ENGAGEMENT IN HEALTH EQUITY

TRAVERE® THERAPEUTICS

At Travere Therapeutics, our mission is to identify, develop and deliver life-changing therapies to people living with rare disease. By understanding their unique challenges, amplifying their experiences and advocating for a more compassionate healthcare system, we endeavor to make a lasting impact on the lives of those living with rare diseases.

We believe that in order to be true advocates for patients, we must advocate for equitable access to diagnoses and treatment. While we stand firm in our resolve to address healthcare inequities, we recognize that true impact cannot be done alone. It requires a united effort, a community. We embrace collaboration with dedicated partners who share our passion and determination. Together, we aspire to forge a path toward a future where no one is left behind.

Travere's strategic approach to addressing health disparity centers around forming dynamic alliances with advocates and organizations that share our vision. We work side by side with these partners to confront and overcome the health disparities faced by rare disease patients. Our collaborative efforts aim to overcome the boundaries of race, ethnicity, sexual orientation, gender identity, age, geography, and socioeconomic status.

For three plus years, Travere has supported the creation of impactful programs and initiatives aimed at mitigating health disparities. We have actively collaborated with and provided support to organizations of all sizes to combat bias and eliminate disparities among individuals affected by rare diseases.

Travere has focused its health equity efforts in the following areas:

- Creating Impactful Partnerships
- Understanding the Role of the Caregiver in Clinical Trials
- Gathering Diverse Perspectives
- Educating and Empowering Communities
- Bridging the Digital Divide

Within this Health Equity Report, we present an overview of our initiatives and strategic collaborations aimed at tackling health disparities among rare disease patients from many diverse populations.

> **"Of all the forms of inequality, injustice in health care is the most shocking and inhumane."**
>
> **Martin Luther King, Jr.**

CREATING IMPACTFUL PARTNERSHIPS

Travere forms powerful partnerships with leading organizations aimed at improving the quality of life for individuals grappling with rare diseases. Our collaborators pioneer innovative, patient-centric approaches that boldly confront the unique challenges and barriers experienced by those affected by rare diseases.

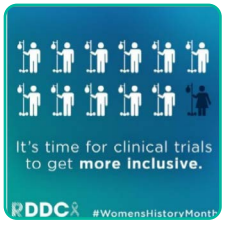
RARE DISEASE DIVERSITY COALITION

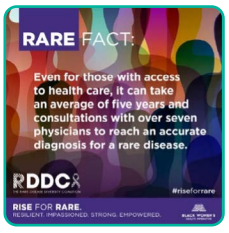
One of these key partnerships is with the Black Women's Health Imperative (BWHI). BWHI is a non-profit organization striving to solve the most pressing health issues that affect Black women and girls in America. In the last 40 years, BWHI has become a leader in health policy, education, research, knowledge and leadership development designed to improve Black women's health outcomes.

In 2020, BWHI launched the Rare Disease Diversity Coalition (RDDC). Comprising more than 200 rare disease advocates, healthcare and diversity experts, and industry stakeholders, the RDDC aims to identify and promote evidence-based strategies to mitigate the inequitable impact of rare diseases on communities of color. Their goals include:

- Reducing racial disparities in the rare disease community
- Identifying and advocating for evidence-based solutions to alleviate the disproportionate burden of rare diseases on historically marginalized populations
- Putting forth efforts to achieve greater equality within the rare disease community

As the founding sponsor of the RDDC, Travere's patient advocacy, government affairs, and executive teams work closely with RDDC by actively participating in the steering committee and working groups.

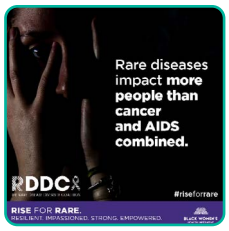


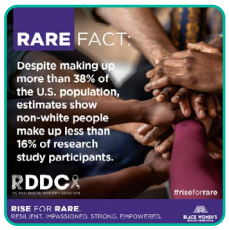


Offering Opportunities to Early-Career Healthcare Professionals

The effects of systemic racism have impacted access to medical education for people of color. According to the Association of American Medical Colleges, only 5% of physicians identify as Black and 6% identify as Hispanic, with an even smaller fraction specializing in rare diseases. Consequently, patients seeking healthcare professionals from underrepresented backgrounds face difficulty finding supportive care.

Travere and RDDC unite under a mission to empower, uplift, and ignite the passion of aspiring and early-career physicians and other medical professionals of color. At the heart of this collaboration lies RDDC's transformative Rare Disease Fellowship Program, crafted to empower fellows with a 6-month immersion into the world of rare disease advocacy. This unique experience serves as a powerful catalyst, granting fellows invaluable insights into the distinct health disparities and unparalleled obstacles faced by communities of color impacted by rare diseases. The program fosters a new generation of diverse medical leaders who will reshape the landscape of rare disease care.





