

PRIVACY POLICY

Last modified: March 3, 2014

The Hairy Cell Leukemia Foundation (the “**Foundation**”) is committed to protecting your online privacy. Your use of our website, hairycellleukemia.org (the “**Website**”), indicates your acceptance of this Privacy Policy (the “**Policy**”). If you do not accept all of the terms of the Policy you should not use the Website. This Policy may change so please refer back to it periodically.

1. **Information the Foundation Collects.**

- a. While using the Website you do not have to provide personal identifying information and you decide the amount of information you provide. The Foundation collects only information that you choose to submit.
- b. In order to provide you with information through our “Ask an Expert” service, the Foundation will ask you to provide your name and e-mail address, and any information (which may include personal medical information) relevant to the question you would like to pose.
- c. If you wish to participate in our Patient Data Registry, the Foundation will ask you to provide your name and e-mail address to one of its participating institutions www.hairycellleukemia.org/patients/data-registry.

2. **Our Use of Information You Provide.**

- a. The Foundation collects your information in order to advance understanding of hairy cell leukemia (“**HCL**”) and to connect you with individual and institutional experts on the disease.
- b. The Foundation uses personal identifying information collected about you through our “Ask an Expert” service to respond to your requests for information. In order to respond to your request, the Foundation will share the message you submit through the service with medical professionals associated with our www.hairycellleukemia.org/about-us/centers-of-excellence. In addition, any question posed by you through the service and the corresponding expert response may be posted to the Website, after your identifying information has been removed, to increase understanding of HCL.
- c. The Foundation shares the personal information you provide through its Patient Data Registry with our www.hairycellleukemia.org/about-us/centers-of-excellence so that they may contact you and obtain your medical information directly. The Foundation does not have access to information provided by you directly to Centers of Excellence.

- d. The Foundation may disclose personal identifying information about users of the Website to respond to subpoenas, court orders, legal process, and other law-enforcement measures and to comply with other legal obligations. The Foundation may also disclose information to protect and defend the legal rights, interests, and safety of the Foundation, our employees, agents, and contractors and to protect the safety and security of the Website, Website users, and members of the public, and as otherwise disclosed in the <http://www.hairycellleukemia.org/pdf/Terms-of-Service.pdf>.
3. **Security.** The Foundation treats security seriously and take reasonable measures to protect each Website user’s personal identifying information. All information entering the Website system is encrypted using Secure Sockets Layer (“SSL”) software. The Foundation is not, however, responsible for any information you share with other users of the Website or with third parties. While the Foundation strives to use industry-standard practices to protect your information, it does not guarantee the absolute security of your information.
4. **Privacy Protection for Children.** In furtherance of the terms of the Children’s Online Privacy Protection Act, the Foundation will not knowingly permit persons under the age of 13 to provide information through the Website or otherwise. If the Foundation later learns that any user is under the age of 13, it will take appropriate steps to remove that user’s information from our databases and restrict that user’s access to the Website.
5. **Links to Other Websites.** The Website may contain links to third-party websites. The Foundation is not responsible for the privacy practices, policies, or content of those other websites. Once you link to a third-party website, you are subject to the terms of service and privacy policy of that site.
6. **Notification of Changes.** If the Foundation decides to use your information in a manner different from that stated at the time of collection, it will notify you by email. You may choose whether or not the Foundation may use your information in this manner. In addition, if the Foundation make any material changes in our privacy practices that do not affect your information already stored in the Website’s database, it will post a prominent notice on the Website regarding the change. In some cases when the Foundation posts a notice, it may also email you to notify you of the changes to this Policy. The Foundation will update and amend this Policy if and when it determines an update or amendment to be necessary. Please check back often to read the most updated and amended Policy.

7. **Contact Information.** For any questions relating to this Policy, please contact Earl Stone by any of the following means:
- a. **By Email:** info@hairycellleukemia.org
 - b. **By Mail:** Hairy Cell Leukemia Foundation, 790 Estate Drive, Suite 180, Deerfield, IL 60015
 - c. **By Phone:** (224) 355-7201