

# JOINT *Matters*



## Transitioning to Adult Rheumatology Care

In the United States, hundreds of thousands of children aged 17 or younger live with juvenile rheumatic conditions. Although they make up a small percentage of the nearly 60 million individuals with rheumatic disease, these young individuals face unique challenges as they transition to adult care. How can rheumatologists best support them as they enter adulthood?

### Defining Transition

In the medical field, the term “transition” often refers to gaining independence and becoming self-sufficient in managing health care. Within this process, health care providers typically focus on specific, measurable outcomes that indicate the successful transfer from pediatric to adult care.

Despite the long-standing concept of transition, the outcomes of those transitioning to adult care remain poor. Long-term data indicates that patients with juvenile idiopathic arthritis (JIA) continue to experience disease activity, pain and ongoing medication use even with the introduction of newer biologic agents. Also, young people with childhood-onset

lupus often have more severe health issues and damage compared to adults, and the transfer of care is associated with reduced health care utilization and irregular follow-up appointments.

Therefore, the transition is more than just a physical transfer to an adult health care provider for these patients. Patients want to learn how to manage their rheumatic condition by themselves, especially as they reach milestones typical of their age group, such as getting a driver’s license, exploring college life, employment, financial responsibility and pursuing romantic relationships. In our mixed methods [study](#), a majority of young patients expressed a preference for learning transition skills, such as filling medication prescriptions, discussing their medical history and tracking symptoms, from their rheumatology health care teams. However, in reality, they learned these skills from their parents. It’s worth noting that while 95% were comfortable speaking to their rheumatologist about their symptoms, only 47% and 59% were comfortable discussing how their rheumatic disease affects sexual/reproductive health and mental health with their rheumatologist, respectively. When it comes to young people, health

### ARTICLE BY:



Peter Chiraseveenuprapund, MD,  
University of Utah Health



Kristine Carandang, PhD,  
Young Patients’ Autoimmune  
Research & Empowerment  
Alliance

and wellness should be viewed from a holistic perspective. Therefore, the transition should ideally integrate and align with routine tasks and life goals to achieve overall well-being, which, in turn, can facilitate continued long-term engagement with health care.

## Supporting Health Management in Early Adulthood

Open communication and trust-building are essential elements of transition preparation throughout the entire process from pediatric to adult health care. It is crucial to clearly and explicitly identify which aspects of care are related to the transition and how they support patients' independence within and outside the clinic. For example, the **'Got Transition'** program developed by [The National Alliance to Advance Adolescent Health](#) provides guidance for physicians, patients and families to collaboratively approach the transition process systematically. The program includes components such as establishing a timeline and expectations, assessing readiness for self-care, monitoring patients' progress, preparing for the differences between pediatric and adult clinics, the process of transfer and finally, transfer completion. According to our focus groups, young patients unanimously agreed that utilizing the resources and format found on the 'Got Transition' website would have improved their transition experience.

### TRANSITION TIPS FOR RHEUMATOLOGISTS

- Empower your young adult patient to feel inspired by the transition. Emphasize the importance of having more control and decision-making in creating a treatment plan that matches their lifestyle.
- Delineate skills and knowledge that are needed to promote health maintenance. Provide time and resources for your young adult patient to build confidence in these skills in the clinic (for example, a list of questions to ask during a visit).
- Allow parents to support the process (e.g., through coaching), but speak directly to your young adult patient. Set boundaries for where parents' authority ends, and your young adult patient's autonomy begins.

## Continuing to Improve Patient Engagement

In many cases, pediatric rheumatology bears most of the responsibility in preparing young individuals to transition to adulthood. However, adult rheumatologists also play a critical role in ensuring a successful transition; some patients may need more assistance in developing independent self-care skills. Similar to adults with rheumatic diseases, adolescents and young adults are committed to achieving positive outcomes and want to be actively involved in shared decision-making for new treatments. Toward the end stages of transition, treatment and disease management goals need to be carefully established by the young adult and their rheumatologist when transitioning to adult care. We propose that

proper implementation of transition care ultimately involves providing patient-centric care, which incorporates holistic measures focusing on participation, longer-term life events such as fertility and family planning, emotional well-being, coping and financial status.

