What a start to the year!

Dear **Lucretia**,

We can't contain our excitement anymore - our first ever NR2F1 Foundation sponsored post doc is here! What an achievement! With your help we raised enough last year to begin sponsoring our very own 3 year post-doc, to exclusively research BBSOAS! Read all about how we have awarded a 3 year grant for our very first NR2F1 Sponsored Post Doc Researcher at Heidelberg University, check it out.

In addition we already have a nice list of achievements this year and are working towards more. It was fantastic to have so many families in person and online at last months BBSOAS Family and Scientific conference.

This year we need to raise a minimum of $205,000 to pay for the commitments and grants we've awarded, as well as operating cots. Because of this we have our busiest year yet of fundraising activities and are extremely grateful to you, our community, for getting involved. It is truly a global effort with fundraising happening in the US, UK, France and the Netherlands. All the links are below if you'd like to sponsor and support the NR2F1 Foundation in our effort to find answers for our BBSOAStrong.

Its also my first newsletter as President! I recorded a video (here) to introduce myself, and look forward to meeting more of you in person in the coming months, and years.

Best

Jen Coughlin *(Ediths Mum and NR2F1 Foundation President)*

Grants and Sponsorship

- The NR2F1 Foundation awards a **3 year grant** to Dr Schaaf at the University of Heidelberg for a post **doctoral fellowship to investigate the molecular biology of NR2F1 and BBSOAS - read the press release here**
- The NR2F1 Foundation issued a **grant to Dr. Magdalena Laugsch** to support her attending the The **European Society of Human Genetics** 2024 conference. Dr.Laugsch will use the conference to get input and feedback on her NR2F1 projects

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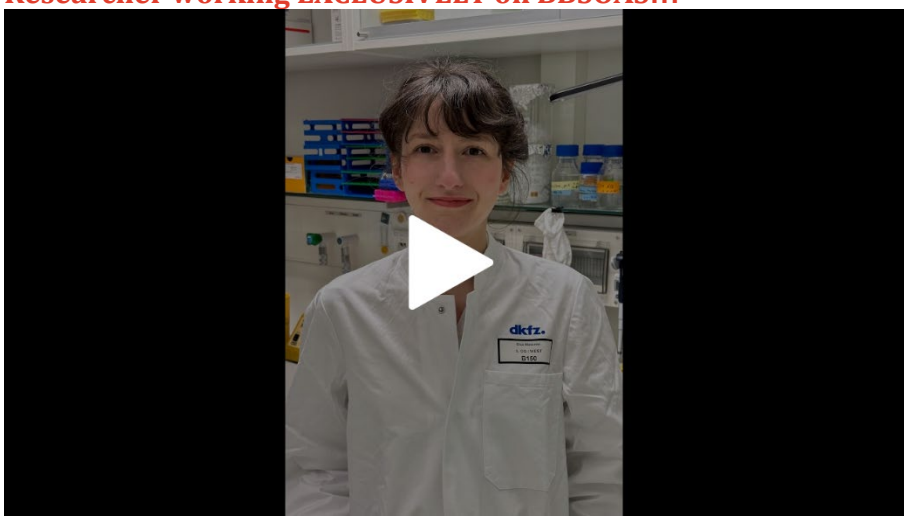
Meet Dr Wassmer - our first ever NR2F1 Foundation Sponsored Post-Doc Researcher working EXCLUSIVELY on BBSOAS!!!



2024 BBSOAS Conference

Read all about the conference in our blog here

Click HERE for 2024 BBSOAS Conference Presentations, Videos and Photos

Please note, videos of the conference are being uploaded on an ongoing basis, bear with us.....technical delays!

If you attended the conference (in person or online) you'll also receive an email with more info

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New Scientific Advisors

We are delighted to welcome two of our existing NR2F1 researchers to officially join the Foundation as Scientific Advisors. Dr. Studer (France) and Dr. Henning (Germany) have both been working on NR2F1 for a significant amount of their career and we are so grateful to them for all their efforts

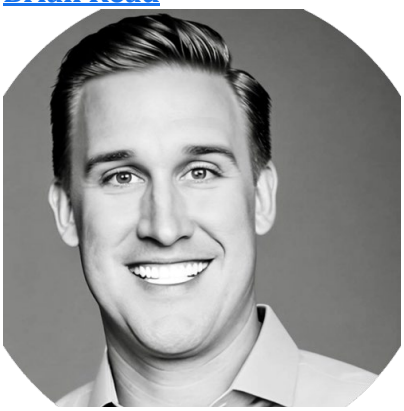
Michèle Studer, PhD

Henning Fröhlich, Dr. rer. nat.

