

Resource Directory



Resources listed are not endorsed by DSAWM, but are a list of options that are available. If you know of additional West Michigan resources, please let us know at 616-956-3488 or director@dsawm.org. For more information, visit dsawm.org/resources.



Sibling Resources

Siblings play an important role in the lives of people with Down syndrome. During childhood, siblings provide friendship and companionship. In older adulthood, many siblings will become the primary guardian or caregiver for their sibling with Down syndrome. Throughout this unique journey, resources are available to support and provide guidance to siblings, their families, and the loved ones for whom they care.

Community Supports

For Younger Siblings

- **Grand Rapids Area Sibshops** provide an opportunity for school-age children and teens to meet other children who understand the unique experience of having a sibling with special needs, share their experiences and feelings, and learn more about their sibling's special needs. Learn more and register to participate at siblingsupport.org/sibshops/find-a-sibshop-near-you or follow the Grand Rapids Area Sibshops Facebook page at [@siblingsgroup](https://www.facebook.com/siblingsgroup).
- **Sibling Support Project** is the first national program dedicated to the life-long and ever-changing concerns of millions of brothers and sisters of people with special health, developmental, and mental health concerns. Learn more at siblingsupport.org.
- **Siblings Learn About Down Syndrome** is a website offering resources to create workshops for siblings of those with Down syndrome. Materials include age-based activities covering a wide range of topics from handling behavior challenges and the benefits of having a sibling with Down syndrome to being a policy advocate. Activities include Human BINGO, Down syndrome Jeopardy, Sensitivity games and more. Learn more at siblingslearnaboutdownsyndrome.com.
- **Eyes Different Than Mine** is a children's book by local author and sibling Erin Johnson about the unique relationship between neurodiverse siblings. Purchase the book at erinrhodesjohnson.com/book.

For Adult Siblings/Caregivers

- The **NDSC Adult Sibling Program** offers many workshops at their Annual Convention for adult siblings and caregivers. Additionally, their **Adult Siblings Toolkit** is available to download for free and designed to jump-start conversations with parents about becoming more involved in their brother or sister's life. Siblings can use this information to be effective advocates and perhaps, caregivers, after their parents are no longer able. Learn more and download the toolkit at ndscenter.org/programs-resources/adult-siblings.

- **MI-OCEAN (Michigan Older Caregivers of Emerging Adults with Autism and other Neurodevelopmental Disabilities)** (ddi.wayne.edu/miocean or 313-577-6368) is a statewide project aimed at addressing the needs and health concerns of aging caregivers (age 55+) of adults with intellectual and developmental disabilities. The project uses a family support model to identify and address various issues that may negatively impact the health and well-being of aging caregivers and those that depend on them. Learn more at ddi.wayne.edu/miocean.
- The **NDSC Family Care Toolkit** allows caregivers to record and keep all important information in one place relevant to the care for a person with Down syndrome. The toolkit is divided into 6 sections – Home, Family, Daily Living, Medical, Resources, and Emergency – which includes everything from how to use remotes to emergency medical consent forms. Download the kit at ndscenter.org/programs-resources/family-care-toolkit.
- Published by NDSS (National Down Syndrome Society), the **Aging and Down Syndrome: A Health & Well-Being Guidebook** provides an overview of the medical and psychosocial needs that are unique to individuals with Down syndrome as they age. Download the guidebook online at ndss.org. Physical copies are available at DSAWM.
- **Siblings Learn About Down Syndrome** (siblingslearnaboutdownsyndrome.com) is a website offering resources to create workshops for siblings of those with Down syndrome. Materials include age-based activities covering a wide range of topics from handling behavior challenges and the benefits of having a sibling with Down syndrome to being a policy advocate. Activities include Human BINGO, Down syndrome Jeopardy, Sensitivity games and more. Learn more at siblingslearnaboutdownsyndrome.com.

