



International Outreach Program

To improve survival and quality of care
of children with cancer in countries with
limited resources

Raul C. Ribeiro, MD

August 23, 2013

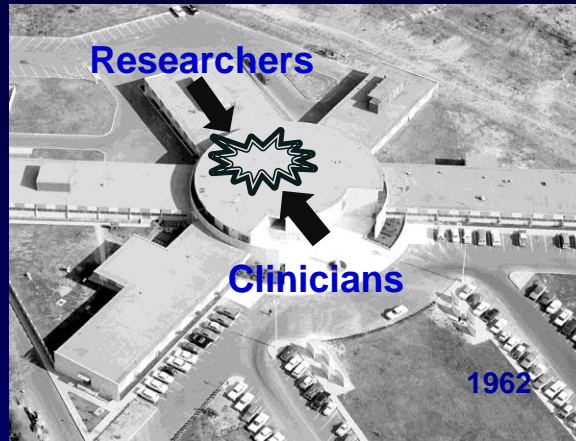
Outline

- Conceptual Basis of the St. Jude International Outreach Program
- Methodology for Implementing Sustainable Cancer Care in Low- and Mid-Income Countries
- Developing networks for improving survival and quality care in pediatric oncology

St. Jude Children's Research Hospital Model



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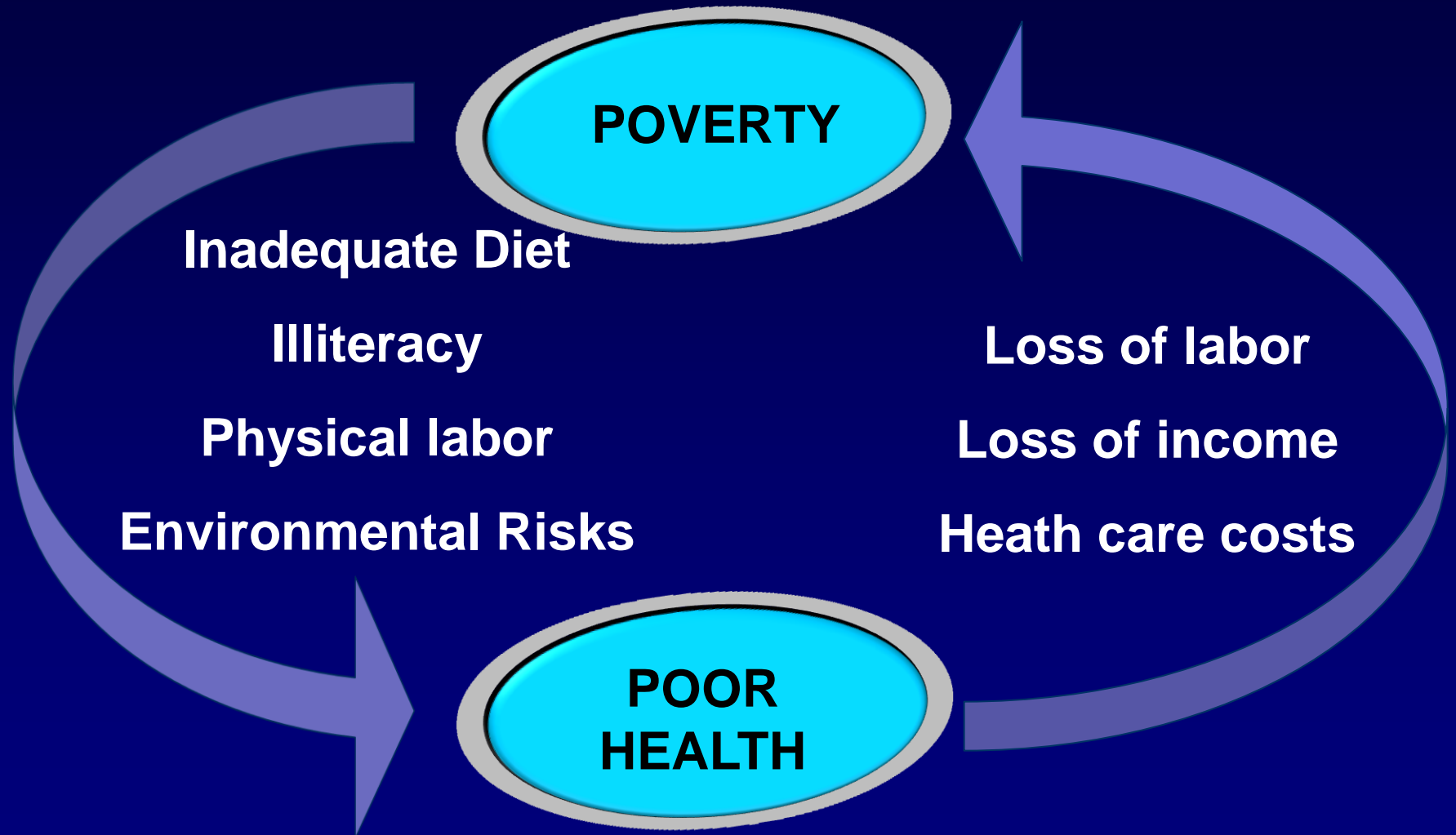


National Resource with a Global Mission

Principles

- No child should die in the dawn of life
- Finding cures, decreasing suffering
- Treatment based on evidence (research)
- No child should be denied treatment or treated differently based on the parents' ability to pay
- Long-term commitment to patients and families

