

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT



# COLLABORATING FOR CURES

Dysautonomia International  
10th Annual Conference  
July 14-17, 2022

# WELCOME!

Dear Conference Guests,

On behalf of our Board of Directors, welcome to Dysautonomia International's 10th Annual Conference, Collaborating for Cures!

We can't believe we've been doing this for 10 years. What a journey it's been! We invite you to join us during the Awards Ceremony as we honor volunteers and physicians who are outstanding advocates for our community, and celebrate 10 years of Dysautonomia International's advocacy, awareness, and research progress.

Whether it's your first time joining us or you've been with us since our first conference a decade ago, we hope you will enjoy the program. Throughout the conference, we'll hear the latest research updates and treatment ideas from the leading experts in autonomic nervous system disorders and related conditions.

Of all of the things we have accomplished as an organization in the past decade, one of the most important accomplishments was building a well-connected collaborative community. In that spirit, we encourage you to use the Discussion forum and other interactive features of the conference to connect with other community members and discuss ways we can collaborate further to improve the lives of millions of people living with autonomic disorders.

We're looking forward to a long weekend of learning and fun, and we hope you are too!

Warmly,

Lauren Stiles  
President & Co-Founder



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PO BOX 596  
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We established a relationship with Dysautonomia International in 2016 to help support their research efforts towards treatment of autonomic diseases, including POTS, and we remain proud partners today. Learn more about Vitassium and access exclusive benefits at [vitassium.com/dysconf2022](http://vitassium.com/dysconf2022)

# Get the most out of your conference experience by engaging with others!

Q&A DURING  
THE SESSIONS

LIVE CHAT WITH  
THE EXHIBITORS

DISCUSSION  
FORUM

## #DysConf2022 Challenge



Log in to the Attendee Hub to play the #DysConf2022 Challenge. Earn points for engaging with Exhibitors, attending sessions, and other conference activities.

Dysautonomia International will award prizes to the top 20 scorers on the #DysConf2022 Challenge Leaderboard as of July 17, 6:00PM Eastern. Prizes include Dysautonomia International swag, gift cards, and goodies from our Sponsors and Exhibitors.

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- Stand test
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- Carotid sinus massage test
- Drugs administration test

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# 5 WAYS TO GET INVOLVED



## 1. JOIN A DYSAUTONOMIA INTERNATIONAL SUPPORT GROUP

We offer support groups in all 50 US states and 60 other countries.  
Get connected!

## 2. HELP US ORGANIZE GRAND ROUNDS ON POTS OR AUTONOMIC DISORDERS AT YOUR LOCAL MEDICAL SCHOOL OR HOSPITAL

Contact [events@dysautonomiainternational.org](mailto:events@dysautonomiainternational.org) or call 631-202-1720.

## 3. HOST A FUNDRAISER FOR DYSAUTONOMIA INTERNATIONAL ON FACEBOOK

Learn more!

## 4. FOLLOW US AND SHARE OUR EDUCATIONAL CONTENT ON SOCIAL MEDIA

Find us on [Facebook](#), [Twitter](#), [Instagram](#), and [LinkedIn](#).

## 5. ORGANIZE A DYSAUTONOMIA AWARENESS MONTH ACTIVITY IN OCTOBER

Contact [events@dysautonomiainternational.org](mailto:events@dysautonomiainternational.org).

# AWARDS CEREMONY & KEYNOTE ADDRESS

SATURDAY, 5:30 - 6:30PM ET

## DYSAUTONOMIA INTERNATIONAL



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## Celebrating a Decade of Dysautonomia Advocacy

We'll kick off the Awards Ceremony highlighting the work of our dedicated board members, volunteers and staff, who have, over the past decade, helped Dysautonomia International grow from a hopeful idea dreamed up in a hospital bed to an international community of patients, caregivers, clinicians, researchers and other allies that are working to improve the lives of people living with autonomic nervous system disorders.

