Janet and Brain

Janet and Brian, parents of Michael.

Michael had SMA-Type 1. He died at 23 months.





DIAGNOSIS

SMA ran in the family, and then it hit us in the face

https://youtu.be/GtP0jNgPaV4

Janet: My son Michael was, he was a funny little guy. He was beautiful and he loved life, he loved cupcakes and cake and food and ducks.

Brian: That's right on the ball and he loved everything sensory like we go through stores and he'd have his arms up in the wheelchairs touching all the -- I hate to say it, the underwear and the bras, as we went through.

Janet: we really knew he loved ducks when we went to the emergency room I think the second time and he had a duck, and he kept telling everybody in the emergency room, all the doctors and nurses, I got a duck. And it was I got a duck every -- and then after that, it was everything -- he had other toys but the duck was a thing, I got a duck and he had -- so of course, I bought him a thousand ducks and little oriental trading ducks, you know the little rubber duckies and he'd sort them every night and make daddy sort them every night.

Brian: All 89 of them.

Janet: He loved cake because we would feed him, and my mother-in-law would make him hash and we'd call it cake, and he'd eat it or meatloaf and call it cake and eat it.

Brian: You say what do you want for breakfast, cake.

Janet: Cake.

Brian: What do you want for lunch, cake and what do you want for dinner, cake.

Janet: Cake. And he got cake for everything.

Brian: Michael was diagnosed with spinal muscular atrophy, and the way I always described SMA as it is for short is it's just like Lou Gehrig's disease except it attacks small children. It's a form of accelerated form of muscular dystrophy which is actually the deletion of the SMN1 protein on chromosome five in the DNA. The severity of the disease is determined by how much SMN2 protein there is, so there's four different stages of SMA. There's SMA1, SMA2, SMA3

and SMA4 is actually adult onset SMA. So, the diagnosis is depended upon one the person is diagnosed with the disease.

Janet: He was diagnosed at nine months. We knew before that that Michael had SMA or we thought he had SMA but we were waiting for the diagnosis. Brian's had a brother who passed away from SMA when he was 15 months old, so his mother was -- knew when she looked at Michael that he had SMA but we didn't talk about it until we had to talk about it. And then we were hit in the face with the reality of the disease, so --

Brian: I knew he had it, it was just a question of the blood test to confirm it.

Brian: I've known about SMA since as long as I could remember but my mom called it by it's own term Werdnig-Hoffman's disease, that's when I knew he has this Werdnig-Hoffman's disease. And every time we went to the pediatrician, I kept telling her.

Janet: He kept saying I got -- I want him to roll over, he's got to roll over, he's got to sit up and he wasn't doing these things. And we kept, you know the monthly checkups are whenever, he just wasn't doing that. So, eventually at nine months, she referred us to early intervention and his own occupational therapist, was the one who said you need to go somewhere now so we went to Boston Children's Hospital to the neurology department and the neurologist confirmed it with the blood test that he had SMA. And that's --

Brian: He called just before I went to work, I work nights at the time and I called my parents because they were, of all places, at the casino to come home and I waited and for some reason, instead of staying home, I went to work, shocked. I just wanted to work.

Brian: The only thing I ever thought of about that was if there was a family to be born into with SMA, this was it because of the experience of my parents, she was working with severely disabled children, she has a master's degree in early childhood education. It's just not that there's any perfect family thing to be born into with a disease like that but I guess, ours wasn't a bad one.



Brian: The doctors, they kind of lean towards a feeding tube and a ventilator, they don't say you have to but they kind of lean you towards that. And we had made that decision long before that that we weren't going to do that.

Janet: I really -- my decision-making process really was -- it wasn't even a decision, it was what was going to happen because I worked in a special -- a severe special needs classroom, I had seen --

Janet: Because I worked in the special needs classroom, I had seen children with -- that were not eating, that were tube fed, that were in wheelchairs and they were highly medicalized children and I just knew that I didn't want my son to be like that because these children struggled just to breath and I just couldn't see our son doing that. I mean, he struggled everyday with his life but not on his own, not with equipment. So, it wasn't a decision that I made, it was just the way it was. I don't even think we even talked about it.

