

## **Summary of ECD Global Alliance Internet Chat February 3, 2018**

3 Attendees

- One patient had recently had a PET scan and a cardiac echo. They are due to see Dr. Diamond in NYC in February.
- There was a brief discussion regarding blood glucose levels. One comment was that dabrafenib can affect these.
- One member on the chat suffers from dizziness.
- Two patients sometimes have their scans done at facilities closer to home, and then the results are sent to their consultant. However, one patient noted that if they need to see the consultant anyway, it is sometimes easier to have everything done in the same place.