#### ROBIN AND CARLA VIDEO SELECTS

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Carla, mother of Nathan, Audrey, and Talia. Talia died at 23 months from infantile Tay-Sachs. Robin, mother of Carla.

Title: Delivering (mom) and learning (grandmother) the diagnosis: "I wanted to control the blast because I was the epicenter."

Youtube Link: <a href="https://www.youtube.com/watch?v=O90w4R9LINA">https://www.youtube.com/watch?v=O90w4R9LINA</a>

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) and her mother Robin remember how Carla delivered the news and Carla's wanting to protect her parents from such sadness.

### Transcript:

**Blyth:** Robin, when Carla called you with the diagnosis to tell you, and I know that Carla was keeping you apprised leading up to that, but what were the things that you... what were you worried most about once you got the diagnosis as it relates to Carla and her family.

**Robin:** How do you survive? How do you survive something so cruel and mean and unexpected and terrifying? And how will they do it? And I know I said on the phone that night, I will be there. I meant mentally, and physically, and spiritually and I said it that night, whatever happens, I will be beside you.

Carla: Well, and when I told her of the diagnosis, it had been after two days of us knowing the probable diagnosis, and I withheld from her because I wasn't ready to make that public yet. We were waiting for one more test to fully confirm but I also I didn't want to let them in on it yet, and I remember in that first reveal I had already sort-of figured out a way to present it and manage my own reaction, and I said, you know this is this is going to be terrible, this is going to be brief, is not going to take up the entirety of our lives -- which was a fear of other diagnoses -- and I think I even said that in that moment, we can mourn for a day but then we've got to get together and do this.

So I think I was afraid of my parents falling into a pit of despair when I had already steeled myself up even though I didn't really know what was coming ahead, but I knew that I needed everyone around me to have the energy to focus on it and not wallow.

**Robin:** Because Larry and I were tested for the disease in 1978 and we knew what it was, we knew what Carla was saying to us when she said it.

Carla: Not a good day.

Robin: Not 9:30 at night either. That's also how I knew it was something bad

**Blyth:** Carla, hearing you describe the build-up to your, sort of what I hear you saying is, you thought very hard about, you were sending a message to your mother about the tone you wanted to take with all of this and you were queuing her for how you wanted the family to be thinking about it and doing that. Did you do that partially because you were trying to protect your mother from her own grief?

Carla: Certainly, I think my parents are, they are wonderful helpers, and they find solutions to things, and here I was presenting us with a problem with no real solution and so I worried about both of their ability to be in that. But my mom and I specifically have a, we talk about emotional things, and we talk about stories of other people's tragedies frequently and sort-of... we like to put ourselves in other people's shoes and picture the world through their eyes, and now we were in possession of this terrible story and so I worried, just like I worried for myself, I think I see a lot of myself in my mom, and so I certainly worried about my parents' emotional ability to handle it because we hadn't ever been through something so serious before.

**Robin:** Well thank you for worrying so much about me. It's your daughter, it's for us to have to worry about you.

Carla: You said that frequently, but I couldn't stop. I think I wanted to, I wanted to control the blast since I knew I was the epicenter, Talia was the epicenter, I thought she was like holding a hand grenade, and I thought I needed to control the external blast and you guys, the grandparents, were in that blast zone so I wanted to do as much proactive controlling of the universe as possible. But I think my mom did remind me repeatedly like, this is... this is your... you are at the center of this, stop worrying about me so much.

Title: "She said, 'don't cry in front of me, ever."

YouTube Link: <a href="https://www.youtube.com/watch?v=X-BgUuqI7Y4">https://www.youtube.com/watch?v=X-BgUuqI7Y4</a>

Description: Robin, mother of Carla, and Carla, talk about how they negotiated showing their emotions around their sad emotions following Talia's diagnosis.

Transcript:

**Blyth:** Do you remember feeling like, "Carla is telling me how she wants this to go so I am taking my cue from her and I gotta --

**Robin:** Well I'll give you the biggest cue she gave me. She said, "don't cry in front of me, ever." And so I... I did pretty good Carla, I don't think I -- In other words she said, this will upset me, watching you be upset will upset me. I don't think I stopped crying for a year, but I never cried in front of Carla so that was... I wanted to do what would be best for her. I had plenty of people I could cry in front of, I could cry all by myself, you know I mean --

**Carla:** But also in those first few weeks, we always spoke a lot, but you called me a lot a lot, and then you said, I only feel good if I'm with you --

Robin: I only feel safe, I think I said I only feel safe --

Carla: I only feel safe if I'm with you, I want to be with you. And I said, "well that's not going to work for me. You can't be with me all the time, you're not moving in you know, I have to... the way that I was going to survive was to maintain my life as normally as possible and that includes my privacy and you did a good job respecting that too.

