



# MILLION VETERAN PROGRAM

ISSUE 4 | WINTER 2016-2017

## MVP Insider

A Newsletter for Million Veteran Program Participants

# MVP reaches 500,000 volunteers – how did we do it?

MVP reached a major milestone on Aug. 1, 2016, when we welcomed our 500,000th volunteer to the program. This achievement was the result of years of planning, foresight, and determination to build a genomic research database to improve health care for Veterans and all Americans. Here's a breakdown of the key steps along the way that helped us get to where we are today.

### Laying the groundwork

The groundwork for VA genetic research was laid in 1999 when a DNA Bank was created by the VA's Cooperative Studies Program. Then in 2006, the VA Genomic Medicine Program (GMP) opened the door for personalized medicine—health care tailored to individuals' needs, based on their genetic markers.

The Million Veteran Program began pilot work in 2009 to evaluate methods and survey instruments for recruitment and enrollment. In March 2011, MVP launched with 11 vanguard sites and enrolled our first participant in Boston. This set the stage for what has become a groundbreaking research resource, thanks to continuing Veteran volunteerism.



At the 2016 DAV national convention in Atlanta, Jenny Hui (left), MVP senior research coordinator, thanks Navy Veteran Dennis O'Connell for enrolling in MVP. O'Connell is joined by his wife, Marilyn, and service dog, Keeper.

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## 500,000 volunteers

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By January 2012, nearly 18,000 Veterans had volunteered, and plans to add another 10 sites and several smaller satellite facilities were underway. The 100,000th Veteran was enrolled only 10 months later, and by March 2014 a quarter-million were enrolled.

Eventually, MVP would grow to 52 main enrollment sites and 65-plus satellite locations in 37 states. Ultimately, MVP strives to reach out to all eligible Veterans with the opportunity to participate via site expansion, web enrollment, and partnerships with other agencies.



Robert Wallace, a Vietnam Veteran and adjutant general for the Veterans of Foreign Wars, enrolls in MVP at the group's summer 2016 national convention.

### Launching the first studies using MVP data

By fall 2014, VA investigators were presented with their first opportunity to plan projects using genomic data collected by MVP. The program currently supports the following studies already underway:

1. Gulf War Illness Risk Factors
2. Posttraumatic Stress Disorder Risk Factors
3. Functional Disability in Schizophrenia and Bipolar Illness
4. Genetic Vulnerability of Sustained Multi-Substance Use
5. Genetics of Cardio-Metabolic Diseases in the VA Population
6. Pharmacogenomics, Risk Factors, and Therapy Outcomes in Kidney Disease
7. Cardiovascular Disease Risk Factors
8. Genetic Risk for Age-Related Macular Degeneration in Diverse Veteran Populations

### Becoming part of the Precision Medicine Initiative

On Jan. 20, 2015, President Obama announced the Precision Medicine Initiative (PMI) in his State of the Union address. The PMI will enable researchers, providers, and patients to work together to develop individualized care. MVP was poised to serve as a vanguard component of the PMI cohort.

### The push to 500K

In spring 2016, MVP launched "Sound Off: March to 500K"—a push to reach the 500,000 mark by the end of July. The coordinating centers in Boston and West Haven set up five leadership teams comprised of coaches and mentors from those sites, and they worked with the MVP Information Center in Canandaigua, New York, and field champions from Indianapolis, Durham, Portland, Palo Alto, Pittsburgh, and Manhattan. The teams brainstormed ways to boost enrollment, including local site events, direct follow-up with non-responders, new mailing strategies, and specialized training for local staff.

### Working hand in hand with VSOs

Community engagement and outreach have become important components of the MVP strategy. In July 2016, MVP representatives attended the Veterans of Foreign Wars (VFW) national convention in Charlotte, North Carolina. The event was a big success for recruitment and was an effective way to spread awareness about MVP. VFW leaders had the opportunity to meet with the MVP team and return to their posts armed with knowledge and enthusiasm about the program.