This year, RDDC hosted two young medical professionals, pairing each of them with The Alliance to Cure Cavernous Malformations and Gillette Children's Healthcare Specialty to expose them to the challenges that people living with rare diseases face. Next year, RDDC will be providing two new fellows a chance to work with two new rare disease organizations.

Encouraging Dialogue Within Families

As genetic factors contribute to approximately 80% of all rare diseases, knowing one's family health history can support family planning, preventative screening, and appropriate lifestyle choices. Nevertheless, some patient populations are hesitant to discuss their medical histories with family members.

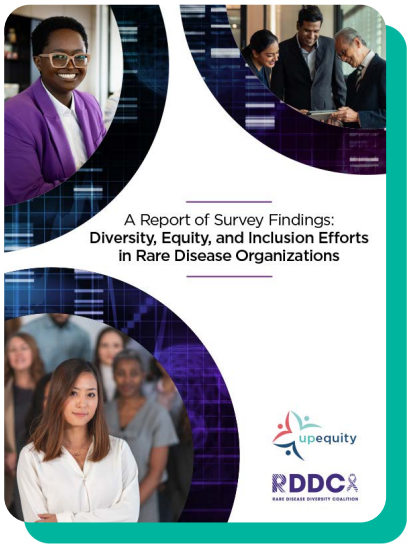
With the support of Travere, RDDC and Global Genes joined forces to launch "Know Your Family History," a screening and media campaign encouraging families of color to familiarize themselves with their medical histories and consider genetic screening options. This initiative included the creation of two distinct websites, knowyourfamilyhistory.org and conozcasuhistoriafamiliar.org, to reach a broader audience.

Expanding Patient Engagement

In 2022, RDDC conducted a survey to evaluate the breadth and effectiveness of diversity, equity, and inclusion (DEI) efforts among rare disease advocacy organizations. Released during 2023 Rare Disease Week in Washington, D.C., the results of the survey led to a list of recommendations for patient advocacy organizations. They include the following:

- To increase organizational commitment and accountability for DEI, patient advocacy organizations should create and hire positions specifically for DEI, create accountability metrics, create trackable DEI missions, and assess DEI Milestones.
- To increase the effectiveness of DEI initiatives and activities, organizations should create resources that identify opportunities to creatively engage diverse people, conduct assessments to identify and target development opportunities, identify DEI training, and create accessible DEI toolkits.
- To increase communication strategies, organizations should create DEI checklists that offer guidance including social media toolkits and connect with diverse organizations across social media platforms that may not be specific to their therapeutic areas.

Detailed findings of the report can be found here: A Report of Survey Findings: Diversity, Equity, and Inclusion Efforts in Rare Disease Organizations.



As a follow up to the organizational survey, RDDC and the National Rare Disease Organization (NORD) launched a national survey to understand the perspectives of historically marginalized patients and caregivers and their experiences with healthcare access and affordability. The initiative aims to identify gaps along the diagnostic and therapeutic journeys. The results of the survey will be released in February of 2024.

RDDC's goal is to continue to address the underlying causes of health disparities in the rare disease community and ensure diverse populations receive the support and resources they need to improve health outcomes. With backing from patient advocacy organizations, healthcare institutions, the government, and companies like Travere, RDDC is investing in its future growth.

NEPHCURE FOR RARE KIDNEY DISEASE (NEPHCURE)

Travere partners with NephCure, a leading organization that provides support to patients with rare protein-spilling kidney diseases, such as IgA nephropathy and focal segmental glomerulosclerosis (FSGS). These diseases disproportionately affect communities of color.

Travere supports NephCure's efforts to build a health equity team and connect with and educate African American/Black, Asian/Asian American, and Latino patient communities.

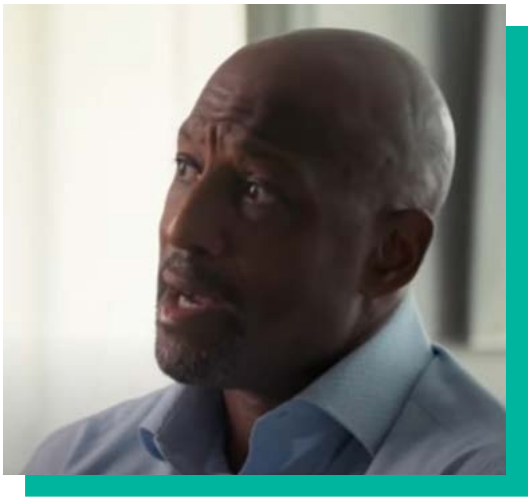
Specific activities and programs included:

- A partnership with the HEAL Collaborative to launch pilot programs at predominantly African American churches in Atlanta and Chicago to raise awareness about FSGS and provide opportunities to learn about your individual risk for kidney disease. In addition, NephCure has recently partnered with a church in Philadelphia to launch a similar program. These education and screening programs have collectively reached thousands of people in their local communities.

