

Summary of ECD Global Alliance chat held on Saturday 13th June 2009

8 Present:

- A new member joined the chat for the first time and was welcomed to the group. They are currently searching for a local physician who is knowledgeable in ECD. The difficulty in finding an ECD knowledgeable doctor in your local area was discussed. One suggestion was to find a teaching hospital nearby and then call them for a referral within their physician base.
- An email has been received from the Histiocytosis Association of America (HAA) regarding the TV program, 'Mystery Diagnosis'. Program makers are looking for ECD patients and their families to submit their stories for possible use in a TV program. NORD had been contacted regarding this and had said that patients who had participated in the program in the past were pleased with the way TV staff had handled their stories. An email regarding this will be sent to members soon.
- There was a brief discussion on eye involvement with ECD. One patient has been blinded by tumors in the eye orbits. One member described a tumour behind one eye. Both these members reported that radiotherapy had not been effective in treating the tumours. One member had received steroid injections into the eye socket which had helped. Another member described a recent increase in eye sight problems.
- A question was raised about diabetes insipidus – three members on the chat suffered from this.