

**:Down
Syndrome
Association
of Minnesota**



**There's promise
and potential
in every moment.
Especially this one.**

**Down Syndrome Association
of Minnesota New Parents' Guide**

**Whatever you feel at
this moment is a-ok.**

Joy. Uncertainty. Anticipation. Worry.
Or, most likely, a combination of all of the above.

We're here to help, offering access to trained staff, community experts, and connections to parents who've been in your shoes and walked this exact same path.

Because we—and everyone we connect you with—want you to know that you and your family will be ok. In fact, better than ok—because you're joining a community of caring, happy, thriving families who will walk by your side, every step of the way.

In the following pages, you'll find some basic information and resources for deeper research. Plus all the ways that the Down Syndrome Association of Minnesota can connect you with the right people, right when you need them.

Our mission: To empower individuals and families, to create community, and to celebrate the abilities of people with Down syndrome.

Welcome. We're so happy you're here.



:DSAMn



Understanding Down Syndrome

A quick search online will give you plenty of information about Down syndrome—but we'll review the basics here.

Down syndrome is a genetic condition caused when abnormal cell division results in an extra full (or partial) copy of chromosome 21¹. Because of this, your baby's development and physical features are different, including intellectual disability and developmental delays. How much and what kind can be different from person to person.

Down syndrome is not a disease. It's a syndrome, meaning it's a combination of traits and conditions that typically exist in people who have this extra chromosome (a condition known as a trisomy). The physical features and medical needs can vary widely, but people with Down syndrome often have low muscle tone, small stature and have increased risk for certain medical conditions. Some kids with Down syndrome need a lot of medical attention, while others don't need all that much at all.

Nothing you did, or didn't do, caused your baby to be born with Down syndrome. There are no known behavior or environmental factors that cause Down syndrome. Down syndrome is the most common chromosomal condition occurring across all races, nationalities, and socioeconomic classes. In Minnesota, about one of every 575 children is born with Down syndrome, about 120 babies per year.²

Your biggest question may be: what does the future hold? No two kids with Down syndrome are the same. Your child may grow and develop at a different pace than other children, and may be slower to hit milestones—but they will hit them. If you ask parents of children with Down syndrome, they'll tell you that their kids attend school, pursue interests like sports, arts, and music; and make plans for their adult lives, just like every other child.

¹ Mayo Clinic

² Minnesota Department of Health and Minnesota State Demographic Center, 2018 Data



Pregnant with a child with Down syndrome?

The first thing to know: It's going to be ok.

We're here with the most valuable resource of all: the opportunity to connect with other parents who have been right where you are at this moment. Call or text our dedicated parent line at **651-231-8932** or send a note to dsamn@dsamn.org. And above all, remember that every question is ok, every emotion is ok, and help is here for everything that comes next.

What do my test results mean?

There's no way to know exactly what the future holds for your child. But you can anticipate that your child will need some special care, from specific healthcare considerations to educational plans for different ways of learning. And while children with Down syndrome need extra support, an increasing number grow up to live independent and semi-independent lives.

Will having a baby with Down syndrome change my pregnancy?

There are some medical concerns to watch for/monitor when you're pregnant with a baby that has Down syndrome, so ask your prenatal caregivers all the questions you have, starting conversations that will help you prepare for your baby's arrival. Other than that, assuming you are healthy, gather information and discuss options with friends and family, and focus on enjoying your pregnancy!

What resources do you recommend as I get ready for my baby's arrival?

In addition to the person-to-person connections that we offer (see page 10), you can also check out upcoming events, gatherings and groups on pages 13-16. Everyone is welcome, regardless of their stage of parenting, and all offer the chance to learn more and meet families like yours. And there are even more resources available for you to check out at www.dsamn.org



Did you recently welcome a child with Down syndrome?

The first thing we want to say: Congratulations.
The second thing: However you feel right now is just fine.

You're embarking on a journey of discovery, for you as a parent, for your family as a unit, and for your child as they grow, learn and thrive. We're here to help every step of the way, ready for your call or text at **651-231-8932** or email at dsamn@dsamn.org. Ask a question, tell us about yourself, introduce us to your new baby, and let us share what we know—and who we know—to make everything a little easier to take on.

How can I connect with other families like mine?

First, reach out to our organization. Our staff is specially trained to make one-to-one matches with other families in similar situations as yours, plus they are deeply familiar with the programs and resources available throughout Minnesota.

What does my path forward look like?

While every family's experience is different, you can expect to partner with health care providers and experts in Down syndrome to support your child in every way. By talking with our staff plus parents who have been in a similar situation, you can start to understand the challenges you may face in each stage—as well as the rewards and joys.

What resources do you recommend as I raise my child?

