



NTG NDSS

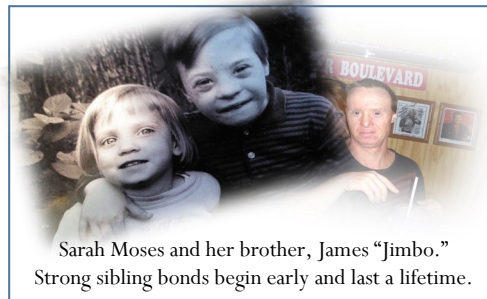
CAREGIVER NEWS

HONORING SIBLINGS

Jadene S. Ransdell, B.S. Caregiver News Co-Editor

Siblings are such an important part of our community. Some siblings help aging parents navigate their brothers' and sisters' care. And other siblings are the primary people in the lives of their loved ones—the siblings who have direct or indirect responsibility for every aspect of their brothers' or sisters' lives.

Siblings are the focus of this issue of the *NTG NDSS Caregiver News*. Inside you will find resources that may be of help to you whether you are just starting the journey that finds you responsible for your family member's life, or you have been supporting him or her for some time. Several siblings have written articles about the relationships they have (or had) with their brothers and sisters. Each story provides a glimpse into their lives, and we believe that many of you will identify with the love and compassion they share.



Sarah Moses and her brother, James "Jimbo."
Strong sibling bonds begin early and last a lifetime.

If you would like to connect with siblings and others who are on the Alzheimer's/ Dementia journey you can join the Facebook support group, *Down Syndrome and Alzheimer's/Down Syndrome Regression*. Sarah Moses, a member of the group for over a year, once wrote, "So much of what we go through is talked about on this page and it brings me comfort to know we are not alone." She recently shared the death of her brother "Jimbo," and from her photos, it is evident that those special sibling bonds begin at a young age.

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"...it is fair to estimate that there are at least 4 million brothers and sisters of people with developmental disabilities in the United States alone..."

The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults with Disabilities,
Emily Holl, Don Meyer, November 2014

"Three quarters of primary caregivers report that caring for their sibling is a full-time job, and 30% say they don't receive emotional, physical, or financial help from other friends and family."

Mass Mutual & Easter Seals: Sibling Disability Study (2012)

"There may be no relationship... that's finer, harder, sweeter, happier, sadder, more filled with joy or fraught with woe, than the relationship we have with our brothers and sisters."

Jeffrey Kluger
TED Radio Hour, NPR

A TRIBUTE TO SIBLINGS

Jadene S. Ransdell, B.S., Co-Editor, NTG ☞ NDSS Caregiver News

I have long been aware of the very special role that siblings play in families, and am honored to once again share a reprint of A Tribute to Siblings that I wrote when my older son left us to join the Coast Guard. It first appeared in this newsletter in the July/August 2017 edition.

As a volunteer with the NTG, and now as a consultant with the NDSS, I have had many wonderful opportunities presented to me over the past several years. I believe the best part of the work I get to do is meeting other families who are also walking this path of aging with a loved one who has an intellectual disability and has or is suspected of having dementia.

I have not been surprised at the number of siblings I've met who are helping a parent or are totally responsible for their brother or sister. Every month, I talk with many people about how incredibly loving, loyal and caring these siblings are. Many make the care of brothers and sisters a life-priority. As a mother, I take great comfort in witnessing the special connections between siblings. In 1991 I wrote about my older son's influence on raising my son with Down syndrome. I am pleased to say thank you, once again.

When he was born I knew he was the most beautiful infant in the universe. Gazing at me in wide-eyed wonder, he looked so perfect; I knew he was destined to do great things. Michael was special. Indeed he was a special child. Oh, not because he had some type of disability or just because he was my baby, but because of the way he would live his life.

His earliest years were typical of most little ones, filled with love and admiration from mom and dad and all the relatives. We swelled with pride at each new first. And then one day, just before he was two and a half years old, his world was put into a different tilt. He became the older bother...the "other" child.

It came as a shock to us when we were told that Michael's bother had Down syndrome. I have learned a lot about the world of disability over the years. I have come to view Matthew as a great teacher of life. Some of my most valuable lessons, however, have come from Michael. He has been the quiet hero in my life, sneaking my education in while I didn't realize I was being taught.

Michael has helped me maintain balance—reminding me not to live my life wrapped up in disability. He has kept me smiling and laughing, always best at helping me laugh at myself. He has taught me humility and acceptance of my own weaknesses and mistakes. Most of all he has taught me to see his brother through different eyes. Michael never saw a baby with Down syndrome; he only saw a little brother. He was the first in our family to see beyond the disability. He has taught me that each of us has a role in the family. He has modeled acceptance to his peers and shown me the way of life as a typical kid, at the same time giving me a barometer for Matthew's life.

