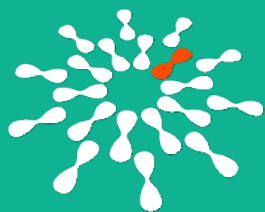


**NORD**<sup>®</sup>  
National Organization  
for Rare Disorders

## LATINOS AND RARE DISEASES

*Building Equitable Access in the  
Rare Disease Community*





# NORD®

National Organization  
for Rare Disorders

## ABOUT US

The National Organization for Rare Disorders (NORD®) is the leading independent advocacy organization representing over 30 million Americans affected by a rare disease. NORD is committed to the identification, treatment, and cure of more than 7,000 rare diseases, of which approximately 95% are still without an FDA-approved treatment or therapy.

NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. For more than 40 years, NORD has led the way in voicing the needs of the rare disease community, driving supportive policies and education, and advancing medical research and providing patient and family services for those who need them most. NORD is also home to over 330 disease-specific member organizations and their communities and collaborates with many other organizations on specific causes of importance to the rare disease community.

**Alone we are rare.  
Together we are strong.®**

## SPECIAL ACKNOWLEDGEMENT

The National Organization for Rare Disorders (NORD®) extends a special thank you to all of the patients, families, and caregivers that made this programming possible by participating in our listening sessions and sharing their stories.

### *Prepared By*

Darby Gavin, Community Engagement Manager,  
National Organization for Rare Disorders (NORD®)

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## INTRODUCTION

Millions of Americans impacted by rare disease face significant health inequities, which are systematic differences in the health status of different population groups. Within the rare disease community, health inequities are heightened by factors such as geographic location, income, race, ethnicity, citizenship, language, education level, gender, ability, and age. According to 2020 Census data published by the Office of Minority Health, there are 62.1 million Hispanic people living in the United States, making this group the nation's second largest racial or ethnic group after non-Hispanic whites. The National Organization for Rare Disorders (NORD®) hosted community listening sessions for Latino/a/x rare disease patients, families, and caregivers to gain a better understanding of the challenges and barriers they encounter in accessing care, treatment, support services, diagnosis, and information. In this report, we will share our learnings from the listening sessions and the engagement model we employed to reach Latino people affected by rare disease.

## PURPOSE

The purpose of this report is to share the engagement model utilized and best practices learned throughout the course of our listening session programming. We intend for our model to be applied and evolved by other stakeholders — both in the rare disease space and the field of public health at large — that are aiming to increase engagement with Hispanic and Latino Americans and other populations impacted by social determinants of health (SDOH).

## ENGAGEMENT MODEL

### Landscape Analysis

The first step of NORD's approach to this programming was to conduct a landscape analysis of Latino engagement stakeholders in both the rare disease space and other fields. It was critical for NORD to identify trusted community leaders and organizations within Hispanic and Latino communities that served the target host cities for our listening sessions; those cities were Houston, New York City, and the Washington, D.C. metro area. Our stakeholder mapping exercise yielded 86 individuals and organizations with experience in Latino engagement,

some specific to the rare disease space, and some not. NORD identified stakeholders by focusing on the following types of entities within our catchment area:

- [NORD® Rare Disease Centers of Excellence \(RD CoE\)](#)
- Community Health Centers
- Federally Qualified Health Centers
- Faith-based Organizations
- Community Organizations
- Patient Advocacy Groups
- Disease Specific Support Groups

In addition to mapping leaders in Latino engagement, we also conducted a literature review of existing peer-reviewed research related to the intersection of Latino/a/x identity, rare disease, and other social determinants of health.

## Stakeholder Engagement

### Planning Committee

After identifying stakeholders, NORD engaged them through two different modes: via a planning committee and through subject matter expert interviews. Between December 2022-March 2023, NORD held four virtual planning committee meetings with external stakeholders during the planning phase of the programming. During planning committee meetings, discussions were focused on engagement strategies, cultural competency, participant recruitment, listening session question development, communication tactics, immigration, trust building, accessibility, and more.

