

## Summary of ECD Global Alliance chat held on Saturday 15<sup>th</sup> January 2011

8 Present

- Messages posted prior to the chat indicated that some ECD patients suffer from crumbling teeth and/or jawbone. Several patients feel the cold especially, and one patient suffers from cold fingers.
- One patient mentioned feeling tired all the time. They tend to sit and sleep a lot and when they do get up their legs feel weak. This patient is receiving interferon.
- One patient has made contact with another ECD patient who lives only five miles away! Several members on the chat said that they had never met another patient.
- A question was asked about whether ECD patients have a tendency to suffer from water retention. Two patients on the chat said that they have this problem.
- A new member was welcomed to the chat. Their spouse has ECD which was diagnosed five years ago. The patient has multiple organ involvement in their lungs, heart and kidneys.
- Members on the chat discussed the various treatments they were receiving/had received. Two patients have recently started treatment with kineret. This is a treatment used on label for severe rheumatoid arthritis and used off label for a few ECD patients in US, France and Canada. Both patients felt that the initial indications were positive. One patient (with multiple organ involvement) is taking interferon. One patient had a six week course of 2cDA which they thought was effective in stopping masses growing. One patient has received treatment with imuran and tamoxifen. This patient has ECD in the retroperitoneal area, renal arteries, long bones, both eyes and now (more recently) the brain stem. The patient is receiving high dose methotrexate intravenously for the lesion in the brain stem. Another patient takes a lower dose of methotrexate on a weekly basis.
- Several patients on the chat had a number of biopsies before they received a diagnosis. Several patients mentioned that getting a diagnosis had taken a long time.
- One caregiver mentioned that their spouse had so many specialists, it was difficult to know who to go to at times. One member mentioned that they had asked one consultant to take on a co-ordinating role, for another patient there was one consultant who was an obvious 'lead'.
- The next chat will be held on Saturday 22<sup>nd</sup> January at 3pm EST.