## KEYNOTE: How Empowered Patients Are Changing Healthcare "e-patient Dave" deBronkart



Dysautonomia International is all about empowering patients to be their own best advocates, for their own healthcare, and on behalf of the broader patient community. Dave deBronkart is one of the most empowered patients we know, so who better to come talk to us about the amazing things we can get done to transform healthcare for the better when empowered patients get involved.

After surviving stage IV kidney cancer, Dave quit his job in and found a new calling in life, democratizing healthcare by helping patients with a wide variety of health conditions become **empowered, engaged, equipped** and **enabled**... e-patients!

Dave is co-founder and chair emeritus of the Society for Participatory Medicine. He served as Mayo Clinic's 2015 Visiting Professor in Internal Medicine. He is the author of "Let Patients Help: A Patient Engagement Handbook," which resulted in his popular TED talk of the same name, and "The Birth of a Battle Cry: Gimme My Damn Data." He's working on a new book, "SuperPatients," highlighting patients who rolled up their sleeves and advanced scientific knowledge when medicine was out of answers for them, something we are trying to do at Dysautonomia International. Tune in to the Keynote to get inspired and find out how you can transform healthcare as an empowered patient or ally that supports empowered patients.



# DYSAUTONOMIA INTERNATIONAL 2022 VOLUNTEER OF THE YEAR

## Darcy Bolanz

Darcy Bolanz is an incredible advocate for our patient community. She worked in healthcare until deciding to stay home to assist her daughter, who lives with a form of dysautonomia.

Darcy has been an active volunteer for Dysautonomia International for many years. She co-founded and leads Dysautonomia International's Ohio Support Group, which currently has over 1,300 members. She organizes monthly support group meetups, fundraising events, and Dysautonomia Awareness Month lightings throughout the state. Darcy has obtained multiple Dysautonomia Awareness Month proclamations from state, county and local government offices over the years.

When she's not giving media interviews to educate the public about dysautonomia, she's helping newly diagnosed patients and their caregivers connect with helpful resources and support. She also rallied pediatric hospitals in her area to get involved in raising awareness about dysautonomia, and she serves as a Parent Advisor for Akron Children's Hospital.



# DYSAUTONOMIA INTERNATIONAL 2022 PHYSICIAN OF THE YEAR

## Dr. Svetlana Blitshteyn



Dr. Svetlana Blitshteyn is the Founder & Director of the Dysautonomia Clinic in upstate New York, where she sees patients with POTS, neurocardiogenic syncope, and other forms of dysautonomia. She completed her neurology training at Mayo Clinic, and is a Clinical Associate Professor of Neurology at the University at Buffalo Jacobs School of Medicine and Biomedical Sciences.

Dr. Blitshteyn is well known for her compassionate skilled dysautonomia care and her expertise in helping patients with severe headaches and migraines. She's also our go-to expert for advising pregnant dysautonomia patients, as she was the first researcher to write about POTS and pregnancy.

Dr. Blitshteyn has volunteered as a member of Dysautonomia International's Medical Advisory Board for nearly a decade. She was one of the first autonomic specialists to use social media to educate the patient community and fellow clinicians, and she has developed quite a following. She regularly lectures on POTS and other autonomic disorders for medical professional societies, to help train more doctors on how to care for dysautonomia patients.

# 2022 AMELIA MOORE SPARKLE AWARD FOR COMPASSIONATE ADVOCACY

## Karyn Bishof



Karyn Bishof acquired SARS-CoV-2 while working as a firefighter and paramedic in Florida in spring 2020. Shortly thereafter, she developed Long COVID and its associated conditions, including POTS. In the two years since, Karyn has become an outstanding advocate for people living with POTS, ME/CFS, Long COVID, MCAS and other complex chronic illnesses.

Despite suffering immensely from her own health issues, and trying to figure out how to navigate life as a disabled single mom, Karyn saw a need to organize, educate and advocate for the newly forming "Long COVID" patient community.

