

The Myositis Issue

Vol. 2, No. 5 | Summer 2026

The distance between
knowing and being believed.

**RARE
AWARENESS
RADIO
ENCORES**



From the editors

ENCORES is a publication about communities and the nonprofit advocacy organizations that exist to serve and remain accountable to them.

These advocacy organizations occupy a unique position.

They sit at the intersection of families, researchers, clinicians, funders, and policymakers.

They sit at the intersection of perspectives often shaped in isolation from one another.

They sit at the intersection between what is possible and what is experienced today.

It is in this gap that we begin.

Through Rare Awareness Radio, we speak with the parent who built a foundation, the researcher who redirected a career, the clinician navigating a diagnosis without a treatment to offer. We speak to the people closest to bridging the gap.

Those conversations become the framework for what you read here. They are edited, contextualized, and expanded into narratives that make complex, often fragmented knowledge accessible across audiences.

What appears in these pages reflects what the community knows, what the science has established, and what remains unresolved.

What appears here is the beginning of what is possible.

RARE AWARENESS RADIO ENCORES
Vol. 2, No. 5 | Summer 2026
ISSN 3143-5173

PUBLISHER
Community Resonance Foundation
Belfast, Maine

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ACKNOWLEDGEMENTS / SPONSORS

Rare Awareness Radio is a community-anchored storytelling initiative that brings lived experience and scientific insight into clear narratives.

Community Resonance Foundation is a nonprofit organization working to translate patient and caregiver experience into insights for healthcare, research, and policy.

The Myositis Association is a nonprofit organization dedicated to improving the lives of persons affected by myositis, funding innovative research, and increasing myositis awareness and advocacy.

The OMSLife Foundation is a nonprofit advocacy organization supporting those affected by Opsoclonus Myoclonus Ataxia Syndrome.

HERstory In Color is a community-centered nonprofit supporting women of color living with rare and multiple chronic illnesses.

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In this issue

Most people have never heard of myositis. Most doctors, when they first encounter it, reach for a more familiar label: lupus, rheumatoid arthritis, ALS, ordinary fatigue. The disease hides inside more common categories, and patients often spend years with misdiagnoses before someone looks closely enough to find the right name. For a condition affecting the muscles, skin, lungs, and heart, sometimes several organs or systems at once, being misidentified is not a minor inconvenience. It is years of treatment that does not work, or years without treatment at all.

This issue of ENCORES brings together seven voices from the myositis community, through Rare Awareness Radio and in partnership with The Myositis Association (TMA), to examine what it takes to be visible when you have a disease few people know exists.

Laurie Boyer led TMA's Board of Directors from 2024-2025, a position that came after losing her brother Tommy, a healthy 39-year-old, to MDA5 dermatomyositis with interstitial lung disease. She reflects on guiding a small organization with international reach through affinity groups, research redirections, and advocacy campaigns.

Ed and Marilyn McGrath have experienced decades of dermatomyositis that started with a lupus misdiagnosis, years on prednisone, and a near-fatal sepsis episode from rituximab. They share how community support helped sustain them, and how they now help others find their footing.

Holly Jones was diagnosed with polymyositis and interstitial lung disease at 19 and told she would not live to 24. She was also told she would never meet another woman of color with myositis within hours of home. Two decades later, she has built the community she was told did not exist.

Vance Robinson lives with inclusion body myositis (IBM), a progressive muscle disease with no approved treatment. Now a full-time wheelchair user navigating daily life through adaptation and persistence, he has built the First Pitch Campaign, bringing myositis awareness to baseball fields across the country.

Jen Swisher is a physician assistant who works in emergency medicine and teaches full-time at Chapman University's PA program. A rheumatologist dismissed her as a tired mother. She went home, connected her own MRI, biopsy, and myositis panel results, and called the office with the diagnosis herself.

Dr. Iazsmin Bauer Ventura is Director of the University of Chicago Myositis Program, a practicing rheumatologist, and a member of the institution's multidisciplinary interstitial lung disease team. Her work shows that progress in myositis is not only about new therapies, but about building places where expertise is shared, patients are trusted, and research reaches those long left out.

Dr. Namita Goyal is the Director of Neuromuscular Medicine at UC Irvine and the 2024-2025 chair of TMA's Medical Advisory Board. She trained herself in muscle biopsy at Massachusetts General Hospital because her patients were waiting too long for diagnoses. She is deeply involved in IBM research, including two trials with 2026 readouts.

Together, these accounts describe a community constructing the infrastructure of visibility while waiting for medicine to catch up. The disease is still rare. The diagnostic odyssey still happens. IBM still has no treatment. Together, the work of making myositis visible continues.

A brief introduction to myositis

A disease family hiding in plain sight.

Idiopathic inflammatory myopathies (i.e., myositis) are a family of related conditions that affect muscle, skin, lungs, and other organ systems in different combinations and to different degrees. What unites them is a shared difficulty: they are uncommon, clinically variable, and often require expertise across multiple specialties to diagnose and manage correctly. As a result, patients frequently move through the healthcare system without a clear answer, or with a diagnosis that only partially explains what is happening. Even when identified, treatment decisions are shaped as much by uncertainty and variation as by established standards of care. [1,2]

How it begins

The first signs of myositis vary by subtype, but most forms of myositis share a common opening pattern: progressive weakness. For inclusion body myositis (IBM), it begins with the quadriceps (muscles at the front of the thigh) and finger flexors (muscles that curl the fingers). Patients experience unexpected falls, difficulty gripping objects, buttoning clothing, opening jars. For most other myositis subtypes, onset is associated with progressive proximal weakness (loss of strength in the large muscles of the shoulders, hips, and thighs closest to the center of the body). Patients notice that tasks requiring these muscle groups become difficult and then impossible: rising from a low chair, climbing stairs, lifting groceries, raising arms above the head to wash or style hair, or holding the neck upright.

Onset is often gradual, unfolding over weeks to months, which contributes to diagnostic delay as the symptoms can be mistaken for deconditioning, depression, aging, or other, more familiar conditions. [3]

But weakness is only part of the picture. These systemic diseases affect multiple organ systems, with varied expression and severity by subtype.

The subtypes

The inflammatory myopathy family is typically divided into five major subtypes that appear in contemporary clinical practice. [4,5]

Dermatomyositis (DM) is characterized by the dual involvement of muscle and skin. The skin manifestations are often the most visible early signs: a heliotrope rash (a violet-to-purple discoloration affecting the eyelids), Gottron's papules (raised reddish lesions over the knuckles and bony prominences of the hands), and a V-sign or shawl sign pattern of redness over the chest, shoulders, and upper back. These rashes can be severe, sometimes described by patients as resembling repeated outbreaks of shingles in intensity and discomfort.

IDIOPATHIC INFLAMMATORY MYOPATHY

Idiopathic: Of unknown cause.

Inflammatory: Describes the mechanism. The immune system becomes dysregulated and generates inflammation within muscle fibers and other tissues.

Myopathy: A disease of the muscle.

