



## ***Learning From Communities, Best Practices in Community Based Research*** **May 4, 2023**

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| <b>12:00 pm</b>            | <b>Welcome and Introduction</b> <ul style="list-style-type: none"><li>• <b>Gwen Darien</b><br/><i>Executive Vice President, Patient Advocacy and Engagement</i><br/>Patient Advocate Foundation &amp; National Patient Advocate Foundation</li></ul>  |
| <b>12:10 pm – 12:45 pm</b> | <b>Finding Community Through Images</b> <ul style="list-style-type: none"><li>• <b>Silvia Cunto-Amesty, MD</b><br/><i>Assistant Professor of Medicine</i><br/>Columbia University Irving Medical Center</li></ul>   |
| <b>12:45 pm – 1:15 pm</b>  | <b>Sacred Partnerships</b> <ul style="list-style-type: none"><li>• <b>Alma McCormick, MA</b><br/><i>Executive Director</i><br/>Messengers for Health</li><li>• <b>Suzanne Held, PhD</b><br/><i>Professor</i><br/>Montana State University</li></ul>   |
| <b>1:15 pm – 1:45 pm</b>   | <b>The Power of Co-Creation in Developing Tools to Advance Trust</b> <ul style="list-style-type: none"><li>• <b>Melanie Lawrence</b><br/><i>Patient Advocate and Research Advisor</i><br/>Cystic Fibrosis Community</li><li>• <b>Stacy Van Gorp, PhD</b><br/><i>Advocate for People with Cystic Fibrosis and Trust Researcher</i><br/>Cystic Fibrosis Community</li></ul>               |
| <b>1:45 pm – 1:55 pm</b>   | <b>Finding Financial Resources</b> <ul style="list-style-type: none"><li>• <b>Tracy Hollis</b><br/><i>Patient Education Resource Specialist</i><br/>Patient Advocate Foundation</li></ul>   |
| <b>1:55 pm – 2:25 pm</b>   | <b>Citizen Scientists Driving Research</b> <p><b>Moderator:</b> <b>Gwen Darien</b>, <i>Executive Vice President, Patient Advocacy and Engagement</i><br/>Patient Advocate Foundation &amp; National Patient Advocate Foundation</p> <p><b>Panelists:</b></p> <ul style="list-style-type: none"><li>• <b>Karriem Watson, DHSc, MS, MPH</b><br/><i>Chief Engagement Officer</i></li></ul> |

All of Us at the National Institutes of Health

**Additional Panelists TBA**

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| <b>2:25 pm – 2:45 pm</b> | <b>Building Community: Patients Leading Research Priorities During the COVID-19 Pandemic</b> <ul style="list-style-type: none"><li>• <b>Charlene Berke, R.T. (R)(T)(ARRT)</b><br/><i>Project Director, Upper Midwest Palliative Care Education Network</i><br/>Avera Sacred Heart Hospital</li><br/><li>• <b>Jamie Stokley</b><br/><i>Founder</i><br/>Helping Hands of the Cape Fear &amp; Helping Harvest Foundation, Inc.</li><br/><li>• <b>Mary Mukira</b><br/><i>Manager, Grassroots Advocacy</i><br/>National Patient Advocate Foundation</li></ul> |
| <b>2:45 pm – 3:20 pm</b> | <b>Assessing Meaningful Community Engagement</b> <ul style="list-style-type: none"><li>• <b>Maret Felzien, MA</b><br/><i>Community Partner</i><br/>Eastern Plains for Colorado</li><br/><li>• <b>Ayodola Anise, MHS</b><br/><i>Senior Director of Operations</i><br/>Milken Institute</li></ul>  |
| <b>3:20 pm – 3:50 pm</b> | <b>The Power of Community: A Research Partnership in Alaska</b> <ul style="list-style-type: none"><li>• <b>Ay'aqulluk Jim Chaliak</b><br/><i>Tribal Member</i><br/>Native Village of Nunapitchuk<br/><i>Director of Preventative Services</i><br/>Yukon-Kuskokwim Health Corporation, Division of Behavioral Health</li><br/><li>• <b>Katie Cueva, ScD, MAT, MPH</b><br/><i>Assistant Professor of Health Policy</i><br/>University of Alaska- Anchorage</li></ul>   |
| <b>3:50 pm – 4:00 pm</b> | <b>Summary &amp; Closing Remarks</b> <ul style="list-style-type: none"><li>• <b>Alan Balch, PhD</b><br/><i>Chief Executive Officer</i><br/>Patient Advocate Foundation &amp; National Patient Advocate Foundation</li></ul>  |
| <b>4:00 pm</b>           | <b>Advocates in Action Podcast Excerpt</b><br><b>The Tide That Lifts All Ships</b> <ul style="list-style-type: none"><li>• <b>Pamela Browner White</b><br/><i>Senior Vice President of Communications</i><br/>American Board of Internal Medicine (ABIM)</li></ul>   |