general data on physician specialists suggests what the workforce study called “substantial declines” in rheumatologists between age 59 and 68. “Beyond age 68, the labor force participation rates level off with about 60% of male and 40% of female professionals continuing to participate in the labor force through age 75 at which point the predictive model assumes all rheumatologists will have retired.”

The workforce survey asked respondents when they planned to reduce their work efforts either prior to or at full retirement. Younger rheumatologists plan to reduce work effort earlier than their older counterparts, as do women. This data may be biased because any physicians currently older than 60 who have retired were not counted in the results. Overall, rheumatologists expressed satisfaction with their current work level and environment. About half said they would like their current workload to remain the same; the other half said they wanted their workload to decrease.

With new efforts to improve chronic care management of patients with rheumatic diseases as well as to promote early screening and prevention if possible, Dr. Harrington says the challenge to align clinical practice in a way that meets the needs of patients and rheumatologists in practice is a long-term project. “We continue to move from reactive medicine to primary prevention. How will the system manage this change?” he says. “The impact of current and pending technological advances and practice efficiencies is difficult to quantify,” says the ACR report. “Moreover, future changes not anticipated here will undoubtedly have effects.”

Terry Harrnett is writing the workforce study series.

Who Is Hiring?

Position Recruiting Now Within Five Years

Rheumatologist 30% 50%
Pediatric rheumatologist 5% 7%
PA or NP 10% 25%

Wait-Reduction Strategies

• Establish longer follow-up treatment intervals as appropriate to avoid backlogs;
• Use advanced practice nurses to care for patients requiring more education, coping skills, and monitoring;
• Build into the daily schedule appointment times for patients requiring same-day access;
• Shorten the time between when a patient calls to make an appointment and the date of the appointment to reduce cancellations; and
• Work with primary care physicians to reduce unnecessary referrals.

WEB RESOURCE

Download Patient History forms at www.rheumatology.org/practice
AutoCure brings together researchers across Europe to combat RA

When it comes to doing research in RA, it pays to have a good international and multidisciplinary mix of partners. International collaborations allow for access to a wide variety of scientific expertise, extra resources, and, in clinical trials, a larger number of patients.

While international collaborations can be fraught with complexities, the European Union (EU) seems to have discovered how to facilitate the process by making it relatively easy to establish research networks through the European Commission (EC)—the legislative body of the EU.

“I think the EU is built on a philosophy of cooperation and the idea that there is strength in working together,” says Antonia Mochan, spokesperson for science and research at the EC. “Whether that makes things more or less difficult than in North America, I’m not able to judge. But it’s certainly a cornerstone of our work in science and many other policy areas.”

One such international network is the newly formed AutoCure, which has a mandate to study aspects of inflammatory rheumatic diseases. Indeed, AutoCure consists of 26 partners—19 major universities throughout Europe, six industrial partners (small to mid-size pharmaceutical companies), and the European League Against Rheumatism (EULAR). It was launched March 1, 2006, and has a five-year mandate.

According to Lars Klareskog, MD, PhD, coordinator of AutoCure, there are three main goals for the network. “One is to try to understand the causes of disease, two is to develop better prognostic markers, and three is to develop new therapies,” he says. Dr. Klareskog is also professor and head of rheumatology at the Karolinska Institute in Sweden.

At present, there are 22 research projects in the AutoCure network—a mix of new research and projects already underway at individual centers that now have been combined.

RA: Neglected No Longer

Until recently, rheumatology research in the EU “was a neglected area,” Dr. Klareskog told TR in a telephone interview. Each year, the EC calls for research proposals in specific science and medical areas.

“A number of us formulated the idea for this particular consortium,” he says. AutoCure was proposed, and won.

A total of 25 institutions and more than $14.5 million later (provided by the EC as a result of the competition), AutoCure was born. There is no other body in the world that facilitates the ability for researchers from a relatively large number of different countries to work together in such a way, says Dr. Klareskog. Additional funding also finds its way into AutoCure projects through government and rheumatology-related agencies from different countries, as well as some corporate funding. There are numerous research projects under AutoCure, ranging from basic science to large clinical trials to projects focused on data management and cost-efficiency.

Some of these projects were already operating, but now, as part of AutoCure, they are part of the wider network with access to more expertise, patients, and resources.

International Cohort Approach

Tom Huizinga, MD, PhD, chair of the department of rheumatology at Leiden University in the Netherlands, is principle investigator of a project using existing population cohorts that have now been joined together to study predictors of clinical outcome in patients with arthritis. The project has participants from 16 partners and pulls together three key European cohorts: the Norfolk Arthritis Register (NOAR), the Leiden Early Arthritis Cohort (EAC), and the Swedish Epidemiologic Investigation of Rheumatoid Arthritis (EIRA).

Whereas the cohorts had about 2,000 people each, combined they represent more than 6,000. The cohorts are being used to investigate how genetic and environmental factors affect the chronicity RA in both adult and pediatric populations. Researchers will investigate the patterns of structural damage that occur with chronicity over time in both adults and children, taking into account severity of disease and type of treatment.

This “new pan-European cohort allows us to find even small associations with significant statistical power. This is relevant because it leads to a better understanding of RA,” says Dr. Huizinga. There will be a centralized reading method for X-rays to standardize interpretations, and datasets will be pooled so there will be a common database.

The AutoCure network allows for easier information sharing. “People exchange data earlier, as well as materials, as if they are members of the same club,” says Dr. Huizinga.

