

## Hemophilia Foundation of Southern California Needs Assessment Survey

1. We would appreciate your feedback to assess our present programs and services and to better understand what needs may be met in future programming.
2. Which of the following types of programs or services have you or your family used or participated in during the past 2 years? **(CHECK ALL THAT APPLY.)**
  - Family Support Programs (i.e. retreat)
  - Financial Assistance
  - Scholarship Program (academic)
  - Summer Camp
  - Educational Seminars and Conference (i.e. regional meetings, family information day)
  - Newsletters
  - Website ([www.hemosocal.org](http://www.hemosocal.org))
3. How valuable are the programs or services listed below to you and your family? **(CHECK THE APPROPRIATE RESPONSES.)**

Program	Description	Very Valuable	Valuable	Somewhat Valuable	Not Very Valuable	Unaware of Program	Do Not Utilize
Campership Program	Sponsors youth to attend summer camp at Painted Turtle.						
Newsletter	Informational Material						
Family Retreat	Supportive, educational and fun weekend with workshops for parents and children						
Family-oriented events (i.e. museums, sports)	Opportunity for parents and children to meet other families						
Educational Seminars Family Information Day	Informative lectures and workshops						
Emergency Financial Assistance	Financial assistance for food, shelter, etc						

4. How did you hear about these programs and services? **(CHECK ALL THAT APPLY.)**
  - Contacted the Hemophilia Foundation directly
  - Received information in the mail
  - Hemophilia Newsletter

- Hemophilia Treatment Center Staff
- Other: \_\_\_\_\_
- Unaware of some of these programs before reading this survey.
- Please list the programs you were unaware of before reading this survey:

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5. Is there anything that keeps you from using the programs and services offered by the Hemophilia Foundation? If so, please describe (i.e. distance, didn't know about them).

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6. Below is a list of patient and family NEEDS identified by the Foundation. How important is the development of programs and services in these areas to you and your family? **(CHECK THE APPROPRIATE RESPONSE.)**

Identified Need	Very Important	Important	Somewhat Important	Not Important
Communication with others affected by bleeding disorders				
Adult Programs and Services				
Increased awareness of Foundation programs and Services				
Patient and family involvement with Foundation events (i.e. fund raising and recognition events)				

7. Do you have NEEDS other than those listed above that you would like the Foundation to address? If so, please describe.

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**We would like to ask some general questions that will assist us in interpreting survey findings. Please answer the following questions to the best of your ability.**

1. Number of individuals in your household with a bleeding disorder. Adults:\_\_\_\_\_ Children:\_\_\_\_\_
2. My relationship to the person(s) with a bleeding disorder is **(CHECK ALL THAT APPLY.)**
  - Myself
  - Parent
  - Sibling
  - Grandparent
  - Spouse/Partner
  - Other: \_\_\_\_\_

3. My family is affected by the following bleeding disorder(s): **(CHECK ALL THAT APPLY & CIRCLE SEVERITY.)**

Hemophilia A  
Mild  
Moderate  
Severe  
Inhibitor

Hemophilia B  
Mild  
Moderate  
Severe  
Inhibitor

von Willebrand  
Type 1 (Mild)  
Type 2 (or other variant)  
Type 3 (severe)  
Unsure

Please identify any other factor deficiency or bleeding disorder that affects your family:

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4. Bleeding disorder treatment is received through: **(CHECK ALL THAT APPLY.)**

Treatment Center (circle center)  
Children's Hospital of LA (CHLA)  
Orthopaedic Hospital  
City of Hope  
Childrens of Orange County (CHOC)

Home Infusion  
 Local Hematologist  
 Family Physician

Emergency Room

Other: \_\_\_\_\_

5. How far do you live from where you receive care for your bleeding disorder? **(CHECK ONLY ONE.)**

Within 30 minutes driving distance  
 30 minutes to 1 hour

1-2 hours  
 More than 2 hours driving distance

**OPTIONAL: The following information will better equip the Foundation to provide services to meet the financial needs of patients and families.**

6. Total number of individuals in your household. Adults: \_\_\_\_\_ Children: \_\_\_\_\_

7. What is your family income before taxes? **(CHECK ONLY ONE.)**

Under \$20,000       \$40,001-\$50,000       \$70,001-\$80,000       Over \$100,000  
 \$20,000-\$30,000       \$50,001-\$60,000       \$80,001-\$90,000  
 \$30,001-\$40,000       \$60,001-\$70,000       \$90,001-\$100,000

8. To the best of your ability, please estimate your annual out-of-pocket cost for the medical care of the individuals(s) with a bleeding disorder. **(CHECK ONLY ONE.)**

Estimate: (please estimate to the nearest \$100.00)

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Unknown/Unable to estimate

***Thank you for completing this survey.***

***Your feedback is helpful as we look to improve the Hemophilia Foundation of Southern California's programs and services.***

The following is a list of SERVICE IDEAS the Foundation is interested in developing. How valuable would these services be to you and your family. **(CHECK THE APPROPRIATE RESPONSE.)**

Service	Would be Valuable	Would Not Be Valuable	No Opinion
Case Management for community resources and insurance help			
Mentor Programs (i.e. teen, adult, parent)			

9. Are there PROGRAMS or SERVICES other than those listed above that you feel would be useful to you and your family? If so, please describe.

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10. Please rate the Hemophilia Foundation of Southern California on the following. **(CHECK THE APPROPRIATE RESPONSE.)**

Characteristic	1 Excellent	2 Good	3 Adequate	4 Fair	5 Poor	No Opinion
Providing programs that meet the current needs of you and your family.						
Quality of information on programs and services offered by the Foundation.						
Overall assessment of the Hemophilia Foundation programs and services.						

11. Additional Comments:

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