Michael has begun a life of his own, having just recently left home. I have never been so keenly aware, as I am now, of the positive influence siblings of children with disabilities can have on the quality of life in a family. I am so in awe of that contribution. To Michael and all the siblings in our families, thanks for all you do!



Left: Matt at about four months, Michael about three years old.
Right: Matt at about 40 years old, Michael about 42 years old.

LESSONS LEARNED FROM MY BROTHER, BARRY

Wendy Headrick, Florida

I am blessed to be Barry's sister. I was nine when he was born, in 1961. At that time, my parents were told to put him in an institution and tell the other two kids that he died!!

I shudder when I think of what could have happened to him with no one to love him like we do. I found a book by Dale Evans Rogers; *Angel Unaware* and from that time on, I felt like he was our gift. You see my parents never really talked to me as a kid about having a brother with Down syndrome. Just not their way. I became his teacher and loved playing with him...my very own doll! I learned responsibility and babysitting at a young age—babysitting for Barry and many of his young friends. As the years passed, I met many children and adults with differing abilities, fell in love working with them and decided to become a Special Education teacher. Barry served as the subject of all the papers I completed in college, and I had a wonderful career teaching for 30 years before retiring.

While I was busy teaching in a couple of different states, Barry remained at home with our parents. He graduated from high school and with the help of my parents found a full-time job at a grocery store chain where he worked for 21 years as a full-time employee with full-time benefits. Throughout those years, different co-workers took an interest in him and watched out for him. Our dad was his primary support and problem solver. The store was two blocks from their house so once my dad retired, he was available to help solve problems. Prior to that, they did try job coaches occasionally but that never really worked. Barry was well liked at his job and his managers always said that they wished they had more workers like him who had his determination and dedication to his work. Barry was recognized in our town for his work and won other awards. He began competing in Special Olympics as an 8-year-old swimmer, and a few years later represented New Jersey at the Second International Special Olympics in Los Angeles. He also was a bowler for probably 30 years, and has tons of trophies and medals.

When Barry was 46, our dad had a stroke and died. I realized that my mom also had some issues with aging and that it would not be safe for Barry and her to stay in their home, so they moved in with my husband and me. It

was a hard move for both since Barry had lived in the same house from birth and had many activities and friends. But Barry is Barry and he adjusted to his new home.

We found many new activities and friends and he grew comfortable with us. He had a part-time job that he loved. I was his job coach since, initially, we tried a coach with an agency, and it was disastrous. The boss was willing to let me coach based on my professional and personal experience. One of the tasks Barry had to do was to make 12 pots of coffee before the store opened for business. Once he got pretty good at that, the deli workers told me to stay home...they would teach him what he needed to know next. See, that's one thing that I learned...he just needs to get his foot in the door and then his personality and love for others wins everyone over!

That same thing has happened with all our friends. When Barry moved in with my husband and me, we became a trio and now love doing things together. Everyone just expected Barry to be with us and he was accepted into our many activities and commitments.



Wendy and her brother Barry.

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LESSONS LEARNED FROM MY BROTHER, BARRY

Wendy Headrick

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Our mom died four years after they joined us, and we eventually moved to Florida where we now live. Barry will gladly tell you that he loves Florida because he got tired of working in the snow! Now he is 59 years old and was busy with volunteering before COVID. Soon, he will gradually start back to his three-day-a-week program; however, his other volunteer position is on hold until it is safe enough for him to return.

I have learned so many lessons from him. Over the years he has taught me about unconditional love...he loves me no matter what I do or how cranky I might get. He is kind and compassionate and truly cares about other people. He will always check to make sure people are doing OK and pray for those who are ill or hurt. Throughout his life, he has dealt with various situations and still loves all. His heart is so pure.

Barry has a great sense of humor and keeps us laughing. Sometimes I think he spends his time thinking of things to say to make us laugh. As COVID closed things down, he created a new schedule; each day starts with a 1.5- or 2-mile walk. From there, he helps with things around the house and enjoys his various coloring and shredding projects. He loves seeing friends and participating in activities through Zoom. When he left school, he read on a 3rd grade level and enjoyed sports magazines but that faded over the years. But he recently decided that he was interested in literacy tutoring through our local GiGi's Playhouse and has a terrific tutor. He enjoys reading some simple books again!

Now to the harder part. In the past year or so I have noticed declining skills and a few times have noticed behavior that is quite unlike him. He has gotten very frustrated with himself that he forgets things. There have been episodes of syncope and he is being followed by a neurologist and cardiologist to figure out the cause of the syncope episodes. He, at times, has forgotten how to spell his middle name and he no longer remembers absolutely everyone's birthday. We find that we have to make sure we have his attention before giving him a simple direction. Where we used to give 3-4 step directions, we now try for only 1, or maybe 2 steps. Barry will repeat stories a lot and has begun to recreate his memories; and many are new and unrealistic. Of course, he does have a comeback when I question his memory...that I didn't live at home with him at that time! We did live apart for at least 35 years.

