

ATHN DATA SUMMIT 2017

A Look to the Future

Ellis Neufeld, MD, PhD

Chair Elect, ATHN Board of Directors

Overview

- Board of Directors Considerations
- Network and Partnerships
- Positioned for Growth (new directions already in play)
- Ready for the Future (potential new avenues)

Considerations for ATHN Board of Directors

We think not only about the data and the projects, but about the organization and its financial stability

2 minutes of unofficial SWOT analysis

- ATHN Strengths
 - The Database, our Team, our Network (all of you), our ongoing partnerships and collaborations
- ATHN Weaknesses
 - Low overhead rate, high need for volunteer labor, ROI from clinical projects develops slowly
- ATHN Opportunities
 - Aiming for steady funding; aiming for nimble response to change; participating at the cutting edge of new developments (ATHN7 and ATHN8, others)
- ATHN Threats
 - Federal funding environment, time of great change in the field
 - As Master Yoda says: “Difficult to see- Always in motion is the **future**” (Sometimes this will be an opportunity- examples)

Direct and indirect costs (why they matter)

- Grants nearly always fund *projects*, not *infrastructure*.
- ATHN is constituted to support the community largely through data (hence this Data Summit)
- Data managers and site personnel (like you) are *direct costs*.
- Lights, electricity, hospital executives (like your speaker) are examples of *indirect costs*.
- If you or I or ATHN gets a new grant, the direct costs, no matter how many \$\$, don't pay to keep the lights on, they are spent on the project.
- Fortunately for us:
 - The CDC grant shows how a low-overhead project supports and expands ATHN's mission and yours together.
 - With diversified projects we can spread out the fixed overhead costs
 - Enlightened partners have greatly supported ATHN infrastructure
 - Novo Nordisk initially, Hemophilia Alliance, some partner centers (Indiana, HoG, Boston).

Our Network, our Partnerships

Teamwork, ATHN, and the Future

- We would not be able to carry out our mission without our ATHN Affiliates, government, industry, non-profit sponsors and community partners
- Our network is made up of accomplished, passionate professionals dedicated to answering difficult questions to improve care
- We are exploring **adding to our network, with non-federally funded HTC's and other organizations**

Answering the need, leading research

More and more,

- Researchers are collaborating and using **ATHN** data
- Funders are approaching us
- HTCs are eager to participate

ATHN: Positioned for growth

New directions upon which ATHN has embarked

Outcomes

New! ATHN Outcomes Committee

Chair, Mark Skinner

- Developing priorities for outcome measures and tools to be used in ATHN projects

Grant opportunities

- Exploring Patient Centered Outcomes Research Institute (PCORI) and other opportunities, in conjunction with partners

Population-Based Studies Leverage ATHN strengths

- **ATHN 7: Non-Factor Products Study**

An Observational Cohort Study of People with Hemophilia with and without Inhibitors Treated with Current Therapy or a Non-Factor Product: A Study of Safety, Effectiveness and Practice

- **ATHN 8: PUPs Study**

US Cohort Study of Previously Untreated Patients (PUPS) with Congenital Hemophilia

ATHN: Ready for the Future

Potential new avenues

On the Horizon

- International data harmonization
- von Willebrand disease
- Rare coagulation disorders
- Adverse event reporting
- Gene therapy
- Other opportunities?

Thank you

With you – the ATHN network – we can make all of this possible.

The future looks exciting!