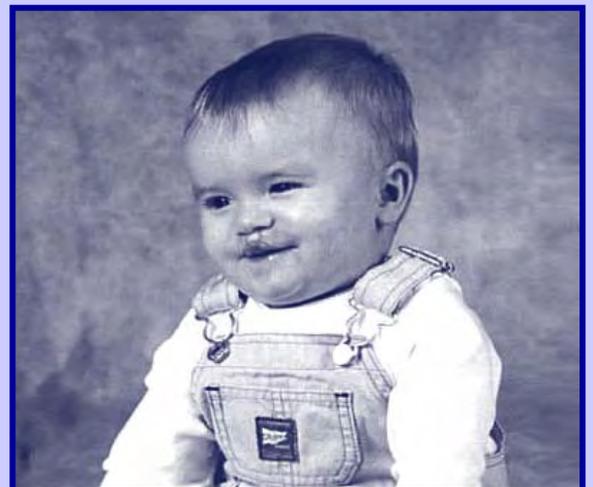
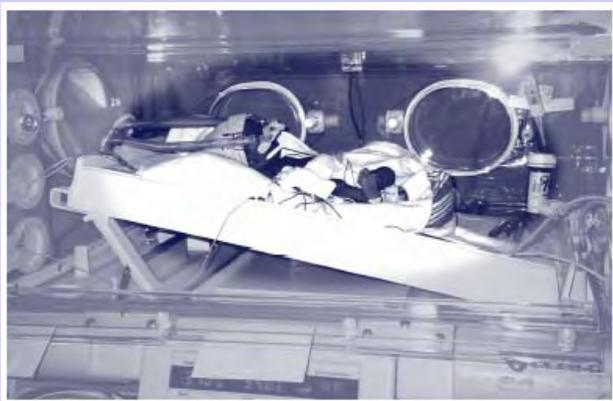


Special Care for Special Kids



A Guide for Michigan Families

From the Michigan Department of Community Health
Genetics and Birth Defects Follow-up Program



Acknowledgements

We are deeply indebted to the many parents and staff members who took the time to review and provide comments on this family guide book from its earliest stages—your patience, help, and numerous suggestions were invaluable.

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Revised 2006 by the Michigan Department of Community Health,
Genetics and Birth Defects Follow-up Program

Dear Family,

The birth of a baby is both a joyous and overwhelming experience. It is often said that *'having a child changes everything'*, but having a child with a birth defect or genetic condition brings even greater challenges. We realize that every child and family has different needs, and want to inform you about the wide range of resources and services available to help Michigan families. The purpose of this Guide is to assist you in caring for your child. You might find some of the information helpful right now, whereas other sections will be useful in the future.

Our goal is to provide general information that may assist parents of infants and children with any type of special health care need. This Guide is meant to help parents start building a 'medical home' for their child together with primary care providers and/or other community-based services. It includes information about the different types of pediatric specialties; where to find pediatric and genetic services; how to prepare for doctor visits; where to find special equipment; forms; and more. If you have not already started a care notebook to keep track of your child's health information and paperwork, we suggest using this as a way to get organized.

"Families build a 'medical home' when they connect with the medical professionals, caregivers and community to provide care to help a child thrive and remain at home."

- From a Michigan parent of a child with special needs

This Guide was created by the Genetics and Birth Defects Follow-up Program at the Michigan Department of Community Health, in collaboration with the Children's Special Health Care, Family Center for Children and Youth with Special Health Care Needs and *Early On*[®]. Medical professionals as well as parents contributed to this Guide. We have tried to pass along some of their advice and insights gained from many years of experience caring for children with special health needs. We recognize that every child is unique, and every family has different support systems available. This book is NOT intended to replace specific instructions given by your child's doctor or medical team. However, we hope you find the information useful as you start building a 'medical home' to meet your own child's special health needs.

Sincerely,

Carrie Langbo
Nancy Peeler

Mary Marin
Joan Ehrhardt

Jane Simmermon
Rosalyn Beene-Harris

Janice Bach



Preface

The **Special Care for Special Kids** Guide is organized along the theme of helping families create a 'medical home' to provide comprehensive care for a child's special needs. 'Medical home' is a way of thinking about how to organize and coordinate the many different kinds of services often needed by children with birth defects or genetic conditions. Assuring 'medical homes' for all children with special health care needs is part of the "Healthy People 2010" plan developed by the United States Department of Health and Human Services. Our patchwork quilt motif was chosen to represent the way many different resources and services can be brought together to help families meet their child's needs.

To request additional copies of the Guide, call toll-free 1-866-852-1247 or e-mail genetics@michigan.gov. It can also be downloaded free of charge from www.migeneticsconnection.org.

**Read more about
Healthy People 2010:
www.healthypeople.gov/**

**HEALTHY
PEOPLE
2010**

**Understanding and
Improving Health**



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Introduction

**“Learning as much as possible
about our children’s medical
condition has proven
invaluable.”**

- A family from Kalamazoo, MI



Birth Defect Defined

Chances are, you received this Guide and are reading it because you are a parent, family member, or care giver of a new baby or young child diagnosed with a birth defect that has or will result in special health or educational needs. **You are not alone.** Each year in Michigan about 10,000 babies are found to have a birth defect in the first two years of life.* Many more are diagnosed with some type of developmental disability after age 2.

What is a **birth defect**? It is any condition present at birth that may interfere with a child's growth and development. Birth defects may affect how the body is formed. They can also affect how parts of the body work, including the brain. Some birth defects cause problems with both learning and physical development.

The causes of many birth defects are not known. Some birth defects are caused by changes in genetic make-up and/or factors in the environment. Once a child is found to have a birth defect, special services are available to help families understand the cause of their child's health problem.

Some children born with a birth defect are later found to have a genetic "syndrome". The word **syndrome** refers to a medical condition in which one or more different features occur together. These features might include a major birth defect, minor physical traits, or problems with learning. A child with a syndrome may have many of the features or only a few. The diagnosis of a syndrome helps to alert parents and medical specialists what to watch for, based on the findings and types of problems that occur most often in other children with the same condition.

A syndrome is often recognized by **clinical findings**, based on common traits observed on a physical exam. In some cases, the physical findings are hard to recognize, so **genetic testing** will be needed to make the diagnosis. Children with a syndrome sometimes require additional support and medical treatment.

Did you know?

In the past, a syndrome was often named after the doctor who first described it. Today, thanks to better laboratory tests, the underlying cause of many syndromes has been found.

For example, Down syndrome was named after Dr. J. Down who first described it in 1866. Today, the condition is also called Trisomy 21, reflecting the cause: three copies of the #21 chromosome.

Birth defects alone can also cause significant health risks. In Michigan and across the country, birth defects are the leading cause of infant death, accounting for more than 20% of all deaths. New medical tools and treatments have allowed many babies with serious problems to survive after birth, but the risks do not necessarily end once they leave the hospital. Many children with a birth defect are able to survive to be adults, but they often need close medical attention and support to reach their full potential.

As a parent or caregiver of a child with a birth defect you are a key member of your child's health care team. You can help to ensure your child receives the medical care, support and follow-up needed after birth and throughout childhood.

*For more information on Michigan birth defect statistics, visit www.michigan.gov/mdch, click on Statistics & Reports.

Medical Home Defined

According to the American Academy of Pediatrics, a 'medical home' is **not** a building, house, or hospital, but rather an approach to providing comprehensive primary care. It is a way of thinking about the entire system of care that must be in place to meet a child's special health needs. Children and their families who have a 'medical home' receive the care that they need from a pediatric health care professional whom they trust. As your child's primary care giver, you are encouraged to act as a partner with your child's pediatric health professionals to access and coordinate the specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of your child.

Having a 'medical home' means that your child's care is:

Accessible

1. The doctor is located in your community.
2. The doctor accepts your insurance.
3. The doctor's office is accessible to those who are disabled.
4. The doctor will be available after hours or in emergencies.
5. If needed, the office is accessible by public transportation.

Family Centered

1. Your knowledge is recognized.
2. You begin to know your doctor.
3. You are recognized as the primary caregiver for your child.
4. Decision-making is shared with you.

Continuous

1. The doctor is aware of other medical consults and procedures.
2. The same doctor attempts to see your child at each visit.

Comprehensive

1. The care is given by a skilled doctor addressing all of your needs.
2. Extra scheduled time is allowed if needed.
3. Information is given to you about private and public resources.

Coordinated

1. The parents assist with developing the care plan for a child.
2. The care plan is shared with all of your child's providers.
3. Child and family are linked to support services.
4. One central record is maintained on your child.

Primary care is the regular care, such as check-ups and immunizations, needed by all babies and young children. It is especially important for children with birth defects, genetic conditions, or other special needs to have a permanent 'medical home' that coordinates primary care with the specialty care and services they often need.

Compassionate

1. The doctor expresses concern for your child's well being.
2. The care is given in an empathetic manner.

Culturally Effective

1. Your cultural beliefs are recognized and involved in the care plan.
2. Your doctor calls for an interpreter when needed.
3. You are given written materials in a language understood.

Learn more about 'Medical Home':

American Academy of Pediatrics

www.medicalhomeinfo.org, click on Tools/Resources for Families

The National Center for Medical Home Initiatives for Children with Special Needs

- Tools for Families
- Tips for Families
- The benefits of a 'medical home'
- Parents as partners in the 'medical home'
- Brochures and presentations for families

Building Early Intervention Partnerships with Your Child's Doctor: Tips from and for Parents

is a brochure from the Washington State, Department of Health and Social Services. Download from **www.medicalhome.org/4Download/tips_english.pdf** Also in other languages at **www.medicalhome.org/leadership/brochures.cfm**

Medical Homes in Michigan

www.medicalhomeinfo.org/states/state/michigan.html

- Information about events in Michigan to improve access to 'medical homes' for children with special health care needs. Michigan Medical Home Contact Person information provided.

The Center for Children with Special Needs

www.cshcn.org/resources/medicalhome.cfm

- A tool kit from Washington State that helps primary care providers, health professionals and medical office staff work together with families of children with special needs.

Health Care Rights & Responsibilities

As care giver for a child with extra health needs, you will be dealing with the health care delivery system, possibly for the first time or to a greater extent than in the past. It may help you to know that a **Consumer Bill of Rights and Responsibilities** was approved in 1998 by the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry. The information in that document has been used as a framework by many health care provider practices. To help you better understand and advocate for your child in relation to the Consumer Bill of Rights and Responsibilities, the following guiding principles have been adapted* and presented below.

Your Health Care Rights*

- 1. Information Disclosure.** You have the right to receive accurate, easily understood information about your [child's] health plan, professionals, and care facilities. You can receive additional help if you do not understand any information given to you so that you can make informed health care decisions for yourself or your children.
- 2. Choice of Providers and Plans.** You have the right to choose health care providers [for your child] that will help you to make sure that you have access to appropriate (*the right kind of*) high-quality health care.
- 3. Access to Emergency Services.** You have the right to access emergency health care services [for your child] when and where the need arises in the event of severe pain, an injury or sudden illness that would put your [child's] health in danger.
- 4. Participation in Treatment Decisions.** You have the right and responsibility to take part in all decisions related to [your child's] health care. If you are unable to take part, then you have the right to have someone (parents, guardians, family members) else represent your interests.
- 5. Respect and Nondiscrimination.** You and your child have the right to considerate, respectful, and nondiscriminatory care from all members of the health care system.
- 6. Confidentiality of Health Information.** You have the right to communicate (written or verbally) with your health care provider in private and to have your [child's] health information kept private. You have the right to review and have a copy of any medical records. You also have the right to request changes to your [child's] medical record.
- 7. Complaints and Appeals.** You have the right to a fair, timely, and objective review of any problem you have with your [child's] health care provider. This may include complaints about how you were treated by health care personnel, waiting times, or the level of quality of a health care facility.

And Responsibilities*

1. Practice healthy habits in your environment such as exercising and eating a healthy diet, *and help your child to have healthy habits too.*
2. Take part in specific health care decisions [for your child].
3. Work with your [child's] health care providers in forming and carrying out a treatment plan.
4. Tell your [child's] health care provider relevant information about what you [and your child] need and want.
5. If you have a problem, use the internal system to address an issue.
6. Practice safe behaviors that will not spread disease.
7. Recognize that there are risks and limits of the practice of medicine and humanity.
8. Know what your health care plan covers.
9. Show respect for others and health workers.
10. Make a good faith effort to meet the cost of services.

*Adapted from www.hcqualitycommission.gov/final/append_a.html.



Accessible Care

"It's so important to find a doctor in your community that accepts your insurance and is aware of your child's special needs. Having this information and a plan in place for after hour care will make sure you are ready to face any medical emergencies with your child."
- A family from Royal Oak, MI



Finding Pediatric Specialty Clinics

Many children with birth defects require care from specialists in university-based or other large medical centers. These centers are also called “tertiary” care or regional pediatric centers. This directory is for informational purposes only and listing of any particular health system does not represent endorsement by the Michigan Department of Community Health. Rather, it is meant to give you an idea of the types of specialty services available and where they are located. You can read more about the different types of pediatric specialists on page 34 in the section titled “Continuous Care”. Because of the large number and changing nature of specialty clinics, this list may not be complete. Ask your child’s care providers, or contact the hospital nearest you for complete and up-to-date information on their services.

	Behavior/Developmental	Cardiology	Communication	Dental & Oral Surgery	Dermatology	Endocrine & Diabetes	Fetal Alcohol Syndrome	Gastroenterology	Genetics	Hematology/ Oncology/ Hemophilia	Immunology (Allergy)	Metabolic	Myelodysplasia	Nephrology	Neurology/ Neurosurgery	Ophthalmology	Orthopedics	Physical & Occupational Therapy	Plastic & reconstructive surgery (craniofacial)	Psychiatric Services	Pulmonology	Urology
CENTRAL MICHIGAN																						
Sparrow Health System 1215 E. Michigan Ave. Lansing, MI 48912 517-364-1000 www.sparrow.org/childrenscenter/	X	X				X		X	X	X	X		X	X	X	X	X	X	X		X	X
EASTERN MICHIGAN																						
Covenant Healthcare System 700 Cooper Saginaw, MI 48602 989-771-6000 www.covenanthealthcare.com						X									X				X			

	Behavior/Developmental	Cardiology	Communication	Dental & Oral Surgery	Dermatology	Endocrine & Diabetes	Fetal Alcohol Syndrome	Gastroenterology	Genetics	Hematology/ Oncology/ Hemophilia	Immunology (Allergy)	Metabolic	Myelodysplasia	Nephrology	Neurology/ Neurosurgery	Ophthalmology	Orthopedics	Physical & Occupational Therapy	Plastic & reconstructive surgery (craniofacial)	Psychiatric Services	Pulmonology	Urology	
Genesys 1 Genesys Parkway Grand Blanc, MI 48439 810-606-5000 www.genesys.org		X				X		X							X								
Hurley Medical Center One Hurley Plaza Flint, MI 48503 810-257-9000 or 800-336-8999 www.hurleymc.com/		X				X				X													
NORTHERN MICHIGAN																							
Munson Medical Center 1105 Sixth Street Traverse City, MI 49684 231-935-5000 www.munsonhealthcare.org	X	X				X			X	X	X								X				
SOUTHEASTERN MICHIGAN																							
Children's Hospital of Michigan 3901 Beaubien Detroit, MI 48201 888-DMC-2500 www.chmkids.org	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

	Behavior/Developmental	Cardiology	Communication	Dental & Oral Surgery	Dermatology	Endocrine & Diabetes	Fetal Alcohol Syndrome	Gastroenterology	Genetics	Hematology/ Oncology/ Hemophilia	Immunology (Allergy)	Metabolic	Myelodysplasia	Nephrology	Neurology/ Neurosurgery	Ophthalmology	Orthopedics	Physical & Occupational Therapy	Plastic & reconstructive surgery (craniofacial)	Psychiatric Services	Pulmonology	Urology	
Henry Ford Hospital 2799 W. Grand Blvd. Detroit, MI 48202-2689 313-876-2192 www.henryfordhealth.org	X	X	X		X				X		X			X	X	X	X		X				X
Oakwood Hospital 18101 Oakwood Blvd. Dearborn, MI 48123-2500 313-593-7000 www.oakwood.org	X		X												X			X					
Providence Hospital 16001 West Nine Mile Southfield, MI 48075 248-849-3000 www.providence-hospital.org			X															X	X				
University of Michigan C.S. Mott Children's Hospital 1500 E. Medical Center Ann Arbor, MI 48109-0286 734-936-4000 www.med.umich.edu/mott/	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X

	Behavior/Developmental	Cardiology	Communication	Dental & Oral Surgery	Dermatology	Endocrine & Diabetes	Fetal Alcohol Syndrome	Gastroenterology	Genetics	Hematology/ Oncology/ Hemophilia	Immunology (Allergy)	Metabolic	Myelodysplasia	Nephrology	Neurology/ Neurosurgery	Ophthalmology	Orthopedics	Physical & Occupational Therapy	Plastic & reconstructive surgery (craniofacial)	Psychiatric Services	Pulmonology	Urology
William Beaumont Hospital 3601 W. Thirteen Mile Rd. Royal Oak, MI 48073-6769 248-577-9270 www.beaumont-hospitals.com	X	X	X			X		X	X	X					X		X	X			X	X
SOUTHWESTERN MICHIGAN																						
Bronson Health Care 601 John Street Kalamazoo, MI 49007 269-341-7654 www.bronsonhealth.com		X						X		X			X	X	X		X		X			
UPPER PENINSULA																						
Marquette General Hospital 580 W. College Ave. Marquette, MI 49855 800-562-9753 ext. 4777 www.mgh.org		X					X		X	X					X				X		X	
WESTERN MICHIGAN																						
Spectrum Health DeVos Children's Hospital 100 Michigan St., NE Grand Rapids, MI 49506 616-774-7444 www.devoschildrens.org/	X	X		X	X	X	X	X	X	X	X			X	X	X	X	X	X	X	X	X

Finding Genetic Services

Many families find a genetics clinic appointment helpful. Genetic services may include a diagnostic work-up, testing if needed, and counseling to discuss the nature of a child's condition. Genetic counseling may also include a discussion of inheritance and the chance of recurrence in other children or relatives. Information on available resources and support groups is usually provided. More information about genetics is included in the back of this book. Listing in this directory is for informational purposes only and does not represent an endorsement by the Michigan Department of Community Health.