He has also begun to be more involved with his TV shows and tells them goodbye when he has to leave—something he never did before. It could be a result of COVID and the isolation, however we try very hard to keep him engaged in a variety of activities. His balance has deteriorated, and he is very fearful of falling. He often says he is an old man now and doesn't like it. His body has aged, and he is much slower. It is noticeable, even to our friends.

All of this is very sad for me to watch. While I have seen these declines, he is still learning some new things, remains funny and is the sunshine in our home. Only God knows about his future but whatever it is, we will love him and be right there with him.



Wendy and Barry.



OUR ALZHEIMER'S STORY

Mary Merriman, Michigan

My brother, Pete, is exactly two years older than me. For the first fifty years of my life he was right next to me or just a few steps behind. He wanted to do everything I did, whether it was learning to ride a bike, playing tag, or going to college and getting that first apartment. Explaining to Pete why certain things were out of his reach had to have been some of the hardest conversations our mom ever had.

Pete has always been outgoing with a smile that can warm the coldest heart; I was an awkward child with thick glasses who never felt like she belonged. One of the many gifts my brother has brought to my life is the people who are drawn into his orbit and by extension my world. After the last five years I am even more grateful for those people.

Pete's early regression was easily overlooked as our family grew to include spouses and a nephew. It wasn't until after our dad passed away that I started to become aware of the skills Pete had lost. Initially I thought he was angry with me for making dad go away; some people suggested it was his way of grieving.

Ten months after dad died, Pete moved into his own apartment with direct care staff and a roommate. I had always planned on Pete living with me when our parents were gone, but it didn't work out. He no longer had the desire or the ability to keep up with me. Pete had always loved going places with my husband and me, but not anymore. His staff had mentioned the possibility of Alzheimer's; my husband and I even attended a workshop sponsored by the Alzheimer's Association and the ARC. Still, I refused to consider that possibility.

He preferred to be in his apartment with his familiar routine, staff and belongings. No matter how hard I tried to make him happy when we were together, he couldn't wait to get back to his apartment, and my feelings would be hurt. After three years of angry words, hurt feelings, and tears I couldn't ignore the possibility any longer. Pete spent Christmas in Florida with my husband and me. He was battling a cold the entire time; he was even confused and disoriented at one point. When he returned home, he ended up in the hospital for five days with pneumonia.

After spending those five days with him at the hospital, I finally sat down to fill out the NTG EDSD (a dementia screening tool for people with intellectual disabilities). It hit me like a ton of bricks. As I filled out the form, I started remembering all the things Pete no longer did. He could no longer follow the Detroit Tigers or Lions ball games; he was no longer capable of relaying the events of his day or a story. Just a few short years earlier he would interject sarcastic comments into a conversation causing everybody in the room to start laughing.

How had this happened without anybody noticing? The guilt and loss were overwhelming. I don't believe our story is unique. I think Alzheimer's has a way of sneaking up on people. Pete, like any non-disabled person struck by this horrible disease, was able to cover his forgetfulness in the early days. That smile and sense of humor continued to serve him well.

Happily, Pete's fan base has continued to grow. In addition to all the family and friends who have offered their support and encouragement over the years, I have been fortunate enough to find wonderful caregivers who are not only devoted to Pete but care for us as a family too. Through the NDSS and NTG, I have met incredible people, parents, and siblings alike, who are on this journey with me. Although our stories are not the same, there are some common threads, like the unconditional love people with Down

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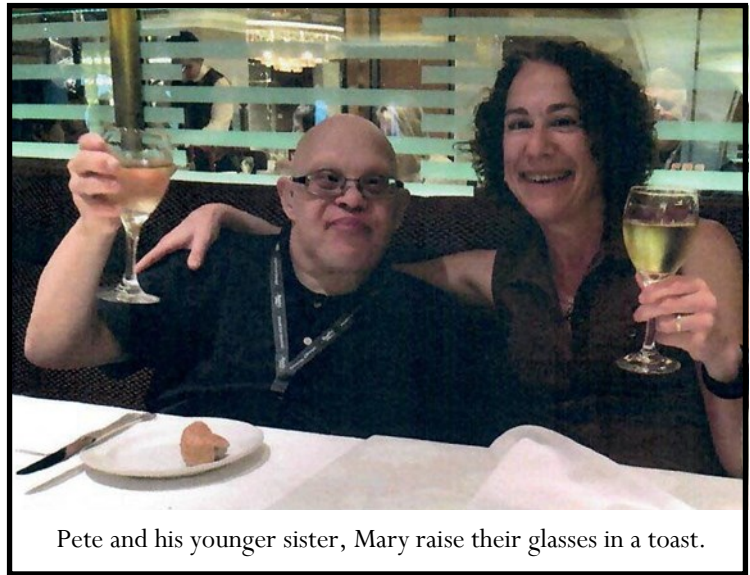
OUR ALZHEIMER'S STORY

Mary Merriman

(Continued from page 5)

syndrome give, their capacity to forgive, and their affection.

