connecting the dots

Dysautonomia International

CONFERENCE & LOBBY DAY

July 11-14, 2014 • Washington, DC

welcome.

Dear Conference Guests,

On behalf of the Board of Directors and the Conference Host Committee, I am honored to officially welcome you to the second annual Dysautonomia International Conference & Lobby Day! This year, in addition to the Patient Conference, we are hosting a CME Workshop, so we welcome all of the medical professionals who are joining us. Thank you for your interest in expanding your knowledge of autonomic disorders.

This year's conference is packed with many fantastic events. There will be educational sessions presented by some of the world's leading experts in autonomic disorders. There will also be breakout sessions specifically for patients, for parents, for teens and for caregivers; physical therapy sessions to get us upright and moving around; laughter yoga to remind us all how important laughter is to our health; and much, much more.

We have an unprecedented opportunity to participate in POTS research during this conference which will be discussed in detail on Saturday morning. Dysautonomia International is thrilled to be supporting groundbreaking medical research, as this is the primary mission of our organization.

Please be sure to join us for the Awards Dinner on Saturday and the Dessert Reception on Sunday – both opportunities for us to honor all of you who have supported Dysautonomia International in the past year – not to mention time to relax and have some fun! We are also looking forward to a busy day when we travel to Capitol Hill for Monday's Lobby Day.

Don't forget to visit the vendors who have joined us this weekend to share information and products in support of our community!

We are truly excited to share this weekend with you and thank you for your continued support of Dysautonomia International.

Sincerely,

Ellen J Kessler

Ellen J. Kessler
Chair, 2014 Conference Host Committee
Dysautonomia International Vice President & C.F.O.

speakers.


Hasan Abdallah, M.D., F.A.A.P., F.A.C.C., F.S.C.A.I.
Medical Director, The Children's Heart Institute


Tobie Beckerman, M.D.
Beckerman Women's Health


Nira Berry
CEO, LaughingRx


Svetlana Blitshteyn, M.D.
Clinical Assistant Professor
Department of Neurology
UB School of Medicine & Biomedical Sciences


Gisela Chelimsky, M.D.
Professor of Pediatric Gastroenterology
Medical College of Wisconsin


Thomas Chelimsky, M.D.
Chairman & Professor of Neurology
Medical College of Wisconsin
President, American Autonomic Society


Kamal R. Chémali, M.D.
Associate Professor of Neurology
Eastern Virginia Medical School
Director, Sentara Neuromuscular & Autonomic Center


Pradeep Chopra, M.D.
Clinical Assistant Professor of Medicine
Alpert Medical School at Brown University
Director, Interventional Pain Management Center of Rhode Island


Glen A. Cook, M.D.
Department of Neurology
Walter Reed National Military Medical Center


David Goldstein, M.D., Ph.D.
Director, Clinical Neurocardiology Section
National Institutes of Neurological Disorders & Stroke
National Institutes of Health


Jennifer Hursey, M.Ed.
J. Hursey Consulting


Morwenna Opie, Ph.D.
Clinical Psychologist
London Nightingale Hospital


Alan Pocinki, M.D.
Clinical Associate Professor of Medicine
George Washington University Medical Center


Satish R. Raj, M.D., M.S.C.I., F.A.C.C.
Associate Professor of Medicine & Pharmacology
Autonomic Dysfunction Center
Vanderbilt University Medical Center

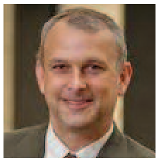

Amanda Ross
Penn State Hershey Heart and Vascular Institute
Penn State University College of Medicine


Paola Sandroni, M.D., Ph.D.
Professor of Neurology
Director, Autonomic Laboratory
Mayo Clinic


Elyse Schwartz, M.S.W.
Boston University School of Social Work


Beth Scott, C.P.T.-N.S.C.A.
Balanced Fitness, LLC


Julian Stewart, M.D., Ph.D.
Professor of Pediatrics, Physiology & Medicine
Director, Center for Hypotension
New York Medical College


Steven Vernino, M.D., Ph.D.
Professor & Academic Vice-Chair
Department of Neurology & Neurotherapeutics
UT Southwestern Medical Center

president's message.

