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2023 Patient Advisor Retreat

Patient Engaged Research Center

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All of Us Research Program PFAC

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What is All of Us?



The goal of the *All of Us* Research Program (AoURP) is to help improve the future of health by accelerating health research and medical breakthroughs. The AoURP is part of the National Institutes of Health (NIH) Precision Medicine Initiative and seeks to help researchers understand more about why people get sick or stay healthy.

The *All of Us* Research Program has established nationwide partnerships to build a research cohort to advance precision medicine. **One million** or more people living in the U.S. are being asked to share various types of health data over 10 years or more to build the largest and most **diverse health database** of its kind.

Learn More:
<https://henryford.joinallofus.org/learnmore>



Placement Scope & Goals

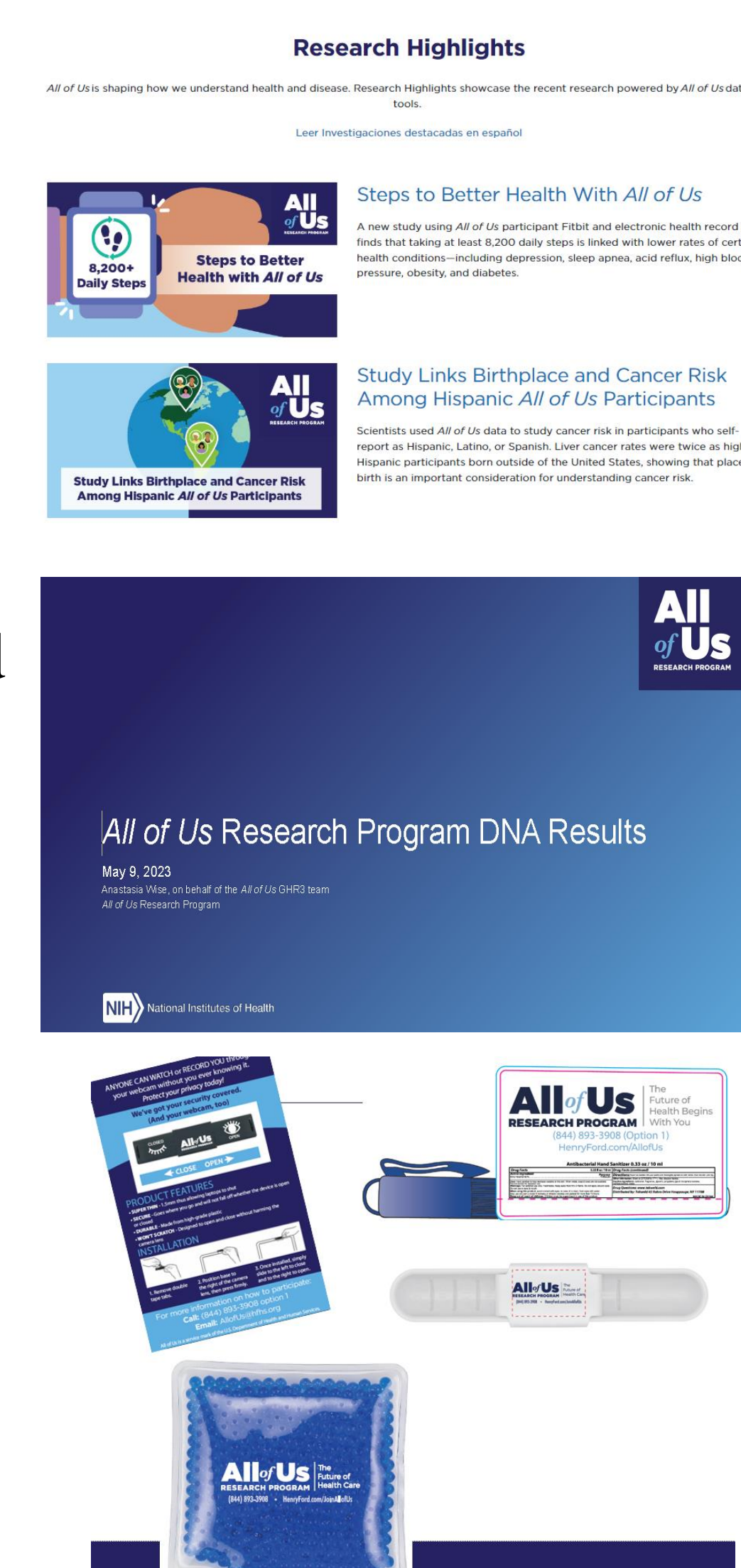
Invitation: Call for Participation on the *All of Us* Research Program PFAC - "The Henry Ford *All of Us* Team wants to thank you for being our partner in this effort to speed up health research and medical breakthroughs." Active participants in the program are invited to join the PFAC.

