

# LEAP

Johns Hopkins University  
School of Medicine  
Division of Rheumatology  
Winter 2026

AUTOIMMUNE MYOSITIS

## PARTNERING TO ADVANCE THERAPY

A BEAUTIFUL MARRIAGE  
COLLABORATING  
IN SARCOIDOSIS

WITH PATIENTS EVERY  
STEP OF THE WAY  
VISIONARY PHILANTHROPY

As we navigate the unprecedented challenges facing academic medicine and the U.S. health care system — funding uncertainty, threats to insurance coverage and more — it's easy to feel discouraged. That's why it is crucial for all of us at Johns Hopkins Rheumatology to remain laser-focused on the mission that has long been our north star: advancing the health of patients with rheumatic diseases and keeping our patients at the center of everything we do.

Fortunately, that's exactly what our physician-researchers and staff are passionately pursuing, as you'll read in this issue of *LEAP*. The programs we are building and the investments our generous funders are making are all consistent with our commitment to being fully grounded in the needs of our patients. Consider the philanthropic vision of renowned Johns Hopkins-trained rheumatologist Thomas Zizic, M.D., who was beloved by his patients for taking the time needed to provide exemplary care. Recognizing the need to "change the system," he has endowed a professorship that is giving Laura Hummers, M.D., Sc.M., co-director of the Johns Hopkins Scleroderma Center, resources that enable her to provide life-changing clinical care and education to each patient, while also studying novel treatments for scleroderma.

You'll also learn how we are changing the paradigm in sarcoidosis by bringing diverse expertise and skillsets to bear. Rheumatologist Kristen Mathias, M.D., M.H.S., the newest member of our faculty, has joined the multidisciplinary team of the Johns Hopkins Sarcoidosis Center, with a focus on developing data-driven approaches to predict outcomes in the disease and to identify patients who would benefit from early steroid-sparing therapies. As Center Co-Director Michelle Sharp, M.D., M.H.S., notes, "Having this bright, rising star from Rheumatology, who is so adept at bringing in her

understanding of and experience in treating autoimmune disorders, is really helping us to reframe our approach to treating patients with sarcoidosis."

And in "Partnering to Advance Therapy," we share how clinician-scientist Julie Paik, M.D., M.H.S., is bringing fresh ideas to the table to dramatically improve care for patients with myositis. Her efforts to study upfront combination therapy in immune-mediated necrotizing myopathies received a significant boost from the National Institutes of Health through funding to launch an Autoimmunity Center of Excellence (ACE) at Johns Hopkins Rheumatology. Achieving ACE status significantly accelerates efforts across Johns Hopkins Medicine — and among the other academic medical centers in the ACE network — to fast-track our understanding and treatment of a wide range of autoimmune disorders.

Of course, none of this work would be possible without our remarkable staff. In this issue of *LEAP*, we introduce you to three exceptional people who have dedicated their careers to making our patients' lives better.

We are incredibly grateful for the generous support from the federal government, foundations, individual donors and the pharmaceutical industry, which enables us to pursue this important work. All of our funders share a commitment to our vision of decoding the underpinnings of rheumatic diseases, defining personalized treatment strategies and advancing human health. Taken together, their support is making it possible — in the face of formidable headwinds — for our team at Johns Hopkins Rheumatology to make leaps at improving the lives of patients with rheumatic diseases.

*Ami A. Shah*

Ami Shah, M.D., M.H.S.  
Director, Division of Rheumatology  
Professor of Medicine



# LEAP

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 **JOHNS HOPKINS**  
MEDICINE



# PARTNERING TO ADVANCE THERAPY

Julie Paik's innovations in precision immunology have gotten a lift with the launch of an NIH-funded Autoimmunity Center of Excellence in the Division of Rheumatology.

*"It always comes back to the patients," says Julie Paik.*

**F**or Johns Hopkins rheumatologist **Julie Paik, M.D., M.H.S.**, one phone call from a long-time patient is unforgettable.

"She was crying with joy. She said, 'I just can't believe it! For the first time in 10 years, I can go to the beach with friends and wear a swimsuit!'" says Paik.

The patient had lived for years with refractory dermatomyositis (DM), a rare autoimmune rheumatic disease that can cause severe skin inflammation, profound muscle weakness and, for many patients, interstitial lung disease or cardiac involvement. The patient had exhausted standard therapies, and nothing had provided meaningful, durable relief.

Around that time, tofacitinib, a Janus kinase (JAK) inhibitor, had been approved by the U.S. Food and Drug Administration (FDA) for the treatment of rheumatoid arthritis. JAK inhibitors control inflammation by decreasing the activity of the immune system.

Paik recognized that tofacitinib's targeted mechanism could be highly relevant to dermatomyositis, in which interferon-driven pathways play a central role in activating and propagating disease activity.

"We had tried everything for her DM, including multiple conventional immunosuppressants, and nothing had worked," recalls Paik, an associate professor of medicine. "I thought a JAK inhibitor might be exactly what this person and many of my refractory DM patients needed," she recalls.