For more information about caring for an aging person with Down syndrome, visit the Aging Resources page of our website at dsawm.org/aging-resources.

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Elvis and the 21st Chromosome

by Erin Doyle Toburen, Cascade

Elvis arrived in blue suede shoes, aviators, and a jumpsuit shortly before the end of my freshman year of college. Already the parents of four children – ages 10 through 18 – the thought of an infant was a decade removed from my parents' mind when they found themselves unexpectedly expecting. On that April morning when the baby arrived, my father called me to announce the baby's arrival.



It was a boy, he said, his name is Liam, but – but – he arrived with an extra chromosome. He arrived smaller than his older two brothers had, but little did we know, his entrance would rock our world. As a college Freshman, I drove six hours home from Steubenville, Ohio, with my college roommate to meet my brother in the NICU. His short visit in the NICU due to a heart murmur for only five days after birth gave us our first glimpse into this beautiful life we had now been given.

A few weeks after returning to college, I sat in a meeting with my sorority sisters where our sorority mother in her mid-thirties brought her adult sister with her. Her sister, born with Down syndrome, was vibrant and beautiful. I bawled. I had not yet grieved over the lost expectation of a sibling born without an extra chromosome. Ashamed because I knew my sorority sisters knew why I was bawling only increased my flood of tears. Our sorority mother soon became my personal mentor, sharing with me who her sister was, how her sister influenced her life, and how her sister was not defined by the fact she was born with Down syndrome. Sixteen years later, I am still grateful to my sorority mother.

“Down syndrome” slowly settled itself into our family’s vernacular and questions swirled. “Down syndrome” – would he go to college? “Down syndrome” – would he be able to talk? “Down syndrome” – would he be able to walk? “Down syndrome” – what does that even mean? “Down syndrome” – what would be his life’s trajectory?

Like everything else in life that is considered outside the everyday “normal,” people began asking questions they should not and voicing opinions they should not. When we mentioned that our youngest brother was born with Down syndrome, people sometimes made the trite (albeit well-meaning) comments such as: “God only sends children like “that” to “special” families, so you must have a special family” or even the suggestion that people born with Down syndrome could be healed “from” Down syndrome, perhaps suggesting my brother could be “healed.” Such well-meaning comments failed to see the reality in which my brother lives. They did not see the three-month struggle my mother went through before he would latch while nursing. They did not see how Celiac’s Disease, a common condition in people born with Down syndrome, impacts his daily life. Most importantly, such comments failed to account for the fact that Down syndrome never defined him, rather Liam would define his own life and influence those around him.

Liam would help influence some of most important decisions in my life. As a college intern for the U.S. State Department, I dreamed of one day becoming a foreign service officer. The adventure, travel, and importance of the diplomatic mission called to me, but Liam called stronger. I knew if I chose a career in the foreign service, I would spend much of my life away from Liam so I chose

law school to keep me stateside. I chose Saint Louis University, because it was only a day's drive from Liam.

My career eventually brought me back home to West Michigan where I practice in-house international corporate law and live five miles from Liam. Living so close to Liam has given me front-row seats to witness the symphony Liam has composed with his life. His symphony crescendos with his gregarious personality, pauses at his thoughtfulness and is driven by his incredible work ethic and Elvis. Oh, so much, Elvis.

When Liam was thirteen, he began watching reruns of Full House like it was his full-time job. His favorite character soon became Uncle Jesse. Liam talked of nothing but Uncle Jesse for months. He would recite entire story lines and facts about Uncle Jesse to anyone who was willing to listen to his two-hour monologues (Thank you, Carl!). Uncle Jesse was suave. Uncle Jesse liked music. Uncle Jesse loved Elvis.

One thing led to another and Liam soon forgot Uncle Jesse. Liam only talked about Elvis. Elvis's horse, Elvis's history, the nuances of the Elvis-Priscilla relationship, and Graceland. If you wanted to listen to music around Liam, it had to be Elvis, and, for the first and only time in his eyes, Liam thought I, his older sister, was cool because I wore aviator sunglasses like Elvis.

