

Racial Disparities in Atopic Dermatitis and Food Allergy:

Physician and Advocacy
Experts Describe Pervasive
Problems and Identify a
Top 10 Solutions Agenda



American
College
of Allergy, Asthma
& Immunology

Situation Overview

Nearly two decades ago, the Institute of Medicine published a groundbreaking report entitled “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,” which concluded that racial and ethnic minorities “receive a lower quality of health care than non-minorities, even when access-related factors, such as patients’ insurance status and income, are controlled.”¹

In just 30 years, more than half of the U.S. population will be people of color.

Today, with the approach of the 20-year anniversary of that report, Dr. Joseph Betancourt acknowledged in a recent interview that little progress has been made. One of the study’s authors and the senior vice president for equity and community health at Massachusetts General Hospital, Dr. Betancourt told NPR: “We laid out a pretty broad and comprehensive blueprint of findings and recommendations. In the area of disparities, we saw some early adopters, some progressive leaders take action. But fundamentally, the real changes that we needed to see, haven’t happened at scale even to today.”²

Awareness of these issues has become more acute since the COVID pandemic, and the impact will only grow in significance.

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In this context, the leadership of the American College of Allergy, Asthma & Immunology (ACAAI) wanted to better understand key issues “close to home” – the effects of racial disparities experienced specifically among patients served by its own members.



The College conducted original research to gain insights into the extent and impact of disparities on people of color who have atopic dermatitis (AD) and food allergies. The universe of Americans affected by these conditions is large: Nearly 32 million children and adults have atopic dermatitis,⁴ and the same number have food allergies.⁵ Both conditions are more prevalent and severe among people of color than previously recognized, according to research.⁶

To better understand levels of awareness and the overall disparity issues, ACAAI surveyed its members, conducted interviews with physicians and advocacy leaders, and hosted a roundtable discussion to further explore the challenges and discuss potential solutions. The research confirmed obstacles to the diagnosis and treatment of AD and food allergy among people of color, with three key findings, many of which are similar to those described in the “Unequal Treatment” report:

- **Physician and Consumer Awareness Is Limited; Time Pressures and Lack of Trust are Significant.** Neither physicians nor consumers are fully informed about the prevalence and severity of atopic dermatitis and food allergy among people of color or about the impact of racial disparities on access to care.

For physicians, there is very little “patient-care time” in health care, making it difficult to prepare for and address the significant obstacles that all patients face. “We are not practicing medicine today; we are practicing time management,” said Michael Foggs, MD, Chief of Allergy & Immunology at Advocate Medical Group of Advocate Health Care in Chicago, Illinois. He said these time pressures make it difficult for physicians to build trust with all patients, which research has shown is a particular obstacle for patients of color. One study found that certain provider behaviors led to mistrust among older African Americans, including spending inadequate time listening and insufficiently explaining treatments.⁷

Another study related to race and trust in healthcare concluded that, “Patterns of trust in components of our healthcare system differ by race. Differences in trust may reflect divergent cultural experiences of Blacks and whites as well as differences in expectations for care. Improved understanding of these factors is needed if efforts to enhance patient access to and satisfaction with care are to be effective.”⁸

- **People of Color Encounter Pervasive Barriers.**

At every turn, people of color face challenges to effective diagnosis, treatment, education, and support.

These challenges range from limited access to primary and specialty care to excessive out-of-pocket costs for testing and medication. “The average American family spends around 11 percent of household income on health care premiums and out-of-pocket costs, but that amount approaches 20 percent for African American households.”⁹

- **Policies Hinder Progress.** According to research, the overall prevalence of food allergy is increasing and disproportionately affecting minority groups.¹⁰ At the same time, research has identified food insecurity as “a critical national problem,” with statistically significant disparities affecting households with children, households with Black or Hispanic members, and households with incomes

below 185% of the poverty threshold.¹¹

For these individuals and households in need, government-sponsored food programs such as WIC and SNAP offer support, but they cover only certain foods, limiting patients’ options, according to panelist Emily Brown, founder of the Food Equality Initiative. As a Black mother of two children with food allergies, Ms. Brown discovered firsthand how challenging it was for her and others receiving WIC and SNAP benefits to purchase safe foods within the programs’ guidelines.

