



THE SOS BULLETIN

Rare. Radiant. Real.

Dear Community,

This June, something powerful happened. Through the Rare & Radiant campaign, we came together—across diagnoses, identities, time zones, and lived experiences—to celebrate the vibrant brilliance that lives at the intersection of queerness and rare disease. It was more than a campaign. It was a collective reclaiming of space, voice, and joy in a world that too often forgets we exist.

Rare & Radiant was born from a truth we know deeply: that 2SLGBTQIA+ rare disease patients often live in the margins of the margins. We're asked to navigate medical systems that don't always affirm us, communities that may not understand us, and identities that don't come with a blueprint. But instead of shrinking ourselves, we chose to shine.

This campaign mattered because visibility is power and storytelling is resistance. When we show up as our full, authentic selves, we remind each other—and the world—that we deserve care, celebration, and connection. Every selfie, every poem, every shared moment at the briefing or showcase was a thread in the fabric of something bigger than any one of us.

To those who participated, who showed up, who saw us and stood beside us: thank you. Thank you for your courage, your creativity, your compassion, and your solidarity. You made this campaign what it was—a movement powered by love, truth, and lived experience.

Rare & Radiant is just the beginning. We're still here. We're still building. And we're not done shining.

With gratitude and pride,

The Stripes of Solidarity Team

Redefining Rare to Rarely Overlooked. Shining a Light on the Extraordinary.

RARE & RADIANT SELFIE

JUNE 1 - 30, 2025

#RareRadiantSelfie

Launched as a call for visibility and joy, the Rare & Radiant Selfie Challenge invited rare disease warriors and allies to show up proudly and authentically—on their own terms and in their own colors. Each submission was a celebration of identity, community, and the power of being seen.

While we didn't reach as many people as we initially tried to plan for, we're deeply proud of what we created—and even prouder of the fact that we saw it through, from beginning to end. Sometimes success isn't measured in numbers, but in connection, and this challenge reminded us that if we can make even two people feel affirmed, valued, and seen—that's meaningful. That's movement.

We're especially grateful to the two incredible allies who participated: both extremely supportive nonprofit leaders and changemakers in the rare disease space who used their platforms to stand beside our vision and help bring it to life. Their solidarity was a reminder that allyship in action makes all the difference—and that building a more inclusive future requires both showing up and standing with.

This challenge was a beginning—not an end. And as we continue to grow, we carry its spirit forward: bold, joyful, rare, and radiant.



