

ID: _____

Date: _____

RESPONSES TO STRESS – [SC] (PR-Son)

This is a list of things about sickle cell disease that children and teenagers sometimes find stressful or a problem to deal with. Please circle the number indicating how stressful the following things have been for your son in the past 6 months.

| | Not at All | A Little | Somewhat | Very |
|--|------------|----------|----------|------|
| a. Not being able to do the things that other kids can do or are allowed to do | 1 | 2 | 3 | 4 |
| b. Having to go to the hospital or clinic so often | 1 | 2 | 3 | 4 |
| c. Missing school days or falling behind in school work | 1 | 2 | 3 | 4 |
| d. Concerns about his family and friends | 1 | 2 | 3 | 4 |
| e. Feeling confused about what sickle cell disease is and why he got it | 1 | 2 | 3 | 4 |
| f. Not understanding what doctors tell him about sickle cell disease | 1 | 2 | 3 | 4 |
| g. Having sickle cell pain crises | 1 | 2 | 3 | 4 |
| h. Concerns about the future | 1 | 2 | 3 | 4 |
| i. Other: _____ | 1 | 2 | 3 | 4 |
| j. | 1 | 2 | 3 | 4 |
| k. | 1 | 2 | 3 | 4 |
| l. | 1 | 2 | 3 | 4 |

Circle the number that shows how much control he generally thinks he has over these problems.

| | | | |
|------|----------|------|-------|
| 1 | 2 | 3 | 4 |
| None | A little | Some | A lot |

Below is a list of things that children and teenagers sometimes do, think, or feel when they are dealing with sickle cell disease. Everyone deals with problems in their own way – some people do a lot of the things on this list or have a bunch of feelings, other people just do or think a few of these things.

Think of all the stressful parts of sickle cell disease that have been stressful for your son lately that you checked off above. For each item below, circle **one** number from 1 (not at all) to 4 (a lot) that shows **how much** he does or feels these things when he has the problems with sickle cell like the ones you indicated above. Please let us know about everything he does, thinks, and feels, even if you don't think it helps make things better.

| | How much does he do this? | | | |
|---|---------------------------|----------|------|-------|
| | Not at all | A little | Some | A lot |
| 1. He tries not to feel anything. | 1 | 2 | 3 | 4 |
| 2. When dealing with the stress of having sickle cell disease, he feels sick to his stomach or gets headaches. | 1 | 2 | 3 | 4 |
| 3. He tries to think of different ways to change or fix the situation. Write one plan he thought of: _____ _____ | 1 | 2 | 3 | 4 |
| 4. When faced with the stress of having sickle cell disease, he doesn't feel anything at all, it's like he has no feelings. | 1 | 2 | 3 | 4 |
| 5. He wishes that he were stronger and less sensitive so that things would be different. | 1 | 2 | 3 | 4 |