Acting on this insight, Paik initiated discussions with a pharmaceutical company and then designed and led a 12-week, proof-of-concept clinical trial of tofacitinib at Johns Hopkins. The trial proved successful: All 10 patients showed marked improvement in their DM symptoms after just three months of treatment, as measured by a validated assessment

of improvement (the ACR/EULAR Total Improvement Score). In addition to clinical improvement, mechanistic studies conducted in collaboration with **Livia Casciola-Rosen, Ph.D.**, in the rheumatology division's NIH-funded Rheumatic Diseases Resource-based Core Center, and **Liliana Florea, Ph.D.**, in the genetics research core, demonstrated downregulation of STAT1 signaling in skin biopsies as well as in type I IFN signaling in skin and muscle biopsies.

The experience turned out to be a pivotal step in establishing Paik's trajectory as a clinical trialist and leader in autoimmune myositis therapeutics research.

"That early myositis study taught me how clinical trials can directly change the lives of patients who have run out of options," she says. "It solidified my commitment to integrating clinical care with thoughtfully designed trials to advance therapies for patients with complex autoimmune diseases."

What's more, that initial project launched Paik on a research path that ultimately led to an NIH grant to establish an Autoimmunity Center of Excellence (ACE) in the Johns Hopkins Division of Rheumatology. The ACE launched in fall 2024 with Paik as principal investigator.

#### NIH/NIAID Autoimmunity Center of Excellence

Establishing an ACE has far-reaching impact because it has a multiplying effect, allowing for increased collaboration among researchers within Johns Hopkins and at the eight other ACE sites across the country.

"It connects investigators across specialties and across institutions so we can design smarter trials and give patients access to emerging therapies more quickly," notes Paik.

At Johns Hopkins, the ACE brings together expertise in rheumatology, neurology, immunology, radiology

**"That early myositis study taught me how clinical trials can directly change the lives of patients who have run out of options. It solidified my commitment to integrating clinical care with thoughtfully designed trials to advance therapies for patients with complex autoimmune diseases."**

Julie Paik, M.D., M.H.S.

#### RELATED READING

**Study of tofacitinib in refractory dermatomyositis: an open-label pilot study of ten patients.**  
*Arthritis Rheumatol.* 2021; PMID: 33258553

**Long-term extension study of tofacitinib in refractory dermatomyositis.**  
*Arthritis Rheumatol.* 2022; PMID: 34369109

and precision medicine to support complex autoimmune-disease trials while integrating state-of-the-art mechanistic studies. Operating within the broader national network, the program also provides access to a shared biorepository, which standardizes sample collection and processing across all ACE sites.

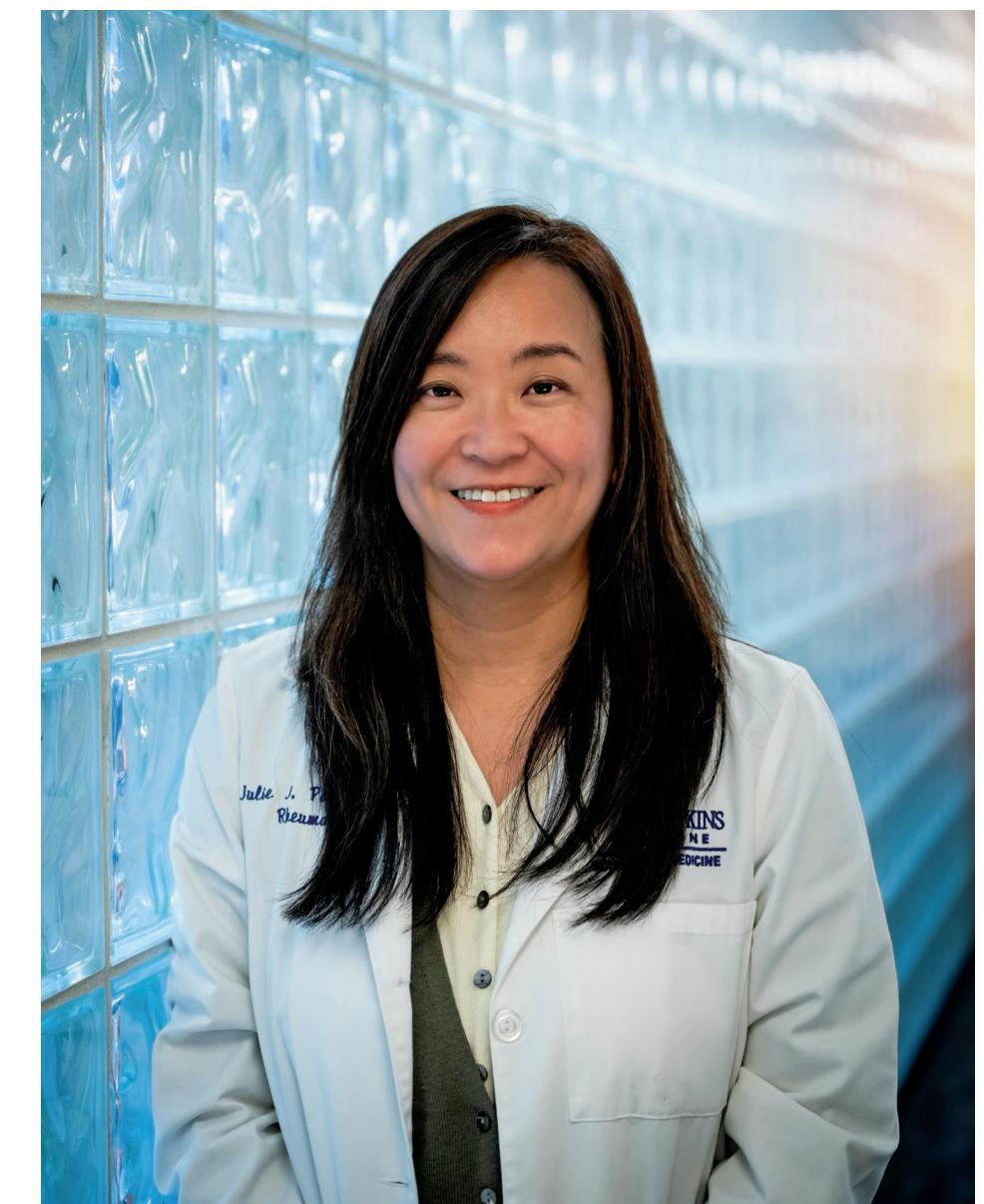
"This will be an indispensable resource to support clinical research projects here at Johns Hopkins and at the other academic medical centers in the ACE network — allowing us to speed up efforts to advance our understanding and treatment of a wide range of autoimmune diseases," Paik says.

