

Nevada Experience Unite Sickle Cell: collaboration and community in sickle cell

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Cure 4 The Kids Foundation



CURE 4 THE KIDS
FOUNDATION

A Division of Roseman University of Health Sciences

Introduction

- Public Health Surveillance activity in Nevada - How many people living with sickle cell diseases? ~ 500-600. Majority resides in Southern Nevada.
- The state offers care for most children living with this disease: Cure 4 the Kids Foundation: Sickle Cell Disease Treatment Center providing comprehensive care for children (and some young adults).
- There is a major gap in quality of care, leading to an increase in morbidity and mortality as youth with SCD transition out of pediatric into adult care.
- Most adults in the state are seen more often in emergency care settings than primary care.

Introduction

- There is also a lack of awareness about SCD within the community, workplace and schools that leads to misunderstandings and unfair treatment of those living with the disease.
- What is the data on the prevalence of sickle cell trait (SCT) in Nevada? How many Nevadan may be unaware of their status as carriers, which confers increased likelihood of having offspring with SCD if the other parent also carries SCT or other significant Hgb Trait.
- Additionally, although serious health effects related to SCT are rare, it is important for those with SCT to be educated about such impacts.

Building a Sickle Cell Program in Nevada

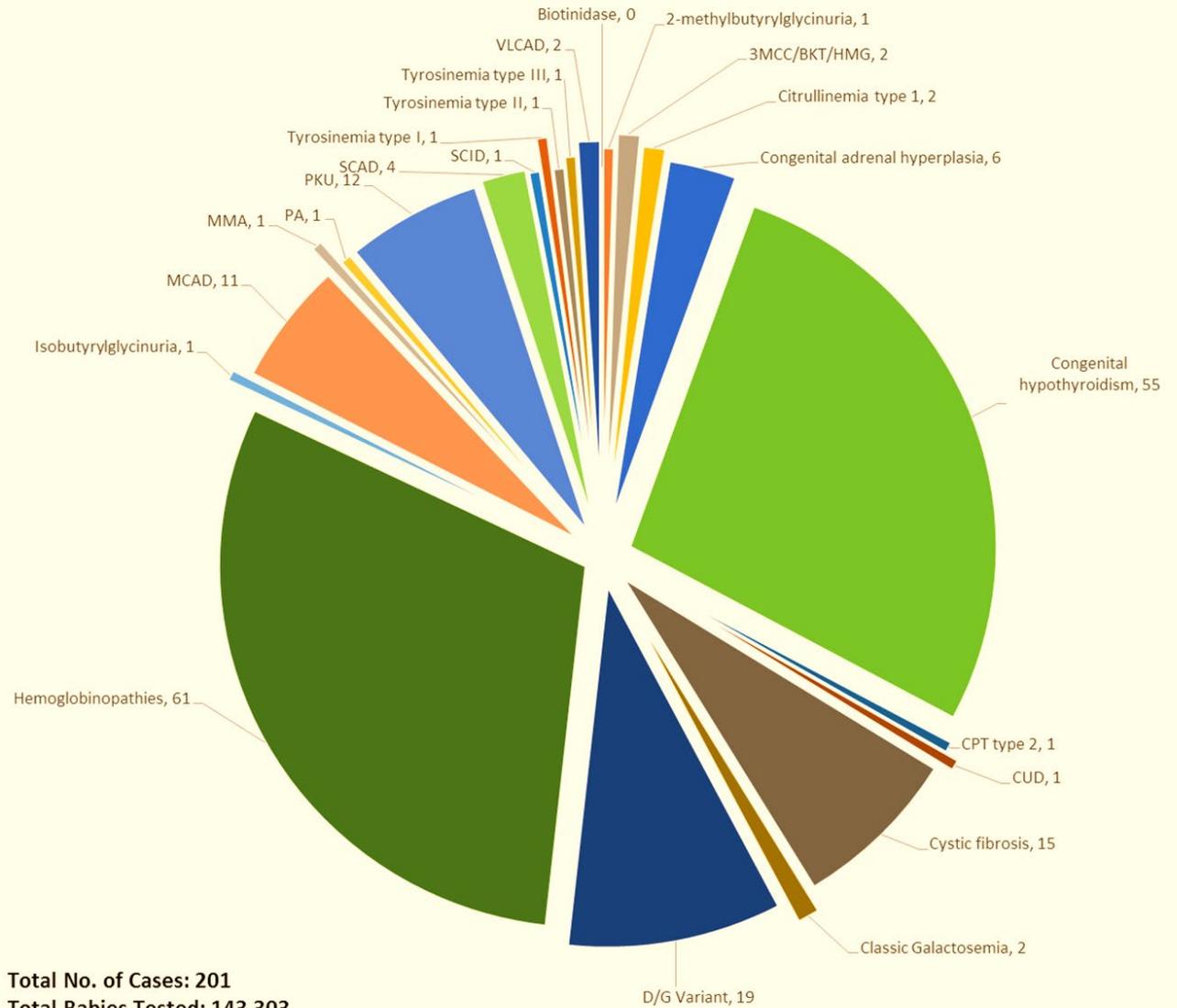
- **Prior to 2014:**
- No comprehensive sickle cell center or a medical home for our patients. Most acute care in the ED, hospitals. Blood transfusions at multiple hospitals
- No community outreach programs
- No initiative to educate other providers in the community
- There was a sickle cell support group that was not very active, and no patient education programs or patient advocacy groups.
- No Transition Program

