

Michigan Care Improvement Registry

Hemoglobinopathy Module



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Chronic Disease Epidemiology
Michigan Department of Community Health
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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 : Edit					MCIR ID : 20198914567		
Name: RON WEASLEY		Birthdate: 09/22/1985		Gender: Male			
		Age: 25 Years 6 Months		County: Kent (41) County			
Address: 14 OTTERY STREET CATCHPOLE, MI 49508-4505				Resp. Party: WEASLEY, MR. AUTHUR			
As of 08/30/2006				Phone: (616) 446-2190			
Series	Immunizations					Other	
	Dose 1	Dose 2	Dose 3	Dose 4	Dose 5	Dose 6+	Status
DTP/DTaP/ DT/Td/Tdap	02/05/1986 DTP (historical) 4mos 14dys	04/15/1986 DTP (historical) 6mos 24dys	05/19/1987 DTP (historical) 1yr 7mos	07/17/1990 DTP (historical) 4yrs 9mos	06/16/2004 Td (adult): Teta -Diph 18yrs 8mos		Tdap DUE NOW
MMR	03/02/1987 MMR 1yr 5mos	08/30/1993 MMR 7yrs 11mos					Series Complete
Hepatitis B	07/30/1997 Hep B (ped/adol) 11yrs 10mos	12/15/1997 Hep B (ped/adol) 12yrs 2mos	05/27/1998 Hep B (ped/adol) 12yrs 8mos				Series Complete
Varicella	07/07/2000 Varicella 14yrs 9mos						Varicella DUE NOW
HPV							HPV DUE NOW
Hepatitis A	05/23/2002 Hep A	03/05/2003 Hep A					Series

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 - Site: Sickle Cell Center - Windows Internet Explorer

Case Roster [Print Help](#)
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[Person](#) | [Case Mgmt](#) | [My Site](#) | [Admin](#) | [Reports](#) | [Other](#)
[Case Roster](#) | [Provider Roster](#) | [Hospital Roster](#) | [Admin](#) | [Print Ltrs](#)

Case Roster

Site: County:
 Case Status: Case Diagnosis:
 Patient Advocate:

Count : 17 [Modify Roster](#)

Sickle Cell Cases

Name	Birth Date	Gender	County	Patient Advocate	Site	Case Status	Case Diagnosis
Fskglj Sgsjd	02/12/2009	F	Ingham	lastran1755	SC Lansing-Jackson	Open	Sickle Cell Anemia
Ewgjlg Rfjlsjg	02/28/2009	M	Ingham	lastran1755	SC Lansing-Jackson	Open	Sickle Beta Thalassemia
Rdgl Tgskf	06/15/2009	M	Jackson	lastran1755	SC Lansing-Jackson	Open	Hemoglobin A + Variant
Wgdllkfg Tgdgj	09/30/2009	M	Ingham	lastran1755	SC Lansing-Jackson	Open	Sickle Cell Anemia
Ngkj Mkjg	12/13/2009	F	Ingham	lastran1755	SC Lansing-Jackson	Open	Hemoglobin SC Disease

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

Name of Disorder	Lab code	Letter to mother	Letter to physician	Verify county	Verify address and phone	Associate provider	Non-NBS result (repeat test)	Penicillin prophylaxis	Mail RuSH brochure	Health Status Form
Hemoglobin SC Disease	FSC	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sickle Cell Anemia	FS	✓	✓	✓	✓	✓	✓	✓	✓	✓
Sickle β Thalassemia	FSA	✓	✓	✓	✓	✓	✓	✓	✓	✓
Hemoglobin C Disease	FC	✓	✓	✓	✓	✓	✓			
Hemoglobin D Disease	FD	✓	✓	✓	✓	✓	✓			
Hemoglobin E Disease	FE	✓	✓	✓	✓	✓	✓			
Hemoglobin H Disease	FH	✓	✓	✓	✓	✓	✓			
Hemoglobin C + <i>variant</i>	FC + <i>variant</i>	✓	✓	✓	✓	✓				
Hemoglobin D + <i>variant</i>	FD + <i>variant</i>	✓	✓	✓	✓	✓				
Hemoglobin E + <i>variant</i>	FE + <i>variant</i>	✓	✓	✓	✓	✓				
Beta Thalassemia Major (β^0)	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 <i>variant</i>	FA + <i>variant</i>	✓	✓	✓	✓					
Hemoglobin S + <i>variant</i>	FSV	✓	✓	✓	✓					

