

THE GLOBAL LEADER IN
DYSAUTONOMIA EDUCATION
WITH A MISSION TO
EDUCATE HEALTHCARE
PROFESSIONALS, PATIENTS
AND COMMUNITIES.

TEN YEAR ANNIVERSARY MARKS JOURNEY FROM GRASSROOTS INITIATIVE TO GLOBAL LEADER

In 2014, newly diagnosed dysautonomia patient Kelly Freeman and her family rallied their community to support founding The Dysautonomia Project. They knew firsthand how elusive answers were in searching for diagnosis of this often-misunderstood condition, so their goal was to bring hope to others by making those answers accessible. With her community's support, Kelly worked through debilitating symptoms to co-author *The Dysautonomia Project: Understanding Autonomic Nervous Systems for Physicians and Patients*. Today, the book is widely regarded as the official handbook for dysautonomia and what began as a grassroots initiative has grown to become the global leader of dysautonomia education.

At TDP's first fundraiser on October 9, 2014, the community gathered to support Kelly and her family's cause. They knew she had suddenly become terribly ill and experienced an arduous search for diagnosis, perpetuating the impression that dysautonomia was rare. It was largely unheard of, even among providers, and most learned how to pronounce it at that first TDP event. Yet, that very evening, the CEO of a local hospital system sat in the audience with tears streaming as he realized what years of searching for answers to his daughter's sickness had not revealed – she had dysautonomia. Seven months later, patient Christina Tournant gave up her life after struggling with symptoms for years only to be told repeatedly it was all in her head. She had lived only a few miles from Kelly Freeman. It quickly became clear that dysautonomia was not rare and TDP's mission could change and even save lives.

In this newsletter, you will read about TDP's groundbreaking programs and resources that have joined the book in the last ten years, leading dysautonomia education worldwide. These tools have been brought to life through collaboration with the world's top specialists, national and local providers and with support from partners like YOU. From the beginning, it has been your support that has made TDP's mission possible. We thank you for making a difference over the past decade and know that with your continued partnership we can look forward to the purposeful work that lies ahead.

In 2014, Kelly Freeman (center) along with her mother Karen Crown and husband Nate Freeman rallied her community to support the founding of TDP.



DYSAUTONOMIA

IS A GENERAL TERM
USED TO DESCRIBE
ANY DISORDER OF
THE AUTONOMIC
NERVOUS SYSTEM. IT IS
AN INVISIBLE ILLNESS
SAID TO BE ONE OF THE
MOST MISDIAGNOSED
CONDITIONS OF ALL TIME.

**EDUCATION IS
THE NUMBER ONE
FORM OF TREATMENT.**

TDP EDUCATES DOCTORS NATIONWIDE



The Residents Course 2024 class included residents practicing in multiple disciplines from across America.

Access to care for patients suffering from autonomic dysfunction continues to widen through the ground-breaking work of The Residents Course, which took place January 31-February 3, 2024, in Clearwater, Florida. Seven world-leading autonomic specialists served as faculty for the intensive three-day course covering vital information not included in medical school curriculum. The Course is presented in collaboration between TDP and The American Autonomic Society and shares vital tools needed to diagnose and initiate treatment with second-year and higher medical residents across six specialties.

“Thank you for organizing this course! There are no providers in our region who specialize in autonomics. I am honored to have attended and am already using what I’ve learned in my day-to-day practice,” shared participant Dr. Jenifer Mocerri, St. Luke’s Hospital, Easton, Pennsylvania.

Next year, the Course will expand to include two residents from Australia. Additionally, a new concurrent one-day training, The Clinician Program, will be offered to train up to 150 established providers teaching vital information not included in medical school curriculum.



The Residents Course faculty features world-leading autonomic specialists. From left to right: Dr. Elisabeth Golden, Dr. David Goldstein, Dr. Laura Pace, Dr. Glen Cook – Course Director, Dr. Nathaniel Robbins, Dr. Howard Snapper, Dr. Kelsey Klaas.

The Dysautonomia Project + The American Autonomic Society
THE CLINICIAN PROGRAM
 ADVANCING AUTONOMIC MEDICINE

TDP is proud to announce The Residents Course is expanding in 2025 to include The Clinician Program, a one-day concurrent training specially designed to instruct clinicians to properly identify autonomic dysfunction, administer clinical exams, interpret lab evaluations, initiate first line therapies and refer to specialists as needed. The program can serve 150 doctors, nurses, and other advanced healthcare providers.

