National Center on Birth Defects and Developmental Disabilities

DD19-1906 Capacity Building for Sickle Cell Disease Surveillance

Session 2: Improving Health Outcomes for SCD through Surveillance

November 21, 2019

Data to Action: Supporting the Policy Process

California Sickle Cell Data Collection Program

TRACKING CALIFORNIA

INFORMING ACTION FOR HEALTHIER COMMUNITIES

Background: California < 2010

- Newborn screening for SCD and SCT late 1990
- Support for SCT genetic counselor training
- Large grants for comprehensive sickle cell care
- Number of Californians with SCD unknown
  - No surveillance beyond NBS
  - Medicaid not tracking
  - Some clinical cohorts

Background: California 2010 - 2016

- Implementation of RuSH, PHRESH, SCDC
- Cutting of funding for SCD and SCT support programs by state
- Cutting of funding for clinical care
- Medicaid expansion
- Move to Medicaid managed care and decreased access to hematologic care for adults

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Sickle Cell Data Collection

Background: California 2017-2018

- Attempt at state legislation to fund care
  - High dollar amount
  - Limited support structure
  - Passed but not funded
- Development of statewide coalition to create state action plan
  - Challenging to bring support together
  - Over 9 months, state action plan drafted by ~50 people
  - Used to generate new interest in state legislature
  - Surveillance data used to support recommendations

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SICKLE CELL DATA COLLECTION

Making Data Useful

- Surveillance data offered and used by almost all of the state action plan collaborators
  - CBOs doing outreach
  - Clinical care centers applying for grants
  - Clinical care centers expanding program
- Data as one supporting component of new legislation
  - Focus on counties (Medicaid)
  - How many people in those counties?
  - Where getting care

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Building Collaborations

- Multiple, diverse stakeholders supported new legislation
  - Care providers
  - CBOs
  - Clinical research
  - Pharma
- Lobbyist hired
  - Knowing how to build the collaboration
  - Crafting narrative
  - Making data a part of the story

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A Messy Process

- Bill moved to ‘budget’ bill at last minute
  - Passed!
  - $15 million over three years
  - New clinical sites
  - Expanded surveillance
  - Grants for CBOs and other services
- Now the hard part begins
  - Who controls the $$
  - Best decisions/limited resources
  - Three years to prove concept

Takeaways

- Wide-reaching collaboration and partnerships needed
- Lobbying matters
- Data help tell a narrative and make it real

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Sickle Cell Data Collection

Improving Health Outcomes with SCD Surveillance

November 21, 2019

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Acknowledgements

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RedHhott in Georgia is supported by the Centers for Disease Control and Prevention (NU58 DD001138).

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Outline

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

- Past uses/findings
- Dissemination/analysis plan

Case Study: RedHhott – *reducing transfusion complications in SCD & thalassemia*

- Data uses/findings
- Provider practices
- Patient practices

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: 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

RedHhott in Georgia

Improving transfusion practice through
data sharing and education

Patients
Donors
Providers
Science

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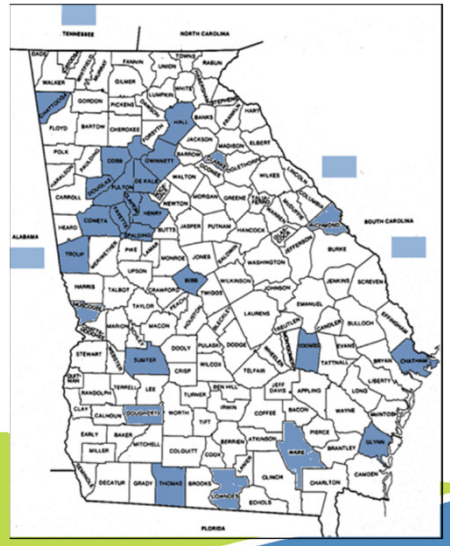
Data uses and findings