Title: The biggest support she gave me was tracking me from afar.

YouTube Link: <a href="https://www.youtube.com/watch?v=UNR\_jUas6Ks">https://www.youtube.com/watch?v=UNR\_jUas6Ks</a>

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) and her mother Robin talk about how Robin provided support, including just being on the other end of the phone.

### Transcript:

Robin: I had a mental calendar in my mind so I wasn't there physically, but I was aware. And in doing that, you know, I could check in and check in and check in. Then I got to ride the metro... the Amtrak from Penn Station, I got to take the 8:10 Adirondack -- you go to Montreal in the spring and people presented their passport at Penn Station, I always found very funny -- and I called Carla from Hudson, New York, I'd be 18 minutes away and she'd pick me up. I rode the rails.

**Blyth:** Carla did you say to your mother expressly this is how you can help me? How did that go?

Carla: I think in terms of physical visits, I have to give a strong shout out to my mother-in-law, who lived closer, and also I have a wonderful relationship which is also, I know not necessarily a typical thing, but she had already been coming once a week, before Talia was diagnosed, to just give me a break because I had two older children and so she continued those once weekly visits, so I knew that I had that break. And I'd say that my mom and I saw each other every other week in person, but we spoke daily. I would say that the biggest support that she was to me, was tracking me from afar. It was always being available so that when I was out of the house shopping for shoes, or something or the grocery store, and I was overcome, or just needed a distraction, I would call her and she would always pick up the phone. And she would maybe start asking me about how I was doing and I would say that's not why I'm calling today, tell me something else, talk about anything else. Tell me about my new nephew, tell me about anything. Or sometimes I would call and that would be the only thing I would want to talk about. And so she was responsive to me and

didn't try to lay too much on me. She listened and followed where I needed the conversation to go.

**Robin:** Even though Carla was calling half the time from the bagel shop. I would be calling and she would say, "no, with cream cheese!"

Carla: We would talk about funerals, and then I would order a bagel, and then we'd go back to talking about funerals. It was jarring, but you --

**Robin:** I got used to intimacy in strange places. But I didn't care. If Carla wanted to call me, you know, I'll be there.

Title: "I was just a grandmother."

YouTube Link: <a href="https://www.youtube.com/watch?v=U07pCAlXsJE">https://www.youtube.com/watch?v=U07pCAlXsJE</a>

Description: Robin, grandmother of Talia, talks about how she was a grandmother to Talia in person, and how she thought about the family all the time and found ways to help, including getting them a dog!

Transcript:

**Blyth:** What, if anything, did you do to try to figure out how to do this? Be a grandmother to Talia...

Robin: I was just a grandmother. I wasn't... I don't think there is a different grandmother to children who are well and children who aren't well. I mean I think you know, you hold them both and talk, you know, I talked to Talia the same way I talked to Nathan and Audrey when they were little. I gave her a bath, you know, since she had an inflatable ring around her head, the others didn't, she was enjoying her bath and every bit as much as the other two. I guess the difference is that I thought more about Talia than I thought about Nathan and Audrey as they were growing up. I thought about her all the time. I thought about the disease all the time. I started giving myself a course in genetics, I have no science background whatsoever, I just jumped into the subject area, and she was never -- Carla was on my mind and therefore Talia was on my mind always, and it's five years after her birth and we're still talking about her. I can talk without crying, but she is there in such a significant fashion.

**Robin**: They talked about getting a dog, and I jumped all over it. All I had to hear was one little bark and I was like oh yes, oh what a great idea, I'll find a dog, I'll find the perfect dog. I can find a breeder -- where do I find a breeder -- oh let me look for that. Just find me the breed, what breed do you want? And we were all set for goldendoodle and then, who is that actor, he got a different type of dog...?

