

2015

17 - 18 November | Istanbul, Turkey Effective International Collaboration

Breakout 2 - Green

'Children get cancer too. How to integrate childhood cancer into child health and primary care services'

Co-hosted by Turkish Association for Cancer Research and Control (TACRC) and St. Jude Children's Research Hospital



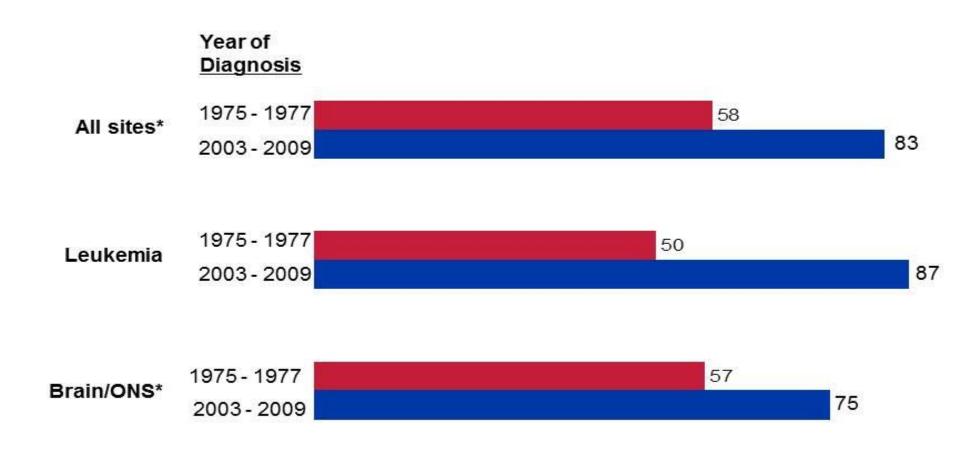
Burden of childhood cancer



 Each year, almost 200,000 children are newly diagnosed with cancer in the world.

 The exact number of new cases is not known as the number of children with cancer is not registered in many countries.

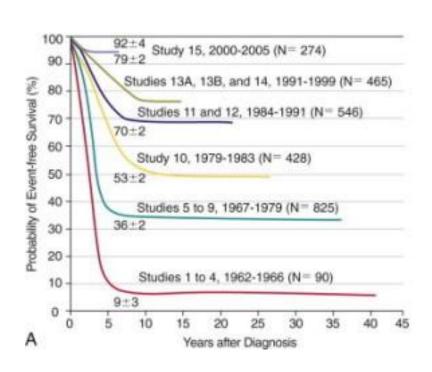
Trends in 5-year Relative Survival Rates for Cancer in Children (0-14 years),1975-2010

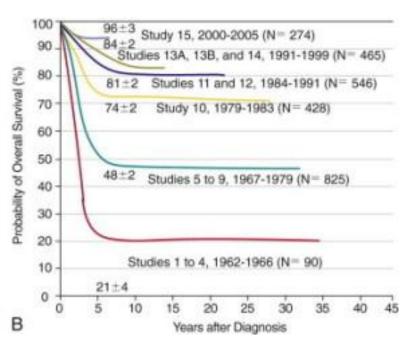


Based on follow up of patients through 2010. ONS=other nervous system.
*Excludes benign brain tumors.
Source: Surveillance, Epidemiology, and End Results (SEER) Program, National Cancer Institute, 2013.









N Engl J Med 354:166-178, 2006)

Overall survival In Children enrolled in CCG & COG studies



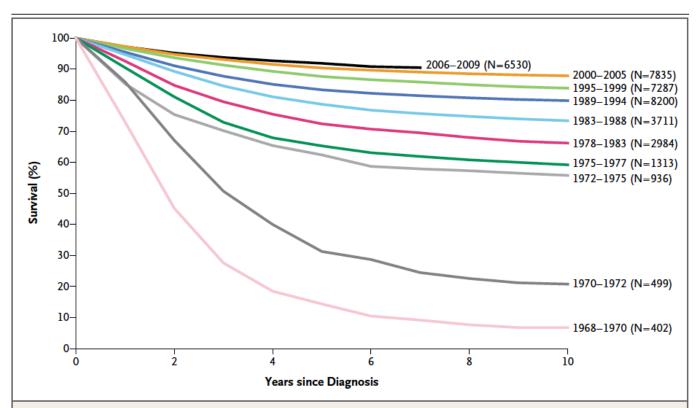


Figure 1. Overall Survival among Children with Acute Lymphoblastic Leukemia (ALL) Who Were Enrolled in Children's Cancer Group and Children's Oncology Group Clinical Trials, 1968–2009.



Survival challenge in childhood cancers

Despite ground-breaking advances in diagnosis and treatment of cancer, children with cancer who live in developing countries have less than a 50 per cent survival rate, as opposed to 80 per cent for children living in developed countries.

Global Goals: SDGs; Sustainable Development Goals



THE GLOBAL GOALS

For Sustainable Development







































Thank you!



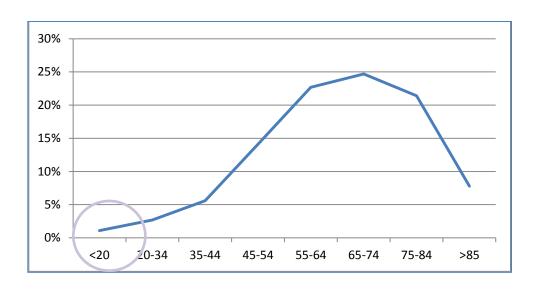




Making Pediatric Cancer a Priority Models for Program Development and Implementation

Carlos Rodriguez-Galindo, MD
Chair, Department of Global Pediatric Medicine
Four Stars of Chicago Chair in International Pediatric Research
Director, International Outreach Program
Executive Vice-President
St. Jude Children's Research Hospital

Pediatric Cancer



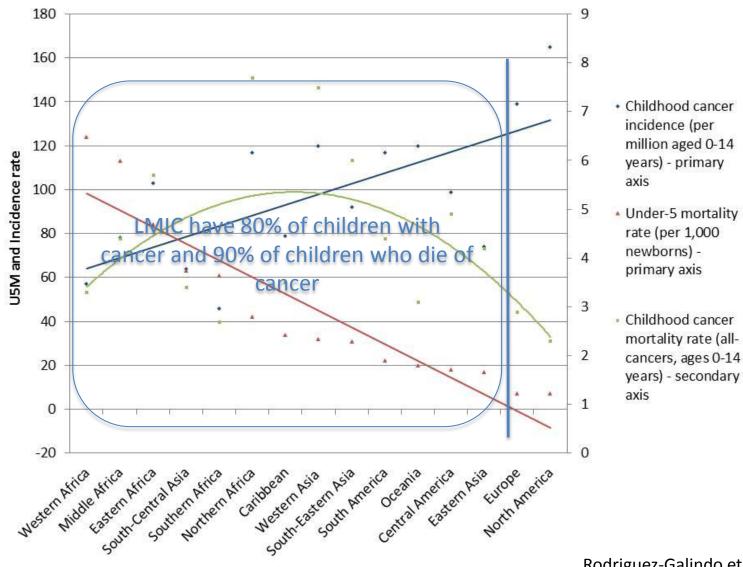
- 1%-2% of all cancers
- Incidence: 15/100,000 individuals <15 years
 - Or: 1/333 children
- Most common disease-related cause of death in children older than 5 years in HIC
- High probability of cure in HIC (80%) and more potential for life years gained than adult cancer



What does it <u>really</u> mean to children?

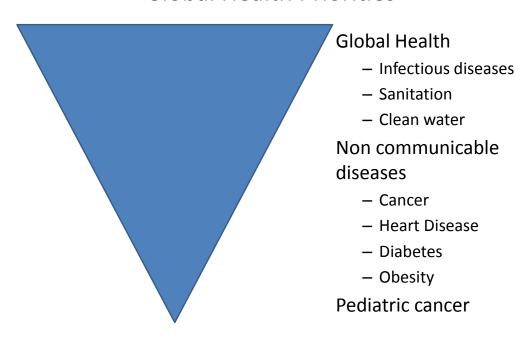
Income Category	Total Population ¹ (n)	Population 0-14 years (as % of population) ¹	Population 0-14 years (n)	Incidence of childhood cancer (per million) ²	Expected childhood cancer cases
High-income countries	1,306,000,000	17.3%	226,068,600	148	22,458
Upper-middle income	2,409,000,000	21.9%	527,089,200	118	62,197
Lower-middle-income	2,561,000,000	32.0%	818,751,700	73	59,769
Low-income countries	848,700,000	39.3%	333,199,620	76	25,323
TOTAL	7,124,700,000		1,905,109,120		180,747
TOTAL FOR LMIC ³					147,289
% LIVING IN LMIC ³					81.5%

