THE JOHNS HOPKINS ARTHRITIS CENTER

2024 Update

A MESSAGE FROM OUR DIRECTOR:

The Johns Hopkins Arthritis Center was established over 30 years ago with a mission to deliver compassionate, comprehensive care for people living with various forms of arthritis, to conduct cutting-edge research to understand the causes of these diseases and how they impact people, and to provide education about arthritis and its treatment for patients, families, and health care providers. We would like to provide you with a summary of our activities and accomplishments in the last year as well as news from the Center and introductions to new faculty. As you will see from this summary, our work continues as we expand our faculty and areas of interest.

We are excited to share the results from studies about biomarker discovery in rheumatoid arthritis (RA), patient-reported outcomes in psoriatic arthritis and RA, several reports on cancer immunotherapy-induced inflammatory arthritis, and information about Sjogren's syndrome.

We appreciate your support of our Center, as patients choosing us to provide your care, as participants in our research registries and studies, and as financial supporters of our work. If you wish to learn more about how you can make a difference, or make a gift to the Arthritis Center or in support of your physician this holiday season, please visit secure.jhu.edu/form/arthritis or contact Molly Dolan, Senior Associate Director of Development, at 630-309-0692 or mdolan6@jh.edu. Without your partnership, none of this would be possible.

Your providers and our staff are always happy to discuss the work we are doing. And I would welcome the opportunity to hear from you with your ideas and suggestions about our programs.

We sincerely hope that you enjoy this update. Happiest of holidays to you and your family!

With best wishes,
Clifton O. Bingham III, MD
Professor of Medicine
Director, Johns Hopkins Arthritis Center

To make a gift to the Johns Hopkins Arthritis Center, please scan this QR code, visit secure.jhu.edu/form/arthritis or contact Molly Dolan at (630) 309-0692 or mdolan6@jh.edu. Thank you!

RESEARCH:

Characteristics Associated with Patient-Reported Treatment Success in Psoriatic Arthritis

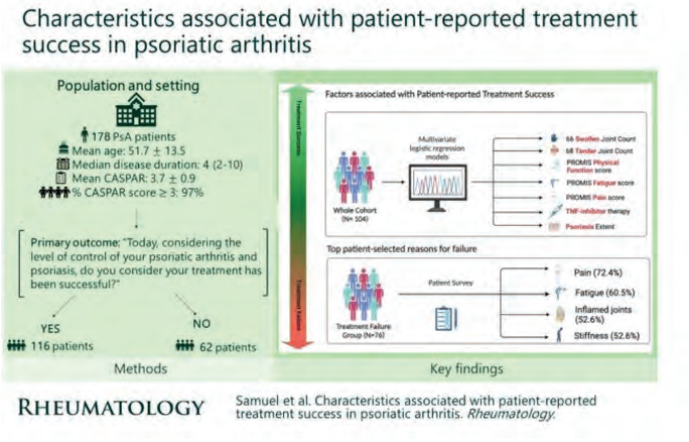
Ana-Maria Orbai, MD, MHS
Director, Psoriatic Arthritis Program

Reducing or eliminating the painful and uncomfortable symptoms of psoriatic arthritis, such as joint inflammation, skin psoriasis, fatigue and stiffness, is an important goal for patients with the condition and for the clinicians involved in their care. One way to reach this goal comes from understanding a patient's quality of life, care priorities and how they define treatment success.

Our team specifically studied whether patients with psoriatic arthritis felt that their treatments were successful or unsuccessful through a survey. Researchers asked 178 adult patients, all treated at the Johns Hopkins Psoriatic Arthritis Program, a simple question: "Today, considering the level of control of your psoriatic arthritis and psoriasis, do you consider your treatment has been successful?" 116 patients answered yes, while the other 62 said no.

Those who said no were prompted with two follow-up questions, one of which asked them to select symptoms of the disease that still bothered them and if/how these manifestations impacted their quality of life. The other question asked if their current symptoms lasted a few months, would they find this acceptable or unacceptable. Using statistical analyses, and several psoriatic arthritis treatment and disease indexes, the team determined a few key takeaways.