Carla: I think we were watching the Westminster dog show and we texted you, actually we've decided that we want a cockapoo, and you just said, "okay." And then you went and did all that research all over again. **Robin:** Yeah, but that dog is part of the household now and it brings... he's a neurotic cockapoo and he brings joy. Title: Going to the affected families conference: I needed my mom nearby 5 YouTube Link: https://www.youtube.com/watch?v=2U2fX XDWeg Description: Carla, mother of Talia, talks about how her mother's presence helped steady her and give her confidence as she entered the larger community of parents affected by Tay-Sachs at the NTSAD family conference. Transcript: Robin: The NTSAD conference in Dallas in 2016 that we went to, first Carla said, I'm not going... okay, okay. Then she said I'm going and I'm going without you... okay. And then as it got closer she said, would you like to come with me? I said, okay. Carla: That was a huge help, and it was such a big deal for me to figure out whether I wanted to be in a space with other affected children, how terrifying that might be to me, whether I could travel by myself with Talia, because David and the other kids were going to stay at because I didn't want to multitask being with them. I was all set to do it by myself -- I'm a go-getter I can do it by myself -- and then it just felt like, well why? Why do I need to do that when I believe I can do this better with my mother? Then I was terrified that my mother would speak too much or embarrass me. It was a whole different... I was concerned on so many different levels. The first day that we got there in the elevator -- my mom is a great, I get nervous talking to people initially, she can engage anybody -- and you talked to somebody in the elevator and you talked and talked and talked and talked and talked and we got off the elevator and I looked at you and I said like, "I think I want less of that" and "I think I want to be the one to maybe start the conversation" but like I needed to do nearby, and I did need you to introduce to a certain extent. Like you provided that first hour of transitional help and then I think I found everybody and then I didn't need you as much, and then you took a step back. It was very very helpful. Title: "I learned you can't take care of the future by planning." 6 YouTube Link: https://www.youtube.com/watch?v=32V8hW83r\_o Description: Robin, grandmother of Talia who had Tay-Sachs disease, learns that all the planning in the world couldn't prevent her granddaughter's diagnosis (though there was an error in the lab). It is humbling.

# Transcript:

Robin: I think ultimately I'm a planner. I think that if you're ready for what... I plan ahead. I think you can... I thought that you could take care of the future by planning, and I realize now that you can't. You're at the whim of circumstances and happenstance and as much as you can think that you're in control and you're planning, it's not the case. So, does that mean that I plan less today? No, I probably plan more. Thinking that if I can really get ahead of this problem, I can nip it in the bud knowing ultimately that it's not true. I liken what happened to Carla to the Greek tragedies that I've read. When one knows one's fate, one does everything possible to avoid that fate, and yet it befalls you. And we were tested for Tay-Sachs, and Carla went to be tested, we did everything right and it befell us. So yeah, I've used that analogy for Greek tragedy people, and yet in Greek tragedy, people... they survive, sometimes right.

**Carla:** I don't know, you told me that pretty early on, and I hated that analogy, and continue to dislike it, but that's okay, we can have different opinions.

Title: Mom to Grandma "I remember us talking about how you were stronger than I was giving you credit for."

YouTube Link: <a href="https://www.voutube.com/watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v="gh4-P7TDvg&t=1s">https://watch?v=1s">https://watch?v=1s">https://watch?v=1s">https://watch?v=1s">https://watch?v=1s">https://watch

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) talks about how she was constantly protective of and worried about her mother's well-being and mental health, as well as everyone else in the family.

#### Transcript:

Carla: I remember at the end of Talia's life, I think I went back into a protective mode over you because I was seeing her day by day and I saw decline and it was scary, but somehow it was it was mine so I was going to be okay, but I was afraid for you to see it. I was afraid the whole time through her life that you would be so affected by it that you would have depression for the rest of your life. And you always said to me, like "Carla I am stronger than you give me credit for" and it's proved to be true. You were present, you did not cry in front of me, and we continue to be able to talk about her and make her a part of our family's Legacy without dwelling, I don't know, without being too darkly affected by her life and her death. But it was a perpetual thought of mine that, I don't know, that somehow you would.... I think it wasn't just you, it was everyone around me. I was worried for my husband, I was worried for my in-laws, that it would drag us down to the point where we were drowning underwater and so I was the puppet master who was trying to make sure everyone's heads were above water at all times. So I don't think it was just you, but I do remember us talking about how you were stronger than I was giving you credit for.

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Title: "I think we all work best when we don't expect each other to change the core of who they are."

