Rod and Oralea

Parents of William, who died at age 8 from GM-1, and siblings Kyla and John.

1 Title: I was drowning in grief but trying to avoid it.

YouTube Link: https://www.youtube.com/watch?v=0PDKPRBN9D0

Description: A father talks about how the hardest part for him was acknowledging the grief. For the mother, it was the loss of her dreams for her son and the new day-to-day logistics. If your child has GM-1 or another pediatric life threatening illness, these parents may help you find your way.

Transcript:

Rod: The hardest part for me as a caregiver for William especially at the very beginning was to be able to focus or not focus, to be able to think -- the hardest part of being a caregiver for William at the beginning was I was still drowning in grief but trying to avoid it. I was focusing on work because work was my getaway. And then work made me take a month's off, paid time off and then I had no option but to go home and be part of the daily routine, and that's when I was able to kind of change from just the day to day and I guess accept and whatnot, but that was the hardest part and that was eight years ago. So --

Oralea: Well, I think at the beginning of diagnosis, it was just a whole changing of my hopes and dreams for my child and trying to learn the medical system and all the day-to-day things that come into caring with the child with severe medical issues.

2 Title: Dividing, Getting Out, Staying In, Accepting Help

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

Description: A couple shares some of the strategies they used to spend time with their healthy children and to also have the family together as a whole. If your child has GM-1 or another pediatric life threatening illness, this couple shares their perspective which may help you find your way.

Transcript:

Oralea: Some of the most helpful pieces of advice or guidance I received when looking at how to help Kyla through the process of her brother's illness was to make time out of our schedule to just focus on her. So I became very aware that I had to make special mummy and daughter dates and we would have a girl's day and we would go to the mall or go to the theater or whatever, or spend time at her Daisy's Troop once a week, volunteering with them, just to carve out some time in my busy schedule to make it solely about Kyla. And I believe Rod did the same as well.

There was times where it was harder as a couple because usually. We had to take care of Kyla and John's needs was to, one of us would have to go with them and the other couldn't. The other one had to stay home with William. So, we always felt like it was --

our family was somewhat divided because we can't do the family thing as an entire unit. It was either Rod taking the healthy children out to their activities or me. I don't think that our children noticed that as much as we did, and you know it was hard.

We ended up having to, to ensure that our family did have some family time and sometimes it will have to be with the exclusion of William because he can't go out and he would stay at home, we would -- we really got respite. And I didn't want to relinquish my care of William because I thought no one could care for him as I could. And I didn't want to spend time away from him but I recognized that we had to do that so we could take our other children out together and go to the beach or whatever, birthday parties, soccer games, and we just had to do it. And then what we also did was we'd spend a lot of time inside the house together, and as a family -- our kids are kind of house mouses because they enjoy the time in the house because that's what we've done for the last seven years. And we created parties at home.

Rod: Yeah, as time progressed, at first William -- we could travel; bring him out of the house. So we would bring him places and bring him to Kyla's soccer game or things like that. But as time went along, it just got that much more difficult. He got heavier. He got bigger, but also the illness factor and as he got sicker, it became much more difficult to take him out of the house. So as that time progressed, it really came down to one or the other of us could take him out. So like Oralea said, we just made an effort to stay at home and really make home a refuge and a fun place to be, if possible.

Oralea: It was a very big struggle to leave William and go out with the other two, especially for me I think because I was just -- you know, I was his caregiver all the time and Rod -- well, I shouldn't say that.

Rod: No, you felt like you were leaving part of your family, you were. You were leaving part of your family and it wasn't fair. But you had to do what you had to do.

Blyth: Were there ways that you helped yourself -- advice that you would give to parents who might be struggling with that, about the value of getting out and then how you can not beat yourself up about it?

Oralea: Well, what I learned looking back is that everybody who came in and became a caregiver for William fell in love with him and he loved them back. I could tell the bonds he had with certain caregivers. And I think in the end, it was good service to William to be able to experience other people in his life -- apart from us. And then we could go out and enjoy our other two children outside of the house and everybody getting a bit of a break from being inside. And William got to spend some quality time with people who gave him something different than what we could give them.

Rod: I guess that played into when we could start doing that as well, because we didn't have caregivers for a very long time. And even for the day-time care that we eventually got, that only started a year-and-a-half ago. So we had someone come in at 11 p.m. and leave at 7:00 in the morning, that doesn't mean that we are going to too many movies at midnight. So there was just not that opportunity until more recently as it was. So I guess

a piece of advice is fight as hard as you can to get some caregiving and help as soon as you can, but we know the uphill battle and road it is to get that care because it's not easy.

