Adult Sickle Cell Clinic at MLK Jr Outpatient Center
On site of infamous hospital, L.A. County tries new approach to serving health needs of area's poor

Los Angeles Times 10/8/2016

Dr. Susan Claster, left, and Dr. Bernadette Manalo, right, talk to patient Philadelphia Philpot at the MLK Jr. Outpatient Center's new sickle cell clinic. (Marcus Yam / Los Angeles Times)
Affiliations and Disclosures

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Objectives

- To articulate the *impetus* for the new Adult Sickle Cell Disease clinic – *why and how* we started.
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- To introduce a *new delivery model* that integrates primary care, hematology and behavioral health.
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Adults with Sickle Cell Disease

- Chronic renal failure
- CNS Dementia – multiple strokes
- Chronic leg ulcers
- PHTN/Cardiac failure – small vessel

Permanent damage: brain, heart, lungs, kidneys, liver, bones and spleen.

- Retinopathy
- Iron overload
- Chronic pain – severe & unpredictable

Psychosocial, vocational, socio-economic challenges
Limited options for adults with SCD

- Shortage - adult hematologists w/special expertise
- PCPs - limited experience
- Non-specialists uncomfortable prescribing Hu
- PCPs and hematologists – uncomfortable managing chronic pain
- Heavy reliance on Medicaid

Erin Marcus – Our healthcare systems abandons adults with Sickle Cell Disease
Sickle Cell Today in the US

Dismal  Unacceptable  National Embarrassment

Massive Societal Indifference at all levels

Preventable deaths and morbidities cannot be allowed to be considered the norm - Craig Hooper, PhD., Director, CDC Division of Blood Disorders, Thrombosis and Hemostasis Societies of North America – April 2016

Disclaimer: The findings and conclusions are those of the author and do not necessarily represent the official position of the Center for Disease Control and Prevention.
Why Los Angeles?

51% of Californian adults with SCD live in L.A.

SCD mortality higher in L.A. than rest of the country

Powars Medicine 2005

No comprehensive clinic besides Kaiser
### Sickle Cell Disease – Southern California

<table>
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<th>City</th>
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<th>Pediatric</th>
<th>Adults</th>
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<tr>
<td>San Diego</td>
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<td><strong>3038</strong></td>
<td><strong>1300</strong></td>
<td><strong>1738</strong></td>
</tr>
</tbody>
</table>

20-80% of patients Hispanic in some cities

Source: RuSH-2004-2008
Transition from Pediatric to Adult Services is Risky

- Teen and young adults suffer from more frequent SCD-related complications than younger patients
- Increased ED utilization after transition
- Longer travel distance to an adult SCD center is a risk factor for unsuccessful transition
- Until now, there has been no public clinic offering tailored, coordinated services to the adult SCD population in Los Angeles County
HRSA Pacific Sickle Cell Regional Collaborative
2014-2017

http://pacificscd.org/

Goals
- Increase provider knowledge
- Increase evidence based therapy - hydroxyurea
- Improve access to care

GRANTEE: The Center for Inherited Blood Disorders
Mobilizing the Partners

Internal - Pacific Region

- **Alaska**: Providence Hospital, Anchorage
- **Arizona**: University of Arizona Cancer Center, Tucson
- **California**: Center for Inherited Blood Disorders*, UCSF Benioff Children’s Hospital Oakland, UC Davis
- **Hawaii**: Kapi‘olani Medical Center, Honolulu
- **Idaho**: St. Luke’s Mountain States Tumor Institute, Boise
- **Nevada**: Children’s Specialty Center, Las Vegas
- **Oregon**: Oregon Health Sciences University, Portland
- **Washington**: Seattle Children’s Hospital, Seattle
- **Guam**: Department of Health & Social Services
- **CBO**: Sickle Cell Disease Foundation of California

*Backbone organization – Regional Grantee

External

- Government – federal, state, local
- Health Professions Societies
- Research Consortia
- CBOs
The Center for Inherited Blood Disorders

