



Navigate. Inspire. Cure. Educate.

ONE MORE STEP

OUR MISSION

To inspire people with epilepsy to take one more step towards achieving a fuller life.

Phil Haydon, Ph.D. and the Sail For Epilepsy team are on a mission to sail the oceans of the world to raise awareness surrounding epilepsy. The journey begins in the summer of 2021 to:

- inspire people with epilepsy;
- raise funds to support research for a cure;
- promote awareness of epilepsy and educate the public

THE VOYAGE

This voyage is about more than sailing. Sail For Epilepsy will post photos, videos, and blogs as well as 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 fuller life, despite epilepsy.

A ship tracker is available on the Sail For Epilepsy website. We have an international social media audience and offer an e_newsletter. We want those affected by epilepsy to join us on our voyage and will share inspirational stories of those taking One More Step.

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.

Our hope is that this voyage will inspire people effected by epilepsy to ask themselves, are you able to do something to improve your quality of life? Can you take one extra step to do something you haven't done before, with the necessary safety measures in place?

“ I hid my epilepsy from the world for decades for fear that people – colleagues – would view me differently if they knew I had it. About a decade ago, I decided to start talking about it. Phil Haydon, President, Sail For Epilepsy ”



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Epilepsy



Valerie Benjamin Randy Tracy Teguo Caleb Julie Aurora Donna Catherine
Haley Rose Erick Hannah Grant Kristin Jennifer Morgan Hunter Gregory
Dustin Elizabeth Christine Reagan Laura Roberta Anne Cathryn Jennifer
Jenny Hayden Loretta Addyson Heather Nicolette Jennifer Ryan Alison
Brandon Arlene James Sonny Kristy Tash Celine-Eva Cassandra Joannie
Dylan Howie Jon Joan Ellie Sailor Trudy Danise Miguel Susan Heather

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JOINING THE JOURNEY

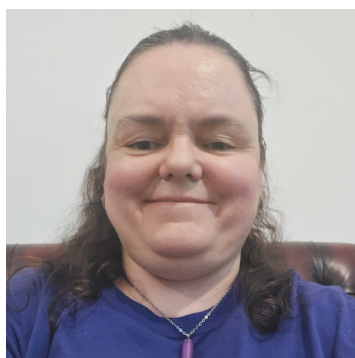
INSPIRATIONS

We are encouraging people with epilepsy, their families, and their caregivers to share ways that they are challenging themselves, by taking one more step, to live fuller lives. In fostering this dialogue, we hope that others will be inspired to take similar actions to improve their quality of life. To recognize the courage of the One More Step Challenge participants, they will become our Virtual Shipmates. We will add their first names to the hull of our boat, giving these brave individuals the opportunity to come along for our exciting voyage.

HOW WILL YOU TAKE ONE MORE STEP?



ANTHONY: Milford, CT
Continuing to show up every day as a brave 6-year-old who deals with the fears of doctors appts, needles, and epilepsy related issues.



HELEN: Leeds, United Kingdom
Walking 100 mile for Epilepsy Society Charity, to raise money.



TYLER: South Africa
Learning to play the drums.



CASSANDRA: Portsmouth, NH
Living daily by my personal motto: "While I can't control what happens to me in life, I CAN control how I respond". I will use creative arts to turn obstacles into new successes.



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DR. PHILIP HAYDON

NEUROSCIENTIST WITH POST-TRAUMATIC EPILEPSY

When Phil Haydon was 15, he was heading home from the last day of school when a drunken teenager threw a house brick, hitting him in the forehead. This caused a depressed compound fracture of his skull, which in turn triggered post-traumatic epilepsy. He was in and out of the hospital and eventually fitted with a vitallium plate to cover the hole in his skull. He was given medications to prevent seizures and Phil has been fortunate to have his epilepsy pharmacologically controlled since 1976.

After his accident, he initially struggled, but gradually he managed to apply himself and is now the Annetta and Gustav Grisard Professor and Chair of the Department of Neuroscience at Tufts University School of Medicine. Phil runs an active lab researching a range of neurological disorders, including epilepsy.

RESEARCH

For thirty years Phil's research has focused on roles played by glial cells in the modulation of neurons and recently into the use of glial targets as therapeutic interventions for brain disorders. Some of his studies published in the 1990s have led to innovations in the neurosciences, demonstrating that glial cells are active participants in brain signaling in health and disease. Since moving to Tufts

University School of Medicine in 2008, his research has focused on the importance of glial cells in neurological and psychiatric disorders. Phil has also received several prestigious awards, including a McKnight Investigator Award and the Jacob Javits Award from the National Institutes of Neurological Disorders and Stroke.

SAILING

In 2007, Phil took American Sailing Association (ASA) classes on the Delaware River. After moving to Boston, he purchased a boat that he has sailed about 18,000 nautical miles, largely in the New England coastal waters. He was bitten by the racing bug in 2015 and finished 3rd overall in the 2017 Bermuda 1-2. Phil won the Newport, RI based double-handed Ida Lewis race in 2019 and continues to train in weekly yacht club summer sailing series.

“ I want to give back to the community. I want to help other people with epilepsy take One More Step towards achieving a fuller life. ”

Phil Haydon, President, Sail For Epilepsy



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PARTNERS

SUPPORTING RESEARCH & OUTREACH

A proportion of all funds donated to the Sail For Epilepsy program will immediately flow through to our partners. The balance will be used to support the Sail For Epilepsy program, including such items as costs for satellite data to engage with people with epilepsy, families and caregivers while sailing offshore; docking costs for in-port events; and boat upgrades for offshore sailing. At the end of the program all assets will be sold and all funds will be donated to our partners.



During the Sail For Epilepsy program, skipper Phil Haydon will be flying a Tufts University School of Medicine flag to raise awareness and money for epilepsy research. About 50 million people worldwide have epilepsy and one third of patients do not have their seizures controlled by current medications. A percentage of all online and corporate donations will go directly to the Tufts School of Medicine for research into the basic causes of epilepsy. From this work, the goal is to identify new causes for epilepsy to set the stage for discovery of the next pharmaceuticals designed for those patients who are currently treatment resistant.

“ Our thanks to Sail For Epilepsy and their generous donors. The 2020 gift supports our mission to help the 100,000 living with epilepsy in New England. ”

Susan Linn, President/CEO, Epilepsy Foundation New England



By partnering with the Epilepsy Foundation of New England, Sail For Epilepsy's goal is to help support their outreach to those living with epilepsy, their families, and caregivers. Their camps provide people with epilepsy the opportunity to enter into a variety of programs (including sailing camps!). This objective resonates with our ambition of inspiring people with epilepsy to take one extra step to try and accomplish new goals and achieve a fuller life, with the necessary safety measures in place.



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