THE JULIET VIOLA KNIFFEN FOUNDATION SUPPORTS THE RESIDENTS COURSE

TDP is proud to announce its partnership with the Juliet Viola Kniffen (JVK) Foundation, marked by a significant three-year grant of \$95,000 in support of The Residents Course. This generous support addresses the critical need for availability of providers trained in identifying, diagnosing, and treating autonomic disorders, which affect an estimated 14 million in America.

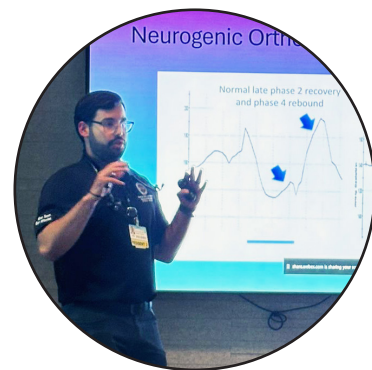
Sharon Yoh, President of the JVK Foundation, expressed enthusiasm about the partnership, stating, “We are thrilled about this partnership and the opportunity to support the important work of TDP and The Residents Course. We know these efforts will positively impact those living with dysautonomia by increasing the number of doctors trained to identify and treat this often-misdiagnosed condition.”

Through collaboration and dedication to advancing medical education, TDP and the JVK Foundation are improving the accessibility of diagnosis and treatment for millions of dysautonomia patients across America.



THE RESIDENTS COURSE ADDRESSES GLARING LACK OF PROVIDERS

As part of the Course, participants deliver comprehensive summaries in their respective medical school communities across the nation. The summaries cover crucial content relating to the understanding of autonomic disorders, with the aim of broadening access to quality care for patients in every corner of the country.



Dr. Gustavo Ramos Ortiz,
 Internal Medicine Residency
 FSU Sarasota Memorial Hospital Program



Dr. Yuanyuan Tan, Neurology Residency
 Texas Tech University Health
 Sciences Center at Lubbock Program



Dr. Tajwar Taher, Family Medicine Residency
 Rutgers Health Robert Wood Johnson
 University Hospital Somerset

TDP CELEBRATES TEN YEARS!

Supporters and patients came together on February 15, 2024, to mark a decade of TDP's impact in a celebration hosted by founding board member Molly duPont Schaffer and sponsored by long-time donor Tampa Bay Trust.



Molly duPont Schaffer & Susan Serra



Ashleigh Pike, Vonda Hudson & Beth Pike



Terry Igo, CEO Tampa Bay Trust



Duggan Cooley & Meg Lokey



Amy Flaherty & Cassie Braswell



Michele & John Streitmatter



Rick Reeder, Deana Goldasich & Pamela Reeder



TDP's Past & Present Board Members: (back) Nate Freeman, John Hiers, Molly duPont Schaffer, Terry Igo, Susan Serra, Hunt Brand, Jason Jensen, Tanya Repka, June Bryant, (front) Beth Pike, Susan Rolston, Karen Crown, Kelly Freeman, Alexandra Key, Polly Stannard.



Karen Crown & John Hiers

TOP ENEMIES OF DYSAUTONOMIA: STRESS AND PAIN



Emotional Stress



Atmospheric Stress



Physical Stress



Orthostatic Stress



Pain

Living with dysautonomia presents a unique set of challenges, with stress and pain emerging as the top enemies for patients grappling with this complex condition. Understanding the impact of stress and pain is vital, as they have the potential to trigger symptoms and exacerbate the challenges patients face.

EVERYDAY SITUATIONS STRESSFUL FOR DYS PATIENTS

SHOWERS



When showering, the following things can worsen symptoms:

- Standing still, especially under hot water.
- Humidity from hot water.
- Having your arms above your head when lathering.
- Bending over to wash your lower body.

CHORES



When doing chores, the following things can worsen symptoms:

- Standing still next to a hot stove.
- Loading/unloading the dishwasher.
- Folding laundry and loading/unloading the washer & dryer.
- Sweeping, mopping and vacuuming.

SHOPPING



When shopping at big stores, the following things can worsen symptoms:

- Huge parking lots and store space that require lots of walking.
- Sensory overload, such as loud noises and temperature changes.
- Bending over or reaching to grab items.

The key for dysautonomia patients is to empower themselves with knowledge. Recognizing triggers allows patients to take proactive measures to minimize their impact on daily life. By identifying potential stressors and implementing coping strategies, patients can regain a sense of control and enhance their quality of life. Here are a few tips:

Identify Your Stressors:

Recognize and acknowledge the factors that trigger stress and body pain. Whether it's emotional stress, environmental factors, or physical exertion, understanding your triggers is the first step towards effective management.

