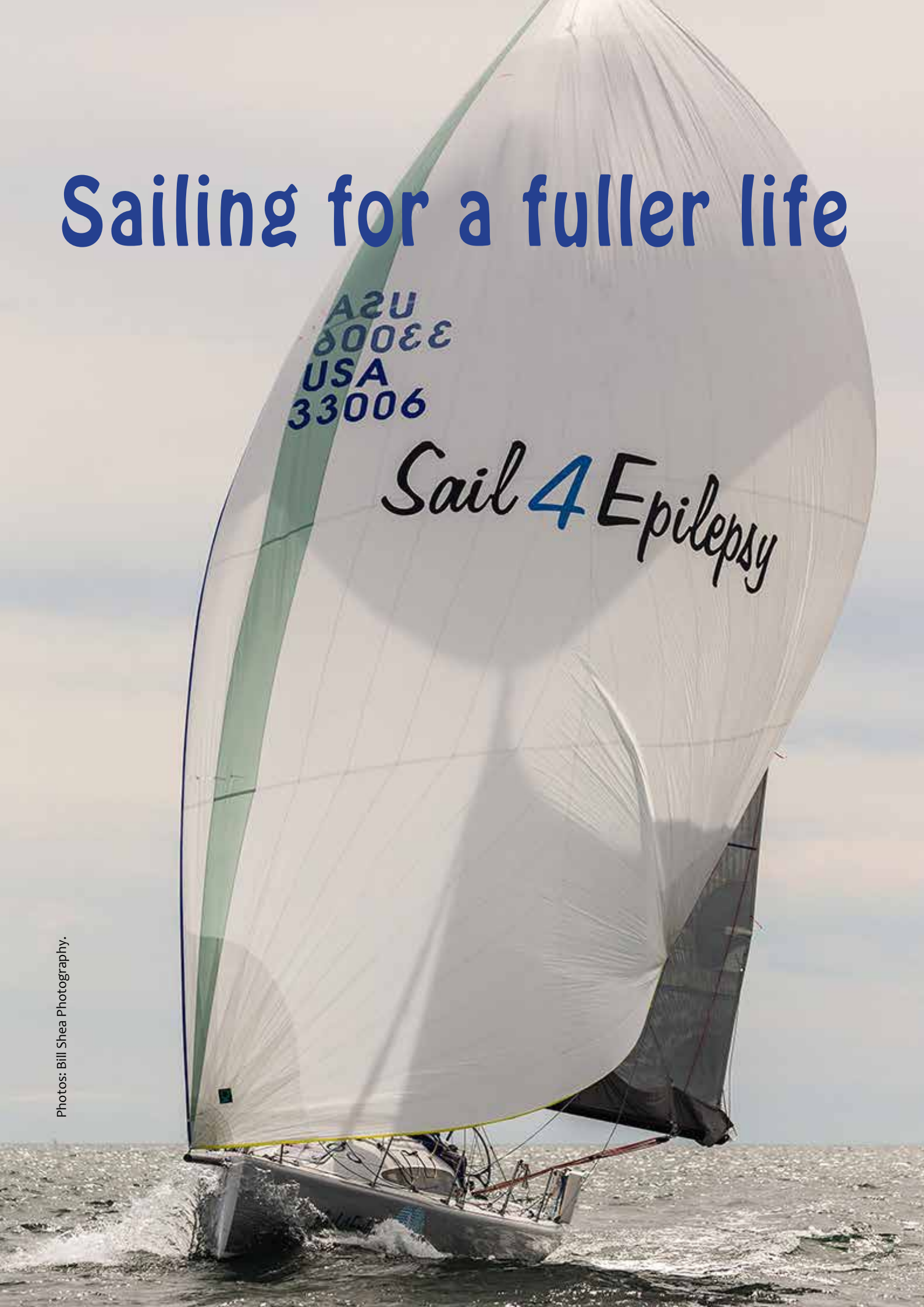


# Sailing for a fuller life

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*Sail 4 Epilepsy*



When Phil Haydon was 15, he was biking home from school when a drunken teenager threw a house brick that struck him on the forehead. This accident caused Phil to develop epilepsy. He has managed to be seizure free for many years and, despite early struggles, has had a successful career as an internationally recognized neuroscientist.