Dear Friends,

It's conference time again! We're glad to see many familiar faces here, and so many new faces too. With your help, Dysautonomia International is growing rapidly and we've accomplished quite a bit since last year's conference.

Last September we brought a delegation of families affected by dysautonomia to the Rally for Medical Research Hill Day to tell Congress why funding medical research is so important to our families, and to our entire nation.

In October we celebrated our second Dysautonomia Awareness Month. Volunteers across the world organized "Cupcakes for a Cure" fundraisers, held "Dysautonomia Dress Down Days" at work and school, obtained Dysautonomia Awareness Month Proclamations and much more.

In November we conducted our first survey of over 700 POTS patients. The results were startling; we learned that the average diagnostic delay experienced by POTS patients who participated in the survey was 5 years and 11 months!

We reached a major milestone last December when we issued our first four research grants. The funds are being used to study pharmacological and non-pharmacological treatments for POTS, to seek more information about the brain physiology of POTS, and to explore the possible overlap between autoimmune diseases and POTS.

In January we joined the MSA Coalition and the American Autonomic Society to testify before the Food & Drug Administration in favor of the approval of droxidopa, a drug used to treat neurogenic orthostatic hypotension associated with multiple system atrophy, Parkinson's and non-diabetic autonomic neuropathy. We celebrated in February when the drug was approved!

In March we launched our first attempt at crowdfunding medical research, which was a resounding success! Within two months, the "crowd" – patients, caregivers, friends and family – raised over $50,000 for the newly created POTS Antibodies Research Fund. This fund will be used for cutting edge medical research on adrenergic antibodies that have been identified in some POTS patients.

In April we cheered on Dr. Tiffany Brainerd, a pediatric anesthesiologist at Harvard and dysautonomia patient herself, as she ran the Boston Marathon in honor of Dysautonomia International and hundreds of patients who contributed photos for her marathon banner. We hope this will be the first of many inspiring "Team Dysautonomia" events we can all cheer for!

In May over 1,000 “What Is Dysautonomia?” brochures were distributed to neurologists who visited the Dysautonomia International booth at the American Academy of Neurology annual meeting in Philadelphia. And we were thrilled to welcome a new member to our Medical Advisory Board, Dr. Roy Freeman, Professor of Neurology at Harvard Medical School and Director of the Center for Autonomic and Peripheral Nerve Disorders at Beth Israel Deaconess Medical Center.

All the progress made in the past year is because of people like you. As an all-volunteer organization every task or project is carried out by someone who cares, someone who is willing to lend their time and talent to our collective cause, with support from our generous donors. We are building a movement for change so that current and future dysautonomia patients will have access to quality healthcare and all of the resources they need to live a better life, including more effective treatments.

Every single one of you attending this conference is part of this movement. Thank you for being here.

Warmly,

Lauren

Lauren E. Stiles, Esq.
Dysautonomia International President & Co-Founder

sponsors.

Lundbeck

CHELSEA THERAPEUTICS

Multiple System Atrophy
The MSA Coalition®
Support - Education - Research - Advocacy

rsdsa
SUPPORTING THE CRPS COMMUNITY

Children's National™
Health System

ADC®
American Diagnostic Corporation

CERTIFIED POLAR PRODUCT
POLAR

The Stiles Family

Ellen & Jonathan Kessler

silent auction.

Up For Bid!

A Taste of the Hamptons Gift Basket
Arizona Gift Basket
Armada Skis
Axon Optics Polarized Sunglasses
California Beach BBQ Gift Basket
Dysautonomia Divas Summer Survival Tote
Dysautonomia Themed Jewelry
Flavors of Italy Gift Basket
Florida Sunshine Gift Basket
Ocean Essence Therapy One Hour Massage
Polar Products Cooling Vests & Neck Wraps
Williams-Sonoma
Wines of Long Island
Wisconsin Cheese & Wine Basket
Women's Basket of Fun
and more...

Don't miss the Silent Auction during the Saturday night Awards Dinner!