Brian: Once.

Janet: Did we?

Brian: We talked about it the last day for about 30 seconds.

Interviewer: The last day.

Janet: Yeah.

Brian: For about 30 seconds.

Interviewer: Why did it come up on the last day?

Janet: Well, because we were -- it came up the last day because we had the choice to make and we listened to the doctors tell us about the surgery to get him on the ventilator and the feeding tube. And we had -- first for a second, we thought well, we'll listen to it and we'll -- maybe we'll do it and then, it was just not an option, I was afraid we were going to lose him on the operating table. So, I just couldn't do it and it sounds weird, but Michael -- Brian's out of the room and Michael mouthed the words help me and I knew that he wanted to just be -- there was a nurse with me too and when he said help me and it wasn't because he was in pain, he was just done, he was tired so that was it.

Brian: And we also believe that a feeding tube and a ventilator wasn't a decision for him, they would've only benefitted us. So, I don't want say it's a selfish decision but I think that decision would've been for us, not for him.

Interviewer: Yeah, so tell me a little more about that, I remember on the phone, Janet you talked about how Michael loved food, so --

Janet: Michael loved to eat food and he loved to talk and he loved to sing. And I just could not imagine him being stopped and not being able to sing and not being able to eat and being in our house and not doing those things. So, it just -- it wasn't for us. We pictured him in our dining room which would -- we think it'd be the place that he might have been in and like what kind of

life for him we thought would that be for him to be in a bed and in our dining room instead of being free.

Brian: It was harder to tell our parents than it was to make that decision, telling them was much worse

Brian: Telling them that we were going to let him go.



WORKING WITH THE MEDICAL TEAM

I relied mostly on the early intervention people to help focus on the living.

https://youtu.be/pm42qOGsU7o

Janet: I took over the daily chores of taking care of him. I worked previously as an early intervention teacher, I was doing -- and even before, I was doing early intervention years before and then I was an assistant for a severe special needs classroom. So, I was familiar with the diseases and familiar with it somewhat. So, you know, his PT came here, his OT, yeah PT and OT, the nurse speech therapist, they were here on the rug and I was there every second of therapy, watching and trying to learn and trying to get him to do what we could and you know, finding the best toys for him, finding the best food for him because a lot of the time, if you go to the doctors, SMA doctors, a lot of them are not really -- they don't really tell you a lot about how to care for them except putting you know like, the tubes in him or the medical stuff but not like the daily living stuff. So, I relied more on the early intervention people because that was my goal to keep him normal. So, we did that and I mean, we went swimming twice or three a week, we went horseback riding, we did everything in those two years that we could. And I mean, shopping at least twice a week in the underwear section, we went out to eat as often as we could.



Janet: The doctor that we had was very good at -- like he actually -- he didn't help us make the decision for Michael, but he helped us in our decision with what we decided and he told us you have to tell your parents and he set up a room and we each took turns talking to our own parents and that was hard, especially I think for your parents -- for you and your parents because that was the first time your father ever showed emotion about it, I mean he cried for the first time. I mean, my parents were hurt but they understood. I had talked to my parents before because

during that time, there was a lot of talk about like these experimental things that we could try and -- like they wanted to fly my son to Mexico for some shots or whatever, I don't know and I -- we said no. That was just not going to happen. So they knew what was coming that we were not going to do these things to our son.

Brian: Speaking for myself, I'm pretty concrete on the way -- my feelings on the way SMA is treated, it's a genetic disease where the chromosome is a defect, I don't believe in this day and age, there's a medication that can replace a chromosome or protein on a chromosome. So, that's why I didn't want to go for the medication, the experimental trials plus as awful as it sounds, you don't know if your child's getting the medication or the placebo. So, it could all be for nought, and I know I couldn't. It might help children down the road, but in that instance -- I know that's a selfish decision on my part but it is what it is.