Contact and Provider Information

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

Person Information : Edit		MCIR ID : 500947951	
Name:	Grover Monster	Birthdate:	10/23/1997
		Age:	13 years
Gender:	Male	County:	Saginaw (73) County
Address:	123 Sesame Street		
	Saginaw, MI 48601		
As of 10/21/2010	Resp. Party:	Oz, Frank	
	Phone:	(989) 466-8230	
Immunizations <input type="checkbox"/>		Other	
Follow Up			
Case Diagnosis:	Hemoglobin A + Variant	Case Status:	Open
Case County:	Saginaw	Patient Advocate:	oneillr (Sickle Cell Center)
Comprehensive View			
Tasks	Notes	Prophylaxis Details	Lab Results
Physicians			
Mother			
Associate Provider			
	Provider Name	Specialty	Address
	County	Phone Number	
	SCOTT HOTCHKISS	Not Specified	1890 SOUTH US131, PETOSKEY MI 49770
		Emmet	(231) 487-6000

Penicillin Prophylaxis

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

Task Details	
Type*	Check Prophylaxis
Status*	Active
Due Date*	05/10/2010
Antibiotic*	Penicillin
Prophylaxis Status*	Initially Started
As Of*	03/05/2010
Task Notes	
Add Note	
05/12/10	Attempted to contact mother on 5/1/10 by phone

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)

Task Details			
Type*	<input type="text" value="Record non-NBS Lab Result"/>	Status*	<input type="text" value="Active"/>
		Due Date*	<input type="text" value="07/12/2010"/>
Test Date*	<input type="text" value="07/01/2010"/>	<input type="checkbox"/> Test Inconclusive Due to Transfusion	
A	<input type="text"/>	A2	<input type="text" value="1"/>
	%		%
S	<input type="text" value="21"/>	F	<input type="text" value="78"/>
	%		%
C	<input type="text"/>	D	<input type="text"/>
	%		%
E	<input type="text"/>		
	%		
Other	<input type="text"/>	Specify:	<input type="text"/>
	%		
Possible Barts	<input type="checkbox"/>		
Lab Result*	<input type="text" value="FS (Sickle Cell Anemia)"/>		
Task Notes			
Add Note			

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

Health Status Assessment Form

Task Details

Task Type*

Task Status*

Select Form*

Task Notes

[Add Note](#)

Insurance	Health Education	General Screenings	Demographics
Provider Visits	Hospitalizations	Sickle Cell History	SCD-related Screenings
TCD			
Transcranial Doppler screening in the past 12 months			<input type="checkbox"/> <i>Clinically Verified</i>
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't Know <input type="radio"/> N/A			
Echocardiogram			
Echocardiogram in the past 12 months			<input type="checkbox"/> <i>Clinically Verified</i>
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't Know <input type="radio"/> N/A			
Pulmonary Function Testing			
Pulmonary function test in the past 12 months			<input type="checkbox"/> <i>Clinically Verified</i>
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't Know <input type="radio"/> N/A			
Mammogram			
Mammogram in the past 12 months			<input type="checkbox"/> <i>Clinically Verified</i>
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't Know <input type="radio"/> N/A			
Pap Smear			
Pap smear or gynecological exam in the past 12 months			<input type="checkbox"/> <i>Clinically Verified</i>
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't Know <input type="radio"/> N/A			
Colon Screening			
Colonoscopy in the past 12 months			<input type="checkbox"/> <i>Clinically Verified</i>
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't Know <input type="radio"/> N/A			
Prostate Screening (PSA)			
Prostate-specific antigen (PSA) test in the past 12 months			<input type="checkbox"/> <i>Clinically Verified</i>
<input type="radio"/> Yes <input type="radio"/> No <input type="radio"/> Don't Know <input type="radio"/> N/A			

