

Michigan Department
of Community Health



Rick Snyder, Governor
Olga Dazzo, Director

Michigan Hemoglobinopathy Surveillance and Quality Improvement Project

Awardee Face-to-Face Meeting
April 5, 2011

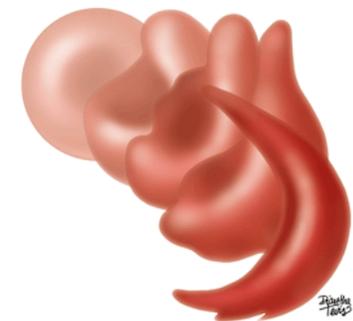
Presenters (alphabetical order):

Violanda Grigorescu, MD, MSPH

Mary Kleyn, MS

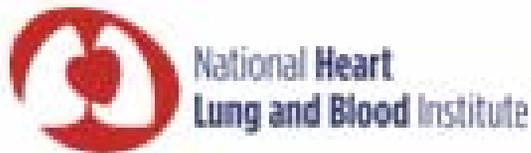
Robin O'Neill, MPH

Wanda Shurney, MD

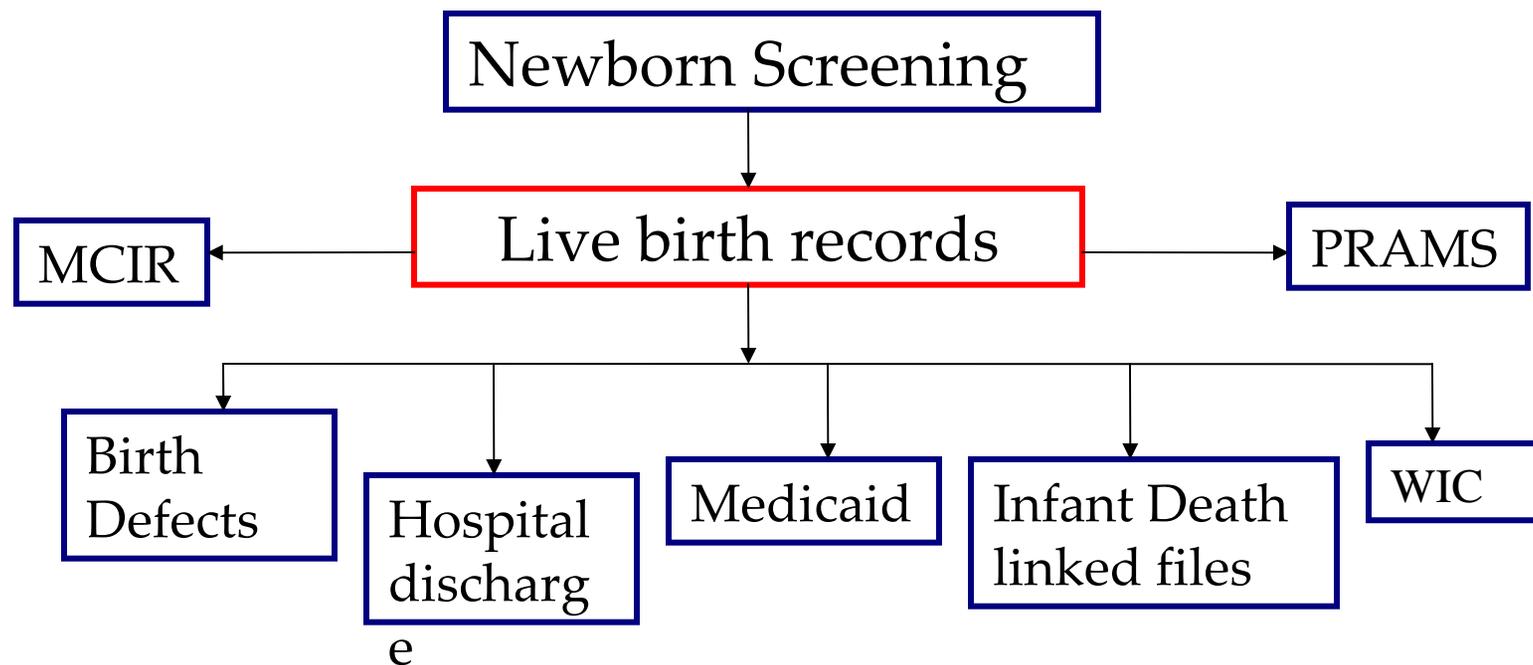


Barrier: Data Collection

- Data sources being used:
 - Newborn Screening
 - Live births and deaths certificates
 - Birth Defects Registry
 - Hospital discharge
 - Medicaid
 - MCIR- immunization
 - PRAMS
 - BRFSS
 - WIC



Linkages



Data in Blue boxes are all linked through the use of Live births as intermediate files

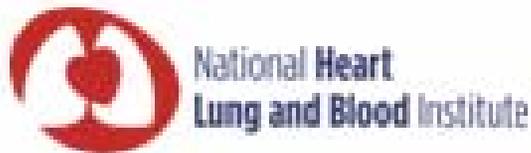


Barriers

- ❑ No major barriers
- ❑ Different time schedules for linkages due to data ownership (i.e., hospital discharge, WIC)
- ❑ Need for more resources for a continued and sustainable linkage process
- ❑ More validation studies

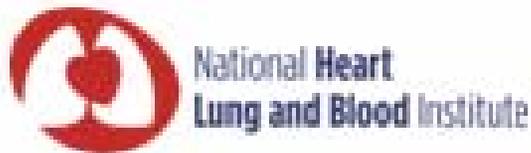
Planning for linkages

- ❑ Assigned staff to certain linkages
- ❑ Assure they have the knowledge to do so
- ❑ Mentoring, Supervision, Follow up and QA/QI methods in place
- ❑ Some Linkages performed in the Vital Records office: prior to RuSH
- ❑ Other linkages performed in the Division of Genomics, Perinatal Health and Chronic Disease Epidemiology: NBS linked with live births prior to RuSH