YouTube Link: <a href="https://www.youtube.com/watch?v=1xttXY4PheQ">https://www.youtube.com/watch?v=1xttXY4PheQ</a>

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) speaks frankly about she didn't want or expect their circumstances to change her. "You can change because circumstances will shape you, and I am a deeper person because of having parented Talia, but I am not CHANGED."

# Transcript:

Carla: I think we all work best when we don't expect each other to change the core of who we are. Just because this massive trauma entered our lives, didn't mean I wanted to change everything about myself, I was still going to view the world with sarcasm and humor and be direct. I didn't want my mother to change who she was. I didn't want her to turn into only talking to me about light and fluff and distraction, I wanted to talk about the real stuff that we had always talked about. It's important that you honor who you are and not allow the circumstance to change the core of you, because then you're left at the end with a different person. You can change because circumstances will shape you, and I am a deeper person because of having parented Talia, but I am not a... I'm not ~changed~ whatever that means.

**Robin:** Well, I can relate far easier to other people's tragedies. I have empathy for loss beyond my small circle. It's definitely changed me.

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Title: "My mom initiated conversations about plans for arrangements after the death. I was initially not very happy to be brought into the ideas."

YouTube Link: https://www.youtube.com/watch?v=VPRGRqUumVI

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) and her mother Robin talk about how Robin brought up the idea of where Talia would be buried and the service and what those were. Carla speaks frankly about imagining the coffin and the impact it would have on others, and briefly considering cremation.

#### Transcript:

**Robin:** The first conversation was, we were walking with Talia in the stroller to the strawberry patch and we were you know, almost back home, I think it was four miles we were walking, and I told you that your father had extra plots at the family burial area which was, at that point, like 2 hours south of where you lived, and you said, "I can't see her being so far away from us."

**Carla:** I do remember actually that you were the one who first brought up these logistics because you are a planner and it took a few starter conversations

before I let it rest in my mind and get to the point where I could then start to think about planning it. And I think I remember the first few conversations I was not very happy to be brought into those ideas because you did have a very, you had a very clear idea of what you thought would be the best for her, I hadn't started to think about it at all so of course I was immediately offended that you had put thought into it, and then of course we ended up going with your plan because your plan, as as almost always, I think it's through, I go in a full circle, and then I go, it was what my mom suggested before anyway.

**Robin:** But it was having months and months to think it through that allowed you, allowed us, all of us, to -- and as you know, your in-laws had strong feelings against cremation.

Carla: I was very afraid personally about the size of the coffin. I just was so terrified about the image of that, and therefore of that image hurting my other children, or disturbing the people around me, and so for a brief second I thought about cremation which in the Jewish tradition is very... is not usually done and my in-laws very strongly asked me not to, given their legacy specifically with the Holocaust, and so that seemed like an easy way to honor that. I wasn't seriously contemplating it, but it was enough that they had strong feelings about it and I would never make a choice that was specifically against someone else's wishes, just seems hurtful.

**Robin:** Carla, you also didn't, as I recall, you didn't want any children, and you knew your friends would come with their children, and you didn't want any children to have to be in the presence of the coffin. And so I guess, with my mother I'd had a funeral and I'd had a memorial service, a memorial program, we had divided the two and ultimately there was a graveside funeral and I thought it was beautiful that your brother brought his three children and your your cousin Bill brought his two pre-adolescent children. Family was there, not friends with children, but family and family with children was there and Carla spent a lot of time on the gravestone which is beautiful, which reflects Talia.

**Blyth:** when you're parenting a child who is dying, it is a particularly unique situation and one that is arguably, not arguably, very eligible for a lot of fraught encounters around the grandparent parent advice situation so so how did --

Carla: No, I think my mother has a strong history of planting a seed of suggestion, making that seed into like a bullet of suggestion, that bullet point is in you and then it sort-of infects you and you're like, I think I have an idea but it was her, it almost always was her, and she usually right. So, even my husband, we go back and we're like, she was right. So, I give her,I give her credit but no, she definitely, she's okay suggesting things, and I shut it down and then eventually I come back around.

