

STS/EACTS Latin America Cardiovascular Surgery Conference
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info@cardiovascularsurgeryconference.org
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Challenges for Implementation of Multicentric Registries of Pediatric Cardiac Surgery in Latin America

Nestor Sandoval R.

**Fundación Cardioinfantil-Instituto de
Cardiología
Bogotá, Colombia**

**Member Steering Committee IQIC.
Member WDSPCHS**



Background

Congenital heart surgery is rapidly evolving in developing nations with increasing surgical volumes and better outcomes.

limited infrastructure and trained personnel, few dedicated pediatric cardiac programs, suboptimal funding and lack of health insurance policies.

There is no a database that attracts and reaches all countries, and many centers.

There is now a desire or interest from “established Societies” to involve centers in developing countries (LA) in these databases projects.

Why implementation of a multicentric registry so important

- Using clinical data drives the best practice.
- Guidelines for clinical practice.
- Clinical research.(publications)
- Public reports outcomes.(important for patients, families government and insurance companies.
- A Good “competition”.
- Generates commitment and responsibility.

Essential elements of a database

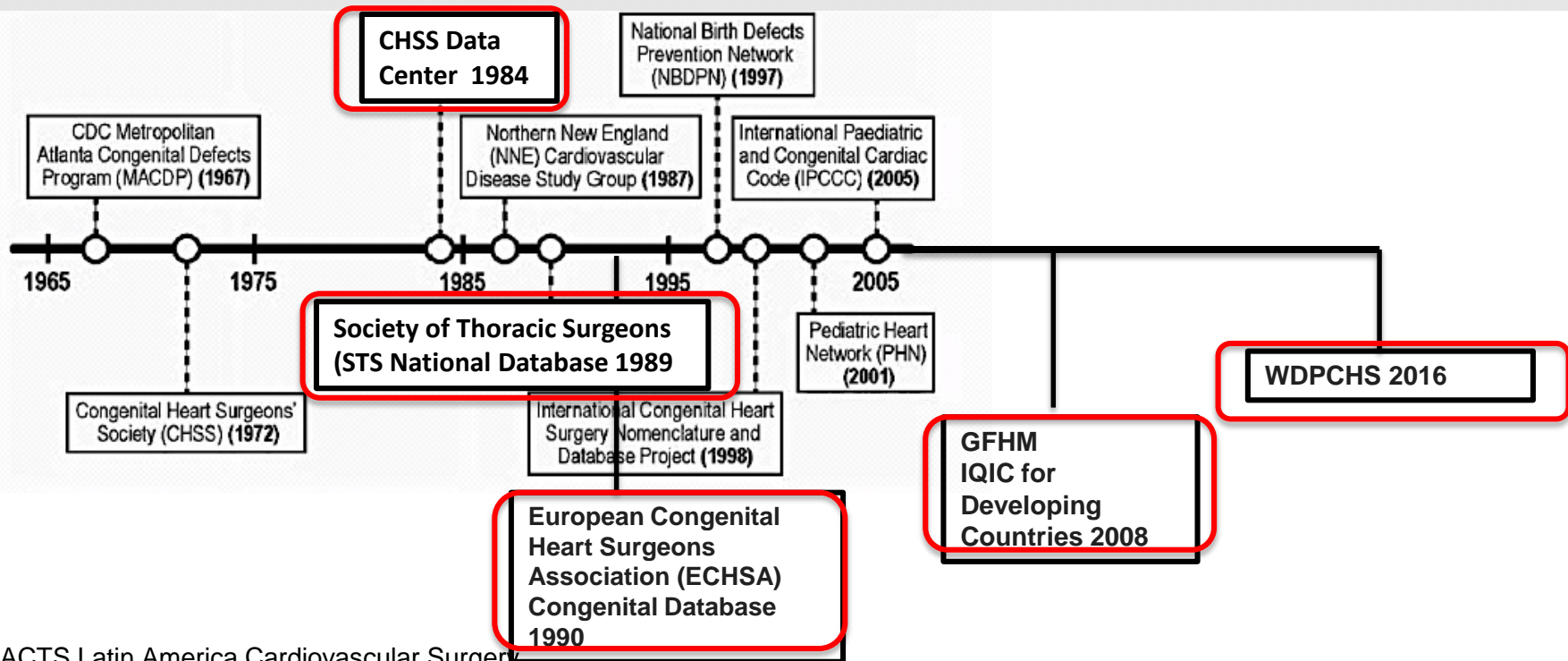
- 1. **Nomenclature:** Use of a common language and nomenclature.
- 2. **Database structure:** Defined and uniform core data set.
- 3. **Complexity stratification:** Mechanism to evaluate case complexity.(Rachs-1 STAT)
- 4. **Data verification:** Mechanism to assure data accuracy.
- 5. **Subspecialty collaboration:** Cardiology, CV surgery, anesthesia, critical care.
- 6. **Longitudinal follow-up:** Mechanism for lifelong follow-up.
- 7. **Quality improvement:** Mechanism for measurement of performance and improvement.

