

Equity Equals Excellence

A Blueprint for Access



FARE

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Letter of Reflection From FARE Diversity, Equity, Inclusion and Access (DEIA) Roundtable Leadership

Healthcare is a critical need for all people and communities, yet racial disparities in healthcare have existed throughout our history. Patient advocacy groups, like FARE, the world's largest funder of food allergy research, exist to serve all patients suffering the impact of disease. As such, FARE has dedicated itself to ensuring that everyone in the food allergy community has access to the treatment and the standard of care they need regardless of race, income, ability or circumstance.

In 2020, FARE set out to convene a conversation that would create a path forward for patient groups to prioritize, address inequities and ensure all members of patient communities are fully represented, especially in the areas of clinical research and care.

The report that follows was developed as a result of a series of dedicated discussions and thoughtful reflections around the important issues of diversity, equity, inclusion and access (DEIA). It outlines barriers and solutions to serve as a guide for FARE and other patient advocacy organizations as we embrace and expand DEIA to better serve patient populations. The roadmap within seeks to advance conversation and collaboration with Black, Indigenous and People of Color (BIPOC) and lower-income community members, ensuring that the underrepresented and under-resourced have seats at the table and their needs are met.

We thank all those who have lent their unique voices throughout these discussions, sharing insights to build consensus on how patient advocacy organizations can advance DEIA in communities. Your contributions are invaluable. We are especially grateful to the expert facilitation skills of Dr. Debra Joy Pérez, an expert in advancing organizational equity, inclusion and diversity.

Together, we have an opportunity to change the future for patient communities across the world, and we welcome you to join us on this journey to a better and more equitable tomorrow.

Sincerely,



Dr. Milton Brown
FARE Board of Directors



Dr. Kaye Cole
FARE Board of National Ambassadors



Michael Frazier
FARE Board of National Ambassadors



Lisa Gable
Chief Executive Officer, FARE



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Executive Summary

Equity Equals Excellence

A Blueprint for Access



Goals: Establish an expert-guided roadmap that supports efforts by organizations like FARE to:

1. Build and maintain a pipeline for the next generation of Black, Indigenous and People of Color (BIPOC) entrepreneurs, healthcare providers, nutrition educators and researchers to reduce the institutional barriers and the systemic and structural racism faced by these communities.
2. Identify equitable, inclusive and respectful strategies that engage and build awareness in communities, particularly communities facing institutional barriers and systemic racism.
3. Expand the development and dissemination of patient-centered interventions that improve access to high-quality care for BIPOC and/or low-income communities.

Blueprint for Access Process

- *Blueprint for Access* was developed as a culmination of a three-part virtual Roundtable Series on Diversity, Equity, Inclusion and Access (DEIA). The series was led by:
 - A facilitator with expertise in navigating DEIA conversations
 - Non-profit, academic, research and industry experts in DEIA
 - FARE leadership and staff
- The FARE Roundtable Series on DEIA focused on:
 - Creating brave and safe spaces for uncomfortable conversations on DEIA
 - Highlighting our nation’s progress and exploring how much further we need to go to meet the needs of providing high-quality healthcare for all patients
 - Discussing human resource and talent-building practices that elevate DEIA
 - Supporting equitable engagement within communities and more inclusive research

Blueprint for Access Lessons

- **To build and maintain a pipeline for a more diverse and inclusive generation**, it is important to engage young people early, recruit and build intentionally to foster belonging and ensure equity, impact collegiate education when possible, and expand professional development opportunities.
- **To improve equitable access to resources**, it is important to listen, learn and give back with intention throughout the community engagement process. Equity equals excellence.
- **To improve equitable access to research**, patient organizations must work with clinical research teams to build trust while “meeting communities where they are” with open, honest and accessible information about studies and findings, as well as practical accommodations that support and simplify participation.

Blueprint for Access Use Case Statement

FARE is laser-focused on paving the way to equitable access for a high quality of care for all patients living with food allergies. *Blueprint for Access* provides us a framework to do so, and we encourage all readers to use this resource as a guide toward change at the organizational, community, governmental and societal levels.

