HFXD in America

Welcome to the HFXD in America survey. Thank you for taking the time to complete this survey that will help assess the patient and caregiver experience with hereditary factor X deficiency (sometimes referred to as FX).

This survey will take approximately 10-15 minutes to complete. *Please complete this survey only once.*

* 1. Are you a patient with hereditary factor X deficiency or are you assisting with this survey as a caregiver of a person with hereditary factor X deficiency?

Please note that this is not the caregiver survey. If you wish to complete the caregiver survey, please use the other link provided on our website.

- ◯ I am a patient
- ◯ I am a caregiver assisting with this survey

TITLE: Hereditary Factor X Deficiency (HFXD) in America: Quality of Life and Treatment Experience in Patients with Hereditary Factor X Deficiency (HFXD)

PROTOCOL NO: P21.004.BPL
IRB Protocol # 20214176

SPONSOR: Bio Products Laboratory

STUDY-RELATED PHONE NUMBER: 919-602-0283

INFORMED CONSENT

You are invited to participate in a research study being conducted by Bio Products Laboratory (BPL). The purpose of the study is to assess the patient and caregiver experience with hereditary factor X deficiency (HFXD), including the path to diagnosis and treatment, specific burdens of disease management, and unmet needs. If you choose to participate in this study, you will be asked to complete an online survey about your experience, as a patient or as a caregiver, about your experience with HFXD. This online survey should take approximately 10-15 minutes to complete. When you finish the survey your participation in this research is complete.

PARTICIPATION

Your participation in this survey is voluntary. You may refuse to take part in the research or exit the survey at any time without penalty or loss of benefits to which you are otherwise entitled. You may refuse to answer any question for any reason. This is not a treatment study. Your alternative is to not participate in this research study.

BENEFITS & RISKS

You are not expected to benefit from this research study. Your responses may help us learn more about this bleeding disorder that can be used to more fully understand its impact on the lives of patients and family members. There are no foreseeable risks involved in participating in this study other than those encountered in day-to-day life. However:

- The possible risks or discomforts of the study are minimal, though you may feel uncomfortable answering some personal or health-related questions.
- Some of the survey questions may be distressing to you as you think about your experiences with this bleeding disorder.
- There is also the possible loss of confidentiality.

You will receive, upon completion of the survey, a digital reward that will be made available at the end of the survey.

CONFIDENTIALITY

The survey will be completed anonymously, no personal identifiable information (PII) will be collected or stored during the survey. Your survey answers will be stored initially with SurveyMonkey.com in a password protected electronic format. Your IP address attached to your Wi-Fi network will only be collected at time of the survey, however it will not be stored once the survey is completed and will not be linked to the final survey data. Only the deidentified data related to the survey answers will be downloaded, along with that from many other research subjects, into an anonymous dataset for analysis.

At the completion of the survey, your email address will be collected for compensation purposes only. It will not be linked to the final survey data and will be stored on a different server not accessible by the study team.

COMPENSATION

You will be rewarded $25 for completing the Patient Survey.

Once you have completed the survey you will be asked if you want to redeem your reward. The redeem button will take you to another website where you will be able to provide an email address where a unique reward link will be sent. Using this unique reward link, you can redeem and download your gift card to a list of unique retailers or donate to a list of approved charities. This can only be done at the end of the survey and must be done at that time, or you will lose your opportunity for compensation. No names will be collected in this step, and you will not be contacted in any way following redemption of the gift card. There is no cost to your participation.

CONTACT

If you have questions, concerns, or complaints, or think this research has hurt you or made you sick, talk to the research team at the phone number listed above on the first page.

If you have further questions or concerns about your rights as a participant in this study, contact HFXDinAmerica@aesara.com.

This research is being overseen by WCG IRB. An IRB is a group of people who perform independent review of research studies. You may talk to them at 855-818-2289 or researchquestions@wcgirb.com if:

- You have questions, concerns, or complaints that are not being answered by the research team.
- You are not getting answers from the research team.
- You cannot reach the research team.
- You want to talk to someone else about the research.
- You have questions about your rights as a research subject.

* 2. **ELECTRONIC CONSENT:** Please select your choice below. You may print a copy of this consent form for your records. Clicking on the “Agree” button indicates that

· You have read the above information
· You voluntarily agree to participate

- ◯ Agree
- ◯ Disagree

3. How did you hear about this survey?

- ◯ From a family member or friend
- ◯ From a health care provider
- ◯ From a treatment center
- ◯ From a specialty pharmacy
- ◯ From social media
- ◯ From a patient advocacy group (such as the National Hemophilia Foundation)
- ◯ Other (please specify)

* 4. Have you been diagnosed with hereditary factor X deficiency (HFXD)?

- ◯ Yes
- ◯ No

5. Are you currently receiving care at a Hemophilia Treatment Center (HTC)?

- ◯ Yes
- ◯ No, I've never received care at an HTC
- ◯ No, but I have received care at an HTC in the past
- ◯ Not sure

* 6. What is your age in years?

Please ask your parent or guardian to help you take this survey

7. Do you have any close relatives that have a history of unusual bleeding (prolonged bleeding or easy bruising)? Please select all that apply.

- [ ] Parent
- [ ] Sibling
- [ ] Child
- [ ] Aunt/Uncle
- [ ] Cousin
- [ ] Grandparent
- [ ] Other (please specify)

  _____

- [ ] None of the above

8. At what age were you first diagnosed with hereditary factor X deficiency?

If you cannot recall, please skip to the next question.

_____

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9. Thinking back to the time of your **first symptoms** (such as prolonged bleeding, easy bruising, joint or muscle pain)

How long did it take for you to visit a health care provider after your first symptoms appeared?

- ◯ Within 3 months
- ◯ Between 3-6 months
- ◯ Between 7-12 months
- ◯ Over 12 months
- ◯ I do not recall

10. **Before you were diagnosed with hereditary factor X deficiency**, did you receive any treatments for your first symptoms? Please select all that apply.