Title: GM-1/Putting support in place for the siblings.

YouTube Link: https://www.youtube.com/watch?v=LGxGcDdwvo0

Description: Parents talk about the impact their son's illness had on their older daughter over the years and the valuable support she received during his life. If your child has GM-1 or another pediatric life threatening illness, these parents' perspectives may help you find your way.

Transcript:

Oralea: She was five when he was diagnosed and started his decline. I think at that point, she didn't quite understand everything that was going on. And like Rod said, we could take William out still. So it didn't impact her life a lot. I think what I first noticed is when she was in about first or second grade and someone commented to her about William's wheelchair at school when it had a malfunction. And that was a negative comment and she came home very upset by that. And I think at that point, she recognized that he was, you know, different from other siblings. And then we always just kept talking to her. We just kept talking to her and openly discussed. If she had questions we answered it as honestly as we could with -- given her developmental stage and we never held anything back from her.

Rod: She was in grief counseling with hospice right off the bat; that's one of the services they did have in place that we could take advantage of. So she went -- how often, once a week or one a month?

Oralea: Once a month.

Rod: Once a month and had a grief counselor, Amy, who she would go and visit with at hospice house for an hour or whatever it was. We did that for a fair while and even today Amy would call every now and then to check in on Kyla and make an effort to come and see her.

Oralea: One of the reasons I sought someone like that out was because I always thought we would be grieving. We were grieving after diagnosis and after William's death and I want Kyla to have someone outside the family to go to. And so that's why we sought out hospice, and it has been a good thing for Kyla. But I then recognized, as she got older, she found the people that she was comfortable with and she sought out. And you know, it turned out to be her guidance counselor at her elementary school. And in fact, the day William died that's where she wanted to go. It was not to her current guidance counselor, but to her guidance counselor from her old school. And she attended William's funeral and Kyla was very pleased to see her, of course, not because of the circumstances, but she really -- it really helped Kyla. But that wasn't someone we chose for her, that was who she chose to go.

3

Yeah. I talked to her over the phone and a few times at pick up. She would march out with Kyla because Kyla had a bad day and then we would discuss what they did to help Kyla through her period of being sad. But she came to us with a lot of great ideas and we talked to Kyla and we allowed Kyla to work with her. She helped Kyla -- she set Kyla up with that volunteer position in the kindergarten. So once a week Kyla would go to the kindergarten class and I think the idea was to -- it was their doing the bucket filling philosophy. So if your bucket was a bit empty, to fill it up, you help fill up other people's buckets. And so that was her philosophy and that's what she was with Kyla. She let her volunteer and by helping others that helped Kyla.

4 Title: GM-1/Educating the siblings teachers on what is going on at home.

YouTube Link: https://www.youtube.com/watch?v=XdOtI8CzvGI

Description: A mother and father talk about educating their other children's teachers about their son's illness and prognosis and about the social environment at home. If your child has GM-1 or another pediatric life threatening illness, these parent's perspective may help you find your way.

Transcript:

5

Rod: It was part of our job as Kyla and John's parents, definitely to educate people around them, people around us, people around everywhere about William's illness.

Oralea: And they --

Rod: And the allied diseases.

Oralea: Yeah, and the impact that those illnesses have. For instance, John just started preschool and he started rather late because I was afraid that the germs that he would bring home. So I went and talked to the teachers about the situation that John didn't have play dates, he didn't have any socialization with kids of his own age, he socialized a lot with Kyla's friends, and a lot with nurses and other adults in the house, but no one of his own age. And so I explained why, and about two months into school I get pulled aside picking him up and they were like well, he is not really playing well with the kids of his own age in his classroom and they were really concerned about him. I'm like, well, if you think about his social environment at home, this is, you know, this is one of the reasons I did finally think that he needed to go to preschool was to be involved with kids of his own age. But you know, I had to re-explain and re-teach the teachers about our situation at home and what prevented him from learning to share properly and handling issues with peers.

Title: GM-1/A sibling sharing her critically ill brother with her friends.

YouTube Link: https://www.youtube.com/watch?v=0zs5DEnB5PY

Description: A mother shares how her older daughter shared her brother with her friends and how the friends from younger years were totally normal with William. If your child has GM-1 or another pediatric life threatening illness, this mom's perspective may help you find your way.

