

# new parent guide



*a collection of  
stories and tips  
for your  
new adventure*



[www.idahodownsyndrome.org](http://www.idahodownsyndrome.org)

The Treasure Valley Down Syndrome Association is a 501(c)(3) non-profit, tax-deductible organization.

# Dear new parent,

Congratulations on the birth of your baby! On behalf of the Treasure Valley Down Syndrome Association, we are excited for the adventure you are starting! This brochure provides an introductory overview about Down syndrome and a lot of it was written by other parents who were once in your shoes, or at least a similar situation.

Like all people, those with Down syndrome have a variety of talents and abilities. And, like their siblings, many people with Down syndrome graduate from high school, attend college, hold meaningful jobs, and may learn to drive or get married. All bring unique qualities into the world. With proper support, people with Down syndrome thrive from birth through adulthood and give back far more than they receive. Undoubtedly, people with Down syndrome enhance our world.

Parents of babies with Down syndrome have varying feelings and deal with it in different ways. We want you to know that no matter how you are feeling, it's okay.

One of the best examples of having a baby with Down syndrome was written by Emily Perl Kingsley. She describes it like planning a fabulous vacation trip to Italy. You buy guide books and study up on the places you want to see. You even learn some Italian phrases. And after months of eager anticipation, the flight attendant on the plane says, "Welcome to Holland." There has been a change in the flight plan and there you must stay.

Even though you're shocked and have always dreamed of going to Italy, the important thing to remember is they haven't taken you to a horrible disgusting, filthy place. It's just a different place.

*"So you must go buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.*

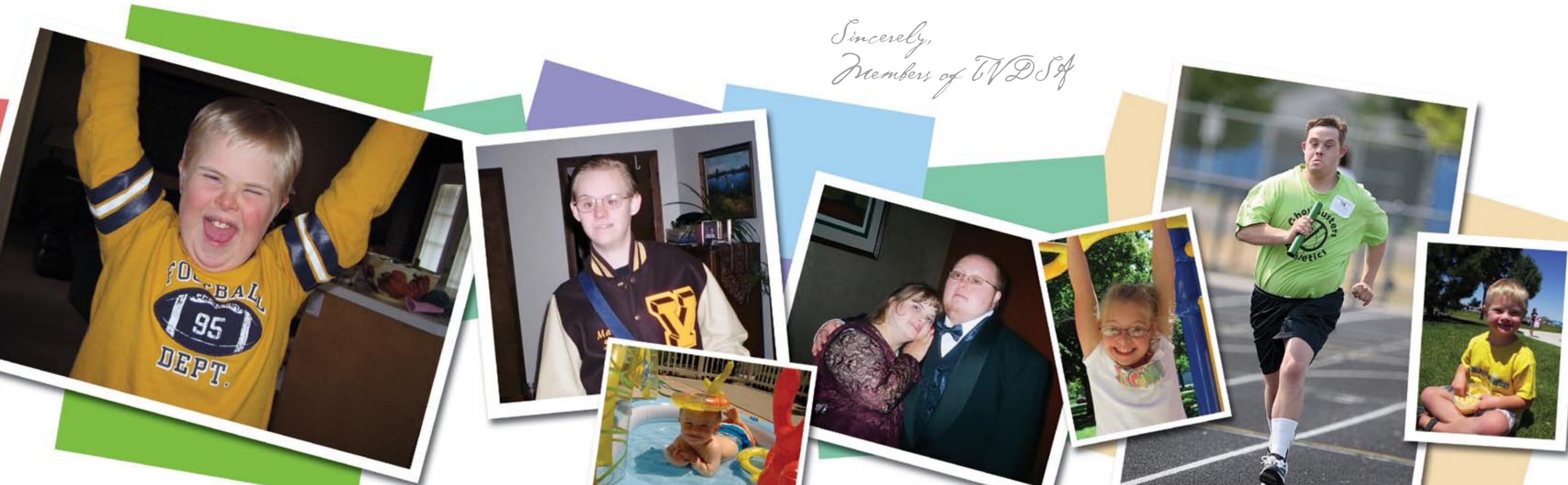
*It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you can catch your breath, you look around ... and you begin to notice that Holland has windmills ... Holland has tulips. Holland even has Rembrandts.*

*But everyone you know is busy coming and going from Italy ... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say 'Yes, that's where I was supposed to go. That's what I had planned.'*

*But ... if you spend your life mourning that fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland."*

The Treasure Valley Down Syndrome Association (TVDSA) was formed to be a helpful support for parents of children with Down syndrome. You can learn more about what we offer in the following pages. Most of all, we hope you find this booklet useful. And we look forward to meeting you and your little one soon!