Purpose and Process of the FARE Roundtable Series on DEIA

Background

Food allergies are a serious health threat to 32 million Americans. They can exact a significant toll on quality of life and trigger serious economic challenges while also subjecting patients and families to the daily risk of life-threatening anaphylaxis. As with other diseases, food allergy is no stranger to racial and income disparities. For instance, the only food allergy treatment approved by the U.S. Food and Drug Administration (FDA) is specific to peanut allergy and requires access to specialty care that is not equitably available to all communities.

Recent research demonstrates that Black Americans are significantly more likely than white Americans to develop food allergies (Gupta et al., 2018; Gupta et al., 2019). Additionally, Black and Latino children are at higher risk of adverse outcomes from food allergy compared to white children. Yet, data shows that Black food allergy families, as well as food allergy families in the lowest income bracket, are spending much less on specialist visits than those in higher income brackets. When access to specialty care is limited by financial barriers and time constraints, increased spending on emergency medical care and poorer health outcomes for families can result down the line.

Access to safe and affordable food is also an issue. FARE, in partnership with McKinsey & Company and Global Strategy Group, found that food-allergic individuals spend 5 percent more than the average consumer. These consumers face burdens accessing the food they need, visiting multiple stores and stocking up to find safe, tasty and affordable foods. Those who are unable to spend more have an even greater challenge (FARE, 2020). Costs incurred for food allergy-related emergency department visits and hospitalizations are 2.5 times greater for low-income children than for higher-income children. Increased hospital care costs for low-income children are likely attributable to difficulties in accessing epinephrine and safe, affordable food (Bilaver et al., 2016). These families must face all the typical challenges of raising a child with food allergy without the security of life-saving epinephrine and access to food that is safe for them to eat.

The barriers preventing BIPOC and/or lower-income community members from accessing specialty care also affect rates of diagnosis. Recent studies suggest that rates of official diagnosis of food allergy are 87 percent lower among a Medicaid population than a general population (Bilaver et al., 2020; Gupta et al., 2018). Living with an undiagnosed food allergy can raise the likelihood of accidental ingestion. Discrepancies in diagnosis may disproportionately affect Black and Latino Americans, as they are around twice as likely as white Americans to be covered by Medicaid (Kaiser Family Foundation, 2019). Additionally, Black Americans are 8 percent and Hispanic Americans are 22 percent more likely than whites to not have any health insurance (Sohn, 2017).



Purpose and Process

The lack of access to safe and affordable care and management strategies is not unique to those with a food allergy, but is reflective of gaps that exist between racial and socioeconomic groups requiring medical and nutrition support across the United States. The FARE Roundtable Series on DEIA aimed to take the learnings from DEIA experts in other disease areas to develop patient advocacy-driven solutions that will help FARE and other organizations navigate these issues and expand opportunities to improve health outcomes for underrepresented and under-resourced populations.

The three-part virtual meeting, which was modeled after the FARE Oral Immunotherapy Summit (Pepper et al., 2020), focused on major areas in patient advocacy DEIA. The Roundtable was led by the FARE CEO Lisa Gable as well as leadership from FARE's Board of Directors and Board of National Ambassadors to ensure the learnings from the Roundtable were integrated at the highest level of the organization. A Roundtable Facilitator skilled in DEIA conversation was identified to help participants engage with each other and create space for a more honest conversation.

Representatives from FARE’s Human Resources, Education, Events, Advocacy, Communications and Research teams were selected as support staff. Several preparation meetings took place with FARE leadership, the FARE support team and the Roundtable Facilitator ahead of the first Roundtable session and between sessions as a means to debrief and reflect.

The following topics were selected for each session:

In Session I, the Roundtable Facilitator set the stage for conversations on DEIA with several group exercises, including professional and personal stories related to DEIA. Participants discussed how to implement best practices in DEIA as an organization, whether in hiring practices or the process of fostering the next generation of leaders.

In Session II, the Roundtable Facilitator began with additional discussion-building exercises before addressing considerations for community engagement and research in a DEIA framework.

In Session III, the Roundtable Facilitator led a discussion of the current events that highlighted our nation’s progress in access to care and management strategies and explored how much further we need to go to meet the needs of all patients. This led to an examination of the role that private clinics and consumer packaged goods manufacturers can play in advancing DEIA.