Transcript:

Oralea: I was always aware when Kyla's friends came over because William, his bed was in our family room with all the machines around him. When they were younger, it was much easier because the kids would come in and just ask, bluntly ask, what's that? And then I could explain it and it was good. As Kyla got older, especially this last year when she hit middle school and a lot of her friends were new, and they were -- they came in and they didn't want to ask. But Kyla, I have to say, Kyla always introduced her friends to William. She would bring them over and say this is my brother William; not explaining anything more, but she would always introduce them. And of course her friends from younger years, they were totally normal with William and they still asked how he was doing and that. But her newer friends, you know, especially they are 12, heading into adolescence, they are a little bit more standoffish.

6 Title: He taught her compassion and empathy towards others.

YouTube Link: https://www.youtube.com/watch?v=1an8lguxZZA

Description: A mother shares her older daughter's anger towards children calling someone a 'retard.' If your child has GM-1 or another pediatric life threatening illness, this mom's perspective may help you find your way.

Transcript:

7

Oralea: The only other time that I recall her being very upset, and she was more mad than upset, she was at lunch and some of the boys were joking around and they started using the word "retard." And she got very -- she was very mad. She was just like, mum, I thought they were making fun of William. And I told them that was mean and rude and they shouldn't call anybody retard. So she knew enough to stand up for her brother and she -- I think he taught her a bit of compassion and empathy towards others.

Title: How it has been for little brother John (age 4)

YouTube Link: https://www.youtube.com/watch?v=jTqjT6smZPA

Description: Parents talk about their 4-year old's understanding of his older brother's illness and death. If your child has GM-1 or another pediatric life threatening illness, these parents' perspectives may help you find your way.

Transcript:

Rod: It's hard to tell... John doesn't seem to really quite understand. I mean, he knows the words. You know, if he was here and you walked him, chances are one of the first things he would say to you is he would have walked in and said, "William died." And then he wouldn't have said anything more about William and that would be that and he would have moved on. But there are not a lot of other things that I've observed John thinking about William too much, now thinks that -- like the nurse thing. He used to sleep on the couch every night. He'd go to bed, and sometime in the middle of night he would wake up and then come and lie down next to the nurse. His favorite thing to say was who is coming tonight? Carol is here tonight. Oh, okay, okay, Carol is here tonight. Who is here tomorrow night? Clover is here tomorrow night. Okay, I'm going to sleep

with Clover tomorrow night and so on and so forth. So he knew which nurses he really liked and which ones he didn't. And if he woke up at midnight or 1:00 in the morning, he would come out and check to see who was there and decide whether he wanted to sleep on the couch or not. And most nights he slept on the couch. And it was easier for us because he wasn't coming and waking us up.

Oralea: Yeah.

Rod: So I mean that's gone now, obviously so he doesn't have the nursing here but he is

Oralea: But he doesn't ask anymore. He doesn't ask who is coming in tonight. So he knows they are not coming. And he knew we -- in September before William died, which was in February, we had a balloon release for one of William's friends who had passed away the year before. And so that really got John asking questions --well, where are those balloons going, why is Caleb in heaven. So that's when I tried to start telling him, well, you know, he was sick like William, and it's not something you can get, but you know, they were born and you know, one day their body will just get too tired and they will pass on and they will go to heaven.

Rod: And he has been asking since then, even within the last week, about death and dying and heaven and -- well, what was it that he said?

Oralea: Oh, he --

Rod: I don't want to grow old. I'm going to stay four forever because I don't want to die.

Oralea: Yeah, he said that. He said, I don't want a fifth birthday party because I want to stay four because I don't want to go to heaven.

Rod: So he's been thinking about it.

Oralea: So he's thinking about it. And it literally comes out in one sentence. He'll say something very blunt like -- ask a direct question like why did William die. And then, you know, I'm reeling trying to find the answer. Before I can even find an answer that I think is even partially the whole answer, he's gone, and you know, his thoughts were somewhere else. But it has been a bit disruptive in his life.

Rod: Yeah.

8

Oralea: And we find at school he is clinging to us more as we say goodbye to him, acting out here and there, so...

Title: GM-1/A mom's perspective on supporting the siblings of a critically ill child.

YouTube Link: https://www.youtube.com/watch?v=nHcnAMmU6yU

Description: A mom talks about how difficult it is to see her other children be sad and suffer and not be able to fix it. If your child has GM-1 or another pediatric life threatening illness, this mom's perspective may help you find your way.

