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Children's HeartLink homenageia Brasil nos Estados Unidos da América

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

Ulisses Alexandre Croti¹, Lilian Beani², Domingo Marcolino Braile³, Joseph A Dearani⁴

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A parceria entre a fundação americana Children's HeartLink (CHL) e o Serviço de Cardiologia e Cirurgia Cardiovascular Pediátrica do Hospital de Base (FUNFARME) – Faculdade de Medicina Regional de São José do Rio Preto (FAMERP) continua evoluindo e dando frutos [1].

No ano de 2011, aconteceram duas visitas com equipes constituídas por cirurgiões, anestesistas, fisioterapeutas, enfermeiros e membros da CHL, com diversas operações, discussões de condutas e integração das equipes, refletindo diretamente em mudança de visão e comportamento local. Uma terceira visita específica de enfermagem e fisioterapia também teve impacto muito positivo em nossa equipe. A cada visita, a integração reflete um crescimento visível aos olhos!

Paralelamente a essa integração, o serviço continuou avançando na participação do banco de dados mundial baseado no escore de risco RACHS, denominado *International Quality Improvement Collaborative for Congenital Heart Surgery (IQIC team)*, liderado pela Dra. Kathy Jenkins, do Boston Children's Hospital da Harvard Medical School [1,2].

O *IQIC team* ministrou aulas mensalmente via internet à nossa equipe de São José do Rio Preto, durante os anos de 2010 e 2011. Essas aulas foram traduzidas e adaptadas para a nossa realidade pela professora Adília Maria Pires Sciarra,

pelo cirurgião cardiovascular pediátrico Ulisses Alexandre Croti e pela enfermeira Sirley da Silva Pacheco, sendo ministradas pelas nossas enfermeiras às técnicas de enfermagem e à toda equipe de assistência do Serviço.

A Dra. Kathy Jenkins assinou a permissão de utilização dos direitos autorais desse material didático, permitindo que todas essas aulas fossem utilizadas no Brasil e, dessa forma, pudéssemos transmiti-las não somente à nossa equipe, mas também disponibilizá-las a outros centros interessados (Figura 1).

A fundação CHL, responsável por toda essa ajuda em nosso meio, é mantida por dinheiro oriundo de alguns eventos, doações de pessoas físicas e de empresas, como, por exemplo, a *Medtronic Foundation* (<http://www.childrensheartlink.org>).

Nesse contexto, em 2011, fomos convidados a visitar a *Mayo Clinic Foundation*, em Rochester, MN, EUA, aos cuidados do Dr. Joseph A. Dearani, e o *Children's Hospitals and Clinics of Minnesota*, em Minneapolis, MN, EUA, com o Dr. David Overman, ambos os serviços inteiramente voltados para o tratamento das cardiopatias congênitas.

Foram dias de muito aprendizado e oportunidade de observar o modo de trabalho dessas equipes, cada qual com suas características, porém ambas com uma preocupação que nos chamou a atenção: desejavam que nós entendêssemos a importância de se ter o paciente em

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primeiro lugar, como foco principal e motivo de nosso trabalho. Nos deixaram muito claro que, para isso se tornar factível, é necessário primeiramente material humano, pessoas altamente treinadas, que gostam e acreditam no que fazem, além de tecnologia, ensino, pesquisa e, fundamentalmente, algo que algumas vezes falta em nosso meio, uma gestão adequada de toda a complexa estrutura envolvida no tratamento das cardiopatias congênitas.

Outra importante motivação do convite para irmos à Minneapolis foi o evento denominado *HeartLink Gala*, que ocorreu em 16 de setembro de 2011.

O *HeartLink Gala* é um jantar de gala com intuito de arrecadar fundos para que a Fundação possa prosseguir executando seus projetos nos diversos países com os quais mantém parceria. O evento aconteceu no Hotel Hilton, em Minneapolis, MN, EUA. Teve como presidentes honorários Theresa e Richard Davis, presidente e CEO do US Bank, e como convidados de honra, Ulisses Alexandre Croti e Lilian Beani, médicos do Hospital de Base, representando o Brasil na parceria com a Fundação CHL.

Veja alguns momentos do evento acessando o link:
<http://www.rbccv.org.br/video/v27n1/>



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Date 4 / 11 / 11

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 Marcelino Braile;

Ulisses Alexandre Croti;

Humberto Liedtke Junior

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Foi uma noite com inúmeras homenagens à cultura e aos costumes do Brasil e presença de aproximadamente 800 convidados, sendo arrecadados \$780,000 dólares em doações nessa única noite, segundo informou publicamente o site da Fundação (<http://www.childrensheartlink.org>).

Nesse evento, tivemos a oportunidade de ler um discurso previamente preparado, o qual é transcrito abaixo (Figura 2).



Thank you from Children's HeartLink!
Your support is so important to our partners in
Brazil and around the world.

Thank you for attending
the 2011 HeartLink Gala.
With your help, we raised over
\$780,000 to support our partners
around the world. We simply could not
have done it without you!

Please enjoy photos from the Gala, now
available on our website at
childrensheartlink.org/gala2011

Sincerely,
Children's HeartLink

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Acreditamos que, com esse relacionamento sólido, duradouro, introdução de novos protocolos, e, de certa forma, a “internacionalização da equipe”, estamos no caminho certo de melhoria de qualidade no atendimento aos pacientes em nosso centro e esperamos em futuro próximo poder servir de modelo para outros centros do País que queiram se organizar e evoluir no atendimento à criança cardiopata.

A seguir, a íntegra do discurso:

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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