



# Our Commitment to Privacy

Partners in Bleeding Disorders Education (“Partners”)<sup>s</sup> respects the privacy of every individual who visits our Website, [www.partnersprn.org](http://www.partnersprn.org). This notice explains our online information practices, and links to it are posted throughout the Website. By visiting the Website, you accept the practices described in this notice.

## 1. Information Collection and Use

Partners is the sole owner of the information collected on this site. We will not sell your information to others outside of Partners.

Partners collects data from visitors to the site via various registration forms, including those completed when joining Partners and when applying online for live events. Data include all Personally Identifiable Information (PII) and other non-public information. Data include, but are not limited to, student data, metadata, and user content.

Completion of forms on the Partners Website is optional. Information collected via the forms is entered into the Partners database. The visitor will be placed on a list to receive Partners e-mail communications, including announcements of new online activities, surveys of the HTC community, etc., as well as occasional communications by regular mail. Visitors who do not wish to receive communications from Partners have the opportunity to opt out at any time.

[www.PartnersPRN.org](http://www.PartnersPRN.org) users should be aware that while data collected on forms is protected, PII disclosed voluntarily in comment, testimonial, or blog areas is viewable by others and may result in unsolicited messages from others.

Partners may use de-identified data for product development, research, or other purposes. Data will have all direct and indirect identifiers removed. This includes, but is not limited to, name, ID numbers, date of birth, demographic information, location information, and Hemophilia Treatment Center ID.

Except as stated in this privacy policy or at the time of collection, a user’s PII will not be transferred or shared with any individual, company, sponsor, vendor, organization or other entity outside of Partners, except for fulfillment and mailing houses contracted by Partners for the sole purpose of disseminating Partners medical, program and promotional materials. Partners may also disclose account information when we have reason to believe that disclosure is necessary to identify, contact or bring legal action against someone who may be intentionally or unintentionally causing injury to or interference with Partners’ rights or property, other [www.PartnersPRN.org](http://www.PartnersPRN.org) users, or anyone else that could be harmed by such activities.

Partners will not change how data are collected, used, or shared under this Privacy Policy without advanced notice to constituents.

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## 2. Traffic data

Each time a visitor comes to the Partners Website, we count, track and aggregate the visitor's activity into our analysis of general traffic flow at our site. To these ends, we may merge information about visitors and visits into group data, which may then be shared on an aggregated basis with our sponsors, but we will not disclose your individual identity. When we do present aggregated information to outside companies, no one will be able to identify or contact you.

## 3. Data Security

Partners stores and processes data in accordance with best practices. This includes appropriate administrative, physical, and technical safeguards to secure data from unauthorized use. Partners will conduct periodic risk assessments to identify and remediate any identified security vulnerabilities in a timely manner. Partners will engage in best practices in the event of a PII or other data breach, including providing a written incident report to affected constituents.

Partners limits access of its constituent data to key personnel, on a need only basis, to effectively carry out work duties. However, as effective as these measures are, no security system is impenetrable. We cannot guarantee the security of our database, nor can we guarantee that the information you supply will not be intercepted while being transmitted to us over the Internet.

## 4. Links

Partners' Website includes links to other online resources. Partners is not responsible for the privacy practices or information on other sites. Website that have links on our Website do not have access to personal information or traffic data from [www.PartnersPRN.org](http://www.PartnersPRN.org), and do not collect personal information from you via our Website.

However we do not control the privacy policies of those sites or businesses to which we provide hyperlinks or access. Upon clicking one of these links, you will exit the Partners Website and enter the linked site. We encourage our visitors to read the privacy statements of every Website they visit.

## 5. Use of Cookies

A cookie is a small amount of data that is sent to your browser from a Web server and stored on your computer's hard drive. We use cookies in a limited way to help deliver information, to identify unique browsers that visit us, and to track usage throughout our Website.

The information about site usage that Partners collects through cookies is aggregated into general reports about usage and is not tied to individual identities.



Other companies that place links on our site do not have the ability to assign cookies to you via the Partners Website, however, upon clicking one of these links, you will exit the Partners Website and enter the linked site. You are encouraged to review the linked sites' use of cookies as well.

## 6. Surveys and Polls

In order to create content for the HTC community, it is important to gain insight into the needs of the community. To this end, Partners will periodically conduct voluntary surveys and polls of site users stored in the Partners database to obtain aggregate needs assessment and other opinion data. Such information may be compiled and shared in the aggregate with sponsors and other third parties, but no personal details will be traceable or associated with specific individuals.

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<sup>5</sup> Partners in Bleeding Disorders Education (“Partners”) is a collaborative program and, in the context of Our Commitment to Privacy, includes the following organizations and groups: Partners Advisory Board, U.S. HTC Network Regional Coordinators, Indiana Hemophilia & Thrombosis Center, National Hemophilia Foundation, and Hemophilia Foundation of Michigan.