SZN Rare Disease Month Social Media Toolkit

This toolkit was created to make it **easy, flexible, and impactful** for State Zebra Network members to share rare disease awareness, education, and advocacy messages across social media.

You don't need to be a communications expert to use these graphics - just choose what works best for your organization and your audience.

- A set of **ready-to-use social media graphics** (Facebook- and Instagram-sized)
- **Multiple caption options** for Facebook, Instagram, Twitter/X, and LinkedIn
- Optional hashtag sets you can customize
- Messaging grounded in rare disease research, policy history, and patient experience

How to Choose a Caption

Each graphic includes **2–3 caption options per platform**. You can:

- Pick one and post it as-is
- Lightly edit language to reflect your organization's voice
- Add a sentence about your local community, mission, or lived experience

There's no "wrong" choice. The goal is to share accurate information in a way that feels authentic to you.

How Much Can I Customize?

We encourage personalization!

You can:

- Add your organization's perspective or story
- Tag partner organizations or advocates
- Adjust hashtags for your audience
- Pair posts with links to your website or resources

Please avoid:

- Changing statistics or factual claims
- Adding medical advice or treatment recommendations
- Editing graphics in ways that alter the core message

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Platform Tips

Facebook
Great for community-building and longer captions. Consider adding one sentence of local context or a call to action.

Instagram
Visual-first and concise. Use 3–6 hashtags and keep captions skimmable.

Twitter/X
Short and direct. One strong sentence is enough (hashtags optional).

LinkedIn
Professional and policy-focused. These posts work well when paired with advocacy, research, or workforce perspectives.

When to Post

These graphics are **evergreen** and can be shared:

- During Rare Disease Month
- For awareness days
- When policy issues arise
- Anytime you want to elevate rare disease voices

You don't need to post everything - use what aligns with your goals.

Final Encouragement

Rare disease awareness grows when many voices speak together. Whether you post once or many times, your participation helps:

- Increase visibility
- Share accurate information
- Strengthen advocacy efforts
- Build community

Thank you for being part of the State Zebra Network.

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State Zebra Network – Social Media Copy Options

This document provides **ready-to-use social media copy** for State Zebra Network member organizations. For each graphic, members can choose from **2–3 message options per platform**. Copy is adaptable across Facebook, Instagram, Twitter/X, and LinkedIn. Graphics may be used in either Facebook or Instagram sizes, depending on member preference.

Tone guidance:

- Facebook & Instagram: warm, accessible, community-focused
- Twitter/X: concise, punchy, awareness-driven
- LinkedIn: professional, policy- and impact-oriented

Members may adapt hashtags, tag partners, and personalize posts while keeping core messaging intact.

Suggested Hashtag Sets (Use 3–6 per post)

*(Hashtags are optional and may be customized based on audience or campaign goals.)

Facebook
#RareDisease #RareDiseaseAwareness #PatientVoices #HealthEquity #AdvocacyWorks #StateZebraNetwork

Instagram
#RareDisease #RareDiseaseAwareness #RareButNotAlone #ZebraStrong #PatientAdvocacy #HealthJustice

Twitter/X
#RareDisease #RareDiseaseAwareness #PatientsFirst #PolicyMatters

LinkedIn
#RareDisease #HealthPolicy #PatientCenteredCare #ResearchMatters #Advocacy

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1. 10,000+ Rare Diseases. Millions of Lives.

(Subtle fact-based enhancements included to reflect current research while keeping posts social-friendly.)

Facebook / Instagram

- Option 1: Rare diseases are often invisible—but the people living with them are not. More than 10,000 known rare diseases affect millions of lives, with new conditions identified each year. #RareDiseaseAwareness
- Option 2: Rare doesn't mean few. Millions of individuals and families are impacted by rare diseases—and they deserve answers, care, and hope.
- Option 3: Behind every rare disease statistic is a real person, a family, and a future worth fighting for.

Twitter/X

- Option 1: 10,000+ rare diseases. Millions of lives. Rare is everywhere. #RareDisease
- Option 2: Rare diseases may be uncommon individually, but together they affect millions.

LinkedIn

- Option 1: More than 10,000 rare diseases impact millions of individuals worldwide. Addressing rare disease requires coordinated policy, research investment, and patient-centered care.
- Option 2: Rare disease is a public health issue hiding in plain sight—one that affects millions of families across the country.

