



# TRACK-FA NEWSLETTER

**TRACK-FA** is a longitudinal natural history study that tracks brain and spinal cord changes in individuals with Friedreich's ataxia (FA). We have a team of researchers from Australia, USA, Germany, Brazil and Canada in collaboration with global industry partners. We are testing the sensitivity of neuroimaging biomarkers to provide a basis to include them in future clinical trials.

## WHY BIOMARKERS?

Measuring the impact of treatments for Friedreich's ataxia is challenging. Biomarkers can help us understand if treatments are targeting the right tissue in the brain and spinal cord more quickly.

This will be important for next generation gene therapies that aim to target a specific region of the brain and/or spinal cord in order to slow down progression of disease.

## AT A GLANCE

### Baseline recruitment update

As of November 2022, 165 individuals have been enrolled globally, including 122 Friedreich's ataxia participants and 43 healthy matched controls, whose ages range from 6 years to 42 years old (Figure 1).

This means that we have now reached over half of our overall recruitment target - but we are still in need of many more in order to achieve our goal.

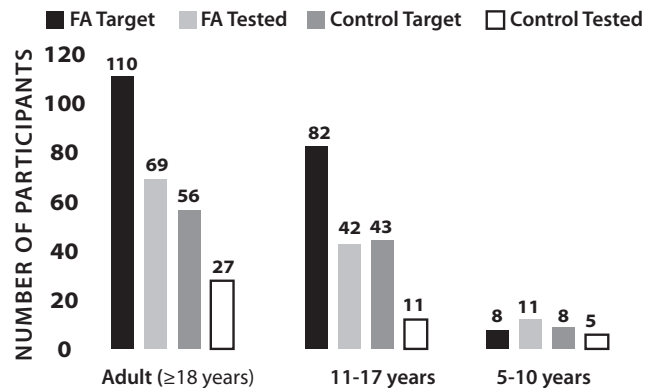


Figure 1. Recruitment summary (NOV 2022) by participant group and age

## Follow-up study visits are underway

As of November 2022, around 55 participants have returned to complete their second TRACK-FA study visit (see Figure 2). The longitudinal design is a key feature of the TRACK-FA study. By following individuals over two years, and across three study visits, we will be able to discover sensitive neuroimaging biomarkers of disease progression of FA. Our earliest participants will start their third and final study visit for TRACK-FA in February 2023

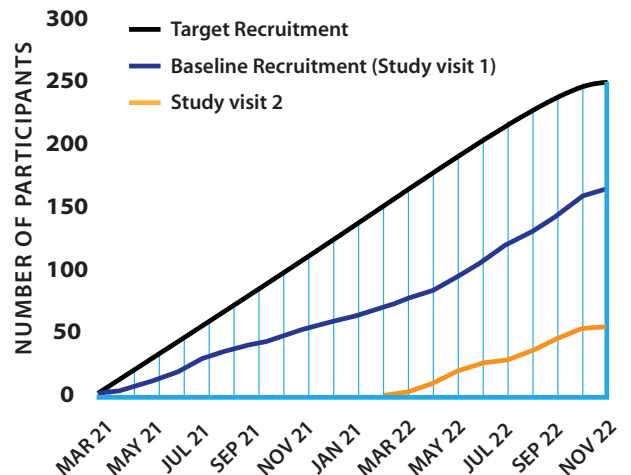


Figure 2. Cumulative study-wide recruitment (NOV 2022) for FA and control participants combined for study visit 1 and 2

## Statistics Summary

Across study visits 1 and 2, our participants have so far contributed to over:

- + 815 clinical tests
- + 220 blood samples
- + 220 MRI sessions
- + 565 cognitive and mood assessments
- + 220 speech assessments

We thank everyone who continues to participate in TRACK-FA and contributes to the growing database to build our knowledge!

## TRACK-FA Scientific Publication

We're delighted to announce that we have published our first TRACK-FA scientific article! Our article presents the background on the TRACK-FA study and the scientific procedures (see below). You can read our article for free online here:

<https://pubmed.ncbi.nlm.nih.gov/36410013/>

### *A natural history study to track brain and spinal cord changes in individuals with Friedreich's ataxia: TRACK-FA study protocol*

