

Spinal Muscular Atrophy Foundation Privacy Policy

The Spinal Muscular Atrophy (SMA) Foundation (referred to herein as "SMA Foundation", "we" or "us") respects the privacy of users of the SMA Foundation Web Site and we are committed to protecting it. We recognize your need, as a user of this site, for appropriate protection and management of the personal information we learn about you while you visit our Web Site. This privacy policy lets you know how we use and protect that information. The information that we receive depends on what you do during your visit, and what service(s) you request.

Purpose and Scope

This privacy policy discloses what information we gather about you when you visit our Web Site. It describes how we use that information and how you can control it.

Effective Date

This policy is effective as of January 1, 2011.

Information the SMA Foundation Gathers and Tracks

The SMA Foundation collects two kinds of information about visitors: 1) data that visitors volunteer by signing up to receive news, make a donation, complete surveys or request information; and 2) aggregated tracking data we collect when visitors interact with our Web Site.

Personal Information

When you request a service or information, make a donation, submit feedback or participate in a forum or survey, we may need to ask you for personal information such as your name, address, email address and telephone number. If you choose to provide us with information regarding a medical condition, we will use this information in conjunction with our use of your other personal information, as set forth in this privacy policy.

We do not send you information unless you request it or we believe that the information would benefit your business needs. If you do not want to receive further information from us, simply contact us at info@smafoundation.org and request to be removed from the Registration or contact list. Once we receive your request, we will use commercially reasonable efforts to remove your name from the contact list. If you wish to update any of your personal information, please contact us at such email address, and we will use commercially reasonable efforts to update your contact information accordingly. Please be aware, however, even if we update your personal information in our contact list, or we remove such information, it may still be stored in other databases (including those kept for archival purposes) and may still be used to compile aggregated or demographic information for supply to third parties in accordance with this privacy policy. It is our policy to not provide information that identifies you personally to a third party without your permission, except to process or fulfill your requests, or as otherwise set forth in this privacy policy.

Non-Identifying Information

We may collect information about our visitors, customers, page views, traffic patterns and related site information. This information helps us evaluate and improve our site and is sometimes useful for marketing and investment analysis. We may share this information with third parties, but only in aggregate statistical form that includes no personally identifying information.

Use of "Cookies"

Cookies are small files that many web sites place on your hard drive that allow such web sites to identify you. The use of cookies is a standard and common practice of many web sites. For example, if you allow a site to remember your login name or password, the site places a cookie on your computer. We may place cookies on your computer to allow us to identify you during future visits to our Web Site. We may use cookies to measure Web traffic, to offer you certain services and to customize your visit. However, if you do not wish to receive cookies, or want to be notified of when they are placed, your browser may permit you to do so. In many browsers, you can change the browser settings to warn you before accepting cookies or to block cookies. If you

block cookies, you may not be able to use certain site features or functions, or the Web Site may not operate in an optimal mode.

Disclosure to Third Party Service Providers

Certain third party service providers that we use to enable us to provide the Web Site and related services may have access to your personal information. These third party service providers are required not to use your personal information other than to provide the services requested by the SMA Foundation. You expressly consent to the sharing of your personal information with our service providers for the purpose of providing such services.

Transaction Information

If you choose to make a donation to the SMA Foundation through the Web site, we will request certain personal information and your credit card information (collectively, "Transaction Information") and the donation amount will be billed to your credit card. The Transaction Information is used only to process your transaction and is not shared with third parties except those who assist us with processing your donation transaction. By making a donation on our Web Site, you agree that we can share your Transaction Information with such third parties for this purpose. We do not retain your credit card information, but do retain a record of your donation transaction for administrative purposes.

Security

We use reasonable security procedures to protect the information you share with us from unauthorized access or disclosure.

Privacy Protections for Children.

Our Web Site is not directed at children. Therefore, we do not wish to receive, nor do we knowingly collect personal information from minors.

Linked Sites

Our Web Site may link to other web sites not controlled by the SMA Foundation. . Although we try to be careful in the selection of our strategic service and technology partners, we are not responsible for the privacy or security practices of any other web sites, and you acknowledge and agree that any use of such other web sites is entirely at your own risk. You should carefully review the privacy and security practices of the other web sites before you provide such web sites with any of your personal information.

European Union Users

YOU EXPRESSLY CONSENT TO THE SMA FOUNDATION'S PROCESSING OF YOUR PERSONAL INFORMATION IN ACCORDANCE WITH THIS PRIVACY POLICY. YOUR PERSONAL INFORMATION MAY BE PROCESSED BY THE SMA FOUNDATION IN THE COUNTRY WHERE IT WAS COLLECTED AND IN THE UNITED STATES. UNITED STATES LAWS REGARDING PROCESSING OF PERSONAL INFORMATION MAY BE LESS STRINGENT THAN THE LAWS IN YOUR COUNTRY.

IF YOU REPRESENT AN ORGANIZATION, YOU WILL BE RESPONSIBLE TO ENSURE THAT EACH MEMBER OF YOUR ORGANIZATION (INCLUDING EMPLOYEES AND CONTRACTORS) ABOUT WHOM PERSONAL INFORMATION MAY BE PROVIDED TO THE SMA FOUNDATION HAS GIVEN HIS OR HER EXPRESS CONSENT TO THE SMA FOUNDATION'S PROCESSING OF SUCH PERSONAL INFORMATION.

Other Disclosures

Although your privacy is very important to us, due to the existing legal, regulatory, technical and security environment, we cannot fully ensure, nor do we warrant, that your private communications and other personal information will not be disclosed to third parties. For example, we may be required to disclose your personal information to the government or other third parties under certain circumstances, or third parties may unlawfully intercept or access transmissions or private communications. Additionally, in the unlikely event we need to

investigate or resolve possible problems or inquiries, we can (and you authorize us to) disclose any information about you (including personal information) to private entities, law enforcement or other government officials as we, in our sole discretion, believe necessary or appropriate. In all instances, we will cooperate fully when required by law to provide information regarding visitors.

Changes to the Privacy Policy

We reserve the right to change this privacy policy at any time. If we update this privacy policy, we will place a notice on our Web Site indicating such update. You are responsible to review the updated privacy policy so that you are aware of our then-current privacy practices. If you object to any such changes, you must cease using our website. Continued use of our website following notice of any such changes shall indicate your acknowledgement of such changes and agreement to be bound by the terms and conditions of such changes.

Feedback; Removal from Contact List

If you have a question or comment about the SMA Foundation's Web Site, or wish to update your contact information or be removed from our contact list, please email us at info@smafoundation.org.

Transfer of Information

Notwithstanding anything expressed or implied in this privacy policy, in connection with an assignment, sale, joint venture or other transfer or disposition of some or all of the assets of the SMA Foundation or its affiliated entities, you agree that we can accordingly assign, sell, license or transfer any information, including personal information, that you have provided to us to those third parties directly involved in the transfer or disposition of such assets.

Incorporation

This Privacy Policy is incorporated into and made part of the SMA Foundation Web Site Terms of Use, which can be found at [www.smafoundation.org/about us](http://www.smafoundation.org/about_us).