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NR2F1 Foundation Board <carlie.monnier@nr2f1.org>
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Welcome

August 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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Secretary

Jeff Thelen
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Director

Meet Dr. Veerhal Shah - Newest member of the NR2F1 Foundation Scientific Advisory Board

We have been honored that Dr. Shah has accepted our invitation to sit on the Foundation Scientific Advisory Board. Dr. Shah has met with numerous BBSOAS patients and their families and has a deep understanding of the symptoms involved, particularly in the area of vision impairment and cortical visual impairment. His expertise in pediatric neuro-opthalmology is immense and so is his enthusiasm to further BBSOAS research.

We are also excited to announce that Dr. Shah will be speaking at the 2022 Conference.

Dr. Shah works at Cincinnati Children’s Hospital Medical Center in the Division of Pediatric Ophthalmology. He is also Assistant Professor at the UC Department of Ophthalmology.

READ MORE ABOUT DR. SHAH

Let's welcome Kyle, Scientific Officer, to the NR2F1 Foundation Team!

Kyle J. Horning received his bachelor’s degree in neuroscience in 2010 from Drew University. He continued his training in neuroscience as a research technician at the Maryland Psychiatric Research Center until 2013, where he began graduate school at Vanderbilt University. At Vanderbilt, he received additional training in toxicology and bioinformatics while studying gene and environmental interactions in the context of Huntington’s disease for his dissertation. He received his PhD from Vanderbilt in neuroscience in 2020. In January 2021, Dr. Horning joined COMBINEDBrain as a postdoctoral fellow in translational science. In June 2021 he also became the first Scientific Officer for the NR2F1 Foundation.

Meet Simón from Chile

Cuantos años tiene Simón, y cómo escogieron su nombre?
How old is Simón and how did you choose his name?

Simón tiene 4 años recién cumplidos. Fue difícil escoger el nombre, de un listado de muchos nombres que me gustaban junto a mi familia fui eligiendo uno que fuera fácil de pronunciar y no muy repetido. Quería que se devorara el mundo por eso llegué a Simón ya que tiene un equivalente en muchos partes del mundo. Hoy su nombre ha derivado a nuestro Mon o Monito.

Simón is 4 years old. It was difficult to choose a name. From a list of names that I liked, my family and I wanted something that was easy to pronounce and not too common. I wanted him to conquer the world & that's how I decided on the name Simón. It has an equivalent in many parts of the world. Today his name has become our Mon or Monito (monkey).

Tres palabras que describen a Simón:
Three words to describe Simón:

Energético, Perseverante, Feliz

Energetic, Persistent, Happy

¿Cómo y cuándo fue Simón diagnosticado con BBSOAS?
How and when was Simon diagnosed with BBSOAS?

Click HERE to Continue Reading About Simón

Meet Charly from France

Charly is a 22 year old from Nice, France. His mom, Angélique is President of NR2F1 France, our sister Foundation. (Read more about NR2F1 France in the Announcements below.)

Comment avez-vous choisi le prénom de Charly?
How did you choose the name Charly?

C'est moi (Angélique) qui ait choisi son prénom car j'aime beaucoup l'acteur Charlie Chaplin.
I chose his name because I really like the actor Charlie Chaplin.

Trois mots qui décrivent Charly:
Three words that describe Charly:

Doux, jovial, calme
Gently, happy and calm

Comment et quand Charly a-t-il été diagnostiqué avec BBSOAS?
How and when was Charly diagnosed with BBSOAS?

Click HERE to Continue Reading About Charly

Introducing our Sister Foundation

Angélique Véré - President
Secretary - David Martinez
Treasurre - Anne Morin

L’association NR2F1 France apporte soutien aux personnes qui sont atteintes des troubles associés à une déficience du gène NR2F1 ainsi qu’à leurs proches.
The association NR2F1 France supports individuals and their loved ones affected by NR2F1 gene variants.

NR2F1 France will fill a gap in much-needed support for Europeans affected by BBSOAS.
Carlie Monnier, Board President, is looking forward to speaking virtually at the first NR2F1 France Scientific Conference in March 2022 on behalf of the NR2F1 Foundation.

Read More About NR2F1 France

After months of preparation, the NR2F1 Foundation launched the first-ever BBSOAS patient registry with Backpack Health...just 24 hours later, the NR2F1 Foundation, and the hundreds of patients they serve, was left in the lurch and forced to start all over again from ground zero.

Read More About What Happened

COMING SOON

The Foundation is now partnering with Across Healthcare Matrix in developing the first-ever BBSOAS Patient Registry!

Please stay tuned for exciting announcements on our various social media platforms.

Are you interested in promoting your business for a cause you can feel really good about?
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

Conference Sponsorship Package

Register Now!

BBSOAS Families - Are you familiar with the Federal Quota Program?

It is a program for blind and low vision students. Schools need to fill out an application and have a doctor's note verifying eligibility. If accepted, the school can order materials from the American print house for the blind catalog at no extra cost to them.
Stephanie, a BBSOAS mom worked with her daughter Charlotte's school to enroll her in the program. She received a ton of great materials for her to use at school (light box, light box kit, all in one board, magnifier, sensory and braille books).

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".
At the end of each session, an NR2F1 Foundation Board member will join to answer any questions re the Foundation, future projects, conference, etc.

The next Parent Support Zoom call will be
Saturday, August 28th, 6p EST
Link will be in our private FB page and emailed to BBSOAS Families.

Euclid Ave. Designs is a husband and wife duo who enjoy working together and making handcrafted wood items for the home and family. In honor of their nephew Henry who lives with BBSOAS, they donated $750 worth of sales in April to the NR2F1 Foundation.

Do you have a business you would like to share with the BBSOAS community and beyond?
Let's Talk!
Send us a message via Facebook or email Carlie via our website or email directly at: carlie.monnier@nr2f1.org

Help lead the way to answers!

Help fund NR2F1 research and awareness initiatives

What does the future look like for those who have BBSOAS?
Your tax-deductible donation will support research that could lead to life-enhancing treatments and interventions for those affected by this rare genetic mutation, a biennial family conference and outreach efforts.

Make a Donation Today!

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.