

# State of Sickle Cell Disease: Progress and Challenges The Caribbean

## 4th World Congress on Sickle Cell Disease 2022 Paris June 17, 2022

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# Agenda

- The Caribbean
- The Caribbean Sickle Cell Disease Scorecard
- Progress
- Challenges
- Lessons

# The Caribbean



## Who are we? Languages

Language	Inhabitants (Millions)*	Number of Nations/ Territories**	Largest countries
Spanish	≈26	3	Cuba, Dominican Republic, Puerto Rico
French	≈12	4	Haiti
English	<6	16	Jamaica, Trinidad & Tobago
Dutch	<0.2	3	Curacao

## Where are we?

# Characteristics of the Region

## Political Status

- Independent Island Nations
  - Antigua and Barbuda.
  - The Bahamas.
  - Barbados.
  - Cuba.-Sp
  - Dominica.
  - Dominican Republic-Sp
  - Grenada.
  - Haiti-Fr
  - Jamaica.
  - Saint Kitts and Nevis.
  - Saint Lucia.
- Mainland
  - Belize
  - Guyana
- United States of America
  - Puerto Rico
- United Kingdom- overseas territories:
  - Anguilla, Bermuda, BVI, Cayman, Montserrat, Turks & Caicos
- Europe
  - France: Guadeloupe, Martinique, Saint Barthelemy, St Martin, French Guiana
  - Holland: St. Maarten, Saba and St. Eustatius

# Ethnicity

- Indigenous peoples- Taino, Caribs & Ciboney
- Europeans
- Africans
- Asians
  - Trinidad & Tobago: 38% Indian, 36% African, 24% Mixed
  - Guyana: 44% Indian, 30% African, 17% Mixed
- Middle Eastern

# Population of 43,462,842 (0.6 global population)

- Cuba (11,326,616)
- Haiti (11,402,528)
- Dominican Republic (10,847,910)
- Puerto Rico (2,860,853)
- Jamaica (2,961,167)
- Trinidad and Tobago (1,399,488)
- Guadeloupe(400,124)
- Martinique (375,265)
- Bahamas (393,244)
- Barbados(287,375)
- Saint Lucia(183,627)
- Curaçao(164,093)
- Saint Vincent and the Grenadines(110,940)
- Grenada(112,52)
- United States Virgin Islands(104,425)
- Aruba(106,766)
- Antigua and Barbuda(97,929)
- Dominica(71,986)
- Cayman Islands(65,722)
- Saint Kitts and Nevis( 53,199)
- Sint Maarten(38,666)
- Turks and Caicos Islands(38,717)
- British Virgin Islands(30,231)
- Caribbean Netherlands (26,223)
- Anguilla(15,003)
- Montserrat(4,992)

## Economics (USD)

- |           |                     |       |
|-----------|---------------------|-------|
| • France  | • The Bahamas       | \$38K |
| • Holland | • Trinidad & Tobago | \$15K |
| • UK      |                     |       |
| • USA     |                     |       |
|           | • Guyana            | \$7K  |
|           | • Haiti             | \$1K  |

