V BOLD REPORT

25+ YEARS OF IMPACT

Science. Innovation. Achievement.

VASCULITIS FOUNDATION®

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VF RESEARCH PROGRAM

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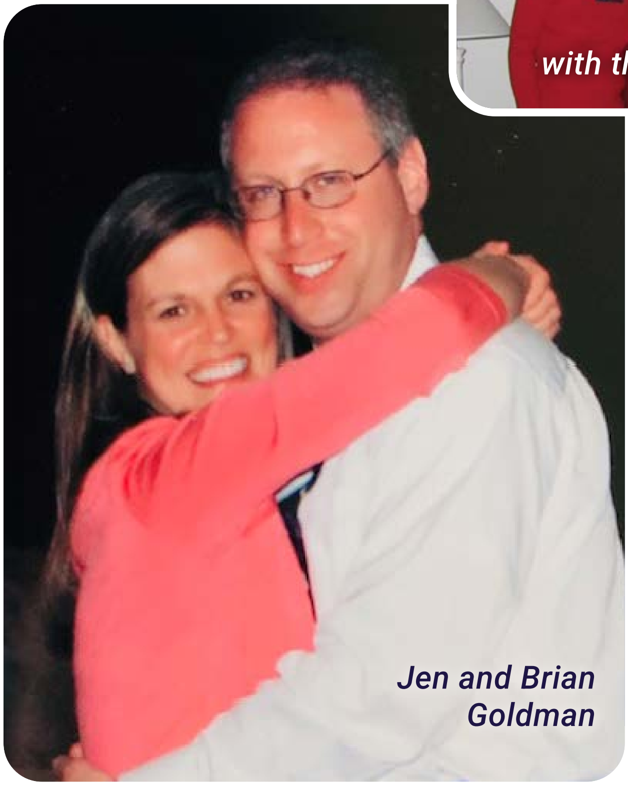
Brian Goldman


Jen & Brian Goldman with their son, Brandon


Jen and Brian Goldman

> *"Research is more than just data and studies—it's the key to unlocking hope for the future. To me, it's about finding solutions that could have saved my wife, and preventing others from experiencing the same loss. Every breakthrough brings us one step closer to a world where vasculitis no longer takes lives, and that's why I'm dedicated to supporting research."*
>
> **— Brian Goldman,**
> *President, VF Board of Directors*

VF RESEARCH STUDIES SUMMARY IN HISTORICAL CONTEXT


Jessica Olona

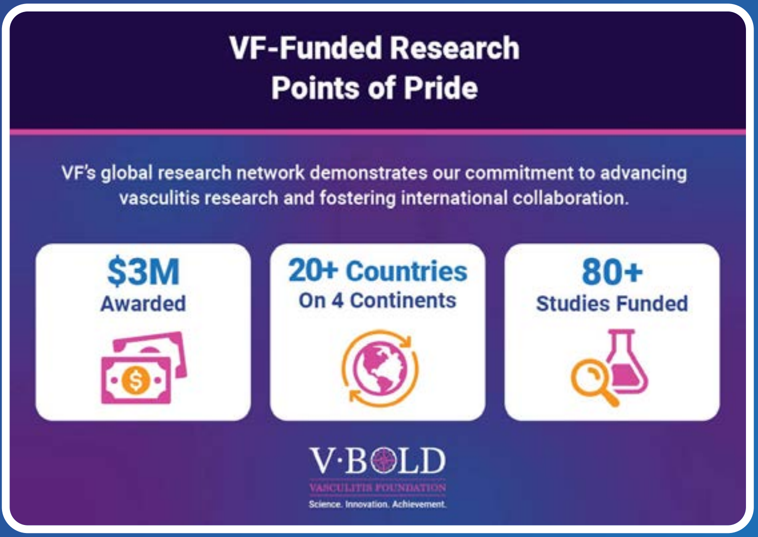
Over the past two decades, vasculitis research has evolved from scattered clinical observations into a growing field of targeted, translational science. The Vasculitis Foundation (VF), celebrating its 40th Anniversary, has played a pivotal role in that evolution — particularly by investing in early-career researchers through its VF Research Program. These efforts reflect a larger historical trend in rare disease advocacy: recognizing that breakthroughs often begin with foundational support for promising new minds.

The VF Research Program was launched in July 1999 at the request of **Nancy Olona**, who urged the WGA (now VF) Board of Directors to create a research initiative to complement its awareness and education efforts. Nancy made the appeal on behalf of her then six-year-old niece, **Jessica**, diagnosed with GPA just seven months earlier. Over the next three years, Nancy, her family, and friends raised more than $50,000 to support the new program and the first grant was awarded in 2002. To date the VF has funded over 80 studies and almost $3,000,000 in research.

ANCA-associated vasculitis (AAV) emerged as a clearer diagnostic category, with clinical trials like PEXIVAS (2020) providing global guidance on management. Now, VF-funded research is pushing beyond disease control toward personalized medicine, organ-specific targeting, and mechanistic understanding – hallmarks of 21st-century translational medicine.

The VF Young Investigator Award is an annual international grant competition supporting researchers within five years of fellowship, offering up to $50,000 over two years to advance pilot or ongoing vasculitis studies. Applications are peer-reviewed and ranked on research significance, design, evidence, investigator training, institutional support, and budget.

The VF currently funds two new studies per year as funding is available.


VF-Funded Research Points of Pride

VF's global research network demonstrates our commitment to advancing vasculitis research and fostering international collaboration.

$3M Awarded

20+ Countries On 4 Continents

80+ Studies Funded

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2025 YOUNG INVESTIGATOR AWARDEES

AUDRA HOROMANSKI, MD

Institution: *Stanford University School of Medicine, Palo Alto, California* 🇺🇸

Funded: *2025*

Focus: *Nationwide Analysis of Intrahepatic Cholestasis of Pregnancy in Patients with Systemic Vasculitis*

Dr. Audra Horomanski's journey into vasculitis research began during her residency and fellowship. **"I took care of a number of patients with vasculitis during my residency and fellowship who were very ill and made incredible recoveries with our current therapies,"** she recalled. This experience deeply impacted her, solidifying her commitment to the field. **"Seeing the difference we can make as rheumatologists in the lives of these patients always stuck with me, we have the privilege of helping people get their lives back."**

The VF's 2025 Young Investigator Award has been granted to Dr. Horomanski, a dedicated rheumatologist whose passion for improving the lives of vasculitis patients shines through her work. As the Director of the Stanford Vasculitis Clinic and Program Director of the Rheumatology Fellowship in the Division of Immunology and Rheumatology at Stanford University, she is at the forefront of patient care, medical education, and groundbreaking research.

As a Young Investigator, Dr. Horomanski is honored to be supported by the VF, an organization that **"does an incredible amount of advocacy for our patients and supports vasculitis research."** Her primary goal is to empower vasculitis patients in their family planning journeys. **"My big goal is to better understand how the different types of vasculitis and the needed treatments affect pregnancy so that we can better guide our patients in their family planning journeys,"** she stated. This critical area of research will provide much-needed guidance for patients and their healthcare providers.

Dr. Horomanski envisions her study contributing to a broader understanding of pregnancy in vasculitis patients. **"For a long time, patients with vasculitis were recommended to not pursue pregnancy due to the use of medications harmful to the fetus or disease manifestations that made pregnancy very high risk,"** she said. However, **"Improvements in therapy have really opened up the reproductive opportunities for our patients, but we are still lacking in knowledge on how to best counsel and monitor them during their pregnancy."**

2025 YOUNG INVESTIGATOR AWARDEES

PATRICK TAUS, MD

Institution: *University of North Carolina Kidney Center, Chapel Hill, North Carolina* 🇺🇸

Funded: *2025*

Focus: *Genome-wide Identification of ANCA Autoantigen Regulators*

Dr. Patrick Taus has dedicated his career to reimagining how we treat ANCA-associated vasculitis, a rare autoimmune disease that can cause life-threatening organ damage. Inspired by advances in cancer research, Dr. Taus believes that the same kind of precise, targeted therapies that have transformed oncology can be applied to autoimmune diseases—giving patients safer, more effective treatment options.

Currently, most vasculitis patients must rely on powerful drugs that broadly suppress the immune system. While effective, these treatments often come with serious risks, including infections and long-term side effects from steroids. Dr. Taus envisions a different future: one where therapies directly target the proteins driving vasculitis, leaving the rest of the immune system intact.

With support from the VF Young Investigator Award, he is using cutting-edge CRISPR technologies to study how one of these proteins—proteinase-3—is regulated in the body. By screening the entire human genome, Dr. Taus aims to uncover new pathways that could be precisely blocked, breaking the destructive inflammatory cycle without compromising patients' overall health.

Backed by the expertise and resources at the University of North Carolina at Chapel Hill, and guided by world-renowned mentors, Dr. Taus is positioned to make discoveries that could change the treatment landscape for ANCA vasculitis.

"I'm very thankful to be a recipient of a Young Investigator Award from the Vasculitis Foundation," Dr. Taus shared. **"My goal is to help bring patients closer to a future where they no longer have to fear the devastating side effects of current therapies."**

Your support makes this kind of bold, innovative research possible—offering real hope for better, safer treatments for people living with vasculitis.

RESEARCHER SPOTLIGHTS

ALEX VILLA-FORTE, MD

Impact on Research and Contributions to Vasculitis Care

OUR FIRST GRANT

The Vasculitis Foundation (VF) awarded its first research grant in 2002 to **Gary S. Hoffman, MD**, and his fellow, **Alexandra Villa-Forte, MD**, for their study **"Short-Term Cyclophosphamide Therapy in a Cohort of Over 200 Wegener's Granulomatosis Patients."** This landmark retrospective review of 12 years of patient data helped change the standard of care by demonstrating that shorter courses of cyclophosphamide, followed by methotrexate, could effectively treat severe disease while reducing long-term toxicity. The results were published in Medicine in September 2007.

Dr. Villa-Forte began her career with a strong focus on vasculitis research, later expanding her efforts to improve access to specialized care for patients. Her clinical and academic work has shaped practice in the field—through studies comparing treatments for GPA (Granulomatosis with Polyangiitis) and uncovering the high risk of recurrent venous thrombosis in GPA patients.

Beyond her research, Dr. Villa-Forte has trained and mentored rheumatology and vasculitis fellows, lectured widely, and published extensively. She credits VF's early support as pivotal in her career and encourages future specialists to seek mentorship and advanced training. She emphasizes that investing in vasculitis research and education is key to improving outcomes, expanding access to expert care, and driving progress in treatment.

In October 2025, Dr. Villa-Forte joined the Vasculitis Foundation's Board of Directors, bringing her extensive clinical expertise and deep commitment to the vasculitis community into a new leadership role. As a Board member, Dr. Villa-Forte now helps shape the Foundation's strategic direction, ensuring that patient voices and clinical perspectives are at the heart of every initiative.

VF FUNDED RESEARCH 2017-2024

JESSICA BLOOM, MD, MSCS

Institution: *Children's Hospital Colorado, Aurora, Colorado*

Funded: *2024*

Focus: *Expanding Pediatric Data and Enrollment in the VPPRN Vasculitis Registry*

Dr. Jessica Bloom's goal is to increase pediatric patient enrollment by working with the Vasculitis Patient-Powered Research Network (VPPRN) to enhance engagement among pediatric providers and patients on both a national and international level. This expansion project includes addressing which patient-reported outcome measures are most relevant and appropriate for use with children. By expanding the VPPRN's pediatric data, Dr. Bloom aims to enable the development of more significant and relevant studies concerning the impact of vasculitis in children and young adults.

Historical Significance: This work is a pivotal advancement in pediatric vasculitis research, filling a critical data gap. By significantly expanding the VPPRN for children, her efforts will enable more targeted studies and improved treatments for young patients globally.

Continuing the global collaboration ethos born from the pandemic, **Dr. Cecillia Barnini** is studying kidney biopsies to compare AAV with other renal diseases. Her goal is to uncover disease mechanisms that may lead to earlier, personalized interventions.

Historical Significance:
Dr. Barnini's work echoes the shift in medical science from symptom control to root-cause exploration, a defining movement in modern immunology.

CECILIA BARNINI, MD

Institution: *Medical University of Innsbruck, University Medical Center Groningen, Austria/Netherlands*

Funded: *2024*

Focus: *Kidney Involvement in ANCA-Associated Vasculitis*

VF FUNDED RESEARCH 2017-2024

PEI-YU CHEN, BS, MS, PHD

Institution: *Yale University, New Haven, Connecticut* 🇺🇸

Funded: *2023*

Focus: *siRNA Nanoparticle Therapy Targeting TGFβ in Endothelial Cells*

"

During my research study, I made a discovery that changed the way we think about blood vessel damage in ANCA-associated vasculitis. We found that TGF-beta — normally a **"helper"** signal in the body — can turn harmful when it goes out of control, like a fire meant to warm the house that instead burns it down. This helped explain why blood vessels become inflamed and damaged in vasculitis.

Even more importantly, we developed a new way to **"cool the fire"**: tiny medicine-carrying particles that deliver treatment directly to the blood vessel lining. In our studies, this approach not only calmed inflammation but also started healing the vessel walls. Seeing this potential shift from basic science to real solutions showed me just how much hope research can bring.

The study also gave me the confidence to pursue bold, high-risk ideas. With my mentors' support, I explored unconventional paths that ultimately led to creating a brand-new lipid nanoparticle delivery system. This platform has already been tested safely in monkeys and could one day deliver personalized therapies directly to inflamed vessels — offering treatments that are more effective and less toxic than current options.

My research has also shifted the field's understanding of vasculitis: we showed that the blood vessel lining (endothelium) is not just a passive victim of inflammation, but an active driver. This insight explains why past attempts to block TGF-beta globally failed — and why our precision targeting approach could succeed.

Beyond the lab, I've shared this work at national and international meetings, collaborating with experts across immunology, vascular biology, engineering, and clinical medicine. These conversations have sparked new collaborations and inspired others to think differently about how to treat vascular inflammation.

The VF's support was absolutely critical. Their willingness to invest in a high-risk, high-reward idea gave me the freedom to think differently — and that has made all the difference. Every dollar given fuels not just research, but hope — the hope that one day, people with vasculitis will have safer, more effective, and more personalized treatment options.

Historical Significance: Vasculitis is complex, but that means there are many opportunities to make a real impact — as long as we keep patients at the center of our motivation. "

VF FUNDED RESEARCH 2017-2024

ALVISE BERTI, MD

Institution: *University of Trento, Italy* 🇮🇹

Funded: *2023*

Focus: *Assessing Transcriptomic Profile, Immunoglobulin Repertory and Identification of Proteinase 3-Specific Autoantibodies from Auto-Reactive B Cells in Healthy Subjects and Patients with ANCA-Associated Vasculitis*

Dr. Alvise Berti's VCRC-VF fellowship provided crucial training as a physician-scientist, with mentorship being the cornerstone of his development. Beyond his primary mentor, the fellowship connected him with a network of physician-scientists who significantly contributed to his professional growth.

