EULAR President Emery Welcomes Attendees to 2010 Congress in Rome

Welcome to Rome and the 11th annual Congress of the European League Against Rheumatism!

Rheumatology continues to see advances in diagnosis and treatment. This annual forum is the perfect chance to hear cutting-edge scientific and clinical information, as well as to mingle with patients, physicians, surgeons, scientists, health professionals in rheumatology, and professionals representing the pharmaceutical industry.

Many of you have observed the steady increase in the number of participants as well as the number of submitted and presented abstracts at the EULAR Congress each year since 2000. This year, we expect 15,000 participants—more even than the 14,000 we had in Copenhagen.

This continuing growth reflects the growing success of rheumatology in helping our patients. Contributions to pathophysiology, epidemiology, and therapeutic management have modified several destructive—and sometimes lethal—diseases into manageable, chronic conditions. For the first time, rheumatologists speak of remissions in rheumatoid arthritis. The treatment regimens in some member countries are now 20 years old, providing us with a rich source of knowledge.

Survey Measures Social Impact of Pain From RA

The results of an international survey of women with rheumatoid arthritis illustrate the impact that continuing pain can have on their relationships and productivity—an issue that may not always be appreciated by their physicians.

In a PARE session on diversity today, Dr. Vibeke Strand will present data from surveys of European and North American women that describe the negative impact of RA on productivity, work, leisure activities, emotional health, and relationships.

“Terror was some variability by country, but I was struck by how similar the responses were,” she said in an interview with EULAR Congress News. “Pain seems to be a very paramount issue. Many women say they still have pain despite taking medications.”

The survey was conducted during a single month in the summer of 2009 in seven countries (the United States, United Kingdom, France, Germany, Italy, Canada, and Spain) of women aged 25-65 years who had been diagnosed with RA at least 6 months earlier. The mean age of the 1,958 respondents was 46 years, which Dr. Strand said was a little younger than the typical age of women with RA in clinical trials (which is about 54 years).

Of respondents, 75% had been diagnosed with RA at least 1 year earlier and nearly 70% described their disease as moderate to severe. Overall, 12% described their disease as severe, 57% as moderate, and 31% as mild. Interestingly, the proportion of women describing their disease as severe was higher in the United States and France. Dr. Strand said, although in both the United States and France, RA is treated fairly aggressively, biologics are widely available.

Continued on page 12
Health professionals in rheumatology play a significant role as they work closely with physicians and patients. Another important aspect of their work is to conduct research in the multidisciplinary field.

The EULAR Congress is a unique opportunity to highlight some of the important work that health professionals in rheumatology carry out in both the clinical and academic realms. The Congress also gives health professionals in rheumatology the time and place to promote their and EULAR’s shared goals, which include stimulating, promoting, and supporting the research, prevention, and treatment of rheumatic diseases and the rehabilitation of affected patients, according to Kåre Birger Hagen, Ph.D., who is EULAR’s vice president representing health professionals in rheumatology, and a professor at the University of Oslo.

“I think all stakeholders within the field agree that health professionals in rheumatology play an important role both as clinicians and researchers. Health professionals in rheumatology are now increasingly taking advanced roles as health care providers, both as single practitioners and as team leaders and team members in multidisciplinary teams,” Prof. Hagen, a physical therapist, said in an interview with EULAR Congress News. Clinically, health professional in rheumatology play an important part in the management of such highly prevalent diseases as back pain and osteoarthritis. They typically provide what are considered to be the core treatments—as opposed to adjunct medical treatment—for these conditions. For example, health professionals in rheumatology provide patients with exercise therapy and patient education, which (according to most international guidelines) are considered core treatments for back pain and osteoarthritis, Dr. Hagen noted.

In research, an increasing number of health professionals in rheumatology are pursuing doctoral degrees and conducting studies to that end. With their advanced degrees, they are achieving academic positions at hospitals and universities, where they contribute to the effort of advancing the goals of improving the understanding and treatment of rheumatic diseases, he said.

Among the health professionals in rheumatology-related research to be presented at the EULAR Congress this year are numerous abstracts displaying the range of benefit that these professionals bring to patients and the field. One, to be presented at the Outcomes Science session on Thursday by Jackie Hill of the University of Leeds (England), will describe the outcomes in patients with rheumatoid arthritis at a nurse-led clinic. Data from the meta-analysis suggest that nurse-led care may help reduce disease activity in rheumatoid arthritis.

A health professional in rheumatology session on Wednesday will focus on gender issues in rheumatologic diseases from a multidisciplinary perspective, and another session will describe outcomes of a specialised, multidisciplinary, rheumatic rehabilitation program.

