

Dysautonomia International Conference & Lobby Day July 17-20, 2015 • Washington, DC

Welcome!

Dear Conference Guests,

On behalf of the Board of Directors, I am honored to officially welcome you to the third annual Dysautonomia International Conference & Lobby Day.

This year's conference is packed with fantastic events. Many of the world's leading experts in autonomic disorders are here to help educate patients, caregivers, physicians and healthcare professionals. There are a wide variety of topics and speakers offered throughout the weekend. Be sure to plan your schedule in advance so you don't miss the sessions most important to you.

Once again, we are offering an opportunity to participate in POTS research during the conference. Details of the research study will be shared during the patient program on Saturday morning. Dysautonomia International is proud to be at the forefront of "patient-powered research" to advance our collective understanding of dysautonomia.

We look forward to seeing you at the Awards Banquet on Saturday evening, a wonderful opportunity for us to have some fun, dance and celebrate all of you who have supported Dysautonomia International this past year. And we are thrilled to have such an enthusiastic delegation traveling together to Capitol Hill on Monday for a day of lobbying, to educate our elected representatives on issues important to the dysautonomia community.

We are truly excited to have all of you here to share this weekend, learn from an impressive roster of speakers and get to know one another. Thank you for joining us, and we look forward to your continued support of Dysautonomia International.

Sincerely,

Ellen J. Kessler

Vice President & CFO

Chair, 2015 Conference Committee

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Information Desk

Friday	3PM - 10PM
Saturday	8AM - 9PM
Sunday	8AM - 8PM

You can also reach the Information

Desk at: conference@

dysautonomiainternational.org.



Special Events

Meet the Authors

Saturday, Noon - 2PM Conference Center Lobby

Stop by the Vendor Fair to meet physician authors Dr. Blair Grubb and Dr. Lisa Sanders. Dr. Grubb will be signing copies of his books, *The Calling* and *The Fainting Phenomenon: Understanding Why People Faint and What To Do About It*. Dr. Sanders will be signing copies of her book, *Every Patient Tells a Story: Medical Mysteries and the Art of Diagnosis.*

Awards Banquet

Saturday, 7PM - 11PM Luray A, B, C

Registered conference guests are invited to join us for a special celebration, honoring Dr. Blair P. Grubb as the 2015 Dysautonomia International Physician of the Year. Dr. Lisa Sanders, New York Times columnist and inspiration for the TV show House, will deliver the Keynote. Dinner, dancing and a silent auction will follow. Don't forget to stop by the red carpet to have your photo taken.

Dysautonomia Lobby Day Training

Sunday, 7PM - 9PM Luray C, D

For those who pre-registered to attend Dysautonomia Lobby Day, there is a mandatory training session on Sunday from 7-9PM. The session will include a review of our 2015 Capitol Hill strategy and tips to help us be effective citizen advocates. You will meet with your lobby day group and receive a personalized lobby day meeting schedule. Dessert will be served at the end of the session. **Coach buses will depart for Capitol Hill from the hotel entrance on Monday morning at 8AM sharp, and will return between 3PM and 4PM.**

Interview Booth

Saturday & Sunday, Noon - 2PM Luray D

All conference guests are invited to stop by the interview booth this weekend, whether you're a patient, caregiver, physician or industry professional. Let us know, what does dysautonomia mean to you? How has it impacted your life? If you could teach the world one thing about dysautonomia, what would it be? What are you doing to advocate for the dysautonomia community? Dysautonomia International will use footage from the interview booth to create dysautonomia awareness content and educational videos.

Speakers



Hasan Abdallah, MD
Founder & Director
The Children's Heart Institute



Angela A. Fletcher, PsyD

Assistant Professor of Psychiatry & Behavioral Science

Director, Behavioral Pain Medicine Program

Children's National Health System



Richard Boles, MDMedical Director
Courtagen Life Sciences, Inc.



