

2013

DYSAUTONOMIA
PATIENT CONFERENCE
& LOBBY DAY

July 6-8, 2013 ■ Washington, D.C.

DYSAUTONOMIA INTERNATIONAL



AWARENESS



ADVOCACY



ADVANCEMENT

WELCOME MESSAGE

Dear Conference Guests,

On behalf of the Board of Directors and Conference Host Committee, I am honored to extend you a warm welcome to the 2013 Dysautonomia Patient Conference & Lobby Day.

We have so much in store for you this weekend, beginning with a roster of speakers that includes the world's leading experts in autonomic disorders. These speakers will educate us through talks on a variety of topics designed to give us all a much better understanding of dysautonomia. Saturday night we will enjoy a banquet dinner with a keynote address by an author who will share her fascinating personal health journey with us. Sunday, a vendor fair will be open during the lunch break for you to browse and shop. Fun, small group activities are planned throughout the weekend for our teenage guests, and there will be numerous opportunities for informal networking and socializing for everyone. Monday we will get down to business on Capitol Hill, meeting with our elected officials to discuss matters important to the dysautonomia community.

We hope that you enjoy this educational, fun-filled weekend and that this conference will be the first of what becomes an annual gathering.

Sincerely,

Ellen

Ellen J. Kessler, C.P.A.
Chair, 2013 Conference Host Committee
Member, Board of Directors

DYSAUTONOMIA INTERNATIONAL



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OUR SPEAKERS



**Hasan Abdallah, M.D.,
F.A.A.P., F.A.C.C., F.S.C.A.I.**

Children's Heart Institute



**David S. Goldstein, M.D.,
Ph.D.**

Nation Institutes of Health



Svetlana Blitshteyn, M.D.

University at Buffalo School of Medicine



**Matthew A. Petersen,
B.S.N., R.N.**

Mayo Clinic



Susannah Cahalan

(Keynote Speaker)

Author of *Brain on Fire: My Month of
Madness*



Alan G. Pocinki, M.D.

George Washington University
Medical Center



Kamal R. Chémali, M.D.

Sentara Heart Hospital



**Satish R. Raj, M.D.,
M.S.C.I., F.A.C.C., F.H.R.S.**

Vanderbilt University School of
Medicine



Pradeep Chopra, M.D.

Brown Medical School



Peter C. Rowe, M.D.

Johns Hopkins University
School of Medicine



**Rachel Leder Couchenour,
Pharm.D., M.B.A.**

Chelsea Therapeutics



Paola Sandroni, M.D., Ph.D.

Mayo Clinic

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6151 Executive Boulevard
Rockville, MD 20852

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Sandy Tobias

MESSAGE FROM THE PRESIDENT

Dear Guests,

Thank you for joining us at the 2013 Dysautonomia Patient Conference & Lobby Day. This is an exciting opportunity for all of us to meet fellow dysautonomia patients, their families, and some of the best dysautonomia experts in the world.

It has been wonderful to see so many people come together to make this event happen. It was less than 12 months ago that a few people in a Facebook chat came up with this idea. At first it was a, "wouldn't that be cool someday," kind of idea. But after we let it sink in for a few days, we all came back to the same chat and decided "we have to do this ASAP!" And that is how we ended up here today. A group of regular folks coming up with an idea, then putting their passion and hard work into making it a reality.

Dysautonomia International officially launched last October and hit the ground running. Our multi-talented all volunteer Medical Advisory Board, Patient Advisory Board and Board of Directors have set forth an ambitious agenda and have started to work on that agenda with fierce determination. The following is a summary of some of things we are working on.

RESEARCH

We want more research, because we realize that the more we know about how autonomic disorders work, the better we will be able to treat them, and hopefully someday cure or even prevent them.

We have already raised over \$25,000, and we expect to issue our first round of small scale research grants in late 2013. We're also supporting researchers in other ways, by assisting with the design of research studies, facilitating patient recruitment for research studies, and encouraging patients to sign up for the National Institutes of Health (NIH) Autonomic Disorders Consortium Research Registry. Perhaps most importantly, we have been engaged in the battle to restore the massive billion dollar budget cuts to the NIH, which is the federal agency that funds almost all independent medical research in the U.S., including most research on autonomic disorders. We are also seeking to increase the allocation of existing NIH resources dedicated to autonomic research so that more funding is available for scientists who are studying autonomic disorders.