Nate Milam II (He/Him)
Stripes of Solidarity



Daniel DeFabio (He/Him)
Global Genes



Carter Hemion (He/They/It)
Stripes of Solidarity



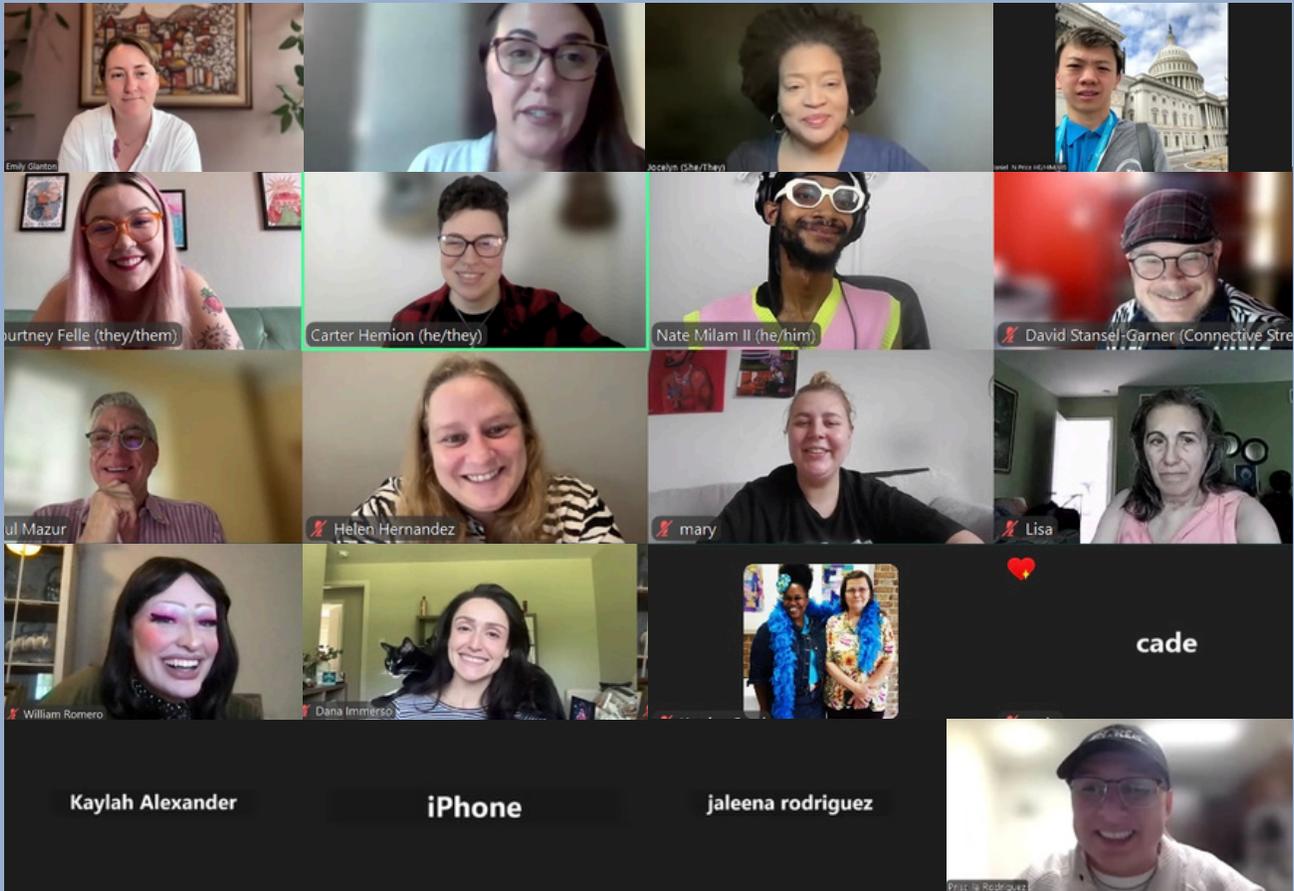
Jenifer Waldrop (She/Her)
Rare Disease Diversity Coalition



Stripes of Solidarity

RARE & RADIANT BRIEFING

JUNE 6, 2025



#RareRadiantBriefing

The Rare & Radiant Pride Briefing was a powerful space where lived experience met action. Hosted by SOS during Pride Month, this virtual gathering brought together 2SLGBTQIA+ rare disease patients, advocates, researchers, and policy leaders to name truths that are too often overlooked—about access, visibility, identity, and survival at the margins of care.

Our speakers educated and ignited powerful conversation. Together, we unpacked the structural and cultural barriers queer rare disease patients face and co-created a list of shared priorities for change—centered on equity, inclusion, and intersectionality. From barriers in clinical trial access to the need for affirming providers, the dialogue was honest, brave, and deeply rooted in lived experience.

The energy in the (virtual) room was undeniable. People showed up ready to speak, listen, and shift the narrative—and that's exactly what we did. This briefing was a catalyst for long-term work, and a reminder that policy and healing must be built together, in community.



@stripesofsolidarity



Stripes of Solidarity



2SLGBTQIA+ RARE DISEASE COMMUNITY PRIORITIES



RARE & RADIANT BRIEFING

Stripes of Solidarity exists to amplify underrepresented voices in the rare disease space by equipping advocates with meaningful tools, and promoting equity across research, policy, and care. Through lived experience, creative advocacy, and intentional collaboration, we aim to challenge systems, close gaps, and champion solidarity across the rare disease landscape.

SOS is shifting how the rare disease community shows up—louder, prouder, and more connected than ever. Rare disease advocacy is about re-imagining the systems that failed us and building something far more powerful in their place. Together, stripe by stripe, we're creating a future where no one feels rare alone. On June 6th, 2025, Stripes of Solidarity was proud to host its inaugural open forum dedicated to 2SLGBTQIA+ voices in the rare disease community.