The technical skills gained — particularly in study conception, analysis, statistics, and data interpretation — proved invaluable for conducting impactful research. This training solidified his research focus on vasculitis, which he has continued to pursue after his VCRC-VF fellowship training.

Dr. Berti's research work has improved understanding of prognosis for specific vasculitis manifestations, including: renal manifestations in ANCA-associated vasculitis and long-term respiratory characterization in EGPA. His translational research has helped explain B cell pathophysiology in ANCA vasculitis, contributing to potential future treatment advances.

Today, Dr. Berti serves as a vasculitis expert in his region, creating a referral network with other specialists (ENT, internal medicine, pulmonologists, nephrologists, and rheumatologists) who seek his expertise for treatment advice and follow-up care for vasculitis patients.

VF FUNDED RESEARCH 2017-2024

DAVID MASSICOTTE-AZARNIOUCH, MD

Institution: *University of Ottawa, Canada*

Funded: *2023*

Focus: *Steroid-sparing Approaches in AAV (SAFE-T trial)*

Building on PEXIVAS, **Dr. David Massicotte-Azarniouch**'s research tackles one of vasculitis care's most persistent problems: over-reliance on high-dose steroids. His work seeks to validate a globally accessible, low-steroid protocol using existing immunosuppressants—critical in making safer treatment a realistic standard of care worldwide, not just in wealthy nations.

Historical Significance: This study represents a significant effort to overturn decades of high-dose steroid reliance in AAV treatment.

Dr. Lynn Fussner's project investigates how genetics and immune signaling contribute to disease activity and treatment response. It aligns with current trends toward biomarker discovery and genotype-guided care, reflecting how patient-tailored approaches are reshaping chronic disease management, even in rare autoimmune diseases like vasculitis.

Historical Significance: AAV treatment has relied on empirical approaches; this project signals a new era of biomarker-driven, precision medicine for vasculitis.

LYNN A. FUSSNER, MD

Institution: *The Ohio State University, Columbus, Ohio*

Funded: *2021*

Focus: *Monocytes, PR3, & Alpha-1 Antitrypsin in AAV*

VF FUNDED RESEARCH 2017-2024

ERIC GAPUD, MD, PHD

Institution: *Johns Hopkins University, Baltimore, Maryland* 🇺🇸

Funded: *2024*

Focus: *Immune Signaling in ANCA Vasculitis and Clinical Subtyping*

Diagnosed with an autoimmune disease during medical school, **Dr. Eric Gapud** brings unique empathy to his research and clinical practice. Supported by the VF's **Dr. Darwin James Liao Memorial Fund**, his work explores alternative immune mechanisms beyond cell-killing, suggesting that current models of ANCA-associated vasculitis (AAV) may be incomplete. His goal is to subtype patients based on immune profiles, enabling personalized therapy selection—a modern evolution of vasculitis care in line with precision medicine trends. Dr. Gapud represents a new era of clinician-scientists with lived experience, blending human insight with bench-to-bedside research.

Historical Significance: His work challenges long-held beliefs about ANCA-associated vasculitis, moving the field towards a more nuanced understanding of the disease and paving the way for a new era of personalized medicine in vasculitis care.

Tocilizumab (TCZ) was a breakthrough in treating giant cell arteritis (GCA), enabling reduced steroid use. But 40% of patients relapse on TCZ. **Dr. Maria Cid**'s VF-funded study investigated arterial tissue response to TCZ and sought biomarkers to predict effectiveness, reducing trial-and-error prescribing.

Historical Significance:
Dr. Cid's work addresses the critical need to understand why biologics work for some and not others, a defining challenge of 21st-century rheumatology.

MARIA C. CID, MD

Institution: *Hospital Clínic Barcelona, Spain* 🇪🇸

Funded: *2019*

Focus: *Predictors of Response to Tocilizumab (IL-6 blockade) in GCA*

VF FUNDED RESEARCH 2017-2024

DAN JANE-WIT, MD, PHD

Institution: Yale University, New Haven, Connecticut 🇺🇸

Funded: 2018

Focus: Endothelial Cell Inflammasomes in ANCA-Associated Vasculitis

"

During my research study, I gained expertise in translational methodologies to study human immune responses in vasculitis. These skills—particularly coupling high-throughput studies with bioinformatic algorithms—have been invaluable in shaping my career as a physician-scientist.

I was fortunate to have the mentorship of Dr. Jordan Pober and Dr. George Tellides, whose support continues to guide my research path. Their mentorship encouraged me to pursue a career integrating patient care and scientific discovery. Today, I treat cardiology patients, including those with transplant-related vasculitis, while leading a research program that investigates the molecular drivers of vascular inflammation.

One of the most meaningful outcomes of my vasculitis research was the discovery of a gene called ZFYVE21, which I am now studying for its role in vascular inflammation. I hope these discoveries will one day reveal new therapeutic targets for vasculitis and related conditions.

Beyond the lab, I am committed to mentoring the next generation of physician-scientists. I serve on thesis committees for students at all levels and mentor postdoctoral fellows through organizations such as the Yale Postdoctoral Association, the American Transplant Association, and the Yale BBS Diversity and Inclusion Collective.

Vasculitis research is a rewarding but challenging field. **My advice to future researchers is to remain persistent and not be discouraged by setbacks—scientific progress is often built on persistence. Looking ahead, I see tremendous opportunities in areas such as vascular aging, tissue engineering, and immune modulation.**

I remain grateful to the Vasculitis Foundation for supporting my development at an early and formative stage. That support gave me the foundation to pursue innovative and high-risk research, which has since been sustained by national funding agencies.

"

VF FUNDED RESEARCH 2017-2024

SOLBRITT RANTAPÄÄ DAHLQVIST, MD, PHD

Institution: *Umeå University, Stockholm, Sweden* 🇸🇪

Funded: *2019*

Focus: *Pre-clinical AAV Development via Microbiome, Antibodies, and Genetics*

This landmark study examined blood samples collected years before disease onset, comparing individuals who developed AAV with matched healthy controls. By analyzing microbial DNA, antibodies, and protein markers, the team hoped to identify early predictors of disease.

Historical Significance: This work was among the first to explore preclinical autoimmune disease trajectories in vasculitis, potentially enabling early intervention or even prevention—a goal long considered unreachable.

Dr. Sonia Sharma's team explored how loss of ADA2 enzyme function disrupts immune metabolism in DADA2, a rare genetic vasculitis. This study aimed to reveal metabolism-targeted therapies that dampen pro-inflammatory pathways across multiple vasculitis syndromes.

Historical Significance: This positions vasculitis as a metabolic disorder — a paradigm-shifting concept with potential relevance beyond rare monogenic forms.

SONIA SHARMA, PHD

Institution: *La Jolla Institute for Immunology, La Jolla, California* 🇺🇸

Funded: *2018*

Focus: *Metabolic Dysregulation in DADA2 Vasculitis*

VF FUNDED RESEARCH 2017-2024

LAURA MOI, MD & EUVAS COUNCIL

Institution: *European Vasculitis Society/EUVAS*

Funded: *2018*

Focus: *Long-Term Outcomes in ANCA Vasculitis – EUVAS Inception Cohort*

Dr. Laura Moi led a long-term follow-up of over 900 AAV patients recruited in landmark EUVAS trials from 1995–2010. The team analyzed cancer risk, renal outcomes, drug exposure, relapse, and mortality—data critical to shaping future guidelines.

Historical Significance: This was the longest-running longitudinal vasculitis cohort globally. It transformed past clinical trial data into a predictive tool for 21st-century risk modeling.

DIVI CORNEC, MD, PHD

Institution: *Mayo Clinic Rochester & Brest University, France*

Funded: *2017*

Focus: *PR3-Specific B Cells in AAV*

This study characterized the PR3-specific B cells responsible for generating ANCA autoantibodies. Using a novel detection method, **Dr. Cornec**'s team aspired to determine whether these B cells predict relapse risk, potentially guiding personalized use of B-cell-depleting drugs.

Historical Significance: First project to track ANCA-producing B cells in real time—a possible future biomarker for individualized therapy decisions.

MARY H. FOSTER, MD

Institution: *Duke University, Raleigh, North Carolina*

Funded: *2017*

Focus: *Humanized Models of Gene-Environment Interactions in ANCA Vasculitis*

This study aimed to develop the first dual-humanized animal model of AAV—incorporating both human immune cells and human susceptibility genes—exposed to environmental triggers (e.g., silica).

Historical Significance: This may be the first scalable model for studying real-world gene-environment interaction in vasculitis, crucial for drug development and prevention research.

VF FUNDED RESEARCH 2017-2024

MARK GORELIK, MD

Institution: *Baylor College of Medicine, Houston, Texas*

Funded: *2017*

Focus: *Follistatin-Like-1 Blockade in Kawasaki Disease*

Dr. Mark Gorelik targeted Follistatin-like-1, a molecule found elevated in children who develop coronary aneurysms in Kawasaki disease. Blocking this molecule may prevent long-term heart complications.

Historical Significance: This project aimed to revolutionize Kawasaki care by stopping aneurysm development early, replacing the current one-size-fits-all approach with targeted intervention.

Building on previous work by OMERACT, the study incorporated input from patients, caregivers, clinicians, researchers, industry leaders, and policymakers through a three-round survey process. Participants reviewed and prioritized AAV-related outcomes to determine which are most important for measuring in clinical trials. The final ICF-based AAV Core Set included outcomes endorsed by at least 70% of participants in any group.

Historical Significance: This effort ensured that future clinical trials reflect outcomes that matter most to patients, helping guide more patient-centered vasculitis research and treatment evaluation.

NATALIYA MILMAN, MD, MSC, FRCP(C)

Institution: *Ottawa Hospital Research Institute, Canada*

Funded: *2017*

Focus: *Finalize an Updated ICF Core Set for ANCA-associated Vasculitis (AAV)*

VF FUNDED RESEARCH 2002-2016

2016

Prof. Dr. Peter Heeringa, University Medical Center Groningen, Netherlands
Prof. Mark Little, Trinity Health Kidney Centre, Dublin, Ireland
Robert Micheletti, MD, University of Pennsylvania, Philadelphia, Pennsylvania

2015

Jonathan Choy, PhD, Simon Fraser University, Burnaby, Canada
Susan Jick, DSc, Boston University, Massachusetts
Renate Kain, MD, PhD, Medical University of Vienna, Austria
Davide Martorana, PhD, University Hospital of Parma, Italy
Parameswaran Nair, MD, PhD, FRCP, FRCPC, McMaster University, Hamilton, Canada

2014

Lindsay Lally, MD, Hospital for Special Surgery, New York City, New York
Kim Liang, MD, University of Pittsburgh, Pennsylvania
Carola Vinuesa, MD, MSc, PhD, Australian National University, Canberra, Australia

2013

Susanne Benseler, MD, MSCE, PhD, The Hospital for Sick Children, University of Toronto, Canada
Paul Brogan, BSc, MBCHB, MRCPCH, MSc, Ph.D., FRCPCH, UCL Institute of Child Health and Great Ormond Street Hospital NHS Foundation Trust, London, United Kingdom
Ritu Chakravarti, PhD, Cleveland Clinic Lerner Research Institute, Cleveland, Ohio

2012

Shadi Swaidani, PhD, Cleveland Clinic Lerner Research Institute, Cleveland, Ohio
Sharon Chung, MD, University of California, San Francisco, California
Cornelia Weyand, MD, PhD, Stanford University School of Medicine, Stanford, California
Carolyn Thorpe, PhD, MPH, University of Pittsburgh, Pennsylvania

2011

Felipe Andrade, MD, PhD, Johns Hopkins University, Baltimore, Maryland

VF FUNDED RESEARCH 2002-2016 *CONTINUED*

2010

Amr H. Sawalha, MD, University of Oklahoma Health Sciences Center, Oklahoma City, Oklahoma

Megan E. B. Clowse, MD, Duke University, Raleigh, North Carolina

Raashid Ahmed Luqmani, MD, Nuffield Department of Orthopaedics Rheumatology & Musculoskeletal Science, Oxford, England

2009

Jianguo Liu, MD, Saint Louis University School of Medicine, St. Louis, Missouri

2008

C.M. Weyand, MD, Emory University, Atlanta, Georgia

Neil Bowles, PhD, Institute of Human Genetics, University of Utah, Salt Lake City, Utah

Alan Salama, MBBS, PhD, FRCP, Renal Section, Division of Medicine Imperial College, London, England

2007

Jochen Zwerina, MD, University of Erlangen, Germany

Patrick Nachman, MD, University of North Carolina Kidney Center, Chapel Hill, North Carolina

2006

Rula Hajj-Ali, MD, Cleveland Clinic, Cleveland, Ohio

Antje Mueller, MD, Csernok, MD, and **Peter Lamphrect, MD,** University Hospital of Schleswig-Holstein, Campus Lübeck, and Rheumaklinik, Lübeck, Germany

2005

David A. Cabral, MBBS, FRCP(C), British Columbia Children's Hospital, Vancouver, Canada

Nadine Tanenbaum, MD, Duke University, Raleigh, North Carolina

Peer Malte Aries, MD, and Wolfgang L. Gross, MD, PhD, University Hospital of Schleswig-Holstein, Campus Lübeck, and Rheumaklinik, Lübeck, Germany

Daniel Albert, MD, University of Pennsylvania School of Medicine, Philadelphia, Pennsylvania

VF FUNDED RESEARCH 2002-2016 *CONTINUED*

2004

Robert DeVellis, PhD and Delesha Carpenter, PhD, MSPH, University of North Carolina, Chapel Hill, North Carolina

Katherine Siminovitch, MD, FRCP(C), ABIM, Mount Sinai Hospital, Toronto, Canada

Wolfgang L. Gross, MD, PhD, and **Peter Lamprecht, MD,** University Hospital of Schleswig-Holstein, Campus Lübeck, and Rheumaklinik, Lübeck, Germany

2003

Deborah Stearns-Kurosawa, PhD, Oklahoma Medical Research Foundation, Oklahoma City, Oklahom

2002

Robert Inman, MD, University of Toronto, Canada

BUILDING A RESEARCH LEGACY FOR THE FUTURE

Together, these projects reflect the Vasculitis Foundation's strategic, global approach to nurturing talent and innovation. By supporting researchers across career stages and continents—from Johns Hopkins to Barcelona to Umeå—the VF is shaping the future of vasculitis treatment through:

- ***Mechanistic clarity***
- ***Biomarker discovery***
- ***Therapy personalization***
- ***Prevention research***
- ***Real-world accessibility***

From steroid-heavy survival to targeted, tolerable therapies, the arc of vasculitis care is changing—and these researchers are at the forefront.