David S. Goldstein, MD, PhD

Director, Clinical Neurocardiology Section

National Institute of Neurological Disorders & Stroke



Gisela Chelimsky, MDProfessor of Pediatric Gastroenterology
Medical College of Wisconsin



Jeffrey P. Greenfield, MD, PhD Associate Professor of Neurological Surgery Weill Cornell Medical College



Thomas Chelimsky, MDProfessor of Neurology
Medical College of Wisconsin



Blair P. Grubb, MD

Professor of Medicine and Pediatrics

Director, Syncope & Autonomic Disorders Clinic

University of Toledo



Kamal Chémali, MD
Associate Professor of Neurology
Director, Sentara Neuromuscular & Autonomic Center
Eastern Virginia Medical School



Jared Heyman Founder & CEO CrowdMed



Robin Fabian, RN, BSN
Syncope Nurse
Children's National Heart Institute
Children's National Health System



Laurence Kinsella, MDAdjunct Professor of Neurology
SSM Health / St. Louis University



Mandana Fisher, PT, DPT
Physical Therapist
Children's National Health System



Michael J. Labellarte, MD
Psychiatrist
CPE Clinic, LLC

Speakers



Josh Milner, MDChief, Genetics & Pathogenisis of Allergy Section
National Institute of Allergy & Infectious Diseases



Paola Sandroni, MD, PhD
Professor of Neurology
Director, Autonomic Laboratory
Mayo Clinic



Mohammed Numan, MD
Associate Professor of Pediatrics
Co-Director, Dysautonomia Center of Excellence
University of Texas Health Science Center at Houston



Wolfgang Singer, MD Professor of Neurology Mayo Clinic



Morwenna Opie, PhD
Clinical Psychologist
London Nightingale Hospital



Julian Stewart, MD, PhD
Professor of Pediatrics, Physiology & Medicine
Director, Center for Hypotension
New York Medical College



Alan Pocinki, MDClinical Associate Professor of Medicine
George Washington University Medical Center



Brad T. Tinkle, MD, PhDMedical Director of Clinical Genetics

Advocate Children's Hospital



Satish R. Raj, MD
Associate Professor of Cardiovascular Medicine
University of Calgary
Adjunct Associate Professor of Medicine
Vanderbilt University



James J. Riviello Jr., MDProfessor of Neurology and Pediatrics
Columbia University Medical Center



Lisa Sanders, MDAssociate Professor of Medicine
Yale School of Medicine

2015 Physician of the Year



Blair P. Grubb, MD Professor of Medicine, Cardiovascular Medicine & Pediatrics The University of Toledo

Please join us Saturday night at the Awards Banquet as Dr. Blair Grubb is presented with Dysautonomia International's 2015 Physician of the Year award, honoring him for his extraordinary contributions to the dysautonomia community.

Nominated by several of his patients, Dr. Grubb is as well-known for his expansive knowledge of autonomic disorders and innovative treatment approaches as he is for his caring and compassionate bedside manner.

Dr. Grubb is a Professor of Medicine and Pediatrics at the University of Toledo, where he also serves as Director of the Clinical Cardiac Electrophysiology Program and the Syncope and Autonomic

Disorders Clinic. He is one of the world's leading authorities on syncopal disorders and has authored over 240 scientific papers, 35 book chapters and five books. His clinic actively manages 4,000 dysautonomia patients from around the world, in addition to patients who visit for one-time consultations.

Dr. Grubb is a talented artist and writer, who has published over 50 essays and poems, as well as many photos and drawings.

He was married to the late Barbara Straus, M.D. for 38 years and has two children, Helen and Alex.

Congratulations Dr. Grubb!

We are proud to honor you as the 2015 Physician of the Year!

A Message From The President

Dear Conference Guests,

Over the past year, Dysautonomia International has made meaningful progress on our goals of increasing the pace of POTS research, educating medical professionals about autonomic disorders, raising awareness and empowering patients to be their own best advocates.

Our dedicated POTS Research Fund, created in December 2013, has issued \$308,000 in research grants to date, including the largest private POTS research grant ever!

We hosted and facilitated physician education programs on autonomic disorders at prestigious institutions such as Duke University, Texas A&M, Children's Hospital of Los Angeles, and right here at our own annual conference in Washington, DC. Additional programs are being planned in several cities later this year.

We were invited to present on our "Patient-Powered Research" at a National Institute of Neurological Disorders & Stroke conference last fall, and we're continuing to build relationships with leaders at the National Institutes of Health.

We've succeeded in obtaining major press coverage on autonomic disorders in the New York Times, Boston Globe, Huffington Post, US News & World Report, Cosmopolitan, Neurology Now and dozens of local media outlets.

