



## Passage Bio Partners with InformedDNA® to Offer Genetic Counseling and Testing for Patients with Frontotemporal Dementia (FTD), a Form of Early Onset Dementia

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- *No-cost genetic screening and counseling program aimed at identifying FTD patients who have certain inherited genetic mutations to guide early treatment intervention and awareness of clinical trials*
- *Passage Bio is evaluating gene therapy candidate, PBFT02, for treatment of FTD with granulin mutations*

PHILADELPHIA, May 03, 2021 (GLOBE NEWSWIRE) -- [Passage Bio, Inc.](#) (NASDAQ: PASG), a clinical-stage genetic medicines company focused on developing transformative therapies for rare, monogenic central nervous system disorders; and InformedDNA, the nation's leading genetics services organization, today announced a collaboration to provide no-cost genetic counseling and testing for adults who have been diagnosed by their physicians with Frontotemporal Dementia (FTD).

The [testing program](#) will facilitate identification of patients with FTD with certain inherited genetic mutations, providing an important step for early and precise treatment intervention, as well as supporting clinical trial recruitment and enrollment. FTD is a debilitating form of early onset dementia that currently has no approved disease-modifying therapies. Approximately 30 percent of all FTD is hereditary and most commonly involves a mutation of the granulin (GRN), C9orf72 or *MAPT* genes – all of which are tested for in this program.

"FTD is a life-threatening condition that progresses rapidly and has an average survival of eight years after onset of symptoms, so it is critical that patients are identified as early as possible to achieve the best outcomes for them," said Bruce Goldsmith, Ph.D., president and chief executive officer of Passage Bio. "By partnering with InformedDNA, we are able to offer patients with FTD an option to potentially identify whether there is an inherited genetic mutation causing their disease. This will enable clinicians to intervene sooner with an appropriate treatment approach for their specific form of the disorder. We believe this collaboration can serve as a valuable resource for the FTD community, allowing for earlier treatment or participation in clinical trials aimed at finding innovative treatment options."

Adults who have been diagnosed with FTD by a doctor are eligible for genetic counseling and testing for certain genetic mutations at no cost through the Passage Bio-sponsored program. Individuals will receive initial and post-test genetic counseling over the phone from InformedDNA genetic counselors who are highly trained in hereditary neurological conditions. If the individual elects to proceed with genetic testing following initial counseling, then the genetic counselor will coordinate the test order and sample collection. Test results will be available in approximately three weeks from laboratory receipt of the individual's sample. If patients test positive for a genetic mutation, in addition to counseling, they will be given information about potential treatment and clinical trial options specific to their mutation, if available.

"It's estimated that FTD affects 50,000-60,000 Americans and it is the leading cause of dementia for those under the age of 65. We're proud to leverage our deep expertise in the genetics of neurodegenerative diseases and our extensive community-based referring physician network to increase access to genetics services for patients with frontotemporal dementia," said Karmen Trzupsek, director of clinical trial services at InformedDNA.

Additional information on the FTD genetic counseling and testing process offered through the program, as well as tools and information for healthcare providers, patients and caregivers, is available at <https://informeddna.com/passagebio-ftd/>.

### Passage Bio Plans to Initiate a Phase 1/2 Clinical Study for an FTD Gene Therapy

Passage Bio is developing PBFT02, an adeno-associated virus (AAV)-delivery gene therapy, for the treatment of patients with FTD with granulin (GRN) mutations. FTD is one of the more common causes of early-onset (midlife) dementia, causing impairment in behavior, language and executive function, and occurs at similar frequency to Alzheimer's disease in patients younger than 65 years. In approximately 5 to 10 percent of individuals with FTD – 3,000 to 6,000 people in the United States – the disease occurs because of mutations in the GRN gene, causing a deficiency of PGRN, a complex and highly conserved protein. The mechanism by which PGRN deficiency results in FTD is uncertain, but increasing evidence points to PGRN's role in lysosomal function.

More information about the global Phase 1/2 PBFT02 study, upliFT-D, can be found at [ClinicalTrials.gov: NCT04747431](https://clinicaltrials.gov/NCT04747431).

### About Passage Bio

At Passage Bio (Nasdaq: PASG), we are on a mission to provide life-transforming gene therapies for patients with rare, monogenic CNS diseases that replace their suffering with boundless possibility, all while building lasting relationships with the communities we serve. Based in Philadelphia, PA, our company has established a strategic collaboration and licensing agreement with the renowned University of Pennsylvania's Gene Therapy Program to conduct our discovery and IND-enabling preclinical work. This provides our team with enhanced access to a broad portfolio of gene therapy candidates and future gene therapy innovations that we then pair with our deep clinical, regulatory, manufacturing and commercial expertise to rapidly advance our robust pipeline of optimized gene therapies into clinical testing. As we work with speed and tenacity, we are always mindful of patients who may be able to benefit from our therapies. More information is available at [www.passagebio.com](http://www.passagebio.com).

### About InformedDNA

InformedDNA is the authority on the appropriate use of genetic testing. It leverages the expertise of the largest, independent staff of board-certified genetics specialists in the U.S. to help ensure that patients, clinicians, [health plans](#), [health systems](#), employers, pharmaceutical companies and all

stakeholders have access to the highest quality genetic services. Key offerings include clinical genetic counseling, genetic testing utilization management, genetic testing [payment integrity](#), and expert genetics [support for clinical trials](#). For more information: <https://www.informeddna.com/>.

### **Forward-Looking Statements**

This press release contains “forward-looking statements” within the meaning of, and made pursuant to the safe harbor provisions of, the Private Securities Litigation Reform Act of 1995, including, but not limited to: our expectations about timing and execution of anticipated milestones, including initiation of clinical trials and the availability of clinical data from such trials; our expectations about our collaborators’ and partners’ ability to execute key initiatives; our expectations about manufacturing plans and strategies; our expectations about cash runway; and the ability of our lead product candidates to treat their respective target monogenic CNS disorders. These forward-looking statements may be accompanied by such words as “aim,” “anticipate,” “believe,” “could,” “estimate,” “expect,” “forecast,” “goal,” “intend,” “may,” “might,” “plan,” “potential,” “possible,” “will,” “would,” and other words and terms of similar meaning. These statements involve risks and uncertainties that could cause actual results to differ materially from those reflected in such statements, including: our ability to develop and obtain regulatory approval for our product candidates; the timing and results of preclinical studies and clinical trials; risks associated with clinical trials, including our ability to adequately manage clinical activities, unexpected concerns that may arise from additional data or analysis obtained during clinical trials, regulatory authorities may require additional information or further studies, or may fail to approve or may delay approval of our drug candidates; the occurrence of adverse safety events; the risk that positive results in a preclinical study or clinical trial may not be replicated in subsequent trials or success in early stage clinical trials may not be predictive of results in later stage clinical trials; failure to protect and enforce our intellectual property, and other proprietary rights; our dependence on collaborators and other third parties for the development and manufacture of product candidates and other aspects of our business, which are outside of our full control; risks associated with current and potential delays, work stoppages, or supply chain disruptions caused by the coronavirus pandemic; and the other risks and uncertainties that are described in the Risk Factors section in documents the company files from time to time with the Securities and Exchange Commission (SEC), and other reports as filed with the SEC. Passage Bio undertakes no obligation to publicly update any forward-looking statement, whether written or oral, that may be made from time to time, whether as a result of new information, future developments or otherwise.

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