PHYSICIAN AWARENESS

We want the medical community to diagnose dysautonomia patients faster, so future patients don't have to endure physically, emotionally and financially draining misdiagnoses, as so many current dysautonomia patients have. Once patients have been properly diagnosed, we want them to have access to physicians knowledgeable about their condition, close to home, so they can receive proper follow-up care. We've taken several preliminary steps towards making this a reality. We've given presentations and hosted educational booths at medical conferences. We've started a Speaker's Bureau of medical professionals, medically-savvy patients, and caregivers who are able to speak at medical schools, nursing schools, colleges and

other places where we can educate medical professionals about autonomic disorders. We developed teaching tools that can be used over and over again in different settings, so that we can ensure our educational presentations are accurate and consistent. We have started to develop an EMT/EMS training program with experienced EMT educators.

PUBLIC AWARENESS

We want “dysautonomia” to be a household phrase someday, just like Autism and Parkinson’s have become. We have actively pursued media coverage of autonomic disorders, taking special care to emphasize the need for accuracy in the media. We’re seeing results. Our Dysautonomia Awareness Month campaign launched last October resulted in positive press coverage in several states. Our Dysautonomia Tweet-A-Thon reached 300,000 Twitter users in one day. After making our turquoise “Dysautonomia Awareness” ribbon graphic available for free, tens of thousands of people saw that ribbon all over the internet, on posters at events, and even on our shirts. We are working to get articles about dysautonomia published in newsletters and on websites of other patient advocacy groups, such as those that focus on Lyme Disease, Diabetes, Sjogren’s Syndrome and other conditions that can cause dysautonomia.

EMPOWERED PATIENTS

We want to provide patients with tools that educate and empower them to become their own best advocates. We launched our website in October of 2012. Our website contains plain English summaries of even the most complex autonomic disorders, as well as in-depth journal articles, tips on exercise, lifestyle modifications, dealing with financial issues, legal issues, and more. We also provide patients with ways to connect and learn from our shared experiences, through Facebook, our Interactive Global Map, and for our younger patients, through the one-on-one POTS Pals program. We are also creating a video library of accurate and informative videos on autonomic disorders, available for free through our website.

And that is just the short list of our goals and the projects we are working on to attain them.

What’s most exciting is that people are reaching out to us because they want to learn more. How can we get involved? How can we help? How can we work together? Those questions are music to our ears. We are an all volunteer organization, so none of the work we are doing would be possible without the hard work of our volunteers and the generosity of our donors. We hope that as you learn more about Dysautonomia International this weekend, you will consider becoming part of our volunteer team.

Working together, we can make great things happen!

Warmest regards,



Lauren E. Stiles, Esq.

President, Dysautonomia International

The following have kindly donated to our
silent auction.

We appreciate your support:

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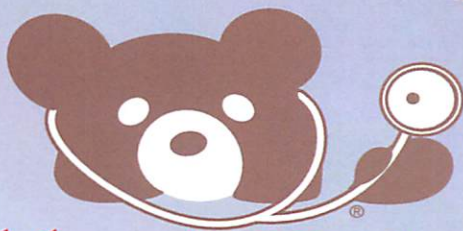
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Jordan & Daniel:

We honor you both for your fortitude, resilience and grace in fighting back. Your heroic journey has inspired us all.

We are your admirers -
**Nancy, Mark
& Blair Penn**





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Children's National Medical Center
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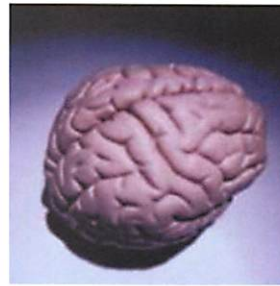
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Led by **Dr. Svetlana Blitshteyn**, a neurologist specializing in autonomic disorders and a medical adviser to Dysautonomia International. Providing in-office and phone consultations.
Contact us at:

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EVERY LOCKET TELLS A STORY...WHAT'S YOURS?