- Working with an African American-owned communications agency to launch a multichannel awareness campaign that included both digital ads and culturally appropriate landing pages to:
  - Raise awareness about the prevalence of rare kidney diseases in African Americans,
  - Meet African American patients earlier in their journeys and
  - Connect them to trusted resources for credible information.

  Collectively, these efforts led to more than 400 newly identified kidney-health curious individuals connecting to NephCure.

- The success of the awareness campaign led to an opportunity to create a video with Alonzo Mourning, an NBA Hall-of-Famer and Olympic Gold medalist whose career was abruptly impacted by FSGS and kidney failure. The inspiring video gained 1.3M+ impressions, 230K+ views, and hundreds of new followers for NephCure while raising awareness of FSGS and the need to get regularly screened for kidney disease. The video and corresponding campaign was recognized with a Gold Winning Anthem Award.



- Working with a health literacy writer to develop culturally appropriate educational materials to increase accessibility. These materials have been translated into different languages, and the Chinese-language version is available on the Asian and Pacific Islander American Health Forum (APIAHF) website to increase discoverability. APIAHF is the oldest and largest health advocacy organization working with Asian Americans, Native Hawaiians, and Pacific Islanders communities across the nation.

Inequities in access to proper healthcare by individuals in communities of color who are impacted by kidney disease are significant. This is even more so in RKD (rare kidney disease) as these diseases often go undetected and access issues become worsened. These diseases also tend to be more aggressive and debilitating, further adding to patient hardship and burden. Travere has actively partnered with NephCure to address these issues for many years, long before the current wave of attention. Most importantly, these programs have been designed to provide real-world hands-on activities that engage patients and make a real difference in underserved communities."

Josh Tarnoff, CEO, NephCure for Rare Kidney Disease

According to Kidney Disease Improving Global Outcomes Clinical Practice Guidelines, African Americans, specifically those of West African ancestry have higher prevalence of APOL1 high risk variants, a greater risk of APOL1-associated nephropathy that commonly presents as FSGS. They are also at higher risk of kidney disease progression. It is estimated that 13% of the African American/ Black population in the US carry the high-risk variants.

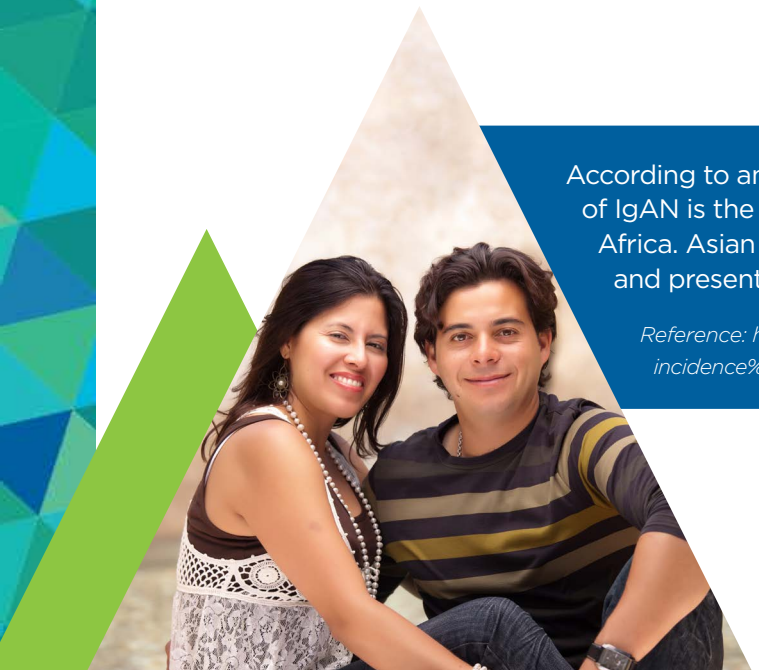
Reference: Kidney Disease: Improving Global Outcomes (KDIGO) Glomerular Diseases Work Group. KDIGO 2021 Clinical Practice Guideline for the Management of Glomerular Diseases. Kidney Int. 2021 Oct;100(4S):S1-S276. doi: 10.1016/j.kint.2021.05.021. PMID: 34556256

- Raising disease awareness through sharing patient stories. Travere partnered with NephCure to host a panel during the Black Health Matters' Summit, "Men's Health: Rare Kidney Disease Across Generations," with men from different age groups coming together to share their unique and personal experiences with FSGS. Travere also supported NephCure's Rare Kidney Disease: DEFINED webinar, highlighting two young patients' perspective on living with rare kidney disease. Additionally, NephCure worked with Asian Women for Health to record a podcast sharing Sabrina Qiao's journey with rare kidney disease: "The Healing Power of Personal Narrative & Kidney Health Advocacy." NephCure also traveled to Joshua Albright's home in Atlanta to record his testimony of being diagnosed with FSGS as a 17-year-old, and how that impacted his mental health and outlook.