This space was designed by and for 2SLGBTQIA+ rare disease advocates and welcomed allies, policymakers, nonprofit leaders, and anyone interested in helping build a more inclusive and equitable rare disease future. It collaboratively brought together stakeholders to share stories, identify key community needs, and develop a working list of actionable priorities for the next year. These priorities are categorized by sectors for our allies to understand where we most need them to speak up and advocate with us.

POLICYMAKERS AT ALL LEVELS

- Support research funding, incentivize orphan drug development, increased newborn screening access and updates, regulation of medical costs, access to hormone replacement therapy and related care, reproductive health care, and policies improving data equity, clarity, and protection.
- Oppose all anti-2SLGBTQIA+ bills, criminalization of and loss of privacy related to HIV and STIs, policies allowing intersex genital mutilation, cuts to Medicaid, addition of Medicaid work requirements, exclusion of undocumented immigrants from healthcare, increases in copay costs, bans on gender transition care, bans and funding prohibitions on abortion care, and all proposals that would limit access to care.

FEDERAL AGENCIES

- Improve clarity in drug labeling to reduce harms of white labeling to patients for the sake of profit.
- Continually develop guidance for Contract Research Organizations (CROs) and regulatory bodies on how to bring together patient communities, industry, payers, and agencies to collaborate on shared issues.

HEALTHCARE PROVIDERS

- Understand patients as people beyond their diagnosis.
- Proactively seek training and connections with patient advocacy groups to understand rare diseases, 2SLGBTQIA+ populations, intersex variations, and best practices for serving these populations.
- Push against cisheteronormativity and stigma around intersex bodies.
- Take the time to learn about complex conditions when treating patients. Own up to mistakes and misdiagnoses.

INDUSTRY & RESEARCHERS

- Collaborate with patient organizations to continually get to know those impacted by products and include patients as stakeholders from the beginning of research and development. Continually access resources developed by patient advocates to learn about what matters most to them in therapy development from the beginning.
- Reframe strategic outreach to patient communities to connect with, listen to, and build trust with them to promote more inclusive and diverse clinical trials with culturally competent language. Thoroughly share information about the investigation and desired outcomes for transparency, even when keeping more detailed information for internal use only.
- Learn about common experiences in patient populations and consider how strict criteria and boilerplate language may limit significant demographics of patient community, rare or ultra-rare variants of conditions, and those with multiple common comorbidities in addition to the primary condition being studied.

PATIENT ADVOCACY GROUPS

- Connect with other stakeholders and use your voice to advocate for community priorities.
- Develop and share resources with allies on how to support someone through a diagnosis or discovering their identity.
- Consider who is invited and who is not in the room when planning events.
- Proactively work with diverse communities to reach patients where they are at.

PAYERS/INSURANCE

- Expand telemedicine access.
- Improve coverage of off label treatments.
- Improve access to whole genome sequencing.

REMINDERS FOR LGBTQIA+ RARE DISEASE COMMUNITY MEMBERS

- Understand yourself and your intersectionality. Get to know your mind, body, and spirit, keeping in mind that you are the expert of you. Take up space and embrace yourself—hold your power.
- Set boundaries—not to evade conflict, but to take care of yourself. Remember that you cannot take care of anyone else without taking care of yourself first.
- Build intergenerational and cross-community relationships.
- You are strong and resilient— put it into action.

REMINDERS FOR ALLIES

- Support organizations that build networks, fund research, and provide emotional support to patient communities.
- Understand that being 2SLGBTQIA+ and being rare, ultra-rare, and/or undiagnosed are all natural variations of being human.
- Health equity means every identity, every story, every single time.