### Subject Matter Expert Interviews

NORD conducted eight subject matter expert (SME) interviews with patient organizations and Latino engagement leaders to understand how they reach, engage, support, and advocate for the Hispanic and Latino community in the United States. Our SME interviews were one-hour in length and were conducted via Zoom. We held interviews with staff from the following entities:

- Baylor College of Medicine/Texas Children's Hospital
- The Akari Foundation
- Hermansky-Pudlak Syndrome Network
- Hemophilia Foundation of Southern California
- Children's National Rare Disease Institute
- Parent to Parent of New York State

- New York Mid-Atlantic Caribbean Regional Genetics Network
- A Latino Engagement expert, formerly employed at a NORD rare disease member organization.

## Community Engagement

### Interpretation

NORD offered listening sessions in both English and Spanish. Through our stakeholder engagement exercises, we learned that live interpretation during the listening sessions would jeopardize the sanctity of the session. Planning committee members expressed concern over bilingual listening session participants being distracted by the quality of the interpretation. One planning committee participant shared, “Sometimes people do not want to be translated, they just want to be heard.”

All communication leading up to the listening sessions was conducted in either English or Spanish depending on the language preference of the individual. Language preference was collected on the listening session online registration form, which was available in both English and Spanish. NORD hosted sessions in both English and Spanish and there was no interpretation that occurred during the sessions. After the Spanish listening sessions were held, notes were transcribed to English.

**Best Practice: Engage community members in whichever language they prefer to speak. If that is not possible, utilize a professional interpreter who is also a cultural broker.**

### Venue

The external planning committee provided recommendations on types of venues to consider for the listening sessions, and those with knowledge of the target cities made recommendations on specific venues that would be trusted and comfortable locations for potential participants. We received many different venue recommendations including community centers, restaurants, health clinics, faith-based locations, and more. Important considerations to make while assessing potential locations included accessibility by public transportation, ADA parking availability, safety of the neighborhood, reputation amongst community members, and proximity to our target population (which we determined anecdotally through subject matter expert

interviews and through Census data). We decided to host our in-person sessions at the following locations:

- United Way of Greater Houston, 50 Waugh Dr. (Houston)
- West Side YMCA, 5 W 63rd St. (New York City)
- Renaissance Downtown Hotel, 999 9th St. NW (Washington, D.C.)

**Best Practice: Select a venue that is well-known amongst your target community, is accessible by public transportation, is ADA accessible, and has onsite parking or accessible parking nearby.**

### Communication

Language preference and preferred style of communication were collected on the listening session registration form. The external planning committee emphasized the need to accommodate multiple types of communication methods to ensure potential participants were not left behind as a result of technology barriers.

What is your preferred way to communicate with us? Check all that apply:

- Phone call
- Text
- Email
- WhatsApp message
- WhatsApp call
- Other

The image above is a screenshot of the question regarding communication preference that was on the listening session registration form.

After an individual completed the online registration form, they received correspondence confirming their attendance for the listening session they selected. Registrants also received a reminder one week before the session, and one day before the session. With the exception of two individuals, everyone who was registered for an in-person session did attend. In contrast, for our first virtual listening session, only 23% of those who originally registered attended. As an effort to improve attendance, we called each person registered to attend our second virtual session one week prior, and our attendance rate improved to 63%.

Individuals that were not able to complete the online registration form independently were contacted via phone call by NORD staff who were able to provide support in both English and Spanish.

**Best Practice: Organizations need to be flexible with the types of communication methods they offer when engaging populations that may have varying levels of access to or knowledge of technology. The best way to ensure ease of communication is to ask for a preferred method of communication. We also recommend communicating via phone call whenever possible; it is the most personal form of communication and we found that it eased participant fears and fostered trust.**

## Engaging Participants

### Inclusion Criteria

- Individuals with a rare disease.
- Undiagnosed individuals suspected of having a rare disease.
- Current or former caregivers of individuals either with a rare disease or with an undiagnosed condition suspected of being a rare disease.
- Individuals identifying as Latino, Latina, Latinx, Hispanic, or those of Mexican, Caribbean, and South or Central American descent.
- Individuals living in the United States regardless of citizenship status.

