



Global **Heart** Network Platform

Cultivating Global Collaboration to Bring Cardiac Care to All Children in Need



Dear Friend,

Welcome to the **Global Heart Network (GHN)**. Across the globe, organizations work to bring medicine to those in direst need. They arrive in every hour of requirement and valley of the earth. Volunteers work 24 hours a day. These organizations' constituents must communicate effectively 7 days a week. The Global Heart Network packs the power of collaboration into a web-based platform. Make it yours: log on.

The seed of the network was a question I posed during my Master's Research, completed at the University of San Francisco. Eighty four organizations were asked, "Is there a need for greater collaboration to serve the pediatric cardiac community?" The overwhelming response from the survey participants was yes. The GHN platform answers the cries for collaboration.

Join the initiative. Support the platform. Honor the lives taken by cardiovascular disease. This project is dedicated to the children who knew cardiovascular disease too well, especially Oscar, Elise, Mohammed, and Chekihou. Welcome to your network; we've been expecting you.

Yours,



Annabel Lavielle
annabel@globalheartnetwork.net
Tel: 1 415 832 0653

The Global Heart Network

What is It?

The **Global Heart's Network's** vision is a world where every child who requires heart surgery, wherever they are in the world, is able to undergo quality treatment with dignity.

Our **mission** is to:

- To unleash a new era of collaboration in global humanitarian efforts in cardiac care
- Develop and sustain the Global Heart Network Platform (GHNP), a servicing platform dedicated to the task of fostering collaboration amongst organizations and individuals who work to provide cardiac care to under-served regions
- Support service optimization to help solve the inequity of pediatric cardiac care worldwide
- Decrease the rate of child mortality
- Create a movement of international cooperation that will minimize resources and maximize cooperation with each stakeholder in the value chain

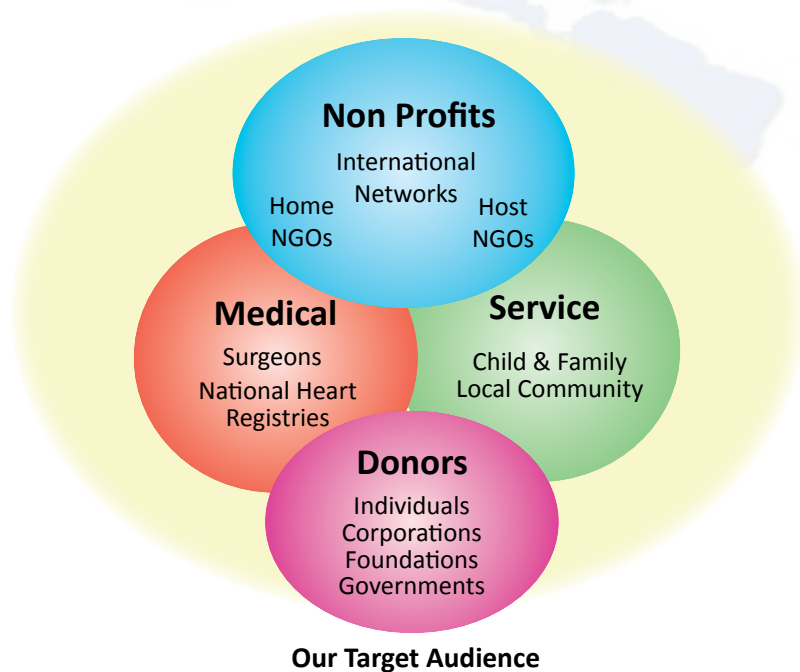
The **Global Heart Network** is unique in that its focus is to serve the organizations and individuals working in pediatric cardiac care in the developing world. It is also unique in that it is not in competition with any other group searching for scarce financial resources. It is through this non-traditional and innovative route that we hope to encourage collaboration amongst organizations.

The Global Heart Network

Who Do We Serve?

The primary means for realizing our goal is the development of the **Global Heart Network Platform**. This platform is dedicated to the task of helping organizations collaborate more effectively and more efficiently. The GHNP will operate as a clearing house and information repository, thus creating a more uniform approach to providing quality cardiac care to children in under-served areas.

