10 September 2021

Dear global HD patient community,

As part of our ongoing partnership and following your request to receive important and timely updates about the Roche/Genentech HD clinical programme, we wanted to share an update.

Today we presented our plans for data analysis of the Phase III GENERATION HD1 study at the European Huntington’s Disease Network (EHDN) congress. This presentation outlined our current progress, what work still needs to be done and our plans for sharing further data.

Whilst we are making good progress, several steps are required before we will be able to share the clinical trial findings with the community. These steps include combining all the available data in the programme together, reviewing all of the data and interpreting it in collaboration with experts in the field. These efforts will include a thorough analysis of the data to understand what factors could affect how people respond to treatment (for example; disease stage or other patient differences, or length/amount of treatment). These analyses will also help us better understand the mechanism behind HD.

The study programme continues to collect a huge amount of data that will help further the whole HD field. These to date include ~2000 statistical outputs with data from >40,000 samples, and we have dedicated people working through those steps as fast as possible.

**When will Roche share further GENERATION HD1 data?**

We are committed to data sharing so that understanding about the use of tominersen and broader HD treatment research can advance. We also believe it is important to share complete data that has been properly analysed and interpreted.

We understand the urgency to provide answers to the open scientific questions and hypotheses, and we will keep the community updated on next steps for the programme and data sharing.

**Thank you to all participants, their families and the whole HD community**

We continue to be thankful to the entire HD community for their ongoing collaboration, support, and commitment, especially all study participants, their families, trial investigators and site staff, as well as the steering committee. This includes the ~85% of participants who have decided to continue the study until completion, who will help the community to advance our understanding of HTT lowering as a potential treatment approach for HD. Your ongoing contribution to the tominersen programme is invaluable.

Sincerely,

David West
Senior Director, Global Patient Partnership,
Rare Diseases

Mai-Lise Nguyen
Senior Group Director, Global Patient Partnership, Rare Diseases