NORD utilized a variety of outreach methods to promote the listening sessions and identify potential participants within the target cities. Those methods included:

- Asking local community organizations to share our posters either on their own social media or distribute hard copies if they have an in-person office space.
- Asking disease specific support group organizers to share our social media graphics with their group.
- Posting our flyers in local community health clinics.
- Posting our flyers in NORD® Rare Disease Centers of Excellence.
- Email distribution to NORD Rare Action Network® members.
- Email distribution to NORD Patient Assistance Program enrollees and email subscribers.
- Promotion at virtual and in-person Rare Disease Day® celebrations.
- Tabling at NORD® Rare Disease Centers of Excellence during clinic hours.
- Running radio advertisements (we only did this for one of our target cities).

On the listening session registration form, we asked how the person learned of our listening sessions. Here is the response distribution:

- 24% NORD Email
- 24% Community Organization
- 21% Social Media
- 15% Friend/Family
- 6% NORD Rare Disease Day Celebration
- 6% NORD Website
- 4% Other

During the outreach process, NORD emphasized transparency and participant privacy. Our planning committee encouraged communicating the intentions and goals of the listening sessions in all promotional materials and outreach activities. Planning committee members shared that lack of transparency could deter people from attending the session and perpetuate fear and distrust. NORD advertised the listening sessions as private events that required registration.



### Join the National Organization for Rare Disorders (NORD) in-person for a community listening session!

We are hosting community conversations with Latino/a/x rare disease patients, families, and caregivers. NORD wants to hear your experience getting diagnosed and living with a rare disease.

- All information shared during the sessions will remain confidential and will not be shared with any third parties.
- Compensation for in-person participation will be provided.
- The listening sessions are family friendly for relatives of individuals that are registered to attend the listening session. There will be games for kids, delicious food, and free NORD swag!
- These listening sessions are private events and open only to Latino/a/x Rare Disease patients and caregivers, registration is required.



*The image above is a screenshot of a promotional poster that NORD utilized to promote the listening sessions.*



Per the recommendation of our planning committee and subject matter experts, the listening session registration form required minimal information. Requesting an abundance of personal information on the registration form would have deterred people from registering and participating. The only required questions on the form were:

- What is your first name?
- Please provide your phone number.
- Do you or anyone that is attending a session with you have any dietary restrictions?
- How did you learn about our listening sessions?

To reduce the financial burden of attending an in-person listening session, NORD provided assistance with local transportation to the listening session to those who needed it, and each family received a \$50 Visa or Amex gift card for participating. NORD also covered the cost of parking for in-person participants at the New York City and Washington, D.C. listening sessions. The Houston listening session venue offered free parking.

Financial assistance for local transportation was provided in the form of Uber gift cards that were emailed to participants prior to the session to prevent them from incurring any out-of-pocket transportation expenses. Uber gift cards were provided because cash reimbursement requires a Social Security number or Taxpayer ID and requesting such personal information would have deterred people from participating and utilizing the transportation assistance. In total, NORD provided \$399 in Uber gift cards, parking assistance, and public transportation assistance.

Food was served at each listening session. At the New York City listening session, food was served buffet style at the beginning of the session. At the Houston listening session, we held a community dinner in-between the sessions. Below are the examples of the two different schedule formats we tested.

#### **New York Schedule**

Listening Session #1 10am-11:30am  
*(breakfast served at the beginning)*  
Listening Session #2 12:30pm-2pm  
*(lunch served at the beginning)*

#### **Houston Schedule**

Listening Session #1 4pm-5:30pm  
Community Dinner 5:30pm-6:30pm  
Listening Session #2 6pm-7:30pm



The community dinner format provided an invaluable opportunity for individuals from session #1 and session #2 to connect with one another. It also created a warm, comfortable, casual space for participants to connect with NORD staff and volunteers. Participants from the first session stayed at the community dinner until the 2nd listening session had concluded because they were immersed in conversation with other participants. NORD provided takeout containers to participants so they could take food home for their families.