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While these challenges are daunting, the panelists identified nearly 30 possible solutions for healthcare systems, advocacy organizations, policymakers, payers, the allergy and asthma community, and academia to consider. They then prioritized them into a “Top 10 Solutions Agenda,” fully described later in this White Paper. Their list included such efforts as:

- Identifying ways to enroll more people of color into clinical trials and recruit more people of color into medical school.
- Educating primary care physicians and specialists using webinars, videos, and podcasts.
- Improving access to safe foods.
- Analyzing the long-term cost savings of longer appointment times, which could be allotted to any patient with complex needs – including patients of color – and working with health systems and insurance companies on making such systemic change.
- Creating and disseminating culturally appropriate materials for patients.

In Summary:

“Our goal with the research and this White Paper is to zero in on the ‘real world’ challenges that exist for patients of color with atopic dermatitis and food allergy,” said Mark Corbett, MD, president of ACAAI and a board-certified allergist. “From there, we want to move the needle to make things better. Health care disparities should not exist in this country. This is our effort to bring about change.”

The Foundational Data: Atopic Dermatitis and Food Allergy in the U.S.

The Challenges in Diagnosing Atopic Dermatitis in People of Color



Approximately 22 million adults and nearly 10 million children are living with atopic dermatitis (AD), and its prevalence among people under age 18 has increased from 8 percent to 12 percent in the last 25 years.¹² Studies indicate that AD affects more African American, Black, and European-American children than Latino children. Still, African American, Black, and Latino children tend to have more severe AD than white children.¹³

Diagnosing AD in people of color presents challenges that lead to misdiagnosis or delays in diagnosis, according to Luz Fonacier, MD, immediate past president of ACAAI and a board-certified allergist and immunologist with NYU Langone Health in Long Island, New York. “Atopic dermatitis is very prevalent, persistent, and severe in people of color, but the continuing misperception is that it doesn’t affect African Americans or Latinos,” she said.

Dr. Fonacier attributed some of these misperceptions to medical school textbooks and nationally recognized online medical resources, which say the condition is “characterized by an itchy, red rash” and typically use photos of white skin when providing examples of AD.^{14, 15}

In contrast, the ACAAI website provides this expanded description of AD (or eczema):

“In people of color, eczema can be uniquely different in appearance. It is often hard to identify because the redness may be obscured in darker skin. Instead, eczema may present as dark brown, violaceous, or ashen gray.”¹⁶

When panelist and pediatrician Ruchi Gupta, MD, MPH, found a total lack of pictures of eczema in Black infants, she and her team took pictures of their own and created an educational resource for physicians. “You have to start somewhere,” she explained.

The Under-Diagnosis of Food Allergy Among People of Color

Food allergy affects approximately 8 percent of children in the U.S., and studies show that Black children are twice as likely as white children to have allergies to multiple foods.¹⁷ Recent evidence also suggests that food allergy outcomes are more severe among Black Americans than white Americans, including higher levels of anaphylaxis (a life-threatening allergic reaction) and death.¹⁸ In addition, there is evidence that as food allergy prevalence increases for all children in the U.S., the greatest increase is among non-Hispanic Black children.¹⁹

Black families also have more difficulty accessing appropriate safe food, medical care, and lifesaving medicine like epinephrine.²⁰ “A food allergy diagnosis doesn’t just affect the single person, but the entire family and at times the entire community,” said Erin Martinez, interim CEO of Food Equality Initiative.



The ACAAI Research Methodology

Membership Survey: A survey was sent to the 4,820 physician members of ACAAI to:

- Determine the level of awareness among ACAAI members of the diagnostic and treatment challenges people of color face when it comes to accessing care for AD or food allergy.
- Understand the kinds of problems/challenges their patients of color may describe.
- Discover what resources, if any, physicians find helpful for their patients of color.

The survey had a 4.6 percent response rate (200). Of the respondents, 68 percent were white and 21 percent Asian/Pacific Islander. Less than 6 percent identified as Latino or Black/African American. The respondents worked primarily in private practice (73 percent) and in a suburban location (61 percent).