Major Themes From the Roundtable Discussions

Creating Safe and Brave Spaces for DEIA Conversations

Establishing ground rules during the first session set the Roundtable on a course to success. Identified as important by the Roundtable Co-Chairs and led by the Facilitator, these guidelines were put in place via participant feedback in the virtual chat box. The Roundtable Facilitator also called upon individuals to share their own ground rules, ensuring that all participants had a voice and input from the outset.

Ground rules helped to set a safe, inclusive space for all Roundtable participants, which felt especially important during difficult conversations.

In addition to ground rules, additional exercises that were important to these conversations included:

- honest self-reflection on how one’s identity impacts one’s lived experience as an advocate for access to high-quality care
- resources and homework assigned between sessions on pertinent topics
- word clouds to visualize participants’ experiences
- real-life context given for DEIA work

“We are not representatives of an entire community”

“See a discussion from the point of view of the speaker”

“Be respectful of experiences that are different than your own”

“‘Two ears/one mouth’ is an invitation to listen with intention before responding with intention”

“Stories stay, lessons leave”

“Throw glitter, not shade”

“Speak from an ‘I’ perspective”

Building a Leadership Pipeline

Roundtable participants discussed the need to support the next generation of healthcare providers, allied health professionals like registered dietitian nutritionists (RDNs), and entrepreneurs who have entered the space early and holistically as integral for improving equity and diversity. These individuals often serve as educators, caretakers and service/resource providers for communities, making their diversity in race, culture and lived experience especially important.



For instance, while Black people are almost 13 percent of the general population (U.S. Census Bureau, 2020), they make up just 5 percent of practicing physicians and 8 percent of practicing registered nurses (Association of American Medical Colleges, 2019; U.S. Department of Health and Human Services, 2019). Similarly, about 6 percent of practicing physicians and 10 percent of practicing nurses are Latino or Hispanic, while the U.S. population is 18 percent Latino or Hispanic (Association of American Medical Colleges, 2019; U.S. Department of Health and Human Services, 2019). Increasing representation in healthcare and research is critical to expanding access to care and, ultimately, improving health outcomes for all communities, including for individuals with food allergy. This was demonstrated in a National Bureau of Economic Research study, which found that Black men seen by Black doctors agreed to more invasive preventive services than those seen by non-Black doctors—an effect that seemed to be driven by better communication and more trust (Alsan et al., 2019).

Participants discussed steps that can be taken to improve diversity in the healthcare community by supporting the next generation of BIPOC healthcare providers and researchers. These include:

1. **Engage early.** Encourage young people (such as high school students) to take an interest in the field by providing opportunities to learn, ask and engage. Remove the financial and social barriers to doing so.
2. **Recruit and build intentionally.** When bringing in new BIPOC and/or women team members (for example, students, staff, fellows, interns), an infrastructure of equity is needed to help recruits succeed throughout their career. For example, welcoming a cohort of diverse team members can be less isolating, so that each new individual doesn't feel like a "square peg in a round hole."
3. **Impact collegiate education.** Engage with professional and student societies to create learning opportunities specifically for those with historically marginalized identities.
4. **Develop and advocate for affordable, accessible professional opportunities.** Identify barriers that BIPOC physicians and allied health professionals may encounter when applying for funding opportunities and conference presentations and when submitting manuscripts. Ensure your review panels are diverse and recognize that traditionally marginalized people often do not have access to the same networks. Patient advocacy organizations can also push for these improvements within the federal funding process.

"I've been in situations where I was paid well and was given the appropriate title, but I wasn't included in the decision making. Other times I'd been included in the decision-making, but I wouldn't be invited to the golf club outing and I'd learn about it in the hallways."

- Roundtable participant

"You can have the same title but be expected to do twice the amount of work."

- Roundtable participant

Maintaining Leadership Equity

Building diversity by having historically underrepresented people on leadership teams is not enough. An inclusive culture of belonging must be created and intentional efforts in equity must be undertaken to maintain an environment where all individuals thrive as an organization.

Roundtable participants discussed the need to develop equity along five different variables in the workplace:

1. **Pay equity** – Compensating employees similarly when they perform the same or similar duties.
2. **Status equity** – Providing employees with the same or similar standing, title or ranking when employees perform the same or similar duties within an organization.
3. **Decision-making equity** – Enabling employees with the same or similar status the ability to make decisions of similar weight.
4. **Social inclusion equity** – Providing employees of a similar status the opportunity to engage in social activities.
5. **Work-load equity** – Ensuring that teams divide work fairly.

