

HAPPY NEW YEAR!

Welcome to the January edition of our quarterly newsletter! In this newsletter we will be highlighting our support group and Facebook page as well as an opportunity to become Kent County's Parent Partner. We will also cover a diagnosis that has some new treatment options, answer frequently asked questions, and get an update from our Fetal Infant Mortality Review program. And as the cold months continue, we have included a few winter activities that are low cost and family friendly!

PARENT SUPPORT GROUP

On the second Tuesday of each month, Kent County's CSHCS team holds a parent support group for families of children with special health care needs. The goal of the support group is to increase family support, knowledge, and advocacy. We have been meeting at the Kent County Health Department, but recently partnered with the Children's Healing Center to have them host. In the future, we hope to continue to partner with the Children's Healing Center and host more support groups there!

Staff from CSHCS is in attendance and there is always childcare and food provided. We encourage those who are not able or comfortable to attend in person, to get involved through our Facebook group, *Families with Special Needs Connect!*

We are currently in need of a parent of a child with special health care needs to become our Parent Partner. As the Parent Partner, you would facilitate the support group and manage the Facebook group listed above. The Parent Partner would be compensated for their work with both the support group and Facebook page. If you are interested in hearing more about the role you can reach out to Brandi Berry at brandi.berry@kentcountymi.gov.



DID YOU KNOW?

You may be eligible for reimbursement for travel and/or lodging through CSHCS depending on if transportation is a barrier to care, the distance of travel, and if you are enrolled in another form of Michigan Medicaid. If you would like to find out if you qualify for transportation assistance, please reach out to one of our CSHCS team members!

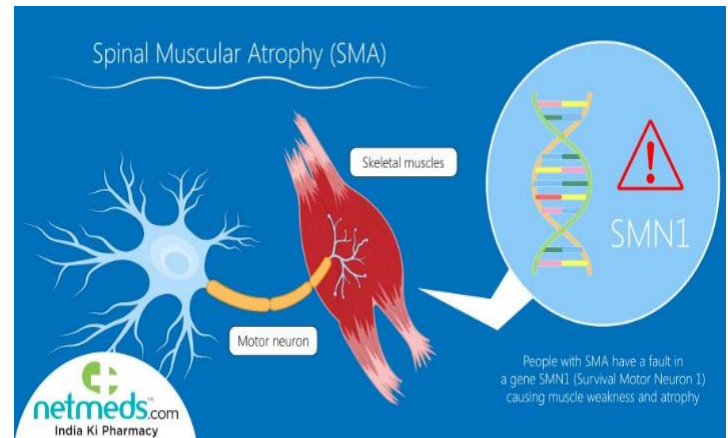


DIAGNOSIS OF THE QUARTER

Spinal Muscular Atrophy (SMA) is a genetic disease that affects the central and peripheral nervous system as well as voluntary muscle movement. It involves the loss of nerve cells in the spinal cord due to a decreased production of a motor neuron protein called SMN. In the most common form of SMA, there is a wide variety in the age of onset, symptoms, and rate of progression.

Symptoms of SMA cover a broad spectrum, ranging from mild to severe. The primary symptom is weakness in the voluntary muscles, with those closest to the center of the body being most affected, and typically the lower limbs are more greatly affected than the upper limbs.

Research on treatment has largely focused on ways to increase the body's production of the SMN protein. In 2016, the FDA approved Spinraza for the treatment of SMA, which was designed to treat the underlying defect in SMA. In 2019, the FDA approved Zolgensma which is the first gene-replacement therapy for a neuromuscular disease. Zolgensma is administered to pediatric patients younger than 2 years of age with SMA. In 2020, the FDA approved Risdiplam, also known as Evrysdi, for treatment of SMA in adults and children two months of age or older. Evrysdi is designed to increase levels of the SMN protein.



Along with medications, there are a variety of other therapies and treatments to assist with the effects of SMA including forms of respiratory support, swallowing supports, equipment to support skeletal system, physical therapy, and others.

Frequently Asked Questions

My child's diagnosis is on the CSHCS eligible diagnosis list, does that mean my child is eligible for CSHCS?

- Not yet, the diagnosis must also meet the criteria for severity, chronicity of the condition, and the need for treatment by a specialist. A medical consultant for CSHCS makes this decision based on a recent medical report.

My primary insurance denied this medical expense, will CSHCS cover the cost?

- CSHCS will not cover medical costs that aren't first approved by the primary insurance. The exception is if the primary insurance says it's 'not a covered benefit'. The most common example is that many insurances do not cover hearing aids. CSHCS will cover hearing aids for eligible diagnoses related to hearing loss.