Janet: I don't think I was tempted at all with any experimental things, they just scare me. I know I wouldn't do experimental things for myself so I wasn't going to put my son through anything experimental, it's just -- it wasn't something that I even thought about doing. I guess, I was just organic for me.



Janet: Heather was a big part of Michael's life, you know, she helped me as much as I would let her because I didn't let anyone really do anything for him if I was there but she still can't deal with him not being here. She doesn't talk about it, she's not here tonight because she doesn't want to talk about it and think about it. She's very closed off about it, still I mean --

Brian: We took her to grief counseling.

Janet: We did, she did go for a couple of months. I think she still could use some more but as an adult, she'll probably find her way and do it. But it was hard for her, I mean that was her buddy.



Brian: He had his best checkup that day, then we turned around on the mass pike and almost thought we lost him in the back seat of the van.

Janet: Yeah. Yeah, we should've taken him to the hospital right then but we got him revive -- like pepped up, his lung collapsed on the way home from the clinic. We didn't know that but we saw him gasp and then, hoarse -- you didn't even pull over, I just jumped out, got him out of his little car seat and try to -- you know, pounded on his chest, did a little chest PT, we're on his back and he was okay. Okay for the moment and then --

Brian: He was back to himself when we were home.

Janet: And then that night, a few hours later, we were in the emergency room.

I never want to see another person, a child, an adult, it was horrific.

Janet: His little chest was all --

Brian: His chest was compressed on one side from belling breathings or it was compressed on one side and that -- you can almost see what's holding him. It looked like you could feel the front of him through the back of him, he was breathing so hard.

Janet: Yeah

Brian: That's when that doctor said he needs to go on a ventilator like now.

Interviewer: I'm so sorry, that must have been so hard.

Janet: Yeah.

Interviewer: And all the preparation in the world doesn't prepare you for that moment.

Janet: No, it doesn't prepare -- in that moment, you're just on adrenaline and you're just -- you're not prepared for anything that's going to happen. Yeah, it was tough, it was hard. I don't remember a lot of it, I remember going in the ambulance and being in the emergency room but there are certain things I don't remember. I remember his breathing but I don't remember other stuff.

Brian: I don't forget that much.

Janet: Yeah, you don't forget anything.

Janet: I didn't sleep the whole ten days we were there, 11 days we were there.

Brian: We were up, watching.

Janet: Yeah, watching and living on coffee

Brian: He was in for 11 days, September 2nd to the September 13th. And they tried to get him off the ventilator about three or four days into his stay because they said if he didn't get off at some point, he was never going to be able to get off, because he just kept getting weaker and weaker and then relying on the ventilator to breath, he wasn't going to be able to breathe on his own. So, they tried to get him off at about four days in and that's when they put him back on it because it just wasn't going to come off. And that's when they started talking about the feeding tube and about the ventilator. And then we walked down the hall and --

Janet: Yeah, we walked down and said it's time, he needs to rest, he's done.

Janet: Yeah. We wanted him happy, so he is happy.

Brian: What you said was maybe we should let him go, I guess I don't forget much.



SPIRITUALITY

People say things happen for a reason but I haven't found the reason vet.

https://youtu.be/zFVeSoQg6Is

Janet: I mean I prayed even before he was born, not for SMA but I prayed that he was healthy like every single day, that was healthy, that he was going to be happy, that -- and then you pray that he's going to -- every night, let me have one more day and then I kind of got angry, I guess. I don't -- didn't lose my faith but it wasn't as strong as it used to be, I mean I'm getting back to it but it's just a little -- it's hard. I used to take Michael to church with me and you know, it was hard to think that why is this happening but it just -- sometimes things happen. I mean, looking back, I know that things happen -- people say things happen for a reason but I haven't found the reason yet, I'm hoping to. It just hasn't happened yet.