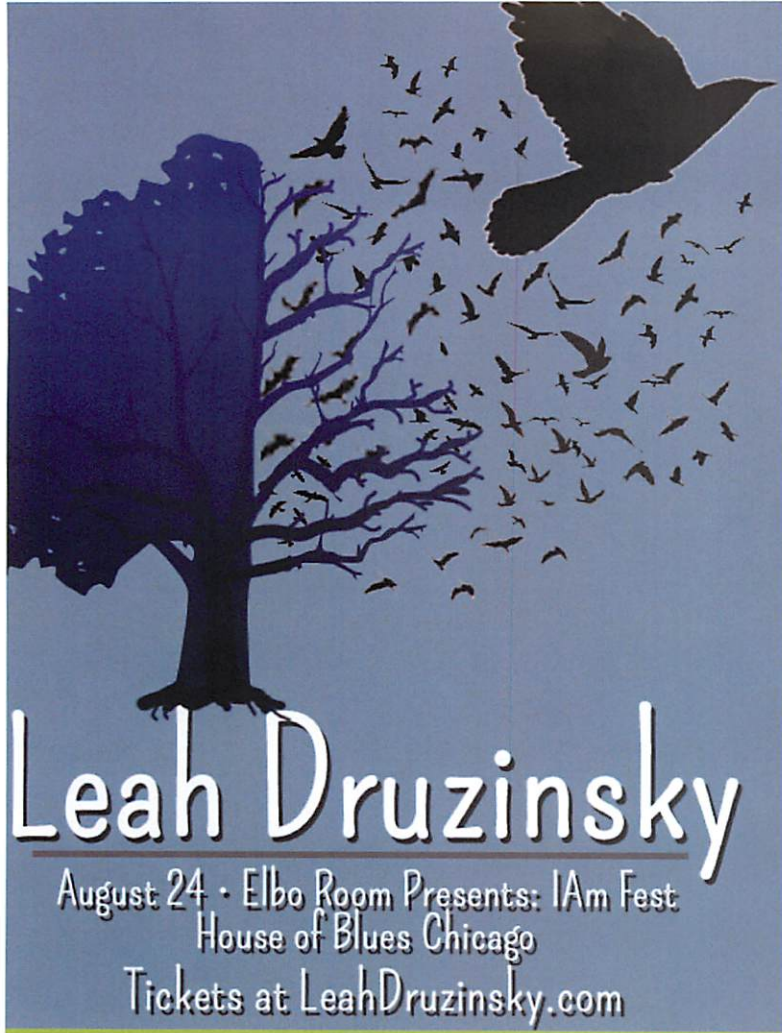
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Keep up
the good
work!

**NAOMI &
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“LET’S FEEL BETTER”

Dragging Dysautonomia through my Twenties One Blunt and Belligerent Blog Post at a Time.

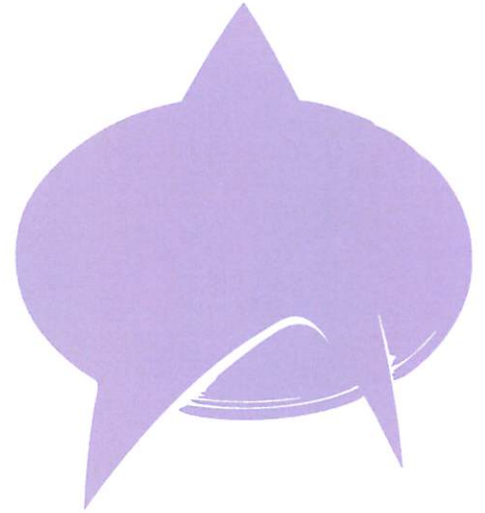
A blog by Ilana Jacqueline

*As seen on Cosmopolitan.com

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& Sue

Wishing Lauren,
Jodi and Ellen the
very best at the
1st Dysautonomia
International
Conference. Great
job!

Clover Yordanova

Never doubt that a small group of thoughtful committed citizens can change the world. Indeed, it is the only thing that ever has.

-Margaret Mead

Jodi, Ellen, Clover, and the rest of the Dysautonomia International team, we are so thankful for all of your hard work and dedication. Keep proving that Margaret Mead was right!

The Stiles Family

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