Hemophilia of South Carolina

2016 Advocacy Outreach Survey

Thank you in advance for your assistance to Hemophilia of South Carolina's State Advocacy Coalition for Hemophilia and Bleeding Disorders. This coalition is comprised of strong leadership from local healthcare individuals, HSC advocacy community members and national leader's well versed and committed to advocacy for those living with bleeding disorders. Your commitment to this survey will allow us to work on your behalf to alleviate the barriers you can face with access to quality care and treatment, education and support services. Please complete this survey before ***September 2, 2016*** *and mail, fax, or email it to the Chapter. You do not need to sign your name (unless you choose to do so) as this is an anonymous survey. Please answer all questions to the best of your ability and honestly. There are 42 total questions. The survey will take approximately 15 minutes or less of your time. Thank you!*

MAIL to: Hemophilia of South Carolina
439 Congaree Road, Suite #5
Greenville, SC 29607
FAX: 864-244-8287
EMAIL (Scan and Send): info@hemophiliaofsc.org
QUESTIONS: 864-350-9941

Personal Information

1. Do you or someone in your household have a bleeding disorder, and do you wish to participate in this important survey for individuals with bleeding disorders living in South Carolina?
   (Circle Please)

   YES
   NO
   COMMENTS_____
   _____
   _____
   _____

2. Do you live in South Carolina? *(Circle Please) (If you do not live in South Carolina, you do not need to take this survey but thank you anyways!)*

   YES
   NO

3. If your answer was yes to number 2, which region of South Carolina do you reside in?
   (Circle Please)

   UPSTATE
   MIDSTATE
   LOW COUNTRY

4. Which of the following age groups applies to you? *(Circle Please)*

Less than 1 year
1 to 18 years
19 to 34 years
35 to 44 years
45 to 54 years
55 to 64 years
65 years and older

5. Do you yourself have a bleeding disorder? *(Circle Please)*

YES
NO

6. What type of bleeding disorder do you have? *(Circle Please)*

HEMOPHILIA
Von WILLEBRAND DISEASE
OTHER (please fill in) _____
I am a caretaker, spouse, sibling, or other. I do not have a bleeding disorder.

If you are an individual, skip to question 10. If you are a caretaker of someone with a bleeding disorder continue to question 7

7. Are you a parent of a child or children that have a bleeding disorder? *If yes, how many? (Circle Please)*

1 child
2 children
3 children
4 or more children
NO

8. Which of the following age groups applies to your child(ren) that have a bleeding disorder? *(Circle Please)*

1 to 5 years
6 to 11 years
12 to 18 years
19 to 25 years
26 to 40 years
41 to 60 years
61 years and older

9. What type of bleeding disorder does your child(ren) have? *(Circle Please)*

HEMOPHILIA
von WILLEBRAND DISEASE
OTHER (Please fill in) _____

10. How many people do you have living in your immediate household? *(Circle Please)*

1
2
3
4
5
6
MORE THAN 6

11. How many people in your household have a bleeding disorder? *(fill in please)*

# of individuals affected: _____

12. How and when were you and/or your family member's with bleeding disorder diagnosed? *(Circle all that apply)*

FAMILY HISTORY
PRE-NATALLY
BIRTH (through complications or routine blood tests)
CHILDHOOD
TEEN / YOUNG ADULTS
ADULTHOOD
FROM COMPLICATIONS (Surgery, Dental procedures or at a Doctor's visit)
MENSTRUAL CYCLE (complications)
OTHER (please provide)_____

13. How many (approximately) bleeds did you or your family members have last year? *(Circle Please)*

NONE
1 bleed
2-5 bleeds
6 or more bleeds
I do not remember.
Other_____

HealthCare Questions

14. Which of the following options best describes your primary health insurance? *(Circle Please)*

    EMPLOYER PROVIDED
    PRIVATE INSURANCE THAT YOU PAY OUT OF POCKET
    FEDERAL MARKETPLACE
    MEDICARE
    MEDICAID
    DO NOT HAVE INSURANCE
    OTHER- *Please provide:* _____