Later the same month, MVP staff attended the Disabled American Veterans (DAV) national convention in Atlanta. The DAV group showed tremendous support for MVP and produced record enrollment numbers. The engagement team for these efforts included staff from the Boston and West Haven coordinating centers, two MVP national study coordinators, and local research staff. Most notably, on Aug. 1, Army Veteran Michael Smith from Montgomery, Alabama, became the 500,000th Veteran to volunteer for MVP while

attending the convention, just hours before President Obama delivered his address to the group in person. The president acknowledged the milestone in his speech:

“And here, I want to thank Veterans across our country for being part of another mission: our precision medicine initiative to revolutionize health care with treatments that are tailored for each patient. As of today, more than 500,000 Veterans—maybe some of you—have stepped forward and donated your health

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## Thanks to local MVP teams for 500K enrollment milestone

Reaching 500,000 Veteran enrollees was not only a victory for MVP as a program, but also a reflection of the hard work and dedication of our sites at a local level. These staff members are the people making sure that the site runs smoothly, that everyone has a job to do, and that the schedules are working for both staff members and Vets. They are the people who go through the consent forms with you, answer your questions, and draw your blood.

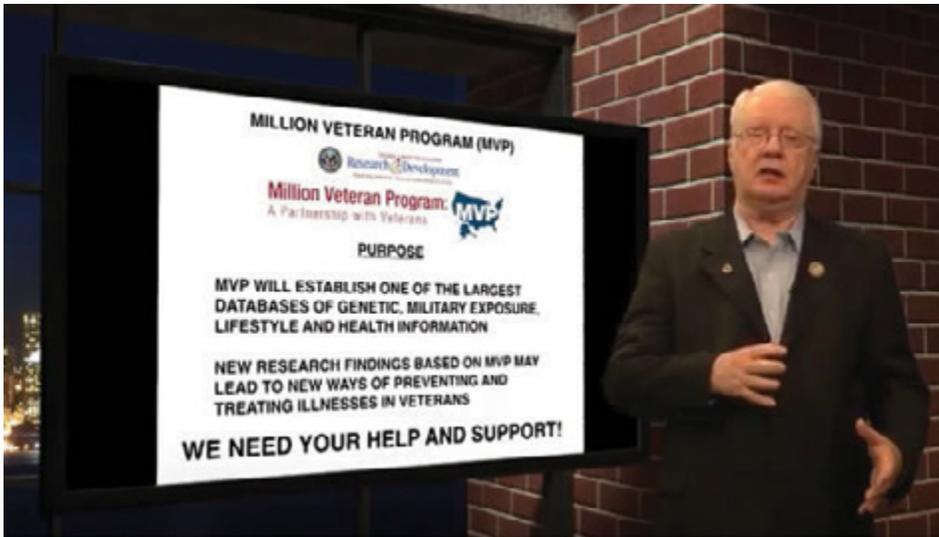
MVP site staff work tirelessly to bring attention to the Million Veteran Program by educating people in their area about the possibilities and benefits of a large-scale genomic collection. All local MVP team members dutifully play their role to move the program forward, and for this they deserve an enormous thank-you.

To mark this milestone, local sites across the country organized events that not only recognized the work they had done, but also honored our MVP Veterans, who have so generously donated their time, history, and blood toward a brighter future for all. ●



Staff at the Edward Hines, Jr. VA Hospital in Illinois recruited Veterans for MVP during VA National Research Week this past spring.

# Army Veteran John Walker, MVP enrollee and volunteer extraordinaire



A scene from John Walker's video, in which he talks to his fellow Veterans about MVP.

Army Veteran John Walker, who served in Vietnam, is not only an MVP participant—he's also an exceptional volunteer on behalf of the program. A patient at the Edward Hines, Jr. VA Hospital in Illinois, John created his own "testimonial" video about MVP and has been using it to reach out to other Veterans in his area to tell them about the program and why it's important. To the right is John's story, in his own words. We appreciate his being an enthusiastic ambassador for MVP. Check out his video online. Search for "JW MVP Program" in YouTube, or type in [www.youtube.com/watch?v=6Dl1nE5dvM8](http://www.youtube.com/watch?v=6Dl1nE5dvM8).

While on a medical appointment in the endocrinology department at the Hines VA, I noticed a flyer about the Million Veteran Program and how to become a volunteer. After my appointment, I searched for their office to find out more about MVP and was introduced to Ms. Stephanie Keen. I told her I wanted to help in any way I could, as it is so important for the health of our current and future Veterans.

I believed that my background—not only in the medical arena as a national sales manager for a leading medical instrument company, but also in

web design, television-quality video, marketing, and social media—could help in signing up volunteers to donate a sample of their blood for the MVP gene studies.