Auction Donors

Armada Skis
Axon Optics
Penny Barnard
The DiBona Family
Dysautonomia Divas
Dan and Nicole Estenson
Cathy Hower
The Jagfeld Family
The Kessler Family
The Koos Family
Cathy Morrison, Courtney Powell & Usher
The O'Connor Family
Polar Products
Crista Procopio
The Samghabadi Family
The Stiles Family
Williams-Sonoma
The Yendes Family
Zebra in a Party Hat (Robin Smith)

leadership.

Board of Directors

Lauren E. Stiles, Esq. - President

Ellen J. Kessler, C.P.A. - Vice President & C.F.O.

Jodi Epstein Rhum - Vice President

Clover Yordanova - Secretary

Medical Advisory Board

Hasan Abdallah, M.D., F.A.A.P., F.A.C.C., F.S.C.A.I.
Thomas Ahern, M.D.
Svetlana Blitshteyn, M.D.
Kamal R. Chémali, M.D.
Thomas C. Chelimsky, M.D.
Satish R. Raj, M.D., M.S.C.I., F.A.C.C.
Paola Sandroni, M.D., Ph.D.
Julian M. Stewart, M.D., Ph.D.
Roy L. Freeman, M.D.

Patient Advisory Board

Jennifer Samghabadi, F.N.P.-C. - Chair
Jenny Deutsch
Kyla Jones
Kristina Marie
Doreen O'Connor
Crista Procopio
Amanda Ross
Roberto Salvatierra Duran
Teressa Wright
Angela Yendes, R.N.

contact.

New York

Dysautonomia International
67 Woodlawn Ave.
East Moriches, NY 11940

Washington, D.C.

Dysautonomia International
6151 Executive Blvd.
Rockville, MD 20852

✉ **E-Mail: info@dysautonomiainternational.org**

Facebook: www.facebook.com/dysautonomiainternational

Twitter: @Dysautonomia

Vimeo: www.vimeo.com/dysautonomia

special thanks.

Dysautonomia International would like to express our tremendous gratitude to all of the speakers participating in the 2014 conference. Thank you for sharing your time and expertise with us.

Host Committee

Kathy Dimeo
Jane Herbert
Katherine Hut
Lisa Miller Hut
Daniel Kessler
Jordan Kessler
Becky Linford
Kirk Linford
Catherine Morrison
Courtney Powell
Heidi Riordan
Jill Ruhnke
Elyse Schwartz