**Best Practice: Conduct outreach to potential participants through a variety of communication streams to ensure reach amongst groups with varying levels of technology and healthcare access. Provide compensation to participants to help mitigate the financial burden of attending and provide assistance with transportation costs. Incorporate a community meal into the program to provide an opportunity for participants to connect with one another and build relationships.**

#### **Continuing Engagement**

It's critical that commitment to serving the target population is conveyed through engagement that is sustained and nurtured. We learned from subject matter experts that the Latino rare disease population experiences transactional engagement with entities in the rare disease space, and such interactions result in disengagement, distrust, and animosity.

*“We [Hispanic people] are recruited when we are needed and discarded when we are not.” - Rigoberto Garcia, MPH, Hemophilia Foundation of Southern California*

NORD is committed to serving the Latino rare disease community as a part of our mission to improve the health and well-being of all people with rare disease. As NORD continues to sustain and grow Latino outreach and engagement, there are also efforts underway to increase the accessibility of educational materials for Spanish speaking patients, caregivers, and families. **NORD has over 190 of our Rare Disease Reports available in Spanish on our website, and that number is projected to surpass 200 by the end of 2023.** Our rare disease reports are critical sources of information for patients and caregivers impacted by diseases for which very little information and research is available. NORD is also focused on translating our core programmatic information to Spanish to increase equitable access to the services we provide to the rare disease community.

**Best Practice: Translate diversity, equity, and inclusion theory into action by establishing and implementing a plan for continuous engagement that serves the needs of the target population and aligns with the mission of the organization.**

### **Virtual Listening Sessions**

We originally planned to focus on hosting in-person listening sessions. Through conversations with our planning committee, we decided to host virtual listening sessions as well to capture the voices of patients, caregivers, and families that would not be able to attend an in-person session. We hosted two virtual sessions; one that was specific to patients and caregivers in New York, and the other being a national listening session. We held the virtual sessions in both English and Spanish concurrently. When a participant joined the Zoom, we automatically assigned them to the breakout room based on their language preference indicated on the registration form. We had greeters that spoke both Spanish and English in the main Zoom room as people arrived to ensure all our participants could communicate with a staff member in the language they were most comfortable communicating in.

**WELCOME TO NORD'S COMMUNITY LISTENING SESSION!**  
**¡Bienvenido a la sesión de escucha comunitaria de NORD!**

Thank you for joining us! In a moment we will assign you to join a virtual breakout room based on the language preference you chose on your registration form.

¡Gracias por estar con nosotros! En un momento, lo asignaremos a una sala de reuniones virtual según la preferencia del idioma que usted eligió en el formulario de registro.



rarediseases.org 1

*Above is an image of the slide that was shown on screen share as participants joined the main Zoom.*

We used the same registration form for both our virtual and in-person sessions and participants could select whichever session they wanted to attend. The Zoom links for the virtual sessions were manually distributed by email, text, or Whats App. It was very important that Zoom links were not automatically distributed to anyone who filled out the registration form. Prior to distributing the Zoom link, we confirmed attendance and instructed participants that the Zoom link should not be shared with anyone not registered to attend to maintain the integrity and privacy of the session.

**Best Practice: Ensure access to bilingual staff throughout the entire session and do not share the virtual meeting link publicly.**

NORD has over

**190**

**DID YOU KNOW?**



Rare Disease Reports available in Spanish on our website, and that number is projected to surpass 200 by the end of 2023.

# SNAPSHOT OF COMMUNITY RESPONSE

Between April 2023 and June 2023, NORD held five in-person community listening sessions, and two virtual sessions. Across all seven sessions, there were:

- 58 participants in total
  - › 35 people participated in a Spanish session
  - › 23 people participated in an English session

Listening session participants were given the opportunity to fill out an optional survey. Of the 29 survey respondents:

- 72% were born outside the United States in countries including El Salvador, Mexico, Uruguay, Argentina, Ecuador, Dominican Republic, Nicaragua, Cuba, and Colombia
- 28% were born in the United States and Puerto Rico

The listening sessions were open to all Latino/a/x rare disease patients regardless of disease state. Multiple disease classifications were represented by participants, including genetic conditions, primary immunodeficiencies, neurological, blood, metabolic, rheumatological, pulmonary, and other types of rare disorders. We also had multiple participants representing the undiagnosed community.