CONCLUSION

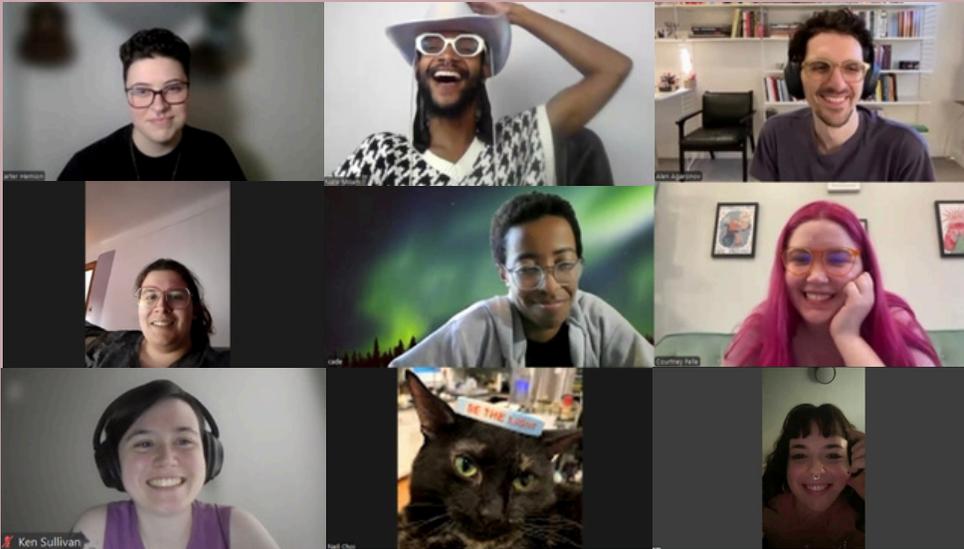
As a 2SLGBTQIA+ rare disease community, we have identified numerous needs across all aspects of our lives that impact our ability to survive and thrive. We ask all stakeholders of the rare disease ecosystem to reduce burden on patients and families by practicing allyship every day. This can look like learning from 2SLGBTQIA+ rare disease community members and sharing our resources, taking action on community priorities you are involved with in the rare disease space, supporting community-led initiatives with your time, donations, and/or voice, or even creative collaboration with community leaders to push forward our most urgent initiatives. Together, we are building a stronger rare disease community and invite you to join us in being the change we need to save and improve quality of life for 2SLGBTQIA+ rare disease patients and families.



RARE RAINBOW SHOWCASE

JUNE 27, 2025

#RareRainbowShowcase



INTERSEX DISCO
Courtney Felle (They/Them)



(DIS)ORIENTATION
Carter Hemion (He/They/It)

To close out Pride Month, we gathered for the Rare Rainbow Creative Showcase—a vibrant, soul-filling celebration of expression, identity, and community. We welcomed powerful, intersectional advocates who shared their stories through art, performance, and truth-telling that moved us deeply. What made the night even more special were the impromptu presentations from audience members who felt inspired to share their own voices in the moment—a testament to the safety and magic of the space we created together.

The vibes? Immaculate. From shared laughter to moments of reflection, this showcase was a joyful and unapologetic space where we were free to be our whole, radiant, and rare selves. Together, we celebrated the end of Pride with connection—surrounded by creativity, affirmation, and community care.





RARE RAINBOW CREATIVE OF THE YEAR

CADE BRAYNEN (They/Them) Orange, Texas

“I am a transmasculine, Black disabled/chronically ill/neuro-diverse zebra surviving Texas as best as I can! Life forced me here for now, so I make do. I feel so deeply and colorfully, so with artistry and writing I'm able to convey those thoughts and experiences that I never truly get a chance to in public life. That is what my works are about. The first digital art here was initially created after I received my POTS and fibromyalgia diagnoses, and I continually worked on it once I got diagnosed with EDS in summer 2023. It is a simplified glimpse into what I live with daily. The second submission, in 2 parts, is a short comic exploring the internalized misogyny I had growing up and how I dealt with it.”