Centers offer a variety of clinics including pediatric, reproductive and adult services	Satellite or outreach sites?
STATE GENETIC CENTERS	
Ann Arbor	
<p>University of Michigan Health System (UM) 1500 E. Medical Center Dr. Ann Arbor, MI 48109-0318 www.med.umich.edu</p> <ul style="list-style-type: none"> • <i>Breast & Ovarian Cancer Risk Evaluation Program 734-764-2248</i> • <i>Medical Genetics Clinic- Adult and Cancer 734-763-2532</i> • <i>Inherited Retinal and Macular Degeneration 734-936-8173</i> • <i>Neurogenetic Disorders Clinic 734-936-8173</i> • <i>Pediatric Genetics Clinic- includes biochemical genetics 734-764-0579</i> • <i>Perinatal Assessment Center 734-764-6834</i> 	Y E S
Dearborn	
<p>Oakwood Hospital 18181 Oakwood Blvd. Dearborn, MI 48124 313-593-8483 www.oakwood.org</p>	
Detroit	
<p>Henry Ford Medical Center (HF) New Center One Suite 700 3031 W. Grand Blvd. Detroit, MI 48202 www.henryfordhealth.org</p> <ul style="list-style-type: none"> • <i>Genetics Clinic Division 313-916-3188</i> 	Y E S

Centers offer a variety of clinics including pediatric, reproductive and adult services	Satellite or outreach sites?
<p>Detroit (continued)</p> <p>Wayne State University / Detroit Medical Center (DMC) www.dmc.org</p> <ul style="list-style-type: none"> • <i>Cancer (Karmanos Institute) 313-966-7780</i> • <i>Children's Hospital of Michigan Metabolic Clinic 313-745-3208</i> • <i>Pediatric Genetics Clinic (Children's Hospital) 313-745-4513</i> • <i>Neurogenetics Clinic (Harper Hospital) 313-577-8317</i> • <i>Reproductive Genetics Clinic (Harper Hospital) 313-745-7067</i> 	
<p>East Lansing</p>	
<p>Michigan State University (MSU) B240 Life Sciences Building 138 Service Road East Lansing, MI 48824 517-353-2030 www.healthteam.msu.edu/clinics/Genetics</p>	<p>Y E S</p>
<p>Grand Rapids</p>	
<p>Spectrum Health (SH) 21 Michigan NE Grand Rapids, MI 49503 616-391-2700 www.spectrum-health.org</p>	<p>Y E S</p>
<p>Royal Oak</p>	
<p>William Beaumont Hospital (WBH) 3535 W 13 Mile Road, Suite 329 Royal Oak, MI 48073 www.beaumont-hospitals.com</p> <ul style="list-style-type: none"> • <i>Pediatric Genetics Clinic 248-551-0847</i> • <i>Reproductive Genetics Clinic 248-551-0395</i> • <i>Cancer Genetics Program 248-551-3388</i> 	

GENETIC OUTREACH CLINICS BY LOCATION		TEAM
Big Rapids		SH
	Pediatric Associates of Big Rapids 616-391-2700	
Flint		MSU
	Mott Children's Hospital 517-353-2030	
Gaylord		UM
	NW Community Health Agency of Michigan 734-764-0579	
Kalamazoo		MSU
	MSU Kalamazoo Center for Medical Studies 517-353-2030	
Marquette		UM
	Marquette General Hospital 734-764-0579	
Midland		HF
	Mid-Michigan Regional Medical Center 313-916-3188	
Saginaw		HF
	Covenant Houghton Hospital 313-916-3188	
Traverse City		UM
	Munson Medical Center 734-764-0579	

Managing Medical Bills

Keeping track of medical bills is a complicated task. It is often tricky to know whether a service or piece of equipment will or won't be covered by insurance. Finding other sources to fund medical bills can be frustrating, tiring, and time consuming. Being organized and determined will pay off in the long run.

■ Bills

✓ **Always provide up-to-date information to the billing department.** Often this is one of the biggest challenges to ensuring you receive the correct bill.

✓ **Attempt to have your questions answered.** If you are unsure about how to phrase a question, do not be afraid to ask for help. Talking with a billing specialist will often uncover more questions you might want to ask, as well as the answers!

✓ **Keep track of all bills including paid bills.** It helps to put the date and/or check number on the bill when you pay it. Whenever you speak to someone regarding a bill, keep a record of the person's name, date, time, and what you discussed for future reference.

"At first, we thought our insurance would take care of everything but we later found out that some things just weren't covered."

- A family from Ann Arbor, MI

✓ **Understand the collection process.** Knowing how long bills, and payments, can take to go through the system can save you time and frustration.

✓ **Negotiate a plan for payments.** It is common for providers to offer installment or other payment options, but you may need to ask for them.

■ Diagnosis

✓ **Obtain a diagnosis for your child.** You may be eligible for certain programs with the right diagnosis.

✓ **Ask your child's doctor, office manager or billing specialist for the correct words to use in order to get reimbursed.** Knowing the correct billing terminology can help to get services covered.

✓ **Ask your child's doctor to discuss future health risks to help with financial planning.** Although many problems may never arise, you can take comfort knowing that you have prepared for all of the possibilities.

■ Health Insurance

- ☑ **Learn about all of the differences between health insurance plans.** Sometimes you can coordinate between more than one health plan to try to get the most coverage.
- ☑ **If you have a choice, choose the plan that will meet most of your needs.** If you can choose from more than one insurance plan offered by your employer, or if health insurance is available through more than one parent, compare the benefits of each. Sign up for the insurance that will provide the best coverage for your child's special health care and still meet the needs of other family members. Remember to re-evaluate which plan is best every time you have a chance for "open enrollment".
- ☑ **Keep a telephone log of all conversations with health insurance plans.** Being able to track where problems occurred can help to resolve them later. Your log might include:
 - **Date and time of conversation**
 - **Name of person and his/her title**
 - **Information discussed**
 - **Action/plan that was arranged**
- ☑ **Ask about benefits.** Benefit options are reviewed often. There may be some benefits that have just been approved and are considered supplemental information, such as:
 - **Frequency and amount of services allowed**
 - **Lifetime coverage caps**
 - **What is considered a pre-existing condition**

Finding Help for Health Care Bills

The cost of medical care continues to rise, and even families with “good” insurance often have many out-of-pocket medical expenses for the services their child needs. It is important for you to find out what state and national resources might be available to help cover the cost of current or future medical bills. Note that some of the programs offering help require that you apply very early in your child’s diagnostic process. Listed below are some agencies and programs that can be contacted for further enrollment information and eligibility requirements.

■ Michigan Resources

- **Children’s Special Health Care Services (CSHCS)**

A program administered by the Michigan Department of Community Health that helps to coordinate and pay for hospital and outpatient specialty medical care. Eligibility is based on a child’s medical condition, and how severe it is or how long it is expected to last. More than 2,000 diagnoses are eligible for coverage. CSHCS may cover diagnostic evaluations, office visits to specialists, prescription drugs, equipment and other costs related to medical care and treatment of the child’s eligible condition. CSHCS may pay for therapeutic equipment and other items when there is no other source of payment. Child must be under age 21 years.

Visit: www.michigan.gov/cshcs

View: www.training.mihealth.org (free online course describing CSHCS)

Phone: 1-800-359-3722

- **Children with Special Needs Fund**

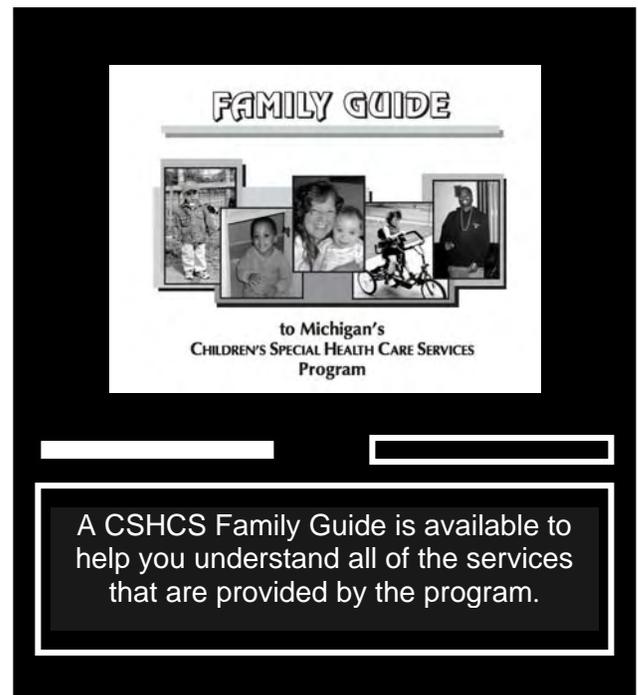
The Fund provides services and equipment to children under age 21 years with special health care needs that no other resource-- including state or federal programs-- pays for.

Visit: www.michigan.gov/csnfund

Phone: 517-241-7420 or 1-800-359-3722 (CSHCS Family Phone Line)

- **Children’s Waiver Program (CWP)**

CWP is a federal program that provides services to children under age 18 with developmental disabilities and who have challenging behaviors and/or complex medical needs. CWP is for children who reside with their birth or adoptive parents and are in need of intensive community living supports and/or private duty nursing services, regardless of their parent's income. Waiver services may include: family training; specialty services (e.g.



A CSHCS Family Guide is available to help you understand all of the services that are provided by the program.

music, recreation, art and massage therapy); community living supports; transportation; respite care; environmental accessibility adaptations; and specialty medical equipment. Although the program is at its capacity (413 children statewide), a waiting list is maintained. To request more information regarding eligibility or to submit a prescreen application for the program, contact your local Community Mental Health Services Program.

Phone: **Your local Community Mental Health Services Program**

For the telephone number call: **517-335-8216**. Contact the Board Association directly at **517-374-6848**.

- **Family Support Subsidy Program**

The Family Support Subsidy provides a monthly stipend (~\$220) to some birth or adoptive families whose child has severe cognitive impairment, severe multiple impairments, or autism, as determined by the local public or intermediate school district. The stipend must be spent on special needs that occur as a result of caring for a child with a severe disability at home. To be eligible, the family's most recently filed Michigan income tax form must show a taxable income of less than \$60,000. Family Support Subsidy applications are available at all Community Mental Health Services Programs.

Visit: **www.michigan.gov/mdch**, then search "Family Support Subsidy"

Contact: Cheryl Thelen, **517-241-5773**, or e-mail Thelenc@michigan.gov

- **Medical Adoption Subsidy**

The Adoption Subsidy Program is administered by the Michigan Department of Human Services and provides a financial subsidy and/or medical subsidy to encourage the placement of children with special needs with adoptive families. Support subsidy assists with the payment of expenses related to caring for and raising the child. Medical subsidy assists with the costs of necessary treatment for a physical, mental, or emotional condition which existed, or the cause of which existed, prior to the adoption.

Visit: **www.michigan.gov/adoption**

Phone: **517-373-3513**

- **MIChild Health Insurance**

The MIChild Health Care program is administered by the Michigan Department of Community Health for low income uninsured children of Michigan's working families. This program is for children under age 19 and there is a household income eligibility requirement. Enrollees receive a comprehensive package of health care benefits including vision, dental, and mental health services.

Visit: **www.michigan.gov/michild**

Phone: MIChild **1-888-988-6300**

- **Under 21**

Medicaid is available to persons under the age of 21. There is an income eligibility requirement for this program. If income is over the limit, there might still be some assistance available for medical expenses. Enrollees receive a health care package that may include vision, dental, and mental health services.

Phone: **Your local health department or 'local county human resources'** as listed in your phone book.

■ National Resources

- **American Academy of Pediatrics -**
www.medicalhomeinfo.org/tools/Ins_Families.html
Health insurance information for families with links to:
 1. Health Insurance Guide from ABC for Health: A Family's Guide to Advocating for Your Child with Special Needs- **www.abcforhealth.org**
 2. Children's Defense Fund -
www.childrensdefense.org
 3. Insure Kids Now -
www.insurekidsnow.gov
Phone: **1-877-KIDSNOW**
- **Internal Revenue Service (IRS)**
Publication #502: Medical and Dental Expenses
Explains how to itemize out-of-pocket expenses for tax deduction
Download form: **www.irs.gov/pub/irs-pdf/p502.pdf**
Phone: **1-800-829-3676**
- **New England SERVE**
"Paying the Bills, Tips for families on financing health care for children with special needs"
Download booklet: **www.neserve.org/neserve/ptb.html**
Phone: **617-574-9493**
- **Social Security Administration**
Supplemental security income (SSI) is a federal program that provides monthly payments and enables state Medicaid coverage for children with severe mental, emotional and physical disabilities.
Visit: **www.ssa.gov**
Phone: **1-800-772-1213**
TTY: **1-800-325-0778**

Where else to look for help paying medical bills:

- ✓ **County or city health department:** the Children's Special Health Care Services coordinator may have ideas on where to find help for your child's special medical bills
- ✓ **Michigan Department of Human Services:** may direct you to hospital, clinic or health department funds
- ✓ **Local town hall:** may alert you to possible funds through private endowments
- ✓ **Support groups and other families:** can share ideas for financial support
- ✓ **The Arc Michigan and other advocacy groups:** may be aware of funding sources or agencies that provide services at low or no-cost.
- ✓ **Internal Revenue Service:** ask for tax-saving information. It might be possible to itemize out-of-pocket medical expenses and receive a tax deduction. *For example, this might include home adaptations, food or clothing costs that would not be normally incurred, prescribed medications, as well as transportation costs to medical appointments.*



Family Centered Care

"Our doctor always made my husband and me feel we had a part in planning our child's medical care. He recognized that we knew our child the best, and this was very important to us."