## KEY FINDINGS

### Access Barriers

Across all seven community listening sessions, **the biggest challenge identified in accessing care or treatment for a rare condition was out-of-pocket costs for medical appointments, medication, and treatments.** In every single session, participants expressed frustration over income limits for Medicaid qualification. Participants shared that they've been forced to decrease their income to qualify for Medicaid because they cannot afford the deductibles that are extremely high with private insurance. It's critical to note that Hispanic people have the highest uninsured rates of any racial or ethnic group in the United States. Data reported by the Census Bureau in 2020 shared that 49.9 percent of Hispanics had private insurance coverage, compared to 73.9 percent of non-Hispanic whites. Also in 2020, the Office of Minority Health reported that 18.3 percent of Hispanics were not covered by health insurance, compared to

5.4 percent of the non-Hispanic white population. In addition, **participants shared that it's very challenging to secure financial support from community organizations because the funding available is limited,** and many organizations do not return phone calls.

### Accessing Medical Information

Participants shared that they have accessed medical information from a variety of sources including the internet, Facebook groups, friends in the medical field, genetic counselors, other patients, primary care physicians, and disease specialists. The majority of participants reported that they prefer to receive medical information from medical professionals, and they appreciate the medical professionals that deliver information in a clear, direct, and professional way. Some participants shared their anxiety and fear over pieces of information they've found on the internet. One individual said that they try not to google their disease because "... the internet gives you the worst-case scenario, and the severity of the disease differs depending on the person." In some situations, participants shared they've been forced to rely on information available on the internet and in Facebook groups because there is such little information available on their disease, and **they don't have access to a doctor that specializes in their condition.** Of all the listening session participants that completed our optional survey, 60% reported that they receive care from a doctor that specializes in their disease, and 32% reported they do not. The remaining 8% of respondents were undiagnosed or were caregivers to undiagnosed patients.

### Quality of Life

When asked how rare disease impacted quality of life, participants overwhelmingly cited the negative toll on their mental and emotional health. **Participants described feelings of hopelessness and exhaustion associated with insurance denials, symptom management, travel for appointments, educating medical professionals about their disease, fertility, finances, and more.** Two male participants shared that their rare disease diagnosis has rendered them "useless," as they're no longer able to provide and care for their family, which has had significant negative consequences on their mental health.



Many participants expressed that their social lives have been severely impacted by rare disease. One patient shared:

*"... It has been hard for me to develop friendships. It is hard to feel safe with people. I feel like a hassle to friends who want to do things that I can't do."*

Participants across each listening session also shared that they have experienced intense isolation due to their inability to connect with other people who understand the hardships rare families endure. Some participants experienced rejection within their own families because of their disease.

## Support Services

The most impactful source of support identified by the majority of participants was other patients and families that they've met and become close friends with throughout their rare disease journey. Participants found other people in their disease specific communities predominantly through Facebook groups. Other common supports that were identified included:

- Family members
- Disease specific support groups
- Disease specific organizations
- Faith-based groups
- Social workers and therapists
- Medical specialists

## Reimagining Rare

At the conclusion of each listening session, facilitators asked participants to envision a world without any resource limitations and to brainstorm resources and services that would improve some of the challenges identified during the session.

Participants shared that in an ideal world:

- Physicians would have time to listen to patients.
- Patients would have a notetaker accompany them to all medical appointments.
- Physicians would be honest with patients about their diagnosis and would provide medical information in simple language that patients can understand.
- Physicians would take patient concerns seriously.
- The cost of care and insurance coverage would not be something we constantly worry about.

- Government, pharmaceutical companies, community organizations, doctors, and patients would work collaboratively to help the rare disease community as a whole.
- There would be more people who understand rare diseases.
- Everybody dealing with rare disease would have access to a therapist or social worker.
- Every rare disease would have an ICD-10 code.
- There wouldn't be such long wait times for services like disability, housing, and financial assistance.
- Increased availability of medical information on rare disease that is written in gender inclusive language.
- Eradication of misdiagnosis.