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Public Health Research in Congenital Heart Disease

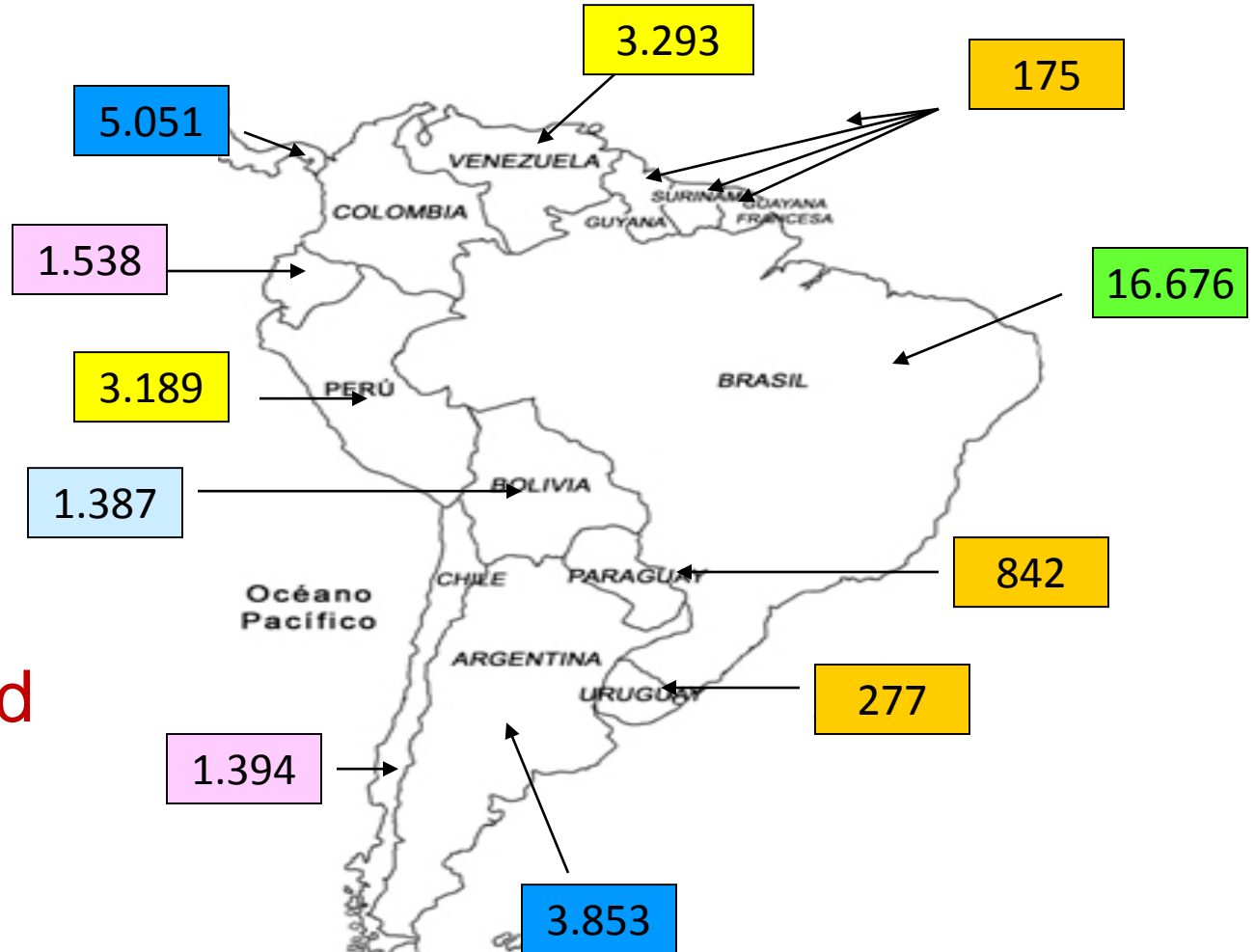
Diego A. Lara, MD, MPH, and Keila N. Lopez, MD, MPH

The Lillie Frank Abercrombie Section of Cardiology, Baylor College of Medicine, Texas Children's Hospital, Houston, Tex, USA