- Travere partnered with NephCure and a host of others to advocate for legislative change aimed at benefiting patients of color. Our joint efforts have focused on championing the proposed New Era of Preventing End-Stage Kidney Disease Act, which would be landmark legislation for improving the nephrology landscape through increasing disease education among physicians, diagnostic tools to reduce delayed diagnosis, advancing rare kidney disease research, and ensuring equitable access to kidney care and treatment for underrepresented communities.

"Travere has been an exceptional partner in our work to address the unequal burden of rare kidney disease on communities of color and improve the quality of life for individuals who are impacted by these rare kidney diseases. The partnership and Travere's efforts to coalesce and drive the larger field forward have made a consequential impact on our ability to expand our programming and reach more individuals, earlier in their disease journeys."

Lauren Eva, Executive Vice President, Professional Relations, NephCure for Rare Kidney Disease



According to an article published in the Clinical Kidney Journal, the incidence of IgAN is the most frequent in Asia, followed by Europe, and lower in Africa. Asian patients show more frequent acute lesions in renal histology and present poorer renal outcomes compared with Caucasians.

Reference: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10695519/#:~:text=The%20incidence%20of%20IgAN%20is,difference%20between%20Asians%20and%20Caucasians

UNDERSTANDING THE CAREGIVER'S ROLE IN CLINICAL TRIALS

Clinical studies offer promise for new innovative treatments for rare disease patients. Yet, marginalized groups have historically been underrepresented in clinical research trials. Because of this, the results of research on new products like medications, vaccines, and medical devices may not be fully generalizable to patients of color and other marginalized communities.

To address clinical trial representation, we must acknowledge the significant role caregivers play in the participation of rare disease patients in clinical trials. A report published in 2020 estimates that 1 in 5 adults are caregivers of another person. In addition to assisting with day-to-day needs, caregivers also engage in discussions with providers and make treatment decisions on behalf of their loved ones. At times, a patient's ability to participate in a clinical trial depends entirely on the availability and willingness of a caregiver. Therefore, it is important to understand what considerations caregivers make when considering a clinical trial, and the obstacles they may face when participating such as transportation issues, the ability to take time away from work, and any barriers that may impact the ability to adhere to the trial protocol.

The National Alliance for Caregiving (NAC) is a national organization that builds partnerships in research, advocacy, and innovation to make life better for family caregivers. The NAC expressed strong interest in probing questions about the caregiver's role in clinical trial decision-making. Travere, with similar interests, stepped in by providing support for a series of roundtable discussions to better understand the considerations caregivers of color make when choosing to engage and enroll in clinical trials.

During the final roundtable discussion, the NAC convened caregivers and professionals from healthcare, pharma, and biotech to brainstorm recommendations for ways to increase clinical trial participation. Key themes across the recommendations included relationship building, clear communication, and inclusive and accessible trial design. Specific advice included:

- Developing relationships with community-based organizations that have the trust of populations which may be difficult to reach (e.g., people experiencing homelessness) can enhance access
- Establishing peer-to-peer support groups with people who have taken part in clinical trials and can provide information to interested caregivers who may have questions or hesitations
- Creating appropriate ways to support trial participation that do not involve traveling to a physical site such as telehealth study appointments

According to the Food and Drug Administration (FDA), "...minority racial and ethnic groups comprise nearly 40% of the U.S. population; however, 75% of the 32,000 participants in the trials of 53 novel drugs approved in 2020 by the FDA were White."

- Actively communicating to participants and their caregivers during the trial and about the results after the trial is over
- Allowing the caregiver and patient to give feedback on their experience after they complete the clinical trial to inform how future protocols and inclusion criteria considerations are developed and implemented
- Educating medical students and providers about implicit bias to improve referral of underrepresented patients to healthcare services including clinical trials

The recommendations from the series were disseminated widely across NAC's extensive network of members and collaborators, as well as featured in a STAT News opinion piece. The piece was co-authored by Jason Resendez, president and CEO of National Alliance for Caregiving, and Dr. Sharon Inouye, director of the Aging Brain Center at the Hinda and Arthur Marcus Institute for Aging Research in Boston. The recommendations are available for pharma and biotech companies, as well as medical institutions, to help increase access to and improve clinical trial participation.

> **Our partnership with Travere has been critical to helping NAC shine a spotlight on the many inequities family caregivers face. By working together, we can ensure that all family caregivers have the support they need to provide quality care, while also protecting their own health and well-being."**
>
> **Jason Resendez,** President and CEO, National Alliance for Caregiving

GATHERING DIVERSE PERSPECTIVES

There cannot be success in our work without understanding the lived experiences and unique needs of the communities we serve. The insights learned through multiple advisory board meetings and our Rare Disease Patient Advisory Council allow us and others to create more effective resources, relevant education, and meaningful solutions.

ADVISORY BOARD MEETINGS OFFER NEW INSIGHTS

When Travere committed to advancing health equity, we understood that we needed to broaden our education about the populations we serve. Over the last few years, Travere hosted advisory board meetings with stakeholders from four different racial/ethnic communities. The goal of conducting these meetings was to gain a better understanding of the issues and challenges facing ethnically diverse communities with rare kidney diseases. The findings have allowed Travere to learn and adopt best practices, as well as engage these communities more effectively.