VCRC-VF FELLOWSHIP PROGRAM

ILYA PECKERMAN

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VASCULITIS FOUNDATION
Science. Innovation. Achievement.

As the VF celebrates it's 40th Anniversary, we are proud to reflect on the remarkable progress we've made—together with our members, donors, and medical and research partners—in transforming the lives of people affected by vasculitis. While we honor our past, we remain focused on the future: continuing to drive forward programs that support patients, educate medical professionals, and advance research.

A cornerstone of this mission has been addressing the critical need for training skilled healthcare providers who can diagnose and treat vasculitis effectively. Early detection and expert treatment are vital for helping patients regain their health and live full, successful lives. Yet, a significant shortage of physician-investigators equipped to lead the charge in vasculitis care and research persists.

> *"The VF's support for training and research is crucial to sustain the pipeline of clinicians and investigators focused on vasculitis. Training early-career investigators or sub-specialized clinicians is not an easy task, and in the current landscape, efforts like the one from the VF are determinant."*
>
> **— Sebastian Sattui, MD, MS** ***and VF Board Member***

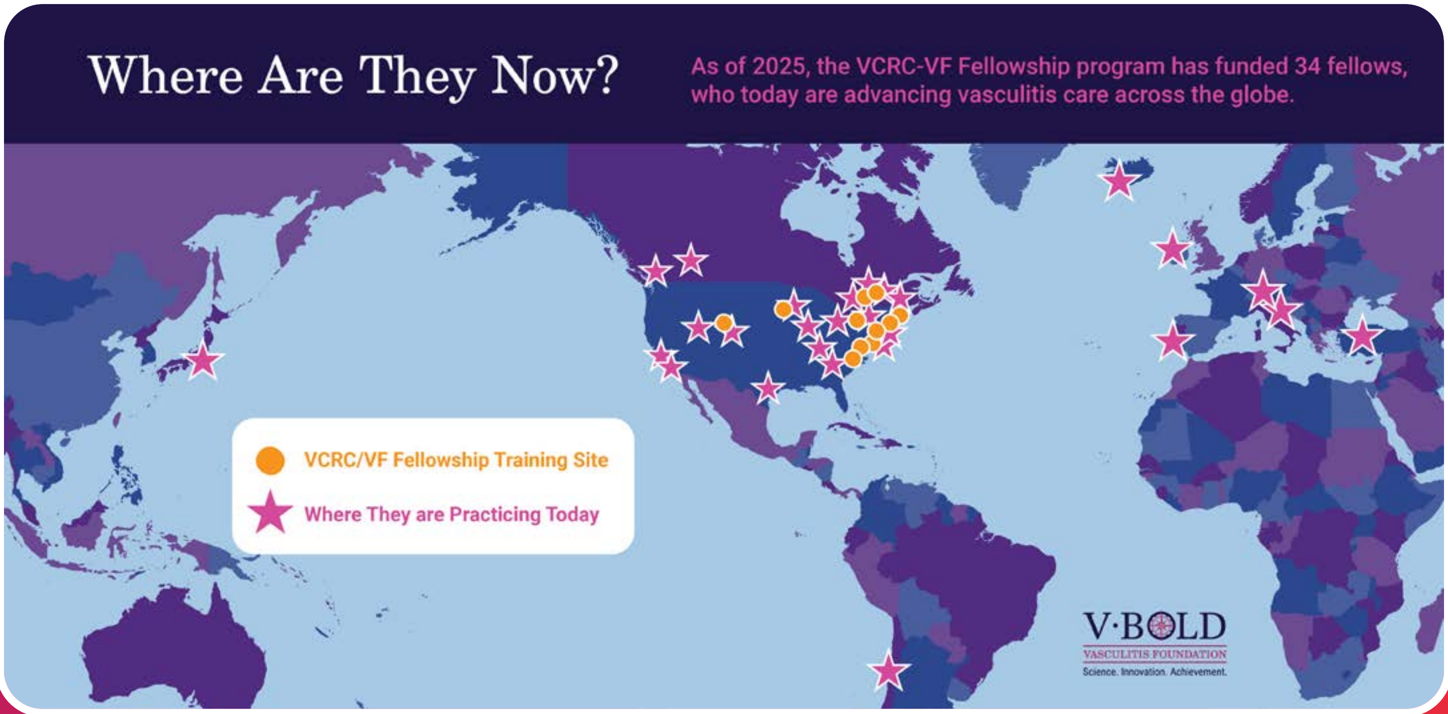
TWO DECADES OF IMPACT:
BUILDING A GLOBAL NETWORK OF VASCULITIS EXPERTISE

Established in 2005, the VCRC-VF Fellowship is a mentored training program of up to two years for physician-investigators who have a strong interest in vasculitis. The fellowship was established in partnership between the Vasculitis Clinical Research Consortium (VCRC) and the Vasculitis Foundation (VF).

The fellowship provides a period of specialized training with an emphasis on clinical and/or translational patient-oriented clinical investigation. Fellows are trained by senior faculty mentors at VCRC-affiliated sites in North America that have established distinct clinical and research programs in vasculitis.

Since the program's inception, we have funded 34 fellowships at many of the world's most respected institutions, including:

- ***Boston University***
- ***Children's Hospital Colorado***
- ***Cleveland Clinic***
- ***Hospital for Special Surgery***
- ***Johns Hopkins Medical Center***
- ***Mayo Clinic Rochester***
- ***McMaster University***
- ***National Institutes of Health (NIAMS)***
- ***The Johns Hopkins Hospital***
- ***University of North Carolina***
- ***University of Pennsylvania***
- ***University of Toronto***



Where Are They Now?

As of 2025, the VCRC-VF Fellowship program has funded 34 fellows, who today are advancing vasculitis care across the globe.

EXPANDING ACCESS TO EXPERT CARE AROUND THE WORLD

A key goal of the VCRC-VF Fellowship is to train physician-investigators not only to provide exceptional care and conduct groundbreaking research—but also to establish new vasculitis programs in underserved regions.

Thanks to this initiative, VF-trained experts have helped launch or lead vasculitis centers in Canada, Chile, France, Iceland, Ireland, Italy, Japan, Portugal, Switzerland, Turkey, and throughout the United States. Combined, the fellows have published over 650 journal articles.

This global network of trained specialists is a testament to the power of focused investment in medical education. By equipping fellows with the tools and mentorship they need, we are not only improving outcomes for today's patients—we are building a legacy of care that will reach further and faster for generations to come.

Pamela Pekerman

THE POWER OF DONOR IMPACT

Our fellowships have been made possible by the vision and generosity of our donors.

The **Ilya Peckerman Fellowship Award**, established in 2010 by Ilya's daughter Pamela and family/ friends provides funding for research and fellows around the world. The goal of the fund is to further the expertise and accessibility to treatment for patients with vasculitis.

Darwin J. Liao

In 2019, the **Darwin James Liao, M.D., Fellowship**, created by the late Dr. Liao's family supported a special award for Dr. Eric J. Gapud's fellowship at The Johns Hopkins Vasculitis Center. Today, Dr. Gapud serves as Clinical Team Leader at the U.S. Food and Drug Administration (FDA) and continues his vasculitis research at the NIH, demonstrating the far-reaching impact of a single investment.

VOICES FROM THE FIELD:
THE LASTING IMPACT OF THE VF FELLOWSHIP

We recently surveyed our former fellows to learn how the fellowship program shaped their careers and advanced the field of vasculitis. Their responses paint a powerful picture of the fellowship's ripple effect, highlighting how investing in physician-investigators transforms the entire landscape of care.

A LAUNCHPAD FOR CAREERS AND A CATALYST FOR RESEARCH

Fellows overwhelmingly reported that the program was the single most important factor in their decision to pursue a career in vasculitis. The protected time for research, dedicated mentorship, and exposure to a wide variety of complex cases gave them the confidence and expertise to become leaders. This support enabled them to tackle high-risk, high-reward research projects—from identifying biomarkers to shaping new treatment protocols—that have directly improved patient outcomes.

BUILDING A COLLABORATIVE GLOBAL COMMUNITY

The fellowship does more than train individuals; it builds a community. Fellows spoke of transformative mentorships that evolved into lifelong collaborations. The connections forged through the VF and VCRC network fosters an environment where knowledge is shared freely across centers and continents. This collaborative spirit extends to patients, who are seen as integral partners in the research process.

CREATING HUBS OF EXPERTISE

Perhaps the most significant impact is the "ripple effect" of the training. Armed with specialized skills, former fellows have established new vasculitis clinics in areas where none existed, creating vital hubs for patient care and local medical education. They now mentor their own trainees, teach at national and international conferences, and develop clinical guidelines, ensuring that vasculitis expertise continues to spread and benefit communities everywhere.

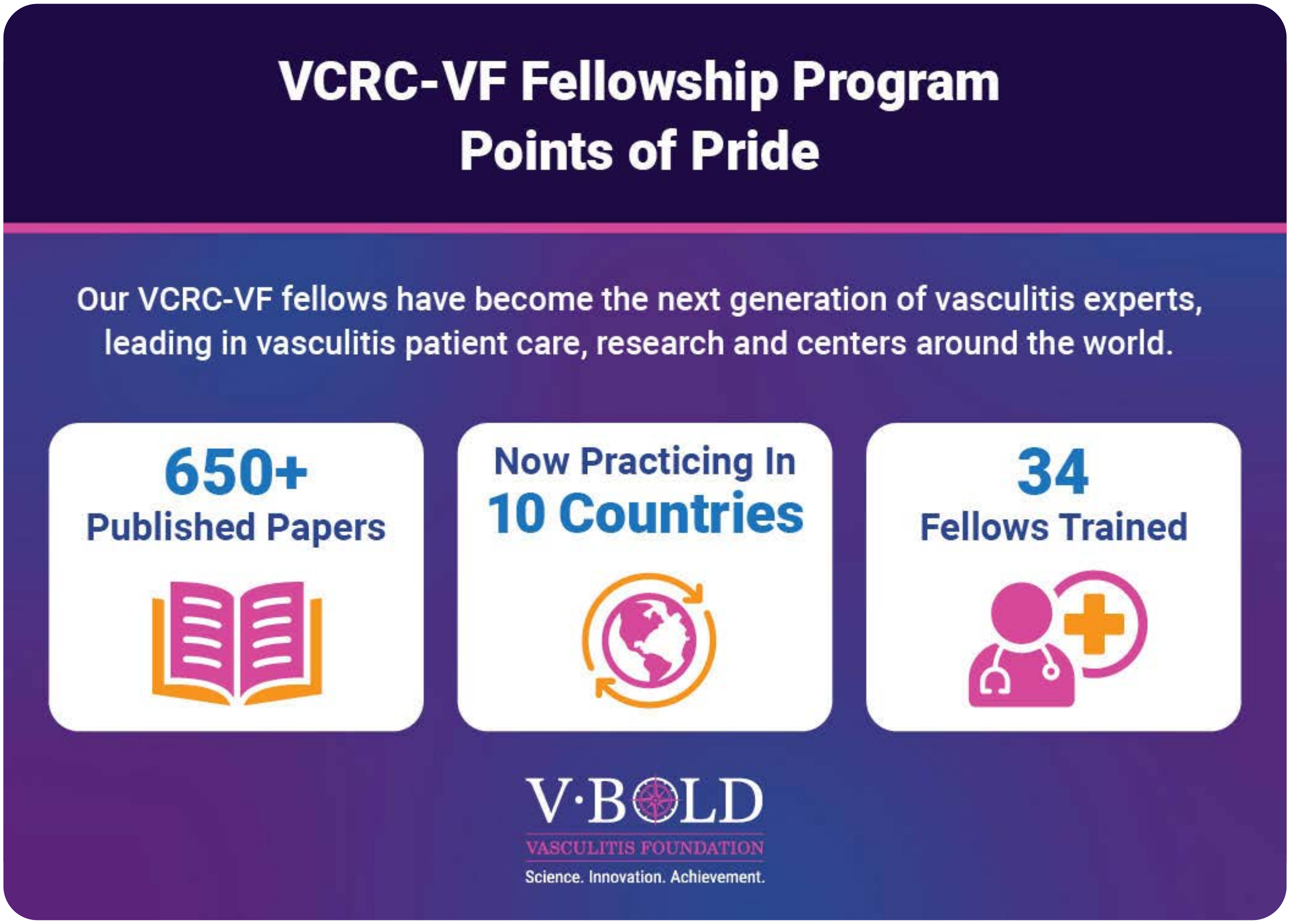
KEY OPPORTUNITIES FOR THE FUTURE

Based on their experiences, our fellows identified several critical areas for future focus:

Unanswered Scientific Questions: Prioritize research into what causes vasculitis, how to personalize treatment to prevent relapse, and ultimately, how to find a cure.

Training and Education Needs: Expand educational outreach to general practitioners and other specialists to shorten the time to diagnosis. Continue growing the fellowship program to build a robust pipeline of experts.

Global Care Delivery: Develop innovative models to deliver specialized care to patients in rural and underserved areas, including low- and middle-income countries.



VCRC-VF Fellowship Program
Points of Pride

Our VCRC-VF fellows have become the next generation of vasculitis experts, leading in vasculitis patient care, research and centers around the world.

650+
Published Papers

Now Practicing In
10 Countries

34
Fellows Trained

FELLOW SPOTLIGHTS

ALVISE BERTI, MD, PHD

2019–2021 Fellowship: *Mayo Clinic Rochester*

Now: *Consultant, University of Trento,*
Santa Chiara Hospital, Trento, Italy 🇮🇹

Dr. Alvise Berti describes his vasculitis fellowship as **"fundamental"** to his career path, providing the specialized training and mentorship that helped him develop advanced skills in study design, data analysis, and interpretation. Through the VCRC-VF program, he gained access to a vibrant network of physician-scientists, enabling research that has advanced understanding of disease prognosis — particularly in renal and respiratory involvement — and illuminated B cell mechanisms in ANCA vasculitis.

Since returning to Italy, Dr. Berti has served as a regional expert for physicians treating complex vasculitis cases, offering guidance and follow-up care that improves patient outcomes and expands knowledge across specialties. He encourages future fellows to **"work hard to make the most of it"** and suggests adding patient and donor presentations to highlight the fellowship's impact. His journey reflects how donor-supported training creates long-lasting change in vasculitis care and research.