Another project is using two large, existing Swedish cohorts to study the predictors of rheumatic disease in healthy populations. Lead by researchers at Umea University in Sweden, with contributions being made by six other partners, the study will use the Northern Sweden Health and Disease Study (NSHDS) and the Maternity Cohort of Northern Sweden (MCNS) cohorts.

The NSHDS cohort includes 122,800 biological specimens from 79,940 people. The MCNS includes 102,800 samples from 78,700 pregnant women who had been screened for rubella since 1976.

The databases are especially useful for long-term studies because each person in the Sweden is identified by a unique national identification number. These numbers are used in a centralized disease register which is part of a national socialized healthcare system, and makes it easier to do long-term tracking of health changes.

In the study people who develop early RA will be identified through the national disease register. Their identification number will be matched to the two cohorts to identify blood samples that had been provided prior to disease onset. From this, various genetic and antibody studies can be undertaken to look for disease markers. Also, the populations who develop RA will be surveyed about environmental influences that may be linked to their disease.

In about a year, researchers anticipate integrating a third cohort into the study, this one from the United Kingdom, which also has a national, socialized healthcare system.

Tease out Disease Predictors

Sharing cohorts comes in handy for AutoCure’s second goal: that of developing better prognostic markers for disease. “You need large cohorts that you can follow over many years where you can take samples and test new assays,” says Dr. Klareskog.

Another project lead by Dr. Huizinga and colleagues at the University of Leiden, entails 11 research groups working together to find predictors of response to new therapies. This will be done through a series of clinical trials, including newly launched trials and expansion of previously existing trials.

“Many projects in AutoCure have been going on for years, but now can be brought together,” says Dr. Klareskog.

Clinical trial formats within AutoCure will be standardized, and researchers will investigate new targeted therapies in patients with recent onset disease. Standardization between different international centers will ensure patient selection and evaluation is performed using the same protocols, and that data collection and analyses are done in the same rigorous manner.

In fact, a multi-center clinical trial that was already being conducted by three of the network members, Stop Arthritis Very Early (SAVE), is now part of AutoCure and will be expanded. The trial investigates whether an additional pulse of prednisone added to standard medication is beneficial for treating RA. Plus, several targeted therapies that were already under development by some of the partners will be available to AutoCure trials for further study.
Dr. Blakely, a rheumatologist in private practice in Kearney, Neb., is referring to his electronic medical record system or EMR—an approach to recording patient data that is being adopted by rheumatologists across the country.

Jump into EMR Adoption

For many practices, the start-up phase is the most challenging part of adopting an EMR. Herbert S.B. Baraf, MD, expects the EMR system that his 11-physician rheumatology group in Wheaton, Md., is installing to go live in June; that is about six months later than originally planned—and after more than a year’s worth of installation, training, practice redesign, and unexpected costs.

“Anyone who looks at this as a plug-and-play purchase doesn’t understand it,” says Dr. Baraf. “This is a very complicated thing and it requires physicians to roll their sleeves up and jump in.”

Dr. Blakely, who began using the EMR when he opened a new solo practice in January 2006, says that, by the end of the first month, his nurses were in tears. Richard H. Blau, MD, a rheumatologist with a private practice on Long Island, N.Y., can relate. He had installed an EMR system in 2003 as one step to a paperless office.

“This is not easy. It’s not painless either,” he says. “Each time I added a new software module, such as a document manager or computerized fax, my staff was initially skeptical. However, after a week of use and a little training, they all were able to appreciate the benefits of the new programs.”

Thus, Dr. Blau sides with others who make it to the other side of the EMR adoption mountain and report a beautiful view.

Bits, Bytes, and Benefits

Mark L. Robbins, MD, MPH, has been using an EMR for nearly 15 years at Harvard Vanguard Medical Associates, a 600-member multispecialty group in the Boston area. The system’s top benefits include better communication and coordination among physicians treating a patient and the ability to track trends—such as lab results—to pick up subtle changes in a patient’s condition.

Future benefits include the ability to report quality-of-care measurements and health outcomes needed to participate in pay-for-performance initiatives.

“The computers help you take a disease like rheumatoid arthritis or lupus and create your own tracking systems for following patients over time, and then export that in a format that ultimately you will be reimbursed on,” says Dr. Robbins.

Paul H. Waytz, MD, who leads a 10-member rheumatology practice in Edina, Minn., believes the EMR system installed four years ago paid for itself through lower staff and transcription costs in about 18 months.

“I would never go back,” he says. “I’m not much of a techie, and I was able to learn it—and I don’t have any paper notes.”

Even Karen S. Kolba, MD, who says EMR technology has saved neither time nor money for her solo practice in Santa Maria, Calif., would not choose to return to pen and paper.

“The advantage is that I now have better documentation,” she says. “If I were ever audited, I could point to it and say, ‘Look, here are the things I did on this patient,’ and those things probably weren’t all there in my dictated notes.”

What’s the Cost?

The expenses associated with moving to EMR vary so widely that the oft-touted “$20,000 per physician” may be too general for planning your budget. Here are some actual EMR setups used in rheumatology practices and their costs.

Large, multi-office group practice: Installation costs are still being tallied at Arthritis and Rheumatism Associates P.C., the largest rheumatology practice in the Washington, D.C., area. As of November, Dr. Baraf, the managing partner of the practice, estimated that nearly $500,000 would be invested in the system, including hardware, software, new phone lines, and start-up expenses such as chart extraction and scanning.