Challenges: The Health Care Vicious Cycle in Countries with Limited Resources



St. Jude International Outreach Conceptual Basis

- Based on the St. Jude Hospital Model
- Consider the context
- Approach (cultural humility)
 - Developing non-paternalistic clinical and advocacy partnerships with communities on behalf of **defined populations**



Approach

“Humility helps us to understand the obvious truth: No one knows it all; no one is ignorant of everything. We all know something; we are all ignorant of something”

Paulo Freire

Cancer and other factors



Breaking the Vicious Cycle

- Integrated Management of childhood illnesses
- Support education and training of a broad range of health professionals
- Support of local mission-oriented individuals to produce changes in health care
- Support community groups

Model of Collaboration

Twinning Model

- Pediatric Hematology/Oncology Unit
- Emphasis on diagnosis and treatment
- Community support (grassroots Foundation)
- Communication with St. Jude
- Commitment to quality of care
 - Dedicated physicians and nurses
 - Full time program director (physician) and nurses
 - Building local capacity and sustainability
- Record keeping and hospital-based registries

Identifying and Supporting Leaders


Managers do things right, while leaders do the right thing(s).” -- Warren Bennis

- **Salary Supplementation**
 - **Physicians**
 - **Nurses**
 - **Others**
- **Continuing Education**
- **Network**

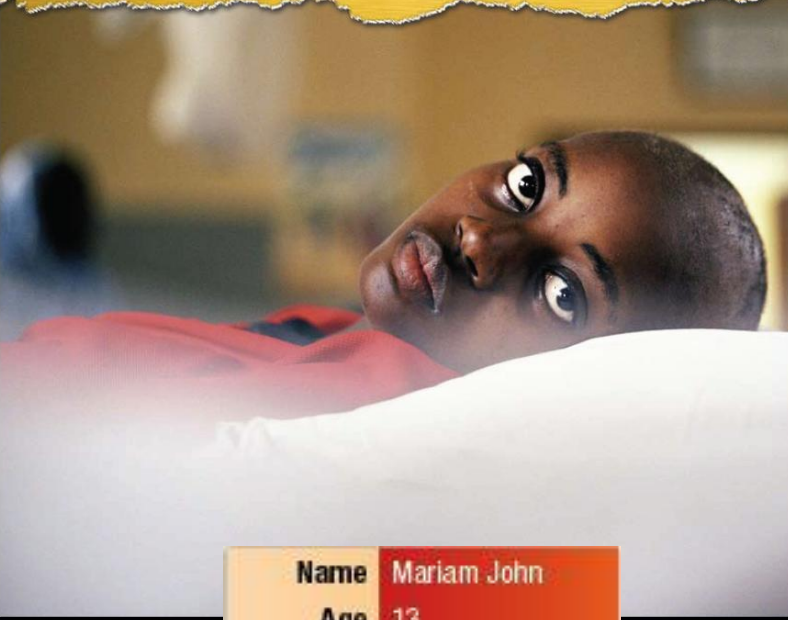
Characteristics of Treatment at St. Jude Partner Programs

- General
 - Correct diagnosis
 - Treatment guidelines based on medical evidence
 - Single arm observational study
 - Detailed data collection and ongoing analysis
 - Goals
 - Increase access to care
 - Reduce toxic death
 - Reduce abandonment
- } Improved Survival