The GHNP serves all stakeholders in the value chain. It will connect nonprofits to other nonprofits (working in the same or similar areas); to the medical corps who work with the nonprofits; to service providers (e.g., local hospitals, medical providers) and to service recipients (e.g., families who are seeking assistance, expertise and treatment for the children), and to donors whose funds support the good work of NGOs.



The Problem:

The Prevalence of Pediatric Cardiac Cases in the Developing World

Consider these facts:

- “Congenital heart defects are the most common form of birth defect, occurring in 4-8 per 1,000 live births” *March of Dimes Global Report on Birth Defects*
- Congenital heart defects are the leading cause of birth defect-related deaths in all nations.
- Over 50% of children born with heart defects will require at least one invasive surgery.
- Early detection and treatment can save the lives of the vast majority of children with congenital heart defects.

Diagnosed early,
congenital heart disease is almost
100%
treatable

But this is also a fact:

“Acquired heart diseases in children affect the heart after birth and tend to be more prevalent in the developing world than in the developed. Lack of support for encompassing public health programs or prevention of cardiovascular disease is a major factor.”

- Children’s HeartLink Report: *Linked by a common purpose: Global efforts for improving pediatric heart health.*

The Range of Global Inequality in Cardiac Care

“Every year, approximately 90% of more than 1,000,000 children who are born with congenital heart disease around the world receive sub-optimal or no access to care.”

– Neirotti, R., 2004, Paediatric cardiac surgery in less privileged parts of the world. *Cardiology in the Young*, 14, 341-346.

Although there are approximately 4000 cardiac surgical centers in the world, they are distributed unevenly. Here lies the problem: While heart defects affect children from all nations there are vast inequities to the extent to which countries are able to provide their affected children with quality cardiac care. This graph shows the number of cardiac surgical procedures per million people in various regions of the world (1997).

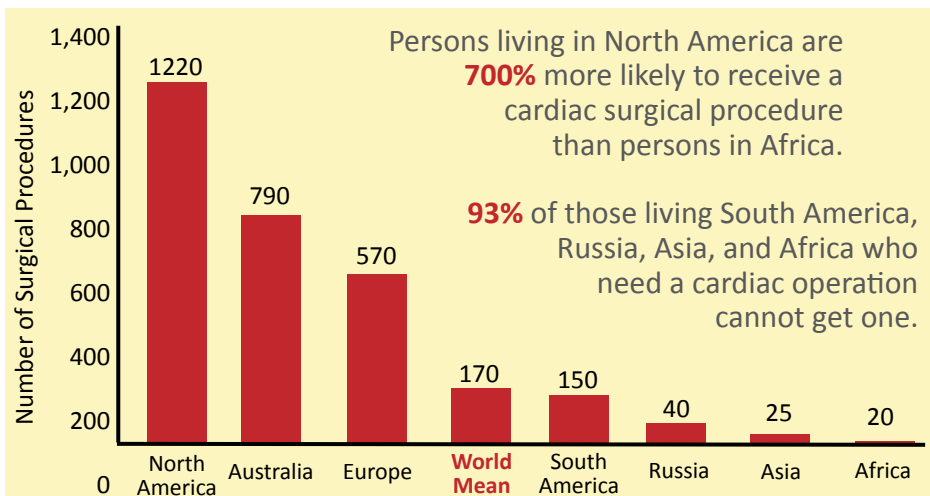


Figure 1. Number of Cardiac Surgeries by Geographic Region. Entries consist of number of surgeries per million. Adapted from Unger, F. (1997). Worldwide survey on cardiac interventions, *Cor Europaeum*, 7, 128-46.

The Range of Global Inequality in Cardiac Care

Global Access to Quality Cardiac Care



The problem of global inequality in cardiac care is impacted by:

- Fewer facilities to treat pediatric heart disease
- Shortage of trained pediatric cardiac specialists
- Prohibitive costs of cardiac treatment
- Shortage of health care workers
- Lack of basic health care
- Lack of investment in public health sectors
- Competing priorities to health care
- Migration of health care workers to developed countries

Solving the Problem: *A Web-Based Platform for International Collaboration*

There are over 80 world organizations that devote at least part of their efforts and resources to providing access to quality cardiac care for children in under-served areas. Yet we face a paradox: While collaborative solutions are central to the work of nonprofits, there is a stunning absence of collaboration among nonprofits working in the field.

