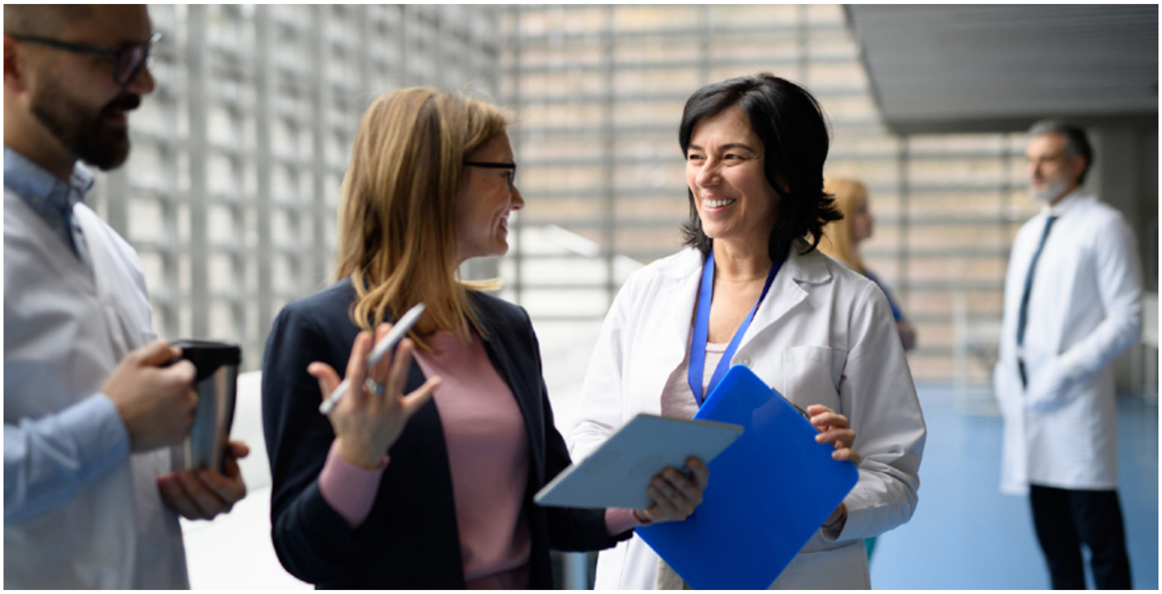
SUMMER 2025

Arthritis Foundation

# JOINT *Matters*



## Supporting Evidence-Based Care

Advancements in drug discovery and research have changed the treatment landscape for juvenile idiopathic arthritis (JIA). However, some rare JIA subtypes and their associated complications still lag JIA in optimal treatments. The low prevalence of these conditions, lack of clear clinical endpoints and disease heterogeneity lead to treatment variability. Adding to the complexity are the numerous medication options: How does a clinician choose which medication to use?

"We have evolved to a situation where many different doctors treat pediatric patients with rare rheumatic diseases differently. The reason for that is that we don't yet know the best treatment approach for many of our patients," says **Emily von Scheven, MD**, pediatric rheumatologist at the University of California, San Francisco Benioff Children's Hospitals. "Providers do what they think is best, or what they were trained to do by their mentors, or what they read about."

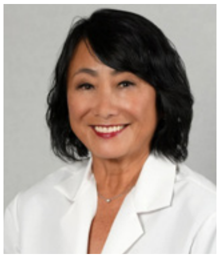
In rare disease research, consensus treatment plans (CTPs) can be valuable tools for guiding treatment decisions. Even more importantly, CTPs help reduce treatment variability and assist researchers in identifying treatments that are the most effective. Unlike randomized clinical trials, which are the gold standard for evaluating interventions, CTPs are standardized treatment plans that can then be evaluated in observational prospective studies, which are more time- and cost-effective.

It is essential to note that CTPs differ from practice guidelines, which are established when there is sufficient research to determine the most effective therapeutic intervention. CTPs, on the other hand, are necessary for conditions where evidence-based medicine is lacking.