Brian: The last thing, then I'll be done, is it affected me more than Janet because we're on the same line as people don't understand. I lost friends over this.

Janet: We both did, we both lost friends.

Brian: You can still talk to her, I will never speak to him again.

Janet: I would -- that would be a big thing for parents to tell parents that -- even your friends sometimes are not going to be there, they say they are -- you lost your best friend, I had a friend who was a nurse, oh I'll go with you to the hospital if you need to, never saw her. He passed away, nothing from her and then my other friend, who I don't really consider a friend anymore. She's on Facebook but I don't -- won't do anything with her, she had a son, same age as my son. She went to -- she came to visit once, and of course Michael was -- he was like -- eight months, six, seven, eight months, he was little but he wasn't doing anything -- he was just on the floor and her son was able to move. You know, it was an okay visit and that was the last time we ever got together except for one other time, I told her we were going to be in the Boston area for his clinic. Oh, I want to get together, let's go to the park, I said we can't go to the park because we've had a six hour visit, you're not going to take your son who's -- I mean, we're all exhausted, we -we're not going to play in the park. And I explained that to her and she said, okay, well maybe another time, never heard from her again. She actually, a couple of years -- last year, she sent something -- she sent me a duck and she said this has been on my tree for so long, I want you to have it now, I hope this helps you remember Michael. I'm like what -- I don't need your duck. You know, it was -- she thought she was being nice and a little olive branch, but it really wasn't, it wasn't what we needed. If she -- we needed -- I needed an apology, I think or I'm sorry, you know, something but she didn't -- she didn't give us anything. So, I won't be mean to her but I'm not -- I don't consider her a friend.



Janet: I didn't want any counseling, I didn't want to be in that realm of the disease, so we just did everything we could just to live life, he said cake every day, I mean you don't eat cake every day or you shouldn't.

Brian: Like you wouldn't.

Janet: I wouldn't. You know, so like the swimming and the horseback riding and the --

Brian: I forgot about that. He loved the horseback riding therapy.

Janet: And that was because of our great occupational therapist. He suggested because Michael loved farming animals, because of the ducks, he loved the other farming animals and he was like you know, he should learn horseback riding or have him go horseback riding, okay. I mean, and that's not even the best thing for someone with a respiratory disease but well, well, we did it.

Brian: He did like it.

Janet: He loved it. I mean, that was the best thing we could've ever done for him, for us to see him do.

I took a picture of him almost every day. I don't think I even did it consciously, I just did it. I think you asked me one time, like I have a picture of his ear or his little fingers and you're like what is that, it's just a sweet little ear but I mean, now I have a picture of his sweet little ear.

You need to make memories to have a whole life with your child. https://youtu.be/kC-IJZcLVOM

Janet: Oh, tell parents of a newly diagnosed child with SMA to trust your gut because you know what's best for your child and what's best for your family, because you just know. I mean, every parent -- every mother, I think knows. And also I always tell every new parent anyway regardless of diagnosis or non-diagnosis to take pictures as much as possible, like even a little ear because you never know when you're not going to see that little ear. And just -- I think also just to have your child be a child, have your child -- you know, not be so afraid because the nurse told me this also that we -- the way we worked with Michael was different than some other people that she's worked with, like we let him get dirty, I mean, we let him do -- ride a horse, we let him go to the mall, I don't -- some parents are so afraid of it -- with SMA, for diseases and -- or just a common cold, you have to be -- I will tell them you have to be cautious but to -- don't let it hold you back because you need to have those memories with him and have a whole life with your child.



Janet: The videos, I haven't really looked at. I did look at a few -- today actually, the pictures I'm just -- oh, we have some pictures around the videos, the real -- like every day photos, I'm just getting to look at, I started putting them in albums last year. So, I do little bits at a time because I can't do more than like an hour a time for -- and then I can't do it anymore for several weeks. I don't know --

Brian: We still had every toy, every piece of clothing downstairs.