While organizations want to collaborate, they are often in competition for scarce resources. While the actions of innovative donors and particularly effective nonprofits may temporarily improve matters in particular places and time, such fragmented and individual efforts are unlikely to create the type of long-lasting reform that is urgently required. How can small, non-collaborating, unaccountable and underfunded nonprofits create workable solutions for this large-scale problem?

Our research shows that there is a need for a new collaborative approach to philanthropy and nonprofit work – one that will create conditions for innovation and integration of services.

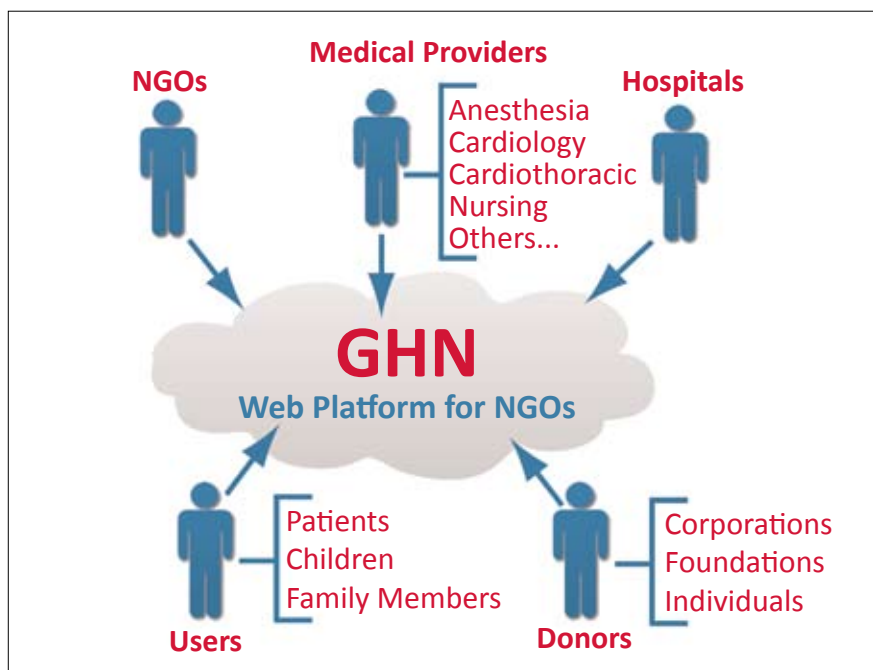


The **Global Heart Network Platform** provides a vehicle in which stakeholders can coordinate their expertise in order to more efficiently provide cardiac care for under-served children.

The Global Heart Network Platform

The **Global Heart Network Platform** will provide a centralized portal and resource for fostering communication, disseminating knowledge, storing and accessing data bases, coordinating services, fundraising, and collaborating on projects that benefit children in need of cardiac care.

The Global Heart Network Platform



The GHNP will function as a clearinghouse where stakeholders can gain access to people, knowledge, databases and other resources needed to actualize their missions.

Benefits of the Global Heart Network Platform

“In the long history of humankind (and animal kind, too) those who learned to collaborate and improvise most effectively have prevailed.” - Charles Darwin

