

COMMUNITY LEADERS PATIENT CHAMPIONS

BONUS SESSION: NAVIGATING RESOURCES FOR RARE



MICHIGAN MEDICINE
UNIVERSITY OF MICHIGAN

NORD STUDENTS FOR RARE



RARE DISEASE DAY®



NORD®

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





CDKL5
RESEARCH COLLABORATIVE
Hope rises when people rise!™



KATHERYN ELIBRI, DO

President and founder
of CDKL5 Research
Collaborative





RACE FOR IMMUNOLOGY

EVELYN ARGIROKASTRITIS

President and founder of Race for Immunology





MANY HANDS
LIFESHARING COMMUNITY

JANICE FARREHI, MD

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





@doctor.phoebe
@dr.tommymartin

PHOEBE MARTIN, MD

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.com

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

CITATIONS

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-shockley-colon-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>