Social Media Kit

Health Equity for People Living with PNH: Creating a Level Playing Field

About This Social Media Kit

On behalf of the Rare Disease Diversity Coalition (RDDC) and people with rare blood disorders like PNH, thank you for sharing *Health Equity for People Living with PNH: Creating a Level Playing Field*.

Led by the Rare Disease Diversity Coalition and PNH Health Equity Steering Committee, this report highlights barriers to care, particularly for minoritized and marginalized groups, including Black and Indigenous People of Color (BIPOC), Lesbian, Gay, Bisexual, Transgender, Queer and/or questioning, Intersex, Asexual and other diverse identities (LGBTQIA+), residents of rural areas, people with incomes below the federal poverty level, immigrants, limited English proficiency who experience greater barriers to timely diagnosis, treatment, and ongoing care.

This Social Media Toolkit is designed to disseminate key findings from the report, highlight identified challenges, share recommendations, and further collaboration between stakeholders.

We encourage you to use this toolkit to help amplify the findings in this report, ensuring broader awareness of the gaps and barriers in accessing necessary healthcare for rare disease patients and fostering dialogue about the needs of diverse populations who are living with rare blood disorders.

In This Kit

1. Key Messages to Guide Your Social Media Content
2. Sample Posts and Key Accounts
    a. Instagram, X (formally Twitter) and Facebook
    b. LinkedIn
    c. Graphics

Key Messages to Guide Your Social Media Content

Core takeaways

By focusing on accessible treatment, supportive care, and inclusive research, these recommendations aim to foster more equitable health outcomes for all PNH patients.

Top aims:

- **Increasing Equitable Access to Treatments and Resources**
    - Ensuring PNH patients have equitable access to FDA-approved treatments and comprehensive resources is essential. Recommendations include expanding telehealth services, reducing financial burdens through advocacy for Medicaid expansion and insurance reform, and simplifying prior authorization processes to reduce barriers. These efforts will prioritize underinsured and geographically isolated patients, making life-saving therapies accessible to all.
- **Fostering Patient-Centered, Culturally Competent Care**
    - The report emphasizes the need for healthcare systems to integrate patient voices and address social determinants of health (SDOH) that affect PNH care. Training providers in cultural competence, integrating shared decision-making tools, and establishing PNH coalitions to support caregivers and families are critical steps. Enhancing provider awareness and fostering inclusive patient-provider relationships aims to empower PNH patients in their care journey and improve treatment adherence.
- **Promoting Inclusive Research and Data Collection**
    - To reduce PNH disparities, increasing diversity in clinical trials and research is imperative. Strategies focus on developing inclusive study designs and engaging community-based organizations to build trust and encourage participation among underserved groups. Improved representation in research will lead to more accurate, comprehensive insights into PNH, helping tailor therapies and treatment guidelines that address the unique needs of all patient populations.
- Through collaborative, multi-stakeholder efforts across healthcare providers, advocacy organizations, and policymakers, these recommendations offer a pathway toward a more equitable and patient-centered PNH care model.

Trackback to the Mission of RDDC

- RDDC’s Mission Rare Disease Diversity Coalition addresses the extraordinary challenges faced by historically underrepresented rare disease patients as encompassed by social determinants of health (SDOH). The Coalition brings together rare disease experts, patients, healthcare professionals, diversity advocates, and industry leaders to bring about evidence-based solutions that alleviate the disproportionate burden of rare diseases on marginalized populations.

Sample Posts and Key Accounts

Instagram, X, Facebook

Key Accounts

- Instagram
    - Black Women's Health Imperative
        - @blkwomenshealth
    - Rare Disease Diversity Coalition
        - @rarediseasediversity
- X formally Twitter
    - Black Women's Health Imperative
        - @blkwomenshealth
    - Rare Disease Diversity Coalition
        - @rarediseasediv1
- Facebook
    - Black Women's Health Imperative
        - https://www.facebook.com/BlackWomensHealthImperative/
    - Rare Disease Diversity Coalition
        - https://www.facebook.com/p/Rare-Disease-Diversity-Coalition-100086789036888/

Sample Posts (Long)

🩸 Transforming PNH Care: A Step Toward Health Equity 🩸

Living with paroxysmal nocturnal hemoglobinuria (PNH) shouldn't mean getting stuck behind extra barriers to quality care, especially for patients from historically underserved communities. Health equity in PNH means access to the best treatments, financial support, and compassionate care for all.

Tap the link in our bio to read our latest report on how to help people.

Here's how we can make a difference:

➡️ Improve Access to Treatment: By simplifying approval processes, reducing non-medical switching, and prioritizing telehealth and mobile clinics, we're working to ensure PNH patients get the care they need, wherever they live.