Our volunteers have organized awareness and fundraising events around the world. 2015 highlights include the Boston POTS Walk, a 250-mile "Pedaling for POTS" bike ride completed by the Pi Kappa Alpha brothers from Arkansas State, a lively "St. Paddy's Party to End POTS" in New Jersey and, just a few weeks ago, 13-year old Boaz Schwartz's climb to the summit of Mt. Kilimanjaro to raise funds for dysautonomia research.

Turquoise will light up the night sky at several landmarks this October to recognize Dysautonomia Awareness Month, including Niagara Falls, the Zakim Bridge in Boston, the CN Tower in Toronto, the Calgary Tower, and Wells Fargo's Duke Energy Center in Charlotte. Viewing parties are being planned in each city.

It is not easy to live with dysautonomia, but hope is on the horizon. William James Mayo, co-founder of the Mayo Clinic, said, "[t]he glory of medicine is that it is constantly moving forward, that there is always more to learn. The ills of today do not cloud the horizon of tomorrow, but act as a spur to greater effort."

As we gather this weekend, let's commit to learning even more about dysautonomia and reach towards a new horizon together.

Sincerely,

Lauren Stiles, Esq.

President & Co-Founder Dysautonomia International

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The Kessler Family

The Stiles Family

Silent Auction & Raffle

Raffle

Purchase \$5 raffle tickets for a chance to win this Stamina rowing/recumbent bike combo, valued at over \$1,199. Tickets will be on sale at the Information Desk on Saturday and during the Awards Banquet. The winning ticket will be drawn at 10PM on Saturday night during the Awards Banquet. You do not have to be there to win.



Silent Auction

Stop by the Silent Auction during the Saturday night Awards Banquet to check out some of the great items up for bid.

NYC "Model for a Day" Experience with Alexandra Agro

from America's Next Top Model

Coach Wristlet

Dog Lovers Gift Basket

Skratch Labs Hydration Gift Basket

STOP POTS Bracelet

Zebra-themed gifts

Silver "Hope, Love and Faith" bracelet trio

DAVIDsTEA Gift Set

Baker's Bundle Gift Basket

Assorted Gift Cards

Ice Cream Social Gift Basket

Gourmet Chocolate Dipped Spoons Bouquet

...and much more!

Thank you to our auction donors for their generous support!

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Rachel Allison

Shellev Banik

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Emily Cardwell

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Alice Diana

The DiBona Family

Leanne Holman Garcia

Susie & Shannon Grover, Hill Country POTS Teens

Cathy Hower

Joy's Homemade Almond Biscotti

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The O'Connor Family

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Target

Five Ways to Get Involved With Dysautonomia Research!

- 1. Continuing a tradition that began last year, we're hosting another cutting-edge POTS research study during this weekend's conference! Attend the research information seminar on Saturday morning to learn how you can get involved (Luray A, B, C, 9:15AM 9:45AM).
- **2. Sign up for Dysautonomia International's Interactive Global Dysautonomia Map** By providing your email address, we'll send you announcements about important dysautonomia research projects from time to time. www.dysautonomiainternational.org/map.php
- **3. Sign up for ResearchMatch** ResearchMatch matches healthy people and individuals with any medical condition with researchers looking for study participants. Dysautonomia International worked with ResearchMatch to create a POTS Registry.

www.dysautonomiainternational.org/POTS Registry

- **4. Sign up for the Autonomic Disorders Consortium Contact Registry** The Consortium includes major autonomic research centers like Mayo Clinic, Vanderbilt and Harvard. If you provide your contact information, researchers may contact you when they are looking for patients with your autonomic disorder. www.rarediseasesnetwork.org/ARDCRC/register
- 5. Look for clinical studies with open enrollment on www.ClinicalTrials.gov.









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Live: to exhibit vigor, gusto, enthusiasm. Live life to the fullest.

Dr. Grubb, you truly are Physician of the Year 2015. Thank you for allowing me to live more fully. You're full of heart.

