`My Life, Our Future
Scientific Publications and Presentations
Last updated: February 14, 2018

2017

Peer-Reviewed Publications

• Novel approach to genetic analysis and results in 3000 hemophilia patients enrolled in the My Life, Our Future initiative
  o 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
  o Blood Advances 2017 May; 1(13): 824-834

Peer-Reviewed Poster Presentations

• A Survey of F8 and F9 Variants in My Life, Our Future for Evidence of Alternative Splicing in Hemophilia
  o 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 BA
  o International Society for Thrombosis and Haemostasis Congress, July 8-13, 2017, Berlin, Germany

• My Life, Our Future: Development of the World’s Largest Genetic Research Repository for Hemophilia
  o Authors: Aschman DJ, Bias V, Konkle BA, Morales J, Pierce G, Ruuska S, Koerper MA
  o National Hemophilia Foundation Annual Meeting, August 24-26, 2017, Chicago, IL, USA

• Genomic Characterization of F8 and F9 Copy Number Variants in the My Life, Our Future TOPMed Hemophilia Cohort
  o Authors: Wheeler MM, Aschman DJ, Pierce G, Konkle BA, Morales J, Johnsen JM, Nickerson DA
  o American Society of Human Genetics Annual Meeting, October 17-21, 2017, Orlando, FL, USA

Oral Presentations

• The My Life, Our Future Hemophilia Project: Update
  o Presenter: Konkle BA
  o Western States/Region IX Annual Meeting, April 2-4, 2017, San Diego, CA, USA

• The My Life, Our Future Hemophilia Project: MASAC Update
  o Presenter: Konkle BA
  o National Hemophilia Foundation’s Medical and Scientific Advisory Council (MASAC) meeting, April 9, 2017, USA

• My Life, Our Future: Program Update
  o Presenter: Morales J
  o Great Plains Hemophilia Treatment Center Regional Meeting, May 7-8, 2017, Dallas, TX, USA

• My Life, Our Future: Program Update
  o Presenter: Pierce G
• National Hemophilia Foundation’s Medical and Scientific Advisory Council (MASAC) meeting, August 26, 2017, Chicago, IL, USA

• **My Life, Our Future: Making Knowledge Hereditary**
  o Presenter: Ryan SE
  o *Mountain States Hemophilia Network Regional Meeting, October 5, 2017, Snowbird, UT, USA*

• **Growing Our Understanding of Hemophilia: MLOF Program Update**
  o Presenters: Branch C, Gonzales S, Konkle BA
  o *American Thrombosis and Hemostasis Network Data Summit 2017, October 20, 2017, Chicago, IL, USA*

2016

**Peer-Reviewed Publications**

• **Genetic Analysis of Bleeding Disorders**
  o Authors: Edison E, Konkle BA, Goodeve AC
  o *Haemophilia. 2016 Jul;22 Suppl 5:79-83*

**Peer-Reviewed Poster Presentations**

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

• **Genetic Variant Analysis in Children and Adults with Hemophilia: Experience from a Large Hemophilia Center in the US**
  o Authors: Lemons J, Escobar M, Cantini M, Cannon K, Brown D, Nguyen T ad Rodriguez N, The University of Texas Health Science Center at Houston, Houston, TX, USA
  o *World Federation of Hemophilia World Congress, July 24-28, 2016, Orlando, FL, USA*

• **A “Genotyping Day” to Facilitate Efficient Enrollment for a National Project**
  o Authors: Smith J, Hatcher N, Martinez R, Balasa V, Hemophilia Treatment Center, Valley Children’s Hospital, Madera, California
  o *World Federation of Hemophilia World Congress, July 24-28, 2016, Orlando, FL, USA*

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

**Oral Presentations**

• **My Life, Our Future: Genotyping for Progress in Hemophilia - Program Update**
  o Presenter: Pierce G
  o *National Hemophilia Foundation’s Medical and Scientific Advisory Council (MASAC) meeting, February 26, 2016, Washington, DC, USA*

• **My Life, Our Future: Research Application and Review Process**
  o Presenter: Konkle BA
  o *Thrombosis and Hemostasis Societies of North America Summit, April 14-16, 2016, Chicago, IL, USA*
• Genetic Analysis of Bleeding Disorders
  o Presenter: Konkle BA
  o World Federation of Hemophilia World Congress, July 24-28, 2016, Orlando, FL, USA

• Aligning Stakeholders’ Views to Advance Integration of Precision Medicine into Clinical Care
  o Presenter: Skinner M
  o Veterans Administration Precision Medicine Conference, August 24, 2016, Arlington, VA, USA

• Tapping into the Data and Sample Repositories to Initiate Research Projects: Launching the My Life, Our Future Research Repository
  o Presenter: Morales J
  o American Thrombosis and Hemostasis Network Data Summit 2016, October 6, Chicago, IL, USA