Patient, Consumer and Community Consideration in a DEIA Framework

Roundtable participants discussed how to begin the engagement process and identify community liaisons for patient-centered and community-centered work.

Prior to Community Engagement

Conduct landscape analysis. This is important to understand the historical and current events that have implications on the current condition of the community. Community mapping or geo-mapping is an important part of this step, which can assist in targeting the most appropriate areas and neighborhoods based on your population and its local resources (or lack thereof) that contribute to the social determinants of health. It can also be helpful to reach out to local clinics and health centers to identify common challenges and gaps in care and resources. This might be especially important in pediatric and primary care settings.

Reach out to your networks. It can be critical to know someone in the community before engaging. Connect with local people you know who work within the community (for example, church members, sorority/ fraternity members, school faculty, physicians, nurses, and social workers).

While Engaging With the Community

Identify community liaisons and cultural brokers. As defined by Family Voices, **community liaisons** are “trusted individuals who may or may not live in a certain community, yet have knowledge of a community’s strengths, preferences and needs,” and **cultural brokers** have additional insights into the values, beliefs and practices of the community (Jones and Thomas, 2009, p. 8).

Patient Advisory Boards

One avenue for patient advocacy organizations may be the community advisory boards at local hospitals serving Medicaid and low-income populations. When thoughtfully engaged by their hospitals, these community and patient advisory boards can be active participants in improving how care is delivered. Researchers and clinicians can play a key role in connecting you with patients who have impactful stories to share.

Lead with the “one mouth, two ears” mindset. Listen to the community: Do not attempt to tell the community what they need. Connect back to community resources and organizations even outside of your company’s wheelhouse, especially when addressing co-morbidities that the community is facing. Avoid parachuting in a solution, and allow the community to be the messenger. Validate what you “think” might work with your community liaisons and advisors to bless it and then partner actively in the messaging, in events, and in talkback sessions.

Post-Engagement

Disseminate data and information back to the community. Any insights, including quantitative and qualitative data, should be disseminated back to the community in a timely manner. Data sharing, as well as any subsequent needs assessment, should be made accessible to the community. The lack of accessible information, data and resources allows for myths and mistrust to perpetuate.

Roundtable participants discussed the following steps to make resources developed for and by communities accessible. Such information should be delivered:

- **via a trusted messenger that the community wants to hear from.** Ask the community who that messenger is early on (for example, a physician, patient or local official).
- **in a manner that is culturally sensitive.** Certain words and phrases do not resonate well with certain communities.
- **in a format that is accepted by the community.** This would include Americans with Disabilities Act compliance.
- **on a platform that the community is willing to use.** Ask the community what that platform is early on (for example, social media, radio, in-person).

Unconscious Bias

Unconscious bias can result in failure to engage BIPOC communities. Examples include patients not being asked to participate in research because of assumptions of mistrust, employees being overlooked for critical career advancement opportunities, students missing out on mentorship prospects, and entrepreneurs being locked out of powerful fundraising networks. Unconscious bias can also result in a failure to recognize signs and symptoms equitably, which has been seen in cases where Black people are assumed, even to this day, to have a higher level of tolerance to pain. In fact, half of medical students and residents surveyed by University of Virginia researchers held one or more false beliefs, including “Black people’s nerve endings are less sensitive than white people’s”; “Black people’s skin is thicker than white people’s”; and “Black people’s blood coagulates more quickly than white people’s” (Hoffman et al., 2016). These biases contribute to racial disparities in pain assessment and treatment.

Institutions like medical schools can use unconscious bias training to help build cultural competency among people with power, helping them learn to recognize and manage bias to promote better decision-making.

Patient Advocacy Groups: Powerful Partners in Improving DEIA in Research and Clinical Care

Patient advocacy organizations can play an important role in supporting, collaborating toward and advocating for diversity, equity and inclusion to ensure access to research. Given the importance of clinical research in developing new treatments, prevention strategies and cures, this is a vital area where representation can improve patient and community outcomes. For instance, treatment safety and efficacy can differ among people, and when trials are not representative, the results are not generalizable. Thus, efforts to improve accessibility are essential not only for BIPOC and/or low-income communities, but also for the whole of the patient population.

