VASCULITIS FOUNDATION
CELEBRATING 40 YEARS
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Dear Friend,

Forty years ago, vasculitis was a shadow. Patients were isolated, doctors had few answers, and families were terrified. The Vasculitis Foundation (VF) was born from a simple, urgent necessity: **no one should have to walk this path alone.**

The VF was founded in 1986 by a close family friend, Marilyn Sampson, following her diagnosis of Wegener's (now granulomatosis with polyangiitis, or GPA). My parents often helped Marilyn with the group. In 1994, my father was diagnosed with GPA, and our family experienced firsthand the fear, confusion, and desperate search for answers that so many families facing a vasculitis diagnosis know all too well.

That personal experience has shaped and fueled my commitment to the VF for decades. And as we celebrate our 40th anniversary, I am struck by how much the landscape has changed—and how much work remains.

Lucy, diagnosed with Takayasu arteritis in the 1990s, remembers the profound isolation of those early years. *"There was no social media. There was no internet at all,"* she recalls. It took nearly three years of being dismissed—told her symptoms were "just stress" or that she was "too young to have a stroke"—before she finally found an answer. After being told she had five years to live, she spent hours in medical libraries researching and reading everything she could get her hands on. Discovering the VF had a huge impact on Lucy; she finally felt like she was a part of a community and was no longer isolated.

Kenia, diagnosed with Behçet's disease in the 2000s, remembers, *"The biggest challenge early in my journey was being believed,"* she says. When she attended her first VF support group meeting, she received booklets and resources that she used to educate her doctors. *"The Foundation is the core of how I get what I need,"* Kenia shares. *"If I need information, if I need to talk to someone, if I'm confused, I know I can go there."*

By the 2010s, advances in disease education, research, and treatment were beginning to change what a vasculitis diagnosis could mean. Victor, diagnosed with GPA in 2012, credits the VF with helping save his life. He attended his first symposium in Philadelphia in 2013 while on 24/7 oxygen, barely able to walk 10 yards. *"The information presented by the VF and the doctors changed my life,"* he says. Today, Victor looks at the medical advances made possible by research and sees a future that once seemed unimaginable. *"If you have to get this disease, now is a better time than 15 or 20 years ago,"* he says. *"The outlook was rather grim back then."*

Today, in our 40th anniversary year, Chloe—diagnosed with ANCA-associated vasculitis at just 20 years old—represents both how far we've come and how far we still have to go. Her journey to a diagnosis was far shorter than Lucy's, but it was still too long. Chloe spent a year and a half searching for answers before finally receiving a

diagnosis. When she found the VF, she immediately connected with patient stories and a community that understood what she was going through. *"To be able to talk to somebody who has had a similar experience, it humbles you and makes you grateful,"* she says.

Chloe's story—and Lucy's, Kenia's, and Victor's–shows what 40 years of progress can mean for someone living with vasculitis. And that progress has been possible because supporters like you have invested in the work of the VF.

Together, we have:

- Trained 34 clinical fellows who are now vasculitis specialists, helping expand access to expert care
- Funded more than 80 research studies that have advanced our understanding of vasculitis and brought us closer to better treatments
- Supported the development of the 2021 ACR/VF Treatment Guidelines, giving healthcare providers evidence-based guidance for vasculitis care
- Built a global video library of webinars, expert lectures, and other resources accessible to patients and healthcare providers
- Educated thousands of doctors and community members through symposiums, conferences, and medical meetings
- Built a network of support groups where patients can find validation, connection, and hope

But our work is far from over.

Patients today, like Chloe, still face many of the same challenges Lucy, Kenia, and Victor faced. Without access to a doctor who understands vasculitis, a patient can still spend months—or even years—searching for a diagnosis. Without a community like the VF, they can still feel isolated, dismissed, and alone. The landscape has changed—but only because people like you have helped change it.

Forty years ago, we were a small group determined to make a difference. Today, we are a global community. But for every patient who finds us, there is another who will be diagnosed tomorrow—facing the same fear my father did decades ago.

Please help us make sure that no one has to face vasculitis alone. Your support will help fund the next 40 years of education, research, connection, and hope.

With heartfelt gratitude,

Joyce A. Kullman
Executive Director, Vasculitis Foundation

P.S. ***Your gift today can help ensure that no patient has to search alone, wait years for answers, or face vasculitis without the support of a community that understands. Please donate at vasculitisfoundation.org. Thank you for 40 years of standing with us and for helping us build the next 40 years together.***