➡️ Empower Patients & Caregivers: Shared decision-making tools, support groups, and coalitions focused on PNH patients help everyone feel empowered and informed.

➡️ Ease Financial Burdens: Increased financial aid and better insurance coverage can remove obstacles to treatment, especially for low-income and underinsured patients.

➡️ Enhance Provider Education: Training doctors in cultural competence, gender sensitivity, and PNH-specific treatments lead to more compassionate, effective care.

➡️ Promote Inclusive Research: Diverse clinical trials representing all communities ensure we're truly improving outcomes for every PNH patient.

These steps create a healthcare system that respects, supports, and uplifts every person affected by PNH. Together, we're making PNH care more equitable, compassionate, and accessible. 💪✨Read the full report here bit.ly/rddcpnh

#PNH#RareDisease #InclusiveHealthcare #PatientAdvocacy #HealthEquityMatters #CareWithCompassion #Hematology #ClinicalTrials

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How do we help people living with PNH? Here are the recommendations from the Rare Disease Diversity Coalition and the PNH Health Equity Steering Committee:

1. 💊 Access for All: Expanding PNH treatment access starts with trained providers. Cultural competency and patient-centered communication are key to equitable care. Let's support initiatives making this a reality! #PNHSupport #InclusiveCare #HealthEquity

2. 💵 Making PNH Care Affordable: For many PNH patients, financial barriers can feel insurmountable. Partnerships with pharmaceutical companies and nonprofits will help patients access essential treatments affordably. #PNHAffordableCare #PatientAdvocacy #RareDiseaseSupport

3. 🤝 Patient Voices in PNH Care: Empowered patients make empowered decisions. Shared decision-making tools help patients feel heard, informed, and in control of their care. Let's keep PNH care collaborative! #PatientEmpowerment #PNH #InclusiveHealthcare

4. ❤️ Creating a Community for PNH Patients: Patient support networks and mental health programs make a difference in the PNH journey. Together, we can build a support system that includes every voice and fosters hope. #PNHCommunity #MentalHealthSupport #RareDiseases

5. 📱 Telehealth for Every Patient: Bringing PNH care to remote areas means expanding telehealth and establishing mobile clinics. Quality care should be accessible no matter where you live! Read the full report here bit.ly/rddcpnh

#Telemedicine #HealthForAll #EquitableAccess

🩸 Addressing Health Inequities in PNH Care 🩸
For people with paroxysmal nocturnal hemoglobinuria (PNH), health inequities can make timely diagnosis and access to life-saving treatments challenging. Barriers like socioeconomic status, language, and racial disparities affect patient outcomes and delay care, leading to severe complications. Together, we can advocate for equitable care, improve access to essential treatments, and empower PNH patients for a healthier future. 💪

Read the full report here bit.ly/rddcpnh

#PNH #HealthEquity #RareDiseaseCare #PatientAdvocacy

Sample Posts (Short)

Empowering patients and caregivers through shared decision-making is essential for equitable PNH treatment. By prioritizing open communication, we're working toward a healthcare model that truly listens to and values patients' voices.

Tap the link in our bio for the latest PNH report.

#HealthEquity #PNH #PatientAdvocacy #SharedDecisionMaking

Creating a multi-stakeholder coalition dedicated to PNH advocacy helps to strengthen the voices of underserved communities. Together, patients, caregivers, and providers can work with policymakers for real, impactful change.

Tap the link in our bio for the latest PNH report.

#PNHCommunity #HealthEquity #TogetherForPNH

To truly address health equity in PNH, inclusive clinical trials are essential. Reflecting diverse patient backgrounds ensures treatments meet everyone's needs. Let's push for trials that represent all communities.

Tap the link in our bio for the latest PNH report.

#ResearchEquity #PNHResearch #DiversityInResearch

🌍 Supporting PNH Patients from Diverse Backgrounds 💙
PNH patients from Black, Hispanic/Latino, and Asian American Pacific Islander communities face unique health disparities. By tailoring care to address the specific needs of each group, we can improve outcomes and bring more equity to PNH care. Supporting diversity in treatment is essential!

Tap the link in our bio to read how we can support more patients from diverse backgrounds and circumstances.

#HealthEquity #PNH #InclusiveCare

🏥💡 Breaking Down Barriers to Access PNH Care🏥💡
For PNH patients, factors like geography, income, and cultural differences impact access to critical care. Let's prioritize support for patients facing these barriers through resources, advocacy, and accessible care models. Together, we can build a more inclusive future in healthcare. 💪

Tap the link in our bio to read how we can support more patients from diverse backgrounds and circumstances.

