A Public Health Plan to Address Sickle Cell Disease Across the Lifespan 2015 ~ 2018

Michigan Department of Health and Human Services (MDHHS)
Lifecourse Epidemiology & Genomics Division (LEGD)
Hemoglobinopathy Quality Improvement Program (HemQIP)

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Presenter Disclaimer

• I do not have any financial conflicts to disclose.

• This presentation is provided for informational and educational purposes.

• Lessons learned in this presentation are those of the author and do not necessarily represent the official position of the Michigan Department of Health and Human Services.
MDHHS & Sickle Cell Disease Association of America – MI Chapter, Inc. (SCDAAMMI) Partnership

- Provide a centralized diagnostic/medical coordinating center for follow-up of children with positive newborn screens for hemoglobinopathies since 1987; - parent/provider notification, coordinate confirmatory testing, initiation of penicillin prophylaxis/monitoring adherence and referrals

- Follow-up for children with hemoglobin traits;

- Clinical/psychosocial support services and education for the SCD population;

- Clinical expertise to the Newborn Screening Program (NBS);

- Hemoglobin electrophoresis testing; and

- Health Status Assessments
SCDAA-MI (Central Location and Satellite Sites)
Michigan Sickle Cell Data

- From 1987 – 2016 a total of 1,908 newborns detected/confirmed
- NBS averages 64 cases annually
- Approximately 2,600 newborns identified as having sickle cell trait annually
- Nearly all detected were black (95%)
- 3,624 individuals identified in patient level claims data living and residing in Michigan.
- Majority of patients live in Detroit, Flint, Saginaw, Southfield, Lansing, Ypsilanti, Grand Rapids, Pontiac and Benton Harbor
Strategic Priority 2.4 (2013)
“Design a public health approach to SCD across the lifespan”

- Child & Adolescent Health Centers
- Children’s Special Health Care Services
- Family Center for Children & Youth with Special Health Care Needs
- Division of Immunization
- Maternal Infant Health Program
- Women, Infant, and Children’s Supplemental Nutrition Program
- Michigan Hemoglobinopathy Quality Improvement Committee (HemQIC)
- SCDAA-MI
- Specialized Sickle Cell Clinics
Strategic Plan Development

- Lifecourse Epidemiology & Genomics Division & Children’s Special Health Care Services took the lead
- Small workgroup formed
- Literature & State Plans Reviewed
Connecticut Department of Public Health (Designing a Comprehensive System Across the Life Span: Connecticut’s State Plan to Address Sickle Cell Disease and Trait – 2007)


http://www.afro.who.int/sites/default/files/2017-06/afr_rc60_8.pdf

SICKLE-CELL DISEASE: A STRATEGY FOR THE WHO AFRICAN REGION

Report of the Regional Director

Executive summary

1. Sickle-cell disease (SCD) is an inherited disorder of haemoglobin. It is the most prevalent genetic disease in the WHO African Region. In many countries, 10%-40% of the population carries the sickle-cell gene resulting in estimated SCD prevalence of at least 2%.

2. The situation in the Region indicates that current national policies and plans are inadequate; appropriate facilities and trained personnel are scarce; and adequate diagnostic tools and treatment are insufficient.

3. Deaths from SCD complications occur mostly in children under five years, adolescents and pregnant women. Strategies and interventions to reduce SCD-related morbidity and mortality should focus on adequate management of these vulnerable groups.

4. This strategy provides a set of public health interventions to reduce the burden of SCD in the African Region through improved awareness, disease prevention and early detection. The interventions include improvements in health-care provision; effective clinical, laboratory, diagnostic and imaging facilities adapted to different levels of the health system; screening of newborns; training of health workers and development of protocols; genetic counselling and testing; accessibility to health care; establishment of patient support groups; advocacy; and research.

5. Success in implementing identified interventions will depend on the commitment of Member States to integrate SCD prevention and control in national health plans, and provide an environment conducive for various stakeholders to contribute to the reduction of SCD prevalence, morbidity and mortality.