Tips from Parents

While families gain tremendous support from the resources and services available through health care teams and community providers, they also tell us there is no substitute for learning from other families who have already dealt with some of the same challenges you now face. The following tips include ideas, websites, and organizations that are some favorites passed along by Michigan families whose children are enrolled in the Children's Special Health Care Services program. If you have a favorite tip to share, please let us know so we can include it in the next edition of the guide book.

Contact us at: BDRfollowup@michigan.gov

■ Adoption

National Foster Parent Association

An organization that provides support to foster parents in achieving safety, permanence and well-being for the children and youth in their care. This organization also promotes mutual coordination, cooperation and communication among foster parents, Foster Parent Associations, child care agencies and other child advocates.

Visit: www.nfpainc.org

"Many costs are waived when adopting a child with pre-existing special needs. Medical subsidies are often given regardless of insurance. Adoption subsidy can also be granted later in a child's life. Good adoption resource centers will be aware of all available resources."

■ Advocacy

Exceptional Parent

A company that provides "information, support, ideas, encouragement & outreach for parents and families of children with disabilities, and the professionals who work with them". Links to various sources including vendors, equipment and toys are available on their website as well as a nationwide directory of camps, schools and residences for children with special needs.

Visit: www.eparent.com

Phone: 1-877-372-7368

Bridges 4 Kids

A non-profit parent organization providing a comprehensive system of information and referral for parents of children from birth through transition to adult life by creating partnerships between families, schools and communities.

Visit: www.bridges4kids.org

E-mail: info@bridges4kids.org

The Arc

Advocates for the rights and full participation, as well as access to services and supports for people with intellectual and developmental disabilities.

National: Visit www.thearc.org or call **1-800-433-5255 ext. 5460**

Local Chapters: Visit www.arcmi.org or call **1-800-292-7851**



■ Books/Toys

Many national support groups have information about how to obtain stuffed animals, toys or books related to a child's specific special need.

Visit: www.GeneticAlliance.org, for a list of national organizations; or click on "Support Group Directory" at www.MIGeneticsConnection.org to find chapters in Michigan.

- * "If you can show a therapeutic use for a toy, certain organizations like Children's Special Health Care Services or the Trust Fund may cover the cost of the toy."

■ Camps/Recreation

As your child grows, think about ways to help them experience the same activities that kids typically enjoy.

Camp-O-Rama – Provides an annual listing of camps in Michigan available for persons with special needs.

Download from: [//Media.ccreesa.org](http://Media.ccreesa.org) (click on Camp-O-Rama Information)

- * "YMCA's and Community Centers may offer discounted or free passes if you can document a therapy or need for an activity in your child's care. Contact your local YMCA or Community Center to see if any such services are available for your child."

Volunteering makes a difference!

1. "Volunteer at a summer camp to educate and assist with your child's special needs."
2. "Contact camp counselors and educate them about your child's special needs prior to attending the camp."
3. "Many camps have 'buddies' to assist children who have special needs allowing them to attend camps for all children."

■ City/Community/Utilities

- * Many communities/cities have grants and federal money to cover costs of building ramps at residential homes. Municipal money may also be available. Contact your local city hall or township office.
- * Contact fire and police department and 911 dispatch to ensure they have a file on your home regarding a child needing specialty medical care, i.e. oxygen, so that they may respond to your home first in the event of an emergency/natural disaster.
- * Notify the utility company of your child's need for electricity to power ventilator/oxygen/other necessary medical equipment. This ensures you will be on a priority list and they will call your home to alert you to the duration of a power outage and provide information on where to take your child to the nearest facility with a generator.

■ Clothing

There are some simple modifications you can do to make wearing clothes more comfortable for a child who has mobility issues or needs special equipment that interferes with dressing.

- * "You are still able to buy cute styles. Just modify the back to allow easier dressing/undressing by cutting the back neckline open and use iron-on Velcro for the child with reduced mobility/bracing."
- * "Remove zippers/buttons and replace with Velcro if child has fine motor difficulties or limb defects."
- * "Bigger sizes and sweats/running suits allow easier dressing/undressing."

■ Cooking/Nutrition/Eating

- * "Make your own baby food and freeze it in ice cube trays."
- * "Many adaptive supplies such as special spoons and other eating utensils may be found at regular baby food retail stores."
- * "Carnation Instant Breakfast Shakes or Breakfast Bars® are often very appetizing to a child. Good source of nutrition and calories for the child who won't eat or not gaining weight. Fairly cost-effective as well."

■ Education

In addition to learning from the staff at your local intermediate school district, try to:

- * Speak with other parents of children in special education
- * Speak with other parents of children with similar special needs that are in inclusion programs
- * Volunteer as a Room Parent or participate in other school activities

■ Equipment/Supplies

Children's Special Health Care Services – For children with an eligible condition, will cover cost of diapers & wipes after child turns 3 years of age. The vendor will ship the diapers to your home.

■ Mobility/Wheelchairs

Children's Special Health Care Services – May cover the cost of a wheelchair. Make sure you are enrolled prior to ordering.

Michigan Secretary of State – Any person who uses a wheelchair or who transports a member of their household who uses a wheelchair will receive a 50% reduction in the fee for their handicap vehicle registration. The vehicle does not have to be fitted with a wheelchair lift to qualify.



Obtain a prescription from your doctor for any supplies needed related to your child's diagnosis

■ Positioning

- * "While a child is awake consider using a washable stuffed animal to position/prop. It is much more kid friendly and less 'institutional' than propping devices/pillows"

Note: Positioning or propping while sleeping is not recommended by the American Academy of Pediatrics

■ Travel

Medical

Mercy Medical Airlift

A charitable organization helping those in need of air medical transportation.

National Patient Travel Helpline: **1-800-296-1217**

National Patient Ticket Helpline: **1-800-325-8908**

Visit: **www.mercymedical.org**

Wings of Mercy

Provides free air transportation for people with limited financial means who need treatment at distant medical facilities.

Serving West Michigan, Phone: **1-888-78-MERCY (63729)** or **616-396-1077**

Serving East Michigan, Phone: **1-866-32-MERCY (63729)**

Recreational**The Guided Tour, Inc.**

A professional supervised travel and vacation program in the United States for people 17 years of age and older with developmental and/or physical problems.

Visit: **www.guidedtour.com**

Phone: **1-800-783-5841**

Travel Access Services Corporation, TASC

International organization helping people with disabilities find hotels, amenities and more to allow a comfortable travel experience.

Visit: **www.tascinternational.org**

U.S. Department of Transportation

Toll free hotline for air travelers with disabilities. Education available about air travel rights for persons with disabilities. Assistance with service animals, seating, boarding and de-boarding, connecting assistance, stowage of equipment and other accommodations.

Available 7 a.m. to 11 p.m. EST, every day

Phone: **1-800-778-4838** voice

TTY: **800-455-9880**



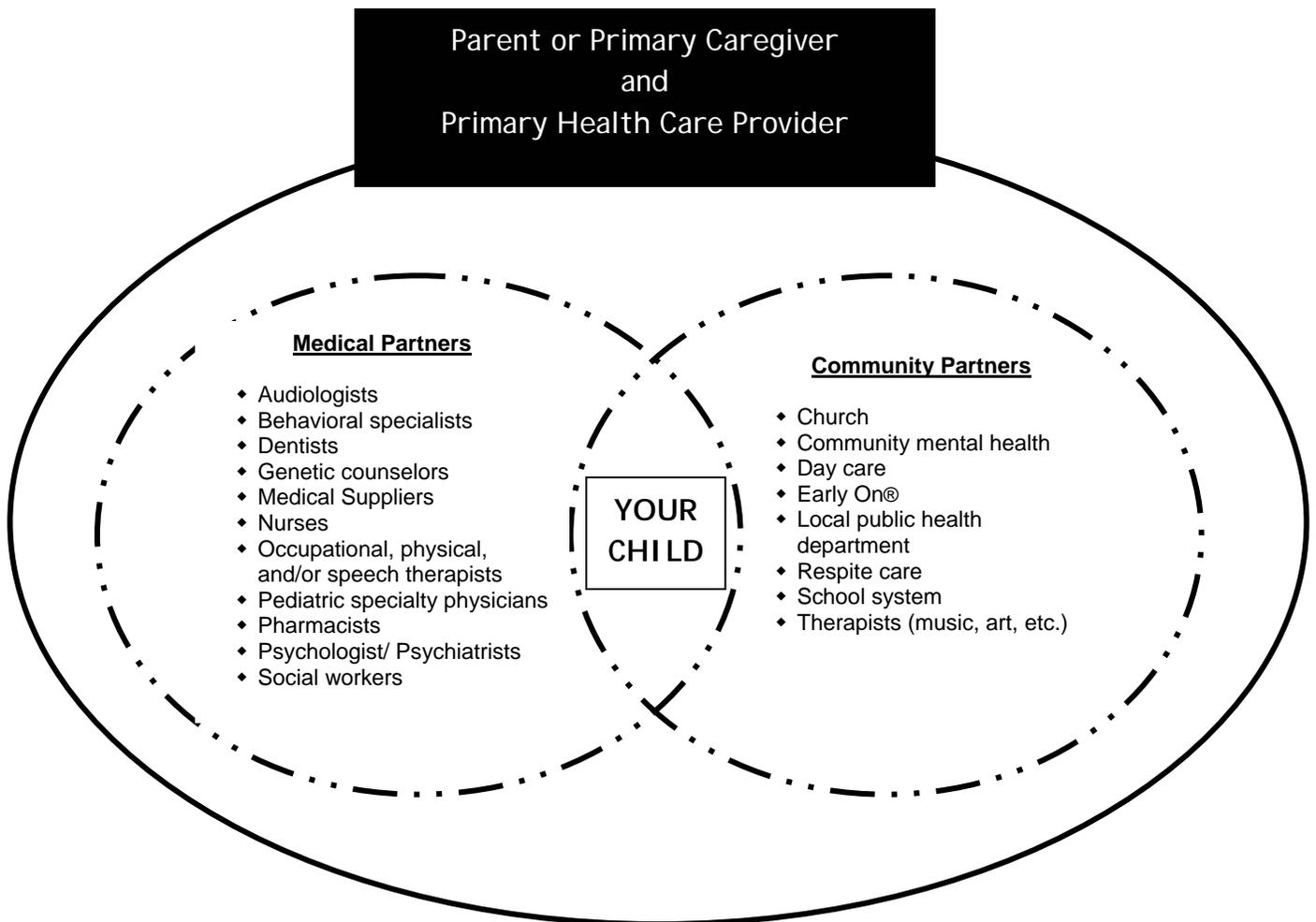
Continuous, Comprehensive, Coordinated Care

"Our pediatrician was always aware of the results from our specialty care visits and reviewed with us the letters sent to him by these specialists. It just reassured us that everyone was on the same page."



Multi-Disciplinary Team Partners

Children with birth defects often have multiple needs—both physical and emotional—that benefit from health care and other services provided by a number of different health professionals, educators, and community agencies. A well developed and coordinated care team is important to assure the best possible outcome for your child's health. Ideally, parents work together with a child's primary doctor or nurse to identify needs and coordinate services available through the health care system and community settings, as shown in the diagram below.



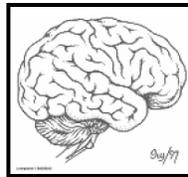
Understanding the Pediatric Specialties

Doctors specially trained to care for children from birth to young adulthood are called **pediatricians**. They provide general health care, and are also concerned about the social, physical and emotional health of a child. **Family practice** (also called family medicine) doctors are trained to care for people from birth to old age, and may also provide general health care for children with special needs. Some pediatricians focus on one particular organ or type of disease. These doctors are called **pediatric specialists**. An overview of the different specialty areas that may be on your child's care team is provided below.



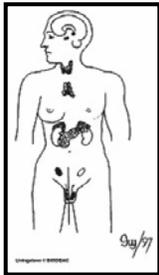
Cardiology/Cardiovascular Surgery

Medical care/ surgery of the heart. Diagnosis and treatment of any type of heart defect or disease including the vessels of the heart and circulatory system.



Neurology/Neurosurgery

Medical care of the brain, central and peripheral nervous system. Diagnosis and treatment of any birth defect/disorder involving the brain, spinal cord and nervous system.



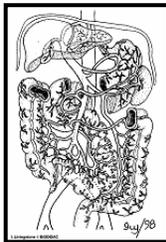
Endocrinology

Medical care of the internal glands. Diagnosis and treatment of any disorder of the internal glands affecting things such as growth and hormone levels.



Ophthalmology

Medical care of the eye. Diagnosis and treatment of any type of birth defect/disease affecting the eyes.



Gastroenterology

Medical care of the organs of the digestive system including the mouth, stomach and intestines.

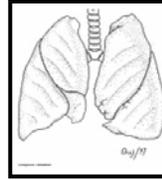


Orthopedics

Medical care of the bones. Diagnosis and treatment of any birth defect/disorder involving the body's skeletal system.



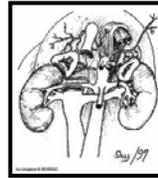
Hematology/Oncology
Medical care of disorders affecting the blood, circulatory system and cancers.



Pulmonology
Medical care of the lungs. Diagnosis and treatment of any type of birth defect/disease of the lungs.



Surgery
General surgery for disorders, injuries and birth defects. Plastic surgeries including specialties such as Craniofacial Surgery.



Urology/Nephrology
Care of the kidneys, urinary tract and genitourinary tract. Diagnosis and treatment of any type of birth defect/disease involving the kidneys, urinary tract or genitourinary tract.

Other Possible Care Team Members

Families are encouraged to maintain a close relationship with their child's primary care provider. In addition to your primary and specialty care physicians, there are other kinds of health professionals who may assist your child and family, as described below.

Audiologists are trained to assess a child's hearing. They help determine if a child's speech or learning delays could be due to a loss in hearing. They often work closely with a child's speech pathologist, teachers and doctors.

Child psychologists or psychiatrists are trained to treat psychological problems in children. Some children have behavioral, emotional or psychological problems just as some may become physically ill. Many behavioral or emotional problems can be reduced or corrected with a treatment plan that may include therapy and/or medication.

Dentists are trained to diagnose, prevent, and treat problems with teeth or mouth tissue. They provide preventative dental care. They also perform corrective surgery on gums and supporting bones to treat gum diseases. Dentists extract teeth and make models and measurements for dentures to replace missing teeth. They provide instruction on diet, brushing, flossing, the use of fluorides, and other aspects of dental care.

Genetic counselors have training in medical genetics and counseling. They provide information, support and resources to families affected by a birth defect or genetic disorder. Their role includes educating patients about genetics and risk factors based on review of family history and test results, interpreting test results for patients, and supporting patients with short-term counseling and referrals to additional specialists as well as support services.

Geneticists are doctors trained in medicine (MD) or research (PhD) with specialized training in medical genetics. They are trained to identify rare types of birth defects and syndromes. They may order tests to find the reason for a child's health or learning problems. Geneticists often help coordinate a child's care with other medical specialists, and may help the primary pediatrician develop a care plan to meet a child's special health needs. They provide support and resources to families affected by a birth defect or genetic disorder.

Nurses are trained to care for healthy or ill children who have medical, physical or emotional needs. They may care for a child in a hospital, clinic, office or at home. They provide nursing and supportive care, and help teach parents how to provide specialized care for their child.



Occupational therapists are trained to help children gain the skills they need for daily living. They assess the home and recommend improvements to better meet personal needs. They assess a child's skills and design treatments to enhance these skills. They may use the aid of orthotic devices with therapy.

Pharmacists are trained to distribute drugs prescribed by physicians and other health practitioners and provide information to patients about medications and their use. They advise physicians and other health practitioners on the selection, dosages, interactions, and side effects of medications. Pharmacists also monitor the health and progress of patients in response to drug therapy to ensure the safe and effective use of medication.

Physical therapists are trained to help people with mobility. They assess whether a child is having difficulties with motor skills and movement. They help children with problems from an injury, birth defect or health condition such as cerebral palsy and muscular dystrophy.

