The American Thrombosis and Hemostasis Network

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

- **Impact of the 340B Pharmacy Program on Services and Supports for Persons Served by Hemophilia Treatment Centers in the United States**
  Authors: Malouin R, McKernan L, Forsberg A, Cheng D, Drake J, McLaughlin K, Trujillo M

- **A cross-sectional analysis of cardiovascular disease in the hemophilia population**

- **Genotypes, phenotypes and whole genome sequence: Approaches from the My Life, Our Future haemophilia project**
  Authors: Konkle B, Johnsen JM, Wheeler M, Watson C, Skinner M, Pierce GF
  *Haemophilia* 2018 May;24(56): 87-94.

- **Transition of care for patients with venous thromboembolism: Rationale, design and implementation of a quality intervention project conducted at American Thrombosis and Hemostasis Network (ATHN) affiliated sites**
  Authors: Jaffray J, Rajpurkar M, Sharathkumar A, Patel K, Munn J, Cheng D, McCarthy E, DeSancho M
  *Thrombosis Research* 2018 February;163: 146-152.

- **Novel approach to genetic analysis and results in 3000 hemophilia patients enrolled in the My Life, Our Future initiative**
  Authors: Johnsen JM, Fletcher SN, Huston H, Roberge S, Martin BK, Kircher M, Josephson NC, Shendure J, Ruuska S, Koerper MA, Morales J, Pierce G, Aschman DJ, Konkle B

- **Radionuclide Synovectomy/Synoviorthesis (RS) in Persons with Bleeding Disorders: A Review of Impact of National Guidance on Frequency of RS using the ATHNdataset**


- **Genetic Analysis of Bleeding Disorders**
  Authors: Edison E, Konkle BA, Goodeve AC
  *Haemophilia* 2016, 22 (Supp.5), pg. 79.

- **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* 2015 1-7 DOI:10:111/hae.12810.

- **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
Peer-reviewed poster presentations

- **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
  *American Journal of Preventive Medicine* 2011 December; (Suppl.4), pg. 332-337.

- **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

- **Transition of Care for Adult Patients with Venous Thromboembolism**
  ATHN Data Summit 2018, October 25-26, 2018, Chicago, IL.

- **Opioid Use in Hemophilia Is Under-Reported in the ATHNdataset: A Call to Action**
  Authors: Peltier SJ, Mazepa MA, Nelson SF, Cheng D, Reding MT
  ATHN Data Summit 2018, October 25-26, 2018, Chicago, IL.

- **The Effect of Socioeconomic Status and Urbanization on Rates of Self-Infusion and Bleed Rate in Adolescents with Severe Hemophilia**
  Authors: Agnew C, Apollonsky N, Cheng D
  ATHN Data Summit 2018, October 25-26, 2018, Chicago, IL.

- **First Look at My Life, Our Future Carrier Data from a Pilot Site**
  Authors: Puetz J, Johnson L, Hugge C, Buchanan P
  *The International Society on Thrombosis and Haemostasis (ISTH) 64th Annual Scientific and Standardization Committee (SSC) meeting*, July 18-21, 2018, Dublin, Ireland.

- **Extended half-life factor concentrate use for patients with moderate and severe hemophilia among U.S. HTCs**
  *The International Society on Thrombosis and Haemostasis (ISTH) 64th Annual Scientific and Standardization Committee (SSC) meeting*, July 18-21, 2018, Dublin, Ireland.

- **A Survey of F8 and F9 Variants in My Life, Our Future for Evidence of Alternative Splicing in Hemophilia**
Analysis of F8 And F9 Variants in the First 3000 Hemophilia A and B Patients in the My Life, Our Future (MLOF) Project
Authors: Konkle B, Johnsen JM, Ruuska S, Koerper MA, McAllister S, Aschman DJ
Thrombosis and Hemostasis Societies of North America (THSNA) Summit, April 14-16, 2016, Chicago, IL

A “Genotyping Day” to Facilitate Efficient Enrollment for a National Project
Authors: Smith J, Hatcher N, Patterson F, Martinez R, Balasa V
American Thrombosis and Hemostasis Network (ATHN) Data Summit, October 6-7, 2016, Chicago, IL

A Real-World Assessment of New Coagulation Factors through the American Thrombosis and Hemostasis Network (ATHN): ATHN 2: Factor Switching Study
Authors: Neufeld EJ, Journeycake JM, Aschman DJ, Cheng D, McCarthy EG, Watson CD and the ATHN 2 Steering Committee
HTRS 2017 Scientific Symposium, April 6-8, 2017, Scottsdale, AZ