The latter study, to be presented Friday at the rehabilitation abstract session by Tunid N. Dager, a clinical psychology specialist at Diakonhjemmet Hospital in Oslo, will describe the personal impact and individual experiences of participating patients. Interviews with patients who completed the 4-week, hospital-based program demonstrated that health professionals are an integral part of helping patients regain dignity and self-respect through the promotion of disease control and coping skills, and through their efforts to improve understanding about the disease and about the relationship between rehabilitation and outcomes.

Well-targeted rehabilitation, which is often provided by health professionals in rheumatology, has the potential to create outcomes of major positive personal impact, according to Ms. Dager. Indeed, part of the focus of health professionals in rheumatology is to improve the patient’s role as the “key expert of his or her own treatment,” Prof. Hagen said.

The related research to be presented during the Congress demonstrates the varied ways in which health professionals help to promote the important shared goals of all those serving in the field of rheumatology, he said.

Selected Sessions

Health Professionals in Rheumatology: Gender Issues in Chronic Rheumatic Diseases From a Multidisciplinary Perspective

Wednesday, 15:00-16:30 Room 10 C

Outcomes Science: How to Improve Early Access to Care?

Thursday, 13:45-15:15 Room 10 F-G

Abstract Session: Rehabilitation

Friday, 10:30-12:00 Room 7 A

Visitors Discover Millennia of Medicine in Rome

The history of medicine in Rome spans not just centuries but more than two and a half millennia, since the city’s mythological founding on 21 April 753 B.C., the date celebrated by the ancient Romans themselves.

Unfortunately, those early times are shrouded in mystery, and it is not really until the beginning of the classical era in Roman history that a real sense of medicine in Rome can be developed. And that medicine, such as it was, was not really Roman, but Greek.

In fact, the most famous Roman physician in history, Galen (circa 129-199/217 A.D.), was actually Greek by birth.

Considered by many as one of the chief pioneers of surgery, Galen was born in the town of Pergamon on the Aegean Sea in what is now Turkey. His education as a physician occurred in Greece before his arrival in Rome, with a stint in Egypt, and he was known for his advocacy of anatomical studies. He is quoted as saying, “Look at the human skeleton with your own eyes. This is very easy in Alexandria, so that the physicians of that area instruct their pupils with the aid of autopy.” He spent several years serving as a physician to gladiators in Pergamon where he developed many of his surgical techniques.

Because dissection of human cadavers was forbidden by Roman law, he did his anatomical studies on monkeys and pigs. This led to some misleading conclusions in human anatomy that remained in common belief for hundreds of years, as Galenic medicine spread across the Western world. Many of his anatomical mistakes stood until they were corrected in the Renaissance by Vesalius.

In his mature years, Galen served as personal physician to Marcus Aurelius and his son during both plague and war, and—other than a brief flight from Rome for political reasons—he spent most of his later years in that city as a physician to the upper classes.

Unsurprisingly, given its focus on gladiatorial games and warfare, Roman physicians excelled in anatomy and surgical techniques, some of which were not surpassed until the modern era. They performed cataract operations, catheterisation, skull trepanation, and even primitive cosmetic surgery (removing excess skin, including eyelids, or cutting away slave tattoos from freedmen). Samples of many of the surgical instruments that were in use in classical Rome were found, exquisitely preserved, in the House of the Surgeon in Pompeii. (Pompeii is an easy day tour by bus or train from Rome.)

In terms of drugs and cures, however, Roman medicine was almost completely in the specialty.

Perhaps its greatest success was in public health, with the realisation that sanitation was important. The focus of large and small Roman cities on proper sewage and pharmaceutical vases. The related research to be presented during the Congress demonstrates the varied ways in which health professionals help to promote the important shared goals of all those serving in the field of rheumatology, he said.

The hospital itself, which is still functioning, is one of the oldest in Europe, and is considered of great architectural and historical interest. (Upon entering the hospital, ask at the main entrance to see the museum). The complex was created in 727 A.D. as a guest house for people who wanted to visit the tomb of the apostle Peter. The hospital followed the “Liber Regulae Sancti Spiritus,” one of the oldest sets of clinical rules that exist, which was enshrined in illustrated plates in a 14th-century volume that was produced at the hospital. The book demonstrates how to take care of the sick, the infirm, and the abandoned. The hospital was especially known for caring for abandoned newborns who were left on its “foundling wheel,” which allowed anonymous deposit. Recently, a modern version of the wheel has been installed because of the high rate of infant abandonment today in Rome.

The Eternal Mendicant in front of the main entrance of Santo Spirito Hospital.