*Sincerely,  
Members of TVDSA*



# Things to do when you learn your baby has but you don't need to do them all today!

- **Enjoy your baby.** Play with her, read to her, rock her, cuddle with her, talk to her, gaze at her when she's sleeping, figure out what she likes - and do it often!
- **Connect with other parents of children with Down syndrome.** Look for a Parent Group in your area. The Treasure Valley Down Syndrome Association is here for you. Visit, [www.idahodownsyndrome.org](http://www.idahodownsyndrome.org). Or for other areas, call the NDSC at 800-232-6372 to find the organization nearest to you.
- **Learn more about Down syndrome.** You've probably got lots of questions about your child's diagnosis and what it means for the future. Much information is available on the internet; some through local bookstores and libraries. Check out the copyright dates, though. Anything published before 1990, probably is out-of-date and may not be very helpful. Woodbine House Publishing ([www.woodbinehouse.com](http://www.woodbinehouse.com)) is a wonderful resource on Down syndrome, including books on developing gross motor skills, developing fine motor skills, developing communication skills, teaching reading and math, and medical and surgical concerns. There are also helpful DVD's and books for children.

## about TVDSA

The Treasure Valley Down Syndrome Association (TVDSA) was formed in 1982 by Billie Paetel and other parents of children with Down syndrome. Their goal was to provide support and share information with other families, especially new parents.

Today TVDSA continues to offer encouragement, support and valuable information through meetings, community resources, books, newsletters, events, and more. We're a volunteer-managed organization funded by community support, grants, and our annual event, the Buddy Walk.

We want all parents to have what they need to help their child with Down syndrome reach their full potential. And we want everyone to know that people with Down syndrome have wonderful talents and attributes just like everyone else! TVDSA strives to educate the community about the value and abilities of those with Down syndrome. We are passionate about promoting understanding and supportive environments.

Visit our website at [www.idahodownsyndrome.org](http://www.idahodownsyndrome.org) to become a member.



# Down syndrome...

- **Find out about early intervention programs in your area.** Every state has an Early Intervention Program for babies, from birth until the third birthday. A good source for locating your state's program is the NICHCY website: [www.nichcy.org](http://www.nichcy.org). Click on State Resources and look for Programs for Infants and Toddlers with Disabilities: Ages Birth through 2. This will help you locate the office that serves your county or area.
- **Take care of yourself.** While it's probably the last thing on your "to do" list right now, you can better care for your child if you care for yourself, too. Spend time nurturing the relationships with your partner, other family members and friends. Accept help when it's offered.
- **Connect with a health care provider familiar with Down syndrome and its unique medical issues.** You may want to supplement care provided by your current doctor or nurse practitioner or you may be looking for a new provider. Some cities are lucky enough to have a Down Syndrome Clinic, specializing in the care of babies with Down syndrome. In other cities, you may want to look for a developmental pediatrician. Many HMOs and large clinic systems have a developmental pediatrician on staff. Providers who see lots of children with Down syndrome can be a wealth of information for you and your primary physician.
- **Investigate county resources.** Check your local phonebook and look for a county department name such as Human Services, Community Services or Developmental Disabilities. Your county also may have a Web site where you can find out how to connect with a case manager. A case manager should be able to help you find services that may benefit your child and your family. A case manager can help you connect with a school district, find available community services and tell you about financial resources you may qualify to receive. Families often use these services when their children are older. It's helpful to have connections in place to use when you need them.
- **Don't be afraid to grieve.** Grieving is normal and people express it differently - sadness, tears, anger, fear, depression or withdrawal. It's okay to cry. The baby you have may not be the baby of your dreams. Many parents of children with Down syndrome feel this way. Most also learn that - eventually - they dream new dreams.
- **And again, most importantly, enjoy your baby!** Marvel at his fingers and toes, stroke the hair (or fuzz!) on his head, read Goodnight Moon again and again, watch him watching you, sing to him and give him one or two - or more! - hugs and kisses.



