

### **This Boy We Made Quiz**

Below is a copy of the quiz that will need to be completed using the Google Forms link you received in your email.

- For the following 42 questions, please select the best answer according to the book *This Boy We Made* and author Taylor Harris. The author is referred to as Taylor in the questions.
- You will need a score of 80% to pass and receive CEU credit. You will have 3 attempts to pass. If you do not pass an attempt, use the same link and start the quiz again.
- **When you finish the quiz you will see your score in the top right as a fraction and you will need to do the math to make sure you got an 80%. If not, you can take it again (up to 3 times total). The email saying you passed the course is manual, and it may take up to a day to get sent. So when you don't get a confirmation of completion right away, don't worry, it will come within a day.**
- You also need to complete the evaluation (which is a separate google form) before your CEU request is submitted to NSGC.
- Contact [brittany@theceushop.org](mailto:brittany@theceushop.org) with any questions.

#### **Chapter 1**

1. Throughout the book, Taylor describes motherhood as “Before” and “After.” What defining event differentiates between Before and After for her?
  - a. The moment her first daughter (Eliot) was born.
  - b. Tophs’s first medical crisis at 22-months old.
  - c. When her son (Tophs) received a genetic diagnosis.
  - d. When her third and final baby (Juliet) was born.

#### **Chapter 2**

2. Taylor describes one of Tophs’s pediatricians, Dr. Marcus Potter, and the things that she remembered from the day of Tophs’s first trip to the hospital. Which of the following did she NOT mention when describing Dr. Potter:
  - a. She was not too proud to follow her hunch
  - b. Her tenderness
  - c. How serious and professional she was
  - d. That she called back later to check on Taylor and Tophs
3. Taylor discusses a nervous medical student reading off her note card with a team of people so big a few of them had to wait in the hall because they didn’t fit in their hospital room. She writes “I’m thankful for teaching hospitals, but \_\_\_\_\_ seems destined to get lost in the performance of it all.”
  - a. The details of Tophs as an individual
  - b. Hopefulness
  - c. A diagnosis
  - d. Human touch

4. When Tophs's critical urine sample does not get run in error, Taylor wonders about how that situation might have been different if they were white. She wonders all the following, EXCEPT:
  - a. Would the doctors have apologized for making an error and not running the sample?
  - b. Would they have led the conversation with what they lost?
  - c. Would the same answers they gave the Harris family have sufficed?
  - d. Would they have not gotten billed for the hospital visit?

### **Chapter 3**

5. After the first trip to the hospital, Taylor was under the impression that nothing was truly wrong with Tophs because:
  - a. He had normal prenatal and newborn screening
  - b. Maternal intuition
  - c. Normal bloodwork on his first trip to the hospital
  - d. The "diagnosis of exclusion" of ketotic hypoglycemia

### **Chapter 5**

6. Dr. Quillian calls Taylor with the results of bloodwork. What does she do to indicate that the conversation is moving towards a more serious topic?
  - a. Asks Taylor "Are you sitting down?"
  - b. Changes her voice from light and airy to slower, with a more reserved undertone.
  - c. Requests that Taylor make an appointment since these results should not be discussed over the phone.
  - d. Recommends Taylor get her computer out so that she can google what Dr. Quillian is about to tell her.

### **Chapter 6**

7. After finding low carnitine levels on bloodwork, Tophs was prescribed liquid carnitine which produced the side effect of:
  - a. Lethargy
  - b. An itchy rash
  - c. Smelling like fish
  - d. Smelling like coconut
8. One of the continual challenges with Tophs condition is the "inability to explain" it or "codify something that has been observed in reality but not yet named." Taylor writes that this has been a challenge in which scenario(s):
  - a. When he was experiencing the side effects of taking carnitine
  - b. In special education meetings
  - c. When working with physicians
  - d. All of the above