## Patients Told NORD:

*"If you make too much money you don't qualify for Medicaid, but if you have private insurance the deductibles are very high, and you don't have everything you need covered."*

*"The toll [of rare disease] on my mental health is debilitating. I love all these things and I just can't do them. Not having the simple pleasures that I used to is taxing on my mental health, sometimes more than my physical health."*

*"I do not want to reach out to family members for support because I'm afraid of being a burden."*

*"I don't have insurance and I don't have a high income. I had to go to Mexico for surgery."*

*"I was a young child when I was diagnosed with leukemia and a lot of details were kept from me. I knew I had leukemia but whenever I would ask, I would get yelled at by family and friends."*

*"Talking to other patients about your experiences is powerful because it makes you feel like it's not just in your head when doctors don't listen to you."*

*"My rare disease stole my career."*

*"I'm very confused during medical appointments. There are very few staff members that speak Spanish, and they aren't able to give me information on my disease."*

## Caregivers Told NORD:

*"I felt guilty [after receiving genetic test results] because I found out that the condition was from my side of the family."*

*"As my son is getting older, he's becoming aware of his mobility limitations caused by his rare disease, and it has been heartbreaking for me to watch."*

*"It's very challenging to coordinate care with a multidisciplinary team and bring two children in wheelchairs to appointments in an adaptive van."*

*"I used to work, and I'd leave my daughter with babysitters, but then I found out that they were calling her "cara negra" ("black face") and I couldn't leave her with people who see her as less."*

*"I have a 22-year-old son I feel we have neglected [due to the family's focus on their other child with a rare disease]."*

*"My mother was sick in my home country, and I wasn't able to go and help her. She has passed away now. I had to stay here [in the United States] for my son's medical care. I can never forgive myself for that."*

*"We need insurance for our daughter. She needs a geneticist and a dermatologist. We don't have a diagnosis. We can't lie, we worry about the condition worsening on her eye and how it will affect her eyesight. We are thankful she is in our lives. She is special."*

*"Before my son's diagnosis, every once in a while, he wouldn't be able to use his leg and would have all these bruises, and people accused me of causing the bruises. It has been 14 years now and information has improved, we know how to manage his health. There are times when you are alone, and you need help, and you need to have faith. One day at a time. We try to advocate for him as much as possible, and I've become a resource for other moms."*

*"We're not able to go to the neurologist that we have a referral for because we have DACA, so healthcare options are limited."*

## THE ROLE OF PATIENT ADVOCACY GROUPS IN MINIMIZING HEALTH DISPARITIES

Patient advocacy groups (PAGs) in the rare disease space are uniquely positioned to implement DEI strategies within their organizations that can have a national or potentially global impact. Hermansky-Pudlak Syndrome (HPS) Network is a perfect example of a PAG that has been extremely successful in engaging patients within their community that have not always had access to advocacy opportunities due to various social determinants of health, including geographic location and language. During NORD's subject matter expert interview with HPS Network Executive Director and Founder, Donna Appell, R.N., the discussion focused on the successes the network has had in engaging their patient population in Puerto Rico. One of those successes was the first ever Externally-Led Patient Focused Drug Development (EL-PFDD) meeting held simultaneously in English and Spanish while presenting to the Food and Drug Administration (FDA). To ensure the voices of their patient population in Puerto Rico would be heard during the EL-PFDD, HPS Network removed connectivity barriers by hosting the meeting at a hotel, removed language barriers by having a live translation service, and removed transportation barriers by arranging travel for participants to and from the hotel for the meeting. In addition to removing access barriers, HPS Network has earned the trust and support of their patient population in Puerto Rico by conveying their dedication to the community through action. Donna has been traveling to Puerto Rico since 1993 to meet HPS families and engage them in the network's mission.

Hermansky-Pudlak Syndrome Network's success in embracing inclusivity and accessibility in delivering their mission can be emulated by other patient advocacy groups that approach engagement by utilizing our model that is centered around building trust with stakeholders, leaders, and community members by listening and collaborating together to achieve solutions. When PAGs prioritize infusing intentional DEI strategies into their patient engagement, both individual disease state communities, and the rare disease community, greatly benefit.

