

ATHN DATA SUMMIT 2017

ATHN Awards

Chris Guelcher, Hemostasis RN-BC, MS, PPCNP-BC

ATHN Leadership Awards

- **Lusher-Shapiro Award** - given in honor of the founding co-chairs of ATHN Board of Directors whose vision and leadership brought together a multi-disciplinary board to create the mission and values that have guided ATHN for these past 10 years. This award to be given to a physician or investigator whose leadership has made a substantial impact on the direction of ATHN.
- 2017 Recipient – **Dr. Barbara Konkle**

- **Trish Dominic Award** - given in honor of ATHN's first Treasurer whose passion and administrative leadership was instrumental in structuring and financing ATHN. This award is given to an HTC team member whose leadership has made a substantial impact on the direction of ATHN.
- **2017 Recipient – Pam Bryant**

DREAM Award

Sarah O'Brien, MD

DREAM | AWARD

AN HTRS-AND ATHN-MENTORED
RESEARCH AWARD

Turn a DREAM into reality.

DREAM Award

An HTRS and ATHN Mentored Research Award



- The goal of the DREAM Award is to advance the care of patients with bleeding and clotting disorders by funding research in the field of hemostasis.
 - Research to use the national ATHNdataset
 - Young investigators to be mentored
 - ATHN-Affiliated HTC
 - Database research and statistics
 - Multi-center collaboration is encouraged

2018 Award

- Pre-proposals were due October 6, 2017 and are currently under review for invitation to submit full proposals
- Two grants of \$50,000 over 12 months or one grant of \$100,000 over 24 months, will be awarded to begin July 1, 2018
- Primary mentors must be established clinicians, epidemiologists, or related researchers working in hemostasis at an U.S.-based, ATHN-affiliated HTC
- Second mentors should be experienced in dataset research/statistical analysis
- Supported by an educational grant from Shire

Evaluation Criteria

2018 Award

- Advances Career
- Qualified mentor
- Appropriate research environment
- Clear roles of applicant and mentors
- Timely and relevant topic
- Rationale and aims clear
- Use of ATHN dataset reasonable
- Feasible within timeline
- Realistic budget
- Appropriate statistical plan

DREAM Award Winners



2015 Baxalta Funded		
1 yr.	Tyler W. Buckner, MD, MSc University of Colorado	Regional and center-level variation in utilization of orthopedic surgical interventions in persons with hemophilia
1 yr.	Ming Y. Lim, MB, BChir, MA Medical University of SC	Inhibitors in non-severe hemophilia A patients

DREAM Award Winners



2016 Hemophilia of Georgia Funded

2 yr.	Lynn Malec, M.D. Children's Hospital of Pittsburgh	Is Prophylaxis Putting Hemophilic Joints in the PINK: An ATHN-LINKED Observational Study
2 yr.	Stacy Croteau, M.D. Boston Children's Hospital	Evolving Real-World Use OF Standard and EHL Products in Moderate and Severe Hemophilia Patients: A Practical Application of the ATHN Dataset
1 yr.	Bobby Tran, M.D. Emory University	Characteristics Associated with Prescribed Prophylaxis of Factor Replacement

DREAM Award Winners



2017 Baxalta Funded

2 yr. **Kristina Haley, DO**
Oregon Health &
Sciences University

ATHENA1: Characterizing the impact and treatment of reproductive tract bleeding on women with bleeding disorders.

Highlights

2018 Award



- \$100,000 funding by Shire for 2018
- 10 pre proposals submitted
- 10 willing mentors
- 11 HTC's represented by applicants and mentors
- 38 reviewers available

CARE Award

Chris Guelcher, Hemostasis RN-BC, MS, PPCNP-BC

CARE | AWARD

TRANSFORMING CARE
WITH THE ATHNdataset

ATHN CARE Award

Transforming Care with the ATHNdataset

Care through ATHNdataset Research and Evidence

- A new research opportunity for nurses, social workers, and other members of the HTC interdisciplinary care team.
- The CARE Award will give recipients the chance to use the power of real-world data in the ATHNdataset to answer research questions and ultimately, drive improvements in patient care.

ATHN CARE Award

Thanks to **Novo Nordisk** for making this award possible through a medical education grant.

The ATHN CARE Award is designed to:

- **Advance knowledge** in hemostasis by funding investigator-initiated research or to test quality metrics and intervention strategies conducted by nurses and other members of the interdisciplinary team under the guidance of experienced mentors
- **Transform the care of patients** with bleeding and clotting disorders through the use of the national ATHNdataset.
- **Provide career enrichment** for nurses and other members of the interdisciplinary HTC team dedicated to the field of hemostasis disorders

Award Summary

- The ATHN CARE Award is a competitive award, with scientific review by an **ATHN Research Review panel** under the auspices of the ATHN Research Committee.
 - David Rushlow, Leslie Raffini, Chris Guelcher (Chair), Michelle Witkop, Heidi Lane, Stacy Croteau, Shannon Carpenter
- A pre-proposal process is used to test responsiveness to eligibility requirements, technical feasibility as proposed and scientific integrity
- Eligible applicants are nurses, advanced practice providers (NP/PA), social workers, physical therapists, genetic counselors or other member of the interdisciplinary team at ATHN affiliate HTC.
- Funding up to \$50,000 per recipient for projects lasting up to one-year.