### **Chapter 7**

9. Taylor discusses her own anxiety and writes about how some people want a label for their diagnosis while others do not. For her, a diagnosis offered all the following, EXCEPT:
  - a. Comfort in the naming

- b. A cure
  - c. Access to doctors and therapists knowledgeable about the condition
  - d. Therapy
10. On page 77, Taylor writes, “Nothing has ever threatened to consume me quite like this shame.” What shame is she referring to?
- a. That she had caused Tophs’s health problems by allowing him to fall off the bed as a baby.
  - b. When she didn’t take Tophs to the doctor when he said he was sick.
  - c. Not giving Tophs fever reducing medicine as a baby.
  - d. Not being able to diagnose Tophs’s condition.

### **Chapter 8**

11. Due to the symptoms of quickly flipping through books, staying up at night, hoarse voice, short stature, and reduced sensitivity to pain, Taylor was concerned that Tophs may have:
- a. Russel-Silver syndrome
  - b. VACTERL association
  - c. Smith-Magenis syndrome
  - d. Down syndrome

### **Chapter 9**

12. Taylor describes Tophs’s speech therapist, Anita, and occupational therapist, Liz, as a “dream team of professional women.” What made them a dream team?
- a. They were accommodating of what was best for Tophs and shifted their schedules so that they could work together. Liz could help Tophs get the sensory input he needed to maximize Anita’s speech lessons.
  - b. They wrote extremely detailed summary notes at the end of each appointment.
  - c. Their office had new state-of-the-art equipment.
  - d. They graduated from top programs in their respective fields.

### **Chapter 10**

13. When Tophs went to the ER two months before he turned 3, he had a glucometer read of 48 (abnormal) at home. When he got to the ER the nurse said his blood sugar was 60 (normal). However, a resident decided to have his blood drawn anyway and it was 46 (abnormal). When Taylor reflects on this incident, she writes:
- a. It is dangerous to be Black and sick.
  - b. I told you so.
  - c. We are so lucky that resident was working that day.
  - d. Parenting is so hard some days.
14. When Taylor runs into her daughter’s previous preschool teacher, Paige, at the grocery store, she asks Taylor how she is and Taylor “rattles off specialists and results in a nonlinear ambush.” Taylor describes this as:
- a. “I wanted her to help me solve this mystery, to give us an answer.”
  - b. “I can always feel when I’m carrying too much, holding too much of his body in mine.”
  - c. “I didn’t have anyone to talk to about this, no one seemed to understand.”

- d. "She had always shown such an interest in our family, and I wanted to make sure she was up to date."

### Chapter 11

- 15. The developmental pediatrician made a statement and Taylor thought, "Had he just handed us a life vest or shot a hole through our boat?" What was the statement?
  - a. "We will be able to get a diagnosis, but it might take two years."
  - b. "We recommend more genetic testing, but it may not be covered by your insurance."
  - c. "At least your daughter is not showing any of these same symptoms."
  - d. "His intelligence is at least on the low side of average."
- 16. After waiting months for an appointment with a developmental pediatrician, the doctor evaluated Tophs for \_\_\_\_\_, and said "...\_\_\_\_\_"
  - a. One hour; He's got *something*. We're just not smart enough to figure it out yet."
  - b. Ten minutes; He's got *something*. We're just not smart enough to figure it out yet."
  - c. Ten minutes; "Unfortunately, I'm stumped."
  - d. One hour; "Unfortunately, I'm stumped."