In a city known for its many historical monuments, Rome has relatively few sites dedicated to the history of medicine. The most important and interesting is the Museum of the Sanitary (or Medical) Arts in Rome, which was founded in 1741. The museum is part of the Ospedale di Santo Spirito complex near the Vatican. This small museum is an eclectic mix of materials, mainly from the 17th-19th centuries, including medical oddities, preserved specimens, wax anatomical models that were used in teaching, and artistic anatomical plates and pharmaceutical vases.

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The hospital museum is free and open on Monday, Wednesday, and Friday (09:00-12:00)

Location:
Ospedale di Santo Spirito
3 Lungotevere Sassia
The hospital museum is free and open on Monday, Wednesday, and Friday (09:00-12:00)
Visit booth B1-6 to learn more about RoACTEMRA.
Common Vaccinations Do Not Increase Risk of RA

Immunisation with common vaccines is not associated with an increased risk for rheumatoid arthritis, nor does it trigger the autoimmune disease in individuals who have established risk factors, according to an analysis of data that will be presented by Camilla Bengtsson today.

Although anecdotal reports have suggested that common vaccinations might be inciting agents for RA, no sufficiently powered epidemiological studies have addressed this concern, said Mrs. Bengtsson of the Karolinska Institute in Stockholm. Using data from the Swedish population-based EIRA (Epidemiological Investigation of Rheumatoid Arthritis) data set, Mrs. Bengtsson and associates investigated the possible association between common vaccinations (tetanus; diphtheria; tick-borne encephalitis; hepatitis A, B, and C; polio; and pneumococcus) and RA risk, as well as the impact of vaccinations on two subsets of RA patients: those with and without antibodies to citrullinated peptides.

In today’s Outcomes Science session on the primary prevention of the rheumatic diseases, Mrs. Bengtsson will discuss their findings on potential interactions between vaccination and smoking and between vaccination and the presence of HLA-DRB1 SE alleles, both of which have been implicated as possible catalysts for the disease.

The investigators compared individuals in the EIRA data set who had and had not been vaccinated within 5 years prior to disease onset. Of 1,998 incident cases of RA, 582 (31%) had received vaccinations within 5 years of disease onset, as had 617 (31%) of 1,984 controls. The presence or absence of antibodies to citrullinated peptides had no effect on risk, noted Mrs. Bengtsson. Additionally, there was no association between any specific vaccine and the risk of RA, nor did vaccinations increase the risk of RA among smokers or among carriers of HLA-DRB1 SE alleles, she said.

The results indicate that “immunological provocation with common vaccines given to adults in their present form is not a major risk factor for RA, at least not vaccines administered [within 5 years] before onset of disease,” Mrs. Bengtsson noted, suggesting that clinicians point to these findings to encourage patients to follow recommended immunisation guidelines.

No conflicts of interest were reported.

Outcomes Science
Primary Prevention of the Rheumatic Diseases
Wednesday, 17:00–18:30 Room 10 F–G

Young RA Patients Learn Personal Development Skills

Living with arthritis can be physically challenging for anyone. In young people, arthritis is often devastating, because it can also affect emotional well-being, social development, and educational attainment.

A new personal development programme developed by Arthritis Care, a nonprofit organisation in the United Kingdom, is proving effective for helping young arthritis patients overcome the challenges associated with the disease. The programme will be discussed today at the PARE session on diversity.

The programme was designed to enable young people with arthritis to explore body-image issues, self-esteem, confidence, self-awareness, decision making, relationships, and values and attitudes, according to presenter Kate Fleck, director of Arthritis Care in Northern Ireland. In a comparison of responses to questionnaires that were completed by 30 participants (aged 16-25 years) before and after going through the programme, all reported that they felt less isolated and more positive about their disease. Almost all (97%) reported increased confidence in expressing their disease. Almost all (97%) reported increased confidence in expressing feelings about their condition, and as many reported that they had a more positive outlook for the future.

“The emerging theme from this programme is that a great deal more work needs to be done to raise awareness about arthritis and to reduce the stigma in regard to young people with the disease,” Ms. Fleck said in an interview with EULAR Congress News. Arthritis is often seen as an older person’s condition, which is why young people need to contribute to changing existing attitudes, she explained. Arthritis Care’s personal development programme appears to be making strides in helping these patients do that, she said.

The study findings are based on three residential training events in Northern Ireland and Scotland in 2009, which were facilitated by seven youth volunteers with arthritis who underwent extensive skills and equality training. Similar programmes in both residential and nonresidential settings in Northern Ireland and southern England in arthritis patients aged 12-16 years are also showing positive results, she noted.

