

~ A newsletter of the American Autoimmune Related Diseases Association ~

Ever wonder what you can do to help autoimmune patients be heard, or to advance autoimmune research? Read on to see what some enterprising and committed AARDA supporters have done and are planning to do to help this happen.

Raising awareness in honor of Cara Lian Lebedda

For the last 10 years, Dominica Piscitelli Pavlik has put on an event in Pennsylvania in honor of her cousin, Cara Lian Lebedda, who passed away in 2008 at age 20. Lebedda had thrombotic thrombocytopenic purpura TTP, a rare autoimmune blood disorder. Through her grassroots event, Dominica has raised \$85,949 over the last decade in support of the AARDA mission, particularly autoimmune research. This year, she is the Walk Ambassador for AARDA's Inaugural Pittsburgh Autoimmune Walk on September 29 at Schenley Plaza. Walk with Dominica and AARDA and help us raise awareness in the Pittsburgh area.



Schenley Plaza, Pittsburgh

To register, go to <http://autoimmunewalk.org/locationpage.asp?BranchID=129>.

Community for Autoimmunity

Grassroots organizer Brian Goldstein is working to put on the 2nd "Community for Autoimmunity" event in Levittown, PA on November 16 at McStew's Irish Pub. Thus far, Brian has lined up several performers and is looking for items to raffle off. The first event, held in 2016, raised more than \$1300. His goal for this year is \$2000.

Brian is an autoimmune warrior living with MS. He says: "The autoimmune plague is very near and dear. My wife has rheumatoid arthritis. A close friend has lupus. So I feel the need to keep the ball rolling on awareness."

See the music line-up and learn more at:
<https://www.facebook.com/events/1982437952063293/>



We are grateful to...

...**Kristian Barnard** of Magnolia Melts in Belmar New Jersey, who donated 10 percent of sales during Autoimmune Diseases Awareness Month -- March -- to AARDA! <https://www.facebook.com/MagnoliaMelts/>



...**Nahum Luna**, who raised \$600 for AARDA through live video streaming on Twitch.tv! Nahum has been doing this fundraiser since 2016!

...All the **Facebook fundraisers** who together raised more than \$20,000 in the last quarter.

Our thanks to all!!

Brave Dave Open

Led by grassroots organizer Tom Branthover, the Brave Dave Open has been raising autoimmune awareness since 2003 -- 16 years -- and has raised more than \$125,000 in support of the AARDA mission. The most recent event was held June 7, 2019 at the Blue Mash Golf Club in Laytonsville, MD. The Open is presented by the Brave Dave Foundation, which was founded by **Dave Gearing**, an autoimmune warrior who has been battling multiple sclerosis for 30 years. Gearing was an avid golfer during high school and college and was diagnosed with multiple sclerosis after graduating from law school. To learn more about Dave and his foundation, please visit <https://www.bravedave.org/>



Hannah's Homemade

Hannah Deal was diagnosed with narcolepsy in 2018 after a "frustrating and exhausting" journey to reach her diagnosis. She says: "The lack of awareness and lack of funds surrounding autoimmune disease saddens me; while I first shied away from sharing my diagnosis because of the stigma surrounding narcolepsy, I have since decided I want to do everything I can to raise awareness and support those who are ill in whatever way I can."

One way, is through a business Hannah started called Hannah's Homemade, which offers organic, dairy- and gluten-free nut and granola butters. She is donating 10 percent of sales to AARDA and raising awareness on her web site, and in stores throughout the state of Virginia. Learn more about Hannah



Hannah Deal

Other ways you can help

- **Start a Meetup in your community!** If a support group is not your thing, consider starting a Meetup group instead. Meetups can be upbeat events where people living with autoimmune disease can gather, play games, get to know one another, network, laugh together, learn more about how to live well with autoimmune disease, and spread awareness. Many public libraries and community centers offer space at no or low cost for meetings.
- **Host an Awareness Event or Fundraiser** at your school, place of work, community center, place of worship -- just about anywhere will do! AARDA will send you brochures, flyers and newsletters, and may provide additional help, depending on the size and scope of your event.
- **Volunteer!** If there is an AARDA event in your area, contact us; we are often in need of help to man a booth, assist with registration or set up/break down events. Email scobb@arda.org to volunteer or learn more.
- **Share your autoimmune story.** As part of our advocacy efforts and our ongoing campaign to raise awareness, AARDA presents autoimmune patient stories that illustrate the challenges and needs of the autoimmune community. Whether it's in printed materials, testimony before Congress, or PSAs and YouTube videos, these stories serve to educate and inspire.

Email arda@arda.org to share your autoimmune story, if you'd like to help with advocacy, or if you are interested in doing an awareness event or fundraiser.

Email walk@arda.org to volunteer for a Walk in your area or to help create one.

** AARDA Calendar **

AUGUST

Detroit Walkabout & Public Forum

VisTaTech Center, Schoolcraft College | Livonia, MI
Saturday, August 24, 2019 | 10 a.m. to 2 p.m.
Walkabout: 8 a.m. to 12 p.m. | DiPonio Room
Forum: 10 a.m. to 2 p.m. | Kehrl Auditorium

SEPTEMBER

New York Autoimmune Walk

Hudson River Park, Pier 45 | Manhattan
Sunday, September 15 | 1-5 p.m.
Ambassador: Nika Beamon

Pittsburgh Autoimmune Walk & Public Forum

Forum: 9/28 | Autoimmunity Institute,
West Penn Hospital | 10:30 to 3 p.m.
Walk: 9/29 | Schenley Plaza | 1-5 p.m.



Chris Zurich will perform live at the NY Autoimmune Walk

Ambassador: Dominica Piscitelli Pavlik

NOVEMBER

5th Los Angeles Autoimmune Walk

Culver City Park, Culver City, CA
Sunday, November 3 | 1-5 p.m.
Walk Ambassador: Phyllis Caddell

2nd Community for Autoimmunity

Saturday, November 16, 2019
McStews Irish Pub | Levittown, PA

Visit www.AutoimmuneWalk.org to register or for more information.

QUOTE OF THE QUARTER:

"You are so brave and quiet
I forget you are suffering."

- Ernest Hemingway, "A Farewell to Arms"

STAY CONNECTED:

