The American Thrombosis and Hemostasis Network

Peer-Reviewed Works

The American Thrombosis and Hemostasis Network (ATHN) proudly presents a listing of peer-reviewed works. These would not be possible were it not for the dedication of ATHN Affiliates, scientific investigators and program sponsors.
Peer-reviewed publications

► National Needs Assessment of Patients Treated at the United States Federally Funded Hemophilia Treatment Centers
Authors: Butler RB, Cheadle A, Aschman DJ, Riske B, Senter S, McLaughlin K, Young G, Ahuja S and Forsberg A
*Haemophilia, accepted for publication.*

► Hemophilia and Von Willebrand Disease Patients’ Perceptions of Care at US Hemophilia Treatment Centers
Authors: Aschman DJ on behalf of the NHPCC Needs Assessment Working Group, Shapiro AD, Butler RD, Sharathkumar A, Skinner M and Forsberg A

► The ATHNdataset: A Community Resource for Outcomes Analysis, Public Health Surveillance and Research
Authors: Konkle B, Abshire T and Aschman D on behalf of the American Thrombosis and Hemostasis Network Affiliates
*American Journal of Hematology (2012), 87 (Suppl.1), pg. S159-60. Based upon presentation poster at Thrombosis and Hemostasis Summit of North America Scientific Meeting, Chicago IL, April 29, 2012.*

► The ATHNdataset: A U.S.-Based Dataset for Outcomes Analysis, Public Health Surveillance and Research
Authors: Konkle B, Abshire T and Aschman D on behalf of the American Thrombosis and Hemostasis Network Affiliates
*Haemophilia (2012), 18 (Suppl.1), pg. 27. Based upon presentation poster at the 5th Annual Congress of the European Association of Haemophilia and Allied Disorders, Rome, Italy, February 22-24, 2012.*

► Establishing Community-Based Partnerships to Create a Standards-Based Information Infrastructure
Authors: Aschman DJ, Abshire TC, Shapiro AD, Lusher JM, Forsberg AD and Kulkarni R

► Knowledge and Therapeutic Gaps: A Major Public Health Problem Highlighted in the Rare Coagulation Disorders
Authors: Shapiro A, Soucie JM, Peyvandi, F, Aschman DJ, DiMichele DM on behalf of the UDC Rare Bleeding and Clotting Disorders Working Group and the European Network of Rare Bleeding Disorders Database
Peer-reviewed poster presentations

**Lessons Learned from the Development of an Educational Curriculum for Potential and Confirmed Female Carriers of Hemophilia**
Authors: R. Butler, RN; M. Alabek, CGC; D. Deery, JD; MLURP; K. Miller, RN; S. Cutter, LCSW, MFA
National Society of Genetic Counselors, 34th National Education Conference, Pittsburgh, PA, October 23, 2015. (Project of National Significance funded by the NHPCC through HRSA grant #UC8MC24079)

**My Life, Our Future: A “Genotyping Day” to Facilitate Efficient Enrollment**
Authors: Smith J, Hatcher N, Patterson F, Ruthruien M, and Balasa V
National Hemophilia Foundation 67th Annual Meeting, Dallas, TX, August 13-15, 2015. (Collaborating investigator team in My Life, Our Future)

**U.S. Surveillance of Prophylaxis Use Among Persons with Hemophilia A Receiving Care at Hemophilia Treatment Centers (HTCs)**
Authors: Manco-Johnson M, Byams V, Cooke B, Recht M, Aschman D, Byams V, Cooke B and Oakley M

**Hemophilia Genotyping Results from the My Life, Our Future Project**

**A Cross-Sectional Analysis of Cardiovascular Disease in the Hemophilia Population**

**My Life, Our Future: A Multi-Sector Collaboration to Provide Genotyping Services and a Research Repository for the Hemophilia Community Expands from Pilot to National Program**

**A Cross-Sectional Analysis of Cardiovascular Disease in the Hemophilia Population**

**Community Counts: Preliminary Report of a National Surveillance System for Bleeding and Clotting Disorders**
Authors: Manco-Johnson M, Dudley B, Oakley M, Recht M, Kapica S, Presley RJ, Byams V, Cooke B and Aschman DJ
Thrombosis and Hemostasis Summit of North America Scientific Meeting, Chicago, IL, April 10-12, 2014.