> In 2023, Dr. Berti was awarded a two-year grant through the VF's Young Investigator Program, for a multi-country research collaboration **"Assessing Transcriptomic Profile, Immunoglobulin Repertory and Identification of Proteinase 3-Specific Autoantibodies from Auto-Reactive B Cells in Healthy Subjects and Patients with ANCA-Associated Vasculitis."**

"work hard to make the most of it"

FELLOW SPOTLIGHTS

KEVIN BYRAM, MD

***2017–2018 Fellowship:** Cleveland Clinic Center for Vasculitis Care & Research*

***Now:** Associate Professor of Medicine, Department of Medicine, Division of Rheumatology and Immunology,*
Co-director Vanderbilt Vasculitis Center 🇺🇸

Dr. Kevin Byram's fellowship provided the clinical expertise, mentorship, and confidence to manage highly complex vasculitis patients—skills that now underpin his leadership of Tennessee's only dedicated vasculitis center. Guided by Dr. Carol Langford and VF collaborators, he built lasting professional connections that have fueled both his clinical practice and research contributions, including his work on the 2021 ACR/VF Vasculitis Guidelines Project.

Dr. Byram emphasizes that **"it's hard to measure the full ripple effect of early-career support, but it's real,"** noting that giving a young physician the chance to go deeper into vasculitis creates benefits for the entire patient community. His career is a direct example of how fellowship opportunities translate into new centers of care, expanded access for patients, and nationwide advances in clinical standards.

Today Dr. Byram, past president and current member of the VF Board of Directors, has served as co-chair of the VF Medical Education and Research Committee for the past four years. Under his leadership, the organization weathered the global Covid-19 pandemic and established a board-designated endowment to ensure the VF will be able to fulfill its mission for years to come.

> ***"it's hard to measure the full ripple effect of early-career support, but it's real"***

FELLOW SPOTLIGHTS

MOHANAD ELFISHAWI, MD, MS

2022–2023 Fellowship:
Mayo Clinic Rochester

Now: *Assistant Professor of Medicine, Division of Rheumatic & Autoimmune Diseases University of Minnesota*

🇺🇸

For **Dr. Mohanad Elfishawi**, the most significant impact of his fellowship was **"developing a deeper understanding of the clinical complexities of vasculitis and recognizing the essential role of multidisciplinary, patient-centered care."** Mentored by leading experts across rheumatology, pulmonology, vascular medicine, and nephrology, he gained a broad, integrated perspective on managing these complex diseases.

Now at the University of Minnesota, Dr. Elfishawi has established a vasculitis patient cohort and co-founded a dedicated clinic, bringing specialized care to an underserved population. His research has revealed the long-term aortic aneurysm risks in giant cell arteritis, informing monitoring strategies worldwide. He continues to raise awareness beyond rheumatology, stressing that **"early detection is key to preventing irreversible organ damage,"** and credits VF support for making his career path possible.

Dr. Peter Grayson's fellowship combined advanced clinical experience with a master's degree in epidemiology and biostatistics, creating a foundation for a career in high-impact translational research. Under the mentorship of Dr. Peter Merkel, he built the skills and connections that led to a faculty role and the eventual launch of the NIH Vasculitis Translational Research Program.

At the NIH, Dr. Grayson's team has co-discovered VEXAS syndrome, pioneered molecular imaging in large-vessel vasculitis, and evaluated over 1,000 patients from around the world. Dr. Grayson calls vasculitis research **"a welcoming, supportive community with many unanswered questions,"** and emphasizes that philanthropic support during early career stages can determine whether a promising investigator remains in the field.

PETER GRAYSON, MD, MSC

2006–2007 Fellowship:
Boston University

Now: *Senior Investigator, National Institutes of Health; Chief, Vasculitis Translational Research Program*

🇺🇸

FELLOW SPOTLIGHTS

MATS JUNEK, MD, PHD(C), FRCPC

2023–2024 Fellowship: *McMaster University, Vasculitis Research Group, Hamilton, Ontario, Canada*

Now: *McMaster University, Vasculitis & Rheumatology at McMaster University MVRG* 🇺🇸

With VF fellowship support, **Dr. Mats Junek** gained the time and resources to grow as a clinician-scientist, building essential research skills, clinical expertise, and a global network of collaborators. He describes working with the VCRC as a true **“standing on the shoulders of giants”** moment in his training.

His research has already advanced patient care—improving diagnosis in giant cell arteritis (GCA) and reshaping how physicians understand relapse risk in ANCA-associated vasculitis. By helping estimate an individual’s likelihood of relapse, Dr. Junek is able to guide patients with clearer information and make more confident treatment decisions.

Beyond research, he shares his expertise widely, including as part of an international working group on MRI in GCA and through teaching physicians locally and nationally. **“Vasculitis research always starts and ends with the patient,”** he says. **“Supporting trainees is critical to ensure people living with vasculitis receive the best care possible. We have only just begun to understand these diseases—your support makes the next breakthroughs possible.”**

> ***“Supporting trainees is critical to ensure people living with vasculitis receive the best care possible.”***

FELLOW SPOTLIGHTS

TANAZ KERMANI, MD

***2010–2011 Fellowship:** Mayo Clinic in Rochester, Minnesota*

***Focus:** Rheumatologist, UCLA; Founder & Director, Vasculitis Program at UCLA, Los Angeles, California*

Dr. Tanaz Kermani's fellowship provided dedicated time to build her expertise in vasculitis, both through direct patient care and collaboration with the VCRC investigators. These experiences shaped her into a recognized leader in the field, committed to improving outcomes for patients with rare vasculitis diseases.

Today, Dr. Kermani directs the UCLA Vasculitis Program, offering specialized care to patients across Southern California and training the next generation of clinicians. She calls the fellowship **"invaluable"** for its mentorship, structured learning, and opportunities for meaningful research—underscoring the importance of sustained donor support to advance care and understanding.

Dr. Marta Casal Moura's fellowship delivered specialized training rarely available in her home country, equipping her to manage complex vasculitis cases and lead impactful research. Her experiences at the Mayo Clinic and participation at the 2023 International Vasculitis Symposium deepened her commitment to patient-centered care.

Her studies have influenced treatment protocols for ANCA-associated vasculitis with severe kidney involvement, clarified the role of plasma exchange, and improved histopathology-based outcome predictions. She continues laboratory research on PR3-ANCA vasculitis and affirms that **"donors are not just funding research—they are shaping a future where vasculitis care is smarter, more personal, and always centered on the patient."**

Dr. Moura translates many of the VF's patient-facing educational materials to create resources for non-English speaking patients around the world seeking to learn as much as possible about vasculitis.

MARTA CASAL MOURA, MD, MSC, MSPH

***2010–2011 Fellowship:** Mayo Clinic in Rochester, Minnesota*

***Now:** Doctor of Medicine, Consultant in Clinical Immunology, Porto, Portugal*

FELLOW SPOTLIGHTS

RUONING (LEMON) NI, MD

2024–2025 Fellowship: *Cleveland Clinic Center for Vasculitis Care and Research*

Now: *Clinical Assistant Professor, Rheumatology, University of Iowa Health Care, Iowa City, Iowa*

During her vasculitis fellowship at the Cleveland Clinic's Center for Vasculitis Care and Research, **Dr. Ruoning Ni** gained in-depth clinical expertise through case-based learning with world leaders in the field and hands-on experience establishing a dedicated, multidisciplinary vasculitis center.

Guided by mentors including Drs. Carol Langford, Rula Hajj-Ali, Alexandra Villa-Forte, Adam Brown, and Kinanah Yaseen, Dr. Ni honed skills in early recognition of complications, efficient team-based care, and management of highly complex cases.

Her fellowship research deepened understanding of organ-specific manifestations in ANCA-associated vasculitis and evaluated the diagnostic use of temporal artery ultrasound in giant cell arteritis, revealing variability in practice across healthcare settings. These insights now inform her patient-centered approach, tailored to the resources and needs of diverse systems.

> Dr. Ni credits VF support for providing the mentorship, research resources, and time to pursue high-impact, innovative studies. She believes donor investment in vasculitis research and training is crucial...

> ***"Your support means earlier diagnoses, better treatments, and improved outcomes. We're not just advancing science—we're building a system that sees patients sooner and serves them better."***

FELLOW SPOTLIGHTS

CHRISTIAN PAGNOUX, MD, MSC, MPH

2010–2012 Fellowship: *Mount Sinai Hospital, University of Toronto, Canada*

Now: *Division of Rheumatology at Mount Sinai Hospital, Toronto. North-American Vasculitis Clinical Research Consortium (VCRC), and founder of CanVasc, the Canadian network for research on vasculitides* 🇨🇦

The VCRC-VF fellowship gave **Dr. Christian Pagnoux** two transformative years to develop a vasculitis program in Canada, build international collaborations, and set the course for his career. Working closely with mentors such as Drs. Peter Merkel and Nader Khalidi, he gained the expertise and confidence to launch his own projects while strengthening ties with the global vasculitis community.

Today, he emphasizes that the VF's fellowship program has been essential in training future leaders, creating vasculitis centers worldwide, and advancing patient care. **"The fellowship should not be a one-time experience,"** he notes. **"It opens long-term possibilities—for careers, programs, and discoveries in vasculitis."**

Dr. Kaitlin Quinn's fellowship offered hands-on experience with vasculitis patients well beyond standard rheumatology training, as well as robust research instruction in statistics and data analysis. Participation in the VCRC expanded her professional network and inspired her to earn a master's degree in clinical research.

She now treats patients, conducts research—particularly on imaging for large-vessel vasculitis—and shares her expertise at national and international forums. **"Completing a vasculitis fellowship was the most important factor in my current career path,"** she says, crediting donor support for making this specialized training possible.

KAITLIN QUINN, MD

2010–2012 Fellowship: *Mount Sinai Hospital, University of Toronto, Canada*

Now: *Staff Clinician, National Institutes of Health; Associate Director, Rheumatology Fellowship Program*

🇺🇸

FELLOW SPOTLIGHTS

FRANCISCO SILVA LABRA, MD

2006–2008 Fellowship:
Mayo Clinic Rochester

Now: *Director, Vasculitis Center, Clínica Alemana de Santiago, Chile*

Dr. Francisco Silva Labra's fellowship provided the opportunity to conduct biomarker research under Dr. Ulrich Specks and observe leadership in patient-centered research from Dr. Peter Merkel. These experiences shaped his ability to launch Chile's first dedicated vasculitis clinic, now serving over 300 patients.

Dr. Silva has led international clinical trials, developed national education initiatives, and advocated for improved rare disease policies in Chile. His work refining ANCA testing and exploring ANCA epitopes is advancing diagnostic precision. He calls the VF's support **"transformative,"** fostering both international collaboration and patient empowerment.

Dr. Rennie Rhee credits the VF-supported fellowship for immersing her in comprehensive clinical and research training in vasculitis, solidifying her commitment to the field. Mentored by Dr. Peter Merkel, she gained the expertise necessary to focus her career exclusively on vasculitis care and research.

Today, she treats patients at the Penn Vasculitis Center and continues to advance the science of the disease, embodying the fellowship's role in cultivating dedicated specialists for this rare and challenging condition.

RENNIE RHEE, MD

2014–2016 Fellowship:
University of Pennsylvania

Now: *Assistant Professor of Medicine (Rheumatology) at the Hospital of the University of Pennsylvania, Vasculitis Center*

FELLOW SPOTLIGHTS

KIMBERLY P. LIANG, MD

Funded 2014 Fellowship*, University of Pittsburgh, Pennsylvania*

Now: *Physician-Faculty, University of Kansas Medical Center* 🇺🇸

"My fellowship experience played a pivotal role in shaping my career path. Today, I serve as Director of the Vasculitis Center at the University of Kansas Medical Center, where I lead multiple subspecialty clinics dedicated to caring for people with vasculitis. I am also working to launch clinical trials in vasculitis at our institution, in collaboration with other specialists.

Because vasculitis is so rare, support for research and training programs is essential. These opportunities not only expand the expertise of physicians but also influence the development of new therapies, as pharmaceutical companies increasingly seek input from clinical experts in the field.

To fellows and researchers beginning their journey in vasculitis, my advice is to stay connected—engage with the Vasculitis Foundation and collaborate with subspecialists both locally and nationally. These partnerships are invaluable for advancing care and research in this challenging but rewarding field."

> ***"To fellows and researchers beginning their journey in vasculitis, my advice is to stay connected—engage with the Vasculitis Foundation and collaborate with subspecialists both locally and nationally."***

FELLOW SPOTLIGHTS

SEBASTIAN SATTUI, MD, MS

2019–2021 Fellowship: *Hospital for Special Surgery*

Now: *Assistant Professor, Division of Rheumatology & Clinical Immunology, Director, UPMC Vasculitis Center, University of Pittsburgh* 🇺🇸

Dr. Sebastian Sattui's fellowship provided the protected time for clinical training, research, and mentorship that shaped his focus on the unique needs of older adults with vasculitis. He completed a master's degree, collaborated with VF leaders, and participated in patient-centered initiatives through the VPPRN and VF/VCRC symposia.

His research spans frailty in vasculitis, infection prevention, and real-world evidence for new therapies, alongside leadership in COVID-19 outcome studies. He mentors trainees and advocates for continued VF investment to ensure innovation and equitable care in the future.

Dr. Sattui serves on the VF Board of Directors and the VF's Medical Education and Research Committe.

Dr. Hiromichi Tamaki's fellowship delivered advanced clinical training alongside leading experts, preparing him to manage complex vasculitis cases and conduct meaningful research. Now in Tokyo, he provides specialized care, mentors trainees, and offers expert consultations across Japan, including to remote regions.

He notes that opportunities for rare disease training are limited and calls the fellowship pivotal to his entry into this specialized field. Sustained donor support, he says, is vital to expanding access to expertise and bringing life-changing advances to more people living with vasculitis across the globe.

HIROMICHI TAMAKI, MD

2016–2017 Fellowship: *Cleveland Clinic Center for Vasculitis Care and Research*

Now: *St. Luke's International Hospital, Tokyo, Japan* 🇯🇵

FELLOW SPOTLIGHTS

FLORIDAN KÄS, MD

2025-2027 Fellowship: *University of Pennsylvania, Penn Rheumatology, Vasculitis Center, Philidelphia, Pennsylvania* 🇺🇸

Dr. Floridan Käs's journey into the complex world of vasculitis began during his medical training at the University Hospital of Zurich. **"My interest in vasculitis developed over the past five years during my full-time medical training in internal medicine and rheumatology,"** he explained. This extensive training, with a particular emphasis on nephrology, provided a strong foundation in both systemic and organ-specific manifestations of vasculitis. The diagnostic and therapeutic challenges, coupled with the opportunity to contribute meaningfully to a field where there is still so much to discover and improve for patients, are what drew Dr. Käs to this specialty.