Burden of disease



Pediatric Cancer in the Developing World

Global Health Priorities



The Child with Cancer in Resource Limited Settings



Late presentation and under diagnosis

Deficient supportive care

Abandonment of therapy

Deficient nursing training and support

Deficient palliative care

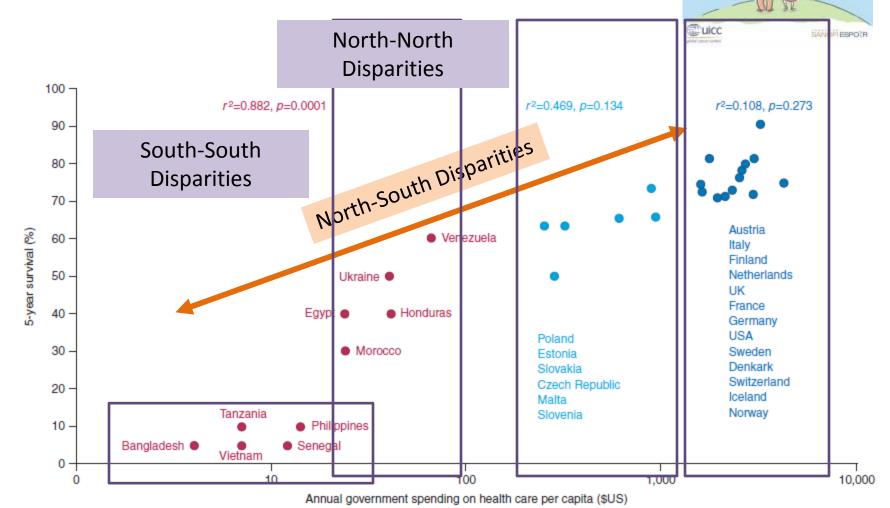




Malnutrition

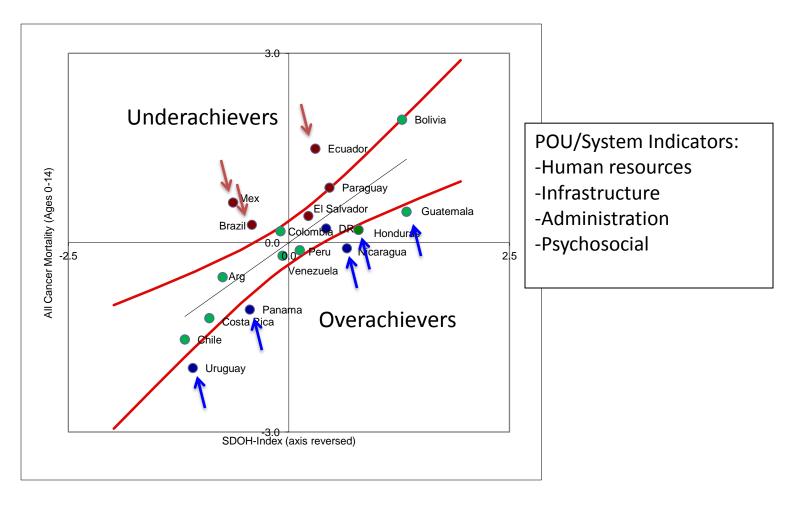


Childhood cancer survival and government annual healthcare spending *per capita:*#1 determinant of survival globally



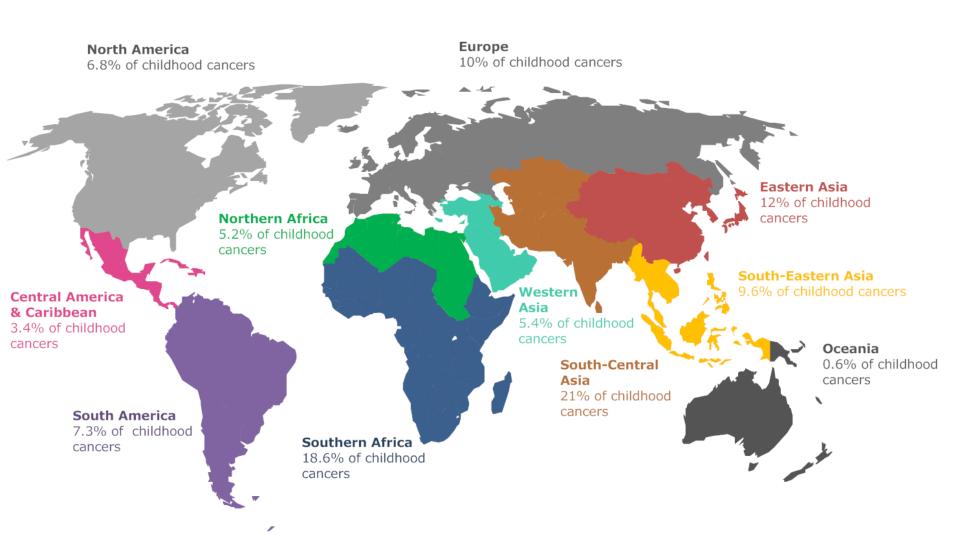
My Child Matters Fighting Childhood Cancer

Measuring Performance: Over and Under Achievers



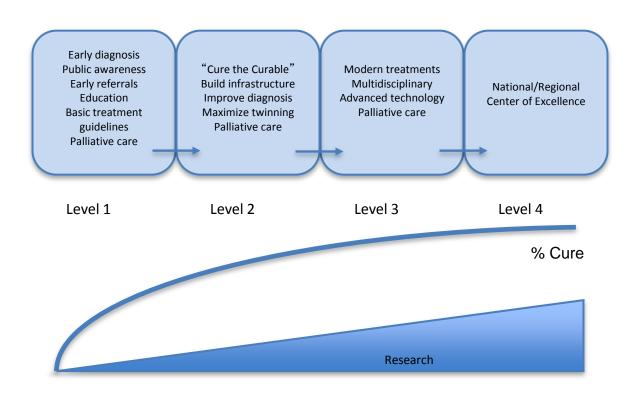
Michael Dworkin Paola Friedrich

Where and how do we start?

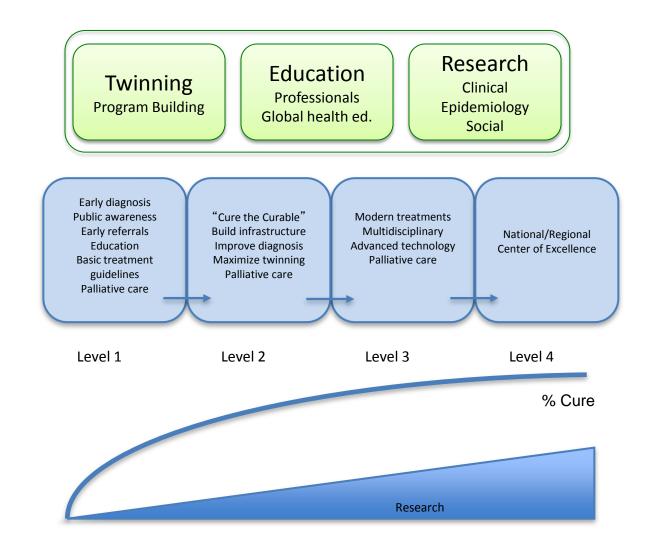


Global Health Initiatives in Pediatric Cancer

The Model



Approach to Pediatric Cancer in the Developing World



Approach to Pediatric Cancer in the Developing World

Twinning
Program Building

Building Capacity

Twinning

Improved Hospital Infrastructure
Dedicated Pediatric Oncologists
Dedicated Oncology Nurses
Infection Control
Multidisciplinary Care
Evidence-based medicine
"best possible treatment"
Social Support - Foundations

