

# ATHNadvoy: HIPAA Notice of Privacy Practices

Effective Date: December 13, 2013

The American Thrombosis and Hemostasis Network (ATHN) is pleased to offer you ATHNadvoy, a electronic web-based and/or hand-held system to track your bleeding events, infusions and other information related to your bleeding or clotting disorder. If you are interested in participating in this service, please read this document and confirm that you agree to it and the related Terms and Conditions statement. These documents outline our sensitivity to your right to privacy and the conditions by which we make these tools available for your use.

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. USING THIS TOOL INDICATES YOUR ACCEPTANCE OF THESE PRACTICES. PLEASE REVIEW IT CAREFULLY

## Our Obligations

We are required by law to:

- Maintain the privacy of protected health information
- Give you this notice of our legal duties and privacy practices regarding health information about you
- Follow the terms of our notice that is currently in effect

## How We May Use and Disclose Health Information

The following describes the ways we may use and disclose health information that identifies you ("Health Information"). Except for the purposes described below, we will use and disclose Health Information only with your written permission. You may revoke such permission at any time by writing to our Privacy Officer.

**For Treatment.** We may use and disclose Health Information for your treatment and to provide you with treatment-related health care services. For example, we may disclose Health Information to doctors, nurses, technicians, or other people outside our office, who are involved in your medical care and need the information to provide you with medical care.

**Research.** Under certain circumstances, we may use and disclose Health Information for research. One example is the inclusion of non-identifiable demographic, clinical or genetic information in a data set like the

ATHNdataset. Another example is a research project that compares the health of patients who received one treatment to those who received another, for the same condition. Before we use or disclose Health Information for research, the project will go through a special approval process. Even without special approval, we may permit researchers to look at records to help them identify patients who may be included in their research project or for other similar purposes, as long as they do not remove or take a copy of any Health Information

**For Health Care Operations.** We may use and disclose Health Information for health care operations purposes. These uses and disclosures are necessary to make sure that all patients with bleeding and clotting disorders receive quality care and to operate and manage the multidisciplinary treatment network. For example, we may use and disclose information to make sure care you receive is of the highest quality. We also may share information with other entities that have a relationship with you (for example, your treatment center) for their health care operation activities.

**Appointment Reminders, Treatment Alternatives and Health Related Benefits and Services.** We may use and disclose Health Information to contact you to remind you that you have an appointment with your treatment center, need a refill of your medication or implement a disease management program. We also may use and disclose Health Information to tell you about treatment alternatives or health-related benefits and services that may be of interest to you.

**Individuals Involved in Your Care or Payment for Your Care.** When appropriate, we may share Health Information with a person who is involved in your medical care or payment for your care, such as your family or a close friend. We also may disclose such information to an entity assisting in a disaster relief effort.

## Special Situations

**As Required by Law.** We will disclose Health Information when required to do so by international, federal, state or local law.

**To Avert a Serious Threat to Health or Safety.** We may use and disclose Health Information when necessary to prevent a serious threat to your health and safety or the health and safety of the public or another person. Disclosures, however, will be made only to someone who may be able to help prevent the threat.

**Business Associates.** We may disclose Health Information to our business associates that perform functions on our behalf or provide us with services if the information is necessary for such functions or services. For example, we may use another company to perform technical support on our behalf. All of our business associates are obligated to protect the privacy of your information and are not allowed to use or disclose any information other than as specified in our contract.

**Blood Specimen, Organ and Tissue Donation.** If you are a donor, we may use or release Health Information to organizations that handle organ procurement or other entities engaged in procurement, banking, transportation or use of blood specimens, organs, eyes or tissues to facilitate organ, eye or tissue donation and transplantation.

**Military and Veterans.** If you are a member of the armed forces, we may release Health Information as required by military command authorities. We also may release Health Information to the appropriate foreign military authority if you are a member of a foreign military.