Arthritis Care is developing a toolkit to allow interested organisations to extend delivery of the training programme to more young patients with arthritis. The programmes work to help them overcome barriers that can prevent them from fully integrating into society, which is important given that young arthritis patients are less satisfied with their lives than are their peers, and tend to lose support at key transition points in their lives. “The personal development programme provides these patients with the tools they need to manage their condition, increase their confidence, and improve their quality of life,” Ms. Fleck said. Ms. Fleck had no disclosures to report.

Cooperative Staffing Model May Help Patients Get, Keep Jobs

A novel programme developed by the Stockholm-based Swedish Rheumatism Association with the aim of easing the pathway to employment for adults who have rheumatologic illnesses will be the topic of a presentation today by Rolf Greiff. Initiated in 2008, the 3-year project, called “Staffing Companies—A Path to Employment,” involves the development, testing, and dissemination of new courses of action that will make it easier for people with rheumatologic disease–related disabilities to establish themselves, or reestablish themselves, in the labour market, according to Mr. Greiff, the project coordinator.

Specifically, the organisation is working with staffing companies who recruit and match individuals from an employment-seeking group with employers who are looking to fill positions. In today’s presentation on work and leisure, Mr. Greiff will describe how his organisation provides the necessary administrative support to facilitate the match.

Ongoing communication with the staffing companies enables working groups within the programme to identify and remove obstacles to a well-functioning system and to refine the model, Mr. Greiff said in an interview with EULAR Congress News.

Public awareness of the staffing programme is promoted through information activities and candidate meetings, as well as newspaper, radio, and Internet-based advertising, according to Mr. Greiff. To date, he has carried out over 50 information activities and 50 candidate meetings, we have appeared in newspapers and on the radio on 14 occasions, our e-letter has over 500 recipients, and our information activities have reached over 200,000 people,” he said.

The most important issues that have to be addressed with this population are the need for work flexibility, given that rheumatologic illnesses are characterised by periods of disease flare which can preclude normal work activity, said Mr. Greiff.

For employers, the need for continuity and stable conditions are important, he noted. Both of these considerations will be addressed through the programme’s staffing-plus method, he said, which will be described in the presentation.

The presenters reported no conflicts of interest.

PARE Session
Work and Leisure: Achieving a Balance Between Work and Life
Wednesday, 17:00–18:30 Room 7 B

Opening Ceremony and Welcome Reception at the Fiera Roma

Wednesday, 16 June 2010 18:45–22:00

The welcome reception will be held after the opening ceremony at the Fiera Roma.

All participants and accompanying persons are cordially invited.
DONT MISS TOMORROW IN HALL 9...

THE NEW ERA IN RA MANAGEMENT: FROM PLANS TO CONSTRUCTION

A ROCHE-SPONSORED SATELLITE SYMPOSIUM OF THE 2010 ANNUAL EUROPEAN CONGRESS OF RHEUMATOLOGY

THURSDAY 17 JUNE, 08:30–10:00, HALL 9, FIERA ROMA, ROME

AGENDA

Introduction and welcome: RA biologic data in the arena
Gianfranco Ferraccioli, Italy, & Josef Smolen, Austria

IL-6 receptor inhibition: The draftsman’s table
Ernest Choy, UK

Tocilizumab efficacy overview: Laying the foundation
Arthur Kavanaugh, USA

Long-term safety and clinical management: The building blocks for stability
Andrea Rubbert-Roth, Germany

Cardiovascular risk in RA: Looking beyond the framework
Naveed Sattar, UK

Inhibition of radiographic progression: Maintaining the structure
Robert Landewé, The Netherlands

Open forum
Questions and answers
Meet the 2010 EULAR Abstract Award Winners!

At tonight’s opening ceremony, the lead authors of the six clinical research and six basic science research abstracts receiving the 2010 EULAR Abstract Awards will be honoured. Winners will each receive a prize of 1,000 euros.

Francesca Bandinelli, M.D., of the University of Florence will receive an award for her clinical science research showing that most young European rheumatologists attend educational courses and take online courses in order to improve the clinical care they give their patients. These preliminary findings come from a survey that was administered to 160 young rheumatologists from 29 countries. The rheumatologists were selected because they attended one of the past two EULAR Congresses, took a EULAR capillaroscopy course, or were named on an e-mail address list of young rheumatologists who trained at European medical schools. Of those who had received training in a European country other than their own, about 39% were trained in clinical care, 28% in research, 10% in imaging, 10% in basic science, and 23% in clinical research. About a third received a grant from a pharmaceutical company.