Interviews: One-on-one interviews with ACAAI leaders and advocacy experts expanded upon the information gathered in the survey, and the insights helped frame the roundtable discussion.

Roundtable: Armed with the survey results and interview insights, ACAAI created a discussion framework for a roundtable, which involved the interviewees plus additional clinical and advocacy experts. Panelists were presented with key findings from both the survey and the interviews, and at regular intervals, time was provided for group discussion.

Solutions Agenda: Following the roundtable, all proposed solutions and action items were compiled into one document, and panelists were asked to prioritize their top five.

Key Findings from Survey, Interviews, and Roundtable

Physicians' Awareness of the Impact of Racial Disparities Is Limited

Time Pressures, Lack of Trust, and Resources Are Obstacles

In the survey, physicians said they are somewhat aware of racial disparity issues affecting their patients, rating their level of awareness at a 73 on a 1 to 100 scale. But 60 percent also said their patients of color have never shared specific challenges with them.

Physicians' awareness level of challenges people of color face



On a scale of 1 to 100, what is your level of awareness of the challenges people of color face in getting a diagnosis and receiving treatment for AD or food allergy?

Percent of physicians who said patients of color share challenges



Have your patients of color ever shared the challenges they face getting a diagnosis or treatment for AD or food allergy?

“Doctors are intellectually and conceptually aware of the challenges patients face but may not have real-world experience with their patient populations,” said Dr. Foggs. He also emphasized that for patients to share concerns or questions with a physician, they must trust them first.

“A doctor has to create an environment of trust, but that takes time – a luxury we don’t have in today’s ‘healthcare as a business’ environment,” he said. “In addition, patients may be embarrassed to share that they can’t afford their medication or don’t understand their diagnosis.”

Other panelists also commented on the importance of trust.

“We have to ask ourselves, ‘What does our environment look like?’” said Rachel Kowalsky, MD, MPH, a pediatric emergency medicine specialist. “Look at our messaging, printed materials, signs, art. Are they inclusive? Who greets our patients and how? All of this contributes to building trust.”

“Trust is not built in one encounter either,” said Wendy Smith Begolka, Senior Vice President, Scientific and Clinical Affairs for the National Eczema Association. “It takes time. You have to ask what each experience looks like and how connections are made with patients over time.”

Unfortunately, for people of color, each healthcare encounter could be with a different provider. According to a Kaiser Family Foundation study, 42 percent of Latino adults and 25 percent of Black adults reported not having a personal doctor, compared with 23 percent of white adults.²¹



“In schools, we see many families who do not have a family physician and we try to explain why this is important and the value of regular checkups,” says Nichole Bobo, MSN, RN, Director of Nursing Education for the National Association of School Nurses. “School nurses report that this is a particular area of concern among families covered by Medicaid.”

Patients of Color Face Pervasive Barriers to Care From Awareness and Diagnosis to Education and Treatment: Obstacles at Every Turn

People of color face challenges at every touchpoint in health care, even before the onset of symptoms, said Ms. Brown. The misperception that AD and food allergy only affects white people is so pervasive that people of color are not aware of their risks or the warning signs, she explained. “If a Black person has a reaction to a food, they don’t even think to tell a doctor. They simply don’t know anything about food allergies,” said Ms. Brown.

The misperception that AD and food allergy only affects white people is so pervasive that people of color are not aware of their risks or the warning signs

Once a patient of color does begin to seek care, the obstacles can be divided into four categories, according to interviewees:

- Access to care.
- The burden of costs.
- Policies and infrastructure that limit access to safe foods, medication, and patient education.
- Inadequate research involving people of color, which may affect treatment effectiveness.

Access to Care. When patients of color are referred to a specialist, either a dermatologist or allergist, the challenges of access begin. First, getting an appointment with a specialist can take months, said panelists. If the patient is covered by Medicaid or is uninsured, this referral becomes even more problematic, as many specialists limit the number of Medicaid and uninsured patients they will see.