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2. More Than 90% of Rare Diseases Have No FDA-Approved Treatment

Facebook / Instagram

- Option 1: More than 90% of rare diseases still have no FDA-approved treatment. Patients are waiting—and policy and research can help change that.
- Option 2: For too many families, hope is still out of reach. Research and policy can change that.

Twitter/X

- Option 1: 90%+ of rare diseases lack FDA-approved treatments. Patients are still waiting.
- Option 2: Innovation can't stop until patients have options.

LinkedIn

- Option 1: Over 90% of rare diseases have no FDA-approved treatment, highlighting the urgent need for sustained research funding and policy solutions.
- Option 2: The rare disease space underscores why incentives, collaboration, and innovation matter.

3. Spotlight: Cystic Fibrosis

Facebook / Instagram

- Option 1: Cystic fibrosis is a rare genetic condition that affects the lungs and digestive system and impacts tens of thousands of people worldwide. Behind every statistic is a person, a family, and a future.
- Option 2: Research has transformed what's possible for people living with cystic fibrosis—but continued progress depends on sustained investment and advocacy.

Twitter/X

- Option 1: Cystic fibrosis affects tens of thousands worldwide. Research and advocacy change outcomes.

LinkedIn

- Option 1: Advances in cystic fibrosis care show the power of research, policy, and patient advocacy working together.

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4. Advocacy Starts With Showing Up

Facebook / Instagram

- Option 1: Advocacy begins with showing up—sharing stories, having conversations, and building relationships.
- Option 2: Change doesn't happen alone. It starts when people come together and speak up.

Twitter/X

- Option 1: Advocacy starts with showing up—and staying engaged.

LinkedIn

- Option 1: Advocacy transforms lived experience into meaningful, lasting change.

5. Policy Can Unlock Progress

Facebook / Instagram

- Option 1: Smart policy fuels research—and research leads to progress for rare disease communities.
- Option 2: The Orphan Drug Act shows how policy can unlock innovation.

Twitter/X

- Option 1: Policy → Research → Progress. It works.

LinkedIn

- Option 1: The Orphan Drug Act is a powerful example of how policy incentives drive rare disease research and treatment development.

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6. Rare Disease Awareness Means Action

Facebook / Instagram

- Option 1: Awareness is just the beginning. Action—sharing, supporting, and advocating—creates change.
- Option 2: Small actions add up to meaningful impact.

Twitter/X

- Option 1: Awareness means action. #RareDisease

LinkedIn

- Option 1: Turning awareness into action is essential for progress in rare disease policy and care.

7. Rest Is Part of the Fight (Self-Care)

Facebook / Instagram

- Option 1: Rest is part of the fight. Taking care of yourself is essential—for patients, caregivers, and advocates.
- Option 2: Self-care isn't selfish. It's necessary.

Twitter/X

- Option 1: Rest is part of the fight.

LinkedIn

- Option 1: Supporting rare disease communities includes recognizing the importance of caregiver and patient well-being.

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8. Spotlight: Amyotrophic Lateral Sclerosis (ALS)

Facebook / Instagram

- Option 1: ALS is a rare neurodegenerative disease that affects nerve cells in the brain and spinal cord, leading to progressive loss of muscle control.
- Option 2: While there is no cure yet, research and supportive care continue to improve quality of life for people living with ALS.

Twitter/X

- Option 1: ALS impacts thousands of individuals and families worldwide. Research brings hope.

LinkedIn

- Option 1: Continued investment in neurodegenerative disease research is critical to improving ALS outcomes.

9. Roughly 1 in 10 People Live With a Rare Disease

Facebook / Instagram

- Option 1: Rare disease affects about 1 in 10 people. Numbers matter—but people matter more.
- Option 2: Rare disease isn't rare when you look at the bigger picture.

Twitter/X

- Option 1: 1 in 10 people live with a rare disease. This impacts all of us.

LinkedIn

- Option 1: Rare disease represents a significant public health challenge requiring scalable, inclusive solutions.

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10. Policy Matters

Facebook / Instagram

- Option 1: Policy matters. Advocacy turns lived experience into lasting change.
- Option 2: When policymakers listen, real progress happens.

Twitter/X

- Option 1: Policy matters—especially for rare disease communities.

LinkedIn

- Option 1: Evidence-based policy transforms patient experience into systemic progress.

11. Valentine's Day – Rare Disease Care Is an Act of Love

Facebook / Instagram

- Option 1: Rare disease care is an act of love—today and every day.
- Option 2: Happy Valentine's Day to the caregivers, advocates, and families showing love through action.

