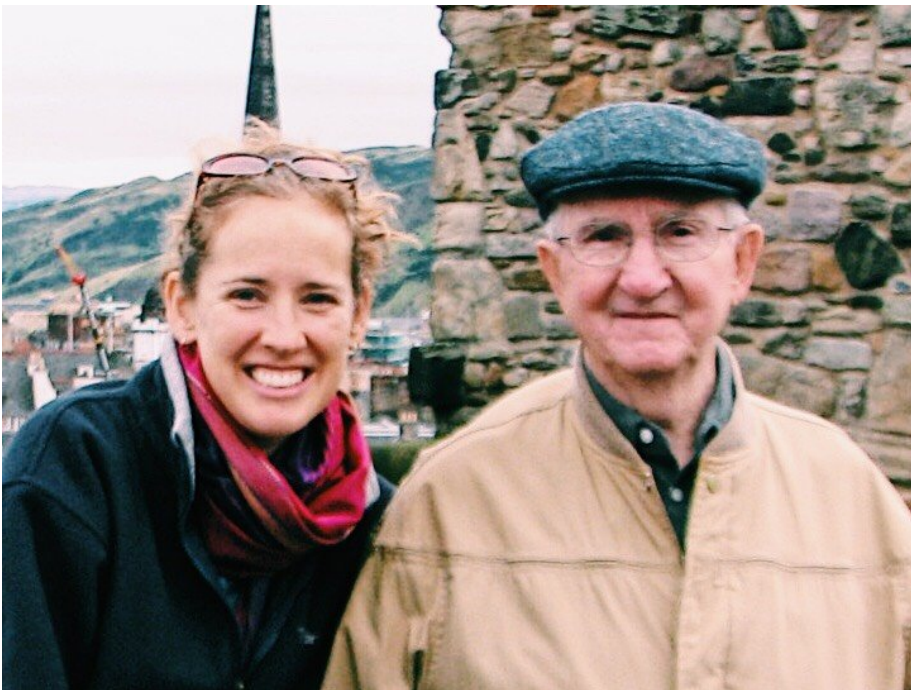


La Jolla doctor donates late father's tissue to help Lyme disease research

by VICTORIA DAVIS

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Dr. Sharon Wampler with her late father Whitfield (W.E.) Wampler.

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Before now, La Jolla biochemist Dr. Sharon Wampler never spoke publicly about the controversy that plagued her father's battle with Lyme Disease. Sharon's father, Whitfield (W.E.) Wampler, was age 92 when he passed away August of 2016. While it's unknown exactly how long W.E. lived with Lyme, his more severe symptoms—including joint failure and loss of hearing and eyesight—spanned over ten years.

"I remember him looking at me while in the hospital and saying, 'I don't understand. Why can't the doctors help me?'" said Sharon, who has worked many years in the Biotechnology industry and who also lives with Lyme. "I had to explain to him that there's not a drug that they can just say, 'Here, take this and you're fixed.' There's so much more to it."

The controversy, which has shadowed W.E. and other patients, like Sharon, with Lyme Disease rests largely in the fact that the Lyme diagnostic tests are, according to Bay Area Lyme (BAL) Foundation's Executive Director Linda Giampa, "only 50 percent accurate." As stated by the BAL, located in Portola Valley, Lyme disease is one of the "most common vector-borne infectious diseases" in the world and is found in 49 of the 50 United States (Hawaii being the exception). There are over 329,000 new cases of Lyme occurring in the country each year.

"Lyme is very difficult to diagnose," said Giampa. "The disease is only running around in the blood for a short period of time, and then it goes and hides in the organs and joints."

"It's 'The Great Imitator'" she added. "ALS, MS and Fibromyalgia are the most common misdiagnosis for people who actually have Lyme."

Currently, the only test available for Lyme Disease is a blood diagnostic, which does not register the Lyme bacteria (*Borrelia Burgdorferi*) that has already made it into the body's tissue. Giampa and Sharon say this is why many people develop Chronic Lyme Disease and are sent home with "insufficient medication" and no knowledge of their true condition.

However, Giampa believes BAL will have a more accurate diagnostic test on the market in five years, thanks to the recent tissue donations. In collaboration with National Disease Research Interchange (NDRI) and Columbia University, BAL launched the very first Lyme Disease tissue bank in the US this past November. Sharon's father was a pilot donor, submitting tissue from his brain, spinal cord, heart, sciatic nerve, skeletal muscle, synovial membrane and eyes.

"I know people who have killed themselves from the physical pain that comes from living with Lyme," said Sharon. "I've had friends call me who are bed-ridden from this asking for help and there's a lot of emotions that come with that. But that's why these tissue samples are so important. I really think this research could be the thing that saves them."

In 2008 Sharon (age 41 at the time) contracted Lyme after being bitten by a tick during a trip in Heidelberg Germany. She never contracted the infamous "bullseye rash" so Sharon tossed the tick and forgot about it. A month later Sharon started getting headaches and sporadic joint pains. Doctors in San Diego tested her for lupus and arthritis, but the results showed no indication that there was anything wrong. Over the next six months, Sharon's condition worsened as she was passed from doctor to doctor.

"My whole body hurt and my heart rate would go up," said Sharon. "I just couldn't figure out what was wrong. I was in the best shape of my life."