As a VCRC-VF Fellow, Dr. Käs has clear aspirations. **"During my VCRC-VF Fellowship, I hope to deepen my expertise in both patient care and clinical/translational research in the field of vasculitis,"** he stated. His overarching goal for the next two years is to become a **"well-rounded clinician-researcher, capable of contributing to meaningful advances in the diagnosis, management, and understanding of these complex diseases."** Dr. Käs is particularly enthusiastic about becoming an **"active member of the international vasculitis community, learning from and collaborating with leading experts and dedicated patient advocates."**

> ***"I hope to deepen my expertise in both patient care and clinical/translational research in the field of vasculitis."***

FELLOW SPOTLIGHTS

YUAN QI, MD

2025-2026 Fellowship: *Division of Rheumatology, McMaster University, Hamilton, Canada* 🇨🇦

Dr. Yuan Qi's interest in vasculitis was sparked during his internal medicine training. **"I managed the overnight transfer of a patient with suspected antineutrophil cytoplasmic antibody (ANCA)-associated vasculitis (AAV) from a small peripheral hospital. He was being considered for plasmapheresis,"** Dr. Qi said. The patient's chest X-ray showed a dramatic "white-out" where blood was filling his lungs, and he was critically ill.

At the time, the PEXIVAS trial hadn't been published yet, and guidelines recommended plasmapheresis for patients with rapidly deteriorating kidney and lung function. They proceeded with the treatment, but just one year later, their approach would have been different. The PEXIVAS trial showed that plasmapheresis had no added benefit in these cases.

This experience left a lasting impression on Dr. Qi and highlighted the dynamic nature of the field. **"This experience shows how rapidly the vasculitis field evolves and embraces new research in clinical practice. That dynamic nature is what excites me about this field,"** he said.

Dr. Qi's current research focuses on a crucial aspect of vasculitis treatment: steroids. "Steroids are a cornerstone in the treatment of autoimmune conditions like vasculitis, including AAV," he explained. "They are highly effective but also known to cause side effects such as weight gain, mood changes, and insomnia, which can significantly impact quality of life."

Ultimately, Dr. Qi envisions his research contributing to a more personalized and effective approach to vasculitis care. His goal is to advance the understanding of how to tailor steroid use based on individual risk, leading to better outcomes for patients.

Dr. Qi started his Master of Science degree in Health Research Methodology (specializing in Clinical Epidemiology) this September, which will further equip him with the skills to address these research challenges. He hopes to one day become a clinical investigator at an academic medical center.

LOOKING AHEAD: OUR COMMITMENT TO THE FUTURE

Thanks to the generous support of our community, the VF Fellowship Program has become a cornerstone of our mission. As we approach the next 40 years for the VF, we are more committed than ever to expanding this pipeline of talent and expertise.

By investing in the next generation of experts, we can ensure that every patient—no matter where they live—has access to the care and hope they deserve for a healthier future.

WHY YOUR SUPPORT MATTERS: VOICES FROM OUR FELLOWS

- ***“We now offer care that is completely different from 20 years ago because of this kind of research and training support.”***
- ***“Supporting trainees now ensures that vasculitis expertise will exist tomorrow in the places it’s needed most.”***
- ***“The VF is a rigorous and thoughtful organization. Its voice, and the voice of patients, is found even in high-impact publications because we are all part of the research itself.”***

The unique symbiosis between patients, clinicians, and scientists, fueled by our community's support, has allowed the VF to build a legacy of sustained excellence and global impact. Together, we can continue to drive the breakthroughs that save lives.

OUR FELLOWS: 2005 – 2025

Amr H. Sawalha, MD
University of Texas, Austin

Alfred D. Mahr, MD, MPH, PhD
Kantonsspital St. Gallen, Switzerland

Alicia Rodriguez-Pla, MD, PhD, MPH
Sierra Pacific Arthritis and Rheumatology Centers, Fresno, California

Francisco Silva Labra, MD, MS
Clinica Alemana De Santiago, Chile

Gunnar Tomasson, MD, PhD
University of Iceland, Reykjavik

Peter Grayson, MD, MSc
National Institutes of Health, Bethesda, Maryland

Eamonn Molloy, MD
The Centre for Arthritis and Rheumatic Diseases, Dublin, Ireland

Atul Khasnis, MD, MS, DipABLM
Georgia Rheumatology Clinic, Tyron

Tanaz Kermani, MD, MSc
UCLA Vasculitis Program, Santa Monica, California

Christian Pagnoux, MD, MPH, MSc
University of Toronto, Canada

Elizabeth Brant, MD
Geisel School of Medicine, Dartmouth, New Hampshire

Rennie Rhee, MD, MSCE
University of Pennsylvania, Philadelphia

Rennie Rhee, MD, MSCE
University of Pennsylvania, Philadelphia

OUR FELLOWS: 2005 – 2025 *CONTINUED*

Natasha Dehghan, BSc, MD
University of British Columbia, Vancouver, Canada

Medha Laichand Soowamber, MD
University of Toronto, Canada

Hiromichi Tamiki, MD
St. Luke's International Hospital, Tokyo, Japan

Amy Archer, MD, PhD
AnaptysBio, San Diego, California

Jennifer Rodrigues, MD, MSc, FRCPC
Humber River Hospital, Hamilton, Canada

Kevin Byram, MD
Vanderbilt University, Nashville, Tennessee

Kaitlin Quinn, MD
National Institutes of Health, Bethesda, Maryland

Stephanie Garner, MD, MSc, FRCPC
University of Calgary, Canada

Alvise Berti, MD
Santa Chiara Hospital, Trento, Italy

Sebastian Sattui, MD, MS
University of Pittsburgh, Pennsylvania

Eric Gapud, MD, PhD
U.S. Federal Drug Administration, Washington, DC

Kinanah Yaseen, MD
Cleveland Clinic Center for Vasculitis Care and Research, Ohio

Jessica Bloom, MD, MSCS
Children’s Hospital of Colorado, Aurora

OUR FELLOWS: 2005 – 2025 *CONTINUED*

Mohanad Elfishawi, MBBCh, MS
University of Minnesota, Minneapolis

Gozde Kubra Yardimci, MD
Hacettepe University, Ankara, Turkey

Marta Casal Moura, MD, MSc, MSPH, PhD
Hospital Santo António, Porto, Portugal

Roger Yang, MD
University of Montreal, Canada

Mats Junek, MD MSc, HRM, FRCPC
McMaster University, Hamilton, Canada

Ruoning "Lemon" Ni, MD
University of Iowa, Iowa City

Sam Falde, MD
Mayo Clinic, Rochester, Minnesota

Yuan (Max) Qi, MD
McMaster University, Hamilton, Canada

Florian Käs, MD
University of Pennsylvania, Philadelphia

VPPRN

VPPRN
VASCULITIS PATIENT-POWERED RESEARCH NETWORK

Peter Merkel, MD, MPH

Rheumatologist, Professor of Medicine and Epidemiology and Chief of the Division of Rheumatology at the University Of Pennsylvania School Of Medicine, Principal Investigator of the Vasculitis Clinical Research Consortium (VCRC), and Co-Principal Investigator of the Vasculitis Patient-Powered Research Network (VPPRN)

"The Vasculitis Foundation is a wonderful organization that I'm quite proud to be both part of and to support with my time and donations. The Vasculitis Foundation is an incredible supporter of research around the world, by both directly sponsoring research and encouraging patients to become aware of research they may want to participate in. Many of the themes are about improving treatment for patients with vasculitis."

— **Peter Merkel**, MD, MPH

Jenn Gordon, PhD

Biomedical Researcher, Co-Principal Investigator of the VPPRN, EGPA Patient

"The VPPRN is built on the premise that patients are partners and true equals, collaborating together with clinical researchers to support the research network. We provide the patient's voice and perspective to research studies, which answer questions that are important to clinicians, and that are important to vasculitis patients and their families."

— **Jenn Gordon**, PHD

VPPRN REPORT OUT

The support of the vasculitis community has powered the VPPRN to grow into what it is today: a highly successful, productive, international online patient registry with 5,000+ from 90+ countries.

The VPPRN's mission is to improve healthcare and quality of life for patients with vasculitis through high-level, patient-centered clinical research. As such, we will continue to strive to find answers to the questions most important to patients living with vasculitis. The VPPRN is a unique research platform that has achieved international recognition and attracts a remarkably diverse group of investigators and patients. Importantly, the VPPRN helps expand the reach of the VF and enhances the VF role as the world's leading patient-focused organization for vasculitis.

VPPRN STUDY CHARACTERISTICS

To uphold a standard of scientific excellence that aligns with our commitment to patient-centered research, a VPPRN study must possess ALL the following characteristics:

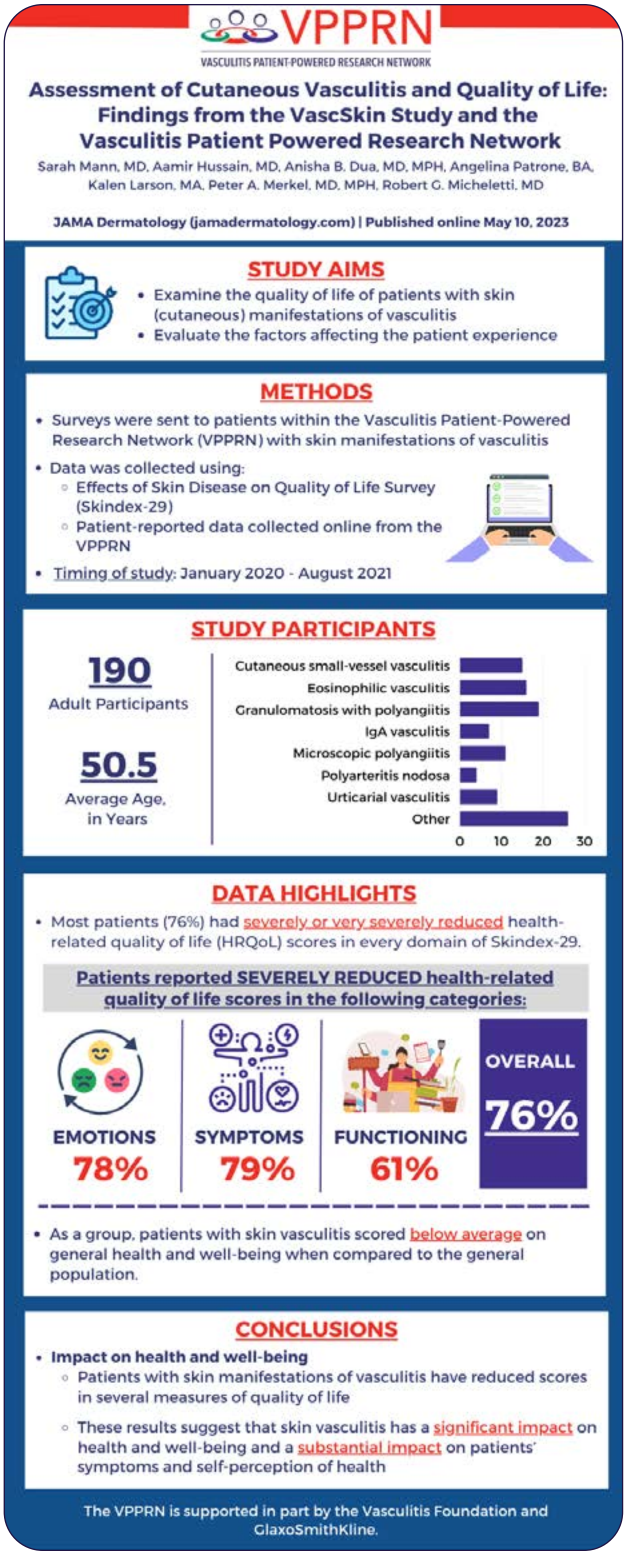
> 1. ***Patient-centered: Asks a research question that is important to people affected by vasculitis.***
> 2. ***Each study has a patient research partner serving as a co-principal investigator.***
> 3. ***VPPRN studies must be scientifically meaningful as well as relevant and important to people affected by vasculitis.***
> 4. ***Include significant patient engagement in ALL aspects of the research study.***
> 5. ***They are involved in the design, implementation, promotion/messaging, and interpretation of our studies.***
> 6. ***Each study utilizes the VPPRN infrastructure and resources including data from the VPPRN patient registry and patients enrolled in the VPPRN patient registry.***

EXAMPLES OF RECENT STUDIES

Robert Micheletti, MD

> *"VascSkin: Skin Vasculitis Quality of Life Survey"*
>
> *– A study to better understand the impact of vasculitis-related skin involvement on patients' quality of life.*

Learn more about VascSkin HERE



VPPRN
VASCULITIS PATIENT-POWERED RESEARCH NETWORK

Assessment of Cutaneous Vasculitis and Quality of Life: Findings from the VascSkin Study and the Vasculitis Patient Powered Research Network

Sarah Mann, MD, Aamir Hussain, MD, Anisha B. Dua, MD, MPH, Angelina Patrone, BA, Kalen Larson, MA, Peter A. Merkel, MD, MPH, Robert G. Micheletti, MD

JAMA Dermatology (jamadermatology.com) | Published online May 10, 2023

STUDY AIMS

- Examine the quality of life of patients with skin (cutaneous) manifestations of vasculitis
- Evaluate the factors affecting the patient experience

METHODS

- Surveys were sent to patients within the Vasculitis Patient-Powered Research Network (VPPRN) with skin manifestations of vasculitis
- Data was collected using:
  - Effects of Skin Disease on Quality of Life Survey (Skindex-29)
  - Patient-reported data collected online from the VPPRN
- Timing of study: January 2020 - August 2021

STUDY PARTICIPANTS

190
Adult Participants

50.5
Average Age, in Years

DATA HIGHLIGHTS

- Most patients (76%) had severely or very severely reduced health-related quality of life (HRQoL) scores in every domain of Skindex-29.

Patients reported SEVERELY REDUCED health-related quality of life scores in the following categories:

EMOTIONS	SYMPTOMS	FUNCTIONING	OVERALL
78%	79%	61%	76%

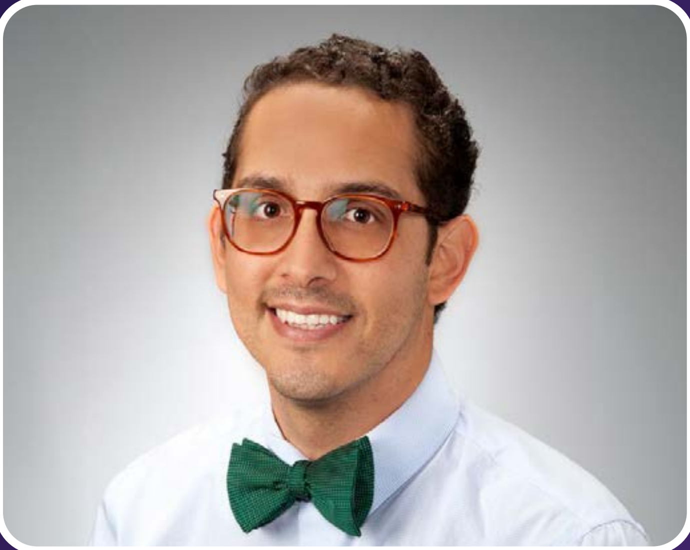
- As a group, patients with skin vasculitis scored below average on general health and well-being when compared to the general population.