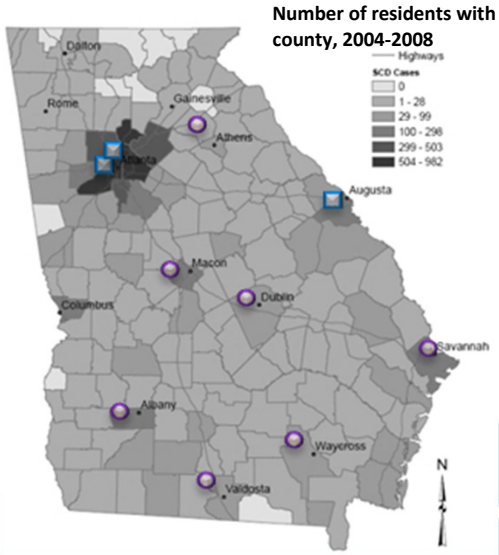
Using SCDC surveillance data to study complications of therapeutic blood transfusions in those with hemoglobin disorders.

- 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).

Provider practices

- Blood bank survey
  - Targeted survey to blood banks transfusing the largest number of SCD patients.
  - 43 responses representing 35 unique institutions in 25 Georgia counties plus three neighboring states.





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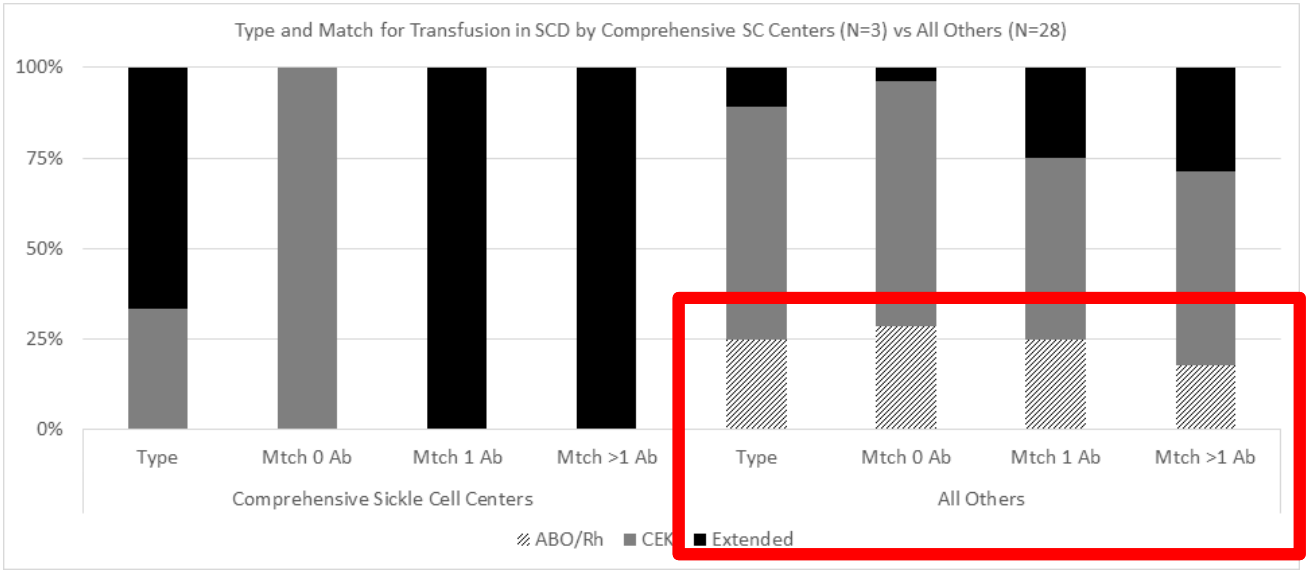
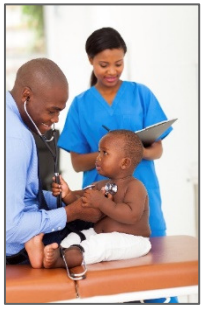
Blood bank survey major findings



*Fasano, Branscomb, Lane, Josephson, Snyder, Eckman (2019). Transfusion Service Knowledge and Practices Related to Transfusion in Sickle Cell Disease and Thalassemia. Transfusion Medicine.



