Chad and Kristina

Parents of Talon, who had a peroxisomal disorder and died shortly before his 2nd birthday, and older brothers Benjamin and Nicholas.



Ultimately, we knew we both wanted the best for our family. https://youtu.be/QGNRTqUfIZU

Chad: Well, I think at first you have a lot of ups and downs, and you have to deal with it your own way as an individual, as a father and as a mother, and so we kinda came together. And you fight through a lot with it, but ultimately, we knew we wanted the best for our family, and we wanted the best life for Talan, so it was kind of a mutual thing where we decided that we have to do something to give back. If our boy can endure what he's enduring, then we're gonna do our 100 percent to make it right, and we did.

Kristina: Yes. I think for myself and Chad when we found out about Talan and wanting to make this a positive experience with his life and with our family's life, I think it was basically around the same time with us. It didn't take me long to figure out that we needed to spend every day with Talan and live life as he was not sick, and that's what we did.

Chad: Talan was definitely the strength of it. He gave us all his strength, and you don't know what's gonna happen, and Talan was obviously pretty silent. But his actions, his smiles and some of his giggles and he was so loud with his love and his strength that it just it put us in our place to our roles where we were, and we always took it and went with it and made it work as a family, to all be supportive of each other and of each other's feelings, and how we deal with it on our own. So it was definitely good, and Talan was definitely our strength with that.

The hardest part for me was that I had to go to work every day to support the family.

https://youtu.be/ft h8ON90bM

Chad: Probably the hardest part for me experience wise with Talan was that I had to go to work every day to support the family and not see my boy as much. Knowing I'm playing my role

as a father to support my family, being self employed and fighting for the work and pushing forward and know you're doing it right in your mind. But to come home to put your child to bed and then waking up and kissing him to say goodbye, to repeat that process all the time played a toll in missing my child now, but he would also always let me know it was okay.

And because I struggled with the fact of not seeing him as much, but I had to be a father to him, I had to be a husband, and I had to take care of my family in a difficult time, so we could all enjoy and give Talan his best life. So it's bittersweet as far as trying to be the head of the household to go to work and still support your son and let him know you love him, but he ultimately at the end made it all okay. And he let daddy know that I was doing okay, so that helped out big time.



RELIGION/SPIRITUALITY

My faith really helped me to push on and help me enjoy my boy.

Chad: Our faith basically what we do is with Talan. My faith is very strong because faith is the foundation of me believing that there's reasons for everything, and I had to believe that to keep me strong. Talan's a miracle. Being a boy with so many odds against him, he smiled, he giggled; things that he really wasn't supposed to be able to do.

He did things that amazed us, and he kept showing us that he already was a little angel, and we just had to look past all the medical stuff, everything that he had wrong. And to us nothing was wrong with him and we used this experience - and I went back into faith and said, okay, god, I said you have a reason for this, and what is it, and you had to keep looking, doing your part believing, had to keep working and supporting the family and going with it.

And having her home with the kids and taking care of Talan basically she was a nurse, and the faith really, really helped me to push on and help enjoy my boy 'cause he could smile back at me. He would turn his head when he heard my voice, and I'd says if that's not a miracle, I don't know what is.

So it strengthened me, and we just pushed on, and Talan kept pushing us and showing us that everything's okay and as a well as God showing us miracles, and every time that you think that you're defeated you forget about it. And we would be very happy every night to have him and every day, so it was very huge for us with our faith.

My faith pulled me through every time.

https://youtu.be/9CVYANRMI c

Chad: Our faith in god stayed strong. We were tested, and I continued to believe there's reasons for Talan's diagnosis, and what was gonna happen with it being my first child is very, very tough for me as my first child because I waited a long time for this and couldn't wait for my new life. Getting the phone call when I was delivering wood and pulling over and screaming,

and I actually yelled at god and said why are you doing this to me, and then, in the same sentence, I put my head down. And I apologized, and I said I'm sorry, you have reasons.

And then there was so much after that as far as the doctors telling you things and all that and seeing Talan and looking at him and then loving as much as you can; this whole experience with Talan made my faith stronger, believing it as far as the 21 months with him. Watching him touch people and not say anything was miracles in my eyes because everybody that came and saw Talan as far as messages and said Talan has changed my life. Well, I wanna be a better parent, I wanna be better to my kids. I don't wanna take things for granted with my kids, and as a family life, do the best that I can.

And there was a lot of followers following us as far as post on Facebook, and I was very, very outspoken about my son, and the things I was dealing with and staying strong. And my faith helped me to be strong. Talan helped me to be strong, would show me many different things where I could actually speak my heart, and it was helping people.

So I was seeing miracles in front of me, and sometimes you don't see them until later on, or when a person would see you and shake your hand and said you are my strength. And I said Talan's my strength, and my faith in god is a lot of my strength in all of it to make me get through this to do what I had to do because there's a lot of times you had some pretty horrible days. And I prayed and relied on my faith, and it pulled through me every time.



Kristina: Talan has two older siblings, Benjamin who's 12 and Nicholas who's 11. Benjamin and Nicholas were so excited to have a baby brother or sister. As soon as Talan was born, they were the first ones in the room. They loved him immediately.

Once they knew Talan was in the NICU, and he was sick, they were upset and confused, but the whole time step by step everything that was going on with Talan we told the boys. They knew about seizures. When we got the diagnosis that Talan was gonna pass away at a young age, they cried. They were sad.

We just talked a lot with them, and all the questions that they had we answered them, and if we couldn't answer them, we would have one of our visiting nurses answer them. Ben and Nick were so involved with Talan.

Kristina: They gave him meds. They gave him his feed. They changed diapers. They gave him tubbies. They didn't see Talan as sick. It didn't matter to them.

We took them to their sports' games, and Talan was there watching them, and -

Chad: They were very supportive and protective of their brother.

Kristina: Very protective of him which was so, so cute and just showed the brotherly love of their little brother, sick or not, and it was great.

Chad: I think it was more after as far as how they felt about Talan passing away, and what was gonna come up, and they honestly were really, really strong with their brother. And I don't think it was really 'til after that they really were in fear of leaving Talan.

I had never had any talks to them about that 'cause they asked a lot of questions. They were really inquisitive of what was gonna happen, when it was gonna happen, and they understood that we wanted it be Talan home with the family and safe and all the above, when it was time for him to go to heaven. And they were apart of all of that, and they did very, very good, very supportive and were strong, so it wasn't 'til after they had fears of the unknown of leaving him there at the gravesite. It was only a certain time of the day you could go and account of their own time.

But before that they had a lot of questions, so what they wanted to know they asked us, and they were very outspoken about that. So they did good as far as not being really fearful of the future.



INVOLVING FRIENDS AND FAMILY/SOCIAL MEDIA

I spoke a lot from my heart about the ups and downs. https://youtu.be/lkhVyDcYrvk

Chad: I used Facebook 'cause Talan had a lot of followers and a lot of people that wanted be updated, and so I spoke a lot from my heart the ups and downs, both sides of it and telling stories of what I was going through physically and then the goods days and all of the above, and the feedback I would get would also help me. People saying well-being strong so ____ going forward, but it helped me get Talan's story out there because I feel it's a great story. I feel that he had a lot to offer, and ultimately, people wanted to know, and I like to speak from my heart as a father to maybe thinking that some father that's having a struggle or some parents that are having a struggle can read this and find what the little things are and the big things are in their own life, and as their family's healthy or not that they can read and say you know what I could be in Chad's shoes and deal with what he's dealing with, but I have a healthy family.

You kinda bring people back to reality a little bit and know that sometimes problems are minor compared to other situations in the world, and so to give words of encourage that we're doing okay, and that Talan's a strength of ours.



WORKING WITH THE MEDICAL TEAM

We wanted him to be home as much as possible ... and not to be scared. https://youtu.be/p_8Ho4GGQHo

Kristina: When Talan got diagnosed, being terminal we number one said we wanted him to be at home as much as possible. That was our number one goal with him before he really did start to decline, so that was always our number one goal. As Talan started to get sicker, and we

knew that this was it, there was nothing else we could do to help him get better except keep him comfortable.

The number one thing we wanted Talan not to be is scared.

Chad: Mm-hmm.

Kristina: That was our number one goal with him, so with that being said, we had Talan's pediatrician. We had Talan's visiting nurse. We had Talan's physical therapist. We also had Talan's doctor's up at Children's which included the PACT team, which is the PACT team was a great support for us.