Sharon was eventually tested for Lyme Disease, and while the test came back positive, doctors said her results were "inconclusive." The test to see if the bacteria-fighting antibodies (Immunoglobulin G and Immunoglobulin M) were active came back both positive and negative. Sharon's doctors dismissed the test and Sharon



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continued to get worse for another year.

“Doctors generally don’t understand the nuances of diagnostic tests,” said Sharon. “They just know positive or negative, so they didn’t believe my test results and the doctor told me it was a false positive,” said Sharon. “He told me, ‘You don’t have Lyme Disease.’”

“We learned about Lyme Disease for maybe five minutes in medical school,” added Sunjya Schweig, who serves on BAL’s scientific advisory board. Schweig went to UC Berkley for undergrad, UC Irvine for medical school and did family practice residency at UCSF in Santa Rosa. He has been working in the field of Lyme disease for 12 years.

“I looked back at some of my medical school textbooks and there were two or three paragraphs on one column, on one page, about Lyme Disease and that was it. It was all very surface level education too about the bullseye rash. Not much more than that.”

Eventually, Sharon was re-diagnosed by a rheumatologist and formed her own team of health care professionals to help her recover, including Michael Kurisu D.O. the Director of UCSD Center for Integrative Medicine who has been treating Sharon for the past nine years. Recognizing there was a problem with the diagnostic system, Sharon fought tooth and nail when her father also started getting tested for Lyme.

Unfortunately, W.E. was not officially diagnosed until 2015. By 2016, Sharon had to move her father into assisted living as his condition continued to grow significantly worse. But he was declined and spent seven weeks in the hospital.

“I was appalled as a scientist and as a patient how we were disregarded by many in the healthcare system,” said Sharon. “I’ve definitely had to get over a lot of anger.”

BAL was the first research facility to donate all their resources to researching Lyme Disease. Now their new tissue bank has been working hard to bring both physical and emotional healing to patients like Sharon and her father. BAL has raised over \$22 million to fund Lyme research and Giampa says much credit is owed to Sharon, her father and the other 35 individuals who have made inquiries for donation.

“These things are heartbreaking, and we do get emotionally tied to the family and their story,” said Giampa, who is also working to develop a novel therapeutic for those already diagnosed with chronic Lyme. “We just had a mother come in to donate the body of her young daughter and that was the hardest of all. But these families want to help. They want to know the death was not in vain.”

Giampa says the biobank has been “tremendously successful” in that researchers who had never invested their time in studying Lyme before are now have the samples and the motivation they need. This past May BAL knew four people personally who passed away from Lyme Disease and there was a memorial held at the facility.

“It’s not discussed nearly enough and, hopefully, we’ve been a big push in that,” said Giampa. “Knowing that we’re all doing something to forward that research, that’s what keeps us going. Things are going to change.”

Sharon has been working with Congressman Scott Peters staff since 2017 to bring Lyme awareness to the San Diego community, having her first meeting in August

2018 with staff of Assemblyman Todd Gloria. Sharon is also part of the patient cohort for "Project Apollo," a personalized medicine effort founded by Dr. Mike Kurisu and based out of UCSD. She's the Lyme patient.

"A lot of the medical community has not caught up," said Sharon. "But the scientific and research community is much more open to realizing that we don't know everything about this disease."

The Bay Area Lyme will be hosting a Lyme fundraiser in La Jolla with SoulCyle March 1. The fundraiser "Ride Out California" is open to the public and is a Spin Class held to raised funds for Lyme Disease Research.

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CHENGTT5 | January 29, 2019

My ALS(Amyotrophic lateral sclerosis) Symptoms started out with a "foot drop" on my left foot. From there my left leg lost all muscle tone and the entire left leg muscles are gone. Also my fingers and thumbs "contract" at times. Left arm loses muscle tone too. My family doctor said there is no cure for ALS, I was just living unhappy life till I saw a blog talking about Best Health Herbal Centre. So many people said positive things about their herbal product which I don't believe at first. I showed my daughter what I saw online about their product and my daughter decided we shall give it a try. Few days later she purchased two bottle of ALS herbal remedy which they said I will use for only six weeks. My life changed automatically after six weeks of applying the herbal remedy as instructed. All my symptoms was terminated completely and am now living ALS FREE .. For more details about their herbal product visit their Homepage www.besthealthherbalcentre.com

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Patrice Pousley | January 28, 2019

This is very exciting that BAL exists. I have chronic Lyme that I have battled for 5 yrs now. I know many others whose lives are a living hell. The fact that BAL exists is wonderful. I know I would want a donation to BAL. Just what I'm not exactly sure as I wouldn't want to go against anything in my religion. Thank you for all you do!

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Luka Kegley | January 28, 2019

My first ALS symptom appeared in 2011. 4 years ago I learnt about ALS/MND successful chinese medicine from Rich Herbs Foundation (www.richherbsfoundation.com), the treatment made a tremendous difference for me. Few weeks into the treatment I had improved muscle strength and coordination, improved speech, improved walking balance, increased appetite, improved eyesight and improved mood swings. 4 years since the treatment, i still feel stronger than ever with no symptoms at all, only occasional tingling on my right foot at night. I feel cured from the disease!

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