

# Welcome

Dyskeratosis Congenita Outreach, Inc. (DCO) was unofficially born in 2006 when two people affected by this rare, genetic condition connected over the common desire to reach out. Together they created a conduit of support among patients and families that had never before existed.

At its inception, DCO was simply a name, a website, and an email address, yet a much-needed component of the dyskeratosis congenita landscape. The absence of a family support group had also been recognized by physicians involved with the National Cancer Institute's (NCI) Inherited Bone Marrow Failure Syndrome Study. It was a void that a team of scientists, led by Dr. Blanche Alter, principal investigator of the study, set about filling by procuring funding to sponsor a family symposium for DC patients. Held in Bethesda, Maryland, in September 2008, the meeting allowed DC families to meet for the first time. Some of them had met informally through the DCO website, but most were coming face to face with another DC patient for the first time. The meeting attendees, who likely would not have met otherwise, bonded over shared experiences. A number of them quickly organized into a group driven to expand the DC community.

Fast forward 16 years, to where we are now. DCO laid the foundation for what would become Team Telomere, Inc., an international community for Telomere Biology Disorders (TBDs). Although outreach was the original framework for the organization, it quickly grew to become a support for families and a hub for research, as well as the leading organization worldwide to support and educate every stakeholder in the TBD community.

To date, Team Telomere has given away thousands of first edition clinical guidelines and 300 care packages to patients in 22 countries. Team Telomere has fundraised over \$400,000 through our annual Million Dollar Bike Ride and has representation in nine countries. In 2021 Team Telomere was selected from over 200 applicants as one of the recipients of the prestigious \$600,000 Rare as One grants from the Chan Zuckerberg Initiative. All of our work over the years has been in support of the foundational mantra of one of Team Telomere's founders, Nancy Cornelius: "You are never alone."

Just as Team Telomere's organization name and focus have evolved over the years, so has our understanding of the underlying disease that unites us: telomere biology disorders. Dyskeratosis congenita is one TBD that will always be a focus for Team Telomere, but many in our community lack the classical mucocutaneous triad characteristic of dyskeratosis congenita and thus do not identify with this terminology. Our patient population spans the very young to the very old and all genders. As evidenced by the length and breadth of these guidelines, virtually any combination of body systems may be affected by this disease, or none at all in some patients. Despite the myriad manifestations, what unites us all lies in our chromosomes. To bridge the gap between our heritage as DCO and our future as Team Telomere, we have chosen to refer to our disease as "DC/TBD" in these guidelines. Although some areas of these guidelines make reference to one or more specific TBDs, our goal is to embrace and provide comprehensive information about all TBDs identified to date and TBDs in general.

Team Telomere is proud to present to you the second edition of Telomere Biology Disorders Diagnosis and Management Guidelines. Our sincere and deep gratitude goes to all those that have come before us to pave the way in science and advocacy. Thank you to our Team Telomere families; we honor your journey and are humbled to walk with you throughout. We maintain that you are never alone.

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