

**Subject:** May 2023 NR2F1 Voice!

**Date:** Saturday, 20 May 2023 at 15:19:14 British Summer Time

**From:** NR2F1 Foundation Board

**To:** jenniferkcoughlin@gmail.com

[View this email in your browser](#)



---

---

# Welcome

**May 2023**

It's been a really busy few months at the Foundation. We have finalised our 5 year Strategic Plan, and are now working towards our Research Roadmap. We've been hard at work applying (and winning) grants, as well as launching our first BBSOAS Centre of Excellence clinic and hosting a series of virtual family support sessions (our next session is tomorrow!). Keep reading to find out more!

We love hearing from you, if you have ideas or feedback on our newsletter, let us know.

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

With thanks,  
[The NR2F1 Foundation](#)



Share



Tweet



Forward

To continue to deliver on our mission, [we need your help!](#)

**Donate** – We greatly appreciate monthly donations to enable us to fund ongoing costs - and critically, drive research. Your employer might also match your donation! It's easy-you can start [Here](#) to find out how to double your donation.

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

Do you know someone in your personal/family networks who could help us? We welcome all who are willing to commit their time - these are the skills we have an immediate need for:

- **SOCIAL MEDIA!!**
- Project Management
- Grant writing
- Web design/management, Search Engine Optimization
- Medical research
- Other non-profit experience

**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. Thank you!**

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

[\*\*Donate NOW\*\*](#)

### **We've launched our 2023-2027 Five Year Strategic Plan**

We are thrilled to present our 2023-2027 strategic plan. The plan outlines our strategic vision for the next five years as we work towards our mission of empowering families and individuals living with rare NR2F1 gene variants through **education, advocacy and research**. In the document we aim to clearly articulate what the organization stands for, what our goals for the future are, and to hold ourselves accountable by measuring and communication progress.

[Check Out The Strategic Plan Here](#)

---

### **The Foundation has been busy!!!**

Thank you to the [NR2F1 Foundation Scientific Officer, Dr. Sarah Poliquin](#), and our [Patient Registry Chair, Katia Roda](#), we are delighted to share that we have been awarded the [Global Genes Health Equity in RARE Impact Grant](#)! With these funds, we will be translating our Patient Registry ClinGen surveys into 3 additional languages (Portuguese, Hebrew and Korean).

At the moment, the Patient Registry platform, Matrix, is available in English, Spanish, French, Italian, Korean, Portuguese and German. The ClinGen surveys within the Patient Registry are currently available in English, Spanish, French and Italian. We will let you know when they become available in the additional 3 languages! Please make sure you have completed all of your surveys in the Patient Registry.

In addition to this grant, we have applied for two other grants  
Please keep your fingers crossed for us!

---

**On Saturday, June 10 one of our very own [NR2F1 Board Members-Jen Nicholl](#) and her husband Eric will be riding in the Million Dollar Bike Ride in Philadelphia, to raise funds for the NR2F1 Foundation. Also don't forget, your employers may offer matching opportunities - our donation tool will help you with this too.**

---

[Read More About The Million Dollar Bike Ride and Donate](#)

---

[Learn More About The A-Z Fundraising Ideas](#)

---

**We are witnessing history in the making!**  
**In collaboration with a multi-disciplinary team led by Dr. Veeral Shah, the NR2F1 Foundation helped make history with the launch of the first day of the BBSOAS Center of Excellence and clinic on April 21st at Cincinnati Children's Hospital. Read more [HERE](#)**

---

We are excited to partner with [COMBINEDBrain](#) and have the chance to collect BBSOAS bio samples (e.g. blood), to be used by researchers in future projects. [COMBINEDBrain](#) is collecting samples at partner conferences across the country, throughout the year. Our goal as a foundation is to collect as many BBSOAS samples from our community as possible, and we need your help! The more we collect, the better our chances to learn more about BBSOAS.

[Click Here To Read More and See The Upcoming Dates June -](#)

**\*\*Next session tomorrow - Sunday 21st\*\***

**Zoom details are on the BBSOAS Parents only Facebook page.  
Not on Facebook? Just email [Ashlee.manjon@nr2f1.org](mailto:Ashlee.manjon@nr2f1.org) or  
[Erin.camper@nr2f1.org](mailto:Erin.camper@nr2f1.org) for the link**

---

**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](mailto:katia.roda@nr2f1.org)

---

Have you checked out our blog?!

[Read the NR2F1 Blog](#)

---

[Click HERE to get your Park Access Pass](#)

---

Questions? Info to Share? Email Brigitte!

---



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