As a Vietnam veteran, who volunteered to serve in Vietnam in 1967 through 1968, I saw this program as an opportunity to volunteer and "get into the fight again," but this time the fight is to find ways to improve Veterans' health care. I have always said: "I am a Veteran, and my oath of enlistment has no expiration date."

Also, I have always been inspired by General Jimmy Doolittle, who stated, "Nothing is as strong as a volunteer."

For me, "pride and honor" is about being dedicated to the well-being of the United States and its citizens, to freedom and democracy, to the memory of those who sacrificed their lives to protect and defend our American liberty and way of life. I feel honored that MVP has welcomed my dedication as a volunteer to this program, which is so important to all Veterans now and in the future. ●

## MVP staff present at American Society of Human Genetics

Before researchers can analyze MVP data, the information that our Veterans provide through surveys, blood samples, and their electronic health records have to be “cleaned,” validated, and confirmed.

A team of core MVP staff have been working on cleaning the genomic data

from blood samples. They shared their methods in six poster presentations at the annual meeting of the American Society of Human Genetics in October 2016. This event is one of the largest genetics meetings in the world.

To have scientifically accurate and statistically meaningful results, we need to start with clean, quality data. This helps ensure we are doing the best quality science. As the old computer-science saying goes, garbage in, garbage out! ●



MVP program director Dr. Suma Muralidhar and MVP colleagues presented at the 2016 American Society of Human Genetics meeting.

## Welcome, new sites!

Nine more sites have joined MVP since fall 2015. Although they are relatively new, these sites have played a big role in helping us reach our 500K milestone. Collectively, these sites have enrolled close to 10,000 Veterans! A big welcome and thank you to the sites below!

Site	Launch Date	Enrolled by 12/1/16
Iowa City, IA	10/13/2015	2,220
Augusta, ME	10/19/2015	927
Northport, NY	11/2/2015	4,447
Manchester, NH	11/3/2015	358
Louisville, KY	11/9/2015	2,082
Muskogee, OK	1/25/2016	1,161
Providence, RI	5/16/2016	332
Salem, VA	5/31/2016	339
San Francisco, CA	11/7/2016	71

(Special congratulations to Northport for achieving such an impressive enrollment number in such a short time!)

The MVP team would like to make sure that we include topics of interest to you in future newsletters. Please send your suggestions our way.

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## A LOOK AT RESEARCH STUDIES INVOLVING YOU, OUR MVP VOLUNTEERS!

Our MVP database is currently being used by two types of research studies, which we refer to as “alpha” and “beta” studies.

**Alpha studies** help to develop MVP infrastructure and could involve re-contacting MVP participants (you!) with opportunities to provide additional data to the Million Veteran Program. You may be receiving a letter from an alpha study in the near future asking if you would like to participate and provide additional information about yourself and your service history. You have the option to participate or to opt-out. If you opt-out of an alpha study, it will not affect your status in the Million Veteran Program. Current alpha studies are researching schizophrenia and bipolar illness; Gulf War illness; and PTSD, as described below:

• **Functional Disability in Schizophrenia and Bipolar Illness**—Dr. Philip Harvey at the Miami VA Medical Center is leading a multicenter observational study to examine genetic risk factors for developing schizophrenia or bipolar disorder (BP) and the functional disability and cognitive impairment

that accompany these conditions. They will compare “case” patients who have one condition or the other with healthy “controls” obtained from the MVP database.

• **Gulf War Illness (GWI) Risk Factors**—Dr. Drew Helmer at the VA New Jersey Health Care System and Dr. Dawn Provenzale at the VA Cooperative Studies Epidemiology



Yang Chen works in the lab at the VA New Jersey Health Care System, where researchers are using MVP data to study Gulf War illness.

Center in Durham, North Carolina, will examine the genes that influence the development of Gulf War illness (GWI) in Gulf War Veterans. Using MVP data, their team will compare “case” patients with healthy “controls” and also look at the relationships between genetic variations, self-reported Gulf

War environmental exposures, and susceptibility to GWI.

• **Posttraumatic Stress Disorder Risk Factors**—Dr. Murray Stein at the VA San Diego Healthcare System and Dr. Joel Gelernter of the VA Connecticut Healthcare System will lead an effort probing the genes that influence the development of PTSD in combat-exposed Veterans. Using MVP data, their

team will conduct one of the largest genetic studies of PTSD and will help to identify genes that improve understanding of PTSD neurobiology.

