



## **COFFIN-LOWRY SYNDROME FOUNDATION PRIVACY POLICY**

### **ARTICLE I - INTRODUCTION**

The Coffin-Lowry Syndrome Foundation (CLSF) is committed to respecting and protecting your privacy. This Privacy Policy (the "Policy") applies to our collection and use of personal information through our website, located at [www.coffinlowry.org](http://www.coffinlowry.org) (the "Site").

### **ARTICLE II - PERSONAL INFORMATION**

CLSF may collect personal information submitted through online application and event registration and donation forms. By submitting personal information to this Site, the User acknowledges that he or she has read this privacy policy, understands it, agrees to its terms and authorizes CLSF to collect, use and disclose personal information pursuant to the terms of this privacy policy.

### **ARTICLE III - SHARING INFORMATION**

Unless we have your consent or except as required by law, your personal information will be held in strict confidence. We use your information only for its intended purpose. By submitting personal information through the Site, you authorize CLSF to share this personal information for the purposes identified, such as CLSF newsletters, family gathering, qualifications for grants, organizing fund-raising events, responding to User inquiries, processing donations, or determining eligibility for CLSF programs. If you do not authorize, contact us at: Coffin-Lowry Syndrome Foundation, 234 Knotting Place, Madison, AL 35758 ATTN: President. If you do not wish to release your personal information to CLSF members, you may still join CLSF and receive newsletters and join the CLSF private Facebook group. However, you will not receive contact information for other families or be provided with family matching services.

Notwithstanding other provisions of this privacy policy, we may share your personal information as required or permitted by law to comply with a subpoena or similar legal process or government request, or when we believe in good faith that disclosure is legally required or otherwise necessary to protect our rights and property, or the rights, property or safety of others, including to advisers, law enforcement, judicial and regulatory authorities.

#### **ARTICLE IV - APPLICABLE LAW/INTERNATIONAL ISSUES**

Because we are committed to protecting your privacy, personal information that is submitted to this Site will be collected, processed, stored, disclosed and disposed of in accordance with applicable U.S. law. If you are a non-U.S. user, you acknowledge and agree that we may collect and use your personal data and disclose it to other entities, as discussed above in “Who We Share It With,” outside your resident jurisdiction. In addition, such personal information may be stored on servers located outside your resident jurisdiction. U.S. law may not provide the degree of protection for personal information that is available in other countries. By providing us with your personal information, you acknowledge that you have read this privacy policy, understand it, agree to its terms and consent to the transfer of such information outside your resident jurisdiction.

#### **ARTICLE V - SECURITY OF DATA**

The security of your personal information is paramount to us but remember that no method of transmission over the internet, or method of electronic storage is 100% secure. While we strive to use commercially acceptable means to protect your personal information, we cannot guarantee its absolute security.

This Site has security measures in place to protect against the loss, misuse and alteration of information under our control. However, we cannot guarantee that such security measures will be sufficient, will not be breached, and that your personal information may not be disclosed or otherwise accessed in an unauthorized manner.

#### **ARTICLE VI -EXTERNAL LINKS**

The Site may, from time to time, contain links to external sites operated by third parties. We are not responsible for these third-party sites or the content of such third-party sites. Once you have left the Site, we cannot be responsible for the protection and privacy of any information which you provide. You should exercise caution and look at the privacy statement for the website you visit.

#### **ARTICLE VII - ACCESSING AND AMENDING YOUR PERSONAL INFORMATION**

If after providing this information to us, you decide at some point that you no longer wish to be contacted regarding the benefits and services we provide, you can simply contact us by e-mail and stop the use of your personal information in this manner.

You may contact us at [clsfoundation@outlook.com](mailto:clsfoundation@outlook.com) or at:

Coffin-Lowry Syndrome Foundation  
234 Knotting Place  
Madison, AL 35785  
(256) 684-2480

### **ARTICLE VIII - PARENTS AND CHILDREN UNDER THE AGE OF 18**

If you are under the age of 18, be sure to ask your parents for permission before you send any information about yourself to this site or to anyone over the Internet. CLSF recommends as a general matter that parents accompany children under the age of 18 when using content on the Internet and that you carefully review this privacy policy before any personal information about children is provided to the site.

### **ARTICLE IX - MEDICAL DISCLAIMER**

Please note that this Site is provided for informational purposes only. It is not intended as a substitute for informed medical advice. The user of this Site should not use this information to diagnose or treat a health problem or disease without consulting with a qualified health care provider, specific tests, physicians, procedures, opinions, or other qualified medical information.

### **ARTICLE X -CHANGES TO THIS POLICY**

This Policy is subject to occasional revisions. We encourage you to periodically review this page for the latest information on our privacy practices and to review our most current privacy statement. If you have any questions about this Privacy Policy, you can contact us at [clsfoundation@outlook.com](mailto:clsfoundation@outlook.com).