- ❑ Having a Schedule for each linkage is important as some are used for programmatic purposes as well



Barrier: Data Sharing

- No authority over all data sets
- Data sharing agreement in place
- Data sharing may be slow due to limited staff
- Shared objectives among data owners:
 - Sometimes difficult to have them on our colleagues/partners' priority list
- Process may be slowed down by:
 - Changes in administration
 - Adjustments in IT and databases infrastructure



SCDAA Michigan Chapter Community Based Organization (CBO)

- The MI NBS Program has collaborated with Sickle Cell Disease Association of America (SCDAA), Michigan Chapter for more than 30 years
 - Dr. Wanda Shurney assumed responsibility as the SCDAA Medical Director and project director for the MDCH contract to provide NBS follow-up services
- Collaborate with many other CBOs
- Network of outreach sites in Grand Rapids/Muskegon, Kalamazoo/Southwest Michigan, Lansing/Mid-Michigan and Flint/Saginaw
- Patient Advocates hired through SCDAA, Michigan Chapter

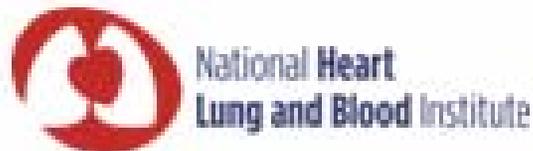




Barrier: Population Outreach

- **SCDAA Michigan Chapter, Inc.**
 - Follow-up for all disease and trait cases
 - Lab confirmation
 - Monitor prophylaxis
 - Annual Health Status Assessment

- **Challenges**
 - Lost to follow-up
 - Identifying cases born before 1987
 - Necessary but Labor intensive data entry