Despite this, large academic institutions may not have the systems, workforce or budget in place to conduct the outreach and engagement needed. In addition, mistrust of clinical research in BIPOC communities, who have historically faced mistreatment by the medical community, can impact representation within studies. This mistrust can lead to a vicious cycle, adding to the bias researchers might have and potentially causing them to not engage BIPOC patients. This, among other access issues, can impact whether communities can equitably learn about applicable research opportunities.

The Roundtable participants discussed the important role that patient advocacy groups can play in bridging the gap in access to information, education and participation in clinical research.

At every step of the research process, there are important considerations for patient advocacy organizations and clinicians to examine collaboratively that can help improve equitable access to clinical research. A few examples include:

Pre-Study Launch

- **Build trust through open honest communication.** Discuss with the community the harmful impact of the disease and the potential beneficial impact of the community's participation in research, as well as any known risks. This is especially important for BIPOC communities, which have historical reasons for mistrust.
- **Select hypotheses to test that are patient-centered.** Focusing on burdens and barriers that are important to the target audience demonstrates respect and appreciation of patients living with the disease.
- **Consider the cost implications of the investigational diagnostic, treatment or prevention strategy in the beginning.** Determine the role of reimbursement through Medicare and Medicaid and other ways to ensure that the product is affordable for lower-income members of the community.
- **Build patient advisory boards that represent the target audience.** These boards can provide the stories, insights and perspectives needed to set research and advocacy teams up for success.
- **Find ways in advance to reduce financial barriers and time constraints to patient/caregiver participation in studies.**
- **Encourage diverse research teams.** Diversity in race, ethnicity, lived experience, religion, gender and spoken language could be key to engaging representative audiences and improving subsequent recruitment and adherence.
- **Assess the composition of existing networks and mechanisms for all steps of study participation and evaluate how to align commitment to DEIA across all partnerships.**

Recruitment

- **Heighten the visibility of clinical trial opportunities by meeting the community where they live or on their own terms.** This can be done through culturally appropriate messages on social media, community websites, radio, TV, recreational centers and transportation hubs. Word-of-mouth messages through places of worship, parent organizations, book clubs and other groups are also important.
- **Hold free, multilingual informational sessions with dedicated Q&A periods to inform decision-making.** Invite community leaders, ambassadors and members to take part in the discussion.
- **Be transparent about the study hypothesis and study design (intervention arm, control arm and placebo).** It is also important to discuss the benefits and risks, data protection and confidentiality.
- **Reduce the rigidity of the inclusion/exclusion criteria when possible.**
- **Develop a plan for just and fair incentives and reimbursement for participation in research.**
- **Acknowledge the history of exclusion that has led to low participation of underrepresented communities and commit to operating differently.**



Post-Study

- **Maintain contact post-study.** Disseminate results to the patient in an accessible format, by the appropriate messenger, in an accessible platform. Consider delivering the major finding through engagement events.
- **Consider the ethics of crossing-over for the placebo arm.**

Beyond the Study Period

- **Develop academic and clinical affiliations, as well as satellite and clinic sites, to improve access to clinical research and care.**
- **Encourage federal representatives to prioritize the need for diversity in recruitment and retention** as well as to increase reimbursement by Medicaid and private insurance.
- **Train and fund more BIPOC investigators** to conduct clinical research to improve representation in clinical trials (Otado et al., 2015).

REFLECTION

FARE has made meaningful and significant changes over the past two years to prioritize Diversity, Equity, Inclusion and Access (DEIA) and to elevate the voice of all patients, particularly BIPOC and/or low-income individuals. We advocate on their behalf, building trust within underrepresented and under-resourced communities and breaking down barriers to care and resources. There is more work to be done, especially after these enriching Roundtable conversations. *Ultimately, we are laser-focused on paving the way to equitable access to the highest quality of care and treatments for all patients living with food allergies.*

The insights and discussions in this Blueprint give us a roadmap to reflect on and to inform our upcoming efforts to improve outcomes for those not traditionally represented in food allergy research, care and treatment. Below are examples of those efforts.

