

ATHNadvoy Privacy Statement

You have been invited to participate in the use of the ATHNadvoy site and we are strongly committed to maintaining your privacy. ATHN provides this service to your Hemophilia Center. In order to use this site, you must be invited by your Hemophilia Center and/or physician and provide personal information. This Privacy Statement tells you how we use, share, and protect the privacy of that information.

ATHNadvoy is designed to be a bridge to facilitate communication between the Patient and his/her Healthcare Professional. It allows the Patient to record their personal bleed and infusion information and to share that information with their Healthcare Professionals in a timely manner.

ATHNadvoy will allow you to record data about your condition and treatment on the Internet. The data you provide when you register or record your treatment information is considered to be personal to you. Personal information is data that can be used to identify or contact you.

This Privacy Statement applies only to this site. Within this site, you may see links to other websites that are not covered by this Privacy Statement. We provide these links for your convenience. You are responsible for any contact you have with these websites, and you should ensure that you are satisfied with the privacy policies of such sites.

This Privacy Statement will let you know the following:

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What information does ATHNadvoy collect from you

ATHNadvoy collects information from you in two ways.

1. Active information collection is when we gather information that you decide to send to us, for instance when you complete a registration form or record your treatment data or send us an e-mail. Active information may include data such as your name, date of birth, phone number, address and email address.
2. Passive information collection is when we collect data from you that you have not actively given us, such as the type of web browser and operating system you use. Passive data does not include personal health information and will not be linked to the personal information you have provided on the ATHNadvoy site.

ATHNadvoy is intended to be used by Healthcare Professionals, Patients and their caregivers. ATHN, as the steward of the ATHNadvoy platform, invites a Hemophilia Center to participate in the use of ATHNadvoy. The Hemophilia Center registers the Healthcare Professionals and invites patients to participate. In order to use the healthcare information section of ATHNadvoy, users must be added to the system as an authorized user at the Hemophilia Center. Once a Hemophilia Center ATHNadvoy Administrator has added a user they will give the user a PIN (personal identification number). Then, when you first log on to the site, you will be required to complete a registration form. During registration, you will be required to choose a username and password. Every time you visit ATHNadvoy, you must provide your username and password in order to get into the areas of ATHNadvoy where personal information can be accessed. Please note that if you choose not to register, you will not be able to use the entire site.

PATIENT AND CAREGIVERS

Your Hemophilia Center may register you for ATHNadvoy by providing your name, address, phone number, date of birth and email address. Once you are a registered user of ATHNadvoy you may enter data about your condition and treatment in the ATHNadvoy site for your Healthcare Professionals to view.

You will also be able to send and receive messages from Healthcare Professionals who are registered users of ATHNadvoy within your Hemophilia Center. The ATHNadvoy two-way messages are intended to augment the communication between you and your Healthcare Professionals, not to replace current or other standard communication or substitute direct communication of therapeutic changes.

The ATHNadvoyMobile Handheld Solution is a software application that runs on a handheld computer, which delivers the core therapy management capabilities of the ATHNadvoy platform. Once treatment data is entered into the ATHNadvoyMobile application it is stored on the handheld device, and will not be accessible by the patient's healthcare provider until that data is synchronized with the ATHNadvoy system. In this case, "synchronization" is defined as the transmission of treatment data stored on the ATHNadvoyMobile device to the secure databases that store all ATHNadvoy user data. The synchronization protocol used to securely transmit (encrypted) treatment data depends on the specific ATHNadvoyMobile device configuration being utilized. An important consideration when using the ATHNadvoyMobile Handheld Solution is the frequency in which data synchronization is performed. The Healthcare Professional only has access to updated treatment data once that data is uploaded to the ATHNadvoy system. Data is stored on the ATHNadvoyMobile device until it has been synchronized with the ATHNadvoy system.

You will be able to export your data to an excel spreadsheet. Once the data has been exported it becomes the responsibility of the person exporting the data to ensure the privacy and security of the exported data.

HEALTHCARE PROFESSIONALS

You may register with us through the Hemophilia Center by providing your country of residence, email address, name, address, phone numbers and pager numbers. This information will be used on the Hemophilia Center home page staff directory so that staff and patients will know how to contact you. Once you are a registered user of ATHNadvoy, you may enter data and view patient information.

You will also be able to send and receive messages from your patients who are registered users of ATHNadvoy within your Hemophilia Center. The ATHNadvoy two-way messages are intended to augment the communication between you and your patients who use ATHNadvoy, and are not to replace current or other standard communication.