Reducing Suffering

FACING THE FACTS #5  www.who.int/chp

SOLVING THE CHRONIC DISEASE PROBLEM

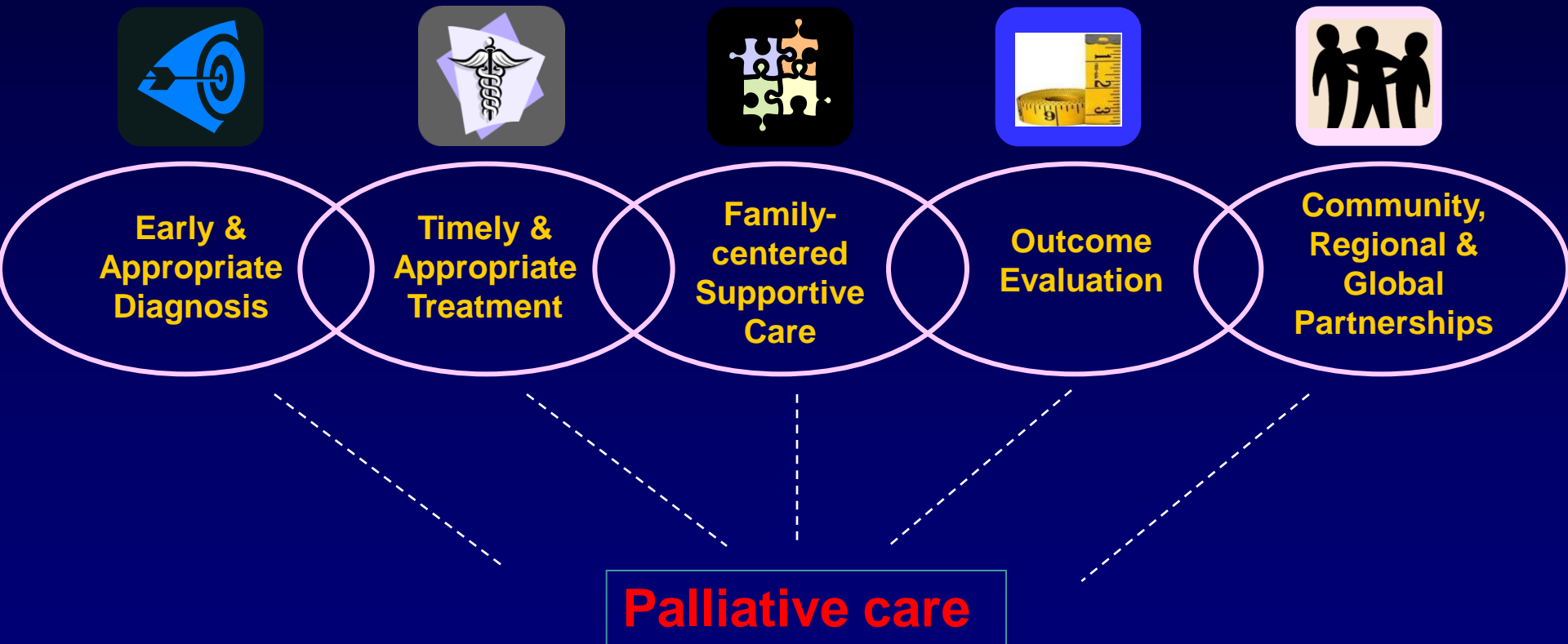


Name	Mariam John
Age	13
Country	United Republic of Tanzania
Diagnosis	Bone cancer



Palliative Care Embedded in Care Pathway

Essential Links to Improving Survival & Quality of Life for Children with Cancer

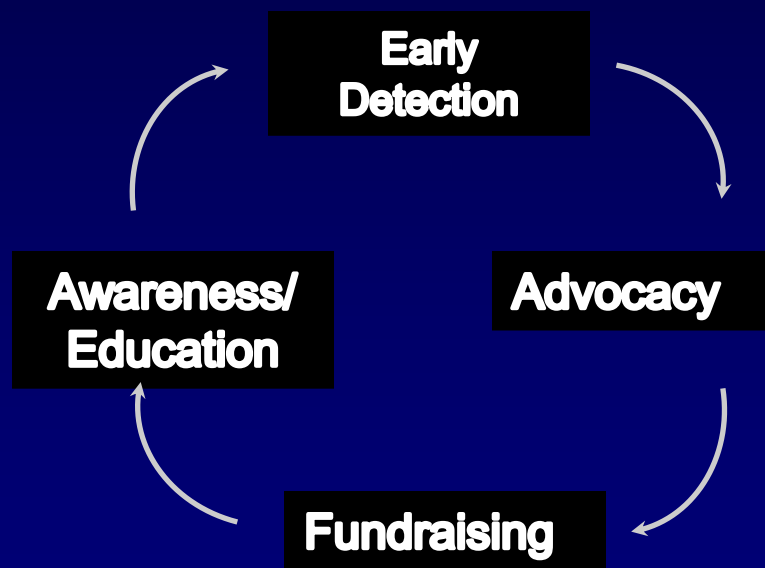


Care Delivery & Health System Strengthening

Catherine Lam, 2013

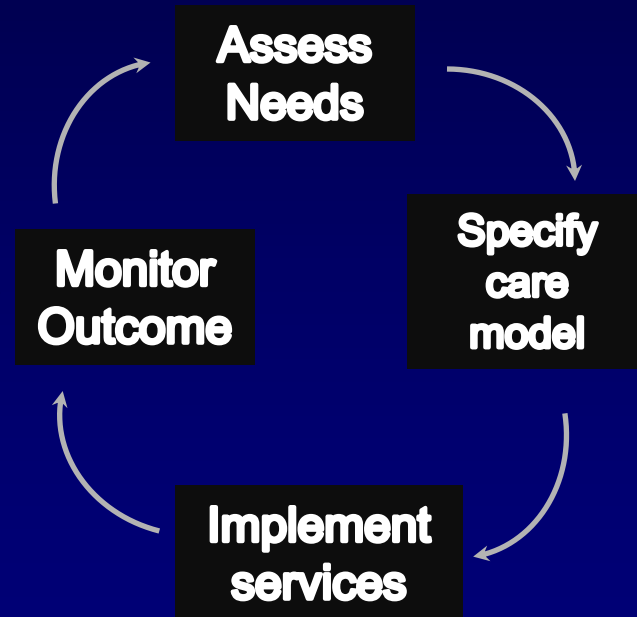
Integrating Community and Health Care in Pediatric Oncology

Community Engagement



Late Diagnosis
Abandonment
Lack of Access to Care

Health Care Delivery



Early Mortality
Relapse
Clinical Investigation

Data Collection and Analysis

- Critical component of our work
- Objective is to integrate data collection into patient care and registry (hospital and population based)
- Increase patient safety and system efficiencies

POND4Kids - Objectives

- **Store patient data** for easy retrieval and analysis in a way that assures quality control
- Provide **uniform data collection** to facilitate meaningful comparison of information among centers
- Provide a single tool for data storage and retrieval to facilitate **training of data managers**
- Develop a **multi-lingual** online system that is available to users at **no cost**

POND4Kids - Patient Summary Page

POND: St. Jude Children's Research Hospital Sign Out

[Home](#) | **[Records](#)** | [Reports](#) | [Exports](#) | [Preferences](#) | [Data-Shares](#) | [Site Admin](#) | [POND Admin](#)

