
NR2F1
FOUNDATION

July Newsletter - we've been busy!

Torrance,

It's been a busy few months over here at Foundation HQ and we are all excited for a summer break! We had a fantastic result from our first big fundraiser of the year generating over $19,500. Of course big fundraisers really help us plan and deliver meaningful impact to you, our community, but we are also so grateful for the smaller campaigns that have been running. A big thank you for those of you that have held Facebook Fundraisers. We love these, every little helps, so any ideas for fundraisers you have, just let us know if we can help you.

Behind the scenes we have implemented a new CRM tool to help us manage all our contact information, donations, and communications like this, more effectively. Boring, but oh so important!

Next up after the summer break we will be hosting a Research Strategy meeting with our Scientific Advisory board. We will create our first Research Roadmap to sit alongside our strategic plan. We can't wait to tell you all about it in our next newsletter.

We are looking ahead to next year and are delighted to announce our BBSOAS Family Conference will take place in April 2024, find out more below.

Wishing you all a great summer (or winter for our Australian readers!).

Million Dollar Bike Ride

A huge thanks to our board member, Jen Nicholl and her husband Eric for raising a staggering $17,500, on behalf of their daughter,

Maggie, for the Foundation!! There's still time to donate now if you'd like to show your support.

Baking a big impact

Wondered how you can get involved in fundraising for us? Check out our latest blog post to see how one BBSOAS aunt has been baking up a storm and raising money.

Grants....we win some, we lose some

We are delighted to have won a grant to attend the NORD Breakthrough Summit and will share what we learn from the conference in out next newsletter.

Sadly we also didn't win another, but one thing is for sure - we don't give up and we learn more and more with every application.

Thanks to winning the **Global Genes Health Equity**

In RARE Impact Grant, we should be ready with the Patient Registry ClinGen surveys in 3 new additional languages (Portuguese, Hebrew and Korean) in the next few months.

2024 Family Conference - in person and virtual

We are excited to announce that we have booked our 2024 BBSOAS Family Conference for April 3-5 2024.

Given overwhelming positive feedback from our last conference, we have again chosen Embassy Suites Orlando Lake Bueno Vista in Orlando, Florida.

Details of how to book your rooms and tickets will be sent on October 1.

Our ambition for 2024 is to increase attendance by 20%, so we hope you can join us for some family fun as well as lots of informative and educational presentations by BBSOAS experts.

We will also be running a fundraiser to help pay for the conference, and will be looking for corporate sponsors. If you are interested in offering your support please reach out.

Have questions or want to help email brigette.hinger@nr2f1.org

Biorepository Roadshow - get involved in research

We are excited to partner with COMBINEDBrain and have the chance to collect BBSOAS bio samples (e.g. blood), to be used by researchers in future projects.

COMBINEDBrain is collecting samples at partner conferences across the country, throughout the year.

Our goal as a foundation is to collect as many BBSOAS samples from our community as possible, and we need your help! The more we collect, the better our chances to learn more about BBSOAS.

Next sessions over summer will be in Colorado, Florida, Tennessee and New York City.

Click here to learn more and email jennifer.coughlin@nr2f1.org to register

Board Member Corner

WHY DID YOU JOIN THE NR2F1 FOUNDATION BOARD?

IN 2018, WITH 5 OTHER BBSOAS PARENTS, WE CO-FOUNDED THE FOUNDATION AND I WAS ELECTED PRESIDENT. WE DID THIS TO ENSURE THAT EVERY FAMILY WHO RECEIVED A BBSOAS DIAGNOSIS WAS NOT ALONE; THAT THEY HAD A COMMUNITY TO TURN TO AND HOPE ON THE HORIZON.

HOW HAS HAVING YOUR #BBSOASTRONG IMPACTED YOUR LIFE THE GREATEST?

SIDELLE HAS CHANGED THE COURSE OF MY LIFE IN SO MANY WAYS. ONE OF THE BIGGEST IMPACTS HAS BEEN ON MY PROFESSIONAL LIFE. BEFORE WE HAD SIDELLE, MY EDUCATIONAL AND CAREER PATH WAS ALREADY ROOTED IN DISABILITY ADVOCACY. I EARNED MY B.S. IN SPECIAL EDUCATION AND THEN A M.S. IN STUDENT COUNSELING WITH THE AIM TO WORK WITH COLLEGE STUDENTS WITH DISABILITIES. SHORTLY AFTER COMPLETING GRAD SCHOOL, SIDELLE WAS BORN. THE PLANS I HAD WERE PUT ON HOLD AS I BECAME A FULL-TIME SPECIAL NEEDS MOM. AS TIME MARCHED ON, I LEARNED TO COMBINE THE EDUCATION AND CAREER EXPERIENCE WITH THE LIVED EXPERIENCE. THIS, I BELIEVE, MADE ME A STRONGER ADVOCATE NOT ONLY FOR MY OWN DAUGHTER BUT FOR ALL THE FAMILIES I WORKED FOR, INCLUDING THE BBSOAS COMMUNITY I CURRENTLY SERVE.

WHAT DO YOU HOPE FOR THE FUTURE OF THE NR2F1

FOUNDATION?

I HOPE THAT IT CONTINUES TO GROW AND THRIVE THROUGH SUSTAINABLE STRATEGIC PLANNING, CONSISTENTLY STRONG FUNDING STREAMS, GLOBAL RESEARCH INITIATIVES AND A NETWORK OF DEDICATED BOARD MEMBERS AND VOLUNTEERS. THE BY-PRODUCT OF ALL OF THIS IS OF COURSE WHAT I TRULY HOPE FOR AND WHAT I WORK FOR EVERY DAY: A BETTER FUTURE FOR ALL FAMILIES LIVING WITH BBSOAS.

Read more about our board members at https://nr2f1.org/board-of-directors

Donate and Support the Foundation

We have a lot going on! Did you know, to just run the Foundation costs around $24,000 a year, and thats before we've hosted a family conference and importantly funded research. If you can support with a one off donation, or even better a monthly reoccurring donation click here to donate.

We truly are so grateful. With your support we can live our mission - to *empower families and individuals living with rare NR2F1 gene variants through education, advocacy, and research*.

Volunteers needed

Are you a social media, or Quickbooks online expert? We could really do with your help, just a few hours a month would make a big difference to us. If you are interested in getting involved, please reply to this email.

Best wishes,

Carlie Monnier

NR2F1 FOUNDATION President

View this email in your browser.

NR2F1 FOUNDATION

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