Firstly, the most common patient-reported symptoms contributing to unsuccessful treatment were pain, fatigue and stiffness. Additionally, patients who reported successful treatment were more likely to have inflammatory arthritis symptoms under control, whereas patients who reported swollen, tender joints faced lower odds of defining their treatment as successful. They also found that those patients on a specific treatment, known as TNF-inhibitor therapy, had 11 to 13 times higher odds to report their treatment as successful compared to those not on this therapy.



Based on these findings, researchers say that this study supports the importance of psoriatic arthritis assessments with patients, access to treatment, and monitoring patients' and disease status on therapy.

Laboratory Insights: PAD Enzymes and Rheumatoid Arthritis

Over the last fifteen years, researchers in the Arthritis Center have collaborated with laboratory scientists, led by Dr. Erika Darrah, to study the immunology of rheumatoid arthritis (RA). One topic of research has been how autoimmunity starts in RA. Some patients with RA have antibodies to normal enzymes that modify proteins. Peptidylarginine deiminase (PAD) enzymes can be targeted by the immune system, and autoantibodies to different PAD enzymes have significance for patients for RA.

Antibodies that recognize both the PAD3 and PAD4 enzymes have been shown to be markers of more severe disease in RA. Patients with these antibodies are more likely to have permanent joint damage. Additionally, the prevalence and extent of interstitial lung disease is markedly higher among RA patients with anti-PAD3/4 cross-reactive antibodies.

Dr. Darrah and others performed a study to evaluate anti-PAD4 antibodies as biomarkers for treatment response. In early RA (those who had disease less than two years), baseline anti-PAD4 antibodies were associated with a greater improvement in disease activity after treatment compared with individuals with negative anti-PAD4.

In contrast to antibodies to PAD3 and PAD4, anti-PAD2 antibodies are seen in less severe RA. In a study of Arthritis Center patients with RA, anti-PAD2 antibodies were not associated with traditional genetic or serologic RA risk factors, including HLA-DRβ1 shared epitope alleles (genetic markers), ACPA, rheumatoid factor (RF), or anti-PAD3/4 antibodies. Antibodies to PAD2 were associated with fewer swollen joints, a lower prevalence of interstitial lung disease, and less progression of joint damage.

While these tests and biomarkers are still investigational, our team is working with companies to develop commercial assays that will be widely available for clinical care. We thank the many patients who have contributed blood for our Arthritis registry that has made these discoveries possible and allows us to study other biomarkers for various forms of arthritis.

Clifton Bingham III, MD
Director, Johns Hopkins Arthritis Center

Laura Cappelli, MD, MHS
Associate Professor of Medicine

New Findings in Cancer Immunotherapy-Induced Inflammatory Arthritis

Laura Cappelli, MD, MHS
Associate Professor of Medicine

Immune checkpoint inhibitors activate the immune system to fight cancer, but can cause side effects like inflammatory arthritis. At the American College of Rheumatology annual meeting in November 2024, there were several different research projects presented highlighting work done at the Johns Hopkins Arthritis Center. First, patients with immune checkpoint inhibitor-induced inflammatory arthritis (ICI-IA) were compared to patients treated with immune checkpoint inhibitors who did not develop arthritis do determine if particular inflammatory proteins were more elevated in the blood of the arthritis patients. We determined that TNF-alpha and VEG-F were uniquely elevated in the patients with arthritis. Also, high levels of VEG-F and IL-6 correlated with more severe arthritis. These proteins represent exciting potential targets for treatment.

Another project evaluated patient reported outcomes in ICI-IA. Pain interference, physical function, and fatigue were increased in patients with ICI-IA arthritis relative to the general population. Pain and physical function tracked with arthritis disease activity, but fatigue similarly affected patients regardless of how severe the arthritis was. Fatigue is an important symptom in patients treated with immune checkpoint inhibitor therapy regardless of their arthritis.

In a third project, the effects of corticosteroid therapy on ICI-IA and cancer outcomes were evaluated. There was no significant difference in improvement in disease activity at first follow up with higher steroid dosing. There was no significantly increased hazard of death for those treated with higher doses of steroids in follow up, but a trend toward increased hazard of tumor progression. Given the conflicting results for overall survival and tumor progression, further studies are needed to address survival bias and clarify the safety of steroids and steroid-sparing immunosuppression in ICI-IA.

