
ADULT CONGENITAL HEART DISEASE

CHALLENGES AND ISSUES IN OUR COMMUNITIES OF LATIN AMERICA

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ADULT CONGENITAL HEART DISEASE

CENTRO CARDIOVASCULAR DE PRY EL CARIBE

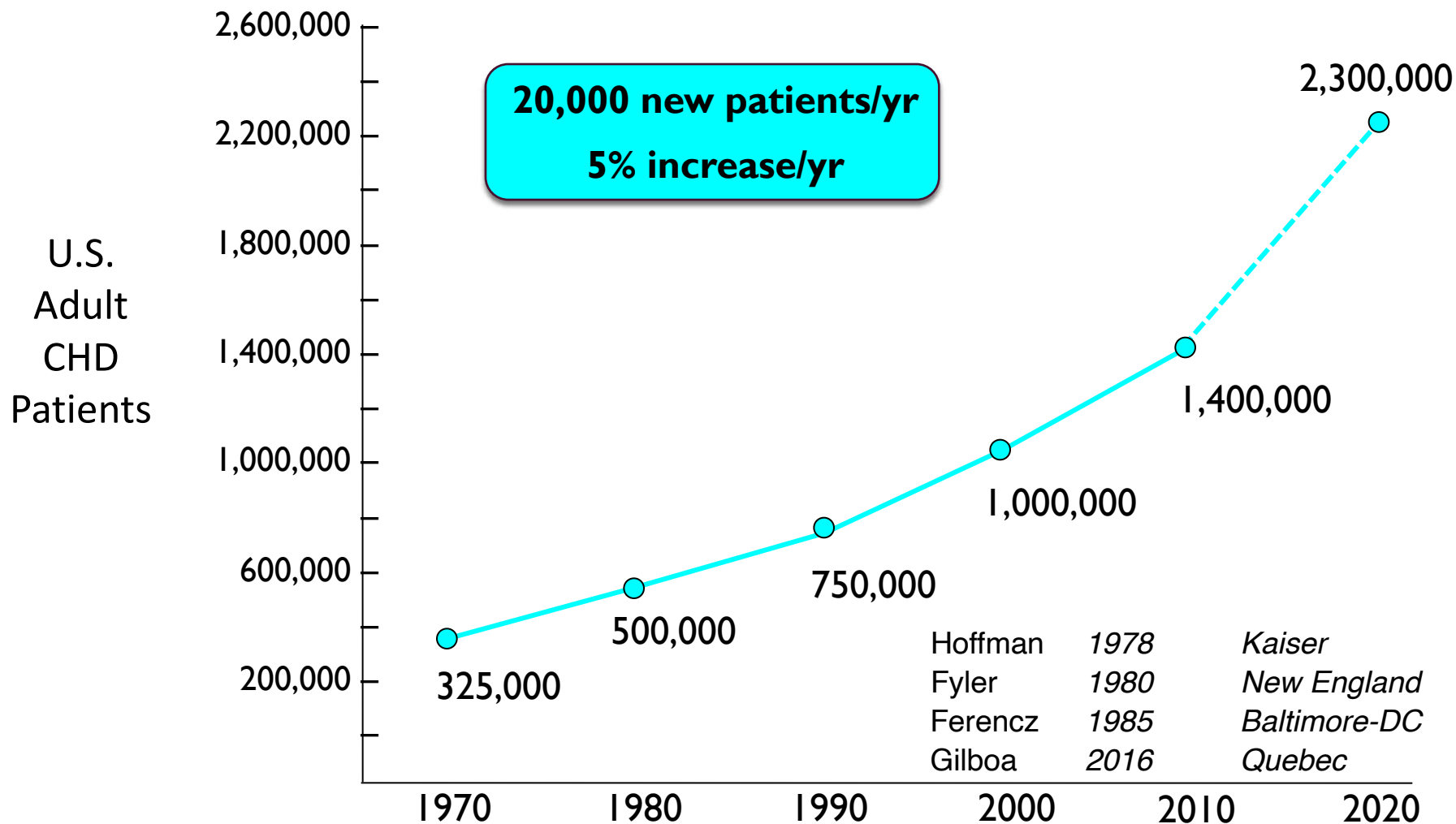
**AFFILIATED WITH BOSTON CHILDRENS HOSPITAL AND BOSTON ADULT CONGENITAL
HEART GROUP (BACH)**



OBJECTIVES

- Describe the main changes in the ACHD field
- To highlight the main challenges found in Latin America (LATAM)
- To mention some of the efforts we are making in LATAM

CHD PATIENTS REACHING ADULTHOOD



ACHD: NON-CARDIAC COMORBIDITIES ARE COMMON

**30% have moderate-severely
reduced lung function**

**30% meet criteria for a major
psychiatric diagnosis**

**10% with severe renal
dysfunction**

Hepatic fibrosis and cirrhosis

**1.6-2x higher prevalence of
malignancy**

2018 AHA/ACC Guideline for the Management of Adults With Congenital Heart Disease

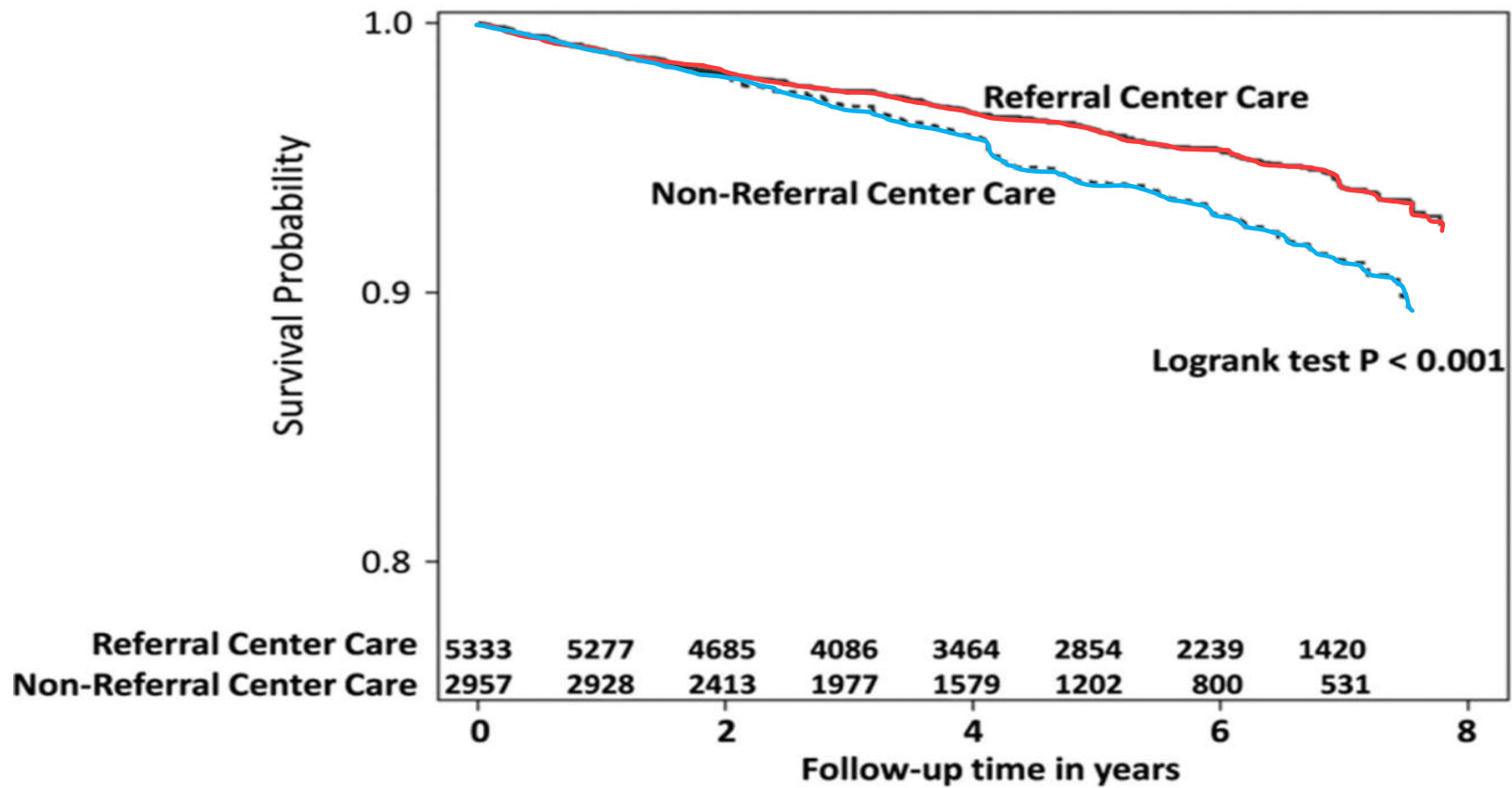
A Report of the American College of Cardiology/American Heart Association Task Force on
Clinical Practice Guidelines

*Developed in Collaboration With the American Association for Thoracic Surgery, American Society of
Echocardiography, Heart Rhythm Society, International Society for Adult Congenital Heart Disease,
Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons*

DELIVERY OF CARE

Recommendations for Delivery of Care		
COR	LOE	Recommendations
I	B-NR	Patients with ACHD AP classification IB-D, IIA-D, and IIIA-D should be managed in collaboration with an ACHD cardiologist.
I	C-LD	Cardiac surgery, catheter-based interventional cardiac procedures, and electrophysiological procedures involving congenital heart lesions in patients with ACHD should be performed by operators with expertise in CHD procedures and in collaboration with an ACHD cardiologist.

ACHD SPECIALTY CARE



WHAT IS THE SITUATION IN LATAM ?

- The birth rate in Latin America and the Caribbean is 2x the rate of North America
- A larger number of births with CHD would be expected for LATAM





Paediatric and congenital heart disease in South America: an overview

C A C Pedra,¹ J Haddad,² S F Pedra,¹ A Peirone,³ C B Pilla,⁴ J A Marin-Neto²

- Most of the large centers that treat CHD patients are financed mostly by a public governmental budget
- Although marked improvements have been achieved in the diagnosis and management of CHD there are still countries which that lacked of equipped centers

VARIATION IN CHD INCIDENCE IN LATAM

- Different ethnic and genetic backgrounds
- Accuracy of diagnosis, which relies on a well-trained doctor using appropriate tools
- Unreliable completion of birth certificates in maternity hospitals





Review

CCHD Screening Implementation Efforts in Latin American Countries by the Ibero American Society of Neonatology (SIBEN)

Augusto Sola ^{1,*}, Susana Rodríguez ¹, Alejandro Young ¹, Lourdes Lemus Varela ¹,
Ramón Mir Villamayor ¹, Marcelo Cardetti ¹, Jorge Pleitez Navarrete ¹, María Verónica Favareto ¹,
Victoria Lima ¹, Hernando Baquero ^{1,2,3}, Lorena Velandia Forero ^{1,3}, María Elena Venegas ³ ,
Carmen Davila ¹, Fernando Dominguez Dieppa ¹, Taína Malena Germosén ¹,
Ada Nidia Oviedo Barrantes ¹, Ana Lorena Alvarez Castañeda ¹, Mónica Morgues ¹,
Aldana Avila ¹, Diana Fariña ¹, Jose Luis Oliva ¹, Erika Sosa ⁴ and Sergio Golombek ¹

- The successful and universal implementation of POS is essential for reducing the mortality associated with CHD and other hypoxemic conditions and will ultimately lead to the survival of many more Latin American babies and then more adults with ACHD

NOTICIAS / CIRUGIA

Puerto Rico logra primera cirugía con Válvula Pulmonar en niño de 13 años

Un paciente de 13 años con Tetralogía de Fallot recibió con éxito la primera Válvula Pulmonar Transcateter en Puerto Rico.

Medicina y Salud Pública

Febrero 14, 2020 || Tiempo De Lectura: 3 min

Comparte en:



La enfermedad cardíaca congénita (de nacimiento) es el defecto de nacimiento más común, que afecta a ocho (8) de cada mil (1,000) niños que nacen al año. Cortesía: Centro Cardiovascular de Puerto Rico y del Caribe.

DISPARITIES IN ACHD ACCESS IN LATAM

- Pediatric cardiovascular and ACHD centers are still lacking
- No official number of ACHD specialized centers.
- Extrapolating the current ACHD population in Latin America and the Caribbean, at least **279 centers** would be needed to meet the needs of this population



THE FIRST ADULT CONGENITAL HEART DISEASE REGISTRY IN THE CARIBBEAN

Poster Contributions

Sunday, May 16, 2021, 9:45 a.m.-10:30 a.m.

Session Title: Spotlight on Special Topics: Global Cardiovascular Health 4

Abstract Category: 56. Spotlight on Special Topics: Global Cardiovascular Health

Authors: Monica Rosario, Aaron Villegas, Humberto Gómez, Nicole Vasquez, Gloria Hermón, Pamela Piña, Adabeyda Báez, Rebeca Pérez, Dhamelisse Then, Janet Toribio, Cesar Herrera, CEDIMAT Cardiovascular Center, Santo Domingo, Dominican Republic

- 501 patients treated in a tertiary center
- CHD complexity
 - 37% mild
 - 52% moderate
 - 11% severe
 - 73% repaired lesions





OUR LOCAL PEDIATRIC DATA

Figura 8: Defectos congénitos del sistema cardiovascular en Puerto Rico, 2003-2018

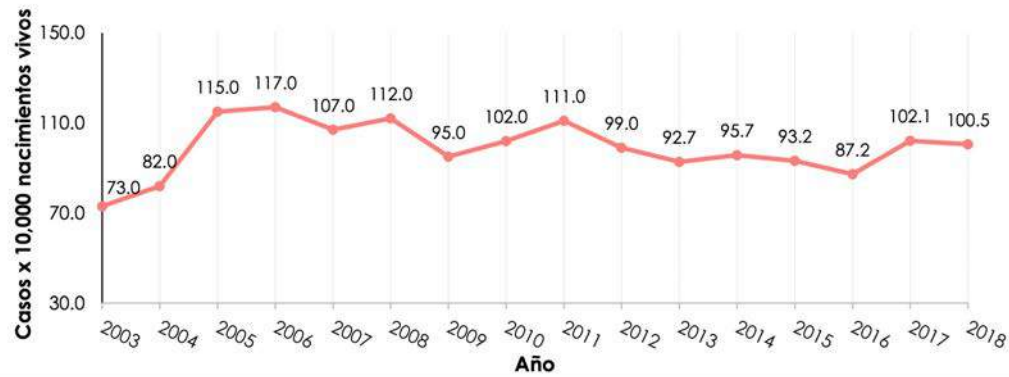


Figura 1: Prevalencia por categoría en Puerto Rico, 2014-2018



*Período 2016-2018





WHAT HAPPENS WITH THE ACHD POPULATION?

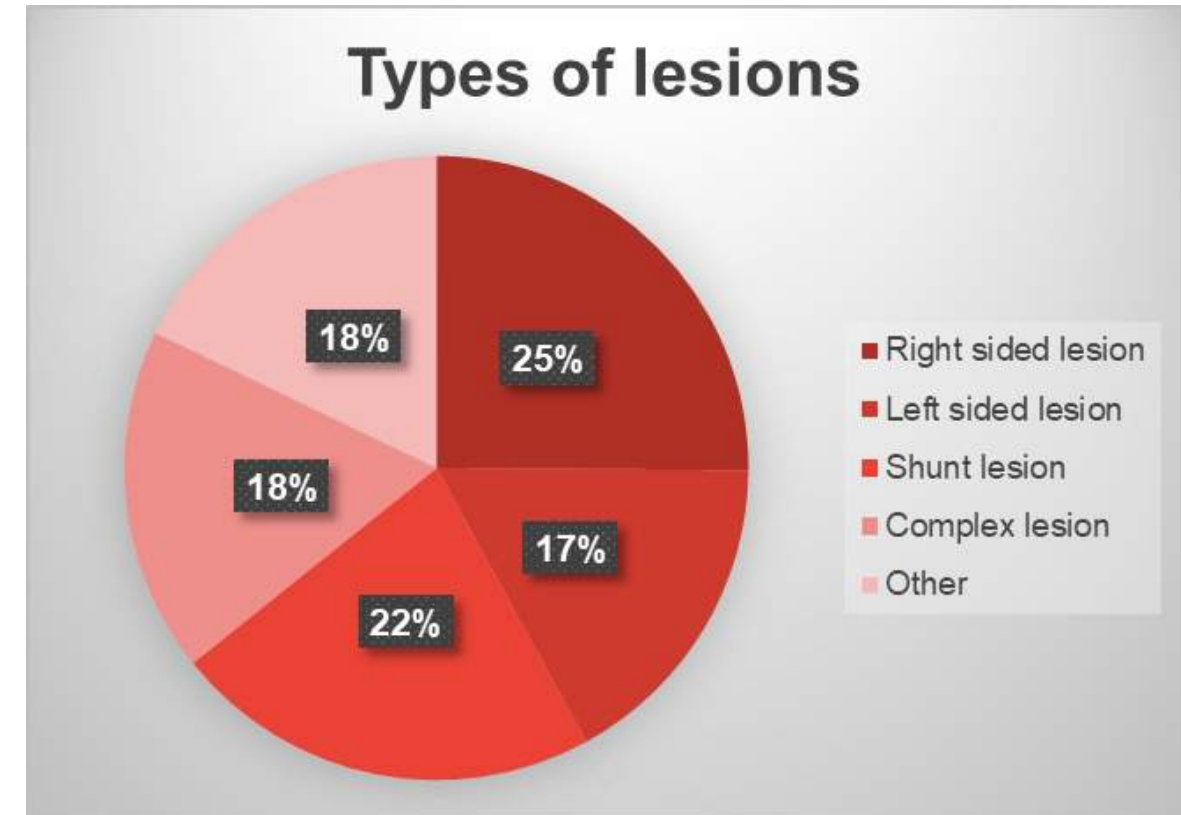
- Suspected that >50- 70% are dispersed around the island or failed to transition to adult CHD care
- There is no formal registry at this date*





WHAT HAPPENS WITH THE ACHD POPULATION?

- Preliminary and still collecting data (single provider)
- 211 patients
- >60% public insurance



MAIN CHALLENGES IN THE ACHD IN LATAM AND THE CARIBBEAN

- No formal ACHD programs
- No formal registry between LATAM/Caribbean countries
 - Unknown prevalence CHD complexity
- No formal transition programs are established
- Unknown specialty for other health providers and health insurance companies
- Limited tools for diagnosis and treatment

CURRENT EFFORTS IN LATAM



- In 2018, the **Adult Congenital Heart Disease Council of the Inter-American Society of Cardiology** (ACHDC-IASC) was founded

- The GOAL

To integrate all the cardiologists in charge of ACHD management in the Central American, Caribbean, and South American countries

- Projects

- i. Work together on ACHD registry projects*
 - ii. Educational activities and cooperation among the various countries
 - iii. Seek integration and cooperation with other global ACHD care
- ii. Continue to grow affiliations between US centers and LATAM

FUTURE PROJECTS

- Develop the directory of ACHD specialists in Latin America and the Caribbean
- Implement the development of Latin American ACHD guidelines
- Formal registries

TAKE HOME MESSAGE

- ACHD patients is a growing population worldwide
- In LATAM and the Caribbean, ACHD centers are still lacking
- Efforts to create a formal registry, ACHD centers and guidelines of care are in process

QUESTIONS



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Gracias !