

Monogenic MINUTE

NEWSLETTER



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MONOGENICDIABETES.ORG

Spring 2020



Welcome!

Welcome to the “Monogenic Minute”, the newsletter of the University of Chicago Monogenic Diabetes Registry!

Your continued participation in the Monogenic Diabetes Registry is greatly appreciated. Whether it's completing an annual follow-up survey, updating your contact information, or referring other family members with diabetes, your involvement is truly the fuel for our studies.

We hope you enjoy this issue of the Monogenic Minute. We welcome any suggestions for future issues in the years to come, as we hope to stay connected with all of you who make the Monogenic Diabetes Registry possible!

COVID-19 Updates



We are thinking of you and your families during this difficult time. Our Monogenic Diabetes Registry is still enrolling participants, but all research materials including sending enrollment packets and completing genetic testing has been placed on a brief hold. We hope to be up and running soon! Should you have any questions/concerns in the meantime, please contact our research coordinator [here](#).



Dr. Meltem Zeytinoglu interviewed several members of the UChicago team regarding managing diabetes during the pandemic. Please speak with your physician before making any medical changes.

[Watch Here](#)

COVID-19 Critical Relief Program

The National Organization for Rare Disorders (NORD) has launched a program to provide much-needed assistance to members of the rare disorder community affected by the COVID-19 pandemic.

NORD will provide financial assistance to eligible patients, covering up to \$1,000 annually, to support critical, non-medical needs.

[To learn more, please visit their website here.](#)

Should you have any questions regarding COVID-19 and monogenic diabetes please reach out to our team.

[Ask Here](#)

Research Updates

Communication Survey

Thank you for your participation in our communication survey. To date, 191 participants provided feedback on their preferred communication methods and formats. We hope to better connect you to one another and our research team through the best platforms. For preliminary findings, please follow the link below.

[Learn more](#)

Monogenic Diabetes Registry

Over 1,900 families, with over 1,000 confirmed monogenic diabetes diagnoses, are currently enrolled in the largest atypical diabetes database in the United States.

[Learn more](#)

Race/Ethnicity Survey

One of the main goals of the Registry is to be a resource to ALL people with known or suspected monogenic diabetes throughout

the US and beyond. We would like to better understand who we are capturing. One area where we have significant incomplete data is around racial and ethnic background. To help with completeness of this important data, we will be sending a short survey that should not take more than 1-2 minutes to complete. Please be on the lookout for it in your e-mail in the next week.

RADIANT (Rare and Atypical Diabetes NeTwork)

RADIANT is a network of institutions across the U.S. who are studying atypical forms of diabetes. This study completes more comprehensive genetic testing on participants with atypical forms of diabetes to better identify and categorize them. As this study is in the early stages, there is not much you need to do at this time, but we will be reaching out to those that are eligible in the next few months.

Do you want to participate in our new and ongoing studies?

[Find out more here.](#)

The Next Generation: Our 2020 Graduates!



Nairi Brown, Boston, MA

Nairi has been with the UChicago team since June 2019. During her time, she provided excellent support during the 2019 Family Meeting and has studied behavior and learning challenges in ABCC8-related neonatal diabetes.

When asked what she enjoyed most about working with MDM she said, "I have done a lot of work with type one diabetes, but I didn't know anything about monogenic diabetes prior to this experience. I've really enjoyed learning about such a small population and getting to know some of the families. I loved being able to



Swathi Balaji, Southern CA

Swathi has been with the UChicago team since December 2016. During her many years with us she analyzed GCK-MODY data in the Registry and cultured brain organoids to better understand MDM and iDEND Syndrome.

When asked what she enjoyed most about working with MDM she said, "One of the most enjoyable things I've worked on this year is creating a TED-talk style video about the Registry for my Science Communication class. I got to interview one of our participants and learn

attend one of the family meetings, and actually meet the people we talk with so often."

In her free time, she enjoys creating and listening to music. After graduation she plans to apply to graduate psychology programs. We wish her the best of luck in all of her future endeavors!

how she got properly diagnosed through the Registry, which changed her life for the better."

In her free time she enjoys singing South Asian classical music and creating comics. After graduation she will be attending medical school and we wish her all the best in her next adventure!

Clinician Corner

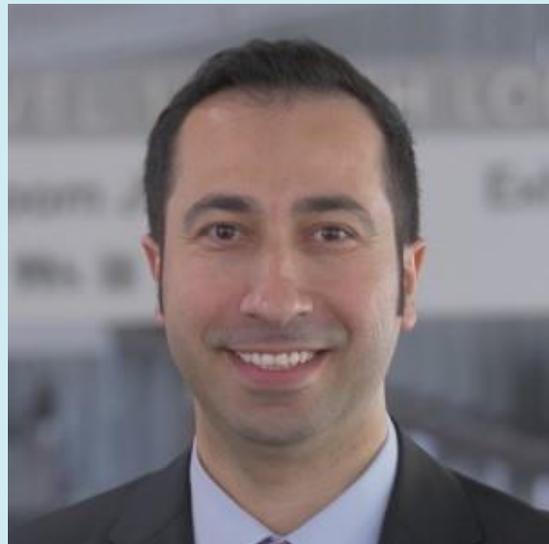
Dr. Halis Akturk

Location/Hospital Affiliation: Barbara Davis Center for Diabetes Adult Clinic, University of Colorado
-Aurora, Colorado

Medical School: Istanbul University
-Istanbul, Turkey

Residency in Internal Medicine: Creighton University
-Omaha, Nebraska

Endocrinology, Diabetes and Metabolism Fellowship: Mayo Clinic
-Rochester, Minnesota



Meet Dr. Halis Akturk! He is a friend to the Monogenic Diabetes Registry and advocate for his patients.

[Enjoy our interview here!](#)

Need to Update Your Contact Information?

[Click Here](#)

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