2017 CARE Award Highlights

- 7 Letters of Intent were received
- 5 Full Proposals were invited
- 10 Mentors
- Multidisciplinary Review Panel (3 MD, 1 SW, 2 NP, 1 PT)
- 2 Awards of \$50,000 each awarded!
- Topics Included:
 - Transition from pediatric to adult care
 - Comprehensive care of women
 - Opioid use
 - HTC utilization
 - Self-infusion in adolescents
 - CVAD Thrombosis

Caroline Agnew, CRNP

Nurse Practitioner, St. Christopher's Pediatric Associates



- Project Title: The Effect of Socioeconomic Status and Urbanization on Rates of Self-Infusion and Bleed Rate in Adolescents with Severe Hemophilia
- Mentor: Nataly Apollonsky, MD
- \$50,000

Skye Peltier, MPH, PA-C

Physician Assistant, University of Minnesota Health, Center for Bleeding and Clotting Disorders



- Project Title: Opioid use in hemophilia
- Mentor: Mark Reding, MD
- Mentor: Marshall Mazepa, MD
- \$50,000

DATA QUALITY COUNTS

Jeff Cornett, RN MSN



ATHN | DQC

DATA QUALITY COUNTS

ATHN Data Quality Counts

Grants to HTC's since 2008

- Support data management at HTC's
- Improve the ATHN dataset
- Increase data quality

Project Activities

- Secure patient authorizations for the ATHNdataset
- Enter complete core data elements for those patients who have been authorized (during this cycle and previously)
- Participate in ATHN Data Matters, ATHN's data quality assurance program

Wide HTC Participation

- 97 HTCs have received funding (2008 - 2017)
- Many HTCs have received funding for multiple years
- 37 HTCs are receiving funding this for 2017-2018
- HTCs must submit an application for the DQC grant.
- An objective review panel reviews the applications

2017-18 DQC HTC's

- Albany Regional Hemophilia and Von Willebrand's Treatment Center
- Ann and Robert H. Lurie Children's Memorial Hospital
- Arizona Hemophilia and Thrombosis Center / University of Arizona Health Sciences Center
- Augusta University Adult Hemophilia Treatment Center
- Bleeding and Clotting Disorders Institute
- Center for Comprehensive Care and Diagnosis of Inherited Blood Disorders
- Central Virginia Center for Coagulation Disorders / Virginia Commonwealth University
- Children's Hospital of Los Angeles
- Children's Hospital of New Orleans

2017-18 DQC HTC's

- Children's Hospital of the King's Daughters, Inc.
- Children's National Hemophilia Center
- Cincinnati Children's Hospital Medical Center / Hemophilia and Thrombosis Center
- City of Hope
- Detroit Receiving Hospital and University Medical Center / Comprehensive Center for Bleeding Disorders and Thrombosis
- East Tennessee Comprehensive Hemophilia Center
- Fort Worth Bleeding Disorders Program
- Hemophilia Center of Central Pennsylvania / Penn State University Milton S. Hershey Medical Center
- Hemophilia Outreach Center

2017-18 DQC HTC's

- Intermountain Hemophilia and Thrombosis Center – Utah
- Iowa Hemophilia and Thrombosis Center
- John Bouhasin Center for Children with Bleeding Disorders
- Michigan State University Center for Bleeding Disorders & Clotting Disorders
- Montefiore Medical Center
- Nationwide Children's Hospital
- Newark Beth Israel Medical Center - Hemophilia Center
- Northwest Ohio Hemophilia Treatment Center at the Toledo Hospital
- Ohio State University Hemophilia and Thrombosis Center
- Rady Children's Hospital, San Diego

2017-18 DQC HTC's

- St. Joseph's Children's Hospital Pediatric Hemophilia Program
- St. Jude Children's Research Hospital
- St. Luke's Hemophilia Center
- University Hospitals Cleveland Medical Center
- University of Connecticut Health Center
- University of New Mexico Ted R. Montoya Hemophilia & Thrombosis Program
- Valley Children's Hospital
- Vanderbilt University Medical Center
- Washington University Center for Treatment of Bleeding and Blood Clotting Disorders

Awards

- Awards range from \$5,200 to \$20,000
 - \$2,500 base funding
 - \$50 for each **new or previously** authorized patient with complete/ updated core data elements
 - \$100 for each **new or previously** authorized **rare disorders** patient with complete/ updated core data elements

THANK YOU!

Supported by

- Hemophilia Alliance
- The Alliance Pharmacy
- Indiana Hemophilia and Thrombosis Center

Securing Data.
Advancing Knowledge.
Transforming Care.