

American Thrombosis and Hemostasis Network

An Update
August, 2007



Agenda

- What is ATHN?
- Where does ATHN fit in addressing data needs?
- How can we collaborate?

Vision

- ATHN's vision is to advance and improve the care of individuals affected by **bleeding and thrombotic disorders**

Mission

- ATHN provides 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.



ATHN Core Values

- Improve **clinical outcomes**
- Facilitate **continuity of care**
- Foster **collaboration**
- Maintain **confidentiality**
- **Conserve resources** through a common infrastructure

Convergence of Needs by HTC's

Knowledge that other countries (e.g., U.K., Sweden, Canada) have robust data sets

Recognition of Need for...

clinical outcomes data
evidence-based clinical standards
ONE national clinical database
consolidate/conserve resources

Adoption of Lab Tracker

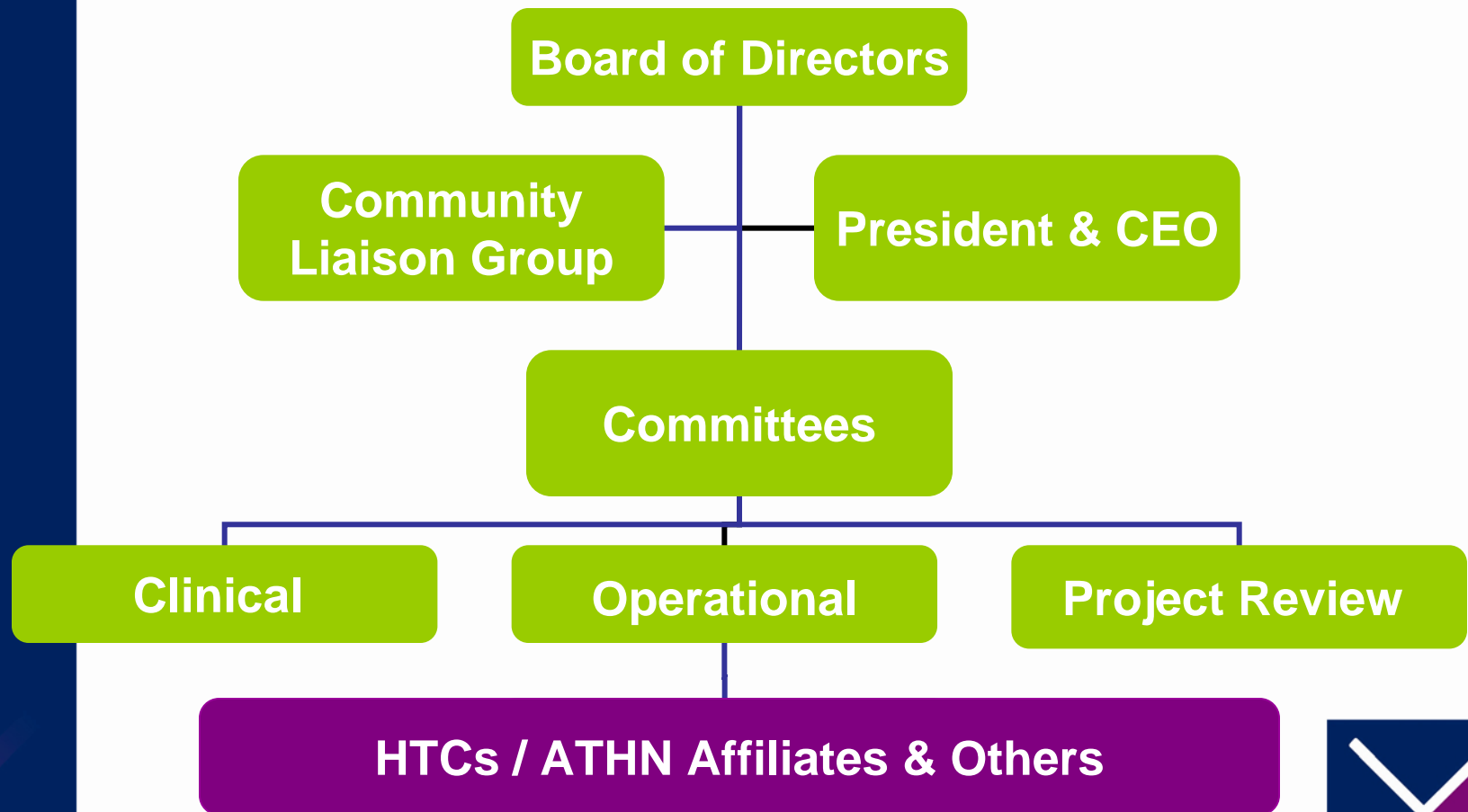
2000 development
2002 rollout
2003 UDC forms
2005 as national tool
2005-7 web version

