

A "Genotyping Day" to Facilitate Efficient Enrollment for a National Project

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OBJECTIVES

My Life, Our Future (MLOF), a collaboration between the American Thrombosis and Hemostasis Network (ATHN), National Hemophilia Foundation (NHF), Bloodworks Northwest (formerly Puget Sound Blood Center) and Biogen, is a program that offers free genotyping for people with hemophilia A and B in the U.S. through participating hemophilia treatment centers (HTCs). Additionally, those who choose to get genotyped through the program have the option to contribute samples collected during the genotyping process to a research repository of blood samples and genetic data to support future research.

At the Valley Children's Hospital (VCH, formerly Children's Hospital of Central California, U.S.) HTC, a site offering MLOF to people with hemophilia, a "Genotyping Day" was implemented with the following goals:

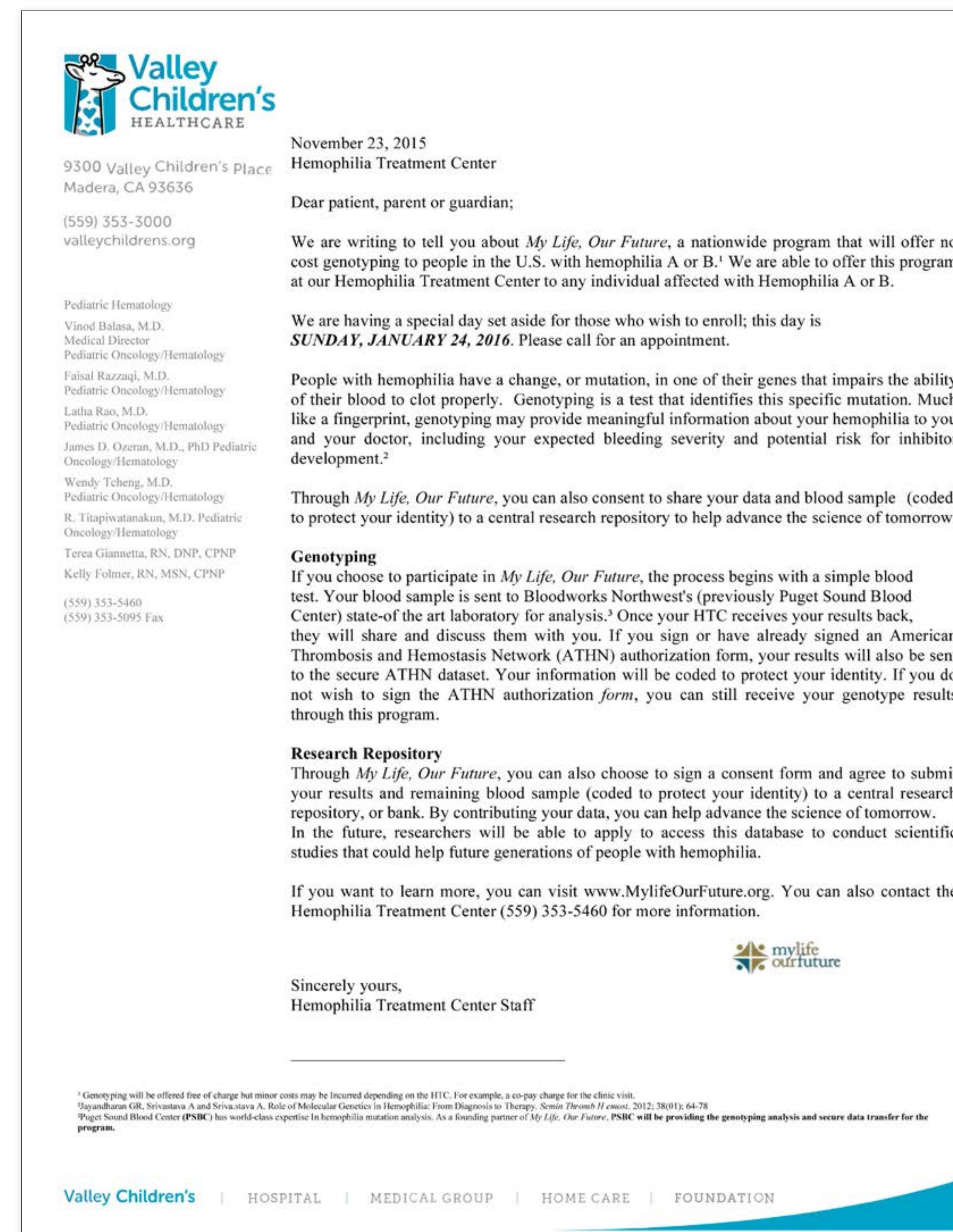
1. Educate patients and families about MLOF
2. Efficiently conduct the genetic testing of patients
3. Create a sense of community impetus for participating

METHODOLOGY

On Sunday, January 24, 2016, the VCH HTC conducted a second MLOF Genotyping Day. This event was held on a day when the clinic was closed to ensure that VCH staff could focus their attention solely on those patients interested in participating in MLOF, rather than impacting regular comprehensive clinic days. Prior to announcing the event, an HTC physician approached VCH administration to confirm support for the Genotyping Day, including approval to pay those employees who would staff the event.

Ahead of the Genotyping Day, letters were sent (see figure 1) and phone calls were made to patients and families informing them of the event. It was emphasized that a limited number of respondents would be eligible to participate. Families were informed further about the event during clinic appointments, and consent to participate was obtained from those interested in advance of the Genotyping Day when possible. During these conversations, as well as in other follow-up phone

Figure 1. Copy of letter mailed to inform patients of *My Life, Our Future*.



calls and emails, HTC staff scheduled participants for genotyping blood draws at 10-minute intervals during a four-hour time frame in which the event was held. On the days prior to the Genotyping Day, each family received a follow-up phone call to remind them of their appointment.