We also had Notre Dame hospice. They came in, and they kinda guided us. He had the child life specialist come in to work with the kids, if they had any questions that we couldn't answer, so we knew we wanted Talan's care to be at home. And that's what we did.

After many stays at Children's, we came to the conclusion in March of 2013 that Talan wasn't gonna be able to get better, and we weren't coming back to the hospital, so we put everything in place. We had hospice, still Talan's visiting nurse and his pediatrician and the PACT team, and we all worked together not to have Talan be scared, and he was not scared not one day of the last couple months of his life.

Even though he was on continuous oxygen, we still continued to do stuff with him as a family. It was much harder to take him out, so we stopped that. We had family parties for him. We celebrated his second birthday party in May, actually two weeks before he passed away and we had visitors, and I said his visiting nurses and the hospice nurse were fantastic with us.

And we made Talan comfortable and not scared, and I think that's what helped Chad and I and Ben and Nick not be scared -



Kristina: So as for medical decisions we had to make, there wasn't that many, and from seeing other parents in hospitals with sick kids, we were pretty lucky. We didn't have anything major that we really had to decide except for stopping the medication 'cause the medication wasn't working anymore.

Kristina: Our doctors with Talan towards the end of life were amazing.

Chad: Mm-hmm.

Kristina: They listened to us. They agreed with us. We had doctors calling us, emailing us to make sure we were okay and calling us off the record just to say they agree with us, and we

made the right decision. And if we told our doctors we wanted to continue trying to treat the pneumonia, they would've been on board with us also.

From day one our doctors especially our neurologist, PACT team and our home healthcare onboard with whatever our decisions were and 99 percent of the time they all agreed with our decision, so were very lucky -

Chad: Mm-hmm.

Kristina: With our healthcare and our doctors and home healthcare.

Ultimately what we decided, they backed us up and we felt comfortable.

https://youtu.be/Gj7y5v6Kaxg

Chad: Okay.

Trying to decide decisions as far as different medical things with Talan, we had options, and we would talk about our options, and then, we had so many different questions. And then it was amazing as far as the doctors and neurologists and PACT team coming in and saying their points and really listening with their hearts of what we wanted and to understand our questions and for us to understand the best things for our son.

Ultimately, what we decided they backed us up, and we felt comfortable, and we understood, and we knew it was right. They gave us enough amount of time to decide and made us feel very comfortable with our decision. As far as Talan, almost treating Talan like their own child of how they would go about it made us decide our decisions very easy and very thankful for that because it was tough in some situations, where I'm looking at it as a father saying, well, I want the best I can for my son but not understanding everything.

They told us, led us aside and it worked for the best. And they were very, very helpful with helping us decide for Talan medical wise.

The hardest part of being a mom was having to make difficult decisions for him.

Kristina: I would say the hardest part of being Talan's mom was having to make difficult decisions for him, knowing that nothing was gonna make him have his fifth birthday or get his license or get married, so making any kind of decision about his life was very difficult for me 'cause in the long run I knew it was gonna be the short time here with him. So I wanted to make it as good and as happy as we could with him, so making decisions for Talan that could have prolonged his life but wasn't gonna make it a good life for him was very difficult because in some way I was selfish.

And I didn't want him to pass away, but I knew that we never wanted him to be scared and if we continued with medications that we knew weren't helping, it was just prolonging his sickness and him not being comfortable and maybe him being scared in the long run. So that was very difficult.

We looked at him for the answers.

Chad: Making decisions for Talan as far as feeling it's courageous and all that, I just feel it was from a heart as a mother and a father to do the right thing for your child at the time, and you felt it was your heart, and a lot of times we actually spent time with Talan, and we looked at him for the answers. The biggest part that we decided together is that Talan to be not scared, Talan to be when it was time it was time, and we didn't wanna prolong it with his quality of life. We wanted it to be a good time with him and not watching him suffer at all.

So as far as making decisions, I feel it's what any parents would do deciding those just from your heart and knowing what's right for your child. I just feel we played the role that we needed to and the best way we knew how.

My faith pulled me through every time.

