



REDUCING TRANSFUSION COMPLICATIONS and other surveillance-supported efforts in hemoglobin disorders

SCDC Webinar
August 30, 2017

Acknowledgements

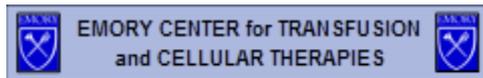
Sickle Cell Data Collection in Georgia is made possible by support from the Association of University Centers on Disability with funding from the Centers for Disease Control and Prevention (CDC-RFA-OT13-1302), and by support from the CDC Foundation with funding from Bioverativ, Global Blood Therapeutics and Pfizer.

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Partners

- Georgia's comprehensive sickle cell centers
 - Children's Healthcare of Atlanta
 - Grady Health System
 - Augusta University
- Emory Center for Transfusion & Cellular Therapies
- Georgia Department of Public Health
- Georgia Southern University
- Sickle Cell Community Consortium
- Sickle Cell Foundation of Georgia



Outline

SCDC – *informing policies, practices, and outcomes for SCD*

- Surveillance data
- Past uses/findings
- Dissemination/analysis plan

RedHhott – *reducing transfusion complications in SCD & thalassemia*

- Data uses/findings
- Provider practices
- Patient practices
- Community practices

Sickle Cell Data Collection in Georgia

Informing policies and practices
to improve outcomes in sickle cell disease



Sickle cell surveillance in Georgia

RuSH – Development and analysis of state-based surveillance for years 2004 – 2008

PHRESH – Additional analysis, dissemination and health promotion

SCDC – Updated and ongoing surveillance, strategic analysis and dissemination

Surveillance dataset

Years 2004 – most recent

Individual-level, w/ IDs for matching & de-duplication

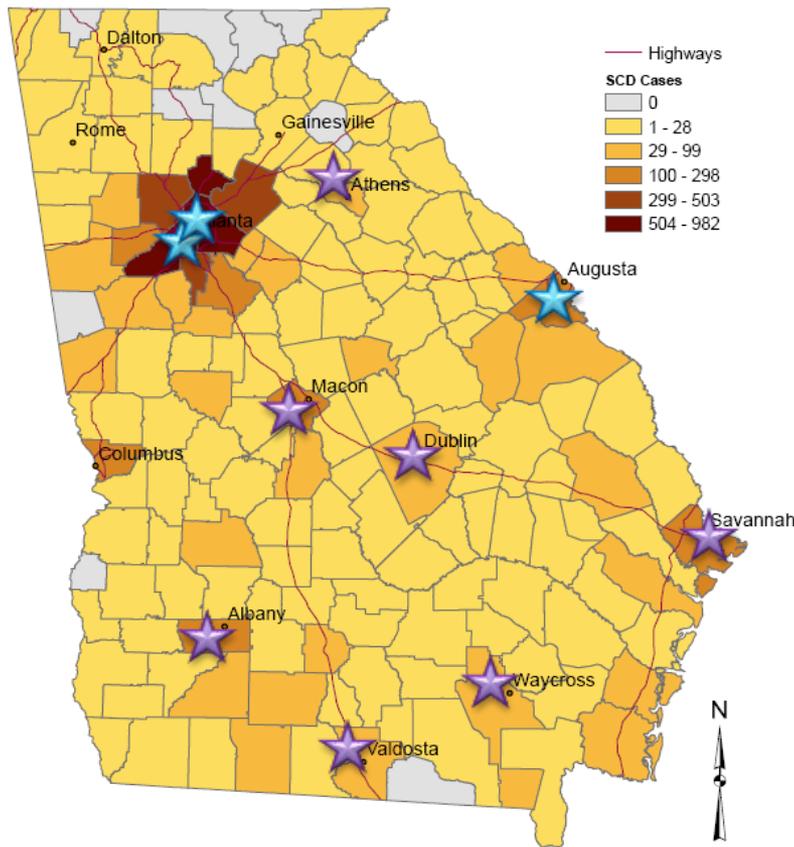
Sources

- Newborn screening
- Vital records
- Medicaid
- Children's Health Insurance Program
- State Health Benefit Plan
- Hospital and emergency department discharge records
- Clinical variables from 3 comprehensive SCD centers

Past findings

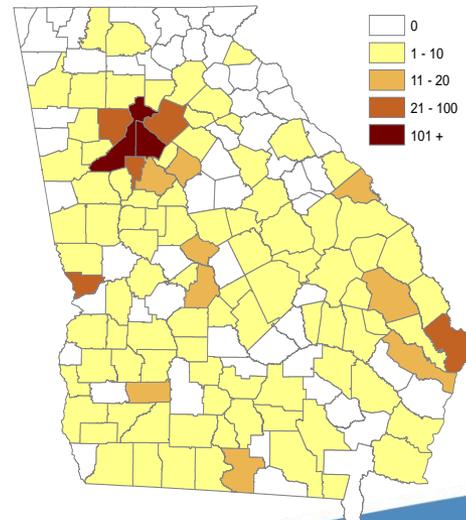
Cases identified: 4,288 confirmed; 3,011 probable; **7,299 total**