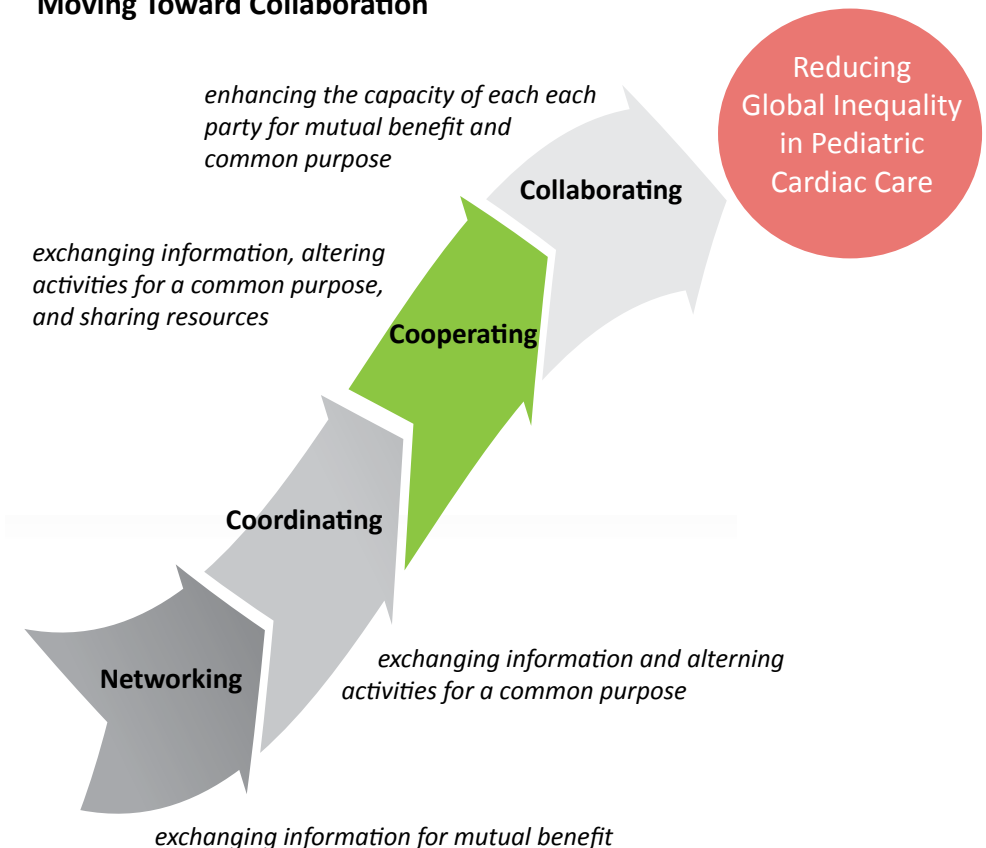
Collaboration is key. Throughout the globe, NGOs, government agencies, hospitals, service providers, and transportation services, operate more or less in isolation from each other. As a result, they are unable to coordinate their efforts to deliver the highest quality services to children in need. Against this backdrop, the benefits of the GHNP are numerous:

- **Work together**, and stop working in silos. The GHNP will operate as a nerve center to help coordinate the work surgeons, organizations and all those in the stakeholder chain
- **Improve efficiency**, and optimize the impact of service on a global level
- **Improve collaboration** within the industry between all stakeholders
- **Help medical corps** learn the ways in which nonprofits can help them advance their mission
- **Raise awareness** of heart disease on a global level
- **Create single source capability** for organizations to share information
- **Document and disseminate** best practices
- **Create rules of engagement**
- **Create best strategies** for the provision and delivery of care
- **Establish links and networking** to exchange ideas
- **Develop new ways** to provide better utilization of available resources

Moving through the Partnership Continuum

Ultimately, the goal of the **Global Heart Network Platform** is to effect change in reducing global inequality in access to pediatric cardiac care through collaboration. Typically, collaboration develops slowly and assumes a series of intermediate forms over time. The GHNP will provide the vehicle through which organizations can move through these steps smoothly to achieve their individual and collective missions. In so doing, they will increase their capacity to maximize care while minimizing competition for scarce resources.

Moving Toward Collaboration



Adapted from: Himmelman, A. (2001). On coalitions and the transformation of power relations: Collaborative betterment and collaborative empowerment, *American Journal of Community Psychology*, 29(2).

THE GLOBAL HEART NETWORK PLATFORM

A Quick View

MEDICAL PROVIDERS

- Post and share case knowledge in public and private forums
- Connect with members participating NGOs/organizations
- Consult with medical personnel in emergency situations
- Post and organize events and meetings

NGOs

- Create groups and members
- Connect with other NGOs and their members
- Post updates on public walls
- Start threads in forums
- Connect users with medical personnel and donors
- Share information

Patients and Families

- Gain assistance obtaining information, treatment, financial assistance
- Search and connect with NGOs, providers, and donating firms
- Receive benefits in funding medical treatments

Donors

- Participate in relevant activities within NGOs
- Gain information about NGO operations
- Connect, share, schedule meetings with NGOs, medical providers, users



The **Global Heart Network Platform** will act as central point of contact connecting NGOs from around the world who participate in providing cardiac care services, medical providers, donors who fund such organizations, service recipients (patients and families) from under-served areas.