Twitter/X

- Option 1: Rare disease care is an act of love.

LinkedIn

- Option 1: Compassion-driven care and policy go hand in hand.

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12. Most Rare Diseases Have No FDA-Approved Treatment

Facebook / Instagram

- Option 1: Most rare diseases still have no FDA-approved treatment—but policy and research can change that.
- Option 2: Patients deserve more options, faster.

Twitter/X

- Option 1: Research and policy can close the treatment gap.

LinkedIn

- Option 1: Strategic policy and funding are critical to accelerating rare disease treatment development.

13. Policy Creates Infrastructure

Facebook / Instagram

- Option 1: Policy builds the infrastructure that makes research, funding, and coordination possible.
- Option 2: Progress doesn't happen by accident—it's built.

Twitter/X

- Option 1: Policy creates the foundation for progress.

LinkedIn

- Option 1: The Rare Disease Act illustrates how policy strengthens research ecosystems.

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14. Spotlight: Sickle Cell Anemia (SCA)

Facebook / Instagram

- Option 1: Sickle cell anemia is a genetic blood disorder that affects red blood cells and can cause severe pain, infections, and organ damage.
- Option 2: Early diagnosis and access to comprehensive care can significantly improve outcomes for people living with sickle cell disease.

Twitter/X

- Option 1: Sickle cell disease impacts millions worldwide. Awareness and advocacy matter.

LinkedIn

- Option 1: Addressing sickle cell disease requires equity-focused research, policy, and access to care.

15. Research Matters

Facebook / Instagram

- Option 1: Every rare disease breakthrough starts with research.
- Option 2: Research gives families hope—and answers.

Twitter/X

- Option 1: Research matters. Full stop.

LinkedIn

- Option 1: Research investment is foundational to innovation in rare disease care.

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16. You Are Not Alone

Facebook / Instagram

- Option 1: You are not alone. Community changes everything.
- Option 2: Connection makes the journey easier.

Twitter/X

- Option 1: You are not alone.

LinkedIn

- Option 1: Strong communities amplify patient voices and outcomes.

17. Diagnosis Delay

Facebook / Instagram

- Option 1: It can take 5–7 years to receive an accurate rare disease diagnosis. That's too long.
- Option 2: Earlier diagnosis means earlier care—and better outcomes.

Twitter/X

- Option 1: Diagnosis delays cost time patients don't have.

LinkedIn

- Option 1: Reducing diagnostic delays is critical to improving rare disease care pathways.

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18. Early Diagnosis Saves Lives

Facebook / Instagram

- Option 1: Too many children don't get the chance to grow up—yet.
- Option 2: Early diagnosis, research, and access to care save lives.

Twitter/X

- Option 1: Early diagnosis saves lives.

LinkedIn

- Option 1: Early intervention improves outcomes and reduces long-term system burden.

19. Family History Matters

Facebook / Instagram

- Option 1: Knowing your family medical history can lead to earlier diagnosis and better care.
- Option 2: Family history matters more than you think.

Twitter/X

- Option 1: Family history matters.

LinkedIn

- Option 1: Family health data supports earlier, more accurate diagnoses.

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20. Spotlight: Huntington's Disease

Facebook / Instagram

- Option 1: Huntington's disease is a rare, inherited neurodegenerative disorder that affects movement, cognition, and behavior.
- Option 2: While there is no cure, research and supportive therapies help improve quality of life for individuals and families.

Twitter/X

- Option 1: Huntington's disease affects families across generations. Research matters.

LinkedIn

- Option 1: Sustained research funding is essential for progress in Huntington's disease and similar conditions.

21. Care Takes a Team

Facebook / Instagram

- Option 1: Rare disease care takes a team—families, providers, researchers, and advocates.
- Option 2: Collaboration makes better care possible.

Twitter/X

- Option 1: Care takes a team.

LinkedIn

- Option 1: Cross-sector collaboration is essential in rare disease care delivery.

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22. Why the Zebra?

Facebook / Instagram

- Option 1: Sometimes, it really is a zebra. Listening leads to answers.
- Option 2: Rare disease reminds us to look deeper.

Twitter/X

- Option 1: Sometimes, it really is a zebra.

LinkedIn

- Option 1: The zebra symbolizes the importance of listening in clinical care.

23. Policy Accelerates Innovation

Facebook / Instagram

- Option 1: Policy accelerates innovation and centers patients.
- Option 2: The 21st Century Cures Act shows what's possible.