“We’re in multiple offices, and that involves linking the offices by high-speed wireless or wired technology,” says Dr. Baraf. “It gets to be fairly expensive the more offices you have.”

Some of the costs were unanticipated. For example, three-year-old servers had to be replaced, adding $50,000 to the original cost estimate.

Mid-sized group practice: Arthritis and Rheumatology Consultants, a 10-physician practice in Edina, Minn., invested about $350,000 on EMR software, hardware, and start-up costs in early 2003. Software licenses cost $9,400 per provider; hardware and training costs were about $125,000, says Dr. Waytz, a partner in the practice.

More hardware was needed when the physicians decided to give up on their original goal of using wireless laptops. “Each doctor and nurse had a small laptop that we carried from room to room,” he says. “It wasn’t reliable; it was cumbersome, and the laptops were too small. It wasn’t working right.”

Solo practice: Dr. Kolba, owner of Pacific Arthritis Center Medical Group in Santa Maria, Calif., and Dr. Blau, owner of Arthritis Institute of Long Island, each purchased the same EMR system for their solo practices in 2003.

Dr. Kolba estimates she spent $15,000 on software, including a package that integrates data from her practice management software, and about $35,000 on hardware, including monitors and printers in each exam room, her office, nurse workstations, and the on-site laboratory.

Dr. Blau reports the software cost between $6,000 and $7,000, while hardware expenses rang in at about $800 per workstation for a total outlay of roughly $12,000. His facility was already wired to accommodate the networked computers.
Purchasing Tips

Faced with hundreds of EMR systems on the market, rheumatologists might do best by buying a system like the one being used by the physician next door.

“Seriously consider getting something that one of your friends already has—even if they’re in a different specialty,” Dr. Kolba says.

She chose a system on the advice of a consultant and has found implementation to be slow and sometimes frustrating. By contrast, a podiatrist who practices on her street is benefiting from Dr. Kolba’s experience with the system.

“He gets a lot of free advice from us, which is fine. I’m happy to share,” she says. “That’s definitely made his experience better.”

Dr. Kolba and other EMR-equipped rheumatologists urge their colleagues to buy a system only after they understand—or develop—the types of support needed to implement it successfully.

Two essentials to making the EMR work: general computer savvy and rheumatology-specific templates that correspond to an individual practice. If a physician’s office has no in-house information technology expertise, that will need to be purchased. Likewise, unless a physician has the skills to customize templates, choosing an EMR system with rheumatology-specific templates—or hiring someone to create them—will be required.

Other tips from rheumatology’s EMR leaders:

**Screen the company first, and then the product it offers:** “There is tremendous turnover in the industry,” says Dr. Robbins, co-author of “Electronic Medical Records for the Physician’s Office,” an issue of the ACR’s *Practitioner.*

Likewise, unless a physician has the skills to customize templates, choosing an EMR system with rheumatology-specific templates—or hiring someone to create them—will be required.

**Prepare to Slow Down**

“You must plan for a reduction in productivity, compared to scribbling in the paper record, which is much quicker,” says Dr. Robbins. “EMRs tend to slow people down, especially when they’re first learning it, and sometimes forever.”

The improved documentation by a template that forces physicians to record their decisions and actions may lead to higher reimbursement levels. Also, for many physicians, EMRs eliminate any dictation at the end of the day.

**Establish Protocols to Tailor the System to Your Practice**

The EMR purchased by Dr. Waytz’ group had no rheumatology-specific templates, so the physicians built them from scratch. One physician was designated to create and change the templates to correspond to the diagnoses, treatment options, and other information applicable to their practice. For the first year or so, the doctors met every six weeks to decide on which tweaks were needed.

“There is still some things that are superfluous and some that I want to add,” he says. “You have to have the group willing to meet to say we want these choices.”

**Reconsider Workflow and Staff Responsibilities**

Dr. Blakeley operates his practice with only a few staff members other than himself: an office manager and a part-time assistant who handle billing; a receptionist/scheduler; two nurses—one to room patients and one to do infusions; and a laboratory technician. The lean staff, which includes no transcriptionist or medical records staffer, is possible only because of the EMR system, he says.

If you are interested in learning more about the Rheumatology Network and the ACR, please visit our website at www.rheumatology.org.

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**Implementation Pearls**

**Give Yourself Time to Learn the System**

“You have to look at this as a marathon and not a sprint,” says Dr. Blau. “It took over a year for us to become paperless.”

At first, he used the EMR for only two patients a day, refining the templates bit by bit as he gained experience with the system’s capabilities. Similarly, he started with a single template—the one for osteoarthritis—and he chose a single nurse to learn the system with him. She then trained other nurses in the practice who, in turn, trained members of the administrative staff.

**Prepare to Slow Down**

“You must plan for a reduction in productivity, compared to scribbling in the paper record, which is much quicker,” says Dr. Robbins. “EMRs tend to slow people down, especially when they’re first learning it, and sometimes forever.”

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**Other Useful Resources**

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Put Hughes Syndrome on Your Radar

Diagnosis of antiphospholipid syndrome is increasing. Here’s how to recognize and treat it.