DM also carries an elevated cancer risk, particularly in older adults, and is associated with a range of autoantibodies (proteins produced by a misdirected immune system) that predict which organ systems are most at risk. DM typically responds to immunotherapy (treatment aimed at suppressing or modulating the immune system), and with early, appropriately aggressive treatment, many patients achieve meaningful disease control. [6,7]

Polymyositis (PM) presents primarily as muscle weakness without the characteristic skin changes of DM. Its classification has been substantially revised in recent years: advances in autoantibody testing have reassigned many cases previously labeled polymyositis into more precisely defined subtypes such as antisynthetase syndrome or immune-mediated necrotizing myopathy. True polymyositis, in the strict current sense, is now considered less common than historical figures suggested. [8]

Antisynthetase Syndrome (ASyS) is a clinically distinct entity defined by the presence of autoantibodies targeting aminoacyl-tRNA synthetase enzymes (proteins essential to protein synthesis). It is typically associated with muscle weakness, arthritis (joint inflammation), mechanic's hands (roughening and cracking of the skin on the fingers), Raynaud's phenomenon (episodic color changes in the fingers triggered by cold or stress), and interstitial lung disease (ILD). ILD is the most consequential complication in antisynthetase syndrome and in several other myositis subtypes, and it is often the primary driver of long-term morbidity and mortality. [9,10]

Immune-Mediated Necrotizing Myopathy (IMNM) is characterized by severe muscle damage with minimal inflammatory cell infiltration on biopsy. It is typically associated with markedly elevated creatine kinase (CK) levels (a blood enzyme released when muscle fibers are damaged, used as a primary diagnostic marker) and specific autoantibodies. IMNM patients often experience rapid, severe weakness and require aggressive early immunotherapy. Certain cases have been associated with statin use (cholesterol-lowering medications), though the majority arise without a medication trigger. [11]

Inclusion Body Myositis (IBM) stands apart from all other subtypes in a clinically critical way: it does not respond to the immune-suppressing medications that typically work for DM, antisynthetase syndrome, and IMNM. [12] IBM is the most common inflammatory myopathy in people over 45 and produces a distinctive pattern of weakness that affects the finger flexors and the quadriceps earlier and more prominently than other muscle groups. Falls and difficulty gripping objects are common early signs.

The disease progresses slowly but relentlessly. Dysphagia (difficulty swallowing due to involvement of the muscles of the throat and esophagus) develops in many patients and increases the risk of aspiration pneumonia (lung infection caused by inhaling food or liquid). IBM is not believed to be a classic autoimmune disease in the same sense as the other subtypes; its pathology involves both inflammatory and degenerative changes in muscle, and its biology remains a subject of active research. [12,13]

The distinction between IBM and the autoimmune subtypes is not merely academic. Approximately 30 to 40 percent of IBM patients are initially misdiagnosed as having polymyositis and treated with immunosuppressive agents that carry significant side effect burdens without benefit. [12] Correct identification of IBM is therefore both a diagnostic and a patient safety imperative.

WHAT MAKES IBM DIFFERENT

IBM	PM, DM, IMNM, ASyS
Limited or no response to immunosuppression	Immunosuppression effective
Initially quadriceps, finger flexors	Predominantly proximal limb muscles
Anti-cN1A antibody (in ~30–75% of cases)	Anti-Jo-1, -MDA5, -SRP, others typically not in IBM
Typically over 45 years old at onset	Varies by subtype; all ages affected

How myositis is diagnosed

Inflammatory myopathies have no single definitive test. Diagnosis typically requires integrating several lines of evidence, and experienced clinicians have converged on a four-component evaluation. [14,15]

1. Creatine kinase (CK) level. When muscle is damaged, CK is released into the bloodstream. Levels modestly above the normal range can have many causes, but CK elevations above 500 units per liter suggest muscle disease and warrant specialist evaluation.
2. Myositis autoantibody panel. Several commercial laboratories offer comprehensive panels testing for the antibodies associated with the major subtypes. Positive results substantially narrow the differential diagnosis and guide treatment planning.
3. Electromyography (EMG) study. Electrical activity of muscles is measured to assess source of weakness. i.e. is the weakness genuinely myopathic (arising from muscle disease itself) as opposed to neurogenic (arising from nerve damage). EMG is useful to exclude other neuromuscular conditions that can mimic myositis.
4. Muscle MRI. Used to identify which muscles are actively inflamed (showing edema, or fluid accumulation, on specific imaging sequences) and which have already undergone fatty replacement (end-stage damage).

AUTOANTIBODIES IN MYOSITIS

Autoantibody	Associated Subtype	Key Clinical Association	Clinical Note
Anti-Jo-1	ASyS	ILD, arthritis, mechanic's hands, Raynaud's	Most common ASyS antibody
Anti-MDA5	DM (amyopathic)	Rapidly progressive ILD, skin ulceration, minimal muscle weakness	Elevated mortality risk; ILD can progress to respiratory failure within weeks
Anti-TIF1-gamma	DM	Elevated cancer risk (especially adults >40), severe skin disease	Recommended malignancy screening at diagnosis, annually
Anti-SRP	IMNM	Severe acute weakness, very high CK	Poor response to standard immunotherapy; may need aggressive combination regimens
Anti-HMGCR	IMNM	Often associated with prior statin use; severe weakness	Statin discontinuation alone insufficient for treatment
Anti-Mi-2	DM	Classic DM skin features; generally better prognosis	Good treatment response; less ILD than anti-MDA5 or antisynthetase
Anti-NT5C1A	IBM only	Highly specific when positive; ~50-60% sensitivity in IBM	Not in standard myositis panels; must be ordered separately

A muscle biopsy remains the gold standard for tissue-level confirmation of diagnosis in most cases and is required for enrollment in most clinical trials. Advances in autoantibody testing have prompted debate in the field about whether biopsy remains necessary in all cases where the antibody profile clearly supports a diagnosis. The current consensus leans toward retaining biopsy as a standard step, particularly when the diagnosis is uncertain, treatment response is inadequate, or IBM must be definitively excluded. [14,16]

For IBM specifically, an additional autoantibody called NT5C1A (anti-cytosolic 5'-nucleotidase 1A) should be ordered separately, as it is not included in standard myositis panels. It is present in approximately 50 to 60 percent of IBM patients and, when positive in the right clinical context, is highly specific for the diagnosis. [12]

Interstitial lung disease as a complication

ILD deserves particular attention because of its frequency and severity across multiple myositis subtypes. Interstitial lung disease (inflammation and progressive scarring of the lung tissue that reduces breathing capacity) can manifest as the presenting feature of the disease, emerge during the disease course, or, in the case of certain autoantibody profiles such as MDA5, dominate the clinical picture entirely. Anti-MDA5-associated dermatomyositis is associated with a rapidly progressive and potentially fatal form of ILD even in the absence of prominent muscle weakness. [9,17]

The gold standard for diagnosing and subtyping ILD in the context of myositis is a multidisciplinary evaluation involving pulmonologists, rheumatologists, chest radiologists, and, in some cases, pathologists reviewing biopsy specimens. This team-based approach is associated with higher diagnostic accuracy than evaluation by any single specialty. [18] Once ILD is identified, treatment decisions must account for both the lung disease and the underlying myositis simultaneously, requiring ongoing coordination across specialties.

Treatment: what exists, what does not

For the autoimmune subtypes (DM, ASyS, IMNM, and PM), treatment is centered on immunotherapy.

Corticosteroids (anti-inflammatory steroid medications, most commonly prednisone) remain the standard first-line agent. However, long-term side effects, including weight gain, bone density loss, elevated blood sugar, and increased infection risk, make corticosteroids unsuitable as a sustained maintenance therapy. Given these concerns, clinicians now move quickly to add steroid-sparing agents as second-line therapy: medications such as methotrexate, mycophenolate mofetil, and azathioprine that reduce immune activity through different mechanisms, allowing prednisone doses to be reduced or eliminated. [19,20]

For patients who do not respond adequately to these approaches, third-line options include rituximab and IVIG (intravenous immunoglobulin, a preparation of antibodies derived from donated human plasma, administered by infusion). IVIG received FDA approval specifically for dermatomyositis in 2021, becoming only the second drug formally approved for any myositis subtype in the United States, after ACTH gel (a hormone preparation that modulates the immune system). For most other subtypes and most other agents, prescribing remains off-label. [19-22]

For patients whose disease does not respond to any of these agents, clinical trials are an important option. The past several years have seen meaningful growth in pharmaceutical investment in myositis research, with multiple parallel trials evaluating new therapeutic targets including CAR-T cell therapy (a form of immunotherapy that engineers a patient's own immune cells to target disease-driving cells) for autoimmune myositis subtypes. [23]

IBM has no approved treatment and does not respond to the therapies used in autoimmune myositis. Management is therefore supportive: physical therapy, occupational therapy, swallowing therapy, and adaptive equipment help patients maintain function and reduce complication risk as the disease progresses. Clinical research in IBM is active, with investigators exploring treatments targeting the mitochondrial dysfunction and protein aggregation features of the disease that distinguish it biologically from autoimmune myositis. [12,13]

A dynamic research landscape

Myositis research has accelerated in the past decade. Autoantibody discovery has redrawn the diagnostic map. Clinical trial infrastructure has matured. Patient advocacy organizations have developed registries, natural history studies, and research funding mechanisms that are increasingly integrated with the academic and pharmaceutical research communities. The result is a field that has moved considerably from where it stood 20 years ago, even as the most fundamental questions, including what triggers the immune dysregulation in the first place and why IBM resists immune-targeting therapies, remain unanswered.

