A Match Made in Heaven

Vickie and Monty Karns met at a Sunday School singles class. Both had been married previously and each had three grown children. They started “going steady” in December 1993. Monty believes it was the dinner his daughter suggested he make with the borrowed china and crystal, but Vickie said it was when he played, “Hey Jude” on the piano. They were married in August 1995.

Monty says there were “red flags” leading up to the ALS diagnosis. Vickie used to whistle, one of those wonderful whistles that gets your attention. One day she just couldn’t anymore. Monty knew they needed to see a doctor, when they were on a hiking trip with friends, but Vickie was not able to finish, as she had done so many times before.

Vickie was diagnosed in May 2015. She lost her ability to speak in October 2015, due to the bulbar onset.

When asked what has been the hardest part of an ALS diagnosis, Vickie indicated trying to keep up with conversations. She always feels behind. People typically ask one question, often followed up by another and while she is typing her answer, they have moved on to the next question. Her neighbor gave her a china bell to ring, which has helped others to stop so she can catch up and be an active participant in the conversation. While Vickie has lost her voice, she hasn’t lost the desire to participate in the conversation.

Monty indicated he misses hearing her voice. He encourages anyone having the opportunity to bank their voice, to do so as soon as possible. Her voice went so fast, it wasn’t an option for them. He knows their kids and grandkids miss hearing her voice as well.

The wonderful, caring support has continued to impress Vickie and Monty. They have always known and felt they were loved, but family and friends have shown that the love is deeper than they had ever known or imagined. The simple things, like planting flowers, making meals, or learning to drive the van has been so appreciated. They are continuing to learn how to ask for help, but it’s hard.

“So, this [ALS] has happened,” Monty said. “We are still a match made in Heaven.”
Meet JoCarolyn Chambers

JoCarolyn Chambers, MSW, LCSW has been named the new Care Services Manager for Oklahoma for The ALS Association. JoCarolyn has been a clinical social worker for over 30 years, specializing in working with individuals and families who are experiencing difficulties and challenges in their lives. She has also done clinical therapeutic work with children, adults, and families as well as in group settings. She has been intricately involved in starting and implementing a bereavement camp for children here in Oklahoma, and has spent a great deal of her career working in the hospice field.

JoCarolyn feels that she is called to be of service to others and is excited to bring her skills and expertise in providing care and support to the ALS community.

“I am honored to be a part of the ALS organization and look forward to building relationships and continuing the excellent work of Sarah Haupt, LCSW who has been in this position for the past several years.”

JoCarolyn’s husband Steve is the senior minister of New Hope Christian Church in Oklahoma City. They have three amazing children, a wonderful son-in-law and the most perfect grandson ever! They enjoy traveling, boating and camping as well as all sports. And even though living in Oklahoma, “our family loyally remains purple and true to the Texas Christian University Horned Frogs where three generations of our family have attended”.

“I look forward to working and advocating for individuals and their families of the ALS community, as well as increasing awareness and providing support and services.”

Go to ProjectRevoice.org to learn more about this exciting new project.

To show the power of this innovation, we have recreated the voice of Pat Quinn, co-founder of the ALS Ice Bucket Challenge. Since Pat did not bank his voice before ALS took away his ability to speak, Lyrebird used footage from his Ice Bucket Challenge appearances and interviews in order to clone his voice.

Pat says this technology will transform the way people with ALS live.

Project REVOICE

The ALS Association is excited to introduce Project Revoice, an innovative new partnership that can help people with ALS record themselves speaking so that they can still use their unique “voice” after losing the ability to speak.

The new technology is powered by the Canadian company Lyrebird and can clone high-quality voices with just a few hours of voice banking. This is an evolving project, so over the next few months, we will be working with our partners to launch a free online tool to allow anyone with ALS to record themselves and clone their voice.

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The Walk to Defeat ALS Expands to Oklahoma Metro Area

The ALS Association is pleased to announce that a second walk will be held this Fall on the campus of the University of Oklahoma. A dedicated group of students have taken the initiative to become a recognized student-led organization to help bring awareness and raise funds for The ALS Association through the Walk to Defeat ALS.

The first walk was started in Tulsa, Oklahoma by a dedicated group of volunteers in 2014. It has allowed The ALS Association to expand its services to individuals and their families in Oklahoma effected by ALS.

Leading the efforts in the West Oklahoma area is Chair, Sierra Jo Sallee. Sierra has a heart for philanthropy and The ALS Association feels privileged that she selected the Walk to Defeat ALS to use her passion and leadership.

“Philanthropy has been a part of my life from a young age.” Sierra noted. We started volunteering together from the time I was 8. Giving back to your community is an essential way to keep your surrounding community thriving and keep yourself grounded. The Walk to Defeat ALS is one way I hope to create a lasting impact on my community.”

Sierra has been working tirelessly for months putting together a committee of students from the University of Oklahoma to help plan and coordinate the event. This group of students have began this journey and hope that other students they enlist will continue their efforts well into the future. The committee meets monthly, even during the summer to ensure a successful event for those with ALS, their families and the surrounding community.

Senior Bradley Gregory, ceremonies chair, got involved for personal reasons. “As someone with a loved one living with ALS, I am so glad to have the opportunity to help plan and host this important event. I look forward to spreading awareness and raising funds with this great group of students and The ALS Association.”

The committee is working to secure a date and site for the Fall, 2018. Continue to watch the Oklahoma website: www.alsa.org/oklahoma or our Facebook page: ALS Association Oklahoma for more details.
The ALS Association is the only national non-profit organization fighting Lou Gehrig’s Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships.

Our vision is to create a world without ALS.

Our mission is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

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