Chad: Our faith in god stayed strong. We were tested, and I continued to believe there's reasons for Talan's diagnosis, and what was gonna happen would being my first child is very, very tough for me as my first child because I waited a long time for this and couldn't wait for my new life. Getting the phone call when I was delivering wood and pulling over and screaming, and I actually yelled at god and said why are you doing this to me, and then, in the same sentence, I put my head down. And I apologized, and I said I'm sorry, you have reasons.

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We never treated Talon like he was sick . . . It was a way of life. https://youtu.be/f0hWDv2zpy0

Kristina: The most important thing I would tell parents who are going through caring for their child who has a life limiting diagnosis or poor prognosis the number one thing is just treat your child they weren't sick. That was the most important thing that we did.

We never treated Talan he was sick ever until the very end because we couldn't take him out. It was difficult. We took Talan to the beach. We took Talan to his brother's sporting events. We took Talan to Disney. We took Talan on a plane to Disney. It was difficult getting everything arranged for something like that, but in the long run, we had such great memories. I would never tell a parent who has a sick child to limit anything with their child or with their family. Do it up, and do it up big, and that's what we always did -

Chad: Yeah, it was part our life. You got so used to it that it wasn't anything different. Everybody did their role, and we just move on and didn't look at anything of what our son Talan had, and it was a way of life. And we didn't look at it any different.

We did everything we possibly could've with him and very glad we did, that we have all these memories, so Talan wasn't short of anything in his life. He was our family. He was our little boy, so we lived our life as natural as possible with him, and we made every moment, and honestly, to us it didn't seem he was sick.

Kristina: We took Talan four wheeling. We took Talan on the sled in the snow. We have pictures and video of Talan making snow angels. We did everything with Talan, and that was the most important, and those are the best memories with him all his little first things, and his parties we threw for him. And it was great.

Chad: Even to the point of on a four wheeling trip that we took around the house in February actually the 8th; she wanted to take Talan out on the four wheeler. I was gonna go in the woods looking deer antlers, and we drove around the cornfields, and we actually found a matching set with my son. And as far as a miracle, that's as close a miracle you can get because finding both sides with your son that sick and being with a family and making it all work, we took him everywhere.



END OF LIFE: Questions and Making Arrangements

We disagreed on open or closed casket.

https://youtu.be/hCbDVXQaYgQ

Kristina: Once we found out Talan's diagnosis, I began his end of life or passing arrangements. We worked with funeral parlor from the beginning from when we brought Talan home from the hospital at nine weeks old, and we went to go visit them just to go over everything. We went another time right before Talan started getting sick, and then, of course, we went when we came home in March and decided that Talan was gonna be on hospice.

Kristina: In the beginning, Chad and I disagreed on the most major thing in a funeral. We disagreed on open or closed casket for our son. Chad wanted the casket to be opened, and I

was adamant and did not want it opened. There was gonna be no compromising on this, so when it came down to it, I'm thankful that I changed my mind, which was to have the casket opened.

As Talan was getting more sick, I couldn't picture him in a casket closed in the darkness, as all of us were just walking around, and we couldn't see him, and that totally changed my mind. And I'm glad that we had it opened.

He looked like an angel. He looked like a 21 month not sick, not puffy, little boy, and it was good. I'm very glad that I changed my mind on all of that.

Chad: You need time to decide. The sooner you do it, you have enough time to adjust to what you constantly battle it in your mind. As far as an open and closed casket for me, it was I didn't want it closed. If I wanna stand two hours, two and a half hours next to my boy, that's my boy, and I wanna be proud standing next to him, and I wanted a few times look over and gaze at him when I wanted to.

I was a proud father to stand next to him, and I wanted people to know that, and I didn't want him to be closed up 'cause that's not what he was about. He was very well known, and as it was, we were very different as far as open and closed casket, and I wanted people to see my boy and pay their last respect for him to help them out with their life with Talan.

But I wouldn't be able to live with myself if I sat through a closed casket knowing my boy's in there because there's a time for that, and that wasn't the time, and you decide that. And we were so different about it even we were gonna have two different times, as far as to walk through and stuff, and I was at peace when we walked in to change our boy to get him ready, and how he looked.

And it just took everything that I fear of seeing right first time after him leaving the house, and we both looked at each other, and we were just happy as could be how he looked. And that's when it kind of really started the change where she was happy that as far as seeing our boy in an open casket.