Number of residents with sickle cell disease by county, 04-08

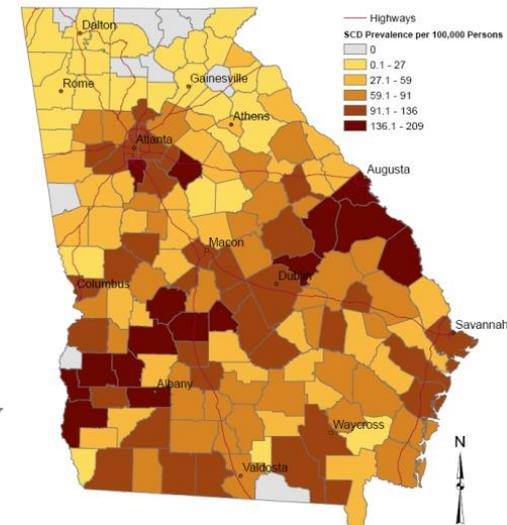


- ★ Comprehensive sickle cell centers
- ★ Public Health Outreach sickle cell clinics

SCD births 2004-2008



SCD residents per 100,000



Past uses

- Scientific papers
 - Accuracy of ICD coding for determining SCD genotype
 - State-based surveillance for SCD
 - Defining SCD mortality
 - Determining adherence to quality measures
- Community outreach displays for 5 Georgia regions
- Fact sheets and white papers
 - Incidence and migration
 - Hydroxyurea use and measurement
 - Contributions to surveillance by dataset
 - Data and statistics for patients, families and advocates
 - Data and statistics for providers

SCDC 3-year plan

TO IMPROVE
OUTCOMES



Dissemination priorities

Data outputs (statistics/maps)

- Geography of patients by demographics
- Geography of utilization by acuity and type
- Geography of providers (specialists & facilities)
- Frequent ED and in-patient presenting reasons
- Quality measures for evidence-based practices



For use by

- Patients/families/advocates
- Providers/health systems
- Public health/policy-makers
- Payers



For action on

- Culturally/linguistically/topically targeted patient and provider education
- Location/allocation of clinics, telehealth, social services
- Payer-provider contracts to ensure in-network care options to meet need
- Workforce incentives to reduce provider gaps
- Trait education and screening
- Quality measure development

Analysis priorities

STUDY TOPIC

TO INFORM

Pediatric to adult transition: Complication/utilization patterns across transition; how they relate to insurance status, age, race/ethnicity, geography

Insurance and other transition-supportive policies

Pain treatment and opioids: Prescribing and filling patterns; treatments associated with lower opioid prescribing; effect of mental health services

Policies/practices for patients, pharmacies, providers, EDs

Aging with sickle cell disease: Complications/comorbidities by race, geography, genotype; associated with pregnancy; menopause transition; predictive of mortality by age group

Practice guidance for adult primary and specialty care

RedHhott in Georgia

Improving transfusion practice through
data sharing and education

Patients
Donors
Providers
Science

Patient knowledge and experience

Knowledge of transfusion complications

- Describe the reason for a blood transfusion as having “low blood”
- Want more information on the reason for having a transfusion and how it will help
- Understand a need to limit transfusions because too many can cause complications
- Concerned about disease transmission, especially HIV and hepatitis
- May associate having antibodies with having been transfused with the “wrong blood” or “bad blood”

Transfusion experience

- Report feeling better after transfusion
- Describe annoyances such as cold rooms, long wait times, itching
- Report lack of follow-up after receiving a transfusion in a hospital

