



**Finalized dates for full council meetings:**

**January 27th, 2022: 3:00 PM- 4:30 PM**

**April 28th, 2022: 3:00 PM- 4:30 PM**

**July 28th, 2022: 3:00 PM- 4:30 PM**

**October 13th, 2022: 3:00 PM- 4:30 PM**

*(We have had issues with invites going through, please contact Erica if you have not received them.)*

---

---



Our very own **Sheldon Berkowitz and Paul Orchard** will be participating in *Rare Disease Day* hosted by CODR on Friday, February 25th. The title is "*Successes & Challenges in Transition of Care for Rare Disorders*" For more information or if you'd like to attend please use this link: [z.umn.edu/rare2022](https://z.umn.edu/rare2022)



*The Star Tribune* has released an article about Minnesota leading the way in ALS therapy. Please read this article: <https://www.startribune.com/new-voices-finally-a-step-in-the-right-direction-for-als/600139565/>


---



**Northern Plains Rare Disease Summit planning committee.** The Council is partnering with Sanford Health's CoRDS program annual summit held in May. We would like to have a Council member serve on the planning committee. If interested, contact Erica

**Retelling of Philoctetes from an individual with a rare disease perspective.** The University of Minnesota Center for Orphan Drug Research and the Department of Theater Arts and Dance are collaborating to develop a new production focused on bringing attention to those diagnosed with a rare disease. The collaboration will adapt the Greek tragedy, *Philoctetes*, to help a Minnesota-wide audience gain greater awareness and deeper understanding of the medical, economic, psychological, and social challenges facing people with rare diseases. The production, developed by students under the artistic direction of Kevin Kling, will be performed February 25-27 (Friday, Saturday and Sunday). You can register here: <https://events.tc.umn.edu/theatre-arts-and-dance/all>

**Patient community led education sessions for newborn screening.** A number of rare disease communities have interest in adding their diseases to the MN newborn panel and are in the process of organizing educational events. If you are interested in learning more, contact Erica



"Will you let your  
reputation stand in the  
way of your service?"

— Ryan Holiday *Courage is Calling*



**MEDICAL SCHOOL**

UNIVERSITY OF MINNESOTA

**Driven to Discover®**

*The Chloe Barnes Advisory Council on Rare Diseases was created in 2019 by the Minnesota Legislature as a collaboration between the University of Minnesota and cross-sector institutions throughout Minnesota with the goal of improving care for the citizens of the state whose lives are affected by rare diseases.*

---

Copyright © | 2021 | Chloe Barnes Rare Disease Council |, All rights reserved.

| University of Minnesota Medical School |

**Our mailing address is:**

mnrdac@umn.edu

Want to change how you receive these emails?  
You can [update your preferences](#) or [unsubscribe from this list](#).



*Copyright © 2022 Chloe Barnes Advisory Council on Rare Diseases, All rights reserved.*

Want to change how you receive these emails?  
You can [update your preferences](#) or [unsubscribe from this list](#).