Social workers are trained to help people make the most use of their abilities and resources. They help people try to overcome social and health problems. They help people recognize their needs and find community services that help best meet those needs. Social workers may work with your child through your school system, community hospital or medical center as well as your child's specialty health clinic. Their services may offer you education and support regarding your child's medical and financial needs.

Speech pathologists and therapists are trained to help children with difficulties in their speech, language or voice that affect the way they communicate. They may also help children with disorders that affect swallowing. They are trained to assess a child's speech and development to find delays. They suggest activities and techniques to develop speech and language for communication.

"When our child was born with a cleft lip, the craniofacial team we chose for him was located in a different hospital. Our social worker from the team was so wonderful. She offered to come to the birth hospital and help us with any feeding troubles- she didn't even work there!"

- A Family from Birmingham, MI

Preparing for Your Child's Medical Care

Preparing for, and arriving on time for a medical appointment can be a hair-raising experience for anyone. Trying to juggle the additional stress of preparing for an appointment for a child with special needs is even more challenging. Some of the tips below may help you organize your thoughts and prepare for doctor's office visits.

1. Prepare for the Doctor Visit

- Write down questions between visits.
- Schedule extra time if necessary for the visit.
- Bring all of your child's records.
- Bring pen and paper to take notes.
- Bring a friend or relative to help with your child.
- Have a list of all current medications.
- Have a list of any reactions to medicines.

"My doctor's secretaries are always so nice. They now know to ask me if I'll need extra time with the doctor when they schedule my child's appointments."

- A family from western Michigan

2. Plan the Time with Your Doctor

- Initially state that you have many questions.
- Ask doctor to rephrase unclear answers.
- Write down doctor's answers/comments.
- Tell your doctor how your child is doing.
- Describe child's successes and setbacks.
- Explain any concerns.

3. Common Parental Concerns for the Doctor

- Is a firm diagnosis possible at this time?
- Is a firm diagnosis possible in the future?
- What will be my child's short- and long-term health and emotional needs?
- How will the condition progress- will it improve or worsen?
- Is my child's development/behavior normal for his/her age?
- How can I help my child reach his/her potential?



Make the most of the time spent with your child's health care provider.

4. After the Doctor's Visit

- If you have more questions, please call your doctor to get them answered.
- Share any new instructions with your family members and caregivers.
- Make sure you write down your next appointment or when you need to call for the next appointment.

Preparing for Special Medical Occasions

In addition to your child's routine health care, there could be a need for tests or additional services. Listed below are some of the questions you might want to ask before agreeing to additional tests, referrals, surgical procedures, hospital stays or medications.

■ Tests and Imaging Procedures

1. What is the purpose of the test?
2. How should I prepare my child for the test?
3. Will my child experience pain or discomfort?
4. What should I bring to make my child comfortable?
5. Are there restrictions prior to the test?
6. Where, when and how will the test be done?
7. How long will the test take?
8. Who will perform the test?
9. Are there any side effects from the test?
10. How long will it take for results?
11. Who will contact me with results and how do I get a copy of the results?
12. Do I need pre-approval through my insurance company?
13. Who do I speak with to determine if my insurance covers the test?
14. How do I get a referral?

"When the doctors told us that they were going to run some tests before her surgery, we thought about so many other questions to ask after they were already done."

■ Referral to a Specialist or Clinic

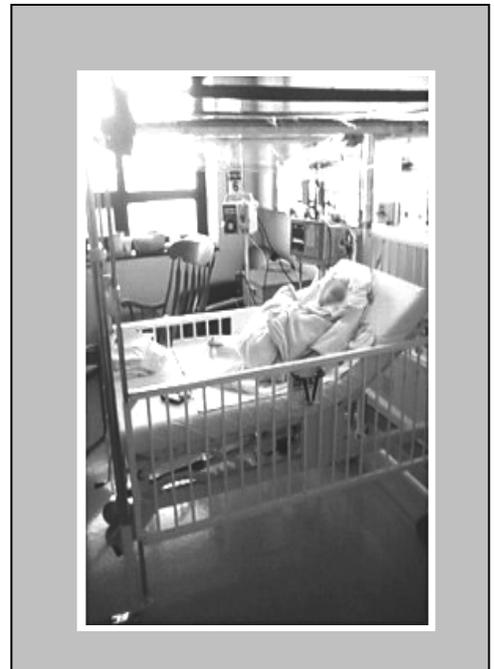
1. Why is the referral being made?
2. What will take place?
3. Is this a one-time visit?
4. Who will contact me with results/recommendations?
5. How do I obtain a copy of the evaluation report?
6. How will the findings be coordinated with my child's care?
7. Is the specialist or clinic covered by insurance?
8. Do I need a referral or pre-approval through my insurance company?
9. How will the parent, doctor and specialist communicate?

■ Surgery

1. What is the purpose?
2. What will happen if it's not done?
3. Are there any risks?
4. How long do we have to decide to pursue surgery?
5. Is there time to get a second opinion?
6. How will we know if surgery is a success?
7. What will be the recovery?
8. What will be the follow-up care after surgery?
9. Will other surgeries be needed?
10. Do I need a referral or pre-authorization?

■ Hospitalization

1. Does the hospital offer a program to prepare my child for his/her stay?
2. What is the length of stay?
3. Can I stay with my child?
4. Who will coordinate my child's care while in the hospital?
5. Who are the doctors providing care?
6. What will the hospitalization cost?
7. Will the hospital billing department contact my insurance company or me?
8. Do I need a referral or pre-authorization?



■ Medications

1. Is there more than one name for the medicine?
2. What does the medicine do?
3. Are there any side effects from the medicine?
4. What side effects indicate an allergic reaction?
5. Is there a different medicine to use if side effects occur?
6. Can other medicines (cough syrup, pain medicine) be given at the same time?
7. Should the medicine be refrigerated?
8. How much of each medicine should be taken?
9. When should the medicine be given?
10. What do I do if a dose of the medicine is missed?

11. Should the medicine be given with or without food?
12. How long should the medicine be taken?
13. Do I need a refill for the medicine?
14. Is there a time when the dose of the medicine will stop working?
15. What is the cost of the medicine?
16. Is there a generic form of the medicine that can be used?
17. Will insurance cover the cost of the medicine?
18. If I have two insurance carriers, how will the medicine be covered?
19. Will I need to pay for the medicine up front and then get reimbursed by insurance?



Resources and Services

Comprehensive care includes finding out about all the resources, services, and support systems available to help your child and family. Since receiving a diagnosis for your child, you may have begun a new journey to find accurate information about the condition and care he or she will need. Listed below are state and national resources that may help families of children with any type of medical condition. There are many programs that are free of charge and are often run by parents or care givers who want to share information.

■ Michigan Information and Support Services

2-1-1 Call Centers provide a data base with over 4,000 health and human service programs as a resource to give or get help. Dial **2-1-1** for information in your county.

Birth Defects Follow-up Program at the Michigan Department of Community Health (MDCH) can help with referrals for support and services by providing resource information for families and health care providers. To speak with the follow-up coordinator or receive materials, call toll-free **1-866-852-1247** or e-mail **BDRFollowup@michigan.gov**.

Bridges4Kids provides a comprehensive system of information and referral resources for parents of all children from birth to adult life with a special focus on those who have disabilities, special needs, or who are at-risk. Call toll-free **1-877-553-5437** or visit **www.bridges4kids.org**.

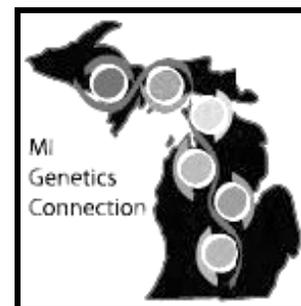
Early Hearing Detection and Intervention (EHDI) program at the Michigan Department of Community Health is building a statewide system for newborn hearing services that helps to assure all Michigan newborns are screened for hearing loss. The EHDI program works with hospitals and clinics to identify newborns and infants with hearing loss, and assure that appropriate diagnostic and intervention services are received. The **Guide-by-Your-Side Program** provides regional parent guides to meet with new families of children from birth to six years diagnosed with hearing loss. For more information on EHDI, please call **517-335-9398** or visit **www.michigan.gov/ehdi**.

Family Support Services provides case management services through your local community mental health agency. Additional services include behavior intervention, family skills development, and respite care services. Contact the Michigan Association of Community Mental Health Boards at **517-374-6848**, if you are unable to find your county mental health services program in your yellow page directory.

Family-to-Family Health Information and Education Center is designed as a virtual center for information, education and/or parent-to-parent support for families of children with special needs in Michigan. Visit www.bridges4kids.org/f2f.

Michigan Alliance for Families provides parent centered support and has a resource center containing informational folders, a lending library and one-on-one support. For more information call **1-800-552-4821** or visit www.wash.k12.mi.us/perform.

Michigan's Genetics Resource Center provides information on genetic services, testing, birth defects, newborn screening and related topics. Call toll-free **1-866-852-1247** or visit www.MIGeneticsConnection.org.



Get Connected!

Newborn Screening Follow-up Program at the Michigan Department of Community Health supports, monitors, and facilitates follow-up diagnostic and treatment services for infants and young children with a presumptive or confirmed diagnosis identified by newborn screening (e.g., metabolic, hemoglobin, and endocrine disorders). To speak with the follow-up coordinator or request information, call toll free **1-866-673-9939**, e-mail mdch-newbornscreening@michigan.gov, or visit www.michigan.gov/newbornscreening.

Parent HELpline is a service provided by Gryphon Place and funded by Michigan Department of Human Services. Trained counselors provide crisis counseling, support and information to anyone who needs help right away. Every call is confidential and is available 24 hours a day, seven days a week at **1-800-942-HELP (4357)**. For 24-hour assistance in Kalamazoo County call 269-381-HELP (4357).

■ National Resources

About. Parenting and Family. is a website that provides resources for 'Parenting Special Needs'. Information for the newly diagnosed and assistance for those with a diagnosis. Information provided on numerous medical conditions as well as information on early intervention, special education, community resources, long term planning and more specifically for children with special care needs. Visit: <http://specialchildren.about.com/>

"Using the support services from national and local groups as well as other parents makes a lot of the difficulties seem more manageable."

Family Village includes information, resources and communication opportunities online for persons with disabilities, their families and other support persons. Visit: www.familyvillage.wisc.edu

Fathers Network celebrates and supports fathers raising children with special health care needs and developmental disabilities. Call **425-747-4004 (x4286)** or visit www.fathersnetwork.org

Genetic Alliance is an international coalition comprised of more than 600 advocacy, research and healthcare organizations that represent millions of individuals with genetic conditions and their interests. Call **202-966-5557** or visit **www.geneticalliance.org** to find out if there is a national group that deals with your child's diagnosis.

Knowledge Path, produced by the MCH Library, includes information on (and links to) web sites, electronic and print publications, databases and online discussion groups. Separate sections list resources on specific aspects of care and development such as adolescent transition, advocacy, financing, and screening. Visit **www.mchlibrary.info/KnowledgePaths/kp_CSHCN.html**

Make-A-Wish Foundation is a volunteer organization that grants the wishes of children with life-threatening medical conditions. Visit **www.wish.org**

March of Dimes is a national advocacy organization whose mission is to improve the health of babies by preventing birth defects, premature birth, and infant mortality. The pregnancy and newborn health education center includes information on birth defects and genetic conditions. Visit **www.marchofdimes.com**

MUMS: National Parent-to-Parent Network connects families of children who have a rare diagnosis. Call toll-free **1-877-336-5333** or visit **www.netnet.net/mums**

National Dissemination Center for Children with Disabilities (NICHCY) is a clearinghouse that offers information, referral, and free publications to families of children with special health needs. Call **1-800-695-0285** or visit **www.nichcy.org**

National Organization for Rare Disorders (NORD) is dedicated to helping people with rare "orphan" diseases that affect only a small number of people. Call **1-800-999-6673** or visit **www.rarediseases.org**

The Arc of the United States advocates for children and adults with intellectual and developmental disabilities to improve support systems and services, connect families, inspire communities and influence public policy. Call **301-565-3842** (Spanish call: **1-800-292-7851**) or visit **www.thearc.org**

Zero to Three is a national, nonprofit, multidisciplinary organization that supports the healthy development and well-being of infants, toddlers and their families. Call **1-800-899-4301** or visit **www.zerotothree.org**

■ Resources & Products for Daily Living

As your child continues to develop, enhanced equipment and technology may be useful. There are many resources available to you and your family. Michigan and national contact information is included below.

Michigan's Integrative Technology Supports (MITS) provides product information from more than 3,000 companies that specialize in adaptive devices, special toys, clothing, equipment, and much more. Call **1-800-274-7426** or visit www.cenmi.org/matr

Type of information available includes:

1. Adaptive car seats
2. Latex-free products
3. Cooking/nutrition resources
4. Bathing and hygiene resources
5. Special toys and playground equipment
6. Special camps and sports activities
7. Wheelchair lifts and ramps
8. Links to other resource sites

Resources and adaptive products are available for daily living:

- ✓ **Clothing**
- ✓ **Computers**
- ✓ **Cooking and Nutrition**
- ✓ **Driving and Transportation**
- ✓ **Education and Learning**
- ✓ **Personal hygiene products**
- ✓ **Recreation** (Vacations, Camps, etc.)
- ✓ **Sports**
- ✓ **Toys**
- ✓ **Wheelchairs** (Beach, Sports, etc.)

Other Resources:

- **Apple Computer** www.apple.com/disability
- **Disabled Children Relief Fund** www.dcrf.com
- **Easter Seals** www.easter-seals.org
- **Microsoft Accessibility Technology for Everyone** www.microsoft.com/enable/default.htm
- **Public Libraries** In your local yellow pages
- **TechConnections** www.techconnections.org

"I couldn't believe the number of adaptive resources available until I started looking into it."

- Aunt of a child from Lansing, MI

Early Intervention & Education

Many families are not aware that early intervention services are available to Michigan children with special needs beginning right after birth. During the preschool years, different types of educational services are available for children with developmental delays, physical, or health impairments. Special education is available until 26 years of age for people with developmental disabilities. These services are provided through your local school district or intermediate school district.

Early On® Michigan is a statewide system that helps to arrange early intervention and other services for children ages birth to 3 years who have developmental delays, disabilities or special needs, and their families. Call **1-800-EARLY-ON (327-5966)** or visit **www.1800earlyon.org** for information on how to enroll.

Who Is Served by *Early On*?

Families with an infant or toddler (under the age of three) who has:

An “**established condition**”, a diagnosed physical or mental condition with a high probability of resulting in a developmental delay:

- ◆ Atypical developmental disorders
- ◆ Congenital malformations
- ◆ Chromosome anomaly/genetic disorders
- ◆ Chronic Illness
- ◆ Inborn errors of metabolism
- ◆ Neurological disorders
- ◆ Sensory disorders
- ◆ Severe infectious diseases
- ◆ Severe toxic disorders

OR a developmental delay in one or more areas of development:

- ◆ Adaptive (self-help)
- ◆ Gross and fine motor
- ◆ Communication
- ◆ Physical (including hearing & vision)
- ◆ Cognitive
- ◆ Social/Emotional

What Services are Provided by *Early On*?

Each family receives (at no charge):

- ◆ Development of an individualized Family Service Plan (IFSP)
- ◆ Evaluation/Assessment
- ◆ Service Coordination
- ◆ Screening

Additional services may be available based upon need.

■ Education Services and Resources

Center for Educational Networking provides information for Michigan families, educators and all of those involved in the education of persons with disabilities. Call **1-800-593-9146** or visit **www.cenmi.org**

Head Start Programs focus on your child's development from 3 to 5 years by providing health and education programs. Families must meet income requirements for their children to participate. Visit **www.mhsa.ws** to locate a Head Start Program in your county.

Intermediate School District (ISD), sometimes called a regional educational service agency (RESA), may provide special services such as speech, occupational or physical therapy and other learning programs. Check your local phone book for your ISD telephone number or visit **www.cenmi.org/se_directory.asp** for the Michigan Directory of Service Providers for Infants, Toddlers, and Students with Disabilities. Scroll down to Section 15-20 for a complete listing of intermediate school districts.

