TELEHEALTH:
VIRUTAL VISITS ACROSS STATE LINES FOR RARE DISEASE PATIENTS

RARE READY

A GENETIC CONDITION COALITION

Sponsored by BioMarin

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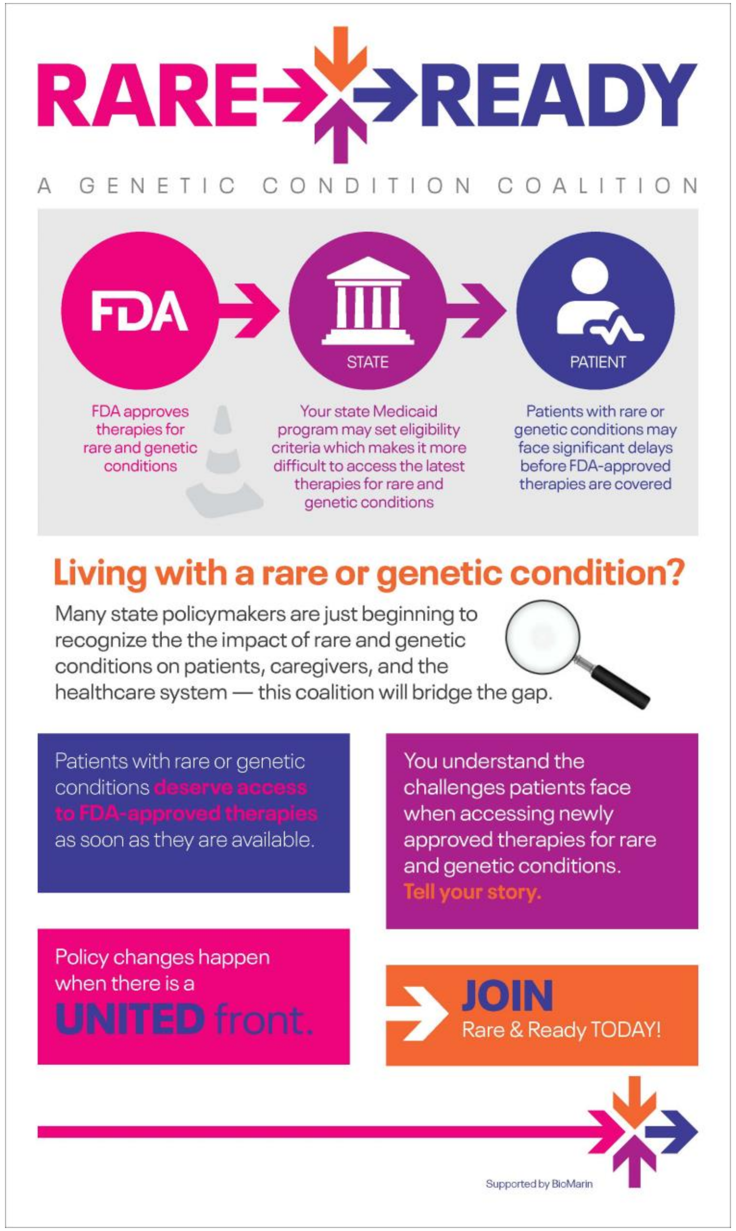
Rare & Ready: A Genetic Condition Coalition

- 40 patient advocacy group members
- Individuals living with rare conditions and their families
- Healthcare providers



RARE READY

A GENETIC CONDITION COALITION

FDA approves therapies for rare and genetic conditions

Your state Medicaid program may set eligibility criteria which makes it more difficult to access the latest therapies for rare and genetic conditions

Patients with rare or genetic conditions may face significant delays before FDA-approved therapies are covered

Living with a rare or genetic condition?

Many state policymakers are just beginning to recognize the the impact of rare and genetic conditions on patients, caregivers, and the healthcare system — this coalition will bridge the gap.

Patients with rare or genetic conditions **deserve access to FDA-approved therapies** as soon as they are available.

You understand the challenges patients face when accessing newly approved therapies for rare and genetic conditions. **Tell your story.**

Policy changes happen when there is a **UNITED** front.

JOIN
Rare & Ready TODAY!

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Rare & Ready: A Genetic Condition Coalition

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Batten Disease Advocates for a Cure

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GAUCHER COMMUNITY ALLIANCE

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REACHING BEYOND THE DIAGNOSIS!