- ☐ Blood transfusions
- ☐ Fresh frozen plasma (FFP)
- ☐ Prothrombin Complex Concentrate or PCCs (Kcentra TM, Beriplex®, Octaplex®, Bebulin®, Profilnine®, FEIBA)
- ☐ Single-factor replacement (Coagadex®)
- ☐ Tranexamic acid (Cyklokapron®, Lysteda®, Novaplus)
- ☐ Aminocaproic acid (Amicar®)
- ☐ Oral contraceptives
- ☐ Conservative management (rest, ice, compression, elevation)
- ☐ I do not recall
- ☐ Other (please specify)

  _____

- ☐ None

11. What was the reason for not receiving any treatment prior to diagnosis? Please select all that apply.

- [ ] My health care provider did not prescribe any treatments
- [ ] My health insurance did not cover the treatments
- [ ] I felt like I did not need treatment at that time
- [ ] I did not have time to receive treatments
- [ ] I do not recall
- [ ] Other (please specify)

12. How long did it take for you to get diagnosed with hereditary factor X deficiency after your first symptoms appeared?

- ◯ Within 3 months
- ◯ Between 3-6 months
- ◯ Between 7-12 months
- ◯ Over 12 months
- ◯ I do not recall

13. How were you diagnosed with hereditary factor X deficiency?

- ◯ After a bleed that required hospitalization
- ◯ After a bleed that did not require hospitalization
- ◯ At birth
- ◯ I do not recall
- ◯ Other (please specify)
- ◯ None of the above

14. Who diagnosed your hereditary factor X deficiency?

- ◯ Primary care provider
- ◯ Hematologist
- ◯ I do not recall
- ◯ Other (please specify)

15. How would you describe the process of getting accurately diagnosed with hereditary factor X deficiency originally (such as going to doctor appointments, receiving tests or labs, etc.)?

- ◯ Very easy
- ◯ Somewhat easy
- ◯ Neither easy nor difficult
- ◯ Somewhat difficult
- ◯ Very difficult
- ◯ I do not recall

16. Please describe your overall diagnosis journey including the experiences with your health care provider.

17. How long did it take for you to start treatment after your first diagnosis?

- Within 1 month
- Between 1-3 months
- Between 4-6 months
- Between 7-12 months
- Over 12 months
- I have not started treatment yet
- I do not recall

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18. What treatments have you **ever** received for hereditary factor X deficiency? Please select all that apply.

- [ ] Blood transfusions
- [ ] Fresh frozen plasma (FFP)
- [ ] Prothrombin Complex Concentrate or PCCs (Kcentra TM, Beriplex®, Octaplex®, Bebulin®, Profilnine®, FEIBA)
- [ ] Single-factor replacement (Coagadex®)
- [ ] Tranexamic acid (Cyklokapron®, Lysteda®, Novaplus)
- [ ] Aminocaproic acid (Amicar®)
- [ ] Oral contraceptives
- [ ] Conservative management (rest, ice, compression, elevation)
- [ ] Other (please specify)

  _____

- [ ] None

19. Which are you **currently** receiving for hereditary factor X deficiency? Please select all that apply.

- [ ] Blood transfusions
- [ ] Fresh frozen plasma (FFP)
- [ ] Prothrombin Complex Concentrate or PCCs (Kcentra TM, Beriplex®, Octaplex®, Bebulin®, Profilnine®, FEIBA)
- [ ] Single-factor replacement (Coagadex®)
- [ ] Tranexamic acid (Cyklokapron®, Lysteda®, Novaplus)
- [ ] Aminocaproic acid (Amicar®)
- [ ] Oral contraceptives
- [ ] [Insert text from Other]
- [ ] Conservative management (rest, ice, compression, elevation)
- [ ] None

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20. What was the reason for not receiving any treatments after diagnosis? Please select all that apply.

- [ ] My health care provider did not prescribe any treatments
- [ ] My health insurance did not cover the treatments
- [ ] I felt like I did not need treatment at that time
- [ ] I did not have time to receive treatments
- [ ] I do not recall
- [ ] Other (please specify)

21. On what type of schedule are you currently receiving treatments? Please select all that apply.

- [ ] Episodic or on-demand (as-needed treatment for active bleeds)
- [ ] Intermittent (periodic) prophylaxis (as-needed treatment to prevent bleeds, such as before a sports game)
- [ ] Regular prophylaxis (routine treatment to prevent bleeds, such as monthly, weekly, twice weekly, etc.)
- [ ] Prior to surgery (as-needed prior to any invasive surgery)
- [ ] Other (please specify)

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22. Please describe how often you receive regular prophylaxis (routine treatment to prevent bleeds, such as monthly, weekly, twice weekly, etc.).

23. What was your health care provider’s reasoning for starting regular prophylaxis? (routine treatment to prevent bleeds, such as monthly, weekly, twice weekly, etc.)

24. How many bleeding episodes did you experience in the **previous 4 weeks**?

- ◯ 0
- ◯ 1-3
- ◯ 4-6
- ◯ 7-9
- ◯ 10 or more

25. What type of bleeding events have you **ever** experienced? Please select all that apply.

- ☐ Bruising/hematoma
- ☐ Nose bleeds
- ☐ Gum bleeds
- ☐ Blood in the urine
- ☐ Heavy menstrual bleeds
- ☐ Bleeding in the joints
- ☐ Bleeding in the muscles (soft tissue bleeds)
- ☐ Bleeding within the skull or brain
- ☐ Bleeding within the digestive tract
- ☐ Bleeding after a surgery
- ☐ Other (please specify)

  _____

- ☐ None

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26. What type of bleeding events are the **most common**?

