

Diseases don't discriminate.



Now more than ever, diversity and inclusion are vital to clinical research. And with more volunteers, medical advancements can become even better. Visit [medicalheroes.org](http://medicalheroes.org) to learn more.

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### Diversity in clinical trials. It's about all of us.

Fifteen years ago, at the age of 42, Israel Robledo was diagnosed with Parkinson's disease. Shocked, he spent the next nine months coming to terms with his diagnosis. "I am a point of concern and barriers to accessing clinical trials."

"In forming a Community Advisory Board that is really diverse in membership – representing not just different races and communities, but also individuals who identify with living conditions and disease areas that Biogen researchers – we have the opportunity to listen and learn," explains Kate Wilson, Biogen's Head of Health Equity in the Patient Engagement, Equity and Transparency team.

**Community Feedback**  
The Community Advisory Board (CAB) was established to serve as a bridge between Biogen team members and communities that have encountered a lack of education, awareness and access to clinical trials. This includes those who identify as Black or African American and Hispanic and/or Latino, and it has recently expanded to include Native Americans, Indigenous People, Asian Americans and Pacific Islanders. Further compounding these issues is the distrust of clinical trials due to historical events and injustices.

"Let's face it, pharmaceutical companies don't have the best reputation," Robledo observes. "But Biogen is building trust. They realize people of different races and ethnicities react differently to medical issues and to clinical trials." The Board was set up in partnership with the Center for Information and Study on Clinical Research Participation (CISCRP), a nonprofit dedicated to educating patients and the public on clinical research participation.

The CAB's role is two-fold: Help inform Biogen team members on issues regarding race, ethnic-

ity, associated health disparities and awareness initiatives, as well as help Biogen to better communicate with underrepresented communities on points of concern and barriers to accessing clinical trials.

"I've been a patient advocate with many pharmaceutical companies, but none have been like Biogen," he says. "When other companies ask for patient input, they say, 'This is what we've done. Tell us if you like it or not.' But Biogen says, 'Tell us what we need to change so that it impacts the patient community the way it needs to.'"

The final products are, as Robledo says, "pretty darn good. I take pride in saying these materials are something that we came up with. Providing a voice is why I became a patient advocate."

**Clear Messaging**  
Through ongoing conversations on messaging, tone and images, Biogen and CAB members have worked together to create honest and transparent communications geared toward underrepresented communities, their healthcare practitioners and their caregivers. "CAB members were co-developers of these materials," notes Wilson. "They had seats at the table, and had direct input and feedback. That is how we built our messaging."

CAB members have provided hundreds of points of feedback on sharing information to patients, ranging from trial descriptions to logistics (such as whether a patient is reimbursed for their travel expenses or paid for their time) to whether a person needs to reveal their immigration status – a real concern for many people and something that Biogen now addresses in its assets. "In all of our materials, we make sure that patients know that information about immigration status will not be collected in any Biogen clinical trial," says Wilson.

## Community Advisory Board Helps Biogen Promote Diversity in Clinical Research



**Looking to the Future**

The CAB and Biogen's work towards building diversity, equity and inclusion into its clinical research is garnering industry attention, winning the 2021 Global Pharma Patient Champion Award. And Biogen's recent addition of voices from other underrepresented communities points toward its continued efforts to better understand the needs and challenges among various populations. The end goal: to better develop potential medicines that are safe and effective for all.

"It's our way of ensuring that a diverse voice is heard and built into our clinical development and the way we approach drug development," Wilson says. "When we look at the work ahead of us to really improve representation in our clinical trials, it's so critical that we're involving the diverse communities and voices in that process."

The devastating impact of the COVID-19 pandemic, particularly on communities of color, has been a painful reminder of the racial and ethnic disparities that have long existed in our country. In the United States, Black people tend to have higher rates of chronic and progressive conditions, such as high blood pressure, diabetes, and cancer, and face greater obstacles when it comes to prevention, detection, and treatment. This is especially true in the breast cancer space.

- Black women are often diagnosed at later stages and can often have a worse prognosis [1];
- Black women face a 20% to 40% higher mortality rate despite overall rates of breast cancer in Black and white women being about the same [2];
- Black women have a 30% recurrence rate and a 52% higher relative risk of death compared to white women [3]; and
- Historically, Black women have been underrepresented as participants in breast cancer clinical research [4].

Through allyship with community partners and leaders in communities of color, Pfizer is focused on continuing to improve diverse representation in breast cancer clinical trials. Most recently, Pfizer partnered with the Tiggerly Foundation to launch Health Equity, Advocacy and Leadership (HEAL) sessions to advance education around clinical trials for Black women with cancer. The program focused on:

- Shedding light on the breast cancer journey for women of color.
- Improving access to breast cancer clinical trials for women of color.
- Building trust and enhancing the relationship between breast cancer patients and their care partners.
- Educating women of color on clinical trials and strengthening their capacity to increase awareness and participation in breast cancer clinical trials.
- Identifying barriers and determining solutions that can improve access to breast cancer clinical trials, with the hope of sharing these learnings in other treatment areas.



## Improving Representation in Breast Cancer Clinical Trials & Developing Better Medicines for All



research for women of color. We are excited to partner with organizations, like Pfizer, to work to transform systems globally – with one vision – to champion Black breast cancer as a social justice issue and eradicate as many barriers as possible that lead to loss of life for Black women."

Race, ethnicity, age, and sex can all impact how different people respond to the same medicine or vaccine. This is why diversity among clinical trial participants is so important. The more diverse a group of clinical trial participants, the more we can learn about the safety and efficacy of a potential medicine or vaccine for people who have characteristics like those of the participants. Participation is entirely voluntary and for those in a position to give it, it is a gift.

As a leading global pharmaceutical company, Pfizer is committed to working with Tiggerly Foundation and communities of color to help reduce health disparities. The HEAL sessions provided an inspiring forum that reinforced old and uncovered new commonalities, obstacles, unique experiences of Black patients, and the gaps in access to clinical trials as an option to consider. Each session allowed Pfizer and patient

advocates from the Tiggerly Foundation to have open and honest dialogues on the disparities for Black women living with breast cancer, and uncover potential solutions and tools for patients, caregivers, healthcare professionals, and clinical site staff.

Carmen White, Pfizer Director, Multicultural Participant Experience said, "I'm so thrilled that the Tiggerly patient advocates, also known as ANGEL Advocates, are among our partners whose insights are being applied to Pfizer's effort to improve the overall trial experience for future patients. I left each HEAL session moved and motivated."

Equity is one of Pfizer's four core values. From medical grants aimed at actively reducing the disparities in care, to resources for patients, caregivers, and healthcare professionals to navigate their unique cancer journeys and treatment decisions, Pfizer has made it a priority to be inclusive, act with integrity, and ensure every person is seen, heard, and cared for.

Representation matters in clinical research because it ensures that medicine and vaccine in development benefit all. The HEAL project demonstrates one way Pfizer is doing its part in ensuring women of color are represented in clinical trials. To learn more about joining a clinical trial, please visit [pfizerclinicaltrials.com/learnmore](http://pfizerclinicaltrials.com/learnmore). With your help, breakthroughs for all are possible.

### References

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