- Community Clinic – not for profit. Specialty Center.
- Sickle Cell...Thalassemia...Thrombophilia...
  Hemophilia...
- Advanced Diagnostic Lab
- Pharmacy
- Federal Grantee – HRSA’s Regional Hemophilia & Sickle Cell Networks
- Founder: Diane J. Nugent, MD, Chief Hematology, CHOC Children’s
- *Sickle Cell Disease Foundation of California on BOD*

http://cibd-ca.org/
Regionalization: Hemophilia’s success

Team based care in regional US Hemophilia Treatment Centers:

40% reduction in mortality\(^1\) & morbidity\(^2\)

Soucie et al., Blood 2000\(^1\) and Haemophilia 2001\(^2\)


Baker et al., Haemophilia 2012
Regional Hemophilia Networks – 140 Centers/8 Hubs

New England 22 HTCs in 10 States & Territories
Core: Mt Sinai, NY

Mid Atlantic 17 HTCs 4 States
Core: Children’s Hospital Philadelphia

Southeast 23 HTCs in 8 States
Core: Hemophilia of Georgia*

Great Plains 13 HTCs 9 States
Core: Gulf States - Houston

Northern 16 HTCs 5 States
Core: Great Lakes Hemophilia*

Mountain: 9 HTCs in 10 States
Core: Oregon Health Sciences University

Great Lakes 18 HTCs 3 States
Core: Hemophilia of Michigan*

Western: 14 HTCs 4 States/Territories
Center for Inherited Blood Disorders, Orange, CA

Northern 16 HTCS 5 States Core: Great Lakes Hemophilia*

New England 22 HTCS in 10 States & Territories Core: Mt Sinai, NY

Mid Atlantic 17 HTCs 4 States Core: Children’s Hospital Philadelphia

Southeast 23 HTCs in 8 States Core: Hemophilia of Georgia*

*Regional Core Center is consumer based organization.
Framework #1 ➔ MLK Adult SCD Clinic

**Collective Impact Model**

Sectors: Clinicians, Public Health, Consumer Based Org

Leadership team

Collaboration highest levels

Shared decision making
Mobilize Partnerships → Catalyze Mutually Reinforcing Activities REGION-WIDE

Commitment of a group of actors from different sectors to a common agenda for solving a complex social problem.

Structuring the Pacific Sickle Cell Regional Collaborative → Departments

- Surveillance and Data
- Clinical Care Capacity
- Provider Education
- Policy / Partnerships
- CBO Capacity
Framework #2 → MLK Adult SCD Clinic

Different Sectors: Clinicians, Public Health, Consumer Based Org

Public Health and Rare Disorders - responsibility to build capacity outside our agency
Regional Networks - Advance Rare Disorder Public Health

• **Surveillance** – *geographic*

• **Knowledge** – *regional networks & databases: share clinical expertise*

• **Health care** - *regional centers of clinical expertise* – specialty access

• **Regional networks of providers** - coordinate treatment & reimbursement
Framework #3 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- Regionalization – responsibility to build capacity outside our agency

- 3 Pillars – Finance/Insurance component

**Chronic Care Model – Regional Adaptation**
Finance models: for team based care, CHWs, preventive outpatient care, adult immunizations...

Wagner et al. 2006
Framework# 4 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- Regionalization – responsibility to build capacity outside our agency
- 3 Pillars – Finance/Insurance component

- Make it happen: structured communications w/Leadership
- MLK Planning Team
  - Leadership reach out – commitment to solve problem. Who and how
  - Marketing – Leadership team bios & abstract
  - Bi-weekly meetings to clinic design & PR

Conceptual framework for the spread of innovations in service organizations
LA Department of Healthcare Services: Initial Buy In

- 9/18/15 – JRB to SC: do you know Mitch Katz, MD, Director
- 9/19/15 – JB drafts script: how to reach out
- 9/20/15 – SC to MK – Hello – Will you help us w/SCD?
- 9/22/15 – MK to SC – YES → talk to Hal Yee, MD, PhD
- 10/2/2015* – Hal Yee, MD, PhD: CMO of LA DHCS – YES → Ellen Rothman, MD, CMO, MLK Jr. Outpatient Center
- 10/16/2015 – Rothman meeting at MLK – YES!
LA Department of Healthcare Services
Initial Meeting  10/2/2015 – 30”

