

## **Summary of ECD Global Alliance Internet Chat** **May 5, 2018**

2 Attendees

- A member who has recently had hand surgery said that the stitches had been removed, and she had had her brain MRI and her echocardiogram. She has been on Mekinist for two months now and the brain MRI will tell whether the treatment has worked.
- A member has recently been to Paris for a review. He has had his dose of Kineret doubled. He had satisfactory results for the stability of the disease, but he still has pain despite the treatment. The doctor proposed to double the dose for two months to see if the pain will disappear.

While he was there he met two other patients and they had talked a bit. One is in remission after 10 years. He has had Pegasys (interferon) and Remicade, with a lot of skin problems. In France, Remicade is used for polyarthritis. Many of this member's friends have skin problems. It is necessary to stay well hydrated. On his new dose of kineret he has to monitor his liver function and report if he has a fever.

- The members described themselves as all being a bit different. "Rats in America, rabbits in Germany and guinea pigs in France." Seeing how we all respond to treatment can give different results for everyone, but it is thanks to these experiences that we can move forward.