For patients, care partners, and families, the consequence of this scientific landscape is a clinical experience defined by complexity, variability, and the ongoing negotiation between what medicine currently offers and what they need.

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# WHAT TOMMY STARTED

In February of the year he died, Tommy Worthington stopped feeling right. He was 39, a sheriff's deputy who worked out every day, the picture of health by any outward measure.

By that spring, papules had appeared on his knuckles. A purple discoloration had spread to his eyelids. By summer, his family had uprooted from their home two hours north of Miami and relocated to the University of Miami Research Hospital, where a team of rheumatologists, pulmonologists, and dermatologists could speak to one another about what was happening inside his body.

Though local doctors had reached the limit of what they could offer, the specialists could name it: amyopathic dermatomyositis with interstitial lung disease, driven by a rare autoantibody called MDA5. They could treat some of it. His muscles responded. His lungs did not. He died that August.

Laurie Boyer, Tommy's sister, carried that summer forward by turning it into work. She recently concluded a 2-year term as chair of the Board of Directors for TMA, the organization her family found after Tommy's death while searching for others who understood what had happened to him.

Over the past 13 years, her involvement with TMA has taken many forms, each grounded in the perspective of a family member simply trying to help. She does it all as a volunteer, alongside a career in education and technology and a busy family life that includes two teenagers and, this past year, a third child she and her husband took in. She describes the balance plainly.

"It's okay to be imbalanced for a period of time. There's an end goal in mind, and the accomplishment from being able to make that happen is second to none."

### What Tommy started

In the hospital, Tommy told his family he could not believe the outpouring of love and support people had shown him.

Friends from childhood came. Colleagues from the sheriff's office reached out. At the University of Miami, staff began calling the family Team Tommy because they rotated through his bedside each night so he would never be alone.

After he died, Laurie and her family kept the name and built a nonprofit around it.

When they first contacted TMA, Laurie assumed it would function like a large national disease charity: chapters everywhere, established financial assistance, systems already in place. Instead, she found deep expertise and committed support groups, but no mechanism for the practical costs that can break families during serious illness.

A mortgage payment when someone can no longer work. A ride to the infusion center. A hotel room near a research hospital.

From 2012 to 2017, Team Tommy helped fill that gap. It provided direct financial assistance and conference scholarships so families who could not otherwise attend TMA's annual patient conference could still be in the room with leading myositis specialists.



*Laurie Boyer, Former TMA Board of Directors Chair and Paula Eichenbrenner, TMA Executive Director*

In 2017, TMA asked Laurie to join the board. "It felt like the right natural progression," she says, "to be able to help on a more national, and international, scale."

### One organization, many diseases

TMA serves patients whose diseases share a name but often little else. Dermatomyositis is not inclusion body myositis. Antisynthetase syndrome is not polymyositis. Symptoms differ. Treatment responses differ. Daily realities differ.

Laurie describes the challenge this way: "It's almost like leading an organization of many different organizational needs." The staff is small: fewer than a half dozen employees. The board, including its chair, serves as volunteers. That reality shapes how the organization works. Laurie describes it as a crawl, walk, run philosophy.

"Sometimes you have to be okay with going back to crawling, because you fell flat on your face trying to run. There really isn't a finish line with an incurable disease. You're looking for a cure, and you just have to put your energy and efforts into moving forward with your mission."



### More than support groups

One of the most consequential initiatives Laurie Boyer helped shape at TMA does not carry her name. At the organization's 2018 patient conference in Minneapolis, she facilitated a women of color panel. It brought together patients whose dermatomyositis can appear differently on darker skin tones, who have faced higher mortality rates, and who have often had less access to specialist care and peer connection.

The response in the room made something clear: this needed to continue.

A second gathering was held virtually. It later became an official affinity group. From there, TMA developed additional groups for veterans, LGBTQIA members, international patients, and people living alone with the disease. Each group shares myositis, but also another layer of lived experience.

*"A lot of times when anyone's battling a rare disease, they go through a process of losing their identity. They've become very much a patient. Affinity groups allow more of the human element to come through."*

### Research that can be felt sooner

TMA's research strategy has also broadened. Historically, the organization funded fellowships and longer-horizon cure-focused research. More recently, it has also asked a different question: what could improve care within the next three to five years?

That shift includes work such as exercise science showing that many myositis patients benefit from beginning movement earlier, rather than waiting for inflammation to fully subside. "Once you lose muscle, it's so hard to get it back," Laurie says. "Why have a double uphill battle?"

### Teaching people they can act

In 2025, TMA's proclamation campaign pushed advocacy closer to home. Patients and families contacted state officials to pursue recognition of Myositis Awareness Month. "A lot of light bulbs went off," Laurie says. "People realized: I didn't know it was that easy to do, and that I can impact my local community, my state."

### The next thirty years

What gives Laurie the most hope is not only the past 33 years of TMA, but the next 30. Two years ago, she spent significant time reviewing board applications, thinking carefully about what skills the organization would need in the years ahead. She speaks often about future focus: not only what an initiative solves now, but what it builds later. "For an organization that's been around 33 years," she says, "where we are and what we're focusing on might be different than someone who's been in it for five years."

MyoCon, TMA's annual patient conference, remains the clearest expression of that work. Newly diagnosed patients meet families who have lived with myositis for decades. Specialists answer questions directly. People who often navigate the disease in isolation find themselves in a room full of others who understand it. "There's no way your bucket isn't filled after attending a conference," she says. "It's what pushes us through every single day."

Tommy Worthington never attended a TMA conference. He died before his family had fully found their way to the organization. His sister has now attended more than a dozen.

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This article was based in part upon the recorded interview available on Soundcloud, Apple, Spotify, Audible, iHeartRadio and YouTube.

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Make a difference.
Visit myositis.org.





They came home from Jamaica with a problem for which they did not yet have a name.

Ed and Marilyn McGrath had gone to celebrate their anniversary. They were working people who had built a life together and liked to travel when they could.

But before the trip ended, Marilyn started to feel it: a fatigue that was not vacation fatigue, and skin symptoms that were not sunburn. They knew, on some level, that something was not right.

What followed was two years of not knowing what it was.

Their family physician sent them to a dermatologist. The dermatologist looked at Marilyn's rashes and said: lupus. That diagnosis, wrong as it turned out, set the terms of her treatment for years.

The answer came from a rheumatologist named Dr. Lee Shapiro, a scleroderma specialist who had published on myositis and understood the disease in ways that most of his colleagues did not. A biopsy confirmed it: dermatomyositis.

"I call him the man," Ed says of Dr. Shapiro. "He finally pinpointed what was wrong."

The path to Dr. Shapiro was not the result of a referral system working as intended. It was geography. The McGraths happened to live near Dr. Shapiro and were able to access resources perhaps not available in less urban areas. For families navigating the same diagnostic journey today, without the accident of that proximity, the road to a correct diagnosis is likely longer.

What rarity actually means

The thing about rare diseases, Ed has come to understand after more than two decades alongside this one, is that the rarity compounds itself.

"Marilyn suffers from a rare disease. Rarely have people heard of the disease. Rarely do people understand it, even if they've heard of it. Rarely does it get research funding because it's not widely known. And really, do insurance companies fully support it?"

