



# REAMSICKLI

Although the world is full of suffering, it is also full of the overcoming of it.

– Helen Keller



# ABOUT DREAMSICKLE KIDS

Dreamsickle Kids Foundation is the first Sickle Cell Disease (SCD) organization in the state of Nevada established to support patients, their families, and caregivers impacted by SCD. Throughout the last 5 years, Dreamsickle Kids has worked tirelessly to advocate for patients with SCD in Nevada. Through our advocacy, we have successfully increased Sickle Cell awareness and support in the state, improved patient experiences in clinical settings through working with providers to directly support patients and families with SCD, building trust between the patients and providers while also fostering compassion and understanding with medical providers by offering education and resources to help providers better support the patient community. Our goal is to improve health equity and address health disparities experienced by patients with SCD in Nevada. We hope this eBook can be an additional health and financial resource to the SCD community as they navigate life as a Sickle Cell Warrior.

About this book: This eBook serves to provide information to the SCD community of Nevada to ensure awareness of AB254 which is the first SCD bill in Nevada passed in 2019. This bill provides better access to new SCD medications through Medicaid, coverage for supplements which has been an out-of-pocket expense, the establishment of a SCD registry to have an accurate count of SCD patients to allocate more resources and support to those with SCD in Nevada and much more. Sickle cell disease causes \$1.5 billion in lost wages and productivity each year in the U.S. alone, according to the first study of its kind. That comes to more than \$650,000 lost over the average working life of a person living with the painful genetic disorder. Included in this book, is the information intended to provide patients with SCD options to assist with alleviating some of the financial burden associated with SCD and provide information on new and existing resources in Nevada to empower SCD patients and promote health equity

(Reference: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4639479/)



Disclaimer: Dreamsickle Kids Foundation is a recipient of the Financial Advocacy in RARE Impact Grant sponsored by Global Genes. Thanks to this award, the Nevada Sickle Cell Rare Health and Financial Guide is made possible."



By Dreamsickle Kids Foundation

Sickle cell disease (SCD) is a group of inherited red blood cell disorders. Red blood cells contain hemoglobin, a protein that carries oxygen. Healthy red blood cells are round, and they move through small blood vessels to carry oxygen to all parts of the body. In someone who has SCD, the hemoglobin is abnormal, which causes the red blood cells to become hard and sticky and look like a C-shaped farm tool called a "sickle." The sickle cells die early, which causes a constant shortage of red blood cells. Also, when they travel through small blood vessels, they get stuck and clog the blood flow. This can cause pain and other serious complications (health problems) such as infection, acute chest syndrome and stroke.

### About AB254:

Revises provisions relating to sickle cell disease and its variants.

# Benefits to patients and Medicaid and Provider requirements:

- COVERAGE NOW PROVIDED UNDER MEDICAID FOR THE COMPOUNDING (CHANGING FROM SOLID TO LIQUID) OF THE MOST COMMON MEDICATION USED TO MANAGE SCD WHICH CAN BE UPWARDS OF \$100 EVEN WITH MEDICAID INSURANCE, THIS CHANGE HELPS TO REDUCE SOME FINANCIAL BURDEN FOR PATIENTS AND CAREGIVERS THAT IS ASSOCIATED WITH TREATING SCD;
- MEDICAID IS NOW REQUIRED TO COVER ANY NEW FDA APPROVED SCD MEDICATION WHICH COMES TO MARKET AND IS PRESCRIBED BY THE PATIENTS TREATING PHYSICIAN;
- NEVADA HAS CREATED A SCD REGISTRY TO COLLECT DATA ON THE NUMBER OF INDIVIDUALS LIVING WITH SCD IN THE STATE IN EFFORT TO PROVIDE BETTER HEALTHCARE AND RESOURCES FOR THOSE PATIENTS (SCD REGISTRY WEBSITE);
- HOSPITAL CHIEF MEDICAL OFFICERS ARE REQUIRED TO SUBMIT DATA REGARDING THE SCD PATIENTS SEEN AND TREATED BY THEM TO THE STATE TO BE COMPILED FOR THE SCD REGISTRY EVERY SIX MONTHS, DATA IS TO INCLUDE AGE, VARIATION OF THE DISEASE AND ANY OTHER MEDICAL AILMENTS PATIENT MAY HAVE;
- MEDICAID IS REQUIRED TO COVER SUPPLEMENTS WHICH ARE PRESCRIBED TO SCD PATIENTS SUCH AS VITAMIN D AND FOLIC ACID WHICH WOULD REDUCE OUT OF POCKET EXPENSES FOR MEDICATIONS FOR SCD PATIENTS