6. The Regional Committee is invited to examine and adopt this proposed strategy.

Strategic Plan Development

- Hemoglobinopathy Quality Improvement Committee (HemQIC)
  - Provide NBS program and Bureau of Epidemiology & Population Health expert review and input on screening, diagnosis and treatment for hemoglobinopathies
  - Pediatric & adult hematologist, general pediatrician, nurse practitioners, patient advocate, parent/patient consumer advocate, medical consultants, NBS program, laboratory, etc.

https://www.michigan.gov/documents/mdch/Public_Health_Strategic_Thinking_Questions_to_Address_RESPONSES_472318_7.pdf
Strategic Plan Development

- Focus Groups – Detroit, Saginaw, Lansing, Grand Rapids, Benton Harbor


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<th>Meeting Locations &amp; Dates</th>
<th># of Adults living w/SCD</th>
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Sickle Cell Challenges

- Frequent pain, time-consuming ED trips, stigmatization, compromised quality of life
- Impacted school and work performance
- Long-term progressive disease damage
- Navigating the healthcare system; Lack of providers/transition
- Access to treatment
- Hydroxyurea misconceptions, adverse reactions, unaware
- Lack of a support network
- Depression
Strategic Plan Development

- Stakeholder Summit – over 50 participants
  - Education
  - Transition
  - Provider Shortage
  - Psychosocial/Mental Health
  - Medication Adherence
  - Day Treatment
  - Research
Seven Public Health Priorities

- Education of ED physicians & recommended ED guidelines
- Comprehensive transition programs
- Community mental & behavioral health services
- Adherence & underutilization of hydroxyurea
- Coordinated public health research studies
- Statewide-level education
- Increase adult providers
Seven Strategic Goals

I. Education & Awareness (23)
- Develop statewide multi-level messaging and communication strategies to increase awareness of SCD, disease-modifying medical therapies, and SCT.

II. Transition (14)
- Develop and implement strategies for improving transition from pediatric to adult care.

III. Provider Shortage (11)
- Increase availability of providers who treat all aspects of SCD with an emphasis on increasing providers for adults.
Strategic Goals Cont.

IV. Psychosocial/Mental Health Support (9)
- Increase recognition of the need to address psychological issues and provide mental health support for individuals living with SCD and their families.

IV. Medication Adherence (7)
- Develop protocols for improving medication adherence in accordance with the NHLBI Evidenced-Based Management of SCD Guidelines.

IV. Day Treatment Clinics (6)
- Improve acute care in the emergency room or alternative settings.

IV. Research (7)
- Establish a MI SCD Consortium to coordinate public health research efforts.
Lessons Learned
Successes

- NBS Funding
  - Designated staff positions (Hemoglobinopathy Program Coordinator, NBS Epidemiologist, Health Analyst)
  - Online sickle cell pain management course for nurses

- HRSA STORM Grant
  - Expand hydroxyurea education and awareness initiatives
  - Provider trainings / Continuing medical education credits
  - Partner with Federally Qualified Health Centers (FQHCs)
  - Assess hydroxyurea use and providers visits in claims data
Michigan Care Improvement Registry
Notification Alert (MCIR)

A Quick Look at Vaccines Needed for Persons with Sickle Cell Disease

Sickle cell disease is a group of inherited red blood cell disorders. Because people with sickle cell disease are at an increased risk of infection and other health problems, vaccination is especially important. Common infections, like flu, can quickly become dangerous for a person with sickle cell disease. Persons with sickle cell disease should receive all age-appropriate vaccinations following the Centers for Disease Control (CDC) and Advisory Committee on Immunization Practices (ACIP) routine recommended schedule. In addition, people with sickle cell disease are at an increased risk for infection by encapsulated bacteria such as pneumococcal, meningococcal, and Haemophilus influenzae type b (Hib).

Because of this, people with sickle cell disease will need additional vaccine doses. This Quick Look provides guidance for additional vaccine doses needed for persons with sickle cell disease.

