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## Portable Genomics and CFTechnology.org have entered into a partnership to enable cystic fibrosis patients to better collect, manage and share important biometrics with caregivers, researchers and the pharmaceutical industry

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SAN DIEGO, Jan. 17, 2017 /PRNewswire/ -- Portable Genomics and CFTechnology.org (CFT) are teaming up to bring a private and tailored health data management platform to cystic fibrosis (CF) patients' mobile devices and to engage the CF community in the research and drug discovery process.

Jeanne Barnett, CEO of CFT, says, *"We're thrilled that this tool will address patients' needs for collecting important information about their condition, from their biometrics and genetics, to their complex treatment regimens and frequent medical tests. Portable Genomics offers a private process we've never seen before, giving patients total control over their data management and their data sharing with caregivers and professionals."*

Portable Genomics' mobile platform enables users to collect and aggregate data from a variety of sources, including genomics providers, electronic medical records, and personal health monitoring devices. Users can choose to remain the only people to access and use the personal health data stored on their mobile device or in their personal cloud solution.

Portable Genomics' application has been deployed in the CF community for a pilot phase, with a predefined set of data collection modules for CF: Mutations, Microbiology, Spirometry, Lung Microbiome, Hospitalization, Treatments, Nutrition, Supplements, Mood, Demographics, and Outcome Questionnaires. The application also allows users to create their own data collection modules.

*"The digital opinion leaders from our community who participate in this phase are extremely enthusiastic about exploring Portable Genomics' platform. The use of predefined CF modules accelerates adoption, and the customization feature provides a very personal experience,"* reports Barnett.

Patrick Merel, Ph.D., founder and CEO of Portable Genomics, comments, *"The validation of our technology with such an engaged community of patients and caregivers is a major step for Portable Genomics. We are also very eager to enable this community to both drive and participate in research programs with academics and pharmaceutical industry groups that will share in our new business model."*

Part of the agreement between Portable Genomics and CFT is the totally new process Portable Genomics platform enables for data sharing and monetization. In this process patients are in full control and can instantly opt-in or -out of sharing their data. Also, until a data transfer occurs, patients still own the data on their device.

As the very first digital platform to enable this transparent and patient-empowered business model, Portable Genomics shares the revenue with the community if the monetization of data occurs.

*"Patients are willing to share data to accelerate discovery for their condition, and through this new transparent business model, members will have the opportunity to be involved in the revenue chain. Portable Genomics offers a unique value proposition with its proprietary and private solution,"* adds Barnett.

This is a moment of great opportunity for pharmaceutical companies and academic institutions to cultivate new data-driven relationships with patient groups through a digital platform that accommodates the privacy and ownership concerns of patients, answers patients' needs for specific and customizable tools for data collection, as well as meets their expectations for new business models in the precision medicine era.

#### **About CFTechnology.org**

CFTechnology.org is the non-profit organization born of the knowledge and inspiration gathered at CysticFibrosis.com, the largest and oldest global cystic fibrosis community on the web. Comprised of over 16,000 patients, caregivers, and healthcare industry professionals, CysticFibrosis.com and its millions of forum messages are a "search engine" for all things CF. Founder and veteran science educator Jeanne Barnett created CFTechnology.org in 2010 to harness this information and motivation. The organization aims to better understand CF and its co-morbidities, develop more efficient management of treatments, and improve health outcomes and quality of life through learning tools and technology.

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#### **About Portable Genomics**

Portable Genomics is a San Diego-based privately held digital health company revolutionizing personal medicine with the development and commercialization of a mobile platform that enables users to collect, aggregate and share their valuable medical, genomic, behavior and lifestyle data. Through this technology, Portable Genomics seeks to empower patients to control their data and enable users to share data with healthcare providers, academics and life science organizations for improved healthcare and targeted drug discovery. For additional information on Portable Genomics please see [www.portablegenomics.com](http://www.portablegenomics.com).

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