A Multidisciplinary Comprehensive Hemophilia Treatment Center Leverages Care For Sickle Cell Disease

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Indiana's only federally recognized comprehensive hemophilia treatment center
Overview

Describe the care model at the Indiana Hemophilia & Thrombosis Center (IHTC)

◦ Description of multidisciplinary team and programs
◦ Delivery of care throughout catchment area
◦ Collaboration with key stakeholders

Overview of applicability of services for disorders of coagulation to SCD
IHTC Model of Care

Mission
◦ The Indiana Hemophilia & Thrombosis Center is committed to providing the highest quality comprehensive services and holistic healthcare services to patients with bleeding, clotting, and other hematologic disorders, and to their families.

Indiana’s only federally recognized Hemophilia Treatment Center (HTC)

Safety-net provider
◦ Provides care to patients regardless of ability to pay
◦ 501(c)3 non-profit

First HTC to receive national quality certification by the Accreditation Association for Ambulatory Health Care (AAAHC) → Medical Home
Patients Served

Bleeding Disorders (2,500)
- Hemophilia
- Von Willebrand Disease
- Rare Bleeding Disorders

Clotting Disorders (2,000)
- Deep Vein Thrombosis
- Pulmonary Embolisms

Sickle Cell (400)

Other Blood Disorders (1,700)

Approximately 8,000 patients overall
- 16% Medicaid
- 21% Medicare
- 6% uninsured
SCD: ~80-90% Medicaid
Bleeding disorder patients
Amish Outreach Programs

Sickle Cell
Outreach Clinics

Pilot Telehealth program
for sickle trait education

IHTC Services
Throughout State
Extensive Services:
Ongoing Clinical Care & Education

Medical & Multidisciplinary team visits
- Comprehensive clinics, acute care clinics, prophylaxis clinics, home visits, education
- Care on-site at IHTC or through Outreach Clinics

Orthopedic interventions including point of care musculoskeletal ultrasound

Rehabilitation hospital management

Phone triage nurses

Patient, provider and community education

Broad range of clinical research programs

Simultaneous Camps: Bleeding disorders and SCD
Advantages of Service Model

Optimal use of resources
- Extensive services & experience in one center
- Local delivery of expert multidisciplinary services

Concentrated expertise: Program’s focus is non-malignant hematology

Consistent care and services provided throughout state to culturally diverse populations

Combined pediatric and adult program
- Integrated services and transition process
- Deep knowledge of families and patients
IHTC Staff Resources

**BLEEDING DISORDERS**

16 Physicians  
- 7 Pediatric Hematologists  
- 7 Adult Hematologists  
- 2 Adult Hospitalists  
5 Physician Assistants/4 Nurse Practitioners  
26 Nurses  
19.5 Multidisciplinary Staff  
- Dental Hygienists (2), Physical Therapists (4), Social Workers (4), Genetic Counselors (1.5), Career Counselors (2), Dietician (1), Psychologist (1), Child Life Specialist (1), Financial Counselors/Insurance Specialists (3)

**SICKLE CELL DISEASE**

4 Physicians  
- 2 Pediatric Hematologists  
- 2 Adult Hematologists  
- 2 Adult Hospitalists  
3 Physician Assistants/1 Nurse Practitioner  
Nurses: Telephone triage, infusions, acute care  
Multidisciplinary Staff  
Pharmacists  
2 Research Staff  
Specific SCD staff  
- 1 Sickle Cell Program Manager  
- 2 Sickle Cell Program Coordinators
Key Stakeholders

**BLEEDING DISORDERS**
Patients and families

Community care providers
- Primary care providers
- Emergency room physicians
- Other Specialists

Community Based Organizations

State Department of Health

HRSA

CDC

ATHN

**SICKLE CELL**
Patients and families

Community care providers
- Primary care providers
- Emergency room physicians
- Other Sub-Specialists

Community Based Organizations

State Department of Health

HRSA SCD Treatment Demonstration Project: Midwest Consortium

Indiana Sickle Cell Consortium
- Indiana Minority Health Coalition
- Indiana University School of Public Health
- Pediatric Hematologists in Fort Wayne and Lake County
Surveillance
IHTC, ISDH, CDC

82% of hemophilia patients treated within an HTC
80% more likely to self-administer medication
47% less likely to visit ER
Surveillance IHTC & ISDH: SCD Incidence Since 2009

- **Over 75 cases**
- **41-75 cases**
- **16-40 cases**
- **2-15 cases**
- **1 case**
Physicians

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<tr>
<th><strong>BLEEDING DISORDERS</strong></th>
<th><strong>SICKLE CELL</strong></th>
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<tbody>
<tr>
<td>Ped/Adult teams specialize in non-malignant hematology</td>
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<tr>
<td>Peds see adult issues and visa versa</td>
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<td>Large patient base, significant expertise</td>
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<td>Remuneration not based upon volume or payer</td>
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<td>Inpatient &amp; outpatient consistency of care</td>
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<td>Improved transition; minimize lost to follow-up</td>
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<td>Patient perception of medical home</td>
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# NPs and PAs

