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Page 16



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Gretchen's Legacy

Piscotty family, Livermore
Lab Foundation partner
on ambitious goals
of ALS Cure Project

Page 12



PLEASANTON WEEKLY

20

CELEBRATING 20 YEARS OF
AWARD-WINNING JOURNALISM

- 5 | **NEWS** PUSD sets school reopening timeline
- 16 | **TRI-VALLEY LIFE** Theaters grapple with lost year
- 17 | **EDITORIAL** Our election reflections

Gretchen's Legacy

Piscotty family, Livermore Lab Foundation partner on ambitious goals of ALS Cure Project

By RYAN J. DEGAN



Oakland A's outfielder Stephen Piscotty has dedicated himself to finding a cure for amyotrophic lateral sclerosis since his late mother Gretchen's diagnosis. For the 2020 season, the A's created an ALS Cure Project Foul Ball Cutout Zone at the Oakland Coliseum to help raise funds to support the cause. Photo courtesy Oakland A's.

Before Pleasanton's Gretchen Piscotty died in 2018 after battling ALS, her husband Mike and their three sons promised her that they would work together to help find a cure for the infamously aggressive disease.

To help keep that vow, soon after Gretchen's passing Mike Piscotty and sons Stephen, Nick and Austin launched the ALS Cure Project — and recently their nonprofit has been working with the Livermore Lab Foundation on key research for potential treatments for the commonly known but sparsely understood medical condition.

"My really honest feeling is that we will be curing ALS in the not too distant future. I would be terribly disappointed if it weren't in 10 years, but I hope it is going to be less," Mike Piscotty told the Weekly in a recent interview about their new nonprofit's work with lab researchers.

"This is a good example of a local family who took tragedy and is paying it forward. And when you see that kind of unbridled commitment to a cause as volunteers doing it because it is the right thing to do, it's easy to get behind the people who are trying to make a difference," added Susan Houghton, communications and development consultant for the Livermore Lab Foundation, a philanthropic organization associated with Lawrence Livermore National Laboratory (LLNL).

Officially termed amyotrophic lateral sclerosis (and more commonly known as Lou Gehrig's disease, after the New York Yankees first baseman famously diagnosed with the disease in 1938), ALS is a fatal disease that attacks the neuromuscular system of the body, slowly and systematically rendering the person paralyzed and unable to breathe.

A relatively rare disease, approximately 6,000 people get diagnosed with the disease in the United States every year and around 18,000 people have it at any one point in time, according to the ALS Cure Project.

Despite being a very well-known disease in society, a cure currently does not exist and few treatments are available for the disease. No new ALS drugs have been made in over 22 years, since Riluzole in 1995, and patients have an average lifespan of only three to five years, according to the ALS Cure Project.

Further highlighting the long road ahead for finding a cure, Mike Piscotty added that currently there isn't even an effective method for identifying if a patient has the disease. Since a direct test doesn't exist, patients need to rule out a whole host of other potential illnesses before being diagnosed with ALS.

"The piece I've learned about the sad state of affairs is just knowing anything about this disease," Mike told the Weekly. "There's no test for it ... So that makes it really hard for drug companies to know if any of their treatments are working. In some folks it may take them 12 years before they pass, and some will go as fast as Gretchen did."

Gretchen, a longtime active Pleasanton resident and popular attendance secretary at Foothill High School, passed away just over a year after being diagnosed with ALS. Her experience living with the disease gained a national spotlight after son Stephen, a Major League Baseball outfielder, was traded to the Oakland Athletics, allowing him closer to his ailing mother.

While some patients can live for several years or longer after being diagnosed with ALS, Gretchen died after approximately 16 months, on May 6, 2018, according to Mike. She was 55.

"We don't know why the disease progresses, and once it starts what

makes it keep going. What starts it, we don't know," Mike said. "And when you think about all of the advances we've had in medicine ... to be at this point right now is sad, and something we decided we wanted to work toward."

To reach the ambitious goal of finding a cure for the disease in the next decade, the Piscottys' ALS Cure Project has dedicated itself to raising funds for ALS research, with every dollar raised from fundraising events and private donations going directly toward combating the disease.

In order to identify where funds could best be allocated, the project created a research council populated by experts who identify areas of focus and organizations that can accept funds for ALS research.

One such organization that the project has worked closely with is the Livermore Lab Foundation, which has helped dedicate LLNL's resources to helping find a cure for ALS.

"We are fortunate to have committed scientists, researchers and

engineers, many of whom are our friends and neighbors, dedicated to tackling society's most important issues. Their work on COVID-19 this year alone has addressed needs in medical countermeasures, detection and infrastructure. And now, they are tackling ALS," said former Livermore mayor Cathie Brown, whose husband died from ALS in August.

"This rare disease strikes approximately 20,000 individuals each year, including my (husband) Tom. And unfortunately, it gets little research attention," Brown added.

Funding provided by the ALS Cure Project helps the lab take a multi-modal computational studies and physics-based approach to researching the disease, with the first steps being to identify biomarkers — specific indicators used to measure a disease or condition — and to understand the influence of genetics in the disease.

That will ideally lead to a cure or additional treatment options.