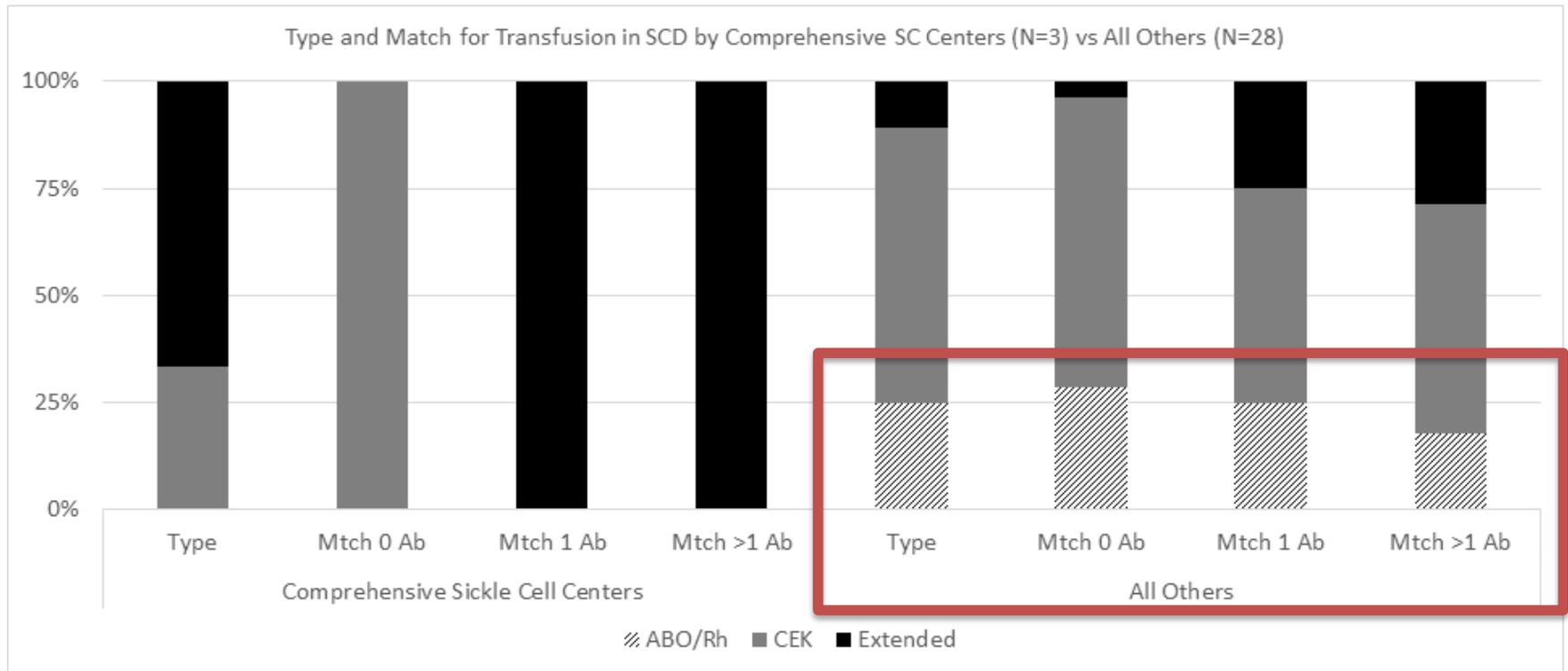
Provider practices

- **Blood bank survey**
- **Systematic literature review**
- **Provider education**

Current evidence-based practice recommendations in SCD

- From the National Institutes of Health, National Heart Lung Blood Institute
Yawn, Barbara P., et al. "Management of sickle cell disease: summary of the 2014 evidence-based report by expert panel members." *JAMA* 312.10 (2014): 1033-1048.
- From the British Committee for Standards in Haematology, General Haematology and Transfusion Task Forces
Davis, Bernard A., et al. "Guidelines on red cell transfusion in sickle cell disease. Part I: principles and laboratory aspects; Part II: indications for transfusion." *British Journal of Haematology* 176.2 (2017): 179-209.

Blood bank survey major findings



Systematic review questions

1. For patients with SCD, does limited or extended serologic matching reduce alloimmunization, and/or hemolytic transfusion reactions as compared to standard ABO/RhD matching alone?
2. For patients with SCD, does limited or extended serologic matching increase cost and reduce availability of compatible units as compared to ABO/RhD matching alone?
3. For patients with SCD, does genotypic matching reduce alloimmunization and/or hemolytic transfusion reactions as compared to serologic matching?
4. For patients with SCD, does genotypic matching increase cost and/or decrease availability of compatible units as compared to serologic matching?

Systematic review findings

Q1: Our review supports that prophylactic limited and extended matching strategies reduce the rate of alloimmunization and the number of antibodies formed per unit transfused (with low Oxford level of evidence)

– Majority of the articles (95%) were retrospective review cohorts and/or case series

Q2: There were no studies that addressed the implications of extended serologic antigen matching on unit availability

– Only 1 study addressing cost: Markov-based decision tree model history-based matching vs prophylactic matching strategy, suggesting cost benefit of history-based matching model.

Q3: There were no studies addressing the impact of genotypic antigen matching on alloimmunization or hemolytic transfusion reactions

Q4: There was limited data showing that genotyping may aid in unit availability in many SCD patients, but no data on genotype matching effects on cost and/or unit availability



Reducing complications of therapeutic blood transfusion in sickle cell disease

INTRODUCTION

James Eckman, M.D.
Peter A. Lane, M.D.
Ross Fasano, M.D.