Aligned With HHS Priorities



- Promote quality and efficient delivery of care through the use of health information technology, including data and messaging standards
 - PHIN, XML, HL7 V2.5
 - Standardized terminologies – SNOMED CT
- Supports emergency preparedness

ATHN Organizational Structure



Community-Based Leadership

The ATHN Board of Directors 2006-2007

- Amy Shapiro, MD
 - Co-chair
- Tom Abshire, MD
- Mary Lou Damiano
- Trish Dominic
- Wanda Foster
- Ann Forsberg
- Bob Fox
- Steve Humes
- Roshni Kulkarni, MD*
 - Ex Officio
- Jeanne Lusher, MD
 - Co-chair
- Robi Ingram-Rich
- Dana Matthews, MD
- Tom Ortel, MD, Ph.D.
- Claire Philip, MD
- Harold Roberts, MD
- Tami Wood-Lively
- Diane Aschman
 - President & CEO



ATHN Committees for 2007

Operational

- Organizational Admin
- Community Relations
- Board Development
- Project Development
- Budget & Finance
- By Laws
- Personnel

Clinical

- Privacy and Data Security
- Technological Development
- Project Review Panels
 - Experienced reviewers needed
 - Volunteer@athn.org



Community Liaison Group

- Consumer Organizations
 - NHF, HFA, COTT, NATT
- Provider based Organizations/Entities
 - HTRS, MASAC, WFH, MASAB,
 - Anticoagulation Forum, VDF, NAFT...
- Government Entities
 - CDC, MCHB, FDA, NHLBI

