

## Summary of ECD Goba Alliance Internet Chat

1 Dec 2012

### **9 Attendees**

- A new member came on but only listened.
- A member has had a couple of days at a hotel away from home, with his wife. The Christmas shopping is now, almost, complete. The member has a 3 monthly meeting with the hospital Doc who directs any treatment. The member is being driven, to the appointment, by his trumpet teacher!! The trumpets will NOT be being played in the hospital waiting room (although it would definitely result in the member being seen by the Doc much quicker!!).
- Another member has arranged to go to Maryland to participate in the NIH study in April, 2013. Members were pleased to hear that one of us will shortly be making a follow-up visit (all the way from Europe) to Maryland!
- Some members are about to start courses of cladribine (known as 2-CDA in the US). One member has already had a course of this treatment. It was given as injections under the skin (subcutaneous), for 5 consecutive days, followed by no treatment for 3 weeks. This went on for 6 months. The injections were not difficult to have, (no side-effects), but this treatment wasn't effective against the ECD. Now, this member is on methotrexate, and nothing else, for the ECD. This is "low-dose methotrexate". The dose is 40 (forty) milligrams, just once a week. Sixteen (16) little 2.5mg strength tablets for breakfast! The plan is that this treatment will be continued "until it stops working"!
- Another member had a 6 month course of Cladribine, one week per month, given by IV drip over about 2 hours. It shrunk the masses that had been found and the side effects were not too bad.
- A member has appeared on You-Tube telling us about his illness. He looks so young and handsome, that another member wondered whether a stunt double had been used! The "handsome man" can be found at:  
[http://www.youtube.com/watch?v=Zv5Rv-py2\\_s&feature=youtu.be](http://www.youtube.com/watch?v=Zv5Rv-py2_s&feature=youtu.be)
- A member is finding that his morphine treatment is helping a little with his leg pain. His scans show that the legs are being affected by the ECD. He will be given the cladribine as IV infusions, and as pills.
- Members then told us their experiences of having pericardial effusions (this is a fluid build-up, in the sac, that surrounds the heart), which is quite a common occurrence in ECD. One member had been diagnosed with one in 2009, and needed a pericardial window (this is where the surgeon cuts a hole in the pericardium, and this allows the fluid to drain away, and this takes the pressure off the heart, itself).

Another member had had a similar situation. They had gone to Mayo with a problem, had an echocardiogram, and were told to proceed immediately to the ER at Mayo Hospital! One hour later they were in the cardiac catheter lab, and had 1700 cc's drained from around the heart. A drain was put in to the pericardial sac, and 400-500 cc were drained every 4-6 hrs. The next week a pericardial window was made, and this worked very well. Initially, the doctors had suspected cancer, but all the tests for that were negative.

Another member had a similar story to share. Initially 1200 cc had been drained. But 2 days later, a further 1900 cc was drained, so a window was inserted.

- Two members on the Chat have developed diabetes.
- A member told us that their sister had had a lump removed, which had turned out to be breast cancer. Further treatment had been carried out and she is OK now. This member is being troubled by shooting pains that go up and down the arm. A visit to the doctor is planned in the next week.
- A member, whose daughter has ECD, asked whether members had any experience of chemotherapy. Her daughter has just been found to have 2 new masses in her chest, just under the sternum (the breast bone), and the interferon has been increased in dose to 80 units, three times a week. Chemotherapy is being considered as treatment. Members had experience of cladribine (intravenous and as subcutaneous injection), tamoxifen tablets, and methotrexate tablets.
- Two members spoke about limb weakness. One has recently had a bad bout of weakness in the legs. He is convinced that this is due to medication. Another member has weakness and pain in the legs and arms, which varies from day to day. The member finds that they need to sit with feet elevated for long periods of the day in order to be able to do other things in the rest of the day.
- A member told us that their doctors were saying that the ECD is a type of cancer. Other members were keen to say that this was definitely not the case. ECD is a histiocytic disease and has not been characterized as a cancer, auto-immune, storage disorder or any other classification.
- A member told us that they have bought a manufactured home in Tennessee so that they will be close to their son, and he will be able "to take care of us in our Old age". It will be nice to be nearby, but it has taken from his son's inheritance.