Building a Sickle Cell Program in Nevada

- **Establish a Sickle Cell Treatment Center:**
 - Comprehensive Sickle Cell Disease Clinic
 - Improved access to acute care: pain and fever management.
 - Develop outpatient transfusion and apheresis program in one site.
 - Research/clinical trial: Minimum Data Set, Pharma, QI Projects
 - Hydroxyurea: education and increase prescription.
- **Newborn screening and counseling:**
 - All babies born with a probable hemoglobinopathy are referred to our clinic for patient/family counseling.
- **Community Outreach and Education:** Family Educational Evening, etc
- **Provider Outreach and Education:** Grand Rounds, Invited Speakers, CME, Sickle Cell Symposium
- **Transition Program**



Identified Newborn Disorders July 2014 - July 2018



Total No. of Cases: 201
Total Babies Tested: 143,303



Confirmed Cases			New Cases Since Last Meeting	
Biotinidase	0	9 Partial deficiency (1 deceased and 1 compound heterozygous)	7 Carriers	
2-methylbutyrylglucosuria	1			
3MCC/BKT/HMG	2	1 Carrier, 1 Mild variant		
Citrullinemia type 1	2	1 carrier, 1 Mild variant		
Congenital adrenal hyperplasia	6	1 Mild deficiency		
Congenital hypothyroidism	55		5	
CPT type 2	1			1st case
CUD	1	Borderline CUD (Primary carnitine deficiency)		
Cystic fibrosis	15	13 heterozygous (One copy of CFTR mutation)	3	1 Carrier
Classic Galactosemia	2	1 carrier		
D/G Variant	19		2	
Hemoglobinopathies	61	FS(26), FSC(14), FSA(5), FC(3), FCA(1), FD(1), FE(2)	9	FS(2), FSC(3), FSA(3), FCA(1)
isobutyrylglucosuria	1			
MCAD	11	2 Mild variant; 1 carrier	3	
MMA	1			
PA	1	1 Mild variant		
PKU	12	5 HyperPhe		
SCAD	4	4 Benign; No tx needed		
SOD	1	Edward's Syndrome (Deceased)	2	1 Di George and 1 Lymphopenia 1 pending
Tyrosinemia type I	1			
Tyrosinemia type II	1	6 Transient		
Tyrosinemia type III	1			
VLCAD	2	6 Carriers		
Total	201			

Hemoglobin Traits	364
FA+Other	50
FAB	94
FAC	44
FAC/Barts	3
FAS	169
FAS/Barts	4



Nevada State Sickle Cell Action Plan

- Increase Education and Awareness
- Advocacy and Training
- Address Gaps in Care
- Assure Timely and Complete Transition to Adult Care
- Prioritize Sickle Cell in the state of Nevada
- Address social and external factors that impact health and health outcomes
- Improve access to sickle cell care based on expert guidelines across the lifespan.

