

Summary of ECD Global Alliance Internet Chat **April 7, 2018**

5 Attendees

- A US member said that those "up North" can keep the snow. She had woken up to snow on her spring flowers! The trees are budding out (despite the snow), so allergy season is starting. She has been on only Mekinist for five weeks now, and has a brain MRI in May. Her dabrafenib was stopped by Dr. Diamond. She still feels dizzy, but has got used to this feeling. She fell in the bathroom last week and sprained her ankle, so she has had to swallow her pride and use a cane! She said that Memorial Sloan Kettering's (MSK) specialty pharmacy overnights her medicine on ice.
- A US member's follow-up PET at the end of February had gone well.
- The French member is running out of drugs, and needs a trip to Paris to get more, but the railway workers are on strike. He usually makes the journey by the train and in less than two hours he is in Paris (500km!). He lives near Strasbourg on the German border, and the train runs at up to 300 km per hour.

When he goes to Paris he will see an endocrinologist because his testosterone is low. He also has a history of synovitis, but lately this has been better. During his last spa treatment he had a good physiotherapist who relieved his symptoms and his fingers have been better for the last five months. Unfortunately, he has been troubled with many migraines. He said that you can relieve your hands with essential oils of Wintergreen mixed in a massage oil.

- The member who works in a kindergarten was asked whether he had had more throat trouble. He had a strep throat infection in February. His throat is the first thing to get affected all of the time. "Maybe because I bite my nails." He has had a viral infection affecting his throat and has been battling laryngitis! This is definitely getting better. A member said that when her son was 10, he couldn't "shake the strep" until he had his tonsils removed.
- A member had found an online article by Dr. Diamond et al about patients on dabrafenib. There were 12 subjects in the article and one of them was also on this chat! This member is now on a dose of two dabrafenib a day (one in the morning and one in the evening), and goes back to MSK at the end of August to have a PETMR. (He said that this was new technology with no radiation.)
- One of the US members said that her husband's family came from Mecklenburg County, Germany in 1890, and they settled in Iowa. Her husband grew up in Chicago and she grew up in Houston, Texas. Her husband's family were Lutheran pastors and farmers.
- Finally a new chatter came on and told us that her disease was stable, but she is having fatigue and muscle pain. She wonders whether other "stable" patients have had this experience.