

New Global Movement Aims to Rewrite Stroke Care with Survivor-Led Solutions

ZURICH, SWITZERLAND, June 26, 2026 /EINPresswire.com/ -- SHINE (Survivors Honouring Inclusion, Networking and Empowerment) launched at the World Stroke Congress in October 2025 as the first global movement led entirely by stroke survivors. Today, the founders share the story behind that moment. It's how three women, each changed by stroke, chose to build an organization that treats lived experience as expertise and turns survivor insight into system change.



"Stories should do more than sit in a room. They should shape the room," says Stacie Broek, Co-Founder & Executive Director. "SHINE ensures survivor voices are integrated upstream into care, research and policy."

Stacie met Stacy Quinn in 2023 through a mutual colleague, and from the start it felt as though they were two peas from the same pod. "I deeply respected Stacy's hopeful, fully charged spirit, and I cherished the close connection we maintained," says Stacie. "I truly believe we were destined to do something wonderful together." She later connected with Melinda B. Roaldsen through a committee and interviewed her for a speech. "Melinda's story was full of hope and positivity," Stacie says. "I brought Melinda and Stacy into the same conversation because their passion and their deep desire to drive change were undeniable. SHINE was born as a call to action to put lived experience at the forefront."

According to a [2024 arterial dissection case report](#), Carotid artery dissection affects about 3 in 100,000 people each year. An arterial dissection is when a tear forms in the artery wall, allowing blood to separate its layers, disrupting the blood flow and potentially causing a blood clot, that can lead to a stroke. Although dissections account for approximately 2% of all strokes, they cause 10% of strokes in younger people (Yaghi et al., Stroke, 2024). All three SHINE founders experienced a carotid artery dissection.

After her stroke at 46, Stacie relearned how to speak and write through intensive daily therapy despite being told she never would. "I don't share my story for its own sake," she says. "It must

frame problems and drive solutions.” Too often she saw survivors invited to speak after decisions were made. “Voices were present, but they weren’t shaping agendas or research. SHINE integrates survivor leadership, not just celebrates it.”

“I was a stroke expert before my stroke,” says Melinda B. Roaldsen, Co-Founder & Scientific Director. “After my carotid artery dissection in 2023, my horizon expanded. I saw the need for more implementation of stroke services along the entire treatment chain and advancement of survivor leadership as a concept.” Invitations to share stories were increasing, she notes, but survivor expertise rarely influenced decisions. “Survivors have first-hand knowledge across the whole treatment journey pathway. Systematically including lived experience makes healthcare more relevant and grounded.”

Melinda adds: “One-in-four people will have a stroke, and two-in-three survivors live with permanent disabilities. Research, awareness and policy can change this and improve outcomes.

After misdiagnosis and frustration, Co-Founder & Communications Director Stacy Quinn created My Stroke of Hope to support carotid artery dissection and stroke survivors, especially young women. “My misdiagnoses showed me how easily the patient and survivor voice gets lost,” says Stacy. “Through SHINE, we’re turning our experiences into change by embedding lived experience, so that care, research and policy are informed by the people they serve.”

From Lived Experience to Leadership

At SHINE’s World Stroke Congress launch, the founders felt a shift. “Clinicians, stakeholders and scientists came up afterward and asked, ‘How can we embed lived experience meaningfully,’” says Melinda. “That mindset, that appreciation of seeing survivor leadership as an integral part, was the most important reaction.”

Survivors consistently report gaps after discharge: support for fatigue management and emotional regulation, better continuity across specialists, and stronger social support. If hospitals added one survivor-informed change tomorrow, Stacie says, it would be a standardized, survivor-led discharge plan that puts the survivor’s own goals and vision at the center. “Personal goal setting is huge for me, and it’s far too often overshadowed,” explains, Stacie. “Everyone on the care team should be working toward the survivor’s plans, vision and goals.”

The biggest gaps in secondary prevention and long-term support fall on people with fewer resources. They also affect women and younger adults, whose symptoms are often under-recognized, and rural or underserved communities with limited access to rehabilitation. The effects of stroke on mobility, speech and cognition can make getting help even harder. “Equity means meeting people where they are with culturally and contextually relevant support and measuring what matters to them,” Stacy says.

At the recent European Stroke Organisation Congress (ESOC), SHINE presented its abstract, From

Voice to Value: A Framework for Survivor-led System Design in Stroke. The work has since been published in the [European Stroke Journal](#), further advancing the conversation on survivor-led stroke care.

About SHINE

SHINE places survivor expertise and lived experience at the center of stroke care, research, and policy. Through global collaboration, advocacy, research, and innovation, SHINE works alongside survivors, healthcare providers, researchers, organizations, and policymakers to ensure that lived experience helps shape the decisions, services, and systems that affect life after stroke. By connecting voices, sharing expertise, and fostering meaningful partnership, SHINE supports a global network of survivors working to influence change and improve outcomes for people affected by stroke.

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