Finally, we evaluated whether hip osteoarthritis is associated with increased development of ICI-IA and whether either ICI-IA or osteoarthritis affected mortality in a group of lung cancer patients treated with ICIs. Hip osteoarthritis as determined from CT of the abdomen/pelvis was not significantly associated with development of ICI-IA in this cohort of lung cancer patients. ICI-IA was associated with decreased mortality. Further studies should evaluate risk factors beyond hip OA for ICI-IA development.

We would like to thank patients seen at the arthritis center for ICI-IA for their participation in research activities. We could not do any of this without you!

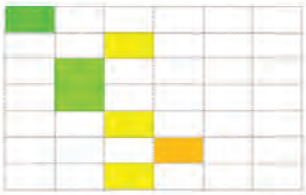
CLINICAL CARE:

Patient Questionnaires for your Rheumatology Appointment

Thomas Grader-Beck, MD
Associate Professor of Clinical Medicine

There is a lot going on behind the scenes in the week before you come in for your office visit. With the help of our state-of-the-art Electronic Health Record system, we designed a set of patient questionnaires that is sent to you 7 days before your appointment through MyChart. The questionnaires are tailored to your specific disease and can be answered before the appointment by logging into MyChart and looking at your upcoming visit. If you do not have MyChart access or you do not have time to fill the questionnaires out beforehand, they will be made available to you in the clinic on your visit day. Your answers are very important for us and, in fact, they play an important role in determining how active your disease is and whether your treatment is working. Most importantly, they provide a good picture of your disease over the years, so do make sure you complete them upfront. Some questionnaires ask also about how you are doing in general, such as your level of pain, fatigue, function, sleep, and mood disturbances. Your answers are compared to averages from thousands of people across the country and displayed back in colors of level of concern (see below). This helps us to identify where you may have specific problems and focus our discussion on those issues. Ask your rheumatologist to show you your profile at your visit!

PROMIS Domain	T score
Physical Function SF10	61.7
Fatigue SF8	57.5
Pain Interference SF8	52.3
Ability To Participate SF8	48
Sleep SF4	57.9
Anxiety SF4	61.4
Depression SF4	55.7



Average or better
Worse: 0 - < 0.5 SD
Worse: 0.5 - < 1 SD
Worse: 1 - < 1.5 SD
Worse: 1.5 - < 2 SD
Worse: 2 SD or more

Learning What is Important to People Living with Arthritis

Clifton Bingham III, MD
Director, Johns Hopkins Arthritis Center

As patients in the Arthritis Center, you have all seen the questionnaires we ask you to complete through MyChart before your visit or on a tablet in the waiting room. Many of you may wonder why we are asking all these questions, and what does it mean for your care.

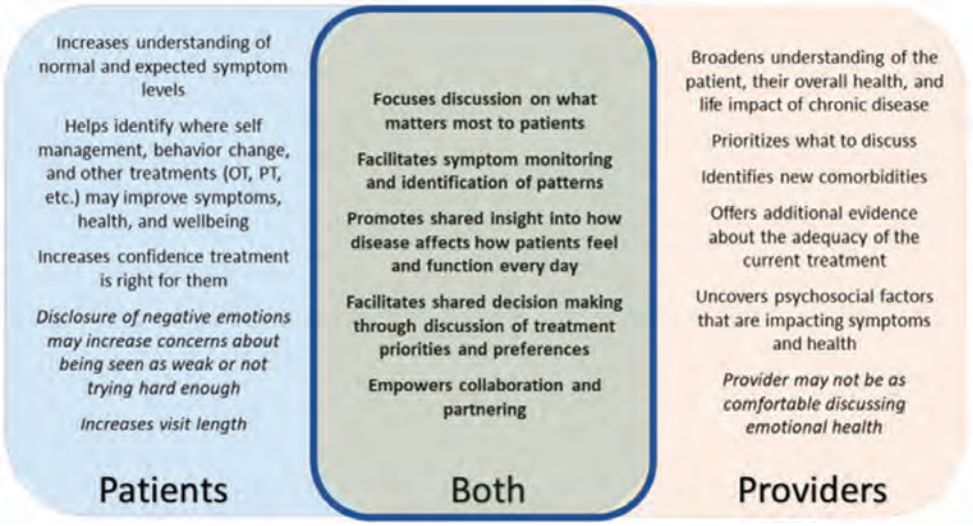
For over 20 years, we have been asking our patients to answer questions about their health to assist our clinical teams in making health decisions, initially on paper forms, and now digitally. We have conducted several research studies, in which we interviewed patients to determine how their arthritis affected their health and what they thought their providers should know about their symptoms and the impacts of their condition on their overall quality of life. In addition to pain and physical function, we learned that arthritis causes fatigue, contributes to poor sleep, and interferes in the ability to participate in life activities. We also heard from patients that anxiety and depressive symptoms were very common.