**Beta studies** are how we refer to our first five data-only studies. Beta study researchers are working on ways to simplify the data-access process for future researchers. These projects are using data in the MVP

database, including your sequenced DNA. This work is the crux of MVP. In the future, there will be thousands of researchers using MVP data to find new solutions for illness and disability. As part of enrolling in MVP, you have consented to allowing researchers to use your coded data in their studies.

Current beta studies are researching cardiovascular disease, kidney disease, cardio-metabolic disease, multi-substance use, and age-related macular degeneration, as detailed below:

• **Genetic Vulnerability of Sustained Multi-substance Use in MVP**—

Dr. Daniel Federman and Dr. Amy Justice at the VA Connecticut Healthcare System, along with Dr. Henry Kranzler at the Philadelphia VA Medical Center, will examine genetic risk factors for chronic use of alcohol, tobacco, and opioids—and the dangerous use of all three together.

• **Genetic Risk for AMD in Diverse Veteran Populations**—

Drs. Eric Konicki and Neal Peachey at the Cleveland VA Medical Center and Dr. Steven Fliesler at the VA Western New York Healthcare System at Buffalo will lead a project to determine whether age-related macular degeneration (AMD) susceptibility genes identified to date in Caucasian-Americans are shared in African-Americans. This question is important because the recent advances in AMD genetics are being used to develop new therapeutics to slow or halt vision loss in the more prevalent forms of AMD.

• **Cardiovascular Disease Risk Factors, Prevalent Cardiovascular Disease and Genetics in the Million Veteran Program**—

Dr. Peter Wilson at the Atlanta VA Medical Center and Dr. Kelly Cho at the Boston VA Healthcare System will lead an effort probing the

genes that influence how obesity and lipid levels affect heart risk. Using MVP data, this study will also look at whether these genetic factors differ among African Americans and Hispanics.

• **Genetics of Cardio-metabolic Diseases in the VA Population**—

Dr. Philip Tsao at the VA Palo Alto Health Care System and Dr. Kyong-Mi Chang at the Philadelphia VA Medical Center will lead a study to explore the role of genetics in obesity, diabetes, and abnormal lipid levels (namely, cholesterol and triglycerides), as drivers of heart disease. This project will lead to a more thorough understanding of the underlying causes of cardio-metabolic disease and help guide the development of new therapies that are safe, effective, and personalized based on patients' genetic profiles.

• **Pharmacogenomics of Risk Factors and Therapies Outcomes of Kidney Disease**—

Dr. Adriana Hung at the VA Tennessee Valley Healthcare System will lead a study focusing on how genes affect the risk and progression of kidney disease. One goal is to examine how patients with diabetes—who often develop kidney problems—respond differently to the drug metformin, the standard first-line treatment for diabetes, based on their genetic profile. The project will also look at the genetics of hypertension, a major risk factor for kidney disease. ●

## 500,000 volunteers

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and genetic data for research, which brings us halfway to our goal of one million Veterans that are doing so.”

We didn't stop there. Later in August, the engagement team traveled to Cincinnati for the American Legion (AL) national convention, proudly letting them know we were half way to our goal and needed their help to continue our mission. Again, Veterans stepped up and volunteered. They also spread the word, and our effort to reach out and engage the Veteran community has been overwhelmingly well-received. MVP has been invited to attend upcoming local and national events for the VFW, DAV, AL, and other Veteran Service Organizations.

### Thanks to you

The single most important element in the success of MVP has been the spirit of volunteerism among you, the Veteran community. You have gotten us here, and you are why we do it. You continue to give, volunteer, support, and sacrifice. And your decision to enroll in MVP gives us just one more reason to say, “Thank you for your service.” ●

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MILLION VETERAN PROGRAM

Connecticut Healthcare System

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# A Partnership with Veterans

We thank our MVP volunteers for serving our country once again and helping us reach the halfway mark of 500,000. MVP is now the largest research program of its kind in the world, and we are poised to make major advances in understanding how genes affect health and disease. This could improve the lives of Veterans and all Americans. Thanks for being our partner.

**Mike Gaziano John Concato**

**MVP principal investigators**