### Chapter 12

- 17. Taylor describes different ways in which she and her husband respond to heavy news (following her son's medical appointment). She states that she responds by \_\_\_\_\_; and her husband Paul responds by \_\_\_\_\_.
  - a. Going numb, then turning inward with existential thoughts; hopping over to another box in his mind and doing the work in front of him.
  - b. Dissociating; doing as much research as he can.
  - c. Diving into her writing; diving into his work.
  - d. Calling her friends to talk through the news; cooking a big elaborate meal.
- 18. Taylor shares that in the days after the first developmental pediatrician appointment that her body was processing sadness or transient depression. Part of the reason for that was:
  - a. The weather had turned cold and dark.
  - b. She had been expecting an answer that day.
  - c. The pediatrician was mean.
  - d. The prognosis was worse than she had been expecting.
- 19. Throughout the book Taylor writes about being in a *liminal* space. This is a space of:
  - a. Ambiguity, of limited knowledge and unlimited unknown
  - b. Clear expectations, and certainty
  - c. Strong boundaries
  - d. Comfort and ease

### Chapter 13

- 20. Taylor stated she resisted the genetic counselor Shelly at first because:
  - a. She was rude and dismissive.
  - b. It was starting to become hard and painful to go to so many medical appointments.

- c. Shelly wasn't the geneticist and Toph's story was hard to tell, and very hard to tell twice in one day.
  - d. She had a long intake form with a lot of questions that seemed irrelevant.
21. Towards the end of her appointment with the genetic counselor and geneticist, Taylor describes them as:
- a. Dismissive
  - b. Brilliant, but cold
  - c. Arrogant
  - d. Steady, confident, genuinely concerned, and brilliant
22. When Paul asked the geneticist, "How do you think he will do?" she replied, "I think his social skills will get him far." Taylor describes her words as:
- a. A doctor's humble but meaningful gift
  - b. A light at the end of the tunnel
  - c. Unrealistic and unscientific
  - d. Nice, but missing what we wanted most, a prognosis

#### **Chapter 14**

23. How did Taylor respond to the first round of genetic testing being normal?
- a. She celebrated by taking the kids out for ice cream.
  - b. She grieved the loss of her would-be friends and belonging.
  - c. She was in denial and demanded they re-run the testing.
  - d. She got very upset and requested a second opinion with a new geneticist.

#### **Chapter 15**

24. When Taylor was told she was a carrier of a *BRCA2* mutation, some of her thoughts included:
- a. "No degree of cognitive behavioral therapy in the world seemed sufficient to hold this."
  - b. "I couldn't protect myself, couldn't protect my children, couldn't promise them Mommy wouldn't get sick."
  - c. "Every bit of my fear was deserved."
  - d. All of the above

#### **Chapter 16**

25. Months before Taylor was found to have a *BRCA2* mutation herself, she published an essay about wondering if she had passed her anxiety down to her daughter. The essay included a line that said, "How do moms who pass down a *BRCA* gene mutation feel?" In reflecting on this writing, Taylor thinks:
- a. She had written her mutation into existence.
  - b. She had always sensed she carried a *BRCA* mutation.
  - c. She had imagined the *BRCA* analogy as a way to make room for a mother's guilt.
  - d. Her anxiety had led her to her truth as a mutation carrier.
26. When Taylor goes for her first appointment at the high-risk screening program at the Clinical Cancer Center, the first person she saw was:
- a. A middle-aged man in a Confederate motorcycle vest and hat
  - b. A friendly greeter who helped her find the office

- c. A hospice volunteer
  - d. A mother holding an infant
27. When Taylor's mother tested positive for the *BRCA2* mutation her mother wondered:
- a. Was Tophs a sort of angel, delivering a message that could save one (or many) members of Taylor's family?
  - b. Did she have cancer cells growing in her right then?
  - c. How often was she going to have to have screening?
  - d. Was she going to be able to find a good doctor?
28. Taylor writes that after her first breast screening appointment she left not knowing what the doctor had found. She said that was because:
- a. The doctor used terms Taylor didn't understand.
  - b. Taylor was so panicked that she couldn't hear.
  - c. The nurse told her to leave, and someone would call her later.
  - d. Either A or B

### Chapter 19

29. At the first consultation with the breast surgeon, the surgeon states, "...if you're having a hard time wrapping your mind around this, it's understandable. This came out of left field for you." Taylor describes her saying this as:
- a. Very far off-base
  - b. A balm for my soul
  - c. A statement that stopped me in my tracks
  - d. Surprising

