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Probably Genetic is a group of geneticists, engineers, and patients seeking to help people with rare diseases access affordable genetic testing. The company has recently launched a no cost genetic testing program for people with neurodegenerative and dementia conditions as part of the The Bluefield Project to Cure Frontotemporal Dementia (FTD). Individuals who m eet the criteria can receive **whole genome sequencing (WGS) and C9orf72 (C9) hexanucleotide repeat testing at no cost.** This testing analyzes the entirety of your DNA for disease-causing mutations associated with FTD and and other conditions.

Eligibility

To participate, candidates must reside in the United States. They must also be experiencing symptoms of a neurodegenerative condition OR have received a clinical diagnosis of frontotemporal dementia (FTD) without genetic testing that has confirm ed a known FTD mutation. Please note the program is for those currently experiencing symptoms; we are not testing the likelihood that an asymptomatic individual will develop FTD or a related condition in the future.

Eligibility for the program is determined by a brief, easy to understand online Symptom Checker. The form is a screening tool that asks questions regarding your symptoms and medical history. Care partners, friends, or family members are encouraged to submit on behalf of their loved one if their loved one cannot complete the Symptom Checker without assistance.

Submission data will be evaluated to assess whether you (or your loved one) are eligible for genetic testing. You will be notified in the following weeks via email.

How it works

- Go to the Symptom Checker website on any internet-connected device. Answer the questions in their entirety. It should only take about five minutes.
- The Probably Genetic team will thoroughly evaluate your Symptom Checker response to assess your eligibility. This typically occurs within one to two weeks.
- If you are eligible, you can claim your test, and the lab will send a kit right to your door. Collect a saliva sample and ship it back in the pre-paid box. You will receive instructions on how to do this via email.
- If genetic testing is offered, you will have access to both pre-test and post-test genetic counseling with a board certified genetic counselor. The genetic counseling sessions are

virtual and are included at no cost to ensure people can make informed decisions and understand the results.

- Results are available in 6 to 8 weeks. This test shows all disease causing mutations, even those that are not dementia related.

- View the status of your Symptom Checker submission and/or test kit through the patient portal. You can download a PDF copy of your genetic report, as well as a file containing your raw genetic data.

Privacy

Patient privacy and the patient experience is of utmost priority. The Bluefield Project to Cure FTD is sponsoring the program, but Probably Genetic will be the custodian of patient data. All internal data structures are HIPAA compliant and the testing pipeline is fully CLIA and CAP certified.

Any data that is passed on to any partner is de-identified and aggregated so that privacy is protected. De-identified, aggregate data could, for example, mean insights on the average wait for a diagnosis or the average symptom profile for a given condition—both of which help patient advocacy and biotech organizations understand patient populations for these rare and ultra-rare conditions.

Take the Symptom Checker Here: https://bit.ly/3gV51Lh

The Probably Genetic team is always open to feedback so the program is as successful as possible for this community!