*Adapted from the Down Syndrome Association of Minnesota [www.dsamn.org](http://www.dsamn.org)*

# Madison Maestretti, age 11

The adventure started when our first child was born. I had a healthy pregnancy, I was young, and I had no idea that it was even possible for me to have a child with Down syndrome. But I did. It seems so bittersweet because we were so very excited and we quickly fell in love with our child, but the announcement that she had Down syndrome brought on a whole new set of feelings. We were overwhelmed, scared, and sad. I know that this is not everyone's reaction, but it truly did not mean that we loved our daughter any less. We just needed time to grieve the loss of what we were expecting, what we had read about in all of the books and what we had prepared for. We didn't bring that typical child home—we were given so much more.

Madison is now eleven and she is such a great kid. She loves French fries, going to the mall, having friends over, and listening to Hannah Montana. She enjoys school, she is in girl scouts, she volunteers in the community, she plays softball, and also takes African drumming lessons. Madison is a sister, a daughter, a classmate, a teammate, and a friend. She has taught us so many things. She reminds us what is really important in life. She has taught us to slow down and take in the scenery. Madison has taught us to work hard and celebrate every achievement (even the little ones). She has taught us to not take anything for granted. She surprises us every day.

You learn how to dream new dreams. No one knows what our children can and can't do. We can only push them, and encourage them, and surround them with people who believe in them. Anything is possible.

Early in our adventure with Madison another parent said 'You have a child with Down syndrome. You are so lucky!' They were so right.

## DOWN SYNDROME FACTS

Down syndrome is a common genetic variation which usually causes delay in physical, intellectual and language development.

*Tonya Maestretti*



*She reminds us what is really important in life.*



## *Asher Gismondi, age 2*

Our son arrived three and a half weeks early. We named him “Asher,” which means “happy,” a name we chose before he was born to signify the happiness this long-awaited child was bringing us. Little did we know, the name would take on an even greater, unexpected significance after his arrival.

Shortly after Asher’s birth, the doctor told us that she suspected he might have Down syndrome, a fact which was confirmed (after some debate among several doctors) by a blood test a few days later. The shock of this news initially knocked the wind out of us, but the fact that Asher has Down syndrome became somewhat irrelevant to us a week later, when we almost lost him. We ended up in the Pediatric ICU because Asher had become severely dehydrated and had dangerously high sodium levels—levels that, as one ER nurse put it, were “inconsistent with life.” I spent my first Mother’s Day praying that my pre-

precious child would live through the day and pleading with God to give my husband and me the privilege of raising him.

### DOWN SYNDROME FACTS

There is wide variation in mental abilities, behavior, and physical development in individuals with Down syndrome. Each individual has his/her own unique personality, capabilities, and talents.

Thankfully, Asher pulled through that trial, and two weeks later we brought him home—this time to stay. At 21 months, he behaves much like other toddlers: he is always on the go, eager to explore and curious about seemingly everything; he loves to play with his dog Tasha and most importantly, balls. He loves to flip through his books, chuckling gleefully when he comes to his favorite pages, and he loves music—music on the radio, music on television, musicals, musical toys, and even (to my surprise and delight) his mother’s singing.

True to his name, Asher is a very happy little guy, who daily melts our hearts with his sweet smiles, his cheerful chatter and squeals of delight, and his infectious laughter. Admittedly, we do still have moments when fear overwhelms us and the future seems daunting. But so much stronger than that fear is our attachment to this child; he is unequivocally the best thing in our lives and we love him to distraction. He is truly a gift (as every child is), and every day we look forward to seeing our lives transformed as we experience life from a new perspective, taking this child as our guide as we journey down this road less traveled.

*Mark and Tammy Gismondi*

*so much stronger than that fear is our attachment to this child*

# Becky Page, age 19

One of the first questions I get when someone asks about Becky is, “did I know she had Down syndrome before she was born?” And the answer is, “No.” In fact, when the nurse whisked her away, I wondered what was going on—everything seemed normal.

Soon, my doctor came back into the room and announced to me that he was pretty sure my tiny baby had Down syndrome. When they brought her back to me, she seemed normal... she looked like a baby... she acted like a baby... she cried and she wanted to eat like a baby. I had no experience with anyone with Down syndrome before, so I wasn't sure what it all meant.

