



Next Full Council Meeting:

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

Annisa Reed, Regional State Policy Manager, Eastern Region, for the National Organization for Rare Disorders (NORD) will be our guest speaker. She will be presenting the findings of the NORD state report card which you can find here: <https://rarediseases.org/nord-state-report-card/>

Undiagnosed Day | April 29th



Thank you Dr. Schimmenti for all your work in the undiagnosed space and making us aware of Undiagnosed Day on April 29th! Please help us raise awareness for the undiagnosed rare disease community by supporting Undiagnosed Rare Disease Day on April 29th! #UndiagnosedDay



Minneapolis/St. Paul Business Journal account Dr. Paul Orchard as a Healthcare Hero! Let's congratulate Dr. Orchard for being recognized as an Innovator with his work on behalf of children with metachromatic leukodystrophy. "He used his expertise in bone marrow transplantation to provide the complex care needed for patients receiving gene therapy treatment."

Article Link: <https://www.bizjournals.com/twincities/news/2022/04/11/2022-health-care-heroes-honorees.html>



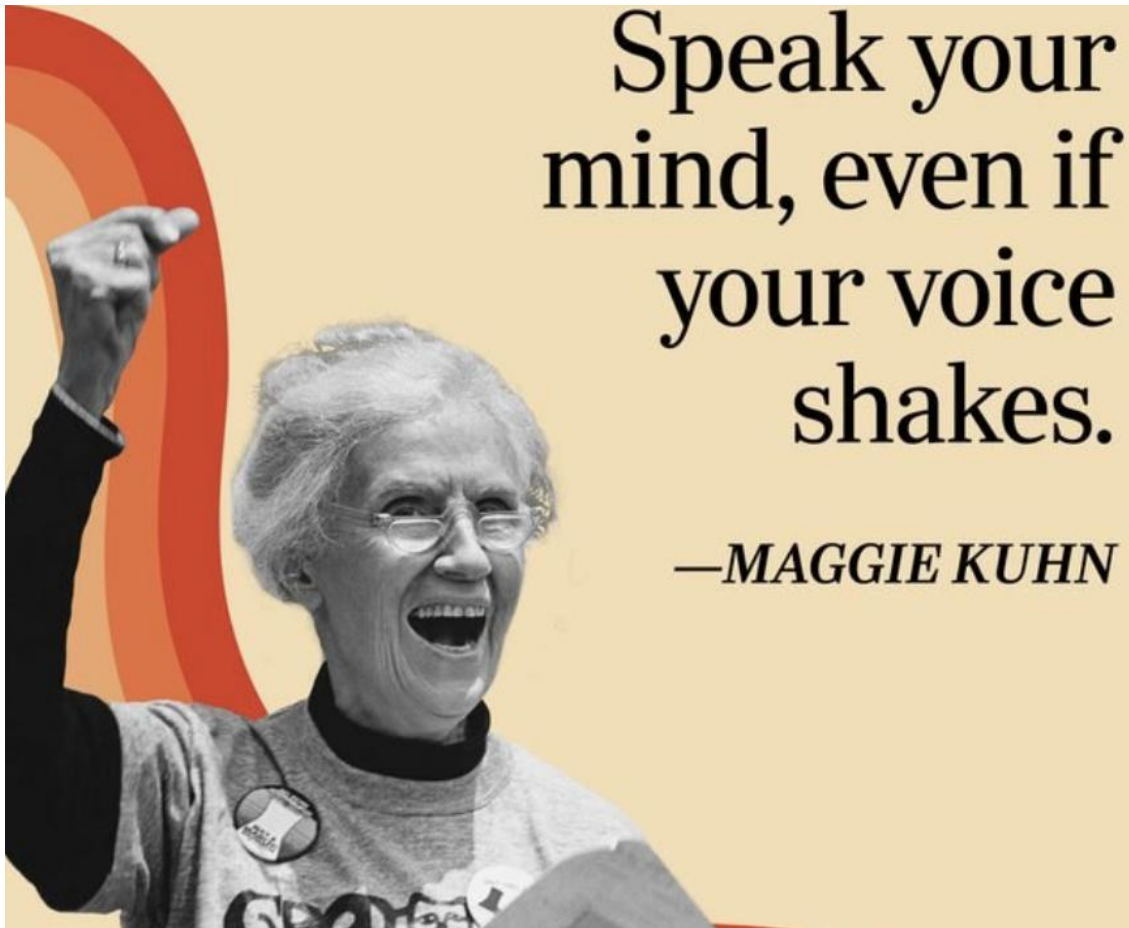
Our very own Coordination of Care Workgroup, led by Sheldon Berkowitz is putting on a Pediatric to Adult Healthcare Roundtable! Please RSVP and spread the word! <https://www.eventbrite.com/e/pediatric-to-adult-healthcare-transitions-a-roundtable-discussion-tickets-300083296217>

The 2022 Great Plains Rare Disease Summit is May 19th-21st. The 2022 Summit will be held in a hybrid fashion and so you have the option to attend in person or virtually. Here is the signup

link: https://app.smartsheet.com/b/form/f2ed621218434fcb86fce40be28a0f6e?utm_campaign=CoRDs+Summit

On May 19th there is a Sanford PROMISE Community Lecture Series. Here is the registration

link: <https://app.smartsheet.com/b/form/5de0416f7f05427782d9e318de3489cc>



Speak your
mind, even if
your voice
shakes.

—MAGGIE KUHN



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](#).