*The Arthritis Foundation would like to thank Drs. Peter Chiraseveenuprapund and Kristine Carandang for the guest editorial.*

The Arthritis Foundation has several resources that can also help in the transition to adult rheumatology care, including Connect Groups, JA Summit, Mentorship Programs and Junior Ambassador Program. [Learn more about the Foundation's JA program and resources.](#)

## ADVOCACY UPDATE

[The Inflation Reduction Act of August 2022](#) included a \$2,000 cap on Medicare Part D out-of-pocket costs and the Medicare Prescription Payment Plan (MPPP, or "smoothing" plan), which allows beneficiaries to spread their prescription drug costs evenly throughout the year. Starting in 2025, there are **vital changes** to Medicare prescription drug benefit (Part D) plans that will be important for many people with arthritis. These changes are not just significant, but crucial for the future well-being of many patients. The Arthritis Foundation is committed to ensuring that patients likely to benefit from these changes have the information and resources they need to enroll in the best plan. The Arthritis Foundation helps to connect patients to resources through our materials, Centers for Medicare & Medicaid support or State Health Insurance Assistance Program (SHIP) counselors to understand whether this program will benefit them and how to enroll. [Learn about open enrollment options.](#) You can also contact our [Helpline](#) for more guidance at 800-283-7800.

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.

## Building a Self-Reliant Indigenous Rheumatology Workforce

The ethnic, linguistic and cultural pluralism in the United States has enriched us in powerful and profound ways. However, not all communities in the country's milieu experience comparable access to the country's infrastructure, especially health care.

Indigenous peoples, who have historically faced discrimination and marginalization, are currently enduring significant inequities in health care compared to other U.S. populations. This situation demands immediate attention as they bear the heavier brunt of infectious, rheumatic and other chronic diseases.

"We still have only a very limited number of Indigenous people in rheumatology care – only 5% of doctors in this country are Indigenous," said Jim Jarvis, MD, professor of rheumatology at the University of Washington and recipient of the [Arthritis Foundation 2023 Diversity, Equity and Inclusion \(DEI\) award](#). "It gives you an idea of how important it is to involve more Indigenous students in clinical care."

Native populations' association with rheumatic diseases may originate in antiquity. Archeological remains of North American Indigenous peoples' bones from thousands of years ago show erosions in the joint that are reminiscent of rheumatoid arthritis (RA) and juvenile rheumatoid arthritis (JRA). These findings suggest that these diseases were prevalent in certain Native tribes long before the arrival of the Europeans. One theory is that rheumatic diseases have since spread globally from the North American indigenous peoples. Yet JRA, for example, can be up to five times more common in Indigenous people than in children with European ancestry.

However, the inheritance of rheumatic diseases might have received a critical, long-term boost. Non-Hispanic American Indian or Alaska Native adults have some of the highest [adverse childhood experiences](#), or ACEs, among U.S. adults. This historical trauma and repeated dislocation due to colonization practices, Dr. Jarvis noted, can leave an epigenomic imprint, increasing the risk and changing the expression of rheumatic diseases in Indigenous peoples across generations.



"We now know that a lot of the trauma response becomes embedded in the epigenome," said Dr. Jarvis. "The scientific world is constantly uncovering more about how the immune system responds to psychosocial trauma."

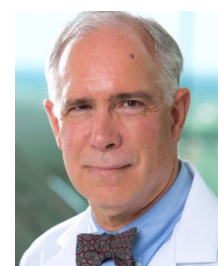
In fact, his team has been studying the underlying epigenomic mechanisms that might increase the risk of pediatric systemic lupus erythematosus and juvenile arthritis.

But considering the complex relationship between rheumatic diseases, Indigenous peoples and the ongoing shortage of rheumatologists, particularly pediatric rheumatologists, poses an even bigger threat to health outcomes. Thus, to reduce the burden of these diseases, workforce solutions must address the Native peoples' unique health care challenges and needs.

With the Foundation's DEI award, Dr. Jarvis is leveraging his extensive experience working with Indigenous children with rheumatic disease to increase the Native representation in the rheumatology health profession to better provide racially concordant care. This award, which recognizes and supports DEI initiatives in health care, is a crucial step in addressing the health care disparities Indigenous populations face.

Dr. Jarvis' team will establish and strengthen relationships with regional Native American communities,

### FEATURED IN THIS STORY:



Jim Jarvis, MD,  
University of Washington



including students in the Blackfeet Community College and the University of Washington's academic rheumatology community. They will also recruit and support these students, early-career physicians and health professionals toward careers in rheumatology care, research and education.

