

## **But Why: A Podcast for Curious Kids**

### **[Living With A Brain Tumor: 11-Year-Old Twins Share Their Story](#)**

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[00:00:21] This is But Why: A Podcast for Curious Kids from Vermont Public Radio. I'm Jane Lindholm. On this podcast, we take questions from kids like you and we find answers.

[00:00:34] In our last episode we answered some questions you've sent us about cancer.

[00:00:39] Now cancer is a disease where the cells in your body grow out of control. It's rare but it does happen and sometimes it even happens to children. We talked with a doctor named Donald Small who studies the kinds of cancer that children get. And he helped us understand what cancer is and how it's treated from a doctor's perspective. If you haven't heard that episode yet, you might want to go back and listen either before or after you hear this episode, it will help give you some context and explain the science and treatment of cancer. But the main part of today's episode is less about the science and more about what it's like to live with cancer in your family. We're going to talk with two young kids who've had to deal with this and they're going to tell us a little bit about their lives and some of the ways they think about how cancer has affected them.

[00:01:29] [Sophie] My name is Sophie. I'm 11 years old and I live in Washington, D.C. [00:01:35] [Isabelle] My name is Isabelle. I'm 11 years old and I live in Washington, D.C.

[00:01:39] [Jane] Isabelle and Sophie Posner Brown are twin sisters. When Sophie was two, her parents found out she had a brain tumor. A tumor happens when there's an unusual growth of cells, so more cells grow in a certain part of your body than should be there. That growth is sometimes cancer, sometimes it's not. Tumors that are not cancer are called benign. Tumors that are likely to spread to other parts of your body are called malignant and they are cancer. There's more about all of those words in our previous episode.

Sophie's tumor was the kind of tumor that the doctors were concerned about, partly because it is cancer and can spread and partly because it's in her brain and

a tumor in your brain can press on the parts of your brain that control how you move how, you talk, how you think.

So Sophie's doctors have been keeping a very close eye on her ever since she was two. She's had three surgeries over the years and had to have a lot of different kinds of treatment, including chemotherapy, which we also learned about in our last episode, where very high powered drugs are used to try to kill the cancer cells. Because of where Sophie's brain tumor is in her body, doctors can't remove the entire tumor without damaging her brain. So she will always have it, at least a little bit of it. And throughout the course of her lifetime that's going to require a lot of visits to the doctor and the hospital and a lot of stress and a lot of worry. And although her twin sister Isabelle does not have a brain tumor that doesn't mean she's not affected by Sophie's illness.

So, since we spent our last episode talking with a doctor about cancer we thought it might be interesting for all you “But Why” listeners out there to hear a little bit from some kids themselves who've actually gone through significant illness. And we're going to talk to Sophie and Isabelle about what their lives are like.

Let's get to know Sophie and Isabelle a little bit. Here are some of Isabel's favorite things to do. [00:03:42] [Isabelle] I like to sing, I like to play soccer, I like to read. [Jane] Sophie, what are your favorite things? [Sophie] I like to sing, I like to act and I like to read.

[00:03:51] [Jane] Sophie, tell me your favorite thing about your sister. [Sophie] Ummm....oh, my favorite thing is that we play a lot of games together.

[00:04:03] [Jane] Isabelle what's your favorite thing about Sophie? [Isabelle] Ah, how she hangs on me, cuz it's really funny because she's always hanging on me

and pulling me into different things just by hanging on me.

[Jane] That's your favorite thing?

[00:04:19] [Isabelle] I, yeah, but it's like annoying but it's also my favorite thing.

[00:04:22] [Jane] Sophie says having a brain tumor affects a lot of different parts of her life.

[Sophie] I don't learn as well as everyone else, like I learn differently and it's affected my hearing and my eyesight and my balance.

[00:04:38] [Jane] Isabelle what would you add when you think about Sophie's cancer and Sophie's brain tumor.