Donors

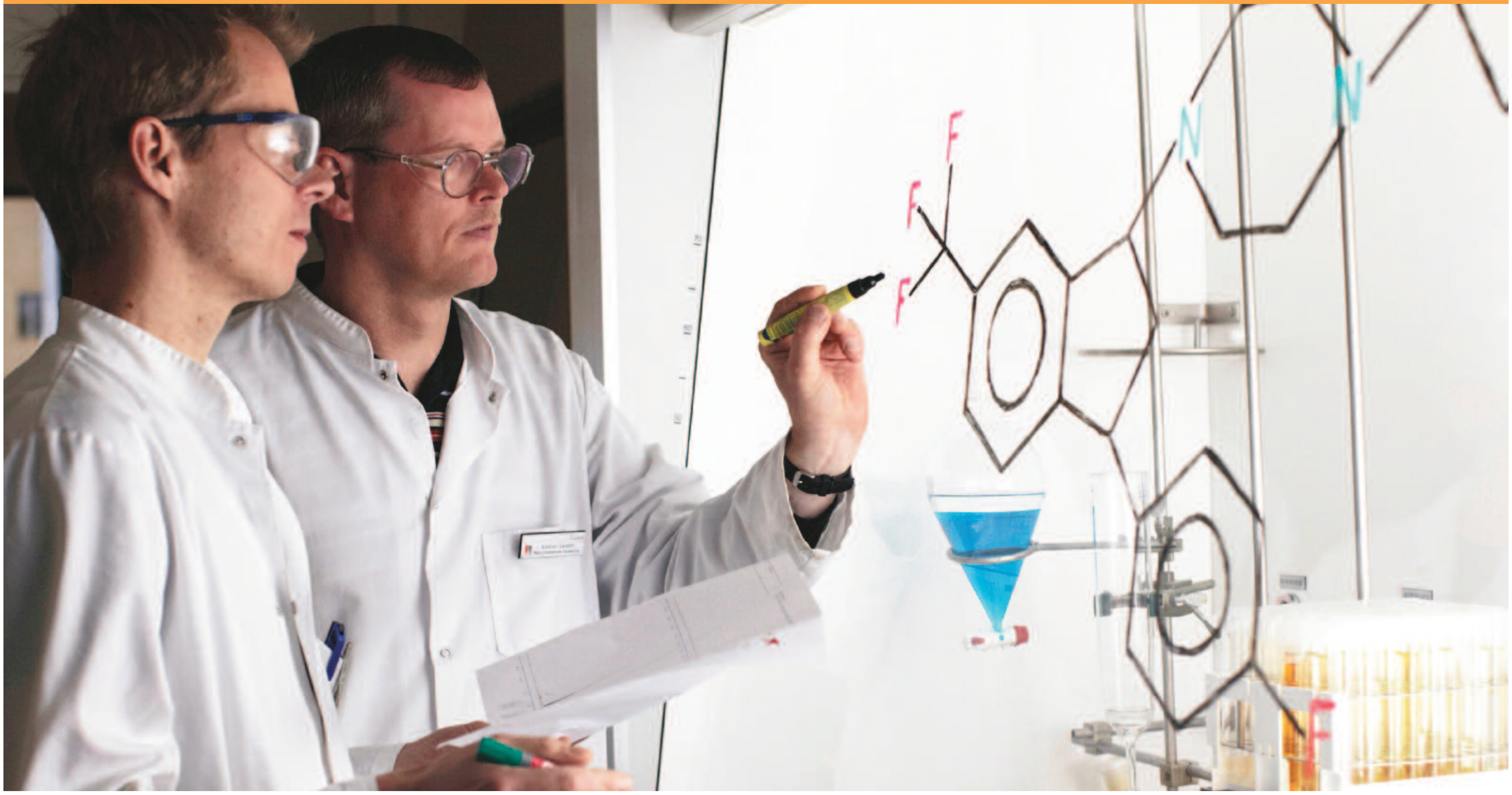
Amanda & Ken Goldstein
Nancy Jacobson Penn & Mark Penn
Deborah & Mordechai Rosen
Kinney Zalesne & Scott Siff
Carol & Marty Segal
Cara & Marc Tommer
Lori & Les Ulanow

2014 Summer Interns

Jennifer Hook
Shannon Linford
Alexandria Soybel

In-Kind Donors

CeraLyte
Drink More Water
Soy Joy



CHELSEA
THERAPEUTICS

Congratulations to
Dysautonomia International
on their 2nd Annual
Conference!

We are very pleased to
support the good work that
Dysautonomia International
is doing.

chelseatherapeutics.com

shout outs!

Thank you Dr. Moodley, best doctor and friend ever! Standing tall, POTSIE.

-Merideth Brooks from Indiana

Wishing Dysautonomia International the best at their 2nd annual conference in Washington DC!

—The Soybel Family

Sending Hugs, Support & Good Health For You Katie!

—Angie Bonnell

Looking forward to Dysautonomia International's 2nd Annual Conference.

Thank you Dysautonomia International for all you do!

—The Samghabadi Family

"People are always blaming their circumstances for what they are. I don't believe in circumstances. The people who get on in this world are the people who get up and look for the circumstances they want, and if they can't find them, make them."
—George Bernard Shaw

—Michaela Benthall

A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles.

You are an everyday hero and amaze me my daughter.

—Alice & Steve Diana

We are so proud of you Alex for interning with Dysautonomia International and helping plan the 2014 conference!

—Trish and Josh

Courage is grace under pressure.
—Ernest Hemingway

The harder the conflict, the more glorious the triumph.
—Thomas Paine

Jenny Deutsch, you light up the world with your spirit. May it continue to shine in everything that you do!

—Linda Deutsch

"Finish each day and be done with it. You have done what you could. Some blunders and absurdities no doubt crept in; forget them as soon as you can. Tomorrow is a new day. You shall begin it serenely and with too high a spirit to be encumbered with your old nonsense."
—Ralph Waldo Emerson

Shout out to Milly Pots! Dysautonomia International would not have happened if you had not introduced me to the world of online POTSies. You were my first POTS friend, and I will always be grateful for the kindness you showed me when I was a scared, newly diagnosed patient. You are an amazing young woman and I am lucky to call you a friend.