- [ ] Bruising/hematoma
- [ ] Nose bleeds
- [ ] Gum bleeds
- [ ] Blood in the urine
- [ ] Heavy menstrual bleeds
- [ ] Bleeding in the joints
- [ ] Bleeding in the muscles (soft tissue bleeds)
- [ ] Bleeding within the skull or brain
- [ ] Bleeding within the digestive tract
- [ ] Bleeding after a surgery
- [ ] [Insert text from Other]

27. Please select all bleeding events that were **traumatic** (caused by an injury) or **spontaneous** (caused by an unknown reason)

	Traumatic	Spontaneous
Bruising/hematoma	☐	☐
Nose bleeds	☐	☐
Gum bleeds	☐	☐
Blood in the urine	☐	☐
Heavy menstrual bleeds	☐	☐
Bleeding in the joints	☐	☐
Bleeding in the muscles (soft tissue bleeds)	☐	☐
Bleeding within the skull or brain	☐	☐
Bleeding within the digestive tract	☐	☐
Bleeding after a surgery	☐	☐
[Insert text from Other]	☐	☐

28. Which type of bleeding episodes **cause you pain**?

	Select all that apply
Bruising/hematoma	☐
Nose bleeds	☐
Gum bleeds	☐
Blood in the urine	☐
Heavy menstrual bleeds	☐
Bleeding in the joints	☐
Bleeding in the muscles (soft tissue bleeds)	☐
Bleeding within the skull or brain	☐
Bleeding within the digestive tract	☐
Bleeding after a surgery	☐
[Insert text from Other]	☐

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29. Please rate your pain for each specific bleed type from a scale of 0-10, with ‘0’ representing no pain, to ‘10’ representing pain as bad as you can imagine

	0	1	2	3	4	5	6	7	8	9	10
Bruising/hematoma	○	○	○	○	○	○	○	○	○	○	○
Nose bleeds	○	○	○	○	○	○	○	○	○	○	○
Gum bleeds	○	○	○	○	○	○	○	○	○	○	○
Blood in the urine	○	○	○	○	○	○	○	○	○	○	○
Heavy menstrual bleeds	○	○	○	○	○	○	○	○	○	○	○
Bleeding in the joints	○	○	○	○	○	○	○	○	○	○	○
Bleeding in the muscles (soft tissue bleeds)	○	○	○	○	○	○	○	○	○	○	○
Bleeding within the skull or brain	○	○	○	○	○	○	○	○	○	○	○
Bleeding within the digestive tract	○	○	○	○	○	○	○	○	○	○	○
Bleeding after a surgery	○	○	○	○	○	○	○	○	○	○	○
[Insert text from Other]	○	○	○	○	○	○	○	○	○	○	○

30. How often (approximately) does your menstrual cycle occur?

- ◯ Nearly continuous bleeding (hard to tell when one cycle ends and another begins)
- ◯ More than one cycle during a month
- ◯ Once a month
- ◯ More than one month between cycles
- ◯ No pattern
- ◯ Not yet menstruating
- ◯ Post-menopausal

31. How long (approximately) does your menstrual period most commonly last?

- ◯ 1-3 days
- ◯ 4-5 days
- ◯ 6-9 days
- ◯ 10 days or more

32. On a "heavy" bleeding day, how often do you need to change protection (pads or tampons) because the item becomes saturated?

- ◯ More often than hourly
- ◯ Every hour
- ◯ Every 1-3 hours
- ◯ Every 4-6 hours
- ◯ Every 7-12 hours

33. Have you ever required any of the following for your menstrual period? Please select all that apply.

- ☐ Changing pads more frequently than every 2 hours
- ☐ Passing large clots in your menstrual period
- ☐ Time off work/school greater than 2 times per year
- ☐ Requiring antifibrinolytics or hormonal or iron therapy
- ☐ Requiring multiple treatments
- ☐ Sought medical evaluation or and was either referred to a specialist
- ☐ Bleeding requiring hospital admission or emergency treatment

34. How much pain do you experience during your periods?

- None
- Mild
- Moderate
- Severe

35. How much does this pain interfere with your normal activities?

- Never
- Rarely
- Sometimes
- Often
- Always

36. During your most recent menstrual period, your blood loss was:

- Light
- Moderate
- Heavy
- Very Heavy

37. During your most recent menstrual period, how much did your bleeding limit you in your work outside or inside the home?

- ◯ Not at all
- ◯ Slightly
- ◯ Moderately
- ◯ Quite a bit
- ◯ Extremely

38. During your most recent menstrual period, how much did your bleeding limit you in your physical activities?

- ◯ Not at all
- ◯ Slightly
- ◯ Moderately
- ◯ Quite a bit
- ◯ Extremely

39. During your most recent menstrual period, how much did your bleeding limit you in your social or leisure activities?

- ◯ Not at all
- ◯ Slightly
- ◯ Moderately
- ◯ Quite a bit
- ◯ Extremely

40. Compared to your previous menstrual period, would you say your blood loss during this period was:

- ◯ About the same
- ◯ Better
- ◯ Worse

41. How would you describe the blood loss during this period?

- ◯ Almost the same, hardly better at all
- ◯ A little better
- ◯ Somewhat better
- ◯ An average amount better
- ◯ A good deal better
- ◯ A great deal better
- ◯ A very great deal better

42. How would you describe the blood loss during this period?

- ◯ Almost the same, hardly worse at all
- ◯ A little worse
- ◯ Somewhat worse
- ◯ An average amount worse
- ◯ A good deal worse
- ◯ A great deal worse
- ◯ A very great deal worse

43. Was this a meaningful or important change for you?

- ◯ Yes
- ◯ No

44. On average, how many bleeding episodes do you experience over a typical month?

- ◯ 0
- ◯ 1-3
- ◯ 4-6
- ◯ 7-9
- ◯ 10 or more

45. How would you best describe **your bleeding episodes**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
I experience the same types of bleeds over time (such as bruising, nosebleeds, etc.)	◯	◯	◯	◯	◯	◯
My bleeding episodes are predictable	◯	◯	◯	◯	◯	◯
It is very easy for me to tell when I am having a bleeding episode	◯	◯	◯	◯	◯	◯
I feel like I can control my bleeding episodes	◯	◯	◯	◯	◯	◯
I feel like I am currently in control of my bleeding episodes	◯	◯	◯	◯	◯	◯
I feel like having HFXD has become a normal part of my life	◯	◯	◯	◯	◯	◯

46. On average, how long does it take to control a bleeding episode **after receiving treatment**?

- ◯ Within one day
- ◯ Between 1 and 2 days
- ◯ Between 3 and 4 days
- ◯ More than 5 days
- ◯ I do not recall

