

ALS survivor's life of challenges

Mariah Fenton Gladis during filming of a documentary about her life with amyotrophic lateral sclerosis, which she has survived far longer than most. (MICHAEL S. WIRTZ / Staff Photographer)



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Her son did not want her to do it.

The ice-bucket challenge might be too much for someone with ALS.

But Mariah Fenton Gladis was tired of seeing everybody else have all the fun - and the satisfaction of raising money to combat a devastating disease for which there is no cure.

So, late last month, the award-winning Malvern psychotherapist sat in the backyard of her Chester County home as her husband, Ron, flipped a bucket of ice water over her head.

"No problem," Gladis says slowly in an online video.

In completing the dare, Gladis was doing what she has done nearly her entire life - stepping up to the challenge.

Founder of the Pennsylvania Gestalt Center, she has lived with ALS for 33 years after a doctor told her she would last no more than two. She turned 66 in February.

"Mariah is remarkable," said Ellyn Phillips, president of the Greater Philadelphia Chapter of the ALS Association. "There is no other word to describe her."

Gladis is one of the few who has survived ALS for more than 10 years.

Amyotrophic lateral sclerosis (ALS) is a degenerative disease that affects nerve cells in the brain and the spinal cord, robbing patients of their ability to control muscle movement.

Patients eventually become paralyzed, and most die of respiratory failure.

Gladis' years of survival rank below that of the brilliant physicist Stephen Hawking, who at 72 has lived with the disease for more than 50 years. Hawking is almost totally paralyzed and communicates via a speech-generating device.

Gladis, who uses a wheelchair, meets with clients four days a week and exercises with a personal trainer five days. She adheres to a strict diet of organic food and vitamin supplements.

Her speech is slow and slurred. Her husband, who is also Gladis' primary caregiver, serves as a translator when necessary.

Research has not yet discovered an explanation for Gladis' longevity, said Leo McCluskey, Gladis' neurologist and medical director at the Penn ALS Center. The condition is an "incredibly variable disorder" with less research funding than other ailments, he said.

Gladis calls the ice-bucket craze sweeping the world "manna from heaven" for a disease she says is forgotten.

The challenge not only has raised millions of dollars for the national ALS Association, but also has brought a spike in donations to the Greater Philadelphia chapter.

The local group is also enjoying an increase in volunteers and interest in the chapter's fund-raising walks scheduled for Rehoboth, Del., next Saturday; Ocean City, N.J. (Sept. 20); Allentown (Oct. 18); and Citizens Bank Park (Nov. 15).

"Our goal," said Tony Heyl, a chapter spokesperson, "is to make sure this awareness continues after the weather starts to cool down."

Gladis - and her family - are doing their part. In addition to the video challenge, Gladis is the subject of a coming documentary produced by her son Coleman, a filmmaker who has worked on shows including AMC's *Mad Men*.

Mariah: Unconditional Hope uses interviews and clips to tell Gladis' story. The soon-to-be completed film - with original music by composer Michael

Bacon of the Bacon Brothers band - will be submitted for consideration to the Sundance Film Festival at the end of the month, Coleman Gladis said.

On Wednesday, Coleman Gladis focused the camera on his mother. Mariah Gladis wore a cheerful melon-green pantsuit that complemented her red hair. She spoke about her life.

A graduate of Temple University and Bryn Mawr College, she met her future husband at a party in 1979.

"I told my friend Dolly, 'Stay away from him. He's mine,' " Gladis said.

Two years later, on the day Ron Gladis planned to propose, she was diagnosed with ALS. She had cramps in her hand that wouldn't go away, and a doctor told her the news.

That day, Ron Gladis put a cigar band on her finger and popped the question anyway.

"Our life together has been about going toward health, going forward, and making things work," said Ron Gladis, a filmmaker and trained engineer who runs his wife's practice and small foundation.

The couple have two children - Coleman, 30, and Luke, 32.

Mariah Gladis continues to take one-day trips with her husband and conducts workshops, including a seminar on forgiveness later this month in Washington.

"I am grateful every day to still be a useful person in the world," Gladis said. "I know many people who did everything right and didn't survive."

To view Gladis' ice-bucket challenge, go to <http://vimeo.com/104063571>

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