Beyond CBO

- Patient Advocates at each site responsible to connect with other community organizations like churches or ethnic groups
- Engage pediatric and adult providers: Michigan Hemoglobinopathy Advisory Committee
- Engage other public health professionals
- Engage leaders and seek political will



Barrier: Population Outreach

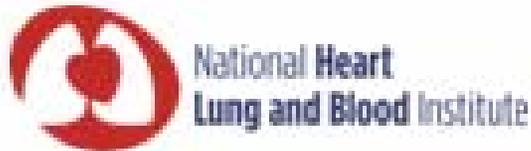
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Barrier: Population Outreach

- Future populations to target:
 - Arab Community
 - Arab Community Center for Economic & Social Services (ACCESS)
 - Latin American Community
 - The Center for Latin and Caribbean Studies
 - West African Community
 - Nigerian American Islamic Center
 - Southeast Asian Community
 - Southeast Asia Resource Action Center (SEARAC)
 - Among Community of Metro-Detroit, Inc.
 - Adult Patients - Patient Advocates and Adult Hematologists



Barrier: Population Outreach

- Michigan RuSH Messages:
 - *"Finally, a way to help experts learn more about kids with sickle cell disease in Michigan"*

Method of learning about Michiganders with sickle cell disease and thalassemia so that we can better understand how these disorders affect their health and what kind of services they need.
- Questions Asked:
 - How will participating in RuSH help my child
 - Questions about privacy
- Gaps in RuSH Messages:
 - Specific examples of how data will be used



Barrier: Collecting information of people with Thalassemia – Alpha Thalassemia

- Time consuming to:
 - Define and standardize the laboratory testing strategies
 - Define the Bart's laboratory cut offs for genetic testing

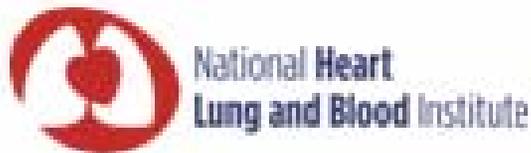
- Need for more resources for genetic testing with timely results and affordable cost

- Need for family history as part of the follow up process besides screening and genetic testing



Communication within the state

- Monthly MI RuSH call
- Meetings of small groups for specific projects:
 - Medicaid group
 - MCIR group
 - ED visits group
- Site visits at the SCDAA MI Chapter- SCD coordination center
- RuSH coordinator attends the monthly patient advocate meetings at SCDAA MI chapter



Communication with other states: Wish List

- ❑ Comparing the linkage algorithms
- ❑ Conduct joint validation studies
- ❑ Develop small group collaborative projects among states interested on the same topics
- ❑ Develop other emerging projects with CDC and NHLBI and seek other funding opportunities
- ❑ Make plans for sustainability
- ❑ Plan for a final pilot project report with recommendations for non participating states



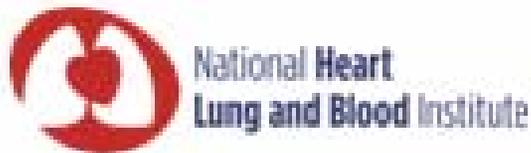
Barrier: Your state's additional barriers

- Difficult to hire highly trained professionals for a short time project
 - Still don't have the evaluator position filled
- Delays in the implementation due to:
 - New tasks for the same limited staff
 - Competing priorities for NBS program
 - Lack of national recommendation on adding thalassemia to the NBS panel



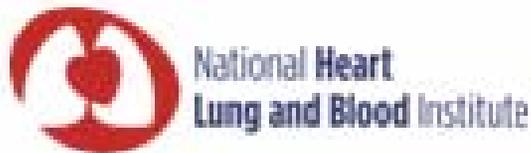
Barrier: Your state's additional barriers (*con't*)

- National and state transition of Public Health
- Potential changes in infrastructure
- State funding based on NBS fees not enough for implementing complex surveillance process and subsequent follow up strategies
- Additional federal support is absolutely necessary



