

## Summary of ECD Global Alliance chat held on Saturday 11<sup>th</sup> June 2011

12 Present

- Two members have held a very successful fundraiser this week at a local restaurant. Over \$1000 has been raised for the ECD Global Alliance. Thanks were expressed for all the hard work that has gone into this event, and the couple kindly agreed to jot down a few thoughts about what made it such a success, in the hope that others may be inspired to do something similar in their local communities.
- A patient described how they have been suffering with numbness and pain in their legs recently. Several other patients on the chat have also had this problem.
- One patient is experiencing double vision in the evenings (this patient has growths in the eye orbits). Another member said that a patient in the group had lost their sight due to tumours in the eye orbits suffocating the optic nerve.
- A patient described how they were doing well but were often tired, partly due to poor bladder control which keeps them awake at night.
- One patient has just been discharged from hospital, where they were being treated for another blood infection. It is thought that it is possible that the port may be responsible for the infections.
- A patient in the group is still in remission and has now lost 60lbs since they stopped taking steroids.
- One couple in the group recently had an interview with their local paper published. The article will be placed on the ECD GA website at the next update.  
(see <http://www.pvtrib.com/main.asp?SectionID=74&SubSectionID=409&ArticleID=54197> )
- Several members have suffered from a skin rash. One patient described itching, red spots, bumps and bruise like spots. Another patient described red lesions all over the calves, which was linked to recurring pancreatitis (the disease has spread to the pancreas). Other patients have also had rashes/discolorations. There is a small amount of information in the medical journals relating to skin issues that appear with ECD. If you are interested in these references, please send an email to [support@erdheim-chester.org](mailto:support@erdheim-chester.org).
- One patient is currently being treated with Actemra, a once monthly infusion used to treat rheumatoid arthritis. It is hoped that, as well as relieving bone pain, the drug will be effective at treating other organs affected by ECD.