The point where we realized it was gonna be Talan's end of life was actually in February, last February, when we figured out that the antibiotics were not helping to clear out Talan's pneumonia. We went back and forth with the doctors because one of the things that they were thinking of was taking his tonsil and adenoids out because they were blocking his airway, which was getting hard for him to breathe and just being infected. We ended up going into the hospital the last time in March, and the doctors said, no, they didn't think that they should do the surgery for the tonsils and adenoids because they felt Talan wouldn't make it through the surgery.

One of the doctors on the ICP floor at Children's who was fabulous who we're still in contact with today actually called me off the record to let me know that our decision not to

have the surgery was the right decision, from a mother to mother that we made the right decision not having the surgery. And our decision to take him on hospice was the best - *Chad:* Hmm.

Kristina: Decision.

We already knew that was gonna be the case, but having a doctor who also is a mom call me at nighttime on her day off to just let me know that our decision was correct made it very clear to us that this was gonna be the end of his life and to just take him home and love him as much as we can.

I wasn't afraid of what the end was going to look like because I am a planner.

https://youtu.be/TuULOWxhf_k

Kristina: I was not scared of what the end was going to look like because I'm a planner, so I had it all planned out what I thought was going to be the best plan I could have ever made. To our surprise though the plan did not come into play. Talan had his own plan, and to be honest, Talan's plan worked out a 100 times better than my plan -

Kristina: And we were not scared at that time or the days to follow.

I think with me I was concerned with Benjamin and Nicholas. I was concerned with our other family members coming to see Talan. Obviously, I was concerned with Talan not being scared, so I didn't have the opportunity to be scared of his end of life or his passing.

Kristina: Yeah, towards the end the number one thing I said to myself was - and I said to everyone around me family when they could call me and say are you okay, do you need anything, and I said I'll be fine. It's after is when I'm gonna be scared, after Talan's passing. After everything calms down, that's the time that I knew I was gonna be scared. Not the month before, the week before, even the day of, I wasn't scared at all 'cause I knew I had other people to take care of.



ANTICIPATORY BEREAVEMENT

I was worried about looking over at the crib being empty. https://youtu.be/Bna_Ofhskew

Chad: I would say my fears around end of life were basically how Talan was gonna pass 'cause we were very strong on him being comfortable, and I didn't wanna see him suffer, and it bothered me a lot. I thought about it most of all because his brothers watching and seeing, me to stay strong as a father to support my family with that and with love and for me not to try to break down.

And I'm just I was worried about how it was all gonna play out. And, again, Talan took care of that and decided on his own - as Kristina being a planner and have to have everything

right too to a tee of what happens - he changed all of that 'cause we were actually in the plannings to help Talan out a little bit, and he decided different. And as far as afterwards, I thought about because obviously him being in our room at night sleeping with his machines and stuff like that, it was never quiet. There'd either be lights on. You'd see his heart rate and stuff and all that. There was always something going on where you always wake up and you one eye and see it, and afterwards when Talan passed, the silence couldn't sleep.

And I was worried about always looking over the crib being empty, and that was one of the first things. I am always everywhere I wanna look I wanna see my boy. I was always nervous of not seeing my boy, so I wanted to make sure I got pictures everywhere I looked in the house. Everything I did I wanted him there.

We're a little different in that way. We're respectful. That's my drive for me every day to go to work to see my boy and remember, so I had fears of missing him, which obviously we do. But now he has his wings as an angel, and he's everywhere with us, and I feel him.



Chad: So as I was closing the door, I looked over at Talan, and Nicholas was kind of laying on top of him holding him, and I noticed that Talan wasn't breathing. And I said, Nicholas, I said get off Talan for a second, and I'm _____ I said he's not breathing, and the hospice nurse Goes now -

Kristina: Pick him up now, and all I remember doing is saying now, and she said now. And for that 30 seconds, I obviously I scooped him up, and I was obviously upset and yelling and saying Talan, Talan, no, Talan and then realized that I can't be upset and crying and yelling as my son's passing away in my arms.

I wanted it to be nice and quiet, so I held him. Chad held him underneath me. Both boys were on either side. We had the hospice nurse call our family. They were all on their way over. Also Talan's visiting nurse who was with him since he was nine weeks old flew right over 'cause we wanted her with us, and it was just quietness, and we were just hugging him.