**Broad
Collaboration**

Key Milestones

January
2006

January
2007

January
2008

Operating
& clinical
planning
committees
develop
strategy

Interim
board
selected

ATHN
incorporated
as non-profit

President
& CEO
hired



Expanding
Operations &
Committees

CDC Grant
Application

Community
Liaison Group

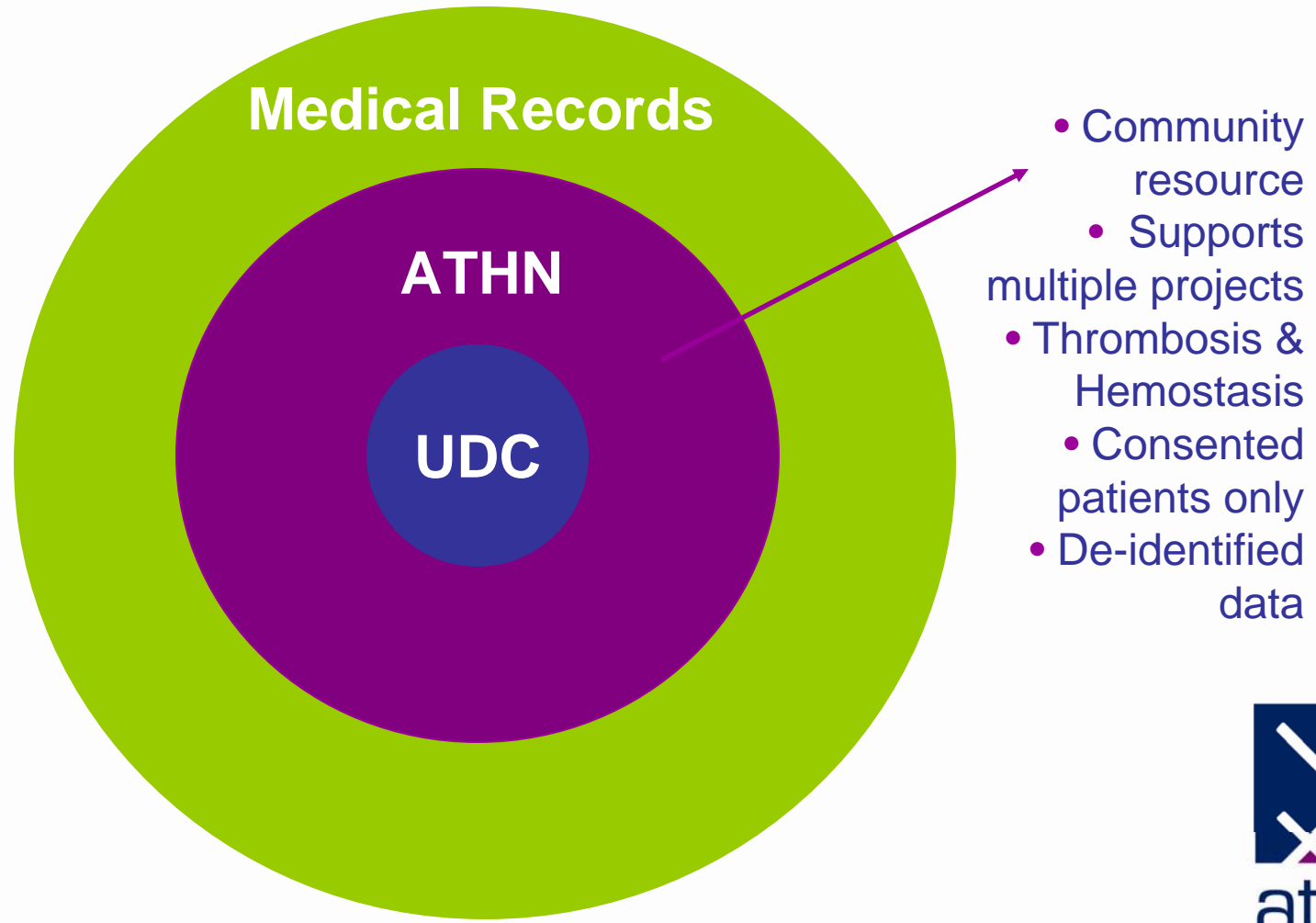
Lab Tracker
web alpha
test at HTC's

Board
Selection
(1/3 new)