Decreased Abandonment
Decreased Toxicity
Improved Cure Rates









CANCER AND BLOOD DISORDERS CENTER













The AHOPCA Experience

Disease- and Problem-Specific Working Groups

Nutrition
Psycho-social
Nursing
Infection Control

Initiatives

Weekly, bi-weekly, monthly web-conferences
Nursing education, continuing medical education
Focused training
Clinical research

ALL
AML
Hodgkin disease
Non-Hodgkin lymphoma
Wilms tumor
RMS and NRSTS
Osteosarcoma
Retinoblastoma

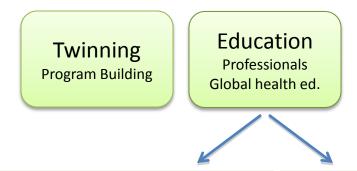
Treatment Guidelines
Protocols
Clinical Research

Approach to Pediatric Cancer in the Developing World

Twinning
Program Building

Education
Professionals
Global health ed.

Approach to Pediatric Cancer in the Developing World



HIC Pediatric H-O Fellowship training Nursing fellowship training

LIC/Partner Sites Pediatric H-O Fellowship training Nursing fellowship training

Research methods Health care policy/administration Epidemiology/Molecular Health economics Medical anthropology

Building regional capacity Integrated research training Visiting professors



Approach to Pediatric Cancer in the Developing World

Twinning
Program Building

Education Professionals

Global health ed.

Research
Clinical
Epidemiology
Social

Cancer Epidemiology

Biology Environment

Psychosocial

Support and education Medical anthropology

Health Services Research

Effectiveness (vs. efficacy)

Quality improvement

Cancer Outcomes

Adherence to treatment Survival

Translational Research

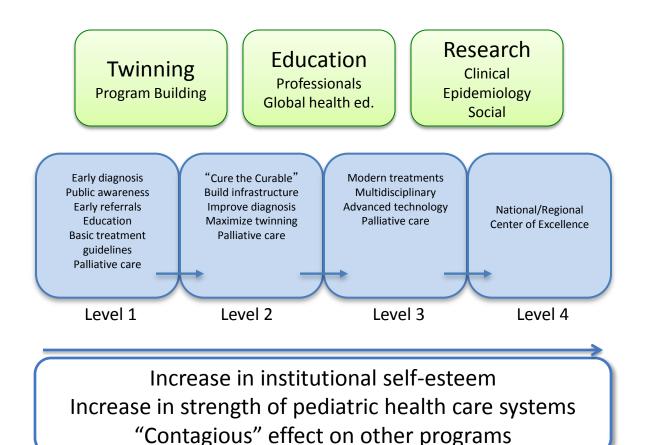
Tumor Biology
New treatment modalities

Ethics and Human Rights

Access to care Research oversight

Integrated Programs – Education/Program-Building Academic Partnerships

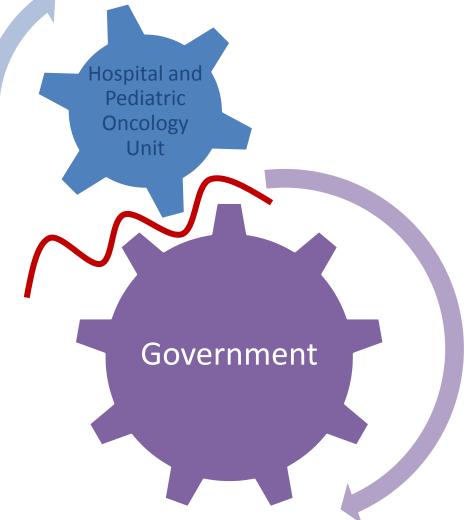
Approach to Pediatric Cancer in the Developing World



Building Pediatric Oncology Programs Model for Sustainability

Due to high-stakes in pediatric oncology, POU attempt to offer subspecialty care that is inherently: -Demanding

