



For Immediate Release

The Rare Disease Company Coalition Announces 2021 Executive Committee

WASHINGTON - June 8, 2021- [The Rare Disease Company Coalition](#), a unified voice of life science companies committed to discovering, developing and delivering rare disease treatments, today announced appointments to its Executive Committee for 2021, following the Coalition's launch on May 13, 2021.

The Rare Disease Company Coalition was established to educate policymakers on the distinct considerations of life science companies operating in the rare disease space. The Coalition believes that constructive dialogue with well-informed policymakers will lead to policies and regulations that enable continued innovation and the cost-effective and timely development and commercialization of resulting treatments for the one in 10 Americans living with rare diseases.

The Coalition is governed by a Board of Directors and supported by an Executive Committee that provides oversight of the day-to-day operations of the Coalition. In addition to named elected positions, the Executive Committee has representation from each of the membership classes of the Coalition.

The following company representatives were elected to serve as Executive Committee members for the inaugural year of the Coalition:

- **Chair:** Betsy Ricketts, Ultragenyx Pharmaceutical
- **Vice Chair:** Greg Chesmore, Acceleron Pharma
- **Secretary:** Tim Kanter, Orphazyme US
- **Member-at-Large:** Christine Harrison, Orchard Therapeutics
- **Member-at-Large:** Deirdre Parsons, Alnylam Pharmaceuticals
- **Member-at-Large:** Geoff Werth, Harmony Biosciences

Supporting the work of the Coalition, Taylor Mason was appointed to serve as **Executive Director** of the Coalition. In addition, the following individuals have been appointed Committee Chairs for 2021:

- **Policy Committee Chair:** Diane Berry, Sarepta Therapeutics
- **Operations Committee Chair:** John Jackimiec, Aeglea BioTherapeutics

To learn more about the Coalition and its commitment to rare disease treatment development and commercialization, please visit rarecoalition.com.

About

The Rare Disease Company Coalition represents life science companies committed to discovering, developing and delivering rare disease treatments for the patients we serve. As an education and advocacy-focused coalition of companies, our goal is to inform policymakers of the unique challenges and promises of rare disease drug discovery, development and manufacturing for small

population sizes in order for critical innovation to continue. To achieve this goal, we will use our unified voice to advocate for long-term, consistent, equitable and sustainable government policies that enable life science companies to continue to bring hope and provide access to approved treatments to people living with rare diseases. For more information, please visit rarecoalition.com

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