Dermatomyositis is an autoimmune condition in which the immune system mounts an inflammatory attack against both the skin and the skeletal muscles.



Marilyn and Ed McGrath

Marilyn's presentation was characteristic: rashes that arrived in episodes Ed compares to shingles, severe, recurring, and painful, and a progressive muscle weakness that worked quietly at first and then with increasing consequence. Things that no one thinks about, such as drying your hair or getting out of a chair, began to cost Marilyn effort she had not needed to spend before.

"Little things that everybody takes for granted," Ed says. "You lose that ability from the muscle standpoint. And there's a lot of pain associated with it as well."

By 2011, Marilyn could no longer hold her arm above her shoulder long enough to dry her hair. Steps were out. A stair lift went in. Grab bars followed. The house became, gradually and deliberately, a place where Marilyn could navigate.

The treatment timeline

What came next was a long accumulation of clinical decisions, most of them made without the certainty that would have made them easier.

Prednisone came first and stayed for seven or eight years. “Prednisone’s a medicine you love to hate,” Ed says, “because it helps people who have autoimmune problems, but it also has nasty side effects.” Then hydroxychloroquine, which led to eye toxicity. Then oral methotrexate, then injectable methotrexate. Ed gave Marilyn the shots himself. When methotrexate lost its effectiveness, they tried rituximab.

During rituximab treatment, Marilyn developed sepsis, a life-threatening systemic infection, and was hospitalized for the better part of a week. “She got septic and it almost killed her,” Ed says, with the matter-of-fact directness of a man who has had many years to process something that could have ended differently. When she recovered, they were back at the question that had been the question throughout: what now?

The answer came, as so many answers had come, from a conference.

The Myositis Association’s Annual Conference

TMA’s annual conference came into Ed and Marilyn’s lives in 2013, when they traveled to Las Vegas for their first one. By that point, they had already spent years learning whatever they could about the disease from the internet, a task made harder by how little there was to find. “It wasn’t until we found The Myositis Association,” Ed says, “that we started to understand: hey, there are other people that have this disease.”

The conference was something else entirely. Look at all these other people who have this disease, he remembers thinking. Look at all these doctors that I can talk to directly. They were, in his word, hooked.

Since then, they have attended ten or eleven consecutive conferences. But the most consequential thing they ever learned at a TMA conference was clinical: at one of them, they encountered IVIG.

Intravenous immunoglobulin, known as IVIG, is a therapy derived from pooled plasma donations from healthy individuals. It received FDA approval specifically for dermatomyositis in 2021, the first drug to carry that indication, on the strength of a phase 3 clinical trial published in the *New England Journal of Medicine* demonstrating significant

improvement in disease activity. IVIG had been used in the myositis community for years before that approval, and Ed and Marilyn learned about it through TMA’s conference programming: doctors on panels, families with notebooks, conversations that happened nowhere else.

“Marilyn’s treatment she’s currently on, we discovered at a TMA conference,” Ed says.

The drug she now receives is called Gammaplex. It is delivered through a port implanted under her skin, via a home infusion service that comes every four weeks and administers the infusions over two consecutive days. It is not a cure. Marilyn has never been in remission. But the difference it has made is not abstract.

“IVIG has enabled her to get back a little bit of her ability. She’s actually walking a little better now... We still sway to the music. It’s given her back some freedom that she lost for the last several years.”

The insurance fight

What Ed observed over years of advocating for Marilyn is that many coverage decisions affecting rare disease patients are made on a financial calculations that have little relationship to clinical necessity. At one point, Marilyn’s insurer was covering her methotrexate. Then, without warning, it was not.

Ed called the company. He worked through levels of the organization until someone explained the reasoning. The explanation was this: if Marilyn had cancer, her methotrexate would continue to be covered, because cancer treatment has a defined trajectory.

But Marilyn has a rare chronic disease. She is not dying from it; she is living with it. And in the insurer's actuarial calculation, that made continued coverage unjustifiable.

"I said: wait a minute. It does the same thing for Marilyn that it does for a cancer patient. So why do you cover it in one perspective and not the other?" Ed remembers asking.

The answer, as he came to understand it, was that the decision had not been made by anyone thinking about Marilyn. It had been made by people thinking about numbers. The decision, in his telling, was operational in its logic, which made it worse rather than better.

"If there's no means to the end, if somebody with a rare disease is fighting the battle and learning how to live with it instead of die from it, they discovered, well, we're losing a lot of money in this," he says.

This is one of the things that newly diagnosed families most need to understand, Ed says: you will have to advocate for yourself. Marilyn has become, in his description, as knowledgeable as any non-clinician he has encountered about her own disease. She learned the pharmacology, tracked the research, pushed back in clinical settings when something did not add up. That knowledge is not incidental. It is a survival skill, and it was built by both of them.

The disease did not arrive for Marilyn alone. It asked things of Ed too, different things, in different ways, with different costs. He administered her injections. He worked through levels of an insurance bureaucracy until he reached someone who could explain a coverage decision. He sat in conference rooms and physician panels accumulating the kind of knowledge that is supposed to come from the health system and often does not. Neither of them was watching from outside.

Ed has a word for this. He offered it to TMA and they adopted it. Not caregiver. Care partner.

Giving back

At TMA's most recent conference, Ed and Marilyn did something they had not done before: they taught.

Working with another care partner, they led a session that split patients and partners into separate groups. Ed sat with the patients; Marilyn with the care partners, so each could speak freely without protecting the other. Questions too difficult to ask in front of a spouse became possible among peers.

The session was the first of its kind at TMA, and the association plans to continue similar programming in this spirit.

Ed and Marilyn have attended TMA conferences for more than a decade. What they offer now is the kind of knowledge that cannot be downloaded: treatment failures, insurance fights, household adaptations, what helps, what does not. They pass along small tools they discovered there, including a car door handle assist device that helps Marilyn push herself out of a vehicle.

They also offer something less tangible. Marilyn often sits with the newly diagnosed and tells them what the first years can look like, and that there is a path through them. You are not alone.

It took two years to reach the right diagnosis, and nearly two more decades to find a treatment that works. Over those years, they built a practical knowledge of how to live through it. Each year, they return to hand that knowledge to whoever needs it next.

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*This article was based in part upon the recorded interview available on Soundcloud, Apple, Spotify, Audible, iHeartRadio and YouTube.*

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# THE VOICE AND THE ECHO

In 2003, Holly Jones was nineteen years old when she was diagnosed with polymyositis and interstitial lung disease. The doctors told her she would likely not live to see twenty-four. They told her she would likely never find another woman of color with her disease within a three-hour drive. The population of people diagnosed with myositis, she was told, was older white women and older white men.

And yet, in the 20 years since her diagnosis she has built one of the most significant peer communities in the country for Black women living with myositis. “Yesterday’s story is not today’s story,” she says.



Polymyositis is a subtype of idiopathic inflammatory myopathy, a disease in which the immune system attacks the body's own muscle tissue, producing progressive proximal weakness and, in many patients, serious lung involvement. In Holly's case, the interstitial lung disease that accompanied her diagnosis would eventually progress to pulmonary hypertension, and later to congestive heart failure and vasovagal syncope. Each complication arrived one at a time, over years.

But at nineteen, the immediate reality was simpler and more brutal. She had been handed a prognosis that said she might not live to see twenty-four, or that her quality of life would be poor if she did. She was told not to exercise. She was told not to get pregnant. She was told to wait.

The loneliness was structural, not incidental. The population she might look to for solidarity was, as she was told explicitly, older white women and older white men. "I felt isolated and alone at 19," she says.

She credits her family for being deeply supportive and for giving her the foundation she needed to keep moving through the illness. Yet the beginning was difficult. They did not believe her at first.

Polymyositis hides itself. Aside from the oxygen tubing, nothing signals the seriousness of her condition. "If I did not wear my oxygen, who would know?" she says. The conversations that followed were long and painful. It took years for her family to understand the reality of her illness. In time, they did.