Back in my room, the routine was the normal baby routine. Feeding, sleeping, and changing diapers are pretty standard even for babies with Down syndrome. When my pediatrician came in, I thought I might get an explanation of what Down syndrome would mean for my daughter and our family. I was disappointed in his explanation. Everything will be slower and we don't know how much—it varies. But he told me to take her home and treat her “normally” and we have done that ever since.

Thanks to an early visit from TVDSA, I learned about early intervention and the Idaho Department of Health & Welfare system when Becky was less than a month old. We started therapy at one month old and met the best developmental therapist there is! She taught me that Becky would be able to do things, but that she might not do them automatically like other kids. It was our job to help her to learn each step in the development toward whatever she wanted to do. We had to break down the steps into bite size pieces that Becky could learn. She taught me that early on, Becky would be able to keep up with the developmental milestones in life, but as she got older, the gap would continually widen. I also learned that Becky would be very habitual and that I wanted her to learn things right the first time and practice them right because once a pattern was set, it would be hard to break. The early intervention speech therapist helped us to do things that would help with her speech later in life. All the therapists were so beneficial to us in those early years.

## DOWN SYNDROME FACTS

In adulthood, many persons with Down syndrome hold jobs, live independently and enjoy recreational opportunities in their communities.

*She plays piano, is a green belt in Kenpo*

Becky was home schooled with “typical” kids most of her school years. She plays piano, is a green belt in Kenpo Karate, downhill skis with Special Olympics, reads and writes at about 4th grade level. She gave a speech at her graduation ceremony. To us, she's pretty normal. She thinks she's normal.

*Joyce Page*



*Karate, Downhill skis with Special Olympics*



*Baylee Fuger, age 8*

Baylee is a blessing. She can fill a room with happiness and smiles. She continually supersedes expectations both academically and in extracurricular activities. Yes there are frustrations at time (but what parent doesn't have any frustrations with their kids?) It does bother me occasionally, when people still jump to conclusions of what to expect or even want from her, as I know she can do so much more. But their subconscious labeling of what they think individuals with Down syndrome (or any other disability for that matter) can do stops them from expecting more. I have full expectations that Baylee will be a valued participant in society. What that means, time will only tell—but already, she has touched so many lives.

Yes your child will always be “different”, but all kids are different in some way. Your love starts way before you learn about the diagnosis. So don't let the diagnosis change how you feel or change the limits your child's future. Let them play football, be on the debate team, learn a foreign language, and be an Olympian (special or regular, it doesn't matter). Protect them by letting them be kids just like everyone else. Expect more from them, because they deserve to be loved and supported as if they didn't have that extra chromosome #21. It's scary (expect to feel that way at least daily), but their excitement with their achievements will be well worth it!

*Barbara and Dave Wienen*

## Telling People About Your Baby

There are lots of ways to tell people about your new baby. Many parents feel it's important to be positive and honest from the start and to introduce it the right way so that all your friends and family will too.

Here's one suggestion. After sharing the news in the usual way: name, height, weight, hair and eyes you might say, “We did also learn that our beautiful new baby has Down syndrome. We know that he/she will have some extra challenges, and we know he/she has some wonderful gifts to share. We are excited to see his/her life unfold. We will celebrate his/her life fully. We are hoping that you will be standing with us as we face the uncertainty of new challenges and uncharted waters and celebrating with us the wonder and joy that this baby brings.”

## public awareness language guidelines

**The correct name of this diagnosis is Down syndrome.** There is no apostrophe (Down). The “s” in syndrome is not capitalized (syndrome).

**An individual with Down syndrome is an individual first and foremost.** The emphasis should be on the person, not the disability. A person with Down syndrome has many other qualities and attributes that can be used to describe them. So, encourage people to use people-first language. “The person with Down syndrome”, not “the Down syndrome person.” A person with Down syndrome is not “a Downs.”

**Words can create barriers.** Recognize that a child is “a child with Down syndrome,” or that an adult is “an adult with Down syndrome.” Children with Down syndrome grow into adults with Down syndrome; they do not remain eternal children. Adults enjoy activities and companionship with other adults.

It is important to use the correct terminology. A person “has” Down syndrome, rather than “suffers from,” “is a victim of,” “is diseased with” or “afflicted by.”