### Chapter 20

30. At the Harris family's first individualized education program (IEP) meeting after they moved to northern Virginia, Tophs was offered three days of school vs the five days he had been receiving in Charlottesville. The IEP team took into consideration:
- a. Tophs's genetic testing history
  - b. Tophs's previous teacher's assessment
  - c. Their norm of giving five-day-a-week spots to children with the most severe disabilities
  - d. The amount of speech therapy he had previously received
31. One of the biggest challenges at IEP meetings for Taylor is:
- a. Having to advocate for her child
  - b. Scheduling the IEP meetings around multiple schedules
  - c. Having to be deficit-oriented so they will not cut Tophs's services
  - d. Having to be strengths-oriented to get the services Tophs needs

### Chapter 21

32. The Harris family lived in Charlottesville during most of the book. Charlottesville was the location of a white supremacy rally that caused violence, injury, and the death of a woman named Heather Heyer. What year did this happen?
- a. 1950
  - b. 1962
  - c. 2017
  - d. 2020

## Chapter 22

33. Taylor writes about the challenges of not knowing the root cause of Tophs's medical problems. Which of the following people is the lack of diagnosis the most challenging for?
- Tophs
  - Taylor
  - Tophs's geneticist
  - Tophs's teachers

## Chapter 23

34. When Tophs was 6 years old, his focus of care shifted from:
- Doctors to school
  - Speech therapy to occupational therapy
  - Genetics to endocrinology
  - The genetic counselor to the geneticist
35. When Taylor went for her first breast MRI, what concerned her the most:
- The noise of the machine
  - Getting stuck in the machine
  - The contrast
  - The results
36. During her first MRI, Taylor describes her experience as:
- Going in and out of prayer, sleep, and a deep, deep peace
  - Chaotic and anxiety provoking
  - Feeling ten times longer than it was
  - Triggering flashbacks of her first anxiety attack

## Chapter 24

37. What is one of the ways that Tophs's education was impacted by his lack of diagnosis from the healthcare system?
- He needed a diagnosis to get a one-on-one aid.
  - It was harder to qualify for a special education classroom, without a diagnosis.
  - He needed a diagnosis to be able to receive any medical treatment at school.
  - It was harder to qualify for an IEP once he turned 7, without a diagnosis.

## Chapter 25

38. After Tophs's trip to the ER following his day at the roller rink, Taylor reflected on what it felt like to live in the liminal space between symptoms and answers. She wrote about how that space offered:
- Constant worry about what was going to happen next
  - Loneliness, but also space to breathe, distance from the settled grief of knowing
  - Sweet and blissful ignorance
  - A space for her fears to get comfortable and set up a cozy home

## Chapter 26

39. After years of not having a diagnosis for Tophs, his pediatrician, Dr. Quillian, wants to:

- a. Do a thorough workup and try to figure it out.
- b. Transfer Tophs's primary care away from her to an academic medical center.
- c. Present Tophs's case at a case conference.
- d. Encourage the family to stop pursuing a diagnosis.

**Chapter 27**

40. When Tophs's MRI results stated, "No evidence of intracranial abnormality," Taylor felt:
- a. Immediate relief
  - b. Uncertainty
  - c. Slow relief that grew
  - d. Shame

**Chapter 28**

41. Tophs is a carrier of a glycogen storage disease. He was seen at Cleveland Clinic's pediatric glycogen storage disease clinic and they told him:
- a. They see other patients who are also just carriers of glycogen storage diseases but who also show dangerous symptoms
  - b. Because he is just a carrier, they do not believe any of his health issues are related to his carrier status
  - c. To modify his diet to eat more protein and less sugar
  - d. A & C
42. When Tophs's was doing virtual school during 2020, he was given the prompt "I am \_\_\_\_\_." How did he complete the sentence?
- a. Perfectly Made
  - b. Mysterious
  - c. Tophs
  - d. Hungry