MEMBER FORUMS

SEARCH ENGINE

Search internal database for NGOs, information, medical providers, financial assistance, etc.

LOGIN

UPDATES POSTED BY MEMBERS

Updates and links about relevant news, events, meetings, donor sources, information, new research and findings, procedures, best practices, and so forth.

OTHER LINKS



Webpage design by Piixeliit (www.Pixeliit.com).

Assessing the Need for a Global Heart Network Platform

What Do International Organizations Say?

Is there a need for the Global Heart Network Platform? To answer this question, we surveyed an international sample of nonprofit organizations and NGOs who provide pediatric cardiac services to children from under-served populations. The purpose of our survey was to answer the following questions:

- Do existing organizations involved in pediatric cardiac care perceive a need for a web-based platform to serve the pediatric care community?
- Would existing nonprofits and NGOs use such a platform if it were developed?
- What sorts of functions should such a platform perform?
- What obstacles must be surmounted in order to launch such a platform?

We developed 28-question survey and sent it to 84 organizations working in the area of pediatric cardiac care around the globe. Forty-seven (55%) of these organizations participated in the survey. The survey questions are contained in Appendix A.

Nature of the Sample

Responding organizations included nonprofit charities (77%), government and health organizations (11%), membership-based nonprofit associations (8%), and limited profit organizations pursuing a social purpose (2%). A full list of the responding organizations is provided in Appendix B.

Of the representatives who completed the surveys:

- 51% were Executive Directors of the organization,
- 25% were Board Members,
- 13% were Founders
- 11% were employed in Operations.

The following contains a summary of our analyses of key research questions.

Strategies for Delivering Treatment

What is the primary way in which pediatric care organizations deliver their services? As indicated in Figure 2, 36% of the organizations train physicians and staff; 26% send surgical teams to developing countries, and 24% create regional cardiac centers in developing countries. Finally, 14% transport children in need of pediatric care to other countries for treatment.

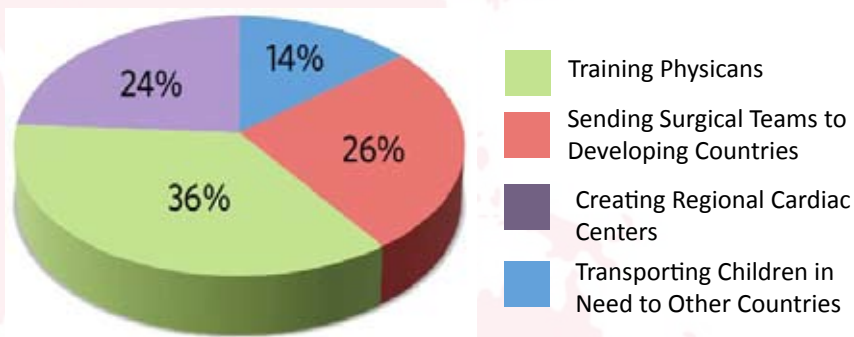


Figure 2. Strategies by Which Sampled Pediatric Cardiac Care Organizations Deliver Treatment

Responses to interview questions indicated that, relative to the goal of producing large-scale change, respondents viewed the task of transporting children in need of pediatric care to other countries as the most onerous and least effective method for creating a workable solution on a global scale.

Geographical Areas Served by Sampled Organizations

The various organizations sampled participated in a total of 231 different programs across the nations that they served. The primary focus of these programs included Africa (75 programs) and Asia (66 programs). Figure 3 identifies percentage of total programs that were allocated to various geographical areas around the globe.

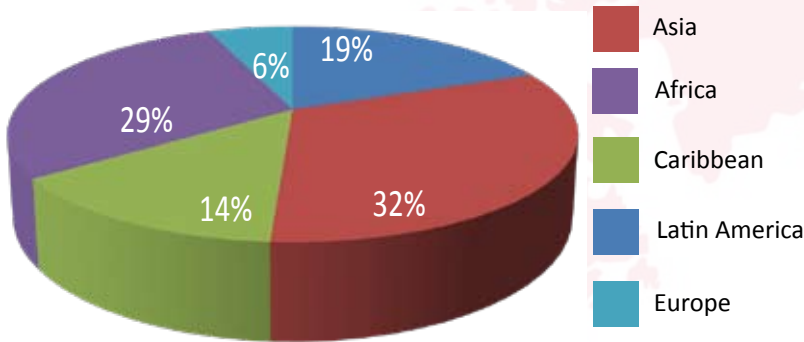


Figure 3. Geographical Areas Served by Programs Offered by Sampled Organizations

Is there overlap within nations in the services provided by sampled organizations? The number of programs providing services in each particular nation served was calculated. The number of programs serving particular nations ranged from one (36 nations) to nine (1 nation). The mean number of programs per nation was 2.6 with a median of 2 per nation.