47. How would you best describe **your experience with your treatments** for hereditary factor X deficiency? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
I feel like my treatments help control my bleeding	◯	◯	◯	◯	◯	◯
I am satisfied with how my treatments control my bleeding	◯	◯	◯	◯	◯	◯
I feel like my treatment helps improve my quality of life	◯	◯	◯	◯	◯	◯
I feel that it is easy to manage my treatments (such as scheduling, transportation, etc.)	◯	◯	◯	◯	◯	◯

48. How would you best describe **the impact of taking care of your hereditary factor X deficiency**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
I feel that taking care of my hereditary factor X deficiency (treatment, rest, visits with health care professionals) takes time away from other activities.	○	○	○	○	○	○

49. To what extent have the following areas of your life been **negatively affected** by your bleeding disorder? Please rate the following statements from “Strongly Disagree” to “Strongly Agree”

"School" includes gym and recess, excluding after school sports. Please include after school sports in "Social Activities"

	None Affected	A Little Affected	Somewhat Affected	Quite Affected	Strongly Affected
Family	○	○	○	○	○
Health/Well-being	○	○	○	○	○
Work or School*	○	○	○	○	○
Friends and Relationships	○	○	○	○	○
Love Life and Partnership	○	○	○	○	○
Economic Status (money/finances)	○	○	○	○	○
Leisure Time	○	○	○	○	○
Social Activities	○	○	○	○	○

50. How would you best describe your experience **living with hereditary factor X deficiency**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
Due to my bleeding disorder, I feel unable to do certain things for my family that I could do if I did not have hereditary factor X deficiency	○	○	○	○	○	○
I feel different from others because of my hereditary factor X deficiency	○	○	○	○	○	○
I feel I cause my family or friends trouble because of my hereditary factor X deficiency	○	○	○	○	○	○

51. How would you best describe your experience **living with hereditary factor X deficiency**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
My parent/guardian does not allow me to do certain things because of my hereditary factor X deficiency	○	○	○	○	○	○
I feel different from others because of my hereditary factor X deficiency	○	○	○	○	○	○
I feel left out when other children do things together	○	○	○	○	○	○
I feel I cause my family or friends trouble because of my hereditary factor X deficiency	○	○	○	○	○	○

52. I am able to talk to _____ about my hereditary factor X deficiency. Please select all that apply.

- [ ] Family
- [ ] Friends
- [ ] Health care providers (doctors, nurses, pharmacists, social workers, etc.)
- [ ] Patient advocacy groups (such as the National Hemophilia Foundation)
- [ ] Social media (such as internet forums)
- [ ] Other (please specify)

  _____

- [ ] None of the above

53. I go to _____ for information about my hereditary factor X deficiency. Please select all that apply.

- [ ] Family
- [ ] Friends
- [ ] Health care providers (doctors, nurses, pharmacists, social workers, etc.)
- [ ] Patient advocacy groups (such as the National Hemophilia Foundation)
- [ ] Internet/medical websites
- [ ] Social media (such as internet forums)
- [ ] Other (please specify)

  _____

- [ ] None of the above

54. In the previous 12 months: Where have you received medical care for **any reason (including for hereditary factor X deficiency)**? Please select all that apply.

- [ ] Urgent care
- [ ] Emergency room
- [ ] Hospital admission
- [ ] Primary care provider
- [ ] Hemophilia Treatment Center (HTC)
- [ ] Other (please specify)

  _____

- [ ] None of the above

55. In the previous 12 months: Where have you received medical care for **your hereditary factor X deficiency**? Please select all that apply.

- [ ] Urgent care
- [ ] Emergency room
- [ ] Hospital admission
- [ ] Primary care provider
- [ ] Hemophilia Treatment Center (HTC)
- [ ] [Insert text from Other]
- [ ] None of the above

56. In the previous 12 months: How many times did you go to each specific location for **any reason**?

	1-2 times	3-4 times	5-9 times	More than 10 times
Urgent care	○	○	○	○
Emergency room	○	○	○	○
Hospital admission	○	○	○	○
Primary care provider	○	○	○	○
Hemophilia Treatment Center (HTC)	○	○	○	○
[Insert text from Other]	○	○	○	○

57. In the previous 12 months: How many times did you go to each specific location for **your hereditary factor X deficiency**?

	1-2 times	3-4 times	5-9 times	More than 10 times
Urgent care	○	○	○	○
Emergency room	○	○	○	○
Hospital admission	○	○	○	○
Primary care provider	○	○	○	○
Hemophilia Treatment Center (HTC)	○	○	○	○
[Insert text from Other]	○	○	○	○

58. In the previous 12 months: How many different medications do you take for **any condition**?

- ◯ 0
- ◯ 1-3
- ◯ 4-6
- ◯ 7-9
- ◯ 10 or more

59. In the previous 12 months: How many different medications do you *currently take* for **your hereditary factor X deficiency**?

- ◯ 0
- ◯ 1-3
- ◯ 4-6
- ◯ 7-9
- ◯ 10 or more

60. In the previous 12 months: How many different medications have you *ever taken* for **your hereditary factor X deficiency**?

- ◯ 0
- ◯ 1-3
- ◯ 4-6
- ◯ 7-9
- ◯ 10 or more

Your Health and Well-Being

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please mark the circle that best describes your answer.

61. In general, would you say your health is:

Excellent	Very good	Good	Fair	Poor
○	○	○	○	○

62. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf:	○	○	○
Climbing several flights of stairs	○	○	○

63. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular activities as a result of your physical health?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Accomplished less than you would like	○	○	○	○	○
Were limited in the kind of work or other activities	○	○	○	○	○

64. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious)?

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Accomplished less than you would like	○	○	○	○	○
Did work or other activities less carefully than usual	○	○	○	○	○

65. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderately	Quite a bit	Extremely
○	○	○	○	○

66. These next questions are about how you feel and how things have been during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
Have you felt calm and peaceful?	○	○	○	○	○
Did you have a lot of energy?	○	○	○	○	○
Have you felt downhearted and depressed?	○	○	○	○	○

67. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
○	○	○	○	○

Thank you for completing these questions!

