



A Mission Driven By Empathy

Frederick Wolfe, MD, started FORWARD because he had a mission to understand the patient experience.

Understanding the day-to-day lives of patients is a vital part of medical research. Unfortunately, for a long time, these experiences weren't considered by many researchers who instead relied on information from other doctors or short-term clinical trials. **Frederick Wolfe, MD, the founder of FORWARD—The National Databank for Rheumatic Diseases, was one of the first researchers in the rheumatology field to gather long-term information and data about the day-to-day lives of his patients.**

Dr. Wolfe passed away this past fall, on September 5, 2023. While many of you probably didn't get the chance to meet Dr. Wolfe in person, we want to tell you, the participants and supporters who make FORWARD possible, about Dr. Wolfe and his impact on FORWARD, the rheumatology field, and his patients, mentees, and peers.

Driven By Empathy

When you ask the people who knew Dr. Wolfe well about him, many will speak of his passion for his work, his expertise in the field of rheumatology, and, most importantly, the unique care and compassion that he had for people, including his patients.

Kaleb Michaud, PhD, director of FORWARD, met Dr. Wolfe when he was young—at age three, to be exact. Dr. Michaud was diagnosed with juvenile rheumatoid arthritis and has fond memories of Dr. Wolfe during the early years of their relationship: "I would see him regularly, although obviously going to the doctor as a kid was never that exciting. But we kept in touch throughout the years."

Dr. Michaud shares, "I've had the chance to look at my medical records and the notes from when he was treating me as a child, and the care and compassion that he had for me is so clear. He really took note of my pain and symptoms and was very thoughtful about the medications that he gave me, always balancing the benefits of the medications and the side effects that they would cause."

"Dr. Wolfe wanted to know the patient experience. That legacy continues at FORWARD because we believe strongly in that mission."

-Kaleb Michaud, PhD, Director of FORWARD

Getting Started—and Never Stopping

“When he first got started with tracking his patients’ symptoms and pain over time, he did it because he was frustrated with the results he was seeing,” Dr. Michaud says. “He wanted to make a real difference in those patients lives.”

As a rheumatologist in the 70’s, Dr. Wolfe purchased a computer to use for tracking bills in his medical office—but quickly learned that he could also track the pain and other symptoms that his patients were having over time, making it quicker and easier to understand the long-term symptoms that his patients had, and how those symptoms were affected by certain treatments or protocols.

“He used that data to say, ‘Hey, some of these patients are different than others,’ says Dr. Michaud. “There was this growing sense that questionnaires could be very helpful, and he started developing the whole sense of patient reported outcomes, which is still being used today in almost all areas of medicine.”

Over time, this work grew to become FORWARD—The National Databank for Rheumatic Diseases, a first-of-its-kind databank that obtains patient-reported data about the day-to-day experiences of people with rheumatic diseases and autoimmune conditions from tens of thousands of patients from all over the United States.

While Dr. Wolfe stopped seeing patients a number of years ago, it didn’t stop his work. Dr. Wolfe continued to ask questions and use patient-reported data in research, resulting in over 650 published papers (in the top 0.01% of published scientists!) and a lifetime of contribution to our understanding of rheumatic diseases.

A Lasting Legacy

Dr. Wolfe’s work went beyond data and publishing papers. His work as a mentor and informal educator informed

Remembering Dr. Wolfe

“[Fred’s] dedication to furthering our understanding of fibromyalgia and promoting its important place in rheumatology was inspirational.”

—Emma Guymmer, MBBS, FRACP from “The global rheumatology community is mourning the passing of US rheumatology professor Dr Frederick Wolfe.”
Rheumatology Republic

“Fred was an unusually generous and collaborative person ... [he] co-authored publications with hundreds of rheumatologists, and shared his ideas, data and interpretations consistently over the years.”

—Theodore Pincus, MD from In Memoriam: Remembering Frederick Wolfe, MD, The Rheumatologist

“Dr. Wolfe was a visionary but I’ll remember him for his generosity and unassuming manner when I was starting my own practice.”

—ACR President Douglas White, MD, PhD, from Celebrating the life of Frederick Wolfe, MD: “The consummate physician-scientist”, Healio Rheumatology

“He was a leader in so many areas, including the importance of listening to our patients, and of using patient reported outcomes. The most amazing thing is that Fred did all of this whilst being in private practice rather than being supported by the resources of a large academic medical center.”

—Daniel Clauw, MD, from Celebrating the life of Frederick Wolfe, MD: “The consummate physician-scientist”, Healio Rheumatology

“Dr. Fred Wolfe was a legend in the field of rheumatology and motivated me to be a better physician and be more stringent in assessment of outcomes.”

—Tim Shaver, MD, regarding his time with Dr. Wolfe

“My mom had severe rheumatoid arthritis and became a patient of Dr. Wolfe’s in 1975. She sang her praises of him until her passing in 1977. Through his care, she was able to enjoy a quality of life that she hadn’t experienced in many years.”

—Willa Applegate, regarding her mother’s relationship with Dr. Wolfe