[SJ Records](#) | [Search Patients](#) | [Browse All](#) | [New Patient](#)

[SJ Records](#) » Patient Summary

Full Name: _____ **Admission Date:** 06 Aug, 2003
POND ID: _____ **Patient ID:** _____ **Patient Cancer Diagnosis:** CNS Cancer
Gender: Male **Race:** latin **Birthdate:** 13 Aug, 2003

Summary

Diagnosis

PATIENT CANCER DIAGNOSIS

Disease	Diagnosed Date	Histology	Status
Neuroblastoma	10 Mar, 2004	Ganglioneuroma	On Therapy (06 Apr, 2004; 15:29)
CNS Cancer	02 Feb, 2004	Oligodendroglial-Anaplastic oligodendroglioma (WHO III)	On Therapy (06 Apr, 2004; 15:29)

QUICKFORMS

- [ALL Summary](#) (0)
- [complex test quickform](#) (0)
- [initial history test](#) (0)
- [MISPHO - TEST](#) (0)
- [New Test Quickform](#) (0)
- [Retino-Mexico](#) (0)
- [Retino-Mexico-Medication](#) (0)

VIEW/ADD FORMS

- [Registration](#)
- [History](#) (2)
- [Immunizations](#)
- [Vital Signs](#) (1)
- [Diagnostic Imaging](#) (0)
- [Physical Exam](#) (1)
- [Diagnosis](#) (2)
- [Labs](#)
 - [Bone marrow and immunophenotype](#) (1)
 - [Chemistry](#) (1)
 - [Hematology](#) (0)
 - [Microbiology](#) (0)
 - [Cerebralspinal Fluid](#) (0)
 - [Urinalysis](#) (0)

Customized "Quickform"

"Standard" Clinical

Protocol Builder

Home SJ Records Reports Exports Preferences Data-Shares **Site Admin** POND Admin

Site Admin Site Users Site Messages Quickforms **Protocols** Data Shares Site Data Backups

Site Admin » Protocols » Local Protocol Library » Protocol Segment » Events

Segment Name: test

Action #	Order	Day	Event type	Comments	Edit	Delete
1	1	3	Ceftazidime (Age Adjusted See Details)	ypepyq;p	Edit	Delete
2	1	4	Actinomycin-D Dose: 10.00 mg/m2, IV	ypepyq;p	Edit	Delete
3	1	5	Actinomycin-D Dose: 10.00 mg/m2, IV	ypepyq;p	Edit	Delete
4	1	6	Actinomycin-D Dose: 10.00 mg/m2, IV	ypepyq;p	Edit	Delete
5	1	7	Actinomycin-D Dose: 10.00 mg/m2, IV	ypepyq;p	Edit	Delete



*Sistema de vigilancia epidemiológica de cáncer
pediátrico para la ciudad de Cali, Colombia*



**Pediatric
Hemato/Oncologist**
Viviana Lotero MD
Ximena Castro MD
Margarita Quintero MD
MSc
Diego Medina MD
Carlos Andrés Portilla
MD
Oscar Ramírez MD MPhil

**Calí's Cancer
Registry**
Luis E. Bravo MD MSc
Luz Stella García MSc
Paola Collazos
Tito Collazos
Mariela Palacios
Juan Carlos Hernández
Julio César Guarnizo

Pathology
Roberto Jaramillo MD

Data managers
Mónica Lotero
Dilia

Advisors
Paula Aristizabal
(California
University)

Eva Steliarova-
Foucher
(IARC)

SPONSOR by "My Child Matters" & St. Jude IOP



Methods

- VIGICANCER - Childhood Cancer Outcomes Surveillance System- was established in January, 2009
- Supported by “My Child Matters” program and Cali’s Poblational Cancer Registry
- First pediatric cancer surveillance system in the country



Methods

- **Selection criteria:**
 - A child with new diagnosis of cancer
 - Treatment in a pediatric oncology facility in Cali
- **Information sources:**
 - Medical records
 - Pathology reports
 - Direct patient observation
 - Parent interviews
 - Death certificates



Methods

- Outcomes
 - Demographic and sociocultural variables
 - Cancer relapse
 - Death
 - Treatment abandonment
 - Secondary tumors
- Events were registered concurrently
- Follow-up every 3 months