As part of the Johns Hopkins ACE portfolio, Paik is the principal investigator of a multicenter, phase II, randomized double-blind clinical trial of ublituximab, a monoclonal antibody that depletes B cells and is already FDA approved for multiple sclerosis.

"There is compelling scientific evidence and clinical rationale for targeting B cells in immune-mediated necrotizing myopathy," she notes. "B cells generate pathogenic autoantibodies and help sustain inflammatory pathways."

This trial focuses specifically on patients with immune-mediated necrotizing myopathy who are positive for anti-SRP and anti-HMGCR antibodies early in their disease course, a deliberate shift toward potent upfront combination therapy. "Our current therapeutic paradigm too often relies on delayed step-up approaches, by which point significant and potentially irreversible muscle injury has already occurred," Paik says.

To directly test this paradigm shift, Paik is enrolling patients in the multi-center phase II trial, which will unfold over the next several years. The central hypothesis of this study is to explore if early treatment (less than one year disease duration) with ublituximab at a critical time of disease trajectory will lead to a durable clinical response in autoantibody positive immune mediated necrotizing myopathy.



#### Collaborating with Pharma

While federal support from NIH/National Institute of Allergy and Infectious Diseases — which launched the ACE program — has been indispensable, Paik has also forged collaborations with the pharmaceutical industry to evaluate the efficacy of novel therapeutic agents.

Across all her projects, Paik's vision centers on a unifying goal: integrating precision immunology with early therapeutic intervention to change the

natural history of myositis. "We now have the tools to identify molecular pathways driving disease and to test targeted therapies in thoughtfully designed clinical trials," she says. "My hope is to begin treatment earlier, personalize it and prevent disability before it starts."

"It always comes back to the patients," she says. "They are the reason we push the science forward." ▲

# A BEAUTIFUL MARRIAGE

Kristen Mathias' expertise in rheumatology is key to the translational research unfolding at the Johns Hopkins Sarcoidosis Center.

**W**hen Kristen Mathias, M.D., M.H.S., joined the multidisciplinary faculty team of the Johns Hopkins Sarcoidosis Center in August 2025, center co-director Michelle Sharp, M.D., M.H.S., could barely contain her excitement.

As a research and clinical fellow, Mathias had brought her expertise in rheumatology to the Sarcoidosis Center for three years. Now, as a newly minted instructor, she would be a permanent member of the team.

"From a patient care perspective, Kristen is one of the best physicians I've ever had the privilege of mentoring and working with," says Sharp, an associate professor of medicine in the division of pulmonary and critical care medicine. "She exhibits an amazing

degree of competence, knowledge and kindness, and is always focused on keeping the patient at the center."

Moreover, Mathias' expertise in rheumatology has been key to the translational research unfolding at the Sarcoidosis Center, Sharp notes. "Having this bright, rising star from Rheumatology, who is so adept at bringing in her understanding of and experience in treating autoimmune disorders such as scleroderma, lupus and myositis, is really helping us to reframe our approach to treating patients with sarcoidosis," Sharp says.

That kind of reframing is crucially needed for sarcoidosis, a poorly understood inflammatory disease that affects more than 1 million people around the world and can attack any organ in the body, often with devastating consequences.