Module 1. Use of Blood Transfusion during Acute Illness

Module 2. Delayed hemolytic transfusion reactions

Module 3. Management of Chronic transfusion

CME/CNE available through CDC
<https://www2a.cdc.gov/TCEOnline>



REdHHoTT

Improving transfusion practice through data sharing and education

Development of this course was supported by Cooperative Agreement Number 5 NU58 DD001138, funded by the Centers for Disease Control and Prevention (CDC). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC or Department of Health and Human Services.

Data uses and findings

Assess the feasibility of using administrative data to study complications of therapeutic blood transfusions in those with hemoglobin disorders.

- Using Georgia RuSH data from 2004-2008, we have health insurance claims (Medicaid, CHIP, SHBP) on 5,505 of our 7,631 SCD patients: about 72% of total cases.
- 45% of the 5,505 had at least one RBC transfusion; 2.7% had at least one RBC X-change in 2004-2008 (identified in claims using a combination of revenue codes, procedure codes, and ICD-9 codes).
- Further examination of claims data to study the following complications:
 1. Transfusion-related infections
 2. Iron Overload
 3. Alloimmunization
 4. Generalized transfusion reactions

Data uses and findings

Transfusion-related infections

- ICD-9 codes exist for most related viral and bacterial infections
- Temporality, especially as it relates to infections is difficult to disaggregate using administrative claims.

Iron Overload

- 7% of patients had a complication of iron overload (ICD-9 code 275.0) and 5.5% had a claim for at least one chelator (identified using a list of NDC codes)
- Expanded definition of iron overload to add any of 3 CPT codes: Cardiac MRI, Ferriscan, or liver biopsy

Data uses and findings

Iron Overload (continued)

- 664 CHOA SCD/thal patients identified with any of the previous codes or a record of a blood transfusion or red cell exchange.
 - 124 (19%) had at least one ICD-9 code for iron overload
 - 138 (21%) filled a prescription for a chelator
 - 80 (12%) had at least one of the 3 CPT codes
 - 22 had no record of transfusion, the range for the rest was 1-140 transfusion events during the 5 year period.
- Additional research to identify the best administrative definition for iron overload (chelators should be included) and a deeper dive into the documentation of transfusion events.
- Administrative claims can be used to identify transfusion events; however not to distinguish the number of blood **units** administered.

Data uses and findings

Alloimmunization

- No diagnosis code for alloimmunization within the administrative data
- Studied CPT code: antibody identification (86870) as a proxy to identify SCD patients who may have developed an antibody; 154 claims for this CPT code in the 3,145 SCD patients (4.9%) with a known genotype.
- 40 alloimmunized children from CHOA were matched with claims from the GA surveillance data. Claims reviewed for the presence of CPT code 86870. The code was identified in 13 (32.5%) of children overall, and 53% (9/17) of children who developed their antibody during the 5-year period of the data.
- Suggests that a diagnosis code for alloimmunization might be considered in the future.

Data uses and findings

Transfusion Reactions

Completed a review of transfusion-related complication investigations documented in 3 blood bank information systems (2004-2008) matched to claims data. Identified 73 events from 65 patients.

- Children: 53% (29/55) included a 999.8 transfusion reaction code; 42% (23/55) included a blood bank investigation CPT code 86078
- Adults: 22% (4/18) included a 999.8 transfusion reaction code; 11% (2/18) included a blood bank investigation CPT code 86078
- While some febrile non-hemolytic reactions, itching and rashes were included in administrative coding, few pulmonary transfusion reactions reported: Transfusion-associated circulatory overload (TACO)/ Transfusion-related acute lung injury (TRALI)

Data uses and findings

Transfusion Reactions (continued)

- Finalizing a research manuscript to discuss findings and planning to use more recent data to analyze ICD-10 coding as well as improved hospital coding that may arise from EMR implementation.
- Inconsistencies in coding of transfusion reactions is important to inform Patient Quality and Safety Indicators used by AHRQ and other quality review organizations.

Other Dissemination

- Mortality review to link deaths in SCD patients to alloimmunization is also underway.

Registry



The NPAR™ mission is to improve the safety and speed of blood transfusions by providing a HIPAA-compliant nationwide database of patient red cell antibody information.

- Hospital EMR systems and blood bank/laboratory information systems not always integrated; blood bank data systems not built for easy data extraction
- Partnering with the National Patient Antibody Registry (NPAR™)
- Blood banks & transfusion services at Georgia's 3 comprehensive SCD treatment centers implementing NPAR™ making transfusion & antibody histories shareable among them via secure web connections
- Study implementation lessons

Biorepository

- Blood banks at Georgia's comprehensive SCD treatment centers participating in a biorepository for blood samples from transfused hemoglobinopathy patients
- CDC aim is to monitor new infections in the blood supply
- Researchers at participating sites may also access samples in future for research purposes
- Both plasma and serum collected; participants being consented for future genetic testing of their samples

More Information

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ghpc.gsu.edu/project/hemoglobin-disorders-data-coordinating-center/