

About DC Outreach, Inc.

In 2008 the National Institutes of Health brought together scientists, clinicians and families affected by dyskeratosis congenita (DC) for the first-ever DC Clinical Research Workshop in Bethesda, MD. From this meeting, the patients and families organized a support group which came to be known as Dyskeratosis Congenita Outreach, Inc. Our mission is to provide information and support to families affected by Dyskeratosis Congenita worldwide, to encourage the medical community's research in finding causes and effective treatments, and to facilitate improved diagnosis by educating medical providers. The group was organized as a 501(c)3 charity in 2009 as a way for families and physicians to become educated about DC and share their experiences with others.

Since then, DC Outreach has started an Internet site, <http://www.dcoutreach.com>, and a related chat forum for members, DC Family Support, at <http://health.groups.yahoo.com/group/DCfamilysupport>. Both are intended to provide the widely dispersed group of people concerned about DC with a way to connect with one another and share information. We are also on facebook at Dyskeratosis Congenita Outreach, Inc.

If you would like to make a charitable, tax deductible, donation to our support group, please make checks payable to DC Outreach, Inc. c/o Rose Galeano-Phillips 128 Franks Rd. Hawley, PA 18428 Thank you.

If you would like to continue to stay in touch with us and to receive our letters, you must reach out to us either through our website or by contacting Nancy Cornelius at snaca6@aol.com or at 914-273-4274 or at 6 Devoe Rd. Armonk, NY 10504. This will probably be our last mailing by the NIH.

DC Outreach, Inc. is operated by an all-volunteer board of directors independent of the NIH. From all those we represent, we thank you for your kind support.



Joe Carlson
President

DC Outreach, Inc.

How to contact us for information or to make donations:

Please visit us on the web at
www.dcoutreach.com

or you may reach our president at:
[*jcarlson@dcoutreach.com*](mailto:jcarlson@dcoutreach.com)

You may also reach our secretary
at
[*ncornelius@dcoutreach.com*](mailto:ncornelius@dcoutreach.com) or at
[*snaca6@aol.com*](mailto:snaca6@aol.com)



A Very Special Invitation!



Dyskeratosis Congenita Outreach, Inc.

and



Together this fall.

Please read on for more information about this exciting long weekend we have planned for you.

Dear Families,

Many of you received a letter from us, via the NIH, sometime last year. We are writing now with very exciting news: We would like to invite you and your family to join Dyskeratosis Congenita Outreach, Inc. (DCO) for a very special extended weekend this fall at wonderful Camp Sunshine in Casco, Maine!

Camp Sunshine is a beautiful lakeside retreat offering many amenities, as well as room and board, to charitable groups that support people/families afflicted with serious illnesses -- at no cost to the people who attend except for their transportation there.. We are honored to have been selected by Camp Sunshine as such an organization.



Our weekend there will be at a glorious time of year -- Thursday, Sept. 30 to Sunday, Oct. 3, 2010 -- smack dab in the heart of fall foliage season, but still early enough to enjoy many of the camp's outdoor facilities and activities. The DC weekend at Camp Sunshine will offer you a truly unique opportunity to convene with other families affected by DC -- parents, children, and individuals alike -- to meet, learn, share experiences and information, commiserate, and support one another in this rare struggle we all share -- and have some fun in the process. What's more, we will be joined by special guests from the medical and research fields who will participate in discussions, answer questions, and share information on any new advances and therapies.

The following doctors have been invited to speak during the weekend:

Blanche Alter, MD, MPH, National Cancer Institute, is a recognized clinical research expert whose

studies investigate cancer-prone genetic syndromes with associated bone marrow failure, like DC.

Monica Bessler, MD, PhD leads The Pediatric & Adult Comprehensive Bone Marrow Failure Center at Children's Hospital of PA and Univ. PA. She studies the pathway of telomere shortening in disorders like DC, and its ways to improve diagnosis, care, and treatment.

Inderjeet Dokal, MD, Barts and The London School of Medicine and Dentistry. His lab's research linked DC with defective telomerase, and looks at possibility of correcting telomere length.

Sharon Savage, MD, National Cancer Institute. Research looks at genetic variation in telomere biology and how this may relate to cancer risk, with implications in identifying genes important in DC.

Jakub Tolar, MD, PhD, University of Minnesota. Laboratory research focuses on stem cell therapy to correct genetic diseases, while clinical work addresses pathways to improve conditioning regimens for pediatric marrow transplant.

Further details about the weekend are still being worked out; we will post them as they develop. Please watch our website for more information. At this point, we ask that you:

- Check out Camp Sunshine's website at <http://campsunshine.org>. Soon the application to formally apply will be posted on the camp's website. **You must apply directly to the camp!**



- Post any thoughts or questions about the weekend by visiting our chat forum, which is at <http://health.groups.yahoo.com/group/DCfamilysupport/join>. This will be the most practical way to ask questions. The DCO board will be watching the forum and answering them regularly, and getting further information from the camp when we don't know the answers. Please do not contact the camp staff directly with questions, as they are in the midst of their summer season and are extremely busy.



- Let us know if you are interested in attending, as it will be important for us to get a sense of the numbers as early as possible -- for planning purposes, and because although we can accommodate a fairly large number of families, space is not unlimited. We have already received requests from several families. To be added to our list of potential attendees, please contact Nancy Cornelius at snaca6@aol.com. You can also call her at 914-273-4274 with any questions or to let her know that you are interested in attending. Remember, the only cost to you is the transportation to get there. Thank you all for your support thus far. We look forward to hearing from you, and to meeting as many of you as possible in late September!

-- The DC Outreach Board