National PKU Alliance

NTSAD
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noah's hope
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PATIENTS RISING NOW

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Rare Disease Innovations Institute

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SCRED
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SRNA
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Siegel Rare Neuroimmune Association

STAC3.org

upequity
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What We'll Cover Today

- Interstate Telehealth Visits for Patients with Rare Disease
- How to Get Involved

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INTERSTATE TELEHEALTH

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Director, Government Affairs
BioMarin

Telehealth Landscape

- Responding to the public health emergency, all 50 states and DC waived – to varying extents – state licensure laws in order to facilitate telehealth across state lines.
- Now 37 states and DC (and counting) have now ended their emergency declarations, and many of the telehealth and licensure flexibilities are expiring with them.
- **No uniformity:** The coverage and reimbursement rules around telehealth visits vary by state and by payer (Medicaid, commercial insurance, employer health plan).
- **No clarity:** Many telehealth policies are not written down and not publicly available. Some are only made on an ad hoc, case-by-case basis, so it is difficult for patients and physicians to know in advance what care will be covered.

Why Interstate Telehealth is Uniquely Important for Rare Disease Patients

- With a limited number of medical experts in their rare conditions, access to telehealth across state lines can be ***critical*** for good disease management for patients with rare conditions.
- This is especially true as travel for rare disease patients and their caregivers can be uniquely complex.
- In addition to patient need, in-state physicians are asking for virtual consults with out of state rare disease physician colleagues to be covered.
- We recognize that telehealth has its limitations. Virtual care should not replace necessary in-person visits. That is not good health care, and not good policy.

There is a need for clear, defined pathways to patient access and payer reimbursement

Hurdles to State-by-State Licensure Exceptions

Physician pushback

(Misplaced) concerns about limiting access to in-person visits

Reproductive health environment

Licensure Carve Out for Out of State Physicians

(A) Rare Disease Carve Out. Licensure, registration, or certification requirements, inclusive of all permits and fees, shall be waived for eligible healthcare providers

(1) Providing telehealth services to a [State] resident who:

(a) is located in a medically underserved area (MUA), defined by the federal Health Resources & Services Administration (“HRSA”) or as designated by the Governor, AND

(b) has a rare disease or condition

defined under Sec. 526 of the Federal Food, Drug, and Cosmetic Act (21 USC 360bb) as “any disease or condition which (A) affects less than 200,000 people in the United States, or (B) affects more than 200,000 in the United States and for which there is no reasonable expectation that the cost of developing and making available in the United States a drug for such disease or condition will recovered from sales in the United States of such drug…”; AND

(c) is under the in-person care of a licensed in-state provider.

(2) The provider is providing peer to peer consultations via telehealth to an in-state physicians treating a patient with a rare disease or condition, and the consultation is related to the rare disease diagnosis and/or treatment of that patient.

(B) CONDITIONS OF CARVE OUT.

(1) The telehealth services provided are appropriate for a telehealth modality and do not require an in-person evaluation.

(2) The telehealth services are related to the resident’s rare disease or condition.

(C) ELIGIBLE HEALTHCARE PROVIDERS. Covered healthcare practitioners include physicians

(1) Holding full, unrestricted medical licenses in their home jurisdiction, AND

(2) With no criminal history and who are not currently under investigation for criminal activities, AND

(3) With no history of controlled substance actions toward his/her medical license.

Policy Pathways for Access

Reciprocity	• Federal legislative path • Unsuccessful thus far
Compact (IMLC)	• Most states members • Arguably onerous
Rare Disease Licensure Exception	• States should adopt licensure exceptions for out-of-state physicians treating patients with rare disorders via telehealth

QUESTIONS

HOW TO GET INVOLVED

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Rx4good

Why Advocacy Matters

Gives a voice to those most impacted by policy decisions.

Serves as a powerful tool for raising disease awareness and offering valuable insight into the patient and caregiver experience.

Messages delivered through storytelling are **22 times more memorable** than facts.[1]

Increases awareness to initiate changes that create better outcomes.

1: *A Good Presentation Is About Data And Story*. Forbes. 2015. https://bit.ly/3IjJQL0. Accessed on 3/12/22.

Effective Ways to Advocate

- Join the Rare & Ready Coalition!
- Encourage others to join the coalition. The more voices – the bigger the impact.
- Meet with decision-makers to share your rare disease experience. Explain the impact of their policy decisions on your community.
- Write an op-ed or letter to the editor.
- Use social media to educate and bring awareness to the issue – make sure to tag and include relevant hashtags.

- Submit comments or feedback on policies and regulations.

Power of Social Media

#Hashtag your way into the conversation

- Keep up with legislative movements
- Follow @rare_ready – share tweets

Use Facebook Groups to spread the word

- Share messages from the Rare & Ready Coalition
- Share responses from elected officials

Let pictures/videos tell the story

- Instagram can paint a picture that emails can’t
- Use videos to tell your rare disease experience

How You Can Help

Join the Coalition

- Contact kari.lato@rx4good.com to join coalition
- Ask others to join

Share Your Experience

- Tell your story
- Meet with decision-makers

Use Social Media

- Follow @rare_ready
- Repost on your social media channels

THANK YOU

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