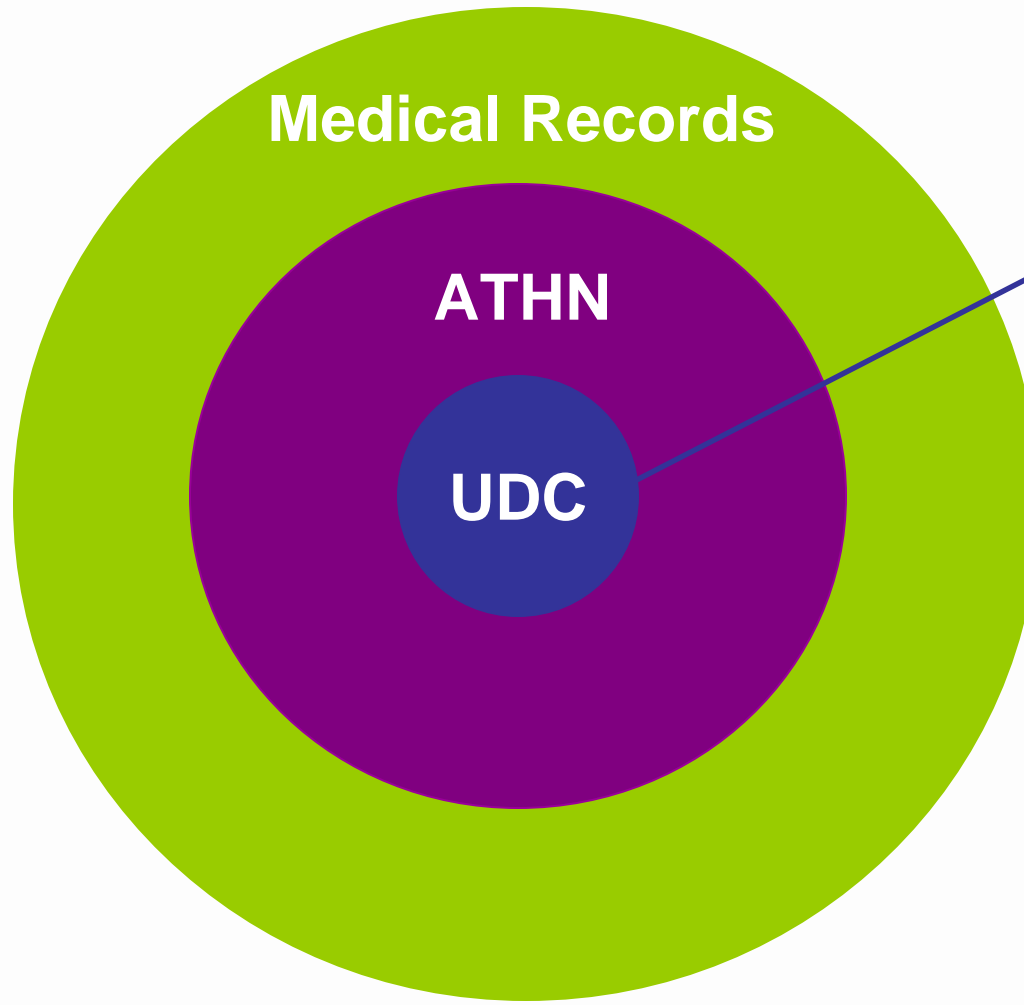


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american thrombosis
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Where Does ATHN Fit?



Where Does ATHN Fit?



- CDC surveillance initiative
- Validated study using Lab Tracker
- Consented patients only
- De-identified data

ATHN Data Elements (preliminary)

Hemophilia A/B, VWD, rare bleeding disorders, thrombophilia and platelet disorders

- Primary diagnosis (disorder, severity)
- Co-morbidities (HIV, hepatitis, joint)
- Family history
- Risk factors
- Diagnostic tests / Lab tests
- Treatment regimens (product, dose, reason)
- Presence of inhibitors
- Procedures / Surgeries
- Infusion / Bleed status
- Allergies
- Demographics / insurance / contact info

Data Capture

- Lab Tracker web used by HTC's
 - Standardized data elements
 - Secure data center, duplicated at second location
- Mechanisms to support local data managers
 - Avoid added burden on HTC's
 - HTC Survey
- Consolidated consent templates
 - Conform to IRB and Privacy Rules
 - Go forward and existing data

Coming
soon!

Data Flow From HTC to ATHN

Patient



HTC



HTC



Secure
Central
Server



De-identified
Consented
Limited
Dataset



Patient



HTC



Care Management
(virtual HTC safe deposit boxes
in a secure server vault)

Public Health
& Research
(includes ATHN)



Data Access by HTC's

- HTC's patient data available 24 X 7
- Multi-uses
 - Federal and state reporting (HDS, Title V)
 - Surveillance reporting (UDC, AEs)
 - Administrative (patient lists, labels)
 - Clinical (referral letters, care plans)
 - Patients (emergency preparedness)
 - Grant writing (practice statistics)
 - Research (patient recruitment)
- Electronic output

