

TRACK-FA NEWSLETTER

ISSUE 6 – DECEMBER

2024



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

In this study, we collect data from participants with FA and control participants at three timepoints: baseline, 12 months and 24 months. We gather a variety of information, including brain and spinal cord scans, as well as clinical, cognitive, speech, mood, and blood biomarker measures.

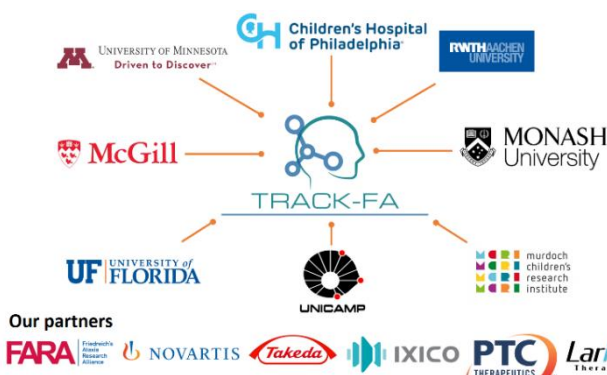
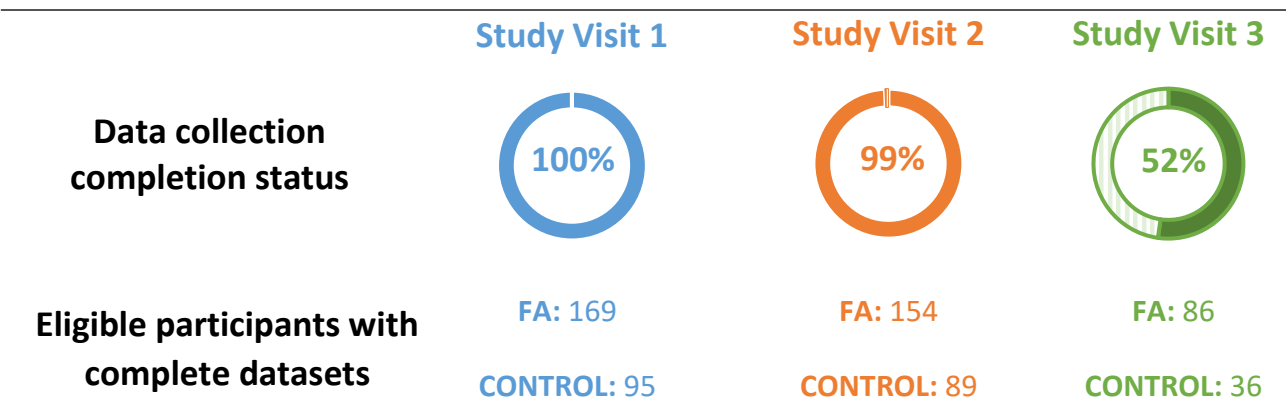
AT A GLANCE

Study visit 2 (12-month follow-up)

In December 2024, data collection is 99% complete for 12-month follow-up assessments. We're excited to commence analysing this data when the final participants have been tested in early 2025.

Study visit 3 (24-month follow-up)

Data collection is more than 50% complete for 24-month follow-up assessments. We anticipate that data collection will be complete for this timepoint in late 2025.



A WARM THANK YOU TO TRACK-FA PARTICIPANTS!

We extend our deepest gratitude to all participants for the time they have dedicated to this important study.

We wish you a safe and prosperous holiday season.

TRACK-FA CONSORTIUM IN-PERSON MEETING, LONDON 2024

The TRACK-FA Consortium usually meets online every month, but in November 2024 we had a special in-person meeting in London in conjunction with the ICAR conference (details on next page). Our extended meeting was a rare and exciting opportunity for us to come together from across the world and plan for the next phase of the study. With our data collection almost complete for the second timepoint (12-month follow-up), we're excited to conduct the longitudinal analysis to identify biomarkers of disease progression.



Figure 1. **Top left:** some members of the TRACK-FA Neuroimaging Consortium after our meeting. **Top right:** TRACK-FA Principal Coordinating Investigator Professor Nellie Georgiou-Karistianis (Monash University) leading a discussion with the Consortium about the next steps for the TRACK-FA study. **Bottom left:** TRACK-FA Neuroimaging Principal Investigator Professor Pierre-Gilles Henry (University of Minnesota) presenting preliminary longitudinal results to the Consortium. **Bottom right:** Principal Coordinating Investigator Professor Nellie Georgiou-Karistianis (Monash University) and Jennifer Farmer (CEO, Friedrich's Ataxia Research Alliance) opening the TRACK-FA Consortium meeting.

TRACK-FA ON DISPLAY AT THE INTERNATIONAL CONGRESS FOR ATAXIA CONGRESS (ICAR) 2024

In November 2024, many researchers from the TRACK-FA Consortium attended the ICAR conference in London (<https://ataxiacongress.org/>). At this event, we showcased the TRACK-FA study through various presentations, including posters and talks. This was an excellent opportunity to share the TRACK-FA study with leading ataxia researchers from around the world, together with industry representatives and advocacy organizations.