"We have a huge talent pool in the Indigenous community, but the talent pool faces really serious economic, social and geographic challenges," said Dr. Jarvis. "Having the funding from the Arthritis Foundation helps

us go to them instead of them coming to us, and the truth is for every 100 students you encounter, you might get one who's interested, and then you focus a lot of effort on that one."

*The Arthritis Foundation would like to thank Dr. Jarvis for his feedback on this article.*

[Learn about the Foundation's efforts in childhood arthritis.](#)

## Announcements



### Request for Proposals: Clinical Rheumatology Fellowship

The Arthritis Foundation is seeking applications from institutional program directors who are interested in using innovative approaches in training to prepare the next generation of rheumatologists to meet the evolving needs of the community. For 2024, there are two main changes in the RFP: (1) The annual funding for the fellowship has increased to \$75K per year. (2) The funding term/duration is now adjusted to coincide with the board eligibility duration of each program.

For application and instructions, please log into [ProposalCentral](#) and search for Arthritis Foundation. The instructions can be downloaded by clicking the paper icon to the right of the words "Rheumatology Fellowship Training." After reviewing the criteria, those who intend to apply should email the Arthritis Foundation with the subject line: "Fellowship – Yes" and in the body of the email indicate "Adult," "Pediatrics," or "Med-Peds." The due date for applications is **Dec. 4, 2024. All applications are due by 5:00 p.m. ET.**



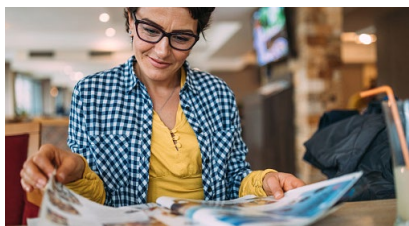
### Steven Taylor Appointed to Advisory Council for NIAMS

The Arthritis Foundation proudly announces the appointment of its President and CEO, Steven Taylor, to the Advisory Council of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). This prestigious role underscores Taylor's leadership in public health and his unwavering commitment to improving the lives of the nearly 60 million adults and hundreds of thousands of kids living with arthritis in the U.S. [Read the press release.](#)



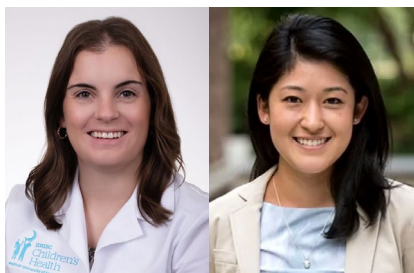
### CARRA — Arthritis Foundation Research Grants

The Arthritis Foundation and [Childhood Arthritis and Rheumatology Research Alliance](#) (CARRA) announced the awardees of this year's CARRA – Arthritis Foundation research grants in July. This year's awards, totaling more than \$1.6 million, will fund research in [juvenile idiopathic arthritis](#) (JIA), pediatric lupus, [scleroderma](#), chronic nonbacterial osteomyelitis (CNO) and other childhood rheumatic diseases. Grant recipients received one of seven award types: advancing biosample collection, large grant, small grant, bridge, fellow, health equity planning grant and mentored career development award. [Read the full news article.](#)



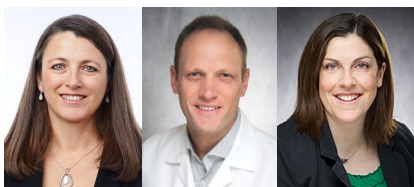
### APEX Award for Publication Excellence

A testament to the importance of our work in the osteoarthritis space, the special Issue of the Hospital for Special Surgery Journal covering the 2023 Hip Osteoarthritis Clinical Studies Conference has won an APEX Award for Publication Excellence. The series of [research articles](#) was guest edited by Jason Kim, PhD, vice president of osteoarthritis programs, and Mathias Bostrom, MD, associate surgeon-in-chief at the Hospital for Special Surgery. [Read the press release.](#)



### PR-COIN — Arthritis Foundation QI Education Program

The Arthritis Foundation has partnered with the Pediatric Rheumatology Outcomes Improvement Network (PR-COIN) to offer critical quality improvement education and training for physicians currently enrolled in a [fellowship program](#). The newly announced 2024-2025 PR-COIN – Arthritis Foundation Quality Improvement (QI) Education Program for Pediatric Rheumatology Fellows – is a year-long training program. This year's awardees are Chelsea Reynolds, DO, from the Medical University of South Carolina, and Rina Ferguson, MD, MBA, from Seattle Children's Hospital. The goal of this program is to advance the development of thoughtful and inclusive improvement leaders in the next generation of pediatric rheumatologists. [Read the full news article.](#)



