

Resource Directory



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



New & Expectant Parent Resources

Congratulations on the birth or expected birth of your baby! You probably have lots of questions. You may be grieving the loss of the baby you expected. You may be angry. These feelings are normal. The most important thing for you to keep in mind is that a Down syndrome diagnosis is not as “life changing” as the fact that you have a new baby. And in most ways, your baby will be just like other infants. He or she will need to be fed, held, and loved. There will be many joys in raising your baby, as well as some challenges along the way. Down syndrome is a condition your baby has, but it is not who your baby is. It’s normal to be nervous about what lies ahead.

Know that when you are ready, the DSAWM is here to support you. Many new parents have found that the single most helpful thing they did after receiving a Down syndrome diagnosis was to talk to other parents of children with Down syndrome. When you are ready, please contact our office at **616-956-3488** to speak with our staff who can help you with additional resources, information, and supports. You can also email us at director@dsawm.org.

Become a Member

DSAWM’s membership is comprised of over 350 families across 12 West Michigan counties. In addition to the outreach that we do within the community through our partnerships and advocacy initiatives, we also offer a wide variety of programming for our members from birth to adulthood. You can read more about our programs and services on our website at dsawm.org/programs. The annual \$35 membership fee is waived for new parents, so your first year of access to programs, services, and events is free to you and your family! Most importantly, as a DSAWM member you join a community of advocates and families who are all committed to the same mission: embracing Down syndrome, empowering individuals, and promoting opportunities for meaningful lives. To become a member, visit dsawm.org/join.

DSAWM Programs and Services for New & Expectant Parents

Learn more about each program by visiting dsawm.org/programs.

A Guide for New and Expectant Parents



New & Expectant Parent Gifts

DSAWM provides new and expectant parents with accurate, up-to-date, compassionate information from leading Down syndrome and medical experts in the form of our New Parent Packet. Expecting parents can also receive information explaining prenatal testing. When new babies arrive, families receive a gift celebrating their new addition. To request information, contact DSAWM at 616-956-3488 or victoria@dsawm.org for more information.

	<p>Member Financial Assistance DSAWM's Member Financial Assistance Fund is designed to provide financial support to families raising individuals with Down syndrome who need help with certain Down syndrome-related expenses including adoption, education, therapy, adaptive devices, respite, and hospital stays. To apply, visit dsawm.org/programs/financial-assistance.</p>
	<p>Oh, Baby! This baby shower for families who have a child with Down syndrome aged 5 and younger is a celebration and an opportunity for parents and siblings to connect with other families experiencing Down syndrome. Oh, Baby is held in August at the Grand Rapids Children's Museum.</p>
	<p>Parents for Parents Parents for Parents mentors are a group of "veteran" moms and dads who have stood in the shoes of new parents of babies with Down syndrome. If you are interested in being connected to a parent mentor or becoming a mentor, contact DSAWM at 616-956-3488 or director@dsawm.org.</p>
	<p>Weekly Update The Weekly Update newsletter is emailed every Thursday and shares upcoming programs and services from DSAWM and our community partners. For new parents, it is an easy way to get connected and learn about the opportunities available to you and your family. To join the mailing list, visit dsawm.org.</p>
	<p>Access! GR Through a partnership with Access! GR, DSAWM can connect members with the rich arts & cultural scene in West Michigan. Free tickets are available in a limited supply for both ongoing venues and special event venues. Accommodations can be made to make sure the arts are accessible to everyone.</p>
	<p>Holiday Party Every December, DSAWM families gather in Grand Rapids and Kalamazoo to visit with Santa and reconnect with friends. The Grand Rapids Holiday Party is a member-only event and is held at alternating venues around Grand Rapids.</p>
	<p>Member Picnic Each summer, DSAWM families gather at Tunnel Park in Holland for a day of friends, food, and fun in the sun. The Member Picnic is a member only event and is held in July.</p>
	<p>Rock Your Socks Dance Rock your socks off at our annual Rock Your Socks Dance in honor of World Down Syndrome Day (3/21). The event is open to anyone interested in celebrating Down syndrome.</p>



Step Up for Down Syndrome

Step Up for Down Syndrome is the largest Down syndrome awareness event in Michigan and DSAWM's biggest fundraiser. Families, friends, and the public are invited to this annual celebration and walk held each September where we come together to support our loved ones with Down syndrome.

Community Supports

Where to Begin

- **Supports Coordination: Early On**

Early On Michigan (1800earlyon.org or 1-800-327-5966) provides free services to families who have children (0-3) who have medical problems or are developmentally delayed. Services can include information, evaluation, linking to services, parent network, and financial help.

- **Finding a Medical Provider for Your Child's Needs**

Looking for a medical provider? The Preferred Medical Provider List is maintained by **Down Syndrome Head Start** and lists doctors, dentists, and other providers recommended by Michigan families experiencing Down syndrome. This list can be viewed at dsawm.org/resources/new-parent-resources. **Please note that Down Syndrome Head Start's website has been down as of November 2018. This list has not been updated since 2017. If you are looking for more up-to-date information, we recommend reaching out on the **Michigan Parents of Children with Down Syndrome Facebook group** at facebook.com/groups/DownSyndromeMichigan.