### **Validation from an unlikely direction**

The thing that changed was not a program or a referral. It was a television show.

Holly was sitting with her husband Kam, watching a television program called *Mystery Diagnosis*, in which patients described their long roads toward diagnosis. A woman on screen was describing symptoms that matched Holly's, point by point. Holly told Kam she wondered if she had been misdiagnosed. She waited through the commercials. At the end of the episode, the woman revealed her diagnosis. She said: I have polymyositis.

"My eyes lit up," Holly recalls. "Because it was a Black woman."



Holly Jones

It was the first time she had seen someone with her disease who looked like her. She used the episode to help family members understand what she was going through.

Hoping to meet the woman in the episode, Holly attended the annual Myositis Association conference in 2019, only to find the woman has passed away the previous year. What she did find was the woman's sister and the woman's daughter, the baby who had appeared in the original episode.

The impact of that episode stayed with her. It gave her an answer at a moment when she needed one, and it gave her a face that reflected her own. "I feel like I have tried these last six years to pay so much honor to her," Holly says.

### **The breakdown that became a beginning**

After living with myositis for nearly a decade and a half, Holly reached a wall. She had been managing conditions, attending appointments, raising children. But something had eroded without her quite noticing it.

*"I got to a place where I was like, I'm just a patient, a wife and a mother. That's all I thought I was. I don't know how I went from Holly to this."*

Her husband's response was characteristic. He did not reassure her; instead, he simply asked, "What are we going to do about it?" Not "What are you going to do?" That distinction, in Holly's telling, was everything. He pointed out that whenever she talked about her story, people leaned forward. Strangers said, "You have to meet this woman." He believed her experience was meant to move others, and that it ought to be used.

She was later invited to a prayer breakfast. Women there prayed over her and told her, "You are going to be the voice of your disease." She did not yet know what that meant. But years earlier, her aunts had given her a framework she never forgot: when you are born, God gives you a gift, and whatever you do with it is your gift back. "If he gave me the gift of inspiration, the gift of encouragement, if I don't use it, then what am I saying?"

She began her advocacy with a radio show called *Krazy N Christian*, using it to share her experience of living with multiple invisible chronic illnesses.

She carried the same message into exam rooms, urging her physicians to see not only her chart, but the community of patients still unseen beyond it.

Then she widened the circle. She began calling The Myositis Association, asking for wristbands, brochures, anything she could put in her doctor's office. She had become, in the telling, that girl who called for supplies every year, known for showing up, but unknown in the full scope of what she was building.

In 2019, TMA held a Women of Color panel at its annual conference in Minneapolis. TMA called Holly. "We do not have anybody with your lived experience on this panel. We need you."

Holly flew from Texas on short notice, spoke on the panel, and delivered the closing remarks. She called for something that did not yet exist: a permanent community for women of color with myositis. She waited to see if those words would take root in someone else. They did not. In 2020, she created the Myositis Women of Color Support Group herself.

In 2021, it became TMA's first official affinity group.

### The three E's

The Women of Color Affinity Group now has nearly 300 members, including patients, caregivers, and allies. Holly built its mission around a framework she developed herself, which she calls the Three E's: Encouragement, then Education, then Empowerment. In that order, by design.

**"When you first come to this group, all we want to do is encourage you. We want to meet you where you are. And once we get you to a space where you can embrace and accept your new normal, we are going to want to educate you."**

Education comes second because a person who has not yet been encouraged cannot absorb information the same way. Empowerment comes third because it depends on both foundations: knowing you are supported, knowing what you are facing, and then stepping into community with enough ground under your feet to move.

The group runs three structured programs. The 'Encouragement Call' connects new members with someone from the group team over Zoom before they are ready for a full meeting. The 'I Got You' System matches a woman from the group to accompany you to a medical appointment you are afraid to attend alone. The 'Be Empowered' program, which the group calls the besties, rotates monthly one-on-one pairings across the membership so that when members attend a TMA conference, they have a familiar face waiting.

### Extending the circle of care

Under TMA's umbrella, Holly has also created the Myositis Africa Support Group and has been involved in the development of the Men of Color Affinity Group.

Holly also advocates for teenagers with chronic illness, who face the disease at an age when the disease is hardest to carry and peer support is hardest to find. She advocates for children who step into caregiving roles for affected parents long before they should have to. She advocates for women in their childbearing years, who are told by a medical system that still too often responds to pregnancy questions with "don't" rather than "here is how." She watches the Women with IBM Affinity Group grow and speaks plainly about what those women are navigating: a subtype of myositis for which, as she describes it, there is no treatment available outside of exercise.

### Writing today's story

When asked to join the TMA's Board of Directors, Holly was not sure she belonged in a room full of physicians and lawyers. TMA told her otherwise.

She believes them now.

"The advocate you see today was not the advocate that started," she says.

In 2003, a 19-year-old woman with an invisible disease was told she might not live to see 24, and that a community of peers who looked like her did not exist. Two decades later, she has built that community, and is widening it, turning the isolation she once felt into connection for others.

In Holly's words, that is being the voice and the echo.

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"I encourage women who want to have children to really work on building your healthcare team first. Make sure your physicians have seen women in high-risk pregnancies in your disease set. See a maternal fetal medicine specialist."



This article was based in part upon the recorded interview available on Soundcloud, Apple, Spotify, Audible, iHeartRadio and YouTube.

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FIRST PITCH



The falls started before the diagnosis did. Vance Robinson was playing golf regularly, a younger man in his prime by any outward measure, and he was falling. On slight inclines. Off curbs. Down steps in parking lots. He would fall, get up, and keep going. “I became like a professional tuck-and-roll guy,” he says. “I never got hurt falling. But I fell often.”

A friend watched one of those falls outside a restaurant and insisted he make an appointment.

About six months later, after tests that briefly raised the possibility of ALS, a neurologist at the University of Washington ordered a muscle biopsy.

The diagnosis was inclusion body myositis. Doctors told him he would grow progressively weaker and might one day need a power wheelchair. They also offered antidepressants. After talking with him, they decided he probably would not need them.

“My happy-go-lucky attitude has helped me out,” Vance says. “It’d be twice as bad if I was a grumpy old man.”

Unlike several other myositis subtypes, IBM does not respond to immunotherapy. Robinson spent several years on prednisone, with swelling and limited benefit. When he retired and moved back to California in 2014, a neurologist at Stanford began weaning him off. He has taken no medication since.

There is still no approved disease-modifying treatment for IBM.

He is now a full-time wheelchair user living alone. Mornings, he says, feel like he played tackle football the night before with no pads. A lift device gets him on and off the toilet. His chair rises to bed height so he can slide across. Grabbers wait throughout the house. Even water changed: the standard 16-ounce bottles became too heavy, so he moved to 8-ounce bottles held in both hands.

“I know there’s going to come a point where I’m going to need more care,” he says. “I’m not at that point yet.”

The first pitch

In 2017, Robinson was still walking with a cane when he threw a ceremonial first pitch at Stanford University. He dropped the cane to throw, then bent to pick it up again. In one motion, the whole situation was visible.

That was the beginning.

Friends had urged him for years to create some kind of awareness effort around IBM, since most of the people around him had never heard of it. He decided to use what May already offered: Myositis Awareness Month. He would show up at college baseball games, wear the disease name on his jersey, hand out wristbands, and throw first pitches.

The first year ran from Stanford south to Cal Poly, UCSB, Pepperdine, and San Diego State.

Each year, the campaign grew. And each year, the disease continued its steady progression.

By 2025, nine seasons in, Robinson could no longer travel more than two hours from his home. But The Myositis Association shared a call for volunteers, and the campaign expanded beyond what he could drive alone. First pitches occurred across the country, and even extended to Cuba.



Vance Robinson and friend

Think ahead

Robinson’s advice to people newly diagnosed with IBM is specific and practical. He does not offer reassurance. He offers logistics.