### FastOA Initiative, Hip Cohorts

Identifying patient groups at high risk for developing hip osteoarthritis over a short time has the potential to be a valuable resource for successful future clinical trials looking into novel treatments. This year, as part of a larger Arthritis Foundation and Osteoarthritis Clinical Trial Network initiative called FastOA, two funding awards have been conferred to investigators seeking to identify and define patient populations at risk of developing "FastOA" of the hip. The awardees, Cara Lewis, PT, PhD, from Boston University, and Michael Willey, MD, and Jessica Goetz, PhD, from the University of Iowa, have received funding of \$150,000 for a year. [Read the full news article.](#)



### Foot and Ankle Arthritis Development Program

The American Orthopaedic Foot & Ankle Society® (AOFAS) and the Arthritis Foundation (AF) announced a new partnership, called the Foot and Ankle Arthritis Development Program, on September 12, 2024, at the AOFAS Annual Meeting in Vancouver, British Columbia, Canada. The program will provide medical students and residents from underrepresented groups with valuable training and mentoring opportunities across the country. Over a three-year period, the AF and AOFAS will select 4-6 medical students and/or residents annually to participate in the program. Applications for the inaugural AF/AOFAS Foot and Ankle Arthritis Development Program will open in November 2024. Participants will be selected in mid-2025 and begin travel in September 2025. For more information about the program, visit [aofas.org/arthritis](https://aofas.org/arthritis).



### Arthritis@Work Program

The Foundation's Arthritis@Work program is free to employers to help their workers be as productive as possible. Arthritis is America's #1 cause of workplace disability — and it drains our economy, totaling over \$300 billion annually in medical and related expenses. Arthritis@Work can help reduce missed workdays and improve employees' physical, emotional and social health. We offer tips and solutions to help the one in four workers in the U.S. who battle arthritis be healthier, happier — and more productive. This program shows employees their employer really cares about their well-being. [Learn about the Arthritis@Work Program.](#)

## COMMUNITY IN ACTION

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

**Carolina Hills Classic Bike Tour (CHC)** is a fully appointed and e-bike friendly road cycling adventure in the foothills of the unmatched beauty of the Blue Ridge Mountains. Fundraising from this event fuels Arthritis Foundation advocacy, scientific research and life-changing programs. Explore the quiet winding roads, vibrant art scene, and welcoming hospitality of this premier Southeastern cycling destination.

**Ride Your Way with Arthritis Cycling Experience** is an opportunity to join the CHC Tour community 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.

To learn more about our events and to participate, [visit arthritis.org/events](https://www.arthritis.org/events).

## LET'S CONNECT!

To ensure you are receiving our most up-to-date communication from *Joint Matters*, [please visit our website](https://www.arthritis.org) to confirm your subscription.

You can also email us at [afscience@arthritis.org](mailto: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. [Learn about our Connect Groups and upcoming events.](#)

### The Link: Arthritis, Diabetes and Heart Disease, October 24, 6:00 - 7:15 pm ET

In this virtual event, participants will learn about the surprising link between having arthritis and developing heart disease and diabetes. Get expert tips on how to spot symptoms of these conditions, find doctors to treat them and ways to prevent or manage complications if you already live with them. [Register for the event.](#)

### VERITY Patient and Community Partnership Forum, October 29, 12:00 - 2:30 pm ET

This is a free, virtual forum where [VERITY](#) faculty, including Arthritis Foundation's [Medical and Science Advisory Committee](#) member Dr. Dan Solomon, will be joined by faculty from organizations such as [OMERACT](#), [EULAR](#) and [Harvard T.H. Chan School of Public Health](#) to discuss the various roles patients can play in research and how to involve patients and communities as partners in research. [Register for the event.](#)

### Inflammatory Arthritis: Challenges and Solutions, November 21, 6:00 - 7:15 pm ET

Learn how inflammatory arthritis can impact more than just your joints and get informed on related conditions that may affect your body from head to toe. This webinar will also include tips on how to spot symptoms, prevent complications and find a doctor to treat them. Also, learn about various treatments and strategies to manage these effects and take charge of your health. [Register for the event.](#)