While many nations had only a single program providing pediatric services, most nations had more than one program. A weakness to this research is that it is not known whether or not these organizations know of each other. Nonetheless, the data suggests the strong possibility of duplicating services. This may be remedied through greater coordination and collaboration.

Do Organizations Want a Global Heart Network Platform? Would They Use It?

“If you build it, they will come.”

– Field of Dreams (1989)

If we build it, will they come? The answer is a resounding “yes”.

Twenty six of the 47 respondents (55%) stipulated that it was extremely important to network with other organizations (mean rating=4.2 on a 5-point scale; median=5). When asked if they perceived a need for a web-based program to unite pediatric care organizations, respondents were overwhelmingly positive. They also indicated that they would use such a platform if it were available. The mean ratings for both of these questions were 4.0; the medians were 4.

Most respondents commented on the value of networking:

“My belief is that we MUST coordinate or there is a resultant intrinsic waste of resources, and areas left unresolved.”

“We pursue collaboration whenever possible to reduce duplication of services and to maximize synergy and progress toward shared or complementary goals.”

“I think we absolutely need such a tool having been in a hospital in Laos with two groups at the same time one from US and one from Japan.”

Only 2 comments out of 47 were less supportive:

“Initially, this would have been a “5”. However, we have found significant “networking” between NGO’s to be virtually impossible to accomplish and institute.”

“Organizations will not cooperate, they are too parochial, mostly about their inability to remove their own egos versus the world needs of delivery of cardiac care”

The Content of the Global Heart Network Platform

What type of content and resources should the GHNP offer?
Respondents indicated that their choice of resources are:



Figure 4. Ideal Contents of the Global Heart Network Platform as Endorsed by Pediatric Cardiac Care Organizations Based On Research Findings (2010)

The Power and Potential of the Global Heart Network Platform

“There is unanimous and passionate interest in the platform”

“This sounds like a great initiative and it is my pleasure to take part...”

“This is a project near and dear to my heart...”

– Responses from Research Participants

Participants in this research expressed interest in three basic types of content:

First, it should provide an **Interactive Forum** in which stakeholders could forge *partnerships* and share *best practices*; view *calendars* of upcoming and annual events, engage in *discussion forums*, and otherwise build coalitions with other related organizations and individuals.

Second, it should function as a **Dynamic Repository of Knowledge**, including *directories* listing related organizations and field-related resources, information about cutting-edge *scientific and expert knowledge*, current cardiac-related *news*, information about *human resources* and the operation of nonprofits.

Third, it should be an actual **Operational Vehicle** through which they could develop their organizations and perform tasks related to their organizational mission. These would include such functions as identifying and making contact with *fundraising* sources, participating in and providing *online training*, and engaging in *advocacy* work.

Additional Functions Identified by Pediatric Care Organizations

Through their open-ended commentary, respondents identified a series of additional functions that may be served by the development of a web-based platform. These include:

- **Scheduling and Monitoring.** Providing access to schedules of other organizations, their missions and operations at any given time
- **Networking.** Linking together independent work groups; parental online networks and discussion boards; directories of individuals who can expedite diverse processes
- **Using Social Media.** An increasingly necessary vehicle for networking, raising awareness and gaining visibility
- **Creating Databases.** Listing hospitals; integrating patient records; assessing strengths and challenges of local hospitals; providing directory of medical centers and physicians; housing subdirectories for particular geographical locations or programs
- **Publishing.** Serving as a publication forum; housing resources related to the *World Journal for Pediatric and Congenital Heart Surgery*; inspiring and supporting the development of new journals
- **Notifying Members of Equipment Availability.** Providing notices on available equipment or exchangeable equipment

Appendix A:

Questions Used in the Survey

The following questions were used in the context of an online survey. For most questions, participants were provided with a series of responses and were asked to indicate their response. For many questions, participants were asked to indicate responses using a five point rating scale. All questions provided the opportunity for participants to provide open-ended responses for qualitative analysis.