> God bless you always. Laura Seil Ruszczyk





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Conference & Lobby Day

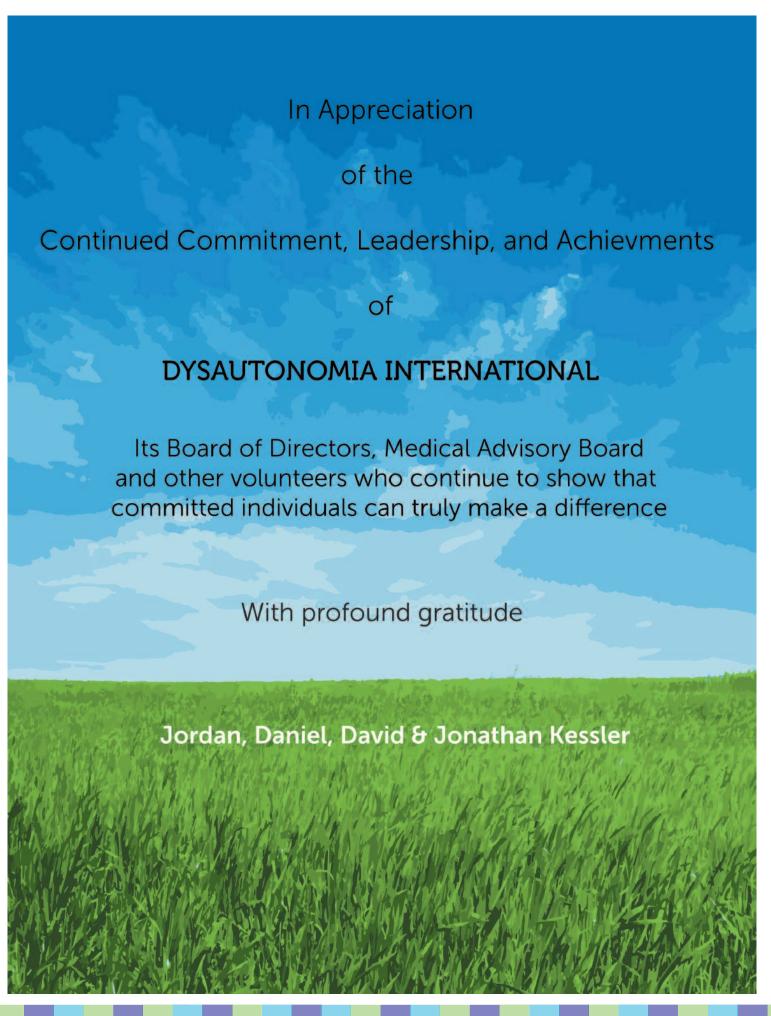
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The Children's Heart Institute is pleased to announce "Taming POTS," a new 3-day weekend program to optimize overall wellbeing in POTS patients who are still struggling despite standard medical therapy. The program includes:

- Individualized evaluation of your POTS symptoms and possible underlying cause
- Optimizing your medical treatment
- Identifying your specific nutritional needs
- Tailored cardiovascular and core strengthening exercises
- Teaching self-compassion and how to defeat "stinking thinking"
- Learning social skills and how not to be left behind as you deal with chronic illness
- Developing coping skills

"Taming POTS" is directed by Hasan Abdallah, MD, an expert in autonomic disorders and Dysautonomia International board member.

Contact us for additional details: POTS@chiva.us



10 Ways To Get Involved!

Run, walk, or roll in a 5K with Team Dysautonomia, or ask friends and family to do it for you.

www.dysautonomiainternational.org/teamdysautonomia

Ask your friends and family to use the Dysautonomia International Amazon Store when they shop online.

Amazon gives 6% of your purchase price to Dysautonomia International, at no extra cost to you! www.dysautonomiainternational.org/amazon

Start a personalized fundraising page on FirstGiving.com to benefit Dysautonomia International. www.firstgiving.com/386592



Request a Dysautonomia Awareness Month Proclamation from your local or state government officials to be presented in October.

www.dysautonomiainternational.org/proclamation

Plan a Dysautonomia Awareness Month event for October in your hometown.

www.dysautonomiainternational.org/getinvolved

Ask your local media to do an article recognizing Dysautonomia Awareness Month this October. For sample press releases, email info@dysautonomiainternational.org.

Write an article about dysautonomia for your school newspaper.

For sample school newspaper articles, email info@dysautonomiainternational.org.

Host a Cupcakes for a Cure bake sale — who doesn't love a cupcake! www.dysautonomiainternational.org/cupcakes

Organize a Dress Down Day for Dysautonomia Research at your office or school. www.dysautonomiainternational.org/dressdown

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Dearest Dr. Grubb

The Nitis Family thanks you for the generous care you have offered Juliana these past 10 years!

We could not have made it through such difficult years without you!

THANK YOU!





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BLACK TIE



We are so proud of the work that the Kessler Family is doing to support the ongoing research of POTS.