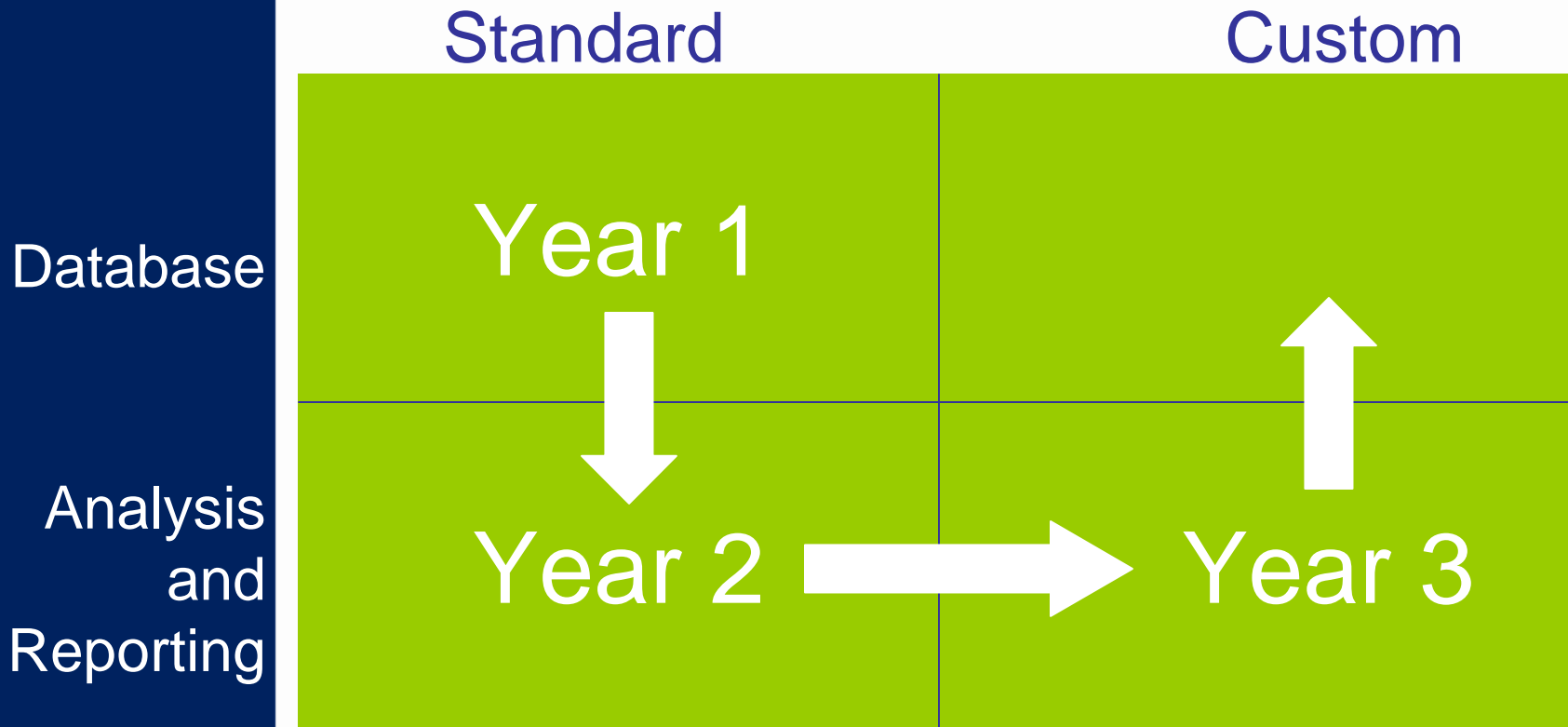
Data Access by ATHN

- Open and transparent process
- Availability to advance a wide range of issues
 - Patient Care & Safety
 - Epidemiology
 - Clinical
 - Advocacy
 - Economic
- Third parties can fund projects
- No one has preferential access

ATHN Project Priorities

- Infrastructure building projects
- Rare bleeding disorder projects
- Thrombosis
- Outcomes projects (with MASAC)
- Investigator-initiated clinical research (with HTRS)
- Nursing, social work, PT projects
- Government opportunities
- Aggregate data for the community

Getting to the Vision Takes Time



What's in It for the HTC?



- Access to outcomes research data and cooperative studies
- Data manager personnel and support
- Improved patient care and treatment from data (Without data there can be no guidelines)

Why Patients Will Participate?



- Help advance the science and practice of care for better outcomes
- Help assess high cost but effective, necessary and expected therapies and regimens, thus preserving access to quality care
- Leave a legacy

ATHN Support: National Groups

ATHN	National
Secure infrastructure	Emergency preparedness
Patient clinical characteristics	Patient recruitment / site selection for treatment studies
Evidence of clinical practices and outcomes	Recommendations of best practices/standards
Data on treatment economics and QOL	Fact-based advocacy and public health promotion

Summary

- ATHN adds capacity
- Voluntary process yields center buy-in
- Outcomes and insights generated can help improve patient care
- Aligned with Executive orders for standardization and quality

- www.athn.org