“In addition, specialists’ offices may not be near public transportation if that is needed,” said Dr. Foggs, “and follow-up visits only increase these access obstacles.” Dr. Kowalsky pointed out that patients may have to take time off work, find childcare, and travel a distance for their appointments, which is difficult. A process that may seem routine for some patients, particularly those in a suburban private practice, may present significant barriers for patients in rural or inner-city environments who are on Medicaid, uninsured, or who have limited financial resources.



Michael Blaiss, MD, Executive Medical Director for ACAAI, who retired from his long-time allergy practice and now sees only patients in an underserved community, said telehealth visits have been helpful alternatives to in-person follow-ups for AD specifically. “Our no-show rate for in-person appointments was very high, but our patients can keep their telehealth appointments because transportation, childcare, and missed work aren’t obstacles.”

While certainly a better option than no visit, two roundtable participants expressed caveats about telehealth visits. Cherie Zachary, MD, a board-certified allergist and Chair of ACAAI’s Diversity Task Force, reminded panelists that not all patients have easy access to the technology needed for telehealth. Abby Allen, MSN, FNP-C, who works in an asthma and allergy practice and is Chair of ACAAI’s Allied Health Professionals Committee, said it is important to be aware that the telehealth option can feel “impersonal” and increase trust issues.

The Burden of Costs: The costs associated with both AD and food allergy are significant, according to recent studies. A survey conducted with members of the National Eczema Association found that “out-of-pocket expenses place a significant financial burden” on all individuals with AD.²² However, the study also revealed that Black survey respondents faced a more severe or devastating impact on household finances than non-Black respondents, partly due to increased out-of-pocket (OOP) expenses not covered by insurance.²³

The study concluded that the “Black race itself was found to be a predictor of harmful financial impact among individuals with AD. Taken together, these findings underscore the real-world OOP expense burden faced by Black Americans with AD.”²⁴

A food allergy diagnosis also presents financial burdens, as families strive to find and pay for safe alternatives to foods that trigger an allergic response, which are often very expensive. Overall, food allergy costs \$24.8 billion annually or \$4,184 per child, including annual medical costs, out-of-pocket expenses, lost labor productivity, and lost job opportunities.²⁵

“These costs can mean the difference between buying safe food for a child with an allergy or buying enough food to feed a family,” says Ms. Brown.

Policies and Infrastructure that Limit Access to Safe Foods and Patient Education: Cost is not the only barrier for people of color with a food allergy. “Food deserts” – geographic areas with few or no stores offering affordable, healthy foods – are a growing problem across the United States. The Department of Agriculture estimates that 19 million people — 6.2% of the nation’s total population — have limited access to a grocery store, and food deserts are “a disproportionate reality for the Black community,” according to a 2014 study from Johns Hopkins University.²⁶

In addition, many patients of color rely on WIC and SNAP benefits. Under these programs, they are offered limited options for safe foods. “These programs limit the brands they will cover, and there are few ‘free-from’ options under SNAP,” said Ms. Brown. (“Free-from” refers to foods that are made without particular ingredients, often the top nine allergens.)

For patients of color who want more information about safe foods, Ms. Brown also describes major obstacles. “When my daughter was first diagnosed, I wanted to learn more, and I researched support groups,” she said. “The only meeting I could find was at a restaurant in the suburbs far from where I lived. When I arrived, I was the only person of color, and I couldn’t even afford to buy the meal. As a Black mother, I felt very alienated.”

Other members of the roundtable asserted that few culturally competent patient education materials exist for AD and food allergy. In the ACAAI member survey, 74 percent said they have found no valuable resources to help their patients of color address access and cost barriers.

Limited Research Involving People of Color.

Roundtable participants voiced concerns that the standards of care for both AD and food allergy are based on studies that are not always representative of people of color.

While Black and Hispanic children are at greater risk of having a food allergy than white children, they are also greatly underrepresented in food allergy clinical trials, according to a University of Missouri-Kansas City School of Medicine analysis.²⁷

Of the 135 published food allergy immunotherapy clinical trials included in the literature review, only about one in eight included information on participant race. And of these, close to 82 percent of participants were Caucasian, 7.6 percent were Asian, just under 3 percent were African American, and 1.2 percent were Hispanic.²⁸

“When it comes to clinical trials, people of color have a significant mistrust of the healthcare system because of past abuses,” said Dr. Zachary. “They don’t want to be ‘experimented on.’”