**Each person has his/her own unique strengths, capabilities, and talents.** Try not to use the clichés that are so common when describing an individual with Down syndrome. To assume all people have the same characteristics or abilities is demeaning. Also, it reinforces the stereotype that “all people with Down syndrome are the same.”

**Adopt preferred language.** Because of the negative uses of the word “retard” that have become common in our society, “cognitive disability” or “intellectual disability” is preferred over “mentally retarded.” Also, “typically developing” or “typical” is preferred over “normal.”

## *Corgan Rukkari, age 4*

My daughter said “cookie” today, and I cried. It came out a little more like “guh-kee” but it was unmistakable what she wanted. Corgan is 4 1/2 years old and she has Down syndrome. Speech is the area of development where she is the most delayed. Although she signs very well, and communicates in other ways, it has been great for us to finally hear her beginning to use her voice. I used to wonder if she would ever speak at all. Before that I wondered if she would ever run or jump, walk, crawl, or even roll over. Now she does all of that so well that I have trouble keeping up with her!

Corgan was not diagnosed until after her birth. I was 23 when she was born, with no family history of genetic disorders; routine ultrasounds had revealed nothing of concern, so there was no reason for an amino. When a doctor came to our hospital room the day after Corgan was born and explained why he wanted to have blood drawn for genetic tests, I honestly believed that he was wrong. He was a young doctor, and I thought he was being overly thorough. He walked me through the “markers” that concerned him, but I was able to dismiss them all. When the test came back positive I was angry.

It really wasn't fair. I had done everything right. I didn't smoke or drink. I ate well, I exercised. There wasn't supposed to be anything wrong with my baby. I didn't know much about Down syndrome. I knew it meant that she would be a “special-ed” kid and I didn't know how I would cope with that. Corgan was my first child. I had a lot of plans for an ideal life, and this didn't seem to fit into them.

I remember talking to my little brother, Eric, on the phone during this time, when Corgan was still in the hospital. I was trying to explain to him about how unprepared I felt, and how sad it made me to wonder if she would ever achieve any of the things I had hoped for her. He was the one who pointed out to me that no child, regardless of any medical diagnoses, will ever exactly meet his parent's expectations. The best any of us can do in this life is to fulfill our own potential. And it finally hit me. There wasn't anything wrong with my child.

*She inspires me every day to try harder to realize my own potential.*

As soon as I stopped seeing her as something that had fallen short of perfection, I was able to see my daughter clearly for the first time as an individual with her own individual wants, needs, and goals to fulfill. And I finally realized that my job as her mother was to help her realize her own potential, no matter how different it may be from the life I had imagined for her.

And the really amazing thing I've come to realize as Corgan has grown is that her ability and my goals really were not all that far apart to begin with. She goes to school. She plays with her younger sister. She participates in family activities and goes with us when we travel. She may not be “functioning at her age level” but she is funny, smart, inquisitive and affectionate. She pushes boundaries, and she is consistently making progress and reaching new milestones. She inspires me every day to try harder to realize my own potential. I am lucky to know her.

*Brady Rukkari*





## Reece Weaver, age 6

We didn't do any testing during the pregnancy. Some have thought that wrong. However, when you are told during your 12-week ultrasound that you were carrying twins but only one has a heartbeat, the only thing that matters is keeping the remaining one safe. Do we regret not knowing Reece had Down syndrome until after he was born? Not for a moment. Would we go back and change anything? Not in a million years. The only time we felt sad during this was when we thought of the child we lost. There was never anything but gratitude and unwavering love towards the surviving child, and that hasn't changed one bit.

What we felt and how we are dealing with our reality doesn't make it the one right way. Just what does that mean—the right way? Does it mean that there is a wrong way? Some of you may be in shock or denial, some feeling pain or guilt, others

anger or depression—none of these is wrong. Everyone deals with life's challenges differently. While you may journey through all these stages at some point, do not despair as what will likely come next is an upturn in your mood or the start of working through all the challenges. Just as acceptance and hope for the future of that special little one being held in your arms will arrive as well—eventually.