For the present time Pete is still happy and outgoing. He doesn't try to keep up with me anymore, he hasn't for some time. It's my turn to take a few steps back and meet him where he is and savor all the hugs, kisses, and smiles he has to offer.



Pete and his younger sister, Mary raise their glasses in a toast.

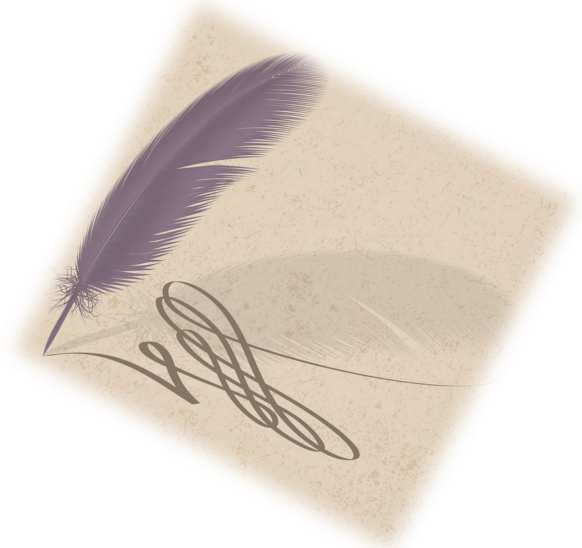
WRITE ABOUT YOUR EXPERIENCES

Jadene S. Ransdell, B.S. Caregiver News Co-Editor

I want to thank each of the siblings who shared their stories with us. Two take-aways I found include Mary Merriman's statement, "Although our stories are not the same, there are some common threads..." and Sharon Miller's discovery that, "Caregiving is not a journey that can be taken alone." My hope is that each writer found comfort in capturing their thoughts and sharing them with us. They are powerful stories, indeed!

I encourage each of you to find some time to write about your journey with Alzheimer's or another dementia. Over the past several years, I have been writing a book (*Letters to Matt: Unwrapping the Gifts of Disability*) about my life as a parent to a son with Down syndrome, Autism, and possibly Alzheimer's disease. I'm also working on some short articles that will be posted on a blog I am about to reactivate. It is such an amazing experience as I recall various events in our lives. I find I am able to work through many emotions as the thoughts get put into words. And, research has shown that writing can promote a sense of calm in people. It is a great habit to start, to pick back up, or to continue as we find ourselves struggling with so many emotions during this pandemic.

So, grab a notebook or journal and spend some time with your thoughts (writing on paper with pen or pencil activates different parts of the brain than keyboarding does...but getting your thoughts out is what is most important). Spend 10-20 minutes each morning (or before going to bed) writing. Write about your day and how you felt about it. Put on paper the fun times and the hard times. You do not have to share your thoughts with anyone else—unless you choose to. And, if any of our readers would like to connect through writing, drop me a note and let's explore a writing group. (jadeneransdellal@gmail.com)



A PETITE LADY WITH A HUGE SPIRIT

Sharon Miller, California

My sister, Robin Trocki, was a determined and courageous woman who set examples of compassion, patience, and fortitude for all who knew her. Despite early dismissals, warnings and discouragement by medical professionals, my parents allowed her to explore her own potential and supported her at home. Robin was an artist, an actor, a friend, a daughter, and a sister. In December of 2019, Alzheimer's disease took her life.

My sister and her twin brother, Tony, were born in 1956. Although they reached early milestones together, Robin's diagnosis of Down syndrome began to cast obstacles between her and her hard-won achievements. It was through her determination and perseverance she would learn the skills she needed to become self-sufficient and independent. For nearly fifty years, Robin would meet the challenges of every day with unique solutions and individual interpretation. As she reached her fiftieth birthday, we began to notice the changes that would eventually lead her into decline.

As her memory failed, she began to experience problems at work. Her speech began to deteriorate, becoming slightly garbled. She would randomly fall with no apparent medical reason. As the disease progressed, Robin would forget the names of people she knew and would repeat things over and over. At night she would busy herself rearranging her apartment rather than sleeping. She would relocate food items from her freezer to her sock drawer. Later, her daily living skills became more compromised making it too difficult, and soon impossible, for her to dress or feed herself. Perceptual problems impaired her ability to walk, taking away her ability to navigate her daily life alone. She became riddled with anxiety and could not leave her bedroom. Small doses of medication offered some relief. One of the most difficult stages of the disease brought Robin's psychosis. She could no longer be in the dark and kept the lights on all night. She began seeing things that terrorized her and while my assurance and presence offered some solace, I was scared to death over what was happening. I relented to additional medication for Robin which, again, offered some relief.

