

Subject: NR2F1 / BBSOAS Year end wrap up - December The Voice
Date: Sunday, 17 December 2023 at 17:01:57 Greenwich Mean Time
From: Carlie Monnier
To: jennifer.coughlin@nr2f1.org



You made 2023 our best yet!

Dear **Jennifer**,

This year has been incredible for the NR2F1 Foundation. The hard work of the last 5 years (yes we celebrated our 5th birthday!) is all paying off and we are moving forward with our commitment and effort to find answers for families living with BBSOAS.

We couldn't have done all this without the incredible partnership of our Scientific Advisors and COMBINEDBrain team.

We are excited to share the years highlights, so please do keep reading, its been a big year!

As a team we are planning to sign off for a few weeks for a well deserved break and to focus on our families, but we can't wait to share with you in the new year our 2024 plans. We have a huge fundraising target ahead next year, but with your continued support, we know we can do it.

Wishing you and your families a happy end to the year, and thank you for your support this year.

Best,
Carlie and Jen

Our achievements

- We raised an incredible **\$125,000**.

(We will share in the new year how its being spent.....its exciting!)

- Created our [5 year strategic plan](#)
- Hosted a [Research Strategy meeting](#) with our board and Scientific advisors to create our research roadmap

- Funded Dr Shah's lab to [test two compounds](#) for the treatment of BBSOAS
 - Funded Dr Schaafs [TRIP BBSOAS](#) research
 - Booked the 2024 BBSOAS Family Conference ([book to attend in person or virtually](#))
 - Collected BBSOAS samples for our [NR2F1 Biorepository](#)
 - Overhauled the [NR2F1.org website](#), added published papers, newly diagnosed recommendations and made the website available in multiple languages
 - Hosted 5 virtual family support sessions for BBSOAS parents
 - Grew the patient registry - [keep signing up!](#)
 - Implemented a new CRM tool, Givebutter, to track all our contacts, diagnosed families, donations and communications
 - Grew our volunteers! Thank you to those who stepped forward from our newsletter appeals for help
-

Volunteer Spotlight

Heather



BBSOAS Ardyns Mom, Heather (MN, USA) has been supporting us since the inception of the parent Facebook group. She is also part of the 'original 5' who got together before the Foundation even existed! Thank you Heather for all your work, we are so grateful.

Cindy



Great Aunt Cindy (NJ, USA) of BBSOAS Edith (London, UK) has been helping much of the year with the implementation of our new CRM tool, Givebutter. She has helped us move all our contacts information from our very old and unsophisticated system, to our shiny new tool! A big shout out for Aunt Cindy, thank you for the hours and patience you have shown. (Some of you will no doubt hear from Cindy the new year when we validate contact info!)

Patrick and Jarno



BBSOAS Uncle, Patrick, at Coughlin Midlige & Garland LLP and Jarno at King & Spalding LLP have been amazing this year providing pro-bono legal advice to the Foundation. Thank you for securing our new trademark (amongst many other things).

If you would like to get involved in 2024, please email us. We need all the help we can get, whatever your background, if you are interested please reach out to chat.

Fundraising Champions

She raised the 'dough' for us! Thank you Sarah, [read how Aunt](#)

[Sarah](#) used her baking skills to fundraise for the Foundation

Facebook Fundraisers: thank you so much for the initiative to start your own independent campaigns to raise for us. From those of you that raised \$20, to Katia showing how she could rally her network and raise \$5,000 in a week, we appreciate you ALL

Million Dollar Bike Riders: Huge thank you to Jen Nicholl and her husband Eric for raising a staggering \$27,000

Halloween Party organiser: Thank you to Kimberley B for hosting an annual halloween party at a local bar in PA and raising \$1,400 by marking up tickets to include a donation to the NR2F1 Foundation on behalf of BBSOAS Maggie

Yardsales: Thanks to Sidelles mom for donating her yard sale takings of \$350

Giving Tuesday matching donation families - a giant thank you to our generous families that put together the \$17,500 matching offer. Big shout out to Moms Kari and Hayley for all the effort they put into promoting Giving Tuesday to their networks on our behalf. What a difference you made

Twitch Stream - thank you to Dad James for having the creative idea of making a fundraiser on his twitch stream

Could you help organise a fundraiser in 2024? *Get in touch. However big or small we can help. We have tools to set you up a webpage, and suggestions on marketing campaigns to help you along. Just drop us an email and we would love to have you onboard helping us move toward our \$365,000 goal!*

Grants - we won some, we lost some

Thank you to:

- **Global Genes**, for the TWO Health Equity grant to translate our Patient Registry surveys into multiple languages
- **NORD** for providing Vice President Jen with an international scholarship to attend the conference in Washington DC
- **COMBINEDBrain** for hosting the amazing Biorepository Roadshow, thanks to their incredible grant

.....and those that we didn't win, well we will be back again next year, armed with the feedback and ready to try again!

Biorepository on the Road Donors

Thank you to the families that showed up for us and donated blood samples to the NR2F1 Biorepository bank. One family drove an amazing 10 hours to donate their sons blood in California.

Thank you for making it possible for research and medical communities to now go and use BBSOAS samples from our biorepository for research studies

Our Board Members - a huge thanks....

The foundation is run by a working board of 9 members. They each give up their own time to make things happen. A huge shout out and thanks from our community to them

- **Brigette** for being the 2024 Family Conference organizing queen!
- **Ashlee** for keeping our social media alive and THRIVING
- **Jen N** for the toughest bike ride shes ever done, to raise money for all our kids
- **Jeff** aka Mr Money for spending his weekends learning QuickBooks
- **Melissa** for being our research expert and not resting until we find answers
- **Katia** for her endless amazing ideas and relentless commitment to the patient registry
- **Tim** for setting us up with awesome pro-bono legal coverage and always asking the sensible questions
- **Jennifer C** for her efficiencies and processes and steering our best Giving Tuesday yet
- **Carlie** for persisting and having the patience and courage to keep the Foundation alive for 5 incredible years



Podcast - you share, we listen



BBSOAS Dad and NR2F1 Foundation Board Member, Tim, recorded this fantastic podcast with the Special Fathers Network.

[Click here to listen](#)

And we must not forget to ask....

We made a commitment to ourselves as a board this year, that we would start asking publically for what we needed. So on that note...if you would like to donate (*and take advantage of year end tax breaks*) as a one off, or even better, help us every month here's my favorite link....

[DONATE NOW!](#)

With hearts full, a sincere thank you and wishing you and your families a wonderful end to the year. We will continue to empower families living with BBSOAS through education, advocacy and research, in the new year!

Sincerely,

Carlie Monnier and Jennifer Coughlin

NR2F1 FOUNDATION President and Vice President (*or Sidelle and Ediths Moms*)

[View this email in your browser.](#)

You are receiving this email because you've previously supported or subscribed to emails from NR2F1 FOUNDATION. [Unsubscribe here.](#)

Powered by **Givebutter**

NR2F1 FOUNDATION
416 E Kenilworth Ave, Royal Oak, MI 48067, USA