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Welcome to the Chloe Barnes Rare Disease Council Newsletter! This newsletter serves the purpose to organize monthly updates and build community between the council members.

Upcoming Events:

The next full Council meeting date is April 29th, 3-4:30

The recording of Rare Disease Day 2021 hosted by the Center for Orphan Drug Research is now [online](#). Thank you Dr. Orchard for moderating!



Let's welcome our new student worker to the Rare Disease Council Team! Samiat Ajibola is currently a third-year student at the University of Minnesota. She serves as the president of the Black Student Union and is next year's Student Body Vice President. Samiat has a special interest in public health and providing equitable health resources to everyone. She is very excited to help us in any way possible.

Please remember to do the following:

- Set up your Box account or google drive to get access to important Council documents. You can begin setting up [here](#). If you are not employed by the University of MN please choose the link under the "continue" button.
 - Please review the list of state agencies and add any agency you would like Erica to reach out to. The agency list can be accessed through Box [here](#).
 - If you are new to Box choose “enroll” to set up a free account with any email address
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Welcome to our newest council legislative appointees!

Two of our legislative appointees did not run for reelection and we are joined by two new appointees! Rep Kelly Morrison is an assistant majority leader in the House and practicing OB-GYN. She received her BA in History from Yale University before attending Medical School at Case Western Reserve University. She completed her residency at McGaw Medical Center, Northwestern University.

Sen Julia Coleman enters her first term representing District 47. She graduated from the University of Minnesota with a degree in political science and sociology and has served in numerous public service roles prior to the election.

A special congratulations to Dr. Kris Ann Schultz!

Dr. Schultz was named the Pine Tree Apple Tennis Classic Endowed Chair in Cancer and Blood Disorders research in 2020!

Read here for more information:

<https://www.childrensmn.org/2021/02/02/congratulations-dr-kris-ann-schultz-pine-tree-apple-tennis-classic-endowed-chair-cancer-blood-disorders-research/>

Opportunities to Get Involved:

DEI Taskforce co-lead: In order to more intentionally pursue our value of diversity, equity, and inclusion, the Council is forming a task force to identify actionable steps we can take to ensure all communities are equally represented in the work that we do. Rae Blaylark has offered to be task force co-lead. If anyone is interested in being lead, please contact Erica Barnes.

Great Plains Summit Speakers:

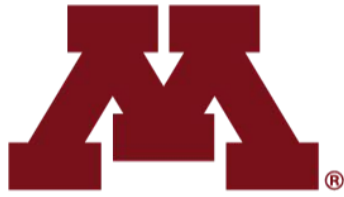
Sanford Health is in the planning stages of its November 2021 Great Plains Rare Disease Summit.

The theme this year will be Technologies for modeling rare diseases. These could include but aren't limited to unique cellular models, animal models, or even in silico modeling of rare diseases to use things like machine learning and artificial intelligence to predict biomarkers or therapeutic targets for diseases that have not been well characterized. If anyone is interested in presenting or would like more information please let Erica know. Also, feel free to share the presentation opportunity with interested colleagues.

Collaboration opportunity:

gMendel™ is an AIGen™ (Artificial Intelligence and Genomics) Research Lab for Rare Diseases Difficult to Diagnose. To address the difficulties in rare disease diagnosis, gMendel® in collaboration with the University of Copenhagen is developing a novel cost-effective, and accurate test for the detection of rare genetic diseases. gMendel® is reaching out to hospitals and advocacy groups worldwide to establish collaborations that will contribute to validating the accuracy and robustness of gMendel®'s proprietary method, while accelerating the AI algorithm development. Founder Chris Kyriakidis would like to communicate with hospitals, HCPs, and KOLs, who may be interested in learning more. You can contact Erica or Chris directly at Chris@g-mendel.com or +4561911033.





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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.

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