

PEER-REVIEWED WORKS 2018

ATHN

NHPCC

COMMUNITY COUNTS

MLOF

ATHN 1

ATHN 2

ATHN 3

ATHN 4

The American Thrombosis & 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

Maternal and Child Health Journal 2018 September;22(9): 1240-1246.

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

Authors: Sood S, Cheng D, Ragni M, Kessler C, Quon D, Shapiro A, Key N, Manco-Johnson M, Cuker A, Kempton C, Wang TF, Eyster ME, Kuriakose P, von Drygalski A, Cox Gill J, Wheeler A, Kouides P, Escobar M, Leissing C, Galdzicka S, Corson M, Watson C, and Konkle B

Blood Advances 2018 June;2(11): 1325-1333.

► **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

Blood Advances 2017 May;1(13):824-834.

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

Authors: Sharma R, Dunn A, Aschman D, Cheng D, Wheeler A, Soni A, McGuinn C, Knoll C, Stein DT, Young G, French J, Sanders J, Davis JA, Tarantino M, Lim M, Gruppo R, Sidonio R, Ahuja S, Carpenter S, Pipe S, Shapiro A

Haemophilia. 2017 Jul; 23(4):e385-e388. Epub 2017 May 24.

► **Radionuclide synovectomy/synoviorthesis (RS) in patients with bleeding disorders: A review of patient and procedure demographics and functional outcomes in the ATHNdataset.**

Authors: McGuinn C, Cheng D, Aschman D, Carpenter SL, Sidonio R, Soni A, Tarantino MD, Wheeler AP, Dunn AL, ATHN 3 Working Group.

Haemophilia. 2017 Aug 24. doi: 10.1111/hae.13318. [Epub ahead of print]

► **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:10.1111/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

Haemophilia 2014, 2 (Suppl.2), pg. 13. Based upon presentation at the 7th Annual Congress of the European Association of Haemophilia and Allied Disorders, Brussels, Belgium, February 26-28, 2014.

► **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

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

American Journal of Preventive Medicine 2011 December; (Suppl.4), pg. S324-331.

Peer-reviewed poster presentations

► **Transition of Care for Adult Patients with Venous Thromboembolism**

Authors: DeSancho M, Malone M, Holmes C, Billett H, Wang TF, Cheng D, McCarthy E, Watson C, Rajpurkar M

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. HTC**

Authors: Croteau SE, Cheng D, Cohen AJ, Holmes CE, Kouides P, Raffini LJ, Silvey M, Thornburg C, Wheeler AP, Neufeld EJ

The International Society on Thrombosis and Haemostasis (ISTH) 64th Annual Scientific and Standardization Committee (SSC) meeting, July 18-21, 2018, Dublin, Ireland

► **Inpatient to Outpatient Transition of Care for Pediatric Patients with Venous Thromboembolism**

Authors: Munn J, Rajpurkar M, Patel K, Journeycake J, Sharathkumar A, Wang M, Watson C, Cheng D, DeSancho M, Jaffray J

The International Society on Thrombosis and Haemostasis (ISTH) 64th Annual Scientific and Standardization Committee (SSC) meeting, July 18-21, 2018, Dublin, Ireland

► **Transition of Care for Patients with Venous Thromboembolism: A Quality Improvement Project with the American Thrombosis and Hemostasis Network**

Authors: Malone M, DeSancho M, Munn JE, Jaffray J, Cheng D, Watson C, Rajpurkar M

Thrombosis & Hemostasis Societies of North America (THSNA), March 8-10, 2018, San Diego, CA

► **Chronic Kidney Disease in the U.S. Hemophilia Population: A Cohort Study**

Authors: Sood S, Cheng D, Shapiro A, Kessler C, Key N, Quon D, Eyster ME, Manco-Johnson M, Kempton C, Cuker A, Ragni M, Gill JC, Kuriakose P, von Drygalski A, Kouides P, Escobar MA, Paroskie A, Wang TF, Leissing C, Galdzicka S, Konkle B

American Society of Hematology (ASH) 59th Annual Meeting, December 9-12, 2017, Atlanta, GA

► **A Survey of F8 and F9 Variants in My Life, Our Future for Evidence of Alternative Splicing in Hemophilia**

Authors: Johnsen JM, Kircher M, Fletcher SN, Huston H, Lannert K, Roberge S, Martin BK, Josephson NC, Shendure J, Ruuska S, Koerper MA, Morales J, Pierce G, Aschman DJ, Konkle B

International Society on Thrombosis and Hemostasis (ISTH) Congress, July 8-13, 2017, Berlin, Germany

► **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 NHPCC Genetics Working Group

World Federation of Hemophilia, Orlando, FL, July 24-28, 2016.