Here are some of the findings from those discussions:

Comparison of Diverse Patient Populations in Accessing Healthcare

Category	African American	Asian/ Chinese	Latino	South Asian	Japanese Americans
Challenges with cost of care/low income	✓	✓	✓	✓	
Challenges with taking off work	✓	✓	✓	✓	✓
Challenges with stigma/fear	✓	✓	✓	✓	✓
Challenges with preventative care/PCP	✓	✓	✓	✓	
Importance of family community	✓	✓	✓	✓	✓
Importance of health literacy	✓	✓	✓	✓	✓
Importance of cultural relevancy	✓	✓	✓	✓	
Importance of dietary guidance	✓	✓	✓	✓	N/A
Language barriers & translation service insufficiency		✓	✓		
Multi-lingual physicians/staff helps in clinical trials participation and treatment adherence		✓		✓	
Respect for physician		✓	✓	✓	✓
Undocumented status – clinical trial participation		✓			N/A
Undocumented status – healthcare coverage		✓			N/A
Undocumented status – adherence to treatments		✓			N/A
Undocumented status – trust in authority		✓	✓		N/A
Disseminating information through community and religious affiliations builds trust and maximizes reach of potential clinical trial participation			✓	✓	
Use of digital platforms for communications (WhatsApp)		✓		✓	✓
Homeopathic remedies usage		✓		✓	
Desire for clinical study sites to be closer to where they live and more easily accessible	✓			✓	N/A
Overall distrust of clinical trials	✓			✓	

Source: Final Summary Report from Advisory Board Meetings

The meetings focused on the following populations: people of African ancestry, Chinese ancestry, Latino ancestry, South Asian ancestry, and Japanese ancestry. It was clear across these discussions that inequitable access to care is pervasive and takes many forms for different populations.

Since the barriers to diagnosis and administration of care can vary, so must the solutions to these challenges. The learnings from each meeting offered practical ways to better reach and support that particular community. For instance, the meeting with African American/Black participants suggested working with trusted community members such as churches and barbershops. The Latino advisors suggested the dissemination of photo novella-style medical information through community health centers and local events. During the meeting with Chinese/Chinese American advisors, we learned the role that digital communications tools such as WhatsApp, WeChat, and Line play in communicating medical information. One of the most insightful learnings that carried through across all the meetings was the vital role family insight and support play in the healthcare decision-making and outcomes of a loved one.

The feedback from the advisory board meetings has been invaluable not just to Travere but to our advocacy partners. We have shared our findings with our patient advocacy partners so that they can use the learnings to tailor their messaging, outreach and programming.

One of our Latino advisory board participants, University of Denver researcher Dr. Lilia Cervantes, was impressed with the insights gathered from the Latino advisory board meeting and published the learnings in BMC Nephrology with an unrestricted educational grant from Travere. You can check out the findings here: Qualitative analysis of stakeholder perspectives on engaging Latinx patients in kidney-related research.

Travere encourages those from outside the company to utilize the information. Together, we will change the healthcare landscape to be more equitable for all.

UNDERSTANDING IGA NEPHROPATHY IN PATIENTS OF CHINESE ANCESTRY

As a follow up to the advisory board meeting with patients, caregivers, and healthcare providers of Chinese ancestry, Travere held an advisory board meeting with nephrologists of Chinese ancestry to:

- Understand cultural and social challenges unique to Chinese/Chinese American patients with IgA Nephropathy
- Understand unique aspects of the Chinese/Chinese American patient journey
- Discuss strategies to overcome challenges experienced by Chinese/Chinese American patients with IgA Nephropathy

Some of the insights learned included:

- Some patients believe that if they feel well, they are well. Encouraging preventative care is key for this community.
- Understanding and balancing cultural beliefs about medicine is important and should be handled with care when treating Chinese/Chinese American patients.
- Safe and informed considerations should be made for ways to incorporate traditional medicine for patients who practice it.

We plan on continuing to learn about the needs of and challenges faced by Chinese/Chinese Americans experiencing rare kidney disease. The learnings from these efforts are critical in informing the development of future initiatives.

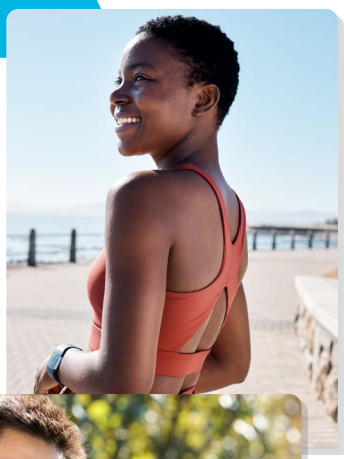
ADVISORY COUNCIL WITH A VARIETY OF PATIENT EXPERIENCES

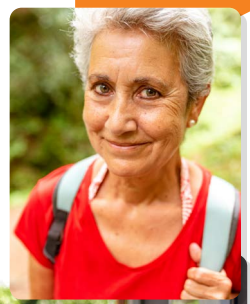
In 2021, the Patient Advocacy team created a Rare Disease Patient Advisory Council to gain insights and input on the issues and topics most relevant and important to the rare patient community. Travere representatives have engaged with the Council to get feedback on topics ranging from educational materials to trial protocols.

