BMS Pediatric Self Report 8-12 Mail Form II:
Research Staff Instructions

Instructions: The first page should be filled out by research staff and then separated from the mail form before sending or giving to the participant.
Fill in contact information at the end of the Introduction for participant in case of questions before sending out mail form or before handing to participant.

After receiving the completed form in the mail or from a participant, go through the survey over carefully to see if the participant missed any questions. If possible, call the participant or ask them in person the questions that were missed. If a participant doesn't want to answer any item or doesn't know the answer and there isn't a box/option for those responses on that item, write: "88" (Decline to Answer/Refused) or "99" (Don't know/Unknown) next to the item.

Remember to fill out the Medical Record Abstraction Form II. For the pain medication items, check the medical record to determine if there were any pain medications prescribed within the data collection window. Note on the Medical Record Abstraction Form II form and enter in the appropriate field during data entry.

Form II Administration:

Follow-up period

- ☐ 1. 6-month follow-up
- ☐ 2. 12 month follow-up
- ☐ 3. 24 month follow-up
- ☐ 4. 5 year follow-up
- ☐ 5. 10 year follow-up

What is the method of administration of this form?

- ☐ 2. Mail
- ☐ 5. Medical Record Review

What is the language of administration of this form?

- ☐ 1. English
- ☐ 2. Spanish

What is the status of this follow-up assessment?

- ☐ 1. Some or all assessment done
- ☐ 2. Death due to burn related complications (update date and cause of death on Patient Status Form)
- ☐ 3. Death due to non-burn related complications (update date and cause of death on Patient Status Form)
- ☐ 4. Unable to locate
- ☐ 5. Refused this assessment
- ☐ 6. Unable to test/med comp/incapable of responding
- ☐ 7. Failed to respond
- ☐ 8. Did not consent to future assessment/withdrew
- ☐ 11. Incarcerated
- ☐ 13. Still in hospital (not discharged yet)
- ☐ 14. Unable to travel for assessment
- ☐ 15. Death (unknown causes) (update date and cause of death on Patient Status Form)

If follow-up status is "unable to locate," mark the best reason, below:

- ☐ 1. Homeless at previous data collection
- ☐ 2. International place of residence
- ☐ 3. Participant is child who was/is in CPS custody or foster care and no contact information is available
- ☐ 4. No known current contact info
- ☐ 5. Other reasons
- ☐ 6. Unable to contact due to Shriners Hospital regulations

Burn Model System Follow-up Survey: Introduction

Thank you for being a part of this study! We want to learn about how children do after a burn injury. Some questions are about your burn injury and other questions ask about you and people around you. You may notice that some questions sound the same. This is not a mistake and is part of the research process. All your information will be kept private. If you are unsure how to answer a question, please give the answer that fits you best. You can choose to skip any questions you don't want to answer or feel uncomfortable answering.

If you have any questions please contact us at: _____.

Your last research study questionnaire was completed on ___/____/_____.

Today's Date: ___ ___ / ___ ___ / ___ ___

Section 1					
The following questions ask about your appearance:					
	Definitely true = 1	**Mostly true = 2**	**Not sure = 3**	**Mostly false = 4**	**Definitely false = 5**
1. I feel that the burn is unattractive to others.	☐	☐	☐	☐	☐
2. I think people would not want to touch me.	☐	☐	☐	☐	☐
3. I feel unsure of myself among strangers.	☐	☐	☐	☐	☐
4. Changes in my appearance have interfered with my relationships.	☐	☐	☐	☐	☐

Section 2				
This is a list of problems that kids sometimes have after experiencing an upsetting event. Read each one carefully and then choose the response that best describes how often that problem has bothered you IN THE LAST 2 WEEKS.				
	Not at all or only at one time	**Once a week or less/ once in a while**	**2 to 4 times a week/ half the time**	**5 or more times a week/ almost always**
1. Having upsetting thoughts or images about your burn injury that came into your head when you didn't want them to	☐	☐	☐	☐
2. Having bad dreams or nightmares	☐	☐	☐	☐
3. Acting or feeling as if your burn injury was happening again (hearing something or seeing a picture about it and feeling as if I am there again)	☐	☐	☐	☐
4. Feeling upset when you think about it or hear about your burn injury (for example, feeling scared, angry, sad, guilty, etc)	☐	☐	☐	☐
5. Having feelings in your body when you think about or hear about your burn injury (for example, breaking out into a sweat, heart beating fast)	☐	☐	☐	☐
6. Trying not to think about, talk about, or have feelings about your burn injury	☐	☐	☐	☐
7. Trying to avoid activities, people, or places that remind you of your burn injury	☐	☐	☐	☐
8. Not being able to remember an important part of your burn injury	☐	☐	☐	☐
9. Having much less interest or doing things you used to do	☐	☐	☐	☐
10. Not feeling close to people around you	☐	☐	☐	☐
11. Not being able to have strong feelings (for example, being unable to cry or unable to feel happy)	☐	☐	☐	☐
12. Feeling as if your future plans or hopes will not come true (for example, you will not have a job or getting married or having kids)	☐	☐	☐	☐
13. Having trouble falling or staying asleep	☐	☐	☐	☐

Choose the response that best describes how often that problem has bothered you IN THE LAST 2 WEEKS.	**Not at all or only at one time**	**Once a week or less/ once in a while**	**2 to 4 times a week/ half the time**	**5 or more times a week/ almost always**
14. Feeling irritable or having fits of anger	☐	☐	☐	☐
15. Having trouble concentrating (for example, losing track of a story on television, forgetting what you read, not paying attention in class)	☐	☐	☐	☐
16. Being overly careful (for example, checking to see who is around you and what is around you)	☐	☐	☐	☐
17. Being jumpy or easily startled (for example, when someone walks up behind you)	☐	☐	☐	☐

Section 3					
Please respond to each item by marking one box per row.					
In the past 7 days…	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost always**
1. I felt mad	☐	☐	☐	☐	☐
2. I felt upset	☐	☐	☐	☐	☐
3. I felt fed up	☐	☐	☐	☐	☐
4. I was so angry I felt like throwing something	☐	☐	☐	☐	☐
5. I was so angry I felt like yelling at somebody	☐	☐	☐	☐	☐

Section 4					
Please respond to each question or statement by marking one box per row.					
<u>Physical Function</u> **In the past 7 days…**	**With no trouble**	**With a little trouble**	**With some trouble**	**With a lot of trouble**	**Not able to do**
I could do sports and exercise that other kids my age could do	☐	☐	☐	☐	☐
I could get up from the floor	☐	☐	☐	☐	☐
I could walk up stairs without holding on to anything	☐	☐	☐	☐	☐
I have been physically able to do the activities I enjoy most	☐	☐	☐	☐	☐
<u>Anxiety</u> **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
I felt like something awful might happen	☐	☐	☐	☐	☐
I felt nervous	☐	☐	☐	☐	☐
I felt worried	☐	☐	☐	☐	☐
I worried when I was at home	☐	☐	☐	☐	☐
<u>Depressive symptoms</u> **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
I felt everything in my life went wrong	☐	☐	☐	☐	☐
I felt lonely	☐	☐	☐	☐	☐
I felt sad	☐	☐	☐	☐	☐
It was hard for me to have fun	☐	☐	☐	☐	☐

Please respond to each question or statement by marking one box per row.					
Fatigue **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
Being tired made it hard for me to keep up with my schoolwork	☐	☐	☐	☐	☐
I got tired easily	☐	☐	☐	☐	☐
I was too tired to do sports or exercise	☐	☐	☐	☐	☐
I was too tired to enjoy the things I like to do	☐	☐	☐	☐	☐
Peer relationships **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
I felt accepted by other kids my age	☐	☐	☐	☐	☐
I was able to count on my friends	☐	☐	☐	☐	☐
My friends and I helped each other out	☐	☐	☐	☐	☐
Other kids wanted to be my friend	☐	☐	☐	☐	☐
Pain Interference **In the past 7 days…**	**Never**	**Almost never**	**Some-times**	**Often**	**Almost always**
I had trouble sleeping when I had pain	☐	☐	☐	☐	☐
It was hard for me to pay attention when I had pain	☐	☐	☐	☐	☐
It was hard for me to run when I had pain	☐	☐	☐	☐	☐
It was hard for me to walk one block when I had pain	☐	☐	☐	☐	☐

Pain Intensity In the past 7 days…											
How bad was your pain on average?...	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
	0	1	2	3	4	5	6	7	8	9	10
	No pain										**Worst pain you can think of**

Section 5					
Indicate how much you agree or disagree:					
	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1. My life is going well.	☐	☐	☐	☐	☐
2. My life is just right.	☐	☐	☐	☐	☐
3. I have a good life.	☐	☐	☐	☐	☐
4. I have what I want in life.	☐	☐	☐	☐	☐

Section 6						
Please respond to each question or statement by marking one box per row.						
In the past 7 days …		**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
I had trouble sleeping when I was itching		☐	☐	☐	☐	☐
I felt angry when I was itching		☐	☐	☐	☐	☐
It was hard for me to pay attention when I was itching		☐	☐	☐	☐	☐
It was hard for me to have fun when I was itching		☐	☐	☐	☐	☐
	N/A (I don't do schoolwork)	**Never**	**Almost Never**	**Some-times**	**Often**	**Almost Always**
I had trouble doing schoolwork when I was itching	☐	☐	☐	☐	☐	☐

Section 7					
Please respond to each question or statement by marking one box per row.					
In the past 7 days…	**No days**	**1 day**	**2-3 days**	**4-5 days**	**6-7 days**
How many days did you exercise or play so hard that your body got tired?	☐	☐	☐	☐	☐
How many days did you exercise really hard for 10 minutes or more?	☐	☐	☐	☐	☐
How many days did you exercise so much that you breathed hard?	☐	☐	☐	☐	☐
How many days were you so physically active that you sweated?	☐	☐	☐	☐	☐

Section 8					
Please respond to each question or statement by marking one box per row.					
In the past 7 days…	**Never**	**Almost Never**	**Some-times**	**Almost always**	**Always**
I had difficulty falling asleep	☐	☐	☐	☐	☐
I slept through the night	☐	☐	☐	☐	☐
I had a problem with my sleep	☐	☐	☐	☐	☐
I had trouble sleeping	☐	☐	☐	☐	☐

Section 9					
Please respond to each question or statement by marking one box per row.					
In the past 4 weeks…	**Never**	**Rarely**	**Some-times**	**Often**	**Always**
I felt I had a strong relationship with my family	☐	☐	☐	☐	☐
I felt really important to my family	☐	☐	☐	☐	☐
I got all the help I needed from my family	☐	☐	☐	☐	☐
My family and I had fun together	☐	☐	☐	☐	☐

Section 10

NEXT ARE SOME QUESTIONS ABOUT WAYS PEOPLE SOMETIMES CHANGE AFTER DIFFICULT EVENTS.

For each of the next statements indicate the degree to which this change happened in your life as a result of your burn injury.

	No change	A little	Some	A lot	Don't know
I learned how nice and helpful some people can be.	☐	☐	☐	☐	☐
I can now handle big problems better than I used to.	☐	☐	☐	☐	☐
I know what is important to me better than I used to.	☐	☐	☐	☐	☐
I understand how God works better than I used to.	☐	☐	☐	☐	☐
I feel closer to other people (friends or family) than I used to.	☐	☐	☐	☐	☐
I appreciate (enjoy) each day more than I used to.	☐	☐	☐	☐	☐
I now have a chance to do some things I couldn't do before.	☐	☐	☐	☐	☐
My faith (belief) in God is stronger than it was before.	☐	☐	☐	☐	☐
I have learned that I can deal with more things than I thought I could before.	☐	☐	☐	☐	☐
I have new ideas about how I want things to be when I grow up.	☐	☐	☐	☐	☐

How long did this survey take you to complete? _____

Is there anything else you would like to tell us?_____
_____
_____
_____

Thank you very much for sharing with us!