

ATAXIA GLOBAL INITIATIVE

worldwide platform for clinical research in ataxias



NEWSLETTER FEBRUARY 2021

- Recorded sessions SCA & ARCA Global meeting 2020
- C-PATH: Memorandum of understanding
- Structure Working Groups

WEBSITE

The AGI website has been moved to a new domain name:

<http://ataxia-global-initiative.net/>.

We are currently working on an update for the website and hope to present that in our next newsletter.

If you have any ideas for the website, please let us know via info@ataxia-global-initiative.net.

CONTACT US

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Dear all,

We would like to update you on some ongoing changes for the Ataxia Global Initiative. The most obvious change: we have updated our logo as you can see at the top of the newsletter. We have created a combined logo to show how SCA Global and ARCA Global are aligned under a single Ataxia Global Initiative (AGI).

But more than looks have changed. After the SCA & ARCA Global conference last October, we have been working to form an AGI office in Tübingen. Annemarie Post has joined Holm Graessner and Birte Zurek in making sure that all practical matters surrounding AGI are taken care of.

In this newsletter, we tell you where to find the recorded sessions of the SCA & ARCA Global meeting, and inform you of the newest developments in AGI with regards to our working groups and AGI's relationship with C-PATH.

Best wishes,
The Ataxia Global Office
Holm Graessner, Birte Zurek & Annemarie Post

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SCA GLOBAL INITIATIVE
ARCA GLOBAL INITIATIVE

RECORDED SESSIONS SCA & ARCA GLOBAL MEETING

Most sessions of the SCA & ARCA Global meeting that took place from 19 - 21 October 2020 have now been uploaded to our website. You can find them under <http://ataxia-global-initiative.net/sca-global/conferences/sca-global-2020/sca-global-conferences-sca-global-2020-programme/>.

MEMORANDUM OF UNDERSTANDING WITH C-PATH

The Ataxia Global Initiative and the Critical Path Institute have signed a Memorandum of Understanding with the principle goal to strengthen the collaboration between AGI and C-PATH with respect to the Critical Path to Ataxia Therapeutics (CPAT). CPAT is a C-PATH initiative set up to drive regulatory acceptance of tools to accelerate therapy development for the genetic ataxias.

The collaboration will be implemented through the working groups of AGI and of CPAT, respectively. Members of AGI working groups will be invited to join the respective CPAT working group and vice versa. Working steps of correspondent CPAT and AGI working group will be tightly coordinated. Moreover, the AGI Steering Committee will assign academic investigators that will represent AGI in the respective CPAT working group.

STRUCTURE WORKING GROUPS

Within AGI, Working Groups (WG) are responsible for establishing an aligned common core of protocols in each domain. WGs cover both SCAs and ARCAs, but focus on specifics in each disease class.

The following WGs are currently active within AGI:

WG #	WG name	WG leads			
1	Clinical outcomes and registries	Thomas Klockgether	Matthis Synofzik		
2	Molecular biomarkers and biosampling	David Mengel	Puneet Opal	Filippo Santorelli	
3	MR biomarkers	Sirio Cocozza	Ian Harding	Pierre-Giles Henry	Gülin Oz
4	Digital-motor biomarkers	Andreas Träschütz	Adam Vogel		
5	Model systems and preclinical trials	Bernard Brais	Francesca Maltecca	Hélène Puccio	
6	Next-generation genomics & platforms	Brent Fogel	Andrea Nemeth	Matthis Synofzik	Stephan Zuchner
7	Policy and patient organization engagement	Holm Graessner	Julie Greenfield	Sue Hagen	

Most WGs have reached out to their members to discuss the next steps in their activities.

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>.

UPCOMING EVENTS

10 - 13 March 2021
Annual Ataxia Conference (NAF)
<https://ataxia.org/2021-annual-ataxia-conference/>

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