Learn Counter Maneuvers:

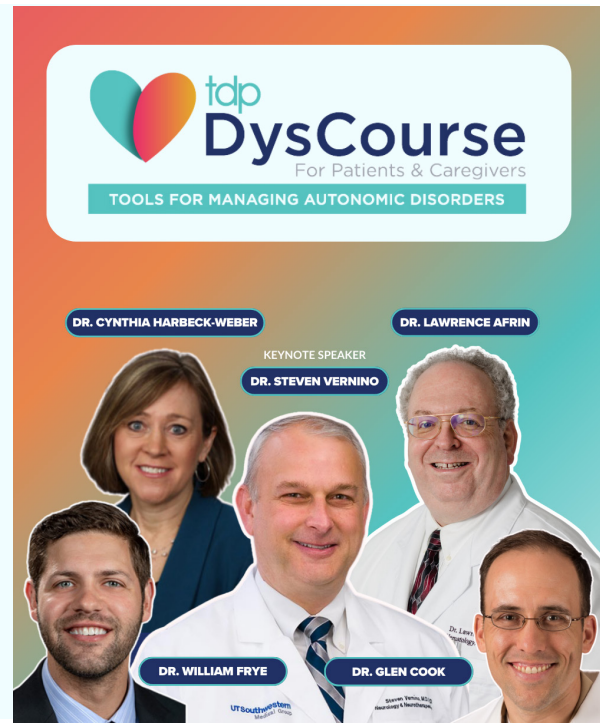
Educate yourself about techniques and maneuvers that can help alleviate symptoms when they arise. This may include relaxation exercises, breathing techniques, or specific physical adjustments to combat orthostatic stress.

Develop Coping Tools:

Cultivate a toolbox of coping mechanisms tailored to your needs. Whether it's mindfulness practices, distraction techniques, or seeking support from loved ones, having strategies in place can help you navigate difficult moments.

Living with dysautonomia is challenging, but with knowledge, awareness, and proactive management strategies, individuals can empower themselves to lead fulfilling lives.

TDP'S DYSCOURSE UNITES PATIENTS IN GLOBAL EDUCATION EVENT



In a world where understanding and support are paramount to dysautonomia patients, TDP continues to pioneer initiatives that resonate across the globe. Last year, TDP unveiled DysCourse: Tools for Managing Autonomic Disorders, as a beacon of education and hope for patients and caregivers. Nearly 800 individuals from seven countries attended.

DysCourse is offered virtually this year, featuring esteemed specialists, covering crucial topics including Autoimmunity in Autonomic Disorders, Mental Health and Suicide Prevention, Mast Cell Activation Disease, Patient & Caregiver Dynamics and a State of Autonomic Disorders Address, offering insights into the clinical landscape and future research.

Partially funded by TDP's annual Pi Day Give Day, this event stands as a tribute to patient Christina Tournant, whose story echoes the struggles of many within the dysautonomia community. DysCourse facilitates the understanding and support Christina never received and honors her by striving to provide validation and understanding to patients worldwide.

THANK YOU TO OUR DYSCOURSE SPONSORS!



THANK YOU TO OUR DYSCOURSE PARTNERS!



THANK YOU PI DAY GIVE DAY MATCHING DONORS!



TDP'S MISSION IN ACTION

Through a generous grant from the Hawkins Family Foundation, TDP has expanded its reach in providing life-changing education to new audiences, programs, and resources, including:

Created Orthostatic Vitals Training program to foster patient diagnosis.

Developed Autonomic Dysfunction Screening poster for exam rooms.

Developed presentation and program for Physical Therapists.

Sponsored Dr. Glen Cook's dysautonomia presentation at 35th Annual Osteopathic Winter Seminar, providing books and resources for attendees.

Presented POTS: The Invisible Illness to MSN and BSN spring, summer and fall students at the University of Tampa.

Invited to present dysautonomia program to Pinellas County, FL school staff members at their Summer Institute.

Invited to present dysautonomia program to Pinellas County, FL school clinic nurses.

Featured guest on Take Care of Your Body by Ry podcast.

Hosted Tampa Bay Advanced Practice Nursing Council dinner featuring a POTS presentation with TDP Board Member June Bryant, DNP.



Hawkins Family Foundation Board Members: Jim Myers, Kevin Hawkins, Terry Hawkins
Executive Director: Angela Hawkins

American Association of Nurse Practitioners Nashville conference exhibitor providing free books and resources, with TDP Board Member June Bryant, DNP presenting POTS presentation.