Localized Action to Build Trust and Enable Access

FARE is launching the FARE Community Access Initiative program in collaboration with South Ward Promise Neighborhood (SWPN), in Newark, N.J. Through this partnership, FARE will work hand in hand with community partners like SWPN to assess the needs and gaps in access to care, resources and research. FARE is also building partnerships with local schools, places of worship, and clinics in the area to strengthen our reach within the community—building a representative community council to serve as advisors and liaisons.

Building on grassroots involvement and utilizing the learnings from this assessment, FARE will work to build trust through localized outreach within the community and will measure impact, with the aim of replicating the model to expand food allergy services in other cities across the country. Our paired goals are:

- Deliver culturally appropriate strategies co-developed with the community to bring awareness to food allergy and improve access to care
- Provide trainings and resources to high-needs schools and other critical audiences



Building Better Representation in Research

Insightful and representative data is crucial to the discovery of solutions for all food allergy families. However, at present, the FARE Patient Registry (FARERegistry.org), the largest private food allergy registry in the world, does not sufficiently represent the diversity of the food allergy community. FARE is focused on diversifying the Registry to increase the representation of Black and Latino patients. This will help ensure that the results of clinical trials are more broadly applicable to all members of the food allergy community and will ultimately make new, safe and effective therapies more acceptable and accessible as they are approved.

One way FARE is helping to close these gaps is by establishing a two-year, \$100,000 fellowship program designed to provide mentorship and financial support to Black and Latino graduate student investigators evaluating socio-economic factors impacting healthcare access for food allergy patients. Fellows will facilitate engagement and gather patient-generated health data that will shed light on potential barriers to adoption of new treatments for food allergy patients, with a strategic focus on historically underrepresented communities. The FARE Diversity Fellowship investigators will leverage and enhance the FARE Patient Registry through the diversity of their research participants.



FARE is also in the process of hiring and deploying research coordinators at select FARE Clinical Network sites to facilitate the development of a racially diverse registry of food allergy patients. The grants will be used to assist with FARE Patient Registry recruitment within the clinics to enroll demographically representative participants.

Making Resources More Accessible Through Trusted Community Members

Access to food allergy information and training within under-resourced areas of the country is limited. This leads to a lack of understanding about how to keep those living with the disease safe and included within the community. To begin to address this gap, FARE is developing strategies to build trust and expand access by working with local schools, outreach programs, established community voices and legislative leaders.

- FARE is offering scholarships to Title 1 and Title 1-eligible K-12 schools, Head Start programs, food banks and soup kitchens for the newly launched FARECheck Instructor Training, which is an efficient method to keep all dining staff trained on food safety. In the first year of the program, FARE's scholarships helped train schools reaching 180,000 students.
- FARE also partnered with the National Parent Teacher Association (PTA) and National Association of School Nurses (NASN) to award \$14,000 in funding to 20 different schools/school districts/Parent Teacher Associations, supporting food allergy safety and education at Title 1 schools across the country as part of our inaugural Collaborator Community Impact Awards: Back to School program.
- FARE's Food Allergy Awareness patch has been developed for local Girl Scout Councils across the country, giving girls the tools to engage others in their troop and their families to raise awareness about food allergies and help educate the community. The patch program particularly targets a number of Councils in underserved communities, both rural and urban. For example, in 2020, nearly 20 percent of scouts from the Chesapeake Bay Council were part of a scout program for underserved girls. In the region served by the Diamonds of Arkansas, Oklahoma and Texas, 75 percent of schools are Title 1. And in the urban areas served by the Heart of New Jersey Council, more than 80 percent of scouts are Black.
- FARE will work during the 117th Session of Congress (2021-2022) and beyond to ensure that all children and adults, regardless of their economic status or zip code, have access to life-saving allergy testing. Allergic diseases are the sixth leading cause of chronic illness in the United States and yet, not all Medicare and Medicaid policies, dedicated to providing health care for the most vulnerable Americans, cover both blood (IgE) and skin-prick (percutaneous) allergy tests. FARE will work closely with the Congressional Black Caucus, the Congressional Hispanic Caucus and the Congressional Asian Pacific American Caucus to lobby Congress. Our goal is to support legislation to eliminate this inequity and reduce the unnecessary financial and emotional burden that families and individuals must face when trying to secure safe, accurate and affordable allergy tests.

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