

# CMT Research Foundation Partners with Jenny Decker, CMT Patient Attempting to Solo-Circumnavigate Globe

*Goal is to Raise Awareness of Charcot-Marie-Tooth Disease*

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EINPresswire.com/ -- The [CMT Research Foundation](#) (CMTRF) a non-profit focused solely on delivering treatments and cures for [Charcot-Marie-Tooth](#) disease (CMT)\*, has partnered with Jenny Decker, a 40-year-old nurse battling CMT, a rare neurological disease with no known cure, who last summer launched an effort to become the first CMT patient to sail around the world by herself. She estimates the trip - called Just A Lap - will take about 3 years. If successful, Ms. Decker will make it into the Guinness Book of World Records as the first person to solo-circumnavigate the globe with CMT, a hereditary disease that has already disabled her mother.

"No one knows about CMT and how devastating it can be especially as you age," says Ms. Decker, "My goal is to raise awareness of CMT and help raise funds for The CMT Research Foundation, which has built an extraordinary record of success in funding the right kinds of research projects to find treatments or a cure for all types of CMT."

"In spite of CMT-related problems with her grip, balance, and agility, Jenny is attempting something that few folks in perfect health would attempt. She is an inspiration to the entire CMT community and shows us all what 'Unstoppable' can really mean," says Cleary Simpson, CEO of CMTRF. "We will be cheering for her continued success by tracking her progress on our [website here](#) and updating her story as she moves across the seas. You go, Jenny!"

Ms. Decker retrofitted her sailboat, Tiama with special equipment and other hardware to accommodate her physical challenges. Because CMT interrupts normal nerve conduction to her



Jenny Decker



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arms and legs, Ms. Decker's hands don't listen well to her brain, making simple things difficult, like buttoning a pair of pants or opening a bag of chips. The more she concentrates, the worse her hands tremble. Her legs don't listen well either, often affecting her balance or completely failing her. And it's only getting worse. Ms. Decker's disease makes her unsteady on land, so it's extra difficult to navigate the deck of a rocking boat. She says she is always wearing a harness and is strapped in to prevent going overboard.

"Grabbing lines and reeling things are difficult for me, so I crawl a lot on the boat. I have to hold on to everything. My brain is sending signals to my arms and legs but they really don't want to listen, and fine motor skills are very difficult," Jenny earlier told reporters.

"I want to continue inspiring those with this ailment, or any disability for that matter," Ms. Decker wrote earlier. "I truly believe you can do anything you put your mind to. So, this journey is to inspire all individuals to challenge themselves, set goals, go for them, and share all triumphs or heartaches... It is what makes us feel the most alive as humans and connects us."

As a trauma ICU nurse for 17 years, Jenny is often the only medical professional in the remote areas where she anchors. So, she has volunteered her time and nursing skills resolving multiple medical emergencies. "I want to continue to provide medical aid where needed throughout my sailing. I am currently working on stocking my vessel with more medical supplies to be able to supply lifesaving medical care along my journey," she says.

Ms. Decker left on Just a Lap from Hawaii on June 28th, 2023, and thus far has traveled over 3,200 miles alone through the Pacific Ocean. She is currently moored in Vuda, Fiji for the cyclone season. She is taking this time to make necessary repairs, gather supplies, and spread her message. You can help fund her journey to raise awareness of CMT, by contributing to her Just a Lap GoFundMe page.

CMT Research Foundation (CMTRF) is a patient-led, non-profit focused on delivering treatments and cures for CMT. The foundation identifies significant obstacles or deficiencies impeding progress toward a cure and seeks out collaborators to address these issues. To date, CMTRF has funded 21 projects, of which 6 are completed. Of those 6 completed projects, 5 have clinical candidates. CMTRF's mission to invest in promising science with high potential of leading to treatments and cures was proven effective and ground-breaking when DTx Pharma with a CMTRF-backed program as its lead candidate was acquired by Novartis for \$1 billion. Founded by two patients who are driven to expedite drug delivery to people who live with CMT, the 501(c)(3) federal tax-exempt organization is supported by personal and corporate financial gifts.

\*Charcot-Marie-Tooth encompasses a group of inherited, chronic peripheral neuropathies that result in nerve degradation. CMT patients suffer from progressive muscle atrophy of legs and arms, causing walking, running and balance problems as well as abnormal functioning of hands and feet. CMT affects one in 2,500 people (about the same prevalence as cystic fibrosis), including 150,000 Americans and nearly 3 million people worldwide. At the moment, there is no treatment or cure for CMT.

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