68. Which gender do you identify as?

- ◯ Female
- ◯ Male
- ◯ Transgender Female
- ◯ Transgender Male
- ◯ Non-Binary
- ◯ Prefer not to say
- ◯ Prefer to self-describe:

69. What is your ethnicity?

- ◯ Hispanic or Latino
- ◯ Not Hispanic or Latino
- ◯ Prefer not to answer

70. What is your race? Please select all that apply.

- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ American Indian or Alaskan Native
- ☐ Prefer not to answer

71. Are you of Mediterranean or Middle Eastern descent? While Hereditary Factor X Deficiency can occur in individuals of any ethnic group, people with Mediterranean or Middle Eastern descent have a higher risk of inheriting Factor X deficiency. Please select all that apply.

- [ ] Mediterranean
- [ ] Middle Eastern
- [ ] Neither
- [ ] Prefer not to answer

72. What is your employment status?

- ( ) Student
- ( ) Full-Time Employed
- ( ) Part-Time Employed
- ( ) Unemployed
- ( ) Unable to work due to disability
- ( ) Prefer not to answer
- ( ) Other (please specify)

73. What is your annual income level?

- ( ) Under $20,000
- ( ) $20,001 - $40,000
- ( ) $40,001 - $60,000
- ( ) $60,001 - $80,000
- ( ) $80,001 - $100,000
- ( ) More than $100,000
- ( ) N/A or Prefer not to answer

74. How did you hear about this survey?

- From a family member or friend
- From a health care provider
- From a treatment center
- From a specialty pharmacy
- From social media
- From a patient advocacy group (such as the National Hemophilia Foundation)
- Other (please specify)

* 75. Has your person with a bleeding disorder been diagnosed with hereditary factor X deficiency?

- Yes
- No

The focus of this survey is on your person's hereditary factor X deficiency, which will be referred to as their bleeding disorder.

76. Is your person with a bleeding disorder currently receiving care at a Hemophilia Treatment Center (HTC)?

- Yes
- No, they never received care at an HTC
- No, but they have received care at an HTC in the past
- Not sure

* 77. What is your person with a bleeding disorder's age in years?

78. Does your person with a bleeding disorder have any close relatives that have a history of unusual bleeding (prolonged bleeding or easy bruising)? Please select all that apply.

- [ ] Parent
- [ ] Sibling
- [ ] Child
- [ ] Aunt/Uncle
- [ ] Cousin
- [ ] Grandparent
- [ ] Other (please specify)

  _____

- [ ] None of the above

79. At what age was your person with a bleeding disorder first diagnosed with hereditary factor X deficiency?

If you cannot recall, please skip to the next question.

_____

80. Thinking back to the time of their **first symptoms** (such as prolonged bleeding, easy bruising, joint or muscle pain)

How long did it take for your person with a bleeding disorder to visit a health care provider after their first symptoms appeared?

- ◯ Within 3 months
- ◯ Between 3-6 months
- ◯ Between 7-12 months
- ◯ Over 12 months
- ◯ I do not recall

81. **Before your person with a bleeding disorder was diagnosed with hereditary factor X deficiency**, did they receive any treatments for their first symptoms? Please select all that apply.

- ☐ Blood transfusions
- ☐ Fresh frozen plasma (FFP)
- ☐ Prothrombin Complex Concentrate or PCCs (Kcentra TM, Beriplex®, Octaplex®, Bebulin®, Profilnine®, FEIBA)
- ☐ Single-factor replacement (Coagadex®)
- ☐ Tranexamic acid (Cyklokapron®, Lysteda®, Novaplus)
- ☐ Aminocaproic acid (Amicar®)
- ☐ Oral contraceptives
- ☐ Conservative management (rest, ice, compression, elevation)
- ☐ Do not recall
- ☐ Other (please specify)

  _____

- ☐ None

82. What was the reason for not receiving any treatment prior to diagnosis? Please select all that apply.

- [ ] Their health care provider did not prescribe any treatments
- [ ] Their health insurance did not cover the treatments
- [ ] They felt like they did not need treatment at that time
- [ ] They did not have time to receive treatments
- [ ] Do not recall
- [ ] Other (please specify)

83. How long did it take for your person with a bleeding disorder to get diagnosed with HFXD after your first symptoms appeared?

- ( ) Within 3 months
- ( ) Between 3-6 months
- ( ) Between 7-12 months
- ( ) Over 12 months
- ( ) Do not recall

84. How was your person with a bleeding disorder diagnosed with hereditary factor X deficiency?

- ( ) After a bleed that required hospitalization
- ( ) After a bleed that did not require hospitalization
- ( ) At birth
- ( ) Do not recall
- ( ) Other (please specify)
- ( ) None of the above

85. Who diagnosed your person with a bleeding disorder 's hereditary factor X deficiency?

- ◯ Primary care provider
- ◯ Hematologist
- ◯ Do not recall
- ◯ Other (please specify)

86. How would your person with a bleeding disorder describe the process of getting diagnosed accurately with hereditary factor X deficiency (such as going to doctor appointments, receiving tests or labs, etc.)?

- ◯ Very easy
- ◯ Somewhat easy
- ◯ Neither easy nor difficult
- ◯ Somewhat difficult
- ◯ Very difficult
- ◯ Do not recall

87. Please describe your person with a bleeding disorder's overall diagnosis journey, including the experiences with their health care provider.

88. How long did it take for your person with a bleeding disorder to start treatment for their hereditary factor X deficiency **after their first diagnosis**?

- Within 1 month
- Between 1-3 months
- Between 4-6 months
- Between 7-12 months
- Over 12 months
- They have not started treatment yet
- I do not recall

89. What treatments has your person with a bleeding disorder **ever** received for hereditary factor X deficiency? Please select all that apply.