Transcript:

Oralea: What really hurts me at that moment is that I can't comfort them to the ability that I want to comfort them because there is no comforting to it. You can just hold them and let them talk and agree that this sucks in a lot of ways. But I think that -- as a parent, the hardest thing is watching your child hurt and not be able to fix that hurt. That you know, having Kyla come to me and just weeping in my arms, that's really hard. Because I can't -- I know I can't fix it. I can just support her the best I can.

9 Title: GM-1/A mom's perspective on doing the best that you can for your child.

YouTube Link: https://www.youtube.com/watch?v=MwUT2yAxA-0

Description: A mom talks about the importance of recognizing that you are doing the best you can. If your child has GM-1 or another pediatric life threatening illness, this mom's perspective may help you find your way.

Transcript:

Oralea: Be gentle with yourself because you know, you try to -- there is only -- how can I say this. It's important to not try to fix everything. You have to realize that there are things that you try to the best of your ability and that's okay. And even if it's not what you want, you were hoping for a better ending or a better -- I could have done that better or I could have supported them here better, I should be getting them out more. In the end that's okay, it's their normal. You know, Kyla and John, I think this was their normal. And it wasn't our normal because when we look back to our childhood this was not a normal childhood, but for them it's their normal childhood. And I think it's very important to just be gentle with yourself as you parent and allow yourself to... give yourself some forgiveness.

Rod: Yeah, and each other.

Oralea: And each other, yeah.

Title: The toughest part was learning that I needed to take a break

YouTube Link: https://www.youtube.com/watch?v=R2 iDR2 Mp4

Description: A mom talks about how hard it was to learn to ask for help and to take a break and step-away from the relentlessness of the caregiving. If your child has GM-1 or another pediatric life threatening illness, this mom's perspective may help you find your way.

Transcript:

Oralea: As time went on I think the hardest part of caregiving was the endurance of being on top of everything --

Rod: Being tired all the time.

Oralea: Day and day out -- yes. And I really had to make an effort for self care like even if I don't feel like I should take a break, I could recognize when I needed that break because I would get edgy with everybody, I would snap at my healthy kids for less reasons than I really should have snapped at them. Our relationship would be affected, and then I knew, okay, I needed a day to myself just to take care of myself. And I am not someone who -- I think generally I like to care for others, I don't like to care for myself and I did not like to ask for help. So asking for help was a huge ego-busting thing that I had to finally admit that I can't do it all and ask for help and take some time away from home. Sometimes it just was like a couple of hours going to the mall, walking around or a day of scrapbooking, just to be amongst adults and talking about other things other than day-to-day caregiving, and then I could come back refreshed and I was ready to tackle the next set of issues. But that was the toughest part, it was learning to feel like coming on and knowing that I needed a break.

11 Title: GM-1/ Focusing on quality of life, and the challenges of decision making.

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

Description: A mother and father talk about their focus on quality-of-life for their son, the challenges of decision-making, and how their son "showed us what to do." They fought their fear of regret by letting their son guide them and trusting the process. If your child has GM-1 or another pediatric life threatening illness, these parents share their perspective, which may help you find your way.

Transcript:

Rod: I mean even to the extent of the choices that every family has to make with their child, you are in control really of how long they're going to live to a certain extent, not the length of it but certain choices can shorten that period of time whether it's a trachea, a feeding tube or any of those sorts of things or medications. And so that choice is you're thinking to yourself, wow, what's the right choice to make and of course, everybody has to make that choice, who has children in these circumstances and whatever choice you make is a difficult choice to make and you can feel guilt one way or the other. You weigh what's right for you and them.

Oralea: Yeah. We were always -- I think from the beginning, one of our earliest discussions after diagnosis and after we realized there weren't really any viable treatments available for William that we wanted to have -- we were very cognizant of giving him a good quality of life. And we always kept that as our goal in our care plan was his quality of life. And we let William, in the end, dictate what he could and could not tolerate. And we learned, you know, being with him every day and caring for him, you see subtle responses and you listen to his body and it was him making the decisions and we were just -- some of the decisions we had to make were very hard because you wanted to do more at that moment. You know, you -- as a parent you want to just heal everything and -- but his body was telling us something very much different and we had to respect that. There were many times, especially in the last three years of his life, where he was battling a respiratory infection and we just had to kind of back off. What we were doing was making him more uncomfortable and we could see that, and we just had to back off and we gave him the option of fighting and we tried to support it. But his

body showed us and what he showed us -- and in the end, I think it was him that gave us the lead on what decisions to make.