Start by visiting our website at www.dsamn.org to see online information that you can use to better understand right now as well as what's ahead. In addition to the person-to-person connections that we offer (see page 10), you can also check out upcoming events, gatherings and groups on pages 13-16. We also have a library of resources at our offices and can guide you to the magazines and books that we happily lend to families as they need them.



Connect with life-changing resources.

The prospect of raising a child with Down syndrome can feel overwhelming—like you're having to figure out everything all alone.

But the truth is, thousands of Minnesotans have been where you are right now, and there are resources, experts and friends ready to help.



Reach Out Through the Parent Talk-and-Text Line

A valuable resource for both expectant and new parents, our Talk-and-Text number is here for you, 24/7. Simply reach out to us at **651-231-8932** with a question or a need, and a staff member will respond ASAP.



Connect With—and Through—Our Staff

Providing support, assistance and referrals, our specially trained Parent Connectors are your first stop for any question. Ready with well-researched, culturally responsive resources, your Family Connector is here to:

- Introduce you to another parent or caregiver
- Provide information and support
- Identify programs and community organizations and resources that will be the most helpful to your immediate needs



Additional Down Syndrome Association of Minnesota Resources

The more you learn, the more questions you'll have. It's why the Down Syndrome Association of Minnesota was founded. We're here to help in any way: visit dsamn.org for links to a plethora of information and resources, email us at dsamn@dsamn.org or call our main office at **651-603-0720**.

“Noah and David are like any other pair of siblings. They love playing with toys together, wrestling, giving each other hugs and kisses, and making one another laugh. To Noah, David is just his little brother, his buddy and his best friend!”

—David's mom





Join the Community

The Down Syndrome Association of Minnesota is all about connections—bringing together individuals and families, parents and experts, grandparents and caregivers, all to share information, understand experiences and create better futures.

New Family Breakfasts

We regularly host New Family Breakfasts for parents, grandparents, extended family and friends of just-born babies with Down syndrome. Held in person at our office in St. Paul and via Zoom for families outside of the metro; it's a chance to meet other new families, mingle with our staff, or meet members of our Board of Directors—all people who've walked in your shoes or have special expertise they're willing to share. Check dsamn.org/events to see when the next breakfast is scheduled and to RSVP.

**Meet families
like yours**



Parent Opportunities

Currently, there are DSAMN parent support groups in nearly every community across Minnesota as well as specialty support groups for grandparents, siblings, and Latinx and Somali families. In addition, we offer ways to connect with other parents across the state online. Our staff can match you with other parents who've walked ahead of you for deeper one-on-one relationships. Our parent and family events are also great ways to build your support network. See our website for more information and to get started.

**Connect with
support and
friendship**

Peer Opportunities

As your child grows, you'll want to explore ways to help them socialize and learn next to other kids with Down syndrome. See our website for age-organized resources, from camps to educational support, ongoing programs to adult-transition opportunities.

**Help your
child find
their circle**





Always Learning, Always Growing

Part of the Down Syndrome Association of Minnesota's mission in empowering individuals and families is to make sure everyone has access to experts in child development as well as particular needs of people with Down syndrome.

Online Resources and Webinars

In addition to our calendar of events, dsamn.org offers a wide-ranging array of resources, including links to information and partner organizations for every stage of a child's development (even into adulthood).

Events that Create Connections

We host events and conferences throughout the year to give parents and families access to trusted information, and the opportunity to stay tapped into the most up-to-date research.

Check dsamn.org for our video archives of previous events and online webinars—and if you don't see a topic area or resource you're interested in, just reach out to us to see if there's another way to access the information.

Discussion Groups

DSAMN hosts two Facebook discussion groups for family members and friends of people with Down syndrome: [The Down Syndrome Association of MN Discussion Group](#) and the [Minnesota Moms with Children with Down Syndrome \(Five and Under\)](#).

Additional Reading

This guide is just a start. When you're ready for more information, we suggest the following books from downsyndromepregnancy.org, a program administered by the National Center for Prenatal and Postnatal Resources.

For those receiving a prenatal diagnosis:

Diagnosis to Delivery: A Pregnant Mother's Guide to Down Syndrome

For those receiving a birth diagnosis:

Welcoming a Newborn with Down Syndrome: A New Parent's Guide to the First Month

The Down Syndrome Association of Minnesota includes these books with our materials for parents and providers. If you have not received one, we will happily provide you with complimentary copies.

“ She said, ‘Ask me
anything you want.
No judgements.’
And literally at that
moment, I felt like a
rock was lifted off
my chest.”

—Tallulah's mom





More About Us

Our mission is to empower individuals and families, create community, and celebrate the abilities of people with Down syndrome, helping each one achieve their fullest potential in an accepting and inclusive society.

