



Summer is here and so is Dr Wassmer!

Dear **Jared and Amy**,

Fundraising efforts have truly been happening around the world. From Uruguay to Holland, with events in Philadelphia and next up London where 3 BBSOAS families will come together from London, USA and France! We are beyond grateful for the level of support, this year is our strongest year yet of getting you, are community helping us make an impact.

In the background we are also working on a new research grant project which I can't wait to share more in our next newsletter. We also continue to work on our new website with the support of our amazing team from Red Badger who are building a new site, pro bono (big shout out to Pedro)! We hope to launch by the end of the year.

I've spent a lot of time in the last few months meeting 1:1 with newly diagnosed families. It's been a pleasure and privilege to meet so many of you and hear your stories during this challenging time. If I've missed any of you that would like to have a zoom chat, really informal, just drop me an email.

On a personal note I'm going to be taking a few weeks away from my desk to spend with family over August.

I wish you and all your families well and an enormous thank you, whether you are a donor, supporter or BBSOAS family member, we are grateful to you all.

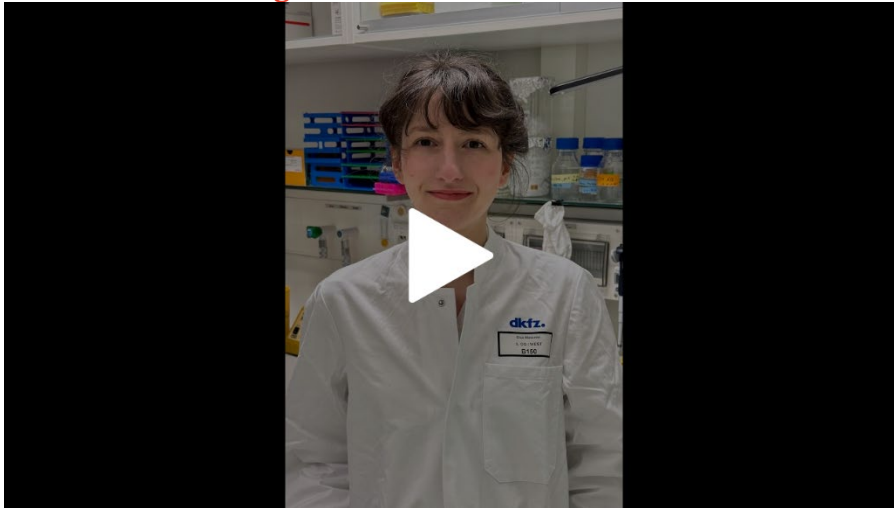
Best

Jen Coughlin (*Edith's Mum and NR2F1 Foundation President*)

Grants and Sponsorship

- Read about the grant the NR2F1 Foundation gave to Dr Laugsch [in our blog here](#)

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



Elsa has been getting settled in Dr Schaaf's lab over the last month or two and we will share an update from her soon, on her journey getting to know more about BBSOAS and the NR2F1 gene.

Volunteers

Victoria - BBSOAS Mom to Corine, thank you for helping with our Facebook parent location info

Laura - BBSOAS friend from Scotland. Laura is helping behind the scenes with our patient count.

If you have any free time and want to get involved, reach out!

Fundraising

Our Goal - where are we?

This year our target is to raise \$205,000 to fund our research projects and operating costs including the conference. We are currently at \$68,000. We have the London (Richmond) Marathon coming up in September, an Haunted Hustle 5k run in October and our annual drive for Giving Tuesday, so we remain optimistic, with your help, to reach our goal.

Take a look at what's been happening in the world of fundraising, its been busy! And remember, if you would like to host a fundraiser, get in touch and we can set you up with your very own page.

Million Dollar Bike Ride



For the second year, the NR2F1 Foundation had an incredible team of 10 athletes riding in the Million Dollar Bike Ride on Saturday June 8 in Philadelphia. What made it extra special is that 3 BBSOAS families took part. And even more amazing, BBSOAS Sidelle, Maggie and Leo joined the team and rode along in the bike with their Moms Carlie, Jen N and Megan!

This amazing event raised a staggering \$33,250

Mathilde's Birthday Fundraiser

Big thanks to Nesrine and Robin for an amazing birthday fundraiser for Mathilde. They asked all friends and family to donate to the Foundation, instead of buying gifts, and raised an incredible \$1180.

And a huge thank you to all those who have had Facebook Birthday Fundraisers for the NR2F1 Foundation! You are all deeply appreciated. Since the very first one, there have been 82 birthday (and other) fundraisers! You know who you are....and we thank you.

Have a birthday or event coming up? Want to help?

Remember - **we can build you your own fundraising page directly tied to the the NR2F1 website.** It's easy! All we'll need are some photos and we'll handle the rest. Contact jennifer.coughlin@nr2f1.org or carlie.monnier@nr2f1.org

100 mile walk Aunt Sarah

BBSOAS Edith's, Aunt Sarah (my big sister!) did the incredible challenge of [walking 100 miles in 4 days in the Walk the World march in Holland](#). She walked a marathon a day and even met BBSOAS Bram and Mom Merel on the way. Huge thanks to Bram and Merel for giving Sarah the encouragement and motivation on the most grueling challenge she has ever done.

Click [HERE for a quick video](#) of Sarah's (and her friend Wendy) experience walking 100 MILES!

Sarah raised an incredible \$5,020. So many donations were \$5, or \$10, and she even had strangers in bars donate to our cause. Thank you so much Sarah for this huge act of kindness towards Edith and all our BBSOASstrong.

Hockey Tournament in Uruguay!

An amazing BBSOAS family in Uruguay partnered with another local family who have a similar condition (Prader Willi Syndrome) and held a hockey tournament

to raise money for the NR2F1 Foundation. Marcela, Pilar's Mom said *"It was an incredible day of fun and above all, raising awareness and visibility of these diseases"*. They raised a whopping \$1,800.

A huge thanks to Marcela and her family - muchas gracias!



Gracias

Thank you to our all our families, we can only do this amazing work with all your support.

Upcoming Fundraisers

Support our marathon runners on September 15



FOR BBSOA

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!)*

First annual NR2F1 Haunted Hustle 5k - Newtown, PA



BBSOAS Mom and Board Member, Jen Nicholl has setup a 5k run in her hometown in aid of the NR2F1 Foundation!

[Click HERE for 2024 Haunted Hustle Sponsorship](#)

Click on the above link if you would like to sponsor our athletes in raising critical funds for the research of BBSOAS!

BBSOAStrong in Action



GO B

Board member Brigitte's BBSOAStrong daughter, Brielle, competed in the Front Range Adapted Triathlon a couple of weeks ago in Erie, CO. What an incredible achievement!

"It was fun! I got to see super heroes. I liked to be able to do it." - Brielle

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

This year our support groups have grown, with lots of options to get involved from around the world

Monthly Support Group - September 28 (links in Facebook group)

NEW!! 18+ BBSOAS Parents/Patients Support Group - September 28 (link in Facebook group)

Parents of our older BBSOAS children thought it would be really beneficial to have a virtual support group so they are kicking off in September. If you have BBSOAS children over 18 or you are a patient over 18 please come along!

Monthly BBSOAS Dads Group - September 29 (link in Facebook Group) they also have a WhatsApp Group - reach out to Tim.Coughlin@nr2f1.org if you would like to join

"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

"I can't express how thrilled I am that I called in. The stories and discussion were fantastic! It's been a journey with many highs and lows, and I'm excited to continue sharing our experiences and learning more about everyone in our group." Mike Johnson, BBSOAS Dad

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!

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 Edith's Mum