She launched the COVID-19 Longhaulers Advocacy Project, with a team of like-minded patient advocates in June 2020. The organization has been instrumental in educating the Long COVID patient community about POTS and other forms of dysautonomia, to help people suffering get diagnosed and treated faster. Karyn also organized some of the earliest research surveys of Long COVID patients, finding that a large percentage of Long COVID patients were being diagnosed with a form of dysautonomia.

Karyn was selected by the National Institutes of Health to serve on the RECOVER Initiative's Ancillary Studies Oversight Committee and also volunteers on the Advisory Board of Dysautonomia International's Long COVID Research Fund, which is focused on ensuring that Long COVID research benefits people with all post-viral syndromes.

### Who is Amelia Moore?

This award is named after Amelia Moore, Dysautonomia International's first volunteer. She was a passionate advocate for fellow chronic illness patients in the dysautonomia, gastroparesis, Ehlers-Danlos syndrome and mitochondrial disease communities, even as she struggled with her own health issues. The award is named the SPARKLE Award because Amelia "shined a light" for so many fellow chronic illness patients going through dark times, and she had a quote on her blog that we love. "She who leaves a trail of glitter will never be forgotten." Sadly, Amelia passed away from an extremely rare neuromuscular disease at the age of 24. With her family's support, we created the Amelia Moore SPARKLE Award for Compassionate Advocacy in 2016. Through this award, we celebrate Amelia's legacy, and recognize those in our community who lead with love and compassion, just like Amelia did.



*"She who leaves a trail of glitter will never be forgotten."*

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Congratulations Dysautonomia International on 10 years of advocacy, education, and support for our community! Your incredible work has made all our lives better.

And medical professionals, thank you so very much for being at this conference. It means the world to us patients!

- The Reich/Lopez Family



# EXHIBITORS

Don't miss the interactive Virtual Exhibit Hall Sessions on July 14, 5:30PM - 6:30pm ET. The Exhibitors will offer educational presentations and live Q&A.



You can visit the Exhibit Booths throughout the entire conference. Engage with the Exhibitors through the Live Chat feature or leave a message for their team.

Visiting the Exhibitors earns you points for the #DysConf2022 Challenge too!



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# AGENDA

## THURSDAY, JULY 14, 2022

- 10:00 - 10:10AM ET WELCOME TO COLLABORATING FOR CURES!**  
Lauren Stiles, JD  
Dysautonomia International
- 10:10 - 11:05AM ET INTRODUCTION TO AUTONOMIC NEUROLOGY**  
Brent Goodman, MD  
Mayo Clinic
- 11:05 - 12:00PM ET OVERVIEW OF POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME AND ORTHOSTATIC INTOLERANCE**  
Svetlana Blitshteyn, MD  
University at Buffalo
- 12:00 - 12:10PM ET BREAK**
- 12:10 - 1:00PM ET SYNCOPE, PACEMAKERS & ABLATIONS IN DYSAUTONOMIA**  
Blair Grubb, MD  
University of Toledo
- 1:00 - 2:00PM ET POTS & PREGNANCY**  
Research Update: Kate Bourne, University of Calgary  
Panel Discussion: Shannon Koplitz, Jackie Cinnamon, Amanda Miller, PhD  
& Cece Collins
- 2:00 - 2:40PM ET DYSAUTONOMIA: ASSOCIATIONS WITH GASTROINTESTINAL DYSFUNCTION, JOINT HYPERMOBILITY & AUTOIMMUNITY**  
Jay Parischa, MD  
Johns Hopkins
- 2:40 - 3:10PM ET BREAKOUT SESSIONS**  
Breakout A: **What Every Newly Diagnosed Patient Needs to Know**  
Teagan Orr, Dysautonomia International
- Breakout B: **Gentle Reclined Exercise Class**  
Tove Pinaar, Wood Biokineticist
- Breakout C: **Pediatric POTS: Ask Abdullah Anything!**  
Hasan Abdallah, MD, The Children's Heart Institute