Goal: Share ideas, suggestions, and feedback about the program by becoming a member of the *All of Us* Advisory Council. You are asked for your feedback and suggestions as Advisors.

When: The council meets (online) every other month for 90 minutes (5:00-6:30 pm) to discuss updates on the program. Advisors receive a \$25 gift card for each online meeting they participate in.

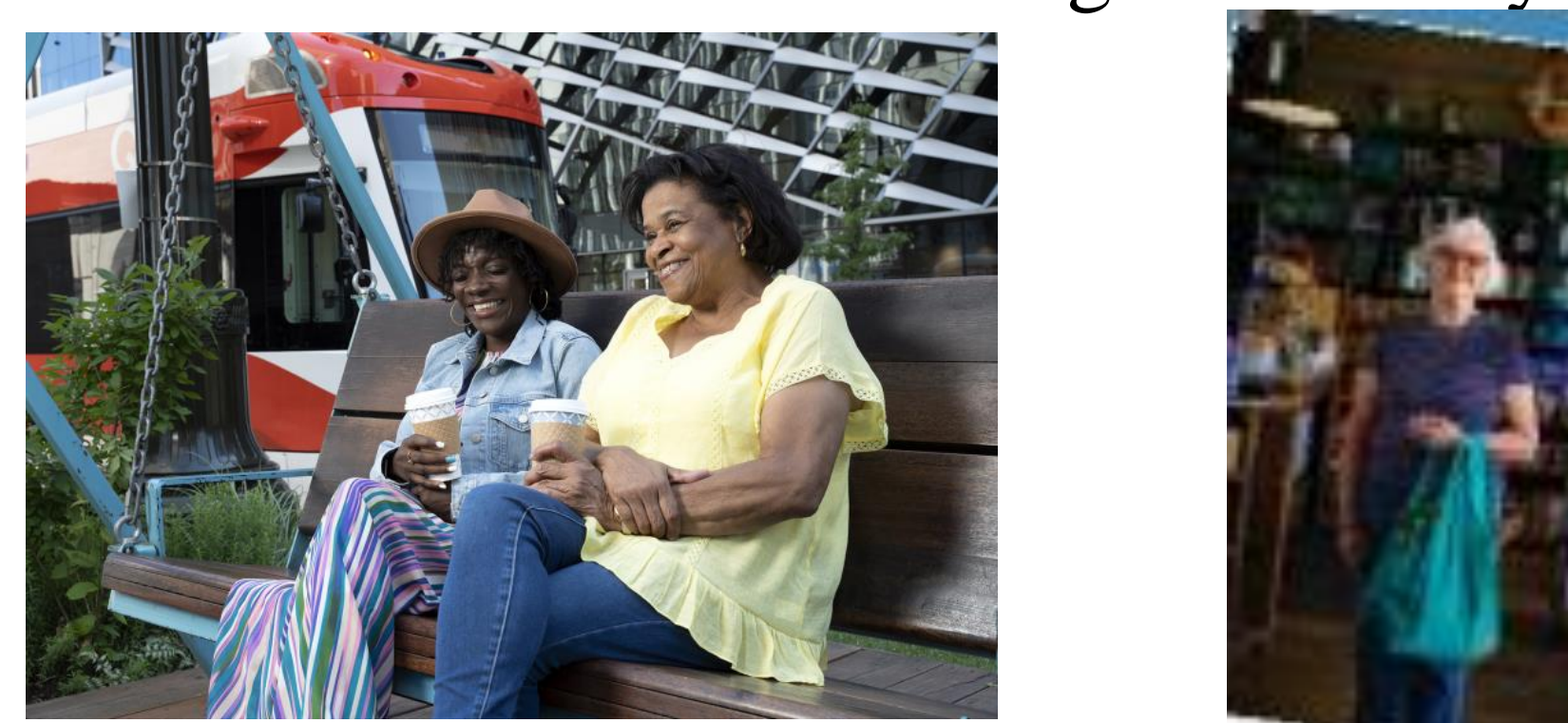
Past & Current Projects

- In 2023, the program released Researcher Highlights on research being done with the program. Advisors learned about these projects & provided feedback on return of value.