- [ ] Blood transfusions
- [ ] Fresh frozen plasma (FFP)
- [ ] Prothrombin Complex Concentrate or PCCs (Kcentra TM, Beriplex®, Octaplex®, Bebulin®, Profilnine®, FEIBA)
- [ ] Single-factor replacement (Coagadex®)
- [ ] Tranexamic acid (Cyklokapron®, Lysteda®, Novaplus)
- [ ] Aminocaproic acid (Amicar®)
- [ ] Oral contraceptives
- [ ] Conservative management (rest, ice, elevation, management)
- [ ] Other (please specify)

  _____

- [ ] None

HFXD in America

90. Which are they **currently** receiving for hereditary factor X deficiency? Please select all that apply.

- [ ] Blood transfusions
- [ ] Fresh frozen plasma (FFP)
- [ ] Prothrombin Complex Concentrate or PCCs (Kcentra TM, Beriplex®, Octaplex®, Bebulin®, Profilnine®, FEIBA)
- [ ] Single-factor replacement (Coagadex®)
- [ ] Tranexamic acid (Cyklokapron®, Lysteda®, Novaplus)
- [ ] Aminocaproic acid (Amicar®)
- [ ] Oral contraceptives
- [ ] [Insert text from Other]
- [ ] Conservative management (rest, ice, elevation, management)
- [ ] None

91. What was the reason for not receiving any treatments after diagnosis? Please select all that apply.

- [ ] Their health care provider did not prescribe any treatments
- [ ] Their health insurance did not cover the treatments
- [ ] They/I felt like they did not need treatment at that time
- [ ] They/I did not have time to go receive treatments
- [ ] Do not recall
- [ ] Other (please specify)

92. On what type of schedule is your person with a bleeding disorder currently receiving treatments? Please select all that apply.

- [ ] Episodic or on-demand (as-needed treatment for active bleeds)
- [ ] Intermittent (periodic) prophylaxis (as-needed treatment to prevent bleeds, such as before a sports game)
- [ ] Regular prophylaxis (routine treatment to prevent bleeds, such as monthly, weekly, twice weekly, etc.)
- [ ] Prior to surgery (as-needed prior to any invasive surgery)
- [ ] Other (please specify)

93. Please describe how often your person with a bleeding disorder receives regular prophylaxis (routine treatment to prevent bleeds, such as monthly, weekly, twice weekly, etc.).

94. What was your health care provider’s reasoning for starting regular prophylaxis? (routine treatment to prevent bleeds, such as monthly, weekly, twice weekly, etc.)

95. How many bleeding episodes did your person with a bleeding disorder experience in the **previous 4 weeks**?

- ◯ 0
- ◯ 1-3
- ◯ 4-6
- ◯ 7-9
- ◯ 10 or more

96. What type of bleeding events has your person with a bleeding disorder ever experienced? Please select all that apply.

- ☐ Bruising/hematoma
- ☐ Nose bleeds
- ☐ Gum bleeds
- ☐ Blood in the urine
- ☐ Heavy menstrual bleeds
- ☐ Bleeding in the joints
- ☐ Bleeding in the muscles (soft tissue bleeds)
- ☐ Bleeding within the skull or brain
- ☐ Bleeding within the digestive tract
- ☐ Bleeding after a surgery
- ☐ Other (please specify)

  _____

- ☐ None

97. What type of bleeding events are the **most common**? Please select all that apply.

- [ ] Bruising/hematoma
- [ ] Nose bleeds
- [ ] Gum bleeds
- [ ] Blood in the urine
- [ ] Heavy menstrual bleeds
- [ ] Bleeding in the joints
- [ ] Bleeding in the muscles (soft tissue bleeds)
- [ ] Bleeding within the skull or brain
- [ ] Bleeding within the digestive tract
- [ ] Bleeding after a surgery
- [ ] [Insert text from Other]

98. Please select all bleeding events that were **traumatic** (i.e., caused by an injury) or **spontaneous** (i.e., caused by an unknown reason)

	Traumatic	Spontaneous
Bruising/hematoma	☐	☐
Nose bleeds	☐	☐
Gum bleeds	☐	☐
Blood in the urine	☐	☐
Heavy menstrual bleeds	☐	☐
Bleeding in the joints	☐	☐
Bleeding in the muscles (soft tissue bleeds)	☐	☐
Bleeding within the skull or brain	☐	☐
Bleeding within the digestive tract	☐	☐
Bleeding after a surgery	☐	☐
[Insert text from Other]	☐	☐

HFXD in America

99. Which type of bleeding episodes cause your person with a bleeding disorder **pain**?

	Select all that apply
Bruising/hematoma	☐
Nose bleeds	☐
Gum bleeds	☐
Blood in the urine	☐
Heavy menstrual bleeds	☐
Bleeding in the joints	☐
Bleeding in the muscles (soft tissue bleeds)	☐
Bleeding within the skull or brain	☐
Bleeding within the digestive tract	☐
Bleeding after a surgery	☐
[Insert text from Other]	☐

HFXD in America

100. Please rate your person with a bleeding disorder pain for each specific bleed type from a scale of 0-10, with ‘0’ representing no pain, to ‘10’ representing pain as bad as they can imagine

	0	1	2	3	4	5	6	7	8	9	10
Bruising/hematoma	○	○	○	○	○	○	○	○	○	○	○
Nose bleeds	○	○	○	○	○	○	○	○	○	○	○
Gum bleeds	○	○	○	○	○	○	○	○	○	○	○
Blood in the urine	○	○	○	○	○	○	○	○	○	○	○
Heavy menstrual bleeds	○	○	○	○	○	○	○	○	○	○	○
Bleeding in the joints	○	○	○	○	○	○	○	○	○	○	○
Bleeding in the muscles (soft tissue bleeds)	○	○	○	○	○	○	○	○	○	○	○
Bleeding within the skull or brain	○	○	○	○	○	○	○	○	○	○	○
Bleeding within the digestive tract	○	○	○	○	○	○	○	○	○	○	○
Bleeding after a surgery	○	○	○	○	○	○	○	○	○	○	○
[Insert text from Other]	○	○	○	○	○	○	○	○	○	○	○

Other (please specify)

HFXD in America

101. How often (approximately) does your person with a bleeding disorder's menstrual cycle occur?

- ◯ Nearly continuous bleeding (hard to tell when one cycle ends and another begins)
- ◯ More than one cycle during a month
- ◯ Once a month
- ◯ More than one month between cycles
- ◯ No pattern
- ◯ Not yet menstruating
- ◯ Post-menopausal

102. How long (approximately) does your person with a bleeding disorder's menstrual period most commonly last?

- ◯ 1-3 days
- ◯ 4-5 days
- ◯ 6-9 days
- ◯ 10 days or more

103. On a "heavy" bleeding day, how often does your person with a bleeding disorder need to change protection (pads or tampons) because the item becomes saturated?