Local School District. Your local school district may provide services such as speech and occupational therapy as well as assist you in obtaining other early intervention services for your child. You may wish to contact your school system to learn more about the services available to your family.

The **Michigan Department of Education- Office of Special Education and Early Intervention Programs** along with your local school system has created programs to aid every child with special learning needs from birth through the age of 25 years. Call **517-373-0923**; TTY: **517-373-9434**

Project Find identifies children and youths from birth to 26 years with special needs and helps refer families to the educational services that will most help a child. Call **1-800-252-0052** for more information.

Preparing for Transitions

As your child grows, he or she will reach various milestones that signal transition to another stage of life: from infant to toddler, from pre-school to school age, and later from teen to adulthood. Transitions include not only the changes in your child's independence and ability to care for him or herself, but also changes in the kinds of providers who may work with your child and family. While your child is still a baby or toddler, it may be hard to imagine him or her as an adult one day. Although it may not be possible for every child, depending on the type of birth defect or special needs, your goal as a parent should be to help prepare your child to work as an adult and live as independently as possible.

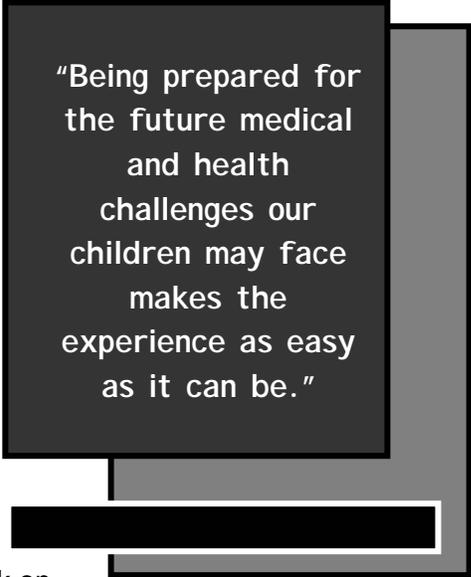
Listed below are some simple tips to keep in mind as you look ahead to each stage of transition.

1. Start preparing early for each transition towards levels of independence.
2. Ask for help or advice when needed.
3. Keep accurate records and have a system for keeping track of documents. Having good records will help with transitions in the medical and educational systems.
4. Have the same expectations for your child with a birth defect that you do for your other children.
5. Help your child to understand the condition over time, and how to take care of his or her own special medical needs to the greatest possible extent.
6. Help your child to become a person who can advocate for him- or herself when you are not around.

The following websites provide useful information about transition issues.

Children's Special Health Care Services, Transition to Adulthood includes worksheets for parents/caregivers and youth on transitioning to adulthood, a timeline beginning at age 14, as well as links to resources. The brochure, **Family Guidance: Transition Planning for Youth**, outlines some of the skills youth will need as well as issues to consider relating to health care coverage, education and employment. Visit www.michigan.gov/cshcs, and then click on the link to "Transition to Adulthood".

Healthy and Ready to Work National Center includes information on understanding systems, access to health care, as well as tools and resources to help youth and families make informed choices. Visit www.hrtw.org/ then click on the "tools and resources" tab for samples of transition care plans and portable medical summary sheets.



"Being prepared for the future medical and health challenges our children may face makes the experience as easy as it can be."

Michigan Directory of Service Providers for Infants, Toddlers, and Students with Disabilities and website focuses on educational/vocational issues from birth through 26 years of age. Visit: www.cenmi.org/se_directory.asp

National Center on Secondary Education and Transition publishes a series of “Parent Briefs” on transition topics. Visit: www.ncset.org/publications/default.asp#parent

Transition Timeline from the Center on Human Development and Disability, University of Washington, provides ideas on how to start preparing for transition, beginning at birth. Visit: www.depts.washington.edu/healthtr/Timeline/timeline.htm



Compassionate Care

"Last winter, we spent almost every day at the pediatrician's office because our son was so sick. Unexpectedly we received a phone call that Friday night from his pediatrician. He wasn't on call that weekend and wanted to check on my son to make sure he was doing ok before he left. It was a wonderful feeling knowing he truly cared about our son."



Parent-to-Parent Support

There are a number of ways for parents and family members to find support. Listed below are some suggestions on how to connect with support groups in Michigan. Some Michigan hospitals and *Early On* programs also run support groups. Contact your local hospital and *Early On* Coordinator for information.

■ Support Groups

Family Support Network of Michigan (FSN) is for families who have children with special needs. FSN helps families come together for emotional support. Trained volunteer parents offer practical suggestions for day-to-day living, and information about services that can help your family. The volunteers include parents of children with birth defects and genetic conditions. For details, phone the CSHCS Family Phone Line at **1-800-359-3722**.

Michigan Genetic Support Group Directory. Condition specific support groups in Michigan may be found in the on-line directory at **www.MiGeneticsConnection.org** or by calling toll-free **1-866-852-1247**. National organizations that may have a Michigan contact person are listed at **www.geneticalliance.org**.

■ Helpful Reading

Some of these books may be borrowed from the Lending Library of the CSHCS Family Center for Children and Youth with Special Health Care Needs. To check, call the Family Phone Line at 1-800-359-3722.

[After the Tears: Parents Talk About Raising a Child with a Disability](#)

Robin Simons, 96 pages, Harvest Books (1987)

[From the Heart: On Being a Mother of a Child with Special Needs](#)

Jayne D. B. Marsh, 149 pages, Woodbine House (1995)

[It Isn't Fair! Siblings of Children with Disabilities](#)

Stanley D. Klein and Maxwell J. Schleifer, 200 pages, Bergin & Garvey (1993)

[Sometimes Miracles Hide: Stirring Letters from Those Who Discovered God's Blessing in a Special Child](#)

Bruce Carroll, 128 pages, Howard Publishing (1999)

Special Children, Challenged Parents: The Struggles and Rewards of Raising a Child with a Disability

Robert A. Naseef, 288 pages, Paul H Brookes Publishing Company (2001)

Uncommon Fathers: Reflections on Raising a Child With a Disability

Donald J. Meyer, 206 pages, Woodbine House (1995)

Views From Our Shoes: Growing Up With A Brother or Sister with Special Needs

Donald J. Meyer, 114 pages, Woodbine House (1997)

Waiting with Gabriel

Amy Keubelbeck, 174 pages, Loyola Press (2003)

You Will Dream New Dreams: Inspiring Personal Stories by Parents of Children with Disabilities

Stanley D. Klein and Kim Schive, 304 pages, Kensington Publishing Corporation (2001)

Taking Care of Yourself

As important as it is for you, as a new parent, to get to know and care for your baby, it is also necessary to take care of yourself. Sometimes, the birth of a child can release a variety of feelings and emotions. The increased medical needs and related worries that are part of having a child with a birth defect, as well as other natural factors in a new mother, can sometimes lead to postpartum depression. Increased responsibilities can sometimes feel like too much for a father and other family members as well. Eating right, trying to get enough rest, and accepting assistance from others can help you through this time in your family's life.

Besides your own or your child's doctor, nurse, social worker, chaplain or other health care provider, you can find more information and help from these resources:

March of Dimes

Information about medical conditions, how to cope with having a baby in the NICU, and tips for family members. Visit www.marchofdimes.com or www.nacersano.org (Spanish)

National Mental Health Association provides resources for all aspects of mental health including depression. Call toll-free **1-800-969-NMHA (6642)** [TTY 1-800-433-5959] or visit www.nmha.org

www.ppdsupportpage.com
Online support and information about postpartum depression

It may help to put your feelings into words. Some parents have written about their feelings of having a child with unexpected challenges. The following are links to some of these essays.

"Welcome to Holland"
www.nas.com/downsyn/holland.html

"A Father's Letter to New Parents"
www.nas.com/downsyn/pino.html

Uplifting Poems, Articles and Assorted Thoughts
www.widesmiles.org/cleftlinks/thoughts.html

Seek professional help if your baby is a few weeks old and you experience:

- Changes in appetite
- Feeling of guilt
- Hard time concentrating
- Little interest in the baby
- Loss of energy
- Restless or slowed movement
- Thoughts about suicide
- Trouble sleeping

From March of Dimes Birth Defects Foundation (2005), www.marchofdimes.com.

■ Respite Care

At times all families need a “break” or “relief” from care giving responsibilities. It may be difficult to find traditional child care when your child has a developmental disability, medical condition or serious emotional disturbance. **Respite care** allows parents the opportunity to leave their child in the care of a trained professional while they find time for relaxation or entertainment. Following is a list of resources to help in your search for appropriate respite care:

- “Relax, Take a Break: A Family Guide to Respite for Children in Michigan: www.michigan.gov/documents/A_Family_Guide_to_Respite_139866_7.pdf
- Arch National Respite Locator Service: www.respitelocator.org/locatorsearch/searchpage.htm
- Michigan Association for Child Care Providers: www.childcareservices.com
- Child Care Aware: www.childcareaware.org
- Child Care Resources: www.childcare.org

Bereavement & Coping With Loss

The loss of a loved one is a very difficult time in any family's life. The loss of a child can bring on additional emotions that can be hard to share with others close to you. Parents often find comfort from those who have experienced a similar loss. Support may be found in many forms including counseling, support groups and reading. Hospice care is also available to help meet the emotional, spiritual and physical needs of families who have a child diagnosed with a life-limiting condition. We have listed a few resources that are available to help families during times of loss and grief.

■ Pediatric Hospice

Angela Hospice

Serving Southeast Michigan

Phone: **1-866-464-7810** (toll-free)

Visit: **www.angelahospice.org/peds.html**

Arbor Hospice

Serving Ann Arbor area, Downriver, Western Wayne/Oakland counties

Phone: **1-888-992-CARE** (toll-free)

Visit: **www.arborhospice.org/services/pathfinders.html**

Hospice of Michigan

Pediatric Hospice Team based in Grand Rapids

Phone: **1-800-642-4021** (toll-free)

Visit: **www.hom.org/peds.asp**

Kaleidoscope Kids

Serving metro Detroit tri-county area

Phone: **313-874-6400**

Visit: **www.henryfordhealth.org**

Michigan Hospice and Palliative Care Organization

Phone: **517-886-6667** or **1-800-536-6300** (toll-free)

E-mail: **mihospice@mihospice.org**

Visit: **www.mihospice.org** and click on "Children with Illness"

■ Support Groups

Broken Dreams

Borgess Hospital, Spiritual Care Department

Kalamazoo, MI

Phone: **269-226-5937**

Compassionate Friends

Visit: www.compassionatefriends.org
(Information on local chapters)

Ele's Place

Peer support groups for bereaved children of all ages, young adults, and their parents
Ann Arbor and Lansing, MI
Phone: **517-482-1315**
Visit: www.elesplace.org

Infant Bereavement Services

Oakwood Hospital
Dearborn, MI
Phone: **313-593-7167**

Newborn Loss and Stillbirth Support Group

University of Michigan, Lamaze Department
Ann Arbor, MI
Phone: **734-973-1014**

Sandcastles

Grief support for children, teens and parents/guardians
Henry Ford Hospital.
Detroit, MI
Phone: **313-874-6881**
Visit: www.aboutsandcastles.org

SHARE, Pregnancy and Infant Loss Support

Bronson Methodist Hospital
Kalamazoo, MI
Phone: **269-341-8886**
Visit: www.bronsonhealth.com

SHARING

For those who have undergone pregnancy termination for fetal diagnosis or anomalies
University of Michigan
Ann Arbor, MI
Phone: **734-936-9758**

Tomorrow's Child/Michigan SIDS Alliance

Phone: **1-800-331-7437**
E-mail: info@tomorrowschild.org
Visit: www.tomorrowschildmi.org

William Beaumont Hospital Support Groups

Bereaved Parents
Royal Oak, MI
Visit: www.beaumont Hospitals.com
(Information on all groups under "Support Groups" Icon)

■ Internet Sites

**Alliance of Grandparents,
A Support in Tragedy**
www.agast.org

A Quiet Refuge
www.quietrefuge.com

Caring Connections
www.caringinfo.org

Babyloss
www.babyloss.com

GriefNet
www.griefnet.org

**Mothers in Sympathy & Support
(MISS)**
www.missfoundation.org

National SHARE office
www.nationalshareoffice.com

National SIDS/ID Resource Center
www.sidscenter.org

Pen Parents Inc.
www.penparents.org

RESOLVE
www.resolve.org

■ Books

Some of these books may be borrowed from the Lending Library of the CSHCS Family Center for Children and Youth with Special Health Care Needs. To check, call the CSHCS Family Phone Line at 1-800-359-3722.

1. **After the Darkest Hour the Sun Will Shine Again: A parent's guide to coping with the loss of a child**
Elizabeth Mehren, Harold Kushner, 192 pages, Fireside (1997)
2. **A Broken Heart Still Beats: After your child dies**
Anne McCracken, Mary Semel, 328 pages, Hazelden Information Education (2000)
3. **A Child Dies, A Portrait of Family Grief**
Arnold, J. Hagan and P. Buschman, The Charles Publishers (1994)
4. **Confronting the Loss of a Baby: A Personal and Jewish Perspective**
Levy, Rabbi Yamin, KTAV Publishing House, Inc. (1998)
5. **Empty Cradle, Broken Heart: Surviving the death of your baby**
Deborah L. Davis, 280 pages, Fulcrum Publishers (Revised Edition 1996)
6. **New Fields and Other Stones: On a child's death: Poems**
Saul Bennett, 97 pages, Archer Books (1998)
7. **Surviving Pregnancy Loss: A Complete Sourcebook for Women and their Families**
Friedman, R. and B. Gradstein, Citadel Press (1996)

8. **The Bereaved Parent**
Harriet Sarnoff Schiff, Viking Press (1978)
9. **The Lively Shadow: Living with the death of a child**
Donald Murray, 208 pages, Ballantine Books (2003)
10. **When a Baby Dies: The Experience of Late Miscarriage, Stillbirth and Neonatal Death**
Kohner, N. and A. Henley, Harper Collins (1991)

■ Videos

“At a Loss for Words: How to Help Those You Care for in a Miscarriage, Stillbirth or Newborn Death Experience”

To order: 1-800-451-5006 or order@paraclete-press.com

“Footprints On Our Hearts: How to Cope After a Miscarriage, Stillbirth or Newborn Death”

To order: 1-800-451-5006 or order@paraclete-press.com





Culturally Effective Care

"Although our daughter's care team felt that my husband should have taken off work to attend each meeting,



WE needed to have him available every evening for her care time at the hospital."

Communicating Your Values

It is important for your child's health care team to be aware of values, beliefs, and practices that are common in your community and important to your family. Although your health team may be familiar with some of the general health care practices or norms for your culture, it is still very important for you to communicate your own personal feelings about how you would like to participate in the health care process.

Listed below are some points for families and health care professionals to keep in mind when seeking to increase cultural awareness in the health care setting.

■ Communication

1. "English as a primary language", does not always mean that everyone is able to understand every word spoken to him or her.
 - Ask questions when you do not understand a word or phrase.
 - Ask a person to slow down when giving you treatment options.
 - Bring another person who can help explain things to you.
2. "English as a secondary language", can mean that a person prefers to use as little English as possible.
 - Get the help of a trained/certified bilingual person to help you better understand information.
 - Ask for visual aids or physical gestures to help you.
 - Ask the person to rephrase the question or instructions if you do not understand the words he or she is using.

■ Values and Attitudes

1. "Family" can be defined in many ways. Share how you define your family members so your child's providers will understand the role they may have in your child's care plan. Let the staff know:
 - How important medical decisions are made in your family
 - Who the people are that need to hear the information from the provider
 - Who in your family provides you with the most support
2. "Health and well-being" means different things to different people. Understanding and sharing what this means for you and your family, can help a provider in developing a management plan. Let the staff know:
 - How you handle your emotions in public and in private
 - What you consider 'healthy' for your child with special needs
 - What you consider a 'good' place to be in their health care
 - What foods you and your child eat to promote good health

3. Religion and other beliefs often influence how families respond to illness, disease, disability and death. Awareness of your belief system will give your child's health care providers a better understanding of what is important to your family. The medical and support staff may wish to know:
- How does your family typically celebrate the birth of a child?
 - What activities does your community offer for families of infants and toddlers?
 - What type of response might you get from your community about your child with special needs?
 - What are the cultural expectations for self-help skills such as dressing and feeding?