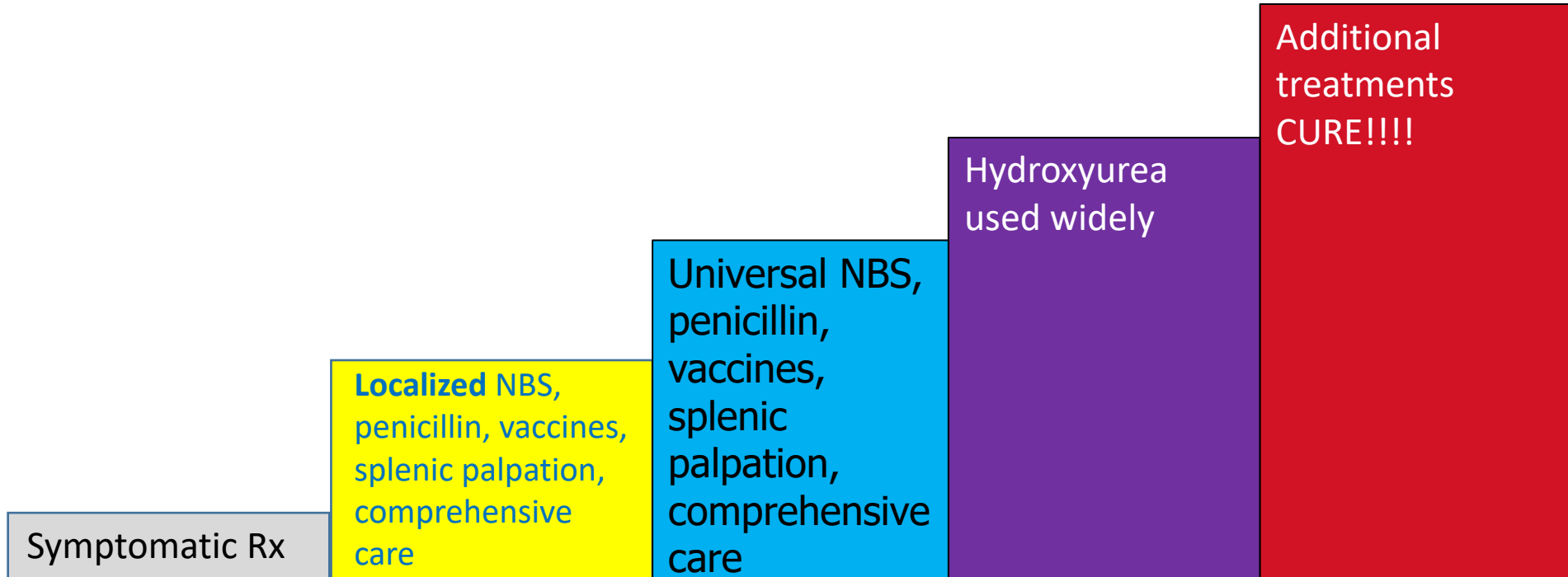
# The Caribbean

- Variety, Sameness, Differences
- A microcosm of the world



# The Caribbean & SCD

## Where are We Now?



- Progress = Collaboration
  - Regional
    - Caribbean Network of Researchers in Sickle Cell Disease and Thalassemia (CAREST)
    - SickKids Caribbean Initiative (SCI)- funded Caribbean Sickle Cell Disease Scorecard
  - National

# Sickle Cell Technical Working Group Jamaica

- Ministry of Health & Wellness
  - Dr. Carol Lord (FHU, (Chair)
  - Dr. Nicola Skyers (NCD)
  - Dr. Jennifer Thame (NPHL)
- SERHA
- NERHA
- WRHA
- SRHA
  - Mr. Donovan Leon (Senior Med. Tech)
  - Mr. Lansford Warren
- Sickle Cell Unit
  - Jennifer Knight-Madden (Co-Chair)
  - Lesley King
  - Monika Asnani
  - Melissa Smith (Nurse Coordinator)
  - Caldee Nicholas (Med. Tech)
  - Toshiba Channer-Wallen
- Sickle Cell Support Foundation  
Morette Wright (Patient)

# Newborn Screening

- Hospitals
  - Public vs Private
  - #s
    - Haiti 122
    - Jamaica 20
    - Tobago 1 + 1
- Home deliveries
  - Haiti (60%)
  - Tobago (<1%)
- Reference labs vs Point of Care Testing
  - Guadeloupe & Jamaica
  - Haiti
  - A work in progress
- Newborn Screening for Sickle cell Disease Using Point-of-Care Testing in Low-Income Setting *Alvarez O.A. et al., Pediatrics, 2019*

# Caribbean Sickle Cell Disease Scorecard

<https://www.caribbeanscdscorecard.org/>



Welcome to the Caribbean  
Sickle Cell Disease Scorecard  
(CSCDS)

Sickle cell related data for  
Caribbean countries and territories

View Data




By viewing the data, you agree to our Terms and Conditions

Data Entry



# Scorecards

## General Report

 Reload Data



Open

**Jamaica**

April 06, 2022



Open

**Guadeloupe**

April 20, 2022



Open

**Haiti**

June 12, 2022

## Indicators

A. Newborn screening  
Indicator

Open

B. Early childhood care  
Indicator

Open

C. NCD Care  
Indicator

Open

D. Covid  
Indicator

Open

E. Training  
Indicator

Open

F. Public Education  
Indicator

Open

G. Advocacy  
Indicator

Open

H. Research  
Indicator

Open

I. Governance  
Indicator

Open

J. Collaboration  
Indicator

Open

# Newborn Screening

## Scorecard

- A. Newborn screening
- B. Early childhood care
- C. NCD Care
- D. Covid
- E. Training
- F. Public Education
- G. Advocacy
- H. Research
- I. Governance
- J. Collaboration