For her part, Mathias says she is honored to bring a rheumatologist's perspective to the team and is

excited to move the needle on this condition. "Sarcoidosis is a complex, immune-mediated disease that affects multiple organs and often responds to immunosuppressive therapies, much like many of our established rheumatic conditions," she explains.

"Yet despite these striking similarities, sarcoidosis continues to lag behind in the development of safe, effective treatments. That's why now is an ideal time for rheumatologists and pulmonologists to come together — to advance a collaboration that can drive meaningful advances in patient care."

Sharp concurs, "Kristen's new role in the Sarcoidosis Center represents a beautiful marriage in our clinical program. I am overwhelmed by the generosity the Division of Rheumatology has shown by their willingness to collaborate and help bring forward a disease that has been neglected around the world."



Kristen Mathias, left, with Michelle Sharp

## RELATED READING

Delays in referral to multidisciplinary care for Black individuals with sarcoidosis. *CHEST Pulm*, 2025; PMID: 40918541

The impact of the unknown: patient experiences with uncertainty in sarcoidosis. *CHEST*, 2025; PMID: 40609858

Working together in sarcoidosis. *Ann Am Thorac Soc*, 2025; PMID: 40479550

# CAUSE FOR DISTRESS

When it comes to living with sarcoidosis, uncertainty rules the day for many patients, according to the results of a qualitative study led by rheumatologist **Kristen Mathias**, which appeared recently in *CHEST*.

The study involved semi-structured interviews with 25 patients from a previously established cohort at the Johns Hopkins Sarcoidosis Center who had been diagnosed with biopsy-proven pulmonary sarcoidosis.

Her team found that uncertainty starts with diagnosis, with participants emphasizing a lack of awareness of sarcoidosis among health care providers, which contributes to delays in appropriate care.

"Then, even after they are diagnosed, participants noted ongoing challenges finding providers who felt comfortable managing their disease," says Mathias. Ambiguity about optimal treatment and unpredictability surrounding the disease's progression both contribute to raising anxiety, uncertainty and even fear about further unknowns, the researchers found.

Taken together, the findings led Mathias' team to conclude that uncertainty poses a major challenge that contributes to delays in care, poor disease control, and/or psychological distress.

"We believe this is the first study to highlight the impact that patient uncertainty has on sarcoidosis disease outcomes and psychological distress," Mathias notes. "Individuals living with sarcoidosis may benefit significantly from targeted interventions to mitigate the impact of illness uncertainty."

## "We found that the team approach improved overall diagnostic certainty for sarcoidosis and for organ involvement."

Kristen Mathias

### Addressing Gaping Disparities

There is no known cure for sarcoidosis, which is characterized by the growth of clumps of immune cells called granulomas in various parts of the body. Symptoms arise from the inflammation spurred by these granulomatous infiltrates over time. They can damage organs — such as the lungs, heart, kidneys, eyes and skin — as well as bones and joints.

Cruelly, sarcoidosis most often strikes people in the prime of life, between the ages of 20 and 50.

Mathias is working with Sharp and other colleagues at the Sarcoidosis Center to make the scientific case for a multidisciplinary approach to diagnosing and treating the disease, and to gain a clearer understanding of its clinical heterogeneity. To do that, Mathias is leading efforts to harness data science by bringing the Sarcoidosis Center onto the Precision Medicine Analytics Platform (PMAP) at Johns Hopkins.

She believes that data-intensive investigations will, in particular, offer insights into gaping disparities in treatment and health outcomes for Black patients in the United States, who are disproportionately affected by the disease. In a recent study published in *CHEST Pulmonary*, Mathias and colleagues found that after a diagnosis of sarcoidosis, the time for referral to a specialized sarcoidosis clinic, in seeking tertiary care consultation, was significantly longer for Black individuals (nine years) than for White patients (five years).

This lag is crucial to address, Mathias notes, since Black individuals have a higher incidence of sarcoidosis, and tend to have more severe disease with higher rates of hospitalization. Moreover, "Earlier detection and treatment in sarcoidosis is key to preserving organ function," she says.

### Sparing the Steroids

At the present time, glucocorticoids (a class of steroid hormones) are the only U.S. Food and Drug Administration-approved

She has also embarked on studies to measure the damage caused by long-term, cumulative exposure to steroid therapies among patients with sarcoidosis. "Our findings could provide extra motivation for the field to adopt steroid-sparing alternatives," she says.