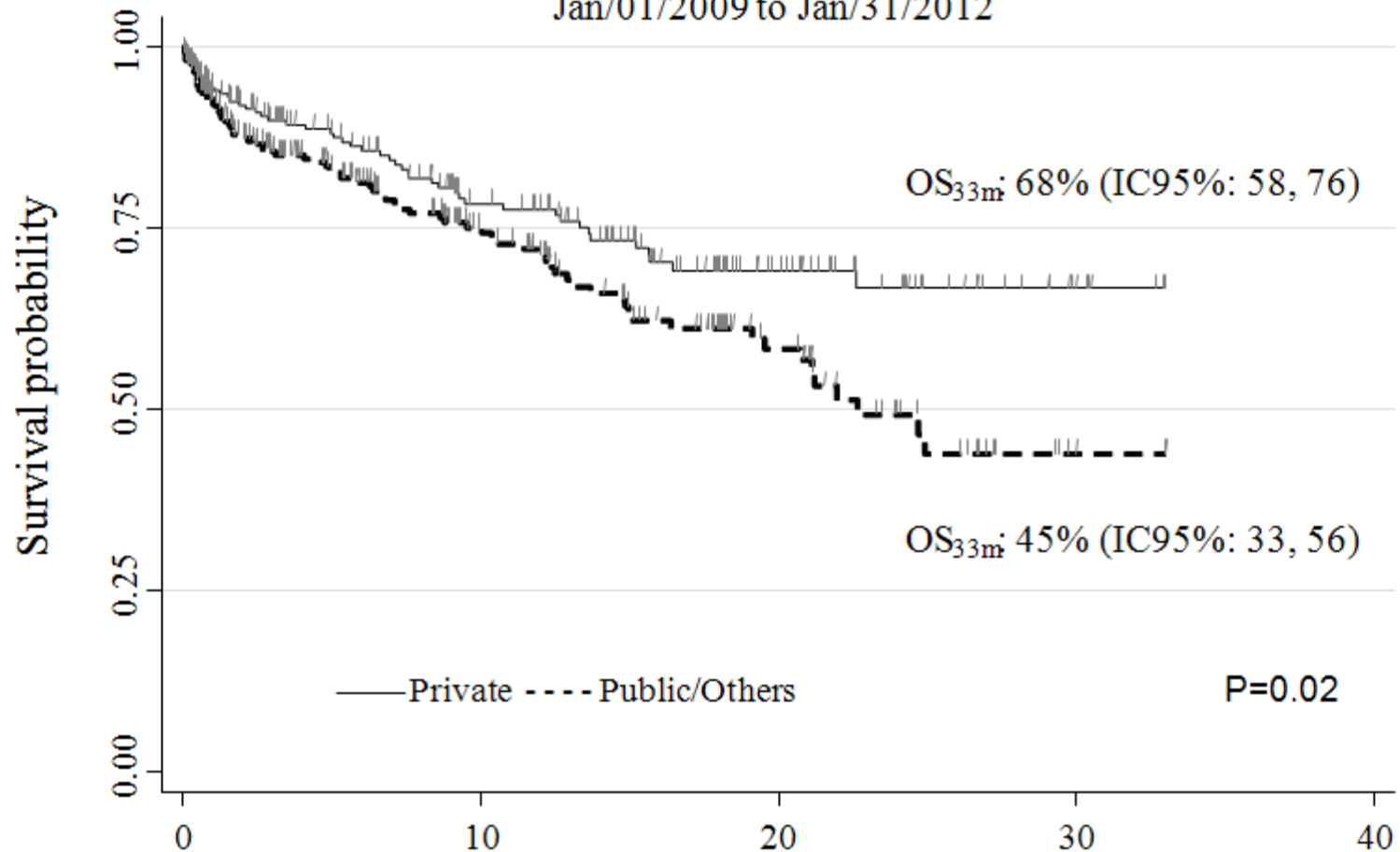
Results

- Data from 01/2009-01/2012
- Children (≤ 15 yrs) with cancer 619
- Followed-up 577
- Median age 6 yrs
- Males 54.9%
- Afrodescendants 17.6%



Childhood cancer overall survival in Cali, by health system insurance category

Jan/01/2009 to Jan/31/2012



Children >15 yrs, n=577

Time since diagnosis (months)

Abandonment of Therapy

- Multifactorial (economic, sociocultural, other)
- Varies from 1% to 40%
- Reduced in most of our partner sites, except Honduras that continue to be 11%
- Recife (35% to 0.5%)
 - Education
 - Financial support for the families
 - Rigorous monitoring of appointments
 - Missing appointment is considered a psychosocial emergency

Early Diagnosis of Pediatric Cancer

- In Recife in 2000, 70% of children with cancer admitted in the Pediatric Oncology at IMIP, were diagnosed with advanced disease
- The rate of death in the first 30 days of diagnosis was 35%

Early Diagnosis of Pediatric Cancer

Major causes of Delayed Diagnosis

- Lack of information and knowledge about children cancer by the community and physicians
- Difficulty of access to quality health care
- Fast growing tumors

