

# ATAXIA GLOBAL INITIATIVE

worldwide platform for clinical research in ataxias



## NEWSLETTER JULY 2021

- Charter
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## UPCOMING EVENTS

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

15 - 17 October 2021  
Ataxia UK meeting

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'  
[Link to more information](#)

Dear all,

The structure of the AGI is evolving. As from today, you can – actually you should – apply for membership or partnership of the Ataxia Global Initiative (AGI). You can find more information on this and on the AGI charter in this newsletter.

One of the organizations that has been a great support from the start, the National Ataxia Foundation (NAF), would like to share with you why they are pleased to be part of the AGI.

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

## CHARTER

In their latest meeting, the Steering Committee approved the AGI Charter. The charter means to formalize the activities of the AGI and set out guidelines for its members and partners. It can be found on <http://ataxia-global-initiative.net/governance/charter/>.

If you have any questions or suggestions, don't hesitate to contact us!

## BECOME AN AGI MEMBER OR PARTNER

The application for membership and partnership of the AGI is now open on our website:

<http://ataxia-global-initiative.net/governance/membership/>  
<http://ataxia-global-initiative.net/governance/partnership/>

(more information on the next page)

Members are individual persons who could be ataxia researchers (academic or industry-based) and clinical investigators, ataxia clinicians, representatives of patient organisations or further persons with a proven interest in ataxia therapy development. Read more about membership in the [AGI charter](#) (Article 2).

Partners are organisations including industry and patient organisations. AGI partnership is not limited to legal entities and may include companies, patient organisations, patient support groups, foundations, academic institutions and research consortia. Read more about partnership in the [AGI charter](#) (Article 3).

## LETTER FROM NAF: THE NATIONAL ATAXIA FOUNDATION - U.S.-BASED BUT GLOBALLY CONNECTED

While the National Ataxia Foundation (NAF) has its headquarters in the United States, the Foundation has always understood the importance of supporting ataxia research at the international level. For each research grant cycle, NAF has awarded funding to countries around the world. NAF is committed to funding the best science to advance ataxia research, and so we do not limit awards to institutions that are only in the U.S. The National Ataxia Foundation has funded researchers in many countries in Europe, as well as Canada and Australia. Additionally, NAF's Ataxia Investigators Meetings (AIMs) have been attended by researchers from all over the world, including Japan, Brazil, Israel, South Africa, Taiwan, and Saudi Arabia.

In 2019, NAF organized the inaugural SCA Global Meeting that took place in Las Vegas, Nevada, in conjunction with NAF's patient/family meeting. The SCA Global meeting was attended by 105 ataxia researchers representing 18 countries. In the Letter of Welcome to attendees, Dr. Tetsuo Ashizawa and Dr. Thomas Klockgether said, "Since all SCAs are rare, we must develop worldwide collaborations to make decisive clinical trials possible with sufficient statistical power. We are here today to tackle this task of kickstarting the Global SCA initiative. We are hoping that this conference becomes a venue for an international academic family of these investigators."

By combining the SCA Global Initiative with the ARCA Global Initiative into the Ataxia Global Initiative (AGI), Dr. Ashizawa's and Dr. Klockgether's hope of an international academic family of investigators has been realized.

The Vision Statement of the National Ataxia Foundation is "A World Without Ataxia." NAF is committed to work in partnership with the entire ataxia community around the globe to move us closer to that vision.

## 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>.

You can submit your proposal for AGI projects until 30 September 2021. For more information: <http://ataxia-global-initiative.net/projects/>

The first Ataxia Global Initiative Symposium will take place on Monday 22 & Tuesday 23 November this year.

<http://ataxia-global-initiative.net/events/agi-symposium-2021/>

All previous AGI newsletters can be found at <http://ataxia-global-initiative.net/newsletters/>

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