- **Team:** Hematologist, Public Health, Sickle Cell CBO ED & Program Director
- **Tight structure = we talk for 10”, listen for 20”**
- **Materials:** Data, Bio’s, Abstract. Logic Model
- **Agenda:**
  - Intros
  - SCD – the Crisis in Los Angeles
  - Federal Response – HRSA Regional SCDTDP Grant Goals, HRSA NBS, NIH SCD Implementation Science Grant
  - Regional Government Partnerships
  - Los Angeles Partnership Opportunities
MLK Adult SCD Clinic Design Begins

Sectors: Clinicians, Public Health, Consumer Based Org

- **Bi-weekly: clinic design** - identify core clinical team components, services, fill SW/Data Mgr. funding gaps (CIBD), training, CHWs (SCDFC $)
- **Bi-weekly PR meetings**: mission, vision, value, tagline. Print, Social
- Summer 2016 – Training clinical staff – trauma informed care
- July 2016 – Mock clinic
- August 2016 – Soft opening
- September 2016 – Webinars – pediatric SCD clinics … and Official Opening
SCD Capacity Building at MLK OPC

- Co-locate team members with SCD experience alongside team members who are new to this realm of healthcare
  - Completed 5 sessions training the new health team about SCD, health maintenance, & team resilience in anticipation of opening
  - Completed a mock clinic with SCD patient volunteers to test workflows
  - Experienced nurse Charlotte Dixon from SCD Foundation of Southern California provides ongoing education
  - Hematologist provides SCD expertise and ongoing consultation for all team members
New! Sickle Cell Clinic at MLK Jr. Outpatient Center

Adults with Sickle Cell Disease...We can provide the care you have always wanted!

“Adults with sickle cell disease deserve health care providers that understand the disease, its complications, and their pain. Knowing the people who worked hard to open this clinic gives me confidence it will meet the community’s needs.”

Mary Brown, President & CEO
Sickle Cell Disease Foundation of
Los Angeles Residents with Sickle Cell Disease age 15-45 Zip code of Residence, 2015.

Data sources: Sickle Cell Disease Foundation of California, and Center for Inherited Blood Disorders.

Map created by UCLA CT ISI as part of PRISM-SCD: Promoting Implementation Science Methodologies for Sickle Cell Disease RFA-HL-16-010
Different Sectors: Clinicians, Public Health, Consumer Based Org

Regionalization – responsibility to build capacity outside our agency

3 Pillars – Finance/Insurance component

Make it happen: structured communications

Complexity – multiple determinants of innovation adoption

Conceptual model for considering determinants of diffusion, dissemination and implementation of innovations in HS Service delivery and organization
Greenhalgh Millbank Quarterly 2004: “Conceptual model for considering determinants of diffusion, dissemination and implementation of innovations in HS Service delivery and organization
WEBINAR FOR PEDIATRIC SICKLE CELL CLINICIANS

New Adult Sickle Cell Clinic at MLK Jr. Outpatient Center in Los Angeles opens September 2016

**Learning Objectives:**
- To articulate the impetus for the new Adult Sickle Cell Disease clinic – why and how we started
- To introduce a new delivery model that integrates primary care, hematology and behavioral health
- To highlight hematology expertise and delineate specialty care opportunities
- To identify referral criteria and eligibility requirements
- To understand the role of the SCDFC in the new clinic

**Presenters:**
- Ellen Rothman, MD, Chief Medical Officer, MLK Jr. Outpatient Center
- Susan Claster, MD Adult Hematologist, Adult Sickle Cell Clinic at MLK Jr. Outpatient Center
- Mary E. Brown, President & CEO, Sickle Cell Disease Foundation of California and lead Community Based Organization – HRSA Pacific Sickle Cell Regional Collaborative