**3:10 - 4:10PM ET**

**SMALL FIBER NEUROPATHY: MORE THAN BURNING FEET**

David Saperstein, MD  
Center for Complex Neurology

**4:10 - 4:40PM ET**

**SJÖGREN'S, AUTOIMMUNE AUTONOMIC GANGLIONOPATHY & OTHER  
AUTOIMMUNE DYSAUTONOMIAS**

Srikanth Muppidi, MD  
Stanford University

**4:40 - 5:30PM ET**

**AUTOIMMUNITY & MAST CELL ACTIVATION IN POTS**

Taylor Doherty, MD  
UC San Diego

**5:30 - 6:30PM ET**

**VIRTUAL EXHIBIT HALL PRESENTATIONS**

**Vitassium:** Q&A with Ella Eastin

**NormaLyte:** Q&A with Sam Lee, PharmD

**Finapres:** Autonomic Testing Presentation and Q&A

**VIM & VIGR:** Fall Compression Sock Collection Overview and Q&A

**Biotek Remedys:** Infusion Services Q&A

**CND Life Sciences:** Skin Biopsy Screening for Alpha-Synuclein Overview and Q&A  
with Dr. Todd Levine

**WR Medical:** Autonomic Testing Presentation and Q&A

**Buoy:** Q&A session

**Cardiogram:** Q&A session

We encourage guests to visit one or more of the Exhibitors during their live presentations. You will also be able to watch the recordings of their sessions on the Attendee Hub until July 20.

# FRIDAY, JULY 15, 2022

- 9:15 - 10:00AM ET**    **NEUROVASCULAR DYSREGULATION DURING EXERCISE IN POTS, ME/CFS, AND LONG COVID**  
David Systrom, MD  
Harvard Medical School
- 10:00 - 10:45AM ET**    **AUTONOMIC IMPAIRMENT IN LONG COVID**  
Mitchell Miglis, MD  
Stanford University
- 10:45 - 11:15AM ET**    **MICROCLOTS & CLOTTING PATHOLOGIES IN LONG COVID**  
Etheresia Pretorius, PhD  
Stellenbosch University
- 11:15 - 11:45AM ET**    **BRAIN IMAGING IN LONG COVID COGNITIVE DYSFUNCTION**  
Anna Starikovskiy Nordvig, MD  
Weill Cornell Medicine
- 11:45AM - Noon ET**    BREAK
- Noon - 12:45PM ET**    **EFFECTS OF NON-INVASIVE VAGAL NEUROSTIMULATION ON GASTRIC MOTILITY IN PEDIATRIC POTS**  
Katja Kovacic, MD  
Medical College of Wisconsin
- 12:45 - 1:15PM ET**    **EXERCISE INTOLERANCE AND CHRONOTROPIC INCOMPETENCE IN LONG COVID: INSIGHTS FROM THE LIINC STUDY**  
Matthew Durstenfeld, MD  
UC San Francisco
- 1:15 - 1:45PM ET**    **AUTONOMIC REHABILITATION APPROACHES TO LONG COVID CARE**  
David Putrino, PT, PhD  
Mount Sinai Health System
- 1:45 - 2:15PM ET**    **CEREBRAL BLOOD FLOW AND ORTHOSTATIC INTOLERANCE IN ME/CFS**  
Prof. Frans Visser  
VU University Medical Center
- 2:15 - 3:00PM ET**    **PANEL DISCUSSION: POTS & ME/CFS: SIMILARITIES, DIFFERENCES AND FINDING THE RIGHT EXERCISE APPROACH**  
Tae Hwan Chung, MD, Johns Hopkins  
Satish Raj, MD, University of Calgary  
David Systrom, MD, Harvard Medical School  
Prof. Frans Visser, VU University Medical Center



