Vasculitis International

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Congratulations on 40 Years of the Vasculitis Foundation

Dear Joyce, and all colleagues at the Vasculitis Foundation,

On behalf of Vasculitis International — the European umbrella foundation supporting vasculitis patient advocacy groups — I am delighted to extend our warmest congratulations on the occasion of your organization’s 40th anniversary.

Forty years ago, Marilyn Sampson did something deceptively simple: she reached out. As a nurse living with GPA herself, she knew that isolation was one of the cruelest features of a rare disease — and she refused to accept it. The Wegener's Granulomatosis Support Group she founded in 1986 was built on a conviction that has proven durable across four decades: *you are not alone, and there is hope*.

Joyce, your own story reflects that same ethos. You came to the Foundation in 1995 not as a professional, but as a daughter — someone whose family had been through the diagnostic odyssey that so many of our patients know all too well, and who had seen what timely diagnosis and committed care can mean. That personal grounding is, I think, inseparable from what the Foundation has become under your leadership as executive director since 2002: an organization that combines scientific rigour with genuine human warmth.

That personal grounding is something I recognise from my own experience. When my wife was diagnosed with GPA in 2002, the Vasculitis Foundation was one of the very few sources of reliable, accessible information available to us. In those early, disorienting months, your website, your materials, and the sense of community the Foundation offered were lifelines — and that is not a word I use lightly. I have never forgotten that, and I never will.

What has been built over these forty years is remarkable. From a single support group in Kansas City, the Vasculitis Foundation has grown into an organization that has shaped the global vasculitis landscape — funding over 80 research studies, championing early diagnosis, supporting thousands of patients and caregivers, and helping establish the clinical infrastructure that today allows us to speak of real treatment advances. The investment in early-career investigators in particular has been visionary: vasculitis medicine today stands on shoulders that the VF helped build.

From a European perspective, the VF's legacy is also a story of inspiration and partnership. The transatlantic connection between our communities has always been intellectually generative. We have learned from you, and we hope the relationship continues to be reciprocal.

Forty years is a significant milestone for any organization in the rare disease space, where sustainability is never guaranteed and the work is never quite done. That the Foundation marks this anniversary with momentum and ambition is a tribute to everyone who has contributed — patients, families, researchers, staff, and volunteers, past and present — and to the steady, principled leadership that has guided it.

We look forward to many more years of collaboration, transatlantic solidarity, and shared progress toward a future where vasculitis is no longer the diagnostic odyssey it once was — and for too many, still is.

With warm congratulations and collegial regards,

Peter Verhoeven Chair, Vasculitis International