We're not saying it won't be a hard journey at times. You may be like us and at times wonder, what the heck am I doing? How can I possibly handle one more crisis or one more well intentioned but insensitive comment without losing it? Look closely at that sweet face, as that has gotten us through times like when the specialist said "it's not like he's 'normal' so we don't need to treat aggressively" or the family member who asked "wasn't there something you could have done?"

No, your journey won't always be easy. However, we can tell you even with the rough patches on the road we have traveled, we wouldn't have missed any of it. Not one bit. Our son has given us more than we could ever have hoped for already in his short life. We are thankful every day for the chance to have him with us, and we hope you too will get to that point.

*Jay and Betty Weaver*

*Our son has given us more than*

*we could ever have hoped for*

# Growing inclusion, inspiring change

People with Down syndrome vote, pay taxes, and volunteer in places such as fire departments, offices, hospitals, schools, and churches. People with Down syndrome are accomplished writers, musicians, photographers, and poets. When people with Down syndrome are given greater opportunities, their achievements grow correspondingly.

Since more and more people with Down syndrome are included in schools, places of worship, workplaces and even television shows, many Americans are now familiar with this fairly common chromosomal variation. However, while many people know of Down syndrome, fewer know much about it. One of our goals is to change that.



## developmental aspects

Children with Down syndrome are more like other children than they are different.

During the first few months of life, a child with Down syndrome behaves like most other infants and generally needs the same care, attention and love.

- Children with Down syndrome usually are smaller than other children.
- Language, motor and intellectual development are generally delayed in children with Down syndrome.
- Most people with Down syndrome experience some degree of cognitive delay, though there is a wide spectrum of mental abilities, developmental progress and behavior in children with Down syndrome.

Source: National Down Syndrome Congress

*Matthew Wisenor, age 25*

We consider it an absolute blessing that Matthew was born with Down syndrome. He is a funny, helpful, sweet young man who we love dearly. His health is also very good and always has been. I cannot imagine our lives without him being just the way that he is. His siblings love him and are fiercely protective of him. His sister and he are especially close to each other. She waited and waited for a sibling and could not have been happier when Matthew was born. She was understanding and worked right along with me with all of his programs. She and he played and played. When his brother Patrick came along the two of them were just like twins for several years and also played and played together. I miss those times more than I can tell you.

*Barbara and Dave Wisenor*

### DOWN SYNDROME FACTS

The incidence of Down syndrome in the United States is estimated to be 1 in every 800 – 1,000 live births.

# Melody Pittard, age 19

We feel so blessed to be Melody's parents. She has brought us all such love and joy.

## DOWN SYNDROME FACTS

The exact causes of the chromosomal rearrangement and primary prevention of Down syndrome are currently unknown.

Melody just turned 19, and has become such a lovely young woman and is an inspiration to our family. This evening she helped to clean the kitchen, practiced her piano, practiced her singing and dancing, played her recorder, helped to care for her sister Jennifer who is sick, and began getting ready for bed. As you can see, she is very ambitious. Melody just came into the room and said, "I love you Mom", and gave me a big hug. We all wouldn't know what to do without our Melody hugs.

Nineteen years ago I cradled our precious baby Melody in my arms, not knowing what the future would bring her and praying that we would know how to guide and help her. I did not see all those years ago, all that she would accomplish but we had high hopes and dreams for her.

Today Melody is a high school senior and a very friendly and talented young woman. She has wonderful friends and teachers who include her. Melody is a beautiful dancer and will entertain you at the slightest invitation. She played with the Vallivue Marching Band for four years! It was amazing to see her playing her Conga Drum at the District III Marching Band competition at the BSU Stadium!

*Our special kids can accomplish their dreams!*

Melody sings in the concert choir, sang a solo for the High School Solo Festival, and participated in the chorus of their High School Musical, "You're a Good Man Charlie Brown." She is active in her church youth group, recently being honored for earning her young woman recognition award. Melody is often asked to lead the music for various church functions. She also alpine skis with the Special Olympics and is taking piano lessons. Recently, she was even a guest speaker with her sister for an elementary school.

Melody loves her family, she loves life, and we love her! She has great plans for her future! Our special kids can accomplish their dreams!

*Bruce and Brenda Pittard*





## *Liam Murphy, age 4*

I was not upset to learn that Liam has Down syndrome. In fact, my husband and I had talked about that possibility while I was pregnant; we agreed that it would not bother us.