■ Translation Services

Good communication is an important key to better health outcomes. Sometimes your child's health provider may come from a different ethnic or cultural background than your family. A language difference may make it difficult for you to understand one another, but remember that what you have in common is a desire to help your child.

Most large hospitals and outpatient clinics are able to provide an interpreter (for the most common languages) if you request one. Be sure to let the office know an interpreter is needed when scheduling your child's appointment. In addition, when calling state programs such as Children's Special Health Care Services, please let them know you need an interpreter to translate for you over the phone, and they will try to connect you with one.

There are many organizations in Michigan that provide language translation services. The services may include translating written documents, interpreting speech, or both. Some translation agencies may charge a fee for their services.

To find a translator, check the yellow pages of your local telephone book under "Translations" or "Translators".

Interpreters may be found through community or government agencies, attorneys, colleges or universities, or translation-related businesses. Translators are not certified by the State of Michigan.

Although English is the primary language for most families in Michigan, there could be a time when you or someone you know might need to have medical care given - either written or spoken - in a different language.

Families may also find health care and other kinds of assistance offered in their native language through community-based organizations. A list of some of the resources available in Michigan for different ethnic groups is included in the next section.

Ethnic Community Resources*

■ Arab-American, Arabic

Arab Community Center for Economic & Social Services (ACCESS):

Main Location

2651 Saulino Ct.
Dearborn, MI 48120
Phone: 313-842-7010
Fax: 313-842-5150

East Location

6451 Schaefer Rd.
Dearborn, MI 48126
Phone: 313-945-8380
Fax: 313-846-4713

Health Services: Community Health & Research Center

6450 Maple St.
Dearborn, MI 48126
Phone: 313-216-2200
Fax: 313-584-3206

www.accesscommunity.org

Arab American and Chaldean Council

Offices in Detroit, Oakland and Macomb counties
28551 Southfield Rd.
Lathrup Village, MI 48176
Phone: 248-559-1990

www.arabacc.org

■ Asian Indian

Michigan Asian Indian Family Services

PO Box 252673
West Bloomfield MI 48325
Phone: 248-477-4985
Crisis Line: 1-888-664-8624

www.maifs.org

* This list is provided for informational purposes only and does not represent an endorsement by the Michigan Department of Community Health. The list may not be complete but is based on information available at the time of printing. Additional services may be identified through your local public health department, community mental health, telephone book, library, or other sources.

■ Hispanic/Latino, Spanish

Child and Family Services of Western Michigan, Inc.

412 Century Lane
Holland, MI 49423
Phone: 616-396-2301
Fax: 616-396-8070
www.cfswm.org/latino.htm

Healthy Start/Healthy Families Oakland

Contact: Teresa Rangel
44405 Woodward Ave, Ste H19
Pontiac, MI 48341
Phone: 248-335-5638 X9 (for Spanish)
Fax: 248-335-6404

El Centro “La Familia”

35 W. Huron, Ste 200
Pontiac, MI 48342
Phone: 248-858-5320
Fax: 248-858-1604

Detroit Hispanic Development Corporation

1211 Trumbull
Detroit, MI 48216
Phone: 313-967-4880
Fax: 313-967-4884
TDD: 1-800-649-3777
www.dhdc1.org

Latino Family Services, Inc.

3815 W. Fort St.
Detroit, MI 48216
Phone: 313-841-7380
Fax: 313-841-3730

Hispanic American Council, Inc.

1356 Portage Rd., Suite A
Kalamazoo, MI 49001
Phone: 269-385-6279
Fax: 269-385-2803

“During one of our visits in the NICU, a parent could not understand what the nurse was telling her because she had very limited English. The next time I saw them, they had an interpreter with them.”

■ Native American

Inter-Tribal Council of Michigan, Inc.

2956 Ashmun St.
Sault Ste. Marie, MI 49783
Phone: 906-632-6896
Toll Free: 1-800-562-4957, 1-877-482-3601
www.itcmi.org

U.S. Department of Health and Human Services - Indian Health Service

Bemidji Area (Serves Michigan, Minnesota, Wisconsin, Illinois and Indiana)
522 Minnesota Ave., NW, Room 119
Bemidji, MN 56601
Phone: 218-444-0458
www.ihs.gov

■ Russian

Michigan Russian Cultural Center

529 Grove St.
Clawson, MI 48017
Phone: 248-288-6834
www.russiangulturalcenter.com

Protection and Advocacy for People With Special Needs

Families caring for a child with special needs may experience unexpected hurdles relating to different aspects of everyday life. Certain laws have been created to protect people with different types of disabilities. Advocacy groups can help you find out about different services that are available to your child, as well as the laws that protect your rights and theirs.

■ The Americans with Disabilities Act (ADA) of 1990

The purpose of the ADA is to ban discrimination on the basis of disability, just as we have protection from discrimination on the basis of race, sex, religion and national origin. The ADA protects against discrimination related to employment, transportation, state and local government services, public accommodations and telecommunications. For more information, visit www.ada.gov or www.disability.gov.

■ Advocacy (Help) Organizations

Listed below are some key resources to help you find an advocate for dealing with your child's special health care or educational needs.

ARC/Advocacy & Resource Center

665 136th Ave. #90

Holland, MI 49424

Phone: 616-738-8570

Toll Free: 800-678-0995

Fax: 616-738-9340

www.arc-resources.org

CAUSE (Citizens Alliance to Uphold Special Education)

Lansing Main Office

6412 Centurion Drive, Suite 130

Lansing, MI 48917

Phone: 517- 886-9167

Toll-free: 1-800-221-9105

Fax: 517-886-9366

www.causeonline.org

Detroit Office

15565 Northland Drive, Suite 506 E

Southfield, MI 48075

Phone: 248-424-9610

Toll-free: 1-800-298-4424

Fax: 248-424-9620

Michigan Commission on Disability Concerns

Department of Labor and Economic Growth

201 N. Washington Square, Suite 150

Lansing, MI 48913

Phone: 517-335-6004 (voice/TTY)

Toll-Free: 1-877-499-6232

Fax: 517-335-7773

E-mail: mcdc@michigan.gov

Michigan Developmental Disabilities Council

1033 S. Washington Avenue

Lansing, MI 48910

Phone: 517-334-6123

TDD: 517-334-7354

Fax: 517-334-7353

E-mail: vonhornr@michigan.gov

www.michigan.gov/ddcouncil

Michigan Protection and Advocacy Service, Inc.

Lansing Office (Central Office)

4095 Legacy Parkway

Suite 500

Lansing, MI 48911-4263

Phone: 517-487-1755 (voice/TTY)

Toll-Free: 800-288-5923 (voice/TTY)

Fax: 517-487-0827

www.mpas.org

Resources for People With Hearing and Vision Loss

Vision and hearing loss may cause a barrier in communication between a family and their child's health care team. Children and/or parents who have hearing or vision loss may benefit from the following support services and organizations.

Communication Access Center

1631 Miller Rd.
Flint, MI 48503
Phone: 810-239-3112
Fax: 810-239-1606
E-mail: info@cacdhh.org

DB (Deaf-Blind) Central

Central Michigan University
Sloan 105
Mount Pleasant, MI 48859
Phone: 989-774-2725 (voice/TTY)
Toll-Free: 1-888-758-0508 (voice/TTY)
Fax: 989-774-1572
www.chsbs.cmich.edu/dbcentral



DEAF Community Advocacy Network (DEAF C.A.N.)

2111 Orchard Lake Rd #101
Sylvan Lake, MI 48320
Phone: 248-332-3331 (voice)
248-332-3323 (TTY)
Fax: 248-332-7334
www.deafcan.org

Deaf Options, Inc.

Human Service Agency for Deaf and Hard of Hearing Individuals
220 Bagley, Suite 600
Detroit, MI 48226-1420
Phone: 313-961-8120 (voice)
313-961-8118 (TTY)
Fax: 313-961-9168

Michigan Association for Deaf and Hard of Hearing

2929 Covington Court, Suite 200
Lansing, Michigan 48912-4939
Toll-free: 1-800-YOUR-EAR (voice/TTY)
Phone: 517-487-0066 (voice)
517-487-0202 (TTY)
Fax: 517-487-2586
E-mail: yourear@madhh.org
www.madhs.org

Michigan Commission on Disability Concerns & Division on Deaf and Hard of Hearing (MCDC-DODHH)

Department of Labor and Economic Growth
Toll-Free: 1-877-499-6232 (voice/TTY)
Phone: 517-335-6004 (voice/TTY)
www.mcdc-dodhh.org (Link to Michigan Disability Resource and Interpreter Directory)

Michigan Relay Center: a statewide telephone service allowing Deaf, Hard of Hearing, or Speech Impaired persons to communicate via TTY with a hearing person who does not have a TTY with the assistance of a specially trained operator. Call toll-free **1-800-649-3777**. MRC also provides informational seminars. For voice, call toll-free **1-800-432-5413**, supervisor's line. Service available 24 hours, 7 days a week.

Michigan School for the Deaf and Blind

Specialized statewide school in Flint for preschool through 12th grade children who are Deaf and/or Blind. Students can live on campus or commute from home daily.
Toll-free: 1-800-622-6730 (TTY/Voice)
www.cenmi.org/msdb-LIO
Visually Impaired Helpline: 1-800-622-6730 (press 1, then 1489)



Keeping Track of Information

"We got so much information from all of our child's providers - for just about every procedure that was done. It was hard to keep track of so much information at one time."



Create a Care Notebook for Your Child

It is a good idea to keep track of your child's health care providers, medications, and other important information. Write down new provider names, phone numbers, medications, etc. as you get them, and then keep the information all together in a notebook or file folder stored in a handy place. Several organizations have developed helpful worksheets and other suggestions on how to create a care notebook. The links to these websites are provided below. On the following pages, we have also provided some forms that may help you start organizing basic information about your child.

Care Notebook and Care Organizer, from the Center for Children with Special Needs, Children's Hospital and Regional Medical Center; Seattle, WA. Download care notebook forms, or order a notebook and/or organizer (\$20 each) from this site.

www.cshcn.org/resources/CareNtbk.cfm

Emergency Information Form for Children with Special Needs, was created by the American Academy of Pediatrics and the American College of Emergency Physicians and is available at <http://aap.org/advocacy/blankform.pdf>

Healthy and Ready to Work National Center: Child Health Status Assessment Forms
Multiple forms and checklists for assessing your child's daily medical state, daily schedule and medication forms, forms for describing and holding a photo of your child in a stable medical state, insurance worksheets, and additional forms.

www.hrtw.org/tools/hrtw_go_tools_curr.php#

The Maine Health Care Notebook. Includes step-by-step instructions for setting up a care notebook, along with numerous forms for keeping track of medical care, finances, emergency information, etc.

www.ccids.umaine.edu/service/maineworks/carenotebook.htm

Washington State Medical Home

Organizing Your Paperwork

www.medicalhome.org/families/paperwork.cfm

Medical Resume

Name	Last	First	Middle
Birth information	Date of Birth	Pregnancy/Delivery Complications	
Diagnosis			
Medications			
Allergies	Medicines	Other (latex, foods, etc)	
Surgeries	Type	Surgeon	Date
Primary Care Physician	Name	Address	Phone
Parent/ Guardian	Name	Address	Phone
Emergency Contact	Name	Address	Phone
Insurance Information			
Medicaid/ CSHCS ID #			

How to Contact My Child's Doctors

Primary Focus of Treatment

Name

Specialty

Clinic/Hospital

Address

City

State

Zip Code

Phone

Primary Focus of Treatment

Name

Specialty

Clinic/Hospital

Address

City

State

Zip Code

Phone

Primary Focus of Treatment

Name

Specialty

Clinic/Hospital

Address

City

State

Zip Code

Phone

Primary Focus of Treatment

Name

Specialty

Clinic/Hospital

Address

City

State

Zip Code

Phone

How to Contact My Child's Service Providers

Service(s)

Agency

Contact Person (Case Manager, Public Health Nurse, Service Coordinator, Therapist etc.)

Address

City

State

Zip Code

Phone

Service(s)

Agency

Contact Person (Case Manager, Public Health Nurse, Service Coordinator, Therapist etc.)

Address

City

State

Zip Code

Service(s)

Agency

Contact Person (Case Manager, Public Health Nurse, Service Coordinator, Therapist etc.)

Address

City

State

Zip Code

Phone

Service(s)

Agency

Contact Person (Case Manager, Public Health Nurse, Service Coordinator, Therapist etc.)

Address

City

State

Zip Code

Phone

Information for Care Givers

All About _____
(Child's Name)

Way of Communicating (Gestures, Signs, Words, Device)			
Daily Routine	Meal times	Snack times	Nap times
Favorites	Foods	Music/songs	Toys/games
	Activities		Calming techniques (back rub, stories, hugging, singing)
Dislikes/Fears			
Allergies			
Special Care Needs	Morning	Afternoon	Evening
	Medical Equipment		
Emergency Phone Numbers			

Preparing for Special Medical Occasions

You may wish to write down your questions and take this form to your doctor's office, or take notes when discussing information about additional medical care for your child such as special tests, referrals to specialists, surgeries and hospitalizations. Questions to think about regarding these occasions can be found on pages 38 - 40 of this guidebook.

Tests

Referral to Specialist or Clinic

Surgery

Hospitalization

My Child's Development

Recording a child's milestones can be a fun way to keep track of progress. It is also an important tool to help spot possible delays in development as early as possible.

My Child:

At Age:

- | | |
|----------------------------|-------|
| Smiled | _____ |
| Laughed | _____ |
| Rolled | _____ |
| Back to stomach | _____ |
| Stomach to back | _____ |
| Sat alone | _____ |
| Crawled | _____ |
| Pulled self to standing | _____ |
| Walked | _____ |
| Clapped hands | _____ |
| Waved | _____ |
| Played peek-a-boo | _____ |
| Held Bottle | _____ |
| Fed self | _____ |
| <u>Speech</u> | |
| Babbled more than 2 sounds | _____ |
| Used Words/Signs | _____ |
| Spoke in Phrases | _____ |

Notes on other observations:



Glossary

"We were glad that medical terms were explained to us but trying to repeat them back to family members became quite a task."

- A mother from central Michigan



Commonly Encountered Medical Terms

You might hear many terms used to describe your child's health status. Here is a list of commonly used medical terms with a brief definition. This glossary was adapted from the USA Birth Defects Genetic Center located at www.southalabama.edu/genetics/bdgc/parentjournal. To find other medical terms not included here, visit www.nlm.nih.gov/medlineplus/mplusdictionary.html.

- **Abrasions** – Rubbing or scraping of the surface layer of cells or tissue from an area of skin or mucous membrane by friction.
- **Abscess** – A cavity containing pus, surrounded by inflamed tissue, a result of localized infection.
- **Acute** – A condition beginning abruptly with sharp or severe intensity, then subsiding shortly after.
- **Anaphylactic Shock** – A severe, sometimes fatal systemic hypersensitivity reaction to a substance, drug, vaccine, food, serum, allergen, venom or chemical.
- **Anemia** – A decrease in hemoglobin in the blood levels to below normal range.
- **Apnea** – Abnormal periods when breathing stops.
- **Arterial** – Of or pertaining to an artery (leads to the heart).
- **Asthma** – Recurring attacks of breathlessness, characteristically accompanied by wheezing when breathing out and varying in severity from day to day.
- **Benign** – Not endangering health or life; not malignant.
- **Blood Gas** – A test for determining the pH and concentrations of oxygen, carbon dioxide, nitrogen, and bicarbonate in the blood.
- **Blood Sugars** – The concentration of glucose in the blood.
- **Bowel Sounds** – A rumbling sound made by the movement of gas in the intestine.
- **Bradycardia** – Slowness of the heart, manifested in a pulse rate usually less than 60 beats per minute.
- **Bronchopulmonary Dysplasia (BPD)** – A chronic lung condition that is caused by tissue damage to the lungs, marked by inflammation exudate, scarring, fibrosis, emphysema, usually occurring in immature infants who have received mechanical ventilation and/or supplemental oxygen as treatment for respiratory distress syndrome.