Check our their impressive bios here on our website

Welcome to our newest Board Members

Brian Read



We welcome Brian, taking over from Jeff Thelen as Treasurer. Brian is a rare disease sibling and brings a unique perspective to the board. We are delighted to have Brians skills and experience on the team.

Patrick Coughlin

Patrick has been volunteering for the past year and this year was voted in as a board member. This marks our first non (BBSOAS)-parent on the board. Patrick is a BBSOAS Uncle so fully behind our mission and committed to helping find treatment for our families.

Fundraising

Walk with Vincent - Shared by Kari, Vincents mom

This year was our third annual Walk with Vincent for BBSOAS and it was amazing. Each year we see more attendees and new faces! This year we had at least 50 - 70 individuals show up and participate. We walk a mile in our neighborhood and Vincent even walked a huge part of the route this year! It's an opportunity for others to be reminded to embrace the limitations of those individuals challenged with a rare disease. It's an opportunity to be kind and show love for all individuals. It's a day to celebrate Vincent and how hard he works to be the best! He is our joy and our world and it blows his father and I away to see the support in the community, for Vincent! This year many of his teachers showed up and it's nice to celebrate with an applause as they are a huge part of his growth.

Setting up the fundraiser page with the Foundation for this event was easy and we did a lot of inviting and marketing through social media and texts.

A huge thanks to Kari for her help, and for raising a huge $2,235!

Look out in the next newsletter to read about Mathilde's birthday fundraiser

Fundraising Get involved

WE ARE

RUNNING BIKING WALKING

FOR BBSOAS RESEARCH

NR2F1 FOUNDATION®

We have a number of fundraising events taking place this year - around the world!! If you would like to join the NR2F1 team and take part, please reply to this email

- **Million Dollar Bike Ride in Philadelphia, US - June 8** We have 3 BBSOAS families riding together from PA, NJ and MI! Check out the team here and consider sponsoring them
- **Walk the World - Nijmegen Netherlands - BBSOAS Aunt, Sarah will walk 100 miles over 4 days - July 16-19 - read more and sponsor here**
- **Richmond, London, UK Marathon - BBSOAS Dad Tim (London) and BBSOAS Dad, Jeff (Pittsburgh, US) and BBSOAS Mom Nesrine (Paris, France) will come together to lead a team on September 15.** *(and yes its in the town where Ted Lasso is filmed!)*

Click on the above links if you would like to donate and support our athletes in raising critical funds for the research of BBSOAS!

Meet a BBSOAS researcher - Dr. Magdalena Laugsch

Meet Dr Laugsh in our latest blog post here and learn about the grant the NR2F1 Foundation awarded

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New research paper -available here on our website click here

- Effective treatment of NR2F1-related epilepsy with perampanel

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BBSOAS Center of Excellence

This cross-discipline clinic led by Dr. Shah, includes comprehensive physical & visual assessments of individuals with BBSOAS. (evaluation of optic nerves, CVI severity testing)

Interested in having your child evaluated at the BBSOAS Center of Excellence at Cincinnati Children's Hospital?

- Email savannah.schell@cchmc.org

OR

- Call the main scheduling at 513-636-4751 and leave a message that you are interested in seeing Dr. Shah for the BBSOAS center of excellence