“Think ahead. Always think one or two years ahead.”

He replaced standard kitchen chairs with higher seating that made standing easier. He bought a recliner with a lift function before he absolutely needed it. He sold two vehicles and, with help from a GoFundMe organized by friends and family, purchased an accessible van with a ramp. When a bench in his home sat too high for visitors, a friend cut four inches off the legs. His old couch became unusable because he could no longer rise from it.

“If you feel like you can’t walk safely anymore, even with a walker, get a scooter,” he says. “Get the equipment when you can still do it.”



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 Learn more about First Pitch and Vance at
<https://www.youtube.com/watch?v=J889QZ0jPog>.

Messages arrive regularly from people he has never met, telling him that watching him has helped them. He does not entirely understand why.

"If you put your name in a hat, and under your name you put your ailment, and you have 15 of your friends there that are your age, by the time you hear the fifth one of their ailments, you're okay with yours."

He is in his 60s and, by his own accounting, doing fine.

Next May, there will be more first pitches. More funds raised. More awareness raised.

"I don't even know I'm helping people," he says. "But I'm helping people somehow."

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*This article was based upon a one on one interview between Vance Robinson and Scott Milligan.*

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# THE FULL PICTURE

The first rheumatologist reviewed Jen Swisher's results and found no clear autoimmune disease. Her ANA panel was borderline. The standard workup, including lupus testing, was negative or close enough to negative that no diagnosis could be confirmed.

The physician's conclusion was simpler than Jen's reality.

"I think you're just a mom and you're tired and you work the night shift," Jen recalls being told. "Just maybe rest a little bit more."

Jen was a physician assistant in emergency medicine. She had worked nights for years and had become a mother in 2015. She knew what ordinary exhaustion felt like.

"I've been doing that since 2015," she says. "What changed from 2015 to 2019? Nothing. I know what it's like to be a tired mom. This isn't it."

The symptoms that began around 2019 were real but hard to assemble. Fatigue so persistent she describes it as feeling like the first trimester of a pregnancy she was not having. Rashes that moved around and did not resolve. Joint pain. Hair loss. The workup she requested through her primary care PA was the first round; the rheumatology referral was the next step; the negative results after that left her with nowhere to go. She went back to the emergency department, to her shifts, and accommodated her body in the ways people do when they cannot get someone to agree that something is wrong.

During the pandemic, the accommodation continued. The question of whether symptoms were burnout, fatigue, or something else became harder to distinguish in an environment where everyone was exhausted. She was working front-line. She got pregnant with her third daughter.

Pregnancy, she would later understand, is a state of natural immunosuppression. Looking back, she can see that her symptoms had a pattern: they improved during her pregnancies and returned afterward. At the time, she was just trying to get through.

Three months after her third daughter was born in 2022, Jen's symptoms stopped being manageable. The hip pain became severe. The rashes became more pronounced. The muscle weakness that had been present as vague discomfort started presenting as something she could not ignore at work: she was having difficulty getting off the stool at her workstation. She could not lift her six-month-old daughter in and out of the car seat. She could not blow-dry and brush her hair.

### **Falling apart, coming together**

She had been referred to dermatology for the rashes, which had not responded to any of the treatments thrown at them, so a biopsy was ordered.

She had sought out an orthopedist for her hip, which had a pre-existing labral tear she wondered had worsened in labor and delivery. He ordered an MRI.

And she had gone back to a concierge rheumatologist who thought she might have seronegative rheumatoid arthritis and was re-running labs.



*Jen Swisher*

Three providers. Three separate workups. None of them talking to each other.

The MRI came back first. The labral tear was stable. But the imaging showed diffuse muscle inflammation.

Within 24 hours, the biopsy result arrived: interface dermatitis, consistent with an autoimmune condition, specifically dermatomyositis.

Jen looked at those two results and knew what she was looking at. She called the rheumatologist and asked him to add a myositis antibody panel to the labs already running.

"He's like, sure, but that's really rare. There's no way it's going to be that," she says. "I said, it's fine. Just humor me."

A week later: a panic call on her voicemail. "You call me back right away." It was not a normal doctor voicemail. She already knew what it would say.

The myositis panel had returned positive for TIF1-gamma, an autoantibody associated with dermatomyositis and, in adults over 40, a high association with underlying cancer.

### Navigating next

Every rheumatologist in Southern California had a nine-month waiting list, even for a patient with a confirmed myositis diagnosis who could not get off a stool at work. Jen used her hospital's internal messaging system to reach a rheumatologist colleague. "I backdoor texted her," she says. "I never do this for myself." She sent her case. She had the appointment the following week.

That rheumatologist's best friend turned out to be the department chair of the UCLA Myositis Center an hour away. Within weeks, Jen was being seen at a center whose specialists told her the first treatment plan she had been given was insufficient. "No, no, no," the myositis center told her. "You have to hit this hard and fast."

The treatment that followed was aggressive and extended. IVIG started immediately, while she was still breastfeeding (a brief window of compatibility). Mycophenolate was added once she stopped breastfeeding. High-dose prednisone. Six months to get the disease to settle. A taper attempt that triggered a significant flare. The refractory course led to the addition of rituximab. Two rounds of rituximab plus maxed-out doses of the other medications finally achieved what her care team calls low disease activity.

"Minus the fatigue of maybe just being a full-time working mom with a chronic disease and three kids," she says, "I'm as close to baseline as I'll probably ever get. I feel like I'm functioning and not struggling."

She returned to full-time work in July 2024.

*"I don't know how anybody without a medical background navigates this after doing it myself as a PA."*

### What she teaches now

The worst part of her diagnosis, Jen says without hesitation, is UV exposure. Ultraviolet light is a known trigger for dermatomyositis flares. She lives in Southern California. She has three young children who need to be outside. "I'd say that's the worst part about my diagnosis," she says. "I probably would take everything about it, but I live on the beach with small children who have to be outside."

She teaches full-time at the Chapman University PA program. She gets one clinical day per week in the emergency department. The classroom and the exam room now run alongside each other, and her experience as a patient runs through both.

The diagnostic journey that took three years, involved four specialties, and was resolved when she connected her own MRI and biopsy results has changed the way she approaches clinical judgment. She tells her students that rare disease can look like common disease for a long time. She tells them that the patient's story is always the beginning of the workup.

What the rheumatologist missed, Jen did not miss. The system did not catch it; a PA with the right knowledge, in the right body, at the right time, caught it herself.

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MORE THAN THE SUM

On Thursdays, Iazsmin Bauer Ventura works in a clinic built around the idea that no single specialist is enough. She shares space with three pulmonologists at the University of Chicago who focus on interstitial lung disease, or ILD, a group of conditions marked by inflammation and progressive scarring of lung tissue. They review scans, breathing tests, and lab results together, with the patient in the room.

For patients whose disease crosses organ systems and resists easy answers, that kind of room can change everything.

The Thursday clinic is one expression of a larger structure. Every other week, Ventura joins a formal multidisciplinary conference where pulmonologists, chest radiologists, pathologists, and rheumatologists review new and difficult cases together. Each specialty sees something the others cannot. What they produce collectively is something none of them could produce alone.

Why the room matters

Interstitial lung disease is not one disease. It is a category that includes many distinct disorders with different causes, trajectories, and treatment implications. Some cases are idiopathic, meaning no clear cause is known. Some are driven by environmental exposures. Some emerge as a complication of autoimmune disease.

That distinction can be life-changing.

A patient whose lung disease is tied to myositis may need immunosuppressive treatment. A patient with idiopathic pulmonary fibrosis may require an entirely different strategy. Another patient may need a medication stopped, an exposure removed, or a diagnosis reconsidered altogether.

No single physician reliably resolves all of that alone. The radiologist interprets imaging patterns. The pathologist reads biopsy tissue when available. The pulmonologist understands lung physiology and progression. Ventura's role is to ask whether the lungs are reflecting a broader rheumatic disease such as myositis, lupus, or systemic sclerosis.