It's a process.

Blyth: Did you have any fear of regrets?

Oralea: Yeah, you know, when we had to make some pivotal caregiving or medical intervention decisions I always thought am I -- like --

Rod: Am I doing this for William or am I doing it for us?

Oralea: That was always the question we had to ask. And that usually brought us to the right answer because, you know, for me it would be like let's go full force and keep him here as long as we can, but when we saw, you know, what some of those decisions, when we thought about what they could do for his body and when we looked at William, we knew some of those decisions were -- wouldn't be in his benefit, they'd be for our benefit. So we really tried to let him guide us.

For instance, I could tell he didn't like Nebuliser masks and at a point in time we were given the option of doing a BiPAP machine, which would help his lungs, and then so that brought the contraption in and at that point he was very desperate to take him through this illness. And so the contraption came into the home and I looked at it and I just knew my son, I'm like, oh, he's not going to be happy with that mask even if -- and I don't think the benefit of what the machine could have done for him would have changed the course of that particular illness at that time. So I nicely said to the tech that came in, I'm like, you know what, can you just take that back. And you know William did -- he fought through that illness without the BiPAP machine. So obviously it was the right choice for him.

At times my doctor would call me up and we would have very heart to heart conversations about different medical interventions that we could do. And she always brought me back to -- I told her what my goal was for William and she said you know, you always told me it was his quality of life, we are entering into a different phase, if you want to keep that goal, you know, I'd be hesitant to try this new intervention. And I looked at William and I knew that that wouldn't have been best for him.

Title: GM-1/The importance of collaboration between the parents, doctor, and the palliative care team.

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

Description: A mother and father talk about finding their son's pediatrician, about how the doctor practiced palliative medicine, and about the impact and value of the collaboration between parents and doctor. If your child has Gangliosidosis (GM-1) or another pediatric life threatening illness, these parents share their perspective and may help you find your way.

Transcript:

Oralea: Absolutely. Actually the first time we met with his pediatrician that stayed with him from age three to his death at age eight and a half... She was the one we explained what our goals were. We were having issues with our hospice because they didn't have a doctor on board that could meet our needs and so we found doctor -- or they found Dr. Wazeena [phonetic], we went and met with her. And she was... that's the word she used -- she was like, "well, it sounds like you want palliative care for him." Then she was like, "I can do that." And honestly I didn't even think palliative care was for children, I had a vision that it was just what you do with the elderly, but -- and that's how the -- palliative care made the biggest difference for William.

Rod: Once we got Dr. Wazeena on board then that made all the difference in the world. And she came on board because hospice did not have the appropriate programs and every time William got sick they had to take them off the hospice to send him to the hospital. So we brought William in to see the CEO of the local hospice and sat down with him and that afternoon he had made a couple of phone calls and found Dr. Wazeena.

Oralea: And one thing that I have to say with Dr. Wazeena, William's pediatrician, always, I was a partner in his care and she listened to me and we discussed things about William as equals. She wasn't telling me what I should do, I wasn't telling her what she should do, it was a true collaboration with him and I really think that made a difference in the decisions we made for him and the quality of his life to the end.

Rod: You were a partner in the care but you were the boss, especially when it came to other people than Dr. Wazeena, the nurses -- but even Dr. Wazeena, you guys would talk it over but you were the ultimate -- we were the ultimate decision-makers but you were the boss.

Oralea: I think it's very important though to find a doctor who will take your lead and who will work with you and recognize that you know your child. And that none of these decisions are easy and they're there as an instrument to help give you the tools to care for them.

Title: GM-1/The benefits of not making arrangements ahead of time.

YouTube Link: https://www.youtube.com/watch?v=xshQsJ37FSM

Description: A recently bereaved mother and father talks about how they didn't plan much ahead of time, but how the services came together beautifully after their son's death and there were benefits to waiting to plan. If your child has GM-1 or another pediatric life threatening illness, these parents share their perspective which may help you find your way.