| WHEN DEALING WITH THE STRESS OF SICKLE CELL DISEASE: | How much does he do this? | | | |
|---|---------------------------|----------|------|-------|
| | Not at all | A little | Some | A lot |
| 6. He keeps remembering what happened with sickle cell disease or can't stop thinking about what might happen. | 1 | 2 | 3 | 4 |
| 7. He lets someone or something know how he feels. (<i>remember to circle a number.</i>) → Check all he talked to: <input type="checkbox"/> Parent <input type="checkbox"/> Friend <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Pet <input type="checkbox"/> Clergy Member <input type="checkbox"/> Teacher <input type="checkbox"/> God <input type="checkbox"/> Stuffed Animal <input type="checkbox"/> Other Family Member <input type="checkbox"/> None of these | 1 | 2 | 3 | 4 |
| 8. He decided he is okay the way he is, even though he's not perfect. | 1 | 2 | 3 | 4 |
| 9. When he is around other people he acts like he does not have sickle cell disease. | 1 | 2 | 3 | 4 |
| 10. He just has to get away from everything when he is dealing with the stress of having sickle cell disease. | 1 | 2 | 3 | 4 |
| 11. He deals with the stress of having sickle cell disease by wishing it would just go away, that everything would work itself out. | 1 | 2 | 3 | 4 |
| 12. He gets really jumpy when he is dealing with the stress of having sickle cell disease. | 1 | 2 | 3 | 4 |
| 13. He realizes that he just has to live with things the way they are. | 1 | 2 | 3 | 4 |
| 14. When he is dealing with the stress of having sickle cell disease, he just can't be near anything that reminds him of sickle cell. | 1 | 2 | 3 | 4 |
| 15. He tries not to think about it, to forget all about it. | 1 | 2 | 3 | 4 |
| 16. When he is dealing with the stress of having sickle cell disease, he really doesn't know what he feels. | 1 | 2 | 3 | 4 |
| 17. He asks other people or things for help or for ideas about how to make things better. (<i>remember to circle a number.</i>) → Check all he talked to: <input type="checkbox"/> Parent <input type="checkbox"/> Friend <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Pet <input type="checkbox"/> Clergy Member <input type="checkbox"/> Teacher <input type="checkbox"/> God <input type="checkbox"/> Stuffed Animal <input type="checkbox"/> Other Family Member <input type="checkbox"/> None of these | 1 | 2 | 3 | 4 |
| 18. When he is trying to sleep, he can't stop thinking about the stressful aspects of having sickle cell disease or he has bad dreams about having sickle cell disease. | 1 | 2 | 3 | 4 |
| 19. He tells himself that he can get through this, or that he will be okay. | 1 | 2 | 3 | 4 |
| 20. He lets his feelings out. (<i>remember to circle a number.</i>) → He does this by: (Check all that he did.) <input type="checkbox"/> Writing in his journal/diary <input type="checkbox"/> Drawing/painting <input type="checkbox"/> Complaining to let off steam <input type="checkbox"/> Being sarcastic/making fun <input type="checkbox"/> Listening to music <input type="checkbox"/> Punching a pillow <input type="checkbox"/> Exercising <input type="checkbox"/> Yelling <input type="checkbox"/> Crying <input type="checkbox"/> None of these | 1 | 2 | 3 | 4 |
| 21. He gets help from other people or things when he is trying to figure out how to deal with his feelings. (<i>remember to circle a number.</i>) → Check all that he went to: <input type="checkbox"/> Parent <input type="checkbox"/> Friend <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Pet <input type="checkbox"/> Clergy Member <input type="checkbox"/> Teacher <input type="checkbox"/> God <input type="checkbox"/> Stuffed Animal <input type="checkbox"/> Other Family Member <input type="checkbox"/> None of these | 1 | 2 | 3 | 4 |
| 22. He just can't get himself to face the stress of having sickle cell disease. | 1 | 2 | 3 | 4 |
| 23. He wishes that someone would just come and take away the stressful aspects of having sickle cell disease. | 1 | 2 | 3 | 4 |

You're half done. Before you keep working, look back at the first page so you remember the aspects of having sickle cell disease that have been stressful for your son lately. Remember to answer the questions below thinking about these things.

| WHEN DEALING WITH THE STRESS OF SICKLE CELL DISEASE: | How much does he do this? | | | |
|--|---------------------------|----------|------|-------|
| | Not at all | A little | Some | A lot |
| 24. He does something to try to fix the stressful parts of having sickle cell disease. Write one thing he did: _____ _____ | 1 | 2 | 3 | 4 |
| 25. Thoughts about having sickle cell disease just pop into his head. | 1 | 2 | 3 | 4 |
| 26. When he is dealing with the stress of having sickle cell disease, he feels it in his body. (remember to circle a number.) → Check all that happen: <input type="checkbox"/> His heart races <input type="checkbox"/> His breathing speeds up <input type="checkbox"/> None of these <input type="checkbox"/> He feels hot or sweaty <input type="checkbox"/> His muscles get tight | 1 | 2 | 3 | 4 |
| 27. He tries to stay away from people and things that make him feel upset or remind him of stressful aspects of having sickle cell disease. | 1 | 2 | 3 | 4 |
| 28. He doesn't feel like himself when he is dealing with the stress of having sickle cell disease, it's like he is far away from everything. | 1 | 2 | 3 | 4 |
| 29. He just takes things as they are; he goes with the flow. | 1 | 2 | 3 | 4 |
| 30. He thinks about happy things to take his mind off the stressful parts of having sickle cell disease or how he is feeling . | 1 | 2 | 3 | 4 |
| 31. When something stressful happens related to having sickle cell disease, he can't stop thinking about how he is feeling. | 1 | 2 | 3 | 4 |
| 32. He gets sympathy, understanding, or support from someone. (remember to circle a number.) → Check all he went to: <input type="checkbox"/> Parent <input type="checkbox"/> Friend <input type="checkbox"/> Brother/Sister <input type="checkbox"/> Pet <input type="checkbox"/> Clergy Member <input type="checkbox"/> Teacher <input type="checkbox"/> God <input type="checkbox"/> Stuffed Animal <input type="checkbox"/> Other Family Member <input type="checkbox"/> None of these | 1 | 2 | 3 | 4 |
| 33. When something stressful happens related to having sickle cell disease, he can't always control what he does. (remember to circle a number.) → Check all that happen: <input type="checkbox"/> He can't stop eating <input type="checkbox"/> He can't stop talking <input type="checkbox"/> He does dangerous things <input type="checkbox"/> He has to keep fixing/checking things <input type="checkbox"/> None of these | 1 | 2 | 3 | 4 |
| 34. I tell myself that things could be worse. | 1 | 2 | 3 | 4 |
| 35. His mind just goes blank when something stressful happens related to having sickle cell disease, he can't think at all. | 1 | 2 | 3 | 4 |
| 36. He tells himself that it doesn't matter, that it isn't a big deal. | 1 | 2 | 3 | 4 |
| 37. When he is faced with the stressful parts of having sickle cell disease, right away he feels really: (remember to circle a number.) → Check all that he feels: <input type="checkbox"/> Angry <input type="checkbox"/> Sad <input type="checkbox"/> None of these <input type="checkbox"/> Worried/anxious <input type="checkbox"/> Scared | 1 | 2 | 3 | 4 |
| 38. It's really hard for him to concentrate or pay attention when something stressful happens related to having sickle cell disease. | 1 | 2 | 3 | 4 |
| 39. He thinks about the things he is learning from having sickle cell disease, or something good that will come from it. | 1 | 2 | 3 | 4 |