The answer can reshape prognosis, treatment, and monitoring from the first visit onward.

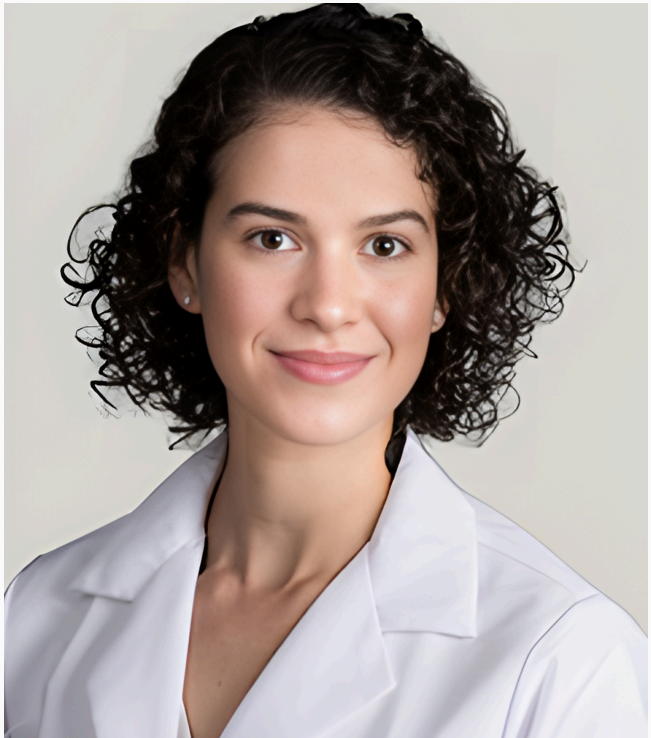
"We don't have a standardized prescription," she said. "We really need to take into account a lot when it comes to prescribing the right thing and treating these patients the right way."

The road to Chicago

Ventura grew up in Brazil and came to the United States more than a decade ago. She completed internal medicine training in New York before moving to Chicago for rheumatology fellowship, then joined the faculty at the University of Chicago in 2019.

She had been drawn to rheumatology since medical school. Unlike specialties organized around a single organ system, rheumatology often requires seeing the whole patient at once.

"We don't have a specific system we focus on," she said. "We see patients whose diseases can affect virtually any system."



Dr. Iazmin Bauer Ventura

She was also fascinated by lung disease and dermatology during training. Myositis, which can affect muscle, skin, and lungs in the same patient, became what she described as a natural fit.

At Chicago, that fit became practical. The institution had a substantial myositis population, a longstanding ILD program, and senior mentors deeply experienced in both areas. Ventura stepped into a field where collaboration was not theoretical. It was already expected.

Trust is clinical infrastructure

When Ventura joined the faculty at the University of Chicago six years ago, she had a clear priority: bring myositis clinical trials to the Chicagoland community for the first time and make sure those trials enrolled patients from the communities that clinical research has historically excluded. For her, these were not separate goals.

Her practice is on the South Side of Chicago. A substantial portion of her patients are from underserved communities, including African Americans and patients without private insurance, whose first encounter with the medical system for this disease often came late, when the disease had already caused damage that earlier intervention might have prevented. The published literature documents this pattern across virtually every disease category: patients from racial and socioeconomic minorities receive diagnoses later, experience more severe disease at diagnosis, and have worse long-term outcomes. In myositis, this is acute.

The barrier to changing this pattern is not simply awareness. It is trust, specifically the historically justified mistrust that many communities of color have toward medical research, rooted in documented histories of exploitation that are not distant history but living memory for many families. Enrolling these patients in clinical trials requires, first, having a relationship with them built on respect and demonstrated over time.

"Unless that relationship between patient and doctor is one of trust and respect, we're not moving forward"

Her approach is not programmatic. It is relational. She knows her patients' family members. She knows their struggles beyond the clinic. She has been their physician long enough to have accumulated the kind of shared history that allows a patient to hear a clinical trial offer and believe it is being made in their interest.

Her site has become one of the highest-enrolling locations for a major dermatomyositis trial and is one of the most active sites in the US on the use of cell therapy to treat myositis, as well as systemic sclerosis, and lupus.

Decades in the making

The University of Chicago ILD natural history registry has operated since the early 2000s and now includes more than 2,000 patients, creating a dataset that supports research at the University of Chicago and international multicenter collaboration in clinical research. What this infrastructure enables is research often not feasible within a clinical trial or at any single institution, yet essential to future clinical trials and multicenter studies.

Natural history registries provide researchers with a longitudinal view of disease and, when coupled with biospecimens, can help identify biomarkers, refine disease classification, and ultimately inform better treatment.

Unfortunately, longstanding government funding for these irreplaceable data repositories has come under significant pressure in the United States. The threat to that foundation is something Ventura addresses directly and without hedging.

"There is no investment in research if there is no support," Ventura says. "The United States may lose its position as the frontrunner in research development."

She also points to the economic case: published analyses have found that public investment in biomedical research generates returns far beyond the initial dollars spent through economic activity, innovation, and better health outcomes.

Infrastructure capable of supporting complex, multi-site, long-duration studies takes years, sometimes decades, to build. It does not rebuild quickly.

A new therapeutic era

Ventura trained in a period when treatment options for myositis were far more limited. For years, few therapies carried formal regulatory approval, and many were used off-label. Even when physicians believed a treatment could help, access often meant delays, appeals, and peer-to-peer insurer reviews that could stretch for weeks.

"We're talking about weeks and weeks of patients waiting. And the disease keeps going. The disease is not waiting for you."

The FDA approval of intravenous immunoglobulin, or IVIG, for dermatomyositis marked a turning point. That approval followed publication of the ProDERM trial in the *New England Journal of Medicine*, which provided the clinical evidence base the field had long lacked. It validated what many specialists had long observed in practice while making insurance coverage far easier to obtain. The same journal published in March 2026 the results of the biggest clinical trial in dermatomyositis, the VALOR trial, which revealed disease improvement and steroid-sparing capacity of brepocitinib. This trial opened the door of a new era of targeted therapies in dermatomyositis and other types of myositis.

She sees the larger story as momentum. Trials are advancing across dermatomyositis, necrotizing myopathy, antisynthetase syndrome, and, more cautiously, inclusion body myositis, where effective options remain especially limited.

"I am extremely privileged that I'm seeing, in the myositis community, this boom of possibilities," she said.

More than the next drug

The Thursday clinic continues. The biweekly MDT meeting continues. The registry grows. Trials enroll. Patients still arrive with symptoms that do not fit neatly inside one specialty.

Ventura's work suggests that progress in diseases like myositis is not only a matter of discovering the next drug. It is also a matter of building places where fragmented expertise becomes shared judgment, where mistrust becomes participation, and where patients no longer move from silo to silo assembling their own care.

"It's satisfying to us because they're feeling that we are providing the best care possible to the patient," she said. "There's nothing like it."

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This article was based in part upon the recorded interview available on Soundcloud, Apple, Spotify, Audible, iHeartRadio and YouTube.

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# WHAT SLIPS THROUGH



The patient had been on seven different immunotherapy agents. He had a diagnosis of polymyositis and a medical record long enough to document years of treatment attempts, each one failing the previous one, one of them causing pancreatitis and a hospitalization. He was referred to Namita Goyal for refractory polymyositis. She reviewed what had been done. She examined him.

She looked at his fingers.

His muscle weakness was not the symmetric proximal pattern that polymyositis typically produces. It was concentrated in his finger flexors: the muscles that curl the fingers inward, a pattern that IBM patients develop and polymyositis patients typically do not.

She ordered the NT5C1A blood test, an autoantibody associated with inclusion body myositis that is not included in the standard myositis antibody panel and must be requested separately. She did another muscle biopsy. This time the pathological features of IBM were visible. She took him off everything.

