A detailed map of the Caribbean region, including parts of North and South America. The map shows major islands and countries such as the United States, Mexico, Central America, and the Caribbean Sea. An inset map in the top right corner shows the entire Americas with a red box highlighting the Caribbean region. The text is overlaid on the map.

Current Advocacy Work in Sickle Cell Disease (SCD): The Caribbean Perspective

**Global Alliance of Sickle Cell Disease Organizations Webinar
June 19, 2020**

Jennifer Knight-Madden

Chair, Sickle Cell Trust Jamaica

**Vice President, Caribbean Network of Researchers in Sickle Cell Disease and
Thalassemia**

The Caribbean



Who are we?

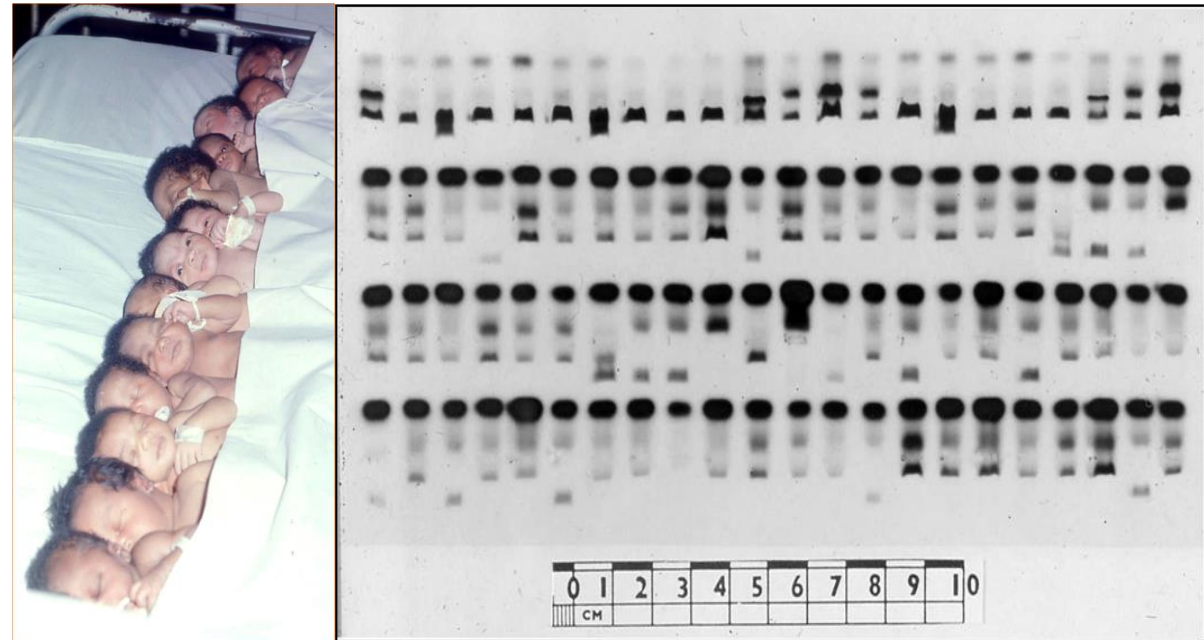
Where are we?

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

The Caribbean & SCD

WHO Designated Region	Number of annual affected births	Percent of total affected births	Incidence of affected births per 1000 live births
Africa	233,289	84.5	10.1
Americas (exc. Caribbean)	5,714	2.1	0.4
Caribbean	3,333	1.2	4.3
Eastern Mediterranean	6,491	2.4	0.4
Europe	1,292	0.5	0.1
South-East Asia	26,037	9.4	0.7
Western Pacific	13	0.005	0.0005
WORLD	276,168		

Is the Caribbean important to SCD?



Is SCD important to the Caribbean?

Advocacy in the Past Decade

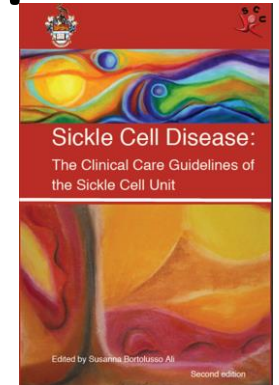
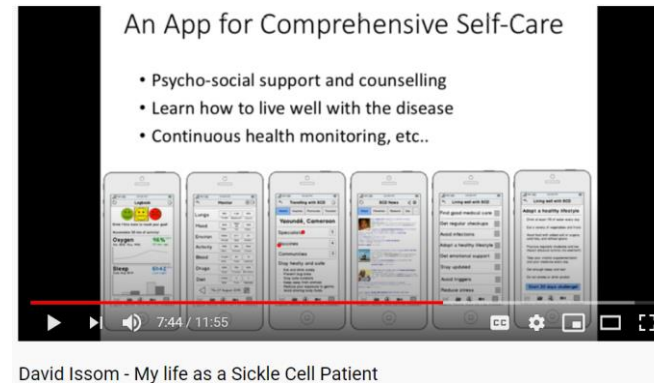
- **National & Regional cooperation**
 - Jamaica Sickle Cell Support Foundation, Shak's Hope, Sickle Cell Unit & Sickle Cell Trust
 - Caribbean Network of Researchers in Sickle Cell Disease and Thalassemia
- **Implementation of newborn screening and early childhood care**
 - Cuba, Guadeloupe
 - Jamaica
 - Tobago, Grenada
 - Trinidad, Haiti, Antigua, Guyana
 - The French territories through European funds in the framework of a European territorial cooperation program (INTERREG Caribbean) supports NBS in small island states
- **Integration of SCD care into public health as an important aspect of Maternal and Child Health and a major Chronic Non-communicable Disease**
 - Sickle Cell Technical Working Group, MOHW, Jamaica

Challenges Facing SCD Advocacy

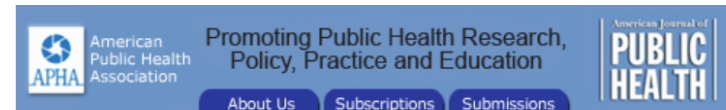
- **Isolation (Geography, Languages, History)**
- **Impact of political changes**
- **Framework**
 - **COSCA (Caribbean Organisation of Sickle Cell Associations)**
 - **Now defunct**
- **Funding**
 - **Not dependent solely on charismatic individual**

How can patients and patient organizations advance SCD advocacy for the future?

- Organize
- Use of technology
- Locate, understand, educate and motivate the seats of power
- Move public opinion



Journal List > Am J Public Health > v.106(5); May 2016 > PMC4985101



[Am J Public Health](#). 2016 May; 106(5): 851–853.

PMCID: PMC4985101

Published online 2016 May. doi: [10.2105/AJPH.2016.303078](https://doi.org/10.2105/AJPH.2016.303078)

PMID: [26999505](https://pubmed.ncbi.nlm.nih.gov/26999505/)

CAREST—Multilingual Regional Integration for Health Promotion and Research on Sickle Cell Disease and Thalassemia

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Thank You!

- The mountains ahead can be climbed



- Just look back at how far we have come and give thanks