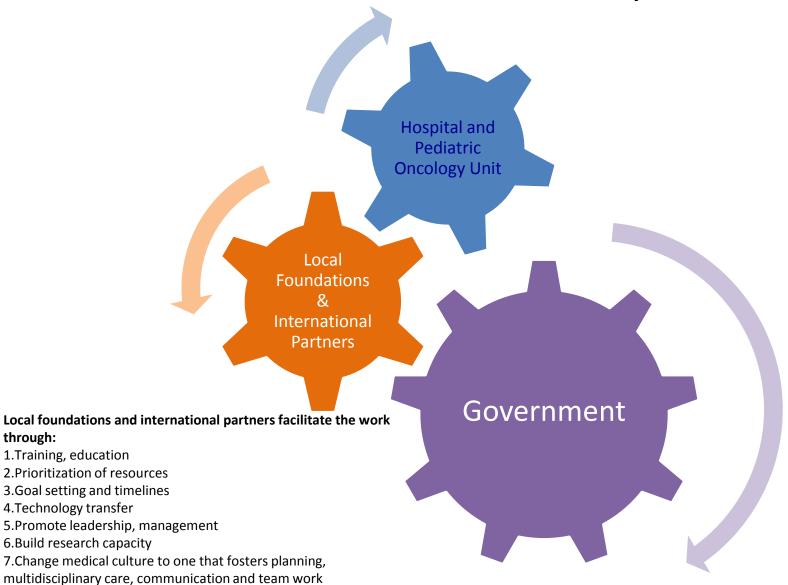
- -Complex
- -Time-consuming
- -Expensive
- -Multi- and interdisciplinary



The government is dealing with:

- -High volumes
- -Competing needs
- -Population changes
- -Increased burden of non-communicable diseases
- -Political changes
- -Budgetary constraints
- -Fragmentation concerns
- -Accountability issues

Building Pediatric Oncology Programs Model for Sustainability



Building Pediatric Oncology Programs Model for Sustainability

Government

- Regulation: rights, drugs, services, policies
- Financial support: personnel, drug procurement
- Infrastructure: public services, primary care
- Early diagnosis: education, referrals

Foundations

- Advocacy: local, national, international
- Patient support: psychosocial, education
- Financial support: in partnership with government and hospital
- Support for growth and strategic planning

Hospital

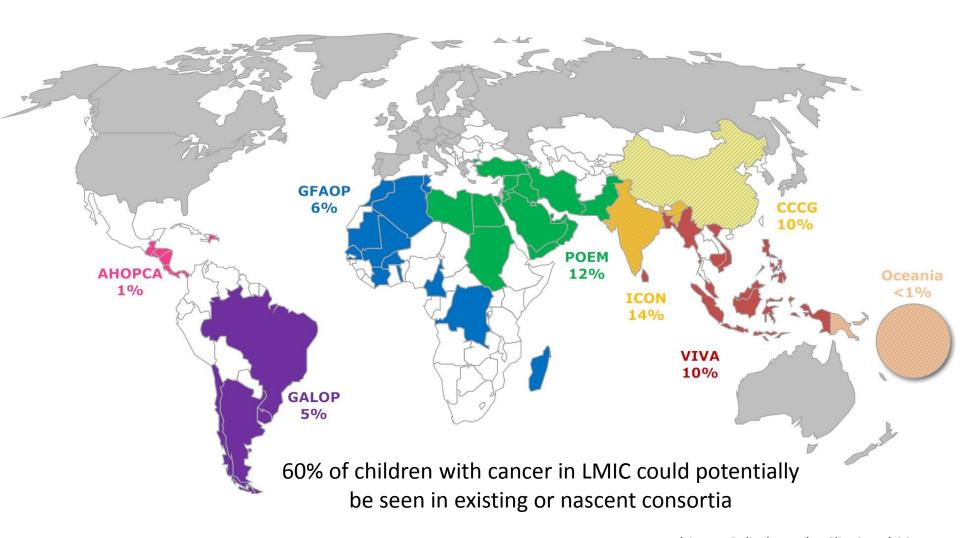
- Care delivery, strategic planning and growth
- Organization of referrals, satellites, networks
- Implementation of quality systems
- Academia

Net cost: \$\$, Human resources, etc.

Practical Points for Program Building

- Level-adjusted objectives
- Incorporation of metrics and performance
- Gradual implementation of initiatives and progression through levels
- Sustainability and business models
- Key dimensions
 - Quality assessment and implementation
 - Training and capacity building
 - Incorporation of research methods
- Regional expansion twinning²
 - The power of the region

Regional Collaborative Initiatives in Pediatric Cancer



Beyond Program Building

Approach to Pediatric Cancer in the Developing World

Twinning
Program Building

Education Professionals

Global health ed.

Clinical Epidemiology Social

Research

Academic centers must assume responsibility Change in philosophy – new vision ... new mission Strong commitment

Not 'mission work' Integrated within programmatic goals Education: students, residents, fellows Financial support

"Breakthrough in Pediatric Cancer"

Moving Forward ...

Late diagnosis - Cultural or socioeconomic barriers The Problem - Lack of information at primary care level Poor referral to pediatric oncology units - Deficient health care system - Lack of recognition of existing centers Lack of pediatric oncology units - Lack of infrastructure, drugs - Lack of trained personnel - Fragmented care Early detection campaigns Education of primary health care providers The Priorities Development of pediatric oncology units **Education and training** Development of referral networks Financial support for drug procurement 'Twinning' models - Mentorship The Partnerships - Training and supervision Advocacy and support - Parents organizations - International agencies Regional networks - Consortium model - 'You will not walk alone' Research and implementation science Development of new evidence base The Growth Development of centers of excellence

Regionalization, satellite centers

Consortia

Thanks!



carlos.rodriguez-galindo@stjude.org





Accomplishments of a Retinoblastoma Awareness Campaign through the distribution of Flyers during the Annual Vaccination Campaign in Honduras

Dra. Ligia Fu
Fundación Hondureña para el Niño con Cancer
Servicio de Hematooncologia Pediátrica
Hospital Escuela Universitario
Tegucigalpa, Honduras
Centroamerica