I kept feeling his pulse slowly going, and then, an experience that I had that it's hard to explain because I use the words the best part of Talan's life was when he passed away. It was the most connected I have felt to my child as my child passed way, and what happened was I was holding him, so it was probably after a good half hour or so of holding him, I felt the sensation a warmth go through my chest. And I saw a fogginess come through my eyes, and all of sudden I just said he's gone, or he left.

And the hospice nurse came over, checked him, and he passed away. And it was better feeling than actually giving birth to him, and it was an awesome feeling because I'm not a person who would think situations like that or feelings or emotions could happen. And it happens.

Chad: Last hour of Talan's life I'm holding him, and I just I spoke to him.

He went peacefully. He was just breathing, slowing his breathing down he went to sleep, and I just kept talking to him. And I said to him I'll continue to be the father to let people know who you are, and what you've done for all of us, and what you've meant. And what you started I wanna keep it going.

It didn't really hit me until I actually looked at my wife and said I wanna hold my boy after he passed away, and she kinda gave me look, and I said give me my boy. And when she passed him over, that for me opened the flood gates, and I just released, and I cried. And I just cried and told him I was very happy and proud of him, and I sat there with him 'til the hearse came, and I held him.

And I knew it was gonna be to a time where I had to walk him out, and so my mother had a blanket that she had with a prayer on it, and we wrapped Talan up in that. And I remember them trying for respect to cover his face, and I said no, and I walked out the door. And I did everything I possibly could to stay strong to know this is the last time my boy's going out of this house, and I wanted to be the one, his father, to walk him out of this house and to put him in that hearse felt kinda cruel.

And I had to put him in there. I gave him his kiss. I told him I loved him, as the boys and my wife were there with him, and I walked back to the house. My father and my father in law met up with me, and said you got to be the strongest individual I know, and I walked in the house, grabbed his sock monkey and a lacrosse stick that they made for us the lacrosse team and football team. And I laid with it, and I curled up in a ball and cried.



I have fears come out now more than I thought they would.

Kristina: The days before Talan passed or the weeks I didn't know what my fears were going to be after, and as of present time, some fears some randomly come out that I never even though of. For an example is Talan being buried in a cemetery, now the snow's gonna come, so my fear is oh my gosh Talan's gonna be buried under all that snow. So that's a little fear that I never thought I would have that comes up or the fear of having and wanting another child and wondering if Talan's mad that we're having another child, or if Talan is excited we're having another child. Those are just a couple examples, but for the most part, I have fears come out more than I thought they would, and that's one thing I'm learning is how to deal with my fears and how to just cope with them.

My fear is that I'm not spending enough time visiting him.

https://youtu.be/bv65g5iDUc4

Chad: Worries I have that I really didn't think I was gonna have before was visiting Talan at the cemetery. You never feel you spend enough time. You always feel you're rushing around doing things, running around, and you'll swing by to go visit Talan, and then you speak to him. And then I start off speaking to him this, and I said, no, I said now you look off where he is.

And I always turn back and keep looking and saying is that enough time. I mean you can't put minutes, hours or days. You can't put anything into that what's enough time. You have to feel it. You have to know that you went there, you saw your boy, and it's different seeing your child.

So my fear is I'm not always spending enough time with him visiting him, and when you drive away, you feel guilty, but things that help me with that is I have pictures on my dashboard when I drive. And I look at the smiles, and I remember through the pictures and speaks to me through pictures in saying I know you see me, I know you visited me.

It's okay because you never feel right leaving. When you driving away, it's looking in the rearview saying you're leaving your child. I hope he knows that I still love him the same so and that's how I remember my boy's constant pictures and videos that I have that I always took, take as many pictures and videos as possible because those memories are always close to your heart.

I Look at the pictures and the pictures say so many things.

Chad: So my fears of my missing him it was all it worked out. I look at the pictures, and the pictures say so many things to you of him smiling and his happiness, and certain times you bring yourself back to those memories and changed. It changed what I thought before as far as my fears to now know we gave him the best possible life we could've, and, again, he made him comfortable with my fears at the end. And he still does with continuing different things in my life, and he's still working miracles.