The Patient Advocacy team took great care to recruit patients and caregivers who are diverse in age, gender, location, racial and ethnic background, and disease state. Of the 12 members, 25% are men, 42% are people of color, and 50% are caregivers or care partners. They represent a mix of urban, suburban and rural environments and are from as far east as Boston and as far west as Honolulu.

Teams from across the company have sought guidance from this knowledgeable group on everything from the readability and usability of written instructions for dispensing pediatric dosing for a clinical trial to reviewing survey questions intended for patients and caregivers.



EDUCATING AND EMPOWERING RARE DISEASE COMMUNITIES

To fuel progress across the rare disease community, Travere partnered with three key rare disease organizations – National Organization of Rare Diseases (NORD), Global Genes, and EveryLife Foundation – all committed to improving DEI and health equity for the rare disease patients we all serve.

NATIONAL ORGANIZATION FOR RARE DISORDERS

The National Organization for Rare Disorders (NORD) is a leading national non-profit founded in 1983. NORD's mission is to improve the health and well-being of people living with rare diseases and their families by driving policy, advancing research and improving care.14. With more than 330 patient advocacy organizations as members, NORD is an important convener and educator of rare disease patient organizations.

Travere, along with several other companies, supported three webinars on diversity, equity, and inclusion in 2021, hosted by NORD. Over 1,100 individuals from rare disease organizations worldwide tuned in and learned the essentials of inclusivity, membership outreach tactics, and board development strategies to better reflect their communities. The webinars were a success and culminated in the development of a three-part toolkit to inform and guide patient advocacy groups on how to prioritize equity and accessibility for their disease communities.

In 2022, Travere also supported NORD's DEI work to convene its Hispanohablantes advisory group among other key opinion leaders and develop a new patient listening program for Spanish-speaking Americans living with rare disease. This multi-location initiative will enable improved understanding of the experiences, challenges, and needs of this community and will result in shared learnings for expanded engagement. This work is critical for continuing our efforts to promote understanding and ensure that no one with a rare disease gets left behind.

NORD Webinar Attendees Said...

For a small foundation like ours, this kind of programming is so valuable - the speakers were excellent."

"We were all in agreement that this was one of the most productive conversations on DEI that we had experienced... This was about telling the story, not being talked to."

"We plan to open up conversation amongst ourselves about how we can do a better job of moving from intention to action to impact."

93%
of attendees said the webinars strengthened their understanding of diversity, equity and inclusion

92%
said they will use what they learned for future programs/projects

Rare disease organizations from the U.S., Kenya, Pakistan, Hungary, the Philippines, Columbia, India, and Peru attended the NORD webinar series

GLOBAL GENES

Global Genes is a nonprofit dedicated to eliminating the burdens and challenges of rare diseases for patients and families globally. Global Genes helps patients find and build communities, gain access to information and resources, and connect to researchers, clinicians, industry, government, and other stakeholders.

RARE Health Equity Forum

Global Genes has launched several initiatives in recent years to foster dialogue on health disparity, inspire future medical professionals to work in rare diseases, and assist patient advocacy groups in becoming more inclusive. In addition, Global Genes' launched the first-of-its-kind RARE Health Equity Forum (previously the RARE Health Equity Summit), a forum designed to talk about the unique and complex issues and solutions needed to achieve health equity in the rare disease space. Sponsored by Travere in 2021, 2022, and 2023 and hosted in partnership with the Rare Disease Diversity Coalition, the Forum brings impassioned stakeholders from across the rare disease and health equity communities.

Hosted both virtually and in person in 2022, the Forum hosted nearly 300 attendees from the academic, caregiver, corporate, government, advocacy, general healthcare, and scientific arenas.

The event included experts discussing topics ranging from diversity in clinical trials to global health equity, bias in healthcare, and medical gaslighting. Travere's CEO Eric Dube, Ph.D., took part in a panel, "The Diversity of Diversity" where he emphasized the need to prioritize intentionality. "We have to have the intent of ensuring that no patient, no family is left behind, and with that, we have to suspend what we know about... the diagnostic odyssey. We have to remind ourselves that we don't know the experience of...underserved communities. In moving from intent to understanding, we must listen." Dube stated, underscoring the importance of humility when approaching this work.