[00:04:42] [Isabelle] Well I think like, I'm glad that she's getting better because and I don't really remember the days when she was, um, really sick. Ah, I just know that she didn't, always come to school and there wasn't always things she could do, so that makes me sad sometimes but sometimes it got me out of doing things.

[Jane] (laughter) Was that good?

[00:05:03] [Isabelle] Yeah that was the plus side.

[Jane] Isabel, what do you remember about what kinds of treatments Sophie has had to have, visits to the doctors stays in the hospital that kind of stuff?

[00:05:14] [Isabelle] She's had lots of MRIs, um lots of IVs and shots so they don't really bother her anymore. [00:05:22] There used to be lots of surgeries. Um, cheek pain there's been cheek pain which she's had to have things done for.

[00:05:31] [Jane] It sounds like you know a lot about what your sister's been going through. [Isabelle] Probably know more than her.

[Jane] Why do you say that?

[Isabelle] She doesn't remember anything.

[Jane] Because of the brain tumor or just because that's the way she is?

[Isabelle] That's just her. [00:05:43] She claims she remembers stuff but she doesn't remember stuff like that all the time.

[Jane] [00:05:49] Sophie, you haven't had to go through chemotherapy for a few years. Do you have a sense of how that's changed your life, does it feel different?

[Sophie] Ever since I went off it, I feel like I've been at school more and it's been easier for me to learn.

[00:06:05] [Jane] What do you feel like is the hardest thing for you about having to deal with your brain tumor, Sophie?

[00:06:13] [Sophie] I think it is probably, some, like some stuff I don't always want to do that I have to do for it. Somethings I want to do that I can't do because of my brain tumor, so that's probably the hardest thing.

[00:06:30] [Jane] What do you feel like you can't do because of your brain tumor?

[00:06:33] [Sophie] I used to not be able to do sports, and like gymnastics. I still can't do gymnastics but I don't want to do sports, so...

[Jane] You don't?

[Sophie] No

[00:06:43] [Jane] Is that what your sister was whispering.

[Sophie & Isabelle] Umm hmm

[Jane] So now you can do sports though some sports and you can do some activities that you didn't used to be able to do, that must feel good?

[Sophie] Yeah.

[Jane] Isabelle, for you, what's the hardest thing for you about Sophie's illness?

[00:07:02] [Isabelle] Uh, well sometimes I can't do things because she has stuff. Also, it's sometimes missing things like, for, I play for a travel soccer team and we had a game during the Race For Hope, and I had the option to miss that. But I went to my game and I missed the Race For Hope for the first time. So sometimes it's hard to miss things like that and sometimes I don't, sometimes it like when she can't do stuff. I can't do this stuff, so.

[00:07:25] [Jane] The Race for Hope is a fundraiser for Brain Tumor Research which is something both Sophie and Isabelle care a lot about and it's a fun way to try to raise money. People run or walk or race and other people give them money to do it. The money is then given to organizations that look for cures and treatment for brain tumors.

[00:07:45] [Jane] Isabelle, I want to ask you, you're saying something about one of the hard things is when Sophie has to go into treatment, or there other things that you can't do some of the things that you want to do and it's really hard to have a sister or brother who's sick because not only are you worried about them and you love them and you want them to get healthy but sometimes it can feel really complicated to feel sort of angry at your sibling because they're getting a lot of attention or because it's preventing you from doing things that you want to do. Have you experienced any of that feeling?

[00:08:21] [Isabelle] Ah, Yeah, especially, like a while ago. I felt like sometimes they didn't really think about what I wanted and they just thought about her. I know that's not true anymore but like sometimes when you get upset or you're having a bad day you just feel that.

[Jane] [00:08:41] So how do you deal with that, when you're having those feelings?

[Isabelle] [00:08:43] Sometimes I'll just read to escape, write about it out sometimes and just relax

and try and like not think about it.

[Jane] [00:08:54] Sophie, are there things that you think Isabelle does really well in helping you and helping make you feel better when you are sick?

[Sophie] [00:09:04] Um, when I'm not feeling good or something, she can always make me laugh.