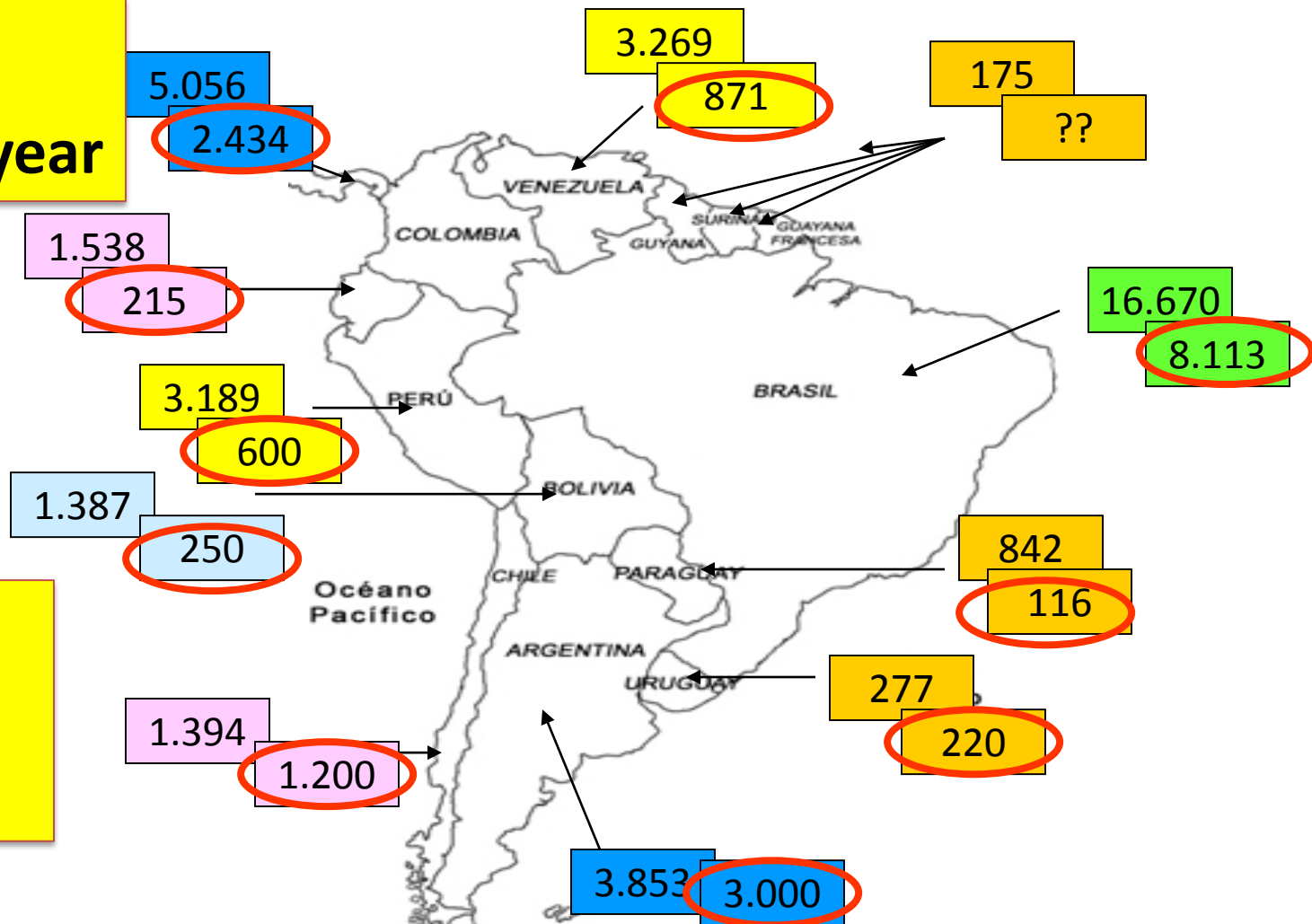
South America

41.100
new child need
any treatment



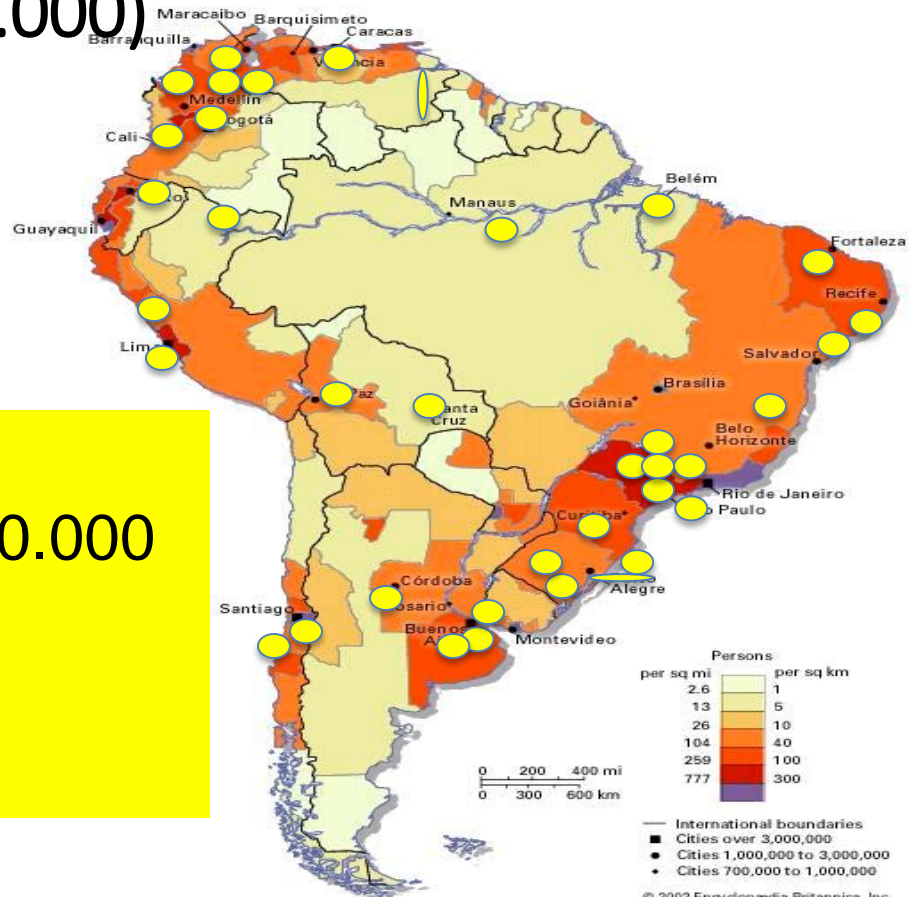
Number of Procedures / year

60% children have no any treatment



Cardiac units per million in South America (418'000.000)

