Michigan Care Improvement Registry
Hemoglobinopathy Module

Division of Genomics, Perinatal Health, &
Chronic Disease Epidemiology
Michigan Department of Community Health

April 15, 2011
Michigan Care Improvement Registry (MCIR)

- MCIR: a web-based surveillance application created in 1998 for tracking school-exclusionary vaccinations in Michigan
  - Allows for real-time maintenance and analysis of immunization information
  - Facilitates coordination among public health, health care providers and medical laboratories (i.e. NBS)
  - Contains over 3 million adult vaccination records
  - Expanded in 2006 to include adult vaccinations
  - Expanded in 2010 to include hemoglobinopathy follow-up for cases detected in NBS
# Immunization Module

**Person Information:**
- **Name:** RON WEASLEY
- **Birthday:** 09/22/1985
- **Gender:** Male
- **Age:** 25 Years 6 Months
- **Address:** 14 OTTERY STREET, CATCHPOLE, MI 49508-4505
- **Resp. Party:** WEASLEY, MR. AUTHUR
- **Phone:** (616) 446-2190
- **As of 08/30/2006**

## Immunizations

<table>
<thead>
<tr>
<th>Series</th>
<th>Dose 1</th>
<th>Dose 2</th>
<th>Dose 3</th>
<th>Dose 4</th>
<th>Dose 5</th>
<th>Dose 6+</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td>DTP/DTaP/DT/Td/Tdap</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>02/05/1986</td>
<td>04/15/1986</td>
<td>05/19/1987</td>
<td>07/17/1990</td>
<td>06/16/2004</td>
<td></td>
<td>Tdap DUE NOW</td>
<td></td>
</tr>
<tr>
<td>DTP (historical)</td>
<td>DTP (historical)</td>
<td>DTP (historical)</td>
<td>DTP (historical)</td>
<td>Td (adult): Tetra-Diph</td>
<td>18yrs 8mos</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4mos 14dys</td>
<td>6mos 24dys</td>
<td>1yr 7mos</td>
<td>4yrs 9mos</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MMR</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>03/02/1987</td>
<td>08/30/1993</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MMR</td>
<td>MMR</td>
<td>7yrs 11mos</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Series Complete</td>
</tr>
<tr>
<td>Hepatitis B</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hep B (ped/adol)</td>
<td>Hep B (ped/adol)</td>
<td>Hep B (ped/adol)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11yrs 10mos</td>
<td>12yrs 2mos</td>
<td>12yrs 8mos</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Varicella</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Varicella DUE NOW</td>
</tr>
<tr>
<td>07/07/2000</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Varicella</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14yrs 9mos</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HPV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>HPV DUE NOW</td>
</tr>
<tr>
<td>05/23/2002</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hep A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>03/05/2003</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hep A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hepatitis A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>05/21/2002</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hep A</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**MCIR ID:** 20198914567
MCIR-Tracking Sickle Cell and Thalassemia in Michigan

- Specific module within MCIR for hemoglobinopathies (sickle cell disease, sickle cell trait, thalassemia)
- Launched October 2010
- Used by SCDAA staff to document case follow-up
- Generates letters to mother and physician
- Facilitates coordination among SCDAA-MI staff and Michigan Department of Community Health (MDCH)
- Allows for real-time maintenance and analysis of follow-up information
Case Roster

Case Roster

Case Roster

Site: All Sites Cases
County: All Counties
Case Status: Open
Case Diagnosis: Any
Patient Advocate: Bellatrix Lestrange (lestran1755)