## BLEEDING DISORDERS
- Dedicated to non-malignant hematology
- Develop expertise in particular areas e.g. transition
- Design/participate in programs to enhance care/outcomes
- Increase medical capacity
- Able to perform home visits

## SICKLE CELL
- Dedicated to non-malignant hematology
- Develop expertise in particular areas e.g. transition or chronic pain management
- Design/participate in programs to enhance care/outcomes
- Increase medical capacity
# Nursing

## BLEEDING DISORDERS

- Dedicated ped/adult telephone triage
- Live person, immediate access
- Develop expertise in non-malignant hematology
- Consistent care/follow-up
- Able to perform home visits

## SICKLE CELL

- Dedicated ped/adult telephone triage
- Live person, immediate access
- Develop expertise in non-malignant hematology
- Consistent care/follow-up
## Physical Therapy

### BLEEDING DISORDERS
- Experts in specific disorders, musculoskeletal issues
- Consistent care
- Experts in rehabilitation based upon disorder
- Perform & interpret Point of Care
- Musculoskeletal US

### SICKLE CELL
- Experts in specific disorders, musculoskeletal issues
- Consistent care
- Provide non-opioid pain management techniques
- Chair yoga education
- Assessments for non-SCD causes of chronic pain
Social Work & Financial Counselors

**BLEEDING DISORDERS**
- Experts in specific disorders
- Knowledgeable of community services, assistance
- Consistent care for patients/families
- Assures insurance coverage, assists with applications
- Able to perform home and inpatient visits

**SICKLE CELL**
Psychologist

**BLEEDING DISORDERS**

Knowledgeable of disease states, impact on psychological health & outcomes

Performs neuropsych testing

Member of chronic pain working group

Provides counseling

**SICKLE CELL**
Career Counselors

**BLEEDING DISORDERS**

Knowledgeable of disease states, impact on education, employment

Assist patients/families with school/community education

Knowledgeable of state regulations for services

Advocates for patients with diverse school systems

**SICKLE CELL**


Dental Hygiene

BLEEDING DISORDERS
Knowledgeable of disease states, impact of dental care on outcomes
Performs assessments
Facilitates referrals
Designs care plans, interventions

SICKLE CELL
Genetic Counselors

**BLEEDING DISORDERS**

- Knowledgeable of disease states, resources for genetic testing
- Assess insurance coverage, cost of testing
- Provides genetic counseling
- Develops/inputs family trees in electronic system
- Assists families with informing other family members

**SICKLE CELL**

- Provides genetic counseling
- Connects families interested in preimplantation genetic diagnosis with reproductive technology specialists
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<td>Extend services of center to communities</td>
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<td>Overcomes distance/travel barriers</td>
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<td>Performs home assessments, education</td>
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<td>Assists with local care</td>
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<td>Assures follow-up, communication with center</td>
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<td>Consistent face of program within community</td>
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IHTC SCD Specific Programs

EMILY RIEHM MEIER, MD
Indiana Newborn Screening Program

Since 2009 the Sickle SAFE Program has provided Screening, Assessments, Follow-up, and Evaluations for children born with sickle cell disease in Indiana.

Program coordinators perform home visits, regular phone follow-up and act as a resource for families and PCPs of children from birth – 3 years with sickle cell disease.

Current efforts include:
- Sickle Cell-abration
- Validated Adherence Scales
- Patient, family and provider education
- School based interventions (504, IEP)
HRSA SCD Treatment Demonstration Project: STORM

Goals

- Increase the number of providers treating people with SCD in Indiana
- Increase the number of providers prescribing disease modifying therapies, such as hydroxyurea
- Increase the number of people who receive care from providers with greater knowledge of SCD treatment
ISDH SCORE Program

Sickle cell

Care coordination
  ◦ Improve adherence to screening tests, medications

OutReach
  ◦ Community Health Worker in Lake County
  ◦ Initiate TCD screening in Lake County

Education
  ◦ Educate providers about hydroxyurea, importance of TCD screening
Aspire Grant: Addressing Local Gaps in Care

Outreach clinic at Pediatric Hematology clinic in Allen County to increase HU prescriptions according to 2014 NHLBI guidelines.

Primary need in Allen County: Unable to transition pediatric SCD patients to adult provider.

Family Medicine Residency that is a certified Patient-Centered Medical Home and provides care to HIV-infected adults in Fort Wayne.
Family Medicine Residency Program

Strengths:
- Behavioral Health
- Diabetes Educator
- Pharmacist on staff to do medication education
- Family Medicine residents cover all Fort Wayne hospitals
- Centrally located within the city
- Comfortable collaborating with subspecialists
Leveraging an HTC Model for SCD Care

Staff comfortable with multidisciplinary approach
  ◦ Similarities in multidisciplinary staff needs for both populations

Established outreach leveraged to address gaps in care for SCD

SCD programs developed as part of existing HTC services: Camp

Support from Indiana State Department of Health and Legislature for SCD

IHTC collaboration with patients, families, community organizations leveraged for SCD

IHTC culture of communication with primary care physicians supports integrated approach for SCD

IHTC dedication to provide consistent level of care throughout the state
The Indiana Hemophilia and Thrombosis Center (IHTC) provides advanced care for both adult and pediatric patients with rare blood disorders.

Visit IHTC.org