**WEBINAR DETAILS:**
10:00 – 10:30 am (PST)
Click Here to Join the meeting via WebEx
Meeting Number: 927 990 010
Meeting Password: 6/0/rC2/6

1:00 – 1:30 pm (PST)
Click Here to Join the meeting via WebEx
Meeting Number: 925 555 420
Meeting Password: 6/0/rC2/6

**JOIN BY PHONE**
(866) 546-3377
Audio Passcode: 843314
Framework #6 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- Regionalization – responsibility to build capacity outside our agency
- 3 Pillars – Finance/Insurance component
- Make it happen: structured communications
- Complexity – multiple determinants of innovation adoption

**Haines: Framework for Successful clinical networks**
External support, perceived leadership, internal management key
Successful Networks (Haines Nd Kitson)

Figure 2. Representation of a causal pathway for the outcomes of effective clinical networks.

Haines et al., Implementation Science 2012

These factors may be included in models aiming to explain the mechanisms linking the outcomes of successful networks.
Framework #7 → MLK Adult SCD Clinic

- Different Sectors: Clinicians, Public Health, Consumer Based Org
- Regionalization – responsibility to build capacity outside our agency
- 3 Pillars – Finance/Insurance component
- Make it happen: structured communications
- Complexity – multiple determinants of innovation adoption
- Successful networks: External support, perceived leadership, internal management key
- Boundary spanning – key to effective collaborations.

Collective Action for Implementation: A realist evaluation of organizational collaboration in healthcare
Boundary spanning – key to effective collaborations

Interplay of resources (context) and facilitation (mechanism).

Credible individuals → cross boundary work, facilitation and direct impacts.

Boundaries: Organizational, philosophic, semantic, professional, geographic

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Patient-Centered Medical Home: Core Elements

- Comprehensive
- Coordinated
- Continuous
- Accessible
- Patient-centered
- Culturally appropriate
“Did you ever feel like you’re part of something greater than yourself?”
How effective is the PCMH Model? Questions remain about its value

- Literature - mixed quality
- Affordable Care Act included support of CMS demonstration projects to study this model
- Comprehensive Primary Care Initiative, large CMS-funded demonstration
  - followed 497 adult practices in 7 regions
  - at the midway point in the study (NEJM 2016):
    - No savings in expenditures
    - Minimal improvements in quality and experience metrics
How effective is the PCMH Model?
Some promising findings for our setting

- Moderate support for hypothesis that medical homes provide improved health-related outcomes for children with SCD

- PCMH is able to partially, but not completely, alleviate disparities in care encountered by African American children with complex health care needs compared to their white counterparts as measured by ED utilization
Why is Primary Care Critical?

成年人中有SCD超过40岁的成年人有不同的医疗保健需求

- 更多与终末器官损伤和衰竭有关的访问
- 更多与常规健康状况如糖尿病和心脏疾病有关的访问
- 预防性医疗保健和成人免疫接种在专科护理中常常被忽视
Specialty Care Medical Homes? Few and far between

- National survey of 372 specialty medical practices with 1-19 physicians
- 85% of the responding practices reported providing primary care services to fewer than 10% of patients
- 10.3% reported providing primary care to 20% of patients
- Only 1.7% reported providing primary care for more than 50% of patients

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MLK Outpatient Center

- 136,500 Square Feet
- 104 Exam Rooms
- 70 clinics serving primary care, specialty and subspecialty care
- Ambulatory Surgery Center with 5 Operating Suites
- Full spectrum Rehabilitation Services
- Pharmacy
- Radiology, Nuclear Medicine, MRI
Advanced Practice Medical Home

- Integrated with primary care & NP
- Hematology specialty care
- Preventive care specific to SCD
- Behavioral health counseling
- Social Worker & Data Management
- Alternative therapy for pain
- Peer Navigators & Community Health Workers
- Outpatient, emergency, inpatient care
- Case Management

* Sickle Cell Disease Foundation of California
** Center for Inherited Blood Disorders
Specialty Care Services on Campus

- Neurology
- Orthopedics
- Ophthalmology
- Cardiology
- Gastroenterology
- Urology
- Pulmonology and Pulmonary Function Testing
- Women’s Health
Additional Services – Harbor UCLA

- Transfusions and erythrocytopheresis
- Inpatient admissions and Intensive care
- ER Services
- Additional subspecialty care
Services unavailable on-site at MLK OPC?

