Advocacy Background and Rare Disease Engagement

As a rare cancer survivor and patient advocate, my work is shaped by lived experience, hard-earned perspective, and a commitment to improving outcomes for those navigating rare and ultra-rare diseases. What began as a personal medical journey has evolved into sustained national advocacy focused on awareness, research access, and patient-centered legislative reform.

I have found that presenting this work in a concise, resume-style format best reflects both the depth of my experience and the platforms through which I have contributed.

Henry (Hank) Heren
Rare Cancer Survivor | Patient Advocate | Grassroots Leader

Advocacy Highlights

YouTube – *Histiocytic Sarcoma Patient, Hank: Full Interview*
Shared my personal journey with histiocytic sarcoma to raise awareness of this ultra-rare cancer and amplify the patient voice. This interview focuses on diagnosis challenges, treatment realities, and the emotional and systemic gaps faced by rare disease patients. Histiocytic Sarcoma Patient, Hank, Full Interview

YouTube – *Phase 1b Mayo Clinic Trial for Oral Selective Inhibitor for Histiocytic Neoplasms*
Participated in and documented my experience in a groundbreaking Phase 1b clinical trial at Mayo Clinic. This platform highlights the critical importance of research access, innovation, and patient inclusion in advancing rare cancer treatments. Phase 1b Mayo Clinic Trial for Oral Selective Inhibitor for Histiocytic Neoplams/Lymphomas

Podcast – *Beyond The Diagnosis* (Episode 078): "From Misdiagnosis to Mission – One Patient's Journey with Rare Disease"
Shared my story to underscore the urgent need for timely and accurate diagnosis, while advocating for policy, research, and systemic reforms to better serve patients with rare and ultra-rare conditions.
podcasts.apple.com/us/podcast/beyond-the-diagnosis/id1559264513?i=1000704600331

Presentation – *Uniting for a Cure: Centralizing Rare Cancer Data to Save Lives*
Developed and delivered a patient-centered presentation advocating for a centralized national rare cancer data bank. The presentation uses powerful imagery and concise analysis to convey real-world challenges from the patient perspective, with each slide offering clear context and policy relevance. (Available for review; live Zoom presentation available upon request.)

Legislative Advocacy – Direct Engagement, Proposals, and Testimony
Engaged in one-on-one meetings with congressional representatives and participated in national-level advocacy conferences to present and advance patient-driven legislative initiatives, including:

- The Comprehensive Health and Patient Protection Act of 2025
- Bridging the Gap in Rare Disease Diagnosis and Treatment Act
- Rare Cancer Research and Access Act of 2025
- Safe Food and Chronic Disease Prevention Act of 2025
- Safe Drinking Water Fluoride Reform Act of 2025
- Prescription Drug Affordability Act of 2020 (reintroduced as part of broader reform)
- Uniting for a Cure – A National Rare Cancer Data Bank
- Rare Disease Patient Bill of Rights
- Veterans Health Benefits Upgrade Proposals
- Congressional Efficiency & Accountability Act (CEAA)
- Patient and Physician Checklist

Community and Stakeholder Engagement
Actively participated in numerous webinars and virtual conferences alongside patients, caregivers, clinicians, researchers, advocacy organizations, pharmaceutical representatives, and government agencies. These engagements focus on collaboration, education, and advancing meaningful dialogue across sectors within the rare disease ecosystem.

At the heart of my advocacy is compassion for patients facing uncertainty, for caregivers carrying unseen burdens, and for families navigating systems that too often feel indifferent. My work is guided by integrity, perseverance, and a deep respect for collaboration, grounded in the belief that meaningful change happens when we listen first and act with purpose. I strive to lead with humility, speak with honesty, and remain steadfast in the conviction that every patient story matters, especially those too often overlooked. Advocacy, to me, is not about visibility or recognition, but about service, ensuring that no one facing a rare disease feels invisible, unheard, or alone.