Like the Full House era, our family hoped Elvis was simply a phase. My dad complained about Elvis every time someone mentioned him. My parents spent their honeymoon driving through the Upper Peninsula of Michigan in August of 1977 when Elvis died and the only thing one could hear on the radio was Elvis music. Unlike the Full House era, Elvis was a new way of life.

When Liam's quest for all-things Elvis could not be satiated by historical facts or the Sirius-XM Elvis station being played 24-hours a day, Liam decided he wanted to become a real-life Elvis Tribute Artist ("ETA"), and an ETA he has become. For the past several years, Liam has taken dance and music lessons to improve his voice and stage presence. He practices every day – sometimes for hours – at our farm on his music. He entertains his seven nieces and nephews with his music and dancing to make sure they get to see him realize his dream someday. He beams with pride when my three-year-old daughter insists on calling him "Uncle Elvis."



His inspiration for his hard work and drive has been the ETAs he has met over the past several years at the various events my parents traveled around the country taking him to see. The first of these was Elvis Tribute Artist Jake Slater my mother and Liam met while vacationing in Northern Michigan.

Thanks to Mr. Slater and the other ETAs who have inspired him Liam began performing to large audiences in 2019. Last April, Mr. Slater performed at Liam's sixteenth birthday party and let Liam sing alongside him in front of over a hundred people. In July, Liam attended the Graceland Performing Arts Camp at Graceland where he met other Elvis fans for the second summer in a row and made friends across the country. Then in October, Liam made his YouTube.com debut when he performed "Peace in the Valley" at the 27th Annual Elvis Annual Fantasy Festival in Portage, Indiana. The proceeds from the event benefited the Porter County Special Olympics. Liam has since performed at company Christmas parties, represented Elvis fashion at the National Association for Down syndrome Fashion Show in Chicago, and sang at a wedding.

Thanks to Elvis, Liam keeps in shape so as not to hinder his chances of someday competing to become an Ultimate Elvis Tribute Artist. Thanks to Elvis, Liam tells us that he loves performing because he likes to make people happy and make the world a brighter place. Thanks to Elvis, Liam constantly reminds us that our chromosomes do not define us. Thanks to Elvis, Liam is determining his own life's trajectory. Thanks to Elvis, Liam has found his voice.

My Sister Chloe

by Peyton Brill, Grand Haven

Down syndrome is something that many people struggle to understand. I've spent the last 11 years learning about it from my younger sister Chloe and there's still so much more to learn. Over time, I have noticed how Chloe is constantly treated differently by others. I want to follow her and shield her wherever she goes, but that is just not possible. I have also become accustomed to mixed reactions from people when they learn that Chloe has Down syndrome. One of the hardest reactions to respond to is when people say "oh, I'm sorry..." as though Down syndrome is a burden. Fortunately, having Chloe in my life has taught me the importance of patience. Having patience keeps me from becoming angry at other people's lack of knowledge and instead helps me to teach them about what Down syndrome really means.



When Chloe was about five, we went to Crazy Bounce and she was ecstatic, like a kid in a candy store. The slides were steep and slippery, but she was determined to get to the top. Years later, I still vividly remember Chloe working her way up the giant tiger slide. Ignorant teenagers began sprinting up behind us. One boy began making rude remarks about Chloe and her speed. I asked him to stop, but he in turn decided to shake the slide. As much as I wanted to go teach that kid a lesson, I just turned towards Chloe and followed her the rest of the way up. People with Down syndrome are often known for their unconditional love and so often I wonder how they manage it given the way they are so often mistreated. If the boy who made fun of Chloe had fallen, she would have been the first to run up and give him a hug, no matter how he had treated her, because that is just who she is.