Multiple participants also noted that transportation and technology present additional barriers to people of color when it comes to involvement in research. Many research sites are centrally located at hard-to-reach academic medical centers rather than in community-based facilities. And clinical trials have become more complex and technology-based in recent years, putting additional burden on those without a computer or high-speed Internet access.

While minority participation in clinical trials is low, much research needs to be done. The National Eczema Association (NEA) reports that, based on a study they recently conducted, African Americans often have more severe AD and less control over symptoms. NEA wants to better understand why. “We are committed to understanding the patient lived experience of AD, and especially to researching the impacts and associations that may be different for those with skin of color,” said Ms. Begolka.

While Black and Hispanic children are at greater risk of having a food allergy than white children, they are also greatly underrepresented in food allergy clinical trials

Both Dr. Zachary and Dr. Kowalsky emphasized that research should be as specific as possible to be valuable. “Most studies use the word ‘Black’ to describe some participants, but I honestly don’t know what that means,” said Dr. Zachary. “My biology may not be the same as the biology of someone from Nigeria or Somalia, for example. We need to shift the focus from ‘race’ to ‘biology.’”

The **Top 10** Solutions Agenda

Recruitment, Education, and Policy Change Among Highest Priorities

The following solution recommendations reflect the panelists' top priorities for addressing racial disparities in the diagnosis and treatment of AD and food allergy in people of color. These recommendations are meant to spur discussion among members of the allergy and asthma community, healthcare systems, payers, advocacy organizations, policymakers, and academic leaders, all of whom have the opportunity to play a role – individually or in partnerships – in creating change.

1 Explore ways to enroll more people of color into clinical trials.

While panelists recognized that this is a long-term solution, they believe the importance of building trust between people of color and medical researchers is vital to prevention, early detection, and treatment.

2 Recruit more people of color into medical school, and particularly into the specialty of allergy, asthma, and immunology.

“It all starts with medical school,” said Dr. Fonacier. “We need more people with Black and brown skin in our field, and we need to ensure that everyone is better educated about atopic dermatitis and food allergy in people of color.”

3 Increase outreach to high school students.

In support of priority #2, panelists recommended working more closely with high school students in STEM (Science, Technology, Engineering, and Math) programs. They suggested reaching out to students in their own communities and in areas where they travel to generate interest in medical careers.

4 Increase awareness and education among specialists.

Panelists recommended that ACAAI and its partners continue to develop webinars, videos, and podcasts for asthma and allergy specialists about diagnosing and treating AD and food allergy in people of color and understanding the impact of racial disparities on costs and access to care.

5 Increase awareness and understanding among primary care physicians – and leverage community outreach to educate patients.

In support of priority #4, panelists also recommended increasing education among primary care physicians – the first line of defense for patients with AD and food allergy. Since it often takes time for patients to schedule an appointment with a specialist, educating primary care physicians would help ensure that patients receive appropriate diagnostic tests and treatments as early as possible.

“We also need to develop culturally competent handouts to support physicians who are caring for patients early in the process,” said Dr. Gupta. “And we need to be in the community, in places where people are – health fairs, churches, schools – to get the message out. It can’t all be provided in doctors’ offices.”

6 Advocate for revised WIC and SNAP policies to increase access to safe foods.

While SNAP covers a wide range of foods, benefits are calculated based on such factors as household size, but they do not take into consideration cost differences. For families managing food allergy, those costs can be considerable.

“The challenge for food allergy families is you don’t get any extra SNAP dollars because you have food allergy [and you] pay more for your food,” said Ms. Brown in an article in *Allergic Living*. “The benefit doesn’t go as far as it would for a family that didn’t have these medical needs.”²⁹

7 Develop a photo library of atopic dermatitis in people of color.

With so much information in medical school textbooks focused on AD in white skin, panelists recognized the need to develop and promote a comprehensive resource of images that educate physicians about what AD looks like in skin of color. Some of the participants have existing resources that can be combined and added to over time. Images may be used in informal learning activities such as online forums.

