



THE DYSAUTONOMIA PROJECT

CREATING HOPE THROUGH EDUCATION

POTS* PATIENTS SHARE THEIR JOURNEY WITH TDP SUPPORTERS

POTS patients shared an intimate look at their journey as part of a panel discussion and Q & A segment at The Dysautonomia Project's (TDP's) annual Donor Soirée on April 26, 2018. The panel detailed their journey to diagnosis and how TDP has helped. More than sixty core supporters gathered at the home of board member Molly and Trevor Schaffer for the event which was generously underwritten by The Tampa Bay Trust Company.

"This was a great reminder that POTS patients are often made to feel like it's all in their head since most doctors don't understand the symptoms. That makes our mission at TDP all the more important," shared Carlton Ward, TDP board member.

*Postural Orthostatic Tachycardia Syndrome is a common form of dysautonomia.



[Led by longtime area news anchor Al Ruechel (left), nurse educator Cheryl Faber and patients Kelly Freeman (with Nate Freeman), Morgan Boykin and Emily Anne Cato shared the realities of the patient journey.]



A reason why TDP is so near and dear to my heart is they simply believe in me.



- Morgan Boykin, POTS patient



MISSION:

To educate physicians, patients, and communities about dysautonomia.



VISION:

To reduce the time of diagnosis from 6 years to 15 minutes.



WHAT IS DYSAUTONOMIA?

Dysautonomia is a general term used to describe any disorder of the autonomic nervous system. It is an invisible illness that may be one of the most misdiagnosed medical conditions of all time. The biggest problem in autonomic medicine today is the lack of knowledge about dysautonomia among physicians and communities.

1 IN 100
TEENS
HAVE
POTS

Mayo Clinic estimation

TDP EVENTS IGNITE THE COMMUNITY

π DAY

By The
Numbers

\$30,000+ Raised
550+ Donors
350+ In Attendance
320 Racers & 63 Teams

PI DAY 5K MAKES GREAT STRIDES

Hundreds of patients found support and validation at the POTS Pi Day 5k on March 10, 2018 at Seminole Park. The chip-timed race, co-chaired by former TDP board member Tava Wilson and current board member Tanya Repka, honored the memory of Tava's daughter and POTS patient Christina Tournant while creating synergy and hope by bringing patients and supporters together.

"This race is a perfect way to honor Christina and bring patients together so they know they're not alone. TDP's book and the hope we create makes sure other's don't struggle in finding help like my family did," said Tava.

Christina's story remains a powerful motivator for us all to focus on education.



[Tava Wilson (bottom right) takes time to cheer patients on.]



[More than 1,400 miles away in Rochester, Minnesota the Freeman family hosted a 1K with patients and families in honor of our event.]



The Dysautonomia Project has
changed my life.



- Shelby Bates, Colorado patient

[Thank you to Shelby & Emily Anne Cato for raising \$8,500 from 25 states!]

INAUGURAL 6:15 PARTY GROWS TDP SUPPORT

TDP's vision of turning the 6 year average time to diagnosis to 15 minutes has become the inspiration of our biggest celebration: The 6:15 Party. On November 9, 2017, 165 partygoers generously supported both live and silent auctions helping to raise more than \$43,000! Live band Public Option and a sumptuous dinner served at stations throughout Carlouel Yacht Club's seaside grounds had patrons moving and grooving throughout the evening.

Many thanks to 6:15 Party Chair and TDP board member Susie Jinks along with her hardworking and very appreciated committee for a beautiful evening: Dana Ford, Laura Jensen, Julia Marquardt, Anne Pace, Beth Pike, Patty Rilling and Sue Steward.



[Kelly Freeman, TDP founder and POTS patient, (right) shares exciting developments TDP has experienced with founding supporter Cynthia von dem Bussche.]

Come celebrate with us at the next
6:15 PARTY!

SAVE THE DATE

Date: November 15, 2018

Time: 6:15 PM

Where: Carlouel Yacht Club, Clearwater
Live Music by Public Option

4 AMAZING INITIATIVES DONORS HAVE MADE POSSIBLE



NURSING EDUCATION

4 Nursing Education Programs reached 365 Hillsborough & Pasco School Nurses & 35 University of Tampa Nursing Master's program students with POTS information & books.



CONFERENCES

480 books given to physicians at the Florida Osteopathic Medical Association, American Autonomic Society & Florida Suncoast Pediatric Conferences.



THE POTSCAST

8 podcasts released sharing vital information of hope & healing while creating community for patients & caregivers.



THE BOOK

5,800 books distributed worldwide reaching as far as Israel, Australia & the Czech Republic.



A huge thank you to everyone at The Dysautonomia Project for everything they do to spread awareness because it's really important. - Adéla Odrihocká, Czech Republic patient



Watch Adéla's video on our website!

HELP TDP BOOK FULFILL A GLOBAL NEED

**# of books distributed by TDP worldwide; map does not include 3,638 TDP books shipped through Amazon.*



FREE BOOK FOR YOUR DOCTOR PROMOTION!

Would you like TDP to send your board-certified physician a free book? From **6/15/18 - 7/15/18**, we'll be glad to do so, and we'll send it along with a handwritten note stating the book was sent on your behalf. To take advantage of this offer, and for complete instructions, visit us at TheDysautonomiaProject.org/book-promo.



A MESSAGE FROM NATE FREEMAN, TDP Board President 9 HOURS OF SLEEP IMPORTANT FOR TEENS WITH DYSAUTONOMIA

Actually, getting good sleep is important for every teen, but it's critical for teens with dysautonomia because it helps to reduce symptoms.

My wife and I spent a few cold few weeks in Rochester, MN this February and March learning how teens can better manage their symptoms once they know they have dysautonomia. One thing that surprised us is the emphasis put on a good night's sleep. According to Mayo Clinic pediatrician, Dr. Philip Fischer, teens with dysautonomia need 8.5 to 9.5 hours of sleep every night. Though important for every teen, it's critical for teens with dysautonomia because it helps to reduce the symptoms.

This is difficult to implement. Homework, sports, retreats, school events, and just family life all tend to get in the way of going to bed on time as a teenager—sleep becomes a precious commodity. If you add to this challenge the typical symptoms of dysautonomia (brain fog, fatigue, headaches, palpitations, stomach pain, etc.), getting a good night's sleep is very difficult.

The Mayo Clinic recommends the following practices to help achieve better sleep hygiene:

- | | |
|---|--|
|  Don't nap during the day |  Diaphragmatic breathing |
|  Exercise |  Focus on relaxation after 9 pm |
|  Don't eat sugar or big meals in the evening |  Make a bedtime routine |



[Lisa Rooker (left) was cheered on by patient Morgan Boykin and many others.]

TDP BOARD MEMBER FINALIST IN WEDU BE MORE AWARDS

TDP was honored to nominate board member and patient advocate Lisa Rooker for the 2018 WEDU Be More Awards Volunteer of the Year. Lisa was a finalist for this coveted title in Tampa Bay's non-profit community - but to the many whose lives she's saved and those she tirelessly serves she is absolutely the big winner.

She devotes her time 24/7 to not just me but all patients. She's the only reason I am diagnosed.

- Emily Anne Cato, POTS patient and TDP volunteer

GET INVOLVED

- Make a donation today. Give online at TheDysautonomiaProject.org/donate-now or use the enclosed envelope.
- Take advantage of our **FREE BOOK PROMO** (See inside page)

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