Transcript:

Oralea: No. And -- no, we -- we never said -- we had a general idea about what we wanted to do for William's funeral and final resting place, but besides the general idea we didn't have any logistics down. And -- because we -- I just felt like I can't do that while he was still living, that was not my -- I was caregiving for him, I was not going to think about the day that that would no longer be. And so the day he died, I remember

turning our friend, Jen, who was here and said, I didn't plan anything, and I knew a lot of parents had because parents had told me it is good to plan ahead, then you know it's there and you don't have to worry about that planning, and I couldn't do it. So Jen turned to me and she was like, Oralea, she is like, "Every day, people die by accident and they still have funerals, it can be done, don't worry about it. You were busy caring for William, do not worry about it."

Rod: A lot of people helped us put the plans together at hospice.

Oralea: Well, you know, hospice came immediately and they helped us choose a funeral home. And it all came together and both of his services were beautiful. The logistics worked. And at that time it actually was something I needed because I needed to have time to concentrate on something and so I was planning. I always planned Williams' birthday parties and we always had these big parties for each birthday. So this was his big farewell and it gave me a purpose in those two weeks. We had two funerals for William, so it's kind of a double whammy because we had a lot of friends and family around us here in Florida, but my husband and I are both from Canada, so we also felt we needed to give our family up in Canada, and friends up there, a chance to say good-bye to him. So the two weeks that we spent planning, it was a big healing process as well. I wouldn't have changed it -- looking back, I wouldn't have planned it earlier, I'm happy with how it worked for us and it really -- both services celebrated William and they were beautiful.

Rod: And so much changed in the seven years since diagnosis that when we initially talked about it we said, well, we knew we wanted to bury him next to his father, his grandfather in Canada and that's about the one thing that we decided. And so here we are seven years later, we weren't planning on doing a service in Florida because we just moved to this part of the state a month before diagnosis, we didn't know anybody. So if he is not going to be around in six months or a year, why would we have a service here? We don't know anyone here, he'd never known anyone, we'll just do something in Canada. Well, seven years later he knew a lot of people and we knew a lot of people. So we had a service here in Florida and then we flew William up to Canada and we had a service up there and then buried him next to his grandfather.

14 Title: GM-1/Not thinking about after your child dies, before they actually pass.

YouTube Link: https://www.youtube.com/watch?v=ngH2WCCAoZQ

Description: A mother and father talk about staying focused on the present and choosing not to imagine the future. If your child has GM-1 or another pediatric life threatening illness, these parents' perspectives may help you find your way.

Transcript:

Rod: We didn't really let ourselves think about the after before too much, a little bit, I mean you always, you always think about the future and whatnot, but we didn't plan the funeral or any of those sorts of things beforehand because we didn't want to really -- we didn't want to think about it too much.

Oralea: Your mind always went there, your mind always went to where it going to be, what's it going to be like without William, I can imagine what's going to be like without William, but we never -- he was still very much present with us and we decided to live each day to the fullest with him and he was living and we were living with him. We didn't go beyond that.

15 Title: GM-1/His final moment was so peaceful.

YouTube Link: https://www.youtube.com/watch?v=ZE-ZRU1cYk

Description: A mother shares how peaceful her son's final days were and how proud she is of the full life that he had. He did a lot in his 8-and-a-half years. And "when he took his last breath, all those years came together and it was a perfect moment for him." If your child has GM-1 or another pediatric life threatening illness, this mom's perspective may help you find your way.

Transcript:

16

Oralea: I think from the time of diagnosis I played into my head all the different scenarios of the final few moments with William. That I would regret things that we didn't get to do with him, unfinished things. The care choices we made, I was fearful of all of that. But when the final moment came, everything came -- all our care choices that we made throughout his life really came to a point and all met together and William's last moments were very peaceful.

He simply exhaled and he had all his family in and around him at home and I think every scenario that I played in my head was much worse than that moment for us. I'm not saying that that will be everyone's journey, but for us his final moment was so peaceful and I was so thankful for him that that moment was the way it was for him. And you know, it was the -- it was the days after have now been our hardship, but it was never William's hardship and that was what our goal was. Our goal was to keep him comfortable, with a good quality of life, and experience life. You know, when I was planning his funeral, I was sorting through pictures, but as I was going through his pictures, I looked and this boy, who was only eight-and-a-half years old, lived a very full life.