I was fearful and unprepared. In the early years, the progression was slow and could often be explained away by distraction or exhaustion, which caused me to become impatient and frustrated by her behavior. I knew nothing of Alzheimer's at this time and urged Robin to do better, not knowing that I was holding her responsible for something over which she had no control. Watching the changes tore me up and I was unable to grasp what was going on. My sister lived in an adaptive-living residence and I was besieged with staff complaints and unrealistic expectations. Her friends were frustrated, and I was running interference. These new and unexpected issues sent my own anxiety off the charts and kept me fearful of what was next. There was always something next. Alzheimer's is relentless.

Robin participated in a University of California Los Angeles (UCLA) research study focusing on people with Down syndrome. The UCLA team gave us information that was sorely needed. The research team at UC Irvine offered



Sharon and her sister Robin enjoying some beach time.

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A PETITE LADY WITH A HUGE SPIRIT

Sharon Miller

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me invaluable guidance and support during Robin's struggle as her condition progressed. I believe this outlet of information, assistance, and encouragement helped me to endure the most difficult period of my time caring for my sister. They allowed me to ask questions and the answers allowed me to manage my care routine and control my thought process which easily spiraled out of control.

Robin came to live with me for the last seven years of her life. Every day there were new problems to solve while trying to maintain my own life. At times it was overwhelming and often frightening. Robin's life had always been filled with fun and activity, and I was determined to continue to fill her days with the same stimulation and laughter. Toward the end, Robin's ability to swallow, as well as her breathing, became compromised. Pneumonia was a constant fear and I became panicked and desperate. Soon, her condition worsened, and she was eventually placed on hospice. Robin passed away at the age of 63.

Caring for my sister was the happiest, saddest, and most rewarding time of my life. Our home was filled with love and kindness, and I learned to look for the silver lining in every situation. Above all, I learned the value of acknowledging that I needed help. Caregiving is not a journey that can be taken alone.

My name is Sharon. My email address is trockimiller@yahoo.com. Some of you may know my sister. She played Jean Sylvester, Sue Sylvester's sister in Glee. She was a petite lady with a huge spirit. I miss her dearly.



Sharon provided care for Robin through the end of her sister's life.

A FAMILY BLESSING

Yolanda Villarreal, California

Our mom had terminal cancer in 2004; although she did not ask us to care for Maria she was very concerned for Maria's well-being, and did not want her to go to the state either. So, I believe that, when I told mom I would take care of Maria, she was able to die in peace, a day or two day later.

Maria graduated high school and remained at home with mom, as she never trusted anyone with Maria. But the day my mom died Maria started in a day program. Maria loved her program and it was so convenient for me, as it was just a block away from my work.

Maria has been a blessing for our family; she changed our lives forever. Every life that has been touched by Maria has been changed and blessed through her humor and presence. After 10 years, I asked my family for help with Maria. She lived with my older sister for about 4 to 5 years until that sister lost her battle with cancer in 2019. At that time, Maria came back to live with us.

Her condition changed a lot while she was away. It has become more difficult to care for her as she has further memory and behavior issues. I have the backing of my family. My husband has been in support of Maria living here, and I have another sister who also helps. While every day is a blessing, that's not to say it doesn't come without challenges, though. But I pray that God helps me through this journey to care for her.

This pandemic has made it even more challenging as the day program has closed. I work from home now and caring for Maria is a HUGE challenge. I pray every day for patience and knowledge to get through this and give the best care for Maria as well as for my husband and family. It's a juggle but a very rewarding juggle. I do it all for the love of God and this sweet blessing called Maria.

HENRY: MY SPECIAL ANGEL

Sandra Sharples, New Jersey

My name is Sandra and my brother Henry is my Special Angel! He was born on a beautiful September day in 1975. Even though I was only 8 years old at the time, I remember every detail. I woke up in the middle of the night and my grandmother was there because my mom had gone to the hospital. I woke up my sister to tell her and we were both so excited. We couldn't wait for my dad to come home to let us know whether it was a boy or a girl. The next morning there wasn't a cloud in the sky, and my father came home from the hospital so excited to tell us that my mother had a boy! There was only happiness for all of us—the doctors didn't say that anything was wrong with him.

My father went back to the hospital later that day and when he came home, he said that the doctors wanted to do some tests on the baby because they thought his cry was weak and his right eye was partially closed. They said it would take 4 weeks for the results to come back but didn't think anything was wrong. When my mom came home with him, I was over the moon—his golden hair and shiny blue eyes stole my heart! We treated him like a little doll and my parents had a cradle for him in their room, so he looked like a sweet little angel in it. None of us thought that anything was wrong with him and when my mom went for his two-week check-up, the doctor still didn't think anything was wrong.

