

Children's HeartLink honors Brazil in the United States of America

Children's HeartLink homenageia Brasil nos Estados Unidos da América

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DOI: 10.5935/1678-9741.20120026

RBCCV 44205-1367

The partnership between the American Foundation Children's HeartLink (CHL) and the Department of Cardiology and Pediatric Cardiovascular Surgery, Hospital de Base (FUNFARME) - School of Medicine Regional São José do Rio Preto (FAMERP) continues to evolve and bearing fruit [1].

In 2011, there were two visits with teams consisting of surgeons, anesthetists, physiotherapists, nurses and members of the CHL, with several operations, conduct discussions and integration of teams, directly reflected in a change of vision and local behavior. A third specific nursing and physical therapy visit also had very positive impact on our team. At each visit, integration reflects a visible growth!

Alongside this integration, the service continued to advance in the share of global database based on RACHS risk score, called Quality Improvement Collaborative International Congenital Heart Surgery (IQIC team), led by Dr. Kathy Jenkins, of the Boston Children's Hospital, Harvard Medical School [1,2].

The IQIC team has given classes monthly via the Internet to our team of São José do Rio Preto, during the years 2010 and 2011. These lessons have been translated and adapted to our reality by Professor Adília Maria Pires Sciarra by pediatric cardiovascular surgeon Ulisses Alexandre Croti and nurse Sirley da Silva Pacheco, being

given by our nurses to nursing technicians and the support staff of the Service.

Dr. Kathy Jenkins signed the permission to use the copyright for teaching materials, allowing that all of these classes were used in Brazil and thus we could transmit them not only to our staff but also have them available to other centers interested (Figure 1).

The foundation CHL, responsible for all this help in our environment is maintained by money from some events, donations from individuals and companies, for example, the *Medtronic Foundation* (http://www.childrensheartlink.org).

In this context, in 2011 we were invited to visit the Mayo Clinic Foundation, Rochester, MN, USA, under the care of Dr. Joseph A. Dearani, and the Children's Hospitals and Clinics of Minnesota, Minneapolis, MN, USA, with Dr. David Overman, both services entirely focused on the treatment of congenital heart disease.

Those were days of much learning and opportunity to observe how these teams work, each with its own characteristics, but both with a concern that caught our attention: they wanted us to understand the importance of focusing on the patient first, as main reason for our work. They have made clear that for this to become feasible, it is first necessary human resources, highly trained people,

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who love and believe in what they do, in addition to technology, teaching, research, and fundamentally, something sometimes lacking in our country, proper management of the entire complex structure involved in the treatment of congenital heart disease.

Another important motivation for the invitation to Minneapolis was the event called *HeartLink Gala*, which took place on September 16, 2011.

The *HeartLink Gala* is a dinner gala with the intention to raise funds in order to the foundation continue running their projects in different countries with which it has partnership. The event was held at the Hilton Hotel in Minneapolis, MN, USA. It had as honorary presidents Theresa and Richard Davis, president and CEO of U.S. Bank, and as guests of honor, Ulisses Alexandre Croti and Lilian Beani, doctors at the Hospital de Base, representing Brazil in partnership with the CHL.

It was a night with numerous honors to the culture and customs of Brazil and attended by approximately 800 guests and raised \$780,000 dollars in donations that single night, according to reported publicly by the Foundation's website (http://www.childrensheartlink.org).



FACULDADE DE MEDICINA DE SÃO JOSÉ DO RIO PRETO

Copyright Permission Request

Date 4 / 11 / 1)

Dear Ms;

Kathy Jenkins

I (we) hereby as partner site in Brazil of the International Quality Improvement Collaborative for Congenital Heart Surgery (IQIC) program, require permission for copyrighting to use the module-class slides of the 2010 & 2011 Webseminars presentation for: Brazilian translation; adapted environmental local context and technological use to widespread this knowledge throughout the country.

Please indicate agreement by signing below

Kathy Jenkins

Yours sincerely; Solicitors:

Adilia Maria Pires Sciarra;

Domingo Marcolino Braile;
Ulisses Alexandre Croti;

Humberto Liedtke Junior

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In this event, we had the opportunity to read a speech prepared in advance, which is transcribed below (Figure 2).

We believe that with this solid, lasting relationship, introduction of new protocols, and, somehow, the "internationalization of the team," we are on the right track of quality improvement in patient care in our center and hope in the near future to serve as a model for other centers in the country who want to organize and evolve in the care of children with heart disease.

The following is the full speech:

Speech Friday, September 16, 2011



Good evening,

Ladies and gentlemen, friends of Children's HeartLink, its collaborators and volunteers.

I am very honored and proud to be here with you all!
I would like to say so many special things and thank
each one of you, who have given us such a warm welcome
in this wonderful city, in such a grand Country that has
helped us so much.

I would also like to be able to give lectures as a good speech, but unfortunately I don't have the gift.

Therefore, I will do as a former Brazilian vice-president once said: "Speeches must be like the skirt of a woman:

not too short so as to shock us and not too long so as to make us sad".

Therefore, I will say a few words that might translate our feelings, sharing the work Children's HeartLink has carried out in Brazil.