He wasn't mobile, but he had a Halloween costume every year. He had the St. Patrick's Day shirt every year. He was the honorary coach for the New York Mets. He had a birthday party with over 100 people in attendance in Canada. He had many birthday parties in Florida with lots of people and lots of noise around him. He had girlfriends. He had a first kiss. He did a lot in his eight and a half years. And I'm very proud that we were able to create those memories. At that time I was creating them for us, but he experienced them. And when he finally took his last breath, he -- all those years just came together and it was a perfect moment for him, not so much for us, it was hard. But I was really thankful that he went... all our care goals met, and we were able to keep him at home and he felt loved every day of his life.

Title: GM-1/A sense of relief after her son's peaceful passing.

YouTube Link: https://www.youtube.com/watch?v=DOIisJe6ScE

Description: Seven years after her son's diagnosis, in the hours following his death, a mother exhales. If your child has GM-1 or another pediatric life threatening illness, this mom's perspective may help you find your way.

Transcript:

Oralea: He was in my arms for a good couple of hours after he passed away and I think for the first time since diagnosis, which was just over seven years prior, I think that was the first time I exhaled. I was anticipating that moment of death from the time we heard that moment would come and that I was so fearful of what it would look like, I was fearful of seeing my child suffer through it. I didn't know... it was a big unknown. And I think when he -- he was in my arms and he was so incredibly peaceful and he went so peacefully for us, and I think that was the first time I just -- I relaxed and exhaled in seven years. It's a different -- you know, it's not easy, but that moment, there was an exhale.

Title: GM-1/These parents talk about the perspective they learned from their critically ill son.

YouTube Link: https://www.youtube.com/watch?v=aI1hYWMDTKs

Description: Recently bereaved parents talk about all they learned during their son's 8 years, including the perspective they gained. If your child has GM-1 or another pediatric life threatening illness, these parents share their perspective, which may help you find your way.

Transcript:

17

Rod: There's been absolute positive growth in my life and it isn't too soon after William's passing because this isn't something that just happened, this was -- we were fortunate to have William for eight and a half years and so we had a long time to live with and adapt and learn and recognize where things are going and to grow with that and just the changes. Eight and a half years is a difference between 30 and 40, so just that alone I'm sure played into it but also just you grow up and mature and he certainly helped make me mature.

Oralea: I think he brought life into perspective for us. His diagnosis came shortly before the big economic crash and we went through a lot of tough economic times that were unrelated to William's disease and diagnosis, and of course his healthcare played into some of those economic hardships. I think if William didn't give us the perspective of what truly mattered in life, some of that would have played a harder toll on our marriage than what they did, and we were able to get through it. And I think it's because of William, he was the blessing that showed us what was truly important and as long as we are a family unit and could work together we can make it through.

Rod: Yeah, we never gave up.

	Oralea: No, he never gave up. William showed us what fighting was like, he never gave up, so you know, we learned from him.
18	Title: GM-1/A new chapter begins after the death of your child.
	YouTube Link: https://www.youtube.com/watch?v=Qx-ffWCTQRg
	Description: A recently bereaved mother and father talk about the bittersweet, novel experience of now being able to travel freely with their other children. If your child has GM-1 or another pediatric life threatening illness these parents share their perspective which may help you find your way.
	Transcript: Rod: I don't believe the term liberated would be a term I would use, but it was that you could see that now there was your next phase of life was starting, like the phoenix rising from his ashes, you are now one chapter is finished and another one is about to begin, but not liberated.
	Oralea: Also we realized we could go out with our children and plan a family vacation and there is a bit of guilt not a bit, there is a lot of guilt with that, but seeing our children going to Canada, we took William home to Canada to be buried and going as a trip to Canada for our kids it was very much a vacation time for them.
	Rod: Yeah.
	Oralea: And there was some joy in being away together even though our purpose there was very heartbreaking and hard. But there was a joy of being together away from home which we never really had.
	Rod: Yeah.
19	Title: GM-1/The changes in everyday life after your child passes away.
	YouTube Link: https://www.youtube.com/watch?v=Lh 910ZNtMA
	Description: A recently bereaved mom talks about the poignant adjustment to how different the house feels and sounds and how different the flow of her day feels. If your child has GM-1 or another pediatric life threatening illness, this mom's perspective may help you find your way.
	Transcript: Oralea: Yeah, it's you know, William's only been gone one month, but I think the biggest transition for me at this point is that there are not people coming into my house every day. We never locked the doors because there was always someone here 24/7. So you know, the other day we went out and we forgot to lock the door. But I'm just the emptiness that the house has right now, the quietness is very difficult. I'm finding I don't recognize what I did in the day until it was very abruptly stopped. And for William, I didn't recognize that, you know, no matter where I was in the house, I listened to his breathing and I could

tell if he needed me to come over and suction him right away, or if he was okay, or if he was just sleeping. I catch myself listening for his breathing. So, that's... retraining myself is very hard. Or going outside, you know, the day I was outside, one of us was always in the house with William, and I was outside talking to a neighbor and Rod came over and started talking and I got panicked. I'm like, what, who is inside with William? No one needs to be in the house with William anymore. I think that transition is very difficult for us or for me. Just not having those things that you did everyday without thought, all of a sudden you recognize that they are gone.