Nevada Experience

Unite Sickle Cell: collaboration and community in sickle cell

Linetta Barnes, BSN, RN
Founder & President
Sickled Not Broken Foundation of NV



SICKLED NOT BROKEN
FOUNDATION OF NV

Community Based Organizations

- **DreamSickle Kids Foundation #MakeSickleCellPopular**
 - <https://dreamsicklekids.org>
 - Founder/Executive Director: Georgene Glass
- **Sickled Not Broken Foundation of NV**
 - <https://www.sicklednotbroken.org>
 - Founder/President: Linetta Barnes, BSN, RN
- **Adult Sickle Cell Foundation of Nevada**
 - <https://ascdfonv.org>
 - Founder: Pamela White



Increase Education and Awareness

- Strategy 1: Increase Sickle Cell Trait and Sickle Cell Disease Education.
- Strategy 2: Raise public awareness about SCT and SCD through coordinated activities.
- Strategy 3: Statewide Patient Education.
- Strategy 4: Educate Health Professionals.
- **Partner with CBOs:**
 - Partner with CBOs to increase awareness through social media, support groups, events, etc
 - Coordinate Patient and Family Educational Evenings with CBOs. They spread the word, help with transportations, call the patients and families to invite and confirm attendance. They move the community.
 - DreamSickle is VERY active in social media, events, media: tv, radio, etc making sickle cell disease popular
 - They work with other non-profit organizations eg Black Nurses Rocks, NORD, Sickle Cell Community Consortium, Foundation Alliance, etc

Complications of Transfusions

Organs that may be affected by iron overload



- Iron Overload, How To Treat:
 - Reduce frequency of blood transfusion. ONLY transfuse if needed
 - Iron chelation therapy
 - Deferoxamine (Desferal) IV, SQ
 - Deferiprone (Exjade, Jado/4)
 - Deferiprone (Ferropro)
 - Automated Apheresis (Exchange Transfusion)

las vegas

morning
BLEND



1ST ANNUAL SICKLE CELL DISEASE SYMPOSIUM

SICKLE CELL UNITE: BRIDGING THE GAP
SC UNITED: BRIDGING THE GAP

ENCOURAGE THE UNION OF SICKLE CELL WARRIORS AND HEALTHCARE CHAMPIONS

ENHANCE QUALITY OF CARE, DECREASE STIGMAS & MISUNDERSTANDINGS

FREE SEPTEMBER 14, 2019
REGISTRATION 7:30 - 8:30 AM **FREE**
CONFERENCE 8:30 AM - 4 PM

AUDITORIUM OF BREAKTHROUGH BUILDING
ONE BREAKTHROUGH WAY LAS VEGAS, NV 89135

MULTIPLE SPEAKER SESSIONS
LUNCH WILL BE SERVED

PLEASE RSVP to LINETTA by September 9
<https://sicklecellunite.eventbrite.com> or
702-417-3175 or EMAIL: LINETTAB@SICKLEDNOTBROKEN.ORG



DREAMSICKLE KIDS FOUNDATION PRESENTS:

2ND ANNUAL LAS VEGAS SICKLE CELL Walk

09.21.19
7 AM TO 12:30 PM

FACE PAINTING • MUSIC • JUMPERS • RAFFLES/GIVEAWAYS

SPONSORED BY:

WALK AMBASSADOR & WARM UP INSTRUCTOR

MISA MASTERS

HOSTED BY:

AK

#MAKESICKLECELLPOPULAR

LOCATION: PEARSON COMMUNITY CENTER 1625 W. CAREY | WWW.DREAMSICKLEKIDS.ORG

\$35 ADULTS \$25 KIDS 6-17 *KIDS 5 AND UNDER FREE* | REGISTER AT: WWW.2019DREAMSICKLEWALKLV.EVENTBRITE.COM

Assure Timely and Complete Transition to Adult Care

- Strategy 1. Increase access to knowledgeable, quality care for adults with SCD
- Strategy 2. Provide training and support to adolescents and young adults to increase self-efficacy
- Strategy 3. Increase access to and uptake of trait testing and genetic counseling
- **Partner with CBO:**
 - Sickled Not Broken Foundation: Transition Program
 - Encouraging teenage patients to attend Camp Crescent Moon with Sickle Cell Disease Foundation of California



Advocacy and Training

- Strategy 1: Increase Capacity for Advocacy.
- Strategy 2: Advocate on State Action Plan.
- Strategy 3: Increase Advocacy in Key Areas.
- Strategy 4: Prioritizing Sickle Cell Disease in the state of Nevada
- **Partner with CBOs:**
 - Increase capacity for self-advocacy and empowerment among people living with SCD and their families and advocates. Increase effective SCD advocacy, overall.
 - Advocate for decision makers – legislators, state agencies and hospital and health care leaders – to support and implement Action Plan policy goals. **OUR LATEST VICTORY: AB254 SICKLE CELL BILL**
 - Increase effective advocacy on SCD, especially in the key areas of 1) availability of trait testing and follow up, 2) better transition to adult care; 3) protecting student civil rights; and 4) the effect of opioid legislation on SCD.