**Hemophilia Genotyping Results from the My Life, Our Future Project**
Authors: Konkle BA, Tarantino M, Eyster E, Pipe S, Ruuska S, Shendure J, Johnsen J, McAlister S, Bias V, Pierce GF and Aschman D
Thrombosis and Hemostasis Summit of North America Scientific Meeting, Chicago, IL, April 10-12, 2014.

**My Life, Our Future: A Multi-Sector Partnership to Generate Genotype and Research Data Within the Hemophilia Community**
Authors: Kueebaugh K, Koerper M, Frick N, McAlister S and Aschman D

**Utilizing National Electronic Data Infrastructure to Longitudinally Follow the United States (US) Bleeding Disorders Population**
Authors: Manco-Johnson M, Dudley B, Oakley M, Recht M, Kapica S, Byams V, Cooke B and Aschman DJ

**Survey of the Support Needs of the HTC Staff by National Hemophilia Program Coordinating Center**
Authors: Forsberg A, Butler B, McLaughlin K, Baker J, Oldfield D and Aschman D

**Community Counts: A US National Surveillance System for Bleeding and Clotting Disorders**
Authors: Manco-Johnson M, Dudley B, Oakley M, Recht M, Kapica S, Presley RJ, Byams V, Cooke B and Aschman DJ

**The ATHNdataset: A Growing Resource for Outcomes Analysis**
Authors: Konkle B, Neufeld E, and Aschman D on behalf of the American Thrombosis and Hemostasis Network Affiliates
Hemostasis and Thrombosis Research Society, Chicago, IL, June 14, 2013.

**My Life, Our Future: A Multi-Sector Collaboration to Provide Genotyping Services and a Research Repository for the Hemophilia Community**
Authors: Konkle B, Aschman DJ, Bias V and Pierce G

**The ATHNdataset: A Collaborative Effort to Build a National Standardized Data Source from Within the Hemostasis and Thrombosis Community**
Authors: Konkle B, Abshire T and Aschman D on behalf of the American Thrombosis and Hemostasis Network Affiliates

**ATHN Advoy: A Collaborative and Community-Driven Approach for Innovation in Electronic Bleed and Infusion Logging Technology**
Authors: Watson C and Kueebaugh K with ATHN Advoy Beta-Testers

**A Standards-Based Information Infrastructure for Rare Bleeding and Clotting Disorders**
Authors: Forsberg A, Parker LH, Thomas J and Aschman DJ on behalf of ATHN

**Adopting a Standards-Based Information Infrastructure for Rare Disorder Communities**
Authors: Baker JR and Aschman DJ on behalf of ATHN

**American Thrombosis and Hemostasis Network: Expanding Capacity for Electronic Data Management**
Author: Aschman DJ
World Federation of Hemophilia, Istanbul, Turkey, June 1-5, 2006
Peer-reviewed national and international oral presentations

► A Cross-Sectional Analysis of Cardiovascular Disease in the Hemophilia Population

► Causes of Death Among Patients with Bleeding Disorders Receiving Care at US Hemophilia Treatment Centers, October 2011-December 2014
Authors: Oakley M, Manco-Johnson M, Dupervil B, Dudley R, Recht M, Voutsis M, Byams V and Aschman DJ
American Public Health Association Annual Meeting, Chicago, IL, October 31–November 4, 2015

► My Life, Our Future, Genotyping for Progress in Hemophilia
Author: Konkle BA
Food and Drug Administration Workshop: New Methods to Predict Immunogenicity of Therapeutic Coagulation Proteins, Bethesda, MD, September 17-18, 2015.