Inclusion is getting better, but there is still a long way to go. Part of the reason I love camping with my family is because we can escape the small-town bubble where we spend so much of our time. Traveling with someone who has Down syndrome is thought by many to be a hassle. I will be the first to admit that sometimes the stimulation of visiting new places and trying new things can be a bit much for anyone, especially someone with special needs. When my family first got a camper, we had no clue how things were going to go, but there is no way to tell unless you try. For Chloe, our motor home has become a second home. It's a place that she is familiar with and where she can return to if trying new things gets overwhelming. We have gone on all sorts of trips and Chloe has met many new friends. So many of the people we meet along the way are kind and open-minded. Kids from the campground will run up to our site looking for Chloe and they'll all run off together to play. Nobody is born with the biases that are so often directed towards individuals with special needs. Seeing Chloe with all the accepting people we've met while traveling helps me to see that even though there are those who may try to break her down, there are a lot of people who will always support and stand up for her.

Throughout my life, I have been blessed to meet friends from my community with Down syndrome and they are honestly some of the most down-to-earth people I have ever met. At my school we have a program called POPS which stands for Power of Peer Support. The focus of the club is increasing inclusion in the school. Even simple lunches together can create great memories and show the value in small moments of acceptance, especially because people with special needs are so often left out. I have seen so many friendships form through this club and learned a lot about people who I did not know that well. Keeping a club going at school can be difficult. Many

people are focused on more popular activities and are scared to try something new. Receiving messages from parents of students with special needs about how much POPS means to them and their child has pushed me to reach out and grow the club and inclusion in the school.

Recently, I ran an event called Buddy Games. During the event, individuals with special needs were paired with a buddy who stayed by their side and encouraged them as they practiced basic soccer skills like passing, dribbling, and shooting. Afterwards, a scrimmage game was held for everyone to participate in. Over 40 people participated and many of the volunteer buddies were students from Grand Haven High School. The event was totally eye-opening. Seeing inclusion on the field was just a small step towards eliminating some of the biases that people have about those with special needs. The smiles on everyone's faces were ear-to-ear and you could feel the unconditional love. Chloe often asks to participate on school teams, but those teams tend to progress quickly and, while she is just as capable as everyone else, sometimes she needs the pace to be modified. Buddy Games was not only an opportunity that allowed Chloe and others to play on a sports team that fit their needs, but it also gave everyone who came the ability to learn about others who they perceive to be unable.

The hardest part of having a sibling with special needs is seeing the way others put her down. Learning to let Chloe work through this challenge on her own is difficult and I constantly find myself stepping in to guard her. Chloe is strong though. There are days when she completely amazes me in how she carries herself so independently and, through it all, with love.

Change for the Better

by Chloe Peters, Forest Hills

I was always considered the princess of the family. Surrounded by two big brothers, habitually I was spoiled and always obtained what I wanted. Photographs of me splashed the walls of our house. The world revolved around my needs. I only realized I received the most attention from my parents when it was suddenly stolen from me in November of 2009. My family transitioned from a family of five to a family of six. The newest addition was yet another boy, so the princess label remained with me, but the label did not bring the attentive spotlight it always held.



My newest brother, Cale, was considered “different” to most people. At my age, I was unaware that most babies did not spend the first month of their life in the hospital. Like me, Cale was given a label. However, his label was something I had never heard before: Down syndrome. I feared the word “different.” It was always attached to a negative connotation, but I quickly learned that I did not have to treat Cale any differently. Over time, the picture frames on the walls contained pictures of my little brother instead of me. I respected the change because in exchange I changed myself for the better. I learned to love others no matter if they are “different” or not.

Sometimes, even a princess needs to experience change. Change pushed me to experience and learn new things. Cale taught me to respect everyone. I learned life is not all about me. Cale opened my eyes to see that you get more out of life if you encourage and love others for who they are. Little did I know the affectionate eight-year old I know now would have the greatest impact on my life. I am thankful for losing my spotlight, for I learned far more watching the light shine upon my little brother.