



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, which takes about an hour. You do not need to attend the conference hosted by the rare disease organization that day.

2023 ROADSHOW Dates & Locations

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|--------------------|--------------|-------------------|
| IRF2BPL | Sept 22-23 | Cincinnati, OH |
| KCNQ2 | Sept 29-30 | Chicago, IL |
| NARS1 | Oct 1 | Minneapolis, MN |
| ISP7/ Prader Willi | Oct 5-7 | Denver, CO |
| TBRS | Oct 12-14 | San Antonio, TX |
| COMBINEDBrain | Oct 15 | Washington DC |
| FAM177A1 | Oct 29 | Mercer Island, WA |
| ADNP | Oct 30-Nov 1 | Los Angeles, CA |
| SynGAP1/SLC6A1 | Dec 1-3 | Orlando, FL |

How: Contact Dr. Clara Tang (KSF Director of Research) at clara@kabukisynromefoundation.org to further determine eligibility and the best way to participate.