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Welcome to the June Chloe Barnes Rare Disease Council Newsletter! This newsletter will continue to serve the purpose of organizing monthly updates and build community between the council members.

**Upcoming Events:**

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

Saturday, June 19th is World Sickle Cell Day. Please wear red in support of the community and share a selfie #SickleCellMN. For more information contact Rae Blaylark.



**Hey!! Don't forget to...**

### **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 send our student worker, Samiat, your contact information for the Council Directory. Please email her at [ajibo013@umn.edu](mailto:ajibo013@umn.edu).
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### **A special congratulations to our team members!**

1. Paul Orchard was recently covered for his groundbreaking care for children with MSD <https://www.fox9.com/news/u-of-m-doctors-perform-first-bone-marrow-transplant-therapy-to-treat-rare-condition>
2. Rep Tony Albright participated in a webinar panel hosted by NORD (National Organization for Rare Disorders) that will be available in June. The topic was passing legislation to form a Rare Disease Advisory Council in your state.

Thank you, Rep. Albright, for your leadership!

### **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.

#### Gene-Targeted Therapies | Early Diagnosis and Equitable Delivery Meeting

Thursdays, June 3, 10 and 17, 12:00 pm – 4:30 pm EDT

The National Institutes for Health (NIH) invites stakeholders throughout the scientific research, advocacy, clinical practice, industry, and lay communities, including the general public, to attend a three-day meeting and [submit comments or questions](#) relating to the effective, efficient and equitable distribution of gene-targeted therapies. [https://events-support.com/events/Gene-Targeted\\_Therapies\\_June\\_2021/page/2357](https://events-support.com/events/Gene-Targeted_Therapies_June_2021/page/2357)

### **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](mailto:Chris@g-mendel.com) or +4561911033.



“Volunteers do not necessarily have the TIME;

they just have the HEART.”

– Elizabeth Andrew



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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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