► **New Hemophilia Treatment Center Staff Orientation: A Standardized Approach**

Authors: Droze K, Packman J, Forsberg A, Butler R, Tussing T

World Federation of Hemophilia, Orlando, FL, July 24-28, 2016.

► **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

World Federation of Hemophilia, Orlando, FL, July 24-28, 2016.

► **A Cross-Sectional Study of Females with Congenital Bleeding Disorders Enrolled in the ATHNdataset**

Authors: Haley K, Sidonio R, Cheng D, Shapiro A, Manco-Johnson M, Aschman D, Recht M

World Federation of Hemophilia, Orlando, FL, July 24-28, 2016.

► **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

World Federation of Hemophilia, Orlando, FL, July 24-28, 2016.

► **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

World Federation of Hemophilia, Orlando, FL, July 24-28, 2016.

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

Authors: Manco-Johnson M, Recht M, Kulkarni R, Dupervil B, Byams B, Dudley B, Aschman D, Voutsis M, Humes S, Oakley M

World Federation of Hemophilia, Orlando, FL, July 24-28, 2016.

► **Radionuclide Synovectomy/Synoviorthesis (RS) in Patients with Bleeding Disorders: A Review of Demographics and Procedure-Related Outcomes from the ATHNdataset**

Authors: Lim M, Aschman D, Ahuja S, Carpenter S, Cheng D, Davis JA, French J, Gruppo R, Knoll C, McGuinn C, Pipe S, Sanders J, Shapiro A, Sidonio R, Soni A, Stein DT, Tarantino MD, Wheeler A, Young G, Dunn A

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 ATHNdataset**

Authors: Sharma R, Dunn AL, Cheng D, Ahuja S, Aschman D, Carpenter S, Davis J, French J, Gruppo R, Knoll C, Lim M, McGuinn C, Pipe S, Sanders J, Sidonio R, Soni A, Stein D, Tarantino M, Wheeler A, Young G, Shapiro A

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 ATHNdataset**

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, Deery 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, Ruthrolen 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)**

Authors: Kulkarni R, Malouin R, Vallad-Hix C, Carlson L, Bird M, Aschman D, Forsberg A, Trost Z and Greenhoe R

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**

Authors: Sood SL, Cheng D, Shapiro AD, Kessler CM, Key NS, Quon DV, Eyster E, Manco-Johnson MJ, Kempton CL, Fogarty PF, Ragni MV, Gill J, Kuriakose P, von Drygalski A, Kouides PA, Escobar MA, Neff AT, Wang TF, Leissing CA, Galdzicka S and Konkle BA

American Society of Hematology 56th Annual Meeting, San Francisco, CA, December 6-9, 2014.

► **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**

Authors: Aschman DJ, Koerper M, Ruuska S, McAlister S, Eyster E, Baker L, Tarantino M, Gonzales S and Konkle B

American Public Health Association, New Orleans, LA, November 16-19, 2014.

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

Aschman D, Eyster E, Pipe S, Tarantino M, Shapiro A, Kempton C, Ruuska S, McAlister S, Bias V, and Konkle BA

National Hemophilia Foundation 66th Annual Meeting, Washington, DC, September 18-20, 2014.

► **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, Sharathkumar A and Aschman DJ

World Foundation of Hemophilia 2014 World Congress, Melbourne, Australia, May 11-15, 2014.

► **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

World Federation of Hemophilia, Melbourne, Australia, May 11-15, 2014.

► **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

American Public Health Association Annual Meeting, Boston, MA, November 4, 2013.

► **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

American Public Health Association Annual Meeting, Boston, MA, November 4, 2013.

► **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

National Hemophilia Foundation Annual Meeting, Anaheim, CA, October 3-5, 2013.

► **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

American Public Health Laboratories Newborn Screening Symposium, Atlanta, GA, May 5-10, 2013.

► **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

National Hemophilia Foundation Annual Meeting, Orlando, FL, November 8-10, 2012.

► **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

National Hemophilia Foundation Annual Meeting, Orlando, FL, November 8-10, 2012.

► **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

American Public Health Association, San Diego, CA, October 25-29, 2008.

► **Adopting a Standards-Based Information Infrastructure for Rare Disorder Communities**

Authors: Baker JR and Aschman DJ on behalf of ATHN

American Public Health Association, October 25-29, 2008.

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