

## Summary of ECD Global Alliance chat held on Saturday 31st July 2010

9 Present:

- A patient asked whether anyone had any suggestions to overcome the feeling of exhaustion all the time. Some patient's doctors have prescribed a medication called provigil that helps some with feelings of sleepiness and fatigue, although it doesn't help everyone. It was agreed that the hot weather made this problem worse.
- One patient is due to start a workup before a kidney transplant. They had recently read an article about an ECD patient in Australia who had received a kidney transplant.
- One patient suffers from nystagmus (involuntary eye movement) and has recently had an MRI of their eyes.
- A patient is currently experiencing considerable difficulty walking, due to problems with balance and pain.
- The NIH (National Institute of Health) is considering the possibility of conducting a study on ECD. An email giving more details about the study was sent on 24 July to all members. If you are interested in participating in the study, and have not yet sent an email ([support@erdheim-chester.org](mailto:support@erdheim-chester.org)) stating this, please do so. It is expected to be a long running study so there will be plenty of time for participation. Everyone who is interested in participating should begin gathering their medical records, so that once approval is obtained the study can begin immediately. The NIH will cover the cost of travel, food and lodgings for US participants. It is hoped that the study may commence before the end of the year if all goes well.
- A question was asked with regard to how the group hopes to raise money for research. This might be from various sources, from fundraisers with the general public, by asking those who are interested if they might be prepared to make a donation, and through grants. Donations may be sent to the Treasurer of the Global ECD Alliance, the address is:  
ECD GlobalAlliance  
c/o Ralph Stallard, Treasurer  
6375 Thomas Jefferson Highway  
Charlotte Courthouse, Va 23923 USA.'
- There was a discussion about the work of the ECD Global Alliance Medical Advisory Board. One ECD researcher has recently commented 'It's absolutely great the network that's originating from the Medical Advisory Board.' There are plans to host teleconferences of the Medical Advisory Board at least 2-6 times a year. Our organization's grant proposal has a deadline of August 11<sup>th</sup> so there will

probably be a few more calls during that time as the Board makes evaluations as to which proposals are the most appropriate.

- A number of members are hoping to arrange fundraisers in the near future. The group is in the process of creating a library of useful information that may be used by members during fundraising/awareness events. If anyone would be willing to help put this information together, please send an email to [support@erdheim-chester.org](mailto:support@erdheim-chester.org). It is hoped to make this material available on the website shortly.
- The next chat will be held on Saturday 7<sup>th</sup> August 2010 at 3pm EST.