

Prophylaxis Survey 2010

1. What is your role at your Hemophilia Treatment Center?

- Physician
- Nurse
- Nurse practitioner
- Physician Assistant
- Social worker

Other (please specify)

2. For how many years have you been taking care of children with hemophilia?

- 0-5
- 6-10
- 11-20
- 21-40
- >40

3. What is the name of your Hemophilia Treatment Center?

4. Which Region is your Hemophilia Treatment Center affiliated with?

- | | |
|--|--|
| <input type="checkbox"/> Region I | <input type="checkbox"/> Region V-East |
| <input type="checkbox"/> Region II | <input type="checkbox"/> Region VI |
| <input type="checkbox"/> Region III | <input type="checkbox"/> Region VII |
| <input type="checkbox"/> Region IV-North | <input type="checkbox"/> Region VIII |
| <input type="checkbox"/> Region IV-South | <input type="checkbox"/> Region IX |
| <input type="checkbox"/> Region V-West | <input type="checkbox"/> Region X |

5. What is the your primary focus at your Hemophilia Treatment Center?

- Children only
- Children and adults

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6. How many children (age less than 18 years) with hemophilia do you take care of at your Hemophilia Treatment Center? If you do not take care of children you may stop the survey.

1-10

11-50

51-100

>100

For the purpose of this survey prophylaxis is defined as long-term continuous (at least 46 weeks per year) treatment with factor.

Primary prophylaxis is initiated prior to the development of a target joint.

Secondary prophylaxis is initiated after the development of a target joint.

7. Do you routinely prescribe prophylaxis for children with severe hemophilia?

No

Yes

8. For what percentage of severe hemophilia patients without a target joint do you prescribe primary prophylaxis? Please mark an answer for each age range.

N/A means that you have no patients in that age range without a target joint.

	N/A	0-25%	26-50%	51-75%	76-100%
12-23 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2-5 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6-11 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12-18 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. For what percentage of severe hemophilia patients with a target joint do you prescribe secondary prophylaxis? Please mark an answer or each age range.

N/A means that you have no patients in that age range with a target joint.

	N/A	0-25%	26-50%	51-75%	76-100%
2-5 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6-12 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13-18 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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10. What is the primary reason for prescribing prophylaxis for each age range?

	primary prophylaxis	secondary prophylaxis	prevent inhibitor formation
12-23 months	jn	jn	jn
2-5 years	jn	jn	jn
6-12 years	jn	jn	jn
13-18 years	jn	jn	jn

11. How often do the following motivate you to prescribe primary prophylaxis?

	Always or almost always	Often	Sometimes	Never
Family history of hemarthroses	jn	jn	jn	jn
Personal history of first hemarthrosis	jn	jn	jn	jn
Personal history of soft tissue bleeds	jn	jn	jn	jn
Family request	jn	jn	jn	jn

12. How often do the following impact your prescription of primary prophylaxis?

	Always or almost always	Often	Sometimes	Never
Type of genetic mutation	jn	jn	jn	jn
Family history of inhibitor	jn	jn	jn	jn

Comments:

13. How often do the following decrease your willingness to prescribe prophylaxis for an individual patient?

	Always or almost always	Often	Sometimes	Never
Financial concerns	jn	jn	jn	jn
Lack of venous access	jn	jn	jn	jn
Concern that patient/family will not be adherent to prophylaxis	jn	jn	jn	jn
Lack of published trials comparing prophylaxis and on-demand therapy	jn	jn	jn	jn

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14. How do you assess adherence to continuous prophylaxis in your patient population? Please check all that apply.

- Factor levels
- Electronic Logs
- Hand Written Logs
- Veritas-Pro (hemophilia specific adherence measure)
- Pharmacy records
- Frequency of joint bleeds
- Joint examination
- Attendance at school/work
- Participation in physical activity/sports

15. How do you assess success of continuous prophylaxis? Please check all that apply.

- Frequency of joint bleeds
- Joint exam
- Measure of health related quality of life
- Attendance at school/work
- Participation in physical activities/sports

16. What percentage of your pediatric patients on prophylaxis give at least 80% of the recommended infusions?

	0-25%	26-50%	51-75%	76-100%
overall	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12-23 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2-5 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6-12 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13-18 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17. Have you decided not to prescribe prophylaxis for a patient because of adherence concerns within the last two years?

