

TBCK Weekend: Conference + Family Gathering

Hello TBCK Weekend Attendees!

Thank you so much for joining us for TBCK Weekend! It was such a pleasure to have our community come together both in-person and on Zoom. We are so grateful to our conference planning team and volunteers who helped out immensely, especially given the new plan! We are so grateful to our researchers and their lab teams that participated and who contribute to the growing body of TBCK research.

We thank you all for your patience and understanding as we did our first shot at a bilingual and two locations conference in order to be as inclusive as possible. So, thank you for being patient and flexible, but we are TBCK parents, researchers, or advocates- so we know that a change of plan is usually the plan. ;)

Thank you all for being here. We know that the weekend carries a lot of hope through the research and connection among families, but it also carries a bit of heaviness too. We understand there is space for both and we hope that through connections made today you know that you are part of a community, that together we will continue to give our TBCK kids (and adults!) the best lives possible.

Thanks again to Dr. Bhoj, Dr. Ortiz-Gonzalez, Dr. Downes, Madison Riffe, Abdias Diaz, + Francesco Gavazzi. Thank you to our parent panel! Thank you to Inez Vazquez, Cindy Leung, and Yesenia Davila for all your efforts, especially in running it all with Nikki's absence. Thank you to our incredible translators on Zoom! SO many thank yous!

I only wish I was able to attend in person! It was great to "see" so many of you! Thank you and well done!

We will find the answers together and we are so proud of this TBCK Community! Thank you!

Nikki + The TBCK Foundation

nikki@tbckfoundation.org (email is the best way to reach me!)

*** Please take 2-3 minutes to complete this survey ASAP:

https://docs.google.com/forms/d/e/1FAIpQLSfGfXGI_tvOCBoKuO8Ga97khEWumeA5NRPcW1PSWD0t_CxhsQ/viewform

TBCK Community Important Links

TBCK Community Registry:

This is a link that each family should complete for their TBCK Child.

https://docs.google.com/forms/d/e/1FAIpQLSfoktdNnlOoD8211B_jHCSgngPN_Plufly6x6Xmkh0mGsr1TO/viewform?c=0&flr=0&vc=0&w=1

Natural History Study Survey:

This is the link that Dr. Ortiz-Gonzalez spoke about and it corresponds to the QR code- for natural history study

<https://redcap.chop.edu/surveys/?s=DLDXKNTX4N>

Shared TBCK Weekend Photo Album:

Please post ALL of your photos!

<https://photos.app.goo.gl/rVqAZp1PVuKnyAzq7>

Resource Center (recently updated):

This is a link to a list of helpful resources on our website, please reach out if you have additions.

<https://tbckfoundation.org/resource-center>

Dr. Downes Storycollider Podcast:

<https://www.storycollider.org/stories/2022/8/12/anomaly-stories-about-rare-diseases?format=amp>

Important Emails:

bhoje@chop.edu (Dr. Elizabeth Bhoj)

tbckresearch@chop.edu

Recordings:

Zoom Recording Links: Part One: (missed the opening session)

https://us02web.zoom.us/rec/share/_uXi8OmG1ihCNVQaJCar4h_lqez8zGPXjOOan8mrDQfAu431_XnNbhLw75Kg_u1h.fEK8MfcuJ0-jg9Le?startTime=1665235576000

Zoom Recording Link: Part Two:

https://us02web.zoom.us/rec/share/_uXi8OmG1ihCNVQaJCar4h_lqez8zGPXjOOan8mrDQfAu431_XnNbhLw75Kg_u1h.fEK8MfcuJ0-jg9Le?startTime=1665251053000