

ARSACS NEWS

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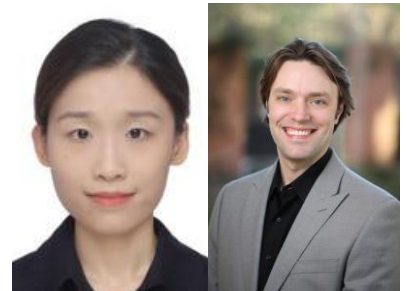
THE FOUNDATION IN ACTION

Once again, the Foundation continues to advance its mission through several ongoing initiatives: supporting research, collaborating with the scientific community, and preparing for upcoming events.

RESEARCH

Advancing Our Understanding of ARSACS

The work of Drs. Wolter and Wang is among the projects funded by the Foundation to better understand the mechanisms of ARSACS and open the door to new avenues of research.



OUTREACH

Building International Connections

The Foundation took part in a scientific conference in Milan that brought together researchers, clinicians, and representatives of the international community.

Learn more about this major event initiated by parents.

TEAM & COMMUNITY

A New Team Member Joins the Foundation

Valérie Deraiche has joined the Foundation to contribute to its work and strengthen connections with the community, particularly through social media, the website, and the sharing of relevant information and events. **Welcome, Valérie!**



ADVANCING OUR UNDERSTANDING OF CHARLEVOIX-SAGUENAY ATAXIA

Research by Drs. Justin Wolter and Huaxia Wang

How might potential treatments help protect cells affected by ARSACS? This question is guiding the research of Drs. Justin Wolter and Huaxia Wang at the University of Wisconsin–Madison.

With financial support from the Ataxia Charlevoix-Saguenay Foundation, their team is preparing to compare eight therapeutic candidates in a mouse model. By examining how each candidate affects gene activity in different types of brain cells, the researchers hope to better understand their effects and identify promising avenues for the development of future treatments.

The researchers submitted their first-year progress report to the Foundation. During this period, they finalized the selection of the eight candidates and conducted a pilot experiment confirming that their approach can detect changes in gene activity following treatment. These steps are laying the groundwork for the comparative study planned for the second year.

For more information, [read the full first-year report.](#)

RESEARCH BRINGS HOPE

We are pleased to announce the funding of [11 new research projects for 2026–2027](#), which will contribute to a better understanding of the disease and the development of new therapeutic approaches.

A heartfelt thank you to the **Richardson Trust Fund** and **Action for ARSACS Foundation USA (AFA)** for their invaluable support of research.

Congratulations to all the researchers selected!



Fondation de
l'Ataxie Charlevoix-Saguenay

Parce que
la recherche guérit

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MILAN 2026 — HIGHLIGHTS FROM AN INTERNATIONAL SCIENTIFIC MEETING

On September 24, 2026, the Foundation, represented by Sonia Gobeil, participated in the conference *Focusing on Rare Conditions: Advances, Challenges and New Horizons in ARSACS* in Milan.

This international meeting provided an opportunity to review the latest scientific advances, current challenges, and therapeutic perspectives. It also aimed to foster discussions among researchers, clinicians, and partners from different countries in order to strengthen collaboration around this rare disease.



ADVANCING ARSACS RESEARCH

8th International ARSACS Symposium
November 9, 2026 | 1 p.m. to 5 p.m. | Atlanta, Georgia

The Foundation is proud to present the **8th International ARSACS Symposium**. This **free, in-person-only event** will bring together researchers, clinicians, and members of the community.

A unique opportunity to come together around research, scientific advances, and the future of ARSACS.

[Learn more and register](#)

A NEW DIRECTOR OF PROGRAMS AND COMMUNICATIONS

Last August, Valérie Deraiche joined the team. As someone living with Charlevoix-Saguenay ataxia herself, she brings her personal and professional experience to the Foundation's mission. In particular, she will help raise awareness of the Foundation's research projects and activities while strengthening connections with the community, both here and abroad.

"Through my work at the Foundation and my sports activities—bungee fitness, climbing, and para athletics—I want to do my part for the community and show that it is possible to live a fulfilling life despite the disease."



**If you also have a story to share, we would love to hear from you.
Your experiences, challenges, and successes can help raise awareness of ARSACS, build connections, and bring hope to other members of the community.
Contact us to share your story.**

19th DÎNER DES PRODUCTEURS **Thursday, November 26, 2026 | Montréal**

This year, the Ataxia Charlevoix-Saguenay Foundation will hold the **19th edition of the Dîner des producteurs**, under the honorary chairmanship of **Mr. Pierre Miron of iA Financial Group**.

This important event will help support the community and enable the Foundation to continue its mission.

We will have the pleasure of welcoming Chef Christophe Hay of Fleur de Loire, France, as well as Mr. Thomas Perrin of France, representing the Perrin family, renowned in the wine industry.

Beyond fundraising, the evening will bring together partners, donors, and members of the community around a common goal: advancing research, building connections, and supporting the ARSACS community.

Thank you to all the individuals and organizations who make this collective effort possible.



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