### Improved Treatment Through Teamwork

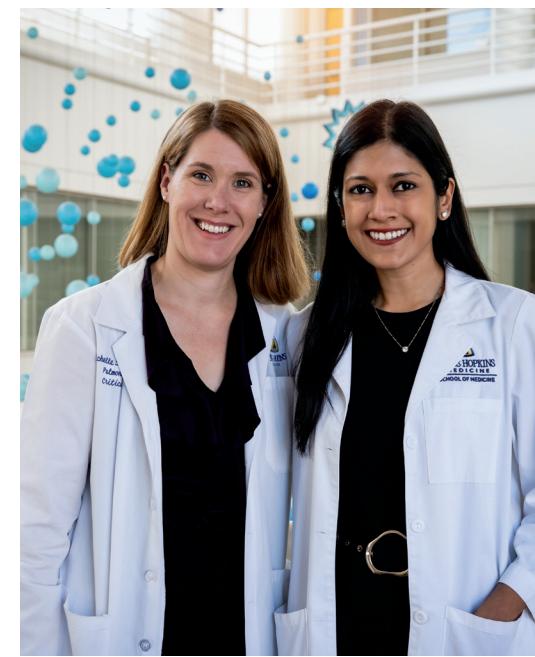
During her time as a fellow within the Sarcoidosis Center at Johns Hopkins, Mathias saw firsthand how important it is for patients to receive care from a multidisciplinary team of clinicians, which is often not the norm since there are a limited number of multidisciplinary centers across the country.

"By the time patients come to us, they have seen as many as 10 specialists without a definitive diagnosis. They are frustrated and exhausted," says Mathias. "After bouncing around from doctor to doctor, without getting definitive answers, many feel uncertain, overwhelmed and depressed." (See sidebar, "Cause for Distress.")

At Johns Hopkins, these patients are evaluated by a wide-ranging team of specialists, all in one place, whose work on their behalf is closely coordinated. In addition to rheumatology, the center's multidisciplinary team includes expertise in pulmonology, cardiology and neurology. Ad hoc specialists are available in dermatology, ophthalmology, radiology and pathology.

Mathias explains that the team meets weekly to review individual patient cases. They discuss imaging tests — such as CTs and MRIs — and go over the patient's lab reports, clinical history and pathology reports. Together, they decide whether a diagnosis of sarcoidosis is warranted. If it is, they decide together on a treatment plan, which sometimes involves further diagnostic testing and, if organ damage is particularly severe, referral to organ transplant specialists. Often, the team prescribes use of immunosuppressive drugs.

Mathias, who earned a master of health science degree in clinical investigation from Johns Hopkins Bloomberg School of Public Health during her fellowship training, also sees patients in the Division of Rheumatology's Scleroderma Center. She notes that steroid-sparing therapies, including biologics, have long been used effectively to treat patients with scleroderma. The insights she's gained with these patients are informing her efforts to plan clinical trials to test steroid-sparing strategies for sarcoidosis.



Michelle Sharp, left, and Kristen Mathias

In that pursuit, the Precision Medicine Analytics Platform (PMAP) at Johns Hopkins Medicine will prove invaluable. PMAP is a large-scale data repository that exists in the cloud and includes clinical EMR data, open notes, imaging data, genomic and molecular data, wearable data, and operational and financial data (for value creation).

"PMAP provides a data pipeline that we can query with clinical questions and look at data for specific patient cohorts, both within our center and within the Johns Hopkins Health system at large," Mathias says. "Ideally we can get a better handle on clinical heterogeneity to identify patient phenotypes. For example, with PMAP, we can start to address the question: Why do some patients with sarcoidosis develop musculoskeletal manifestations, such as inflammatory arthritis and myopathy, while others do not?"

More targeted understanding of each patient's immunologic dysregulation will enable researchers to develop more effective treatments for different phenotypes, she explains.

"We found that the team approach improved overall diagnostic certainty for sarcoidosis and for organ involvement," Mathias reports. What's more, it altered the use of immunosuppression management in 123 out of 171 cases (72%), she reports. Oral glucocorticoid-sparing agents were introduced in 31 and biologic agents were initiated in 34 of these 171 cases.

"Our findings suggest that multidisciplinary discussions may provide the confidence to pursue more timely and aggressive treatment in patients who do not tolerate or respond to first- and second-line therapies," Mathias notes.

### Tapping into Precision Medicine

Looking ahead, Mathias and others in the Johns Hopkins Sarcoidosis Center believe the key to more targeted treatment in sarcoidosis will lie in the ability to sort patients into different subsets and follow their disease trajectory.

That work and other opportunities she's pursued were key to her decision to remain at Johns Hopkins after she completed her fellowship training in rheumatology, Mathias says.

"Johns Hopkins offers a really unique environment because there is so much motivation to innovate, and if you want to make something happen, you don't get institutional pushback but instead the response is: 'How can we help you?'" □

PROFESSORSHIP INSTALLATION

Seated (left to right):  
Nadia Hansel, Shannon  
Bishop, Carol Ziminski,  
Thomas Zizic, Laura  
Hummers, Ami Shah

Standing (left to right):  
Robert Wise, Clinton  
Bingham, Antony Rosen,  
Shifflett, David Hellmann,  
Brendan Antiochos,  
Fredrick Wigley, Stephen  
Mathai, Allan Gelber,  
John Miller, Clifton

Bingham, Antony Rosen,  
Jemima Albayda, Alan Baer,  
Lisa Christopher-Stine,  
Kwisha Patel



# WITH PATIENTS EVERY STEP OF THE WAY

A new professorship supports Laura  
Hummers in her quest to dramatically  
improve patient care for scleroderma.

