



MAVEN PROJECT Privacy Policy

This website ("the Website") is run by MAVEN Project ("we", "our" and "us"). This Privacy Policy applies to our website located at www.mavenproject.org (and its sub-domains and subpages) and describes the information we may collect from you and explains how we use, store, and share your personal data. You can visit most pages on the Website without giving us any information about yourself, but sometimes we need this information to provide the information or services that you request. This Privacy Policy explains data collection and uses in those situations. By visiting the Website, you consent to the information practices described in this Privacy Policy.

Please note: this Privacy Policy does not cover links to other websites. We are not responsible for the privacy policies and practices (including the use of cookies) of other websites even if you access the third-party website using links from our Website. We recommend that you check the privacy policies of each website you visit and contact the owner or operator of the website if you have concerns or questions.

We may update our Privacy Policy in the future. Any changes to this Privacy Policy will be posted on this page, and where appropriate, we will notify you by email that there has been a change. Please check back frequently to see any updates or changes to this Privacy Policy.

THE INFORMATION WE COLLECT & HOW WE USE IT

Below is a summary of the types of information (including personal information) we may collect, store and process as part of our mission and the services we provide. In sum, we never sell any of the information we collect from you. We may share such information with our business partners for the sole purpose of advancing our mission and providing the information and services you request.

We collect personal information when you voluntarily submit non-public personal information through our Website by requesting information, signing up for an account or other services, receiving electronic notices or other similar communications, making donations, and other similar activities.

Please note that Personal Information provided to us may be collected, stored and processed in the United States of America.

POINT OF COLLECTION	INFORMATION COLLECTED	PURPOSE OF PROCESSING	WHOM DO WE SHARE THE INFORMATION WITH
Website	<p>Your personal information (patients, caregivers, providers, and other Website visitors), including but not limited to your name, country, postal address, email address, phone number, date of birth, other contact information, and any other information collected on through our Website information collection points; Disease-specific information based on the information you provide or request; Financial information you may provide as part of any donation process in which you participate (please see our Donor Privacy Policy)</p>	<p>To send you information and provide services in response to your requests (<i>e.g.</i>, newsletter sign-up, registration for conferences or webinars). To process any donation that you have made. Assemble general website traffic and disease-related statistics (which do not include the personal information of any person), for the advancement of our mission.</p>	<p>We do not sell any such information.</p> <p>We may share such information with business partners as necessary to provide you with the information and services you have requested.</p> <p>Aggregated and anonymized data (no personal information) with lawmakers, regulators, and pharmaceutical industry representatives, for funding. We may share your contact information with other nonprofit organizations whose activities or services may be of interest to you.</p>
<p>Website Cookies and Browsing Information</p>	<p>Browsing Information about you, including but not limited to your device (mobile, tablet, desktop, including location and your IP address).</p> <p>Website cookies automatically collect certain information from our Website visitors - Please see our Cookie Policy.</p>	<p>To personalize and enrich your experience on our Website (including our mobile site) and to improve our Website experience and performance.</p>	<p>We do not sell any such information.</p> <p>We may share such information with business partners as necessary to maintain and improve the website.</p>

			Third-party agencies (for example Google Adwords) appointed by us collate and use this data to create a personalized service for you on our behalf and provide us with information about the traffic to our Website.
Surveys and Special Events	Your personal information (patients, caregivers, providers, and other Website visitors), including but not limited to your name, country, postal address, email address, phone number, date of birth, other contact information, and any other information collected as part of the applicable survey or registration process. This may include providing such information through third-party websites.	<p>We partner with other organizations who wish to learn more about you to create more effective treatments. We will contract with them to create surveys to gather your thoughts and experiences. If we send you a survey it is because:</p> <p>(1) You agreed to take the survey; or (2) You registered for a run/walk/fundraising event with us; or (3) You have opted-in box (<i>e.g.</i>, by checking the appropriate box as part of an interaction with us) to say you want to hear from us.</p> <p>You may always decline to take a survey, and if we send you one it is because we believe it may provide valuable information related to our mission.</p>	<p>We do not sell any such information.</p> <p>We will only share your personal information collected through surveys as disclosed to you in the applicable survey.</p>
At events	Photographic images and other information you may provide to us at an event (<i>e.g.</i> , name, address, and date of birth).	To the extent we use stand-alone images of you (<i>i.e.</i> , not within a group) for marketing or educational materials, we will ask you to provide your consent (including signing a clearance form, which you can always refuse).	<p>We do not sell any such information.</p> <p>We will only share your personal information collected through surveys as disclosed to you in the applicable survey.</p>

