

Short Bowel Syndrome Awareness Month

Basic Background Information:

- First Name
- Last Name
- Gender
- Age
- Are you a patient or caregiver?
- If you are a caregiver, how old is your loved one with short bowel syndrome (SBS)? (patients put N/A)
- At what age were you (or your loved one) diagnosed with short bowel syndrome (SBS)?
- Other than short bowel syndrome (SBS), do you suffer from any other conditions? (GI and non-GI related)

Short Bowel Syndrome (SBS) Specific Questions: You can choose to answer all of these, or just a few. It is completely up to you!

1. Describe your diagnostic journey.

- a. What were your initial signs and symptoms that caused you to seek medical attention? How old were you when this started?
- b. How did you find your doctors? (referral, internet, word of mouth)
- c. How long did it take to get diagnosed?
- d. Were you misdiagnosed? If yes, what diagnosis did you get? Did you have multiple misdiagnoses?

2. Treatment

- a. What treatments have you tried (both medical, surgical, holistic)?
 - i. Have any treatments worked?
- b. What are you currently doing to treat your condition and its symptoms?
 - i. How well does your current treatment support your ability to live your best life?
- c. What are the most significant disadvantages or complications of your current treatments?
 - i. How do they affect your daily life?
 - ii. Have you had side effects with any of these treatments?

3. Nutrition

- a. Are you on tube feeds?
 - i. What type of tube do you have?
 - ii. What type of formula do you use?
 - iii. How do you administer your feeds (bolus or pump)?
 - iv. If you have a G-tube, do you use it for decompression or venting? Does this help your symptoms?

- v. How long have you been on tube feeds?
- b. Are you on parenteral nutrition (PN)?
 - i. How long have you been on it?
 - ii. How many hours are you cycled?
 - iii. Do you have any complications such as blood clots, lack of access, liver damage, frequent infections?
- c. Do you see a dietician or nutritionist?
- d. Who manages your nutrition?
- e. Are you able to eat or drink anything by mouth?
 - i. If yes, what kinds of food are you able to eat?
 - ii. How do you eat (i.e. small meals throughout the day)
 - iii. Are you able to keep yourself well-hydrated?

Impact of Short Bowel Syndrome (SBS) on Your Life

1. Do you have any advice for someone who has just been diagnosed with short bowel syndrome (SBS)?
2. How has short bowel syndrome (SBS) affected you and/or your family financially?
3. Has short bowel syndrome (SBS) affected your ability to live independently? If so, how?
4. How has short bowel syndrome (SBS) affected your relationships?
5. Has short bowel syndrome (SBS) impacted your ability to complete school/the school day?
6. How does short bowel syndrome (SBS) impact your activities outside of school or work?
7. Has short bowel syndrome (SBS) affected your career choice or ability to have a job?
8. Has short bowel syndrome (SBS) affected your intimacy or reproductive health?
9. How has short bowel syndrome (SBS) affected your mental health or stress level?
10. Are there any other ways you can think of that short bowel syndrome (SBS) has affected your life?