Azza Abdel-Gadir, a doctoral candidate at University College London, will be honoured with a basic science research award for her investigation showing that B-cell lipid presentation controls the homeostatic and immunoregulatory function of iNKT cells in healthy controls, but not in SLE patients. The data from her analysis of a group of patients before and after rituximab treatment indicate that iNKT cell proliferation is B-cell dependent. These findings suggest that B cells have a pivotal role in iNKT cell function. In addition, Ms. Abdel-Gadir and her associates propose that rituximab treatment may work in part by “resetting” B-cell-iNKT cell interactions, and these “reset” B cells and iNKTs help maintain tolerance by regulating each other’s function.

Turid Nygaard Dager, a specialist in clinical psychology with the National Rehabilitation Centre for Rehabilitation in Rheumatology at Diakonhjemmet Hospital in Oslo, will receive a clinical research award for her work on how patients experience the outcomes of specialised multidisciplinary rheumatic rehabilitation. Findings from her interviews with patients showed that the rehabilitation programme restored their sense of self-respect and dignity, whereas well-targeted rehabilitation, which is an ongoing, active process, has the potential to create outcomes of major personal impact.

Salvatore de Vita, M.D., professor of rheumatology at the University of Udine (Italy), will receive a clinical abstract award for his work showing that rituximab is effective in patients with mild rheumatoid arthritis and less severe disease. The Rituximab and Rituximab in Patients (RARP) study enrolled 126 patients with rheumatoid arthritis who had not received rituximab previously. The patients were allocated to either placebo or rituximab (375 mg/m²) given as two intravenous infusions on days 1 and 15. After 24 weeks, 9% in the placebo group and 0% in the rituximab group had experienced a ≥70% improvement in the 28-joint disease activity index. The study also showed that rituximab treatment did not alter the activity of concurrent disease-modifying antirheumatic drugs. The findings support the hypothesis that the difference in drug response between patients given placebo and those given rituximab is related to the baseline disease activity.

Paul Klaarenbeek, M.D., of the University of Amsterdam’s Academic Medical Center will receive an award for his basic science research showing that a new high-throughput sequencing protocol detects marked differences in the T- and B-cell receptor repertoires between blood and synovial tissue of a patient with rheumatoid arthritis. Dr. Klaarenbeek and his colleagues used a newly developed protocol based on massive parallel sequencing, which overcomes current limitations and produces a true measure of the repertoire of more than 100,000 receptors in a single experiment. Using this technique, they performed the first quantitative, high-resolution analyses of the complete TCR and BCR repertoire in an RA patient. They found clear differences between the TCR repertoire in synovial tissue, compared with control peripheral blood and an RA patient. Several expanded clones were found only in ST, which suggests localization or local retention of T-cells. The BCR repertoire also showed expanded clones within the ST. Further studies will elucidate the role of these clones in RA.

Yuya Kondo, a graduate student at the University of Tsukuba (Japan), will receive a basic science award for his work in mice showing that overexpression of the T-bet gene suppresses collagen-induced arthritis via an interferon-gamma-independent mechanism. These findings influenced both the incidence and severity of collagen-induced arthritis. These findings led to the idea that the suppressive mechanisms of arthritis might underlie the dysfunction of antigen-specific, CD4-negative T cells. CP-690550 may have a clinical effect on patients with rheumatoid arthritis through the inhibition of immune cells, mainly on Th1 and Th17 cells, thereby leading to inhibition of interleukin-6, IL-8, and MMP3 production by synovial cells. Therefore, the mechanism of action of the anti-inflammatory effect of CP-690550 varies from that of the biologic agents, suggesting its usefulness on RA.

Julia Fridman Simard, Sc.D., of the clinical epidemiology unit at the Karolinska University Hospital in Stockholm will receive a clinical research award for her nationwide cohort study showing that a new high-throughput sequencing protocol detects marked differences in the T- and B-cell receptor repertoires between blood and synovial tissue of a patient with rheumatoid arthritis. Dr. Klaarenbeek and his colleagues used a newly developed protocol based on massive parallel sequencing, which overcomes current limitations and produces a true measure of the repertoire of more than 100,000 receptors in a single experiment. Using this technique, they performed the first quantitative, high-resolution analyses of the complete TCR and BCR repertoire in an RA patient. They found clear differences between the TCR repertoire in synovial tissue, compared with control peripheral blood and an RA patient. Several expanded clones were found only in ST, which suggests localization or local retention of T-cells. The BCR repertoire also showed expanded clones within the ST. Further studies will elucidate the role of these clones in RA.

Elias Stagakis, M.D., of the University of Crete in Heraklion, Greece, will receive a basic science award for his work showing that miR-21 regulates key signalling pathways in T lymphocytes that mediate B-cell hyperresponsiveness in systemic lupus erythematosus, and thus may represent a potential therapeutic target in this disease. In his examination of 25 differential miRNAs, miR-21 was the highest up-regulated miRNA in SLE patients, compared with healthy individuals, and correlated strongly with lupus disease activity.