By Graham R.V. Hughes, MD

Brief History of APS
In 1983, my colleagues and I described in detail a syndrome involving—uniquely—both arterial and venous thrombosis, and including prominent neurological features, including strokes, seizures, memory loss, and chorea. In addition, this syndrome was associated with occasional thrombocytopenia, livedo reticularis, labile hypertension, recurrent miscarriage, and internal organ thrombosis such as Budd-Chiari syndrome.1 2 Recognized we that the syndrome was "sufficiently different from typical systemic lupus to warrant separate consideration"—originally calling it the anticardiolipin syndrome.3 Led by the late Aziz Gharavi, MD, and E. Nigel Harris, MPhil, MD, DM, we set up sensitive immunoassays for antiphospholipid antibodies (aPL), changed the name to APS, and introduced the term primary APS for stand-alone cases.4

The worldwide interest in this syndrome has led to its recognition in a wide variety of clinical states increasing diagnosis. Indeed, it seems a fairly safe prediction that APS will overtake lupus in prevalence. A rough one-in-five rule seems to apply for the contribution of APS to various clinical conditions—one in five cases of recurrent miscarriage, one in five strokes in people under 45, one in five cases of deep vein thrombosis (DVT). Eventually, this estimate may also pertain to other major illnesses including myocardial infarction in the young, idiopathic teenage epilepsy, and possibly even migraine.

Pathogenesis and Clinical Features
APS is an autoimmune disease in which antibodies directed against phospholipid-protein complexes appear to lead directly to thrombosis. Like all autoimmune diseases, APS will overtake lupus in prevalence. A rough one-in-five rule seems to apply for the contribution of APS to various clinical conditions—one in five cases of recurrent miscarriage, one in five strokes in people under 45, one in five cases of deep vein thrombosis (DVT). Eventually, this estimate may also pertain to other major illnesses including myocardial infarction in the young, idiopathic teenage epilepsy, and possibly even migraine.

Neurological Considerations
Stroke: The most feared complication of APS is stroke, with up to 20% of strokes in people under 45 possibly having this etiology. In this setting, the MRI can be misleading (e.g., false negatives) and we look forward to the development of more sensitive and available screening techniques. Estimates for the frequency of stroke in patients with APS vary widely, and some studies have been hampered by methodological problems.5

Memory loss: Second only to headache, memory loss is possibly the most common complaint in APS. Despite a number of published psychiatric studies on APS, it is probable that the extent of the problem is still underestimated. Here's one example from a patient I recently saw: a young woman with APS improved her word-finding score from 15% to 95% after three weeks of subcutaneous heparin. This sort of result is not uncommon in our own clinical experience when formal testing is undertaken.

Multiple sclerosis: In a recent patient survey, 32% of aPL-positive patients in our clinic had had a previous possible diagnosis of MS considered.6 This finding raises important issues. Firstly, differential diagnosis can be difficult. Secondly, we have seen APS patients in whom borderline aPL readings were dismissed as epiphenomena and yet in whom anticoagulation resulted in sustained clinical improvement.

Other neurological: Seizures are a feature of APS. Interestingly, in many patients the seizure frequency improves with anticoagulation and worsens with a falling international normalized ratio (INR). Recently, it has been estimated that up to 15% of cases of idiopathic teenage epilepsy may be related to aPL.5 Movement disorders of all descriptions can occur in APS and range from chorea to tics to parkinsonism. Balance problems are particularly common—and, as yet, underreported.

Heart and Lungs
Although the association between aPL and myocardial ischemia is well recognized, there still seems to be a wide range of figures published—between 5% and 15% prevalence of aPL in patients with myocardial infarction (MI), for example. Whatever the figure, the link is of extreme importance in terms of MI prediction and prevention. Sletnes et al., in a study of nearly 600 patients surviving an acute MI, found 13.2% positive for aPL.7 Further, a strong correlation between aPL and the risk of recurrent cardiovascular events in a series of young survivors of MI has been observed.

Although the current message is that routine aPL screening is not indicated in the evaluation of patients with an MI, it is clear that aPL are a significant risk factor for post-transplant renal thrombosis and, importantly, that anticoagulant therapy could improve outcome.8 The important experience gained from observations of aPL on the outcome of renal transplantation has led to more routine aPL testing in the fields of liver, heart, lung, and marrow transplant surgery.

The link between renal artery stenosis and APS has been one of the most interesting and potentially one of the most important. In the 1983 description of APS, I reported "these patients’ blood pressure often fluctuates, apparently correlating with the severity of the livedo, suggesting a possible renal-vascular etiology. However, this group of patients rarely has primary renal disease."9 Recently, my colleagues (notably Shirish Sangle, MD, and David D’Cruz, Laboratory slide tests were recorded previously. This situation raises the possibility that in some cases, the thrombotic connection is being missed.

Heart valves: One aspect of APS that separates it from other major clotting disorders is valvular disease. (See Table 1, p. 20.) The use of two-dimensional and Doppler echocardiography has shown a variety of lesions, including thrombotic vegetations, thickening, and stenosis. The mitral valve is by far the most commonly involved, with mitral regurgitation reported in up to one-fourth of all patients.

The pathogenesis of valvular lesions is still uncertain. However, in some cases, a rapid combination of thrombosis and valve dehiscence leads to an early requirement for valve surgery.

Kidneys
The discovery of APS has had at least three important consequences in nephrology. First, it has altered the focus of renal biopsy in lupus to include renal microthrombosis. Second, it has proved an important diagnostic (and therapeutic) indicator in renal transplantation. Third, it has revealed the interesting discovery of renal artery stenosis and hypertension associated with aPL.

