

Subject: February 2023 NR2F1 Voice!

Date: Tuesday, 28 February 2023 at 21:52:43 Greenwich Mean Time

From: NR2F1 Foundation Board

To: jenniferkcoughlin@gmail.com

[View this email in your browser](#)



Welcome

February 2023

We want this newsletter to be valuable for you so please, share your feedback and suggestions to help us improve.

We hope you don't but at any time you can simply click the unsubscribe link.

Do you know someone who may like to read our newsletter? Please share!

Sincerely,

The NR2F1 Foundation Board



We need your help!

Did you know it costs over \$24,000 just to run the NR2F1 Foundation on an annual basis?

That's *before* we've funded critical Research like [TRIP](#) [BBSOAS](#) or paying the salary of our Scientific Officer and Engagement Activities such as the [NR2F1 Conference](#) and project-based work like matching grants (all of which *triple* our operating costs.)

We've lost the support of the Amazon Smile program. *To continue to deliver on our mission, we need your help!*

If you would like to consider ***supporting the Foundation and it's work financially or otherwise:***

Donate – We welcome and greatly appreciate any recurring donations to enable us to fund ongoing costs on a forward basis. Please also consider any matched funding donations from employers or others!

Fundraise – Can you organize a local fundraiser, either to support ongoing costs or to fund continuing research? We can help you! Contact [Carlie](#) to find out more.
carlie.monnier@nr2f1.org

Volunteer – We are a small group of families, contributing what we can with the skills we have and we'd welcome your time, expertise and experience to support the mission! Contact [Carlie](#) to find out more. carlie.monnier@nr2f1.org

Please also consider your own personal/family networks! We welcome all who are willing to commit their time, but to highlight just a few of the areas we can use immediate help with:

- Project Management
- Grant writing
- Web design/management, Search Engine Optimization
- Medical research
- Other non-profit experience
- ***And most importantly...anyone with lived experience with BBSOAS and a willingness to help others!***

We understand and fully appreciate we live in challenging times - but we need your help and support to continue building the BBSOAS community, supporting families, and driving critical research to improve the lives of each and every family impacted.

Contact [Carlie](#) to find out more. carlie.monnier@nr2f1.org

[Donate NOW](#)

[Learn More About Rare Disease Day](#)

A message from the NR2F1 Patient Registry Committee:

A robust patient registry is needed in order to move forward with research/clinical trials!

Are you a BBSOAS parent interested in helping?

PLEASE [contact us!](#) We would love to give you more details.

katia.roda@nr2f1.org

TRIP BBSOAS Fundraising Campaign

Help us invest in a better future for all those living with the rare disease, BBSOAS.

The NR2F1 Foundation's top priority for BBSOAS research has been to grow our international research network and strengthen the [NR2F1 Foundation Global Alliance](#).

[We cannot do this alone. We need your help!](#)

The NR2F1 Foundation was the catalyst in connecting [Dr. Michele Studer of NR2F1 France](#) and her lab at the University of Nice with [Dr. Christian Schaaf of the NR2F1 Foundation](#) and his lab at Heidelberg University in Germany. These two researchers are a 'dream team' of

experts in their respective fields: one in the NR2F1 gene and one in BBSOAS, respectively.

Help us launch this crucial research!



With your investments, we will be able to jumpstart a project called TRIP BBSOAS (Translational Research Investigating Phenotypes of BBSOAS). This joint project between Drs. Studer and Schaaf will give us insights into the role of the NR2F1 gene in brain development, and its downstream targets and pathways. Importantly, it could also be used as the basis of future therapeutic treatments.

You are investing in a more powerful kind of return; a better life and hope on the horizon for people all over the world living with BBSOAS.

[Learn More About Trip BBSOAS](#)

Have you checked out our blog?!

[Read the NR2F1 Blog](#)

**"We have too much time and too much money!"
Said no nonprofit organization, ever.**

Let's be honest, as a nonprofit, we are more limited by our resources and time than our opportunities to create impact. This is why we are developing a strategic plan in order to increasingly deliver impact in a way this is sustainable.

[Click HERE to read more](#) and see pics from our recent weekend in Atlanta working to develop our strategic plan!

**We are nearing the finalization of trademarking the NR2F1
Foundation Logo!**

This process was started in August, 2021 and we are thrilled that it is nearing the end. Stay tuned and we will share with you all as soon as it becomes official!

[Final Chance to SHOP the NR2F1 Store](#)

[Read the Patient Resource Brochure](#)

[Read the Provider Resource Brochure](#)



Want to change how you receive these emails?
You can [update your preferences](#) or [unsubscribe from this list](#).