Elke Theander, M.D., Ph.D., of Malmö (Sweden) University Hospital will receive an award for her basic science research showing that the antimalarial agent chloroquine, even at low concentrations, has anti-inflammatory effects in salivary gland biopsies. This new and strong predictor of non-Hodgkin’s lymphoma in primary Sjogren’s syndrome. Findings from her examination of 136 biopsies showed that patients with germinal centre-like structures had 15 times the risk of developing NHL, compared to those without.
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**Linking mechanism of action to personalised healthcare: A ‘positive’ direction for the RA patient**

**Satellite Symposium chaired by Professor Paul Emery**
Hall 9, Fiera Roma, Italy, Thursday 17th June 2010, 17:45 - 19:15

- **17:45 - 17:50** Introduction | Paul Emery
- **17:50 - 18:00** Approaching the details: Making sense of the mechanism of action | Edward Vital
- **18:00 - 18:20** Gaining consensus: Personalised healthcare and patient outcomes | Paul-Peter Tak
- **18:20 - 18:30** Optimising patient benefits: Understanding the value of biologic treatment strategies | Andrea Rubbert-Roth
- **18:30 - 18:50** Confidence in safety: Years into our experience, are we on firm ground? | Paul Emery
- **18:50 - 19:00** Real-life experience and personalised healthcare: From the clinical trial to the patient in the clinic | Xavier Mariette
- **19:00 - 19:15** Concluding remarks and panel discussion | Led by Paul Emery

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EULAR’s Standing Committee on PARE (People With Arthritis/Rheumatism in Europe) is focused on empowering patients to take a greater role in their own care. And at this year’s Congress, the PARE programme puts the most emphasis yet on collaboration between patients and health professionals.

The 2010 PARE programme features sessions with patients, clinicians, and health professionals that are aimed at getting all three groups to learn from one another, said Marios Kouloumas, chair of the EULAR Standing Committee on PARE.

For example, a multidisciplinary team will offer guidance in a two-part, interactive “Facing the Facts” workshop on Saturday that will tackle some of the issues that emerge when patients first receive a rheumatic disease diagnosis. The first part of the workshop will include tips on how physicians can better support patients during their input, patients will be ready to support, so that when researchers seek their input, patients will be ready to supply it. On Friday afternoon, the PARE programme will include a session on the progress of the patients’ participation in research initiative, Mr. Betteridge said.

“We believe that patients have to be very well informed about their disease, and the treatments available, and about the side effects,” Mr. Kouloumas said in an interview with EULAR Congress News.

Making patients equal partners in their disease management has been an ongoing focus for PARE. Mr. Neil Betteridge, vice president of EULAR representing National PARE organisations, told EULAR Congress News that he feels a lot of excitement this year about what can be achieved together. Within EULAR, more activities are being designed with input from clinicians, health professionals, and patients, instead of having those people working in isolated information silos.

Mr. Betteridge, who previously served as EULAR vice president representing National PARE organisations, said that there has been a shift within EULAR toward greater direct collaboration among clinicians, health professionals, and patients. “When decisions are arrived at through that close collaboration, those decisions tend to be better decisions,” said Mr. Betteridge, who is also the chief executive of Arthritis Care UK. “It has very practical benefits. It isn’t simply a nice thing to do.”

This year’s PARE programme aims to build on that collaboration. One new “Marketing Arthritis” session on Thursday will feature politicians, journalists, and even celebrities who will share how advocates can do a better job of educating patients and recruiting them to help.

Another issue is the diversity among rheumatology patients. Although rheumatic diseases such as arthritis are often identified with older women, rheumatic diseases affect people of both sexes and all ages and ethnicities, Mr. Betteridge said. In the diversity session today, he will focus on how different groups cope with their disease and how to better support hard-to-reach groups.

PARE is also involved in an effort to get patients more involved in research, not just as participants but as experts who can help in the planning process. PARE has been identifying patients with an interest in research and giving them training and support, so that when researchers seek their input, patients will be ready to supply it. On Friday afternoon, the PARE programme will include a session on the progress of the patients’ participation in research initiative, Mr. Betteridge said.