We used an advanced system developed by the NIH to evaluate these symptoms with high precision. This system is called PROMIS® (Patient Reported Outcome Measurement Information System). It was developed using advanced statistical methods, and chooses the next questions based on your previous answers. The system then reports the level of your symptoms on a scale that compares your score to that of the average person in the US population. The values that are reported are very reproducible and can be tracked over time as your symptoms change. When your medical record is opened on the screen in the room, you may see the display that shows your responses with color codes (green for good, yellow and orange for caution, and red for severe levels)

Our clinicians use this information to quickly see what is happening with your arthritis and how it affects your life. For instance, If we see that you have high levels of anxiety, we may ask about what stress you are under and how you are coping. Or we may see that your sleep is poor and think about reasons for that and whether more evaluation may be needed.

We also use this information in our research studies for rheumatoid arthritis and psoriatic arthritis to determine the ways that different medications may affect these different symptoms, and how we can use this information to better determine who may respond best to one treatment or another. We are also looking at how symptoms like fatigue may be linked to biomarkers in the blood.

We have spoken with many of our patients and clinicians about the “value” that they find from this information. We found that both patients and clinicians felt that these data could improve communication about how illness was affecting quality of life and could change decisions about treatment.



EDUCATION:

Rheumatoid Arthritis and Sjogren's Disease

Thomas Grader-Beck, MD
Associate Professor of Clinical Medicine

Did you know that patients with Rheumatoid Arthritis can suffer from Sjogren's disease? Sjogren's disease is an autoimmune disease that attacks the tear and salivary glands leading to dry eye and dry mouth as well as many other symptoms. Women are more often affected than men. We estimate that about 10-20% of RA patients suffer from Sjogren's and it is important to recognize this complication to prevent damage to the eyes and mouth, including severe dental decay and tooth loss. Blood tests, tests that check salivary and tear function, ultrasound of the salivary glands and sometimes a small biopsy of the glands in the mouth can help to establish the diagnosis. Treatment may include as little as using preservative-free artificial tears regularly as well as xylitol lozenges or gum and over the counter fluoride toothpaste. In more severe cases of dry eye, special drops containing immunosuppressive medications are used, and sometimes even tears produced from your own blood and special lenses may be required. Dry mouth medications can help to prevent damage to your mouth, improve comfort and prescription strength fluoride toothpaste containing calcium phosphate and help to keep your teeth strong. It is important to note that not all dryness symptoms are due to Sjogren's disease: medications, other illnesses, age and hormonal changes can also contribute. Let your rheumatologist know if you have dry eye or dry mouth symptoms and they will be able to help you determine what testing and treatment is best in your situation.

Will Medicare Cover my Biologic Medication?

Laura Manning, RN
Nurse Coordinator

Will Medicare cover my Biologic Medication?

Medicare annual enrollment is Oct 15-Dec 7. If new to Medicare, sign up three months before you turn 65 to avoid a lapse in treatment.

You will enroll in Medicare A and B through Social Security (ssa.gov). You can search and enroll in supplemental and prescription plans at Medicare.gov (1-800-Medicare), or you can work with a licensed Medicare Broker (this service is free to you) or directly with an insurance company.