While I was not upset that Liam has Down syndrome, I sure was upset by other things. I realized soon after he was born that he might not be able to breastfeed successfully. This possibility had me in tears. How could I connect with him? Wouldn't I feel like I was babysitting someone else's child? I don't even know how to take care of a baby without breastfeeding! I am so very grateful that, over the course of several weeks, Liam and I did learn to breastfeed together. What looked like inability at the time was really just a longer road to learning.

Liam was also born with Hirschsprung's disease. In order to live, he needed to have ten centimeters of his colon removed. He was transferred to the NICU while I was discharged to go home. I cried quite a bit about this. Actually, I still get tears when I remember this part.

Once Liam was home, the next few weeks were wild and exhausting. Every three hours round the clock I dilated Liam's non-functioning colon, tried to breastfeed (often unsuccessfully), pumped my milk, and put the pumped milk into his NG tube. After his surgery, everything was easier. His colon worked, and he began nursing better and better. Pretty soon I didn't have to pump or use the NG tube. During those weeks it seemed we were stuck in the midst of a huge storm. But it didn't last very long, and we were on our way.

My 14-year-old daughter told me something just two months ago. On the day Liam was born, our other children were in the room when the doctor came in and said he thought Liam had Down syndrome. This daughter, age nine at the time, leaned over and asked her older sister, who was 16, "Is that a problem?" The older one replied, "No, that's not a problem."

She was right. Liam is engaging, fun, interesting, enthusiastic, lovable, and loving. Yes, he has an intellectual disability. But this does not diminish him in any way. When he learns something new, we beam with joy. The process of learning is exciting for Liam. Watching him learn is exciting for us. The speed of his learning is not an issue.

*I am certain that we are better people because we have Liam in our lives.*

Recently, I came across notes I had jotted down in 2004 a few months before Liam was born. On it I had written three goals I have in raising children: 1) that our children would become model citizens who contribute to society according to their ability, 2) that our children would know that they are deeply loved, and 3) that our children would, at the end of their lives, be fit for heaven. Down syndrome does not interfere with any of these goals. And I am certain that we are better people because we have Liam in our lives.

*Jay and Betty Weaver*

# Resources

## National Resources

The following organizations can answer many of your questions, offer support and refer you to resources:

**National Down Syndrome Society (NDSS)**

800-221-4602 or [www.ndss.org](http://www.ndss.org)

**National Down Syndrome Congress (NDSC)**

800-232-6372 or [www.ndscenter.org](http://www.ndscenter.org)

Ask your doctor about important health screenings at different ages. Clinical guidelines can be found at the following medical professional association websites:

**American Academy of Pediatrics**

[www.aap.org](http://www.aap.org)

**American Academy of Family Physicians**

[www.familydoctor.org](http://www.familydoctor.org)

## Local Disabilities Groups and Resources

**Treasure Valley Down Syndrome Association (TVDSA)**

[www.idahodownsyndrome.org](http://www.idahodownsyndrome.org)

**Idaho Parents Unlimited, Inc. (IPUL)**

IPUL is a statewide organization which works to train and inform parents of children with disabilities in a multitude of areas. They also work to empower and engage people with disabilities through various opportunities. Other programs help to sustain the health and well-being of Idaho families that include a child with special needs.

208-342-5884, 1-800-242-IPUL or [www.ipulidaho.org](http://www.ipulidaho.org)

**The Arc**

The Arc believes that individuals with disabilities should be given every opportunity to achieve their goals and to become actively-involved community members in all facets of their lives. They support this effort by providing services, such as developmental therapy, recreation, rehabilitation, and residential care, which increase individual skills.

208-343-5583 or [www.thearcinc.org](http://www.thearcinc.org)

**Idaho Families of Adults with Disabilities (IFAD)**

IFAD is an independent group of families supporting all of Idaho. Their mission is to provide either formal or informal natural supports for Idaho's adult citizens with disabilities and a source of accurate information and peer support.

[www.ifad.us](http://www.ifad.us)

**The Idaho Council on Developmental Disabilities (ICDD)**

ICDD was created by federal and state law to advocate for Idahoans with developmental disabilities to assure that they have access to needed community supports, individualized services and other forms of assistance that promote self-determination, independence, productivity, and inclusion in Idaho communities.

