

Extended family is very important in any child's life, but that network of support becomes crucial to families who have a child with Williams syndrome. We asked several grandparents to answer some questions and they gave some great candid advice. We thank them all for opening up in the spirit of helping others with what they've learned. Enjoy their responses.

In a one sentence "blurb," describe the role of a good WS grandparent.

- a. There cannot ever be too much time spent with a Williams grandchild-- time spent is everything.*
- b. Being a good WS grandparent means loving, embracing, and accepting the WS child as one would do with any grandchild!*
- c. The role of a good WS grandparent would to me be the same as for any grandparent: Be loving and supportive.*
- d. Sure, there are differences between children with WS and without but in the end all that we want for them is to be loved and accepted. I think one of the most important things we can do is to lead by example. We should all always CHOOSE KIND!*
- e. Be supportive and provide unconditional love.*
- f. Be available, patient, open, fair, non-judgmental, loving and yourself.*

What advice do you feel qualified to give a grandparent who has just found out their grandchild has been diagnosed with WS? Please feel free to share your initial thoughts when you were in their place, and how those feelings/understanding may have changed over the years.

- a. Initially a great deal of fear, so many unknowns. There were no obvious physical signs or symptoms—only some developmental delay. At the time of diagnosis she was 16 months old. It was my daughter, after researching online, who asked that she be tested for Williams syndrome. There was relief that we had a diagnosis but I think initially there was a sense of isolation. No one that I spoke with had heard of Williams. Now that she is 9 years old with contact with other Williams families of sharing experiences and a great deal of hope and optimism that sense of being alone is no longer there.*
- b. Visiting Erin and Adam in the hospital after they gave birth to Knox, we both already knew something was askew since Knox's facial markers were already prominent. We didn't say anything and waited for a diagnosis (I should mention that I, Erin, and my*

husband all had careers in hospital settings). Once the potential diagnosis of Williams was suggested, I think our paths changed a bit from the norm. Our daughter (Knox's mother) quickly went into the panic spiral that I am sure is quite normal for parents getting such news. However, my husband and I were members of a close social circle for many years that included friends with a young adult Williams child who frequented adult events (parties, picnics, bowling, etc.) so we reacted quite differently because we absolutely loved the individual we knew. Of course, we have concerns given the current nature of politics and worry that we won't always be around to provide guidance and protection, but that really isn't any different than how we feel about all of our grandchildren. So, no, we didn't feel loss, or embarrassment, or some sense of unfairness. All of that is to the credit of the people we know and interact with who of been on this journey for 24+ years. They are great people, their son is an articulate delight, their lives are different, but not in a lesser way – just different.

- c. My first reaction to Trent's diagnosis was grief. I grieved for my daughter, for the difficulty of her life as a parent of a child with Williams, and I grieved for Trent, and wondered how his life would unfold. He was only six weeks old at this point. The advice I would give is that your grandchild is much more than a child with Williams. He/she is a precious gift of love, and Williams is not a sentence. Trent will be 4 soon, and has achieved many, many accomplishments. My daughter has worked very hard with him, and has taken him for every therapy session he has qualified for. She has spent endless hours on the phone, wading through the maze of special services and doctor appointments. But, that child is so special, and capable of much more than you would think!*
- d. From the day Thom was born we knew that there was a possibility that he had WS. The diagnosis was confirmed shortly thereafter, but my daughter and son in law needed time to absorb the information and didn't tell us for a few months. From what I have learned since then this is not unusual. I had never heard of WS so the first thing I did was google it (use the WSA website instead!). I am not sure what website I was on but I remember sobbing when I read that most people with WS end up living in group homes. Back then and even now it is the "scary thing:" Thom will more than likely always be dependent on other people.*
- e. When I was first told that my grandchild had WS, of course I shed a few tears. Not for my granddaughter, for I knew that she would always be deeply loved and cared for, but rather for my son and daughter-in law. I feared the strain raising a special needs child would have on their lives and on the life of Coralie's big brother.....that the dreams they had for their family would now be changed, made more difficult.*
- f. As a person who spent my career working with special needs adults, children*

and their families, when my granddaughter was diagnosed with WS I was shocked, dismayed and worried. I thought of all the many challenges ahead for Payton and her parents and what my role should be. I would advise the grandparents to learn about WS and ask the parents the appropriate ways in which they might assist them and support them in coping with their child's disability. As Payton grew older, the challenges that she and her parents actually had to face could not have been totally predicted by anyone. Payton does not have the cardiac issues that some children have and her health has been relatively good. As she has grown older other challenges have presented themselves.

When your family experienced a WS diagnosis, what advice/information did you find helpful, and what did you think should be avoided?

- a. I thought a lot of the info my daughter was getting about the personalities of WS kids was extreme, based on my first hand experiences. The medical complications are overwhelming and I think it's important to point out that every kid is different and you really need to reach across different groups medically for information – i.e., there are many syndromes and situations where cardiac is compromised so seeking info from broader groups that have additional research is important. As far as cognitive and social aspects of development, the WS group is the best source and the work they do to raise awareness is very important. Advocacy for WS kids and especially developing awareness within the medical and first responder communities, is pretty important.*
- b. Facts and information about William's syndrome were helpful. Emphasis should be on the immediate with whatever interventions are appropriate and needed. Admission by the MD's involved if they are not familiar or have experience with Williams, appropriate referrals to specialists as needed. To be avoided is an assumption that potential is limited. Our grandchild today is reading at the minimum 1 grade level beyond where she is. Overall performance with assistance is at grade level. That does not match with the info given at time of diagnosis.*
- c. The WSA website and the parent group were invaluable. And the more we moved toward being on the inside, and learning about Williams through conventions, walks, and specialists, the more we learned and accepted. I would avoid stereotyping your WS grandchild – Trent is simply Trent to us!*
- d. First and foremost enjoy the fact that you have a precious grandchild to love. You can't go back and repeat those first few days and weeks! I would then recommend finding out as much as you can about WS. Finding out what you are dealing with is far better than the fear of the unknown. The best website is of course the official WS website. It has the best information and it is presented with compassion.*

- e. *I realize now how foolish it was of me but I really didn't consider that there would be any issues when Thom was born so I was totally surprised. I didn't realize it then, but I went through the five stages of grief and loss. It wasn't a pleasant journey but I am afraid it is necessary to get to that "land" of acceptance. This may sound hokey but I would recommend reading the poem "Welcome to Holland" by Emily Perl Kingsley. It really helps to put things in perspective. I have read it more than a few times. The one thing that I wish that I could have avoided was well-meaning friends and family that would say "maybe it will be a mild case." I don't know how you can avoid this but I didn't take any comfort in that.*

- f. *The first place I went to was the WS Assoc. website. When my son and daughter-in-law obtained books from the WS Assoc. website, they gave them to me to read when they were done with them. I also attended a WS luncheon, where I have the opportunity to meet WS families and hear stories, as told by WS children and adults. This was very informative, especially when teenagers and adults with WS spoke about their happy lives.*

What are the joys of having a grandchild with WS?

- a. *She is very loving, very verbal, loves any kind of music especially opera. She went last year to the NY Opera and never moved for 2 ½ hours--was just enthralled with the performance.*

- b. *The joys are innumerable! I have a non-Williams grandson as well, and both bring great joy! Trent is full of life, sweet, loving, friendly, and so much fun to watch because he is so darn cute. Trent does not let anything stand in his way, and I would move mountains to clear the path for him!*

- c. *With Thom being my first grandchild, I have nothing to compare him to as far as a grandchild without WS. All that I know is being Thom's "PaPa" is the most incredible thing. Thom is my grandson, period. I don't think of him as my grandson with WS anymore than if he has a sibling that is born with asthma. I'm sure I experience the same joys as any other grandparent except even more because Thom is mine!*

- d. *I have found that having a WS grandchild is a true blessing. She has boundless love, never tires of giving and receiving hugs and kisses, and has a happy personality that brightens my darkest day. You just cannot be unhappy around her. She finds joy in even small things, which reminds me to do the same. She may be a little slower at reaching milestones, but I know she will get there eventually. Right now I am just enjoying her journey and cheering her on.*

- e. *Not any different than any other grandkid... Might develop at a slower pace, but still just a kid learning things. I haven't noticed any difference with Knox, other than his*

pace. Once we got past the first 6 months of screaming that is... That was horrible for my daughter.

- f. They light up every place they go. They LOVE everyone and we have said repeatedly if everyone in the world had 1% of the happiness the twins do our world would be so wonderful.*
- g. Payton is a character. She is funny, loving, inquisitive, friendly and very likeable. She was called "the mayor" of the grade school. Knew everyone by name and spoke to everyone. I have great hopes for her and I think she will be capable of developing strengths and skills that will serve her well and allow her to live independently in a community with certain supports as an adult. She is a wonderful member of our family and her personality and individualism keeps unfolding in very unique and amazing ways. She can always surprise us with her humor, what she observes and how she expresses it.*

What are the challenges?

- a. Not having an awareness of strangers, and the risk and danger involved is number one. Melt downs with the fine line of determining cause and then appropriate intervention I think is probably the most difficult.*
- b. When my grandson is fearful of his many dr. appointments, I hurt for him. I worry about the stress on my daughter and son-in-law. I worry about where Trent will be as a young adult, and what his capabilities will be. I always want to be a source of support for my daughter, but as I age, I may not be present to help as much.*
- c. The medical issues are the most challenging. I got a text from my daughter yesterday saying she was concerned because Thom wasn't eating or drinking. She was able to get him in yesterday afternoon to see his pediatrician and today he seems to be on the mend. There have been times like this before where it has required a hospital stay.*
- d. The only challenge I find is in giving her brother the same amount of time and attention that I give her. When I am with both of them, she demands most of the attention, so I make sure to find time to spend her brother only. Sometimes we go to the movies, and I often watch him while she is at therapy.*
- e. For a grandparent: worrying about your kid more than worrying about your grandkid... My daughter carries the weight of the world some days – that's harder than worrying about Knox. Don't get me wrong, she (my daughter) is super human and is handling Knox's diagnosis in a way that makes me beyond proud and not at all*

- afraid for his future. But the pressure on her is immense, which worries me more than anything.*
- f. Schooling has been one of the biggest challenges. The system doesn't seem to "want" them. They don't seem to want to be bothered with knowing about the syndrome. I feel they (the school) want to hide all children with special needs.*
- g. Payton is now in middle school and has been having behavioral problems that are interfering with her success at school, within the community and at home. Her parents have consulted professionals regarding ways to help her and have started medication that they hope will help with her impulsivity etc. Not an easy decision for them as they wanted to avoid meds. Payton also exhibits autistic behaviors that are being addressed. Payton has two younger sisters and behavioral outbursts on her part can often interfere with family activities and day to day living. It is a challenge for her parents to modify the behaviors and at the same time address the needs of her sisters. The efforts to aid this present situation is ongoing.*

If you've been successful at helping as a caregiver, what has your family found most useful? Any things you learned to let go?

- a. I am a short term care giver-a few hours at a time as well as up to two weeks when Mom and Dad are travelling on business. She understands when Mom and Dad are home and I am there they are in charge. When they are away she understands that I am.*
- b. I think just knowing that I will come whenever needed, even though I live two hours away, is most useful. I know that supporting the WSA walk, and planning to go to the next convention, means a lot to my family. I have learned to let the small stuff go, and to enjoy every moment we are with the kids.*
- c. I try to provide emotional support. I think one of the most important things you can do is be a good listener.*
- d. I let go of my opinion – unless asked for it's a burden...I try to be available whenever my daughter needs a break, or an ear. I take my queues from her. I don't offer advice unless asked – I don't meddle.*
- e. When Coralie was first diagnosed, I told my family that I would help in any way they wanted or needed me to. Mostly that has turned out to be babysitting. I never refuse when asked. I often watch her older brother while she is at therapy, and do*

the same when Coralie has various appointments related to her WS. There are also times when mommy wants or needs time with Coralie alone, as well as when mommy and daddy need their time alone without any kids. I also try to support them by attending local fund raising events.