Michigan's Year 1 Accomplishments

- Hire the RuSH coordinator: Robin O'Neill
- Assure good communication and coordination among RuSH PI, RuSH coordinator, NBS program manager and Director of SCDAA MI Chapter
- Work as a team
- Follow up the surveillance plan and do not act randomly



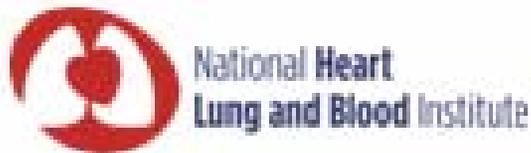
Michigan's Year 1 Accomplishments (con't): Objectives accomplished

- ❑ RuSH Website developed
- ❑ Education materials for thalassemia adopted
- ❑ Adjust the follow up strategies and add more education as necessary
- ❑ Improve the coordination between MDCH, SCDAA MI Chapter and MiHemAdCo
- ❑ Held MiHemAdCo meetings and focused on the implementation of new strategies from MICR module for SCD to screening for thalassemia



Michigan's Year 1 Accomplishments (con't): Objectives accomplished

- ❑ Survey questions in both, PRAMS and BRFSS
- ❑ Question in CON (Certificate of Need) for EDs
- ❑ Use different data sources and performed linkages
- ❑ Developed groups that work on special issues: MCIR, Medicaid, ED visits
- ❑ Received approval from the NBQAAC to officially implement the screening for thalassemia
- ❑ Implement the SCD module in MCIR
 - Perform training
 - Implement the health status assessment form



Michigan's Year 1 Accomplishments (con't): Objectives accomplished

Preliminary health status assessment form findings (n=54)

Case Diagnosis		%
Sickle Cell Anemia	33	61.1
Hemoglobin SC Disease	16	29.6
Sickle Beta Thalassemia	5	9.3
Sex		
Male	21	38.9
Female	33	61.1



Michigan's Year 1 Accomplishments (con't): Objectives accomplished

Preliminary health status assessment form findings (n=54)

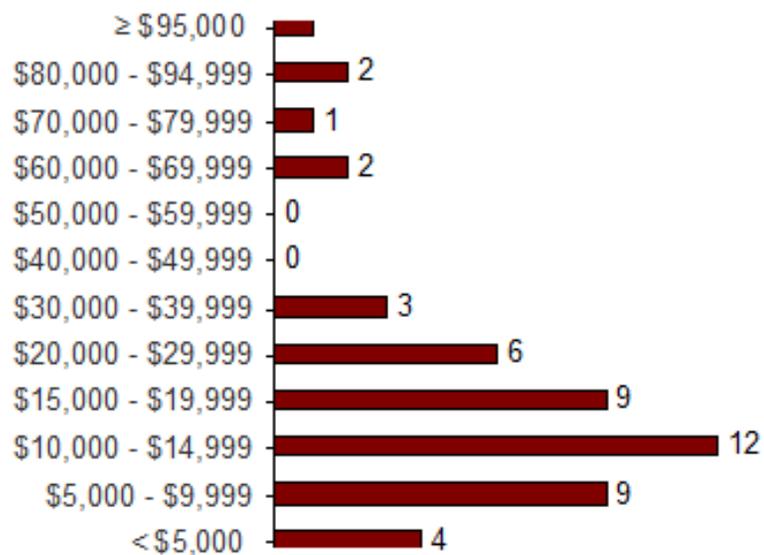
Insurance (can have multiple)		%
No insurance	0	0.0
Medicaid	31	57.4
Medicaid HMO	12	22.2
Private	8	14.8
MI Child	3	5.6
Medicare	1	1.9
Medicare HMO	0	0.0
Other Insurance	0	0.0
Government Assistance (can have multiple)		
WIC	37	68.5
CSHCS	28	51.9
Early On	7	13.0