140 centers
1 Ped Cardiac Center / 2'900.000



Pediatric Databases with impact in Latin America

CHSS

STS

ECHSA

IQIC

WDSPCHS

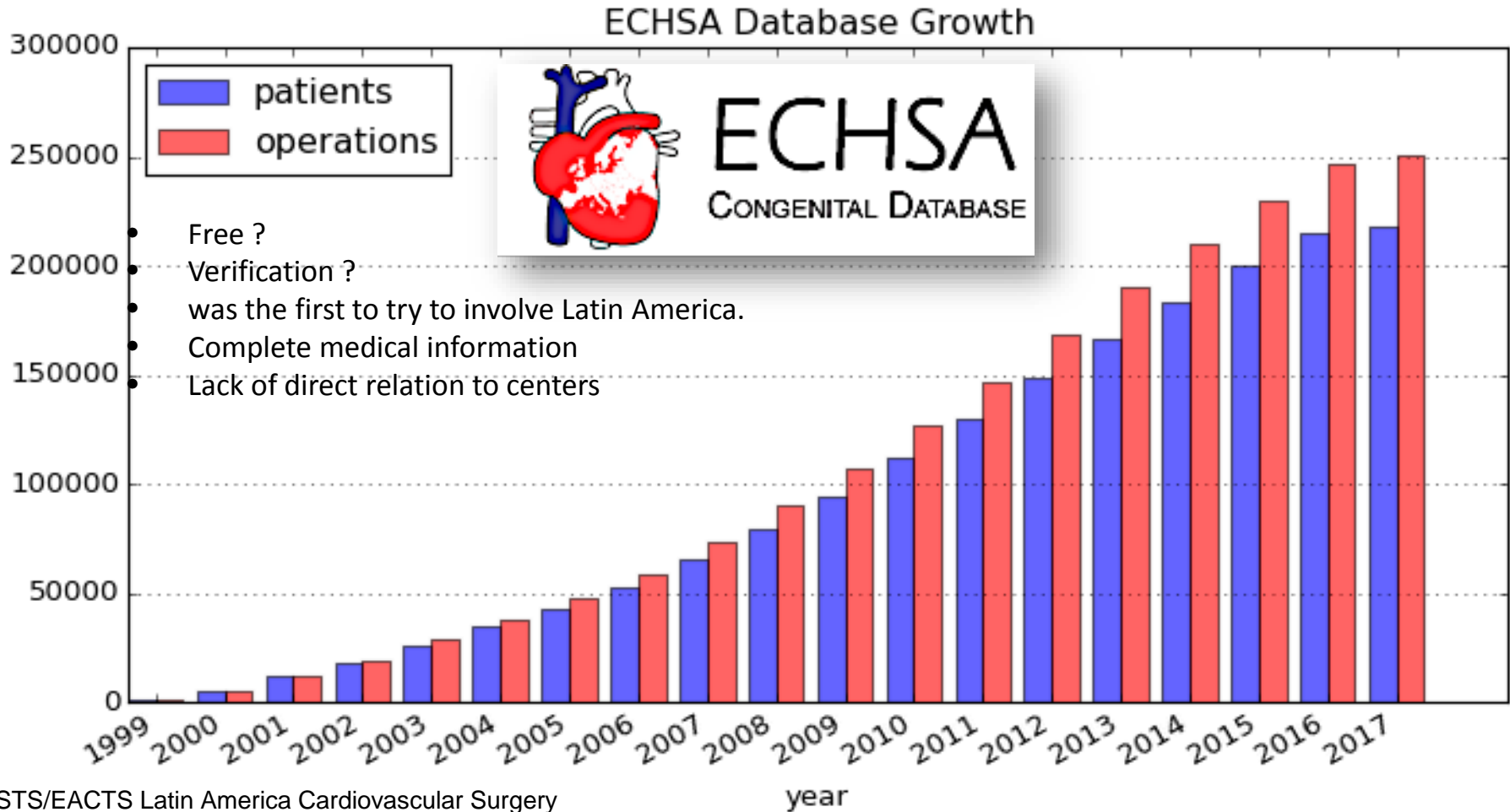


CHSS
Congenital Heart Surgeons' Society



Limited
Cost

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STS Public Reporting Online

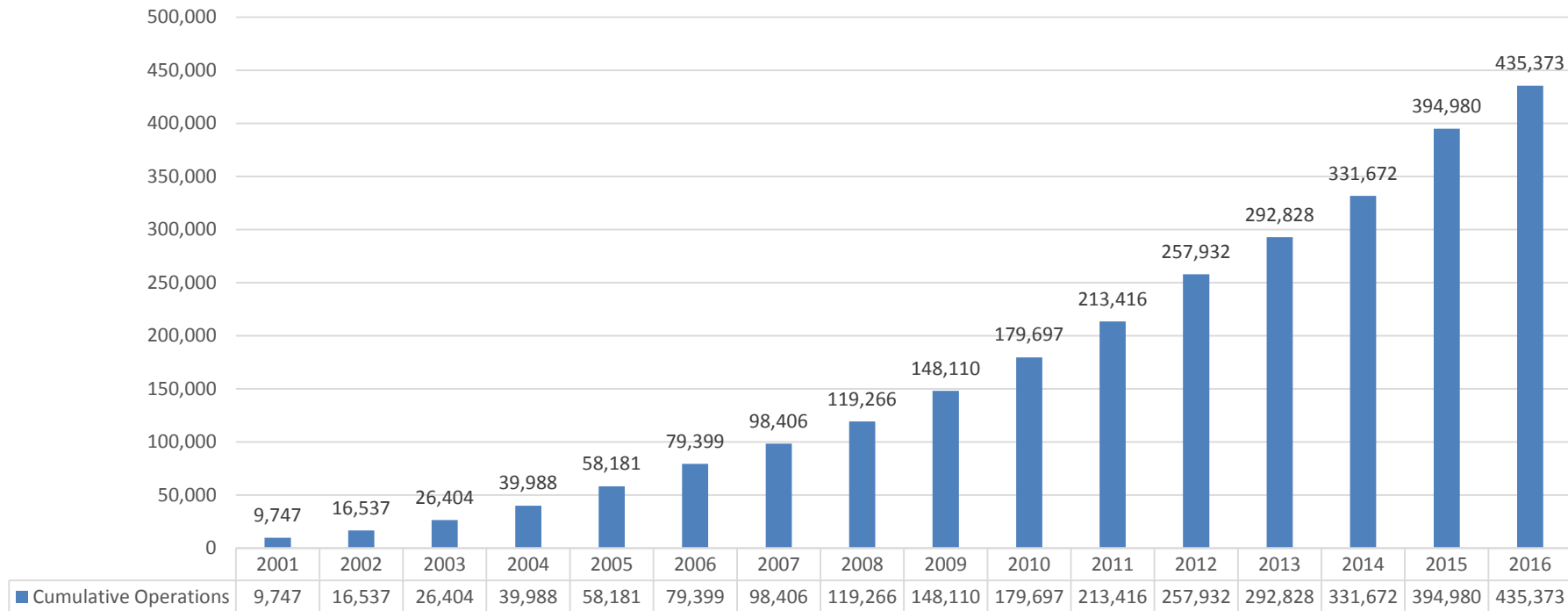


The Society
of Thoracic
Surgeons

Society for Thoracic Surgery Congenital Cardiac Surgery Database

- Largest database in the world
- 125 centers in the US and 8 in Canada .
- Verified audited data
- Risk adjusted data
- Platform for QI and transparency
- National Quality Forum endorsement

Growth in the STS Congenital Heart Surgery Database Cumulative operations over time



Jacobs JP, Jacobs ML, Mavroudis C, Tchervenkov CI, Pasquali SK. **Executive Summary: The Society of Thoracic Surgeons Congenital Heart Surgery Database – Twenty-sixth Harvest – (January 1, 2013 – December 31, 2016).** The Society of Thoracic Surgeons (STS) and Duke Clinical Research Institute (DCRI), Duke University Medical Center, Durham, North Carolina, United States, **Spring 2017 Harvest.**

STS Public Reporting Online



The Society
of Thoracic
Surgeons

Society for Thoracic Surgery Congenital Cardiac Surgery Database

- Limited mainly to US and Canada and ????
- “Expensive” for LA countries.
- Hard to fill all the variables

- Free
- Webinars and meetings
- Verified audited data
- Limited medical information
- Mortality 30 days
- Publications
- Future?

International Quality Improvement Collaborative *for Congenital Heart Surgery in Developing World Countries*



Annual Data Report 2016

Fundacion Cardioinfantil de Bogota
Bogota, Colombia

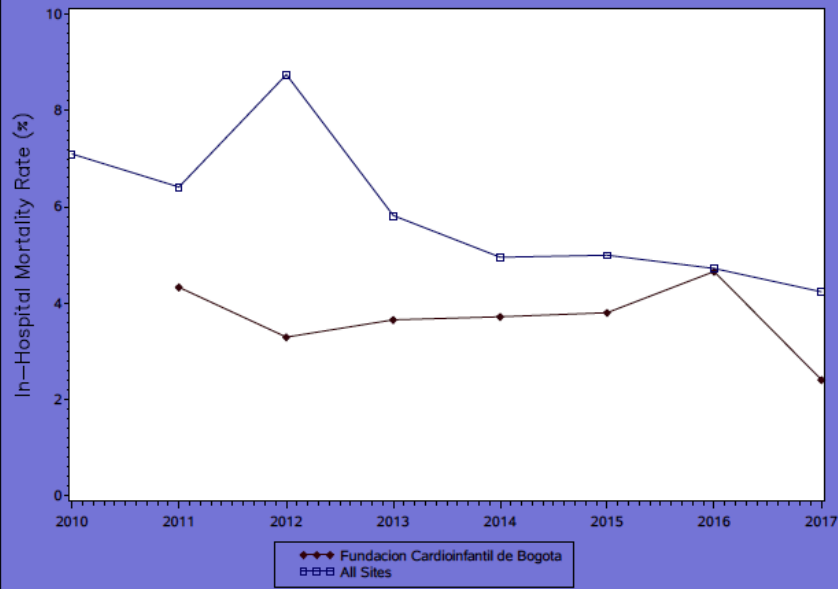
International Quality Improvement
Collaborative
for Congenital Heart Surgery



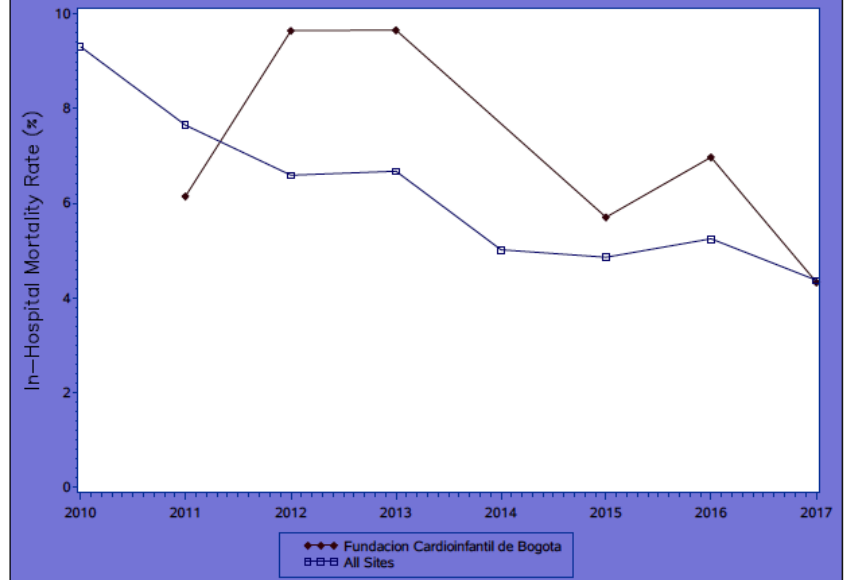
2017 Semiannual Data Summary #1

Fundacion Cardioinfantil de Bogota
Bogota, Colombia

Unadjusted In-Hospital Mortality Rates

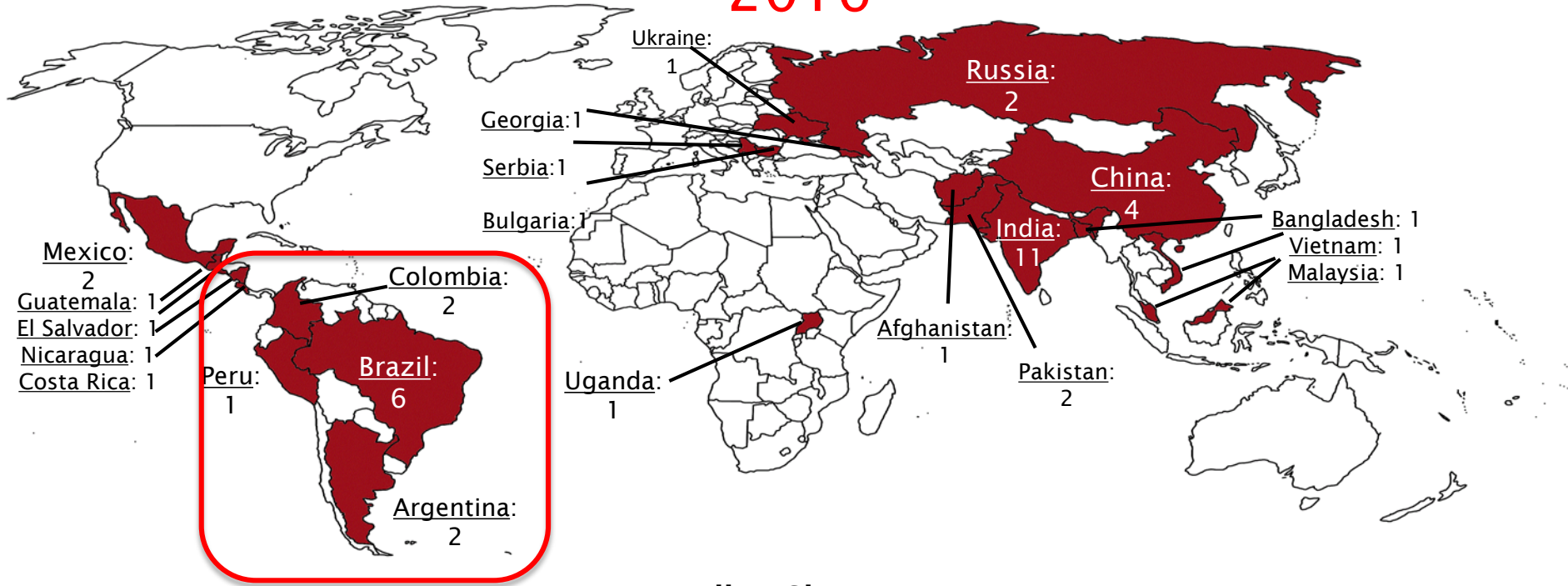


Unadjusted In-Hospital Infection Rates



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Participating Centers(21 countries) 2016



Founding Sites

- UNICAR, Guatemala City, Guatemala
- Clinica Medellin, Medellin, Bogota*
- Frontier Lifeline Hospital, Chennai, India
- National Children's Cardiac Surgical Center, Minsk, Belarus*
- Armed Forces Institute of Cardiology, National Institute of Heart Disease, Rawalpindi, Pakistan

