

TERMS AND CONDITIONS OF USE OF SICKLECELLDISEASE.NET

AGREEMENT

BY ENTERING THE NCEC-SCDAA SITE, YOU ACKNOWLEDGE AND AGREE THAT YOU HAVE READ AND UNDERSTAND THESE TERMS AND CONDITIONS OF USE OF SICKLECELLDISEASE.NET, THAT THE PROVISIONS, DISCLOSURES AND DISCLAIMERS SET FORTH BELOW ARE FAIR AND REASONABLE, AND THAT YOUR AGREEMENT TO FOLLOW AND BE BOUND BY THEM IS VOLUNTARY AND IS NOT THE RESULT OF FRAUD, DURESS OR UNDUE INFLUENCE EXERCISED UPON YOU BY ANY PERSON OR ENTITY.

YOU ALSO AGREE TO HOLD NCEC AND ITS GRANTEEES, AND EACH OF THEIR OFFICERS, DIRECTORS, MEMBERS, AND AGENTS HARMLESS FROM ANY CLAIM, COMPLAINT OR DAMAGE ARISING OUT OF OR IN CONNECTION WITH YOUR USE OF THE SITE.

SUMMARY OF IMPORTANT LEGAL INFORMATION

The sicklecelldisease.net website (the "Site") is produced for the National Coordinating and Evaluation Center (NCEC) -SCDAA, the grantees participating in the Sickle Cell Disease Newborn Screening Program and their partners. All use of the Site is subject to the Terms and Conditions set forth below. By entering and using the Site, you acknowledge that you have read and understood such Terms and Conditions and that you agree to abide by them. The Site is designed for informational and educational purposes only. NCEC does not endorse, guarantee, warrant, or recommend any products or services discussed or advertised on the Site or linked from the Site. The NCEC-SCDAA retains all copyrights and other proprietary rights in or relating to any content, including any software or educational materials, provided on the Site. You may download and print a small number of copies of the content for scientific or educational uses. You may not sell, transfer, reproduce, transmit, distribute, perform or display such content for any commercial purpose without the express consent of the NCEC-SCDAA.

PRIVACY POLICY NCEC-SCDAA provides the following privacy policy (the "Privacy Policy") in order to demonstrate our firm commitment to privacy. The Privacy Policy may be amended from time to time. The NCEC home page will indicate the date that the Privacy Policy was most recently updated.

a. **Collection of Personal Information.** NCEC -SCDAA may ask for information about our users at the point of downloading educational materials. This information tells us about the types of people (e.g., providers vs. patients, grantees vs. nongrantees) who use the Site and helps us in the development of materials for our grantees and their clients.

b. **Use of Personally Identifiable Information.** NCEC-SCDAA will not sell or otherwise transfer or disclose personally identifiable information to third parties without the user's prior consent except as may be required by federal, state or local law, or by exigent circumstances. NCEC-SCDAA also may use your profile information on an aggregate basis -- without personal identifiers -- to develop and display new features and content for the Site, and to provide others with aggregate information about our users and the usage patterns of the Site. NCEC-SCDAA

also may perform statistical analyses of user behavior (on a de-identified aggregate basis) in order to measure interest in and use of the various areas of the Site.

c. **Retention of User Information.** It is not possible for a user to delete his or her profile from our database, nor is it feasible to delete all traces of a user's activity in the system. Messages posted to a forum are examples of user activities that are not feasible to delete.

d. **Voluntary Disclosure of Personally Identifiable Information on Forum Boards.** Users should be aware that when they voluntarily disclose personally identifiable information (for example user name, email address) on an Interactive Area of the Site, that information, along with any substantive information disclosed in the user's communication, can be collected and correlated and used by third parties and may result in unsolicited messages from third parties. Such activities are beyond the control of the NCEC and the NCEC is not responsible for the discoverability of any user's identify by methods beyond our control.

e. **Cookie Technology.** NCEC collects non-personal identification information through the use of "cookie" technology and/or Internet Protocol ("IP") address tracking. Cookies are small text files a website can use to recognize repeat users and facilitate the user's ongoing access to and use of the site. **Non-personal identification** information might include the browser used by the user, the type of computer, the operating systems, the Internet service providers and other similar information. The NCEC system also automatically gathers information about the areas the user visits on the Site and about the links the user may select from within the Site to other sites. **NCEC cannot control the use of cookies by advertisers or third parties displaying data on the Site or whose sites a user visits or links to from the Site. Most browsers are set to accept cookies. You can set yours to refuse cookies, or to alert you when cookies are being sent.**

f. **Links to other sites.** The Site contains links to third party websites. These links are provided solely as a convenience to users and not as a guarantee, warranty, or recommendation by NCEC of the content on such third-party websites or as an indication of any affiliation, sponsorship or endorsement of such third party websites. NCEC is not responsible for the content of linked third-party sites and does not make any representations regarding the privacy practices of, or the content or accuracy of materials on, such third-party websites. If you decide to access linked third-party websites, you do so at your own risk. Your use of third-party websites is subject to the terms of use for such sites.

g. **Security of Information.** NCEC is committed to keeping user information secure, and uses industry standard technology in an attempt to achieve that goal.

h. **Parental Permission.** NCEC does not intend that children will use the Site. Some of the information available on the Site may not be appropriate for children. **USERS UNDER 18 YEARS OF AGE MUST OBTAIN PARENTAL PERMISSION TO USE THE SITE.** Adults should not assist unauthorized children to access the Site. NCEC will not knowingly collect, use or disclose personally identifiable information about visitors under 18 years of age.