The cornerstone to developing CTPs is getting the providers to agree on the treatment plans to be tested. Consider a condition where a lack of an established

**FEATURED IN THIS STORY:**

Emily von Scheven, MD
University of California, San Francisco



Yukiko Kimura, MD
Hackensack Meridian Health

standard of care has led to variability in treatment for patients with the same condition. To arrive at a CTP, these existing treatments are validated with literature review, and the prescribing details are delineated by health care providers using consensus methodologies, like Delphi surveys and consensus meetings. Once developed, CTPs are disseminated through peer-reviewed publications for use in general practice. They are then evaluated by practitioners through focused observational prospective studies to determine the best therapeutic intervention.

For rare juvenile rheumatic diseases, CTP-based observational studies require collaborative efforts involving a network of institutions.

"It's challenging to assemble enough patients to have the sample size and power that you need to answer questions about what treatments are most effective," says Dr. von Scheven. "We need to band together in pediatric rheumatology and pool all of our patients' information from across the country."

With funding from the Arthritis Foundation, the Childhood Arthritis and Rheumatology Research Alliance (CARRA) collects patient outcomes data using CTPs in the **CARRA Registry**, which includes over 70 active registry sites across North America. The registry has now enrolled more than 14,000 patients and has collected more than 1,450 biosamples associated with clinical data.

"The registry allows us to collect data from patients in a prospective and uniform manner," says **Yukiko Kimura, MD**, pediatric rheumatologist at the Joseph M. Sanzari Children's Hospital at Hackensack Meridian Health. "Once we standardize the treatments using CTPs, pediatric rheumatologists can then collect and save data about the patients who are treated with CTPs using the registry and learn how effective they are."

For example, **a recent prospective observational study called Start Time Optimization of Biologics in Polyarticular JIA (STOP-JIA)**, led by Dr. Kimura, compared the effectiveness of three CTPs that differed by when biologics were started on untreated polyarticular JIA (pJIA) patients enrolled in the CARRA registry. The study shows that patients who received treatment according to the early combination CTP, where a biologic and methotrexate are started together, actually spent significantly more time with inactive disease than patients who followed the step-up CTP, where methotrexate was given first and a biologic was added only if needed.

Currently, CARRA investigators have developed CTPs for 12 pediatric rheumatic conditions, including several forms of juvenile idiopathic arthritis, **lupus nephritis**, **juvenile localized scleroderma** and **juvenile dermatomyositis**. CTPs are revised when necessary if a particular treatment option in the CTP proves to be less effective or if a new drug becomes available on the market.

"We want to understand the best way to treat our patients," says Dr. von Scheven. "The registry and CTP activities are significant steps forward in the CARRA and the Arthritis Foundation's research agenda aimed at improving outcomes in pediatric rheumatic disease."

# ADVOCACY UPDATE

### DoD Arthritis Research Program Funding Restored in FY26 Appropriations Bill

The Arthritis Foundation is pleased to share that the Arthritis Research Program at the Department of Defense that was cut in the Fiscal Year 2025 Continuing Resolution has been restored in the FY26 Defense Appropriations bill. The program, a decade-long advocacy effort for the Foundation, was initially authorized in 2023 before it was interrupted by the Continuing Resolution. The Arthritis Foundation will continue to support this program as the research budget proceeds to congressional review.

### Pennsylvania Advocacy Day and Awards Presentation

The Arthritis Foundation hosted an advocacy day and awards presentation in Harrisburg, PA, with some amazing Arthritis Foundation Advocates. Members of the Foundation's advocacy team met with legislators supporting copay assistance toward patient cost-sharing. Foundation Advocates secured sponsorship for the House companion version of the bill. Advocacy Pioneer Awards were presented to the sponsors and champions of the biomarker testing legislation passed in the previous legislative session.

Are you ready to make a difference? ***Take the first step by visiting the Arthritis Foundation's Action Center***. There, you can find a topic that resonates with you and start advocating for change.

# PROs: What Patients Say Matters

An unsung hero of his time, surgeon Ernest Amory Codman was an impassioned advocate for the "end result system," which prescribed the systematic and prospective follow-up of patients to assess long-term treatment outcomes. His idea was largely rejected by the medical establishment of his time around the turn of the 20th century for its misalignment with prevailing surgical practice norms. However, it became influential in laying the groundwork for patient-reported outcomes (PROs), an emerging practice in modern medicine to improve quality and transparency in health care.