Medicare plans vary by state. Use search tools on Medicare.gov, or consult your broker, or insurance advisor to identify a plan that will cover your medications, doctors and particular situation. Biologics are Specialty Medications (Tier 5), therefore may have a high co-pay.

What if I can't afford the copay?

While you will no longer qualify for co-pay programs, biologic manufacturers offer patient assistance programs for individuals meeting eligibility and income requirements.

What happens if I need an infusion?

Infusion medication also qualifies for manufacture cost savings depending on income. Infusions are covered under Medicare medical benefit, rather than pharmacy benefit. In most cases, if you have a supplement or secondary plan, infusions will be covered entirely.

Where can I find more help?

Ssa.gov, Medicare.gov, state official website or state department of aging.

Insurance Process

Victoria Ruffing, RN, BC
Director of Nursing and Patient Education

Doctor writes prescription electronically → **Sent through to Johns Hopkins Specialty Pharmacy (JHSP)** → **Insurance checks if it needs prior authorization (PA)**

If no PA needed

Prescription will be filled at JHSP or the insurers Specialty Pharmacy, (i.e. Express Scripts or Accredo)

If PA needed

JHSP will complete, we sign and send to insurance company

If we cannot write a second appeal

We can ask for a fair hearing with the insurance commission of State of Maryland

If insurance approves

If insurance denies the PA

An appeal must be done or in some cases a different medication is prescribed

If appeal is unsuccessful

We may be able to write a second appeal (some insurance companies only allow one appeal)

What can you do?

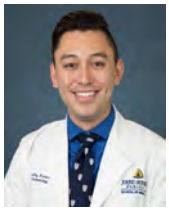
Complete any needed consent and return to us as quickly as possible.

See if your insurance benefits include a case manager to assist.

Let your HR Department know you are having difficulty with insurance company

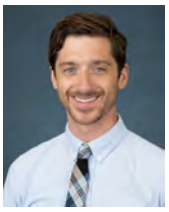
AWARDS, APPOINTMENTS, AND RECOGNITION:

New Faculty



Dr. Timothy Kaniecki
Assistant Professor of Medicine; Arthritis and General Rheumatology

Dr. Desh Nepal
Assistant Professor of Medicine; Arthritis and General Rheumatology



Dr. Michael Cammarata
Assistant Professor of Medicine; Musculoskeletal Ultrasound and Injection Clinic (MUSIC)

Recognition

Two Arthritis Center members received highest honors at the American College of Rheumatology/Association of Rheumatology Professionals Annual Meeting in November 2024.

Vicky Ruffing, RN BC-Rheum received the Distinguished Clinician Award. This award is presented to an ARP member who is engaged in clinical practice and demonstrates outstanding clinical expertise in arthritis and rheumatic diseases. This is a wonderful recognition of Vicky's many contributions to our field through outstanding patient care, leadership including as a founding member of the Rheumatology Nurses Society, and educational initiatives with wide ranging impact for patients and providers.

Susan Bartlett PhD (Adjunct Professor of Medicine, Rheumatology) received the Master's Designation from the ACR in recognition of her many outstanding contributions to rheumatology, with a unique health psychology and behavioral medicine lens. Her body of work has focused on encouraging positive health behaviors (weight loss, physical activity and treatment adherence) in individuals with chronic medical conditions and on developing and validating patient-reported outcomes in rheumatoid arthritis.

Our Arthritis Center Faculty Released 37 New Publications in 2024

Current Appointments and Positions

- **Dr. Jemima Albayda**—ACR Guidance Project for Ultrasound use in procedures and diagnosis of soft tissue disorders, Chair; International Faculty at the University of Santo Tomas (Philippines); guest editor Frontiers in Immunology
- **Dr. Susan Bartlett**—PROMIS Health Organization, President
- **Dr. Clifton Bingham**—PROMIS Health Organization, Board of Directors; Medical and Scientific Committee Member and Chair of PRO Committee for the Arthritis Foundation; Critical Pathway Institute RA PRO Working Group Member; Centers for Disease Control Arthritis Expert Advisory Panel; Co-Director RADIOS Consortium for rheumatic adverse events due to cancer immunotherapy
- **Dr. Laura Cappelli**—Society for Immunotherapy of Cancer (SITC) rheumatic IRAE criteria, ACR/EULAR Committee for to develop Classification Criteria for Immune Checkpoint Inhibitor Inflammatory Arthritis, Site Director RADIOS Consortium
- **Dr. Uzma Haque**—American College of Rheumatology (ACR) Committee on Education
- **Dr. John Miller**—LymeX Diagnostic Prize advisory panel
- **Dr. Ana Maria Orbai**—President's Council for the Medical Board of the National Psoriasis Foundation