**Public Health Risks.** We may disclose Health Information for public health activities. These activities generally include disclosures to prevent or control disease, injury or disability; report births and deaths; report child abuse or neglect; report reactions to medications or problems with products; notify people of recalls of products they may be using; a person who may have been exposed to a disease or may be at risk for contracting or spreading a disease or condition; and the appropriate government authority if we believe a patient has been the victim of abuse, neglect or domestic violence. We will only make this disclosure if you agree or when required or authorized by law.

**Health Oversight Activities.** We may disclose Health Information to a health oversight agency for activities authorized by law. These oversight activities include, for example, audits, investigations, inspections, and licensure. These activities are necessary for the government to monitor the health care system, government programs, and compliance with civil rights laws.

**Data Breach Notification Purposes.** We may use or disclose your Protected Health Information to provide legally required notices of unauthorized access to or disclosure of your health information.

**Lawsuits and Disputes.** If you are involved in a lawsuit or a dispute, we may disclose Health Information in response to a court or administrative order. We also may disclose Health Information in response to a subpoena, discovery request, or other lawful process by someone else involved in the dispute, but only if efforts have been made to tell you about the request or to obtain an order protecting the information requested.

**Law Enforcement.** We may release Health Information if asked by a law enforcement official if the information is: (1) in response to a court order, subpoena, warrant, summons or similar process; (2) limited information to identify or locate a suspect, fugitive, material witness, or missing person; (3) about the victim of a crime even if, under certain very limited circumstances, we are unable to obtain the person's agreement; (4) about a death we believe may be the result of criminal conduct; (5) about criminal conduct on our premises; and (6) in an emergency to report a crime, the location of the crime or victims, or the identity, description or location of the person who committed the crime.

**Coroners, Medical Examiners and Funeral Directors.** We may release Health Information to a coroner or medical examiner. This may be necessary, for example, to identify a deceased person or determine the cause of death. We also may release Health Information to funeral directors as necessary for their duties.

**National Security and Intelligence Activities.** We may release Health Information to authorized federal officials for intelligence, counter-intelligence, and other national security activities authorized by law.

**Protective Services for the President and Others.** We may disclose Health Information to authorized federal officials so they may provide protection to the President, other authorized persons or foreign heads of state or to conduct special investigations.

**Inmates or Individuals in Custody.** If you are an inmate of a correctional institution or under the custody of a law enforcement official, we may release Health Information to the correctional institution or law enforcement official. This release would be if necessary: (1) for the institution to provide you with health care; (2) to protect your health and safety or the health and safety of others; or (3) the safety and security of the correctional institution.

## Uses and Disclosures That Require Us to Give You an Opportunity to Object and Opt

**Individuals Involved in Your Care or Payment for Your Care.** Unless you object, we may disclose to a member of your family, a relative, a close friend or any other person you identify, your Protected Health Information that directly relates to that person's involvement in your health care. If you are unable to agree or object to such a disclosure, we may disclose such information as necessary if we determine that it is in your best interest based on our professional judgment.

**Disaster Relief.** We may disclose your Protected Health Information to disaster relief organizations that seek your Protected Health Information to coordinate your care, or notify family and friends of your location or condition in a disaster. We will provide you with an opportunity to agree or object to such a disclosure whenever we practically can do so.

## Your Written Authorization is required for Other Uses and Disclosures

The following uses and disclosures of your Protected Health Information will be made only with your written authorization:

1. Uses and disclosures of Protected Health Information for marketing purposes; and
2. Disclosures that constitute a sale of your Protected Health Information.

Other uses and disclosures of Protected Health Information not covered by this Notice or the laws that apply to us will be made only with your written authorization. If you do give us an authorization, you may revoke it at any time by submitting a written revocation to our Privacy Officer and we will no longer disclose Protected Health Information under the authorization. But disclosure that we made in reliance on your authorization before you revoked it will not be affected by the revocation.

