

# Be Prepared – Make Sure You're Ready!



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September is National Preparedness Month and Hurricanes Gustav and Ike, with wave heights of more than 15 feet, 125 mile per hour winds and evacuations up and down the coast, are providing real life reminders that families need to be prepared in case of an emergency or disaster. This is especially true in the hemophilia community.

As the mother of a son with severe factor VIII hemophilia, I am especially concerned about the additional challenges that emergencies and disasters create. The need to plan is particularly important in order to accommodate our family's unique needs. Disasters such as these hurricanes can disrupt access to care, create uncertainty and leave persons with bleeding disorders unable to get the treatment they need when they need it most. How can we avoid these disruptions and make sure we are prepared and ready if we have to seek medical treatment elsewhere in the event of an emergency?

The easiest way to begin is to use the resources already available in the hemophilia community. The National Hemophilia Foundation (NHF) recommends patients gather important emergency medical information and keep it with them.

This is the most important first step to ensure uninterrupted treatment. To help families with this critical piece of planning, a new program is being rolled out through which Hemophilia Treatment Centers (HTCs) systematically provide NHF recommended information to patients in a portable form. This program – called ATHNready – focuses specifically on the hemophilia community and is being led by the American Thrombosis and Hemostasis Network (ATHN).

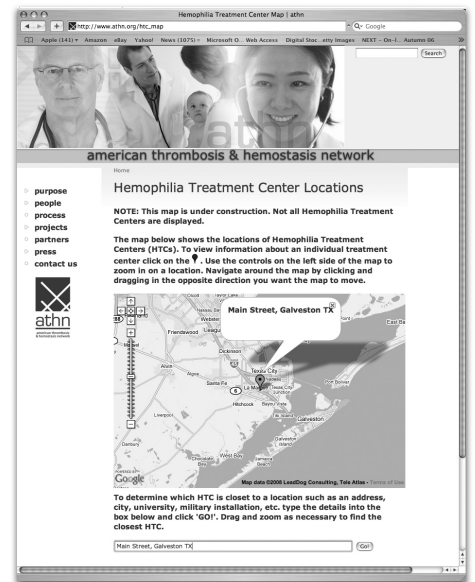
ATHN is working in partnership with HTCs to apply lessons learned from past disasters, such as Hurricanes Katrina and Rita. With advice from NHF and members of the ATHN Community Liaison Group, including Ray Stanhope, Chair of the Board of Directors, NHF; and the Hemophilia Federation of America (HFA) President, Chad Stevens; members of the Committee of Ten Thousand (COTT), the National Alliance for Thrombosis and Thrombophilia (NATT) and others; ATHNready will ensure that medical information is safe and available where and when we might need it most. A pilot program is underway.

## With ATHNready and through HTCs, patients will be able to:

- Get their core health information on a wallet sized flash drive, something that can be with them at all times and used wherever they are and whenever they need it.
- Enjoy comfort and peace of mind knowing that their core health information is secure, backed-up regularly and available when they need it.
- Be protected by a virtual safety deposit box with electronic health information so that appropriate care can be provided in a timely manner.



In conjunction with the Centers for Disease Control and Prevention, ATHN has mapped the location of all HTCs around the country in an interactive format available on the ATHN web site [www.athn.org](http://www.athn.org). Patients displaced by a disaster or moving to another location can quickly and easily identify a comprehensive HTC anywhere in the U.S.



## ATHN's Partnership with HTCs

HTCs across the country are signing up to be a part of ATHN. This means they are part of a special group of centers across the country, called ATHN Affiliates. These centers are committed to improving the care of people with bleeding and clotting disorders. Working with ATHN, these centers are collecting, storing and managing patient health data through a secure national database that follows all privacy guidelines. From this database, a smaller, subset of non-identifiable patient health data will be used for research purposes and to aid in policy decision-making. This subset of data is called the ATHNdataset. In the ATHNdataset, information that can identify an individual is stripped away, of course, and replaced with a unique identifier. Doctors, scientists, policy ►

makers and other health care providers will use the information in this dataset to help them better understand bleeding and clotting disorders. The goal is to have health information on every person diagnosed with a bleeding disorder in the United States. The data will be used for the common good and improve the lives of all those managing bleeding/thrombosis disorders.

The system used by ATHN Affiliates will also make it possible for HTC's to back up patients' medical information automatically. Up-to-date data will be available to support patient care and treatment wherever a patient is and whenever he or she needs it in the event of an emergency or disaster.

Through the ATHN dataset, each patient's health information will be combined with data from other patients around the country to help ensure that health care decisions and policies are based on complete, standardized information, as opposed to pieces of data that must be put together. This will lead to:

- A better understanding of the issues affecting the health of people with bleeding and clotting disorders,
- Increased knowledge of the genetics and natural history of these disorders,
- The ability to study clinical outcomes of persons with bleeding and clotting disorders and develop standards of care,
- A close watch on FDA approved therapies, and
- Increased support and community education.

More and more HTC's recognize that the ATHN Affiliate program is an initiative whose time is now. To date, over 80 HTC's have become ATHN Affiliates – more than double the number of

those signed on just a few brief months ago. The strength of ATHN Affiliate HTC's is not merely in the growing numbers, it's in the breadth and depth of the experience, expertise and data collection the Affiliates bring in support of ATHN's mission – to advance and improve the care of individuals affected by bleeding and thrombotic disorders.

Now is an ideal time to think about and begin to develop personal and family emergency plans. The ATHNready program can be part of your plan and will help to ensure you have all your medical information ready – where and when you need it.

## About ATHN



ATHN is a non-profit corporation founded in July 2006 in response to the following nationally identified needs related to bleeding and clotting disorders:

- Research that links medical interventions with clinical outcomes;
- Evidence-based clinical standards;
- Standardization and an improved means of collaboration with one national database; and
- Conservation and consolidation of scarce resources.

ATHN carries out its vision by providing stewardship of a secure national database that can be used to support clinical outcomes analysis, research, advocacy and public health reporting in the hemostasis and thrombosis community. ATHN's values – improving clinical outcomes and care, facilitating continuity of care, fostering collaboration, maintaining confidentiality and conserving resources through a common infrastructure – guide database development.

**To learn more about ATHN and ATHN Affiliate HTC's visit [www.athn.org](http://www.athn.org). Ask your HTC how to be prepared.**

## About the Author

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