My PCP ordered some tests, will CSHCS cover the costs of those tests?

- No, orders must come from a specialist on the child's authorized provider list for the diagnosis on the CSHCS list.

What is the difference between Medicaid and CSHCS?

- CSHCS is a program for children with special medical care needs. They must meet the eligibility criteria to qualify for the program. Unlike Medicaid, CSHCS does not have an income limit to be able to enroll. Medicaid is a federal program which utilizes income to determine eligibility.

Does CSHCS cover mental or behavioral health services?

- No, CSHCS does not cover mental or behavioral health services but your child may be able to participate in programs run by MDHSS or Network180.

My child has Medicaid and CSHCS, why do I need CSHCS?

- In the instance that your child loses their Medicaid, the providers treating their eligible diagnosis would still be covered by CSHCS. If your child's Medicaid closes, please contact your local CSHCS representative.

Does CSHCS cover PT, OT, or Speech therapy?

- CSHCS may cover PT/OT/SLP if it is related to the eligible diagnosis. Then CSHCS follows the Medicaid manual regarding therapy limitations.





FIMR UPDATE

In March of 2021, Kent County's Fetal Infant Mortality Review Program was reinstated with the help of grant funding from the First Steps Kent Early Childhood millage. The program holds monthly meetings with a group of local professionals to review each infant death case to then generate initiatives to reduce maternal and infant mortality. Our focus areas include maternal health and infant deaths related to unsafe sleep.

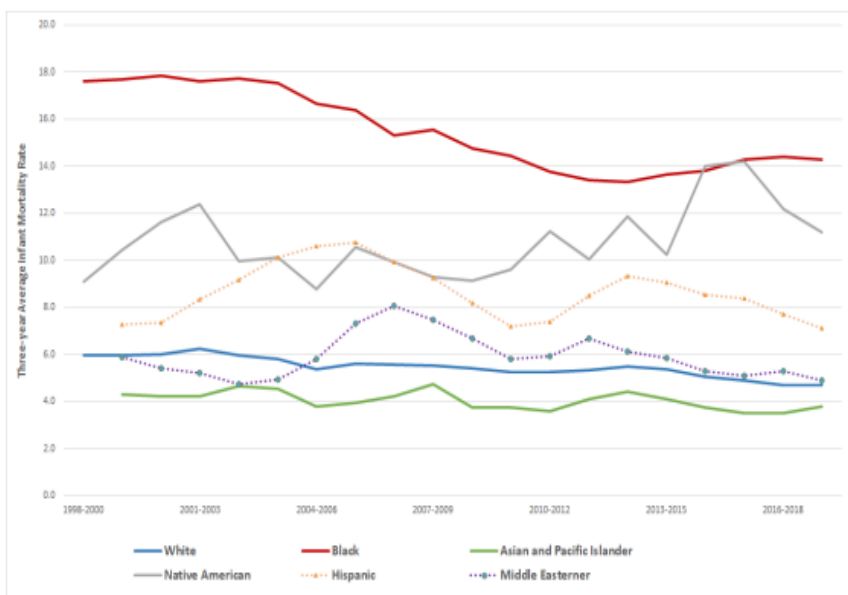
To target maternal health, initiatives are aimed at improving systems of care and utilization of home visiting programs such as Nurse Family Partnership and the Maternal Infant Health Program. The goal is to prevent fetal and infant deaths related to prematurity which make up about 31% of infant deaths in Kent County.

Other initiatives include increased education for healthcare professionals to then inform community members on infant safe sleep practices, as well as making sure that every infant has a crib or bassinet they can be placed in alone, with no blankets, pillows, toys, or other children. In Kent County about 24% of infant deaths are due to unsafe sleep practices.

As discrimination is still prominent in our community, the FIMR program is also working towards health equity, having an equal opportunity for black and brown infants to survive as white infants. In Kent County, a black infant has 2.5 times the risk and a Hispanic infant has 1.4 times the risk of dying compared to a white, non-Hispanic infant.

Figure 3

Three-year Average Infant Mortality Rates by Race and Ancestry, Michigan Residents, 1998-2019



Ensuring safe living environments, equal access to care, and increased support are vital to the overall health and wellbeing of our community's mothers and babies. Stay tuned for further updates and information from FIMR!

WINTER ACTIVITIES

World of Winter
Jan. 7th to March 6th
Grand Rapids



Frederik Meijer's
Children's Garden Winter Exploration
Wednesdays & Thursdays
December through February



Snow Shoeing
Rentals available at
Pigeon Creek Park &
Hemlock Crossing



GR Children's Museum
Open Thursday-Sunday
Monthly events free with admission



616-632-7066



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