

## **A study to identify the unmet needs of individuals and families living with dyskeratosis congenita (DC) and related telomere biology disorders (TBDs)**

Researchers from the Clinical Genetics Branch at the National Cancer Institute (NCI) are conducting a study designed to better understand your needs and experiences living with dyskeratosis congenita (DC) or a related telomere biology disorder (TBD). The purpose of this study is to learn more about the informational, social, and emotional needs of families like yours. Dr. Sharon Savage is the principal investigator of this study and Ms. Catherine Wilsnack and Dr. Camella Rising are the study coordinators.

We invite you to participate in this study if you are:

1. Involved in the Team Telomere community AND
2. 18 years old or older AND you are:
3. An individual diagnosed with DC or a related TBD OR
4. A caregiver of an individual with DC or a related TBD OR
5. A bereaved parent of a family member who died due to complications of DC or a related TBD

You may participate in this study if you already participate in other studies at the NCI or elsewhere.

The study involves completing an online survey that should take no more than 20 minutes and completing an approximately 1-hour telephone interview. Your total time involved in the study should be no more than 90 minutes. You may choose to complete only one portion of the study (only the survey or only the interview).

Your participation in this study is completely voluntary and you may withdraw from the study at any time. Your survey answers will be anonymous, and information you share during the interview will be kept confidential. If you complete BOTH the online survey and interview, then you will have the option to choose either a \$30 Target e-gift card or an Amazon e-gift card as acknowledgement of your time and effort. If you complete only one part of the study, then you will not receive this compensation.

To begin the study by agreeing to participate and completing the online survey, please click [\*\*HERE on this link\*\*](#). Note that the survey may be easier to complete on a tablet or desktop computer than on a mobile phone. After completing the survey, you will be asked if you would like to participate in the interview. If yes, we will ask for your contact information on a separate online form to keep your survey answers anonymous. Ms. Wilsnack or Dr. Rising will contact you to schedule a date and time for the interview that is convenient for you.

If you prefer to participate in the interview first, or only participate in the interview, please agree to participate and provide your contact information by clicking [\*\*HERE on this link\*\*](#). Ms. Wilsnack or Dr. Rising will contact you to schedule a date and time for the interview that is convenient for you. At the end of the interview, you will be asked if you would like to complete the online survey. If yes, Ms. Wilsnack or Dr. Rising will email you the hyperlink to agree to participate and complete the online survey.

We greatly appreciate your consideration of participating in this study. Your participation will help the researchers understand how to better provide clinical care that meets the needs of families like yours and provide a direction for future research. If you have any questions about the study, please contact Camella Rising, PhD, MS, RDN, at 240-276-5262 or [\*\*camella.rising@nih.gov\*\*](mailto:camella.rising@nih.gov).

Sincerely,

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