REFERENCES: WHAT IS SICKLE CELL DISEASE?

HTTPS://WWW.CDC.GOV/NCBDDD/SICKLECELL/FACTS.HTML AB254: HTTPS://WWW.LEG.STATE.NV.US/SESSION/80TH2019/BILLS/AB/AB254\_EN.PDF





Health plan carriers offer valueadded benefits to improve the health outcomes of their participants. Not only is that good for you, it can potentially save the plan money. When you are healthier, you may be able to avoid more expensive care.







Helping You SAVE MONEY with NO-COST extra benefits

Health Plan of Nevada's Medicaid Plan



NEW! SAM'S CLUB<sup>™</sup> membership (starts in 2022) NEW! No-cost or discount services like haircuts (starts in 2022)

NEW! Gym membership (starts in 2022)

NEW! Healthy Food for You (\$25 healthy food savings card) (starts in 2022)

NEW! WW® membership (starts in 2022)

NEW! MyHPN Essentials for Baby - choice of car seat or portable crib (starts in 2022)

Mom's Meals® (free delivered meals as part of our diabetes management program)

NEW! Dental benefit for adults (starts in 2022) VISA® gift cards for certain wellness visits and immunizations

Up to \$60 in VISA® gift cards for healthy pregnancy rewards

Rides to medical and behavioral health appointments, pharmacy and social services Free cell phone with 1,000 free minutes or 1.5 GIGS of data and unlimited texting from Lifeline

Make the most of your health plan.

For more information, call **1-800-962-8074**, TTY **711** or visit **MyHPNMedicaid.com**.

Boys & Girls Club Membership for kids ages 5-18

Some benefits are only available to those who qualify.

ATENCIÓN: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-962-8074 (TTY: 711).

Health plan coverage provided by Health Plan of Nevada







# SilverSummit Healthplan Gets You More

# Finally, a Health Plan **THAT GETS YOU. WE GET YOU MORE** than just your medical needs.



- WE GET YOU SAVINGS: \$800.00+ in Visa\*gift card rewards by going to the doctor and joining programs.\*
- WE GET YOU HEALTHY: No referrals required for specialty care (go to a specialist without having to see your PCP first!)
- WE GET YOU STARTED: Moms choose a car seat, baby shower in a box (includes a newborn essential kit) or SafeSleep cribette kit\*
- WE GET YOU CARE: New Moms choose manicure, pedicure or 30-minute massage.\*
- **WE GET YOU BETTER:** Same day mental health appointments.
- WE GET YOU SMARTER: Free tutoring for your kids.\*
- WE GET YOU THERE: Free rides to medical, dental, vision and other appointments.

# **WE GET YOU MORE FREE EXTRA BENEFITS**

# For Easy Healthy Living

- Free Costco® Card
- Free pharmacy home delivery
- Up to \$120.00 of free over-the-counter items shipped directly to you
- Free home delivered meals program\*
- Additional dental cleanings & x-rays
- Free smart phone & free talk, text & data from Safelink Wireless
- Free extra savings program for Dollar General, Family Dollar, CVS, and Walgreens
- Free Weight Watchers®membership\*
- Telehealth: safely get care from anywhere
- 24/7 Nurse Hotline
- Free Coaching Support Programs\*
- Local staff to help access community resources