#PNHSupport #SDOH #HealthcareAccess

💙 Empowering PNH Patients with Strong Support Networks✨
Mental health resources, culturally respectful care, and community support make a difference in PNH management. By prioritizing these essential support systems, we can help every patient live well and fully. 💙✨

Tap the link in our bio to read how we can support more patients from diverse backgrounds and circumstances.
#PNHCommunity #HealthEquity #SupportSystems

LinkedIn

Key Accounts

- Black Women's Health Imperative
    - https://www.linkedin.com/company/black-women's-health-imperative/
- Rare Disease Diversity Coalition
    - https://www.linkedin.com/company/rare-disease-diversity-coalition/

Sample Posts (Long)

👩⚕️Making the PNH Health Inequities Visible🔍

For individuals living with paroxysmal nocturnal hemoglobinuria (PNH), disparities in care can have life-threatening consequences. Data from our latest report shows that people from marginalized communities often face barriers in accessing timely and specialized care for this rare disease, with non-English speakers, low-income patients, and racial minorities experiencing disproportionate delays.

Every barrier delays early diagnosis, critical for managing severe PNH complications like chronic fatigue, thrombosis, and hemolysis. We must work to remove these and improve health equity. Only together can we drive real progress in equitable PNH care, ensuring all patients receive the comprehensive support they deserve.

Read the full report here bit.ly/rddcpnh

#HealthEquity #PNH #PatientAdvocacy #RareDiseases #HealthcareReform

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How do we help people living with PNH? Here are the recommendations from the Rare Disease Diversity Coalition and the PNH Health Equity Steering Committee:

1. 🔹 Improving PNH Care Access: Making FDA-approved treatments accessible is critical for patients with PNH. We're advocating for expanded provider training on cultural competency, pain management, and updated clinical guidelines to ensure patients receive comprehensive, empathetic care. #HealthEquity #PNHCare

2. 💸 Addressing Financial Barriers for PNH Patients: High treatment costs should never prevent anyone from accessing care. By expanding financial assistance and partnering with non-profits, we're pushing to ease financial burdens for patients and focus support where it's needed most. #PNHTreatment #FinancialSupport

3. 👥 Empowering PNH Patients and Providers: From shared decision-making to dedicated advocacy, we're committed to empowering PNH patients. Tailored tools, forums, and feedback loops will help personalize care and keep patients at the center of their health journey. #PatientEmpowerment #PNHAdvocacy

4. 📣 Breaking Down Bias in PNH Care: To promote true equity, we need more than treatments—we need culturally sensitive care. Our initiatives advocate for ongoing bias training and standardized protocols, ensuring that every patient is respected and understood. #InclusiveHealthcare #PNHEquity

5. 🌐 Using Telehealth for Remote PNH Care: Expanding telehealth and creating mobile clinics are pivotal steps in overcoming geographical barriers to PNH treatment, especially for rural patients. Together, we can bring essential care closer to every community. Read the full report here bit.ly/rddcpnh #Telehealth #RuralHealthcare

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🔍 Driving Health Equity for PNH Patients: Key Recommendations for Transforming Care

Paroxysmal Nocturnal Hemoglobinuria (PNH) is a rare, life-altering condition that disproportionately affects communities facing socioeconomic barriers, racial disparities, and other social determinants of health.

But it doesn't have to be that way. We partnered with some amazing groups to help address these inequalities head-on. There is a path forward to bridge the gap and bring compassionate, equitable care to every PNH patient.

Get full access to the report here: bit.ly/rddcpnh

Interested in our research and recommendations we're making to improve health equity and reduce barriers in PNH care? Here are 5 areas of focus:

1. Increase Equitable Access to Treatment: Simplify the approval process to reduce non-medical switching and prioritize telehealth access and mobile clinics that greatly enhance treatment accessibility. For patients in rural and underserved areas, these changes offer a lifeline, ensuring they receive timely care and support. 🏥📱

2. Enhance Patient and Caregiver Experiences: With shared decision-making tools and a PNH-focused coalition, patients and caregivers can be better supported. Multilingual decision aids, community-driven coalitions, and targeted advocacy ensure every patient has a voice in their care journey. 🤝👩⚕️

3. Reduce Financial Barriers: Expanded financial assistance programs and better insurance coverage for PNH treatments are crucial for underinsured or uninsured patients. Collaborations with insurers, pharmaceutical companies, and patient advocacy organizations can alleviate financial burdens, making treatment more accessible to those most in need. 💸💊