Florida Nurse Practitioner Network annual conference exhibitor providing free books and resources with TDP Board Member June Bryant, DNP presenting POTS presentation.

TDP Medical Ambassadors **provided Grand Rounds.**

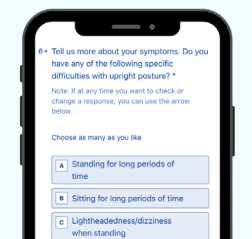
Presented and shared resources to neurological chronic illness support group.

TDP OFFERS FREE ONLINE PATIENT ASSESSMENT TOOL

TDP's Patient Assessment Tool has been used by nearly four thousand patients since June 2023 and is easily accessed at dysproject.org. This educational assessment stands alone as the only tool of its kind available anywhere, empowering patients with vital information in understanding their condition.

What Is The Patient Assessment Tool?

This free groundbreaking tool was created by TDP for **diagnosed & undiagnosed** patients to keep record of their symptoms and for use during discussions with their healthcare providers.



Access the Patient Assessment Tool at dysproject.org

TDP BRINGS DYSAUTONOMIA AWARENESS TO FLORIDA'S CAPITOL HILL

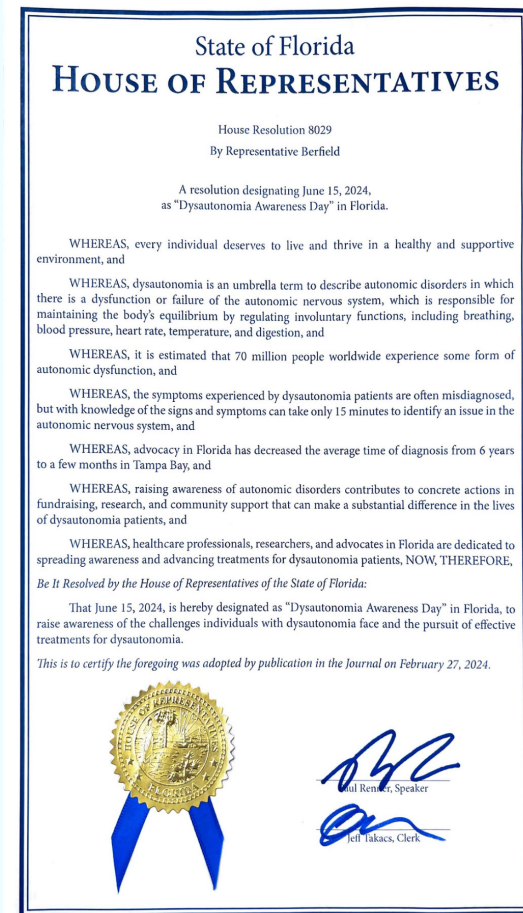
JUNE 15, 2024, DESIGNATED AS DYSAUTONOMIA AWARENESS DAY

On March 5, 2024, TDP's education efforts reached the Florida State Capitol. A collaboration with state Representative Kim Berfield led to the publication of a resolution in the House Journal designating June 15, 2024, as "Dysautonomia Awareness Day" in Florida. This date significantly reflects TDP's vision statement of reducing the average time to diagnosis from six years to just fifteen minutes through simple, in-office testing.

"To improve healthcare for Floridians we must encourage them to be active participants and advocates for their own health. To achieve that sometimes requires first increasing awareness and education to ensure they can obtain the right diagnosis and treatment. Recognizing June 15th as Dysautonomia Awareness Day will further this effort for the betterment of all," shared Rep. Berfield.

The presence and support of the Pinellas Community Foundation, represented by CEO Duggan Cooley and COO David Bender, added weight to TDP's Tallahassee visit. Their guidance and partnership highlight the importance of community alliance in advancing dysautonomia education. Patient Sadie Hudson and caregiver Vonda Hudson also graciously accompanied TDP, sharing firsthand the devastating impact of dysautonomia and significance of TDP's work.

This victory for awareness marks the start of several projects between TDP, Rep. Berfield and others to broaden education across the state. With unwavering dedication and collaborative efforts, TDP will continue to strive for a future where dysautonomia awareness is widespread, diagnosis is swift, and support is readily available for all.



TDP was well represented in Tallahassee with guests, staff and board including Pinellas Community Foundation COO David Bender, Ronnie Freeman, Ashleigh Goforth, Sadie Hudson, Vonda Hudson, Alexandra Key, Rep. Kim Berfield, Carlton Ward, Pinellas Community Foundation CEO Duggan Cooley and Cheryl Faber.