[Jane] [00:09:12] Sophie was saying earlier how there are things that she can't do because of her brain tumor and her eyesight and her hearing, she has trouble with and she couldn't do gymnastics. But are there things that you think Sophie does really well because of her brain tumor or ways that she is skilled at things because simply because she has this brain tumor?

[Isabelle] [00:09:33] Well she's really good at like thinking which might be weird but she has really good ideas because of her experiences and she knows a lot of things from her experience.

[00:09:48] Um, She's very tough and strong emotionally, not strong, not emotionally but she's like tough and can handle things. So, she's very strong emotionally.

[Jane] Are you strong emotionally too? [Isabelle] Definitely.

[00:10:06] [Jane] We're talking about what it's like to grow up with cancer. Coming up we'll get some advice from Sophie and Isabelle and we'll talk with someone who works on Cancer research and wants to share a little bit about what her work is like. But first a message for the adults listening.

[00:10:22] [Jane] This is "But Why" a podcast for curious kids. I'm Jane Lindholm and today we're learning about what it's like to live with a serious illness.

Sophie and Isabelle Posner Brown are eleven year old twins who live in Washington, D.C. Sophie was diagnosed with a brain tumor when she was two, so the whole family has had to live with Sophie's condition.

Obviously that's really hard for Sophie because it's in her body and she has to face surgeries and medicine and the side effects of her tumor and her treatment.

But it's also hard on Isabelle who not only loves and supports her sister but has had her own life impacted by Sophie's illness. I asked Sophie to offer some advice for us in case any of us ever find ourselves facing a serious illness.

[Sophie] Even when there's like, bad parts about going through this experience, every once there will be times, when you'll, there's stuff you'll really want to do and you can do that. So, even when there's tough parts along the way there's good things that come out of it.

[Jane] [00:11:30] And Isabelle has some advice for kids who have a friend with a serious illness like Sophie's.

[Isabelle] I think they should know, you can ask questions to your friends but don't make it like, what, your whole everything, your whole friendship's based on. Don't create a pity friendship or don't just be that's all you talk about because, there are, these kids are also normal just with something different about them.

[Jane] Does that happen sometimes where you feel like you've seen those sort of pity relationships?

[Isabelle] [00:12:00] Ah, no I don't think that's happened with my sister especially since I've been there for her. And I have helped her a lot. (Giggling)

[Isabelle] [00:12:09] But, I do know that it's especially difficult with a twin who has a brain tumor because that twin gets all the attention. And then it's, umm, I'm Sophie's sister. So there's ups and downs.

[Jane] If you do ever find that you have to go to the hospital Sophie, thinks there are some things that might be helpful to keep in mind and maybe even to have with you.

[00:12:30] [Sophie] Well maybe that it is helpful to have, like, a stuffed animal that your, that you will always bring with you to surgeries in the hospital. Because that really helped me and I still have that stuffed animal for everything I go through, so.

[Jane] [00:12:45] So what does your stuffed animal look like? [Sophie] Um, It's a bunny.

[Jane] Does it have a name?

[Sophie] Yeah, his name is Lou. [Jane] Did you name him?

[Sophie] [00:13:54] I have named him multiple things. His name is Lou now, and he's a boy. But he used to be Lucy and a girl.

[Jane] How does Lou help you? To have Lou with you when you have to go to the hospital?

[00:13:07] [Sophie] Well he makes me kind of like feel like I can just hold tight on something and that I'm not alone, even when that person can't talk.

[00:13:49] [Jane] That's really important to have that somebody, that something, that's with you that you can hold tight to. I know that feeling too.

[00:13:56] Well, Sophie and Isabel I really appreciate you both talking to me. This is really great and special and I think the other kids who listen to "But Why" are

really going to appreciate hearing from you. Because it's one thing to hear from adults but it's really important to hear from other kids. And so you are both very powerful people and I really am glad that you were willing to talk with us.