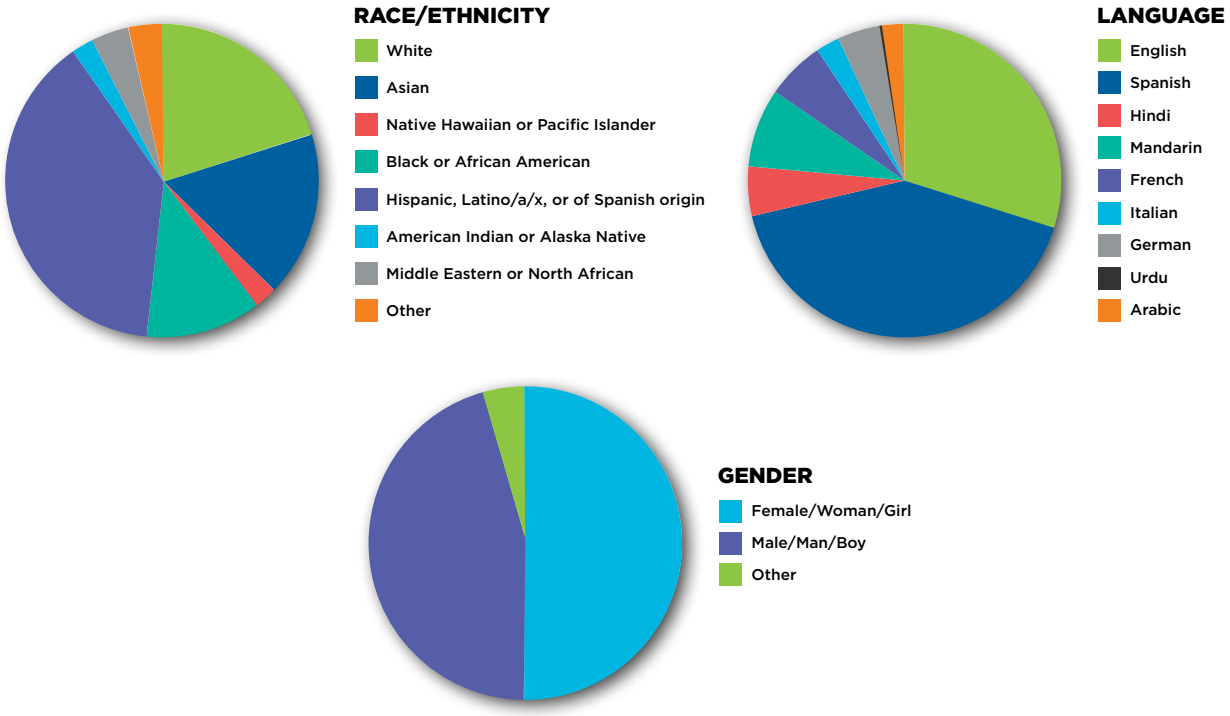
Travere CEO Dr. Eric Dube (bottom right) with Former CEO, at Taysha Gene Therapies R.A. Session II (bottom left), Associate Commissioner for Minority Health and Director of the Office of Minority Health and Health Equity in the Office of the Commissioner at the Food and Drug Administration (FDA) Rear Admiral Richardae Araojo (top right) and Director, Office of Orphan Products Development at the FDA Sandy Retzky, D.O., J.D., M.P.H. on "The Diversity of Diversity" panel at the 2022 Global Genes Health Equity Conference.

Health Equity in RARE Impact Grants

During 2022, Global Genes awarded eight organizations with grants funded by corporate sponsors, including Travere, to address challenges that affect underserved and underrepresented patient communities. These grants allow the awarded organizations the ability to create data collection tools, resources, and processes to better understand the needs of underserved communities and engage them. The populations served by the projects undertaken by the awardees were broad and diverse. Below are the populations served:

Populations Served by Awardees

Source: 2022 Global Genes Rare Health Equity Report



> Health Equity has always been at the heart of what we do, what we provide, and what we work to achieve at Global Genes. It is a commitment that we have made to those we serve in the community and those, like Travere, who we are lucky enough to partner with. We continue to grow and evolve our programs and resources to ensure that we are meeting the needs of patients, with an intentional focus on underserved and underrepresented communities. This is a promise that we made when Global Genes was founded, and one that we continue to make a key priority."

Charlene Son Rigby, CEO, Global Genes

EVERYLIFE FOUNDATION

The EveryLife Foundation for Rare Diseases has a mission to empower the rare disease patient community to advocate for science-driven legislation and policy that advances equitable access to lifesaving diagnoses, treatments and cures. In a bid to drive inclusivity, Travere sponsored EveryLife Foundation's Diversity Inclusion Advocacy Fellowship Program in 2020. The 12-month fellowship was based at the Washington, D.C. office and focused on promoting access to diagnostics, treatments, and cures for rare disease patients of color and other historically marginalized communities. The fellow also evaluated diversity efforts across industry and government bodies, including the NIH, FDA, CMS, and HRSA, to drive impactful change. The role added so much value to the Foundation's work that the latest fellow has since been hired as a full-time employee.

With support from Travere, EveryLife also added the Diversity Empowerment Award to its annual RareVoice Awards to honor advocates or organizations who strive to empower diverse voices in rare disease advocacy. Travere is proud to sponsor this important award that acknowledges those leading the charge to reduce health disparities and advance equitable change.

