



ATHN Community Liaison Group Fact Sheet

**The ATHN Community Liaison Group...
a vehicle for advice and a conduit for
communication.**

What are the purposes of this group?

The purpose of the ATHN Community Liaison Group is to:

- To bring together an advisory group of the various not-for-profit groups in support of a community-wide resource,
- To enable two-way communication between the ATHN Board of Directors and numerous community stakeholders on project direction, status, progress, issues and challenges,
- To facilitate alignment with broader community needs and
- To formally identify representatives responsible for being a conduit for communication with parent organizations.

What is the history of this group?

ATHN's mission is to provide stewardship of a secure national database, adherent to all privacy guidelines, which will be used to support clinical outcomes analysis, research, advocacy and public health reporting in the hemostasis and thrombosis community. In a joint effort with the Centers for Disease Control and Prevention (CDC), Division of Blood Disorders, ATHN is creating a formal coalition with the 134 federally funded Hemophilia Treatment Centers (HTCs)

and other providers of care to individuals with bleeding and clotting disorders across the U.S. To attain its vision, ATHN seeks to foster collaboration in the community. During the planning meetings prior to the incorporation of ATHN in early 2006, creation of a Community Liaison Group with representation of key organizations was envisioned. Toward that end, ATHN seeks formal input from and collaboration with non-profit organizations in the community representing patients and providers as well as government agencies through its Community Liaison Group.

Which organizations have been invited as active participants?

Not for profit organizations representing national consumer networks, professional groups and government entities have been invited to collaborate with ATHN and provide input into the work of ATHN.

- National Hemophilia Foundation (NHF),
- Hemophilia Federation of America (HFA),
- Committee of Ten Thousand (COTT),
- National Alliance for Thrombosis and Thrombophilia (NATT),
- Hemophilia and Thrombosis Research Society (HTRS),
- NHF's Medical and Scientific Advisory Committee (MASAC),
- NATT's Medical and Scientific Advisory Board (MASAB),
- Vascular Disease Foundation (VDF),
- Venous Disease Coalition (VDC),
- Anti-coagulation Forum,

- World Federation of Hemophilia (WFH),
- HRSA Maternal and Child Health Bureau (MCHB),
- U.S. Food and Drug Administration (FDA),
- National Heart Lung and Blood Institute (NHLBI)

Collaborating organizations have been asked to appoint a representative.

Will other organizations be invited to participate actively or as observers?

We envision the ATHN Community Liaison Group as an ever-evolving entity that reflects ATHN's growth and direction as well as the natural evolution of the community. This list of invited organizations by no means precludes other non-profit organizations from becoming involved. From time to time, other constituencies, including pharmaceutical or other industries, may be invited to provide information, advice or input for consideration by this group, or as observers to the deliberations of this group.

Who will Chair this meeting?

The Co-Chair of the ATHN Board of Directors will chair the meeting.

What do we want to accomplish during the first meeting?

During this inaugural meeting of the Community Liaison Group, ATHN hopes to celebrate its successes to date and to create a shared perspective about:

- What the community stands to gain by collaborating with ATHN;
- When key milestones can be realistically achieved;
- How data privacy, security, and access will be implemented;
- How ATHN can best engage and bring value to patients and families;
- What uniquely collaborative research agenda ATHN should pursue.

How will participants offer input to ATHN during the meeting?

The meeting is designed to provide ample opportunity for input and discussion. First, each

organization will be provided 7-10 minutes to share with the group: how your organization hopes to benefit; what projects you would like to collaborate on; and what ATHN can do to address your hopes and expectations. Additionally, breakout sessions during the meeting will help stimulate discussion on key issues and facilitate structured feedback.

Where will the meeting be held?

This inaugural meeting will be held at

- The Carolina Inn
211 Pittsboro Street
Chapel Hill, North Carolina 27516
919-918-2721 (phone)
919-918-2795 (fax)
www.carolinainn.com

The Carolina Inn, first opened in 1924, provides gracious hospitality as one of the Historic Hotels of America and a National Trust Historic Preservation.

How will the costs of the meeting be covered?

Participating organizations will be expected to fund any hotel accommodations and travel expenses associated with the meeting. Lunch will be provided. If costs would preclude attendance, ATHN would, on an individual basis, consider offering assistance with travel and hotel costs.

Have a question?

For questions or support, about the meeting logistics, please contact::

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For other inquiries about ATHN, contact:

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