Patient Sadie Hudson and caregiver Vonda Hudson shared personal accounts of dysautonomia's impact on their family

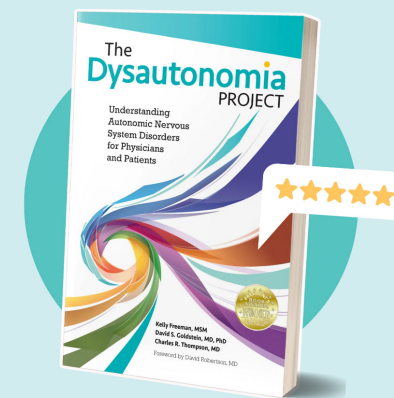


TDP BUILDS PARTNERSHIP IN JAPAN

In April, TDP founders Kelly and Nate Freeman traveled to Tokyo, Japan to meet with Tomoko Ishii, head of the POTS & Dysautonomia Japan organization, a new global partner in dysautonomia education. Their organization provides an annual seminar for patients and physicians in Tokyo.

Tomoko and her husband, Tatsuya, started the organization in 2017 after Tomoko, a POTS patient herself, suffered for 6 years undiagnosed. Now Tomoko works part-time navigating Tokyo in her motorized wheelchair and volunteers in her free time educating others in Japan. Like Kelly, Tomoko hopes her efforts in dysautonomia education will give hope to other patients and ultimately reduce the time to diagnosis in Japan.

In July, IMK Books, a Tokyo based publisher, plans to release *The Dysautonomia Project* book in Japanese.



"This book has helped my doctors feel empowered to treat me and recognize other patients who are similarly affected."

It helped educate my own family too."

-Patient

FREE BOOK PROMO!

Have a **FREE** book sent to your healthcare professional!

TDP will send your healthcare professional a **FREE** copy of our book from 6/15/24 - 7/15/24.

We'll even include a note stating the book was sent on your behalf.

For complete instructions, visit us at thedysautonomiaproject.org/book-promo/

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TDP's Leadership Circle recognizes donors who fuel our mission with lifetime giving of \$5,000 or more of vital support that brings hope to dysautonomia patients around the world

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Pinellas Community Foundation

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*Deceased

♥ Recognizes donors who have supported TDP since inception in 2014

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TOP CLINICIANS PARTNER AS MEDICAL ADVISORS AND AMBASSADORS

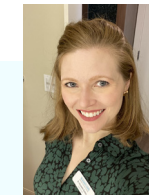
TDP MEDICAL ADVISORS

Doctors and/or researchers with advanced, specialized training in autonomic medicine who provide science-based input aiding in TDP's content development, serving as program faculty or presenters in educational programming.



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Prog. Dir. Nat'l Capital Consortium Neurology Residency
Assoc. Prof., Neurology, Uniformed Services University



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Neurologist
Subspecialization in neuromuscular and autonomic disorders
Asst. Prof. University of Texas at Tyler



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Asst. Prof. of Pediatric and Adolescent Medicine
Mayo Clinic Children's Center



Nathaniel Robbins, MD

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Massachusetts General Hospital /
Brigham and Women's Hospital

Howard Snapper, MD, FACC, FAAS

Cardiologist
Director Autonomic Disorders Division and Autonomic Lab
Wellstar Health System



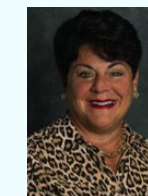
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Physicians, nurses, and healthcare providers who champion TDP's mission by providing autonomic medicine education.



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Dir. Cardiac Rehabilitation, Morton Plant Hospital



June Bryant, DNP, APRN, CPNP-PC

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Vice Chair Health Profession Division, Nova Southeastern University



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Neurologist
Clinical Neurosciences of Tampa Bay



Umesh Patel, MD, FACC

Cardiologist
Louisiana Heart Center



Will Frye, PhD, BCB, ABPP

Pediatric Psychologist
Johns Hopkins All Children's Hospital



Miguel Trevino, MD

Internal Medicine Physician
Private practice in Clearwater



WE CANNOT DO IT WITHOUT YOU!

It's **YOUR** support that makes the life-changing work of TDP possible.
Every donation brings hope through education to patients and families worldwide.

Go to
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to donate today.



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at our premier annual fundraiser

GALA an incredible evening in a
unique venue
live entertainment
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and a special dining experience
under the umbrella **CROWN MERCEDES**

We invite you to be a part of the excitement as we commemorate our remarkable 10-year journey, from humble beginnings as a grassroots initiative, to becoming the world's leading advocate for dysautonomia education!

www.DysProject.org

GET INVOLVED

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www.dysproject.org

Take advantage of our
FREE BOOK PROMO

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