- 3:00 - 3:30PM ET**      **MECHANISMS OF CHRONIC PAIN & FATIGUE: DYSAUTONOMIA, INFLAMMATION & EHLERS-DANLOS SYNDROME**  
Jessica Eccles, MBChB, PhD  
Brighton & Sussex Med. School
- 3:30 - 4:00PM ET**      **DYSAUTONOMIA INTERNATIONAL RESEARCH PROGRAM UPDATES**  
Lauren Stiles, JD  
Dysautonomia International
- 4:00 - 4:30PM ET**      **PLATELET AND INNATE IMMUNE DYSFUNCTION IN POTS**  
William Gunning, III, PhD  
University of Toledo
- 4:30 - 5:00PM ET**      **UPDATE ON NEW G-ACHR ANTIBODY TEST TO SCREEN FOR AUTOIMMUNE AUTONOMIC GANGLIONOPATHY**  
John Tzartos, MD, PhD  
National Kapodistrian University of Athens
- 5:00 - 5:30PM ET**      **VAGUS NERVE STIMULATION & MESTINON IN POTS**  
Andre Diedrich, MD, PhD  
Vanderbilt University
- 5:30 - 6:00PM ET**      **PATIENT REPORTED EXPERIENCES & OUTCOMES IN PEDIATRIC POTS**  
Jeffrey Boris, MD  
Jeffrey Boris, MD, LLC
- 6:00 - 6:30PM ET**      **ARRHYTHMIAS IN PEDIATRIC POTS AND ORTHOSTATIC INTOLERANCE**  
Jeffrey Moak, MD  
Children's National Medical Center
- 6:30 - 7:30PM ET**      **GASTROINTESTINAL INFLAMMATION & EOSINOPHILIC ESOPHAGITIS IN DYSAUTONOMIA**  
Josh Wechsler, MD, MSCI  
Northwestern University
- 7:30 - 8:30PM ET**      **VIP SESSION** (pre-registration required, VIP passes are sold out)

# SATURDAY, JULY 16, 2022

- 9:30 - 10:00AM ET    GLOBAL PERSPECTIVES ON DYSAUTONOMIA: GROWING AN INTERNATIONAL MOVEMENT**  
Esther Kyeremah, MD, Greater Accra Regional Hospital, Ghana  
Sarath Menon, MD, Aster Medcity Hospital Kochi, India  
Bernardo Cline, MD, Pediatric Cardiologist, Mexico
- 10:00 - 10:30AM ET    LIFESTYLE STRATEGIES TO MANAGE DYSAUTONOMIA**  
Emily Rich, OT, MOT  
Tucson Medical Center
- 10:30 - 11:00AM ET    DIET AND THE NEUROIMMUNE AXIS: IMPLICATIONS FOR DYSAUTONOMIA**  
Laura Pace, MD, PhD  
Metrodora Institute
- 11:00AM - Noon ET    ORAL HYDRATION, IV SALINE & EXERCISE APPROACHES IN POTS & ORTHOSTATIC INTOLERANCE**  
Tae Hwan Chung, MD  
Johns Hopkins
- Noon - 12:15PM ET    BREAK**
- 12:15 - 12:45PM ET    CANNABIS AS ADJUNCTIVE THERAPY FOR DYSAUTONOMIC SYMPTOMS (POT FOR POTS)**  
Jeffrey Boris, MD  
Jeffrey Boris, MD, LLC
- 12:45 - 1:15PM ET    LOW DOSE NALTREXONE USE IN DYSAUTONOMIA & CHRONIC PAIN CONDITIONS**  
Pradeep Chopra, MD  
Brown Medical School
- 1:15 - 1:45PM ET    MANAGING SLEEP DISORDERS IN DYSAUTONOMIA**  
Mitchell Miglis, MD  
Stanford University
- 1:45 - 2:30PM ET    COMMON DYSAUTONOMIA MEDICATIONS**  
Italo Biaggioni, MD  
Vanderbilt University
- 2:30 - 3:15PM ET    DIAGNOSING & MANAGING HYPERHIDROSIS**  
Malcom Brock, MD  
Johns Hopkins