PROs emphasize patient experience as paramount in measuring health outcomes and offer an opportunity to adjust care based on patient feedback about their well-being, such as pain, fatigue and mental and physical health. Tools, questionnaires and other instruments used to capture and measure PROs for arthritis-related conditions and general health-related quality of life have now proliferated. However, despite research showing that **PRO measures can improve shared decision-making and communication between patients and doctors**, they have yet to be widely adopted in clinical settings, highlighting both barriers and opportunities for optimizing patient-centered care.

How can interested health care organizations integrate PROs into their patient-centered care? Fortunately, there are guidelines on which PRO measures to include and, if relevant, compare outcomes across patients. **The International Society for Quality-of-Life Research recommends considering the following questions**:

1. What are the goals for PRO data collection?
2. Which patients should be included?
3. Which PRO measures should be used?
4. When and how often should the PROs be measured?
5. How should patients complete the PRO measures, and how are they scored?
6. Who will see the results?
7. How will any issues or barriers be addressed?
8. How will the value of PRO use be assessed?

While it may be daunting to go through all these questions when considering the implementation of PROs in arthritis-related care, research and systems are in place that can facilitate their adoption. First, in our review of PRO measures related to arthritis conditions, we found at least 19 existing and well-validated disease-specific and generic PRO measures related to factors important to patients, such as physical health (e.g., function), level of independence (e.g., activities of daily living), social

**EDITORIAL BY:**

Karen E. Schifferdecker, PhD, MPH
Dartmouth College

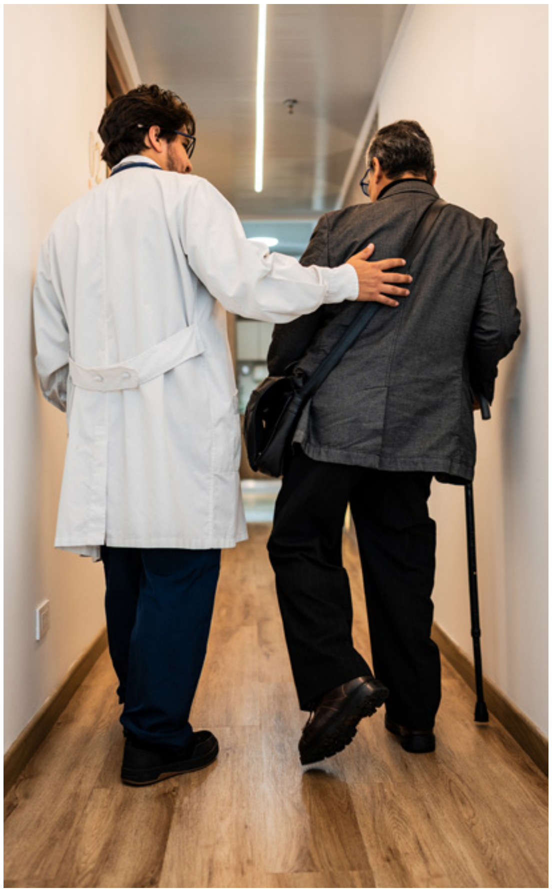
Erin M. Knight, PhD
Dartmouth College

relations and psychological health. There are also a growing number of PRO measures available in electronic health record systems, such as EPIC, including computer-adaptive tests. These health care portals reduce the burden of implementing PRO measures and the time required for patients to complete them.

Lastly, PRO measures have been successfully implemented in rheumatology, orthopedic and primary care settings, and can thus serve as examples that can be emulated elsewhere. For instance, the Department of Orthopedics at the University of Rochester Medical Center has been implementing PRO measures for several years, utilizing data to support patients in making informed decisions about treatment options and realistic outcomes.

Importantly, even with these resources, sites considering the adoption of PRO measures should be mindful of the time and cost to implement PRO measures. They should also assess patient, staff and clinician readiness to collect and use PRO measures. The responsibility for implementing PRO measures should be shared among health care professionals, including doctors, nurses and administrators, to distribute the workload and ensure the efficient use of resources. Ultimately, being clear about the primary goals for adopting PRO measures will contribute to the successful planning, selection, implementation and use of PRO measures. As described by **Dr. Ian Porter and colleagues**, doctors may use PRO measures at the individual patient level to monitor general health status and response to treatment, as well as to facilitate communication between patients and health professionals.