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
- ❑ SCDAACenter staff receives new case of newborn with sickle cell disease
- ❑ Case is assigned to a regional patient advocate based on zip code
- ❑ SCDAAC-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
- ❑ SCDA-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 [Print Help](#)
[Home](#) [Exit](#)

Person	Case Mgmt	My Site	Admin	Reports	Other
Add/Find	Roster	Information	Status	History	

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

MCIR ID	<input type="text"/>	First Name	<input type="text"/>
Last Name	<input type="text"/>	Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female
Birthdate*	<input type="text"/> 	<input type="checkbox"/> MultipleBirthChild	
Mother's Maiden Name	<input type="text"/>	Medicaid ID	<input type="text"/>
Patient ID	<input type="text"/>		
WIC ID	<input type="text"/>		

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

Last Name	<input type="text"/>	First Name	<input type="text"/>
Phone	(<input type="text"/>) <input type="text"/> - <input type="text"/>		

Search and Filtering

Site	<input type="text" value="SC Lansing-Jackson"/>	County	<input type="text" value="All Counties"/>
Case Status	<input type="text" value="Open"/>	Case Diagnosis	<input type="text" value="Any"/>
Patient Advocate	<input type="text" value="Bellatrix Lestrage (lestran1755)"/>		
<input type="button" value="Get Cases"/>			

Count : 17

[Modify Roster](#)

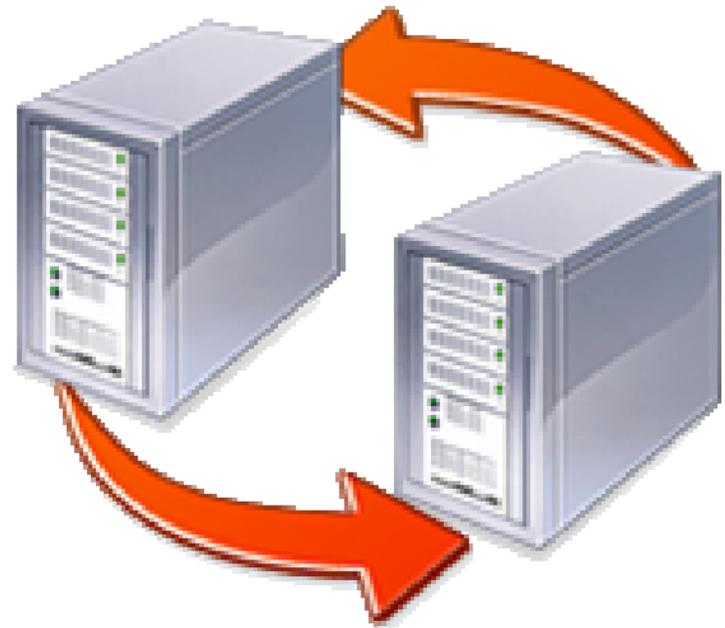
Sickle Cell Cases							
<u>Name</u>	<u>Birth Date</u>	<u>Gender</u>	<u>County</u>	<u>Patient Advocate</u>	<u>Site</u>	<u>Case Status</u>	<u>Case Diagnosis</u>
Fskglj Sgsjd	02/12/2009	F	Ingham	lastran1755	SC Lansing-Jackson	Open	Sickle Cell Anemia
Ewgjlg Rfjlsjg	02/28/2009	M	Ingham	lastran1755	SC Lansing-Jackson	Open	Sickle Beta Thalassemia
Rdgl Tgskf	06/15/2009	M	Jackson	lastran1755	SC Lansing-Jackson	Open	Hemoglobin A + Variant
Wgdllkfg Tgdgj	09/30/2009	M	Ingham	lastran1755	SC Lansing-Jackson	Open	Sickle Cell Anemia
Ngkj Mkjg	12/13/2009	F	Ingham	lastran1755	SC Lansing-Jackson	Open	Hemoglobin SC Disease

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 SCDA-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*

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