These services are provided through linkage with partners.

- Day hospital infusion center
- On-site transfusions or red cell pheresis
Campus Partners

- MLK Jr Community Hospital
- Department of Mental Health
  - MLK Jr Mental Health Urgent Care
  - Augustus F Hawkins Mental Health
- Housing for Health
- Recuperative Care in the Interns and Residents Building
Department of Healthcare Services Partners

- LAC-USC Medical Center
- Harbor-UCLA Medical Center
- Olive View Medical Center
- Rancho Los Amigos Rehabilitation Center
MLK, JR Community Hospital

- Inpatient Admissions and Intensive Care
- ER Services
- Transfusion
Who Is Eligible?

- Adults with Sickle Cell Disease
- Medicaid eligible or uninsured
- Medicare
- Limited private insurance options
- Willing to participate in LA County Department of Health Center managed care services
- Resident of Los Angeles County

How to refer: sicklecellclinic@scdfc.org or (424) 277-3800
MLK Adult SC Clinic Update

- Opened August 11, 2016
- We continue to build our patient panel
- Integrated Team model includes
  - Community Health Worker
  - Nursing Team
  - Primary Care Nurse Practitioner
  - Hematologist
  - Acupuncturist
Primary Care

- Initial screenings at first health evaluation including screening for mental health, cognitive (MOCA), Quality of Life, overall health and lifestyle assessment
- Immunizations
- Identifying non sickle cell issues and discussing with team regarding impact on SCD
- Co-manages patients with Hematology
Community Health Workers

- Support through intake process
- Contact patients before and after visit
- Support for patients in clinic
- Transportation assistance
- Home visits if needed
Additional Plans

- Yoga is available
- Acupuncture will be available shortly
- Peer support group - early planning
- Workforce development – CIBD / MLK partnership with Charles R. Drew University
Patient Characteristics -1

- All from South LA/Long Beach/SE LA areas
- Mix of genotypes with majority SS disease and the rest SC and S beta thalassemia
- 17 scheduled, 14 enrolled in ongoing care
- ~25% are 50+ years of age
- Some: no Hematology care for years
Patient Characteristics - 2

- Noticing significant complexities
  - Effects of transfusions over a lifetime: one patient with liver failure and a transplant d/t iron overload
  - Hydroxyurea management poor, some not on drug
  - Inadequate vaccinations
  - Narrow approach to pain management limited to narcotics only
Patient Vignette

- 60 y/o woman from Belize with genotype S beta thalassemia
- No consistent Hematology care
- 3 pregnancies - transfused for this and multiple other times
- Dec 2015- hepatic failure as a result of iron overload
- Jan 2016- liver transplant at UCLA as a result of untreated iron overload
Outcome Measures

- Quality of Life Scale
- ED Utilization Rates
- Hospitalization Rates
- Immunization Rates for flu, pneumococcal, and meningococcal
- Hydroxyurea compliance
- We are planning an observational investigation with a white paper illustrating efficacies and challenges in a highly integrated model
CDC study

- CDC Foundation and California Rare Disease Surveillance
- Administrative data, Newborn screening, vital records, and case reports from 2004-2014
- Study cohort of adults who live in the MLK catchment area before and after clinic opening
- We hope to show that coordinated care improves outcomes
Closing thoughts

- Creating a new adult Sickle Cell Clinic for a very underserved population is achievable
- Planning & Implementation Expertise: Team approach to healthcare delivery transformation for rare complex disorders - Public Health, Community Based Organization, Specialty Hematology, Advance practice medical home, health communications
- Regionalization promotes capacity building for rare disorders
- Surveillance to monitor outcomes vital to assessing impact
Bibliography


Meaningful Partnerships work!
Thank you