

**Subject:** October 2022 NR2F1 Voice!

**Date:** Friday, 7 October 2022 at 06:59:49 British Summer Time

**From:** NR2F1 Foundation Board

**To:** jenniferkcoughlin@gmail.com

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# Welcome

**October 2022**

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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**BBSOAS Families: Have you joined  
the NR2F1 Foundation Patient**

## Registry?

Join NOW!

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Read More About Tim

Read More About Jennifer

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**The NR2F1 Foundation is a proud board member of COMBINEDBrain and is thrilled to be a part of this \$15K grant!**

***"COMBINEDBrain (Consortium for Outcome Measures and Biomarkers for Neurodevelopmental Disorders)...is pleased to announce they have been awarded a Global Genes Health Equity RARE Patient Impact Grant which will be used to translate the ClinGen Health Surveys into French, German, and Italian, in addition to Spanish and English which are currently available. *These additional languages will allow more rare disease patients from around the world to participate in research.*"***

[Read more HERE](#)

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"Based on research published earlier this year, we have identified a potential molecule that has very promising therapeutic potential

for individuals with BBSOAS. We have recruited six leading NR2F1 and BBSOAS experts to form the first NR2F1 Collaborative Research Group to pursue this new research avenue. An [R01 application](#) is currently being written (submission in Feb. 2023) in hopes to fund a series of experiments that will test these promising compounds in human iPSC models and new mouse models of BBSOAS, in addition to launching the world's first BBSOAS clinic."

***-Dr. Kyle Horning, NR2F1 Foundation Scientific Officer***

[Donate to Further BBSOAS Research](#)

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## Meet Darragh!

"I had the opportunity to speak with Darragh (the 'g' is silent, Da-Ra) Andrews, a 24-year-old Para athlete from Belfast, U.K. recently diagnosed with BBSOAS.

Over Zoom and across the Atlantic, we spoke about her journey as a Para athlete and the life-changing diagnosis of BBSOAS."

***-Carlie Monnier, President, NR2F1 Foundation***

[Click to read the interview](#)

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**On Sunday 9 October 2022, Tim and Chris will be running the Chicago Marathon and have raised over \$115,000 in research funds for the NR2F1 Foundation!!**

**Who are Tim and Chris? [READ MORE HERE](#)**

The NR2F1 Foundation is *deeply grateful and humbled* by the generosity of all of those who have donated and continue to donate.

[Donate to Further BBSOAS Research](#)

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