

**My Life, Our Future**  
**Scientific Publications and Presentations**  
Last updated: December 19, 2018

2018

*Peer-Reviewed Publications*

- **Genotypes, phenotypes and whole genome sequence: Approaches from the My Life, Our Future haemophilia project**
  - Authors: Konkle BA, Johnsen JM, Wheeler M, Watson C, Skinner M, Pierce GF
  - *Haemophilia*. 2018;24(Suppl. 6):87–94

*Peer-Reviewed Poster Presentations*

- **First Look at My Life, Our Future Carrier Data from a Pilot Site**
  - Authors: Puetz J, Johnson L, Hugge C, Buchanan P,
  - *International Society on Thrombosis and Haemostasis Congress, July 18-21, 2018, Dublin, Ireland*
- **Novel structural variants originating in F8 non-coding regions explain previously unresolved cases of severe hemophilia A**
  - Presenter: Wheeler MM
  - *American Society of Human Genetics Meeting, October 16-20, 2018, San Diego, CA*

*Oral Presentations*

- **Genotypes, Phenotypes, and Whole Genome Sequence: Approaches from the My Life, Our Future Haemophilia Project**
  - Presenter: Konkle BA
  - *World Federation of Hemophilia World Congress, May 20-24, 2018, Glasgow, Scotland*
- **379 Novel Structural Variants Originating in F8 Non-Coding Regions in Previously Unresolved Cases of Severe Hemophilia A**
  - Presenter: Wheeler M
  - *American Society of Hematology Annual Meeting, December 2-4, 2018, San Diego, CA*

2017

*Peer-Reviewed Publications*

- **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

*Peer-Reviewed Poster Presentations*

- **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 BA
- *International Society on 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**
  - Authors: Aschman DJ, Bias V, Konkle BA, Morales J, Pierce G, Ruuska S, Koerper MA
  - *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**
  - Authors: Wheeler MM, Aschman DJ, Pierce G, Konkle BA, Morales J, Johnsen JM, Nickerson DA
  - *American Society of Human Genetics Annual Meeting, October 17-21, 2017, Orlando, FL, USA*

#### Oral Presentations

- **The My Life, Our Future Hemophilia Project: Update**
  - Presenter: Konkle BA
  - *Western States/Region IX Annual Meeting, April 2-4, 2017, San Diego, CA, USA*
- **The My Life, Our Future Hemophilia Project: MASAC Update**
  - Presenter: Konkle BA
  - *National Hemophilia Foundation's Medical and Scientific Advisory Council (MASAC) meeting, April 9, 2017, USA*
- **My Life, Our Future: Program Update**
  - Presenter: Morales J
  - *Great Plains Hemophilia Treatment Center Regional Meeting, May 7-8, 2017, Dallas, TX, USA*
- **My Life, Our Future: Program Update**
  - 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**
  - Presenter: Ryan SE
  - *Mountain States Hemophilia Network Regional Meeting, October 5, 2017, Snowbird, UT, USA*
- **Growing Our Understanding of Hemophilia: MLOF Program Update**
  - Presenters: Branch C, Gonazles S, Konkle BA
  - *American Thrombosis and Hemostasis Network Data Summit 2017, October 20, 2017, Chicago, IL, USA*

#### 2016

#### Peer-Reviewed Publications

- **Genetic Analysis of Bleeding Disorders**
  - Authors: Edison E, Konkle BA, Goodeve AC
  - *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**
  - Authors: Konkle BA, Johnsen JM, Ruuska S, Koerper MA, McAlister S, Aschman DJ
  - *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**
  - 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
  - *World Federation of Hemophilia World Congress, July 24-28, 2016, Orlando, FL, 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
  - *World Federation of Hemophilia World Congress, July 24-28, 2016, Orlando, FL, USA*
- **A “Genotyping Day” to Facilitate Efficient Enrollment for a National Project**
  - Authors: Smith J, Hatcher N, Martinez R, Balasa V
  - *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**
  - Presenter: Pierce G
  - *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**
  - Presenter: Konkle BA
  - *Thrombosis and Hemostasis Societies of North America Summit, April 14-16, 2016, Chicago, IL, USA*
- **Genetic Analysis of Bleeding Disorders**
  - Presenter: Konkle BA
  - *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**
  - Presenter: Skinner M
  - *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**
  - Presenter: Morales J
  - *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**
  - Presenters: Branch C, Bryant P, Norton K, Ruuska S
  - *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**
  - Presenter: Konkle BA
  - *National Hemophilia Foundation's 13<sup>th</sup> Workshop on Novel Technologies and Gene Transfer for Hemophilia, October 21-22, 2016, Washington, DC*
- ***My Life, Our Future: Program Update***
  - Presenter: Pierce G
  - *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**
  - Presenter: Johnsen JM
  - *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***
  - Authors: Smith J, Hatcher N, Patterson F, Martinez R, Balasa V
  - *National Hemophilia Foundation Annual Meeting, August 13-15, 2015, Dallas, TX, USA*
- ***My Life, Our Future: A "Genotyping Day" to Facilitate Efficient Enrollment***
  - Authors: Smith J, Hatcher N, Patterson F, Martinez R, Balasa V
  - *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***
  - Authors: Johnsen JM, Fletcher SN, Huston H, Kircher M, Aschman DJ, Bias V, McAlister S, Shendure J, Konkle BA
  - *International Society for Thrombosis 2015 Congress, June 23, 2015, Toronto, Canada*
- ***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
  - *American Thrombosis and Hemostasis Network Data Summit 2015, November 7, 2015, Chicago, IL, USA*

#### 2013

#### 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*

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