Janet: Yeah.

Brian: She finally just breaching into it for her nephew.

Janet: And we also -- that year he passed away, we -- it was mainly me, I had all his little collections of stuff. I had like find a use in the house for, so that's why there's ducks everywhere or I've even tried to incorporated them into our daily life just so they're not like -- they don't look like they're just things, they're like part of us. So, we've incorporated -- well, ducks are huge, and cupcakes have always been huge.

Janet: I love looking at his things, we have -- upstairs, we have shadowboxes of his ducks and then look at them almost every day. I also have just a box of his ducks that I pull out for -- you know, his Christmas ducks or his whatever, Easter ducks or summer ducks. And I love to see his stuff, I mean the clothes eventually I want to do something with, I just haven't been able to take them out, they're in our suitcases. I haven't been able to unpack them yet, I keep saying I'm going to and I just haven't. And his toy is like, Brian said, I can go through them -- I have triples of these toys but I still can't get rid of them, some of them I do give to my nephew but then I'm -- I have to take them back home with me. So, he doesn't ruin them which is silly but it's the way it is for me.

My grief has changed over the years but it still gets me at random times. https://youtu.be/EKBl21qwO1I

Brian: He will be six in September. It doesn't come as often for the longest time, there's a sound or smell or a song, it still happens every once in a while.

Janet: Yeah.

Brian: I try not to look like a fool, crying.

Janet: Crying to a Queen's song or something that Michael liked.

Brian: He used to dance, he could only move his -- basically he could only move his head, his arms and his torso and he'd sit here --

Janet: Yeah.

Brian: Because he couldn't move really anything from the waist down.

Janet: My grief has changed because I could not look at any babies, didn't want to see them, didn't want to hear them and that was my job before Michael and I just didn't want any part of them. In the store, I'd have like panic attacks seeing a child or even a girl, any -- it didn't matter what kind of baby or baby clothes, anything baby related. Now, I can see the babies, now I think they're cute again and I can play with my nephew and things like that because -- I mean, it's still hard if I think too much about it, I get upset but if I just go with it I can go with it and -- but yeah, you're right. Brian's right, there's still like those times, it could be a random weird thing and it gets you.

Janet: Yeah, we always talk about Michael.

Brian: Usually focusing on the good things, unless something comes up then we'll talk about some of the other things but generally, the good things, the happy things.

He should be eight. I should be at little league games. https://youtu.be/Zbw6FIfwpLw

Brian: Oh, yeah, I should be at little league games, right now, if that's what you're referencing. Oh yeah, we think about that all the time, he should be eight.

Janet: Well, I think that's why -- I know that's why I have a hard time with my other nephew who's a year younger, like why him and not -- why is he here and not Michael, I mean, they never got to play together because -- like I miss my nephew's life because I was focused on -- which -- my son's life and it's just a weird -- like there's no bond there because he was too -- he was supposed to be playing with my nephew. And you're supposed to be at birthday parties together, you know. We're playing with our new dog that we have, we always say that oh, Sugar Bear , that's our dog's name, would've loved Michael like oh you know, that should've been -- but it's not.

We didn't get any counseling or do a support group after.

https://youtu.be/HKt52mFEI50

Brian: No. No, we didn't get any grief counseling or support after he died. I think part of it was -- I don't know, it's almost like we prepare ourselves, I mean, I know I wasn't kidding myself of what was going to eventually happen. Like, I was prepared -- even at his wake, I don't think either one of us cried once, it was more consoling the people that come in there because it is shocking to see a 30 inch casket. So, I felt more like we were consoling them. I didn't cry once, I know I didn't

Janet: No, even Heather didn't cry, not the three of us. It was like a little unspoken truth that we weren't -- we're going to cry, we cry later, we cry before but not then. I -- when you said counseling, I looked into things but I just didn't find anything I really needed. My sister is a -- she's a social worker, she had shown me different sights and different things and I write about them but I didn't find them overly helpful to me. I mean, I do -- I think I went on Facebook and sites and like the more I read about things the more I -- that kind of helps me more than like talking to professionals about it. I don't know --

Interviewer: What about a support group, did you think about going to a support group?