| WHEN DEALING WITH THE STRESS OF SICKLE CELL DISEASE: | How much does he do this? | | | |
|--|---------------------------|----------|------|-------|
| | Not at all | A little | Some | A lot |
| 40. After something stressful happens related to having sickle cell disease, he can't stop thinking about what he did or said. | 1 | 2 | 3 | 4 |
| 41. When stressful parts of having sickle cell disease happen, he says to himself, "This isn't real." | 1 | 2 | 3 | 4 |
| 42. When he is dealing with the stressful parts of having sickle cell disease, he ends up just lying around or sleeping a lot. | 1 | 2 | 3 | 4 |
| 43. He keeps his mind off stressful parts of having sickle cell disease by: (remember to circle a number.) → Check all that he does: <input type="checkbox"/> Exercising <input type="checkbox"/> Seeing friends <input type="checkbox"/> Watching TV <input type="checkbox"/> Playing video games <input type="checkbox"/> Doing a hobby <input type="checkbox"/> Listening to music <input type="checkbox"/> None of these | 1 | 2 | 3 | 4 |
| 44. When something stressful happens related to having sickle cell disease, he gets upset by things that don't usually bother him. | 1 | 2 | 3 | 4 |
| 45. He does something to calm himself down when he is dealing with the stress of having sickle cell disease. (remember to circle a number.) → Check all that he does: <input type="checkbox"/> Take deep breaths <input type="checkbox"/> Pray <input type="checkbox"/> Walk <input type="checkbox"/> Listen to music <input type="checkbox"/> Take a break <input type="checkbox"/> Meditate <input type="checkbox"/> None of these | 1 | 2 | 3 | 4 |
| 46. He just freezes when he is dealing with stressful parts of having sickle cell disease, he can't do anything. | 1 | 2 | 3 | 4 |
| 47. When stressful things happen related to having sickle cell disease he sometimes acts without thinking. | 1 | 2 | 3 | 4 |
| 48. He keeps his feelings under control when he has to, then lets them out when they won't make things worse. | 1 | 2 | 3 | 4 |
| 49. When something stressful happens related to having sickle cell disease, he can't seem to get around to doing things he is supposed to do. | 1 | 2 | 3 | 4 |
| 50. He tells himself that everything will be all right. | 1 | 2 | 3 | 4 |
| 51. When something stressful happens related to having sickle cell disease, he can't stop thinking about why this is happening. | 1 | 2 | 3 | 4 |
| 52. He thinks of ways to laugh about it so that it won't seem so bad. | 1 | 2 | 3 | 4 |
| 53. His thoughts start racing when he is faced with the stressful parts of having sickle cell disease. | 1 | 2 | 3 | 4 |
| 54. He imagines something really fun or exciting happening in his life. | 1 | 2 | 3 | 4 |
| 55. When something stressful happens related to having sickle cell disease, he can get so upset that he can't remember what happened or what he did. | 1 | 2 | 3 | 4 |
| 56. He tries to believe that it never happened. | 1 | 2 | 3 | 4 |
| 57. When he is dealing with the stress of having sickle cell disease, sometimes he can't control what he does or says. | 1 | 2 | 3 | 4 |