

## TRACK-FA NEWSLETTER

Issue 01 – July 2022

### TRACK-FA

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 test the potential value of neuroimaging biomarkers and provide a basis to include them in future clinical trials.

### At a glance

#### What have we achieved so far?

107 individuals have participated globally ranging from 6 to 42 years old, including 78 Friedreich's ataxia participants and 29 control participants.

#### Testing Statistics:

- ✓ 390 clinical tests completed
- ✓ 107 blood samples collected
- ✓ 107 MRI sessions completed
- ✓ 276 cognitive and mood assessments completed
- ✓ 107 speech assessments completed

We have many more interested participants who are awaiting their appointments. We are aiming to reach our target recruitment by the end of May 2023.

### Why biomarkers?

Measuring the impact of treatments for Friedreich's ataxia is challenging. Biomarkers can help us understand if treatments are targeting the right tissues 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.

### What is next for this global study?

TRACK-FA is continuing to recruit new participants for baseline visits across a broad demographic. Our earliest participants started follow-up visits in February 2022.

Our first set of imaging data has been processed and measurements compared across sites and study groups.

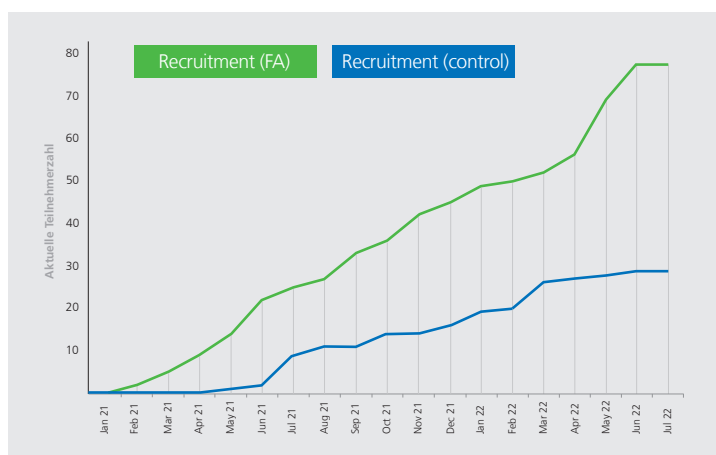
When all baseline visits are complete, we will start to look for relationships between these measurements and factors such as disease severity, age of onset and genetics.

### Participant recruitment by site as of July 2022\*

Study site	Recruitments as of 1 July 2022*	Target recruitment
Melbourne	13	47
Aachen	19	41
Minnesota	15	47
Florida	21	36
Campinas	0	69
CHOP	39	67
Montréal	0	23

\*Does not include future bookings.

### Recruitment statistics as of July, 2022



## COVID-19 impact

Recruitment has unfortunately been significantly affected by the COVID -19 global pandemic. We aim to push through this adversity and are ensuring that all sites comply with all COVID-19 related guidelines as we continue recruitment and testing.



## We are currently recruiting

Enrollment for TRACK-FA is currently open.

### Inclusion criteria (partial) FA participants:

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

### Inclusion criteria control participants:

- ☒ Age  $\geq$  5 years
- ☒ Able to provide written informed consent

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

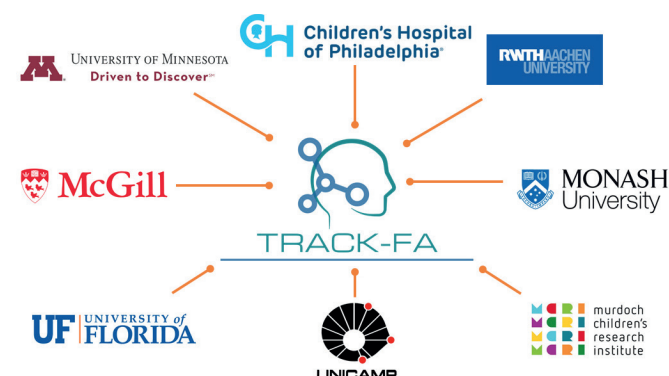
- ☒ Pacemaker, other metallic surgical implants, metallic braces
- ☒ Pregnancy
- ☒ Other ongoing medical conditions, including psychiatric and neurological diagnoses (speak with the site investigator)

We are recruiting control participants that match for sex, age, years of education and handedness. If you know someone that matches yourself, 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 using the link below.

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

We thank you for your ongoing participation in this very important study and look forward to seeing you again at your next visit.



## Contact

If you would like to participate and think that you may meet the eligibility criteria, please get in touch with your closest site from the list below.

### Melbourne , Australia

Monash University, Melbourne, Australia

Study contact: Louise Corben

E-Mail: [louise.corben@mcri.edu.au](mailto:louise.corben@mcri.edu.au)

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### Florida , USA

University of Florida, Gainesville, USA

Study contact: Samantha Norman

E-Mail: [Samantha.Norman@peds.ufl.edu](mailto:Samantha.Norman@peds.ufl.edu)

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### Minnesota, USA

University of Minnesota, Minneapolis, USA

Study contact: Diane Hutter

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Phone: (612) 625-2350

### Philadelphia, USA

Children's Hospital of Philadelphia, Philadelphia, USA

Study contact: Leah Gaetz

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Phone: (267) 275-6352

### Campinas, Brasilien

University of Campinas, Campinas, Brazil

Study contact: Fernanda Bittar, PhD

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### Aachen, Deutschland

Uniklinik RWTH Aachen, Deutschland

Study contact: Ankica Grgic

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### Montréal, Canada

McGill University, Montréal, Canada

Study contact: Martin Chevrier

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## Our partners:

