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

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Sickle cell disease (SCD) is a significant problem in the Caribbean, where many individuals have African and Asian forebears. However, reliable prevalence data and specific health care programs for SCD are often missing in this region. Closer collaboration between Caribbean territories initiated in 2006 to set up strategies to promote better equity in the health care system for SCD patients led to the formation of CAREST: the Caribbean Network of Researchers on Sickle Cell Disease and Thalassemia. We present the effectiveness of collaborations established by CAREST to promote SCD newborn screening programs and early childhood care, to facilitate health worker training and approaches for prevention and treatment of SCD complications, and to carry out inter-Caribbean research studies. (*Am J Public Health*. 2016;106: 851–853. doi:10.2105/AJPH.2016.303078)

The National Institutes of Health's 1987 Consensus Development Conference on Newborn Screening (NBS) for Sickle Cell Disease (SCD) and Other Hemoglobinopathies concluded that the benefits of screening were so compelling that universal screening should be provided.[1] The World Health Organization recommendations for regions where SCD is common include universal newborn screening, integrated care in the primary health system, a specialized center where patients can be assessed at intervals, and ongoing research into the most feasible ways of providing care.[2]

The United Nations recognizes SCD as a global public health concern and works to raise awareness of the disease with the annual observation of World Sickle Cell Disease Day on June 19.[3] Yet, SCD care globally is the epitome of inequity. Proven, inexpensive interventions remain unavailable in many developing countries, where most affected babies are born.

Historically the Caribbean, specifically Jamaica, has played an integral role in knowledge about SCD.[4] The region has clinical centers with research capabilities in Jamaica, Cuba, and Guadeloupe. However, neither NBS (Table 1) nor the simple early childhood interventions are universally available in most Caribbean countries.

Except in the French islands, NBS has traditionally been undertaken using agar and cellulose acetate membranes. These methods lack the required sensitivity and specificity. Acceptable methods include high-pressure liquid chromatography, isoelectric focusing, and capillary electrophoresis, with reference laboratories having at least 2 independent methods of diagnosis. The initial investment and continued costs preclude some of these methods in many places. However, regional laboratories can test samples sent by mail, decreasing per sample costs as throughput increases.

Early childhood care varies with location across the region, but a minimum standard should include pneumococcal prophylaxis and counseling regarding prevention and treatment of complications. National and regional guidelines can be used to improve care.

Most research in SCD is conducted in developed countries where research infrastructure is available. Research in areas with large clinical cohorts, such as Jamaica and Guadeloupe, can continue to add significantly to the literature, and collaboration with other islands can enrich research, giving a regional reach.

A regional SCD organization was formed to advance the SCD agenda regionally. We evaluated the success of CAREST (Caribbean Network of Researchers

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on Sickle Cell Disease and Thalassemia) in achieving its objectives of bridging language, cultural, economic, and geographic boundaries to promote and facilitate hemoglobinopathy NBS across the region; advocating policy change to promote the diagnosis and care of persons with SCD; providing technical assistance and expertise to aid in setting up disease-specific clinics; spearheading the improvement of clinical care to affected persons; developing culturally appropriate educational material; and engaging in, fostering, and participating in hemoglobinopathy research.

METHODS

In April 2006, health professionals from several islands who met in Guadeloupe adopted a resolution for the creation of a permanent structure that would be dedicated to regional collaboration for better development of the clinical management and knowledge of SCD.

A steering committee worked between 2006 and 2011, and in 2012, CAREST was legally registered as a not-for-profit company based in Guadeloupe to be administered by a board formed of 13 English (Jamaica, Trinidad and Tobago), French and Creole (Guadeloupe, French Guiana, Haiti, Martinique), and Spanish (Cuba, Dominican Republic)-speaking health professionals.

RESULTS

CAREST has made presentations to the regional meeting of the ministers of health of English-speaking countries (Caribbean Community, the Caribbean Public Health Agency Meeting, May 2014)[9] and to individual chief medical officers in 3 countries (Grenada, Antigua, Barbados). CAREST has offered subsidized screening for a 2-year period to establish the local prevalence, which policymakers can use in their health care planning. In Jamaica, SCD has been included in the national policy on noncommunicable diseases and specific public health targets set. The response of governments to CAREST has varied (Table 1).

CAREST members have partnered to initiate universal NBS screening in Tobago (started 2008, Guadeloupe), Grenada (started 2014, Guadeloupe), Saint Lucia (started 2015, Jamaica, with assistance from the SickKids Caribbean Initiative), Jamaica (has near-universal screening as of December 2015), and Haiti (scheduled to start March 2016, Guadeloupe, with help from Foundation "Pierre Fabre"). Antiguan policymakers have agreed to initiate NBS.

TABLE 1—Caribbean Countries Where Newborn Screening and Prevalence of Sickle Cell Disease Data Are Available as of January 2016

Country	Screening Method	Carrier Prevalence (Hb S Trait and Hb C Trait), %	Gene Frequencies	Sickle Cell Disease Incidence
Guadeloupe	Universal screening from 1984	10.5	β^S 0.042–β^C 0.013	1/304
Martinique	Universal screening from 1984	10.0	β^S 0.040–β^C 0.012	1/300
French Guyana	Universal screening from 1992	10.0	β^S 0.039–β^C 0.012	1/235
Jamaica	Screening in the southeast, southern, and western regional health authorities from 1995	15.0	β^S 0.055–β^C 0.019	1/150
Cuba	Prenatal diagnosis from 1982	3.1	β^S 0.011[a]–β^C 0.0036[a] β^S 0.053[b]–β^C 0.006[b]	NA
Barbados	997 consecutive births (1995)	4.0 (estimated)	NA	1/497
	NBS implemented by CAREST associated with the SickKids Caribbean Initiative			
Tobago	Universal screening from 2008	12.9	β^S 0.098–β^C 0.036	1/238
Grenada	Universal screening from 2014			
Saint Lucia	Move toward universal screening from 2015			
Jamaica	Universal screening in all public hospitals as of December 2015[c]			

Note. CAREST = Caribbean Network of Researchers on Sickle Cell Disease and Thalassemia; Hb = Hemoglobin; NA = not available; NBS = newborn screening. Information was partly obtained from a workshop carried out in April 2006 in Guadeloupe by health professional from Bahamas, Barbados, Cuba, Dominica, Guadeloupe, French Guyana, Haiti, Jamaica, Martinique, Dominican Republic, and Trinidad and Tobago.[5–8]

[a]Figures for western side of Cuba.

[b]Figures for eastern side of Cuba.

[c]In collaboration with Ministry of Health and Sickle Cell Trust.

Upgraded equipment provided by private sector (Sagicor) donations and a tripartite initiative with Brazil and the Pan American Health Organization facilitated the move in 2015 toward universal screening in Jamaica.

International conferences have facilitated the dissemination and coordination of information sharing (November 2011, Guadeloupe; May 2013, Cuba). The training of medical professionals by CAREST personnel in Grenada and Antigua (2014) has positively affected the management of SCD patients. Updated clinical care guidelines published by the Sickle Cell Unit, Jamaica (2015) provide a resource for clinicians regionally.[10] Joint research projects between Guadeloupe and Jamaica, Trinidad and Tobago, and Cuba have resulted in an exchange of postdoctoral students and publications.[11–14] Projects dedicated to a better understanding of SCD clinical variability focused on the assessment of genetic modifiers are ongoing.

Member states provide educational materials. A shared Web site provides information in French and English (http://www.carest-network.org). Member countries have joined in public outreach, particularly on and close to June 19, which is World SCD Day. CAREST has received support from the Regional Councils of Guadeloupe and Martinique, the general council of Guadeloupe, and the French Foundation "Pierre Fabre" for general expenses. National, regional, and international partners have supported efforts in NBS screening. Various sponsors in host countries have supported international conferences.

DISCUSSION

CAREST has achieved most of its objectives and gained improvements in equity within and between countries in NBS and clinical care. This provides a template for other regions in which collaboration with private sector, civil society, academia, and public health bodies can be facilitated by a regional organization that can also leverage south–south and north–south initiatives to build consensus and drive actions to improve the lives of persons living with SCD.

CAREST will continue to advocate extending NBS implementation in the region with strategies grounded on reducing the test price. At the same time, systematic evaluation of the follow-up of the children identified with SCD will take place, acquiring more accurate data regarding SCD prevalence as well as the quality of health care. The constitution of patient cohorts with equivalent management is planned. This is one of the strengths on which future regional research programs will be built. The organization of regular Caribbean conferences will also allow the development of larger collaborative programs. The last conference was held January 20–22, 2016 in Kingston, Jamaica, with the theme "advances in clinical care and research."

There are other collaborative networks, including the Global SCD Network and the Research Network in Central Africa. Not much has been published regarding the outcomes of their interaction. We hope that this report will stimulate further discussion of successes and impediments experienced by regional and global SCD networks. AJPH

CONTRIBUTORS

J. Knight-Madden, M. Romana, M. Etienne-Julan, L. Keclard-Christophe, and M.-D. Hardy-Dessources wrote the article. J. Knight-Madden, R. Villaescusa, M. Reid, M. Etienne-Julan, L. Boutin, N. Elenga, G. Wheeler, K. Lee, R. Nieves, G. Loko, L. Keclard-Christophe, and M.-D. Hardy-Dessources developed the Caribbean Network of Researchers on Sickle Cell Disease and Thalassemia (CAREST) activities. M. Romana, M. Reid, M. Etienne-Julan, G. Elana, R. Nieves, A. Jones Lecointe, M.-L. Lalanne-Mistrih, G. Loko, and M.-D. Hardy-Dessources created the network "CAREST" as members of a steering committee.

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HUMAN PARTICIPANT PROTECTION

No protocol approval was necessary because newborn screening (NBS) programs for sickle cell disease do not need protocol approval in the Caribbean countries where NBS is implemented.

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