Hospital Escuela Tegucigalpa, Honduras





Retinoblastoma

- Most frequent intraocular tumor (2-4% of tumors in children)
- Signs and symptoms: Leukocoria
- Strabismus, glaucoma
- Survival rate at early diagnosis in developed countries >90%
- Cancer prevention /Early detection

Leukocoria- Early Sign of Retinoblastoma



Abnormal white reflection from the retina of the eye



Before Awareness campaign for Early detection of Retinoblastoma (2003)





DELAYED DIAGNOSIS OF RETINOBLASTOMA

The cases of Retinoblastoma referred to the Hospital presented Extraocular invasion (73%)

EARLY DETECTION OF RETINOBLASTOMA DURING THE MASSIVE VACCINATION CAMPAIGN IN HONDURAS





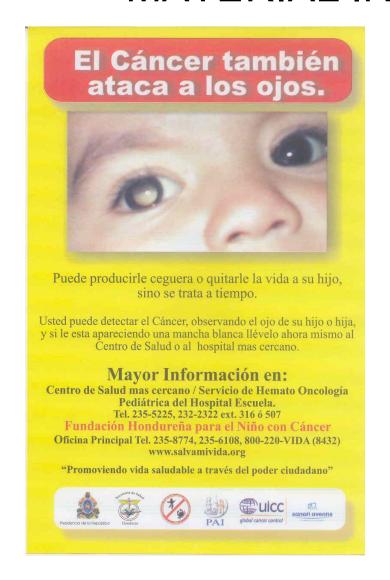
- Annual Massive vaccination campaign (95% coverage) for children less than 5 years old
- Distribution of flyers and posters about Leukocoria a suspicious sign of Retinoblastoma

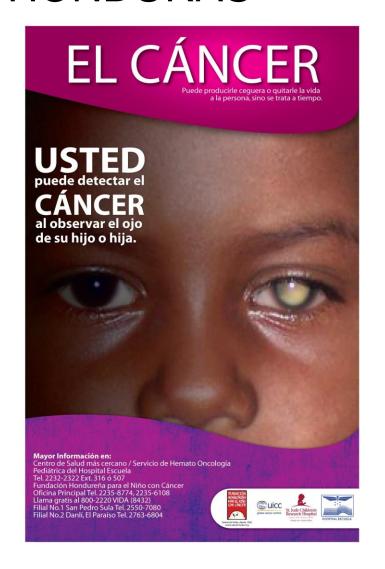
ANNUAL VACCINATION CAMPAIGN + RETINOBLASTOMA AWARENESS



- 500000 Leukocoria flyers distributed to parents
- 1625 Public Health Centers accessed in the country
- \$3000 dollars spent by the Fundacion Hondureña para el Niño con cancer to produce flyers and posters

DISTRIBUTION OF EDUCATIONAL MATERIAL IN HONDURAS





Impact of an Education Program on Late Diagnosis of Retinoblastoma in Honduras Christopher Leander, B.S.,1 Ligia C. Fu, M.D.,2 Armando Peña, M.D.,2 Scott C. Howard, M.D.,3 Carlos Rodriguez-Galindo, M.D.,3 Judith A. Wilimas, M.D.,3 Raul C. Ribeiro, M.D.

Pediatr. Blood Cancer, 2007 Nov;49(6):817-9.

	Pre-Campaign 7/1/956/1/03 (9 years)	_		
	n = 59	%	n = 41	%
Extraocular tumor	43	73%	11	27%
Intraocular tumor	16	27%	30	73 %

Bilateral disease	5	8%	2	5%

Results of the Retinoblastoma's Awareness Campaign in Honduras (2003-2012).

- Number of cases of Retinoblastoma referred to the Hospital increased.
- The Intraocular Retinoblastomas increased to 73%
- Children are detected at a younger age
- With training of the personnel and donation of equipment there is possibility to save not only the life of the children but also their vision

Early Detection of Retinoblastoma after the Awareness Campaign









Donation from St Jude's IOP of a retcam and laser for treatment and follow up of retinoblastoma patients in Hospital Escuela Universitario, Tegucigalpa, Honduras







PATIENT WITH BILATERAL RETINOBLASTOMA ON SURVEILLANCE

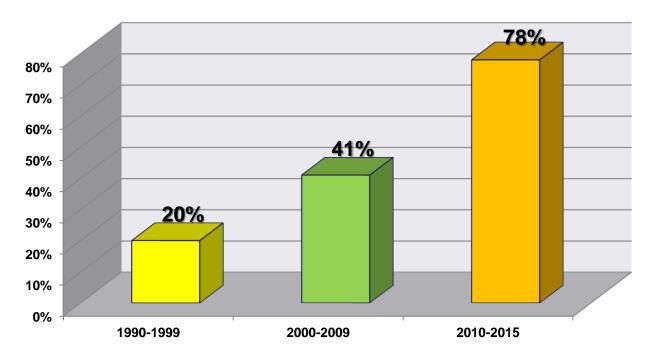


Distribution of Retinoblastoma cases by events and period of time

AÑO	PACIENTES
1990	1
1992	3
1994	1
1995	1
1996	7
1997	5
1998	11
1999	6
2000	4
2001	13
2002	11
2003	13
2004	13
2005	9
2006	8
2007	8
2008	8
2009	13
2010	16
2011	16
2012	11
2013	9
2014	13
2015	3
TOTAL	203

