ISSUE 4
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TRACK-FA NEWSLETTER

AT A GLANCE

Now that baseline recruitment has ended, we are analysing the data – stay tuned for the results in 2024!

Across all study sites, 279 participants completed study visits, including 182 participants with Friedreich's ataxia and 97 matched healthy controls. TRACK-FA participants ranged from 6 to 42 years of age.

Follow-up study visits continue

We are now inviting TRACK-FA participants for their 2nd (12-month) and 3rd (24-month) study visits (Figure 1).

As of November 2023:

- **150** participants have completed study Visit 2, which is over 50% of all TRACK-FA participants!
- **49** participants have completed study Visit 3

We are on track to complete all data collection before the end of 2025.

TRACK-FA achievements

We're so proud of the number of participants who have taken part in this study, and we couldn't do it without you!

The TRACK-FA study is unique because:

- It is the first study to encompass both **children and adults** across disease stages and onsets within a longitudinal cohort.
- We successfully recruited the **largest-ever cohort** of participants with FA – and matched controls – in a multi-modal neuroimaging study on a global scale.
- TRACK-FA dataset uniquely includes **very young participants with FA**, with 10% aged 10 years or younger.
- TRACK-FA will therefore contribute to:
  - better understanding FA progression in young children
  - development of therapies tailored to young children

Thank you to everyone who continues to participate in TRACK-FA!

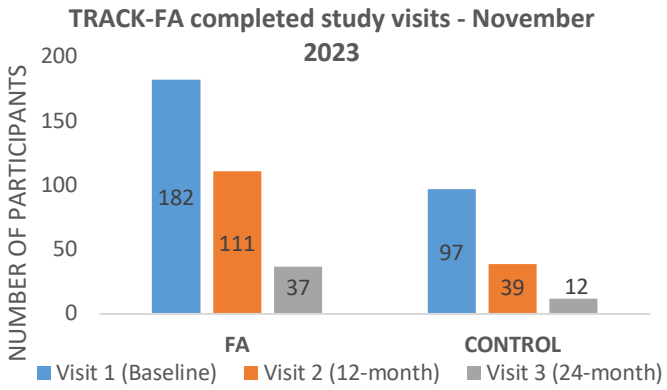


Figure 1. TRACK-FA study visits completed as of November 2023.

A QUICK NOTE ON PERMANENT BRACELETS

These look and feel great, however, they can't go in the MRI scanner! If you are thinking of getting one, please wait until after you have finished participating in TRACK-FA. If you have any questions, please reach out to your local TRACK-FA study team.

Photo from S-kin Studio

The TRACK-FA research team would like to wish you a safe and prosperous holiday season

MEET OUR TRACK-FA TEAM MEMBERS

In the next few TRACK-FA Newsletters, we'll introduce you to some of our team members around the world!

TRACK-FA Research Fellow Dr Susmita Saha (Monash University [Melbourne, Australia])

Role in TRACK-FA: Responsible for neuroimaging analysis

What have you learned from being part of TRACK-FA? Managing a global study like TRACK-FA poses challenges in maintaining data integrity and accuracy. However, the implementation of rigorous quality control processes has proven highly beneficial in this study. Researchers involved in TRACK-FA are dedicated to ensuring reliable datasets, constantly striving to improve standard operating procedures. Collaboration between image processing and statistical sub-groups is a crucial aspect of the study. The Steering Committee is consistently adjusting high-level operational and publication guidelines in response to evolving requirements. Furthermore, the support provided by the Friedreich's Ataxia Research Alliance (FARA) for secondary innovative projects using the TRACK-FA data is commendable. Finally, I've gained valuable insights into the resilience and positivity displayed by individuals dealing with this debilitating disease. Overall, this newfound knowledge and inspiration have fueled my determination to contribute to rare disease research, including Friedreich Ataxia, to the best of my ability.

How long have you been involved in FA research? One and a half years. However, my broader expertise spans over eight years in the fields of neuroimaging and AI-based research.

What are your favorite pastimes? Watching documentaries and talks, music and walking

TRACK-FA Scientist Dr Ian Harding (Monash University [Melbourne, Australia])

Role in TRACK-FA I am a scientist in the Melbourne team, and one of the founding members of the TRACK-FA project. My team focuses particularly on the changes that occur in the cerebellum in people with FRDA, including degeneration and altered iron levels in the dentate nucleus and cerebellar pathways. I work on TRACK-FA with a wonderful collaborative team here in Melbourne, including Dr Susmita Saha and Professor Nellie Georgiou-Karistianis, and have the pleasure of regularly nerding-out with the incredible group of scientists from around the world that this project has brought together.

Highlights of TRACK-FA Study so far Designing the study was thrilling from a scientific perspective. This involved many of the top FA brain imaging scientists from 4 different continents, together with FARA and experts from industry and drug companies, coming together to contemplate where we needed to go next as a scientific community. We started with a truly blank slate - nothing was considered impossible - and together we built TRACK-FA to be a transformative opportunity to take a giant leap forward in our core knowledge about FA and how we can improve the design of the next generation of clinical trials. The implementation stage has been equally inspiring. The effort, dedication, can-do attitude, and expertise of everyone involved - from the scientists and doctors, to site coordinators, imaging technicians, and support staff, and of course all the research participants - is phenomenal to see and be part of.