Four weeks later, when the results came in, my parents learned the news. My sister and I were in school and when we came home, my grandparents were there, and everyone was crying. We had never seen them cry, so we knew something was wrong. They told us the news and that same day, my brother had to go to the hospital for an operation because they also discovered he had pyloric stenosis (an uncommon condition in infants that blocks food from entering the small intestine and often requires surgery). My parents digested the news and we all decided that we would treat him just the same as any baby. My mother even found out that the ARC in our area, offered an infant stimulation class, so he started that when he was only a few months old.

We had so much fun with him when he was a little boy. We played with him all the time, taught him how to talk, walk, and play with us and our friends. He had no trouble at all when he was young. He was enrolled in the ARC program and everyone always loved him! He went to a day camp offered by the ARC and even learned how to swim. Our public-school system had Special Education classes, so he was able to complete his education and graduate from high school at 21.

When he was in high school, he started to get very shy and stubborn, and my parents suspected that some of the regular kids were making fun of him, but he never said anything about it. By the time he graduated, my sister and I were both married and out of my parents' house. They didn't have a separate ceremony for the Special Education class, so he graduated with the entire Class of 1997. We went to cheer him on, and the other kids helped him know when it was time to walk up for his diploma. At that time, he still talked a little bit, but he did start to become more stubborn about doing things. Now, I think it was because he was sad that my sister and I had moved out, but at the time we didn't know that because he didn't say



Sandra and Henry

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HENRY: MY SPECIAL ANGEL

Sandra Sharples

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anything. I was, and still am, especially close to him, so I believe that he was very sad that I wasn't there anymore. My husband and I lived about one hour away, and I was working full-time, so I didn't get to visit as much as I wanted to.

After he graduated, he was employed in a program that the ARC ran, where he got paid for putting together items for a company that contracted their work. He went on the bus to and from work, but he would give my parents a hard time about getting ready and eating breakfast. Sometimes he didn't want to go on the bus, so my father started taking him to work. I wish that I had been there then to help. Throughout the years, he became more and more stubborn and withdrawn—he stopped talking when he was in his twenties. Eventually, when he was in his late thirties, he got very stubborn and didn't want to get up to do things. And even though he was never violent or mean, they said that he couldn't work there anymore because if there was an emergency, it would be dangerous if they couldn't get him to leave. At home, he just wanted to stay in his room and didn't want to come into the living room with my parents anymore. I just wish that he would tell us why he became so withdrawn.

The State of New Jersey said that for him to keep his disability benefits, he would have to be enrolled in Easter Seals and continue a program for socialization. My father is very overprotective and was afraid to let anyone take him out of the house so they asked me if I would work 10 hours per week to keep him socialized. Of course, I agreed, and I've been doing that ever since. We moved closer to my parents' house so now I go there to visit all the time—at least three days per week because I stopped working full-time.

He celebrated his 45th birthday earlier in September. He still just wants to stay in his room and will only come out for lunch and dinner if my father brings him. He's very set in his ways and doesn't like anything out of his routine. He does go shopping with my parents (however, because of COVID-19, my father stays in the car with him now, while my mother goes in the store). Right before the Pandemic started, I found a program that the public library ran for people with disabilities to do arts, crafts, and musical activities, so I enrolled him in it and was taking him once a month. It was great because, even though he didn't talk, he recognized some of the people he used to work with, and he smiled so much. They remembered him too, and all came to hug him. Unfortunately, that program stopped in March.

He still loves to dance, so I always play music when I visit, and we color too. He also reads, so I like to write him notes. I take him for a ride a few times per month and he comes with me if I let him know in advance. It's hard to tell what he's feeling because he doesn't talk, but in my heart, I believe that he understands everything.

When I look in his eyes, I just see pure love and innocence. I love him with all my heart and would do anything for him. I just wish he would talk again and tell us what he's thinking. My husband and I don't have children so we will take him in if something happens to my parents. They're getting older, so it's harder for them, but he loves them and wants to be with them.

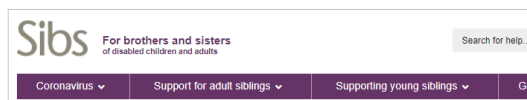
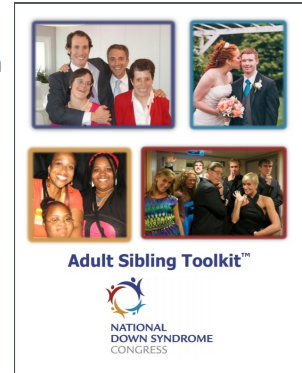
"Brother and sister, together as friends, ready to face whatever life sends."