208-334-2178 or 1-800-544-2433

[www.icdd.idaho.gov](http://www.icdd.idaho.gov)

**Comprehensive Advocacy, Inc. (Co-Ad)**

Co-Ad is a private non-profit legal services organization designated by the Governor as the Protection and Advocacy System for the State of Idaho. Founded in 1977, Co-Ad is the only legal rights organization in Idaho exclusively for people with disabilities.

1-866-COADINC or <http://users.moscow.com/co-ad>

**2-1-1 Idaho CareLine**

The 2-1-1 Idaho CareLine, a program of the Department of Health and Welfare, is a free statewide community information and referral service. They have a comprehensive database with programs that offer free or low-cost health and human services. Dial 2-1-1 or 1-800-926-2588 to reach a customer service specialist.

[www.211.idaho.gov](http://www.211.idaho.gov)

**Special Olympics Idaho**

Special Olympics is an international nonprofit organization dedicated to empowering individuals with intellectual disabilities to become physically fit, productive, and respected members of society through sports training and competition.

208-323-0482 or [www.idso.org](http://www.idso.org)

### DOWN SYNDROME FACTS

Down syndrome is one of the leading clinical causes of cognitive delay in the world—it is not related to race, nationality, religion, or socio-economic status.

# Resources

## Infant Toddler Program

The Infant Toddler Program helps children from birth to age three who have a developmental delay. The Infant Toddler Program is available statewide and provides a variety of therapeutic, educational and supportive services to help both the child and his or her family. Services are provided as early as possible in the child's life. All services are free to families. The program is supported by federal and state law.

<http://healthandwelfare.idaho.gov/Children/InfantToddlerProgram/tabid/78/Default.aspx>

## Katie Beckett Medicaid Program

Katie Beckett Medicaid enables developmentally disabled children to be cared for at home and be eligible for Medicaid based on the disabled child's income and assets alone. Without the waiver, the income of legally liable relatives is counted when the individual is cared for at home. This program enables children with special health care needs or disabilities to be cared for at home instead of in an institution. Only the child's income and resources are used in determining financial eligibility. The cost of care at home compared to the cost in an institutional setting is also used in determining eligibility.

Find out about applying for Katie Beckett Medicaid by contacting the Idaho Department of Health and Welfare or by calling 2-1-1. For tips on applying for Katie Beckett contact A New Leaf at 939-3888.

## Recommended Books and Videos

### Books

Soper, Kathryn Lynard. *Gifts*. Segullah Group, Inc. 2007.

Bruni, Maryanne. *Fine Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals*. Bethesda, MD: Woodbine House. 1998.

Kumin, Libby. *Early Communication Skills in Children with Down Syndrome*. Bethesda, MD: Woodbine House. 2003.

Schwartz, Sue. *The New Language of Toys: Teaching Communication Skills to Children with Special Needs*. Bethesda, MD: Woodbine House. 2004 (3rd Edition).

Skallerup, Susan (Ed.). *Babies With Down Syndrome: A New Parents Guide*. Bethesda, MD: Woodbine House. 2008 (3rd Edition).

Winders, Patricia C. *Gross Motor Skills in Children with Down Syndrome: A Guide for Parents and Professionals*. Bethesda, MD: Woodbine House. 1997.

(Woodbine House is a publisher specializing in books about children with special needs. Their contact information is: 6510 Bells Mill Road, Bethesda, MD 20817; [www.woodbinehouse.com](http://www.woodbinehouse.com); 800-843-7323.)

### Videos

*Down Syndrome, The First 18 Months*. 2003. Featuring interviews with international experts on Down syndrome. Run time 108 minutes. Directed by Will Schermerhorn, Blueberry Shoes Productions, LLC. 703-338-1776. [www.blueberryshoes.com](http://www.blueberryshoes.com).

*Journey of a Lifetime... Beginning with the End in Mind*. 1998. Hosted by Karen Gaffney, this video emphasizes the importance of early intervention. Includes discussions with professionals and family members. Run time 1 hour. The Karen Gaffney Foundation, 815 N.W. 13th Avenue, Portland, OR 97209. 503-973-5130. [www.karengaffneyfoundation.com](http://www.karengaffneyfoundation.com).

## DOWN SYNDROME FACTS

Of all children born in this country annually, approximately 5,000 will have Down syndrome.