Marie-Carmen Amigo, MD, and her colleagues at the Instituto Nacional de Cardiologia Ignacio Chavez in Mexico, did much to highlight the important contribution of renal microthrombosis to the pathological picture in lupus, with changes ranging from small occlusive arteriolar thrombotic lesions to severe renal artery hyperplasia and occlusion with renal parenchymal ischemia.10 In renal transplantation, it is clear that patients with APS are at increased risk for post-transplant renal thrombosis and, importantly, that anticoagulant therapy could improve outcome. The important experience gained from observations of aPL on the outcome of renal transplantation has led to more routine aPL testing in the fields of liver, heart, lung, and marrow transplant surgery.

Rights were not granted to include this image in electronic media. Please refer to the printed publication.
MD) have published a series of patients with renal artery stenosis and hypertension. In a cohort of 500 patients with APS, 173 (34.5%) had definite hypertension requiring therapy. We have now built up a series of APS patients with renal artery stenosis, depicted in Figure 1 (right). The lesions are localized and clearly differ from those of atheroma or fibromuscular dysplasia.

With full anticoagulation, the hypertension in this group of patients proved easier to control. Interestingly, these focal stenotic arterial lesions are seen elsewhere in the body, for example, in the cerebral circulation and in the celiac and mesenteric arteries.

Other Clinical Features

Gastroenterology: As well as Bud-Chiari syndrome—which of APS is a major cause—more focal hepatic thrombosis is frequent, and abnormal liver function tests are frequent in poorly controlled APS. Idiopathic cirrhosis has also been reported in some patients. Celiac axis stenotic lesions were first fully appreciated in angiographic studies of renal artery stenosis. The classical symptoms of post-prandial mesenteric angina were present in most—though not all—of the patients.

Skin: Livedo reticularis is not only an important marker for APS; it could well be a risk factor in itself. (See Figure 2, above right.) Patients with sero-negative APS—as described below—include some with florid livedo. Thrombosis—particularly DVT and skin vessel thrombosis—leads to skin ulceration. For those who conduct skin ulcer clinics, it is clear that a subset of patients exists in whom chronic skin ulceration could well be improved with anticoagulation.

Ear, nose, and throat: My own practice has seen a sharp increase in the number of patients referred by otorlaryngologists, with APS presenting as acute Ménière’s and balance problems, as well as the well-documented acute sensory neural hearing loss. Tinnitus is a frequently complained symptom, and I have previously reported the anecdotal experience of tinnitus in APS improving with anticoagulation.

Blood: Severe thrombocytopenia is fortunately unusual, though borderline platelet counts (e.g., 100,000 to 120,000) are frequent. A possible diagnostic clue is the frequency of pseudolivedo reticularis on automatic ethylenediaminetetraacetic acid blood counts (improving on visual counts). This finding possibly points toward subplatelet membrane abnormalities.

Orthopedics: My colleagues and I have reported a series of idiopathic metatarsal fractures in APS patients, and case reports of other bone fractures (seemingly unrelated to osteoporosis) have appeared. Perhaps the biggest impact in the world of orthopedics will come from more routine screening for prothrombotic conditions prior to hip or knee surgery.

Pregnancy and in vitro fertilization: The improvement in pregnancy outcome in aPL-positive women during the past two decades has arguably been the headline story of APS and is reviewed elsewhere. The role of aPL in the pathogenesis of in vitro fertilization (IVF) implantation failure, among other findings, has led to the use of heparin and aspirin in some IVF regimes, though as yet there is little convincing evidence of benefit.

Sero-negative APS: I assume that all of us see patients with many of the hallmarks of APS, including arterial thrombosis, thrombocytopenia, valve lesions, recurrent pregnancy loss, and so on, in whom aPL tests remain doggedly negative. If situations for this situation might include wrong diagnosis, a disappearance of antibodies over time, or simply that more aPL-related tests are needed. As a clinician, however, I believe that the concept of sero-negative APS is useful, just as sero-negative RA and sero-negative lupus were decades before.

Anecdotes for the Clinically Curious

Neurological features of APS appear almost certainly embrace sleep disturbance. In my clinic, I have an extended family with both APS and autism, which may just be a clinical coincidence. Three of my patients have developed acute anopia. Peripheral and autonomic nerve problems and cases of reflex dystrophy are also being described. As in diabetes, it may be that ischemia of peripheral nerves renders them more sensitive to external pressure. One of my APS patients with lumbar disc disease and severe symptoms of spinal stenosis and claudication improved once anticoagulation was started. Fatigue, as in lupus, is a frequent symptom, and major complaint, and often improves significantly once anticoagulation is started. More difficult to explain, but certainly a frequent observation, is the improvement in the arthritis (in primary APS) with anticoagulants.

Table 1 (below) gives a list of features which I believe are helpful in diagnosis—certainly useful in the differentiation from other coagulopathies.

Treatment

The indications for aspirin (or clopidogrel), heparin, and warfarin are reviewed in detail elsewhere, and I will restrict this section to three specific comments. First, the use of a two- to three-week heparin trial in APS patients with severe frequent headache, but with normal MRIs may be informative. Although a “soft” diagnostic tool with significant placebo input, in some patients the improvement or even abolition of headache and migraine with a course of self-administered heparin (e.g., Fragmin 10,000 units daily) gives some support to the difficult decision to move to warfarin.

Second, it is important to achieve a therapeutic INR with warfarin, ideally with a self-testing INR machine. There is probably no overall correct INR. Usually, arterial thrombosis appears to require a higher INR than venous. In neurology, however, we frequently see a higher INR requirement (e.g., 3.5–4), with the headaches, TIA, and memory impairment predictably returning when the INR falls below, for example, a precise reading of 3.4. For such patients, the use of self-testing machines is as important to a reasonably normal life as is self-measurement of insulin dose in some diabetics.