## Your Rights:

You have the following rights regarding Health Information we have about you:

**Right to Inspect and Copy.** You have a right to inspect and copy Health Information that may be used to make decisions about your care. This includes medical and billing records, other than psychotherapy notes. To inspect and copy this Health Information, you must make your request, in writing, to your ATHN Affiliated treatment center or ATHN. We have up to 30 days to make your Protected Health

Information available to you and we may charge you a reasonable fee for the costs of copying, mailing or other supplies associated with your request. We may not charge you a fee if you need the information for a claim for benefits under the Social Security Act or any other state or federal needs-based benefit program. We may deny your request in certain limited circumstances. If we do deny your request, you have the right to have the denial reviewed by a licensed healthcare professional who was not directly involved in the denial of your request, and we will comply with the outcome of the review.

**Right to an Electronic Copy of Electronic Medical Records.** If your Protected Health Information is maintained in an electronic format (known as an electronic medical record or an electronic health record), you have the right to request that an electronic copy of your record be given to you or transmitted to another individual or entity. We will make every effort to provide access to your Protected Health Information in the form or format you request, if it is readily producible in such form or format. If the Protected Health Information is not readily producible in the form or format you request your record will be provided in either our standard electronic format or if you do not want this form or format, a readable hard copy form. We may charge you a reasonable, cost-based fee for the labor associated with transmitting the electronic medical record.

**Right to Get Notice of a Breach.** You have the right to be notified upon a breach of any of your unsecured Protected Health Information.

**Right to Amend.** If you feel that Health Information we have is incorrect or incomplete, you may ask us or your health provider to amend the information. You have the right to request an amendment for as long as the information is kept by or for our office. To request an amendment, you must make your request, in writing, to [privacyofficer@athn.org](mailto:privacyofficer@athn.org).

**Right to an Accounting of Disclosures.** You have the right to request a list of certain disclosures we made of Health Information for purposes other than treatment, payment and health care operations or for which you provided written authorization. To request an accounting of disclosures, you must make your request, in writing, to [privacyofficer@athn.org](mailto:privacyofficer@athn.org).

**Right to Request Restrictions.** You have the right to request a restriction or limitation on the Health Information we use or disclose for treatment, payment, or health care operations. You also have the right to request a limit on the Health Information we disclose to someone involved in your care or the payment for your care, like a family member or particular treatment center. For example, you could ask that we not share information about a particular diagnosis or treatment with your parent or treatment center. To request a restriction, you must make your request, in writing, to [privacyofficer@athn.org](mailto:privacyofficer@athn.org). We are not required to agree to your request unless you are asking us to restrict the use and disclosure of your Protected Health Information to a health plan for payment or health care operation purposes and such information you wish to restrict pertains solely to a health care item or service for which you have paid us "out-of-pocket" in full. If we agree, we will comply with your request unless the information is needed to provide you with emergency treatment.

**Right to Request Confidential Communications.** You have the right to request that we communicate with you about medical matters in a certain way or at a certain location. For example, you can ask that we only contact you by mail or at work. To request confidential communications, you must

make your request, in writing, to [privacyofficer@athn.org](mailto:privacyofficer@athn.org). Your request must specify how or where you wish to be contacted. We will accommodate reasonable requests.

**Right to a Paper Copy of This Notice.** You have the right to a paper copy of this notice. You may ask us to give you a copy of this notice at any time. Even if you have agreed to receive this notice electronically, you are still entitled to a paper copy of this notice. To obtain a paper copy of this notice, call ATHN at 1-800-360-2846. ,

## Changes to This Notice

We reserve the right to change this notice and make the new notice apply to Health Information we already have as well as any information we receive in the future. We will post a copy of our current notice at our office. The notice will contain the effective date on the first page, in the top right-hand corner.

## Complaints

If you believe your privacy rights have been violated, you may file a complaint with our office or with the Secretary of the Department of Health and Human Services. To file a complaint with our office, contact [privacyofficer@athn.org](mailto:privacyofficer@athn.org). All complaints must be made in writing. **You will not be penalized for filing a complaint.**