- **Cardiovascular** – Related to or involving the heart and blood vessels.
- **Cerebral Palsy (CP)** – A disability resulting from damage to the brain before, during, or shortly after birth and outwardly manifested by muscular incoordination and speech disturbances.
- **Cerebrospinal Fluid (CSF)** – The fluid that flows through and protects the ventricles, brain, and spinal canal.
- **Chest Percussion Therapy** – Systematic pounding on the chest in order to loosen chest congestion.
- **Chronic** – A condition developing slowly and persisting for a long period of time (often lifetime condition).
- **Circulation** – The movement of blood through the vessels of the body that is induced by the pumping action of the heart and serves to distribute nutrients and oxygen to and remove waste products from all parts of the body.
- **Cleft** – Divided; a fissure.
- **Cognition/Cognitive** – The mental process characterized by knowing, thinking, learning, and judging.
- **Colostomy** – Surgical formation of an artificial anus by connecting the colon to an opening in the abdominal wall.
- **Congenital** – Present at birth.
- **Continuous Positive Airway Pressure (CPAP)** – In respiratory therapy; ventilation assisted by a constant air flow delivered throughout the respiratory cycle.
- **Contractures** – Shrinkage of scar tissues, connective tissues, or shortening of the muscles and tendons, producing distortion or deformity.
- **Cutaneous** – Of or pertaining to the skin.
- **Cutdown** – An incision into a vein to insert a catheter for intravenous infusion.
- **Dehydration** – An excessive loss of water from the body tissues.
- **Diagnosis** – Identification of a disease or condition by scientific evaluation.
- **Discharge** – To release a substance or object.
- **Distended** – To be swollen from a force within.
- **Do Not Resuscitate (DNR); No Code** – A written order by a qualified physician instructing not to attempt to resuscitate a particular patient in the event of cardiac or respiratory failure; usually only written for patients that are gravely ill, death is imminent, or death is inevitable.

- **Edema** – Excessive accumulation of fluid in the tissue spaces; swelling.
- **Elimination** – Bodily discharges including urine, feces, and vomit.
- **Emesis** – Medical term for vomit.
- **Epilepsy** – A neurological disorder characterized by recurrent seizures; uncontrolled electrical discharge from the nerve cells of the cerebral cortex (in the brain).
- **Extremity** – A limb of the body; the distal or terminal end; (ex.: a human hand or foot).
- **Exudate** – Material composed of serum, fibrin, and white blood cells that escapes from blood vessels into a superficial lesion or area of inflammation.
- **Febrile** – Feverish or related to fever or rise in normal body temperature.
- **Fissure** – A cleft or groove on the surface of an organ.
- **Fistula** – An abnormal passage from an internal organ to body surface or between two internal organs.
- **Flaccid** – Weak, soft, flabby, relaxed; lacking normal muscle tone.
- **Fontanel/Fontanel** – One of the two soft areas on a baby's scalp, a membrane-covered gap between the bones of the skull.
- **Fusion** – The act of uniting; bringing together into a single entity; uniting two or more bones.
- **Gag Reflex** – A normal reflex elicited by touching the soft palate or back of the tongue.
- **Gastrointestinal** – Part of digestive system that consists of the mouth, esophagus, stomach, intestine, and anus.
- **Gastrostomy Tube (G-tube)** – A latex or plastic tube inserted in a surgical opening in the stomach to provide nourishment.
- **Hemiparesis** – Muscular weakness or partial paralysis affecting one side of the body only.
- **Hemoglobin** – The oxygen-carrying pigment found in the red blood cells, carries oxygen to lungs and other body tissues.
- **Hemorrhage** – A rapid loss of a large amount of blood externally or internally.
- **Hereditary** – Pertaining to a characteristic, condition, or disease transmitted from the parent.
- **Hernia** – The abnormal protrusion of an organ or a part through the containing wall of its cavity.

- **Hydrocephalus** – Abnormal accumulation of cerebrospinal fluid in the ventricles within the skull cavity causing increased pressure.
- **Hyper** – A prefix meaning excessive, above, or beyond.
- **Hypo** – A prefix meaning less than normal, under, beneath, or deficient.
- **Hypoglycemia** – Low level of glucose in the blood.
- **Hypotonia** – Excessive limpness in any body part.
- **Ileostomy** – Surgical formation of an artificial anus by connecting the ileum to an opening in the abdominal wall, through which fecal matter is emptied.
- **Immunosuppressed** – When the immune response is reduced or absent.
- **Input** – Amount of fluids put into the body.
- **Insulin** – A hormone that regulates the level of glucose in the blood.
- **Intubation** – Passage of a tube into the trachea to provide an open airway.
- **Irritability** – Showing signs of being fretful, fussy, touchy and sensitive.
- **Jejunal Tube (J-tube)** – Artificial opening made through the abdomen into the jejunum (part of the small intestine) where a small latex or plastic tube is placed to provide nourishment.
- **Juvenile Diabetes** – An inability to metabolize carbohydrate caused by an overt insulin deficiency; occurring rapidly in children, eventually leading to a dependency on insulin.
- **Ketoacidosis** – Complication of diabetes; an accumulation of ketones in the body that results from by products of fat metabolism when glucose is not available for a fuel source in the body.
- **Labile** – Unstable; characterized by a tendency to change rapidly.
- **Laceration** – A torn and ragged wound.
- **Lethargy** – The state of being indifferent, apathetic, or sluggish; abnormal drowsiness.
- **Leuko** – Of or pertaining to a white corpuscle (blood cell).
- **Local** – limited to a part or place; not generalized.
- **Malignant** – Tending to infiltrate, metastasize, become worse and cause death.
- **Meningitis** – Any infection or inflammation of the membranes covering the brain or spinal cord.

- **Mental Retardation (MR)** – Below average intellectual ability that is equivalent to or less than an IQ of 70, occurs during the developmental period, and is manifested especially by abnormal development, cognitive impairment and problems in social adjustment.
- **Metabolic** – Pertaining to metabolism (all chemical processes in living organisms).
- **Mobility** – The ability to move independently.
- **Musculoskeletal** – Involving all muscles and bones in the human body.
- **Myelomeningocele** – Spina bifida; developmental defect in which a sac containing a portion of the spinal cord, its meninges (membranes), and cerebrospinal fluid protrudes from the spinal column.
- **Nasogastric Tube (NG – tube)** – A tube passed in through the nose to the stomach to provide nourishment or suction excess gastric fluids out.
- **Nebulizer** – A device to produce a fine aerosol spray for dispersing liquid
- **Necrosis** – Localized tissue death.
- **Neurology** – The scientific study of the nervous system especially in respect to its structure, functions, abnormalities, and disorders.
- **Nystagmus** – Involuntary, rhythmic, oscillatory movements of the eyes.
- **Obstruction** – A condition of being clogged or blocked.
- **Obturator** – A device that closes or blocks an opening.
- **Occipital** – Of or pertaining to the occiput (the back of the head).
- **Ocular** – Of or pertaining to the eye.
- **Ophthalmologist** – A branch of medical science dealing with the structure, functions, and diseases of the eye.
- **Optic** – Pertaining to the eye, sight, or vision.
- **Oral** – Of or pertaining to the mouth.
- **Orth-/Ortho** – Straight, upright, normal, or correct.
- **Osteo** – Of or pertaining to the bone.
- **Ostomy** – Surgical procedure where an opening is made to allow passage.
- **Otic-/Ot** – Of or pertaining to the ear.
- **Output** – Total amount of fluid removed or emptied from the body.

- **Paralysis/Paralyses** – Abnormal condition characterized by loss of muscle function, tone, or sensation.
- **Patent** – The condition of being open and unblocked.
- **Peak Flow** – To perform peak expiratory flow rate (PEFR) assessments.
- **Percutaneous** – Procedure performed through the skin.
- **Peripheral** – Of or pertaining to the outside, surface, or surrounding area.
- **Prognosis** – A prediction of the probable outcome of a disease.
- **Prone** – Lying face down on the stomach.
- **Pulse** – A rhythmical beating or vibrating movement of blood corresponding to heart beat, usually counted at the wrist.
- **Rales** – Airflow with abnormal moisture, heard when listening to lungs during inspiration.
- **Reactive Airway Disease (RAD)** – irritant-induced asthma.
- **Reflux** – Abnormal backward flow of fluids.
- **Renal** – Of or pertaining to the kidney.
- **Respiration** – Single complete act of breathing including inhale and exhale.
- **Resuscitation** – Process of sustaining the vital functions during respiratory or cardiac failure.
- **Retractions** – Visible sinking of the soft tissues of the chest area with increased breathing effort.
- **Rhonchi** – Abnormal sounds of airway caused by thick secretions, spasm, or pressure; a rumbling sound more pronounced during expiration that can clear with a cough.
- **Rigidity** – A condition of hardness, stiffness, or inflexibility.
- **Rupture** – A tear or break in an organ or body tissue.
- **Scoliosis** – Lateral curvature of the spine.
- **Seclusion** – The isolation of a patient to decrease harmful stimuli.
- **Secretions** – Releasing some material either functionally specialized (as saliva) or isolated for excretion (as urine).
- **Sedation** – Induced state of quiet, calmness, or sleep by means of hypnosis or medication.

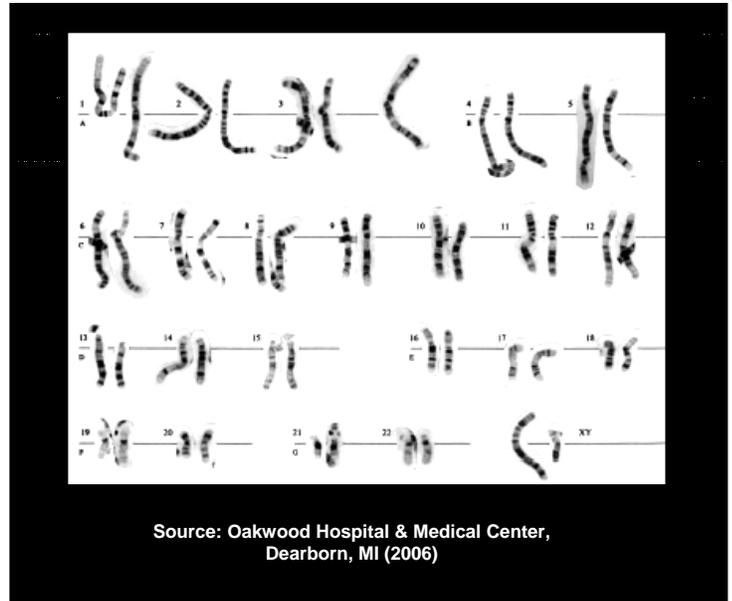
- **Spina Bifida** – A congenital opening of the spinal column with protrusion of the meninges and sometimes the spinal cord.
- **Stridor** – An abnormal, high-pitched, musical respiratory sound caused by an obstruction.
- **Suctioning** – To remove fluid from a body cavity or passage by suction device.
- **Supine** – Lying face up, on the back.
- **Syndrome** – Signs, symptoms resulting from a common cause, presenting a clinical picture.
- **Tepid** – Moderately warm to the touch.
- **Terminal** – Relating to, or being at an end or a body part that forms an end (such as a nerve ending); leading to death, or being close to death; being in the final stages of a fatal disease.
- **Tidal Volume** – Volume of air that passes in and out of the lungs in an ordinary breath.
- **Volume** – The amount of space a substance fills.
- **Voluntary** – Pertaining to an action or thought as a result of a person's free will or choice.
- **Wheeze** – A whistling or sighing noise produced in the act of breathing. It signifies partial obstruction of one or more of the air passages due to spasm, edema, inflammation, foreign body, tumor, or external pressure.

Understanding Genetics

If you have been told your child has a chromosomal or genetic condition, you may want to learn more about what that means. Here are some definitions of the words that might be used to describe the cause of your child's birth defect.

■ Chromosomes

Chromosomes are the structures that carry the genetic material (DNA). They are found in almost all of the cells of the body. Chromosomes are very small and can only be seen under a microscope. In humans, the usual number of chromosomes is 46 (23 pairs). Twenty-two pairs of the chromosomes are called **autosomes**. Autosomes are the same in both males and females, and labeled using numbers (1 to 22). The longest chromosome pair is labeled #1, while the shortest chromosome pair is labeled #22. The twenty-third pair of chromosomes differs between males and females. This pair is the **sex chromosomes**. Sex chromosomes are labeled with an X and Y. Females usually have two copies of the X chromosome while males usually have one copy of the X chromosome and one copy of the Y chromosome.



Source: Oakwood Hospital & Medical Center, Dearborn, MI (2006)

Egg and sperm cells are different than all the other cells in the body. They contain only one copy of each chromosome, for a total of 23 chromosomes in each of these cells. When egg and sperm join at the time of conception, the number of chromosomes returns to a total of 46.

As chromosome pairs divide in the process of egg and sperm cell formation, mistakes sometimes occur. This may result in an abnormal number of chromosomes either in the egg or sperm cells. Abnormal division of the chromosomes (called nondisjunction) happens more often in egg than sperm cells. It can happen at any age, but the chance is higher as a mother gets older.

When a chromosome pair does not divide properly, a fetus may receive only one copy (**monosomy**) or three copies (**trisomy**) of a particular chromosome. More rarely, pregnancies may be conceived with structural differences (pieces added or missing) in the chromosomes. A child may have different medical and learning problems depending on the type of chromosome abnormality.

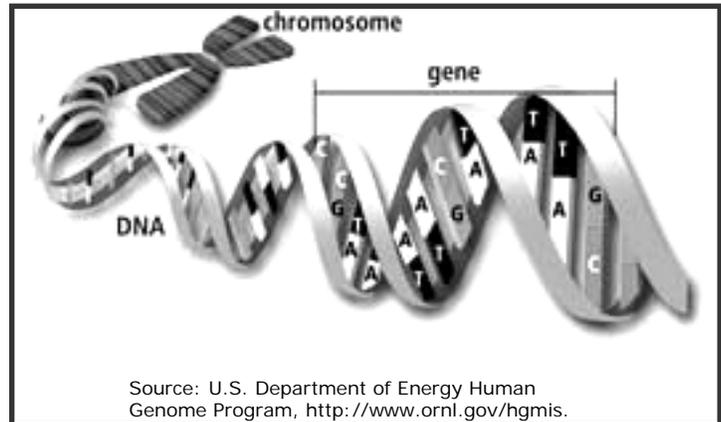
Mother's age	Risk of Chromosome Problem
25	Less than 1 in 500
30	1 in 500
35	1 in 140
40	1 in 40

■ DNA

DNA stands for “Deoxyribonucleic Acid”. It is the major biochemical substance found in chromosomes. Segments of DNA make up the genes.

■ Genes

Genes are the biochemical messages that code for traits and features. They direct the cells how to make proteins that form body structures, as well as proteins that work as enzymes or hormones to carry out tissue and organ functions. The genes are made of DNA within the chromosomes. One copy of each gene (from mother) and one copy of each gene (from father) are contained in each chromosome of a pair. Therefore, two copies of every gene are found in cells. People are



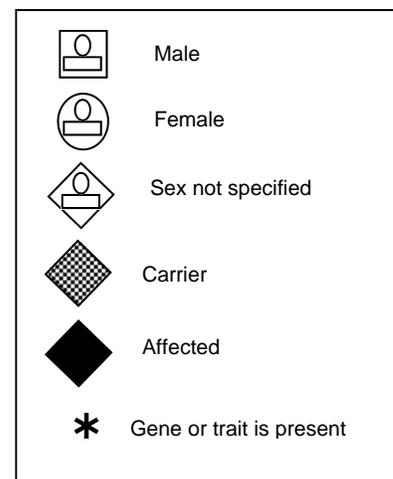
estimated to have about 20,000 different genes. They determine physical features like eye and hair color, height and other traits. Genes also provide instructions for how the body develops and works. Except for identical twins, no two people have the exact same set of genes, although children share half of their genes with each parent.