(From left to right)  
Antony Rosen,  
Nadia Hansel, Myron  
Weisfeldt, Thomas  
Zizic, Laura Hummers,  
Ronald Daniels,  
Theodore DeWeese,  
Ami Shah



**"I felt that if I could support one person's salary then they could devote the time they needed to their research and teaching while also providing outstanding patient care."**

Thomas Zizic, M.D.

**Laura Hummers, M.D., Sc.M.,** had just started her Johns Hopkins rheumatology fellowship in 2000 and was rotating through the Rheumatology Clinic at Good Samaritan Hospital when she noticed a packed waiting room across the hallway, day after day.

She soon learned it was the private rheumatology practice of Johns Hopkins-educated and Johns Hopkins-trained **Thomas Zizic, M.D.**, and partner **Peter Holt, M.D.** "They were absolutely beloved by their patients," recalls Hummers. "Patients knew they would have to wait but when they got in to see them, both would take all the time they needed to care for them. It was such an amazing example of just how important it is to devote time and form long-lasting relationships with our patients," Hummers says.

Zizic, now retired and looking back over a wide-reaching career in rheumatology, remains committed to the ideal that guided his work as a clinician-researcher since he himself was a fellow in the early 1970s.

"Patients with rheumatic disorders frequently have systemic disease that can impact any organ in the body — the kidneys, heart, skin, eyes, liver, muscles, pancreas — and not always at the same time," says Zizic. "It takes you two to three times as long to see a patient properly as it does for an internist, but the reimbursement is the same. We have got to change the system so that physicians get rewarded for the quality of care they provide, rather than the quantity of patients they see."

In 2024, Zizic took an important step in leading that change by establishing the Thomas M. Zizic, M.D. Professorship in Rheumatology and Immunology. "It's just as difficult in the academic setting to see patients properly as it is in private practice," he says. "I felt that if I could support one person's salary, then they could devote the time they needed to their

research and teaching while also providing outstanding patient care."

Hummers, clinical director of the Division of Rheumatology and co-director of the Johns Hopkins Scleroderma Center, is the inaugural holder of the Zizic professorship. "I am incredibly grateful and honored to be associated with Dr. Zizic, a man who really helped change the face of rheumatology at Johns Hopkins," she says.

#### Experiments That Paid Off Big

Zizic's roots at Johns Hopkins are both deep and broad. A proud member of the school of medicine class of 1965, he remained at Johns Hopkins for his internship and Osler residency in internal medicine. Then, after a two-year stint with the U.S. Air Force School of Aerospace Medicine in Texas, he returned in 1969 as a fellow under renowned rheumatologist **Mary Betty Stevens, M.D.**

He was appointed to the faculty as an instructor, and after promotions to assistant and associate professor, he left Johns Hopkins in 1984 to go into private practice, remaining an adjunct faculty member throughout his career.

Two important "experiments" indelibly shaped his early years at Johns Hopkins, Zizic says. The first was in medical school, when administrators aimed to address a "cutthroat culture" by recruiting students with well-rounded interests (Zizic was a competitive undergraduate swimmer at the University of Wisconsin) and by moving away from publishing grades.

"It was no longer about competition; we all wanted to help each other become the best doctors we could be," Zizic says. "To this day, so many of us stay in touch because we truly care about each other. The experience was life-changing in terms of our entrance to medicine — about how we thought about the career we were embarking upon."

Classmate **Myron "Mike" Weisfeldt, M.D.**, an influential cardiologist who enjoyed a long career at Johns Hopkins, concurs. "There was a spirit to our class that was distinctive," says Weisfeldt, who

chaired the Johns Hopkins Department of Medicine from 2001 to 2014. "There were so many 'greats' who went on to lead in medicine. Tom Zizic is one of them, distinguishing himself as a rheumatologist and entrepreneur."

Zizic notes that the second seminal experiment was due to the vision of his mentor Stevens, chair of the rheumatology division, who was the first woman to be appointed a division chief in the Department of Medicine. Her advances dramatically improved care of people with lupus, arthritis and other connective tissue diseases.

Together Stevens and Zizic conceived of a Rheumatic Disease Unit that was based on the second floor of Good Samaritan Hospital in northeast Baltimore.

"Mary Betty recognized that rheumatology involves all of internal medicine," says Zizic, so the unit cared for patients admitted for a wide range of conditions, whether it was the need for a new diagnosis; being in the throes of a rheumatic disease flare; experiencing pneumonia or congestive heart failure; or undergoing hip or knee replacements.

What's more, to help prepare new doctors to see the connections between internal medicine and rheumatologic disease, the duo created a "subintern"

position for senior students who had finished their medicine clerkship and wanted to prepare for an internship in internal medicine. "It proved so popular that by the second year we had to move to a lottery system because there were so many volunteers. Then we expanded the program further," recalls Zizic.