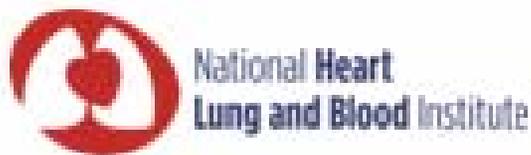
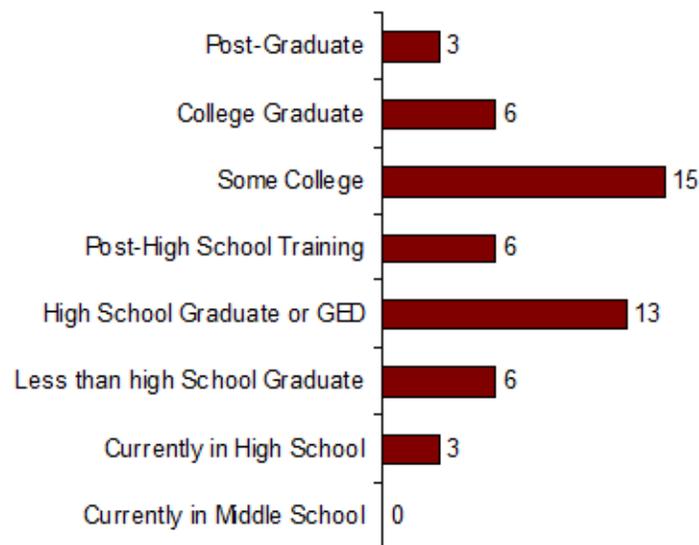
Michigan's Year 1 Accomplishments (con't): Health Status Assessment Form

Preliminary health status assessment form findings (n=54)

Income



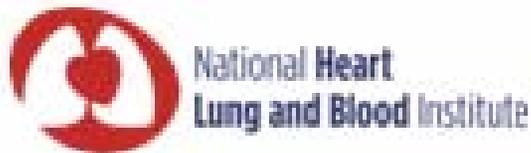
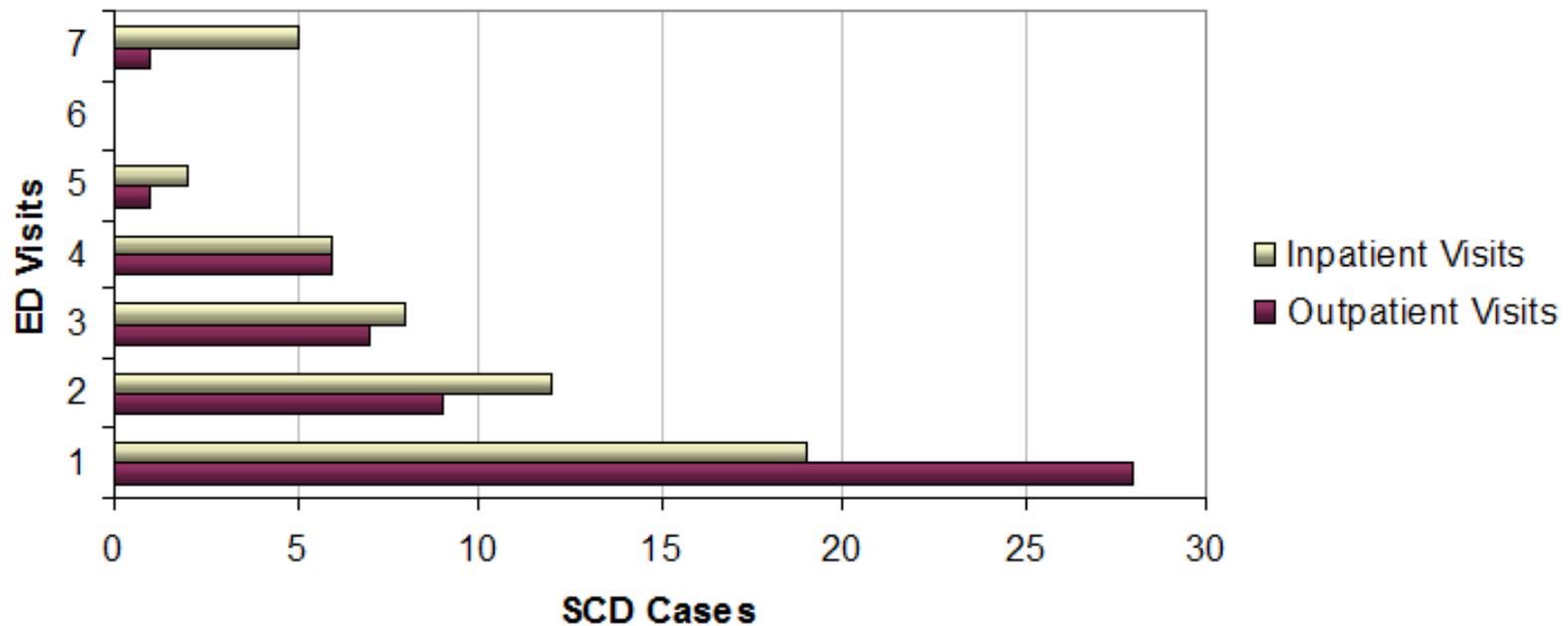
Education