Phil can still feel the sensation of being hit in the head that caused a depressed compound fracture of his skull, which then triggered post-traumatic epilepsy. He initially suffered from absence and tonic-clonic seizures, was in and out of hospital and was eventually fitted with a vitallium plate to take the place of the missing two-inch diameter piece of skull. The medication to control his seizures made it very difficult for Phil to concentrate and study when he went back to school. He gradually managed to apply himself and drew inspiration from his Gran, who lived by the motto “I can and I WILL”. His parents, Jose and Tony, met with teachers and encouraged them not to go easy on him in class. They also pushed Phil to continue to live as normal a life as possible. To this day Phil still wonders how they had the strength to encourage him to return to a semi-normal life, despite going for a year with a piece of missing skull.

“I am sure it must have aged them and I don’t know, as parents, how they had the inner strength to do this,” says Haydon.

Despite struggles in high school and frequently napping in class, (Phil says “due to the medication”), he went on to university to study Physiology. He found that he had an aptitude for research and, influenced by his personal connection to learning about and treating brain disorders, earned his doctorate. He currently runs an active laboratory studying a range of neurological disorders, including epilepsy, as the Chair of the Department of Neurosciences at Tufts University School of Medicine, in Boston. Phil has not let epilepsy prevent him from

living a full life. He is fortunate that his seizures have been medically controlled for over 40 years. After his injury he could have focused on what he couldn’t do, but instead he found ways to participate in activities he enjoyed, with appropriate modifications. He wore an ice hockey helmet while playing cricket and no fastballs were allowed. As an adult he took sailing lessons – and was hooked. Phil then gradually expanded into racing and offshore sailing. He carefully monitors his sleep deprivation and ensures he takes his medication on his regular schedule.

Phil started the non-profit organization Sail For Epilepsy with a mission to inspire people to take One More Step towards living a fuller life, with the necessary safety guardrails in place. He plans to sail the oceans of the world to:

- inspire people with epilepsy
- raise awareness for those with epilepsy
- raise funds to support research into the causes of intractable epilepsy
- educate the population about epilepsy

A proportion of all funds donated to Sail For Epilepsy immediately flow through to their partners, Tufts University School of Medicine and Epilepsy Foundation New England, to support research and community outreach. The balance is used to support the Sail For Epilepsy program.

Sail For Epilepsy will post photos, videos, and blogs as they sail. A boat tracker is available on the Sail For Epilepsy website and they plan to have real-time interactions with people living with epilepsy while underway. During port stops, Phil and his small crew will engage with the local epilepsy community to share his story and hear about ways others are living a full life, despite epilepsy.

When he casts off, Phil will be sailing for more than himself: he is sailing for anyone else with epilepsy, their families, their caregivers, and anyone who has decided

to take an extra step to live a fuller life. He also sails for those who have been lost as a result of epilepsy, to honor their memory and to raise funds for research, so that a future generation of people with epilepsy will have better seizure control.

He hopes that his story will inspire you to join the One More Step Challenge and embark on your own personal voyage. The One More Step Challenge encourages people with epilepsy, their families, and their caregivers to share ways that they are challenging themselves to live fuller lives.

Haydon mused, “Can you imagine if one person got inspired and it changed their life? What if one person learns that epilepsy doesn’t have to be awful and they told their family and friends? I think big things can come from little steps.”

To recognize the courage of the One More Step Challenge participants, Sail For Epilepsy will add their first names to the hull of their boat so that these Virtual Shipmates can join the exciting voyage. Several times a week during the upcoming voyages, they will pick one Virtual Shipmate to feature. By sharing these inspirational stories, Sail For Epilepsy will raise awareness not only about epilepsy but about ways that people with epilepsy aren’t letting this disorder prevent them from living their fullest life possible. Featured Virtual Shipmates will receive a Sail For Epilepsy flag that was flown on the day they were highlighted, with the noon position and their name written on the flag.

#### **Follow the Journey:**

**Website:** <https://www.sailforepilepsy.org>

**Facebook:** <https://www.facebook.com/sailforepilepsy/>

**Instagram:** [https://www.instagram.com/sail\\_for\\_epilepsy/](https://www.instagram.com/sail_for_epilepsy/)

**Twitter:** <https://twitter.com/sailforepilepsy>

**YouTube:** <https://www.youtube.com/channel/UCfoXohTLPk3MoeEMnmw7Vjw>

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