Presentations

- **Dr. Bingham** spoke at the Kentuckiana Rheumatology Association Meeting in Lexington Kentucky, the PROMIS Training Workshop in Chicago, the Arthritis Foundation RA Research Summit in New York, and had an oral presentation of data at the PROMIS Health Organization Meeting in Cologne, Germany.
- **Dr. Cappelli** was invited to speak at the Irish Society of Rheumatology in Kildaire, Ireland and at the American College of Rheumatology Annual Meeting, gave Grand Rounds at University of Michigan and Northwestern University, and spoke at the Arthritis Foundation RA Research Summit in New York and the NY State Rheumatology Society Meeting.
- **Dr. Orbai** presented at the American College of Rheumatology Annual Meeting Review Course on the management of psoriatic arthritis

Grants

- **Jemima Albayda**—Ira Fine Discovery Award
- **Clifton Bingham**—NIH T32 Postdoctoral Fellow Training Program refunded for another 5-year Cycle
- **Laura Cappelli**—Johns Hopkins Catalyst Award
- **John Miller**—Johns Hopkins Clinician Scientist Award
- **Ana Maria Orbai**—Ira Fine Discovery Award; PCORI and AHRQ: Promoting Embedded Research in the Learning Health System (PERLHS), selected as a member of the initial cohort

PHILANTHROPY AT WORK:

How giving can make a difference

For more than three decades, the Johns Hopkins Arthritis Center has led the way in both clinical care and research for arthritis. Charitable gifts advance our mission to deliver compassionate care, cutting-edge research, and quality education and treatment in arthritis for patients and their families.

If you would like to learn more about the work described in this newsletter or make an impact through philanthropy, please consider supporting one of our Center's priorities listed below.

Camille Julia Morgan Arthritis Research and Education Fund

Enable our physician-scientists and researchers to better understand the causes of arthritis, advance its diagnosis and treatment, and deliver quality education for our patients and their families, the public, and other health professionals. Funding will support the Center's priority programs and initiatives.

Psoriatic Arthritis Program Fund

Advance "big-data" research in precision medicine that will impact our understanding and approach to the diagnosis and treatment of psoriatic arthritis. Funding will advance the essential work of coordinators, laboratory technicians, basic scientists, and data scientists in developing cutting-edge technologies and making research discoveries through patient blood sample collection, processing, biobanking, and big-data analyses.

Arthritis Center Endowment Fund

Transform lives both now and into the future with a gift of sustainable funding for our Arthritis Center Endowment Fund. Philanthropy enables our growing faculty and staff to advance transformational research, deliver quality education, and provide patient-centered care through a permanent funding source that will benefit future generations.

Arthritis Center Faculty Gift Funds

Make it possible for our Center's faculty members to pursue high impact research projects, enhance patient education, and improve diagnosis and treatment in their disease specialists. Funding designated to faculty gift funds allows physicians to cover expenses for research, make disruptive discoveries, protect time for teaching, publish findings, and attend conferences.

How to Make an Impact

CONTACT MOLLY DOLAN

Senior Associate Director of Development
Mdolan6@jhmi.edu | 630-309-0692

VISIT OUR SECURE WEBSITE

https://secure.jhu.edu/form/arthritis

SEND A CHECK

Make your gift payable to "Johns Hopkins Medicine, Division of Rheumatology" and indicate a priority or the work of a specific faculty member in the memo.

Mail to: Johns Hopkins University and Medicine
Attn: Department of Medicine/Div. of Rheumatology PO Box 49143 Baltimore MD 21297-9143

THANK YOU FOR YOUR CONTINUED SUPPORT