- Yes
- No

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18. Have you decided to stop prophylaxis for a patient because of adherence concerns in the last 2 years?

Yes

No

19. Please consider the following scenario and answer the question below.

A 2 year old male with severe hemophilia A presents to clinic for a Comprehensive Care visit. There is no family history of hemophilia. The child has had hematomas and two episodes of oral bleeding and one joint bleed. The child lives with his mother, father, and ten-year old sister. His father is a university professor. His mother is a homemaker and volunteers at his sister's school once a week. Venous access has not been difficult for on-demand infusions of factor VIII.

Based on your usual practice, would you prescribe prophylaxis for this patient?

Yes

No

Comments

20. A 2 year old male with severe hemophilia A presents to clinic for a Comprehensive Care visit. There is no family history of hemophilia. The child has had hematomas and two episodes of oral bleeding and one joint bleed. The child lives with his mother, father, and ten-year old sister. His father is a university professor. His mother is a homemaker and volunteers at his sister's school once a week. Venous access has been difficult for on-demand infusions of factor VIII.

Based on your usual practice, would would you prescribe prophylaxis for this patient?

Yes

No

Comments

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21. A 2 year old male with severe hemophilia A presents to clinic for a Comprehensive Care visit. There is no family history of hemophilia. The child has had hematomas and two episodes of oral bleeding and one joint bleed. The child lives with his mother and three siblings. His mother works two part-time jobs and the child attends daycare. Venous access has not been difficult for on-demand infusions of factor VIII.

Based on your usual practice, would you prescribe prophylaxis for this patient?

Yes

No

Comments

22. A 2 year old male with severe hemophilia A presents to clinic for a Comprehensive Care visit. There is no family history of hemophilia. The child has had hematomas and two episodes of oral bleeding and one joint bleed. The child lives with his mother and three siblings. His mother works two part-time jobs and the child attends daycare. Venous access has been difficult for on-demand infusions of factor VIII.

Based on your usual practice, would you prescribe prophylaxis for this patient?

Yes

No

Comments

23. The authors of the Joint Outcomes Study concluded that "Prophylaxis with recombinant factor VIII can prevent joint damage and decrease the frequency of joint and other hemorrhages in young boys with severe hemophilia A."

	Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
Do you agree or disagree with this conclusion?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24. How have the results of the Joint Outcomes Study impacted your clinical practice?

Increased prescription of prophylaxis (please answer questions 25-27)

No change (please answer questions 28-29)

Decreased prescription of prophylaxis (please answer questions 30-31)

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25. Why has the Joint Outcomes Study increased your prescription of prophylaxis? Please mark all answers that apply.

- I am more convinced that prophylaxis improves joint outcomes.
- I have been able to convince more patients that prophylaxis is worthwhile.
- I think that results of this study will improve adherence with prophylaxis.
- Insurance companies are more likely to cover prophylaxis since publication of the study results.

Comments

26. How has your prescription of prophylaxis changed since publication of the Joint Outcomes Study for each age range?

	Increased	Decreased	Remained the same
12-23 months	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3-5 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6-12 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13-18 years	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

27. Which of the following has increased your prescription of prophylaxis? Please mark all which apply.

- Canadian Hemophilia Prophylaxis Study-tailored prophylaxis
- German study to initiate prophylaxis early as a measure to prevent inhibitor formation
- None of the above

Comments

28. Why has the Joint Outcomes Study not influenced your prescription of prophylaxis?

- I am not aware of the results of the Joint Outcomes Study.
- I already prescribe prophylaxis to the vast majority of my patients.
- The results were not convincing enough to change my practice.
- There are too many barriers to prophylaxis.

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29. Which of the following has increased your prescription of prophylaxis? Please mark all which apply.

- Canadian Hemophilia Prophylaxis Study-tailored prophylaxis
- German study to initiate prophylaxis early as a measure to prevent inhibitor formation
- None of the above

Comments

30. Why has the Joint Outcomes Study decreased your prescription of prophylaxis?

31. Which of the following studies increased your prescription of prophylaxis?

- Canadian Hemophilia Prophylaxis Study-tailored prophylaxis
- German study to initiate prophylaxis early as a measure to prevent inhibitor formation
- None of the above

Comments

Thank you for completing the survey.

Please fax to 919-684-5752 or email to thorn006@mc.duke.edu