HPV VACCINATION RECOMMENDATIONS FOR SICKLE CELL DISEASE:

PERSONS AGED 6-18 YEARS:
- Vaccinate according to the routine recommendation, 2- or 3-dose series (depending on vaccine used) at 2 and 4 months or at 2, 4, and 6 months, and a booster dose at 12-15 months. This is a complete HPV vaccine series.
- For children aged 12-15 months:
  - If 0 doses of HPV vaccine were given before age 12 months, give 2 doses of HPV, 0-4 weeks apart.
  - If 2 or more HPV doses were given before age 12 months, give 1 dose HPV.
- For children aged 2 years or older, if the child has not received a primary series and booster dose OR at least 1 dose of HPV vaccine after 16 months of age, give 1 dose HPV.
- If previous dose of HPV vaccine received, give 1 dose HPV.

PCV13 and PPV23 VACCINATION RECOMMENDATIONS FOR SICKLE CELL DISEASE:

PERSONS AGED 6-18 YEARS:
- Note: All recommended PCV13 doses should be administered prior to PPV23 vaccination if possible. PCV13 and PPV23 should NOT be administered at the same time.
- For PCV13, vaccinate according to the routine recommendation, 4-dose series at 2, 4, 6, and 12-15 months.
- Children aged 2 years:
  - If a 3-dose PCV13 schedule was received previously, give 1 dose PCV10.
  - If fewer than 3 PCV13 doses were received previously, give 2 doses PCV13, 0-4 weeks apart.
  - If at least 4 PCV13 doses were received prior to PPV23, give 1 dose PCV13 now, 8 weeks later give 1 dose PPV23.
  - For children aged 6-18 years:
    - If child received PCV13 but not PPV23, give 1 dose PPV23 at least 8 weeks after last PCV13.
    - If child received PCV13 and PPV23 were given, give 1 dose PCV13 now, 8 weeks later give 1 dose PPV23.
  - Persons aged 2 years should receive 2 doses of PPV23 separated by 5 years. Beginning 10 years after completing all recommended doses of PCV13.

PERSONS AGED 19 YEARS AND OLDER:
- Note: All recommended PCV13 doses should be administered prior to PPV23 vaccination if possible. PCV13 and PPV23 should NOT be administered at the same time.
- For adults aged 19 years and older with no previous dose of PCV13 received, give 1 dose PCV13.
- For adults aged 19 years and older with no previous dose of PPV23 received, give 2 doses PPV23, 0-4 weeks apart.
  - For adults aged 65 years and older, give 1 dose PPV23 – this will be the final dose. Ensure 5 years interval from last PPV23 dose.
  - Minimum intervals between PCV13 and PPV23 for adults aged 19 years and older are:
    - If PCV13 given first, wait at least 8 weeks before giving PPV23.
    - If PPV23 given first, wait at least 1 year before giving PCV13.

Meningococcal and MenB vaccination recommendations for Sickle Cell Disease:

PERSONS AGED 6-18 YEARS:
- If using MenB:
  - For children aged 6 at 6 weeks, give 2, 4, 6, and 12 months. This counts as a complete MenACWY series.

Michigan Department of Health and Human Services – Division of Immunization
Successes continued.....

- Leveraging MDHHS programs and resources
- Region 4 Midwest Hemoglobinopathy Workgroup
- Parent Mentor Training
Successes continued.....

- Michigan Public Health Institute Partnership (MPHI)
  - Care Coordination Training
  - Online Pain Management Course for Nurses
  - Online Patient & Family Transition Course

- Children Special Health Care Services Transition Follow-up and Policies

- Expanded Maternal Child Health Risk Identifier Assessment Questions
Challenges

- Lack of synthesis between various projects, grants or groups working on similar activities
- Fragmented work/lack cohesiveness
- Leveraging providers ~ competing clinic obligations
- Timeliness
Challenges continued.....

- Children Multi-disciplinary Specialty (CMDS) Clinics Buy-in

- Passing sickle cell legislation
  - (House Bill No. 4603)

- Day Treatment Clinics

- Addressing psychosocial/mental health needs
Corrections

- Start with an Economic Impact Model **before** the plan
- Timeline longer than 3 years
- The plan evolved, things changed, and that’s okay.
- Identify a clinic champion - You’ll need a “go-getter”
- Reconvene annually and report out to partners and stakeholders
- Develop evaluation methodology early
Thank You

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Hemoglobinopathy Quality Improvement Program website:
http://www.michigan.gov/mdhhs/0,5885,7-339-71550_5104_5279-238127--,00.html