PRO measures may also be used for clinical activities, such as screening and diagnosis, risk stratification and prognosis, prioritization and goal setting, and indication for treatment. Some of our recent unpublished work shows that patients, after trying and failing multiple medications for rheumatoid arthritis, can feel brushed off by the health care system. These results highlight the potential value of incorporating PRO measures into these clinical activities to track progress toward outcomes important to patients while also monitoring their response to treatments.



In summary, PROs provide an additional avenue for acknowledging and utilizing measures that matter to patients, which can improve patient satisfaction, enhance provider and patient communication and inform treatment decision-making. Although PRO measures are not trivial to implement, guidance and systems exist to aid those interested in systematically capturing patient voices.

The Arthritis Foundation would like to thank Drs. Karen E. Schifferdecker, PhD, MPH, and Erin M. Knight, PhD, from The Dartmouth Institute for Health Policy and Clinical Practice, for the guest editorial.

*By supporting research in PROs, the Arthritis Foundation aims to improve treatments and quality of life for people with arthritis while actively engaging them as partners to ensure studies reflect their real experiences and needs. Although the Foundation has been supporting PRO research for many years, a centralized, formal grants program was launched in 2025.*

# Predicting RA's Silent Companion: ILD

Living with **rheumatoid arthritis (RA)** often means frequent pain, unpredictable flares and — if not managed properly — joint damage. In addition to these and other symptoms, comorbidities are quite common in RA patients, with many experiencing cardiovascular, lung and kidney diseases that negatively impact their health outcomes. Despite these coexisting and potentially debilitating health conditions, research emphasis has often been placed on RA rather than its comorbidities.

To focus on **RA comorbidities**, the Arthritis Foundation has granted an **RA Research Program** award to Jeffrey Sparks, MD, MMSc, associate professor of medicine at Brigham and Women's Hospital. With this funding, Dr. Sparks and his team will look for cellular biomarkers to better diagnose, monitor and predict **interstitial lung disease (ILD)**, a comorbidity associated with RA. Soon, this research could lead to the discovery of novel therapeutic targets to treat RA-ILD.

"There's been incredible advances in RA treatments over the past few decades. However, even with these expanded options, ILD in RA patients has not seemed to improve," says Dr. Sparks. "We really need to figure out who is getting ILD and who is getting progressively worse, and certainly treatments that are going to help people with lung disease and RA."

ILD could arise from the same inflammatory processes that have gone awry in RA. The disease is marked by **scarring and inflammation of the lung tissue** and can cause shortness of breath, dry cough and fatigue. There are some known risk factors for RA-ILD, such as high RA disease activity, smoking, age and sex — a man is more likely to get RA-ILD than a woman, despite RA being three times more common in women. However, the impact of ILD on a patient can vary.

"It is a spectrum: Some people have mild severity whereas others have severe ILD," says Dr. Sparks. "As an estimate, 8% to 12% of people with RA have clinically relevant ILD that is diagnosed."

Some patients might even progress to the point that they need supplemental oxygen or a lung transplant. An even more sobering observation is that RA-ILD prevalence has increased two-fold and is one of the few **RA** outcomes that is not improving.

"Many of these patients are on medications for RA, and so their joints are not getting worse, but their lungs are, and ILD continues to progress in some," says Dr. Sparks.

There is an immediate need to identify which patients will get ILD and how the disease progresses.

For their Foundation-funded research, Dr. Sparks and his team, along with co-principal investigators Edy Kim, MD, PhD, and Kevin Wei, MD, PhD, both assistant professors of medicine at Harvard Medical School, will avail themselves of the ongoing Study of Inflammatory Arthritis and ILD in Early RA, or **SAIL-RA**, in which the patients enrolled have early RA. Enrollees will get routine CT scans over two years, so that the investigators can look for abnormal lung features at the very beginning of the disease process. These screening strategies could facilitate finding anatomical biomarkers of early disease so that treatments could slow down the progression of ILD. Combined with the CT scan analysis, researchers will look for cellular biomarkers using RNA sequencing of different types of cells circulating in the blood that would be telltale signs of ILD presence and progression.

"We are so excited about the Arthritis Foundation grant," says Dr. Sparks. "This has been a cross-disciplinary collaboration that includes several sites and investigators, and the grant has played an important role in bringing the project together."