Twitter/X

- Option 1: Policy accelerates innovation.

LinkedIn

- Option 1: Policy frameworks like the 21st Century Cures Act enable patient-centered innovation.

24. Together, We Move Forward

Facebook / Instagram

- Option 1: Together, we move forward. Small actions create big impact.
- Option 2: Progress happens when we move together.

Twitter/X

- Option 1: Together, we move forward.

LinkedIn

- Option 1: Collective action drives sustainable progress in rare disease advocacy.

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Behind the Posts: Where These Messages Come From

The messaging in this toolkit is grounded in current rare disease research, policy history, and patient experience. Many of the facts reflected here—including prevalence data, diagnosis timelines, and policy impacts—are drawn from deeper educational research prepared to inform and strengthen these posts. Special thanks to WI Rare Disease Alliance Intern, Azi Fanale, for compiling the facts for this campaign*.

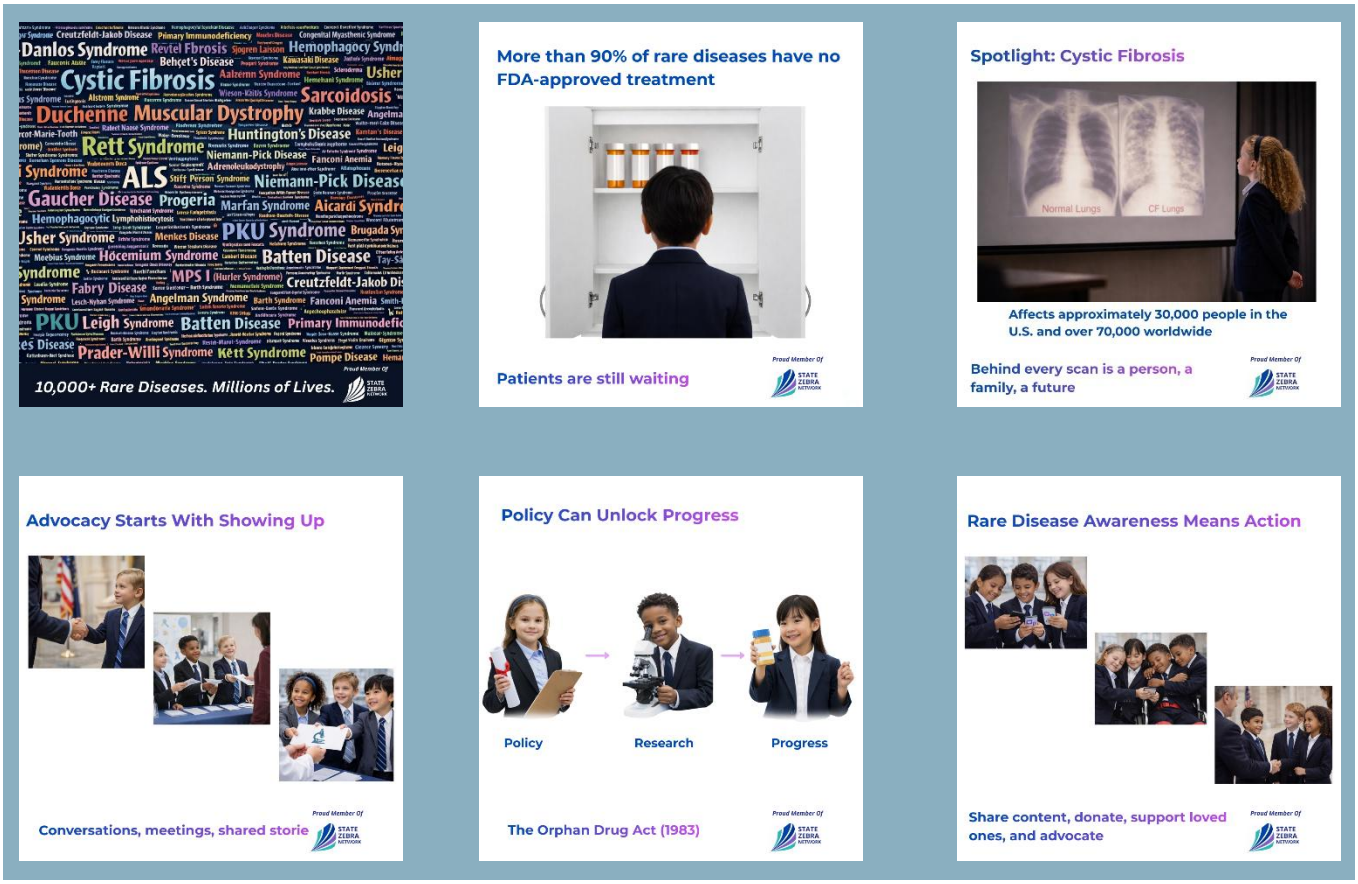
Captions have been intentionally streamlined for social media, but members are encouraged to:

- Add a sentence of context when posting on platforms that allow longer captions (Facebook, LinkedIn)
- Pair graphics with links to trusted resources or organizational webpages
- Adapt language to reflect their community's lived experience

Behind every post is the same goal: **accurate information, human-centered storytelling, and meaningful advocacy.**

**full fact compilation at the end of this document*

Graphics Preview



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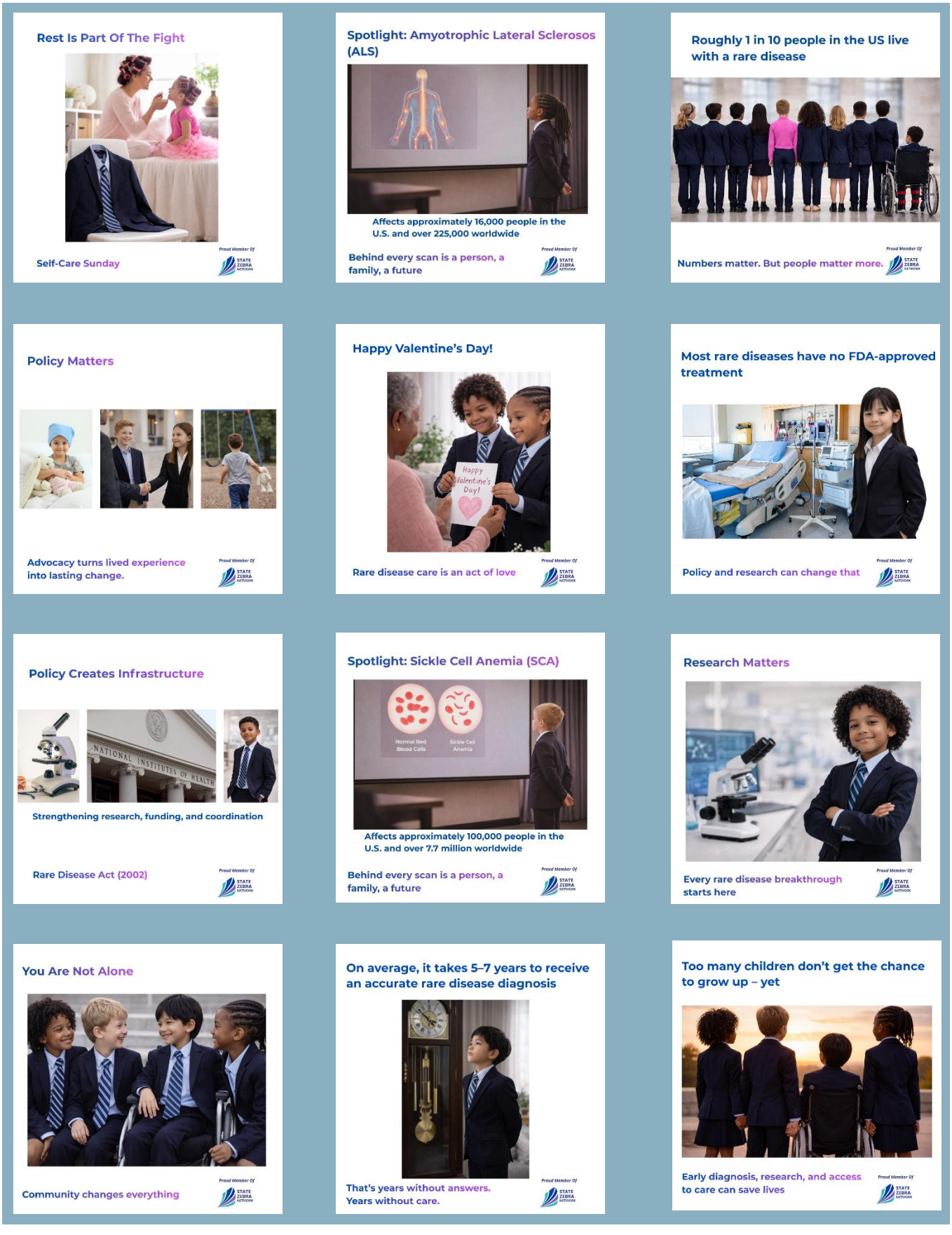

