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### **Letter In Support of a Young Survivor Initiative through the Cleveland Stroke Club**

As members of the Cleveland Stroke Club, my husband and I add our support to Chris Vuyancih's efforts to start a Young Survivor Initiative.

My husband's stroke happened 10 years ago when he was fifty-five. His rehab goal was to regain his skills with the hope of returning to work. But after the first few years, we came to the conclusion that if my husband was not able to return to work as a programmer, early retirement was not a bad alternative. Our social goal was to maintain our pre-stroke lifestyle: maintain our home, friends, marriage, finances, and maybe even take a vacation sometime. Now, as time goes on, retirement is not so hard to face because our friends are retiring and we are becoming in-sync with our cohort.

Retirement was our back-up plan.

But for young survivors, early retirement is not an option--most young survivors cannot afford to retire. Survivors who are in their early 20s have not had a chance to work the years needed to qualify for Disability and Medicare. They have no option to retire, ever, unless they become employed again. Even if a young survivor qualifies for disability, they do not have the advantage of having savings accounts and retirement funds to rely on. Many survivors who are professionals in their forties or early fifties cannot comfortably retire (live on disability, savings, and retirement funds) because they are sandwiched between putting kids through school, caring for aging parents, and welcoming grandchildren into the world.

But even if retirement was financially feasible, no one wants to maintain the lifestyle that they had in their 20's and 30's for the rest of their life. No matter the lifestyle of young people (newly married, young families, struggling student, single, dating, entry level job, one room apartment, living with relatives, tight finances, job uncertainty, vintage car or well used bus ticket, etc.), simple maintenance for the rest of their life is not a desirable option.

The goal of young survivors is to build a lifestyle to have a job, driver's license, home, family, pet, solid financial standing (with savings and a retirement fund), and way to fulfill their responsibilities to their children and parents.

**The challenges to build a lifestyle are different than those needed to maintain a lifestyle.**

**Family** Many young survivors live alone or with a hard working spouse and some have young children. In a very real sense, young survivors are their own caregiver. Young survivors have to wrestle with the fragmented healthcare, rehabilitation, and insurance industries on their own. Young survivors have to figure out their own transportation, housing, family meal preparation, shopping, medication, finances, and implement their own recovery.

**Job** Young survivors, who had nice careers prior to the stroke, often, find that they cannot continue in the profession that they loved. (Although stroke does not impact intelligence, stroke survivors can have problems with memory, communication skills, organizational skills, emotions, fatigue, dexterity, and

mobility.) Young survivors often find themselves retooling to take a part-time, lower-level position. Just getting a job can be a challenging process (retooling, applying, and going through an interview). Once hired, problems can arise when job training and time to learn/adapt are not offered.

**Spirit** The most difficult aspect of being a young survivor maybe the toll it takes on the psyche and relationships. While life goes on for friends and family, young survivors work single-mindedly just to get off of rock bottom. Young survivors may isolate themselves to focus on rehab and to avoid unhelpful people. Young survivors may also find themselves isolated because friends and family drift away. Feelings of stress, anxiety, and depression are often part of stroke recovery and they are made worse by isolation. Recovery is not easy for anyone, but it is especially challenging in the context of young relationships and responsibilities, with limited resources.

**Why we need a Young Survivor Initiative** Although young and retired survivors have many of the same recovery stories and need the same health information, their lifestyles, goals, and life experiences are different.

It seems right, that young people should have occasions to share their stories and help each other. It's good to have friends in your own cohort who are going through the same things. It's good to know that someone understands because they are going through it also. It's good to know, deep in your heart, that you are not alone.

**Our Club is a good place for this initiative.** We have many young members and welcome new members. We have members in almost every area of Northeast Ohio. We are here to stay; we celebrated our 43<sup>rd</sup> Anniversary. We are an independent club; we are self-supporting and do not have to abide by restrictions of medical facilities. We have a newsletter, resource list, Website, FB, monthly email updates to professionals and community leaders, **and** 43 years of community contacts in all walks of life. Our members actively participate in other clubs and community programs and we are open to collaboration. All of these resources continually change based on member input; so we can easily expand and improve them, with the help of young survivors.

Most of all, we want to help support the heroic efforts of our young members to live independently and productively. As a Club we can all support our young members by sponsoring a young survivor forum, by helping young people find resources, by listening, and by understanding.

We are grateful that Chris approached the Cleveland Stroke Club her idea to create a Young Survivor Initiative and we wholeheartedly support her.

Respectfully,

Deb and Roger