The Rheumatic Disease Unit experienced significant growth, expanding to serve patients from both Johns Hopkins and University of Maryland. Zizic and Stevens became full-time faculty members at both institutions, with Zizic serving as associate director of the unit. "We grew from one 36-bed unit to two 36-bed units, training 10 to 12 students and residents," he says.

#### Extending the Legacy of Clinical Research

Zizic recalls that period in the 1970s and early 1980s as a fertile opportunity for clinical research. "Because you had a large concentration of patients with rheumatic diseases all in one place, we could find associations between diseases that we would otherwise not be able to appreciate," he says.

Zizic's collaborations with Johns Hopkins orthopedic surgeon **David Hungerford, M.D.**, were particularly fruitful. The duo published influential

mimics (particularly scleromyxedema), and state-of-the-art therapeutics.

As co-director of the Johns Hopkins Scleroderma Center, Hummers manages a large clinical practice, seeing patients two days a week and participating in a range of clinical trials and clinical investigations in scleroderma. Hummers also co-directs the Scleroderma Precision Medicine Center of Excellence, where she works with colleagues to develop modeling techniques to identify predictors of disease trajectory and increase patient understanding and advocacy in treatment.

"My passion lies in caring for patients and doing meaningful work in scleroderma research to improve the lives of our patients," says Hummers.

She continues, "As clinical director of the Division of Rheumatology, I see my main job as minimizing the 'noise' for our faculty and patients — growing complexities involving insurance requirements, electronic medical record-keeping, financial pressures — to preserve what has always been fundamentally important: focusing on longitudinal care, being with our patients every step of the way, to gain a better understanding of their disease and how it develops, and ultimately to improve care." **1**

# OUR CHAMPIONS OF COMPASSION

**It is our pleasure to shine a spotlight on the remarkable individuals within the Division of Rheumatology. Meet three dedicated professionals with diverse roles but a shared goal: to make life better for our patients.**



## TEAMING UP FOR GROUNDBREAKING DISCOVERY

**GWENDOLYN LEATHERMAN, RN**

*Research Nurse Manager  
Johns Hopkins Scleroderma Center*

Back in the early 1990s, **Gwendolyn "Gwen" Leatherman, R.N.** was just a few years into her role as a clinical nurse with the Johns Hopkins Scleroderma Center when founding director **Fredrick Wigley, M.D.**, invited her to become a research coordinator for one of his new studies.

That experience proved pivotal, planting the seed for her to pursue a career as a research nurse at the center. Today she manages numerous complex research protocols and clinical trials, and guides the work of the center's three research coordinators. "I am passing on what I've learned to others on the team. That kind of mentoring is something that I really enjoy," says Leatherman.

Scleroderma is a rare disease that may cause hardening and tightening of the skin, and can also affect blood vessels and internal organs. While there is currently no cure for scleroderma, Leatherman notes that great progress has been made at improving treatments and outcomes for those living with the condition. That's thanks in no small part to research studies — including basic science, clinical trials and epidemiology investigations — that rheumatologists have led in the Johns Hopkins University Division of Rheumatology since the Scleroderma Center opened in 1990.

"Treatment for scleroderma today is totally different from when I started out," says Leatherman. "We have such a better understanding of what is driving the disease in different groups, or phenotypes, of people."

Fueling these advances is a comprehensive, prospectively collected database that includes more than 4,700 patients, which provides a rich resource for both clinical investigations and basic science projects. It is one of the largest resources for scleroderma research in the world, and it includes a repository containing data as well as blood and tissue samples from patients who choose to participate.

Leatherman explains that these materials are available to researchers — at Johns Hopkins and around the world — who are studying the biological causes of scleroderma, patterns of the disease, potential new treatments and much more.

"Now that we have a better handle on how different types of scleroderma have different risk factors, we have a much better idea of what to look for and what is driving the disease in different subsets of people," says Leatherman, who today works most closely with the center's co-directors, **Laura Hummers, M.D., Sc.M.**, and **Ami Shah, M.D., M.H.S.**

"Our doctors are continually developing tools to better understand the trajectory of disease in different patients, which allows us to provide more targeted and effective treatments," says Leatherman.

One key discovery has been finding the relationship between cancer and certain forms of scleroderma, she notes.

Whether working with patients participating in research projects or clinical trials or mentoring budding research coordinators, Leatherman says she is proud to contribute to research that has significantly improved the quality of life for patients with scleroderma — at Johns Hopkins and around the world.

"To nurses just starting out, I would recommend exploring the role of being a research nurse," Leatherman says. "If you're curious and eager to learn and want to be a part of groundbreaking discoveries, this is an exciting area to pursue."