"Synchronization" is defined as the transmission of treatment data stored on the ATHNadvoyMobile device to the secure databases that store all

ATHNadvoy user data. The synchronization protocol used to securely transmit (encrypted) treatment data depends on the specific ATHNadvoyMobile device configuration being utilized. An important consideration when using the ATHNadvoyMobile Handheld Solution is the frequency in which data synchronization is performed. The Healthcare Professional only has access to updated treatment data once that data is uploaded to the ATHNadvoy system.

Once patient data is entered directly or uploaded from the Mobile device into the ATHNadvoy system, you will be able to import your patients' data directly into Web Tracker.

You will also be able to export your Patients' data to an Excel spreadsheet or into reports that can be provided to the national registry where appropriate. For patients that opt in to the ATHNdataset or consent to be part of clinical research studies, the bleed and infusion history can be appropriately and electronically reported. ATHNadvoy will record the following attributes for each export: Username of the Healthcare Professional who exported data, the country that the user is from, the date and time of the export, the name of the export report and all report parameters (including date range and report fields). Once the data has been exported, it becomes the responsibility of the Hemophilia Treatment Center and you to ensure the privacy and security of the exported data.

Cookies

As many websites do, we use "cookies" to personalize our site for you and to collect information about site usage and the connection of our systems to yours. A cookie is a text file that the site transfers to your computer's hard drive for record-keeping purposes. The cookie assigns a random unique number to your computer.

ATHNadvoy only uses these cookies to keep your connection stable in the event of Internet or server problems and to check that your system works well with our site and to improve the site's function. Some cookies are temporary and are removed by your browser when you finish an ATHNadvoy session. Others remain on your hard drive to remember session or computer information. You can erase the cookies that remain on your hard drive; however, when you do you will again be prompted to provide the information that was contained in the cookie. We use cookies and your IP address (a unique identifier assigned to your computer when logging on to the Internet) to collect data such as your type of web browser, the operating system you use, and the date and time of your visit.

How does ATHNadvoy use the information that it collects

Only you, your caregivers, and staff selected by your doctor at your Hemophilia Center may use the data we collect from you. We may use or release personal information from this site as required, replying to your requests, to comply with the law, as required by legal action, and to protect against liability, the security and integrity of the site and the safety of its users.

Data provided by, or collected from you, will be held on a server in the United States. We have selected a third party in the United States to house and maintain your data, and this company has agreed in writing to protect the privacy of your information. Select people, who work for the outside company, will only look at your data in order to support the server, which stores your data. ATHN does not have access to any individual identifiable personal or treatment data.

We may view and use de-identified aggregate data, and other details regarding site usage, traffic patterns and other information about our site. To de-identify the data means to remove all personal and Hemophilia Center identifiers. To aggregate data means to combine all the data together. In the event of change of ownership, the ATHNadvoy platform may transfer as an asset to the new owner, along with all stated responsibilities.

We will not sell, lease, transfer, share, or otherwise allow access to your personal data with any outside parties, except as we have explained in this Privacy Statement or as we tell you at the time you provide the information.

For your data to be included in the ATHNdataset or used as part of a clinical research study, you will be asked to sign a specific written authorization or study consent.

Your choices regarding the collection and use of your information

We do not want to collect personal data from you that you do not want us to collect. We tell you at all active data collection points whether what we request is required to use the site, or, if it is optional. It is important for your Healthcare Professionals to have accurate information in a timely manner; therefore, we provide you with access to your personal data so that you can update it or correct errors in order to help keep the data current and complete. We may not allow you access to certain information if doing so would harm, or put at risk, another person's privacy, or if we are entitled or obliged by law to withhold the information in the circumstances.

When you give us information at this site, you consent to the use and release of your data as we have explained in this Privacy Statement. You have the right to review and request the

deletion of personal data collected at this site. If you ever decide you do not wish to participate in ATHNadvoy, if you are unable to access your personal data or would like to review your data, you may contact us by email at: ATHNadvoy@athn.org or by mail at the American Thrombosis and Hemostasis Network (attn: ATHNadvoy)

Please note that, in addition to the rights set out in this Privacy Statement, you may have further rights in relation to the use, collection and disclosure of your personal information under data protection legislation specific to the U.S.

What security measures ATHNadvoy has

ATHNadvoy wants your personal data to remain safe. However, there are no systems that are 100% secure or error-free. Therefore, we cannot guarantee the security or accuracy of the information we gather.

