

# MSU and Portable Genomics, teaming up to bring a tailored health data management platform to myositis patients

*Partnership to enable myositis patients to better collect, manage, and share important health data with caregivers, researchers, and pharmaceutical industry.*

LINCOLN, DE, UNITED STATES, May 16, 2018 /EINPresswire.com/ -- Portable Genomics and MSU are teaming up to bring a private and tailored health data management platform to myositis patients' mobile devices and to engage the [myositis community](#) in the research and drug discovery process.

Jerry Williams, the Founder and President of MSU and a myositis patient, reports, "I have been using this App for over two months and have found it beneficial in tracking the various myositis symptoms, complications, and treatments and I look forward to sharing my health data with whom I choose, to seamlessly enhance my personal health and benefit future [myositis research](#)."

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We are excited to partner with Portable Genomics and look forward to feedback from the community about the app benefits, and their willingness to track and share data to accelerate myositis research.”

*Jerry Williams*

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 MSU community for a pilot phase, with a predefined set of data collection modules for the myositis community, developed so far and including: Activity of daily living, ANA panel, Basic biometrics, Complete blood count, Complete metabolic panel, CPK level, Exercise programs, Imaging results, Mobility level, Nerve conduction study, Pain level, Swallowing difficulty, Treatments, and Tracking falls, with more modules coming soon. The application also allows users to create their own data collection modules and choose from other available predefined modules.



MSU and Portable Genomics partnership



## Myositis Support and Understanding

Myositis Support and Understanding Association logo

"We are excited to partner with Portable Genomics in this endeavor and look forward to hearing feedback from the myositis community about the benefits they see and their willingness to track data to better understand their condition, and share their data to accelerate myositis research," says Williams.

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."



Myositis customize smartphone application preview

Part of the agreement between Portable Genomics and MSU is the totally new process the 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.

"In sharing the monetization of data with the myositis community, patients will be compensated for the value of their personal health data and for the work it represents collecting data sets every day, which most have been willing to do for free in the past. This is the meaning of a patient-centered approach and we look forward to the next phase of this [myositis smartphone app](#) and program," adds Williams.

This is a moment of great opportunity for pharmaceutical companies and academic institutions to cultivate new data-driven relationships with Portable Genomics and MSU, representing myositis patients as the leading patient-centered group, 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 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, patient groups 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) and [www.nume.website](http://www.nume.website)

Contact:

Patrick Merel, Ph.D.  
Founder and CEO  
858-405-0498  
pmerel@portablegenomics.com

## More About MSU

Myositis Support and Understanding Association (MSU), founded by myositis patients, was created after identifying a need for more patient-focused programs and services. MSU is an all-volunteer, patient-centered 501(c)(3) nonprofit organization supporting patients and caregivers affected by the Idiopathic Inflammatory Myopathies, myositis, which includes dermatomyositis, polymyositis, necrotizing autoimmune myopathy, inclusion body myositis, and Antisynthetase syndrome, along with the juvenile forms of dermato- and polymyositis.

MSU is instrumental in helping to improve the lives of patients fighting this rare, complicated immune-mediated muscle, skin, and often multi-organ disease by being the very first patient-centered organization to offer live, online, video patient support, education, and activity sessions that simply make sense for those living with a muscle disease that involves limited mobility and with patients spread across the world.

MSU uses technology to connect myositis patients, caregivers, and family members and to collaborate with outside companies and other organizations for unique opportunities that directly benefit the myositis community and help to promote and advance research. The MSU website includes a "Simply Put" education series, offers clinical trial matching, advocacy, various online support options, awareness building programs, need-based financial assistance for patients, and more.

Jerry Williams, Founder and President  
Myositis Support and Understanding Association, Inc.  
302-339-3241  
email us here

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