Bluefield Project’s Sponsored Genetic Testing Program

General Information
- Eligibility:
  - Program includes testing for persons diagnosed with FTD or related disorders in addition to individuals who might be experiencing FTD-like symptoms and do not have an FTD diagnosis. Eligibility may be determined by the use of an FTD-trained Symptom Checker. Submissions to the Symptom Checker can be entered by a loved one or care partner on behalf of the symptomatic person.
  - Unaffected persons with family history: No
- Cost: $0
- Testing available outside the U.S.: No; testing available in all states except New York

Laboratory Information
- Lab: Psomagen
- CLIA Certified: Yes
- Genes Included:
  - GRN
  - C9orf72
  - MAPT
  - Others: includes any pathogenic or likely pathogenic variant in genes related to the participant’s reported clinical phenotype, and secondary findings will be reported back to the participant.
- Test Limitations: C9orf72 expansion test result provides range based on cutoffs (Normal, Intermediate, Extended)
- Sample type: Saliva; buccal (cheek) swab available

Genetic Counseling (GC)
- GC Provider: PWN Health
- Counselors certified by ABGC: Yes
- Counselors with neurodegenerative disease experience licensed in all states requiring licensure: Yes
- Counselors experienced in neurodegenerative disease: Yes
- Pre-testing counseling provided: Yes
- Post-testing counseling provided: Yes
- Offers in-house physician ordering: Yes

Privacy/Legal Considerations
- Validation of Patient Competence: Clinical judgement; genetic counselor will defer testing and ask for power of attorney (POA) if needed.
- Data sharing: Results go to participant; results can be shared with physician upon participant’s request. De-identified information goes to sponsor, no protected health information (PHI) is shared.
- Consent: Single, online consent for eligibility, genetic counseling and testing.

Links
- Bluefield Project sponsorship statement
- Probably Genetic site for program

KEY
- ABGC = American Board of Genetic Counseling
- ACMG = American College of Medical Genetics and Genomics
- CLIA = Clinical Laboratory Improvement Amendment
- GC = genetic counseling, genetic counselor
- HCP = healthcare provider
- PHI = personal health information, protected health information
- POA = power of attorney