-Lauren

Thank you Dysautonomia International!

Thank you Brian, Bre and Nolan for always being there! Potsie friends rock! J.T. and L.S. and many more much love!

—Doreen O'Connor

Congratulations Dysautonomia International on your 2nd conference!

—Stephen Fox

Dear Dysautonomia, You suck, nobody can pronounce your name, & you make us want to puke. Just go away!

-Jeff

shout outs!

Thank you to my neurologist, Dr. Butler, for your continued care and your diagnosis!
-Pickle Juice Girl

A big thank you to Dr. Abdallah who has stood with us from the start and never wavered in his optimism or his compassion!

-The Kessler Family

Shout out to Ellen!
Thanks for putting up with me, fixing my typos, and teaching me about the joys of a good hair straightener!

-Love, Lauren

Daniel and Jordan - We are in awe of your strength and determination. You continue to inspire us every single day. We love you so much!

-Mom & Dad

To our two brilliant children, John & Kyla,Your lives are just beginning and though you have an invisible disability, it does not define you. Your voices will be heard, your stories will be known and your family will always love you/guide you and support you. Always do for others first. Keep hope, love, kindness and life goals at the forefront of your minds and what life gives you back will be immeasurable.
-Love Mom & Dad and all the Brannigan/Howard/Heyder Family

It is the set of the sails, not the direction of the wind, that determines which way we go. Bobby, thanks for being my fearless co-captain who doesn't hesitate to jump out of the boat and push when needed.

-Love, Lauren

Thank you to all of the doctors attending this conference for your interest in helping us understand this illness!

Thank you to the dysautonomia community for supporting the 2014 Dysautonomia International Conference and helping advocate for this cause!

-Alex Soybel

To our amazing PAB - thank you for all your time and dedication!

-Ellen Kessler

Lauren, your courage through this journey has inspired us all. We are all behind you. Walk one step at a time and never, ever, give up.
Te queremos muchísimo,

-Mami, Papi, Samantha, Nana, and Aunts and Uncles

To Lauren Stiles - without your vision, passion and tireless effort none of this would have been possible! Thank you for being my partner and friend.

-Ellen

Dysautonomia International, thanks for making us #POTStrong.

-Kelly

Megan, our brave girl, we are so proud of everything you have achieved.

-Love always,
Mom, Dad & Ben

So thankful to Dysautonomia International for working hard to raise awareness and help people like me.
-Sue S.

Go TEAM DYSAUTONOMIA!

Congratulations to

Dysautonomia International

Its Board of Directors, Medical Advisory Board and other volunteers who have proven that committed individuals truly can make a difference!

With profound gratitude

and appreciation,

Jordan, Daniel, David & Jonathan Kessler

CRPS/RSD *Awareness*

Until there is a cure...

Envisioning a world without CRPS

RSDSA IS PROUD TO SPONSOR

THE 2ND ANNUAL DYSAUTONOMIA INTERNATIONAL CONFERENCE & LOBBY DAY

rsdsa

SUPPORTING THE
CRPS COMMUNITY

Join us for our upcoming events celebrating 30 years of service to the CRPS community

---

Integrated Solutions to CRPS Conference
September 7, 2014
Dallas, Texas

2014 CRPS/RSD Walk for Awareness
September 13, 2014
Cooper River Park, NJ

RSDSA's 30th Anniversary Celebration
October 25, 2014
Princeton, NJ

RSDSA
99 Cherry Street
P.O. Box 502
Milford, CT 06460

www.rsds.org

info@rsds.org

Toll Free 877.662.7737
Fax 203.882.8362

Dysautonomia Information Network (DINET) would like to thank the physicians and researchers who dedicate their careers to dysautonomia research and treatment. We would also like to thank the patients who have taken part in this research.

You give us hope for a better future!

DINET

Dysautonomia Information Network

www.dinet.org

research.

5 ways to get involved with dysautonomia research

1. Attend the POTS Antibodies Research Project presentation on Saturday morning during the conference. Learn how you can participate in an exciting POTS research study happening this weekend. We need healthy people to enroll too! Learn more about the antibodies here: www.dysautonomiainternational.org/POTS-Fund.