The PARE programme also features perennial favourites like the multitopic abstract session. This year’s session will include eight abstracts on a range of topics, and organisers said that it should provide a good demonstration of the variety of research being done by PARE members.
Bristol-Myers Squibb cordially invites you to attend the symposium:

**Closing the gap between treatment guidelines and clinical practice in RA**

Thursday 17 June 2010, 17:45–19:15 • Room 8B, Fiera Roma, Rome

*To be preceded by a cocktail reception in Hall 8 from 17:15 at which you will have the opportunity to meet the presenters*

This meeting will take place during EULAR 2010

Chair: **Professor Michael Schiff** University of Colorado, USA

**Professor Tom Huizinga**

*Changing our approach to RA management – guidelines and implications*

Department of Rheumatology, Leiden University Medical Center, The Netherlands

**Professor Ronald van Vollenhoven**

*Targeted therapies: rationale for earlier use in RA*

Department of Rheumatology, Karolinska University Hospital, Stockholm, Sweden

**Professor Philip Conaghan**

*The role of modern imaging in evaluating the RA disease spectrum*

Section of Musculoskeletal Disease, University of Leeds, UK

**Professor Iain McInnes**

*The science behind targeting the T cell in earlier disease*

Centre for Rheumatic Diseases, University of Glasgow, UK
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visit booth b2-6 at eular 2010
Continued from page 1

In all, 63% of those surveyed said they experienced pain on a daily basis.

Two-thirds of the women said they took part of their medications regularly; of these, 72% said they still experienced daily pain. In addition, 67% said they “agreed or strongly agreed” that they were continually searching for new ideas to help address their pain.

“Pain and fatigue were the main topics of discussion with their physicians, with 87% of those surveyed saying that they mentioned pain in discussions with their physicians.”

In her presentation today, Dr. Strand of Stanford (California) University will explain that the responses indicated that RA-associated pain had a negative impact on work-related productivity and household activities. Of the 1,108 women surveyed who were employed, 71% said that RA made them less productive at work and 23% said they had to stop working because of RA, whereas 71% said they had to switch to part-time work because of RA. The results across the countries were not very different.

The three most common activities that were adversely affected by RA, the survey showed, were housework, shopping, and sleeping. Dr. Strand said. About 29% said that sleeping was always painful, and 48% said they had trouble making plans because of RA. The results across different countries about how they would describe a good day included “free- dom” (Spain), “totally forgetting I have RA” (United Kingdom), and “I’m able to style my hair without pain and use my computer” (United States).

The results of this survey show that in women with RA, “we are not controlling the pain and fatigue as much as we’d like to … and in general, we don’t really look at the social impact of RA as much as we should,” Dr. Strand said in the interview.

There is no simple way to ask patients how well they are doing, but “it would be nice to provide patients with a benchmark” for how they are doing in the context of people without RA, and how they do over time, she added. Although the SF-36 questionnaire, which is used in clinical studies reflects the impact of RA on quality of life, most rheumatologists do not have time or resources to administer this test during a typical visit, she noted.

In Europe, patients can access and complete the SF-36 questionnaire online on their own and compare their results to age- and sex-matched subjects without arthritis, she said. This can serve as a benchmark or “goal for treatment,” she added.

Dr. Strand disclosed that she is a consultant to the manufacturers of all the currently available biologics used to treat RA, and is a consultant and has received research support from UCB.

The survey was funded by UCB, which manufactures Cimzia (certolizumab pegol).

Two of Dr. Strand’s associates for this study were from UCB and Echo Research Ltd.

In addition, 68% said they concealed their pain from family and friends, and 60% said they were depressed a lot of the time, Dr. Strand said.

Having RA also had a negative impact on intimacy: Of single women, 40% said that having RA made it more challenging to find a partner. Of those who were divorced or separated, 22% said that RA had “at least some role” in the decision to separate or divorce (with responses of 24% in the United States and the highest proportion, 39%, in Spain).

In addition, 31% said it was difficult to explain sex needs to a partner, and 55% said they were less self-confident in their sex life because of RA.

When asked to describe a good day, 57% said it was a day free of pain and 58% said a day on which they felt free of fatigue and had energy, whereas 29% said a good day was one on which they were able to do everything they wanted to do. The quotations that were elicited from respondents in different countries about how they would describe a good day included “freedom” (Spain), “totally forgetting I have RA” (United Kingdom), and “I’m able to style my hair without pain and use my computer” (United States).

The survey responses also indicated that the emotional impact of having RA was high, with 47% saying that the emotional impact of RA had no impact on their activities, she noted.

Overall, only 9% said that having RA interfered with daily activities that were adversely affected by RA. In addition, 25% said that driving was always painful, and 48% said they had trouble making plans because of RA. The results across the countries were not very different.