Early Diagnosis of Pediatric Cancer

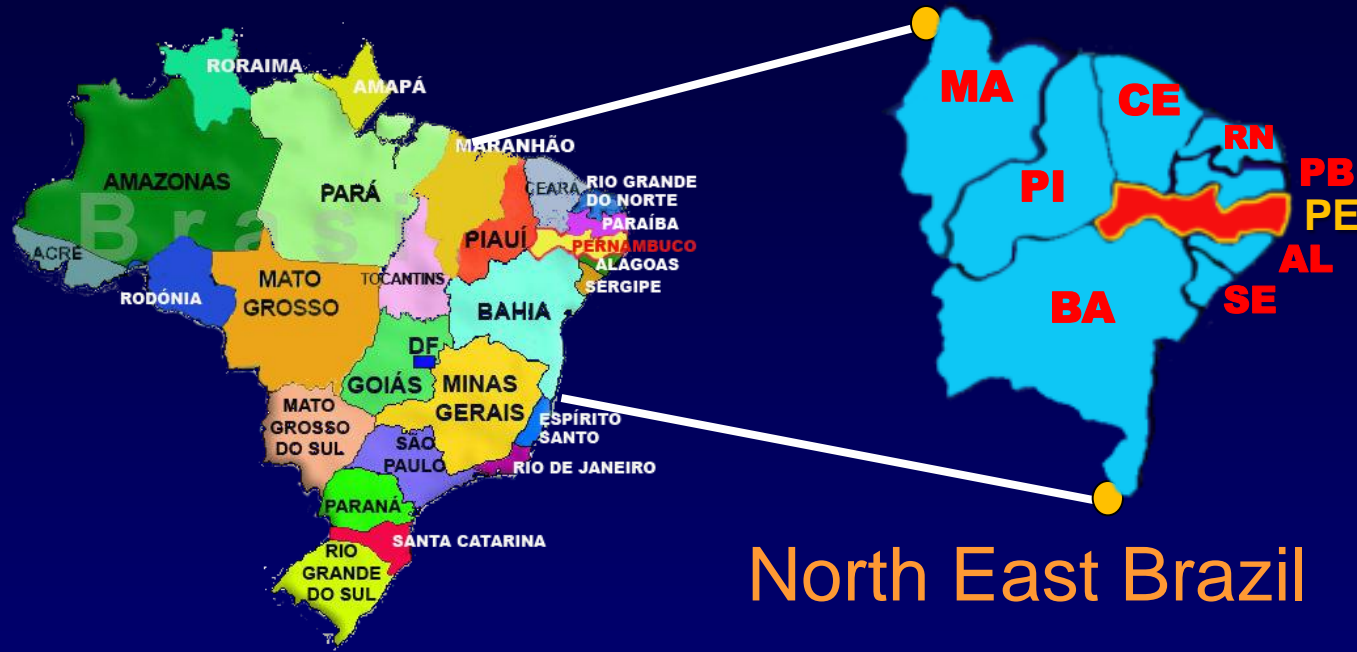
Program Phase I

2002 – Program Start

IMIP / CEHOPE / St.JUDE / NACC

- Methodology: Contact the Health Secretaries/PSF Coordinators
- Presentation of a plan to inform health care professionals about pediatric cancer

Early Diagnosis of Pediatric Cancer



North East Brazil

Number of municipalities in Pernambuco:

184 + One territory (Fernando de Noronha)

Population < 20 anos - 3,182,007

Expected Cases per Year - 420

Source: <http://estados.ibge.gov.br/estadosat/perfil.php?sigla=pe>

Early Diagnosis of Pediatric Cancer

“Training health-care workers of all levels with simple and relevant information, so that lives can be saved”

“This framework rejects both the figure of “**the expert**” who possesses the knowledge and holds the authority and **the relativistic position** of “anything goes” that does not seek the egalitarian inclusion of all”

Community Health Resources



Early Diagnosis of Pediatric Cancer

Educational Program for the Community Health Workers

- Application of Pre test and Post test
- Epidemiology Cancer Children and Youth
Signs and Symptoms
- Logistics of reference: where, how, who
to consult.
- Contra-Reference

fechar

imprimir



INSTITUTO DE MEDICINA INTEGRAL PROFESSOR FERNANDO FIGUEIRA - IMIP
CENTRO DE HEMATOLOGIA E ONCOLOGIA PEDIÁTRICA - CEHOPE

RE: PEDRO HENRIQUE ANGELIM (2012-12-189)

Recife, 13 de Dezembro de 2012.

A Policlínica na COAB de Massangano - Petrolina/PE
Prezada Dra. Etelvina Araújo

Admitimos o menor acima, 9 anos de idade, com história de que em novembro de 2011, o mesmo sofreu pequeno trauma em r. frontal esquerda, evoluindo com hiperemia e nodulação local. Inicialmente, foi atendido pela colega, na Policlínica na COAB de Massangano, que prescreveu ibuprofeno e medicação tópica com melhora parcial. Em fev/12, sofreu novo trauma (ferida corto-contusa) sobre mesma região frontal esq, procurou Hospital da UNIMED em Juazeiro na Bahia, realizado Rx de crânio: normal e prescrito azitromicina. Evoluiu com cicatrização da ferida, porém com permanência da mancha hiperemiada com relevo em r. frontal. Em agosto de 2012, iniciou quadro de fortes dores em membros (ósseas), fez uso de Naproxeno, sem melhora dos sintomas. Em 06/09/12, solicitado por neurocirurgião, RNM de crânio: "Presença de dois processos expansivos envolvendo partes moles extra-cranianas em região frontal bilateralmente, sendo de maior dimensão no lado esquerdo. Esta lesão oblitera a gordura do subcutâneo e entra em contiguidade com a calota craniana", realizou também Cintilografia óssea: revelando padrão heterogêneo da distribuição do radiofármaco com lesões osteolíticas", fez uso de prednisona com melhora temporária das dores ósseas. Em 12/11/2012, realizou biópsia da lesão da fronte, cujo histopatológico revelou: "Lesão de pele consistente com neoplasia blástica de células dendríticas plasmocitóides, sendo encaminhado ao nosso Serviço para avaliação. Apresentava astenia e piora das dores ósseas em membros, EGR, com lesão cicatricial com centro enegrecido em região frontal esquerda, colhido mielograma que evidenciou medula óssea com 21% de células imaturas e indiferenciadas. Paciente confirmado com diagnóstico de Leucemia de células dendríticas plasmocitóides.

Nosso plano terapêutico será com quimioterapia sistêmica por um período de 2 anos e 6 meses, com prognóstico de cura em torno de 60 a 70%.

Agradecemos à confiança em nosso Serviço e nos colocamos à disposição para informações adicionais.