*No longer enrolled



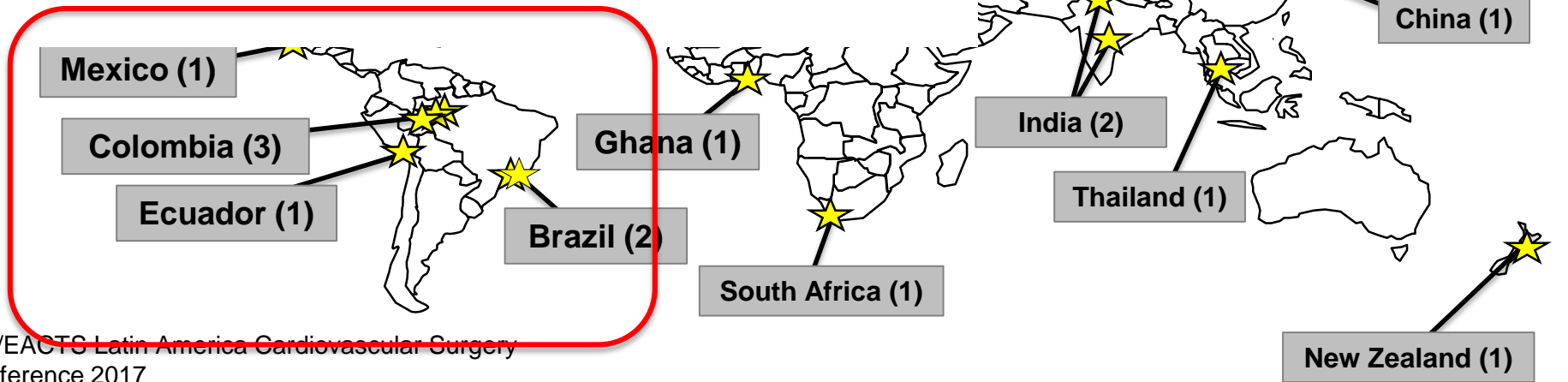
Hearts for Life across the World

WORLD DATABASE FOR PEDIATRIC AND CONGENITAL HEART SURGERY

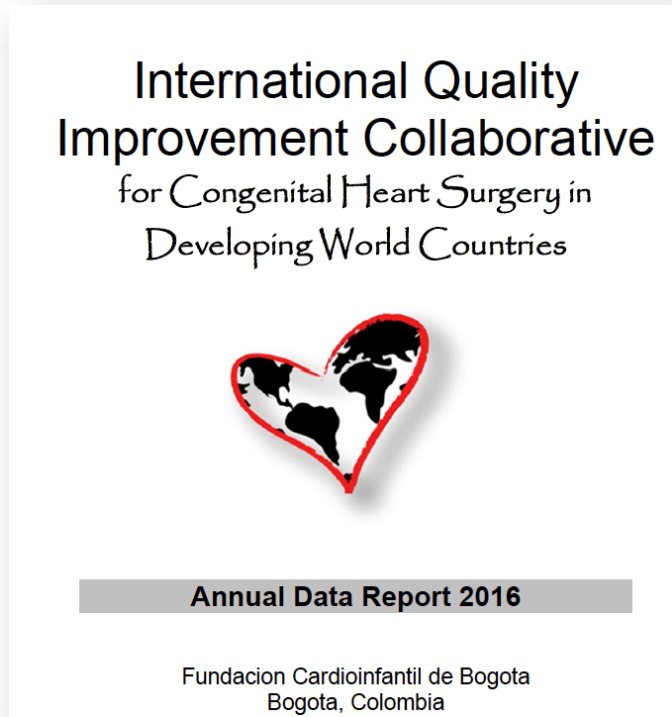
Every child born anywhere in the world with a congenital heart defect should have access to appropriate medical and surgical care!

Currently Participating (18)

- It Is free if one surgeon is member of the WSPCHS
- Easy to fill
- Complete medical information.
- Longitudinal follow up.
- Open for everybody.

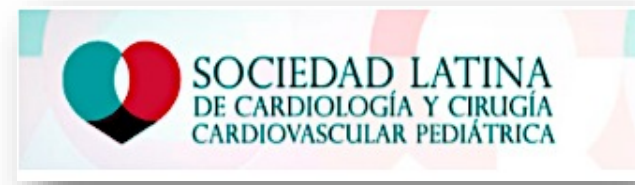
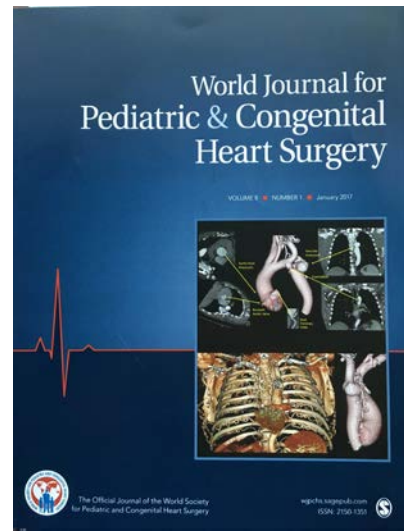


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joint effort to link this two databases

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compatible
allow the migration of information
that several databases can be included

Conclusions

- Databases have produced a overwhelming amount of information to offer the better treatment to our patients, and will allow developing congenital heart surgical programs to evaluate outcomes and compared to themselves and peers.
- All databases are good
- Not need to have more than one database system.
- We need a safe database over time !!!!!!!

Conclusions

- We need to create a platform that allows for the linkage of currently existing continental subspecialty databases
- Leaders.
- Commitment and support of institutions.
- International support.
- Cost is a barrier.

Once you have used it you can not live without it

Let's all get addicted to database Linking Databases



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Thank You