		When we take photographs of groups at these events, we are doing so only to promote our mission and services and to build a sense of community. By attending an event, photographs will be taken and images may be used.	
At events	Photographic images and other information (e.g., name, address, and date of birth).	To the extent we use images of you (i.e., not within a group) for marketing or educational materials, we will ask you to provide your consent and an image rights clearance, which you can always refuse	Publication on the MAVEN Project Website and social media site, marketing, and promotional materials
		When we take photographs of groups at these events, we are doing so for our legitimate business interest of using the images for marketing and promotional materials to promote our business. It is within your reasonable expectations that in attending a public relations event, photographs will be taken and images used in this way	

INFORMATION SECURITY

MAVEN Project has put in place security measures in accordance with commercially reasonable industry practices and procedures to keep personal data as safe and secure as possible, and to protect from unauthorized or unlawful processing and accidental loss, destruction, or damage. However, the Internet and email are not completely secure. Your communications may route through other countries before being delivered, may be intercepted by third parties, and may not always reach the intended recipient – this is the nature of the World Wide Web/Internet. We cannot accept responsibility for any such unauthorized access or loss of personal information that is beyond our control.

We may transfer personal information to countries other than the country in which the data was originally collected to provide you with the services you have requested. These countries may not have the same data protection laws as the country in which you initially provided the information and may not provide the same level of protection.

We have in place appropriate policies, rules, and technical and organizational measures to protect your personal information from unauthorized or unlawful processing, and against accidental loss, destruction, or damage to personal information.

TO WHOM YOUR INFORMATION WILL BE DISCLOSED

Your information may, for the purposes set out in this Privacy Policy, be disclosed to the third parties set out in THE INFORMATION WE COLLECT AND HOW WE USE IT above. We do not sell any personal information that we collect from you.

In addition to the reasons set forth in THE INFORMATION WE COLLECT AND HOW WE USE IT above, we will disclose your personal information to third parties:

- in order to enforce or apply our Website terms of use;
- to protect the rights, property, or safety of us, our staff, our customers, or others. This includes exchanging information with other companies and organizations (including without limitation the local police or other local law enforcement agencies) for the purposes of staff and customer safety, crime prevention, fraud protection, credit risk reduction; and
- if we are under a duty to disclose or share your personal data to comply with any legal obligation or regulatory requirements, or otherwise for the prevention or detection of fraud or crime.

HOW LONG WE KEEP YOUR DATA

We will typically keep your personal data for three (3) years from your last interaction with us to enable us to keep you informed of the latest information about MAVEN Project. In some circumstances, some of your data will be deleted in much shorter timescales, such as our cookies being refreshed in accordance with our Cookie Policy.

YOUR RIGHTS

You have rights regarding the way we store and process your personal information. If you would like to opt-out of any of receiving further communications or services from us, and/or would like to opt-out of us sharing information with other nonprofit organizations whose activities or services may be of interest to you, you can do so by following the instructions in the communication (e.g., following the unsubscribe link in an email) or on our Website by contacting info@mavenproject.org or calling us at 617-641-9743. We will respond to any request received from you promptly. You also can send your updated personal information by mail (or a written request for a hard-copy of your personal information that we maintain) to:

MAVEN Project
PO Box 156781
San Francisco, California 94115
Attn: Compliance Officer

We will also delete the information we have stored from you if you so request by emailing or writing to us at the addresses above. We encourage you to contact us first if you have any queries, comments, or concerns about the way we handle your data.

FURTHER INFORMATION

For further information from us on data protection and privacy or any requests concerning your personal information please email us at info@mavenproject.org