## PARTNERSHIP ENGAGEMENT MODEL: PATIENT ADVOCACY GROUPS AND MEDICAL INSTITUTIONS

In October 2023, NORD hosted additional in-person listening sessions for Latino rare disease patients and caregivers in New York City. These sessions were unique in that they were hosted in partnership by NORD and The Children's Hospital at Montefiore (CHAM). CHAM, part of the New York Center for Rare Diseases, is a designated NORD® Rare Disease Center of Excellence (RD CoE). NORD's RD CoE program is the first national network of hospitals dedicated to diagnosing, treating, and researching all rare diseases, and training the next generation of rare disease clinicians and scientists. Each designated center was chosen for their demonstration of commitment to the rare disease community through research, clinical, and educational initiatives and programs aimed at improving care for rare disease patients.

Genetic counselors at CHAM identified patients eligible to participate based on our inclusion criteria, conducted outreach to invite them to participate in the sessions, and provided the link to the registration form should the individual want to sign up. Once an individual registered, NORD facilitated further communication with participants and oversaw planning and execution of the sessions. The patient advocacy group and medical institution partnership model offers a targeted approach for identifying potential participants and could be a solution for PAGs with limited staff and resources. In addition, affiliation with a medical institution brings brand recognition to the event and may boost attendance among patients and caregivers that do not receive care at the particular clinic but feel comfortable attending because of the familiarity and legitimacy of the institution. Additional recommendations and insights gleaned from implementing the PAG and medical institution partnership model will be disseminated in the near future.

## DRIVING PROGRESS

NORD has a rich history in building trust and support within the rare disease community at large and will continue to lead long-term initiatives to increase inclusion and promote access to rare disease education, diagnosis, and care for Latino rare disease patients and caregivers, and all people impacted by rare disease that are burdened by social determinants of health. NORD is currently undertaking the following efforts to increase access to educational resources, decrease the diagnostic odyssey, and improve quality of care for diverse populations impacted by rare disease:

- The NORD Rare Disease Center of Excellence Program's Diversity, Equity, and Inclusion (DEI) Working Group brings together clinicians, researchers, and others from the 40 designated centers to identify and propose approaches to address inequities in access to rare disease treatment and training of rare disease specialists.
- Translation of our core programmatic materials to Spanish, including information on our patient assistance programs.
- Translation of our rare disease reports — which are vital resources for patients, caregivers, researchers, and clinicians — into Spanish. All of our reports are being translated internally by NORD's Ontology Specialist, Gioconda Alyea, IMG.
- Continued engagement with our listening session participants, the stakeholders that participated in subject matter expert interviews, and our planning committee participants.
- Researching and raising awareness of the experiences in accessing and affording health care for underrepresented rare disease patients and caregivers through our Rare Disease Diversity Survey in partnership with the Rare Disease Diversity Coalition (RDDC). Together, NORD and the RDDC developed the first-ever national survey of underrepresented rare disease patients and caregivers to better understand their unique perspectives. Findings from the survey will be published in 2024.
- Promoting increased diversity of medical professionals in the rare disease space by targeting engagement with pre-health students from diverse backgrounds, collaboration with Latino Medical School Associations, and programming through NORD Students for Rare chapters.
- NORD has developed and will continue to develop educational resources on diversity, equity, and inclusion geared towards leaders, advocates, and nonprofit organizations. [Click here](#) to access NORD's diversity, equity, and inclusion toolkits and webinars.



**NORD believes in the power of community; we support and strengthen a diverse network of patient advocacy organizations, Rare Disease Advisory Councils (RDACs), medical institutions, patients, caregivers, researchers, and educators. Please reach out to NORD's Community Engagement Manager, Darby Gavin, via email at [dagavin@rarediseases.org](mailto:dagavin@rarediseases.org), to learn more about this programming and explore opportunities for collaboration.**

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Luisa Leal, The Akari Foundation

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Claudia Soler-Alfonso, MD, FACMG, Baylor College of Medicine/Texas Children's Hospital\*

Rigoberto Garcia, MPH, Hemophilia Foundation of Southern California

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