"This story," she says, "is very similar in many IBM patients."

"IBM patients, all they have is the hope from these clinical trials. And so clinical trials have become really important. A passion of mine. Because this day and age, how do we not have an effective therapy for one of the most common muscle diseases?"

Inclusion body myositis is not as rare as most physicians believe.

IBM is the most common acquired muscle disease in people over the age of forty-five. It is likely underdiagnosed, and its prevalence increases with an aging population. Unlike dermatomyositis and antisynthetase syndrome, IBM does not respond to the immunosuppressive therapies that work in other myositis subtypes. The result is that approximately thirty to forty percent of IBM patients are initially misdiagnosed as polymyositis and placed on medications that cannot help them. The diagnostic clue, disproportionate finger flexor weakness alongside quadriceps weakness, is consistently overlooked because clinicians focus on larger proximal muscle groups.

"If they have not responded to immune therapy, two things," Goyal says. "Check the blood test" (meaning the NT5C1A antibody, not routinely included in myositis panels) "and examine the fingers."

Goyal has been making this argument for twenty years, since her time at Massachusetts General Hospital, where she trained herself in muscle biopsy because she watched a patient hospitalized with severe progressive weakness while the diagnostic test could not be arranged as an outpatient. She walked to the surgeon's office and asked to be trained. She has performed the procedure regularly ever since, and she credits that decision with shortening the diagnostic odyssey for hundreds of subsequent patients.

### **Building the research the field requires**

The research infrastructure for IBM is now, finally, commensurate with the urgency.

The INSPIRE study, a NIH-funded, thirteen-site natural history study, has enrolled 150 IBM patients across the United States, including at UCI Health where Goyal and her colleague serve as co-investigators. The study is collecting blood, urine, DNA, RNA, and in a subset of patients, muscle biopsy specimens. It is designed to answer the basic questions that clinical trial design requires: how does this disease actually progress, in whom, over what timeline, and what biological signals might predict that progression? Data is expected in 2026.



*Dr. Namita Goyal*

The study exists because those questions have not been adequately answered. All the clinical trials that preceded it, arimoclomol (targeting protein repair pathways), bimagrumab (a myostatin inhibitor that increased muscle mass but did not improve function), and follistatin gene therapy, failed in part because the disease was not well enough understood to design trials that could succeed. Goyal does not describe these as wasted effort. Bimagrumab taught the field something: muscle mass and muscle function are not the same thing. Each trial improved the foundation for the next one.

The most recent investigation is the MUSCLE trial of ulviprubart, an antibody that targets a marker called KLRG1 on the surface of a specific population of T cells. These highly differentiated cytotoxic T cells appear to be resistant to standard immunosuppression and are thought to mediate much of the muscle destruction in IBM. Selectively depleting them, while sparing other immune cell populations, is the mechanism ulviprubart is designed to exploit.



When Goyal's site at UCI was listed as a location for a previous IBM trial, her research manager arrived on Monday morning to find sixty-seven patient messages waiting, sent over the weekend. Sixty-seven people with IBM who had heard there might be something to try.

*The patient community is ready,  
we just need to keep up."*

### **The necessity of community**

Goyal has served on The Myositis Association (TMA) Medical Advisory Board since 2016 including a stint as chair. She attends the annual patient conference, where she sits with patients at lunch and hears directly what the medical system is failing to provide. She describes that conference as essential education, not for the patients, though it is that too, but for her.

"I hear their voices," she says. "I hear what we need to do better."

TMA has also served as a referral pathway: patients who found their way to her clinic at UCI because TMA told them there was someone nearby who specialized in neuromuscular disease. One of those patients had been the leader of the San Diego support group, diagnosed with refractory polymyositis for fifteen years before Goyal examined her hands.

For patients navigating IBM now, Goyal's message is specific: ask for the second opinion. Ask for the NT5C1A antibody test if you carry a polymyositis diagnosis and have not responded to treatment. Know that the medical advisors listed on TMA's website are approachable, that they receive questions from patients nationally and internationally and take them seriously.

And know that someone, somewhere, has looked at the state of IBM treatment and decided that the answer "we don't have anything for you" is not acceptable.

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Across conversations

Myositis hides.

It hides from primary care physicians who have never encountered it. It hides from specialists who recognize it but reach for a more familiar label. It hides behind people who appear well but are failing on the inside. It also hides within itself: a cluster of related but distinct conditions that even experts continue to debate how to separate, treat, and name.

The seven people in this issue are not connected by a shared subtype or a shared outcome. They are connected by a shared problem. Each, from a different position, has spent years trying to be seen with a disease most people have never heard of.

The answers they have built are structural. Laurie Boyer converted her brother's death into thirteen years of organizational work at TMA. Holly Jones built the peer community she was told would never exist. Vance Robinson, without a treatment or therapeutic horizon, built a campaign that has reached millions. Iazmin Bauer Ventura developed a clinical model that refuses to let specialties remain siloed. Namita Goyal trained herself in muscle biopsy because her patients were waiting too long. Ed and Marilyn McGrath and Jen Swisher built solutions to their own diagnostic and treatment odysseys, then returned them to the community so others would not have to navigate the same path alone.

Community appears across every account as the organizing force, embodied here in The Myositis Association. It functions not as a headquarters but as a platform that makes patients findable to one another, connects researchers to the people most affected by their work, and has extended that reach for more than three decades.

Read together, these are not seven separate stories. They are seven views of the same work: building visibility where there was none, building connection where there was isolation, and narrowing, person by person, the distance between knowing and being believed.

SURFACED THEMES

1. The ongoing work of making illness legible.

The diagnostic odyssey does not end at diagnosis. Patients, care partners, and clinicians describe continuous labor translating the experience of disease into a form that medicine, institutions, and families can recognize as real. Surfaced by all voices.

2. The workaround as standard operating procedure.

Access to correct diagnosis and effective treatment consistently required an informal strategy the system did not provide by design: a personal connection, a backdoor referral, a conference panel, a self-ordered lab. Surfaced by Swisher, McGrath, Robinson, Ventura.

3. Demographic position shapes disease trajectory.

Who is diagnosed, when, and with what treatment is not determined solely by biology. Social position, geography, and demographic identity shape diagnostic timing, trial eligibility, and whether peer community is findable. Surfaced by Jones, Ventura, Goyal.

4. The gap between information and usable knowledge.

Information about myositis exists. What reaches patients at the moment they need it is a different and smaller set. MyoCon, TMA's annual conference appears in nearly every account as the place where that gap closes. Surfaced by McGrath, Goyal, Jones.

5. The unacknowledged work of living with serious illness.

Patients and care partners shoulder the hidden work of serious illness: domestic adjustments, emotional regulation, insurance navigation, and sustaining family stability. Surfaced by McGrath, Jones, Boyer.

6. Research as both promise and distance.

Patients are aware of what is in the pipeline. That awareness does not close the gap between where research is and where they are. For IBM patients in particular, the distance is not theoretical. Surfaced by Robinson, Goyal, McGrath, Jones.

7. Positivity as community norm and as pressure.

Every patient and care partner account describes a forward-looking orientation toward illness. The transcripts also record what that orientation is maintained against. The norm of positivity within this community may make certain kinds of distress harder to voice. Surfaced by Jones, Robinson, Boyer, McGrath, Swisher.

In their own words

"Yesterday's story is not today's story."

---Holly Jones

"I know what it's like to be a tired mom. This isn't it."

---Jen Swisher

"People see I haven't changed a bit, except I'm in a power wheelchair."

---Vance Robinson

"We don't want to suffer from it. We want to learn how to live with it."

---Ed McGrath

"There's no way your bucket isn't filled after attending a conference. It's what pushes us through every single day."

---Laurie Boyer

"Nobody is supposed to deal with any disease alone."

---Dr. Iazsmin Bauer Ventura

"This day and age, we should be doing more. We should be doing better."

---Dr. Namita Goyal



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