20 Title: GM-1/Bereaved parents reflect on their journey with their critically ill child.

YouTube Link: https://www.youtube.com/watch?v=C1oM1a2p4vM&t=1s

Description: A recently bereaved mother and father reflect upon the various ways in which they grew as they kept the family together and cared for and advocated for their son. If your child has GM-1 or another pediatric life threatening illness, these parents share their perspective which may help you find your way.

Transcript:

21

Rod: I think the thing that I'm most proud of as William's father is that I was able to raise him and love him and accept his love back as he was. It's that simple.

Blyth: And Oralea, how would you answer that as his mom?

Rod: You can't answer after that can you? That was too good...

Oralea: Yeah, that was good. You know, I was -- I'm proud of all my children and William is no different. And I think as William's mom, I'm most proud of the fact that my son had such an impact on my life, on Rod's life, on my other children's life and on people around me and people who I've never met, without ever saying a word. He was just -- he was here -- he had a purpose here and I'm very proud that I was selected to be his mother.

Rod: It's not as deep, but I'm proud of the fact that we were -- that I was able to not just still even though everything at home was difficult, but that I was still able to continue and drive my work and excel at it and get promotions and change jobs a couple of times in the midst of everything going on and I guess you could say compartmentalize enough that I was able to keep the family taken care of. And that allowed Oralea to stay home full-time, not work and be able to do the things that she did at home because I was able to do that.

Oralea: And I was proud of the fact that I could find my inner voice and strength and fight for my child. I'm pretty quiet and don't like confrontation but when it came to William, I was proud that I could find that inner strength to do what was right and stand up to people so he got what he needed.

Title: GM-1/These parents share how they are memorializing their son, who died.

YouTube Link: https://www.youtube.com/watch?v=2ffwFCoZiF0

Description: A mother and father describe the various ways they are memorializing their 8-year old son who has recently died. Part of his legacy is that mom is now studying for her MSW to help future families. If your child has GM-1 or another pediatric life threatening illness, these parents share their perspective, which may help you find your way.

Transcript:

Rod: William has a bunch of things that we are going to be doing for him. One is that at the funeral home in Canada, part of the service that they provide is to plant a tree. So they are going to plant a tree up in Portage la Prairie, Manitoba and next summer 2015, they'll have a service where we can go up and not just for William, it will be for every person that passed in the previous year, but they will be planting trees all over the place and they will have a service that all those people will be able to go and will be able to attend. So, there will be a tree up there planted for William. And then on the side of our house we're going to be putting in a memorial garden and Oralea wanted to do this now for a couple of years. And we were planning on trying to get it done before he left us. But now it will truly be a memorial garden and we are going to make it quite lavish and extravagant and a very peaceful place for someone to sit and read a book or just sit and meditate or whatever they want to do. So those are two things.

Oralea: And William -- I always felt William taught us so much and he gave kindness out into this world. He showed us the kindness and compassion of strangers and I decided that, you know, as part of his funeral, I wanted to give out random acts of kindness cards in his memory. So they are cards that you give out as you do a random act of kindness and it has a little blurb about William so that he can continue to touch lives even though he is not physically present with us, his spirit and the love that he instilled in us during his life will move forward and continue on as we touch other people's lives. Hopefully they'll touch and it will continue on.

Rod: I'm sure there are other things that will figure out as time goes along, things that we haven't talked about yet that we both will figure out.

Oralea: It is, it is because, you know, I'm starting my master of social work degree, which I started when he was here with me and he sat in my lap and we studied together. So he learned all about human behavior and the social environment and all those fun courses. That degree is William's degree because I haven't -- my background was in pure sciences and plant science and very scientific research. I was never -- I never took one psychology course in my life until I had William and I wanted to really help other families and help the system to help other families. So hopefully moving forward the work that I will be able to do will be in William's memory and it will be him that has pushed me towards that.