Consent form - *Family Member Testing*

Purpose
Your family member has asked you to provide a sample (e.g. blood, saliva) to guide the interpretation of their genomic testing. Whole genome sequencing looks for changes or variations throughout one's DNA. Such DNA variations can cause a gene or a group of genes to function improperly.

How it is performed
Genomic testing is performed on DNA that is usually obtained from a small blood sample. Sometimes saliva samples or inner cheek (buccal) swabs can also be used. Analysis and reporting of the testing data for your family member with health concerns are guided by detailed clinical information and family history information along with up to date published medical and scientific information.

Samples from other family members can aid in the interpretation of the results from the individual with health concerns (e.g., samples from parents along with an individual's sample). The report for the individual with the health concerns might indicate if a genetic variant was inherited from one or both parents. Reports are typically not issued for family members whose samples were used for this purpose.

You do, however, have the option for reporting of secondary findings. If you elect this, a report will be provided with these results. Secondary findings are not related to the reasons for your family member's testing but could have implications for your current and/or future health. The American College of Medical Genetics (ACMG) has recommended the reporting of genetic variants in 81 genes associated with genetic disorders that are considered to be medically actionable in childhood or in adulthood (https://www.acmg.net/PDFLibrary/Secondary-Findings-v3.1.pdf). You can choose to have the ACMG list of secondary findings analyzed for yourself and any pathogenic or likely pathogenic variants in these genes will be reported. Alternatively, you can decline to have the ACMG list of secondary findings analyzed in yourself. The decisions you make regarding the reporting of secondary findings in yourself will not impact the analysis and reporting of findings related to the presenting health concerns in your family member. You can discuss the decision to report/not report secondary findings with your healthcare provider and/or the Alamya Health team (info@alamyahealth.com).

Please check ONE of the following:

___ YES, I DO want secondary findings to be reported in myself

___ NO, I DO NOT want secondary findings to be reported in myself

Risks and limitations

- There may be standard risks associated with blood draw (e.g., bruising, bleeding).

- Inaccurate results can occur due to:
  i) mislabeled samples regardless of strict clinical and laboratory protocols in place to minimize this risk
  ii) inaccurate or incomplete reporting of medical and family history information
  iii) rare technical errors
  iv) other reasons

- Genetic testing may identify the diagnosis for the health problems in your family member. This testing may also indicate that you have the genetic diagnosis even if you do not have the same health problems. Genetic conditions can present differently within families; that is, some individuals may have very few symptoms, whereas others can have a number of symptoms. Genomic testing cannot predict the severity and precise clinical course of the genetic disorder.

- Genetic test results can trigger difficult emotions and, in some cases, cause tension within a family since identifying a genetic diagnosis can have implications for other family members.

- This test might reveal biological relationships that were previously unrecognized, such as non-paternity or non-maternity.

- Genomic data may provide ancestry information (e.g., ethnicity) that could be used for the sole purpose of aiding the analysis of this test.

- Due to limitations in current medical knowledge or testing technology, a genetic variant might not be identified even though one exists and may contribute to or cause health problems.

- Test results might impact insurance coverage and rates, as well as employment. There might be local laws that help protect individuals undergoing genetic testing against discrimination. Please consider discussing this with your healthcare provider.

- This testing currently comprises both clinically validated testing and research testing and is undertaken in an accredited laboratory. In some situations, follow up confirmatory testing might be recommended..

Sample retention, data storage and database participation

After testing, Alamya Health will store the biological sample, if available, and genomic data for the option of reanalysis and reinterpretation in the future. Upon request by a health provider, Alamya Health will determine whether reanalysis or retesting would be preferred.

Alamya Health and its partners adhere to rigorous standards for personal health data storage as guided by laboratory regulatory bodies.

Alamya Health will share de-identified genomic and phenotypic (i.e. clinical) information with select genomic data repositories in order to improve the medical and scientific community's understanding of genetic information. Although sharing such information could support my/my family member's diagnosis and health management, this could also result in no personal benefit. See notices of privacy practice for more details relative to the sharing of genetic information.

After testing is complete, an individual's sample and/or data may be de-identified and used for testing and analytics validation, quality improvement, and product development.

I have reviewed this consent form and have been given the opportunity to ask questions. By signing below, I consent to testing by Alamya Health as described in this consent form.	
Name (print)	**Date of birth** (MM-DD-YYYY)
Signature (if applicable)	**Date** (MM-DD-YYYY)
Name and relationship of legal decision maker to patient (print)	**Signature of legal decision maker**