Third, the use of immunosuppressives has as yet had little effect on disease manifestations. However, research showing possible direct effects of aPL (e.g., neuronal tissue) and the increasing anecdotal experience of success in APS with new agents such as rituximab may stimulate a reappraisal.

Summary

This review highlights some of the clinical and diagnostic aspects of APS, or Hughes Syndrome. With the increasing recognition of the syndrome spreading to all disciplines of medicine, the clinical approach to many diseases is changing. APS is proving a differential diagnostic disease in diseases such as multiple sclerosis and Alzheimer’s disease and in clinical research it is providing insights into mechanisms of hypertension and accelerated atheroma. In the world of anticoagulation, the recognition of APS has had a profound impact both on diagnosis and on treatment.

Dr. Hughes is head of the London Lupus Centre and London Bridge Hospital.

TABLE 1:

<table>
<thead>
<tr>
<th>CRITERION</th>
<th>COMMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>History</td>
<td>Recurrent headache, Childhood and teenage migraine, Arthritis, Family history of thyroid disease</td>
</tr>
<tr>
<td>Exam</td>
<td>Dry Shimer’s test, Livedo, Heart murmurs</td>
</tr>
<tr>
<td>Lab</td>
<td>Borderline platelet count, Borderline C4, Thyroid antibodies</td>
</tr>
<tr>
<td>Table 1 (see below) gives a list of features which I believe are helpful in diagnosis—certainly useful in the differentiation from other coagulopathies.</td>
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</table>
Patients with lupus often get passed from pillar to post,” says rheumatologist Graham Hughes, MD. To ease the burden of those suffering from the disease, Dr. Hughes—who first described the antiphospholipid syndrome (APS) or Hughes Syndrome in 1983—opened the London Lupus Centre (LLC) in January 2006. The state-of-the-art diagnostic facility, alongside the Thames in the shadow of London Bridge, specializes in helping patients with lupus, lupus-related diseases, and APS.

There is expert and compassionate support for patients at every step of the LLC experience. Not only have all seven doctors on staff trained with Hughes and run their own lupus clinics, but the nurses and administrative staff have backgrounds in working with rheumatic diseases. LLC Manager Sandy Hampton, who is often the first person to speak with a patient, knows lupus from a personal perspective. She has spent time in intensive care and undergone a kidney transplant due to the disease.

Busy First Year
In its first year, the need for a clinic of this kind was borne out by the numbers. The LLC had 2,250 consultations with patients from 37 countries who made the journey to London for the care to be found at the LLC. Plans for 2007 are to double these numbers.

Patients, who are referred by their own doctors or hospital clinics, are asked to bring previous medical records with them. In many cases they come for diagnosis or clarification of complicated case histories. The LLC is financed through the revenues brought in by seeing patients, and to a lesser extent by blood tests. While the majority of the LLC’s patients are either covered by insurance through their own country or embassy, approximately a quarter of the patients are self-funded.

The focus of the LLC is to treat the entire scope of problems that lupus patients encounter under one roof. “Each of our eight rheumatologists has a slightly different clinical specialty,” says Dr. Hughes, who is hoping to enlist doctors in other specialties to round out the team.

The team approach is important to LLC patient Cheryl Marcus, who needs the care of a dermatologist, a rheumatologist, and a nephrologist. “Last time I was in, Dr. Hughes heard something he didn’t like when he listened to my heart, so he arranged for me to see the London Lupus Centre heart specialist,” she says.

Marcus feels comforted by the fact that, at LLC, her many doctors are in close communication with each other. “They talk together about my case and make sure that factors like drug interactions and dosages are clearly defined,” says Marcus, who was hospitalized for three years due to severe problems in this area in the past. “It’s great to not have to run from one hospital to another to get to see the doctors I need.”

Successful Start
Success stories abound, including one of an American who was misdiagnosed with multiple sclerosis (MS). He spent five years paying out of pocket for very expensive treatments before coming to the LLC. “It’s not uncommon for APS symptoms to lead to an MS conclusion,” says Dr. Hughes. With proper testing, the patient was found to have APS and now takes aspirin to alleviate his difficulties.

A local dart champion from a small English village began to have trouble remembering where the high mark was on the board. As her memory loss progressed, she came to suspect that she had Alzheimer’s. The LLC relieved her anxiety when physicians there discovered a mini-clot and started her on anticoagulant therapy. She now tests her blood regularly to monitor her international ratio, a procedure that Dr. Hughes highly recommends for all APS patients.

Education is a big component of the LLC’s work. Besides generating books and pamphlets for patients, Dr. Hughes and his staff lecture to general practitioners and lupus symposiums throughout the world. “I tell general physicians that they should always think of lupus when a patient presents with a lot of vague symptoms, such as fatigue, memory loss, migraines, or claustrophobia. It’s terribly easy to dismiss these, but the test is very simple, and when it is APS it is so treatable,” says Dr. Hughes.

Patient-exchange meetings allow LLC patients to talk to others with similar conditions or disease complications, providing mental and emotional support. When there is a lot of information to digest, Dr. Hughes feels that the best way for someone to really “hear” what they need to know is to get it from someone with first-hand experience. For Marcus, who was diagnosed with lupus before it had much media attention, the feelings of isolation were enormous. She appreciates being able to go into the LLC waiting room and know that everyone there is dealing with problems like hers. “If there is someone else there with a leaky aortic valve, she’ll talk with me and I won’t feel as alone as I once did,” says Marcus. “Having knowledge of your own condition and being able to make a connection with others at the Centre makes me feel like Robinson Crusoe finding his man Friday.”

