

## **Summary of ECD Global Alliance Internet Chat**

**13 Dec 2014**

7 Attendees

- One member told us that he has not been on the Chats because he could not get onto the internet. Another is having continuing problems with his 'puter'!
- A member told us that her son, who has ECD, is in Houston seeing Dr. Janku. His current treatment is Gleevec (a pill). He is having trouble with swallowing and choking. They hope that Dr. Janku can help. It was said that he should probably see a Speech Pathologist. These specialize in swallowing problems. His wife is so little that she cannot do the Heimlich maneuver on him (she can't get her arms around him). He even chokes on rice, although his mother thought that this would be something simple to eat. Rice is a difficult food because the small kernels get stuck in the throat. Swallowing is usually automatic, and we don't pay much attention to it. Rice, lettuce, nuts, popcorn, and anything dry, crumbly or stringy/fibrous will be difficult. Also anything with a husk/cover, i.e. corn. Nuts are a wonderful food...unless you have a swallowing issue! Some people can eat them, if they are very careful, and chew extra well. Plus, they need to have water nearby, and alternate sips of water with mouthfuls of food. The member's son has never been very good at chewing his food well, and that could be a big issue. Food needs to be "prepped" well in the mouth.  
His mother gave him some exercises that had been given to her mother-in-law, after her swallowing had been examined. It was suggested that he should also have this examination.
- One member's husband completed his therapy for bowel cancer a year ago and is now "cancer free". The member, herself, has just finished her 6<sup>th</sup> round of CHOP chemotherapy. She had to have this as she was diagnosed as having lymphoma as well as ECD! She will have a test on January 2 with Dr. Janku, an oncologist at MD Anderson in Houston.  
This member was on Anakinra and it took a couple of months before she saw a little improvement. She had a PET-CT, before starting the Lymphoma chemotherapy, and Dr. Janku was very excited about the improvement.
- Another member has problems mainly with her vision. She gets macular edema, and has to go on steroids, because nothing else is effective. She has been on Anakinra 3 months now and will have a PET in January. Hopefully, that will be long enough to notice improvement if there is any.  
She didn't have a lot of pain, just a little in her thighs and around her knee. The Anakinra seems to have helped with that. She would also get fevers and night sweats and these have also subsided.  
She was on Cladribine for 2 months, and then was switched to Clofarabine. This badly affected her immune system and "almost killed" her. Her immune system has not recovered, but the chemo stabilized her for several years. She was diagnosed as having Rosai-Dorfman disease back in 2012. It wasn't until this year (July) that a second biopsy favored ECD. She sees now sees Dr. Diamond at Sloan Kettering in New York.
- A member told us of an upcoming trip to Mayo for scans and to see the oncologist/hematologist. She has been having increased pain, and her platelet count has been somewhat low. She has been

relatively stable for several years, and actually is not on any treatment at the moment. She had 6 months of Cladiribine chemo in 2009-2010. She also had many homeopathic supplements and herbals, prescribed by a Dr. Zieve, a well-known homeopath.

At diagnosis the main worry was the disease around her heart. She had a very large pericardial effusion requiring surgery. She also had disease in her eye sockets, legs, chest, and around the kidneys.

She has needed a lot of sleep ever since she was diagnosed (10-11 hours per night). If she has to wake up early, "it pretty much ruins her day". This is one of the reasons that any kind of work would be so difficult. She also rests during the day.

It seems that the chemo did stop, and reverse, the disease. Along with the supplements which built up her immune system, corrected some imbalances, and reduced inflammation in her body. At first she used to get fluttering vision, especially in the peripheral fields. This has now subsided and there are no significant visual issues.

- Finally, our Norwegian member said hello. She was on a long weekend trip to Barcelona.