**FEATURED IN THIS STORY:**

Jeffrey Sparks, MD, MMSc
Brigham and Women's Hospital

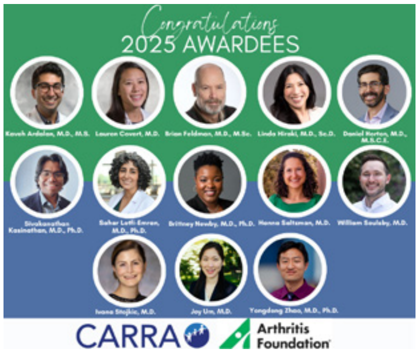
# Announcements

## 2025 Clinical Rheumatology Fellowship Awards

The Arthritis Foundation announced the 2025 Clinical Rheumatology Fellowship awards totaling $825,000, continuing our commitment to strengthening the rheumatology workforce. This year's awardees — Baylor College of Medicine, Boston Children's Hospital, Duke University and the University of Utah — will use the funding to advance innovative training, address workforce shortages and meet the evolving needs of diverse communities. Read the full news article.

## AOSSM and Arthritis Foundation Award for Shoulder Osteoarthritis Research

In partnership with the Arthritis Foundation, the American Orthopaedic Society for Sports Medicine (AOSSM) has awarded a $500,000 multicenter research grant to Michael Davies, MD, from the University of California, San Francisco (UCSF), and co-principal investigators Brian Feely, MD, also of UCSF, and Robert Tashjian, MD, from the University of Utah. This grant is aimed at unraveling the complexities of shoulder pathology and osteoarthritis (OA). Read the full news article.



## 2025 CARRA-Arthritis Foundation Grant Program Awards

This year, the CARRA-Arthritis Foundation Grant Program has awarded nearly $2 million — an increase of $200,000 from the previous year — to advance research in childhood arthritis. The Arthritis Foundation and CARRA each contributed an additional $100,000 to support the grant program. The grant awards will fund research in juvenile idiopathic arthritis (JIA), pediatric lupus, juvenile dermatomyositis, chronic nonbacterial osteomyelitis (CNO) and other childhood rheumatic diseases. Read the full news article.

EASE OF USE
CERTIFIED
Arthritis Foundation®

## Leading the Way in Ease of Use Design

The Arthritis Foundation's Ease of Use® certification program certifies products and packages that have been independently tested and are proven easier to use for people with arthritis and others with chronic pain.

As the Foundation champions life-changing resources for people living with arthritis and chronic pain, we collaborate with both consumer and health care companies to design and bring products and packages to market that are easier to use.

In the consumer arena, we have certified items as small as a tube of mascara or lipstick, to larger items like bed sheets designed to be easier to tuck when making a bed. In the health care arena, certifications range from medical devices, bottles and caps and even pills with indentations, making them easier to pick up and hold.

Companies that are bringing accessible design into their design process are innovatively thinking about many areas — weight, linear force, rotational force, action fatigue, joint placement, grip span, sharp edges, and whether tools, such as scissors, are required to open packaging. These considerations are important when thinking about how they impact someone's day-to-day activities.

Ease of Use-certified products are available in retail stores and online. Certified medical devices, bottles and caps associated with various treatments are available through prescription. See products and packaging with Ease of Use certification.

## Partners for Patients

As a health care provider, you're invited to join Partners for Patients, a program that connects you with patient education resources and a supportive community through the Arthritis Foundation to help improve patient care and outcomes. By becoming a partner, you'll gain access to tools that connect your patients with vital Arthritis Foundation services and support, fostering stronger collaboration and better results. Once you join, we'll highlight our partnership with you in both patient and medical communities and keep you informed on the latest updates and advancements in arthritis research and care. Learn more about the Partners for Patients program.

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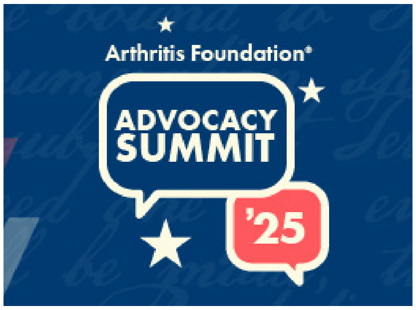
# Events

### Think Tank: PROs in Arthritis Care

The Arthritis Foundation teamed up with Northwestern University Feinberg School of Medicine on April 16 to co-sponsor a roundtable of national experts to discuss advancing care and outcomes for adults living with arthritis. The meeting, co-sponsored by Feinberg's Department of Medical Social Sciences (MSS), divisions of rheumatology and orthopedics, helped lay the groundwork for the Arthritis Foundation's new patient-reported outcomes (PRO) initiative. Read the full news article.