Años	Pacientes	Vigilancia	Abandono	Falleció	Tratamiento	Rehusó	Paliativo	Total	Sobrevida	%
1990-1999	35	7	24	3	0	1	0	35	7	20%
2000-2009	100	36	24	32	5	3	0	100	41	41%
2010-2015	68	26	8	5	27	1	1	68	53	78%
Total	203									

Survival Rate

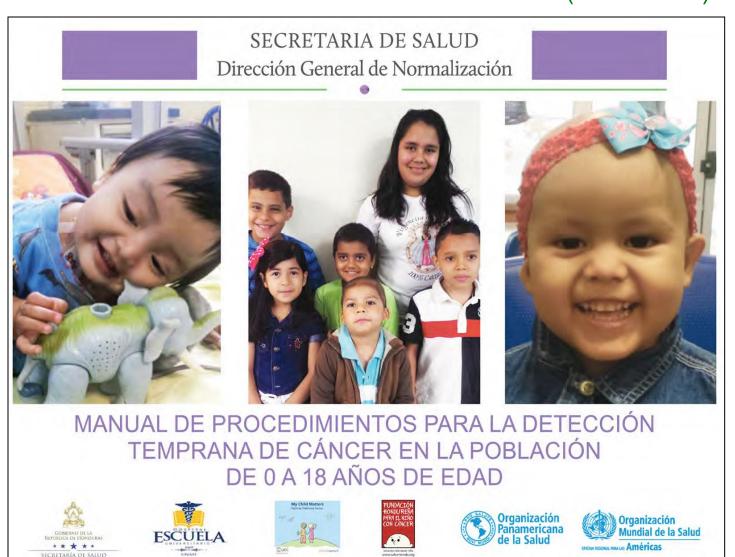


Childhood cancer Awareness Campaign for 2016



- 500000 flyers will be distributed during the vaccination campaign on 2016
- Flyers will be disseminated to parents who attend with their children to the health centers
- The health providers will also be informed of the goals of the awareness campaign

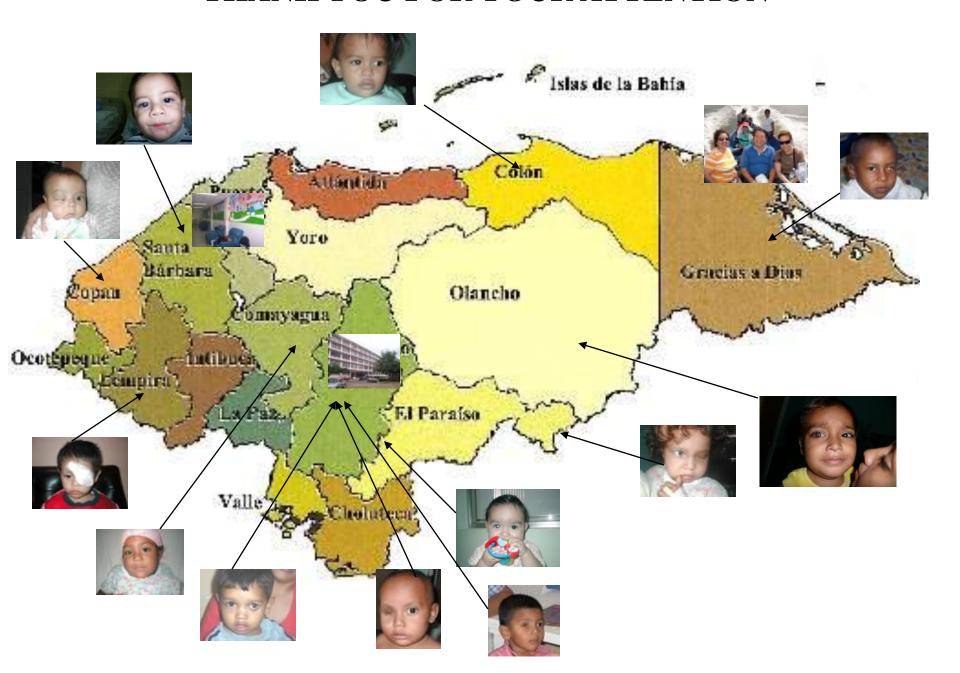
NEXT STEPS: EARLY DETECTION OF CHILDHOOD CANCER:WORKSHOPS TO PRIMARY CARE HEALTH PROVIDERS (2014-2016)



Conclusion

- •Lack of information and awareness about childhood cancer is a critical obstacle for an effective cancer control and cure in developing countries, especially for the detection of cancer at earlier and treatable stages.
- •Comprehensive prevention programs that include strategies to improve knowledge about childhood cancer among communities, health professionals and policy makers will provide the greatest chance of success on childhood cancer survival rate.
- •Retinoblastoma`s Awareness during the Annual Vaccination Campaigns has caused a successful impact in Honduras and it is an example of collaboration between communicable and non communicable disease´s programs.

