

#### American Society of Hematology Helping hematologists conquer blood diseases worldwide

#### SICKLE CELL CENTERS: Alternative Models for Delivery of Care

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#### DISCLOSURES

Research funding: NIH/NHLBI •

Sickle Cell Disease Implementation Consortium (2016-22)

- Research funding: NOVARTIS PHARMACEUTICALS ٠
- **Research funding: GLOBAL BLOOD THERAPEUTICS** ٠
- Consultant: NOVARTIS PHARMACEUTICALS •
- DSMB Chair: MICELLE BIOPHARMA INC •
- DSMB Member: BLUEBIRD BIO •
- EAC Chair: VERTEX/CRISPR •
- EAC Member: **GLOBAL BLOOD THERAPEUTICS** •
- DMC Member: **GRAPHITE BIO** •



## Medical College of Georgia Sickle Cell Center

- Established in 1972 (Comprehensive Sickle Cell Centers)
- NHLBI Funding for 3 cycles: 1972-1988
- Components:
  - Pediatric and Adult Sickle Cell Clinics
  - Hemoglobinopathy Laboratory (Currently THJ Huisman Lab)
  - Clinical Research Program
- Rural Outreach Clinics (1984–present)
- Telemedicine (1995–2004 and 2016–present)
- Continuous NIH Funding since 1972
- Infrastructure funding from the State (Georgia Department of Public Health)



#### **Center for Blood Disorders**

- Shared resources between Hemophilia Treatment Center and Adult Sickle Cell Program ٠
  - Housed in the same building on campus (across from Georgia Cancer Center)
  - Shared personnel, clinical research team, and THJ Huisman Laboratory

#### Staff •

- 2 MDs (Adult Hematologists/Sickle Cell Experts)
- 1 Center administrator (NP and MSN)
- 2 APPs (1P and 1 NP)
- 2 RNs (Clinic Nurse and Nurse Navigator)
- 1 MA
- 1 Office specialist
- 1 Social worker

- **Clinical Research Personnel** 
  - 2 PhD coordinators
  - 1 RN coordinator
  - 1 Data manager



#### Lanzkron S: 2021





#### Adult Sickle Cell Population in Georgia

Location	Number	SS	SC	Sβ⁺	Sβ <sup>o</sup>	Other
Augusta	457	315	91	27	14	9
Albany	156	108	31	9	5	3
Macon	112	77	22	7	3	2
Savannah	72	50	14	4	2	1
TOTAL	797	550	159	48	24	16

#### Georgia Counties Served by Augusta University Sickle Cell Clinics





## SCD Genotype Distribution (in Georgia?)



#### **Center for Blood Disorders**

- Adult Sickle cell operations:
  - Augusta Clinic:
    - Mon-Friday
    - > 1 Hematologist, 1 APP, and 2 RNs
  - VOC Management:
    - > ED Observation unit: Rapid triage and admission (up to 24 hours)
    - Individualized pain plan with PCA
  - Inpatient Management:
    - > Admission to Hem-Onc Service (attending, fellow, resident, and 2 APPs)
    - Average LOS: 4.5 days
  - Outreach Clinics:
    - > 1 MD and 1 APP travel to outreach sites monthly (Macon, Albany/Sylvester, and Savannah)
    - Telemedicine incorporated in 2016
    - Currently monthly Telemedicine clinics; on-site every 6 months

PCA, patient controlled administration



## Sickle Cell Outreach Clinic Sites

- Sylvester (Albany Area)–<u>Hematology Specialists</u>:
  - Phoebe Putney Cancer Center
  - Staff: Nurse Navigator (embedded)
- Macon–<u>Public Health</u>:
  - Bibb County Health Department
  - Staff: RN from GDPH
- Savannah–Primary Care / Consultation Clinic:
  - HCA Family Medicine Clinic
  - Staff: Family Medicine Residents



#### NIMHD Southeastern Exploratory Sickle Center of Excellence

- P20 Grant from NIMHD: 2007-2013 (A. Kutlar and R. Gibson Co-Pl's)
  - MCG, University of Florida and Morehouse School of Medicine partnership
- Aims:
  - Address disparities facing adults with SCD
  - Partner with PCPs and other providers in rural Georgia to address lack of providers with experience in the care of adult SCD patients
  - Create Medical Homes in these locations (R. Lottenberg)
  - Develop ED fast track pathway to treat uncomplicated VOC's (M. Lyon)
  - Develop education programs to train current and future Family Medicine physicians and other providers in SCD care (T. Adamkiewicz)

NIMHD, National Institute on Minority Health and Health



#### Issues/Challenges in the Management of Adult SCD Patients

Adherence to Disease-Modifying Therapies

- Hydroxy Urea (HU): 68% of patients prescribed HU
  - 34% pick up Rx regularly (7-12x/year)
  - 38% pick up Rx occasionally (4-6x/year)
  - 29% rarely or never (0-3x/year)
- Voxelotor: 75 patients prescribed
  - 50% Continue to take
  - 50% Inactive (unable to contact, poor adherence, and GI side effects)
  - Response Rate (increase in Hb > 1 g/dl) [estimated @ 44%]
- Crizanlizumab: 13 patients prescribed (8 started and 5 in process)
  - 1 Discontinued due to side effects
  - 1 No-show for subsequent infusions



# Hub and Spoke: Two Models

- Savannah:
  - HCA Family Medicine (FM) Clinic
  - Staffed by FM Residents
  - Monthly on site clinics, SCD expert supervising residents
  - Monthly lectures to residents on SCD care
  - Currently monthly telehealth
  - SCD expert available for phone/telehealth consultation
  - ED fast track pathway available for Family Medicine patients

- Albany/Sylvester:
  - Phoebe Putney Cancer Center Clinic
  - Staffed by RN Navigator (MCG employee)
  - Currently twice monthly telemedicine clinics
  - Long-term partnership with Phoebe Cancer Center (7 adult Hematology-Oncology providers)
  - Interest in SCD care
  - SCD expert available for phone/telehealth consults
  - ED fast track pathway for VOC available



## Hub and Spoke: Pro and Cons

- PRO:
  - Evidence-based SCD care in rural Georgia
  - Patients do not have to travel > 200 miles
  - Multi-specialty care available locally
  - Local ED fast track care for VOC
  - Possibility of enrollment in clinical research
  - Routine labs performed locally

- CON:
  - Residents change annually (Savannah)
    - Need for ongoing SCD education
    - Risk of reducing SCD care to monthly opioid Rx
    - Inappropriate HU dosing
    - Lack of adequate monitoring (Fe overload, microalbuminuria, ECHO, and ophthalmology)
  - Lack of local technology for monitoring Fe overload (liver and cardiac MRI)
  - Lack of subspecialty expertise:
    - High Risk OB
    - Orthopedic procedures (core decompression)
    - Exchange transfusion capability



# **Essentials of a Sickle Cell Center**

- Infrastructure funding
  - State/local, institution, and philanthropy?
- Dedicated staff
  - MD, APP, clinic nurse, and social worker
- Dedicated space (clinic, clinical research, and SW)
- Access to infusion center

- Collaboration with ED
  - Develop common protocols
  - Individualized pain management plans
- Dedicated clinical research team
  - Establish long-term relationship and confidence
- Access to expert subspecialty care