Reducing complications of therapeutic blood transfusion in sickle cell disease

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

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

INTRODUCTION

Module 1. Use of Blood Transfusion during Acute Illness

Module 2. Delayed hemolytic transfusion reactions

Module 3. Management of Chronic transfusion

REdHHoTT
Improving transfusion practice through data sharing and education

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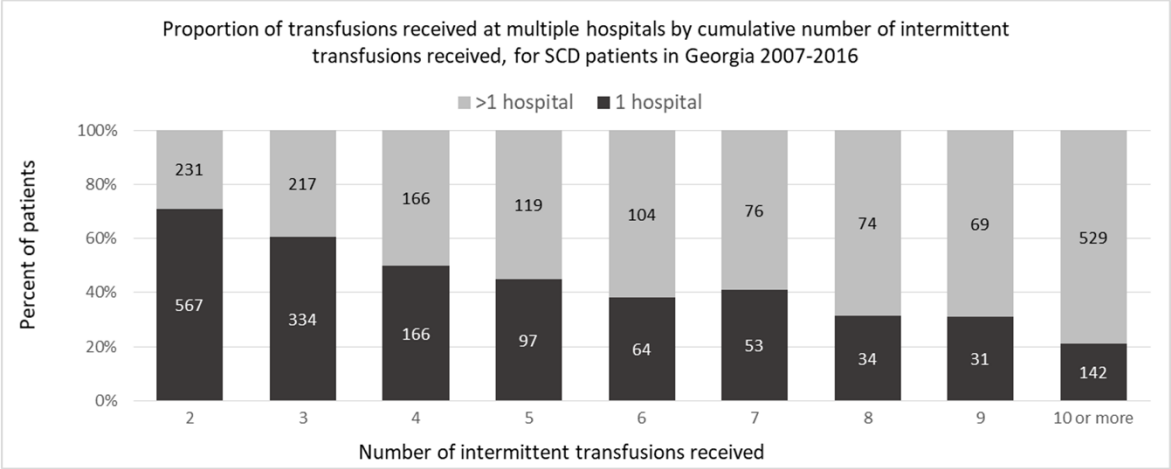
Multisite, Intermittent Transfusions in SCD



- Ten years of SCDC data (2007-2016) showed almost 19% of patients with SCD (1585/8529) received transfusions at more than one hospital.
- The likelihood of multisite transfusions increased from ages 18–40 and with the number of transfusions received.

Tang, A., Eckman, J., Branscomb, J., Zhou, M., Snyder, A. B. (2019) Examining Multisite, Intermittent Transfusions for Treatment of Sickle Cell Disease in Georgia, 2007-2016. *Pediatric Blood and Cancer*. 66(10): e27921. https://onlinelibrary.wiley.com/doi/epdf/10.1002/pbc.27921

Patient & Provider Practices

NPAR
National Patient Antibody 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.

- Providers: Study implementation lessons from NPAR project with Blood banks & transfusion services at Georgia's 3 comprehensive SCD treatment centers implementing NPAR™.
- Patients: Encouraging use of electronic apps or paper-based records of transfusions received.
  - Briefs on available apps and Warrior University webinar series adapted for patient population discussing transfusion complications within SCD and the need to know and track transfusion histories.

Additional Dissemination

- **Transfusions and Iron overload**
- **Alloimmunization**
  - Suggests that a diagnosis code for alloimmunization be considered.
  - Mortality review to link deaths in SCD patients to alloimmunization is also underway.
- **Transfusion Reactions**
  - Completed a review of transfusion-related complication investigations documented in 3 blood bank information systems (2004-2008) matched to claims data.
  - Inconsistencies in coding of transfusion reactions is important to inform Patient Quality and Safety Indicators used by AHRQ and other quality review organizations.

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