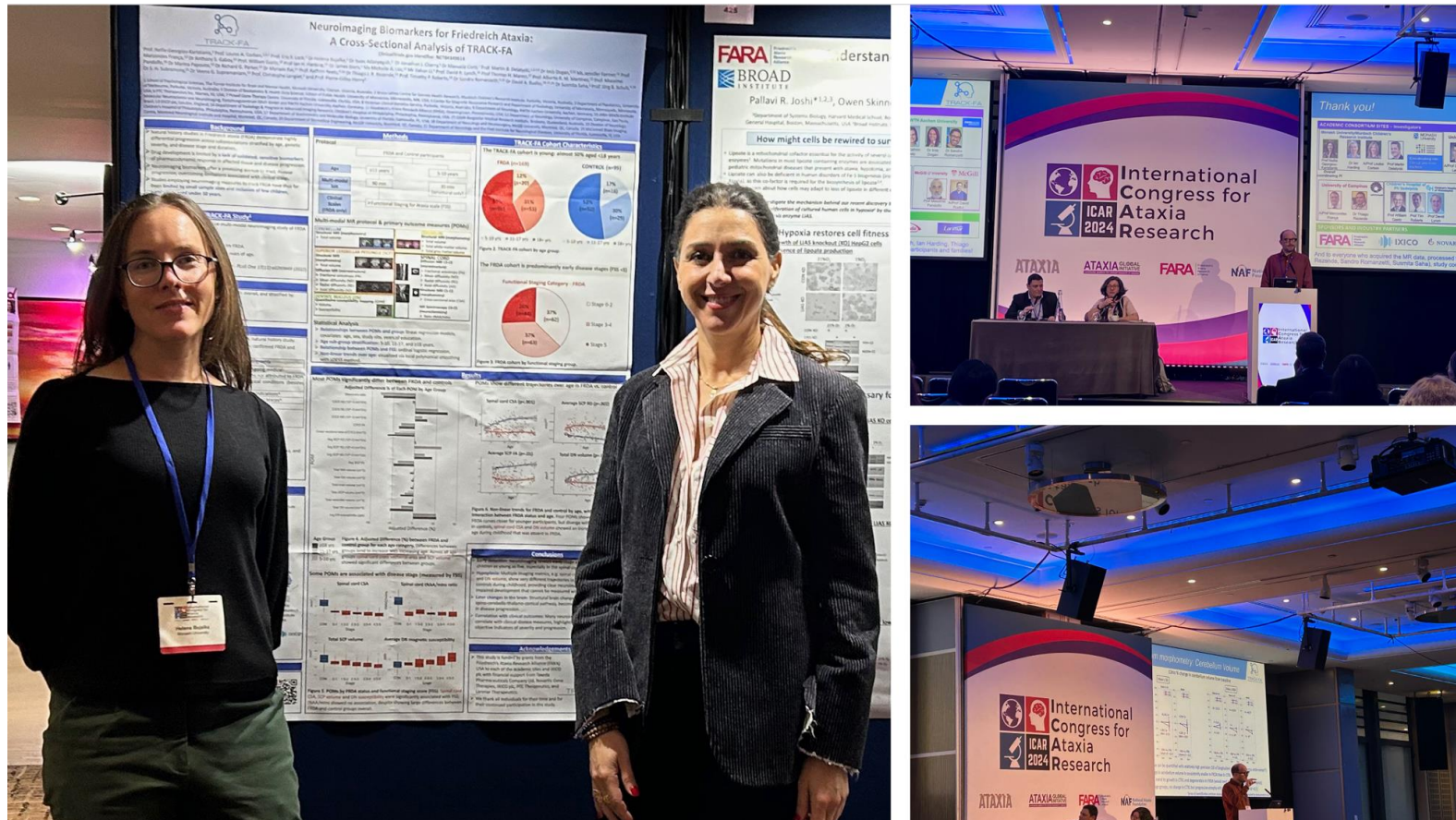


Figure 2 Presenting the TRACK-FA study at ICAR 2024. **Left:** TRACK-FA poster summarising the TRACK-FA cohort at baseline, presented by TRACK-FA Principal Coordinating Investigator Professor Nellie Georgiou-Karistianis (Monash University) (right) and Study Coordinator Dr Helena Bujalka (left). **Right (top and bottom):** TRACK-FA Neuroimaging Principal Investigator Professor Pierre-Gilles Henry (University of Minnesota) presenting preliminary results from longitudinal analysis of TRACK-FA data.

CONTACT YOUR LOCAL TRACK-FA SITE

<p>Melbourne, Victoria, Australia Monash University, Melbourne, AUS Study contact: Louise Corben E: louise.corben@mcri.edu.au T: +61 (3) 8341 6228</p>  	<p>Campinas, Brazil University of Campinas, Campinas, Brazil Study contact: Cynthia Silveira E: silveiracynthia89@gmail.com</p> 
<p>Gainesville, Florida, USA University of Florida, Gainesville, USA Study contact: Mackenzi Coker E: mcoker@peds.ufl.edu T: (352) 294-8754</p>  <p>Powell Center for Rare Disease Research and Therapy <small>DEPARTMENT of PEDIATRICS in the COLLEGE of MEDICINE</small></p>	<p>Aachen, Germany University Hospital RWTH Aachen, Aachen, Germany Study contact: Imis Dogan E: idogan@ukaachen.de T: +49-241-80 80719</p> 
<p>Minneapolis, Minnesota, USA University of Minnesota, Minneapolis, USA Study contact: Diane Hutter E: hutte019@umn.edu T: (612) 625-2350</p>  <p>UNIVERSITY OF MINNESOTA Driven to Discover™</p>	<p>Montreal, Canada McGill University, Montreal, Canada Study contact: Christian Rampal E: christian.rampal@mcgill.ca T: (416)-659-0750</p> 
<p>Philadelphia, Pennsylvania, USA Children's Hospital of Philadelphia, Philadelphia, USA Study contact: Willa Mazullo E: mazullo@chop.edu T: 267-425-4150</p> 	<p>For more information about the TRACK-FA Study, see our website</p>  <p>https://www.monash.edu/medicine/trackfa</p>

Further information

Monash University
Wellington Road
Clayton, Victoria 3800
Australia

E: contact@monash.edu

monash.edu.au

CRICOS provider: Monash University 00008C