CONCLUSIONS

- **Impact on health and well-being**
  - Patients with skin manifestations of vasculitis have reduced scores in several measures of quality of life
  - These results suggest that skin vasculitis has a significant impact on health and well-being and a substantial impact on patients' symptoms and self-perception of health

The VPPRN is supported in part by the Vasculitis Foundation and GlaxoSmithKline.

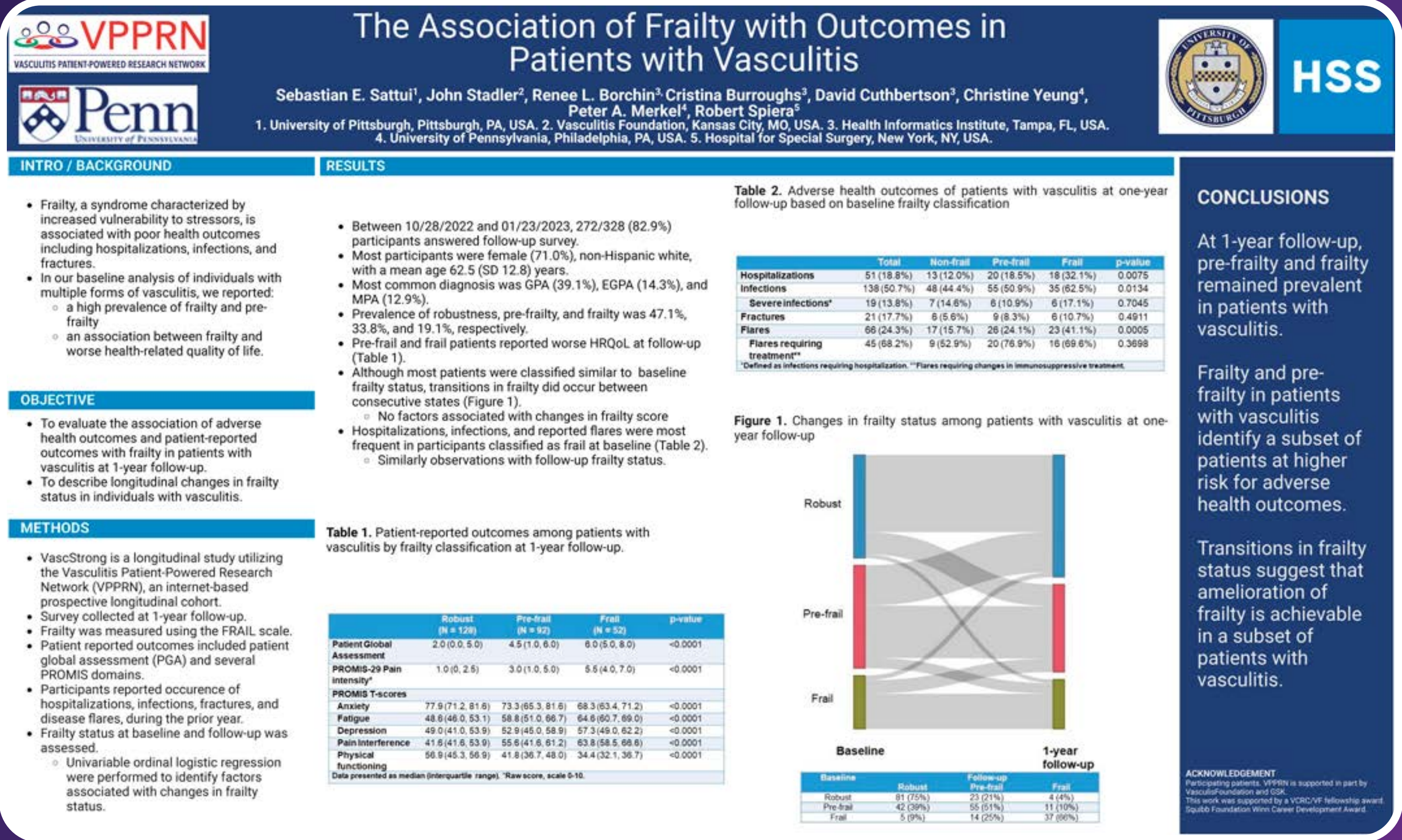
EXAMPLES OF RECENT STUDIES



Sebastian Sattui, MD

> *“VascStrong: Vasculitis Strength Study”*
>
> *– The study describes the prevalence of common health conditions associated with frailty in patients living with vasculitis and describes its impact on health-related quality of life and clinical outcomes.*

Learn more about VascStrong HERE



The Association of Frailty with Outcomes in Patients with Vasculitis

Sebastian E. Sattui[1], John Stadler[2], Renee L. Borchin[3], Cristina Burroughs[3], David Cuthbertson[3], Christine Yeung[4], Peter A. Merkel[4], Robert Spiera[5]

1. University of Pittsburgh, Pittsburgh, PA, USA. 2. Vasculitis Foundation, Kansas City, MO, USA. 3. Health Informatics Institute, Tampa, FL, USA. 4. University of Pennsylvania, Philadelphia, PA, USA. 5. Hospital for Special Surgery, New York, NY, USA.

INTRO / BACKGROUND

- Frailty, a syndrome characterized by increased vulnerability to stressors, is associated with poor health outcomes including hospitalizations, infections, and fractures.
- In our baseline analysis of individuals with multiple forms of vasculitis, we reported:
  - a high prevalence of frailty and pre-frailty
  - an association between frailty and worse health-related quality of life.

OBJECTIVE

- To evaluate the association of adverse health outcomes and patient-reported outcomes with frailty in patients with vasculitis at 1-year follow-up.
- To describe longitudinal changes in frailty status in individuals with vasculitis.

METHODS

- VascStrong is a longitudinal study utilizing the Vasculitis Patient-Powered Research Network (VPPRN), an internet-based prospective longitudinal cohort.
- Survey collected at 1-year follow-up.
- Frailty was measured using the FRAIL scale.
- Patient reported outcomes included patient global assessment (PGA) and several PROMIS domains.
- Participants reported occurence of hospitalizations, infections, fractures, and disease flares, during the prior year.
- Frailty status at baseline and follow-up was assessed.
  - Univariable ordinal logistic regression were performed to identify factors associated with changes in frailty status.

RESULTS

- Between 10/28/2022 and 01/23/2023, 272/328 (82.9%) participants answered follow-up survey.
- Most participants were female (71.0%), non-Hispanic white, with a mean age 62.5 (SD 12.8) years.
- Most common diagnosis was GPA (39.1%), EGPA (14.3%), and MPA (12.9%).
- Prevalence of robustness, pre-frailty, and frailty was 47.1%, 33.8%, and 19.1%, respectively.
- Pre-frail and frail patients reported worse HRQoL at follow-up (Table 1).
- Although most patients were classified similar to baseline frailty status, transitions in frailty did occur between consecutive states (Figure 1).
  - No factors associated with changes in frailty score
- Hospitalizations, infections, and reported flares were most frequent in participants classified as frail at baseline (Table 2).
  - Similarly observations with follow-up frailty status.

Table 1. Patient-reported outcomes among patients with vasculitis by frailty classification at 1-year follow-up.

	Robust (N = 128)	Pre-frail (N = 92)	Frail (N = 52)	p-value
Patient Global Assessment	2.0 (0.0, 5.0)	4.5 (1.0, 6.0)	6.0 (5.0, 8.0)	<0.0001
PROMIS-29 Pain intensity*	1.0 (0, 2.5)	3.0 (1.0, 5.0)	5.5 (4.0, 7.0)	<0.0001
PROMIS T-scores				
Anxiety	77.9 (71.2, 81.6)	73.3 (65.3, 81.6)	68.3 (63.4, 71.2)	<0.0001
Fatigue	48.6 (46.0, 53.1)	58.8 (51.0, 66.7)	64.6 (60.7, 69.0)	<0.0001
Depression	49.0 (41.0, 53.9)	52.9 (45.0, 58.9)	57.3 (49.0, 62.2)	<0.0001
Pain Interference	41.6 (41.6, 53.9)	55.6 (41.6, 61.2)	63.8 (58.5, 68.6)	<0.0001
Physical functioning	56.9 (45.3, 56.9)	41.8 (36.7, 48.0)	34.4 (32.1, 36.7)	<0.0001

Data presented as median (interquartile range). *Raw score, scale 0-10.

Table 2. Adverse health outcomes of patients with vasculitis at one-year follow-up based on baseline frailty classification

	Total	Non-frail	Pre-frail	Frail	p-value
Hospitalizations	51 (18.8%)	13 (12.0%)	20 (18.5%)	18 (32.1%)	0.0075
Infections	138 (50.7%)	48 (44.4%)	55 (50.9%)	35 (62.5%)	0.0134
Severe infections*	19 (13.8%)	7 (14.6%)	6 (10.9%)	6 (17.1%)	0.7045
Fractures	21 (17.7%)	6 (5.6%)	9 (8.3%)	6 (10.7%)	0.4911
Flares	66 (24.3%)	17 (15.7%)	26 (24.1%)	23 (41.1%)	0.0005
Flares requiring treatment**	45 (68.2%)	9 (52.9%)	20 (76.9%)	16 (69.6%)	0.3698

*Defined as infections requiring hospitalization. **Flares requiring changes in immunosuppressive treatment.

Figure 1. Changes in frailty status among patients with vasculitis at one-year follow-up

Baseline	Follow-up Robust	Follow-up Pre-frail	Follow-up Frail
Robust	81 (75%)	23 (21%)	4 (4%)
Pre-frail	42 (39%)	55 (51%)	11 (10%)
Frail	5 (9%)	14 (25%)	37 (66%)

CONCLUSIONS

At 1-year follow-up, pre-frailty and frailty remained prevalent in patients with vasculitis.

Frailty and pre-frailty in patients with vasculitis identify a subset of patients at higher risk for adverse health outcomes.

Transitions in frailty status suggest that amelioration of frailty is achievable in a subset of patients with vasculitis.

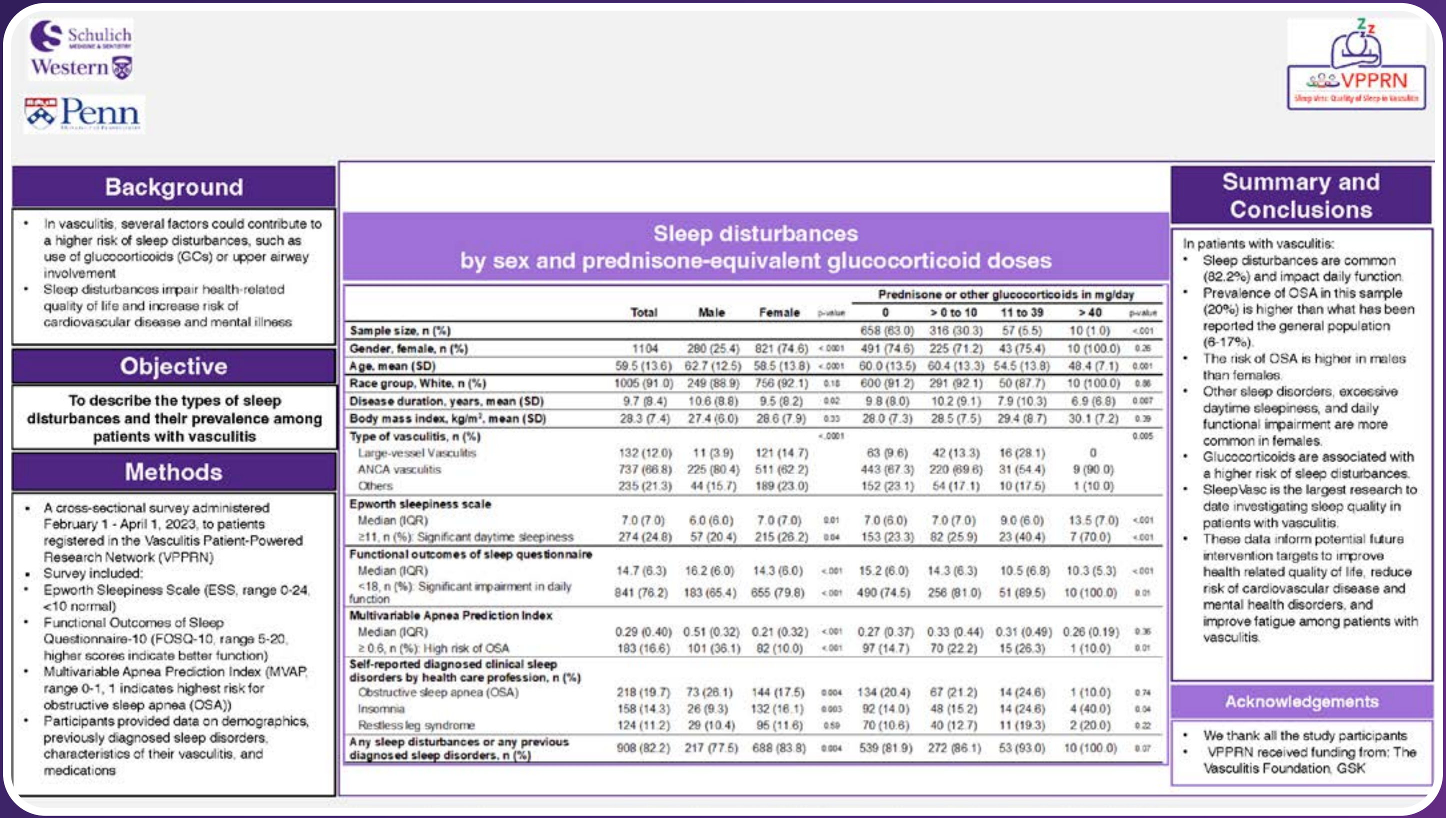
ACKNOWLEDGEMENT
Participating patients. VPPRN is supported in part by VasculisFoundation and GSK.
This work was supported by a VCRC/VF fellowship award. Squibb Foundation Winn Career Development Award.