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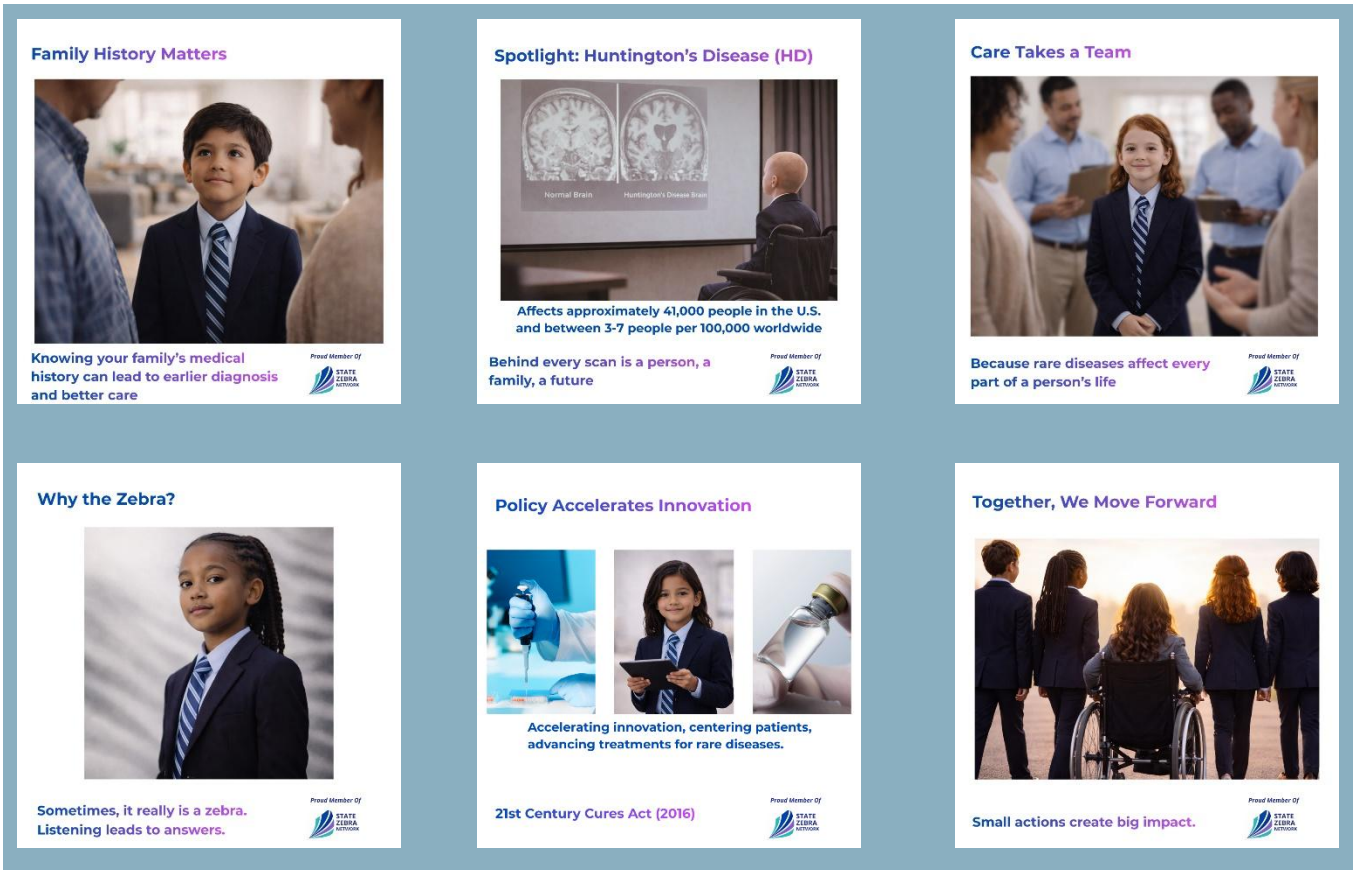

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Rare Disease Month – 28 Facts
Compiled by: Azi Fanale

February 1, 2026

There are over 10,000 known rare diseases, with over 200 new diseases identified each year

February 2, 2026

Only about 5% of rare diseases have an FDA-approved treatment.