The three most common activities that were adversely affected by RA, the survey showed, were housework, shopping, and sleeping. Dr. Strand said. About 29% said that sleeping was always painful, and 48% said they had trouble making plans because of RA. The results across different countries about how they would describe a good day included “freedom” (Spain), “totally forgetting I have RA” (United Kingdom), and “I’m able to style my hair without pain and use my computer” (United States).

The results of this survey show that in women with RA, “we are not controlling the pain and fatigue as much as we’d like to … and in general, we don’t really look at the social impact of RA as much as we should,” Dr. Strand said in the interview.

There is no simple way to ask patients how well they are doing, but “it would be nice to provide patients with a benchmark” for how they are doing in the context of people without RA, and how they do over time, she added. Although the SF-36 questionnaire, which is used in clinical studies reflects the impact of RA on quality of life, most rheumatologists do not have time or resources to administer this test during a typical visit, she noted.

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Modern Imaging
Continued from page 1

of eight PA patients before and after a year of anti-TNF-alpha therapy.

Using a reliability statistic called a standardised response mean, investigators found the baseline and 1-year PsAMRIS scores to be “moderately responsive” for synovitis, flexor tenosynovitis, and periarthritis inflammation, all of which showed a “trend toward decreased levels” during therapy, according to Pernille Bayesen, an OMERACT member and reader in the study, who will present the findings. The results suggest that MRI findings as measured by the PsAMRIS should perform well for these components of disease, said Ms. Bayesen of Diakonhjemmet Hospital in Oslo, during an interview with EULAR Congress News.

The PsAMRIS scores showed less sensitivity to change for bone marrow oedema, erosion, and bone proliferation. “From this study, we cannot say that we’ve confirmed we can show changes” for these measures of disease damage, she said.

Patients in the study had relatively mild disease, however. The scoring system still needs to be evaluated in a larger population of patients with more advanced disease, Ms. Bayesen told EULAR Congress News. At this point, the OMERACT group is “getting there” in terms of demonstrating the effectiveness of the PsAMRIS as a valid instrument for measuring pathological changes in PA. “Use of the scoring system looks promising,” she said.

Session
How Should Modern Imaging Be Used in Arthritis?

Wednesday, 17:00–18:30

Hall 4

Genetics Studies Reveal Role of Interferons in Rheumatic Diseases

Interferon regulatory factor 5 plays an essential role in disease development in the Fc-gammaRIIB-/-Yaa mouse model of systemic lupus erythematous, but its major effects appeared to be mediated through pathways that are independent of type 1 interferon production, according to new, in vivo findings to be presented today.

The research showed, moreover, that interferon regulatory factor 5 (IRF5)–heterozygous mice developed only minimal disease manifestations, which indicates that full expression of IRF5—or a certain threshold level—is required for disease development.

“In terms of treatment [implications], maybe we don’t have to knock out IRF5 completely,” said investigator Dr. Christophe Richez in an interview with EULAR Congress News. “Maybe we just need to decrease IRF5 production to meaningfully decrease severity.”

The findings build upon multiple human genetic studies that have associated polymorphisms in the transcription factor IRF5 with increased risk of developing SLE, as well as several in vitro studies that have attempted to begin defining the biological role of IRF5 in lupus pathogenesis.

Investigators have suggested that induction of type 1 IFN may be the most important role of IRF5, given that IRF5 is involved in the production of type 1 IFN and given that type 1 IFN is implicated in disease pathogenesis.

To examine the mechanism by which IRF5 promotes disease, Dr. Richez and his coinvestigators at Boston University and Stanford (California) University compared the impact of a deficiency of IRF5 and a deficiency of the type 1 INF receptor subunit 1 in the Fc-gammaRIIB-/-Yaa mouse model of systemic lupus erythematous.

They intercrossed IRF5-deficient mice with Fc-gammaRIIB-/-Yaa mice to generate Irf5+/+RII.Yaa, Irf5-/-RII.Yaa, and Irf5-/-IRI.Yaa mice. They also intercrossed IFNAR1-deficient mice with Fc-gammaRIIB-/-Yaa mice to generate Ifnar1+/+RII.Yaa and IFNAR1-/-RII.Yaa mice. When the mice reached 5 months of age, the investigators compared disease manifestations, using age- and sex-matched, wild-type mice as controls.

The IRF5–homozygous mice developed marked lymphadenopathy and splenomegaly, produced high titers of antinuclear autoantibodies, and developed severe proliferative glomerulonephritis. In contrast, the IRF5-deficient Fc-gammaRIIB-/-Yaa mice did not develop such lupus manifestations and had a phenotype comparable to wild-type mice.

Remarkably, the IRF5-heterozygous mice had a phenotype similar to the IRF5-deficient mice—a dramatically reduced level of disease, with a phenotype comparable to wild-type mice.

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