Get Cases

Count: 17

Modify Roster

Sickle Cell Cases

<table>
<thead>
<tr>
<th>Name</th>
<th>Birth Date</th>
<th>Gender</th>
<th>County</th>
<th>Patient Advocate</th>
<th>Site</th>
<th>Case Status</th>
<th>Case Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fskgji Ssjqj</td>
<td>02/12/2009</td>
<td>F</td>
<td>Ingham</td>
<td>lestran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Sickle Cell Anemia</td>
</tr>
<tr>
<td>Ewqj/g Rgjsj</td>
<td>02/29/2009</td>
<td>M</td>
<td>Ingham</td>
<td>lestran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Sickle Beta Thalassemia</td>
</tr>
<tr>
<td>Rgd/g Tgsf</td>
<td>06/15/2009</td>
<td>M</td>
<td>Jackson</td>
<td>lestran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Hemoglobin A + Variant</td>
</tr>
<tr>
<td>Wgqld/g Tgdj</td>
<td>09/30/2009</td>
<td>M</td>
<td>Ingham</td>
<td>lestran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Sickle Cell Anemia</td>
</tr>
<tr>
<td>Nqji Nkqj</td>
<td>12/13/2009</td>
<td>F</td>
<td>Ingham</td>
<td>lestran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Hemoglobin SC Disease</td>
</tr>
</tbody>
</table>
MCIR-Tracking Sickle Cell and Thalassemia in Michigan

- Tasks to document in MCIR:
  - Verify contact information
  - Associate healthcare provider
  - Penicillin prophylaxis
  - Confirmatory lab diagnostics
  - Annual health status assessment
# MCIR-Tracking Sickle Cell and Thalassemia in Michigan

<table>
<thead>
<tr>
<th>Name of Disorder</th>
<th>Lab code</th>
<th>Letter to mother</th>
<th>Letter to physician</th>
<th>Verify county</th>
<th>Verify address and phone</th>
<th>Associate provider</th>
<th>Non-NBS result (repeat test)</th>
<th>Penicillin prophylaxis</th>
<th>Mail RUSH brochure</th>
<th>Health Status Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hemoglobin SC Disease</td>
<td>FSC</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sickle Cell Anemia</td>
<td>FS</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Sickle β Thalassemia</td>
<td>FSA</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hemoglobin C Disease</td>
<td>FC</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hemoglobin D Disease</td>
<td>FD</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hemoglobin E Disease</td>
<td>FE</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hemoglobin H Disease</td>
<td>FH</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hemoglobin C + variant</td>
<td>FC + variant</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hemoglobin D + variant</td>
<td>FD + variant</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Hemoglobin E + variant</td>
<td>FE + variant</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>
| Beta Thalassemia Major (β+)
| Low A | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Hemoglobin C β Thalassemia               | FCA      | ✓                | ✓                   | ✓            | ✓                        | ✓                  | ✓                           | ✓                     | ✓                   | ✓                 |
| Sickle Cell Trait                        | FAS      | ✓                | ✓                   | ✓            | ✓                        | ✓                  | ✓                           | ✓                     | ✓                   | ✓                 |
| Hemoglobin C Trait                       | FAC      | ✓                | ✓                   | ✓            | ✓                        | ✓                  | ✓                           | ✓                     | ✓                   | ✓                 |
| Hemoglobin D Trait                       | FAD      | ✓                | ✓                   | ✓            | ✓                        | ✓                  | ✓                           | ✓                     | ✓                   | ✓                 |
| Hemoglobin E Trait                       | FAE      | ✓                | ✓                   | ✓            | ✓                        | ✓                  | ✓                           | ✓                     | ✓                   | ✓                 |
| Hemoglobin A variant                     | FA + variant | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Hemoglobin S + variant                   | FSV      | ✓                | ✓                   | ✓            | ✓                        | ✓                  | ✓                           | ✓                     | ✓                   | ✓                 |
Contact and Provider Information

- Database of all Michigan healthcare providers
- Case worker can add/remove multiple providers

![Example of a database entry showing personal information, case diagnosis, and associated provider details.](Image)
Penicillin Prophylaxis

- Recommended for children with sickle cell disease until age 5 to prevent infection
- Updates documented in MCIR every 3 months
Confirmatory Lab Diagnostics

