

COMMUNITY LEADERS PATIENT CHAMPIONS

BONUS SESSION: NAVIGATING RESOURCES FOR RARE



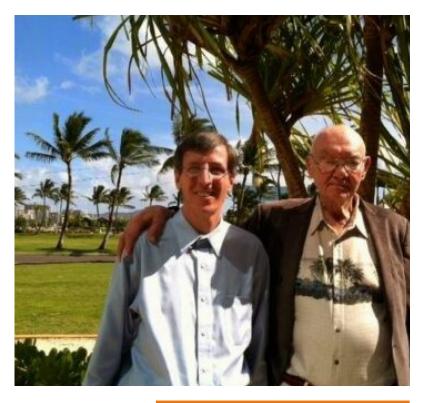
NORD STUDENTS FOR RARE





NORD Students for Rare is an undergraduate organization at The University of Michigan that is affiliated with The National Organization for Rare Disorders (NORD).

Our purpose is to advocate and spread awareness and recognition of rare diseases, to establish professional relationships and partnerships, and to encourage future opportunities within the rare disease space.





DAN DRY DOCK SHOCKLEY

University of Michigan Genetic Hereditary Testing (MGHT) Advisory Board member









KATHERYN ELIBRI, DO

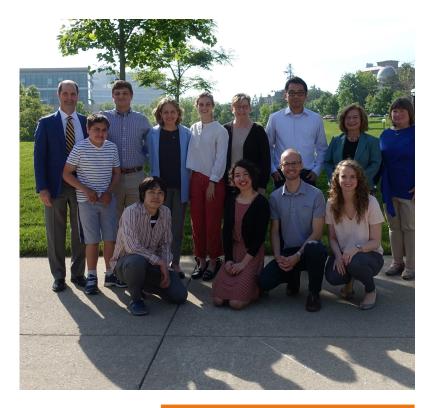
President and founder of CDKL5 Research Collaborative





EVELYN ARGIROKASTRITIS

President and founder of Race for Immunology

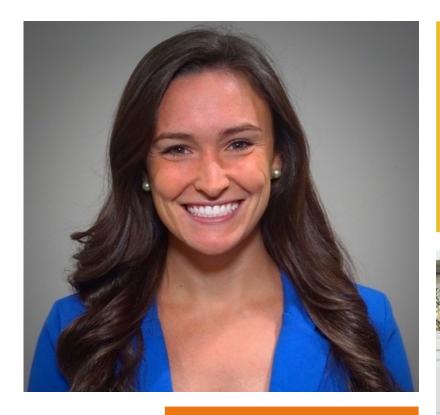






JANICE FARREHI, MD

Parent and Staff Physician, University Health Service, University of Michigan









Pediatric Hospitalist at Arkansas Children's Hospital





RESOURCES FOR RARE

Dan Dry Dock Shockley Rare Showcase

https://www.youtube.com/watch?v=qgK6-UVIAQ0

CDKL5 Research Collaborative

https://www.cdkl5research.org

Race for Immunology

https://www.raceforimmunology.org

Many Hands Lifesharing Community

https://manyhandslc.org

Iwase Lab KDM5C Registry

https://www.brainchromatindynamics.com/

KDM5C Facebook Family Support Group

https://www.facebook.com/groups/kdm5c/about/

The National Organization for Rare Disorders

https://rarediseases.org

REMAINING QUESTIONS?









Dan Dry Dock
Shockley (AFAP)~
dandrydockshockley@gmail.co
m

Dr. Katheryn Elibri (CDKL5)~ katherynef@yahoo.com

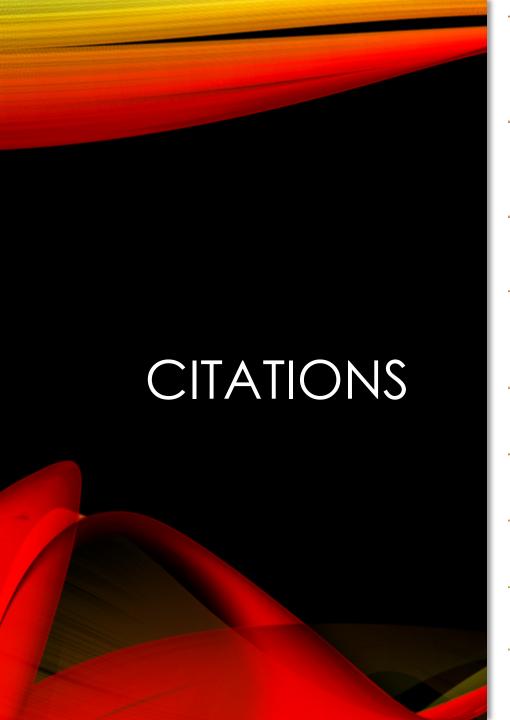
Evelyn Argirokastritis
(NEMO)~
evieargiro@gmail.com

Dr. Janice Farrehi (KDM5C)~ jfarrehi@med.umich.edu



Dr. Phoebe Martin
(Lamb-Shaffer
Syndrome)~

phoebemartinmd@gmail.com



PowerPoint Presentation created by Katelyn J. Roberts (B.S. Neuroscience and Psychology) for The University of Michigan 2022 Michigan Medicine Rare Disease Conference

Slide one:

https://www.oandp.org/events/EventDetails.aspx?id=1221973, https://rarediseases.org

Slide two:

https://rarediseases.org

Slide three:

https://www.ccalliance.org/blog/prevention/dan-drydock-shockleycolon-cancer-warrior-forges-on

Slide four:

https://www.cdkl5research.org

Slide five:

https://www.raceforimmunology.org

Slide six:

https://manyhandslc.org

Slide seven: https://medicine.uams.edu/blog/recent-faculty-appointments-july-2021/, https://en.wikipedia.org/wiki/Instagram

Resources for rare slide:

https://www.flickr.com/photos/bestrated1/2037077881