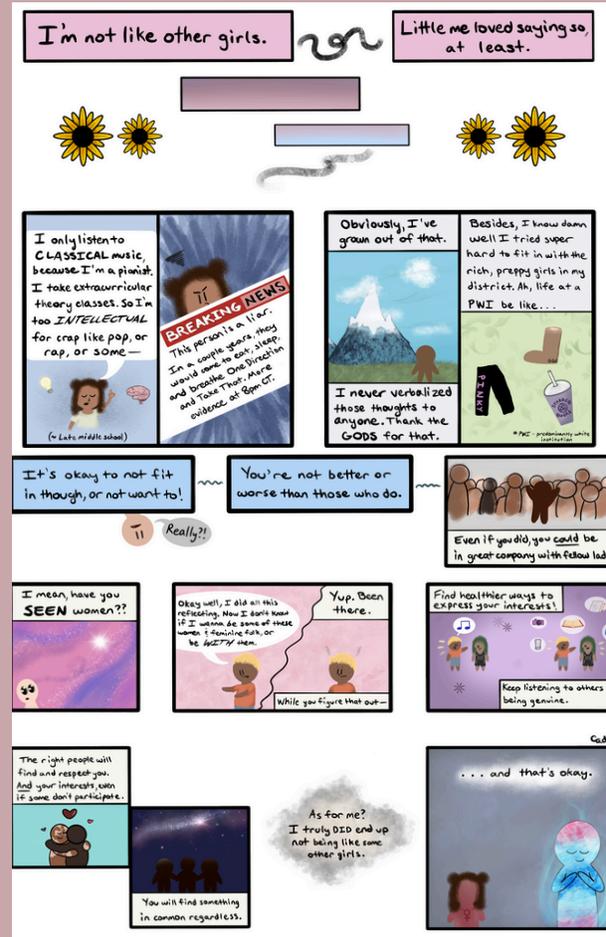
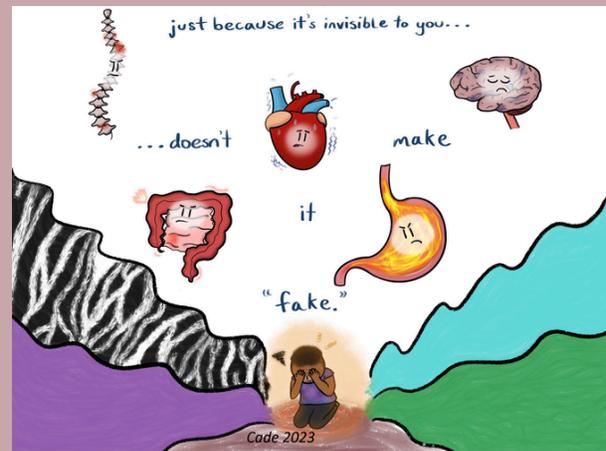
"IN-VISIBLE" + "NOT LIKE OTHER GIRLS"

Cade's winning submission to the Rare Rainbow Showcase is a deeply personal, multi-layered reflection on chronic illness, gender identity, and visibility—both internal and external. Through a vibrant and expressive comic-style format, Cade invites us into their lived experience navigating multiple rare and chronic conditions, including POTS, Ehlers-Danlos Syndrome, fibromyalgia, and scoliosis. Each color and panel carries intentional weight, representing diagnosis ribbons, misunderstood symptoms, and the lifelong process of learning to advocate for oneself in systems that often fail to see beyond the surface.

The piece is an unflinching yet tender response to the skepticism and dismissal Cade has faced—capturing what it feels like to be told you're “too young,” “too healthy-looking,” or simply “faking it.” From a tiny brain in the corner representing mental fatigue, to sunflowers honoring invisible disability, every detail tells a story of survival, frustration, humor, and hard-won pride.

In the second half of the submission—a comic originally created for Women's History Month—Cade explores the complicated evolution of gender identity and the cultural trope of being “not like other girls.” What begins as a reflection on internalized messages unfolds into a realization that's both powerful and poetic: “Technically, I didn't end up like other girls... because I'm not a girl anymore.” That final panel reframes the entire narrative, offering a quiet moment of clarity and self-acceptance.

With vulnerability, wit, and raw honesty, Cade's art exemplifies what it means to be Rare and Radiant. It challenges assumptions, embraces nuance, and reminds us that the act of telling your story—on your own terms—is itself a form of healing.