Robert Brault, Author

Resources

There are a number of resources that may be helpful to siblings of people with intellectual disabilities. In addition to those listed below, there are a number of books, articles and scientific studies on siblings. If you have interests beyond these, we encourage you to explore the internet.

The [National Down Syndrome Congress](#) has a toolkit for adult siblings that is designed to jump start conversations with parents about becoming more involved in their brother's or sister's life. Topic areas include social, health, home, employment, legal & financial, government benefits and resources.

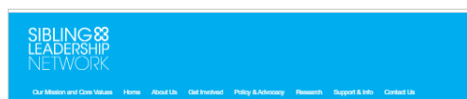


[Sibs](#) is a United Kingdom based

organization for brothers and sisters

of children and adults with disabilities. They have a number of online guides that may be helpful with topics such as:

- Talking to your parents about common sibling issues
- Thinking about the future
- The impact of challenging behavior on you: When your disabled brother's or sister's behavior is harmful or aggressive
- Top tips for adult siblings on working with care providers
- Coping with managing your disabled brother's or sister's care
- What to do if your disabled brother or sister doesn't receive the care that they should
- Adult sibling bereavement



The [Sibling Leadership Network](#) provides siblings of individuals with disabilities the information, support and tools to advocate with their brothers and sisters and to promote the issues important to them

and their entire families.



The [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.



[Sibnet](#) is the internet's oldest and biggest online community just for adult brothers and sisters. It is a remarkably caring and thoughtful community that will welcome you regardless of how

you are feeling about your sib and your family today!



[Down Syndrome and Alzheimer's/Down Syndrome Regression](#) is a Facebook support group for those caring for someone with Down syndrome and Alzheimer's disease or Down syndrome Regression.

There are more than 400 members from around the world, both family members and professionals who support them.

SUPPORT GROUP FACILITATORS CONNECTED



NDSS and the NTG are pleased to announce a collaborative effort to provide technical assistance to those who are serving adults with Down syndrome and their families. This



past summer, Jadene Ransdell reached out to a handful of individuals around the country to see if there might be an interest in sharing ideas with others who are doing similar work. The result has been promising and the group has gathered through Zoom technology to discuss what each is doing, to share resources, and to brainstorm strategies for some of the challenges found in serving people aging with Down syndrome.

We have had representation from the Down Syndrome Association of the Bay Area (California), the Down Syndrome Association of Wisconsin, the Down Syndrome Association of Greater Cincinnati, the Massachusetts Down Syndrome Congress, and local Down syndrome Alzheimer's support groups in California and New Jersey. If any of our readers are supporting adults with Down syndrome and their families and would like to join the conversations, please contact Jadene at jadeneransdellalz@gmail.com.



"I may not be able to solve all of your problems, but I promise you won't have to face them alone."

Your Tango

The greatest gift our parents ever gave us was each other.

"Being Brother & Sister means being there for each other."

The Fresh Quotes

"Siblings—The definition that comprises love, strife, competition, and forever friends."

Byron Pulsifer, Sayingimages.com

LuMind IDSC

The LuMind Foundation was founded by two families in 2004 soon after the decoding of the human genome, which opened the door to biomedical research in the field of cognition research for individuals living with Down syndrome. The mission of the organization was to stimulate biomedical research to develop treatments to improve cognition, including memory, learning and speech. It soon became the largest non-governmental source of funding in the United States for biomedical research for individuals with Down syndrome, granting to top universities including Stanford University, Hopkins University, and the University of California San Diego, among others. Prior to 2015 LuMind Foundation was known as the Down Syndrome Research and Treatment Foundation.

The International Down Syndrome Community (IDSC) began informally in 2008 when a group of moms from around the world answered a need in the Down syndrome community to provide a safe forum for parents to discuss issues ranging from prenatal testing and diagnosis to grief to medical journeys and to find peer-to-peer support and acceptance. IDSC formally merged with the LuMind RDS Foundation in 2019 and the combined organization was renamed to [LuMind IDSC Foundation](#).

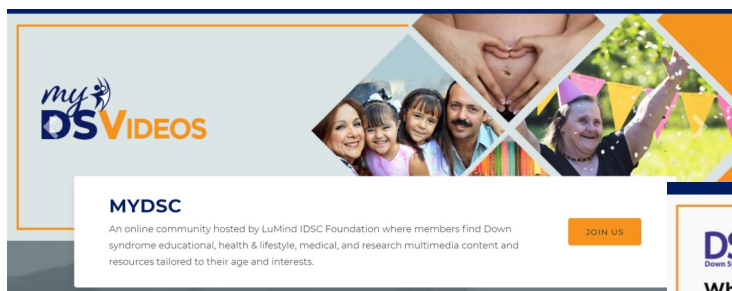
LuMind IDSC has been working hard to provide support and information to families who have loved ones of all ages with Down syndrome. They have recently unveiled two exciting opportunities for families. The first is [myDSC](#) (*my Down Syndrome Community*). Part of their mission is to empower families through education, connections, and support. *myDSC* was developed as a comprehensive, easy-to-search online library. It includes lifestyle, educational, healthcare, medical, and research information. Also included are tools for the personal goals of your loved one with Down syndrome. It is the belief of LuMind IDSC that *myDSC* provides a tailored and unique experience for caregivers and those with Down syndrome.

