Sickle Cell Health Policy:
Regional Rare Blood Disorder Synergies

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Public Health / Policy Directory
Center for Inherited Blood Disorders and UCLA

National Minority Quality Forum – April 25, 2017

CIBD
Center For Inherited Blood Disorders

The Pacific Sickle Cell Regional Collaborative works to ensure that people with sickle cell disease receive quality care, no matter where they live or seek care.
Advancing health policy for Sickle Cell

We are:
• Bridging Sickle Cell & Hemophilia
• Regional approach
• Purpose – collaborate cross sector

Synergies building Sickle Cell:
• Awareness
• Clinic Services
• Healthcare Provider Workforce
• Insurance coverage
• Community Based Organization Capacity
Regional Networks Advance Public Health Goals for Rare Disorders

• Surveillance – *geographic needs identified*

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

• *Regional provider networks* - coordinate diagnosis, treatment & reimbursement

• Knowledge – *regional networks & databases*: share clinical expertise & long term monitoring
# Sickle Cell and Hemophilia – Commonalities & Differences - 1

<table>
<thead>
<tr>
<th>LEVEL = PATIENT</th>
<th>Hemophilia</th>
<th>Sickle Cell</th>
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</table>

**Pain** – Chronic and Acute → Illness burden: $, utilization
- Emergency Room & Hospitalization
- Work / School Loss

Home treatment can prevent/reduce illness (adherence)

Isolation, stigma, caregiver stresses

Disparities – socio/economic, cultural, race/ethnic, geo

<table>
<thead>
<tr>
<th>Hemophilia</th>
<th>Sickle Cell</th>
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<tbody>
<tr>
<td>YES</td>
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# Sickle Cell and Hemophilia – Commonalities & Differences - 2

**LEVEL = HEALTHCARE DELIVERY SYSTEM**

<table>
<thead>
<tr>
<th></th>
<th>Hemophilia</th>
<th>Sickle Cell</th>
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</thead>
<tbody>
<tr>
<td>Regional &amp; Local Centers of Excellence</td>
<td>YES</td>
<td>SOME</td>
</tr>
<tr>
<td>Surveillance – national</td>
<td>YES</td>
<td>NOT YET</td>
</tr>
<tr>
<td>Shortages – knowledgeable providers; PCPs unfamiliar</td>
<td>YES</td>
<td>YES</td>
</tr>
<tr>
<td>Adolescent transition to adult care – gaps &amp; nosedive</td>
<td>YES</td>
<td>YES</td>
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**LEVEL = INSURANCE & ADVOCACY**

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<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Reimbursement / Access to Specialty Teams &amp; Therapies</td>
<td>GAPS</td>
<td>GAPS</td>
</tr>
<tr>
<td>CBOs - Policy Capacity Building</td>
<td>YES</td>
<td>SOME</td>
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**LEVEL = RESOURCES**

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<td>SOME</td>
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<td>YES</td>
<td>NO 5</td>
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</table>
Hemophilia Care – Regional since 1990
Team based care in 140 regional Hemophilia Treatment Centers:
Regionalization: Hemophilia’s success

- 40% lower mortality\textsuperscript{1} & morbidity\textsuperscript{2}

- Soucie et al., Blood 2000\textsuperscript{1} and Haemophilia 2001\textsuperscript{2}


Baker et al., Haemophilia 2012
HRSA’s Pacific Sickle Cell Regional Collaborative

All clinical sites care for **BOTH** Sickle Cell Disease and Hemophilia

**Centers of Excellence synergies**

- Convene to build skills, identify & address common issues

**RANTEE:** CIBD - The Center for Inherited Blood Disorders [http://pacificscd.org/](http://pacificscd.org/)
Structure - the Pacific Sickle Cell Regional Collaborative

- Surveillance and Data
- Clinical Care
- Provider Education
- CBO Capacity

Policy / Partnerships
BUILDING AWARENESS - Government Partners

REGIONS IX & X

- HHS Administrator
- CMS
- Office of Women’s Health
- HRSA - Regional Administrator
- National Health Service Corp
- Bureau of Health Workforce
- Maternal and Child Health
- Office of Minority Health
- Office of Pacific Health
- Home Visiting Program

- Awareness, policy, troubleshoot, strategic linkages
Government Partners Working Group – February 2017
Tratamiento de la enfermedad de células falciformes: ¿Es adecuada la hidroxiurea para usted?

Treating sickle cell disease: Is hydroxyurea right for you?

Traitement de la drépanocytose par l'hydroxyurée: Est-ce bon pour vous?
Adult SC Clinic - CBO **Invaluable**: Design & Staffing
Advanced Practice Medical Home

- Integrated: Hematologist, Primary Care & Nurse Practitioner
- Preventive - specific to Sickle Cell Disease
- Behavioral health counseling
- Outpatient, emergency, inpatient
- Case Management
- Data Management**
- Pain - Alternative therapy
- *Peer Navigator, Community Health Worker, Nurse Educator*

* Sickle Cell Disease Foundation of California
** Center for Inherited Blood Disorders
Workforce Development

Next Generation
• Charles R. Drew University
  • New partnership
  • Blood Disorders curriculum
  • HRSA Regional Hemophilia Network Grant: 2017-2021

• National Association of Hispanic Nurses
• Telehealth: Project ECHO

Planning phase:
• FQHCs / Primary Care Association
• Nurse Practitioners
• Home Visiting Nurses
• Community Health Workers
Why Hispanic Nurses?

“...among Hispanic[s] and ... immigrant[s] ... physicians [are] not screening non-Black patients despite presentation with relevant symptoms.”
Insurance - Federal & State

*Sickle Cell Disease AND Hemophilia*

- Nevada – building comprehensive Sickle Cell C services per Hemophilia Model
- California – Health Homes, Adult Immunization coverage, Managed Medicaid access metrics for rare disorder clients
- State Medicaid Data – utilization, cost, outcomes
- MACRA – MD reimbursement
Regional Rare Blood Disorder Synergies Advance SCD Policy

**Context is Rare Disorders:** many commonalities

- **Policy in all** - Evidence based public health frameworks - overcome partner & policy silos

- **Involve CBO Stakeholders at highest levels**

**Cross sector partnerships:**
- strenghten and transform Awareness, clinical care, workforce, insurance, CBO capacity – reducing disparities

- **Stable resources NEEDED** to build impactful synergies
Acknowledgements

• **Pacific Sickle Cell Regional Collaborative:** This project is partially supported by the Health Resources and Services Administration of HHS under grant number 5 U1EMC27862-03-00, Sickle Cell Treatment Demonstration Program.

• **Western States Regional Hemophilia Network:** This project is partially supported by the Health Resources and Services Administration of HHS under grant number 5 H30MC24045, Regional Hemophilia Networks.
Bibliography


THANK YOU!

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