CRITICAL PATH INSTITUTE

ALS Advocate Ron Newbury Pushes for Progress, Positivity Amidst Adversity

By Alexander Diegel

Ron and his wife, Carrie. Photo Credit: ALS Northwest

Ron Newbury is a former attorney, teacher, and a lifelong outdoor enthusiast. He was diagnosed with amyotrophic lateral sclerosis (ALS) in July of 2022. Like many living with ALS, he had years of unexplained symptoms before his diagnosis: a weakened golf swing, feeling his arms would tire quickly during routine tasks, and more. However, it was during one of his cherished bike trips that things progressed to the point of needing some answers.

While biking down a mountain in October 2021, his neck gave out entirely. “My head just collapsed,” he recalled, describing the moment that forced him to confront the likelihood of a serious condition.

Upon diagnosis, Ron added a new role to his portfolio: rather than retreat from the public and hide from his condition, Newbury instead channeled all of his energy from his previous roles into becoming an ALS advocate. A member of the ALS Association’s Advocacy Program, a Northeast ALS (NEALS) ambassador and involved with regulatory initiatives like Intermediate-Size Expanded Access Trial of Autologous Hybrid TREG /Th2 T Stem Cell Therapy (RAPA-501) of Amyotrophic Lateral Sclerosis, Newbury is determined to ensure that patients have access to hope—not just facts.

“When given the diagnosis, it’s helpful to say, look, there is hope. There are these things that have shown some real efficacy. A standard of care has been established for at least palliative measures that could make everyone’s lives better and give them hope.” In addition to palliative care, Ron pointed to encouraging results that have been seen from unconventional methods, while recognizing the balancing act of an appropriate amount of optimism.

Ron staying active on his exercise bike. Photo Credit: ALS Northwest

Beyond standard medical treatments, Newbury advocates for mental health resources and community support. He emphasizes the psychological toll of ALS and the importance of resilience in facing the disease. “There’s actually a psychologist that joined me in the ALS clinic, for this exact reason, to talk about the mental health component, and the significance of hope, and how it improves outcomes. You know, in the 90s, it used to be, ‘You’re going to die. Go home and get your affairs in order.’”

Critical Path Institute (C-Path) and its Critical Path for Rare Neurodegenerative Diseases (CP-RND) initiative works to bridge that gap. As the neutral convener, C-Path brings together stakeholders, researchers, industry and academia to advance drug development and improve the lives of those, like Ron, with unmet medical needs. CP-RND was founded in September 2022 to lead collaborations that advance treatments to improve the lives of those affected by ALS and other rare neurodegenerative diseases.

Newbury also pointed to major gaps in research dissemination as an issue the ALS community has to work through. Without a centralized platform to share treatment updates, clinical trial information, and patient experiences, too many are left navigating the disease alone.

CP-RND brings together multiple experts in rare neurodegenerative diseases, as well as biopharmaceutical companies, regulators, patient communities and advocacy organizations to accelerate and advance our understanding of disease pathology, treatment options, diagnostics and drug development. It is through his role as an advocate that Ron became connected to C-Path and CP-RND, and noted how the organization’s collaborative nature offered insights he hadn’t seen elsewhere.

Ron and his trusty chainsaw. Photo Credit: ALS Northwest

“I see C-Path more focused, with an aggregation of expertise that may not exist other places. These other groups are great, but with C-Path, we can have conversations that aren’t possible in other forums. I was really intrigued by that early on, in terms of a key difference that C-Path offers,” explained Ron.

“Ron is a great and forward thinking intellect,” He brings a insightful perspective in addressing gaps in ALS research,” stated Dr. Collin Hovinga, C-Path Vice President, Rare/Orphan and Pediatric Disease Programs. “He has already made an impact on the ALS world with his skill in communicating. He can listen to people with lived experience and succinctly communicate priorities and issues; he has drafted some powerful letters to his elected officials to underscore the importance of ALS research.”

As an ALS advocate, Newbury champions patient involvement in clinical trials and research design. Traditional trials, he notes, often exclude those with advanced disease or complex needs. He calls for innovative, patient-centric models that better reflect the diversity of ALS progression.

Despite the challenges, Newbury’s message remains one of empowerment. “There’s strength in numbers, and there’s strength in knowledge,” he says. For those newly diagnosed, his advice is clear: “Stay engaged. Ask questions. Hope is real—and so is progress.”

Ron’s story is a reminder that advocacy begins with voice, but it gains power through action. In the fight against ALS, he ensures both are heard.

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