

PPC Action Alert

Tell Congress to Support Pediatric Enrollment in the All of Us Research Program

The National Institutes of Health (NIH) recently announced further delays in pediatric enrollment in the *All of Us Research Program* and we have a time-sensitive advocacy opportunity for you to speak up for children. **We need you to take action as soon as possible.**

Your senators and representatives can help by joining a letter to NIH on the importance of the inclusion of children in this study.

The *All of Us Research Program* is a long-standing endeavor to collect and examine genomic and health data from a large, diverse sample of people living in the United States. This program will help inform thousands of studies on a variety of health conditions, advancing personalized medical care and treatments that will enhance the quality of life.

Since its inception, the NIH has received more than \$3 billion for *All of Us* in direct funding through both the Cures Act and the annual appropriations process. While the program has enrolled hundreds of thousands of adult participants since its inception, pediatric enrollment has consistently been put off.

After an expected reduction in Cures Act funding, NIH recently announced a further postponement of the long-delayed enrollment of children in the study. The inclusion of children in *All of Us* is critically important to improving the health of young people through improved clinical care, drug therapies, and behavioral interventions. It is essential that *All of Us* begin the important work of enrolling children to maximize the federal investment of this groundbreaking program.

That's where we need your help. You can take action to educate your members of Congress about the importance of including young people in *All of Us* and advocate that they ask NIH to adequately fund pediatric activities.

Three members of the House – Rep. Yadira Caraveo (D-Colo.), Rep. John Joyce (R-Pa.), and Rep. Michael McCaul (R-Texas) – are circulating a **bipartisan letter** and asking for their colleagues across Congress to join them in signing it. This letter will be sent to the NIH, the agency responsible for administering All of Us. The letter asks the NIH to ensure that pediatric activities in the All of Us Research Program are sufficiently funded, as well as requests an update on NIH's plans for pediatric enrollment in All of Us by providing an estimated timeline for initiating the program's expansion to include young people.

Please email or call your U.S. representative as soon as possible and ask them to sign the Caraveo/Joyce/McCaul letter of support for pediatric enrollment into *All of Us*. A template email and phone script specifically for contacting your U.S. representative is available below.

Contact Your Representative Today

Reach out to your U.S. representative today and urge them to sign the Caraveo/Joyce/McCaul letter of support for pediatric enrollment into *All of Us*. You can reach out to them by phone or by email. If you have time, you can call and then follow-up via email to maximize your impact.

By Phone: You can call the U.S. Capitol switchboard at (202) 224-3121 to be connected to your representative's office. You also can find your U.S. representative by going to **House.gov** and using the "Find Your Representative" feature at the top right of the page. To find your U.S. senators, visit **Senate.gov** and use the "Find Your Senators" feature at the top left of the page. The contact information for their Washington, DC, office is available on their websites.

Talking points

- Hello. My name is {First and last name} from {Town}. I am an academic pediatrician specializing in {insert your area of research expertise e.g., pediatric endocrinology, etc.}, and I am calling today to urge {Representative's name} to sign Representative Caraveo, Representative Joyce, and Representative McCaul's letter supporting pediatric enrollment in the All of Us Research Program at NIH.
- Since the program's inception, children have yet to benefit from All of Us despite generous funding provided by Congress.
- Further delays in enrolling children will only slow down the process of new data collection, and will hinder innovative breakthroughs to address genetic, hereditary, and lifestyle disease risks among children.
- Pediatricians know first-hand the returns on investing in pediatric research. Over the past few
 decades, investments in pediatric research have led to major achievements in improving child health,
 reducing mortality among premature infants, and curing certain childhood cancers.
- As biomedical research continues to evolve, children must be included to ensure they have access to next generation treatments and cures that will improve their health and well-being. NIH must prioritize pediatric enrollment in All of Us with currently available funds to ensure continued advancements in child health.
- I hope {Representative's name} will consider supporting pediatric enrollment in All of Us and sign Representatives Caraveo, Joyce, and McCaul's letter.
- Thank you for all you do for children.

By Email: You can email your representative through their website. You can find your U.S. representative by going to **House.gov** and using the "Find Your Representative" feature at the top right of the page. To find your U.S. senators, visit **Senate.gov** and use the "Find Your Senators" feature at the top left of the page. Email your U.S. representative and senators through the contact form on their websites by customizing the talking points below.

Email text:

Subject: Support Pediatric Enrollment in the All of Us Research Program!

As a constituent I am urging you to sign Representative Caraveo, Representative Joyce, and Representative McCaul's letter supporting pediatric enrollment in the *All of Us Research Program* at the National Institutes of Health (NIH).

Since its inception, the NIH has received more than \$3 billion for *All of Us* in direct funding through both the 21st Century Cures Act and the annual appropriations process. This funding has positioned *All of Us* to be at the cutting edge of precision medicine, as this program aims to inform thousands of studies on a variety of health conditions.

While the program has enrolled hundreds of thousands of adult participants since its inception, nationwide pediatric enrollment has consistently been put off. Now, NIH recently announced a further postponement of the long-delayed enrollment of children in the study. Further delays in enrolling children will only slow down the process of new data collection, and will hinder innovative breakthroughs to address genetic, hereditary, and lifestyle disease risks among children.

The inclusion of children in federally funded biomedical research is critically important to improving the health of young people through improved clinical care, drug therapies, and behavioral interventions. Studying children's health will help identify the early risk factors for adult-related disorders and create preventative measures for chronic, lifelong conditions.

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As biomedical research continues to evolve, children must be included to ensure they have access to next generation treatments and cures that will improve their health and well-being. NIH must prioritize pediatric enrollment in All of Us with currently available funds to ensure continued advancements in child health.

Please consider supporting pediatric enrollment in *All of Us* and sign the letter being circulated by Representatives Caraveo, Joyce, and McCaul calling on NIH to address pediatric enrollment in *All of Us*. Contact Elizabeth Tapia (Elizabeth.Tapia2@mail.house.gov) in Rep. Caraveo's office for more information.

Thank you for all you do for children and families in our state.