



Interested in participating in biomarker research?



COMBINEDBrain is traveling to a conference near you

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 our member organizations over the next 6- 8 months and Cure VCP Disease 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 Cure VCP Disease?

Here are the basics:

Who: Any participant diagnosed with a CB Disorder or unaffected sibling.

What: COMBINEDBrain will be collecting urine samples and blood samples (processed for plasma and a finger stick) to be stored in the CB Biorepository and available for select biomarker projects as well as other interested researchers. They will also collect several online surveys to be completed by caregivers.

Where: COMBINEDBrain is collecting samples all across the country this year. Please see attached list of locations to find the closest biorepository collection to you. You may attend ANY of these meetings

Sample Size: Our *goal* is to collect 20 samples from each patient group

How: Contact allison@curevcp.org to further determine eligibility and the best way and location to participate.



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IRF2BPL Foundation, Sept 22nd 2023 (Cincinnati, OH)

KCNQ2 Cure Alliance, Sept 29th 2023 (Chicago, IL)

Rory-Belle Foundation, Oct 1st 2023 (Rogers, MN)

USP7/Prader Willi, Oct 5th-6th 2023 (Denver, CO)

TBRS Community, Oct 12th-13th 2023 (San Antonio, TX)

COMBINEDBrain Meeting, Oct 16th 2023 (Washington DC)

FAM117A, Oct 29th (Mercer Island, WA)

ADNP Kids Research Foundation, Oct 30th-Nov 1st (Los Angeles, CA)

FAST Research Foundation, November (Miami, FL)

SYNGAP1 Research Fund, Dec 1st-3rd 2023 (Orlando, FL)

SLC6A1 Connect, Dec 1st-3rd 2023 (Orlando, FL)



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Who: Any participant diagnosed with a neurodevelopmental disorder (we also need a handful of sibling controls).

What: COMBINEDBrain will be collecting blood samples (processed for plasma and a finger stick). You will need to have you or your child's genetic report available.

Cost: Plasma samples and finger sticks are free!

When: Any participant may attend ANY of the below CB conferences: