

Appendix A

Parent Survey for Brain Tumor Survivor

Please fill out the form to the best of your abilities.

1. Your Participant ID#: _____

Today's date: _____

2. Please fill out the table with information about the survivor.

Age of survivor now	
Age of survivor at diagnosis	
Grade of survivor now	
Grade of survivor at diagnosis	

3. Who takes care of your child with a brain tumor?

☐ Mother ☐ Father ☐ Both ☐ Other: _____

4. Please indicate your marital status at the time your child was diagnosed with a brain tumor

☐ Single ☐ Married ☐ In committed relationship but not married
☐ Divorced or separated ☐ Other: _____

5. Please indicate your current marital status

☐ Single ☐ Married ☐ In committed relationship but not married
☐ Divorced or separated ☐ Other: _____

6. Current age of parents/primary caregiver:

Mother: _____ Father: _____

Other primary caregiver: _____

7. Please mark the box in the table below to indicate the highest level of education attained by your child's mother, father, or other primary caregiver

	Mother	Father	Other primary caregiver
Some high school			
High school diploma or GED			

Some college			
College degree			
Graduate degree			

8. Please describe the types of jobs held by each parent. (Example: Homemaker, Salesman, Unemployed, etc.)

Mother: _____

Father: _____

Other primary caregiver: _____

Appendix B

Survivor Information Survey

1. Please indicate which therapies your child received/is receiving:

	Previously received		Currently receiving	
Neurosurgery	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Chemotherapy	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No
Radiation therapy	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No
None—Observation alone	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Yes	<input type="checkbox"/> No

2. Does your child experience educational challenges that are greater than those faced by most of his/her classmates?

☐ Yes
 ☐ No
 ☐ Not sure

3. Please tell us how your child does in each of the following school subjects. You may enter your child's grade if you know it, or you may indicate how well you think your child is doing in each class:

(If he/she does not take a subject, leave it blank. Please add his/her other subjects in the blank spaces).

Item	Subject	Failing (F)	Below Average (D)	Average (C)	Above Average (A/B)
i.	English				
j.	History				
k.	Social Studies				
l.	Math				
m.	Science				
o.	<i>OTHER</i>				
p.	<i>OTHER</i>				
If failing or below average in any subject, please describe: <div style="border: 1px solid black; height: 100px; margin-top: 5px;"></div>					

For the next several questions, think about your child's typical school day. In the space after the question, please tell us how this affects your child's schoolwork

4. Does your child have trouble concentrating or paying attention?

☐ No ☐ Yes

If yes, please describe: _____

5. Does your child have trouble sitting still? ☐ No ☐ Yes

If yes, please describe: _____

6. Does your child seem confused or out of it? ☐ No ☐ Yes

If yes, please describe: _____

7. Does your child get teased a lot? ☐ No ☐ Yes

If yes, please describe: _____

8. Does your child have trouble seeing? ☐ No ☐ Yes

If yes, please describe: _____

9. Does your child seem overtired or fatigued? ☐ No ☐ Yes

If yes, please describe: _____

10. Does your child have trouble hearing? ☐ No ☐ Yes

If yes, please describe: _____

11. Does your child act disobedient? ☐ No ☐ Yes

If yes, please describe: _____

12. Does your child have trouble using the correct words?

☐ No ☐ Yes

If yes, please describe: _____

13. Does your child get along with other students? ☐ No ☐ Yes

If no, please describe: _____

14. Does your child do things without stopping to think first? ☐ No ☐ Yes

If yes, please describe: _____

15. Does your child have trouble with his/her memory?

☐ No ☐ Yes

If yes, please describe: _____

16. Does your child have trouble finishing what he/she started?

☐ No ☐ Yes

If yes, please describe: _____

17. Does your child have trouble with organization?

☐ No ☐ Yes

If yes, please describe: _____

18. Does your child wait until the last minute to start a project/assignment?

☐ No ☐ Yes

If yes, please describe: _____

19. Does your child miss school frequently? ☐ No ☐ Yes

If yes, please tell us about reasons for missing school and how it impacts him/her:

20. Does your child struggle to solve math problems?

☐ No ☐ Yes

If yes, please describe: _____

21. Does your child work by himself/herself to complete tasks, asking for help only when needed?

☐ No ☐ Yes

If no, please describe: _____

22. Does your child become frustrated easily? ☐ No ☐ Yes

If yes, please describe: _____

23. Does your child forget to complete homework, bring home needed materials, or take completed assignments to school?

☐ No ☐ Yes

If yes, please describe: _____

24. Does your child interrupt others? ☐ No ☐ Yes

If yes, please describe: _____

25. Does your child make careless mistakes? ☐ No ☐ Yes

If yes, please describe: _____

26. Does your child have trouble making friends and/or maintaining friendships? ☐ No

☐ Yes

If yes, please describe: _____

27. Does your child have trouble completing homework assignments? ☐ No

☐ Yes

If yes, please describe: _____

28. Does your child have trouble taking tests? ☐ No ☐ Yes

If yes, please describe: _____

29. Did your child experience educational challenges prior to his/her brain tumor diagnosis?

☐ No ☐ Yes

If yes, how many months/years prior to diagnosis did he/she experience educational challenges? _____

30. How have the educational challenges changed since diagnosis?

☐ Increased ☐ Unchanged ☐ Decreased

31. Does your child receive any educational interventions, i.e. 504 plan, IEP, Title I Program services?

☐ No ☐ Yes

If yes, please complete the following:

Type of intervention (i.e. 504 plan, IEP, Title I)	Grade intervention was started

32. If your doctor wanted to provide you with information about anticipated educational obstacles and recommended support services, how would you prefer to obtain this information? Please mark only one answer.

☐ **Personal visits:** A doctor would meet with you 1-on-1 to discuss the child's diagnosis, potential educational obstacles, and recommended support services. The 1-on-1 meeting would occur at a standard care clinic visit, and we would request that the school liaison also meet with you and your family. You would need to make an appointment and travel to the doctor's office. This option would allow you to ask questions directly to the doctor.

☐ **Web-based instruction:** You would be given an Internet website that you could access from a home or library computer. The website would have information about the diagnosis, anticipated educational obstacles, and support services for children with brain tumors. Links to sites with additional information would be available on the website. Parents and children could share information about personal challenges and successes.

☐ **DVD:** You would be given a disc that you could take home and watch at your convenience. The DVD would have information about the diagnosis, anticipated educational obstacles, and support services. Video segments would include information from doctors, teachers, students, and parents.

☐ **Printed Brochure:** You would be given a typed pamphlet that includes information about the diagnosis, anticipated educational challenges, and support services. Doctors, parents, teachers, and students would contribute to the creation of the brochure.

Appendix C

Interview Questions

- Tell me what you know about cognitive late effects following treatment for brain tumors? (will explain “cognitive late effects” after they answer the question)
 - How did you learn about these side effects? Ex: oncologist, psychologist, internet
 - Did you acquire this knowledge before or after your child’s treatment?
 - Do you feel you have what you know is enough?
 - What would you like to learn more about?
- Please tell me about any cognitive or learning challenges that you have noticed in your child.
 - Any behaviors that are different than their usual self?
 - How have you been helping your child cope with these effects/changes/behaviors? (Strategies)
 - How did you learn about these strategies/methods?

(Skip question if no changes noted above)

- Tell me how you feel when your child experiences these effects/changes/behaviors.
 - Tell me what you think about your ability to help your child cope with these effects/changes/behaviors. (Confidence)
 - What would you like more information on to better help your family work with these effects/changes/behaviors?
- Tell me how you felt about your level of knowledge of cognitive late effects before and after treatment.
 - Can you explain any differences between the two?
 - Do you feel confident/satisfied with your knowledge?
 - How confident/satisfied did you feel before treatment compared to after treatment?
 - What do you think would help you feel more confident?
- What other areas/topics do you feel you would like more knowledge/support in?
- Does a program that would provide you information and resources on cognitive late effects appeal to you?
 - What program structure would work best for you? (Seminar, webinar, booklet, etc.)
 - What would help you be able to attend the program?

Appendix D

Healthcare Provider Interview Questions

Do you discuss cognitive late effects with caregivers of your pediatric CNS tumor patients?

- How do you discuss cognitive late effects with caregivers of pediatric cancer survivors?
- In what format do you give this information?
- When do you give this information?
- What information do you usually discuss?

(If answer is no)

- How important do you feel it may be to discuss cognitive late effects with this population?
- If you could discuss this information, what would you talk about with your patients and their caregivers?

How well do you believe caregivers understand cognitive late effects?

How do you know they understand it?

- Is there a method you use to test their understanding?

What information do you think could be better communicated regarding cognitive late effects?

What other information would you like me to know?