"With Travere's sponsorship the EveryLife Foundation for Rare Diseases established a Diversity Inclusion Advocacy Fellowship, which became a full-time position in January 2023, and elevated its diversity advocacy program. Thanks to Travere's commitment to increasing diversity, equity, inclusion, and accessibility (DEIA), the EveryLife Foundation continues to reach diverse communities and provide resources to empower patient advocacy."

Julia Jenkins, Former Executive Director, EveryLife Foundation

BRIDGING THE DIGITAL DIVIDE

Children's National During the COVID-19 pandemic, safely accessing healthcare became complicated by the need for isolation. Telemedicine emerged as a game-changing solution that demonstrated the far-reaching impact telemedicine can have in treating various health conditions. The Department of Health and Human Services reported a 63-fold increase in telemedicine usage during the pandemic.

However, marginalized communities still lack access to technological devices, broadband internet, and reliable transportation, limiting their options for healthcare providers who understand their rare diseases. This disproportionately affects those living below the poverty line and in rural communities, who could benefit the most from the potential of telemedicine.

Participant Feedback

"At first, I was reluctant because I thought it wouldn't work out, but actually it worked! We have had most of our visits with genetics, and I love it to be honest."

Mother of son, 4, who has Pitt-Hopkins syndrome

Children's National Rare Disease Institute (CNRDI) is one of the first centers focusing exclusively on advancing the care and treatment of children and adults with rare and genetic disease. In 2018, Travere was a founding sponsor of CNRDI and in 2021, Travere partnered with CNRDI to launch the Digital Medicine Diverse Patient Education and Support Program. This patient-focused initiative ensures that patients and their caregivers can effectively utilize telehealth and digital platforms in their treatment. They met with about 12 Spanish-speaking families a month for in-person meetings or intensive phone discussions to set them up for a successful telemedicine visit. Then, they called families the day before a telemedicine visit to see if they had appropriate access and support. Over the course of a year, CNRDI engaged with over 3,000 families to prepare for and ensure appropriate access to telemedicine appointments.

With the program's success, it has continued to evolve, and now includes a "telemedicine room" in the genetics clinic that provides patients with digital devices and a secure internet connection for appointments with doctors around the country. CNRDI shared that the most significant takeaway from implementing this program was the cultural importance of building and fostering trust with patient communities.

Going forward, CNRDI plans to use support from Travere to:

- Create a patient navigation program to guide and support patients with limited health literacy and those whose first language isn't English.
- Launch a genetic counseling internship to support undergraduate students from underrepresented populations.
- Develop 12 videos to add to CNRDI's educational video series for families using telemedicine.

EXEMPLIFYING FEARLESS LEADERSHIP IN HEALTH EQUITY

PharmaVoice is a leading industry publication covering important voices and ideas in life sciences. In 2021, PharmaVoice recognized Travere for fighting health disparity in rare diseases by naming vice president of Patient Advocacy Eve Dryer to the PharmaVoice100 for her work in spearheading Travere's health equity initiatives.

In this video, Eve told PharmaVoice that Travere's commitment to diversity and health equity is embedded in everything the company does, from early research to trials and drug development. "My goal is whether it's two years or five years from now, we will not need to have a diversity coalition because diversity will just be a part of who we are," Eve said.

OUTbio

Travere's leadership is blazing a trail in DEI for not only patients, but for the employees that serve patients in the biotechnology industry. In 2022, Travere's CEO Eric Dube co-founded the San Diego chapter of OUTbio. OUTbio is the biotech industry's largest LGBTQ professionals group. Its mission is to empower the LGBTQ community and its allies in biotechnology and affiliated industries.

SUMMARY

Health disparities have long persisted in the healthcare system. Therefore, achieving greater health equity requires a prolonged and unwavering effort. Just like a winding path, this journey will not be straightforward but will include twists, turns and obstacles along the way.

Travere is ready to take the long journey. However, we can't take it alone. We recognize that no single organization can eradicate health disparities. That's why we are committed to working closely with patient and community organizations and other companies to amplify the cumulative impact of this effort and develop groundbreaking solutions that cater to patients' unique needs, equip them with useful resources, and eliminate barriers to quality care and treatment. By understanding and working closely with diverse communities, we can develop innovative programs that empower patients, provide equitable care, and revolutionize the healthcare system.

Travere is deeply committed to supporting impactful initiatives that support real change by identifying and endorsing tangible actions that can transform the rare disease healthcare system. We hold a strong belief in a brighter future for all individuals with rare diseases, one in which every patient is treated equitably and justly. As such, we are dedicated to playing an active role in the creation of this world.

Together, let us forge a path toward a future where the challenges faced by rare disease patients are recognized, understood, and effectively addressed. Through our collective efforts, we can create a more inclusive and supportive society, where individuals with rare diseases can thrive and receive the care they deserve.