LuMind IDSC is also the founding philanthropic supporter of DSC2U (*Down Syndrome Clinic to You*), developed by experts from Massachusetts General Hospital and Harvard Medical School to bring the best of health and wellness information about Down syndrome to caregivers and primary care physicians around the globe. Only 5% of people with Down syndrome have access to specialty clinics, and about 200,000 do not benefit from the Down syndrome expertise of clinics like the one at Massachusetts General Hospital for Children. Dr. Brian Skotko and his team set out to change that uncomfortable reality with DSC2U.

Through Massachusetts General Hospital for \$49, families can access [DSC2U](#) once. These fees will cover the cost of expenses associated with maintaining and improving this resource. Because LuMind IDSC realizes that this cost may be prohibitive for some families, they are underwriting a portion of this cost for *myDSC* members.

When you become a charter member of [myDSC plus DSC2U](#) for \$37 you save \$12 on DSC2U.

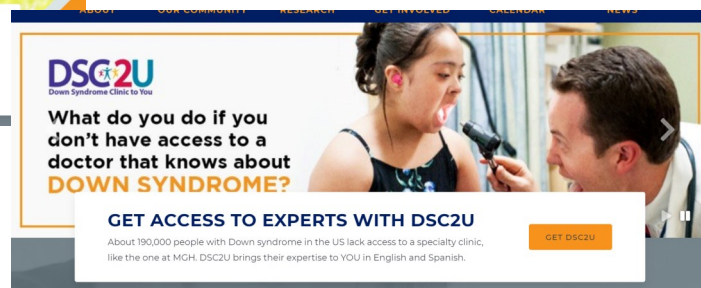
Check out these new resources. They could be game changers for many people.



myDSC VIDEOS

MYDSC
An online community hosted by LuMind IDSC Foundation where members find Down syndrome educational, health & lifestyle, medical, and research multimedia content and resources tailored to their age and interests.

[JOIN US](#)



DSC2U
Down Syndrome Clinic to You

What do you do if you don't have access to a doctor that knows about DOWN SYNDROME?

GET ACCESS TO EXPERTS WITH DSC2U
About 190,000 people with Down syndrome in the US lack access to a specialty clinic, like the one at MGH. DSC2U brings their expertise to YOU in English and Spanish.

[GET DSC2U](#)

Share Your Story

We are now accepting stories for future issues of the *NTG NDSS Caregiver News*. Feel free to contact us with your story idea. We will provide information on how to get your story to us and we are always happy to work with you to write the story you would like to share.



Write to us at ntgfamilyadvocate@gmail.com or rgrimm@ndss.org. Include "NTG NDSS Caregiver News Submission" in the subject line of your email. Below are the topics which will be the focus of upcoming newsletters. Although we welcome pieces on other subjects, primary consideration is given to articles related to these topics.

NTG NDSS CAREGIVER NEWS FOCUSED TOPICS		
ISSUE	SUBJECT	SUBMISSION DEADLINE / DISSEMINATION DATE
Winter 2020	Arts & Dementia	November 1, 2020 / December 21,2020
Spring 2021	Working with Health Care Providers	February 1, 2021 / March 21, 2021
Summer 2021	Living Healthy with Dementia	May 1, 2021 / June 21, 2021
Fall 2021	TBD	August 1, 2021 / September 21, 2021

NTG & NDSS News

The NTG has become a formally incorporated not-for-profit organization under the laws of the State of Maine. Previously, the NTG was an informal association, affiliated with the American Academy on Developmental Medicine and Dentistry. The new status will enable the NTG to expand its scope and activities as well as link more effectively to other national organizations. More information can be found on the NTG's website (www.the-ntg.org). Families and caregivers can affiliate with the NTG via its new 'associate' membership - a form to join is located on the NTG's website.

NDSS and the **NTG** will soon be collaborating with the University of Illinois at Chicago on a new CDC funded 5-year grant on Brain Health, that will focus on intellectual disability and dementia. More details will be forthcoming.

NDSS is pleased to announce that Margot Rhondeau has joined the team as a consultant in Inclusive Health and Wellness. Margot comes to NDSS with a rich background in non-profit organizations and public health programs. Please help us give Margot (the mother of a precious 2 1/2 year old daughter with Down syndrome, by the way) a warm welcome to our organization.

CONTACTS

We're on the web!

www.the-ntg.org/
www.ndss.org

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