

# ATAXIA GLOBAL INITIATIVE

worldwide platform for clinical research in ataxias



## NEWSLETTER MAY 2021

- **SAVE THE DATE:**  
AGI symposium November
- **AGI organisational information**
- **Survey smartphone applications**

## UPCOMING EVENTS

**24 - 27 May 2021**  
**Ataxia Investigators Meeting (virtual)**  
**<https://ataxia.org/aim/>**

**6 July 2021**  
**ERN-RND Ataxia webinar by Adam Vogel**  
**[Link to registration](#)**

**17 - 22 September 2021**  
**MDS Virtual Congress**  
**<https://www.mdscongress.org/Congress-2021.htm>**

**9 November 2021**  
**ERN-RND Ataxia webinar by Thomas Klockgether**  
**[Link to registration](#)**

**22 - 23 November 2021**  
**AGI symposium (online) - 'Getting ready for clinical trials'**

Dear all,

We cordially invite you to the first Ataxia Global Initiative Symposium on 22 and 23 November this year. You can find all current information about this meeting below. More details will follow soon.

In this newsletter, you can find an image that we created to reflect the position of the AGI within the ataxia community. We hope you find this image as useful as we do in explaining to others what AGI does!

Finally, the smartphone section of the digital-motor biomarkers Working Group has created a survey on smartphone applications. They would be very grateful if you could fill it out.

Best wishes,  
The Ataxia Global Office

## AGI SYMPOSIUM - 22 & 23 NOVEMBER 2021 - ONLINE

The first Ataxia Global Initiative Symposium will take place on Monday 22 & Tuesday 23 November this year. The meeting will be fully online. During this meeting, entitled 'Getting ready for clinical trials', you can enjoy keynote talks on various topics, as well as hear the latest on the AGI projects and working groups. The provisional programme is as follows:

### **22 November 2021: 14.00 - 17.00 CET**

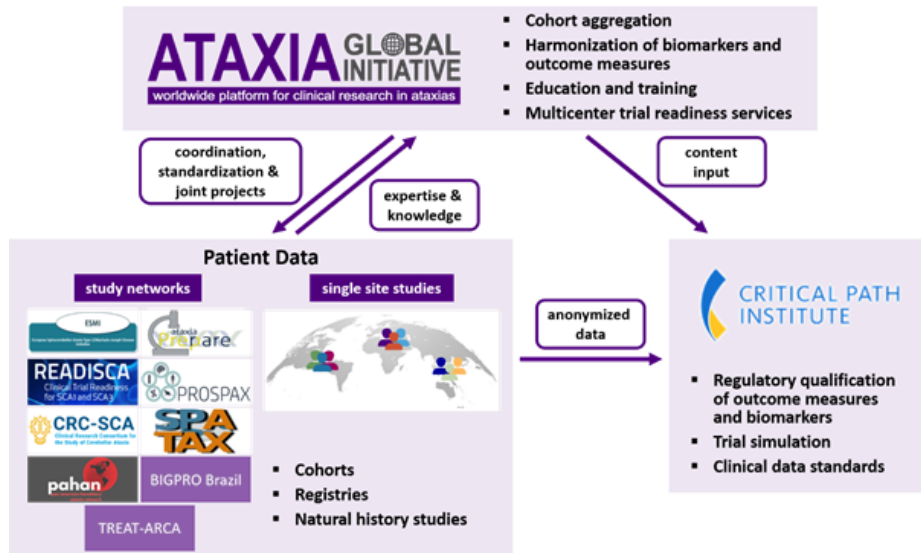
Session 1: Genetics and new targets/pathways  
Session 2: Business meeting

### **23 November 2021: 19.30 - 22.30 CET**

Session 3: Biomarkers and natural history  
Session 4: Therapy

## ORGANISATIONAL INFORMATION

The basis of clinical development of ataxia therapies are patient data and biomaterials, collected by existing networks and single study sites. AGI's goal is to coordinate, standardize, and facilitate collaboration in ataxia clinical research towards achieving trial readiness by aggregating cohorts and standardizing biomarkers and outcome measures. To achieve approval by regulators, AGI collaborates with C-PATH.



## SURVEY SMARTPHONE APPLICATIONS

The AGI Working Group 'digital-motor biomarkers' is looking to understand what smartphone applications and associated devices are currently being used in relation to the management and rehabilitation for people with ataxia. Moreover: which applications would you like to see developed, and which current technology developments should we be aware of. This information will be used to further develop the global collaboration on smartphone use, including applications for funding.

Helen Dawes, Andrea Nemeth and Chrystalina Antoniades would be very grateful if you can complete their survey and forward it to any colleagues you feel may be interested. Please fill out the survey via this link:

[https://brookeshls.co1.qualtrics.com/jfe/form/SV\\_e1GE0gSIRjKjmHs](https://brookeshls.co1.qualtrics.com/jfe/form/SV_e1GE0gSIRjKjmHs)

## CONTACT US

Questions? Items for the next newsletter?

Don't hesitate to contact us!

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## REMINDERS

If you would like to join a WG, please fill out the survey using the following link to provide us with your information:

<https://forms.gle/sCCoEbnhPQiXgXsC8>.

If you no longer wish to receive this newsletter, please send an email to [ataxiaglobaloffice@med.uni-tuebingen.de](mailto:ataxiaglobaloffice@med.uni-tuebingen.de).