- ◯ More often than hourly
- ◯ Every hour
- ◯ Every 1-3 hours
- ◯ Every 4-6 hours
- ◯ Every 7-12 hours

104. Has your person with a bleeding disorder ever required any of the following for their menstrual period? Please select all that apply.

- ☐ Changing pads more frequently than every 2 hours
- ☐ Passing large clots during menstrual period
- ☐ Time off work/school greater than 2 times per year
- ☐ Requiring antifibrinolytics or hormonal or iron therapy
- ☐ Requiring multiple treatments
- ☐ Sought medical evaluation or and was either referred to a specialist
- ☐ Bleeding requiring hospital admission or emergency treatment

105. How much pain does your person with a bleeding disorder experience during their periods?

- None
- Mild
- Moderate
- Severe

106. How much does this pain interfere with your person with a bleeding disorder's normal activities?

- Never
- Rarely
- Sometimes
- Often
- Always

107. During your person with a bleeding disorder's most recent menstrual period, their blood loss was:

- Light
- Moderate
- Heavy
- Very Heavy

108. During your person with a bleeding disorder's most recent menstrual period, how much did their bleeding limit them in their work outside or inside the home?

- Not at all
- Slightly
- Moderately
- Quite a bit
- Extremely

109. During your person with a bleeding disorder's most recent menstrual period, how much did their bleeding limit them in their physical activities?

- Not at all
- Slightly
- Moderately
- Quite a bit
- Extremely

110. During your person with a bleeding disorder's most recent menstrual period, how much did their bleeding limit them in their social or leisure activities?

- Not at all
- Slightly
- Moderately
- Quite a bit
- Extremely

111. Compared to your person with a bleeding disorder's previous menstrual period, would they say their blood loss during this period was:

- About the same
- Better
- Worse

HFXD in America

112. How would your person with a bleeding disorder describe the blood loss during this period?

- ◯ Almost the same, hardly better at all
- ◯ A little better
- ◯ Somewhat better
- ◯ An average amount better
- ◯ A good deal better
- ◯ A great deal better
- ◯ A very great deal better

113. How would your person with a bleeding disorder describe the blood loss during this period?

- ◯ Almost the same, hardly worse at all
- ◯ A little worse
- ◯ Somewhat worse
- ◯ An average amount worse
- ◯ A good deal worse
- ◯ A great deal worse
- ◯ A very great deal worse

114. Was this a meaningful or important change for your person with a bleeding disorder?

- ◯ Yes
- ◯ No

HFXD in America

115. On average, how many bleeding episodes does your person with a bleeding disorder experience over a typical month?

- 0
- 1-3
- 4-6
- 7-9
- 10 or more

116. How would your person with a bleeding disorder best describe **their bleeding episodes**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
They experience the same types of bleeds over time (such as bruising, nosebleeds, etc.)	○	○	○	○	○	○
Their bleeding episodes are predictable by them	○	○	○	○	○	○
It is very easy for them to tell when they are having a bleeding episode	○	○	○	○	○	○
They feel like they can control their bleeding episodes	○	○	○	○	○	○
They feel like they are currently in control of their bleeding episodes	○	○	○	○	○	○
They feel like having hereditary factor X deficiency has become a normal part of their life	○	○	○	○	○	○

HFXD in America

117. On average, how long does it take to control a bleeding episode **after receiving treatment**?

- ◯ Within one day
- ◯ Between 1 and 2 days
- ◯ Between 3 and 4 days
- ◯ More than 5 days
- ◯ I do not recall

118. How would your person with a bleeding disorder best describe **their experience with their treatments for hereditary factor X deficiency**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
They feel like their treatments help control their bleeding	◯	◯	◯	◯	◯	◯
They are satisfied with how their treatments control their bleeding	◯	◯	◯	◯	◯	◯
They feel like their treatment helps improve their quality of life	◯	◯	◯	◯	◯	◯
They feel that it is easy to manage their treatments (such as scheduling, transportation, etc.)	◯	◯	◯	◯	◯	◯

119. How would your person with a bleeding disorder best describe **the impact of taking care of their hereditary factor X deficiency**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
They feel that taking care of their HFXD (treatment, rest, visits with health care professionals) takes time away from other activities.	○	○	○	○	○	○

120. To what extent have the following areas of your person with a bleeding disorder's life been **negatively affected** by their bleeding disorder?

"School" includes gym and recess, excluding afterschool sports. Please include after school sports in "Social Activities"

	None Affected	A Little Affected	Somewhat Affected	Quite Affected	Strongly Affected
Family	○	○	○	○	○
Health/Well-being	○	○	○	○	○
Work or School*	○	○	○	○	○
Friends and Relationships	○	○	○	○	○
Love Life and Partnership	○	○	○	○	○
Economic Status (money/finances)	○	○	○	○	○
Leisure Time	○	○	○	○	○
Social Activities	○	○	○	○	○

HFXD in America

121. How would your person with a bleeding disorder best describe **their experience living with hereditary factor X deficiency**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
Due to their bleeding disorder, they feel unable to do certain things for their family that they could do if they did not have hereditary factor X deficiency	○	○	○	○	○	○
They feel different from others because of their hereditary factor X deficiency	○	○	○	○	○	○
They feel they cause their family or friends trouble because of their hereditary factor X deficiency	○	○	○	○	○	○

HFXD in America

122. How would your person with a bleeding disorder best describe **their experience living with hereditary factor X deficiency**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
Their parent/guardian does not allow them to do certain things because of their hereditary factor X deficiency	○	○	○	○	○	○
They feel different from others because of their hereditary factor X deficiency	○	○	○	○	○	○
They feel left out when other children do things together	○	○	○	○	○	○
They feel they cause their family or friends trouble because of their hereditary factor X deficiency	○	○	○	○	○	○

