Informed Consent Form

Checking the boxes below and adding your signature means:

a) you have been given background material and the opportunity to ask any questions
b) you understand the content of the informed consent
c) you have had the time to consider fully whether you want to join the registry
d) you agree to participate in the registry.

1. I understand that my participation in the registry is voluntary and that I can change my mind and withdraw at any time. Yes ☐

2. I understand that every effort will be made to protect my privacy and my family's privacy. I understand that my personal information will be protected and saved in the registry using a code. However, there is a very small risk that my identity could be revealed.

   Yes ☐

3. I am willing to provide my de-identified medical information to be used for clinical trials and other medical studies related to my disease. Yes ☐

4. I understand that my de-identified information can be used for any approved research study including diseases that are not associated with my disease. Yes ☐

5. I understand that my de-identified information may be shared with other databases for A-T and other related and rare conditions. Yes ☐

6. I understand that I may not personally benefit from participating in the registry or from the use of my de-identified medical information in any research study. Yes ☐

7. I understand that I can withdraw from the registry at any time and remove my information. I also understand that any information given previously and already assigned to a specific study cannot be removed. Yes ☐

8. If any information is obtained through the patient's participation in this registry that has implications for the patient's health, would you like the Registry to tell you so that you can get that information? Yes ☐ No ☐

9. I would like to be contacted regarding any future clinical trials or other studies that I may be able to participate in. Yes ☐ No ☐

10. I understand the content of this form and all my questions were answered. I had enough time to decide that I want to participate in this registry. I was given a copy of the information sheet about the registry. Yes ☐

Name of patient ..... Age if under 16.....

Signature ..... Date .....

Parent or guardian, if patient is under 16 or signature is otherwise required

Name .....

Signature ..... Date .....