

## Summary of ECD Global Alliance chat held on Saturday 6th November 2010

12 Present:

- A paper is currently being compiled on the subject of a patient who has Langerhans and non-Langerhans Histiocytosis. It was discussed that some doctors believe it is not uncommon for an ECD patient to be diagnosed with LCH. However, it is uncommon for an LCH patient to be diagnosed with ECD. ECD is much rarer than LCH.
- At present the website is updated on a monthly basis with papers that are published on ECD. Links are provided to those papers that appear on the internet and summaries are provided for those that just have abstracts. It was suggested that papers be sent each month to members so that people would not have to go to the website to find them. Any comments on this suggestion would be welcome.
- One patient has had a difficult week and is increasingly short of breath; they currently require 8 litres of oxygen 24/7.
- One patient has an MRSA infection at present.
- One patient has felt well enough recently to teach Japanese flower arranging at a local primary school.
- The 10/10/10 fundraiser has raised a little over \$5,500. The organization is getting close to being able to announce funding of an ECD research project. This has only been possible due to a very generous donation. The challenge now is to find a way to continue being able to fund more research. Any thoughts and ideas would be very welcome. Several fund raising initiatives which are being planned by members, including a restaurant fundraiser, were discussed.
- One patient has recently received a good report from their ophthalmologist.
- One patient mentioned that they felt weaker as the days grew shorter and asked if other patients felt the same.
- One patient (who sees a homeopathic doctor as well as conventional medicine doctors) has recently started to take Low Dose Naltrexone. This is an off label use in a much lower dose than is prescribed normally, which has been used successfully to treat auto immune diseases like lupus and rheumatoid arthritis. At a regular dose it is also used to treat opioid addiction. This patient takes many supplements and botanicals recommended by the homeopathic doctor.
- The next chat will take place on Saturday 13<sup>th</sup> November at 3pm EST.