



GAIN CONFIDENCE + MASTER SKILLS

Child's Name _____

PEDIATRIC HEMOPHILIA SELF-INFUSION PROGRAM

INFUSION U – PARENT PRE-PROGRAM QUESTIONNAIRE

1. How would you describe your child's knowledge about his bleeding disorder?

- Not too knowledgeable Somewhat knowledgeable Very knowledgeable No opinion

2. How would you describe your anxiety about your child doing his own infusion?

- Very anxious Somewhat anxious Not at all anxious

3. What is your child's prophylactic treatment and schedule?

4. What is your child's treatment for bleeding?

5. How would you describe your child's ability to cooperate with infusions at home?

- Doesn't cooperate at all Sometimes cooperates Often cooperates Always cooperates

6. Who does your child's infusions at home?

7. What is the average length of time an infusion takes from start to finish?

8. Is your child able to state the name and dose of his factor medication?

- Name only Dose only Both Neither

9. On average, how many times a month does the infusion at home take more than one poke?

- Never Sometimes (1-3 times) Often (3-6 times) Frequently (6+ times)

10. Does your child ever miss an infusion because (check all that apply)?

- Cannot find a vein Child does not cooperate Vein accessed but access lost before infusion is complete
 Factor not available when the infusion is needed

11. How do you record infusions at home?

12. Has your child ever attempted self-infusion?

13. What happens when you are unable to find a vein to give infusion?

14. What would you like your child to gain from this experience?



GAIN CONFIDENCE + MASTER SKILLS

Child's Name _____

PEDIATRIC HEMOPHILIA SELF-INFUSION PROGRAM

INFUSION U – PARENT POST-PROGRAM QUESTIONNAIRE

1. Since completing the infusion program, how would you describe your child's knowledge about his bleeding disorder?

- Not very knowledgeable Somewhat knowledgeable Very knowledgeable No opinion

2. Since completing the infusion program, has your child's treatment schedule changed at all? If so, how?

3. Since completing the infusion program, how often does your child give his own infusion without assistance?

- Always Most of the time Sometimes Never

If you answered "most of the time," "sometimes," or "never" why? (e.g. refusal, time, etc.)

4. Which parts of the infusion is your child consistently able to do by himself? (check all that apply)

- | | | |
|--|--|---|
| <input type="checkbox"/> Mix factor | <input type="checkbox"/> Apply tourniquet | <input type="checkbox"/> Push the factor in |
| <input type="checkbox"/> Prepare work area | <input type="checkbox"/> Cleanse area | <input type="checkbox"/> Remove the needle |
| <input type="checkbox"/> Identify vein | <input type="checkbox"/> Put the needle in | <input type="checkbox"/> Record infusion |

5. Has the average length of time an infusion takes from start to finish changed since completing the program?

- Yes No

If yes, how long was infusion taking prior to the program and how long does the infusion take now?

6. Approximately how many times per month does the infusion require more than one poke, and has this changed since completing the program?

- Never 1-3 times per month 3-6 times per month 6+ times per month Always

Is this More less or same as before?

7. Approximately how many times per month does your child miss an infusion because a vein cannot be accessed?

- Never 1-3 times per month 3-6 times per month 6+ times per month

8. If your child has a port, how many times a month is the port used instead of peripheral vein? Please also describe reason for using the port:

- Never 1-3 times per month 3-6 times per month 6+ times per month Always

Reason?

9. Has your child used any of the techniques learned in class to help him find a vein? (check all that apply)

- Warm compress, warm water, warm towel Squeeze ball
 Extra hydration
 Gravity (monkey arms, hanging arms down for a few minutes before looking for vein)
 Other _____
-

10. How are infusions recorded at home?

- Electronic logs Do not record
 Paper logs Other _____
 Calendar

11. Do you feel that the program met the needs of your child?

- Yes No **Please explain:** _____
-

12. What do you feel were the strengths of the program?

13. Please describe one way (or more) the program might be improved:

14. Is there anything we might do to help you/your child implement practices learned in class at home?

15. We are interested to know what changes (if any) you have seen in your child since completing the program.

Please describe any changes.

16. Five training/teaching sessions were offered during the program. Did the program offer enough sessions for your child to learn self-infusion?

17. Do you feel the age of your child was appropriate to learn self-infusion? _____



GAIN CONFIDENCE + MASTER SKILLS

Child's Name _____

PEDIATRIC HEMOPHILIA SELF-INFUSION PROGRAM

INFUSION U – 3 MONTH POST-PROGRAM QUESTIONNAIRE

1. Since completing the infusion program, how would you describe your child's knowledge about his bleeding disorder?

- Not very knowledgeable Somewhat knowledgeable Very knowledgeable No opinion

2. Since completing the infusion program, has your child's treatment schedule changed at all? If so, how?

3. Since completing the infusion program, how often does your child give his own infusion without assistance?

- Always Most of the time Sometimes Never

If you answered "most of the time," "sometimes," or "never" why? (e.g. refusal, time, etc.)

4. Which parts of the infusion is your child consistently able to do by himself? (check all that apply)

- | | | |
|--|--|---|
| <input type="checkbox"/> Mix factor | <input type="checkbox"/> Apply tourniquet | <input type="checkbox"/> Push the factor in |
| <input type="checkbox"/> Prepare work area | <input type="checkbox"/> Cleanse area | <input type="checkbox"/> Remove the needle |
| <input type="checkbox"/> Identify vein | <input type="checkbox"/> Put the needle in | <input type="checkbox"/> Record infusion |

5. Has the average length of time an infusion takes from start to finish changed since completing the program?

- Yes No

If yes, how long was infusion taking prior to the program and how long does the infusion take now?

6. Approximately how many times per month does the infusion require more than one poke, and has this changed since completing the program?

- Never 1-3 times per month 3-6 times per month 6+ times per month Always

Is this More less or same as before?

7. Approximately how many times per month does your child miss an infusion because a vein cannot be accessed?

- Never 1-3 times per month 3-6 times per month 6+ times per month

8. If your child has a port, how many times a month is the port used instead of peripheral vein? Please describe reason for using the port:

- Never 1-3 times per month 3-6 times per month 6+ times per month Always

Reason?

9. Has your child used any of the techniques learned in class to help him find a vein? (check all that apply)

- Warm compress, warm water, warm towel Squeeze ball
 Extra hydration
 Gravity (monkey arms, hanging arms down for a few minutes before looking for vein)
 Other _____

10. How are infusions recorded at home?

- Electronic logs Do not record
 Paper logs Other _____
 Calendar

11. Do you feel that the program met the needs of your child?

- Yes No **Please explain:** _____

12. What do you feel were the strengths of the program?

13. Please describe one way (or more) the program might be improved:

14. Is there anything we might do to help you/your child implement practices learned in class at home?

15. We are interested to know what changes (if any) you have seen in your child since completing the program. Please describe any changes.