Atenciosamente,

DR(A).: LILIAN CAROLINE DE MELO MOREIRA - CRM: 18989
Oncologista Pediátrica
Serviço de Oncologia Pediátrica IMIP/CEHOPE



PROGRAMA DO DIAGNÓSTICO PRECOZE DO CÂNCER INFANTIL (Fluxograma do Atendimento)



Informações (81) 3267-9200 – 2101-8100

INSTITUIÇÕES:



Early Diagnosis of Pediatric Cancer

- **Before 2008, ACS were selected by indication and received U\$150 per months. The profession was not regulated and had no career pathway**
- **From 2009, the ACS were selected by merit and the salary increased to U\$ 300 month. The Health Secretariat include as career pathway**

Early Diagnosis of Pediatric Cancer

- Visit health regions - 12 (185 municipalities)
- Training program for 1 day for each municipality
- Classes for upper level professionals: Doctors, Nurses, Dentists, Social Workers, and others
- Classes for professionals of medium level: Health Workers, Nursing Assistants and Dental Assistants.

Early Diagnosis of Pediatric Cancer

REGION	MUNICIP	%	SUPER	MEDIO	REFER	TUMOR
R. M DO RECIFE	5	15	331	1209		
ZONA DA MATA	6	7	159	402		B=100
AGRESTE	29	41	766	2772		
SERTÃO	17	28	380	852		M=157
TOTAL	57		1636	5235	424	257



Early Diagnosis of Pediatric Cancer

- In 2013 signed a technical cooperation agreement with the Departments of Health and Education of Pernambuco State transforming the project into an official government program covering the entire state.
- Target 21,000 Health Professionals and 8,000 Education Professionals (Multipliers of Information).

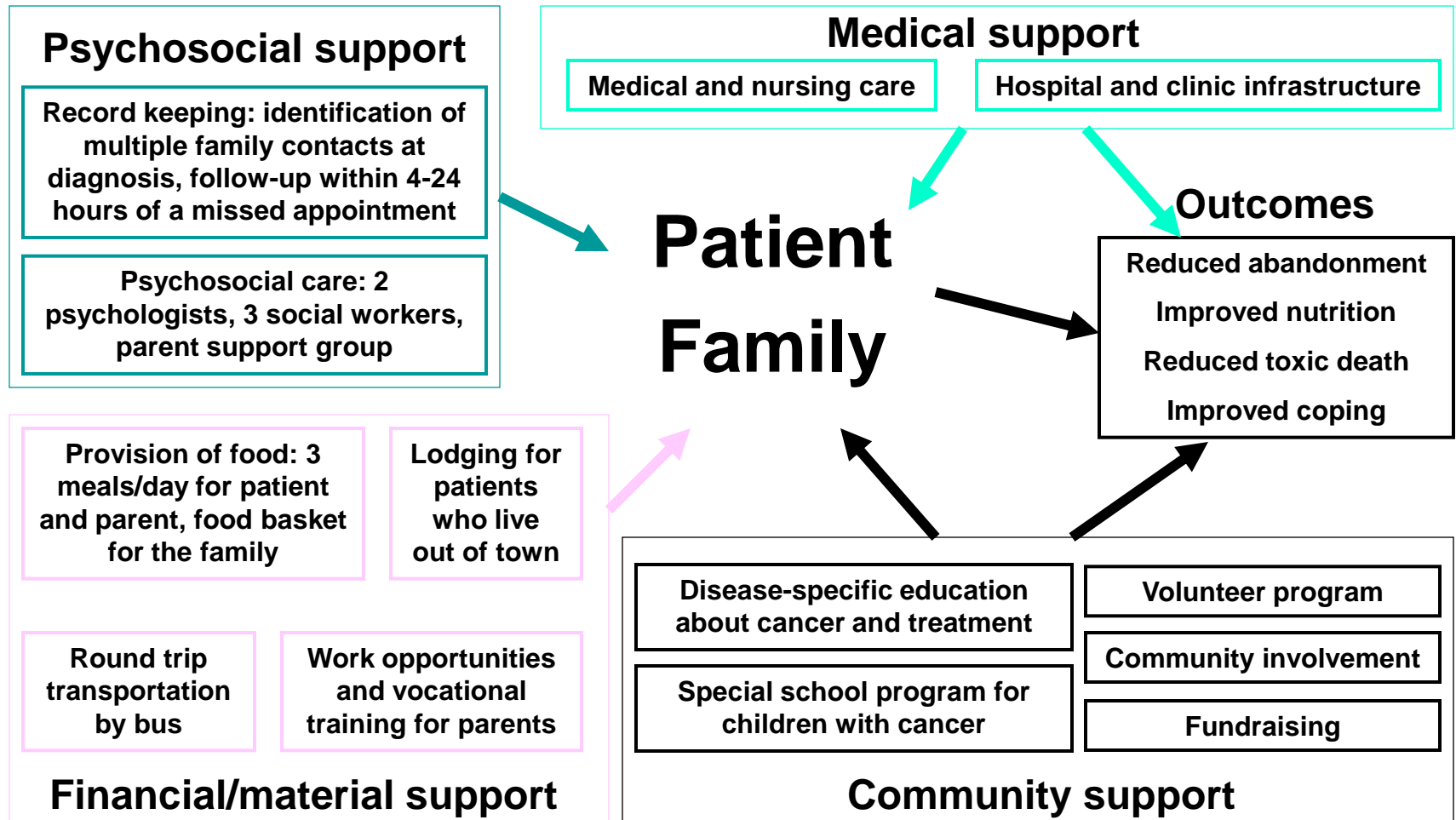
Early Diagnosis of Pediatric Cancer



Alliances



Comprehensive Support



Improved hospital infrastructure



- Infection control
- Pediatric cancer ICU
- Dedicated oncology pharmacy
- Dedicated pediatric oncology nurses
- Electronic Medical Records



