

Hemophilia Genotype Carrier Screening Event

July 19, 2016

4-7 pm

SSM Health Cardinal Glennon

Children's Hospital

**For Potentially Affected Family Members of
People with Hemophilia**

By appointment only. Call

314 577-5332

For eligibility requirement or questions please contact

Cardinal Glennon HTC

314 577-5332

My Life Our Future

Carrier Screening Eligibility Requirements

1. Potentially Affected First or Second Degree Relative of Someone with Hemophilia A or B*
2. All ages accepted. Must be willing to have your blood drawn.
3. Must live in the United States
4. **MUST** have lab report of affected family members genotype or affected family member has to have participated in My Life Our Future (MLOF). Affected family member must allow the Cardinal Glennon HTC to access their MLOF study ID number.
5. If you do not have the affected member's genotype or they did not participate in MLOF, they must agree to participate in MLOF, sign consents, and have blood drawn on July 19 at the time of your visit.
6. Bring lab report of your factor level to the visit if available. If not, we will check your factor level on July 19.

Other Information

1. There is no cost to you!!
2. Held at SSM Health Cardinal Glennon Children's Hospital Bob Costas Center July 19 by appointment only
2. There are two options for participation: Genotype only or Genotype and Repository.

The Repository is the research arm of this program. The repository is like a bank. It securely stores samples and data collected through the MLOF program. If you choose to participate in the Repository arm, your de-identified data will be added to the ATHNdataset and blood samples stored for future research.

To participate in the Repository, you must first agree to participate in the ATHNdataset. This is a secure database sponsored by the American Thrombosis and Hemostasis Network (ATHN). It collects de-identified demographic and clinical information about people with bleeding disorders. It monitors trends and answers questions about bleeding disorders. Nearly 30,000 people in the US are already participating.

3. It takes 3-9 months to get your results back
4. You have the option of linking family information
5. You can change your mind and drop out at any time

* First or second degree family members include sisters, mothers, grandmothers and aunts