1. What is your organization type (NGO, nonprofit, etc.)?
2. Which of the following are your organization's primary strateg(ies) for delivering treatment (training; creating cardiac centers, etc.)?
3. Please name each country your organization has served in 2009 and 2010.
4. How many years has your organization been in existence?
5. Background of founder(s) (surgeon, philanthropist, etc.)?
6. What is your organization's 2009 annual budget in US dollars?
7. Please rate how important it is to network with other organizations working in pediatric cardiac care.
8. Please state if you are part of any national and international networks in pediatric cardiac care (choices provided).
9. Please rate the importance of the following ways of interacting with other organizations working in pediatric cardiac care (networking, coordinating, cooperating, collaborating).
10. What conferences do you attend throughout the year where you have the opportunity to meet other organizations in the field of pediatric cardiac care?
11. To what degree do you feel there is a need for web-based platform and to what degree would you use a web-based platform to unite organizations working in the field.
- 12- Rate the importance of **Focus Areas** for a web-based platform:
28. **Advocacy** (lobbying; coalition building, etc.); **Directories** (NGOs; international associations, etc.) , **Networking** (partnerships; best practices, etc.); **Fundraising** (strategies; donor information, etc.); **Managing Human Resources** (processes and policies; recruitment, etc.); **Education and Training** (programs; conferences, etc.); **News** (newsletters; press releases, etc.); **Calendar** (events, etc.); **Logistics** (sourcing supplies; managing inventory, etc.); **Scientific/Expert Knowledge** (research news; publication archive, etc.); **Other**

Appendix B:

Organizations Participating in the Survey

- | | |
|---|---|
| <ol style="list-style-type: none"> 1. Adult Congenital Heart Association 2. African Heart Network 3. Archiving Working Group 4. Arrhythmia Alliance 5. Children's Hospital Boston 6. CardioStart International, President 7. CardioStart International, Board Member 8. Chain of Hope 9. Children's Cross Connection International 10. Children's HeartLink 11. East Meets West Foundation 12. Emory University 13. Friends of Aldo Castaneda Foundation 14. Gift of Life – Regalo de Vida El Salvador 15. Gift of Life India 16. Gift of Life International 17. Global Healing 18. Haitian Hearts 19. Healing Hearts India 20. Heart Children New Zealand 21. Heart to Heart International Children's Medical Alliance 22. Heart Trust, Inc. 23. Heartbeat International Foundation 24. Heart Gift Foundation 25. Humanitarian Association "Coeurs pour tous" | <ol style="list-style-type: none"> 26. International Cardiovascular Health Alliance (ICHA) 27. International Children's Heart Foundation 28. International Hospital for Children 29. La Chaine de l'Espoir 30. Le Coeur sur la Main 31. Loma Linda University 32. Mecenat Chirurgie Cardiaque Enfants du Monde 33. Medical Mission Exchange 34. Monash Medical Centre 35. Physicians for Peace 36. Preemptive Love Coalition 37. Rotary District 7980 Gift of Life Foundation 38. Save a Child's Heart 39. Seapc Touching Hearts 40. Surgeons of Hope Foundation 41. Team Heart, Inc. 42. University of California San Francisco 43. Variety Children's Lifeline 44. VinaCapital Foundation 45. World Heart Foundation (President) 46. World Heart Foundation (Executive Director) 47. World Society for Pediatric and Congenital Heart Surgery |
|---|---|

Support the Global Heart Network

Help Us Build the Global Heart Network Platform



Dear Friend:

Our work at GHN is not possible without the passionate involvement of our network of supporters. GHN is a brand new organization in formation. We continue to look forward to energetic and shared support that leverage our resources and networks with others. Your gesture of support – in whatever form and at whatever level – including feedback as to the evolution of the project will be greatly appreciated.

With my heartfelt thanks,

A handwritten signature in blue ink that reads "Annabel".

Annabel Lavielle

annabel@globalheartnetwork.net

Tel: 1-415-832-0653

www.globalheartnetwork.net



Global **Heart** Network Platform