2. Sign up for ResearchMatch: www.researchmatch.org. 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. There is also an Ehlers-Danlos Syndrome Registry on ResearchMatch.

3. Sign up for the Autonomic Disorders Consortium Contact Registry: http://www.rarediseasesnetwork.org/ARDCRC/register. 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.

4. Look for studies with open enrollment on www.ClinicalTrials.gov.

5. Keep an eye out for recruiting announcements on the Dysautonomia International Facebook page, www.facebook.com/dysautonomiainternational.

10 ways to raise awareness and support Dysautonomia International

1. Host a Cupcakes for a Cure bake sale.

2. Ask your friends and family to use the Dysautonomia International Amazon Store to do all of their online shopping. Amazon gives 6% of your purchase price to Dysautonomia International, at no extra cost to you!

3. Organize a Dress Down Day for Dysautonomia Research at your office or school.

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

5. Start a personalized fundraising page on FirstGiving.com to benefit Dysautonomia International.

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

7. Plan a Dysautonomia Awareness Month event for October in your hometown, or find one nearby using our interactive map (www.dysautonomiainternational.org/map.php).

8. Ask your school newspaper if you can write a story about your dysautonomia experience.

9. If you have contacts with the media, ask them to do a story about dysautonomia and put them in touch with Dysautonomia International (info@dysautonomiainternational.org).

10. Like, comment and share our Facebook and Twitter posts all over the place!

For more information, please visit www.dysautonomiainternational.org/GetInvolved

Fashionably COOL

CERTIFIED POLAR PRODUCT
POLAR

LIGHTWEIGHT • DISCREET • COMFORTABLE
BODY COOLING VESTS & ACCESSORIES

USE DISCOUNT CODE
& SAVE
10%!
"DI2014"

Polar Products is proud to support Dysautonomia International!

Visit www.polarproducts.com to see our complete body cooling and hot/cold therapy product lines. Please call us at 1.800.763.8423 with any questions.

WWW.POLARPRODUCTS.COM

"Strength does not come from physical capacity. It comes from an indomitable will."
–Mahatma Gandhi

Thank you to all of the With a Side of Salt: POTS Support followers! I have truly enjoyed creating friendships with you, sharing stories and jokes, and helping each other power through our tough times. Together we are POTS strong!
–Crista Procopio

Continued love and support to the Kessler family.

From your friends,

Marcia, Sherrie & Sue

Jordan & Daniel –
for your determination and perseverance,

Ellen –
for your tireless efforts for your
own children, and for all of those
whom you've never met,

We Applaud You.

With Love,
Lisa, Diana, Susie

IN HONOR OF THE
KESSLER FAMILY

WE ARE PROUD TO SUPPORT
DYSAUTONOMIA INTERNATIONAL

KAREN & PAUL WEXLER

Angie Bonnell
Realtor

REALTOR®

WATSON
Auction & Real Estate
4156 S. Twp. Rd. 17 • Tiffin, Ohio 44883
419-443-SOLD (7653)
419-443-1602 fax

EQUAL HOUSING OPPORTUNITY

Email: angiebonnell.realtor@yahoo.com
Cell: 567-207-5487
Fax: 419-443-1602

REALTOR® MLS.

www.firelandsmls.com
www.cimls.com

Ocean Essence Therapy

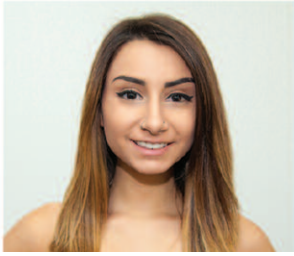
would like to congratulate Dysautonomia International on another great conference!

Stop by our booth this weekend to sign up for a free 5 minute chair massage.

Christine Storms, LMT

Sincerest thanks to our Board of Directors, Medical Advisory Board, Patient Advisory Board and so many other amazing volunteers who lend their time and talents to Dysautonomia International.

With love,
Lauren & Robert Stiles



DYSAUTONOMIA INTERNATIONAL

AWARENESS ADVOCACY ADVANCEMENT