Practice Characteristics of Genetic Counselors Serving the North American Bleeding Disorders Community
Authors: Malouin R, Bergstrom K, Heiman M, Paulyson Nunez K, Forsberg A and the NHPCGC Genetics Working Group

New Hemophilia Treatment Center Staff Orientation: A Standardized Approach
Authors: Droze K, Packman J, Forsberg A, Butler R, Tussing T

National Survey of the 340B Drug Pricing Program: Quantitative Evaluation of the Services Provided by the U.S. Hemophilia Treatment Centers
Authors: Trujillo M, Forsberg AD, Drake J, Cheng D, McLaughlin K, McKernan L

A Cross-Sectional Study of Females with Congenital Bleeding Disorders Enrolled in the ATHN dataset
Authors: Haley K, Sidonio R, Cheng D, Shapiro A, Manco-Johnson M, Aschman D, Recht M

Genetic Variant Analysis in Children and Adults with Hemophilia: Experience from a Large Hemophilia Center in the US
Authors: Lemons J, Escobar M, Cantini M, Cannon K, Brown D, Nguyen T and Rodriguez N, The University of Texas Health Science Center at Houston, Houston, TX, USA

A “Genotyping Day” to Facilitate Efficient Enrollment for a National Project
Authors: Smith J, Hatcher N, Martinez R, Balasa V, Hemophilia Treatment Center, Valley Children’s Hospital, Madera, California

Joint Outcomes in United States (U.S.) Hemophilia Patients: A Report of the Community Counts Registry

Radionuclide Synovectomy/Synoviorthesis (RS) in Patients with Bleeding Disorders: A Review of Demographics and Procedure-Related Outcomes from the ATHN dataset
Thrombosis and Hemostasis Societies of North America, Chicago, IL April 14-16, 2016.

Radionuclide Synovectomy/Synoviorthesis in Patients with Bleeding Disorders: A Review of Malignancy and Myeloproliferative Neoplasms from the ATHN dataset
Thrombosis and Hemostasis Societies of North America, Chicago, IL April 14-16, 2016.

Radionuclide Synovectomy/Synoviorthesis (RS) in Patients with Bleeding Disorders: A Review of Effect of Seminal Publications on Frequency of RS using the ATHN dataset
Authors: Haley K, Sidonio R, Cheng D, Shapiro A, Manco-Johnson M, Aschman D, Recht M
Thrombosis and Hemostasis Societies of North America, Chicago, IL April 14-16, 2016.
Lessons Learned from the Development of an Educational Curriculum for Potential and Confirmed Female Carriers of Hemophilia
Author: Butler R, Alabek M, Deeny D, Miller K, Cutter S
National Society of Genetic Counselors 34rd 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, Ruthrofen 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, Dudley B, Voutsis M and Oakley M
International Society of Thrombosis and Haemostasis (ISTH) 2015 Congress, Toronto, Canada, June 23, 2015. (Award winning!)

Expanding Telemedicine to Medical Homes for Comprehensive Care Delivery for Persons with Hemostatic Disorders: A Pilot Study of the American Thrombosis and Hemostasis Network (ATHN)/National Hemophilia Program Coordinating Center (NHPCC)
International Society of Thrombosis and Haemostasis (ISTH) 2015 Congress, Toronto, Canada, June 23, 2015. (Project of National Significance funded by the NHPCC through HRSA grant #UC8MC24079)

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

Hemophilia Genotyping Results from the My Life, Our Future Project

Technical Assistance Needs to Support Care Delivery for Patients with Bleeding Disorders: Findings from a National Survey of Hemophilia Treatment Centers
Authors: Bellinger JD, Iyer MR, Martin A, Aschman DJ and Forsberg A
Academy Health, 2014.

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

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

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: An Update
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: Keebaugh K, Koerper M, Frick N, McAlister S and Aschman DJ
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

The ATHN dataset: 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 ATHN dataset: 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 Keebaugh 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.
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 RFI (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 29, 2015 (#1U27DD000862)
Re-competed and awarded for Project Period: September 30, 2015 to September 29, 2020 (#1NU27DD001155)

► 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, 2017 (#UC8MC24079-04)
Re-competed and award for Project Period: June 1, 2017 to May 31, 2022 (#UC8MC24079-06)

Completed:

► 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)

► 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)
As always, ATHN gratefully acknowledges the Industry Consortium and our Community Partners for their support.

Thank you to the ATHN Industry Consortium:

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Thank you to our Community Partners:

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Hemophilia Alliance

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BloodCenter of Wisconsin
Indiana Hemophilia & Thrombosis Center, Inc.

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67 Red Rock Circle, Rochester, NY 14626
www.athn.org