

THE TBCK Weekend

Conference + Family Gathering October 7-9, 2022

Children's Hospital of Philadelphia



Special Thanks To:

CONFERENCE PLANNING TEAM

Nikki Stusick Inez Vazquez Cindy Leung
Yesenia Davila Katie Ireland
Alexis Abdullah Amie Clark
Erika Cox Christina Rivera

OUR SPEAKERS:

Kierstin Keller, MS, LCGC

Dr. Xilma Ortiz-Gonzalez + CHOP Neurology Lab

Dr. Elizabeth Bhoj + CHOP Genetics Lab

Dr. Gerry Downes, Madison Riffe + UMass Amherst Lab

**Children's Hospital of Philadelphia for their
conference room space.**

The TBCK Foundation is a proud grantee of the Chan Zuckerberg Initiative's Rare As One Program. It is through this funding opportunity (and the generosity of our speakers) that we are able to host this conference as a donation-only event.

Thank you to all who donated with registration and who support financially and through advocacy throughout the year!

**FRIDAY
October 7**

CHOP Research Building
& Sheraton University
City Hotel

4:00pm-5:00pm

TBCK Research Lab Tours at CHOP

*Location: Colket Translational Research Building 3501
Civic Center Blvd, Philadelphia, PA 19104*

RSVP Only*

Join for a 20 minute tour of the TBCK Research Lab hosted by CHOP TBCK researchers and their teams. Adults are only permitted access to the lab, but children needing supervision can stay in the lobby for the duration of the short tour. Afterwards, feel free to meet and greet with other TBCK families!

6:00-7:00pm (6:30pm Showtime!)

TBCK Kids Pajama Fashion Show

*Location: Sheraton Philadelphia City Hotel 3549
Chestnut Street Philadelphia, PA 19104*

Join for the Second Biennial TBCK Kids Pajama Fashion Show! All models are encouraged to wear their favorite pajamas and strut their stuff on the runway! Enjoy connecting with other TBCK families and advocates before and after the show. It's our favorite way to formally kick-off the weekend.

(Paid parking is first available at the Sheraton for non-guests.)

9:30am

Optional Family Outing

Philadelphia Zoo
Sesame Street Place

Meet up with TBCK families at the Philadelphia Zoo or Sesame Street Place. Parent coordinators will gather a list of attendees on Saturday during the conference.

**SUNDAY
October 9**
Philadelphia Zoo
& Sesame Street Place

**MONDAY
October 10**

Children's Hospital
of Philadelphia

Scheduled time

TBCK Clinic Visits

CHOP TBCK Clinic

All individual appointments
scheduled in advance.

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8:30am

Event Check-in + Meet and Greet Breakfast

9:00am

Welcome from The TBCK Foundation

Meet the TBCK Families slideshow and welcome from *Nikki Stusick*, Co-founder/Executive Director

9:15-9:30am

TBCK FAQ Top Questions

hosted by: Dr. Xilma Ortiz-Gonzalez & Dr. Elizabeth Bhoj

Children's Hospital of Philadelphia's leading TBCK Syndrome researchers/clinicians will be answering the most frequently asked questions about TBCK Syndrome to help set the tone for the day!

9:30am-10:00am

TBCK Syndrome Genetic Counseling

Kierstin Keller, MS, LCGC

Children's Hospital of Philadelphia

Ms. Keller is a genetic counselor at CHOP specializing in metabolic and mitochondrial disorders. She will share information around the genetics of TBCK.

10:00am-10:50am

TBCK Syndrome Neurology

Dr. Xilma Ortiz-Gonzalez, MD, PhD

Children's Hospital of Philadelphia

Dr. Ortiz-Gonzalez MD, PhD, is a pediatric neurologist in the Division of Neurology at Children's Hospital of Philadelphia. Her areas of expertise include: Neurogenetics, TBCK encephalopathy, and Mitochondrial Disorders. This session covers the neurology of TBCK Syndrome, research updates. Q & A to follow.

10:50am-11:00am

Group Photo Break

Speaker sessions will be hosted in English + Spanish. All sessions will be recorded.

www.tbckfoundation.org/conference2022

11:00am-11:50am

TBCK Syndrome Research Updates

Dr. Gerry Downes, PhD + Madison Riffe

UMass Amherst

Dr. Gerry Downes and Madison Riffe are researchers at UMass Amherst studying motor behavior and epilepsy. This session will cover their current research of TBCK Syndrome to better understand the cellular and molecular mechanisms that underlie the disease. Q & A to follow the session.

11:50am-1:00pm

Lunch provided by Corner Bakery

1:00pm-2:00pm

Having An Impact + Breakout Groups

Nikki Stusick + Inez Vazquez

Learn about how you can engage your community to raise funding and awareness for TBCK. Following will be breakout groups to connect with other TBCK families on relevant topics of caregiving.

2:00pm-2:50pm

TBCK Syndrome Genetics

Dr. Elizabeth Bhoj, MD, PhD

Children's Hospital of Philadelphia

Dr. Bhoj MD, PhD, is an attending physician in the Neuroendocrine Center at Children's Hospital of Philadelphia. Her research consists of finding new genetic disorders, determining how they work, and developing targeted treatments for them. This session will cover genetics and research updates of TBCK Syndrome. Q & A to follow the session.

2:50pm-3:00pm

Break + Connecting with families

3:00pm-4:00pm

TBCK Parent Panel

Yesenia Davila, Cindy Leung, Katie Ireland, Jorge Cortez, and Dina Rodriguez. Moderated by: Nikki Stusick

Hear from incredible TBCK Parents on their experiences, insights, and ideas for being a caregiver and advocate.

4:00pm-4:30pm

TBCK Weekend Closing Session

Closing thoughts, surveys, and future planning.

6:00pm-7:30pm

TBCK Community Dinner

Non-hosted at Hard Rock Cafe.

RSVP Only*