- Lab confirmation is required for all non-trait cases
- Methodology: High Performance Liquid Chromatography (HPLC), Isoelectric Focusing (IEF)
- More accurate once fetal hemoglobin levels decrease (age 3 months)
Annual Health Status Assessment

- Annual questionnaire for Michigan residents with sickle cell disease
  - Frequency of hospitalizations
  - Co-morbidities (infections, chronic conditions)
  - Insurance and government assistance
  - Genetic counseling, education

- Patient advocates enter information directly into MCIR

- Not merely a replication of electronic medical records
### Task Notes

**Task Details**

**Task Type**: Assess Health Status  
**Task Status**: Active

**Select Form**: Health Status Form

## Task Notes

### Insurance

#### Provider Visits

- **TCD**
  - Transcranial Doppler screening in the past 12 months
  - Yes  
  - No  
  - Don’t Know  
  - N/A

#### Hospitalizations

- **Echocardiogram**
  - Echocardiogram in the past 12 months
  - Yes  
  - No  
  - Don’t Know  
  - N/A

### Health Education

#### Pulmonary Function Testing

- Pulmonary function test in the past 12 months
  - Yes  
  - No  
  - Don’t Know  
  - N/A

### General Screenings

#### Demographics

- **Mammogram**
  - Mammogram in the past 12 months
  - Yes  
  - No  
  - Don’t Know  
  - N/A

#### SCD-related Screenings

- **Pap Smear**
  - Pap smear or gynecological exam in the past 12 months
  - Yes  
  - No  
  - Don’t Know  
  - N/A

- **Colon Screening**
  - Colonoscopy in the past 12 months
  - Yes  
  - No  
  - Don’t Know  
  - N/A

- **Prostate Screening (PSA)**
  - Prostate-specific antigen (PSA) test in the past 12 months
  - Yes  
  - No  
  - Don’t Know  
  - N/A

**Clinically Verified**
Populating MCIR with New Cases

- Cases born on or after January 1, 2011
- NBS samples sent from hospital to MDCH NBS Lab
- NBS lab results entered into PerkinElmer System
- Electronic Live Birth Records sent to NBS (linked by NBS Epidemiologist)
- All Newborn Screening Follow-up results are entered into MCIR with basic demographic information, contact information, NBS lab information
- SCDAA Center staff receives new case of newborn with sickle cell disease
- Case is assigned to a regional patient advocate based on zip code
- SCDAA-MI staff documents:
  - Lab confirmatory test results
  - All prophylaxis updates (every 3 months)
  - Annual health status assessments
Populating MCIR with Old Cases

- Cases born before January 1, 2011
- Records are manually transferred from paper records to MCIR system
- SCDAA-MI staff documents:
  - Lab confirmatory test results
  - First and last prophylaxis updates only
- Cases receive a health status assessment when entered into the MCIR system
- 40 cases per month entered by descending date of birth
Patient Confidentiality

- Follow-up included as part of NBS, mandated by Michigan Public Health Code
- Unethical to have screening without follow-up
- Institutional Review Board (IRB) approval not required
- All data stored on secure servers, password protected computers
- Identifying information not disclosed in any briefs, reports, other dissemination
- Data access is limited and varies by staff role
Case Assignment and Access

- Cases are assigned to one patient advocate based on zip code:
  - Only this patient advocate is able to edit case information
  - Only staff at MDCH and SCDAA-MI in Detroit can view all case information
  - Cases can be freely re-assigned to other caseworkers by SCDAA-MI administrators
  - All case modifications and data entry tracked by MCIR information technology staff
Search and Filtering

Find Person

Before adding a person, please make several attempts to locate the person in the system.

*PLEASE NOTE:* At least one person name field and a birthdate are required to add a new record.
You may use any other field for identification purposes, but using these fields will not allow you to add a new record.