From the first days through a lifetime.

We support school, employment, and community opportunities as well as early childhood interventions, therapies, and a more proactive stance regarding medical care—all leading to a dramatic increase in quality of life and life expectancy.

The Down Syndrome Association of Minnesota is with individuals and families every step of the way, **with free membership that is open to all.**

"We found out our son would be born with Down syndrome at about 13–14 weeks and most of the pregnancy was spent worrying, fighting, and grieving. I don't want to discount that part of our story. It's important to our family's history. It makes where we are today so much sweeter. The stages that whizzed by with my other kids are savored with this one. Being his mom is a gift. He has given me a confidence that I've never had before and a community I never knew I longed for."

Sarah Curfman • DSAMN Executive Director and Mom to Felix, age 3 (pictured at right).

We had a birth diagnosis with our son, Will. The sense of loss we experienced was enormous. Little did we know that the loss we felt that day would be nothing compared to all we have gained. Will brings us a daily dose of laughter, love and perspective, and for that I am forever grateful. It is simply a gift to be his mom."

Tracy Hafeman • DSAMN Program Manager and Mom to Will, age 15 (pictured at right).





Ku soo biir bulshadeena!

Ururka 'Down Syndrome Association of Minnesota' waa urur aan faa'iido doon ahayn oo gobolka oo dhan leh ujeeddadiisu tahay in la xoojiyo shakhsiyaadka iyo qoysaska, loo abuuro bulshada, loona dabaaldego awoodaha dadka qaba cilladda Down syndrome.

Waxaan tan ku samaynaa annagoo siinayna taageero, gargaar, iyo fursad shakhsiyaadka qaba cilladda Down syndrome-ka iyo qoysaskooda.

Himiladayadu waxay u tahay dhammaan dadka qaba cilladda Down syndrome-ka inay ku guuleystaan awooddooda buuxda ee bulsho aqbasho oo loo dhan yahay. Waxaa naga go'an inaan siino taageero, gargaar iyo fursad shakhsiyaadka qaba cilladda Down syndrome iyo qoysaskooda. Xubinnimadu waa u furan tahay qof walbana oo daneynaya ama xiiseynaya xoojinta, isku xirka, iyo dabaaldega shaqsiyaadka qaba cilladda Down syndrome.

Down Syndrome

Cilladda Down syndrome-ka ayaa ah xaaladda ugu badan ee hidde-sideyaasha. Waxaa sababa qayb aan caadi ahayn oo unug taasoo keenta nuqul dheeri ah oo ah koromosoomka 21aad. Cilladda Down syndrome-ka kuma dhacdo hal jinsi marka loo eego kuwa kale. Waxaa jira ilaa 4,000 oo qof oo qaba cilladda Down syndrome-ka ee Minnesota iyo in ka badan 200,000 oo ku nool Mareykanka. Koromosoomka dheeraadka ahi wuxuu saameeyaa habka uu qofku u koro, jidh ahaan iyo garasho ahaanba; iyo dadka qaba cilladda Down syndrome-ka waxay halis weyn ugu jiraan inay ku dhacaan xaalado caafimaad qaarkood. Si kastaba ha noqotee, iskuul badan oo loo dhan yahay, shaqo, iyo fursadaha bulshada iyo sidoo kale waxqabadada carruurnimada hore, daaweynta, iyo mowqifka firfircoon ee ku saabsan daryeelka caafimaadka — dhammaantood waxay keeneen koror aad u sarreeya oo xagga tayada nolosha iyo rajada nolosha ah. Ururka 'Down Syndrome Association of Minnesota' ayaa kula socda tallaabo kasta oo aad u socoto, oo leh taageero, kheyraad iyo barnaamij loogu adeegayo dadka qaba cudurka Down syndrome iyo qoysaskooda inta ay nool yihiin oo dhan.

Kheyraadka Qoysaska Soomaaliyeed
dsamn.org/Soomaaliyeed



Únete a nuestra comunidad!

La Asociación de Síndrome de Down de Minnesota es una organización estatal sin fines de lucro con la misión de empoderar a las personas y las familias, crear una comunidad y celebrar las habilidades de las personas con síndrome de Down.

Hacemos esto brindando apoyo, asistencia y oportunidades a las personas con síndrome de Down y sus familias.

Nuestra visión es que todas las personas con síndrome de Down logren su máximo potencial en una sociedad inclusiva y de aceptación.

Estamos comprometidos a brindar apoyo, asistencia y oportunidades a las personas con síndrome de Down y sus familias. La membresía es gratuita y está abierta a cualquier persona interesada o apasionada por empoderar, conectar y celebrar a las personas con síndrome de Down.