Without the courage of Daniel and Jordan, and the strength of Ellen and Jonathan, this work would not be possible.

"KEEP ON TRUCKING!"

Love, The Wexler Family



UT DYSAUTONOMIA CENTER OF EXCELLENCE

Our physicians are dedicated to the diagnosis and treatment of Dysautonomia. With our multidisciplinary center we are able to provide excellent comprehensive care.

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lan J. Butler, MD and Mohammed Numan, MD

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"If I am not for myself, who will be for me? But if I am only for myself, who am I?

If not now, when?"

—Rabbi Hillel



Congratulations Dad! Love, Helen & Alex

We Are Proud Partners of Dysautonomia International



The Ehlers-Danlos National Foundation ednf.org

Shout Outs!

CONGRATULATIONS
Courtney on your BSN!
I'm so proud of your
determination, guts,
and spunk.

You're AMAZING! XOXO Mom

Thank you Dysautonomia International for bringing patients, doctors and families together once again for a very educational, informative and fun conference!

-Doreen O'Connor

Congratulations Dr. Grubb!
Your hard work has benefited
all of us, and for that
we are grateful.

Sincerely, The Blumstein Family

A huge thank you to Dr. Abdallah whose kindness and compassion has made this journey more bearable!

-The Kessler Family

Shout out to Dysautonomia International's Patient Advisory Board! Thanks for all of your hard work in pulling this conference together and throughout the year! Love.

Lauren, Ellen, Jodi & Clover

To Meredith,
The strongest girl we know!
Love,

Grandma & Grandpa

To the Kessler Family:
So thrilled to hear that Daniel and
Jordan are doing so well.
Thoughts and prayers are with
those affected by POTS.

Love to all, Marcia Katz & John Pierce

Shout out to Dr. Grubb! You are not my doctor, but I've benefited immensely from your wisdom and wonderful writing. Thank you for everything you do!

With admiration, Melissa Spinner Thank you Lauren Stiles and Ellen Kessler for all your hours of dedication to Dysautonomia International!

-Jennifer Samghabadi, NP

Best wishes
to Emily Remo!
From her advisor
Robin Kucharczyk and
Team Emily at
Monmouth University!

-Robin Kucharczyk

Thank you Lauren – your hard work and total commitment has brought us from a silly idea about a conference to an organization that has made huge strides in advancing research and education!

-Ellen

Thank you Dr. Grubb, you completely transformed my life for the better. Thank you for your dysautonomia advocacy.

Love, Christine Morphis

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Corinthian Reference Lab (CRL) is a commercial diagnostic laboratory specializing in neurological disease detection. We specialize in epidermal nerve fiber density (ENFD) testing. This testing offers patients objective evidence of a neuropathy which can hopefully lead to a more accurate diagnosis. Please contact Greg Davenport for more information: 817-275-5227.

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Dysautonomia International







Stop by our exhibit booth to check out our dysautonomia awareness gear. T-shirts, bracelets, car decals, stickers and more. Make some noise for turquoise!

Ehlers-Danlos National Foundation

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Established in 1985 by Nancy Hanna Rogowski (1957–1995), we are a 501(c)(3) nonprofit organization with a global membership. Our volunteers are the life blood of the organization and make a huge difference to those affected by Ehlers-Danlos syndrome (EDS). By leading the search for knowledge about EDS we are building a community of people who work together to effect change.

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SPONSOR

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The Multiple System Atrophy Coalition is a 501(c)3 charity focused primarily on facilitating and funding MSA research that will lead to the discovery of a cure for this rare and fatal neurodegenerative disorder. The MSA Coalition also provides patient/caregiver education and emotional support, education for healthcare professionals, and leadership in MSA advocacy activities.

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EXHIBITOR

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Washington, D.C. Healthcare Advocates works with individuals of any age who, because of an acute or chronic illness, need help navigating the healthcare maze. We can assist with physician coordination, clinical appointment accompaniment, insurance adjudication and more.

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About Dysautonomia International

Founded in 2012 by a dedicated group of patients, caregivers, physicians, and researchers, Dysautonomia International is the leading 501(c)(3) non-profit focused on assisting patients and families impacted by autonomic nervous system disorders. The organization funds research, physician education, public awareness and patient empowerment programs.

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You may say I'm a dreamer, but I'm not the only one.

-John Lennon



With Love, Lauren & Rob Stiles















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