

CMRR ataxia research team

Who are the team members? Pierre-Gilles Henry (PI), Christophe Lenglet (PI), Dinesh Deelchand, James Joers, Isaac Adenyeguh, Diane Hutter, Katie Gundry, Shannon Smith

How long have you / the others been working on FA? Since 2013

Who was the first fellow FA researcher you met? David Lynch, Massimo Pandolfo, Robert Wilson, Alexandra Durr, Sub Subramony.

What got you interested in FA research? The University of Minnesota has a long history of research and clinical care for ataxias, with the Bob Allison Ataxia Research Center and the Ataxia Center (Dr. Bushara). Research has been done in the fields of genetics and neuroimaging by our colleagues Drs. Orr and Öz, mostly in spinocerebellar ataxias, and former colleague Dr. Iltis who worked on Friedreich ataxia and oculomotor apraxia type 2 and with whom we received our very first FARA grant (the Kyle Bryant Translational Research Award)!

What got you interested in imaging in FA? A particularity of FA is involvement of the spinal cord. Looking at the cord with MRI is technically difficult and few imaging studies had been done, so we wanted to see if more could be done and learned! Also, most studies at the time we started showed that the brain "looks" largely spared in FA. However, thanks to funding from FARA, Ataxia UK, GoFAR, the CureFA foundation and BAARC, we (and others) have now shown that changes do happen over time, albeit small, in various brain areas. We are especially interested in and motivated by our neuroimaging research in FA, as we hope it will help discover sensitive biomarkers for clinical trials.

What do you hope to achieve with TRACK-FA? Our goal is to acquire the largest set of imaging data in FA to date. This will allow us to establish a "benchmark" of disease progression to assess the effect of potential treatments in upcoming clinical trials.

Tell us more about yourself and/ or your journey with FA research may be... We have a strong interest in both imaging and in neurodegenerative diseases. We are proud and excited to have worked with FARA for many years, and now with many new international partners, to discover and validate imaging biomarkers. We are particularly excited to do this crucial work now, as new options for therapies and clinical trials are on the horizon!

How would you like to encourage FA patients to participate at your site? TRACK-FA is really important for "clinical trial readiness". Pharmaceutical companies will use the data collected in TRACK-FA to design their clinical trials. We know that it represents a significant amount of time and effort for participants, especially those who are traveling from far away. We encourage you to participate and we would love to see you in Minnesota!

How would a TRACK-FA visit look like at your site? Before the visit, our research nurse coordinator Diane Hutter will talk with you about the study, make sure you are eligible, and arrange travel.

Participants travel to CMRR at the University of Minnesota for the study and are welcomed by Diane. They undergo a number of tests (clinical, cognitive and mood questionnaires), some of which they are probably already familiar with (like FARS). This is followed by a blood draw and an MRI exam. The entire visit takes about 4 hours (less for young children 10 and under).

Participants would return 1 year and 2 years after the first visit for follow-ups.