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**November NR2F1 Voice!**

1 message

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**NR2F1 Foundation Board** <carlie.monnier@nr2f1.org>  
Reply-To: us20-ae9468752b-e7ab51cef2@inbound.mailchimpapp.net  
To: cwmonnier@gmail.com

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# Welcome

## November 2021

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



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October marked the first BBSOAS collaborative research meeting with Michele Studer (France), Patrick Yu Wai Man (England), Danielle Bosch and Ninke Boonstra (Netherlands), Veeral Shah, Jane Edmond, Nilesh Desai, Sophia and Ming Jer Tsai (all USA), and Magdalena Laugsch and Christian Schaaf from Germany. These researchers who have all focused on different aspects of NR2F1 and to different degrees were able to connect with one another and discuss future projects and research avenues for BBSOAS. Bringing their diverse expertise and knowledge of BBSOAS together is a very exciting step towards advancements in understanding what impact NR2F1 has on the body and through development.

The NR2F1 Foundation is excited to announce that 4 additional iPSC lines are being created to represent our patients with deletions, mutations in the DNA Binding Domain, mutations in the Ligand Binding Domain and mutations at the initiation site. These cell lines which provide an ideal mechanism for the clinical side of research – meaning treatments to help our BBSOAS patients - were able to be created at a steeply discounted cost to the Foundation as part of our COMBINEDBrain membership. They will be housed in the lab of Dr. Shah at Cincinnati Children's Hospital, and the goal is to create a mouse model that represents these BBSOAS patient types and can be used for studies in parallel as well.

## **Sassy - Intuitive - DETERMINED**

### **Meet 6 yr old Brooklyn from Florida!**

Read from Brooklyn's mom, Patience all about Brooklyn and the BBSOAS life.

#### ***How did you choose her name?***

I chose her name because of its meaning of water and stream. It was my hope that she would be a calm little girl however she has proven to be the opposite (lol).

#### ***Three words that describe Brooklyn?***

Brooklyn is a sassy, intuitive, and a very determined little girl. She doesn't let anything get in her way and is by far going to do it her way with an added flavor of sassiness.

