



**We've joined COMBINEDBrain to accelerate biomarker research!**

Samples are now being collected at ROADSHOW events across the United States.

[COMBINEDBrain](#) is a non-profit consortium of over 60 patient advocacy groups for rare, genetic neurodevelopmental disorders. They recognize the need to collect patient samples for researchers to identify [biomarkers](#) to be used to treat /develop treatments for our children.

They are on a mission to collect ~500 samples from member organizations over the next 6-8 months and Kabuki Syndrome Foundation is one of them. Samples collected from our community will be stored and available to researchers across the world.

**Are you or one of your family members interested in participating in this exciting project for Kabuki syndrome?** Here are the basics:

**Who:** Any participant diagnosed with Kabuki syndrome and/or unaffected siblings

**What:** Your urine and blood samples will be collected, processed and stored in the CB Biorepository. They will be available for select biomarker projects as well as other interested researchers. They will also collect several online surveys and your or your child's genetic report.

**Where:** COMBINEDBrain is collecting samples all across the United States this year. **You may give samples at ANY location below. Sample collection will take about an hour.** You do not need to attend the conference hosted by the rare disease organization that day.

**How:** Contact Dr. Clara Tang (KSF Director of Research) at [clara@kabukisynchromefoundation.org](mailto:clara@kabukisynchromefoundation.org) to determine eligibility and register.

**Remaining 2023 ROADSHOW Dates & Locations**

KCNQ2	Sept 29 (9a - 5p) and Sept 30 (9a - 3:30p)	Chicago, IL	Hilton Hotel Chicago, 300 E Ohio St, Chicago, IL
Rory-Belle Foundation	Oct 1 (9a - 5p)	Near Minneapolis, MN	13550 Commerce Blvd, Rogers, MN 55374
Prader Willi/USP7	Oct 6 (12 - 5p) and Oct 7 (8:30a - 4p)	Denver, CO	1672 Lawrence St, Denver, CO
TBRS	Oct 12 (2 - 6pm) and Oct 13 (9a - 5p)	San Antonio, TX	Morgan's Wonderland, 5223 David Edwards Drive, San Antonio, TX 78233

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COMBINEDBrain	Oct 15*	Washington, DC	Hook Hall, 3400 Georgia Ave NW, Washington, DC 20010
FAM177A1	Oct 29*	Mercer Island, WA	77th Ave SE Suite 101, Mercer Island, WA
ADNP	Oct 30-Nov 1*	Los Angeles, CA	Location TBA
SynGAP1/SLC6A1	Dec 1-3*	Orlando, FL	8978 International Drive, Orlando, FL

\*Exact times to be announced. Please reach out to [clara@kabukisynromefoundation.org](mailto:clara@kabukisynromefoundation.org) with questions.