What have you learned from being part of TRACK-FA? TRACK-FA has further validated to me how unique the FA research community really is. There is a true spirit of cooperation - with little ego, competition, or vested interest getting in the way. This is truly a model of how all scientific endeavors should be undertaken. On a more personal level, it has also become clear that I will never be a morning person! In order to get everyone from Australia, North and South America, and Europe onto the same Zoom call, the meeting times here in Australia are often in the early morning. And as my colleagues know all too well, I am often still busy checking for holes in my eyelids at that time!

How did you get involved in FA research? I started as an FA researcher after completing my PhD in 2013, working as a post-doctoral fellow with Nellie Georgiou-Karistianis. Right away I noticed something very different about the FA research community - I wasn't just another junior postdoc working away as a cog in a machine, but I was welcomed, encouraged, and supported by even the most senior people in the field. This feeling of community was strengthened even further as I began to meet and interact with FA patients, and to work with FA research colleagues from around the world. I am now greatly privileged to have my own lab, and consider it a tremendous responsibility to ensure that my students and junior colleagues also experience this connection.

TRACK-FA Co-Principal Investigator Dr Thiago Rezende (University of Campinas [Brazil])

Highlights of TRACK-FA Study so far The most outstanding contribution of the TRACK-FA consortium is the high-quality data generated, which will be used for many years and will provide valuable information to design new clinical trials. In addition, such data might be useful to create new imaging methods to investigate other diseases. Lastly, the team is very hard working and always seeks to deliver the best scientific practices.

What have you learned from being part of TRACK-FA? Multi-site collaborative studies like TRACK-FA put together a unique group of international experts. Being part of such a group is very exciting and I have learned many technical aspects of multicentric studies. Furthermore, the importance of such studies to identify reliable and sensitive imaging biomarkers for future clinical trials and, in concomitance, uncover relevant insights about the natural history is remarkable. Lastly, it is important to acknowledge the small in-house studies. The knowledge obtained from them enabled us to think in creating such initiative.

What have you learned from TRACK-FA participants? The engagement of the patients in all sites is marvelous and keeps me inspired and motivated to deliver better results.

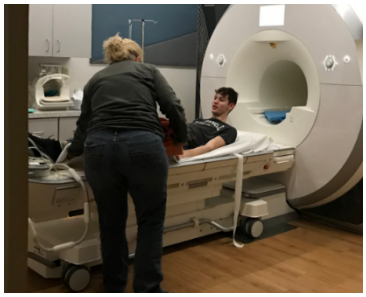
How did you get involved in FA research? I started getting involved in FA research during my PhD in 2014 under supervision of Dr. Marcondes França at University of Campinas, Brazil. The lack of knowledge about physiopathology and the challenge of characterizing the pattern of degeneration of the central nervous system motivated me to pursue this area. Since then, our group has been very active and we investigated the pattern of cerebral damage in pediatric FA patients using a multi-modal neuroimaging approach. In this study, we found results that challenge the concept that FA is a pure degenerative disease. A recent study published and cover of Movement Disorders (journal) led by me inside Enigma Ataxia supports such a concept. Indeed, the findings support the hypothesis that damage to the dorsal column and corticospinal tract follow distinct courses in FA: developmental abnormalities likely define the former, whereas the later may be both developmental and degenerative. In addition, progressive neurodegeneration in the corticospinal tract was consistent with the hypothesis that pyramidal tract damage in FA arises from a ‘dying back’ process. Recently, I have been awarded two FARA grants. The first aims to understand the cardiac burden in FA. The second aims to improve and expand the cerebellar segmentation and analysis using artificial intelligence algorithms.

Tell us about yourself - what's your favourite book/movie/hobbies? I am a proud husband and father of two beautiful boys, Gabriel 3 years-old and Davi 1 year-old. I am affectionate in movies and series, especially those related to medieval histories. In this sense, my favorite movie is the trilogy The Lord of the Rings, which unsurprisingly, is my favorite book. I also love to travel with my family and spend time with my mom and grandma at Três Corações (my and Pelé’s hometown 😊). My hobbies are mount LEGO collections, dance forró (a traditional Brazilian dance) and hiking.

TRACK-FA

If you would like your photo in the next newsletter, please reach out to your local study team!

SOME OF OUR TRACK-FA PARTICIPANTS



control participants

A quote from a TRACK-FA participant: *"I decided to participate in TRACK-FA right when I found it was available at a Canadian site. I love being able to do things to help the Ataxia community, and participating in research is a huge help and so rewarding. TRACK-FA being non-interventional, being in my home country, and requiring only 3 annual visits made the decision to get involved pretty simple for me!"*

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