First of all, I shall say that my wife Lilian and I have been fortunate enough to have been born into families that were able to provide us an education. We belong to a small group in the population of two hundred million living in Brazil.

We are not the typical Brazilians, even though we enjoy soccer! However, we have the responsibility to work to improve our Country.

This partnership and friendship with Children's HeartLink has been a learning and improvement opportunity less fortunate children.

Brazil has the Amazon, one of the largest forests worldwide, with its immense natural wealth and uncultivated land. We are the world's largest beef, soybean and iron ore exporters. We have ethanol, made from sugar cane, used as a clean fuel source. But, above all, we are a cheerful and welcoming people.

However, we do have problems! Seven percent of our population is illiterate and unfortunately over 10% of those who can read and write, are considered functionally illiterate, that is, people who are not capable of reading and understanding a text or carry on simple math calculations.

The public education system is inefficient. A large number of children attend school only to have a meal, which most of the time is the only meal they are going to have throughout the day.

We have severe socioeconomic problems. Although over ninety percent of the population has access to water only seventy-five percent has access to basic sanitation, with a sewage system, even though we pay very high taxes.

Brazilians work about five months per year, only to pay government taxes and in spite of this, our domestic debt is very high and health care is often neglected.

We are, therefore, a Country in need of education and health care!

Twenty thousand children with heart defects are born every year and only a third go to surgery. As a consequence, two thirds of these children die waiting to have an operation or simply are not even able to have a medical visit at a specialized service.

There are not enough specialized services, only twelve in a country as big as ours.

Due to several problems inherent to the complexity involved in the treatment of children, results are often unsatisfactory and not nearly as good as those achieved in your Country.

Something had to be done; you knew it and cared

about it!

And so, at the end of two thousand and eight, we received a visit from Children's HeartLink and were lucky to have been chosen for this partnership.

Since then, we have experienced this wonderful opportunity which goes beyond cultural and political differences, putting down language barriers and prejudice and bringing hope to so many children and to us, health care professionals!

The Children's HeartLink staff and volunteers have simply changed our lives and those of the children we care for.

Everything is done with seriousness, respect and commitment.

The teams of volunteers were led by Dr. Joe Dearani and David Overman, to our hospital on four different occasions. They treated children coming from almost all Brazilian states, often from distances exceeding four thousand miles.

What to say about these teams of volunteers?

They are great in technical expertise and degree of knowledge. There are no doubts about the capacity of the Americans!

Technical aspects such as the standardization of medications, implementation of protocols, infection control, continuous training of the staff, among several other changes which have already taken place during the partnership between the two teams, were and have been very important to improve the health care provided to these children.

However, there are greater lessons and teachings!

They are role models of how to visit the home of other people, with different cultures and habits, respecting everyone, with politeness and a desire to transform everything for the better, always aiming at the well-being of those less fortunate.

We want to emphasize the human lessons, in regards to people, and respect to the human being!

The advices for the professionals in our team to improve communication with one another, to look at the children as human beings, who need our help, and to embrace a mother at a moment of extreme pain.

Motivation towards commitment, quality and safety while providing health care.

Motivation for the team!

Changes in our behavior!

Children's HeartLink has also enabled us to participate in the International Quality Improvement Collaborative for Congenital Heart Surgery in Developing Countries, which allows us to participate in its Database through a remote training course, via the internet, which has provided some amazing results.

This is the first time a Brazilian Pediatric Cardiac

Service analyzes its results so carefully and diligently. In a near future, we will have real data available which will help us improve our results in providing medical treatment to children.

Children's HeartLink is also supporting us to implement an adequate administrative management system with the Board of Directors of our hospital and with São Paulo State government for the new Children's Hospital, which will be inaugurated next year.

We believe that with this support we will be able to increase the number of children with heart disease treated at our institution as well as improve the quality of care, both from a technical and human perspective, which enables us to dream of becoming model and training center for other services in Brazil and Latin America.

How can we measure everything that Children's HeartLink has done in Brazil?

It would perhaps be too simplistic to say, for instance, the wound infection rate has dropped from seventeen to four percent, show you graphics or other statistical data.

These figures cannot translate the happiness of a mother holding her child after heart surgery and taking him or her back home!

This mother, after nine months of pregnancy could not even dream that such an expected child would be born with a severe disease, especially a heart disease, nor could she imagine it would be so difficult to find a place for her child to be treated with quality and safety!

This is what the efforts of Children's HeartLink and its teams of volunteers translate into!

So, we would like to openly thank you for this wonderful experience, which has taught us to look at every child and think:

What does this child really need?

This has motivated us and we hope to be able to continue learning from your examples with your support.

We would like to extend our special thanks to those of you that are here tonight.

You are noble, not only because you make financial donations to help Children's HeartLink and therefore, help make come true the dreams of hundreds of families you will probably never have a chance to meet.

You are noble, because you are here for a cause, attesting the greatness and the way of thinking of American People!

Perhaps, some time into the future, you will no longer remember what was said here about the importance of Children's HeartLink, but you can be sure that the children and families receiving your help will never ever forget what you're doing tonight!

Lilian and I would like to thank you very much for this opportunity and for your patience. God bless you all!

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