Janet: I didn't for -- when is it, compassionate friends, parent's compassionate friends.

Brian: Compassionate friends.

Janet: But I just didn't want to -- I didn't like that. I just didn't really want to go there. We did do one thing, and it's not really a support group but it was healing, I guess for me, there's the angel of hope. It's actually Christmas box angel, it's a book by -- I forgot the author's name but there's a memorial set up in the church --.

Brian: Angel of hope.

Janet: Oh, the angel of hope. My mother-in-law found it, there's stones -- they put stones with your child's name on it and there's -- every December 6th, there's a service memorial -- not a memorial service but --

Brian: It's pretty much a memorial service, it's a candlelight vigil basically.

Janet: Candlelight vigil, yeah. And I found that helpful, we do that -- your mother put a stone for her son next to our stone and occasionally, I'll go up to it because it's more -- it's not a cemetery, it's just a pretty place in the church, outside the church and he doesn't even know, sometimes when I'm in the area in Sturbridge, I'll go to it and just -- for a few seconds, just to

look at and it's peaceful and I think that's helped me. But other than that, I haven't done any counseling or anything.

Interviewer: Do you visit the grave?

Janet: We do visit the grave. I visit it almost as much as the angel of hope, I do change out the little -- I have to have a seasonal flower thing or -- so, every season we change it and my mother who lives in this town in Sturbridge, she'll go and visit it for me and she'll say you know, it's looking good and she goes once a month. So, I do -- and I make sure it's nice or whatever.



Janet: Well, actually we start off in August because August is SMA month. So, we do a little -- with your mother, and we do a little candle lighting of ceremony, we take pictures and we put it on the SMA website. And then, for his birthday we usually eat cupcake and --

Brian: We bring them to the hospital.

Janet: -- and we bring them to the hospital. His mother makes the cupcakes and we deliver them to the hospital, to the PICU Unit and for whoever wants them, the nurses whoever. And the nurses always come out and talk to us and talk about Michael and --

Brian: This past year we had one that chase us down the hall.

Janet: And a lot of times, we just want to just drop them off, we don't need to speak to anybody but they always want to come out and talk to us. And this year, there wasn't anyone around that we knew, so we dropped them off and some nurse -- I don't even know who she -- I don't remember this nurse, came running down the hall, I just want you to know we still think of Michael and the ducks and I mean, they really -- they talk about him and we're there quite often at the hospital for things.

Brian: Easter time, we'll fill up a basket full of --

Janet: Ducks.

Brian: And we'll bring them up there because he was --

Janet: Because the first time we went to the hospital was at Easter time and I remember the nurse saying oh, is the Easter bunny coming today? And I said, well, we'll have to wait till he'd come -- Michael's come home for the Easter bunny to come. She's like no, no, don't worry about it and then we woke up, I must've been sleeping that one night in the hospital -- well, I slept

every night there but the room when I woke up was all decorated with Easter stuff and you know, they try to do really good things for the holidays. So, that was why we started with the Easter, with the basket and the ducks.



Brian: No, not once did we ever think we'd have any regrets. She told the doctors how it was going to be.

Janet: Yeah.

Brian: And I agreed.

Janet: Yeah, that was the first meeting, I told the doctor look --

Brian: We made the choice, we weren't going to take away his food because he loved to eat, we're not going to take away his ability to talk. My only regret is he never got to say mom.

Janet: Yeah.

Interviewer: He never got to what?

Brian: He couldn't say mom, the disease took the ability to form --

Janet: The Ms --

Brian: The Ms and the Os. He could say Dada but --

Janet: Yeah.