AB 254 Summary

- Requires Nevada's Chief Medical Officer to establish and maintain a system for reporting sickle cell disease and its variants; also authorizes administrative penalties for failing to report certain information.
- Requires testing newborns for the presence of sickle cell disease and its variants; allows for parents to be tested at same time.
- Requires Medicaid to cover certain supplements recommended by the Pharmacy and Therapeutics Committee which can be helpful to sickle cell patients.
- Requires a health insurer to include coverage for certain prescription drugs and services for the treatment of sickle cell disease. (Transition plan from pediatrics to adulthood)
- Authorizes a prescription of certain controlled substances for the treatment of acute pain caused by sickle cell disease and its variants for a longer period than otherwise allowed.



Health and Human Services



Assembly Committee on Health and Human Services

Assembly Bill No. 254—Assemblymen Neal; Assefa, Duran, Flores, Gorelow and Thompson

CHAPTER.....

ACT relating to public health; requiring the Chief Medical Officer to establish and maintain a system for reporting certain information on sickle cell disease and its variants; authorizing administrative penalties for failure to report certain information; revising requirements concerning screening infants for sickle cell disease and its variants and sickle cell trait; requiring Medicaid to cover certain supplements recommended by the Pharmacy and Therapeutics Committee; requiring a health insurer to include coverage for certain prescription drugs and services for the treatment of sickle cell disease and its variants in its policies; authorizing a prescription of certain controlled substances for the treatment of acute pain caused by sickle cell disease and its variants for a longer period than otherwise allowed; requiring a health maintenance organization or managed care organization to take certain actions with respect to certain insureds diagnosed with sickle cell disease and its variants; and providing other matters properly relating thereto.



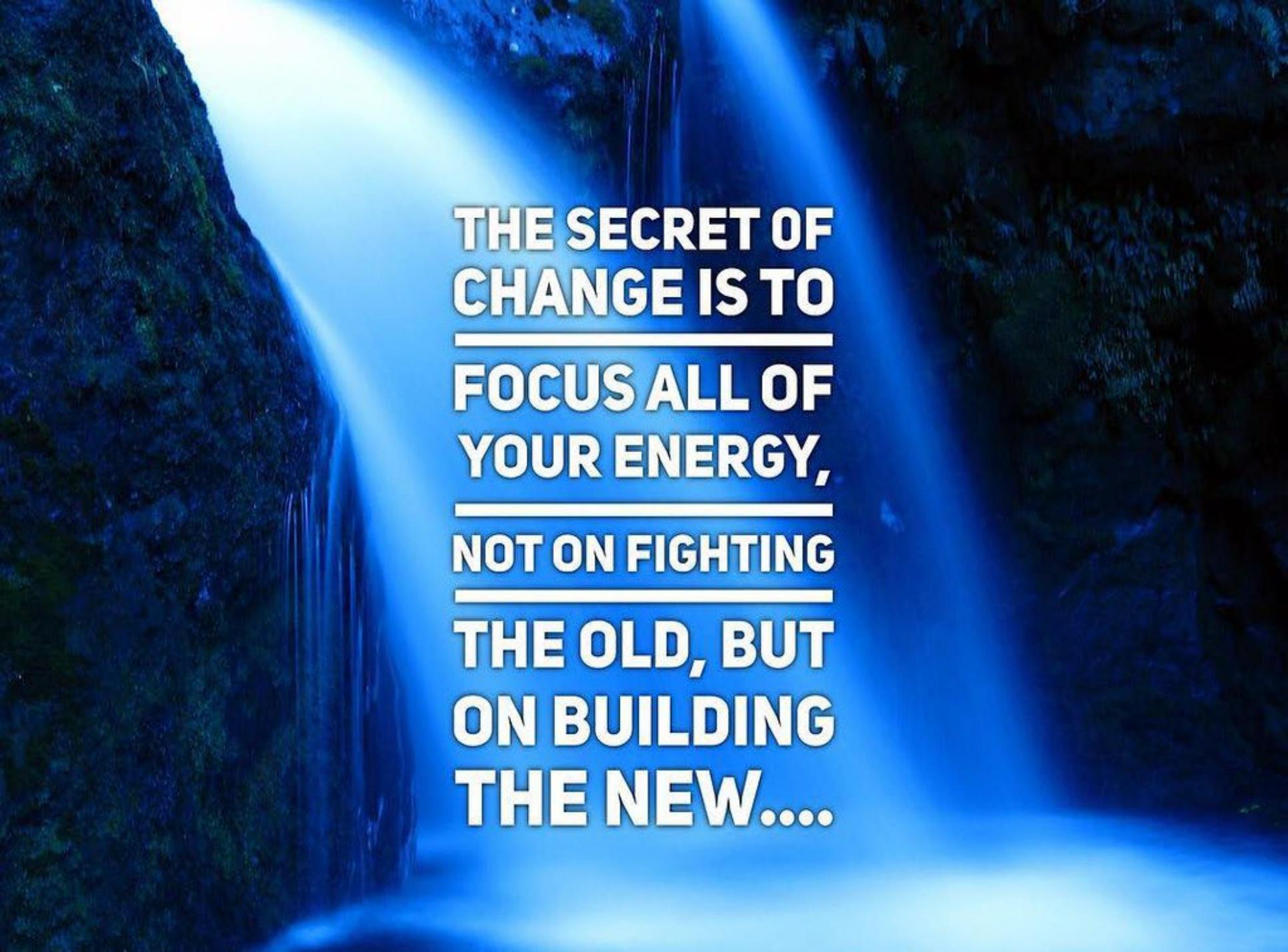
Legislative Counsel's Digest:

Existing law requires the Chief Medical Officer to establish and maintain a system for the reporting of information on cancer and other neoplasms (NRS 457.230). Existing law requires the chief administrative officer of each facility in this State to make available to the Chief Medical Officer or representative the records of the health care facility for each reportable case (NRS 457.250). Section 6 of this bill requires the Chief Medical Officer to establish and maintain a similar system for the reporting of information on sickle cell disease and its variants. Sections 6 and 7 of this bill require hospitals, medical laboratories, certain other facilities and providers of health care to report certain information prescribed by the State Board of Health concerning each case of sickle cell disease and its variants diagnosed or treated at the facility or by the provider, as prescribed by the State Board of Health. Section 8 of this bill requires the chief administrative officer of each facility in this State to make available to the Chief Medical Officer or representative the records of the health care facility for each case of sickle cell disease and its variants for abstraction by the Division of Public Health of the Department of Health and Human Services. Section 9 requires the State Board of Health to adopt a schedule of fees which must be assessed against each health care facility for each case from which information is abstracted. Section 10 provides for the imposition of an administrative penalty against a health care facility that fails to make the records of the facility for each case of sickle cell disease and its variants available for abstraction. Sections 9 and 10 provide for analysis, reporting and research based on the reported information and information concerning cases of sickle cell disease and its variants. Section 15 of this bill provide for the confidentiality of reported information.



Address Gaps in Care

- Strategy 1. Increase access to specialty care and rural care
- *Strategy 2. Improve patient experiences and outcomes in acute care settings*
- *Strategy 3. Improve Pain Management*
- Strategy 4. Increase access to mental health and psychosocial services
- Strategy 5. Create SCD Centers of Excellence: Pediatrics and Adults.
- Strategy 6. Improve access to sickle cell care based on expert guidelines across the lifespan.
- **Partner with CBOs:**
 - Patient advocates – the bridge between patients and providers and institutions. Especially patients from out of state that do not have a physician in town.
 - Provide patient insight and opinions and relaying their experiences to the medical establishments.
 - Act as a resource for patients.
 - **Next project:** to meet with hospital EDs to discuss creating a ‘Pain Management Protocol Set’ using NHLBI and other guidelines



**THE SECRET OF
CHANGE IS TO**

**FOCUS ALL OF
YOUR ENERGY,**

NOT ON FIGHTING

THE OLD, BUT
ON BUILDING
THE NEW....

Conclusion

- Sickle cell disease is a chronic disease that affects the patient and their families from birth through their lifespan.
- Improving the lives of individuals living with sickle cell disease requires the collaboration of multiple organization.
- Community based organizations is critical in bridging the gap between the community and medical professionals.

Thank You

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Questions?