**"Our doctors are continually developing tools to better understand the trajectory of disease in different patients."**

# A FAMILY ENVIRONMENT

## PENNY ATHANASIOU

Arthritis Center Clinic Coordinator  
Senior Medical Office Coordinator

After Penny Athanasiou's son was born with a rare heart anomaly, she and her family found themselves at Johns Hopkins Medicine with the pediatric cardiology team led by **Joel Brenner, M.D.** In the months that followed her baby's heart repair and recovery, she recalls, "The entire team made me feel like they were

my family, and I remember thinking, 'When I go back to work after my children get a bit older, I'd like to work in a hospital-based position at Johns Hopkins to give back what I was given.'

Athanasiou's goal came to fruition in May 2004, when she began work as a patient services coordinator for the Johns Hopkins Arthritis Center. In her role, she is often the first person patients encounter as they seek to make an appointment, get a prescription refilled or obtain a referral to a specialist. The prompt, kind and reassuring responses that Athanasiou provides buoy the spirits of those living with the pain and uncertainty of conditions like rheumatoid arthritis. "I try to create a special bond with each person," she says.

**"There is such compassion and loyalty. I always say that there is a true family environment in the division — that's what makes me love Johns Hopkins the most: that family feel."**

And that bond is a two-way street. "I have patients from the very beginning of my work here, and that bond has lasted for 21 years," says Athanasiou. "My children were little at the time, and they continue to ask about them and I ask about how their children are doing. With my patients, it's almost like an extension of my own family."

Indeed, the theme of family is one that comes up time and again when this mother of three grown sons talks about her career at the Arthritis Center. There is rheumatologist **Uzma Haque, M.D.**, a member of the original two-doctor team who interviewed her many years ago for her position. "She has become like a sister to me," says Athanasiou.

Then there are the nurses, physicians, fellows and staff members she collaborates with on a daily basis, both as Arthritis Center clinic coordinator and when she fills in as senior medical office coordinator for the division.

"Everyone cares about one another, and is always ready to step in to help," she says. "There is such compassion and loyalty. I always say that there is a true family environment in the division — that's what makes me love Johns Hopkins the most: that family feel."

When the workday ends and on weekends, this one-time soccer mom is now a proud "soccer grandmother," who can frequently be found cheering on her grandchildren from the sidelines.

She revels in her close-knit family, which includes her husband of 37 years, Antonios, her three sons and their wives and the two grandkids. Every Sunday, the whole family gathers at her home to enjoy a traditional Greek dinner. "Family dinners are very important to us," she says. On holidays such as Thanksgiving and Easter, she adds more chairs around the table and invites visiting fellows in the division who don't have family in town.

"Johns Hopkins is dear to my heart, and always will be," says Athanasiou.



## EYE ON THE BOTTOM LINE

### KEVIN STARK

Senior Grants and Contracts Analyst

In his role in the Johns Hopkins Division of Rheumatology, **Kevin Stark** sees firsthand the critical impact that sponsored research funding has on advancing the work of the division's clinical and laboratory scientists.

"There are more than 25 principal investigators (PIs) whose research is made possible through grants from the National Institutes of Health, the Department of Defense, private foundations, industry sponsors and other funders," explains Stark. "I really enjoy being able to

connect with these PIs to help them create and develop budgets and assist with allocating how these funds should be spent appropriately and effectively."

Stark joined the division in 2017, leaving his position as an accounts payable representative with Random House Publishing Group after interviewing with then Division Director **Antony Rosen, MB ChB**. "We really connected and meshed well, and I thought to myself, 'This would be the perfect opportunity for me,'" Stark recalls.

Stark's initial optimism has indeed been borne out. As a senior grants and contracts analyst, his work includes developing budgets, reconciling accounts and analyzing monthly finance reports. Stark's efforts involve a very diverse funding portfolio that includes several large federal grants; industry-sponsored grants for clinical trials and investigator-initiated studies; and grants from a variety

**"There are more than 25 principal investigators (PIs) whose research is made possible through grants from the National Institutes of Health, the Department of Defense, private foundations, industry sponsors and other funders."**

of foundations. He works closely with fellow members of the finance team — **Karen Manley, Kerry-Ann Sybliss, Esther Kim, Lori Kahl, Clinton Shifflett and Kwisha Patel**, associate administrator. "Our team communicates very well with one another," says Stark. He notes that cross-training has prepared them to understand — and, if necessary, take on — their colleagues' responsibilities.

"Kwisha is the glue that holds our team together," Stark adds. "She keeps us organized, and ensures that deadlines are met. She also checks in to make sure we are doing OK. She is incredible."

Stark resides in Baltimore City, and when he isn't analyzing financial reports and reconciling budgets, he enjoys taking advantage of all the city has to offer, whether playing pickup games of basketball and softball or trying new restaurants. "I really enjoy dining out in spots around Little Italy and the Inner Harbor," he says. "But I am also happy to hang out at home with friends and watch sports."



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"As we navigate the unprecedented challenges facing academic medicine and the U.S. health care system, it's easy to feel discouraged. That's why it is crucial for all of us at Johns Hopkins Rheumatology to remain laser-focused on the mission that has long been our north star...to make LEAPS at improving the lives of patients with rheumatic diseases."

— Ami Shah, M.D., M.H.S.