DO YOU HAVE A TITIN VARIANT OF UNKNOWN SIGNIFICANCE (VUS)?

Clinical Titin Diagnosis Clarification by experts

If you have genetic test results that shows a variant of unknown significance along with either heart or muscle weakness symptoms the team at Folkhälsan Research Center at the University of Helsinki is interested in helping clarify your possible titin diagnosis.

To participate please FIRST gather the following information:

1. **A copy of your genetic test report**
2. **Copies of any muscle imaging studies including**
    a. **muscle MRI**
    b. **muscle ultrasoud**
    c. **please track down the report and may likely want electronic copies of the actual images**
3. **If you had a muscle biopsy - get a copy of your report**
4. **Family tree - also known as a pedigree if you have one outlining the health of family members. If not, the team will create one.**
5. **Answers to these clinical questions:**
    a. **Current age**
    b. **Age of onset of symptoms**
    c. **Current clinical symptoms**
    d. **Bloodwork of creatine kinase levels (CK)**

Once you have gathered these items, please send an introductory email without records to Dr. Bjarne Udd at bjarne.udd@netikka.fi