One way we protect your personal data is through usernames and passwords. This safety measure only works if you keep your username and password secret. If you ever think your username or password are no longer secret or are being used by the wrong people, contact your Hemophilia Center right away.

When using two-way messaging, it is important to confirm that you have selected the correct names for all recipients. We have implemented security measures. However, we cannot prevent user errors.

When using ATHNadvoyMobile it is important to use the security measures that have been implemented as part of the ATHNadvoyMobile service. These measures have been implemented to try to help secure the information should your handheld device be lost or stolen. ATHNadvoy cannot guarantee the security of the data on a handheld device that is lost or stolen.

ATHNadvoy has implemented security measures to protect the privacy and security of the data within the site. ATHNadvoy cannot guarantee the privacy and security of the data once it has been exported. ATHNadvoy will record the following attributes for each export: Username of the Healthcare Professional who exported data, the country that the user is from, the date and time of the export, the name of the export report and all report parameters (including date range and report fields).

We take other steps to secure your data. For example, any treatment data you give us is sent by a secure link using encryption. Encryption is the translation of data into a secret code. To read an encrypted file, you must have the key that allows you to read it, so that even if someone were able to obtain the data, they would not be able to make sense of it.

How ATHNadvoy protects the privacy of children and persons with legal guardians

Children and persons with guardians who are invited by their doctor to use ATHNadvoy are required to provide the same data as adult participants. This Privacy Statement applies equally to children and adults with guardians.

We require written parental or guardian consent before we allow children or persons with guardians to use ATHNadvoy. If the way we collect personal data changes, we will post the changes here. If there are changes to the policy, we will ask for the parent or guardian's consent before using or disclosing information about the child or adult. We reserve the right to collect, use, and release a person's name and online contact information without parental or guardian consent, to the extent that it is necessary in order to protect the security of our site, to protect us from liability, and as required by law. We always welcome questions from parents and guardians, and encourage them to contact us at the address below.

Parents and guardians have the right to review and request the deletion of personal data collected at this site. To review personal data, or to have data deleted, please notify the Hemophilia Center ATHNadvoy Administrator who will notify ATHNadvoy at ATHNadvoy@athn.org. You also have the right to revoke your consent to our collection of your child's information, or that of the adult to whom you are a guardian, and/or your information. To revoke consent, please contact your Hemophilia Center who will notify ATHNadvoy.

What happens if we change this Privacy Statement

We may change this Privacy Statement at any time. If we do change the Privacy Statement, the new Privacy Statement will be posted here, along with the date it was changed. You will be asked to agree with the changes by way of a notice that will appear the first time you log onto ATHNadvoy after the date of the change. All data we collect or receive after we post the new Privacy Statement will be subject to the terms explained in the new

Privacy Statement. We want you to know that we will not use your personal information, or release your personal information that you provided, before a new Privacy Statement is posted without first getting your consent by way of the notice referred to above. If you do not give us your consent, we will handle your information in the way you agreed to with the previous Privacy Statement. If you do not agree to the new Privacy Statement, you will not be able to use the site. The Privacy Statement will be available each time you sign on to ATHNadvoy, and we encourage you to review the Privacy Statement if you have questions or concerns about entering your personal data.

How you can withdraw from ATHNadvoy

If you ever decide that you do not wish to participate in the use of ATHNadvoy, you may stop at any time by notifying your Hemophilia Center ATHNadvoy Administrator.

How you can contact ATHNadvoy with questions or comments

If you have questions, comments, concerns or complaints about this Privacy Statement, or the information practices of this site, send us an e-mail at ATHNadvoy@athn.org by mail at the American Thrombosis and Hemostasis Network (attn: ATHNadvoy) 72 Treasure Lane Riverwoods IL, 60015.

Please note that if you choose to contact ATHNadvoy directly, you will be providing personally identifiable information to ATHN. If you do not wish to provide this information to ATHN, please direct all questions to your Hemophilia Center ATHNadvoy Administrator, who will contact ATHNadvoy to obtain the information or assistance you need. We will take steps to answer your questions or concerns and will try to fix problems you bring to our attention. We welcome your comments and feedback regarding ATHNadvoy and our services and programs. E-mail may not be secure. As a result, you should carefully consider what information you wish to send to us via e-mail. We suggest that you do not send clinical or medical information via email.

This Privacy Statement was last revised on October 25, 2009.