VCH administration paid the salaries and overtime of 12 employees to staff the event through funding, in the form of a grant, from NHF. The roles of the 12 paid staff during the day of the event were as follows:

- 2 employees served as front desk registrars
- 1 physician was on hand to provide oversight of the Genotyping Day, obtain consent if needed, and address any questions or concerns from the families

- 2 employees acted as patient care technicians for obtaining vital signs and ensuring smooth flow of patients in and out of exam rooms
- 2 nurses helped prepare participants ahead of their blood draws and were able to answer questions about the program as needed
- 2 clinical laboratory phlebotomists conducted the blood draws and prepared the samples for shipment to Bloodworks Northwest for analysis
- 1 research employee handled specimen labels, requisitions, documents and specimen shipments
- 1 social worker was on-site to provide support for families as needed
- 1 child life specialist was available to provide psychosocial support to children and families as needed

In addition to the HTC staff members present, the following hospital staff were available:

- The laboratory ensured that adequate personnel were available to process the samples in a timely manner
- A Spanish language interpreter was present for the entire duration of the event to translate as needed

Representatives from MLOF partner organizations NHF and Biogen attended the Genotyping Day to provide additional information and distribute education materials such as program brochures in English and Spanish.

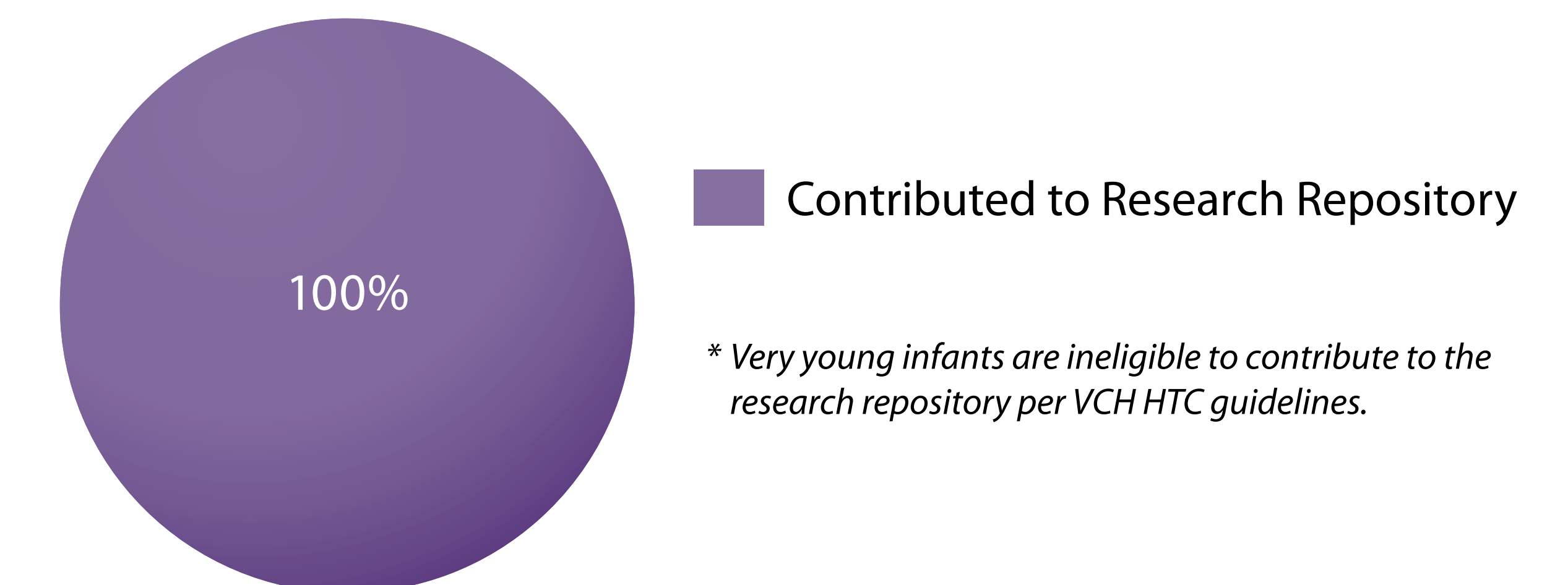
RESULTS

VCH was able to achieve its primary goals for implementing a MLOF Genotyping Day:

- Patients and families were educated on the value of the program, and 24 people opted to participate, including consenting to provide their samples to the research repository to further scientific study (see figure 2)
- To date, 58 patients, who account for more than 40% of VCH patients, have been enrolled in MLOF through two separate Genotyping Days, with 100% of eligible participants contributing their samples to the research repository

- The day offered an efficient way to conduct the genetic testing for both HTC staff and participating patients
- Participants expressed enthusiasm when presented with the opportunity to participate in research and felt comfort in seeing that other people with hemophilia were willing to participate as well

Figure 2. Pie graph noting total participants in MLOF Genotyping Day who contributed to the research repository (n=24; 100% participated).



CONCLUSIONS

A Genotyping Day was found to be a good way to educate and enroll a significant number of people with hemophilia in MLOF in a short period of time. Appropriate preparation and planning of logistical requirements in advance, as well as adequate staffing on-site, are needed to ensure that the event achieves its objectives. This model can be duplicated by HTCs throughout the U.S.

The VCH HTC recognizes the contributions of the MLOF partners in designing the MLOF program, conducting the genetic testing, and supporting the implementation of this project across the U.S.



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