EXAMPLES OF RECENT STUDIES

Christian Pagnoux, MD

> ***"Sleep-Vasc: Quality of Sleep in Vasculitis Research Study"***
>
> *– Study to learn more about the quality of sleep in patients living with vasculitis.*

Learn more about Sleep-Vasc **HERE**



Background

- In vasculitis, several factors could contribute to a higher risk of sleep disturbances, such as use of glucocorticoids (GCs) or upper airway involvement
- Sleep disturbances impair health-related quality of life and increase risk of cardiovascular disease and mental illness

Objective

To describe the types of sleep disturbances and their prevalence among patients with vasculitis

Methods

- A cross-sectional survey administered February 1 - April 1, 2023, to patients registered in the Vasculitis Patient-Powered Research Network (VPPRN)
- Survey included:
- Epworth Sleepiness Scale (ESS, range 0-24, <10 normal)
- Functional Outcomes of Sleep Questionnaire-10 (FOSQ-10, range 5-20, higher scores indicate better function)
- Multivariable Apnea Prediction Index (MVAP, range 0-1, 1 indicates highest risk for obstructive sleep apnea (OSA))
- Participants provided data on demographics, previously diagnosed sleep disorders, characteristics of their vasculitis, and medications

Sleep disturbances by sex and prednisone-equivalent glucocorticoid doses

					Prednisone or other glucocorticoids in mg/day				
	Total	Male	Female	p-value	0	> 0 to 10	11 to 39	> 40	p-value
Sample size, n (%)					658 (63.0)	316 (30.3)	57 (5.5)	10 (1.0)	<.001
Gender, female, n (%)	1104	280 (25.4)	821 (74.6)	<.0001	491 (74.6)	225 (71.2)	43 (75.4)	10 (100.0)	0.26
Age, mean (SD)	59.5 (13.6)	62.7 (12.5)	58.5 (13.8)	<.0001	60.0 (13.5)	60.4 (13.3)	54.5 (13.8)	48.4 (7.1)	0.001
Race group, White, n (%)	1005 (91.0)	249 (88.9)	756 (92.1)	0.18	600 (91.2)	291 (92.1)	50 (87.7)	10 (100.0)	0.86
Disease duration, years, mean (SD)	9.7 (8.4)	10.6 (8.8)	9.5 (8.2)	0.02	9.8 (8.0)	10.2 (9.1)	7.9 (10.3)	6.9 (6.8)	0.007
Body mass index, kg/m², mean (SD)	28.3 (7.4)	27.4 (6.0)	28.6 (7.9)	0.33	28.0 (7.3)	28.5 (7.5)	29.4 (8.7)	30.1 (7.2)	0.39
Type of vasculitis, n (%)				<.0001					0.005
Large-vessel Vasculitis	132 (12.0)	11 (3.9)	121 (14.7)		63 (9.6)	42 (13.3)	16 (28.1)	0	
ANCA vasculitis	737 (66.8)	225 (80.4)	511 (62.2)		443 (67.3)	220 (69.6)	31 (54.4)	9 (90.0)	
Others	235 (21.3)	44 (15.7)	189 (23.0)		152 (23.1)	54 (17.1)	10 (17.5)	1 (10.0)	
Epworth sleepiness scale									
Median (IQR)	7.0 (7.0)	6.0 (6.0)	7.0 (7.0)	0.01	7.0 (6.0)	7.0 (7.0)	9.0 (6.0)	13.5 (7.0)	<.001
≥11, n (%): Significant daytime sleepiness	274 (24.8)	57 (20.4)	215 (26.2)	0.04	153 (23.3)	82 (25.9)	23 (40.4)	7 (70.0)	<.001
Functional outcomes of sleep questionnaire									
Median (IQR)	14.7 (6.3)	16.2 (6.0)	14.3 (6.0)	<.001	15.2 (6.0)	14.3 (6.3)	10.5 (6.8)	10.3 (5.3)	<.001
<18, n (%): Significant impairment in daily function	841 (76.2)	183 (65.4)	655 (79.8)	<.001	490 (74.5)	256 (81.0)	51 (89.5)	10 (100.0)	0.01
Multivariable Apnea Prediction Index									
Median (IQR)	0.29 (0.40)	0.51 (0.32)	0.21 (0.32)	<.001	0.27 (0.37)	0.33 (0.44)	0.31 (0.49)	0.26 (0.19)	0.36
≥ 0.6, n (%): High risk of OSA	183 (16.6)	101 (36.1)	82 (10.0)	<.001	97 (14.7)	70 (22.2)	15 (26.3)	1 (10.0)	0.01
Self-reported diagnosed clinical sleep disorders by health care profession, n (%)									
Obstructive sleep apnea (OSA)	218 (19.7)	73 (26.1)	144 (17.5)	0.004	134 (20.4)	67 (21.2)	14 (24.6)	1 (10.0)	0.74
Insomnia	158 (14.3)	26 (9.3)	132 (16.1)	0.003	92 (14.0)	48 (15.2)	14 (24.6)	4 (40.0)	0.04
Restless leg syndrome	124 (11.2)	29 (10.4)	95 (11.6)	0.59	70 (10.6)	40 (12.7)	11 (19.3)	2 (20.0)	0.22
Any sleep disturbances or any previous diagnosed sleep disorders, n (%)	908 (82.2)	217 (77.5)	688 (83.8)	0.004	539 (81.9)	272 (86.1)	53 (93.0)	10 (100.0)	0.07

Summary and Conclusions

In patients with vasculitis:

- Sleep disturbances are common (82.2%) and impact daily function.
- Prevalence of OSA in this sample (20%) is higher than what has been reported the general population (6-17%).
- The risk of OSA is higher in males than females.
- Other sleep disorders, excessive daytime sleepiness, and daily functional impairment are more common in females.
- Glucocorticoids are associated with a higher risk of sleep disturbances.
- SleepVasc is the largest research to date investigating sleep quality in patients with vasculitis.
- These data inform potential future intervention targets to improve health related quality of life, reduce risk of cardiovascular disease and mental health disorders, and improve fatigue among patients with vasculitis.

Acknowledgements

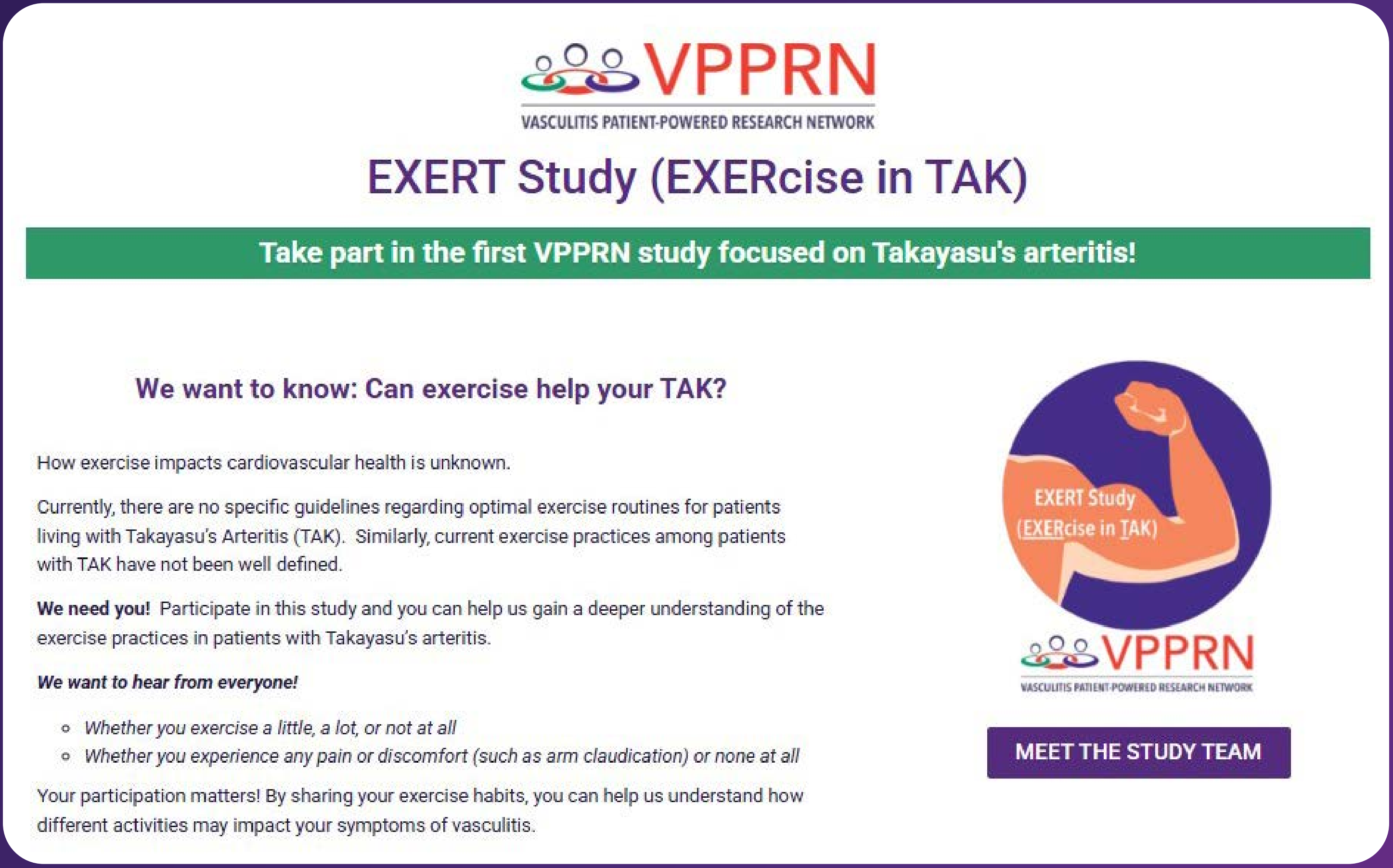
- We thank all the study participants
- VPPRN received funding from: The Vasculitis Foundation, GSK

EXAMPLES OF RECENT STUDIES

Kaitlin Quinn, MD

> *"EXERT Study: EXERcise in Takayasu's Arteritis"*
>
> *– Study to learn more about current exercise practices among people living with Takayasu's arteritis (TAK) and how exercise may impact symptoms of this disease. – Study under analysis*

Learn more about the EXERT Study **HERE**



VPPRN
VASCULITIS PATIENT-POWERED RESEARCH NETWORK

EXERT Study (EXERcise in TAK)

Take part in the first VPPRN study focused on Takayasu's arteritis!

We want to know: Can exercise help your TAK?

How exercise impacts cardiovascular health is unknown.

Currently, there are no specific guidelines regarding optimal exercise routines for patients living with Takayasu's Arteritis (TAK). Similarly, current exercise practices among patients with TAK have not been well defined.

We need you! Participate in this study and you can help us gain a deeper understanding of the exercise practices in patients with Takayasu's arteritis.

We want to hear from everyone!

- *Whether you exercise a little, a lot, or not at all*
- *Whether you experience any pain or discomfort (such as arm claudication) or none at all*

Your participation matters! By sharing your exercise habits, you can help us understand how different activities may impact your symptoms of vasculitis.

UPCOMING RESEARCH INITIATIVES

INVESTIGATOR:

KATHLEEN MCKINNON, MD

“DOCTOR, ARE YOU LISTENING?”

> The study aims to identify the unmet needs of vasculitis patients concerning the patient/provider relationship from the patient perspective. Ultimately, the feedback from this study will serve as an educational tool to providers to inform and demonstrate how the patient-specified needs and preferences can be incorporated into their provider-patient discussions.

INVESTIGATORS:

AUME MESTRE TORRES, MD
CHRISTIAN PAGNOUX, MD

“TOOTHVASC”

> The study aims to identify potential dental and oral complications associated with vasculitis.

View All Past & Current Studies HERE

These projects are important for career development of the investigators, engage patients in meaningful and interesting research, and can provide the data and evidence of feasibility to subsequently apply for research grants for next-level work in the VPPRN, as has been successfully done several times. These projects, of course, are in addition to the many already-completed projects and other ongoing studies (e.g. longitudinal data collection, VPREG, V-SNIFF, PANDA, PedsVPPRN).

The VPPRN is an outstanding established research resource and infrastructure designed to facilitate rapid, efficient, and cost-effective research in vasculitis.

VPPRN RESEARCHER SPOTLIGHTS

MEGAN E.B CLOWSE, MD

Professor of Medicine and Chief of the Division of Rheumatology & Immunology at Duke University, Durham, North Carolina

CATHERINE SIMS, MD

Assistant Professor of Medicine, Division of Rheumatology & Immunology at Duke University, Durham, North Carolina

REPRODUCTIVE HEALTH IN VASCULITIS

In 2010, the VF awarded a one-year grant to **Dr. Megan Clowse** to conduct one of the first and largest studies of pregnancy experiences in patients with vasculitis. The findings revealed that reproductive health was a vital but overlooked need for patients—and launched an entirely new area of research in the field.

Building on these results, Dr. Clowse collaborated with Peter Merkel, the VPPRN, and the VF to create the **Vasculitis Pregnancy Registry (VPREG)** in 2016. This groundbreaking registry connects vasculitis experts and reproductive rheumatologists worldwide, expanding research collaborations and improving clinical guidance.

Her work has already changed practice: today, more vasculitis clinicians proactively discuss pregnancy planning with their patients and feel more confident prescribing safe, pregnancy-compatible medications to control disease during pregnancy.

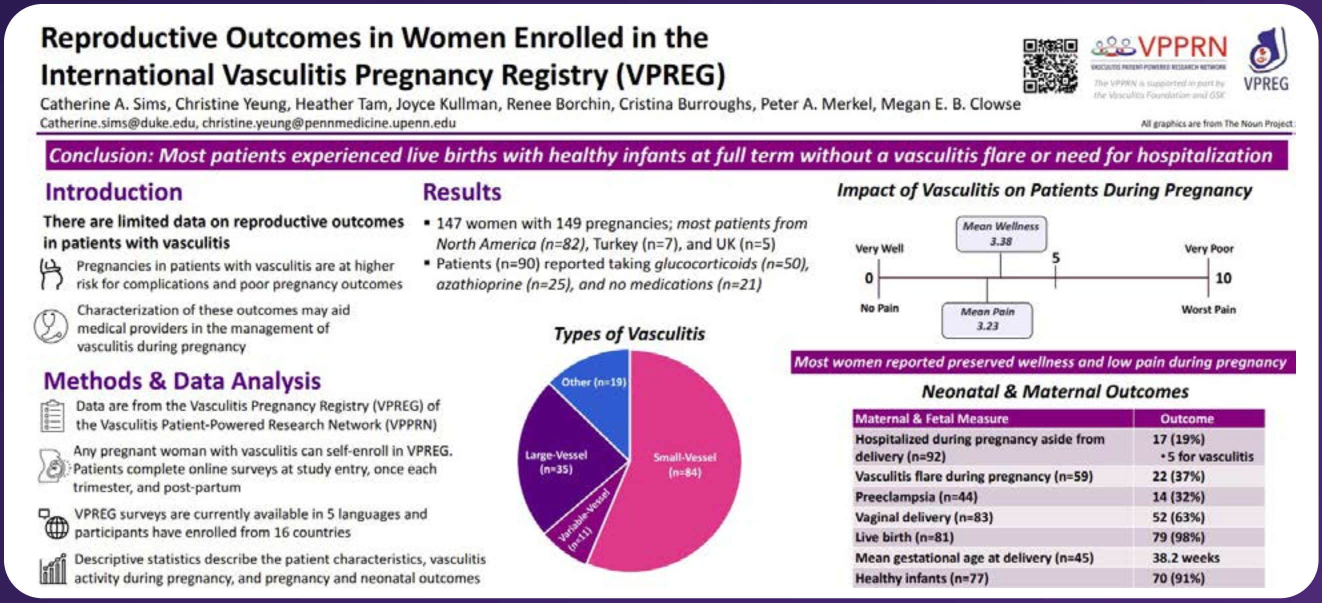
Dr. Clowse has also mentored the next generation of leaders, including **Dr. Catherine Sims**, who has dedicated her career to advancing reproductive women's health and pregnancy management for people with vasculitis.