Francine Kaplan is a medical journalist based in Georgia.
Abstract

The normal synovium forms a membrane at the edges of joints and provides lubrication and nutrients for cartilage. In RA, the synovium is the site of inflammation, and it participates in an organized tissue response that damages cartilage and bone. We identified cadherin-11 as essential for development of the synovium. Cadherin-11–deficient mice have a hypoplastic synovial lining, display a disorganized synovial reaction to inflammation, and are resistant to inflammatory arthritis. Cadherin-11 therapeutics prevent and reduce arthritis in mouse models. Thus, synovial cadherin-11 determines the behavior of synovial cells in their proinflammatory and destructive tissue response in inflammatory arthritis.

Commentary

RA is a debilitating disease marked by bone and cartilage destruction. In the rheumatoid synovium, the fibroblast cells aggressively proliferate and invade the other joint structures. Indeed, these fibroblast-like synoviocytes develop genetic and phenotypic features similar to malignant cells, including expression of proto-oncogenes and loss of contact growth inhibition. Although these cells in the pannus locally invade, they never metastasize. Most of the current therapies for RA are directed toward other components of the immune system. There has been limited investigation into therapies that are directed against the aggressive behavior of the synovial fibroblasts. By targeting cadherin-11, an essential adhesion molecule for synovial development and mature architecture, Lee and colleagues are paving the way for an alternative therapeutic strategy for RA.

FIGURE 1. Synovial fibroblasts express functional cadherin-11. A and B: Normal pannus stained with either control (A) or anti-cadherin–11 (B) antisera. (Magnification, 400x.) Key: P, pannus; B, bone. Source: Science. 2007;315(5814):1007.

RA THERAPY

Cadherin-11 May Be a Therapeutic Target in RA
>> By Mary Corr, MD


Abstract

Objective: To evaluate the efficacy of anti-tumor necrosis factor (TNF) treatments (given for rheumatological manifestations) in reducing uveitis flares in patients with spondylarthropathy in daily practice.

Methods: A retrospective observational study of all patients with spondylarthropathy with at least one uveitis flare treated with anti-TNF in one center (Dec. 1997–Dec. 2004). The number of uveitis flares per 100 patient-years was compared before and during anti-TNF treatment; each patient was his or her own control. The relative risk (RR) and the number needed to treat (NNT) were calculated.

Results: Forty-six patients with spondylarthropathy treated with anti-TNF drugs had at least one uveitis flare (33 treated with anti-TNF antibodies—infliximab or adalimumab—and 13 with soluble TNF receptor—etanercept). The mean age at first symptoms was 26 years, 71% were men. Patients were followed for 15.2 years (median) prior to anti-TNF versus 1.2 years during anti-TNF treatment. The number of uveitis flares per 100 patient-years before and during anti-TNF were, respectively: for all anti-TNF treatments: 5.8 versus 2.1 (p=0.03), RR=2.4, NNT=3 (95% confidence interval [CI] 2 to 5); for soluble TNF receptor: 5.4 versus 8.5 (p=0.92), RR=0.9; and for anti-TNF antibodies: 30.6 versus 6.8 (p=0.001), RR=7.4, NNT=2 (95% CI 2 to 5).

Conclusion: Anti-TNF treatments were efficacious in decreasing the number of uveitis flares in patients with spondylarthropathy. Anti-TNF antibodies decreased the rate of uveitis flares, whereas soluble TNF receptor did not seem to decrease this rate. These results could have consequences for the choice of anti-TNF treatment in certain patients.

Commentary

Acute anterior uveitis occurs in up to 40% of patients with spondyloarthropathies. Recurrent episodes are common and uveitis may be the disease’s most distressing feature for some patients. Although most flares can be treated effectively with local therapy, for patients with frequent flares, it is important to determine if systemic therapy can prevent recurrences or reduce flare frequency. Sulfasalazine and methotrexate have been used with some success to prevent recurrences of uveitis. The growing use of anti-TNF-alpha medications to treat spondyloarthropathies has generated interest in determining if these medications can prevent uveitis flares, and whether effectiveness differs among anti-TNF medications.

This observational study compared rates of uveitis episodes (calculated per 100 patient-years) before and after the start of treatment with etanercept or anti-TNF antibodies (infliximab or adalimumab). The study was limited to patients with spondyloarthropathies who had at least one uveitis episode (although the episode may have occurred after the start of treatment), who were starting their first course of anti-TNF medication, and who had observation on treatment for at least one year. The mean length of observation on treatment was 1.2 years. The study was retrospective; all episodes of uveitis occurred and treatment was started before the study began. The number of uveitis episodes per patient, extending back to illness onset, was determined from
Exercise Habits Do Not Affect Development of Knee OA in Older Adults

Could exercise, due to an increased loading on the cartilage, increase the odds of developing knee osteoarthritis (OA)? Happily, the answer appears to be no. Moderate physical exercise has no effect—positive or negative—on the development of knee OA, according to a study published in Arthritis Care & Research (2007;57:6-12).

Previous research had not answered the question definitively. Lead author David Felson, MD, MPH, professor of medicine at Boston, says older studies used small pools of subjects and didn’t do long-term follow-up measurements. “It takes a long time to develop osteoarthritis, so following people for just a couple of years, especially with a smaller sample, just isn’t enough,” he explains. This new study lasted more than nine years, using more than 1,200 subjects from the Framingham Heart Study database.

