# The Dish: Your Participant Reps—Face-to-Face with Steve Mikita

[www.youtube.com/watch?v=eumPa4N5r70](http://www.youtube.com/watch?v=eumPa4N5r70)

## Title Slide: The Dish, Your Participant Reps

## Title: Face-to-Face with Steve Mikita, July 10, 2017

*Logo of the All of Us Research Program*

## Scene Change

Eric Dishman and Steve Mikita sitting together.

## Dr. Dishman:

Welcome back to the Director’s Corner. Today we are shooting from our face-to-face, so all the consortium members have come from around the country who have been working on the *All of Us* program. And I’m here with Steve Mikita, who’s joined our Steering Committee, to help us understand his motivation and his desire to be part of our Steering Committee and make sure we steer the ship of the *All of Us* program into good waters from now and into the next 75 years. Would you mind sharing a little bit of your own story that, in part, motivates you to participate in this?

## Mr. Mikita:

At 15 months old, I was showing no inclination to stand, let alone walk. My father, who was a physician, brought me to the NIH. And after three days of poking and probing by physicians, the verdict was as unanimous as it was devastating: that I was dying of a rapidly progressive neuromuscular disease. My mother always said something, Eric, that I think is indicative of “Why this program?” Every time I was hospitalized she said, “We are obtaining more information,” what we call health data now, “that will help me take better care of you.”

That is basically the basis of the *All of Us* Research Program. We’re asking people to tell us about themselves, to give biospecimens—and they’re not terribly invasive—but the most important thing, like my parents and I had—we’re inviting them to have a relationship with us.

## Dr. Dishman:

The *All of Us* program wants to reach so many people who may not even really understand what research is—have never had any exposure to it themselves. How do you think we get that message and the importance of them being involved in the research, because they’ve been left behind before?

## Mr. Mikita:

You’re going to be someone or you will know someone who needs answers, and there is a great deal of individuals in this country who are underrepresented in clinical research. That is something that drove me to this particular initiative—is that those individuals—their lives, like my life—their health information, like my health information, matters. And because it matters, it will inform and help researchers more precisely and target answers to everyone’s medical questions. Why do some people in this country not get sick and other people do get sick? And so, that will help us discover new ways, like my mom would say, of making everybody healthier.

## Dr. Dishman:

I’m honored to get to know you personally. I’m thrilled that you’re going to help advise us in what we do as we go forward. And both of us have been resilient in spite of odds that should have said we would be long gone, and maybe research about our resilience will itself become something that empowers others to actually have a better health experience in the future. So thanks for participating in *All of Us*, and it’s going to be a fun journey to go on together.

## Mr. Mikita:

Thank you, sir. I can’t wait.

## Dr. Dishman:

Me too.

## Closing slide

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