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Upcoming Events:

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

On Wednesday, May 12 at 7:30 AM, the Krivit Lectureship is a yearly presentation given through Children's Masonic Pediatric Grand Rounds and focuses on research related to rare, inherited disease. Annie Kennedy, the Chief of Policy & Advocacy in the Everylife Foundation for Rare Disease, will be presenting on the results of their new study regarding the financial implications of Rare Disease. Please join if you can.

Congratulations

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Congratulations to Lee Jones- Her company was highlighted in STAT magazine! Her company is examining the science behind this nascent industry, fleshing out what we know about the ecology of the human microbiome and the various interventions scientists are studying to help keep or make it healthy.

Further learning opportunities:

[Gene-Targeted Therapies I 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

Opportunities to Get Involved:

Provider survey:

The barriers to care workgroup is requesting your help in sharing the provider survey. This 5-minute survey will give the Council invaluable insight into the level of knowledge about rare diseases throughout the medical community in the state of Minnesota. Survey link here: https://umn.qualtrics.com/jfe/form/SV_9n6X4vVrNTmN7pj

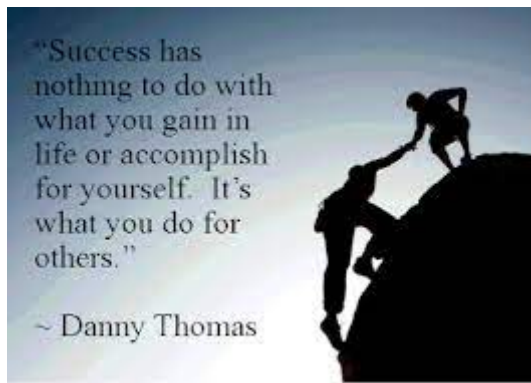
DEI Taskforce co-lead:

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 steering committee and 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 disease. These could include, but aren't limited to unique cellular models, animal models, or even in silico modeling of rare disease 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 participating in their steering committee please let Erica know. Also, feel free to share the presentation opportunity with interested colleagues.





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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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