- f. *Most useful is being patient and having a routine. The best way I have found to help and be most useful has been to be available to take care of Payton and her sisters for a night to allow the parents a “night out”, go along with the family to community events or outings, be a sounding board for resolving problems when asked, and do one-on-one activities with Payton. These seem to be useful and I enjoy doing them.*

Caregivers are important, and some can get burned out. Has this ever happened to anyone in your family and how did it get resolved?

- a. *My daughter has a strong support structure, so I think between all of us we are able to help her avoid getting burned out without anyone else getting burned out in the process. We’re all very lucky in that respect. I know others don’t have that...*
- b. *I know it was very hard on my son to be a single parent with twins who have special needs. Their biological mother hasn't been in their lives since they were about 18 months old. So to avoid him getting burned out, I as his parent stepped up.*
- c. *Definitely, caregivers get burned out and our family is no exception. Thankfully, Payton’s parents give each other opportunities for respite as well as my husband and I and Payton’s other grandparents. Payton’s maternal grandparents drive from New Jersey, where they live, almost once a month to spend time with Payton and her sisters and at the same time lend a hand. Our extended family is always ready to support and assist when needed. Regular family get-togethers, overnights and accessibility are goals that we hope help to avoid burn out.*

Have you had interaction with other families who have a member who is an individual with WS? If so, how does that work and help with the family dynamic? For example, regional events and holiday parties.

- a. *I have close friends with a young adult WS child. It’s exceptionally helpful to know someone. We immediately arranged for my daughter and her husband to meet our friends and their son. I think it helped a ton to tone down much of what they were reading on the internet and also gave her a resource. They have become great friends....*

- b. *We have attended walks and picnics for WS. My daughter is so happy to be among other parents of, and individuals with, WS. The networking helps so much. Speaking with older WS people, teens and adults, gives us hope. Both of Trent's parents have gotten involved with WS events, as has all of my immediate family.*
- c. *We went to our first WS walk in Medford, Oregon a few years ago and met several families. I have stayed in contact with one other grandmother (her grandchild with WS passed away) and I have contact with the lady who hosted the walk. We have been to the Christmas Party in the PNW a couple of times as well. I felt very welcomed at all these events. My son didn't really feel comfortable until one Christmas party that another dad came over and introduced himself to him and talked about his son. We've also been to a walk in Vancouver, WA and took other children with us. Everyone was so open and inviting of everybody who came to support their family members with WS.*
- d. *One thing I have found helpful is the connection that I have made through Facebook with other families that have children with WS. I was able to make these connections through my daughter. There are four families that she is especially close to, and their children, along with my grandson, make up what I call "The Fab Five." Also I am close to another family who has a daughter close to Thom's age so it's actually "The Fab Five plus One." Having this connection has made all the difference in the world. Because of the connections I have made with these other families, it feels as though I have several grandchildren. This is not something that would not have happened if Thom had been born without WS. I have even had the good fortune to meet all of the children that make up The Fab Five even though they are scattered all over the U.S. I am hoping to meet sweet Bess (the "Plus One") in 2018 at the WS conference.*
- e. *I have attended a luncheon, a run, an autumn get together, and visited with another WS family at my children's home. The luncheon was especially helpful. We all sat around in a circle and everyone, including those with WS, got to speak or ask questions. Listening to all the WS family members talk about the joy their special family has brought into their lives was wonderful. A young WS adult told us about her life and advised us not to worry about our young children....that like her, even with their challenges, they would grow up to have very happy lives. She almost made me cry. Her speech wiped out any fears I had for Coralie's ability to find personal happiness.*
- f. *We have had some interaction with other families with WS children. One of the issues in Maine is that we are so spread out and the events in New England can be a location and transportation issue. We are hoping that we can become more proactive in getting families together that are in a geographic location that is feasible for*

travel. I know that Payton's parents are always grateful for any networking with other WS parents and find it very helpful.

Has there been a time when your best intentions didn't work out? What did you learn from that?

- a. Less is better than more--especially at Christmas. Sensory overload needs to be managed.*
- b. My best intentions are restricted to "how can I help"... I can't fix this, or do a better job than my daughter. I don't pretend I can. Our role is love and support; we try to be really good at that part.*
- c. Oh yes. I learned that I should not have expectations that are unrealistic. "Go with the flow" as they say and take one step at a time and try not to be too disappointed with an intention fails.*