February 3, 2026 Deep Dive Cystic Fibrosis

This week, we're spotlighting Cystic Fibrosis (CF), a rare genetic condition that affects approximately 30,000 people in the U.S. and over 70,000 worldwide. CF primarily impacts the lungs and digestive system, causing thick, sticky mucus to build up, which can lead to chronic lung infections, digestive issues, and reduced life expectancy. Thanks to innovative and modern therapies, the life expectancy for people with CF has increased dramatically over the past decades, with many living into their 40s and beyond. CF reminds us of the importance of research, awareness, and community support for rare diseases. Every small step in understanding and innovation can make a huge difference in the lives of those affected.

February 4, 2026

Advocacy can seem like a daunting word, but it's one of the most powerful ways you can make a difference for people living with rare diseases. Even if you don't live with a rare disease yourself, your voice, time, and support can help raise awareness, influence policy, and drive research forward. Here are three quick tips on how to become an advocate!

1. Engage with lawmakers: Advocate for policies that improve access to treatment, insurance coverage, and research funding.

2. Educate your community: Use social media, schools, workplaces, or local organizations to spread awareness about rare diseases.

3. Support fundraising and research efforts: Donations, charity runs, or awareness events provide essential funding for research and patient support.

February 5, 2026

(WI Rare Disease Alliance specific fact)

February 6, 2026 Policy Spotlight: The Orphan Drug Act (1983)

The Orphan Drug Act in the United States has been a game-changer for rare disease treatment. Before this law, pharmaceutical companies had little incentive to develop drugs for conditions that affect only a small number of patients. The Act provides tax credits, grants, and market exclusivity to encourage the development of medications for rare diseases, known as "orphan drugs." Since its passage, the Orphan Drug Act has led to the approval of hundreds of therapies that otherwise might

not have been developed, giving patients with rare diseases new treatment options and hope for better outcomes.

February 7, 2026

Rare Disease Awareness Means Action. Awareness is the first step — action is what creates change. Whether it's sharing educational content, donating to a nonprofit, participating in advocacy efforts, or supporting a loved one, everyone has a role to play in the rare disease community.

February 8, 2026

Did you know? Wisconsin has an estimated 600,000 individuals living with rare disease

February 9, 2026

For individuals and families affected by rare diseases, rest and mental health matter just as much as medical care. Chronic illness can be exhausting — physically and emotionally. Taking time to recharge, seek community, and prioritize mental wellbeing is not a luxury; it's a necessity. Today, we encourage caregivers and patients alike to give themselves grace.

February 10, 2026 Deep Dive Amyotrophic Lateral Sclerosis (ALS)

This week, we're exploring Amyotrophic Lateral Sclerosis (ALS), a rare neurodegenerative disease that affects nerve cells in the brain and spinal cord, leading to progressive muscle weakness, paralysis, and eventually loss of voluntary movement. ALS is sometimes called Lou Gehrig's Disease, named after the famous baseball player diagnosed in 1939. Most cases are sporadic, but about 5–10% are inherited through genetic mutations. There's no cure yet, but medications like Riluzole and Edaravone can slow progression, and physical therapy, speech therapy, and assistive devices help maintain quality of life. Advances in gene therapy, stem cell research, and neuroprotective treatments offer hope for future therapies.

February 11, 2026

Did you know? While each rare disease affects a small number of people, rare diseases collectively impact over 30 million Americans. That means 1 in 10 people in the U.S. lives with a rare condition. Rare diseases aren't actually rare — they're just often overlooked.

February 12, 2026

(WI Rare Disease Alliance specific fact)

February 13, 2026

Policy Matters! Public policy plays a critical role in rare disease outcomes — from funding research to protecting insurance coverage and expanding access to care. When patients, families, and advocates speak up, lawmakers listen. Advocacy helps turn lived experiences into lasting change.

February 14, 2026

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Happy Valentine's day from all of us at WI Rare! Today is a time to celebrate love—but for millions of people living with rare diseases, love also means support, understanding, and connection. Rare diseases affect over 300 million people worldwide, and chances are someone you love—a friend, family member, or partner—is touched by one. This valentines day, show your love by Listening to the experiences of those affected, Spreading awareness about rare diseases, and Supporting research and patient communities.