15. Do you have a secondary health insurance plan in addition to your primary health insurance to help cover the cost of your clotting factor treatments? *(Circle Please)*

    YES
    NO
    I AM NOT SURE AND DO NOT KNOW

    COMMENTS_____
    _____

16. Does your current insurance plan cover access to all clotting (factor) products? *(Circle Please)*

    YES
    NO
    I AM NOT SURE AND DO NOT KNOW

17. If you answered no to #16, did you have to change to a different factor product to be covered by your insurance plan? *(Circle Please)*

    YES
    NO
    N / A

18. Is your current clotting factor covered under your pharmacy benefits or under your major medical? *(Circle Please)*

    PHARMACY
    MAJOR MEDICAL
    I DO NOT KNOW

19. Is your health insurance provided through the South Carolina Federal Market Exchange (MarketPlace)? *(Circle Please)*

    YES
    NO

20. What is the amount of your ***monthly premium payment*** for your health insurance? *(Circle Please)*

Less than 100 dollars
101 to 500 dollars
501 to 1,000 dollars
1,001 to 1,500 dollars
1,501 dollars to 2,000 dollars
More than 2,000 dollars
I am not sure and do not know

21. What is your health insurance ***deductible*** per year? *(Circle Please)*

500 dollars or less
501 to 1,000 dollars
1,001 to 2,500 dollars
2,501 to 5,000 dollars
5,001 to 10,000 dollars
10,000 to 20,000 dollars
OTHER $ _____
I am not sure and do not know

22. What is your ***Co-Pay or Co-Insurance*** per year on your healthcare policy? *(Fill in please)*

$_____ or %_____

23. What is your max ***Out-of-Pocket*** on your plan? *(Fill in please)*

$ _____

24. Did you end up paying the full amount of your health insurance ***deductible*** last year? *(Circle Please)*

YES
NO
I AM NOT SURE AND DO NOT KNOW

25. Did you end up paying the full amount of your health insurance ***maximum out-of-pocket*** last year? *(Circle Please)*

YES
NO
I AM NOT SURE AND DO NOT KNOW

26. How much of that ***deductible*** did you personally pay last year? *(Circle Please)*

0 dollars
250 dollars or less
251 to 500 dollars
501 to 1,000 dollars
1,001 to 2,500 dollars
2,501 to 5,000 dollars
5,001 to 10,000 dollars
10,001 to 20,000 dollars
20,000 dollars or more
I am not sure and do not know

27. Do you receive any assistance paying your ***Co-Pays and Deductibles***? *(Circle Please)*
    YES
    NO

28. Do you receive any *Heath Care Insurance Premium Assistance* through the ***South Carolina Bleeding Disorder Premium Assistance Program*** (PSI)? *(Circle Please)*

    YES
    NO

29. If you answered **YES** to question #28, is the current process required to receive your premium assistance satisfactory? *(Circle Please)*
    YES
    NO
    N/A

30. If you answered **NO** to question #29, what are the barriers or situations that keep the process from being satisfactory? *(Please Explain)*

    _____
    _____
    _____
    _____
    _____
    _____

31. Were you or a member of your family hospitalized due to a bleeding disorder in 2015, and if so, do you remember ***what you paid out-of-pocket*** for your stay? *(Circle Please)*

    500 dollars or less
    501 to 1,000 dollars
    1,001 to 2,500 dollars
    2,501 to 5,000 dollars
    5,001 to 10,000 dollars
    10,001 to 20,000 dollars
    20,000 dollars or more
    YES, BUT I DO NOT REMEMBER HOW MUCH
    NO I DID NOT HAVE TO PAY ANY OUT OF POCKET
    NO HOSPITALIZATION WAS REQUIRED LAST YEAR