	<b>Robin:</b> But if you hadn't come around that would have been okay too. I make suggestions, but I'm not rabid that you must take that suggestion.
	Carla: No, no. Thank you for that clarification. Absolutely, when we go in a different direction, she's fine with it.
10	Video: My mom had no opinion on my daughter's medical care.
	YouTube Link: <a href="https://www.youtube.com/watch?v=NxnYht-X7po">https://www.youtube.com/watch?v=NxnYht-X7po</a>
	Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) talks about how her mother didn't interfere with medical decisions around her care.
	Transcript:  Carla: I will say that for this disease specifically, because we were learning it all at the same time, because my mom wasn't in on the medical doctors appointments, because my husband is a doctor, I think a lot of I spent some time trying to teach her about what was going on with Talia and therefore decisions around her care were never coming from the people around us, aside from my father-in-law who is also a doctor, with whom I would discuss feeding tube questions; whether to put one in, whether or not, and he's a gastroenterologist and he's had experience, many experiences, placing those tubes in people at at end of life, so he had strong opinions and was very comfortable talking to me about them and I welcomed those conversations. I welcomed almost all conversations, I know that that's not everyone's personality, but I think I needed to gather as much information as possible. But in this area specifically, my mother and I, I wouldn't say that you were at the forefront of making a suggestion about her care specifically.
	<b>Robin:</b> Ever. Never because I really, I had no medical background. I had just about no opinion on medical care because, what knowledge did I have to offer any opinion? None.
11	Title: Mother and Grandmother: How we each thought about prayer
	YouTube Link: <a href="https://www.youtube.com/watch?v=KouTEvUbpj8">https://www.youtube.com/watch?v=KouTEvUbpj8</a>
	Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) and her mother Robin reflect on how the diagnosis prompted some anger and reflections about prayer and suffering.
	Transcript: <b>Blyth:</b> Robin, you struggled with the idea and value of Prayer. Did you and Carla talk about that? Not necessarily your own relationship with it or what you were struggling with, but did the two of you talk about prayer at all?
	Carla: We talked about the mourner's kaddish

Robin: Carla has a deeper spiritual life than I do, and I think you're going to services; Yom Kippur services, Day of Atonement services, throughout. I was angrier than Carla throughout, and that's perhaps what has dissipated for me. Carla focused on Talia and giving her the best care possible, and I wasn't with Talia and probably was angrier, have been angrier, for a lot longer than you have. You know, that such a terrible thing happened to my daughter, you know. So, how does that relate to prayer? I questioned the value of prayer, but I never stop questioning the value or prayer. Does that mean I'm praying or you know, moving closer to prayer, moving further away; what's the value, why am I doing this, what are the services, why am I going to services? You know, what does this prayer say? Why do they say it? You know, I'm not going to say that... But I think Carla you were always, you always approached prayer far easier than I did.

Carla: For me, I think that it, I think it both made me feel much more Jewish, since this was like the Jewish disease, and also like a betrayal of Jews since carrier screening has led to almost no Jews getting diagnosed with Tay-sachs anymore. So I, in services I felt like, or when I revealed Talia's diagnosis to other Jewish people, I felt like I was.... either I felt guilty or I felt accused in the sense that they said, "well we got tested, so our kids are safe." And I thought, well, so did I. My family background doesn't have a specific link to the Holocaust but my husband's family does, and his grandmother, Talia's great grandmother, is still alive and was in Auschwitz as a child, I don't think I had to waste any time wondering, why me? because we have a history of why anyone? Why does suffering happen? Why does it continue to happen to our people? So it felt hypocritical of me to have shown up to services the year before Talia's diagnosis and said these prayers of suffering may happen to these people, it may happen, you don't know and then to not show up the next year just because now that person is me. So, I actually feel like it has deepened my connection to the Jewish people and perhaps to the prayers that get said every year and have been said every year for eternity. My belief in God is a different thing, but my belief in my people and our history is stronger now.

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Title: How we recognize Talia on her 'special days. "Sometimes I want her acknowledged, to share, sometimes I don't."

YouTube Link: <a href="https://www.youtube.com/watch?v=Ia0QAT\_RUHY">https://www.youtube.com/watch?v=Ia0QAT\_RUHY</a>

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) speaks about how she wrestles with how she wants to honor Talia's life on the anniversary of her death .... Sometimes she wants to share, sometimes she doesn't.

Transcript:

**Carla:** This continues to be a hard one because I think my mom continues to read my cues, but my cues are confused because I sometimes want her

acknowledged on the day that she died, on her birthday, and I sometimes really don't. Since her death, I feel even more protective of her and like she's just she's mine now and I know she's not just mine, and I'm glad that she is carried by all these other people, but also I don't want my internal emotions to be intruded upon by other people's emotions. And that's sort of selfish sometimes, and yet I'm allowed to be selfish, I know that. So I think this upcoming, this most recent day of her passing, my mom said, "do you want me up there? Do you want us to do anything? or do you not?" and I think I said, not, or I think I had my own plan. I don't know whether that hurts or not.