LLA - RECIFE

LLA-RE 2005

Óbitos Precoces < 30 dias

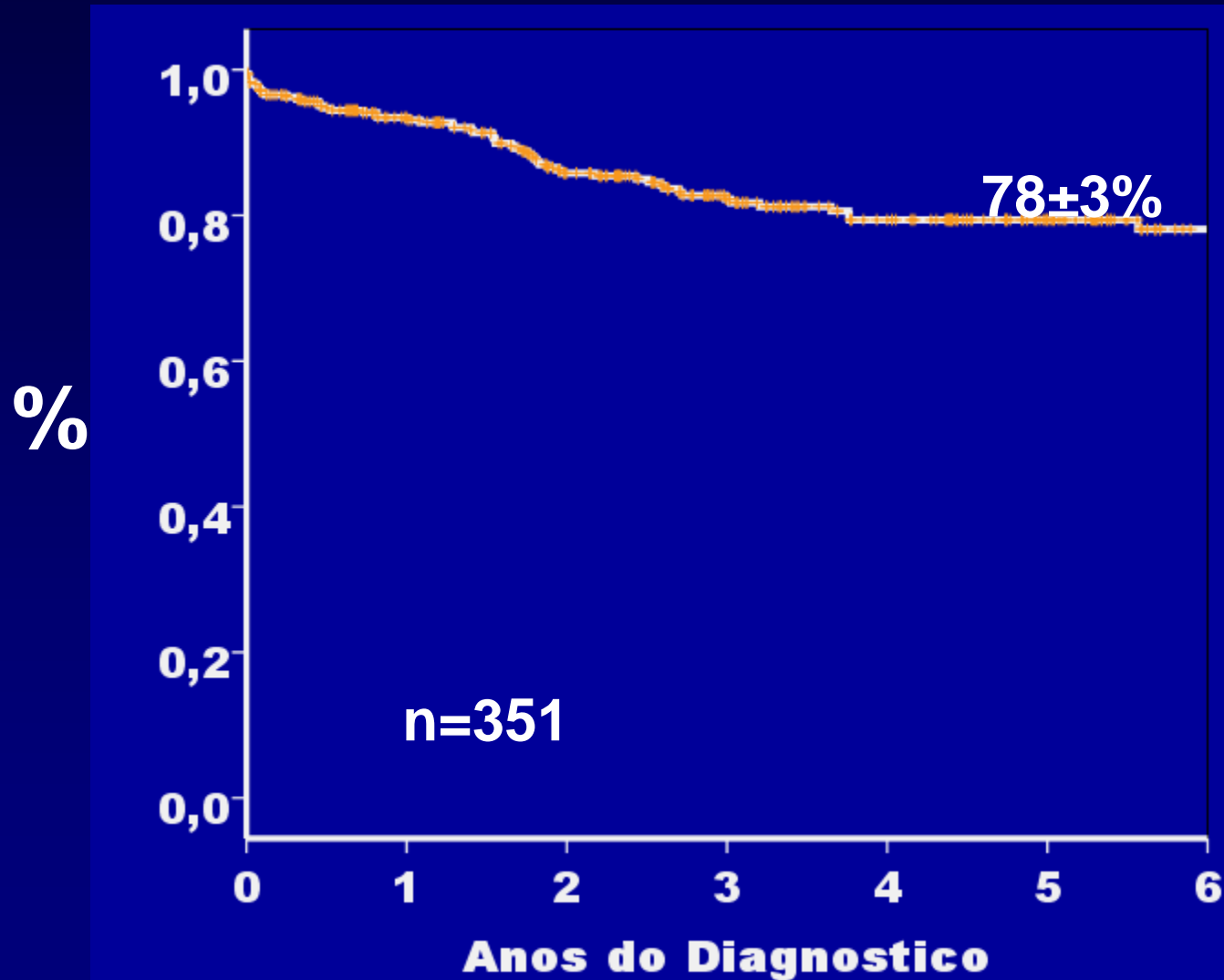
1997-2005 = 32/354 (9%)



2005-2008 = 3/118 (2.5%)

LLA - RECIFE

Sobrevida Global



Pediatric Oncology Team in Recife

N=200 new patients/year

Pediatric Oncologists

- 1-Francisco Pedrosa
- 2-Marcia Pedrosa
- 3-Teresa Fonseca
- 4-Kaline Maciel
- 5-Ivana Botelho
- 6-Mecneide Mendes
- 7-Erika Furtado
- 8-Michele Viana
- 9-Cinthya Rocha
- 10-Mariana Andrade
- 11-Lilian Moreira
- 12-Allan Lima

Other Features

- Full time
- Median salary 11.000,00 Reais for physicians and 3.600,00 for nurses (6 hour per day)
- Overall budget per year is 1 million (55% government and 45% NACC)
- NACC operational costs is 4.5 million per year

Cost vs. Value

Final Remarks

- St. Jude IOP methodology of collaboration with low- and middle-income regions (twinning) is very effective in improving cancer care
- Program sustainability is guaranteed by local foundations and governments
- Training, education, continuing mentoring and long-term relationship are the most valuable offerings
- Partnership with other organizations is critical