CARTER HEMION
(He/They/It)
Advocacy & Accessibility
Coordinator, SOS



NATE MILAM II
(He/Him)
Founder, SOS



@_rareandreal

EPISODE 1: “WE’RE HERE, WE’RE QUEER, WE’RE RARE”

We’re proud to officially launch Rare & Real, a podcast created by and for those living at the intersections of queerness, rare disease, and radical truth. Hosted by Carter Hemion and SOS founder Nate Milam II, Rare & Real is a space where honesty is healing, advocacy is personal, and nothing gets left at the door.

In our debut episode—“We’re Here, We’re Queer, We’re Rare”—we set the tone for what this platform is all about. We introduce the Stripes of Solidarity mission and the reason behind starting this podcast: to hold space for voices too often left out of the narrative. We share our personal rare disease journeys, including real World Pride reflections and how illness and identity often collide in unseen ways.

We also discuss the events that made up the Rare & Radiant campaign, unpack why visibility in rare disease spaces matters, and talk about the joy and power that comes from being unapologetically ourselves—even in systems that don’t always make room for us.

This podcast is a love letter to the rare, the radiant, the real—and this first episode is just the beginning.

NOW STREAMING. COME AS YOU ARE, STAY AS LONG AS YOU NEED.



Rare and Real



@RareandRealPod

ALLY APPRECIATION



Dear Allies,

At Stripes of Solidarity, our mission is built on truth, visibility, and collective care. We know that change doesn't happen in isolation—it happens when people come together across differences to uplift, advocate, and reimagine what equity can look like.

This page is dedicated to the incredible allies who showed up during the Rare & Radiant campaign—not just in name, but in action. From joining our events and sharing space with us, to submitting to the selfie challenge and amplifying our message, these individuals reminded us that solidarity is action. Their presence, care, and willingness to listen, learn, and lead with compassion made a real impact.

Allies are essential to our growth—not to speak over us, but to stand beside us. We are especially grateful for those who support this work not because it's trendy, but because it's urgent; not because it's convenient, but because it's right.

Thank you for believing in a future where every rare disease patient—especially those living at the intersection of queerness, disability, race, and other identities—can be seen, celebrated, and supported. We feel your solidarity, and we carry it with us.

With deep appreciation,

The Stripes of Solidarity Team



RARE & RADIANT REFLECTIONS

NATE MILAM II (He/Him)

The Rare & Radiant campaign has been the biggest and most meaningful project I've ever taken on—and I'm still in awe of what we created together. What started as a few scattered ideas grew into something real, something joyful, and something deeply needed. We built community, created space, and celebrated one another in ways that I'll carry with me for a long time.

This was connection at its peak. We brought together rare disease patients, 2SLGBTQIA+ advocates, artists, allies, and leaders who genuinely showed up. And we didn't just reach our own community—we expanded the conversation and brought new voices into the fold. That's something I'm incredibly proud of.

I'm especially grateful for Carter, who really helped bring this vision to life, for his dedication, care, and brilliance every step of the way. And I'm endlessly thankful to every member of our campaign team and everyone who participated, performed, or simply shared space with us. Because of you, this was one of the most affirming and joyful Pride Months I've ever experienced.

Rare & Radiant reminded me of what's possible when we lead with intention and love. I'm so proud of what we've built—and even more excited for what's next.

CARTER HEMION (He/They/It)

I am so thankful for everyone who participated in the Rare & Radiant campaign with us this Pride Month. Sharing this space with such powerful advocates has been the most personally impactful and fulfilling project I have had the honor of participating in. I am continually impressed and inspired by the resilience, creativity, and determination of our community to re-imagine our future together and find joy in the present.

Together, we shared a briefing, creative showcase, and digital connections. We also opened up new conversations with community members and allies to focus in on what we need right now and how we can work together to build a more understanding and accessible world.

I deeply appreciate every single person who joined us, and especially Nate for inviting us to share in giving life to a vision of compassionate connection and meaningful storytelling in our community through Pride Month and beyond. This month will live with me forever as a time of celebration, honesty, and affirmation in the rare disease and 2SLGBTQIA+ communities, and I cannot wait for what comes next.