"By supporting vasculitis research focused on pregnancies," Dr. Clowse says, **"you give young people living with vasculitis hope that they may be able to fulfill their wish to build a healthy family."**

TODAY

The Vasculitis Pregnancy Registry (VPREG) has over 200+ study participants. Dr. Sims has expanded their research to also understand patients' mental and emotional health and how that impacts pregnancy outcomes. Thanks to the participation and data provided by patients thus far, the VPREG Study Team has already published two manuscripts from the VPREG study in the Journal of Rheumatology:

1. REPRODUCTIVE OUTCOMES FOR WOMEN WITH VASCULITIS: *READ HERE*



Reproductive Outcomes in Women Enrolled in the International Vasculitis Pregnancy Registry (VPREG)

Catherine A. Sims, Christine Yeung, Heather Tam, Joyce Kullman, Renee Borchin, Cristina Burroughs, Peter A. Merkel, Megan E. B. Clowse
Catherine.sims@duke.edu, christine.yeung@pennmedicine.upenn.edu

VPPRN
VASCULITIS PATIENT-POWERED RESEARCH NETWORK
The VPPRN is supported in part by the Vasculitis Foundation and GSK
VPREG

All graphics are from The Noun Project

Conclusion: Most patients experienced live births with healthy infants at full term without a vasculitis flare or need for hospitalization

Introduction

There are limited data on reproductive outcomes in patients with vasculitis

Pregnancies in patients with vasculitis are at higher risk for complications and poor pregnancy outcomes

Characterization of these outcomes may aid medical providers in the management of vasculitis during pregnancy

Methods & Data Analysis

Data are from the Vasculitis Pregnancy Registry (VPREG) of the Vasculitis Patient-Powered Research Network (VPPRN)

Any pregnant woman with vasculitis can self-enroll in VPREG. Patients complete online surveys at study entry, once each trimester, and post-partum

VPREG surveys are currently available in 5 languages and participants have enrolled from 16 countries

Descriptive statistics describe the patient characteristics, vasculitis activity during pregnancy, and pregnancy and neonatal outcomes

Results

- 147 women with 149 pregnancies; *most patients from North America (n=82)*, Turkey (n=7), and UK (n=5)
- Patients (n=90) reported taking *glucocorticoids (n=50), azathioprine (n=25), and no medications (n=21)*

Types of Vasculitis

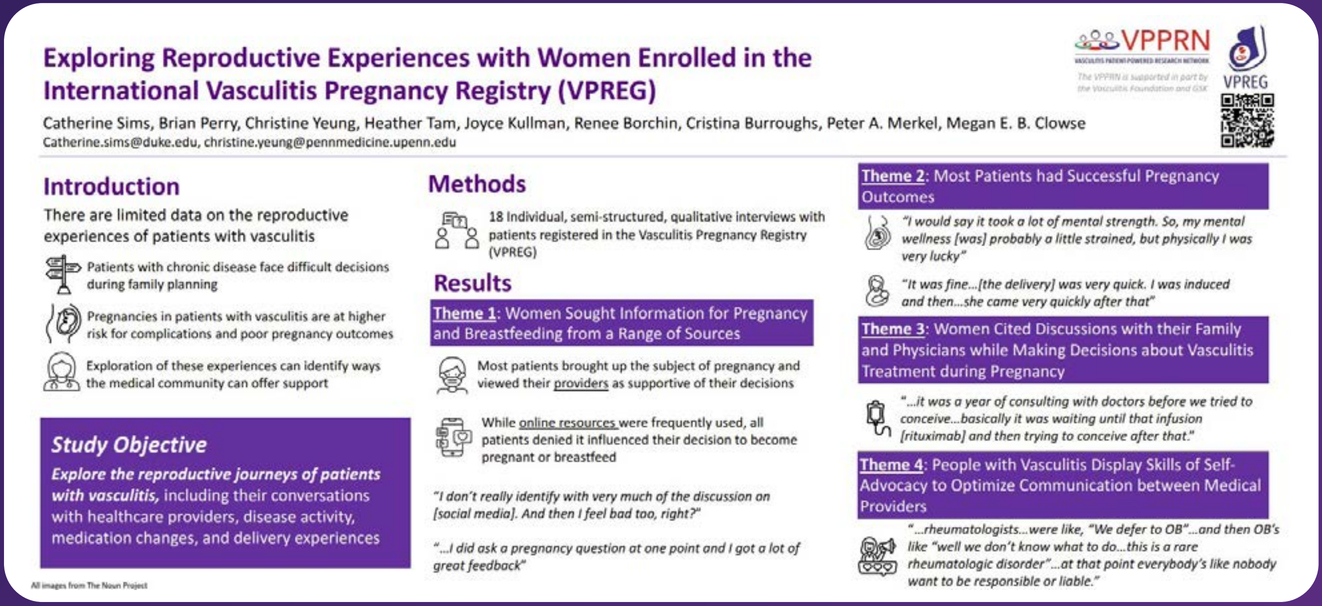
Impact of Vasculitis on Patients During Pregnancy

Most women reported preserved wellness and low pain during pregnancy

Neonatal & Maternal Outcomes

Maternal & Fetal Measure	Outcome
Hospitalized during pregnancy aside from delivery (n=92)	17 (19%) • 5 for vasculitis
Vasculitis flare during pregnancy (n=59)	22 (37%)
Preeclampsia (n=44)	14 (32%)
Vaginal delivery (n=83)	52 (63%)
Live birth (n=81)	79 (98%)
Mean gestational age at delivery (n=45)	38.2 weeks
Healthy infants (n=77)	70 (91%)

2. EXPLORING REPRODUCTIVE EXPERIENCES WITH WOMEN ENROLLED IN THE INTERNATIONAL VPREG REGISTRY: *READ HERE*



Exploring Reproductive Experiences with Women Enrolled in the International Vasculitis Pregnancy Registry (VPREG)

Catherine Sims, Brian Perry, Christine Yeung, Heather Tam, Joyce Kullman, Renee Borchin, Cristina Burroughs, Peter A. Merkel, Megan E. B. Clowse
Catherine.sims@duke.edu, christine.yeung@pennmedicine.upenn.edu

VPPRN
VASCULITIS PATIENT-POWERED RESEARCH NETWORK
The VPPRN is supported in part by the Vasculitis Foundation and GSK
VPREG

Introduction

There are limited data on the reproductive experiences of patients with vasculitis

Patients with chronic disease face difficult decisions during family planning

Pregnancies in patients with vasculitis are at higher risk for complications and poor pregnancy outcomes

Exploration of these experiences can identify ways the medical community can offer support

Study Objective

Explore the reproductive journeys of patients with vasculitis, including their conversations with healthcare providers, disease activity, medication changes, and delivery experiences

All images from The Noun Project

Methods

18 Individual, semi-structured, qualitative interviews with patients registered in the Vasculitis Pregnancy Registry (VPREG)

Results

Theme 1: Women Sought Information for Pregnancy and Breastfeeding from a Range of Sources

Most patients brought up the subject of pregnancy and viewed their providers as supportive of their decisions

While online resources were frequently used, all patients denied it influenced their decision to become pregnant or breastfeed

"I don't really identify with very much of the discussion on [social media]. And then I feel bad too, right?"

"...I did ask a pregnancy question at one point and I got a lot of great feedback"

Theme 2: Most Patients had Successful Pregnancy Outcomes

"I would say it took a lot of mental strength. So, my mental wellness [was] probably a little strained, but physically I was very lucky"

"It was fine...[the delivery] was very quick. I was induced and then...she came very quickly after that"

Theme 3: Women Cited Discussions with their Family and Physicians while Making Decisions about Vasculitis Treatment during Pregnancy

"...it was a year of consulting with doctors before we tried to conceive...basically it was waiting until that infusion [rituximab] and then trying to conceive after that."

Theme 4: People with Vasculitis Display Skills of Self-Advocacy to Optimize Communication between Medical Providers

"...rheumatologists...were like, "We defer to OB"...and then OB's like "well we don't know what to do...this is a rare rheumatologic disorder"...at that point everybody's like nobody want to be responsible or liable."

Learn more about VPREG **HERE**

VPPRN RESEARCHER SPOTLIGHTS

JESSICA BLOOM, MD

2021-2023 VCRC-VF Fellow

2024-2026 VF Young Investigator Award

Assistant Professor of Pediatrics at the University of Colorado-Denver and Attending Physician in Pediatric Rheumatology at Children's Hospital Colorado

PATIENT-REPORTED OUTCOMES IN CHILDREN WITH VASCULITIS

As the first pediatric rheumatologist in the VCRC-VF Fellowship program, **Dr. Jessica Bloom** recognized a significant void in the field: **"Vasculitis is an underserved area within pediatric rheumatology, both in research and clinical expertise, despite its significant morbidity and mortality in children."**

Her fellowship aimed to address how vasculitis uniquely affects children during critical developmental stages. With mentor Dr. Robert Fuhlbrigge, she planned to use the VCRC to assess associations between age at disease onset and clinical manifestations, management, and outcomes for each AAV subtype.

Dr. Bloom's initial goals included creating a dedicated pediatric vasculitis clinic, collaborating with Dr. Michael Wechsler, a world expert in EGPA, analyzing VPPRN data to include patient-reported outcomes, expanding pediatric patient enrollment in vasculitis registries and determining which patient-reported outcome measures are most relevant for children.

> **"Through this fellowship, I gained the expertise necessary to decrease ambiguities in pediatric vasculitis care through clinical outcomes research,"** Dr. Bloom stated. **"I am advancing the mission of the VF by increasing the presence of pediatrics within vasculitis research nationally."**

TODAY

Dr. Bloom has successfully expanded the Vasculitis Patient-Powered Research Network (VPPRN) to include children and pediatric-validated patient-reported outcomes (PROs). After two years of development, her team has created a groundbreaking resource for the pediatric vasculitis community.

Her current work focuses on:

1. ***Focus Group Research:***
   Dr. Bloom is conducting focus groups with children with vasculitis and their caregivers to determine which health domains (such as fatigue, mental health, and peer relationships) are most important to include in pediatric assessments.
2. ***Age-Specific Analysis:***
   By analyzing adult PRO data within the VPPRN and VCRC by age at diagnosis, she identifies additional domains that uniquely impact pediatric patients once they reach adulthood.
3. ***Registry Development:***
   The Pediatric Vasculitis Registry now provides a platform for children's voices to be heard in research, addressing the critical gap in understanding how vasculitis affects younger patients during vital stages of physical and psychosocial development.
4. ***Validation of Child-Appropriate Measures:***
   Dr. Bloom's work ensures that PRO measures for children address various developmental stages and incorporate both parent and child perspectives.

Dr. Bloom's pioneering work has created a new resource and voice for the pediatric vasculitis community, ensuring that children—who have historically been excluded from rigorous investigations—now have representation in vasculitis research and care.

VPPRN
Pediatric Vasculitis Registry

SUMMARY

The VPPRN is a thriving, growing, successful online registry focused on high-level, patient-centered clinical research.

The VPPRN collaborates with many high-quality researchers, especially early career investigators.

PedsVPPRN and the expansion of VPREG will bring new and exciting initiatives to the Network and to the vasculitis community.

VPPRN’s long-standing partnership with the Vasculitis Foundation is critical to the success of the Network.

LEARN MORE ABOUT THE VPPRN HERE

(Vasculitis Patient-Powered Research Network)

CONCLUSION

A LEGACY OF HOPE: LOOKING FORWARD TOGETHER

Twenty-five years ago, the VF made a bold commitment to change the future of vasculitis care. What began with a single research grant in 2002 has grown into the VBOLD program—a transformative initiative that has revolutionized how vasculitis is understood, diagnosed, and treated around the world.

Through your generosity, VBOLD has become a beacon of progress across three critical pillars: VF Research, the VCRC-VF Fellowship Program and the Vasculitis Patient-Powered Research Network (VPPRN).

The impact you've had the past 25 years is undeniable. From steroid-heavy survival protocols to targeted, tolerable therapies. From isolated specialists to a global network of expert care. From unanswered questions to groundbreaking discoveries that bring real hope to patients and families.

> *"During my research, the biggest takeaway for me was learning how much hope research can bring—seeing how basic science can point to real solutions, and how teamwork across different fields can make big ideas possible."*
>
> **— Pei-Yu Chen, BS, MS, PhD, VF-Funded Researcher**

Your support has made every milestone possible. Every fellowship awarded. Every research breakthrough. Every new vasculitis center established. Every patient who received expert care instead of facing their diagnosis alone. This is your legacy—built through your vision, sustained by your generosity, and measured in lives changed.

As we look ahead, the landscape of medical research funding is changing. As traditional funding sources become increasingly competitive and limited, the Vasculitis Foundation's VBOLD program stands as a consistent, reliable lifeline for the next generation of vasculitis researchers and specialists. The pipeline of new treatments, diagnostic tools, and trained experts—the very infrastructure that has transformed vasculitis care—needs your continued support to maintain momentum.

YOUR GIFT TODAY ISN'T JUST A DONATION — IT'S AN INVESTMENT IN CONTINUED PROGRESS.

When other funding sources become more competitive, your contribution becomes the difference between a groundbreaking study moving forward or being delayed. Between a talented fellow choosing vasculitis as their specialty or pursuing another path. Between a patient finding expert care or facing their diagnosis alone.

There are more breakthroughs to be made. More lives to transform. More hope to deliver. And we cannot do it without you.

Thank you for being the driving force behind 25 years of extraordinary progress. Together, we will continue to build a future where every person affected by vasculitis has access to expert care, innovative treatments, and the hope of a full, successful life.

With deepest gratitude for your partnership,

Jouce Kullman, *Executive Director*

VASCULITIS FOUNDATION®

LEARN MORE ABOUT THE VPPRN HERE

INVEST IN THE FUTURE OF OUR VBOLD PROGRAMS AT HERE