8 **Create culturally appropriate patient education materials and partnerships to reach communities of color.**

Participants agreed with the findings of the ACAAI member survey – few culturally appropriate, engaging, multi-language resources currently exist. “So many of the handouts available now are word-heavy,” said Ms. Martinez. “They should be brighter, include graphics, be more engaging.” Ms. Martinez also recommended developing an app to house these resources for both physicians and patients.

“School nurses can also be invaluable partners in this effort,” said Ms. Bobo. “They already have the trust of school communities – teachers, parents, and children – and they are accessible every day throughout the school year.”

9 **Work toward longer appointment times for patients who need them.**

Panelists suggested the need for an analysis to demonstrate the long-term cost savings that would result if doctors had more time up-front with patients with complex AD and food allergy issues. They then recommended using this information to talk with insurance companies and health systems to allow physicians more time with patients who may face unique challenges with their diagnosis and treatment.

Dr. Foggs said that in an ideal world, he would like to see an assessment tool for non-physicians to determine in advance of an appointment whether patients will need more time with the doctor. He also suggested developing specialty clinics for these patients to give physicians more time to develop trust and provide education.

“We need to demonstrate that the current structure is not conducive to addressing patients’ unmet needs,” said Dr. Foggs. “It’s focused only on efficiency and the immediate bottom line, not the long-term impact of poor-quality care.”

10 **Leverage this research and the roundtable participants’ insights to increase awareness and create change.**

“My view has changed quite a bit as a result of this roundtable discussion,” said Ms. Allen. “I thought I was doing everything I could, but I realize I need to ask more probing questions of my patients. Not just, ‘How’s your skin?’ but ‘Did you wake up during the night with itchy skin?’ or ‘When you get sweaty, do you get more itchy?’ I need to give specific examples to help patients open up so that I have insights into what they are experiencing and can provide better care.”

“We need to make sure that all of this information helps us make a difference for our patients,” concluded Dr. Corbett. “It’s time.”

*WIC is the Special Supplemental Nutrition Program for Women, Infants and Children, and SNAP is the Supplemental Nutrition Assistance Program.

Interviewees and Roundtable Panelists

Abby Allen, MSN, FNP-C – Chair, American College of Allergy, Asthma & Immunology Allied Health Professionals Committee

Wendy Smith Begolka – Senior Vice President, Scientific and Clinical Affairs, National Eczema Association

Michael Blaiss, MD, FAAAAI – Executive Medical Director, American College of Allergy, Asthma & Immunology

Nichole Bobo, MSN, RN – Director of Nursing Education, National Association of School Nurses

Emily Brown – Founder and CEO of Free From Market, Founder and former CEO of Food Equality Initiative (FEI)

Mark Corbett, MD, FAAAAI – 2021-22 President, American College of Allergy, Asthma & Immunology

Michael Foggs, MD, FAAAAI – Chief of Allergy and Immunology, Advocate Health Care, Chicago, IL, and Past President, American College of Allergy, Asthma & Immunology

Luz Fonacier, MD, FAAAAI – Immediate Past President, American College of Allergy, Asthma & Immunology

Ruchi Gupta, MD, MPH – Director, Center for Food Allergy & Asthma Research (CFAAR) at Northwestern University Feinberg School of Medicine and Ann & Robert H. Lurie Children's Hospital of Chicago

Rachel Kowalsky, MD, MPH, FAAP – Section on Minority Health, Equity and Inclusion, American Academy of Pediatrics

Erin Martinez – Interim Chief Executive Officer, Food Equality Initiative

Cherie Zachary, MD, FAAAAI – Chair, American College of Allergy, Asthma & Immunology Diversity Task Force

Organizational Resources

American College of Allergy, Asthma & Immunology: <https://acaai.org/>

Eczema in Skin of Color (a campaign created by the American College of Allergy, Asthma & Immunology and the Allergy & Asthma Network): <https://eczemainsofcolor.org/>

FARE: <https://www.foodallergy.org/>

Food Equality Initiative: <https://foodequalityinitiative.org/>

National Association of School Nurses: <https://www.nasn.org/home>

National Eczema Association: <https://nationaleczema.org/>

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