► CDC’s Surveillance Programs in Hemophilia
Authors: Soucie M, Pyle M, Byams V and Dudley B

► ATHN Research 2015 and Beyond: A Briefing for the Patient Community
Authors: Pipe S, Forsberg A and Aschman DJ

► Technical Needs Assessment of US HTC Staff
Author: Forsberg A

► Technical Assistance Priorities: Findings from a National Survey of Federally Funded Hemophilia Treatment Centers in the United States
Author: Forsberg A

► ATHN Research: A Brief for the Patient Community
Authors: Pipe S, Forsberg A and Aschman DJ

► Patients’ Perceptions of Care at the US Federally Funded Hemophilia Treatment Centers
Authors: Forsberg A, Butler RB, Cutter S, Curtis R, Shapiro AD, Sharathkumar A and Aschman DJ

► MCHB-Funded Hemophilia Network and the Creation of ATHN: Information Infrastructure to Improve Emergency and Disaster Preparedness
Author: Aschman, DJ

► F8 and F9 Gene Variants, CADD Scores and Hemophilia Severity in the My Life, Our Future Genotyping Project
Authors: Johnsen J, Fletcher SN, Huston H, Kircher M, Aschman DJ, Bias V, McAlister S, Shendure J and Konkle B
Federal research support

ONGOING:

- **Genetic Modulation of Inhibitor Risk in Hemophilia**
  The National Institutes of Health, National Heart Lung and Blood Institute (NHLBI) has approved to sequence approximately 2188 samples collected through the My Life, Our Future project (Konkle B – PI); samples held by Bloodworks Northwest for My Life, Our Future have been prioritized for sequencing through the NHLBI TOPMed (Trans-Omics for Precision Medicine) program.
  *Initial award: October 2015 through NHLBI Whole Genome Sequencing RFIs (HL-15-253)*

- **Public Health Surveillance for the Prevention of Complications of Bleeding and Clotting Disorders (Community Counts)**
  The Centers for Disease Control and Prevention (CDC) funded ATHN in this cooperative agreement in collaboration with the federally funded hemophilia regions and over 135 hemophilia treatment centers. Manco-Johnson M serves as Scientific PI; Dudley B as Project Director. ATHN Study Manager is used as the electronic infrastructure for Community Counts.
  *Initial award: September 30, 2011 to September 30, 2015 (#1U27DD000862)*
  *Re-competed and awarded: September 30, 2015 to September 29, 2020 (#1NU27DD001155)*

- **Cross-Sectional Analysis of Cardiovascular Disease in the Hemophilia Population**
  The Centers for Disease Control and Prevention (CDC) funded ATHN, with Konkle BA and Aschman DJ as Co-PIs of this cooperative agreement involving collaboration with 19 federally funded hemophilia treatment centers. ATHN Study Manager is used as the electronic infrastructure.
  *Initial award: September 30, 2011 to September 30, 2015 (#1U01DD000761)*

- **National Hemophilia Program Coordinating Center (NHPCC)**
  The NHPCC brings together patients, providers and government entities to improve access and quality of care for patients with hemophilia and other bleeding disorders. Regions are funded separately from the coordinating center. Shapiro AD serves as Medical Director for the NHPCC; Forsberg A as Project Director.
  *Initial award: June 1, 2012 to May 31, 2015 (#UC8MC24079)*
  *Re-competed and awarded: June 1, 2015 to May 31, 2018 (#UC8MC24079-04)*

COMPLETED:

- **American Thrombosis and Hemostasis Network (ATHN): Hemophilia Treatment Center Patient Data Collection Infrastructure and Disaster Preparedness**
  ATHN was the award recipient, working in collaboration with the 12 federally funded hemophilia regions, consumer organizations and treatment center providers. ATHN Ready is a product of this award. The ATHN Ready report is produced using ATHN Clinical Manager.
  *Initial award: June 30, 2007 to December 29, 2009 (#U27DD000319)*