• Accessing Carrier Testing and What It Means to Your Patients and Their Families
  o Presenters: Branch C, Bryant P, Norton K, Ruuska S
  o American Thrombosis and Hemostasis Network Data Summit 2016, October 7, Chicago, IL, USA

• Genetic Laboratory for Bleeding Disorders: The My Life, Our Future Hemophilia Genetic Analysis Project
  o Presenter: Konkle BA
  o National Hemophilia Foundation’s 13th Workshop on Novel Technologies and Gene Transfer for Hemophilia, October 21-22, 2016, Washington, DC

• My Life, Our Future: Program Update
  o Presenter: Pierce G
  o National Hemophilia Foundation’s Medical and Scientific Advisory Council (MASAC) meeting, October 22, 2016, USA

• Novel Approach to and Results of Genetic Analysis of 3000 Hemophilia Patients Enrolled in the My Life, Our Future Initiative
  o Presenter: Johnsen JM
  o American Society of Hematology Annual Meeting, December 3-6, 2016, San Diego, CA, USA

2015

Peer-Reviewed Poster Presentation

• My Life, Our Future: A “Genotyping Day” to Facilitate Efficient Enrollment
  o Authors: Smith J, Hatcher N, Patterson F, Martinez R, Balasa V
  o National Hemophilia Foundation Annual Meeting, August 13-15, 2015, Dallas, TX, USA

• My Life, Our Future: A “Genotyping Day” to Facilitate Efficient Enrollment
  o Authors: Smith J, Hatcher N, Patterson F, Martinez R, Balasa V
  o American Thrombosis and Hemostasis Network Data Summit, October 28-30, 2015, Chicago, IL, USA

Oral Presentations

• F8 and F9 Gene Variants, CADD Scores, and Hemophilia Severity in the My Life, Our Future Genotyping Project
  o Authors: Johnsen JM, Fletcher SN, Huston H, Kircher M, Aschman DJ, Bias V, McAlister S, Shendure J, Konkle BA
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, September 17-18, 2015, Bethesda, MD, USA

My Life, Our Future: F8 and F9 Gene Variants – Predicting Pathogenicity
- Presenter: Johnsen JM
- American Thrombosis and Hemostasis Network Data Summit, October 28-30, 2015, Chicago, IL, USA

2014

Peer-Reviewed Poster Presentations

Hemophilia Genotyping Results from the My Life, Our Future Project
- Authors: Aschman DJ, Eyster ME, Pipe S, Tarantino M, Shapiro A, Kempton C, Ruuska S, McAlister S, Bias V, Konkle BA
- Thrombosis and Hemostasis Societies of North America Summit, April 10-12, 2014, Chicago, IL, USA

Hemophilia Genotyping Results from the My Life, Our Future Project
- Authors: Aschman DJ, Eyster ME, Pipe S, Tarantino M, Shapiro A, Kempton C, Ruuska S, McAlister S, Bias V, Konkle BA
- National Hemophilia Foundation Annual Meeting, September 18-20, 2014, Washington, DC, USA

Hemophilia Genotyping Results from the My Life, Our Future Project
- Authors: Aschman DJ, Eyster ME, Pipe S, Tarantino M, Shapiro A, Kempton C, Ruuska S, McAlister S, Bias V, Konkle BA
- American Thrombosis and Hemostasis Network Data Summit, November 6-8, 2014, Chicago, IL, USA

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 MA, Ruuska S, McAlister S, Eyster E, Baker L, Tarantino M, Gonzales S, Konkle BA
- American Public Health Association Annual Meeting, November 16-19, 2014, New Orleans, LA, USA

Oral Presentations

My Life, Our Future Providing Access to Free Genetic Testing
- Presenter: Ruuska S
- American Thrombosis and Hemostasis Network Data Summit 2015, November 6, 2015, Chicago, IL, USA

My Life, Our Future Preparing for Carrier Testing
- Presenter: Ruuska S
- American Thrombosis and Hemostasis Network Data Summit 2015, November 7, 2015, Chicago, IL, USA

Future Directions: Advancing Knowledge. My Life, Our Future Study Group Report
- Presenter: Ruuska S
Peer-Reviewed Poster Presentations

- **My Life, Our Future: A Multi-Sector Collaboration to Provide Genotyping Services and a Research Repository for the Hemophilia Community**
  - Authors: Konkle BA, Aschman DJ, Bias V, Pierce S
  - *Association of Public Health Laboratories Annual Meeting, June 2-5, 2013, Raleigh, NC, USA*

- **My Life, Our Future: A Multi-Sector Partnership to Generate Genotype and Research Data Within the Hemophilia Community**
  - Authors: Keebaugh K, Koerper MA, Frick N, Konkle BA, McAlister S, Aschman DJ
  - *American Public Health Association Annual Meeting, November 2-6, 2013, Boston, MA, USA*