Countries	Jamaica	Guadeloupe	Haiti
NBS Program <i>Universal(Green); Targetted(yellow); None(Red)</i>	universal	universal	targetted
% infants screened yearly <i>0-50 (Red); 51-80 (Orange); 81-100 (Green)</i>	99	99	

# Covid-19

Countries	Jamaica	Guadeloupe	Haiti	Antigua & Barbuda
Any Covid SCD deaths	Yes but risk unknown	Yes but risk unknown	Unknown	No
Covid vaccines-SCD included in high risk groups?	Yes- late	Yes	No	Yes



# Training

Countries	Jamaica	Guadeloupe	Haiti	Antigua & Barbuda
Annual In Person (Pre-Covid)	<b>&gt;=3</b>	<b>&gt;=3</b>	<b>&gt;=3</b>	<b>&gt;=3</b>
Annual Online	<b>&gt;=3</b>	<b>&gt;=3</b>	<b>&gt;=3</b>	<b>&gt;=3</b>
Clinical Care Guidelines	<b>Yes</b>	<b>Yes</b>	<b>No</b>	<b>Yes</b>

# Links

At least one academic with one project focused on SCD

Yes(Green); No(Red)

Link: CAIHR



Yes

Published at least one manuscript in past three years

Yes(Green); No(Red)

Yes

## I. Governance

Governmental policy regarding care of people with SCD

Yes(Green); No(Red)

Link: Policy in Jamaica re SCD



Yes

## J. Collaboration

Nationals are members of SCI

Yes(Green); No(Red)

Nationals are members of CAREST

Yes(Green); No(Red)

Link: Jamaica CAREST



# Jamaican Policy on SCD



MINISTRY OF HEALTH - JAMAICA

## NATIONAL STRATEGIC AND ACTION PLAN

for the

## PREVENTION AND CONTROL NON-COMMUNICABLE DISEASES (NCDS)

in

JAMAICA

2013 - 2018

# Sickle Cell Technical Working Group Jamaica

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- Sickle Cell Support Foundation  
Morette Wright (Patient)

# Significant Progress

## Ongoing

- Antenatal screening- all
  - Counselling sub-optimal
- Newborn screening >30,000/year
  - Confirmation varies by RHA
- Immunization
  - Pneumovax
- Advocacy
  - + NHF & DrugServ
  - Needs Assessment
- Training
  - ECHOs, Didactics, A&E

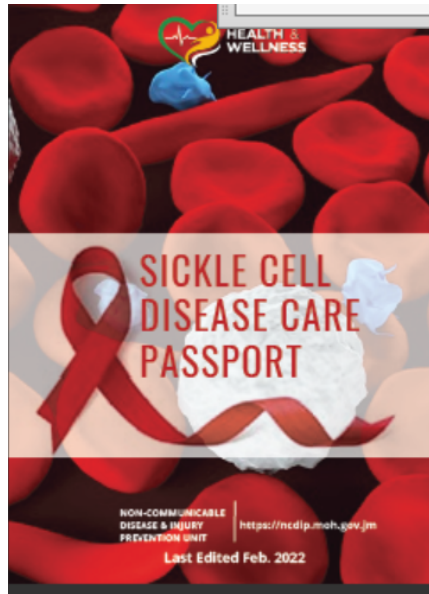
## Being Implemented

- Registers
- Passport
- Encounter forms
- Audits



THE UNIVERSITY  
OF THE  
WEST INDIES

# New Tools



Name:

Gender: Male ☐ Female ☐

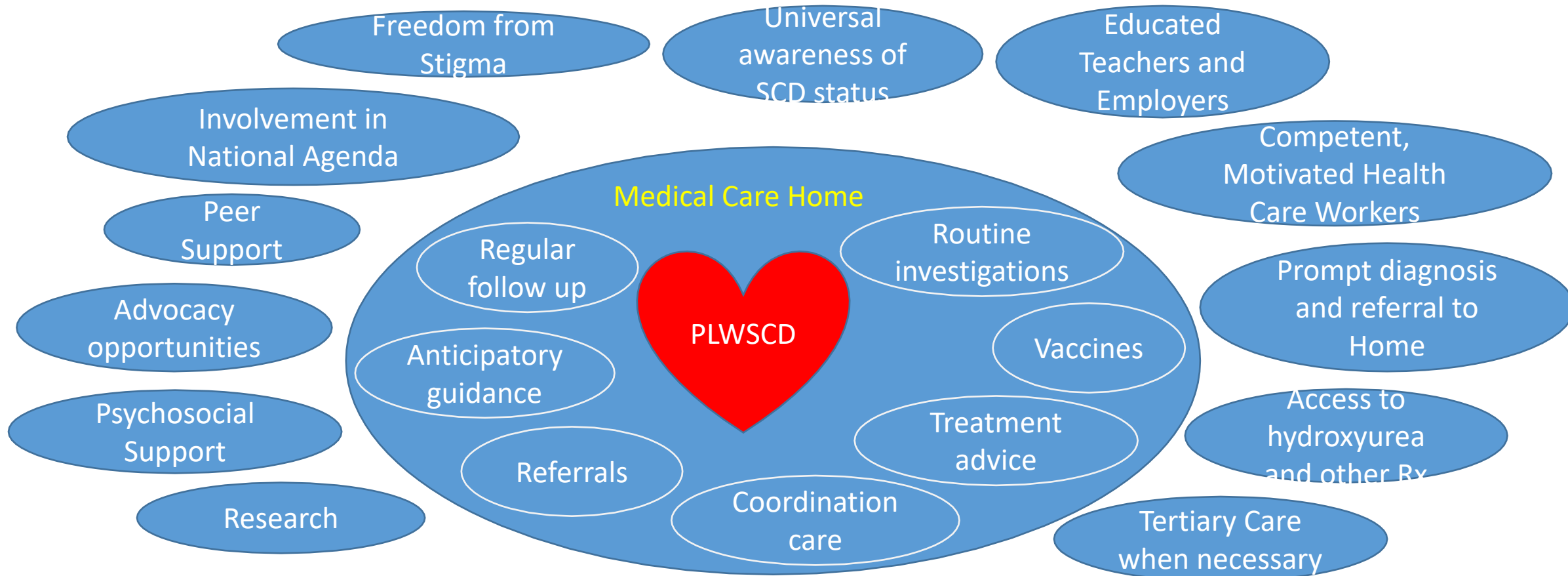
D.O.B:

Health Facility

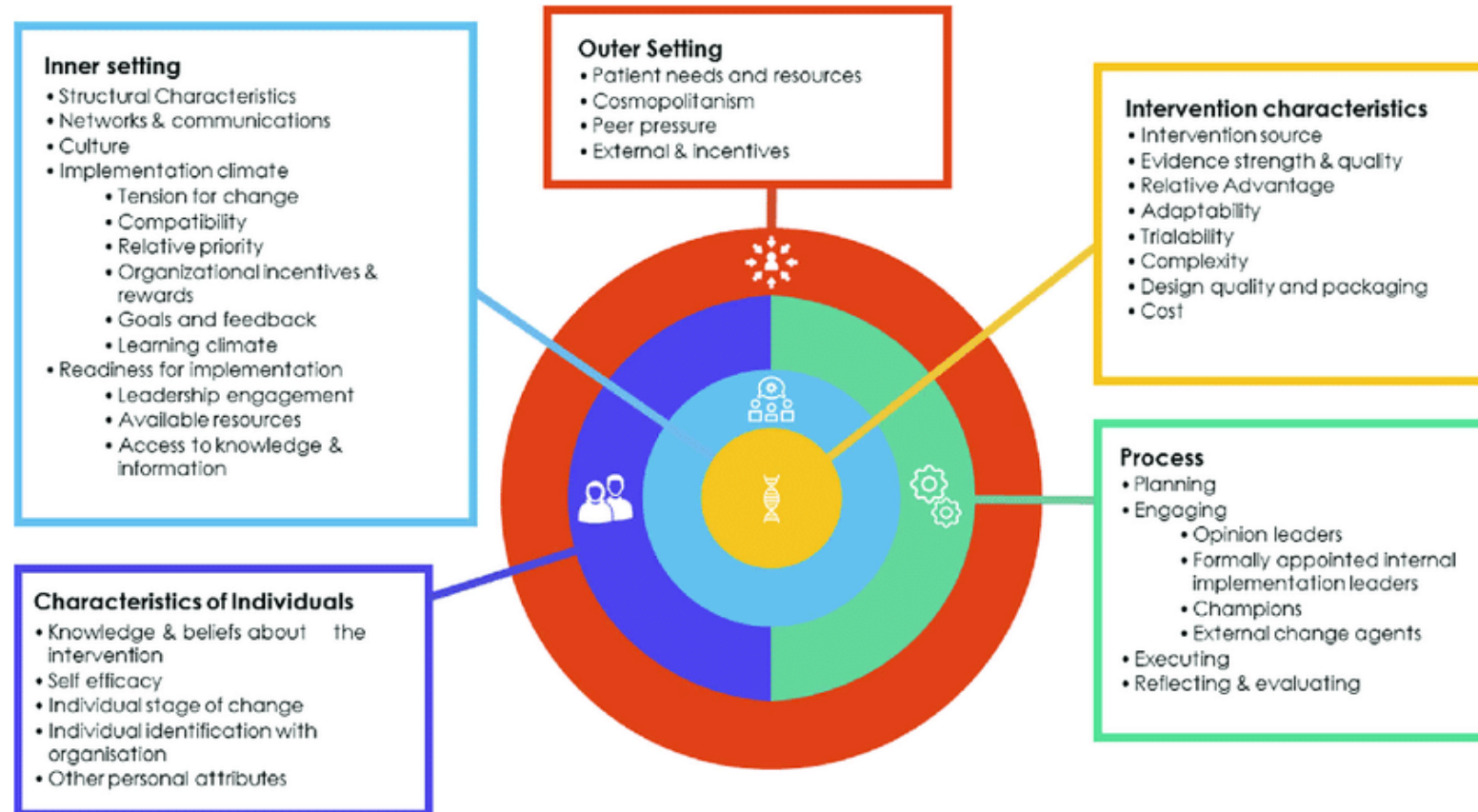
MRN

PATIENT INFORMATION				
Last Name	First Name	Age	Sex: Male / Female	Genotype
VITALS & POINT OF CARE TESTING				
Weight (kg)	Temperature (°C / °F)	Blood pressure	Glucose - fasting	Urinalysis
Height (m)	Pulse / Heart rate	O2 saturation	Hb (stat)	
BMI (kg/m <sup>2</sup> )	Resp. rate			
HISTORY				
Visit type: Routine / Sick	Leg ulcer present: Yes / No Enuresis: Yes / No	Priapism (since last visit): Yes / No	Family planning: Yes / No / NA Type: LMP (if applicable):	Pain crises (since last visit): Yes / No Severity: Home / GP / Hospital
Presenting complaint (s): Fever <input type="checkbox"/> Pain (crisis) <input type="checkbox"/> Cough <input type="checkbox"/> SOB <input type="checkbox"/> Headache <input type="checkbox"/> Weakness <input type="checkbox"/> Other:  Details:		Pain (Abd) <input type="checkbox"/> Pain (other) <input type="checkbox"/> Jaundice (new / worse) <input type="checkbox"/> Vomiting <input type="checkbox"/> Diarrhoea <input type="checkbox"/> Recent hospitalization?: Yes / No Name of Hospital: _____ Date: _____ Reason: Current medication(s): Pneumococcal prophylaxis: Yes <input type="checkbox"/> No <input type="checkbox"/> Drug: Penadur <input type="checkbox"/> Amoxil / Pan V <input type="checkbox"/> Other: _____ Hydroxyures: Yes <input type="checkbox"/> No <input type="checkbox"/> Dose: _____ Other:		
Clinical examination: Well-looking <input type="checkbox"/> Ill-looking <input type="checkbox"/>		Pallor <input type="checkbox"/> Jaundice <input type="checkbox"/>		MSK:
Cardiovascular: Apex: Heart murmur No <input type="checkbox"/> Flow <input type="checkbox"/> Other (details) _____		Respiratory:  CNS: Mental Status: _____ Cranial nerves: _____ Fund: _____ Bulk: _____ Tone: _____ Power: _____ Reflexes: _____ Plantars: _____		Deformity: Limp:
Abdominal: Liver (span) _____ cm (below RCM) _____ cm Spleen (below LCM) _____ cm				Skin: Ulcer(s): Yes / No Site(s): Appearance:

# Person Centered Care of People Living with Sickle Cell Disease (PLWSCD)



# Consolidated Framework for Implementation Research (CFIR)

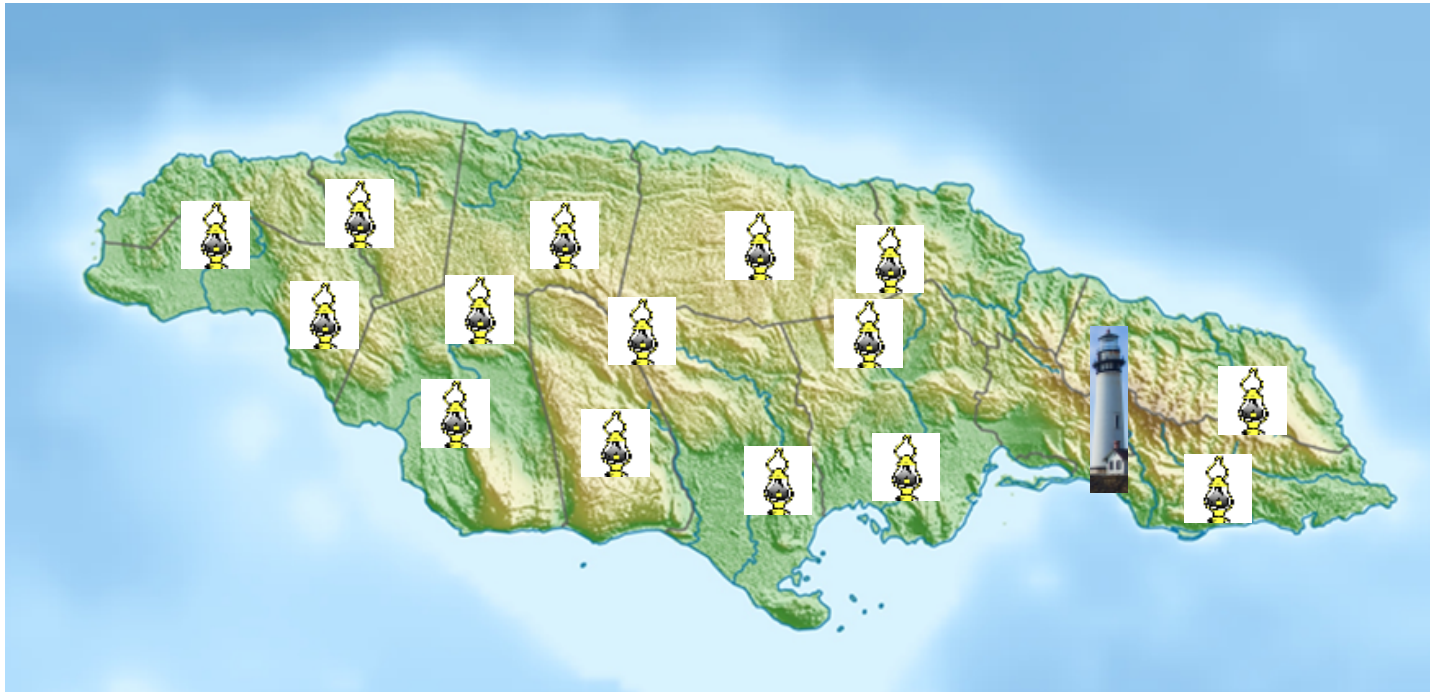




# In the Past- Working in Silos All with the Same Goals



# National Program- Diffusion of Light



# Regional Program Diffusion of Light



## Lessons Learnt in the Caribbean

- Collaboration of Patient/Advocate & Clinician/Researcher & Public Health Practitioners is best BUT start with whoever is willing
- Champions can make a HUGE difference – Thanks KOF
- Smaller is easier. Start small and expand
- Implement thoughtfully learning as you go along; Iterative process
- Individuals (all stakeholders), inner systems and outer systems all play a role in implementing and sustaining progress
- Cannot have champagne system with juice budget
- Have a vision and work together toward achieving it

# Our Model for Success



Passion



# Thank You!

- The mountains ahead can be climbed
- Just look back at how far we have come and give thanks