- We continued our Lecture Series and in May 2023, we had NIH guest speaker Dr. Anastasia Wise educate the advisors on return of genetic results.
- Advisors were educated on local marketing materials and helped select our new SWAG for engagement and outreach to potential participants.



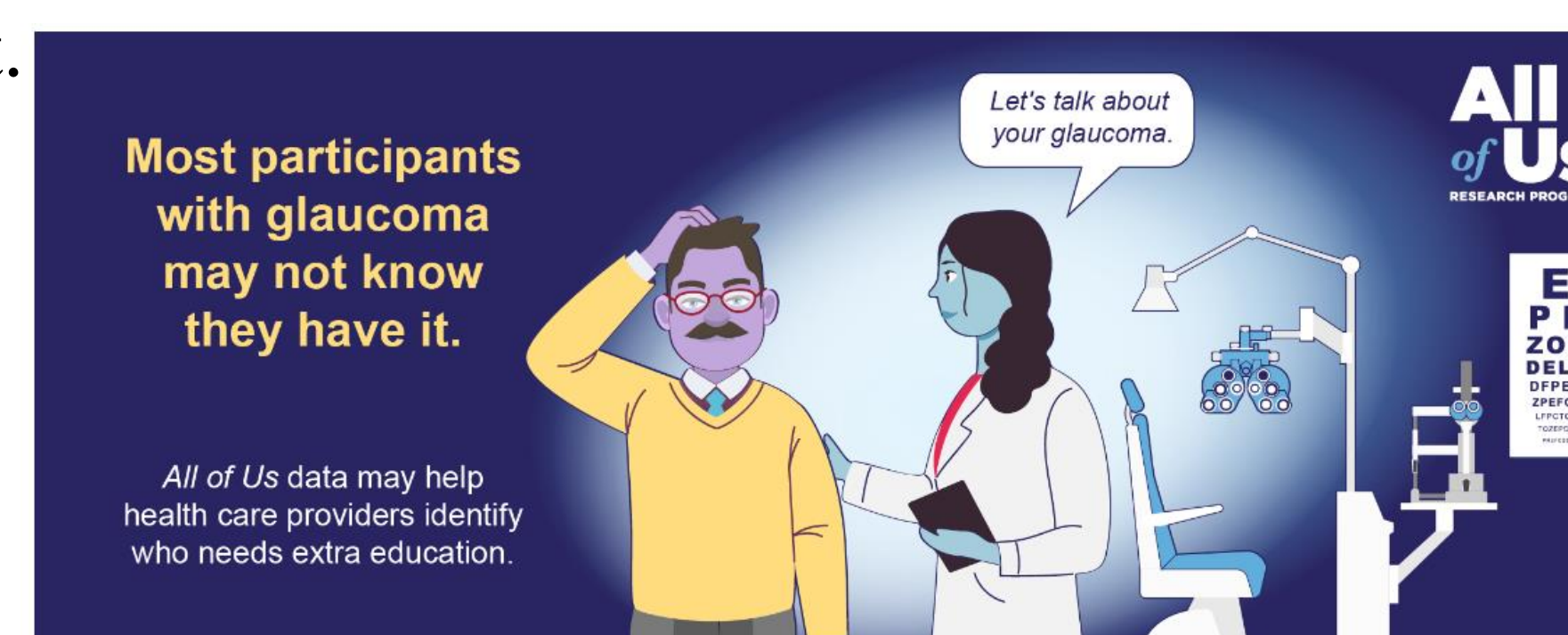
Accomplishments

In 2022, advisors participated in an *All of Us* National Communications photoshoot that took place in downtown Detroit. The areas and landmarks of the photoshoot were picked to showcase our thriving community.