#### ***How and when was Brooklyn diagnosed with BBSOAS?***

Click [HERE](#) to Continue Reading About Brooklyn

**Scroll down to watch an exclusive interview with Zeb, 15 yrs old, from the Netherlands!**

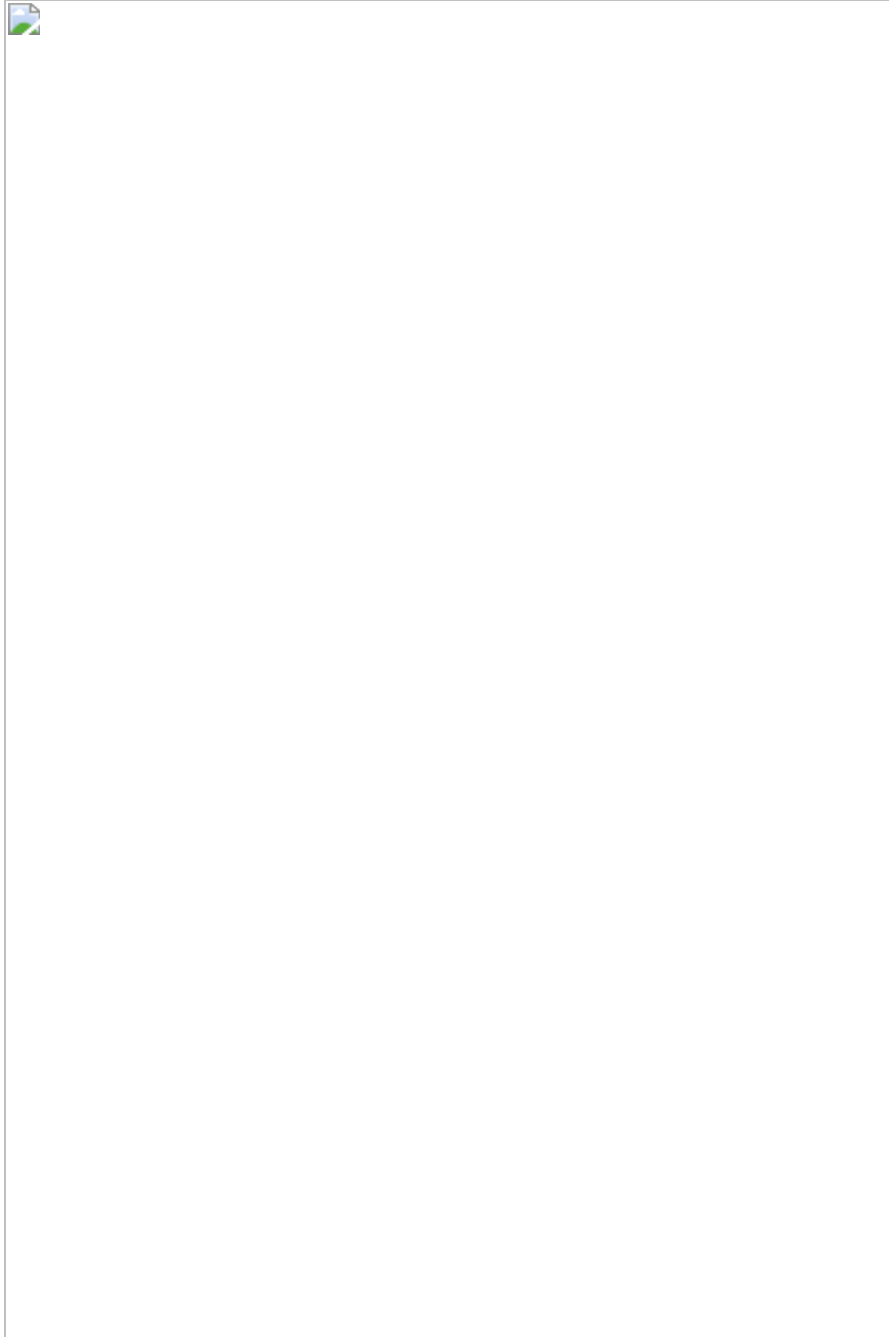
**Zeb is the first person to be interviewed by the NR2F1 Foundation who is diagnosed with BBSOAS.**

# 1st Annual International BBSOAS Awareness Day

December 7th is Peggy Fahed's birthday - BBSOAS patient #1.  
The BBSOAS story begins with her.

*"Peggy, and her father and I are deeply honored and touched. I hope that December 7th will bring progress in scientific discoveries to find solutions to improve the quality of life of our children and adults and alleviate the suffering of all involved."*

— Carmen Fahed, Peggy's mom



[Read More About Peggy's Story](#)

Stay tuned for a special commemoration on December 7th to honor Peggy, her journey and all those living with BBSOAS.

**NR2F1 Merchandise now on sale!**

**Shipping WORLDWIDE**

**All proceeds go towards the mission of the NR2F1 Foundation.**

**T-shirts, Sweatshirts, Hats and MORE**

**Shop Now for the Holidays**

Watch Carlie Monnier, President of the NR2F1 Foundation and her daughter Sidelle say THANK YOU to the Akino family and all those who donated

**Are you interested in promoting your business for a cause you can feel really good about? There is still time!**

**You can provide your TAX-DEDUCTIBLE sponsorship for the 2022 NR2F1 Foundation Family and Scientific Conference!**

**Questions? Send us an email at [info@nr2f1.org](mailto:info@nr2f1.org)**

**Conference Sponsorship Package**

Thank you to Paramark Real Estate and the Epilepsy Foundation for stepping up to sponsor the conference at the Silver level!

**Register Now!**

We appreciate your patience as we prepare for live-streaming of the conference. The link to register to attend virtually will be emailed to all BBSOAS families as well as

Each month, BBSOAS families get together via Zoom, hosted by BBSOAS mom, Katia. It's a wonderful way to learn more about our community, share resources and just talk with others who "get it".

The next Parent Support Zoom call will be the 1st or 2nd Saturday of December.

Date and Link will be in our private FB page and emailed to BBSOAS Families.

### **You shop. Amazon donates to NR2F1.**

You can support the NR2F1 Foundation every time you shop on Amazon! [Visit Amazon Smile](#) and select the NR2F1 Foundation as your charity of choice.

With every purchase you make, Amazon will donate 0.5% to the NR2F1 Foundation.



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