

We Need You: Join All of Us to Advance Precision Medicine

UC San Diego Health researchers call for volunteers to participate in landmark precision medicine research effort

By Heather Buschman, PhD and Yadira Galindo

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Dennis Lyon had a rare form of metastatic basal cell carcinoma. He was told he had two years to live with treatment, one year without. He sought care at five different cancer centers hoping for a different outcome. At one center, he was treated with the only currently available therapy for metastatic basal cell carcinoma. It was ineffective.

Lyon felt hopeless as doctor after doctor told him there was nothing more they could do.

Then, as a last-ditch effort, Lyon came to Moores Cancer Center at UC San Diego Health. There, a patient's case can be reviewed by the Molecular Tumor Board, led by Razelle Kurzrock, MD, director of the Center for Personalized Cancer Therapy. This group of experts from diverse fields scrutinize genomic and other information to determine the best therapy possible for that individual patient. Oncologists are at the table with geneticists, radiologists, biomedical informatics specialists, other medical experts and computer scientists. They took up Lyon's case.

Lyon's tumor DNA had an almost-unheard-of 100 mutations. But, based on his genetic data, the Molecular Tumor Board experts recommended a particular type of immunotherapy that is used for other types of cancers, but is not standard treatment for basal cell carcinoma. They believed the drug would help Lyon because previous studies suggested it was effective against other cancers with genetic mutations similar to his.

It worked. Today, Lyon's tumors have shrunk by more than 90 percent, with very few side effects.

"This is the type of personalized treatment approach we want to be able to take more often, for the benefit of more patients," said by Lucila Ohno-Machado, MD, PhD, professor and chair of the Department of Biomedical Informatics at UC San Diego Health and associate dean for informatics and technology at UC San Diego School of Medicine. "But to do that, we need more information from more people."



That's the goal of the *All of Us* Research Program [↗](#), which officially opened for public enrollment this month

. Led by the National Institutes of Health (NIH), *All of Us* is an unprecedented effort to gather genetic, biological, environmental, health and lifestyle data from 1 million or more volunteer participants living in the United States. A major component of the federal Precision Medicine Initiative, the program's ultimate goal is to accelerate research and improve health.

Unlike research studies that are focused on a specific disease or population, *All of Us* will serve as a national research resource to inform thousands of studies, covering a wide variety of health conditions. Researchers will be able to access data from the program to learn more about how individual differences in lifestyle, environment and biological makeup can influence health and disease. Participants will be able to access their own health information, summary data about the entire participant community and information about studies and findings that come from *All of Us*.

In California, the *All of Us* Research Program is being implemented by the California Precision Medicine Consortium, which is co-led by Ohno-Machado at UC San Diego Health and Hoda Anton-Culver, PhD, at UCI Health. The consortium also includes UC Davis, UC San Francisco, Keck School of Medicine of the University of Southern California, Cedars-Sinai Medical Center and the San Diego Blood Bank. In San Diego, San Ysidro Health is also enrolling participants, and the Scripps Translational Science Institute at The Scripps Research Institute is working with corporate partners to enroll participants nationwide.


“We hope Californians from all backgrounds will want to participate in *All of Us* to help make history and change the future of health,” Ohno-Machado said. “We look forward to sharing this exciting and revolutionary journey with our many participants.”

Congress has authorized \$1.455 billion over 10 years for *All of Us*. More than 25,000 people nationwide have already joined the program as part of a year-long beta testing phase that helped shape the participant experience.

“The time is now to transform how we conduct research — with participants as partners — to shed new light on how to stay healthy and manage disease in more personalized ways. This is what we can accomplish through *All of Us*,” said NIH Director Francis S. Collins, MD, PhD.

“All of Us” is a registered service mark of the U.S. Department of Health & Human Services.

How to participate

- → To learn more about the *All of Us* Research Program and how to join, please visit JoinAllofUs.org 
- → Participants are asked to share different types of health and lifestyle information, including through online surveys and electronic health records, which will continue to be collected over the course of the program.
- → At different times over the coming months and years, some participants will be asked to visit a local partner site to provide blood and urine samples and to have basic physical measurements taken, such as height and weight. In San Diego, that may take place at UC San Diego Health, San Ysidro Health or a San Diego Blood Bank location.

To ensure that the program gathers information from all types of people, especially those who have been underrepresented in research, not everyone will be asked to give physical measures and samples. In the future, participants may be invited to share data through wearable devices and to join follow-up research studies, including clinical trials. Also in future phases of the program, children will be able to enroll, and the program will add more data types, such as genetic data.

Contact: 858-265-1711, allofus@ucsd.edu

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