Raising the Voice of Young Survivors

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Portrait of survivor Amy Edmunds courtesy of Paul A. Olsen

IT'S NOT UNUSUAL FOR ME TO ASK QUESTIONS. Curiosity has been my lifelong companion. As a child, curiosity once earned me a set of *World Book Encyclopedias* for questioning why woodpeckers peck wood. As an adult, curiosity prompted foreign travels across Europe, Africa, Asia, North America, South America and the Caribbean.

So it's no surprise that I was also curious in 2002, after experiencing an ischemic stroke at age 45. I was determined to understand why it occurred. I enrolled in graduate school the same year and chose a research focus on understanding stroke among young adults.

As a student, I was curious about why there were so few publications about the American young-stroke experience. I wondered why there was no advocacy voice for my new identity. And I questioned the lack of social support and recovery resources for young survivors and their families. This inspired me to found YoungStroke Inc., a nonprofit patient advocacy organization. YoungStroke now benefits those like me, young adults who experienced their first stroke before age 65.

Before my stroke, I ate a healthy diet. I often competed in 5K races and had no family history to suggest I was at risk. Yet, I had a stroke following an outpatient surgical procedure.

The stroke affected my memory. After a week in the hospital, I was sent home with a suspended driver's license pending further vision exams. For me, my dependence on others during my recovery was a difficult transition. During this time, I visited several support groups. But I was depressed to observe I was too often the youngest survivor in the room. Even more, their conversations did not address my interests in career, driving or relationships.

Because my memory loss includes the moment of the stroke, I rely on the memory of my mother for the events of that day. In short, I do not know how the stroke felt. For the first few years, I was frightened *every time* I had a headache or any part of my body responded in an odd way. And, it has taken me years to relax.

My stroke altered the way I view myself. I was shaken by the potential of a second stroke. The stroke altered my family's view of me, too. Since then, I routinely receive daily phone checks from my mother or brother … just to make sure I'm okay. Because I share their concern, I have grown to appreciate their outreach.

For a time, I also felt my invisible disability to be minor compared to those survivors with more obvious physical disabilities. But I soon realized these situations offered an opportunity for me to *become the missing voice.*

So, I began to build on my strength for public speaking.

I found my voice as an active volunteer for the American Heart Association/American Stroke Association (AHA/ASA). Over the years, I have

participated in many You're the Cure advocacy trainings. Collectively, these trainings helped me to refine my message. I became comfortable presenting in the community as well as before state legislatures and Congress.

Today I use my voice to emphasize the role of all members of the community to recognize and respond quickly to stroke warning signs. Getting help quickly often depends upon a bystander recognizing the signs and calling 911. For me, this person was my mother. I was totally unaware I was experiencing a stroke as my speech was confused and I experienced temporary blindness.

Getting help at the first sign of stroke is crucial to helping save lives. About 56 percent of Americans cannot name the most common warning sign. Many of these are members of racial/ethnic groups who are at highest risk. This knowledge gap can have deadly consequences. Ignorance of stroke symptoms means many young stroke patients may be misdiagnosed or are delayed in getting access to care.

I also use my voice to spread the word that all stroke survivors are not the same. I help others understand the differences between the needs of young adult survivors and geriatric patients. Stroke may be particularly devastating financially and physically for young survivors, as they face overwhelming challenges to regain independence and return to their jobs and family responsibilities.

I encourage young survivors to have annual assessments with their healthcare team to maximize rehabilitation planning. I challenge respite policies that exclude caregivers of young stroke survivors. Finally, I champion more research and data collection about young stroke.

I was honored to have been invited to address the inaugural *Rally for Medical Research* in Washington, D.C. in 2013 by the American Stroke Association. This event cast YoungStroke Inc. onto a national platform with full-page ads in *Politico* and *Rollcall*.

Last year, I was elected to the Board of Directors of the World Stroke Organization. In this role, I globally represent stroke support organizations. I am also one of two stroke survivors who serve in this capacity. The other is young stroke survivor Patrice Lindsay of Canada. Our images were among those used to promote World Stroke Day last year.

Now 13 years post-stroke, my childhood curiosity remains as steadfast as my desire to voice the unmet needs of young survivors and their caregivers. See the next page to find out how you can get involved with YoungStroke. SC

YoungStroke 2015

In June 2015, YoungStroke launched the first international conference to exclusively address young stroke in Jacksonville, Florida. This unique scientific conference brought stroke patients together with a wide array of healthcare professionals. Neurologists, therapist and other stroke specialists engaged with patients and each other. Its theme, *Visible for Community Change,* challenged attendees to be visible in their hometowns to raise awareness. "YoungStroke 2015 should mark the start of a new era," Bo Norrving, the immediate past president of the WSO, said during his keynote address. YoungStroke 2015 was endorsed by the WSO and sponsored in part by Mayo Clinic.

Survivors Leigh Kost (l) and Tracie-Ann Jessamy at YoungStroke 2015

"I've heard more ideas and research geared towards stroke survivors in my age group in the first day of the conference than I have in the 2 ½ years since my stroke," said survivor Nate Sankary of New Jersey.

Young survivor Toni Hickman of Houston entertained with songs from her album Unbroken, which included lyrics about her stroke experience. Performing artist Ron Daise also debuted an original song titled *"People Gotta Know."*

As a next step, YoungStroke's Fall Retreat is scheduled October 16, 2015, at the Sea Trail Convention in Sunset Beach, North Carolina. The retreat will build on the momentum and collaborative spirit ignited at the June event to create more research projects and publications related to young stroke. As before, survivors and caregivers are encouraged to come share perspectives.

YoungStroke 2016 returns to Jacksonville next year June 25-27. Keynotes include Walter Koroshetz, M.D., director of National Institutes of Health/ National Institutes of Neurological Disorders & Stroke (NIH/NINDS), and Jon Barrick, president of the Stroke Alliance for Europe and CEO of the Stroke Foundation of the United Kingdom. YoungStroke 2016 promises to deliver innovative opportunities for survivor and caregiver participation.