Now in 2023, these photos are being utilized nationally and locally for marketing materials. Our new brochure featuring our advisor Tykesha Lewis Harper.

The advisors' feedback on researcher highlights were escalated to the NIH and the program is planning for participants to be able to review these highlights on their account.



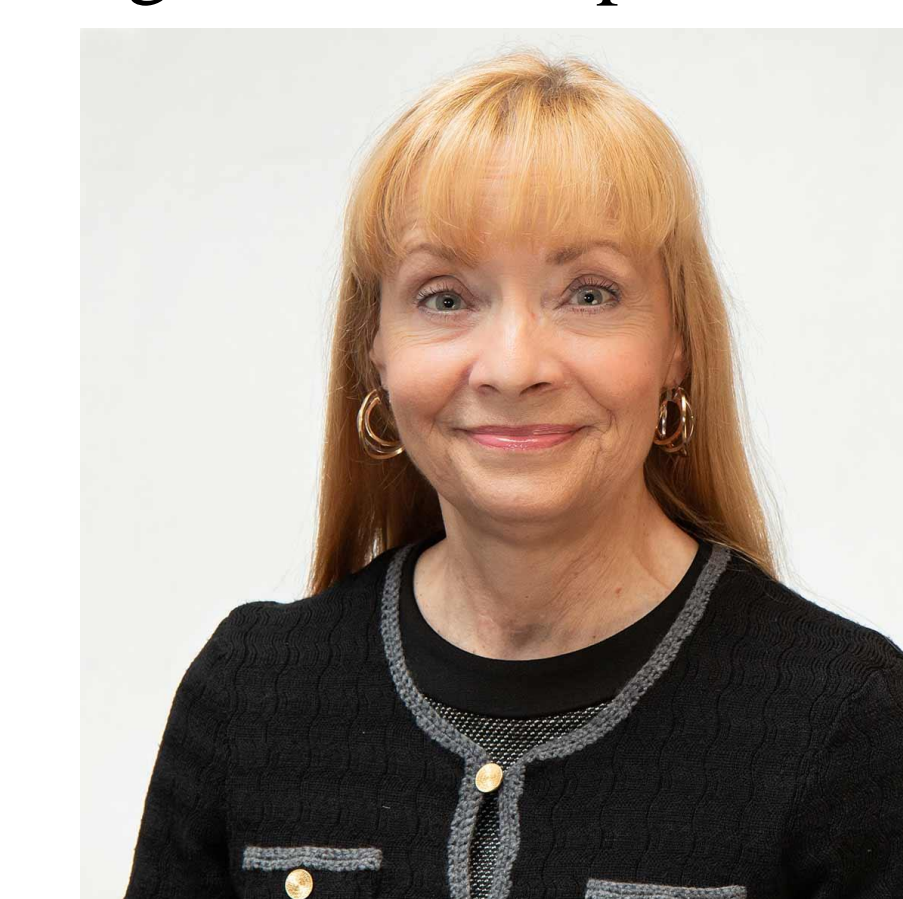
NIH Advisors

Several members have been selected to also serve on National NIH workgroups and councils. Below highlights two advisors who currently sit on these councils and have been a part of the PFAC since 2017:



Rande Bloom (she/her) is a Registered Nurse with an M.B.A. and a Ph.D. in human services, focusing on the leadership of nonprofit organizations. Rande is proud to have been invited to share the voice of AoU program participants with the Henry Ford team at the time of our initial proposal to NIH in 2017.

As a Participant Advisor and Ambassador, she currently serves on the program's Participant Provided Information Committee (PPI) and is a member of the Program's Participant Ambassador Team.



Elizabeth Rubinstein has been honored to serve as a patient advisor for the Henry Ford Health since 2008 to bring the participant voice to the *All of Us* (AoU) Research Program nationally.

She has served in many capacities within the AoU research program since 2017 and currently represents the participant voice on the Advisory Panel to drive value, enrollment, and retention with meaningful participant engagement strategies.

Challenges

- Virtual setting is still a challenge. In the new year, we aim to have hybrid meetings. With the expansion of the group, it is best to continue virtually, as participants are across the state.

Conclusion

- The participant advisor voices will continue to guide the *All of Us* Research Program at both the local and national levels to support awareness, enrollment and retention in the program.