The Family Center for Children and Youth with Special Health Care Needs (Family Center) (michigan.gov or 1-800-359-3722) is also a helpful resource for Michigan families. The Family Center is the statewide parent-directed center within Children's Special Health Care Services (CSHCS) and the Michigan Department of Health and Human Services (MDHHS). It offers emotional support, information, and connections to community-based resources to families of children and youth with special health care needs, as well as provides parental perspectives and input on health care matters while focusing on families' access to coordinated systems of care.

- **Paying for Your Child's Healthcare Expenses: CSHCS & CSNF**

Children's Special Health Care Services (CSHCS) of Michigan (michigan.gov or 1-800-359-3722) provides low or no cost supplemental health insurance for a variety of covered medical diagnoses for individuals under 21 years old. While Down syndrome alone is not a qualifying diagnosis, CSHCS covers over 2,700 physical conditions of which many individuals with Down syndrome may experience at least one. To view a complete list of covered conditions and the contact information for each county's CSHCS branch visit michigan.gov/mdhhs.

The Children with Special Needs Fund (michigan.gov/csnfund or 517-241-7420) provides support for children ages 0-21 in Michigan with special health care needs not available through any other funding source. The Fund helps with the purchase of equipment and services that promote optimal health, mobility, and development, enhancing the lives of children and their families.

Get to Know the Community

- **Parent Support Groups**

DSAWM Parents for Parents Mentors are a group of “veteran” moms and dads who provide support for expectant and new parents. If you are interested in being connected to a parent mentor or becoming a mentor, contact DSAWM at 616-956-3488 or director@dsawm.org.

DSAWM Dads’ Night Out, or DNO, invites fathers raising children with Down syndrome to meet at local restaurants and share experience and support. Visit dsawm.org/calendar for upcoming dates or join the [Dads Facebook Page \(Dads Appreciating Down Syndrome – Grand Rapids, MI\)](#).

DSAWM Moms’ Night Out, or MNO, invites mothers raising children with Down syndrome to meet at local restaurants to share experiences and support. Gatherings are held monthly in three locations: Lakeshore (Grand Haven/Muskegon), Grand Rapids, and Kalamazoo. Visit dsawm.org/calendar for upcoming dates.

Facebook Support Groups

- **DSAWM Members and Families** (facebook.com/groups/DSAWMMembersFamilies) is a place for DSAWM members and families to connect, share resources, and give advice and support to others in the Down Syndrome Association of West Michigan community.
- **DSAWM 21 Shades** (facebook.com/groups/dsawm21shades) is open to all families of color and multicultural families who are raising or love a person with Down syndrome in West Michigan.
- **DSAWM Familias Hispanas y Latinas** (facebook.com/groups/dsawmespanol) is open to all DSAWM Hispanic and Latino families.
- **Michigan Parents of Children with Down Syndrome Facebook Group** (facebook.com/groups/DownSyndromeMichigan) is an online community for parents and caregivers in Michigan who have children with Down syndrome and other chromosomal abnormalities. Sharing experiences, asking questions, posting inspiring items, and sharing resources and news from the special needs community are all enthusiastically encouraged!

The Down Syndrome Diagnosis Network maintains a directory of online support groups for families in a variety of topic areas from feeding support to families of color to GI concerns and more. View the directory at dsdiagnosisnetwork.org/resources-for-dsdn-families.

- **National Down Syndrome Organizations**

- **Down Syndrome Diagnosis Network** (dsdiagnosisnetwork.org or 612-460-0765) connects, supports, and provides accurate information to parents – and the medical professionals who serve them – from the time of diagnosis through age 3, while fostering the opportunity for lifelong connections.
- **Down Syndrome Medical Interest Group – USA** (dsmig-usa.org) is a group of health professionals committed to promoting the optimal health care and wellness of individuals with DS across the lifespan.
- **Global Down Syndrome Foundation** (globaldownsyndrome.org or 303-321-6277) is dedicated to significantly improving the lives of people with Down syndrome through Research, Medical Care, Education and Advocacy.
- **LuMind ISD** (lumindidsc.org or 781-825-1300) accelerates research to increase availability of therapeutic, diagnostic, and medical care options and empowers families through education, connections, and support.
- **National Association for Down Syndrome** (nads.org or 630-325-9112) is the oldest organization in the country serving individuals with Down syndrome and their families.
- **National Down Syndrome Society** (ndss.org or 800-221-4602) is a leading human rights organization for all individuals with Down syndrome.
- **National Down Syndrome Congress** (ndscenter.org or 800-232-6372) is a leading national resource of support and information for anyone touched by or seeking to learn about Down syndrome.

For more information about New & Expectant Parent Resources, visit our website at dsawm.org/resources/new-parent-resources. You are welcome to contact our office with any questions at 616-956-3488 or director@dsawm.org. We are here to support your family!

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