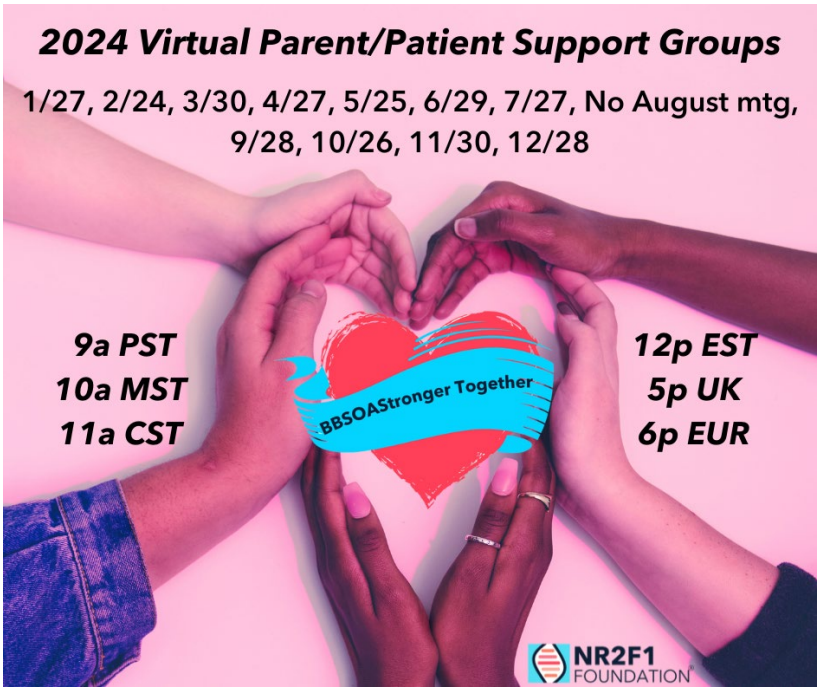
VEERAL SHAH, MD, PHD
PEDIATRIC NEURO OPHTHALMOLOGIST

Parent Support Groups

We have kicked off monthly virtual parent support groups. These take place the last Saturday of each month at 12pm EST. We held our first in January with attendees from US, UK, Poland and France! Parents and patients - A link to each group will be posted in the *BBSOAS Parents Only Facebook group and emailed a day or so before.* Next date - May 25, 2024

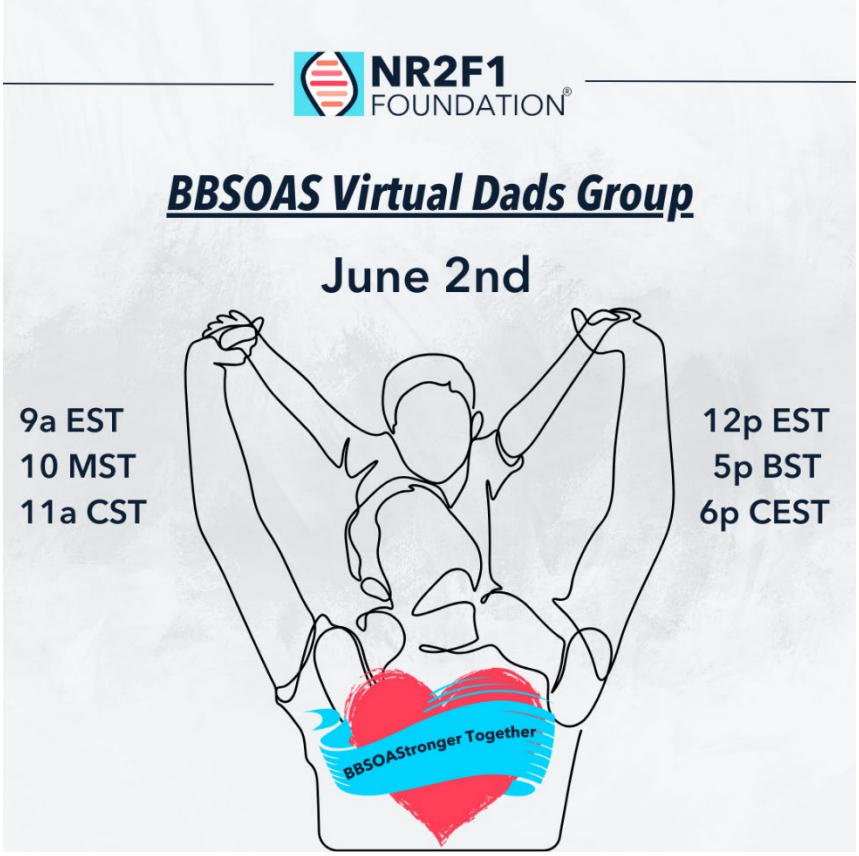
"*It was great to see everyone and thank you so much for what you do! It's been challenging to find others who can relate and it is such a safe and welcoming group when we join these calls."*

- Angelica, BBSOAS Mom



BBSOAS Dads Group

A link to the group will be posted in the *BBSOAS Parents Only Facebook group and emailed a day or so before.* We hope to see you there!
Reach out to tim.coughlin@nr2f1.org with questions



CRID - if you missed the Clinical Research ID (CRID) webinar, watch it here

NEW NR2F1 Shop

Click here to visit and buy your NR2F1 merchandise

(a portion of all profits go to the foundation)

We love hearing from you, so if you've enjoyed this newsletter reach out and say hi!

Sincerely,

Jennifer Coughlin

NR2F1 FOUNDATION President and Ediths Mum