



ECD Global Alliance

Available Volunteer Roles

Thank you for considering lending your skills to the work of the organization. The ECDGA members are a community of people that come together to fight this disease one day at a time. The volunteers help make the day-to-day work possible!

The following roles are open for community helpers to fill within a year. If you or someone you know is interested in serving the community, please contact Jessi via email, Jessica.corkran@erdheim-chester.org. Please include a brief background summary, connection to ECD, contact information, and any other comments regarding the volunteer role of interest.

Roles listed within this document:

- [Awareness Advocate](#)
- [Chat Moderator](#)
- [Internet Search Editor](#)
- [Website Reviewer](#)
- [Story Writer](#)

Additional roles include YouTube management, Blog Writer, Web Data Analyst, Translator (materials into other languages), Grand Rounds Manager (for medical awareness), ECDGA Champion (see below), etc.



What is an ECDGA Champion?

The ECD Global Alliance is committed to including the thoughts and knowledge of the ECD community in the development of programs, materials, and research for people with ECD and their families. ECDGA Champions include people with Erdheim-Chester Disease and their family members. This group directly impacts programs and initiatives for the community by sharing their experiences and insights with the ECD Global Alliance.

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Don't see your skill set listed, but want to help? Please let us know about your idea or passion!



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Awareness Advocate

An advocate is someone who actively supports a cause by becoming a spokesperson, fundraiser, awareness builder, or helps the community affected in any way. You are likely already an advocate!

Description

This role will focus on raising awareness in the medical community. Volunteers will be asked to cold-call doctors and hospitals outside of the directly connected community. This could include sending informational brochures and/or emails, asking them to join the ECDGA, inviting them to our annual medical symposia, etc.

Amount of time estimated to complete

This is an ongoing task! However, there will be focused times of awareness when help is appreciated even more. These usually include the ECD Awareness Week in September and the National Rare Disease Day in February. Planning and outreach for these events begin at least three months in advance.

Timeline

The time required will depend on the volunteer's geographical commitment to the task. If someone is interested in only doing local outreach, it will take less time than for a nationwide campaign. Of course, there is also the option to lead a team of national helpers! Your schedule will navigate the time you can offer to this task. We just ask that a deliverable be accomplished in a reasonable period. (For instance, the volunteer could focus an hour each week within one month to collecting a list of institutions where our materials could be offered, with the following month focused on distribution, etc.)

Requirements

The volunteer needs to have access to a phone. A computer and intermediate computing skills would be helpful. This project is new and would need a template guide created for tracking the institutions contacted (just in an excel document is fine), as well as creating a process of tracking the work in progress (e.g., what centers did we call, if they requested brochures, record name of doctor added to our group, etc.).

Tools/Materials/Assistance provided by ECDGA

- Review of the template created
- Meeting(s) can be held to help with questions and to discuss progress
- Awareness Materials appropriate for each audience



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Chat Moderator

Description

We have monthly virtual chats and additional moderators are needed to help host. If you would like to see if this is in line with your thoughts on patient support, I invite you to attend a chat to get an idea of what's involved. Find the schedule here: <https://erdheim-chester.org/chat-sessions/>.

Amount of time estimated to complete

Each meeting is approximately one hour long. Depending on the audience segment you would like to moderate, some meetings are monthly (peer) and some are bi-monthly (caregiver and grief). Regional and international meetings are usually held quarterly. A summary following the meeting is appreciated to help the ECDGA team track the needs and details of those in attendance. This summary may take you about 30 minutes to type and send. A review of the international emails and documents will be requested for foreign language translation accuracy, adding about 30 more minutes to your volunteer time.

Timeline

Moderators can commit now and begin on the following chat scheduled. As the moderator, the meeting time can be made to fit your schedule, within reason (waking hours of the potential audience taken into consideration).

Requirements

This task will require good listening skills, sympathy, and some knowledge of the ECD community and the ECDGA. The volunteer will not be required to answer questions they do not know the answer to, such as facts about the disease or medical advice.

Tools/Materials/Assistance provided by ECDGA

- Setup - scheduling, emailing, and any correspondence with attendees before and after meeting
- Zoom account access
- Zoom Training
- Tips for how to moderate a meeting
- An ECDGA team member will attend the first session you moderate



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Internet Search Editor

Description

This volunteer updates content placed on other 3rd party websites. For instance, when a person Googles Erdheim-Chester, they will see some old (and often scary) information out there. A startup guide is already lined up with websites that need revision to help you find where to go and how to proceed with changes.

Amount of time estimated to complete

This will depend on the website in question, whether they are easy to reach and inclined to place the new information online or not. This can go at a slower pace with a reasonable deliverable rate of at least two websites updated per month.

Timeline

Start anytime since our guide is ready to share!

Requirements

Knowledge of the ECDGA website to find accurate data. The volunteer will need access to a computer and the internet. Some intermediate computer skills will be needed to navigate emails and website menus. Tracking the progress on a Microsoft Excel template will also be requested.

Tools/Materials/Assistance provided by ECDGA

- Start-up guide with websites that need content edits.
- Meeting(s) can be held to help with questions and to discuss progress.
- Review of content used for updates, if needed.



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Available Volunteer Roles

Website Reviewer

Description

This role involves reading and navigating through the ECDGA website. The Reviewer will search for grammatical errors, link errors, navigation issues, missing events or information, etc.

Amount of time estimated to complete

Several hours or more are needed to review the entire website. However, sections can be segmented for a shorter review process each week/month until the website is reviewed in its entirety. This will depend on the time the volunteer has to offer. There will be certain edits the ECDGA team will also request before they are made live online. This task would average about an hour per month.

Timeline

Can start immediately after deliverables are communicated.

Requirements

The volunteer will need access to a computer and the internet. Some intermediate computer skills will be needed to navigate the website menus and to track the progress on a Microsoft Word template. Good grammar skills and some knowledge of the ECDGA's work.

Tools/Materials/Assistance provided by ECDGA

- Template for tracking edits
- Meeting(s) can be held to help with questions and to discuss progress.



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Available Volunteer Roles

Story Writer

Description

The ECDGA shares stories from the community to help inspire other families fighting ECD, to raise awareness of ECD and the effects it has on families, and to offer an outlet to those that want to feel heard and less alone. The Writer will help coordinate stories from those offered to the Alliance, including editing and formatting, and requesting photos or other additions. The Writer will also spend time in outreach to help create stories in the community. The stories can be told by the person or an interview can be done for the Writer to generate the content into a story.

Amount of time estimated to complete

Editing and formatting existing stories sent in by a community member will only take about an hour. New stories created by the Writer will depend on the storyline, and their pace, and skill level. Approximately three hours is an average for our team to spend on new stories we piece together for the source.

Timeline

Starting on this project will likely require outreach unless a story is in the queue with the Alliance. This means that the Writer would need to begin searching for a story to write or ask a community member to submit them. An All-Call can easily be posted on the closed Facebook group to start the project.

Requirements

The volunteer should have intermediate computer skills and access to a computer and Microsoft Word. (Adobe is a plus.) They should have access to a phone as well. The use of Zoom or another F2F tool would be helpful for interviews.

Tools/Materials/Assistance provided by ECDGA

- Formatting template for stories posted on the website
- Zoom account usage as needed
- Referrals that have expressed interest before
- Access to the Facebook Closed Group for outreach