**Robin:** I honestly am never sure when to bring her name up and when not to bring her name up. We don't live far from the cemetery and we have, my husband Larry and I, have gone down there, you know, just the two of us, we took a walk and we said hello, it was nice.

**Carla:** It's complicated. I have that feeling from the date of death to the date of her birth, it's a month, and it's just a complicated month.

Video: The other grandparents – "We were shared equals."

YouTube Link: <a href="https://www.youtube.com/watch?v=j9EQprHwK-k">https://www.youtube.com/watch?v=j9EQprHwK-k</a>

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) and her mother Robin talk about how the four grandparents grew closer and played their respective roles.

### Transcript:

**Robin:** You know, we definitely were, you know, shared equals and we are closer, well I mean maybe we would've been closer anyway, but we enjoy each other. Certainly at the end of Talia's life when Lally was taking care of her, you were in Denver with Nathan and Audrey at the end of the school year, I didn't want her to be alone, so I went up to her home and it was a hot day, and we sat inside for two hours holding Talia, passing her back and forth. That was a very special... that was a very special moment the three of us were a bond, and that was a beautiful, beautiful -- as beautiful as that day could be -- was beautiful.

**Carla:** Yeah. I mean, that would be, we would hope that our children would gift us the ability to be closer to each other, and I think we all were close to begin with, but I know that it deepened all of those bonds.

**Robin:** Well I mean, we had no dissension... medical dissensions, not like one family wanted A and the other family wanted B. I think that would have been very hard, just very hard. We were... medically, we were all on the same page and I think that, obviously that didn't create, there was no reason to create a dissension over that, so yeah.

Carla: I would say we had four wonderful engaged grandparents, my mother was my emotional help, my father is a lawyer, he was my legal help and my search for what is right in this world. Lolly was my physical and also emotional help, and Michael, her husband, was our medical help. We were well positioned with support in all four vectors, everyone wanted to be involved, everyone had something to offer. I think everyone always has something to offer, it doesn't have to be something as lofty as being a doctor, I think being present and following the needs of the people at the very center of the trauma and being flexible is really all you need. I don't think we would have made it through in as good condition as we did if they weren't there. And also to provide support for my other two healthy children who needed to know that love continues, fun can continue, adventures can continue and that also terrible things happen at the same time, and that's okay. We don't need to run away from it.

14 Title: A mom on finding space for other people's joy.

YouTube Link: <a href="https://www.youtube.com/watch?v=SjJaXnLJOt0">https://www.youtube.com/watch?v=SjJaXnLJOt0</a>

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) talks about 'multi-tasking emotions' -- being happy for others' joy while holding her own sorrow.

# Transcript:

**Carla:** Let me also say that we had a nephew born just after Talia's diagnosis, so there was a family event, there was a bris that we all showed up to, and that was a great challenge in multitasking emotions for me, but it had to have been for my parents. And that was a challenge I think.

**Robin:** Yes, but I mean I would just shout out to Carla's personality because we were at the bris, that's eight days after a Jewish child is born, and Talia is with Carla, and Carla says to her brother, looking at his healthy child, "Dan, your joy is our joy." How can... it was just so beautiful, it was so beautiful Carla.

Carla: I think for me, people always say, "is it hard seeing other happy people or my baby..." my sister, after she had her baby, she asked as we drove away from the hospital together because I was there for that, she was like, "is this hard for you?" And I said, "it's not. Your joy only brings more joy to the world."

What's hard for me is seeing other family members struggle with infertility. It is hard for me to see people struggle in situations that you can't control, but a new joyous face in the world, that doesn't detract from me in any way. It builds the joy that exists in the world and that joy seeps into me.

Title: A mom on how having two healthy older children helped her get through.

YouTube Link: <a href="https://www.youtube.com/watch?v=TKCJR1EmXb0">https://www.youtube.com/watch?v=TKCJR1EmXb0</a>

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) speaks personally about how having two older healthy children gave her a perspective that helped her be a mother to Talia.

# Transcript:

**Blyth**: I'm going to ask a provocative question that I hope does not offend you. Do you think your ability to be as loving and generous was partly because you already had two healthy older children?