## For Families

Free Boys and Girls Club membership\*

# For New and Expecting Moms and Dads

- Free electronic breast pump\*
- Pregnant moms get up to \$175.00 in Visa® gift card rewards
- Annual baby showers including free baby necessities, immunizations, education classes, parenting resources and more\*
- Doula/birthing coach

# **For Taking Next Steps**

- Access to housing: transitional, rapid and long-term supportive \*
- Up to \$300 for equipment for members transitioning from incarceration or pursuing jobs or education\*
- Financial assistance for ID cards, birth certificate and GED\*
- Supportive substance use recovery program with rewards\*
- Job training programs\*
- Resource Center: staffed to assist members, provide meals, showers, laundry, computer access, NA/AA meetings, transportation, employment, peer, primary and behavioral health services.
- Local staff to assist members

\*Applies to qualified individuals.

# **1-844-366-2880** ■ TDD/TYY 1-844-804-6086 ■ **SilverSummitHealthplan.com**

SilverSummit Healthplan complies with applicable Federal civil rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex. SilverSummit Healthplan does not exclude people or treat them differently because of race, color, national origin, age, disability, or sex.

SilverSummit Healthplan cumple con las leyes federales de derechos civiles aplicables y no discrimina por motivos de raza, color, nacionalidad, edad, discapacidad o sexo. SilverSummit Healthplan no excluye a las personas ni las trata de manera diferente debido a su raza, color, pacionalidad edad, discapacidad e sexo.

If you, or someone you're helping, has questions about SilverSummit Healthplan, you have the right to get help and information in your language at no cost. To talk to an interpreter, call 1-844-366-2880, (TTY/TDD: 1-844-804-6086).

Si usted, o alguien a quien está ayudando, tiene preguntas sobre SilverSummit Healthplan, tiene derecho a recibir ayuda e información en su idioma sin costo. Para hablar con un intérprete, llame al 1-844-366-2880, (TTY/TDD: 1-844-804-6086).

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# **Pregnancy Rewards**

Are you going to have a baby? Molina Healthcare wants you to have a healthy pregnancy and baby. You could earn gift rewards with our Pregnancy Rewards program! It is easy. Sign up at MyMolina.com, our secure portal,

# **Transportation**

Lean on Molina for enhanced transportation benefits, like rides to food banks, WIC appointments, job training or interviews and more.

Non-emergency medical transportation is available through MTM. They arrange rides to covered services for members who have no other way to receive a ride to their routine medical appointments. If you qualify for this service and need to arrange non-emergency transportation, contact MTM at 1- (844) 879-7341, TTY/TDD: 711 or call Member Services at 1- (833) 685-2102, TTY/TDD: 711.

Non-emergency transportation is not available to Nevada Check Up members.

Call to schedule your ride. You must give at least 5 working days' notice when scheduling transportation.





# **Case Management**

We have a team of nurses and social workers ready to serve you. They are called Case Managers. They are very helpful. They will give you extra attention if you have:

- Asthma
- Behavioral health disorders
- Chronic Obstructive Pulmonary Disease (COPD)
- Diabetes
- High blood pressure

- High-risk pregnancy
- Obesity
- · Heart Failure
- Organ Transplant
- Members discharged from the hospital
- Other chronic health conditions

Any Molina member may ask for a Case Manager to assist them with their health care needs!

# **Community Resources**

We are part of your community. And we work hard to make it healthier. Local resources, health events and community organizations are available to you. They provide great programs and convenient services. Best of all, most of them are free or at low cost to you.

- Community 4 Me powered by Aunt Bertha. This is a free and confidential service that will help you find local resources. Available 24/7.
- Women, Infants and Children's Nutrition Program (WIC) 1- (800) 863-8942
- Department of Health 1- (775) 623-6575
- Molina Care Management 1- (844) 809-8438, TTY/TDD 711



You can apply online through:

- Access Nevada
   (www.accessnevada.dwss.nv.gov)
   for Medicaid or Nevada Check Up
- Nevada Health Link
   (www.NevadaHealthLink.com) for
   subsidized health insurance

Enrollment can be completed quickly and easily from any computer or mobile device with Internet access. Several organizations have computers that are free to the public.

