

ECD Global Alliance Volunteers Recognized During National Volunteer Week

By Elizabeth Anderson, May 16, 2017

In the U.S., from April 23 – 30, volunteers from around the world were acknowledged for their contributions. The ECD Global Alliance (ECDGA), a non-profit dedicated to supporting people affected by an ultra-rare blood cancer known as Erdheim-Chester Disease (ECD), honored 37 volunteers on their social media channels during the week. ECDGA volunteers are the lifeblood of the organization supporting the community and contributing more than 2,300 hours of service to numerous essential programs and functions.

“National Volunteer Week is an opportunity for the entire community to express gratitude for those serving the patients and families affected by ECD. It gives members a chance to see who is working behind the scenes, helping them to get the support and information they deserve. It is hoped that the ECDGA members are uplifted and encouraged by the knowledge that there is a great group of volunteers fighting for them every day.” ECDGA staffer, Jessica Corkran explains the importance of National Volunteer Week.



The ECDGA operating model heavily depends on volunteers to augment the two part-time organization staffers. ECD patients, caregivers, their families and friends, and medical professionals make up the Alliance’s altruist army. Most contributors help with a single project or once a year, while others help on a more consistent basis. Volunteer tasks range from helping others on social media to financial tracking and filing, along with executing annual events, fundraising, graphic design, resource translations, and supporting patients in their native countries outside the United States. The work performed by these dedicated volunteers supports the ECDGA’s

430 patient members.

RuthAnn Batchelder, the wife of an ECD patient and an ECD caregiver, was one of the 37 volunteers honored during National Volunteer Week for her tireless support of other caregivers through regular online chat sessions. She explains why she volunteers for the non-profit. **“I have been a caregiver for more than twenty years. Because ECD is so rare and complicated nobody seemed to understand what I was going through, and I often felt like I was alone. We all need a place where somebody understands, and I hope our group is that place for our ECD caregivers.”**

The Alliance is also highly supported by volunteer medical professionals who offer their expertise and knowledge to increase medical awareness and implement patient-care projects the organization facilitates and executes. The miraculous ability the grassroots non-profit has had in supporting hundreds of people from

around the globe is solely due to the overwhelming involvement of medical professional and member volunteers.

ECDGA President and volunteer, Kathleen Brewer, notes the importance of volunteerism in supporting the organization's activities. **"We are an international organization, but no one person or one group of people can ever understand or fulfill the needs of everyone. However, if we somehow organize, with everyone doing their part, it would be possible."**

Volunteerism benefits the ECDGA, but it also has positive impacts on the volunteers themselves. Scientific studies have noted that individuals who volunteer enjoy psychological and physical benefits such as increased satisfaction, improved sense of belonging, lower blood pressure, and decreased mortality (https://en.wikipedia.org/wiki/National_Volunteer_Week).

People interested in supporting the ECDGA are encouraged to visit the ECDGA's [volunteer webpage](#) or reach out to staff member Jessica Corkran at Jessica.Corkran@Erdheim-Chester.org. Donations made at www.fundECD.org or by mailing a check to ECD Global Alliance, P.O. Box 775, DeRidder, LA, 70634 can also support the organization's mission and project needs.

Thank you to all the volunteers who dedicate their time, energy, resources, and skill to the work of the ECDGA. You help the ECD community grow stronger every day!

ECD Volunteers recognized during National Volunteer Week on social media

- Bridget & John Gates
- RuthAnn Batchelder
- Dearbhaile Dooley
- Randy Brown, CPA
- Simon Dedrick
- Vivian Dooley
- Abigayle Brewer
- Robert Bunge, MD
- Anzhen Qin
- John Schulz
- Jessica Royal
- Rusty Kuhn
- Teresa Keegan
- Josef Lacy
- Medical Symposium & Patient and Family Gathering Volunteers
 - Sonia Maskas, Susie Cooper, Rose Dooley, Damien Dooley, Ena Brophy, Kevin Rase, Julie and Lexi Jones, Jason Corkran, Charles Balnaves, Alice Nilsen, Pal Feste, Gadi Bauchman, Julieta Fonterosa, Vanessa Poulet, Stephen Morris
- Board of Director Members
 - Linda Adams, PhD, Kathy Brewer (President), Jean Campbell, Pam Fleming, Rachel Mitchell (Treasurer), Glenn Padnick, Juvianee Estrada-Veras, MD