32. Do you feel you have the necessary medical treatment you need to successfully treat you or your families bleeding disorder? *(Circle Please)*

    YES
    NO
    If no, Please explain-COMMENTS:
    _____
    _____
    _____
    _____
    _____

33. In your opinion what is your biggest barrier to receiving quality care and treatment for you or your families bleeding disorder? (Choose all that apply to you)

    TRAVEL DISTANCE
    OUT OF POCKET COSTS FOR VISIT
    NO INSURANCE
    INSURANCE RESTRICTIONS
    TIME NEEDED TO TAKE OFF WORK
    LACK OF ADULT ONLY HEMOPHILIA TREATMENT CENTER IN SOUTH CAROLINA
    OTHER: Please explain_____
    _____
    _____
    _____
    _____
    _____

34. Have you had any problems getting assistance that you or your family needed? *(Circle Please)*

YES
NO
If yes, please explain the assistance that you needed and where you tried to get help from.

_____
_____
_____
_____
_____
_____

35. Do you find it difficult to access a qualified healthcare provider, doctor, or nurse who will care for you or your loved one with a bleeding disorder? *(Circle Please)*

YES
NO
COMMENTS_____

36. Do you receive healthcare for you or your child's bleeding disorder in South Carolina? *(Circle Please)*

YES, AT THE ***Federally Funded Comprehensive Hemophilia Treatment Center*** IN COLUMBIA
YES, AT THE GREENVILLE HOSPITAL SYSTEM, BILO CANCER CENTER (HTC)
YES, AT MEDICAL UNIVERSITY SOUTH CAROLINA (MUSC) HTC
YES, AT A PRIVATE MEDICAL DOCTOR/HEMATOLOGIST OFFICE HERE IN SOUTH CAROLINA
NO, I RECEIVE TREATMENT OUT OF STATE
*** IF OUT OF THE STATE OF SOUTH CAROLINA, PLEASE EXPLAIN THE CIRCUMSTANCES THAT TAKE YOU OUT OF STATE FOR TREATMENT BELOW:

COMMENTS:_____
_____
_____
_____
_____

37. Did you know there is a ***Federally Funded Comprehensive Care Hemophilia Treatment Center*** in Columbia? *(Circle Please)*

YES, I RECEIVE MY TREATMENT THERE
NO, I DID NOT KNOW ABOUT THE HTC IN COLUMBIA

YES, BUT I DO NOT RECEIVE MY TREATMENT THERE BECAUSE;

_____

_____

_____

38. How many times did you or your family member with a blood disorder visit YOUR "HTC" in 2015? *(Circle Please)*

    I did not visit my HTC or Hematologist this past year
    Visited 1-2 times
    Visited 3 times
    Visited 5 to 10 times
    Visited more than 10 times

39. Does your current insurance healthcare plan cover the HTC that you would like to use in network? *(Circle Please)*

    YES
    NO

40. During an emergency visit at hospitals, do you find it difficult to get the help you need in reference to the local doctors getting the proper instructions for your treatment from your Hematologist or HTC? *(Circle Please)*

    YES
    NO
    COMMENTS:
    _____
    _____
    _____
    _____

Healthcare Educational Needs

41. Do you feel you need additional help, or would like to receive additional help, with informing and educating others (see next question) about you or your loved one's bleeding disorder or situational conditions due to living a bleeding disorder? *(Circle Please)*

    YES
    NO
    COMMENTS_____
    _____

42. If you answered yes to question #41, circle all below that apply? *(Circle Please)*

    INFORMING SCHOOLS
    INFORMING NURSES
    GENERAL PRACTITIONER OR PRIMARY PHYSICIANS
    OB/GYN
    EMPLOYERS
    HOSPITAL ER ROOMS
    DAY CARE FACILITIES

-End of Survey- Thank you for taking this survey! We value your input. *Best to you always, Hemophilia of South Carolina*