DWSS Call Center
For Locations and hours, call:
Northern Nevada 775-684-7200
Southern Nevada 702-486-1646
Toll Free 800-992-0900

Which assistance programs are available?

Division of Welfare and Supportive
Services (DWSS) determines Medicaid
and Nevada Check Up eligibility for low-income
Nevadans. Online applications can be completed using
Access Nevada at www.accessnevada.dwss.nv.gov.

<u>Medicaid</u> provides free health care coverage for low-income Nevadans, including:

- Adults between age 19-64 whose household income is at or below 138% of the Federal Poverty Level (FPL) (See chart)
- Children under age 19 whose income is at or below 205% of the FPL
- Pregnant Women whose household income is less than 165% of the FPL
- Parents or Caretakers with income at or below 138% of the FPL
- Supplemental Security Income recipients
- Certain Medicare beneficiaries

Nevada Check Up provides medical and dental benefits for children from birth to 18 years old. To qualify, your income must be at or below 205% of the Federal Poverty Level (See chart).

A small premium, on a quarterly basis, may be required. Checks or money orders must be sent to:

> Nevada Check Up Program P.O. Box 847346 Los Angeles, CA 90084-7346

Enrollment can be completed quickly and easily from any computer or mobile device with Internet access. Several organizations have computers that are free to the public.

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# **Other Access Nevada programs**

- The Supplemental Nutrition Assistance Program (SNAP) helps low-income Nevadans buy nutritious food from local retailers.
- Temporary Assistance to Needy Families (TANF) is designed to help families achieve self-sufficiency by job preparation, work opportunities and support services.

Medicaid and Nevada Check Up services are provided through Managed Care Organizations (MCO) — Anthem Blue Cross and Blue Shield, Health Plan of Nevada, Molina Healthcare of Nevada, and SilverSummit Healthplan. In rural areas and for some coverage groups, the Division of Health Care Financing & Policy (DHCFP) pays claims on a "fee for service" basis.

# Nevada Medicaid (DHCFP Fee for Service)

Carson City: 775-684-3651

Elko: 775-753-1191

Las Vegas: **702-668-4200** 

Reno: **775-687-1900** https://dhcfp.nv.gov



# Anthem Blue Cross and Blue Shield Healthcare Solutions

Participant Services: 844-396-2329

https://mss.anthem.com/nevada-medicaid/home.html

### **Health Planof Nevada**

Participant Services: 800-962-8074

https://myhpnmedicaid.com/Member



# **Molina Healthcare of Nevada**

Participant Services: 833-685-2102

https://www.molinahealthcare.com/members/nv

# SilverSummit Healthplan

Participant Services: 844-366-2880

https://www.silversummithealthplan.com/

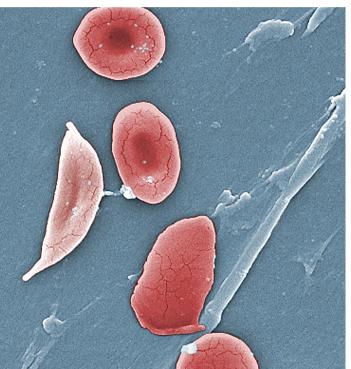
# **Nevada Health Link**



silversummit healthplan

Nevada Health Link is the state's website where Nevadans can enroll in income-based health insurance. Nevada Health Link can help you find a plan that fits your needs and budget. You cannot be denied due to a pre-existing medical condition. For more information, visit www.NevadaHealthLink.com.







QUESTION?

# SCD AND SSI, DO YOU QUALIFY?

Sickle cell anemia requires ongoing treatment, medicines, and hospital stays. If your sickle cell anemia is so severe that it prevents you from working, you may be struggling financially. Because sickle cell anemia is a type of physical disability, you may qualify for Social Security disability (SSD) benefits.