# SATURDAY, JULY 16, 2022

**3:15 - 4:15PM ET**

**STORIES OF HOPE & RECOVERY**

Coppelia Tarantal, RN  
Tiana England  
Dani Mortell  
Lauren & Myrta Matthews

**4:15 - 4:45PM ET**

**BREAKOUT SESSIONS**

Breakout A: **Make Noise for Turquoise!: Getting Involved with Dysautonomia Awareness Month**

Teagan Orr, Dysautonomia International

Breakout B: **Calling all Volunteers!: Dysautonomia International Support Group Leader Training**

Charlotte Florez, Dysautonomia International

**4:45 - 5:30PM**

**AUTOIMMUNE DYSAUTONOMIA: WHAT ABOUT IVIG FOR POTS?**

Steven Vernino, MD, PhD  
UT Southwestern

**5:30 - 7:00PM**

**A DECADE OF DYSAUTONOMIA PROGRESS: DYSAUTONOMIA INTERNATIONAL'S 10 YEAR ANNIVERSARY CELEBRATION**

Keynote Lecture: Dave deBronkart  
Award Recipients: Darcy Bolanz, Karyn Bishof & Dr. Svetlana Blitshteyn

# SUNDAY, JULY 17, 2022

The programming on Sunday, July 17th is part of a separate Continuing Medical Education (CME) course offered by Dysautonomia International and Stony Brook University. The CME course requires a separate registration from the main conference. Registration for the CME course is open until July 13 at [dysautonomiainternational.org/dysconf2022](https://dysautonomiainternational.org/dysconf2022).

if you registered for the CME course, please refer to the [CME Agenda](#) for the list of speakers, topics and lecture times.

# QUICK LINKS

Clinicians... Print this page out for your patients!

## **[dysautonomiainternational.org/doctors](https://dysautonomiainternational.org/doctors)**

A list of physicians who have expertise in diagnosing and treating autonomic nervous system disorders

## **[dysautonomiainternational.org/support](https://dysautonomiainternational.org/support)**

Support groups in all 50 US states, Canada, Australia & several other countries, also a great place to find local doctor suggestions

## **[dysautonomiainternational.org/salt](https://dysautonomiainternational.org/salt)**

Healthy high salt diet tips

## **[dysautonomiainternational.org/exercise](https://dysautonomiainternational.org/exercise)**

Dysautonomia friendly exercise tips and a downloadable protocol

## **[CurePOTS.org](https://CurePOTS.org)**

Dysautonomia International's POTS Research Fund

## **[CureDys.org](https://CureDys.org)**

Dysautonomia International's Dysautonomia Research Fund

## **[LongCovidResearchFund.org](https://LongCovidResearchFund.org)**

Dysautonomia International's Long COVID Research Fund

## **[bit.ly/whatispots](https://bit.ly/whatispots)**

4 minute animated video explaining POTS

## **[bit.ly/whatisdys](https://bit.ly/whatisdys)**

2 minute video explaining what dysautonomia feels like

## **[vimeo.com/dysautonomia](https://vimeo.com/dysautonomia)**

Dysautonomia International's Autonomic Disorders Video Library containing 100+ lectures from the top experts



**To all of our volunteers,  
staff and donors, thanks  
for an amazing 10 years!  
We can't wait to see  
what we can accomplish  
together in the next  
decade.**



# ABOUT US

Founded in 2012 by a dedicated group of patient, caregiver, and physician volunteers, Dysautonomia International is the leading non-profit that advocates for millions of individuals impacted by autonomic nervous system disorders. The organization funds research, clinician education, public awareness, patient empowerment and advocacy programs around the world.

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