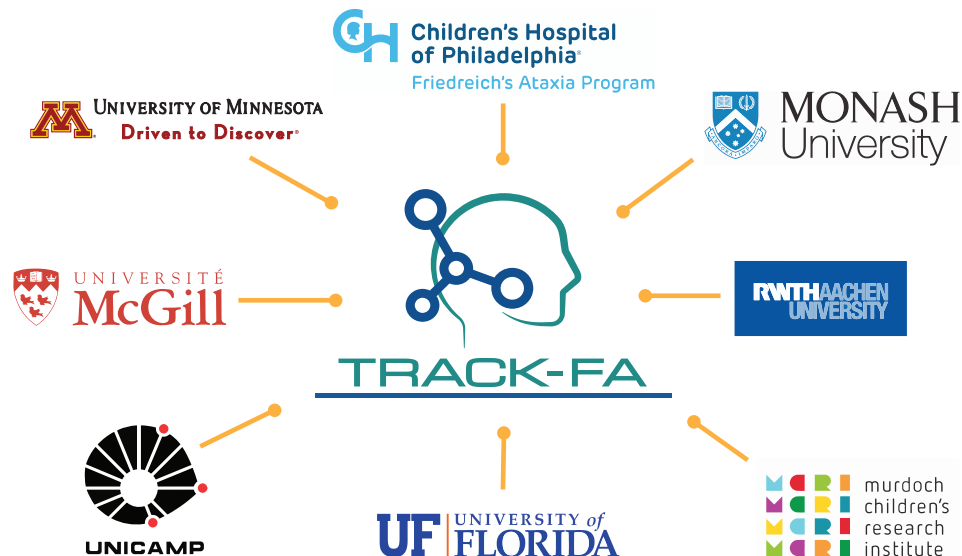
Nellie Georgiou-Karistianis, Louise A Corben, Kathrin Reetz, Isaac M Adanyeguh, Manuela Corti, Dinesh K Deelchand, Martin B Delatycki, Imis Dogan, Rebecca Evans, Jennifer Farmer, Marcondes C França, William Gaetz, Ian H Harding, Karen S Harris, Steven Hersch, Richard Joules, James J Joers, Michelle L Krishnan, Michelle Lax, Eric F Lock, David Lynch, Thomas Mareci, Sahan Muthuhetti Gamage, Massimo Pandolfo, Marina Papoutsi, Thiago JR Rezende, Timothy PL Roberts, Jens T Rosenberg, Sandro Romazetti, Jörg B Schulz, Traci Schilling, Adam J Schwarz, Sub Subramony, Bert Yao, Stephen Zicha, Christophe Lenglet, Pierre-Gilles Henry

## CAMPINAS Commences TRACK-FA

In September 2022, the TRACK-FA site in Campinas, Brazil tested its first participant. We are thrilled to have Campinas on board. This important achievement will help boost TRACK-FA recruitment even further, and will provide an opportunity for individuals in Brazil to participate.



TRACK-FA team at Campinas, Brazil.  
Left to Right: Alberto Martinez, Cynthia Silveira, Rachel Guimarães, Marcondes Franca, Fernanda Bittar, Juliana Ferreira and Thiago Rezende.



### OUR PARTNERS

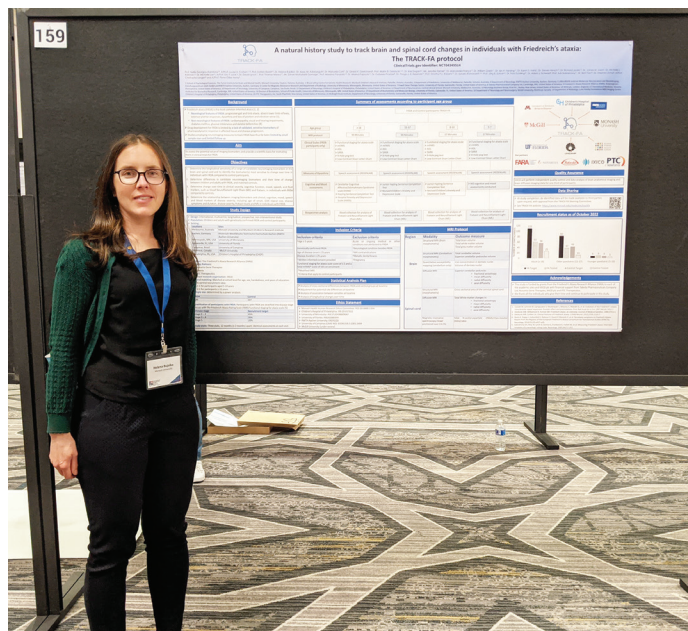


## UPDATE from Dallas, Texas

The TRACK-FA Neuroimaging Consortium meets via videoconference every month, but in November 2022, we held our first in-person/online hybrid meeting in Dallas, Texas.

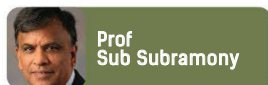
It was a fantastic opportunity for many of our site principal investigators (pictured below), researchers and assistants from around the world to get together in person, celebrate our achievements, and plan for the next phase of TRACK-FA!

We also attended the inaugural International Congress for Ataxia Research (ICAR), where we showcased the TRACK-FA study to a global audience through a talk and a poster presentation by Dr. Helena Bujalka.



Dr Helena Bujalka (TRACK-FA Project Coordinator, Melbourne, Australia) at ICAR. Helena presented a poster at ICAR outlining the TRACK-FA study

## TRACK-FA PRINCIPAL INVESTIGATORS



## Enrollment is still open for TRACK-FA ... but not for long!

### Inclusion criteria (partial) FA participants:

- Genetically confirmed FA
- Age of onset < 25 years
- Disease duration < 25 years
- Disease stage: primarily ambulatory (with and without assistance)

### Inclusion criteria control participants:

- Age > 5 years
- Able to provide written informed consent

### Exclusion criteria (partial) FA & control:

- Pacemaker, other metallic surgical implants, metallic braces
- Pregnancy
- Other ongoing medical conditions, including psychiatric and neurological diagnosis (speak with the site investigator)

We are recruiting control participants that match FA participants for sex, age, years of education and handedness. If you know someone that matches you (FA), and is interested in participating as a control, please ask them to contact one of the researchers from your site.

For more information, you can visit the TRACK-FA website:

<https://www.monash.edu/medicine/trackfa>

If you would like to participate, and think you may meet the eligibility criteria, please get in touch with your closest site (as noted on the right).

To those already enrolled, thank you for your ongoing participation in this very important study.

We look forward to seeing you again at your next visit!

## CONTACT

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