This information identifies the person presenting for medical treatment

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>MCIR ID</td>
<td></td>
</tr>
<tr>
<td>Last Name</td>
<td>First Name</td>
</tr>
<tr>
<td>Birthdate*</td>
<td>Gender</td>
</tr>
<tr>
<td>Mother's Maiden Name</td>
<td></td>
</tr>
<tr>
<td>Patient ID</td>
<td>Medicaid ID</td>
</tr>
<tr>
<td>WIC ID</td>
<td></td>
</tr>
</tbody>
</table>

Information identifying the responsible party for appointments (parent/guardian)

<table>
<thead>
<tr>
<th>Field</th>
<th>Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Last Name</td>
<td>First Name</td>
</tr>
<tr>
<td>Phone</td>
<td></td>
</tr>
</tbody>
</table>

Search | Clear | Cancel
## Search and Filtering

![Screen capture of a webpage showing search filters and case data]

### Filters
- **Site**: SC Lansing-Jackson
- **Case Status**: Open
- **Patient Advocate**: Bellatrix Lestrange (lestran1755)

### Count: 17 Cases

### Sickle Cell Cases

<table>
<thead>
<tr>
<th>Name</th>
<th>Birth Date</th>
<th>Gender</th>
<th>County</th>
<th>Patient Advocate</th>
<th>Site</th>
<th>Case Status</th>
<th>Case Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fskglj Sgsjd</td>
<td>02/12/2009</td>
<td>F</td>
<td>Ingham</td>
<td>lastran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Sickle Cell Anemia</td>
</tr>
<tr>
<td>Ewglg Rfjsig</td>
<td>02/28/2009</td>
<td>M</td>
<td>Ingham</td>
<td>lastran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Sickle Beta Thalassemia</td>
</tr>
<tr>
<td>Rdgl Tgskf</td>
<td>06/15/2009</td>
<td>M</td>
<td>Jackson</td>
<td>lastran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Hemoglobin A+ Variant</td>
</tr>
<tr>
<td>Wgdtkf Tgdj</td>
<td>09/30/2009</td>
<td>M</td>
<td>Ingham</td>
<td>lastran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Sickle Cell Anemia</td>
</tr>
<tr>
<td>Ngkj Mkjg</td>
<td>12/13/2009</td>
<td>F</td>
<td>Ingham</td>
<td>lastran1755</td>
<td>SC Lansing-Jackson</td>
<td>Open</td>
<td>Hemoglobin SC Disease</td>
</tr>
</tbody>
</table>

[Modify Roster]
Creation of SCD MCIR

Where do web-based modules come from?

- Computer programmers contracted through MDCH
- Extensive communication between clinical staff, epidemiologists, and programmers
- Use-case diagrams created for each disorder
- Software used for communicating code errors and quality improvement in place
- Key: use technology to serve our purpose, not to determine our purpose
Data Extraction from SCD MCIR

- Data files extracted from MCIR as text (.csv) files

- Manipulated in SAS for analysis by MDCH staff
Future of SCD MCIR

- Integration into SCDAA-MI workflow
- Automated data extraction and reports
- Use by physicians for case finding, ongoing surveillance across the lifespan
- MCIR module used as a framework for follow-up of other disorders (HIV, Hearing Detection)
Hemoglobinopathy Surveillance and MCIR

- Beyond simple replication of electronic medical records
- Constant validation and quality assurance
- Safety and confidentiality of citizens is top priority
- All data collected is used to improve quality of life and health outcomes
- *Every public health program or intervention begins with the availability of quality data*
Acknowledgments

- Division
  - Dr. Violanda Grigorescu
  - Robin O’Neill, MPH
  - Mary Kleyn, MSc.

- NBS Follow-up Program
  - Dr. Bill Young
  - Karen Andruszewski

- MCIR
  - Kevin Garnett
  - Gordon Chamberlin

- CDC and NHLBI
  - RuSH