

Summary of ECD Global Alliance Internet Chat

6 October 2012

8 Attendees

- Before the Chat started Mark McElwee came on to remind us that Kit and Rich were going to be a bit busy this afternoon! Something to do with them “getting married” or some-such! And Mark, himself, would be missing as well, because he was going to the wedding. The Global Alliance sends its best wishes to them both.
- A member from Australia has been able to reap the benefits of the differing dates that Daylight Saving Time starts in different countries. It has already started in Australia, so it was only 0600!! This member is shortly to be ordained as a deacon, and has just spent 5 days at a Cistercian Abbey, on retreat. For some of our US members, winter is already setting in.
- The member, who has recently had surgery to relieve obstructions to his kidneys, now has both kidneys functioning. His doctor says that after a month or so, he should be back to normal!
- On a recent visit to Houston, a member was told that THEY are on the Cutting Edge of “genomic sequencing”. They will take the cells (DNA) and match it to ECD and try to find a better medication for the patient. At the NIH they are also taking DNA samples.
- Dr Haroche thinks that he might have found a genetic mutation in ECD*, and he telephoned a member a couple of weeks ago, to ask whether for some tissue samples could be sent to France. His work should allow treatments to be directed better, although they couldn't “fix” the mutation.
- A member, who has found it difficult to get to the Chats, told us some good news. There is no sign of the disease, and chemotherapy has been stopped for the last 18 months. 2CDA had been used. The lesions that had been seen in the brain have now gone. Blood counts are still low, but that has been a small price to pay.
- Some members had not realised that the NIH would be doing any follow up visits. They have said that they would like to see people again, a year after the first visit. This will, of course, depend on funding for the programme.
- Two members will be unable to Chat next week. They will both be experiencing the beautiful Fall colours.

*For more information about the BRAF mutation paper written by Dr. Haroche go to:
<http://www.ncbi.nlm.nih.gov/pubmed/22879539>

*Additional ECD associated medical journal articles can be found at: <http://www.erdheim-chester.org/TechnicalPapers.html>