Starting in 1993, Felson’s team took baseline measurements of 1,705 patients, mostly middle-aged subjects from Framingham’s offspring cohort who did not have any signs of OA. Each subject had weight-bearing, fully extended x-rays taken of both knees. They also answered a large battery of detailed questions about their history of knee pain symptoms and regular exercise habits.

Between 2002 and 2005, Felson’s team sought out the initial subject pool to re-peel the measurements. About 75% (1,279 subjects) went through the second examination, which followed the same x-ray protocol as the baseline examination. Blinded to patient data, two independent readers compared each subject’s baseline and follow-up x-rays. They gave each a Kellgren and Lawrence (K/L) grade—a quantitative determination of the incidence of OA. If the two readers disagreed on K/L grades, a third independent reader was asked to adjudicate.

Subjects were divided into three groups based on exercise habits reported during the baseline examination: no walking for exercise, walking less than six miles per week, and walking more than six miles per week. Slightly more than 9% of subjects developed incident OA, with no significant difference between exercise groups.

Overweight subjects were significantly more likely to get OA (13.7% versus 5.9%, respectively); however, overweight subjects who exercised were no different than overweight subjects who did not exercise. For both normal and overweight subjects, exercise did not contribute to an increased risk of OA.

Though this study showed that moderate exercise doesn’t increase the risk of OA, Dr. Felson says older patients should probably avoid more intense exercise. “We would mostly recreational walking. We’re not saying anything about jogging or running—if I’m not sure that’s going to be safe.”

If moderate exercise doesn’t prevent OA, what does? “Keeping your weight down is a good way to keep you from getting it, that much we know,” Dr. Felson says. “And avoid situations where you’re likely to injure your knees.”

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**TABLE 1:**

<table>
<thead>
<tr>
<th>Rate of Uveitis Episodes After Treatment with Either Etanercept or Anti-TNF Antibodies (Infliximab or Adalimumab)</th>
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<tbody>
<tr>
<td><strong>Number of patients</strong></td>
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<tr>
<td>------------------------</td>
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<tr>
<td>Rate of uveitis episodes prior to treatment (per 100 patient-years)</td>
</tr>
<tr>
<td>Rate of uveitis episodes after treatment (per 100 patient-years)</td>
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</tbody>
</table>

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Flares per patient before treatment was higher among those treated with anti-TNF antibodies than those treated with etanercept, but the length of observation before treatment was also longer in the anti-TNF antibody group.

Although few patients were studied, these results are interesting and potentially clinically useful. This study adds to the growing literature on the ability of anti-TNF medications to prevent recurrences of uveitis and supports this literature in suggesting that infliximab may be more effective than etanercept in this regard. There are few data from other studies on whether adalimumab can prevent uveitis. However, this study did not have an untreated control arm, and therefore we do not know how these patients fared compared to patients who were not treated. The accuracy of the methods used in this study to document episodes of uveitis was not reported, and recall by patients of episodes that occurred in the distant past might have been poor, but would be expected to be similar in all patient groups. Concomitant treatment with other disease-modifying medications might have contributed to differences between treatment groups.

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**SCIENCE FROM OUR SISTERS**

Recommended reading from A&R >> By Virginia Hughes

Model Created for Predicting the Development of RA from UA

A point-system model that predicts progression of undifferentiated arthritis (UA) to rheumatoid arthritis (RA) using easily measured clinical variables was published in Arthritis & Rheumatism (2007;56:2:433-440).

When patients initially visit a physician because of joint pain, their arthritis is often in the early stages of disease and cannot yet be classified as RA. Of all patients with UA, in fact, only one-third progress to RA. Early methotrexate treatment can slow progression of RA and prevent joint damage in this patient group. But another 40% to 50% of UA patients eventually go into spontaneous remission, and thus don’t need to be treated with methotrexate, which has side effects including liver toxicity.

“This is a dilemma if you’re trying to achieve the best individual treatment decisions,” says lead author Annette H. M. van der Helm-van Mil, MD, PhD, of Leiden University Medical Center in the Netherlands. “You don’t want to over-treat, but the patients who go on to RA will benefit from early treatment.”

The new model is based on data from 570 patients diagnosed with UA between 1993 and 2005. At the initial examination, patients were asked about pain symptoms and severity of any morning stiffness. Blood samples and hand and foot x-rays were taken. After one year, patients were tested again to see if they had progressed to RA.

The researchers performed a multivariate analysis to see how well each of nine clinical variables—gender, age, symptom localization, morning stiffness, tender joint count, swollen joint count, C-reactive protein level, rheumatoid factor positivity, and presence of anti–cyclic citrullinated peptide (anti-CCP) antibodies—predicted RA progression. The researchers then created a scale ranging from 0 to 14, with different point values assigned for each variable according to how significant it was to predicting RA progression. The most heavily weighted variables were gender, presence of anti-CCP antibodies, and morning stiffness severity.

The scale had strong predictive ability: 91% of patients who scored a 6 or less on the scale did not progress to RA; 84% of patients that scored an 8 or greater did progress to RA. Clinicians could thus be relatively confident in prescribing medication to a patient scoring above an 8.

But the biggest advantage of such a scale, Dr. van der Helm-van Mil says, is that it “will make it easier for patients to be part of the discussion when the rheumatologist is making a treatment decision.” The researchers are now validating their model in various patient groups throughout Europe.