Sickle cell anemia falls under section 7.0 -- *Hematological Disorders*. First, there must be medical documentation that you have been confirmed to have a hematological disorder.

Lab report with a definitive test that establishes that there is a hematological disorder and this report needs to be signed by a physician.

A lab report with a definitive test that determines you have a hematological disorder that is not signed by a physician, but is accompanied by a report from your physician stating that you do indeed have the disorder.

When there is not a lab report of a definitive test, a report from a physician that is persuasive in nature that indicates your diagnosis was confirmed by diagnostic methods or appropriate lab tests.

The Social Security Administration will make every reasonable effort to get the results on the appropriate lab testing. However, costly, complex or invasive tests, such as bone marrow aspirations or clotting-factor proteins will not be purchased.

# **SCD and SSI**

# DO YOU QUALIFY?

Looking at the category of impairments for an individual with sickle cell anemia, here are the determining factors that help Social Security decide if you are disabled:

Painful crises that have been documented requiring either injected or IV narcotics at least 6 times within the last 12 months with at least 30 days between the episodes.

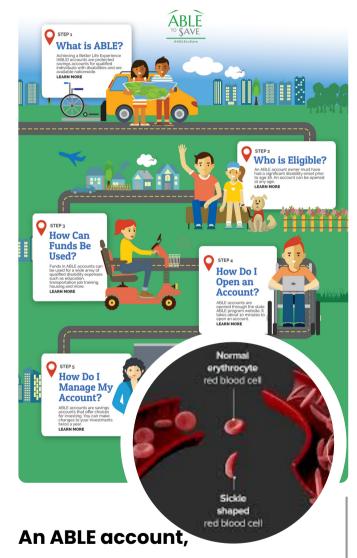
OR

Complications of anemia requiring at least three hospital stays within the last 12 months at least 30 days Each apart. hospitalization should last a minimum of 48 hours and can include time in the FR or comprehensive sickle cell disease center immediately prior to hospitalization.

OR

Hemoglobin measurements of 7.0 grams or less per deciliter at least three times within a 12-month period with 30 days in between the measurements.

Sickle Cell



also known as a 529 ABLE or 529A account, is a state-run savings program for eligible people with disabilities in the United States. Rules governing ABLE accounts are codified in Internal Revenue Code section 529A, which was enacted by the Achieving a Better Life Experience Act in 2014.

### FMLA/ADA Protections

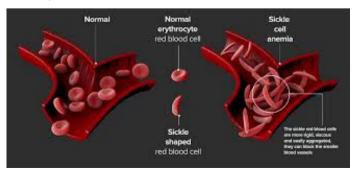
What is FMLA: The Family and Medical Leave Act of 1993 is a United States labor law requiring covered employers to provide employees with job-protected, unpaid leave for qualified medical and family reasons.

It also seeks to accommodate the legitimate interests of employers and promote equal employment opportunities for men and women.

FMLA applies to all public agencies, all public and private elementary and secondary schools, and companies with 50 or more employees. These employers must provide an eligible employee with up to 12 weeks of unpaid leave each year for any of the following reasons:

- For the birth and care of the newborn child of an employee:
- For placement with the employee of a child for adoption or foster care:
- To care for an immediate family member (i.e., spouse, child, or parent) with a serious health condition; or
- To take medical leave when the employee is unable to work because of a serious health condition.

Employees are eligible for leave if they have worked for their employer at least 12 months, at least 1,250 hours over the past 12 months, and work at a location where the company employs 50 or more employees within 75 miles. Whether an employee has worked the minimum 1,250 hours of service is determined according to FLSA principles for determining compensable hours or work.