"What we really feel is that if we can identify biomarkers, if we



LARRY RICKSEN/OAKLAND A'S

A's fan Corey Reich meets Pleasanton native Stephen Piscotty during the A's ALS Awareness Day in 2018.



ALS CURE PROJECT

Gretchen Piscotty, a longtime Pleasanton resident and retired Foothill High School secretary, died on May 6, 2018, about 16 months after she was diagnosed with ALS.

Leveraging LLNL's Capabilities

LLNL uses High-Performance Computing, Bioengineering, and Bioassays to Contribute to the ALS Research and Clinical Communities



Identifying Biomarkers



Understanding Cellular Mechanisms



Investigating the Influence of Genetics



Developing New and Effective Treatments

By partnering with the Livermore Lab Foundation, the ALS Cure Project has been able to utilize the facilities and extensive knowledge found at Lawrence Livermore National Laboratory.

can understand the disease mechanisms and we can hand those to the drug and pharma companies that create therapies, that they are going to be able to go very fast once we do that initial research work. That's what's been very challenging in ALS, is to get people to fund the basic research," Mike said.

The Piscotty family has deep ties to the lab; Mike has worked for years at LLNL as a computer scientist/associate program leader, and Gretchen was an employee there at one time as well.

The lab's facilities and capabilities will also aid the search for a cure, according to Mike, who said the lab's \$400 million supercomputer has helped advance the cause in a way that otherwise may not be possible.

"It's a rewarding experience to make some progress, and obviously you can see how passionate and fired up my dad is about this. It's been an honor to help do all that I can to keep fighting," said Stephen, who serves as the ALS Cure Project's vice president. "I think one thing that has been really cool is to see the community come around our mission and I think a lot of people have caught on to that maybe we are onto something."

"We are grateful to be partnering with Mike Piscotty to take on this grand ALS challenge," added Sally Allen, executive director of the Livermore Lab Foundation. "The search for biomarkers is critical to

an effective path forward. LLNL's exceptional computational capabilities and physics-based modeling will provide an important foundation and hopefully, the road to a cure."

To promote collaboration in the search for a cure, in October the Lab Foundation partnered with the ALS Cure Project to co-host a four-part series of virtual sessions with ALS research leaders from across the world to address key milestones and craft an "ALS Roadmap to the Cure."

"We really addressed some of what are the key areas that we felt where research needed to be applied," Mike said of the gathering. "So we created what we call 'ALS Roadmap to a Cure,' and along this one-page diagram it has the various milestones that these folks felt needed to occur in order to get to a cure."

The group has also not been shy about leveraging Stephen's "celebrity status," as Mike puts it, using Stephen's connections to the Oakland A's and Major League Baseball to help generate funds for research through fundraising drives and charity events like golf tournaments.

The Piscottys have even at times partnered with the A's on several fundraising and awareness events.

"We've enjoyed a wonderful partnership with the ALS Cure Project. It's been incredible to see our team and our entire fanbase rally together to find a cure for ALS in honor of

Gretchen Piscotty, Catfish Hunter and all of the members of the A's family who have been impacted by this horrible disease," Oakland A's President Dave Kaval said.

"From our ALS Awareness Days at the Coliseum, to creating a special fundraising section of cutouts at the ballpark in 2020, we have been proud to support the Piscotty family and their work to raise funds for ALS research," he added.

Throughout his efforts with the ALS Cure Project, Mike said the work can be challenging and emotionally exhausting due to the ultimately fatal nature of the disease. However, he believes that the campaign helps give people hope, which is one of the key objectives of the organization.

"It's challenging to serve a community really that, I hate this term but people use it all the time, they say, 'When you get ALS you have a death sentence.' You don't know when it is going to be or how long it is going to go, but there is no cure so you're working with a basically terminally ill community. (But) it's a blessing to be able to try to work with them and provide hope. We feel a lot of what our organization does is bring hope," Mike said.



From left: Mike, Gretchen and Stephen Piscotty. The Piscottys say Gretchen continues to inspire their ambitious goals for the ALS Cure Project.

Gretchen's legacy continues to inspire the Piscotty family. Even in her final days, Gretchen was eager to hear from people about how they were doing and what they were up to, a lifelong trait that endeared her to many, according to her husband.

"One of (Gretchen's) interesting attributes was that she just loved to have a conversation, and she had so many friends ... people would talk about her she would always ask 'how are you doing? Tell me about you.' That really made it nice for everyone who communicated with her," Mike said.

"We were quite the handful and

she (raised us) seamlessly, getting us to practices and school and all these sorts of things you know. She loved being outdoors, horseback riding was one of her favorite things and she was just very supportive of all of our activities. Whether it was baseball or basketball or anything. Really hammered home the importance of school," Stephen added. "She was just all around everything you could ask for as a mom, and we miss her greatly."

Learn more about the ALS Cure Project, including future events and fundraising opportunities, online at <https://alscure.net/>. ■



Family Little League photo. The love of baseball started early for the Piscotty boys. From left: Gretchen, Austin, Nick, Mike and Stephen.



The grown Piscotty boys have all taken part in the fight to find a cure, with each son being a founding member of the ALS Cure Project.