4. Enhance Provider Education: Comprehensive training for healthcare providers on cultural competence, pain management, mental health integration, and PNH-specific treatments can drastically improve patient outcomes. Educating providers builds understanding and empathy, creating a supportive and knowledgeable care environment. 👨⚕️📘

5. Promote Equity in Research: Increasing diversity in clinical trials and collaborating with community organizations can help ensure research reflects the experiences of all PNH patients. Diversity in research not only drives equitable care but also fosters trust within underserved communities, leading to improved participation and outcomes. 🌍🔬

These efforts require the commitment of healthcare providers, pharmaceutical companies, insurers, patient advocates, and policymakers working together to reshape PNH care. By embracing these recommendations, we take a step forward in building a healthcare system where PNH patients receive fair, accessible, and respectful treatment. Let's work together to make PNH care equitable for everyone. 🌟

#HealthEquity #PNHCare #PatientAdvocacy #RareDiseases #HealthcareReform #ClinicalTrials #HealthDisparities #EquityInCare #PatientEmpowerment

Sample Posts (Short)

Shared Decision-Making as a Path to Equity in PNH Care
Empowering patients and caregivers in PNH care begins with shared decision-making. Collaborative tools that bring in patients' experiences, values, and emotional needs can make all the difference in outcomes. Advocacy for policies that address healthcare coverage and pain management barriers is key for equitable treatment access. Drawing from successful models in HIV/AIDS advocacy, patients and caregivers in the PNH community can influence systemic change.

Discover more in our full report here: bit.ly/rddcpnh

#HealthEquity #PNH #SharedDecisionMaking #PatientEmpowerment

Strengthening Equity through PNH Patient Education & Provider Training
PNH patients deserve a healthcare team trained not just in treatment but also in empathy and understanding. Regular provider education on PNH, including cultural competence and mental health integration, will help address the bias and gaps that too often affect care for marginalized groups. Inspired by successful programs like the Academy of Oncology Nurse & Patient Navigators, PNH-specific training programs can elevate patient support and outcomes.

Discover more in our full report here: bit.ly/rddcpnh

#PNH #HealthEquity #ProviderEducation #InclusiveCare

Reducing Financial Barriers in PNH Treatment
Financial burdens remain a significant hurdle for equitable PNH care. We must advocate for state Medicaid expansion and policies that make insurance processes easier to navigate for underinsured communities. Reducing out-of-pocket costs, streamlining prior authorizations, and addressing socioeconomic disparities can improve access to essential treatments, as demonstrated in rare disease advocacy like #GaucherDisease. Let's work to ensure all PNH patients receive the care they need.

Discover more in our full report here: bit.ly/rddcpnh

#HealthcareAccess #PNH #FinancialEquity #PolicyChange

🌍 Empowering Diverse PNH Communities Through Tailored Support
Patients with PNH from diverse backgrounds—including Black, Hispanic/Latino, and Asian American Pacific Islander communities—often face unique health challenges. Black and Hispanic/Latino patients, for example, experience higher thrombosis risks, while Asian American Pacific Islanders face increased rates of aplastic anemia. By building targeted support systems, expanding patient education, and implementing consistent clinical guidelines, we can help address these disparities and support PNH patients through a more equitable care journey. Let's stand together to support every patient in receiving the care they deserve. 💙🤝

Grab your copy of the full report here: bit.ly/rddcpnh

#PNH #HealthEquity #DiversityInHealthcare

🏥 Overcoming Social Barriers for PNH Patients
Supporting PNH patients means addressing how social determinants of health (SDOH) like geography, income, and

access impact care. Patients in rural or underserved areas may face difficulties accessing specialists or telehealth, limiting timely and comprehensive care. Solutions, such as policy advocacy for Medicaid expansion and telehealth access, can help break down these barriers. Addressing SDOH directly is essential to improving care for all PNH patients, ensuring every patient has an equitable chance to receive the high-quality care they need. 🌟💪

Grab your copy of the full report here: bit.ly/rddcpnh

#SDOH #PNH #HealthEquity #HealthcareSupport

🤝 Bridging Cultural Gaps to Strengthen PNH Patient Support
For PNH patients, socioeconomic and cultural factors can heavily influence care outcomes. Language barriers, health literacy challenges, and cultural differences can create misunderstandings with providers, affecting treatment adherence. Supporting culturally respectful care, expanding language services, and enhancing patient-provider communication are vital steps toward improving PNH outcomes. By building trust and bridging these gaps, we help ensure that every patient, regardless of background, feels understood and supported in their PNH journey. 🌍💙

Grab your copy of the full report here: bit.ly/rddcpnh

#PNH #HealthEquity #InclusiveCare #PatientSupport

Graphics

Download graphics here: https://bit.ly/pnhsocialgraphics