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Next full Council meeting date is July 29th, 3:00pm -4:30pm

HAPPY retirement

A special thank you to council member Janet Zieglar!

Council member Janet Zieglar retired this month and relocated out of state. We wish her the best and are thankful for the addition she was on the Council. With her retirement, the role of social worker is open. If any Council member has a recommendation of a candidate, please pass on the following information to them:

- The Chloe Barnes Advisory Council on Rare Diseases is a cross-sector, multi-institutional collaborative endeavor that seeks to address the gaps in care present in the rare disease patient population. Its vision is a Minnesota where every citizen living with a rare disease has access to a timely diagnosis, expert/coordinated care, as well as individualized treatment, management, and support throughout the lifespan. Its mission is to provide advice on research, diagnosis, treatment, and education related to rare diseases. The all-volunteer Council currently has a vacancy for the position of social worker. If you are interested in being considered for the role and would like more detailed information, please contact Council administrator Erica Barnes at demo0050@umn.edu.

gMendel, the company working on the early and fast detection of rare diseases using data analytics and supported by a Minnesota- Danish collaboration, participated in the Golden Egg competition organised by the Innovation Centre of Denmark and the State of Israel. They wanted to inform the Council that from 100+ submissions to the competition, gMendel was shortlisted to top 3.

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.

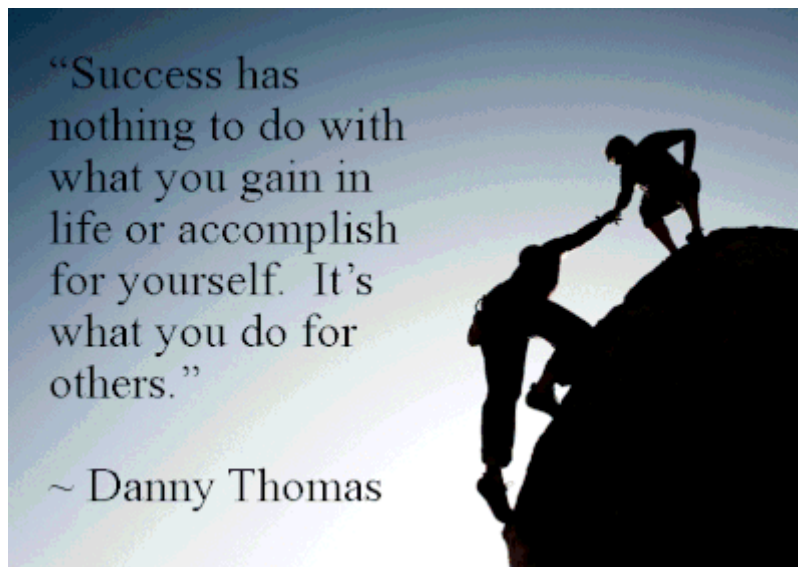
Great Plains Summit Speakers:

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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