February 15, 2026

- 90% of rare diseases do not have treatments, which make them a serious public health problem

February 16, 2026 Policy Spotlight: Rare Diseases Act (2002)

The Rare Diseases Act of 2002 was a milestone for patients living with rare conditions in the U.S. It established the Office of Rare Diseases at the NIH, helping to coordinate research, increase funding, and raise awareness for rare diseases. This Act paved the way for better understanding, early diagnosis, and more focused research into the thousands of rare diseases affecting millions worldwide.

February 17, 2026 Deep Dive Sickle Cell Anemia

This week, we're highlighting Sickle Cell Anemia (SCA), a rare genetic blood disorder that affects red blood cells, causing them to take a rigid, crescent ("sickle") shape instead of the normal round shape. These sickle-shaped cells can block blood flow, reduce oxygen delivery, and lead to severe pain and organ damage. Detected through newborn screening, blood tests, and hemoglobin electrophoresis, and while there's no universal cure, treatments include hydroxyurea, blood transfusions, bone marrow transplants, and supportive care to manage pain and prevent complications.

February 18, 2026

The Importance of Research:

Research is the foundation of progress for rare diseases. From improving diagnostic tools to developing life-saving therapies, every breakthrough begins with research funding and patient participation. Supporting clinical trials and research initiatives helps move the entire rare disease community forward.

February 19, 2026

(WI Rare Disease Alliance specific fact)

February 20, 2026

You're Not Alone: A rare disease diagnosis can feel isolating — but community changes everything. Patient organizations, support groups, and advocacy networks provide connection, understanding, and shared strength. Finding others who "get it" can make even the hardest days feel more manageable.

February 21, 2026

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Here's a fact for your : On average, it takes 5–7 years to receive an accurate diagnosis for a rare disease. Because these conditions are uncommon, many healthcare providers may not immediately recognize the symptoms, and they can overlap with more common illnesses. Patients frequently consult multiple doctors, undergo numerous tests, and sometimes receive misdiagnoses along the way.

February 22, 2026

Roughly 30% of children with rare diseases die before the age of 5

February 23, 2026

Family history matters. Did you know that many rare diseases are genetic? That means a patient's family history can play a critical role in identifying risks, guiding testing, and even helping with early diagnosis. Knowing your family's medical history—conditions, patterns, and unusual symptoms—can help healthcare providers spot rare diseases sooner. For families affected by rare conditions, genetic counseling can provide vital insights and support for making informed decisions about care and future planning.

February 24, 2026

Huntington's Disease

For our last deep dive , we're focusing on Huntington's Disease (HD), a rare, inherited neurodegenerative disorder that causes progressive breakdown of nerve cells in the brain, affecting movement, cognition, and behavior. HD typically manifests in mid-adulthood, though symptoms can appear earlier or later. It's caused by a mutation in the HTT gene, which produces the huntingtin protein. The mutation leads to abnormal protein buildup that damages brain cells. There is no cure, but medications and therapies help manage movement disorders, psychiatric symptoms, and improve quality of life.

February 25, 2026

What Is Multidisciplinary Care—and Why It Matters for Rare Diseases? Many rare diseases affect multiple parts of the body, from organs and joints to the nervous system and more. This complexity means that treatment often requires a team of specialists working together—a model called multidisciplinary care. So, patients may see everything from doctors, to geneticists, to physical therapists, to occupational therapists, to social workers, and nutritionists, all collaborating to address every aspect of the condition and ensure comprehensive care.

February 26, 2026

Zebra Explanation: Why the zebra?

The zebra is a symbol of rare disease diagnosis, rooted in a famous medical teaching by Dr. Theodore Woodward: *"When you hear hoofbeats, think horses, not zebras."* While this approach encourages doctors to consider common conditions first, it has also meant that many people with rare diseases face years of misdiagnosis or delayed care. Today, the zebra reminds us to listen to patients, think beyond the obvious, and recognize that sometimes, the answer really is a zebra.

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February 27, 2026

Policy Spotlight: 21st Century Cures Act (2016)

The 21st Century Cures Act accelerates drug and medical device development and supports patient-focused research. For the rare disease community, it means faster access to innovative therapies and more opportunities for patients to participate in clinical trials.By emphasizing real-world evidence and patient-centered care, this Act is helping bring hope and new treatments to those living with rare conditions.

February 28, 2026

As Rare Disease Month comes to a close, let's take some time to reflect. This month has reminded us that rare diseases touch all of our lives, directly or indirectly. Let's carry forward these lessons, stories, and hope—not just for a month, but every day. Take action by sharing a story, supporting a rare disease organization, or simply checking in on someone you know who is affected. Small actions create big impact.