

LOS ALTOS *Hills*



The Shively Family

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The Shively family, left to right: Linda, Jim and Marge.
Photo by Aaron Alvarez Mendoza.

The Shively Family

Works to Cure SMA

By Abbie Burgess

Inda Shively's daughter Jessica would have turned 23 years old this year. She lived with the progressive neurodegenerative disease Spinal Muscular Atrophy (SMA) until she died in 2005, just nine days before her fourth birthday. She was very bright and used a communication device. She enjoyed the independence that driving a power wheelchair gave her. Her family remembers that she loved to read, attend preschool, and spend time with friends and family. "She has tremendous joy that lives on," says her grandmother, Los Altos Hills resident Marge Shively.

Jessica was diagnosed with SMA at three months old. The news was devastating, as at the time, there were no treatments, and the doctor predicted she likely wouldn't survive to her first birthday. Jessica was never able to roll over, sit, crawl, or walk. By nine months, she needed a feeding tube, and by 11 months, she had a trach tube to help her breathe. She was in and out of the hospital most of her life, common for people with SMA. When Jessica was alive, there were zero treatments available for the condition. In the years since, researchers have found 18 treatments that are in various stages of development. As of now, there are 3 FDA-approved treatments for SMA.

What is Spinal Muscular Atrophy?

You may not have heard of this disease, but about 1 in 50 Americans is a carrier. It affects 1 in 11,000 regardless of race or gender and robs people of physical strength by affecting the motor nerve cells in the spinal cord, taking away the ability to walk, eat, or breathe.

When the Shively family discovered the organization Families of SMA (now Cure SMA), they became acquainted with other families affected by the disease. "We felt we needed to do something. This marked the beginning of our awareness and fundraising efforts."

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Marge began a fundraising newsletter, originally called "Trick-or-Treatment," when Jessica, her granddaughter, was a baby. The newsletter has continued and now includes articles from dozens of local SMA families. Marge expanded her fundraising efforts by hosting a theater party and auction for several years. "After doing two fundraisers a year, we focused on the walk, and we included the expanded newsletter, calling it 'Faces of SMA,' in the mailer for the walk," she describes.

The family took their efforts one step further when Linda started the annual event, NorCal Walk & Roll to Cure SMA in 2003, when her daughter, Jessica, was a year old, to provide a place for local families affected by SMA to connect, raise awareness, and fund research and treatments. This year's walk, held on August 16, is the 23rd year of the event.

With nearly 400 participants, the walk has grown tremendously over the years. To date, the NorCal event has raised over \$1.5 million.

About Cure SMA

Cure SMA NorCal is one of the volunteer-led chapters of the national organization, Cure SMA, across the US. The chapters exist to provide support and opportunities for individuals and families impacted by spinal muscular atrophy (SMA).

Cure SMA has invested \$84 million into three research areas: Basic Research, Drug Discovery, and Clinical Research. They have found four treatments, and several more are in the final stages of clinical development.

The Shivelys are excited to share milestones that the organization has reached, including, as of 2024, 100 percent newborn screening of spinal muscular atrophy (SMA) in all 50 states. There's one goal that the organization is still working toward: finding a cure.

Three of the 29 centers in the Cure SMA Care Network are located in California. The centers are working to develop an evidence-based standard of care.

Eighty cents of every dollar raised is funding research, patient services, awareness programs and family support —over 5,000 SMA patients and families receive direct services from the organization.

Linda Shively's daughter, Jessica.



Marge, as a representative for Cure SMA, was a member of the Los Altos Chamber of Commerce for several years, gaining more community awareness and support.

For 20 years, she also volunteered at KMVT, channel 15's local cable program, "AAUW Connections." In August of 2017, she produced "What is SMA?" with Linda Shively as moderator and several local families connected to SMA as panelists.

Outside of her work with Cure SMA, Marge has been an active community volunteer for decades, including the PTA at Linda's schools and ten years of volunteering at Loyola Kindergarten. She has also contributed

her time to the LAH Club, the local Phi Mu Alumnae chapter, the American Association of University Women (AAUW)—an organization that advances equity for women and girls—and P.E.O., a foundation that supports women's educational advancement around the world. Marge has a unique and longstanding hobby: Marge has been doing porcelain china painting since 1977!

After teaching high school physical education (PE), in 1977, Marge started teaching perceptual motor training (PMT) at Mountain View and Los Altos preschools. The training helps individuals develop the ability to interpret and respond to sensory information with coordinated body movements, enhancing both cognitive and motor skills. She went on to teach adapted PE at different schools and grade levels, including teaching adapted PE for 24 years for DeAnza-Foothill Community College. Graduates of Los Altos elementary schools will remember participating in Junior Olympics, an event that Marge was actively involved in helping put on.

Her work in physical education and perceptual motor training gave Marge a background that made her feel comfortable helping people with disabilities, including helping Jessica.

Jim is now retired after a career working for Varian Associates as an electrical engineer. His main hobby is reading, and he and Marge enjoy outings with their car club. Marge and Jim met at Cal and married in 1961. They bought their home in Los Altos Hills in 1967 and have been actively involved in the community ever since. Marge keeps a local database of neighbors, which is helpful when hosting annual parties to welcome new neighbors and keep up with existing ones.

The couple has been active members of Foothills Congregational Church since they moved to town. Linda grew up in the church, and when she moved into her current residence in Marge's childhood home in Alameda, she joined the Congregational Church there—which happened to be the church where Marge and Jim were married!

Linda grew up in Los Altos Hills and attended Eastbrook, Loyola, Blach Junior High, and Mountain View High School before attending UCLA to earn her degree in psychobiology. After graduating, she worked in Los Angeles for a couple of years before returning to work in the Bay Area. "After I left an unhealthy marriage, Jessica and I lived with my parents in Los Altos Hills for the last two weeks of Jessica's life," she shares.



Linda returned to her career in IT within the healthcare industry and continued honing her speaking skills, which she uses today as an award-winning international motivational speaker. Because of the joy Jessica brought to her life, Linda knew she needed to continue to share that joy with the world. In 2017, Linda launched her business, working with organizations and individuals who want to reduce burnout, unlock motivation, and navigate change by leveraging joy as a strategic advantage. "I love witnessing the transformation in my audiences and with clients through coaching or during retreats," she says.

Her private clients include growth-minded business leaders, royalty, and individuals seeking to live their best lives. Linda's book, *Getting to Joy*, shares practical tips to find your way back to joy. As a gift to readers of this article, she is offering a free copy at GettingToJoy.com/gift.

Linda has studied brain and mind function for over 30 years. She is a certified Master Life and Executive Coach, a Master Practitioner of NLP (Neuro-Linguistic Programming), a Master Hypnotherapist, and a Certified Laughter Yoga Leader.

Learn more about Linda at lindahively.com and support the 23rd Annual NorCal Walk-n-Roll by visiting walk.curesma.org/NorthernCalifornia.

Upcoming Event:

23rd Annual NorCal Walk-n-Roll, Saturday, August 16, Civic Park - East

1375 Civic Dr, Walnut Creek, CA 94596, 10 AM - 1 PM

The Shivelys invite you to join their team, Jessica's Joyful Team:
<https://walk-curesma.donordrive.com/teams/JessicasJoyfulTeam>.

For more information, visit walk.curesma.org/NorthernCalifornia.