# What is FMLA: The Family and Medical Leave Act

### (references:

https://www.ablenow.com/; https://www.ada.gov/cguide.htm#:~:t ext=Americans%20with%20Disabilitie s%20Act%20(ADA,to%20the%20Unit ed%20States%20Congress; https://www.ssa.gov/OP\_Home/rulin gs/di/01/SSR2017-03-di-01.html; https://www.dol.gov/general/topic/b enefits-leave/fmla; https://adata.org/learn-about-ada; https://www.disability-benefitshelp.org/disabling-conditions/sicklecell-disease-and-social-securitydisability)

# CONT..

# ADA vs. FMLA Fact Sheet

Question	ADA	FMLA
General purpose of law?	Prohibits discrimination against individuals with disabilities	Provides leave to employees
Who is eligible?	Individuals with a qualifying disability	Employees who have worked for at least 12 months and at least 1250 hours during the previous 12 months at a location within a 75-mile radius of where at least 50 employees work
What conditions are covered?	"Disability" that substantially limits one or more major life activities (or a history or record of having such a disability).	"Serious health condition" of employee or certain family members of employee. Birth, adoption and foster care placement of employee's child. Certain types of military-related leave.
How is pregnancy covered?	Pregnancy-related leave can be covered by the ADA when an employee develops pregnancy-related impairments (such as anemia, cervical insufficiency or gestational diabetes), that can be considered disabilities under the ADA.	The FMLA covers work-leave related to pregnancy and the birth of a child.
Can medical information be requested?	Yes. Information should be limited to what is needed to confirm that the employee has a disability, determine how much leave is needed, or consider general accommodation options.	An employer may (but does not have to) require the worker to certify the need for work-leave from a medical professional.  The U.S. Department of Labor provides a form for this purpose.
What about light duty?	Employers are not required to remove essential job functions as an accommodation, but if an employer reserves light duty jobs for workers' compensation purposes, it may have to offer such jobs to individuals with disabilities.	An employer can't require FMLA-qualifying employees to work light duty.

How much leave is required?	There is no set amount. As with all accommodations, the amount of leave granted depends on the job and the disability and must be determined on an individual basis. Employers must grant leave as a form of reasonable accommodation unless doing so would cause them undue hardship.	Up to 12 weeks/year for serious health condition related leave. Up to 26 weeks/year for certain military-related leave. Leave may be intermittent and is unpaid but the employer can require or the employee can choose to use accrued paid benefits.
What about benefits?	No specifics under the law, other than the prohibition of discrimination based on disability.	Benefits typically don't accrue during leave, but seniority, service and vesting continue. May require use of certain paid leaves depending on type of FMLA leave.
What about reinstatement?	If leave is required as a reasonable accommodation, the employer generally must keep the employee's position open during the leave.	Generally, employees must be reinstated to the same or a substantially equivalent position.
When could both laws apply?	Employees can have rights under both laws if they meet the definition of "disability" (ADA) and "serious health condition" (FMLA). Employees who have used up FMLA leave can still have rights under the ADA if they meet the ADA definition of a person with a disability. Additional leave (beyond the worker's FMLA leave) could be an accommodation that must be provided under the ADA.	
What about indefinite leave?	Employers are not required to grant indefinite leave and can require workers to provide an approximate return-to-work date. However, the employer must be flexible in situations where the return-to-work date must be changed for medical reasons, unless providing additional leave would cause undue hardship.	
When to consider leave as an accommodation?	Use leave as the last accommodation option. Employers should work with the employee to determine how the impairment impacts the essential functions of the job and what accommodations can be considered. Before resorting to leave as an accommodation, consider the full range of accommodations that could be effective given the impairment, the job and the situation.	

### Sources

ADA vs. FMLA Cheat Sheet, http://www.kansastag.gov/AdvHTML\_Upload/files/ADA-versus-FMLA-Cheat-Sheet-5\_10[1].pdf Work-Leave, the ADA, and the FMLA, ADA National Network, https://adata.org/sites/adata.org/files/files/Work-Leave\_final2017.pdf

# NEVADA RARE RESOURCES





ADULT SICKLE CELL DISEASE FOUNDATION
OF NEVADA