Recursos en español
dsamn.org/espanol

El Síndrome De Down

El síndrome de Down es la enfermedad genética más común. Es causada por una división celular anormal que resulta en una copia adicional del cromosoma 21. El síndrome de Down no ocurre en una raza más que en otra. Hay unas 4,000 personas con síndrome de Down en Minnesota y más de 200,000 en los Estados Unidos. El cromosoma adicional afecta la forma en que una persona se desarrolla, tanto física como cognitivamente; y las personas con síndrome de Down corren un mayor riesgo de desarrollar determinadas afecciones. Sin embargo, oportunidades escolares, laborales y comunitarias más inclusivas, así como intervenciones y terapias en la primera infancia, y una postura más proactiva con respecto a la atención médica, han llevado a un aumento dramático en la calidad de vida y la esperanza de vida. La Asociación de Síndrome de Down de Minnesota está con usted en cada paso del camino, con apoyo, recursos y programación para servir a las personas con síndrome de Down y sus familias durante toda su vida.



Koom nrog peb zej zog!

Down Syndrome Association of Minnesota yog lub xeev uas tsis yog txoj hauv kev ua haujlwm nrog lub luag haujlwm los txhawb cov tib neeg thiab cov tsev neeg, tsim lub zej zog, thiab ua kev zoo siab rau cov neeg muaj peev xwm Down syndrome.

Peb ua qhov no los ntawm kev muab kev txhawb nqa, kev pab, thiab lub sijhawm rau cov tib neeg uas muaj tus mob Down thiab lawv tsev neeg.

Kev Pab Rau Tsev Neeg Hmoob
dsamn.org/hmoob

Down Syndrome

Down syndrome yog qhov ntau ntawm kev mob caj ces. Nws tshwm sim los ntawm kev faib cov cell tsis zoo uas ua rau daim ntawv ntxiv ntawm 21st chromosome. Kev mob qis tsis tshwm sim hauv ib haiv neeg tshaj li lwm yam. Muaj txog 4,000 tus tib neeg muaj mob Down nyob hauv xeev Minnesota thiab ntau dua 200,000 hauv Tebchaws Meskas. Cov chromosome tshwj xeeb cuam tshuam txoj kev uas ib tus neeg txhim kho, ob qho tib si lub cev thiab kev xav; thiab cov neeg mob Down muaj cov kev pheej hmoos ntau ntawm kev txhim kho qee yam mob. Txawm li cas los xij, muaj ntau dua kev kawm hauv tsev kawm, kev ua haujlwm, thiab zej zog zoo li kev tiv thaiv menyuam yaus thaum ntxov, kev kho mob, thiab kev mob siab rau kev saib xyuas kev kho mob - txhua tus tau ua rau muaj kev nce qib hauv lub neej thiab lub neej nce ntxiv. Down Syndrome Association of Minnesota nyob nrog koj txhua kauj ruam ntawm txoj kev, nrog kev txhawb nqa, kev pab cuam thiab kev pab cuam pabcuam rau cov neeg mob Down syndrome thiab lawv tsev neeg thoob plaws lawv lub neej.



Join our community!

The Down Syndrome Association of Minnesota is a statewide nonprofit organization with the mission to empower individuals and families, create community, and celebrate the abilities of people with Down syndrome. We do this by providing support, assistance, and opportunity to individuals with Down syndrome and their families.

Únete a nuestra comunidad!

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Leer más en la página 25.

:Down Syndrome Association of Minnesota

656 Transfer Road, St. Paul, MN 55114

Website: dsamn.org | Phone: 651-603-0720 | Email: dsamn@dsamn.org

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Ku soo biir bulshadeena!

Ururka Minnesota Down Syndrome Association waa urur aan faa'iido doon ahayn oo ka shaqeeya gobolka oo dhan oo leh ujeedo ah in la xoojiyo shakhsiyaadka iyo qoysaska, loo abuuro bulsho, loona dabaaldego awoodaha dadka qaba cilladda Down Syndrome. Waxaan tan ku samaynaa annagoo siinayna taageero, gargaar iyo fursado dadka qaba cudurka Down syndrome iyo qoysaskooda.

Inbadan ka aqri bogga 24.

Koom nrog peb zej zog!

Minnesota Down Syndrome Association yog lub koom haum tsis koom tes thoob plaws lub xeev nrog txoj haujlwm txhawb nqa tib neeg thiab tsev neeg, tsim lub zej zog, thiab ua kev zoo siab rau cov neeg muaj peev xwm Down syndrome. Peb ua qhov no los ntawm kev muab kev txhawb nqa, kev pab thiab lub sijhawm rau cov neeg muaj mob syndrome thiab lawv tsev neeg.

**Nyeem ntxiv rau ntawm
nplooj ntawv 26.**