123. How would your person with a bleeding disorder best describe **their experience living with hereditary factor X deficiency**? Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
They are not allowed to do certain things because of their hereditary factor X deficiency	○	○	○	○	○	○
They feel different from others because of their hereditary factor X deficiency	○	○	○	○	○	○
They feel left out when other children do things together	○	○	○	○	○	○

HFXD in America

124. They are able to talk to _____ about their hereditary factor X deficiency. Please select all that apply.

- [ ] Family
- [ ] Friends
- [ ] Health care providers (doctors, nurses, pharmacists, social workers, etc.)
- [ ] Patient advocacy groups (such as the National Hemophilia Foundation)
- [ ] Social media (such as internet forums)
- [ ] Other (please specify)

  _____

- [ ] None of the above

125. They go to _____ for information about their hereditary factor X deficiency. Please select all that apply.

- [ ] Family
- [ ] Friends
- [ ] Health care providers (doctors, nurses, pharmacists, social workers, etc.)
- [ ] Patient advocacy groups (such as the National Hemophilia Foundation)
- [ ] Internet/medical websites
- [ ] Social media (such as internet forums)
- [ ] Other (please specify)

  _____

- [ ] None of the above

126. Please rate the following statements from "Strongly Disagree" to "Strongly Agree"

	Strongly Disagree	Somewhat Disagree	Neither Agree nor Disagree	Somewhat Agree	Strongly Agree	N/A or prefer not to answer
They have a friend they feel very close to	○	○	○	○	○	○

127. Where do you, **as the caregiver**, go to get information on hereditary factor X deficiency? Please select all that apply.

- [ ] Family
- [ ] Friends
- [ ] Health care providers (doctors, nurses, pharmacists, social workers, etc.)
- [ ] Patient advocacy groups (such as the National Hemophilia Foundation)
- [ ] Internet/medical websites
- [ ] Social media forums
- [ ] Other (please specify)

  _____

- [ ] None of the above

128. In the previous 12 months: Where has your person with a bleeding disorder received medical care for **any reason (including for hereditary factor X deficiency)**?

- [ ] Urgent care
- [ ] Emergency room
- [ ] Hospital admission
- [ ] Primary care provider
- [ ] Hemophilia Treatment Center (HTC)
- [ ] Other (please specify)

  _____

- [ ] None of the above

129. In the previous 12 months: Where has your person with HFXD received medical care for **their hereditary factor X deficiency**?

- [ ] Urgent care
- [ ] Emergency room
- [ ] Hospital admission
- [ ] Primary care provider
- [ ] Hemophilia Treatment Center (HTC)
- [ ] [Insert text from Other]
- [ ] None of the above

HFXD in America

130. In the previous 12 months: How many times did your person with a bleeding disorder go to each specific location for **any reason**?

	1-2 times	3-4 times	5-9 times	10 or more times
Urgent care	○	○	○	○
Emergency room	○	○	○	○
Hospital admission	○	○	○	○
Primary care provider	○	○	○	○
Hemophilia Treatment Center (HTC)	○	○	○	○
[Insert text from Other]	○	○	○	○

131. In the previous 12 months: How many times did your person with a bleeding disorder go to each specific location for **their hereditary factor X deficiency**?

	1-2 times	3-4 times	5-9 times	10 or more times
Urgent care	○	○	○	○
Emergency room	○	○	○	○
Hospital admission	○	○	○	○
Primary care provider	○	○	○	○
Hemophilia Treatment Center (HTC)	○	○	○	○
[Insert text from Other]	○	○	○	○

132. In the previous 12 months: How many different medications does your person with HFXD take for **any condition**?

- 0
- 1-3
- 4-6
- 7-9
- 10 or more

133. In the previous 12 months: How many different medications does your person with a bleeding disorder *currently take* for their **hereditary factor X deficiency**?

- 0
- 1-3
- 4-6
- 7-9
- 10 or more

134. In the previous 12 months: How many different medications has your person with a bleeding disorder *ever taken* for their **hereditary factor X deficiency**?

- 0
- 1-3
- 4-6
- 7-9
- 10 or more

135. Which gender does your person with with a bleeding disorder identify as?

- ◯ Female
- ◯ Male
- ◯ Transgender Female
- ◯ Transgender Male
- ◯ Non-Binary
- ◯ Prefer not to say
- ◯ Prefer to self-describe:

136. What is your person with with a bleeding disorder's ethnicity?

- ◯ Hispanic or Latino
- ◯ Not Hispanic or Latino
- ◯ Prefer not to answer

137. What is your person with with a bleeding disorder's race? Please select all that apply.

- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ Native Hawaiian or Other Pacific Islander
- ☐ American Indian or Alaskan Native
- ☐ Prefer not to answer

138. Is your person with with a bleeding disorder of Mediterranean or Middle Eastern descent? While hereditary factor X deficiency can occur in individuals of any ethnic group, people with Mediterranean or Middle Eastern descent have a higher risk of inheriting factor X deficiency. Please select all that apply.

- [ ] Mediterranean
- [ ] Middle Eastern
- [ ] Neither
- [ ] Prefer not to answer

139. What is your person with a bleeding disorder's employment status?

- ( ) Student
- ( ) Full-Time Employed
- ( ) Part-Time Employed
- ( ) Unemployed
- ( ) Unable to work due to disability
- ( ) Prefer not to answer
- ( ) Other (please specify)

140. What is your person with a bleeding disorder's annual income level?

- ( ) Under $20,000
- ( ) $20,001 - $40,000
- ( ) $40,001 - $60,000
- ( ) $60,001 - $80,000
- ( ) $80,001 - $100,000
- ( ) More than $100,000
- ( ) N/A or Prefer not to answer

141. Would you like to take another survey regarding caregiver burden for an additional reward?

You can take this survey now by selecting "Yes" below, or return to the study website to access this survey at another time.

- ◯ Yes
- ◯ No

Please click HERE to continue to the caregiver burden survey.

Do not click "Done" button below.