Carla: Does it help to have the two previous children? In my situation, absolutely. They were a very clear example of why I could not lose myself to this disease, of why I had to show up and be present and be positive. They gave me a vision of what survival would look like. If Talia herself couldn't survive, then it was my job to make sure the rest of us did survive. It was my job to make sure that Talia's siblings were not warped by the experience in terms of being overly ignored or overly doted upon. They had to remain as they were, which is one of three of my wonderful children. So, yes, it helped because it gave me a vision of what the future would be, which I think is hard to picture when it's your first child and you're not sure. It took away some of that uncertainty as to what comes next, I knew what was going to come next, they were already there. I don't think that they are... I've met a lot of families now and I don't think that it's the essential key to being able to maintain positivity and focus. I've met people for whom it was their first child and they still maintain as well as we all can.

I met a woman recently for whom her son was her first. She asked me, "Is it helpful having your other two?" and I answered, "yes it is" and she said, "I just can't even picture, I just wouldn't picture it being helpful. This is all I want to focus on, this is all I can focus on." So, I don't understand that other experience but also, I would say having other children was helpful up until the very last month of Talia's life, and then I just wanted my focus to be on her and I felt like any distraction was more amplified than I wanted it to be. I really just, I would have been happy just focusing on her.

Title: Writing to process for both mom and grandmother: Observing the experience; Preserving the memories

YouTube Link: <a href="https://www.youtube.com/watch?v=MfkvXSahqb8">https://www.youtube.com/watch?v=MfkvXSahqb8</a>

Description: Carla, mother of Nathan, Audrey, and Talia (died at 23 months from infantile Tay-Sachs) and her mother Robin talk about how writing helped them process what was going on in their lives while Talia was alive and after her death.

Transcript:

**Blyth:** Both of you have written memoirs about this, both of them are yet to be published and I hope that changes. Can you talk, both of you, about the role that

writing has played for you and processing and healing, if it has been a healing activity, and what it has been like to read the other person's version of the story because that's not typical.

TC: 1:17:22

**Robin:** I thought maybe if I could linger a thousand feet in the air and look down on myself I could remove myself from the horror of the present. So I kept a journal, and I started writing, and I have published two books so I like writing. And I thought well, I'll just observe myself because writing is observation. So anyway, that's why I did it, but Carla's impressions are totally different from mine.

TC:1:18:17

Carla: I didn't really start writing until later on in Talia's illness, I started to do a Blog maybe once a month, maybe maybe twice a month, just as a place to both scream, and let people know that terrible things are happening and I'm human and you don't have to tiptoe around me, or you don't.... It was a way of cueing other people as to how to talk to me. I am not a hero mom, you don't have to avoid me because it's all too real, you know, like this is something that happened, now that you know what's happening over there, like you can just come up and talk to me as a regular person.

And then after Talia died and my kids went off... my middle youngest went off to Kindergarten and suddenly my house was quiet, it just felt like if I didn't start writing then, that I was just going to lose the memories and I didn't want to lose the memories. So I wanted to write. It started out much angrier than I think the book has ended up. Partly I just wanted... I needed to process some anger about misdiagnosis or missed carrier screening, but also just about the world's approach to other people's tragedies, you know, human interest stories and how absurd they are.

But I am more introspective, I think than my mom, so we did write similar things and in fact initially, one of the ideas she planted in me was maybe we should write a joint book, which I just had to process it myself, I couldn't figure that out. In addition to a mother-daughter relationship, I couldn't add a co-writer relationship and a grief... Processing grief relationship. It was too much so I wisely said no. And then when it came time to read each other's work, I think we were both terrified. I think I was terrified. I didn't know necessarily whether things would be inaccurately represented or whether my husband would, I don't know, hate my mother's interpretation of our life. She's a fair viewer of the world and she wrote about her experience, not my experience, and she's a beautiful person.

**Robin:** And Carla wrote a love story. She wrote a love story. A tight story between herself and Talia whom she carried for two years. It was just a beautiful view and reminiscence of motherhood and Talia. And mine was, you

know, like you said, this chapter going here and going here, and all those conversations that I had, you know, you could track where I was at any --

Carla: Yours had a worldview. Yours was big and mine was focused.

Robin: And in some ways that was what the experience was --

Carla: Exactly

**Robin:** -- because you were there every moment, and I, you know, came in and out. So I think we wrote the only things we could write.