

ECD Networking Directory Overview

Attached you will find an ECD Directory Registration form. You can use this form to record information you would like to share with those affected by ECD. The information you include will be made available to other participating members of the ECD Global Alliance, but no one else. If you choose to participate by returning the form with your contact information, you will be emailed a file containing the information from others affected by ECD. This will allow participating members to contact each other directly. If you do not choose to participate, you will continue to receive emails sent out to the group, but will not receive a copy of the ECD Directory. Participation is completely voluntary. Many have found it very helpful to communicate one-on-one with others affected by ECD. Such sharing can help improve the support we provide to each other.

If you would like to participate in the ECD Directory, please complete the attached form, sign it and email it to support@erdheim-chester.org. If you do not have access to a scanner, you might be able to take a picture of the form with your cell (mobile) phone and email the picture. If this poses a problem, please send an email to the above address to discuss alternate methods for sending the completed form into the organization.

Any information contained in this directory will be for Directory Members ONLY and not for public use and/or distribution without prior written consent of everyone participating in the directory.

By participating in the directory you agree to protect this information in an appropriate manner. Once this information is distributed to members of the ECD Global Alliance, the ability to ensure what happens to the information is beyond the control of the organization and becomes the responsibility of you and other participating individuals. We ask you to take this responsibility seriously and to understand there is an inherent risk associated with sharing your information.

For this reason you MAY want to use only a first name (or even an alias.) You may not want to include your address and/or phone number. You may want to create a new email address to be included in the directory. Many sites offer email addresses free of charge. (See www.yahoo.com, www.hotmail.com, or www.gmail.com as examples.) If you do create a new email address you will want to be sure to check it on a regular basis as other members may be trying to contact you. Some participants may want to use their existing email accounts and include their phone numbers. The decision is purely personal.

We sincerely believe that all members of the ECD Global Alliance will use the information provided in the ECD Networking Directory in the manner in which it is meant. We are unaware of any intentional misuse of personal information, either in the past or planned. However, we provide this warning because we want everyone to understand that sharing of personal information in today's world will always carry with it a risk. We hope this warning will not keep you from participating, but rather will help you understand every attempt is being made to ensure your privacy while providing as strong of a support structure as possible.

ECD Networking Directory Signup Information

Please note that all areas are optional. Provide only as much information as you feel comfortable disclosing. A separate form is to be filled in for each individual becoming a member.

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| Member's "Screen Name": |
| Member's Name: |
| Relationship to patient: |
| Your Email Address: |
| Your Phone/Cell Number: |
| Your Mailing Address, State, or Country: |
| Patient's Name if not the member: (and/or "screen name") |
| Patient's Sex: M F |
| Year and Patient's Age at Onset of Symptoms: |
| Year and Patient's Age at Diagnosis: |
| Brief Description of Symptoms, Involvement, Treatment, etc. (please limit to 1000 characters.): |

Signature of member for release of information to other Directory Members Only, and agreement to keep information confidential:

_____ Date _____

Signature of patient if patient details or name is included & patient is not the member registering.

_____ Date _____