■ Genetic Syndromes

The term “syndrome” refers to physical features and/or specific health problems that often occur together. Genetic syndromes may result if one or both copies of a gene carry a change (mutation) that causes it not to work properly. Genetic syndromes often affect the body’s physical features as well as how organs work, including the brain. Some examples of genetic syndromes are included in the table on inheritance of common birth defects.

■ Inheritance

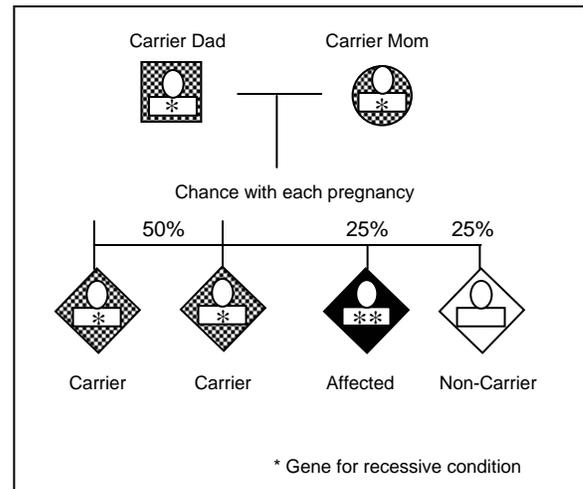
Genetic syndromes may occur in a child by chance alone, as the result of a new mutation in a gene. They can also be inherited, or passed down within the family. Different syndromes are inherited in different ways. The most common forms of inheritance include: autosomal **recessive (AR)**; autosomal **dominant (AD)**; **X-linked (XL)**; and **multifactorial (MF)**. The term “autosomal” means the gene is located on one of the non-sex chromosomes (#1 through #22). The term “X-linked” means the gene is located on the X chromosome. The chromosomal location of many genes causing genetic syndromes is now known. The term “multifactorial” means there are multiple genes and perhaps other factors that contribute to the cause of a condition. Genetics professionals draw family trees or “pedigrees” to assess how a condition or syndrome may be inherited in a family. The symbols in the box are used in the diagrams on the next pages to help you better understand the different patterns of inheritance.



Autosomal Recessive conditions occur when a pair of genes is abnormal. The term “recessive” is used because the disorder is usually hidden when a person has a normal gene in addition to the abnormal or non-working one. Everyone has several abnormal recessive genes. However, recessive disorders do not usually show up unless both copies of the genes in a pair do not work properly. When both parents are carriers, they each have one normal and one abnormal or non-working gene. Different gene combinations may be passed down to their children.

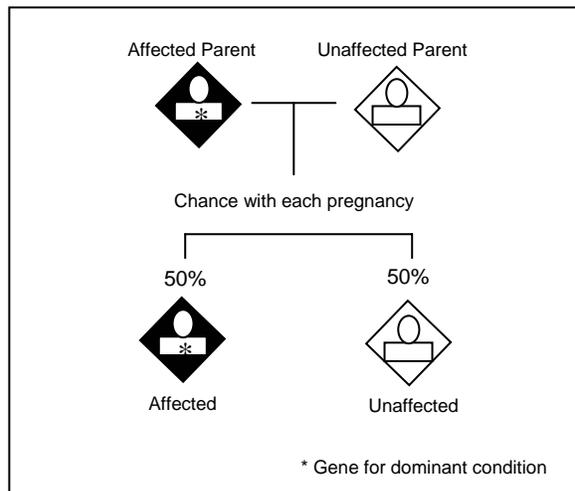
As shown in Figure 1, autosomal recessive conditions can affect both boys and girls. The chance for an affected child is 1 in 4 (25%) with each pregnancy when both parents are carriers of the same abnormal gene. The chance for a carrier child is 1 in 2 (50%) when both parents are carriers. The chance is 1 in 4 (25%) that the child will not be affected or a carrier. Often there is no prior family history of the recessive genetic disorder. The abnormal gene can be passed down for many generations before a child is born affected with the disorder.

Figure 1



Autosomal Dominant conditions result from a single abnormal gene. A change or mutation within the gene causes it to not work properly. The term “dominant” is used because the disorder will usually occur even when the other gene of the pair is normal. Rarely, a child will be born with two copies of an abnormal dominant gene. When this occurs, a very severe form of the disease may result. A parent who carries one copy of a dominant gene mutation is usually affected with the disorder. He or she may pass it to a child. The child receiving the gene mutation will also be affected. In rare instances, a person inheriting the gene mutation will not be affected. However, the unaffected person could still pass the mutation on to his or her child.

Figure 2



Autosomal dominant conditions affect both boys and girls. Figure 2 shows that when a parent carries a dominant gene mutation, there is a 1 in 2 (50%) chance with each pregnancy that the child will inherit the abnormal gene. There is a 1 in 2 (50%) chance that the child will inherit the normal gene, and not be affected by the condition at all. Children who inherit a gene mutation may have signs and symptoms similar to the parent. However, they can also have more severe or milder symptoms. Dominant conditions can also occur without any previous family history. In this case, the gene change arises for the first time in a child. This is called a sporadic or “de novo” gene mutation. In the case of sporadic mutations, siblings (brothers and sisters) of the child with the disorder are likely not at a significant risk.

X-Linked conditions occur when there is a change or mutation in a gene on the X chromosome. Because males typically have only one X chromosome (in addition to a Y chromosome) they have only one copy of every X-linked gene. If a gene on the X chromosome is abnormal because it contains a change or mutation, a male will be affected with signs of the disorder. On the other hand, females typically have two copies of the X chromosome, and therefore have two copies of every X-linked gene. Because most X-linked disorders are recessive, females who have only one copy of the mutation are unlikely to have serious signs or symptoms.

When a father has an X-linked gene mutation, he will likely be affected with symptoms of the disorder. His sons cannot inherit the X-linked condition because boys receive the Y chromosome from their father, and not the X. However, daughters will always inherit the X-linked mutation from their father. (Figure 3) They will all be carriers, but likely not affected by the disorder presuming their mother is not a carrier.

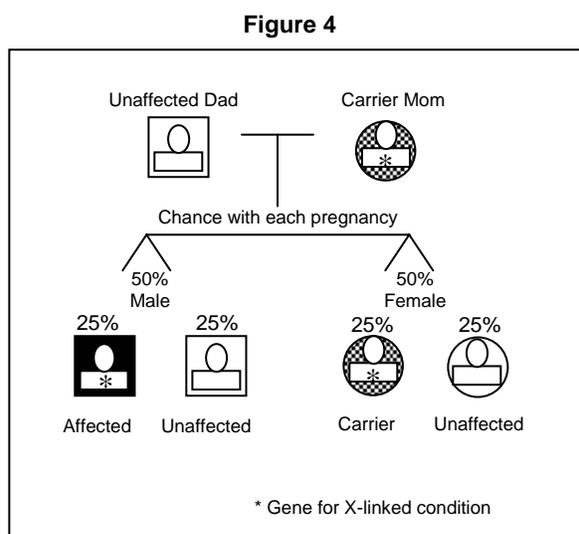
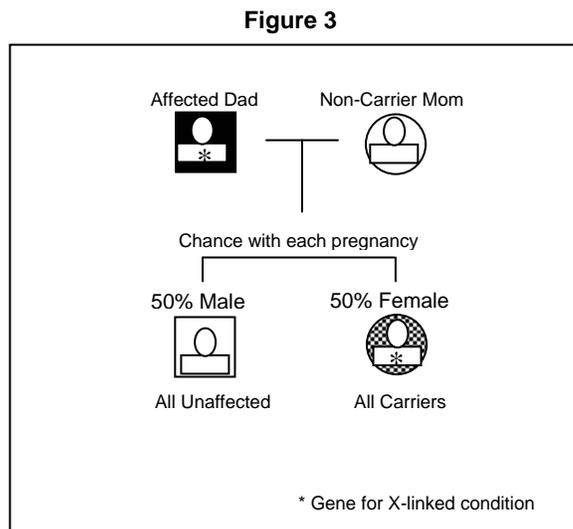


Figure 4 shows that when a mother carries an X-linked gene mutation, there is a 1 in 4 (25%) chance overall with each pregnancy that a son will be born affected with the condition, and a 1 in 4 (25%) chance of having a daughter who is a carrier. Once it is known that the baby is a girl, there is a 1 in 2 (50%) chance she has inherited the abnormal gene, but she will be a carrier like her mother, and usually not affected with the condition. When the baby is known to be a boy, there is a 1 in 2 (50%) chance that he received the abnormal gene and will have symptoms of the disorder.

Multifactorial Inheritance is the cause of many common birth defects and health problems. “Multifactorial” means that many factors can cause the disorder. The factors are both environmental and genetic. The environmental part of most multifactorial disorders is often unknown. A lack of certain vitamins or an exposure to certain medications may be environmental factors increasing the risks for certain birth defects.

The genetic part of most multifactorial disorders is not always clear-cut. One change within a single gene is probably not the cause. More likely, a number of genes passed to a child by mother and father are the contributing factors. The child who has received many variant genes from both parents is at an increased risk for a multifactorial disorder.

If no family history is found, the chance of an affected child is based on how common the disorder is in the general population. After one affected child is born, the risk for a second

affected child rises to about 3-5%. For certain conditions the risk for a second affected child may be higher if the first affected child's problem is severe. When one parent is affected with the disorder the risk for an affected child is approximately 3-5%. Risks for a second affected child after an affected child is born to an affected parent will be higher than 3-5%.

Summary of Inheritance Patterns		
Type of Inheritance	Description	Risk to offspring with each pregnancy
Autosomal Recessive (AR)	<ul style="list-style-type: none"> • Both males and females affected. • Multiple siblings may be affected. • Parents of affected child are carriers without any symptoms. • Parents of affected child may or may not be blood related. 	1 in 4 (25%) when both parents are carriers
Autosomal Dominant (AD)	<ul style="list-style-type: none"> • Both males and females affected. • May affect family members in more than one generation. • Severity may vary in different family members. • Disease may arise in affected person for the first time due to new mutation. • Unaffected parents at low risk for second affected child. 	1 in 2 (50%) when one parent affected
X-linked (XL)	<ul style="list-style-type: none"> • Incidence of the disorder much greater in males. • Female carriers unaffected or mildly affected. • Affected male transmits gene to carrier daughters. • Affected male can not transmit gene to sons. • Affected males in family are related through females. 	1 in 2 (50%) for son when mother is carrier
Multifactorial (MF)	<ul style="list-style-type: none"> • Both males and females affected. • Incidence and/or severity for some conditions may vary based on sex. • Combined genetic & environmental factors, although the factors may not always be identified. 	~1 in 33 (3%) after one affected child. ~1 in 33 (3%) when one parent affected.

Causes of Common Birth Defects & Genetic Conditions	
Condition	Cause/ Inheritance
22q11.2 deletion syndrome	Chromosomal: Usually sporadic; AD for familial cases
Achondroplasia	Autosomal dominant
Angelman syndrome	Chromosomal: Deletion in maternal chromosome #15
Beckwith-Wiedemann syndrome	Most have sporadic genetic mutation, inheritance depends on underlying mutation
Cleft lip and palate	Usually multifactorial; may be part of a syndrome with AR, AD, or XL inheritance
Club foot	Usually multifactorial
Cystic fibrosis	Autosomal recessive
Down syndrome	Chromosomal: Trisomy 21
Duchenne muscular dystrophy	X-linked recessive
Fragile X syndrome	X-linked
Genital and Urinary Tract Defects	Unknown cause, some multifactorial
Hearing Loss	Often genetic, usually AR; may also be multifactorial, or part of a syndrome with AR, AD or XL inheritance
Heart defect (in absence of underlying syndrome)	Usually multifactorial
Hemoglobinopathies (Sickle Cell Disease)	Autosomal recessive
Hemophilia	X-linked recessive
Klinefelter syndrome	Chromosomal: 47,XXY
Marfan syndrome	Autosomal dominant
Neurofibromatosis	Autosomal dominant
Noonan syndrome	Autosomal dominant
Phenylketonuria (PKU)	Autosomal recessive
Prader-Willi syndrome	Chromosomal: Deletion in paternal chromosome #15
Rett syndrome	Nearly all due to new mutations in X-linked gene
Smith-Magenis syndrome	Chromosomal: Deletion in chromosome #17
Spina Bifida	Usually multifactorial
Tay-Sachs disease	Autosomal recessive
Thalassemia	Autosomal recessive
Tuberous Sclerosis	Autosomal dominant
Turner syndrome	Chromosomal: 45,X; or structural rearrangement
Williams syndrome	Chromosomal: Usually sporadic deletion in chromosome #7; AD for familial cases

Prenatal Testing

Some birth defects and genetic conditions are detectable before birth. Parents may wonder what options are available for testing a future pregnancy. Brief descriptions of the different kinds of screening and testing available are provided below.

Maternal Serum Screening

The maternal serum blood test is done to find out if there is a higher chance the baby has certain conditions. The conditions include an open neural tube defect (ONTD) such as spina bifida, Down syndrome, and Trisomy 18. Blood can be drawn from a pregnant woman between 10 and 13 weeks gestation to screen for Down syndrome and Trisomy 18. It can also be drawn between 15 and 22 weeks gestation to screen for those disorders plus ONTD. It is a woman's personal choice whether she desires the test in the first or second trimester of pregnancy. It is important to note that these blood tests cannot rule out ONTD, Down syndrome or Trisomy 18 with certainty. Instead, the blood tests are used to alert a woman that her pregnancy is at a higher or lower risk for the conditions, and that further testing may be indicated. If the screen is positive, genetic counseling is recommended.

Level II Ultrasound Examination

A Level II ultrasound exam is performed between 18 and 20 weeks of pregnancy to view fetal anatomy. The spinal column can be studied for signs of an ONTD. The fetal head and other parts of the developing brain may also provide a clue if this problem is present. The rest of the fetal anatomy is also studied. Most major structural birth defects are detectable, such as heart defects, limb defects, facial clefting and clubfoot. However, a level II ultrasound exam can not find all fetal birth defects. It can not diagnose chromosome problems or all genetic syndromes.



Amniocentesis

Amniocentesis is performed in the second trimester of pregnancy, after 15 weeks gestation. A small amount (about 2 tablespoons) of amniotic fluid is withdrawn from the sac surrounding the developing baby. The fluid is obtained by inserting a needle through the mother's abdomen (lower belly). The needle does not pass through the navel ("belly-button"). A small amount of this fluid can be tested to detect the level of alpha fetoprotein and a second chemical, acetylcholinesterase. These studies are done to rule out the presence of an ONTD. Studies on fetal skin cells found in amniotic fluid are done to find any chromosome problem. An example of a chromosome problem is Down syndrome. Amniocentesis can find more than 98% of pregnancies with ONTDs and more than 99% of pregnancies with chromosome problems. The studies usually performed after amniocentesis will not find genetic syndromes due to DNA mutations. Special tests may be done if requested for DNA mutation analysis. The risk of complications from amniocentesis is usually less than 0.5%.

Chorionic villus sampling (CVS)

This testing is performed at approximately 10 to 12 weeks gestation. The test may be performed either like a Pap smear, or similar to amniocentesis. It is done to find a chromosome problem due to advanced maternal age or family history, and/or to perform testing for a genetic syndrome based on family history. A few of the cells that would eventually develop into the placenta are sampled. The chromosomes in the cells are studied. The chromosomes in these cells should be the same as those in the developing baby's cells. The testing will find over 99% of chromosome problems. A risk of less than 1% for complications is associated with this testing. Testing to find an ONTD cannot be done. The usual studies performed by CVS testing will not find genetic syndromes due to DNA mutations. Special tests may be done if requested for DNA mutation analysis.

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of Community Health*



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