[Sophie & Isabelle] Thank you. Thank you for having us talk to you.

[00:14:01] [Jane] A huge thank you to Isabel and Sophia Posner Brown for being willing to share their story with us. Isabel and Sophie thank you very much.

[00:14:12] In the episode that we did just before this one we had a question from one of you wondering why there is no cure for cancer. We learned that there's no one cure for cancer because there are many different types of cancer and there isn't likely to be a single cure that covers all of them. So researchers have to look at a lot of different types of treatments and medicines and how they work.

[00:14:32] Some cancers have really effective treatments that mean most people who get that type of cancer survive. But other cancers still don't have a cure. The person we were talking to for that episode was an oncologist, a doctor who specializes in cancer. But you should know that there are a lot of people working to find cures and treatment for cancer and they're not all doctors. Researchers and scientists have lots of different types of jobs and titles and places where they work. One of those researchers is the mother of a "But Why" listener. Here's what she sent us.

[00:15:05] [Jessica] Hi Jane and the but why team. My name is Jessica and I live near Philadelphia, Pennsylvania. My 4 year old Max and I love listening to "But Why", I am not a doctor. I work for a pharmaceutical company, a company that invents and makes medicines. My job is testing new cancer treatments.

[Jane] Jessica explained how that testing works. The tests are called clinical trials.

[00:15:27] [Jessica] In a clinical trial for cancer, we take a new medicine that we think will help and give it to people who have cancer. Then we take very careful notes on all of the people taking the medicine to see if it's helping them and if there are any side effects. It takes a lot of work to organize and run these tests which can have hundreds or even thousands of patients in them across dozens of countries. My job is to make sure that all of the doctors treating those patients are giving them all the same amount of the right kind of medication and that they're taking good notes, measuring how well the patient is feeling, if their

cancer is getting better or worse or staying the same and writing down any problems the patients may have during a test like feeling tired or getting a headache. If a lot of patients have the same problem those might be side effects of the medicine. Part of how researchers decide if a medicine works is by looking at how much the medicine helps and comparing it to how bad the side effects are. If it helps more than there are side effects, then it's probably a good medicine.

[00:16:30] [Jane] Did you get that? In a clinical trial, researchers and scientists and the drug company that's working to make the medicine try to see how helpful the medicine is and what the side effects are. Jessica says she really likes her job.

[Jessica] Like it's helped so many people. A medicine I work on, called an immunotherapy, a medicine that helps the body fight cancer by itself is changing how some of the most common and deadly cancers are treated. Giving thousands of people around the world hope. People who before this new medicine would have only had a few months to live now might live for years.

[Jessica] I also get to work with so many wonderful people all around the world and sometimes travel to amazing places to meet them. The people I work with are sometimes doctors and nurses but also scientists, engineers, writers and people with all kinds of different backgrounds. Being a doctor is one way to work in medical research, and it's a very important one. But if you're interested in research or in medicine there are a lot of other ways to be a part of medical research without being a doctor.

[00:17:30] [Jane] Thanks very much to Jessica McLean for telling us a little bit about the medical research she does. Jessica reached out to us because she wanted to make the point that not all cancer researchers are doctors. She and Max were listening and they offered that feedback and we love that. Actually that's kind of how we got in touch with Sophie and Isabelle Posner Brown too. Isabelle and Sophie's mother shared their story with us after Sophie had a question answered in an episode about Poison Ivy.

We love it when you share your feedback and experiences with us. We learn as much from you as you learn from us.

[00:18:06] You can always send an e-mail to questions at, [butwhykids.org](mailto:questions@butwhykids.org). That's also the address where you can send your questions, questions about anything. We will do our best to get you an answer. Be sure to send us your first name, your

town and how old you are along with your question, have an adult record you on a smartphone.

“But Why” is produced by Melody Bodette and me, Jane Lindholm at Vermont Public Radio.

[00:18:32] Our theme music is by Luke Reynolds. We'll be back in two weeks with an all new episode. Until then. Stay curious.