### Advocacy Summit, Washington, D.C., Sept. 28 – 30, 2025

This event empowers Advocates to make their voices heard among lawmakers to improve both treatments and quality of life for those living with arthritis. Bringing together patients, caregivers and health care professionals, the Arthritis Foundation Advocacy Summit empowers Advocates with the training and tools needed to influence lawmakers. This initiative not only amplifies the lived experience of patients but also drives tangible policy changes that improve access to care and quality of life for the nearly 60 million people in the U.S. living with arthritis. Get details about the Advocacy Summit.

### Community Health & Workforce Summit, Virtual, Nov. 14, 2025

Bringing together experts in rheumatology, accessible care and community health, the Arthritis Foundation's Community Health & Workforce Summit will highlight our commitment to growing the rheumatology workforce and improving patient outcomes, as well as to providing patient education and advocacy and building connections. Arthritis Foundation grantees will present their work on cultivating a health care workforce to serve all people with arthritis. **Registration will start in August**. For inquiries on registration, email AFScience@arthritis.org.

## COMMUNITY IN ACTION

Make an impact! Join the Arthritis Foundation's signature events happening at a location near you.

**California Coast Classic Bike Tour**, presented by Amgen, is a scenic bike ride that takes place over eight days and covers 525 miles along the coast on U.S. Highway 1. The tour starts in the heart of San Francisco and ends on the iconic strand of Los Angeles.

**Ride Your Way With Arthritis Cycling Experience** allows you to participate in our signature cycling events virtually if you are unable to attend in person.

**Jingle Bell Run** is the most festive holiday Run for a Reason. Join us as we support the nearly 60 million people in the U.S. living with arthritis at the most fun holiday fundraising run. You and your hospital or practice can get involved in so many ways! Register your hospital, practice or department as a team (and encourage your patients to join). You don't want to miss out!

**Galas and Gatherings** include local fund-raising galas, golf outings, car shows or themed parties. These fun-filled events offer a festive way to help the Arthritis Foundation and benefit our entire community.

To learn more about our events and to participate, visit arthritis.org/events.

## LET'S CONNECT!

To ensure you are receiving our most up-to-date communication from *Joint Matters*, please visit our website to confirm your subscription.

You can also email us at afscience@arthritis.org for queries and to unsubscribe from *Joint Matters*.

## Educational Resources for Your Patients

### Live Yes! Connect Groups

Connect Groups provide supportive social connections and are open to parents/guardians of children with rheumatic diseases and to adults living with any type of arthritis or rheumatic diseases. These virtual and in-person groups bring people together for fun social and informative educational events and activities focused on mutual support and positive coping strategies for living well. Find a Connect Group.

### Managing Pain Beyond Medication, Aug. 28, 7:00 – 8:15 p.m. ET

Gain insights into integrative and non-pharmacologic pain management strategies, including cognitive-behavioral approaches, acupuncture and complementary therapies, by attending this webinar. It will also include an overview of commonly used medications in arthritis care. Register for the event.

### Viva Bien Con Artritis, Sept. 25, 7:00 – 8:15 p.m. ET

This webinar is a culturally relevant, Spanish-language session that empowers Hispanic/Latino communities to manage arthritis more effectively. Panelists will share practical tools and culturally tailored strategies for improved health outcomes. Register for the event.

### The Power of Food and Nutrition for Arthritis, Oct. 2, 7:00 – 8:15 p.m. ET

Investigate the link between nutrition, gut health and arthritis in this webinar. Learn about anti-inflammatory diets, the microbiome's role in systemic inflammation and nutrition strategies to support disease management. Live Spanish translation available. Register for the event.

### Coping With the Emotional Toll of Juvenile Arthritis, Oct. 23, 7:00 – 8:15 p.m. ET

In this webinar, mental health experts and families will discuss the psychological impact of juvenile arthritis. You will learn strategies to support family resilience and emotional well-being. This session can provide valuable perspectives for clinicians and researchers interested in pediatric rheumatology and psychosocial care. Register for the event.

Arthritis Foundation®