Michigan's Year 1 Accomplishments (con't): Objectives accomplished

Preliminary health status assessment form findings (n=54)

Frequency of Annual Emergency Department Visits



Michigan's Year 1 Accomplishments (con't)

□ Examples of indicators:

- Number of infant deaths : 2 deaths out of 317 = 0.6 per 100 born with SCD (2004-2008 birth cohort)
- Percent of birth defects (2004-2006 birth cohort):
11.9% of all SCD and 10.6% of all SCT
- Percent of SCD with age-appropriate immunizations:
4:3:1:3:3:1:4 series by 19-35 months (66.0%) and 3-6 years (71.3%) for kids with SCD (2004-2008 birth cohort)

□ Examples of measurable HP 2020 objectives:

- BDBS1: Developmental) Increase the proportion of persons with hemoglobinopathies who receive recommended vaccinations:
Baseline (2004-2008 birth cohort): 71.3% (4:3:1:3:3:1:4 series)



Michigan's Year 1 Accomplishments (con't): New emerging topics for second year

- Immunization in children with SCD and SCT
 - Poster at the National MCH Epi Conference and National Immunization Conference
 - Another study in progress
- Birth defects in SCD
 - Validation study in progress
 - Preliminary findings presented at the MCH Epi National Conference
- Decreasing the ED visits through collaboration with Medicaid, CON and MHA
- Maternal Mortality in women with SCD and SCT – chart review of maternal deaths in progress
- Sudden cardiac deaths of the young and SCD and/or SCT: adopt and expand the process of MI SCDY



What can CDC and NHLBI do to help remedy problems that we have encountered?

- ❑ Better communication and coordination
- ❑ Don't change the plan as we move along
- ❑ Agreement on the messages given to the states
- ❑ Identify priorities at the federal level that all states must follow
- ❑ Allow and support innovative approaches proposed by participating states as they fit within the context
- ❑ Have clear messages about the continuation of the grant: state must plan as we may not be able to continue the project without federal support



Michigan's view of RuSH

- Unique collaborative effort between clinical practice and research, public health and community based organizations
- Unique opportunity to promote NBS, a comprehensive program at the crossroads of genomics, MCH and chronic disease
- Unique model of using surveillance process to develop long term follow up strategies
- Unique opportunity to implement in Michigan a long standing plan



Acknowledgments

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Bob Swanson

CON

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Medicaid

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Jackie Prokop

MHA

Sam Watson
Brittany Bogan

MiHemAdCo

Chair persons
All members





Thank you!