THANK YOU FOR YOUR ATTENTION



Ghana – Awareness Initiatives, Multi-stakeholder Engagement & Cancer Control Plan

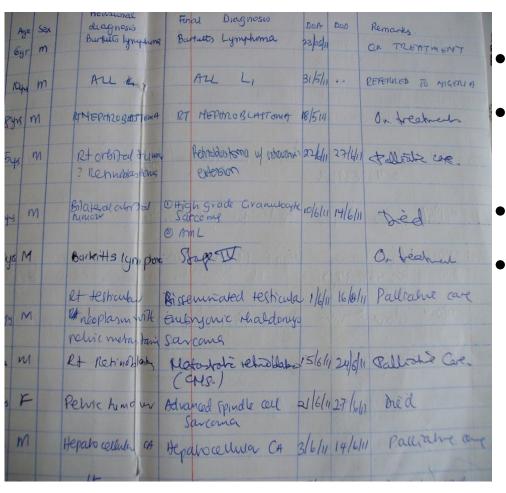
Lorna Awo Renner
Head, POU, Korle Bu Hospital, Accra
WCLS, Nov. 18, 2015

Introduction



- Population over 25million
- 40% under 14 years
- Only two childhood cancer treatment centres
- Only 250 out of expected 1,000 cases report to 2 centres

Necessity for Awareness - Reality



- Only 3 out of 10 treated
- Reality late presentation
- Palliative care
- Early deaths disease, malnutrition

Childhood cancer awareness - challenges

- Literacy levels appropriate IEC materials
- Languages minority groups disadvantaged
- Media prime time, coverage
- Resource mobilization
- Keeping up awareness and advocacy campaigns regular, varied
- Traditional practitioners negative publicity about treatment
- Faith healing
- Socio-cultural beliefs, stigma

Childhood Cancer Awareness - Opportunities

- International designated days/month September childhood cancer awareness month
- Funding sources Twinning programme, fundraising
- Stakeholders participation of GHS, WCC, Afrox, clinicians – design, printing, distribution posters, leaflets.
- Parents group
- Partnering local NGOs
- Celebrity childhood cancer ambassador
- Education MOH/GHS, Universities, Postgraduate college, - health professionals curricula

Awareness creation activities

- Awareness walks
- Media meetings
- Press publications
- Public Fora
- Activities of parent's group funfairs
- Talks TV, radio, schools, places of worship

Posters distributed

CHILDHOOD CANCERS CAN BE CURED







RECOGNIZE THE WARNING SIGNS FARLY

- White spot in the eye, new squint or bulging eyeball
- Unusual lump or swelling anywhere in the body, especially the jaw, neck, stomach or limbs
- Fever for more than two weeks, weight loss, bleeding or tiredness
- Persistent joint, bone or back pain
- Frequent headaches, vomiting or unsteady walking

RECOGNIZE THE WARNING SIGNS EARLY:

Early reporting can save your child's life!













Awareness walks





Media engagement



of Ghana, handing over the Items to the Nursing Officer in unarys.

And the American State of the Choir members. With them are Mr George Adu-Ntow (2nd Lantwel Lamptey (left), on behalf of the choir members.

'Bear full cost of cancer treatment for children'

Story Jennifer Ansah

THF Ghana Parents Association for Childhood Cancers (GPACC) has called on the government to fully bear the cost of treating children with cancers under the Health Insurance Scheme

pertained in other countries, children with cancers should have a separate ward due to their low immunity levels brought about by the chemotherapy treatment. Most cancer symptoms, Dr Renner indi-cated, included signs of the eye such as

trainees pass out at Dzodze

Story: Timothy Gobah

Achievements

	1	
	2009	2012
TOTAL NUMBER	132	158
ALIVE	51	114
PALLIATIVE CARE	11(11
ABANDONED	33 (25%)	10 (6.3%)
DIED	36(27.3%)	23(14.6%

Multi-stakeholder engagement Achievements

- Major support for International childhood cancer conference in-country (SIOP Africa 2010).
- Twinning programme awareness, training multidisciplinary teams, access to drugs.
- Hospital based databases for childhood cancer
- Infrastructure
- Development of satellite centres.
- Oncology outreach nursing service
- Reviewing NHIA drug cover to include childhood cancer

Training



Infrastructure - Day Care Unit

2012 2013





Multi-stakeholder engagement – Panel discussion



- Minister for Health
- Director-General, GHS
- Director, NHIA
- Parent group rep.
- WCC coordinator
- Paediatric Oncologist
- Childhood cancer ambassador
- Outcome NHIA to review inclusion of childhood cancer

International Childhood Cancer Day



- World Health Organization
- Ministry Of Health
- Ghana Health Service
- NGOs
- Parent group
- Health workers
- Hospital administration
- Faith based organizations
- Outcome through WHO, grant from IAEA (UN Women's Guild) for equipment.

Other engagement opportunities

- Sustainability planning meetings WCC, national and local stakeholders
- Support for side meeting childhood cancer at WHA, 2015 (SIOP initiative)
 - Ministry of Health Minister, Chief Director,
 Director PPME,
 - Ghana Health Service Director-General, Director
 Public Health, NCD programme manager

Cancer Control Plans

- Multi-stakeholder MOH, GHS, NGOs, academia
- Support WHO, AfrOx, IAEA, Ghana Atomic Energy Commission
- Completed 2013, launched 2015
- Childhood cancer integrated, representation on all implementation committees
- Resource limitations

Let us **ALL** join our resilient children in the tug of war against childhood cancer!



THANK YOU



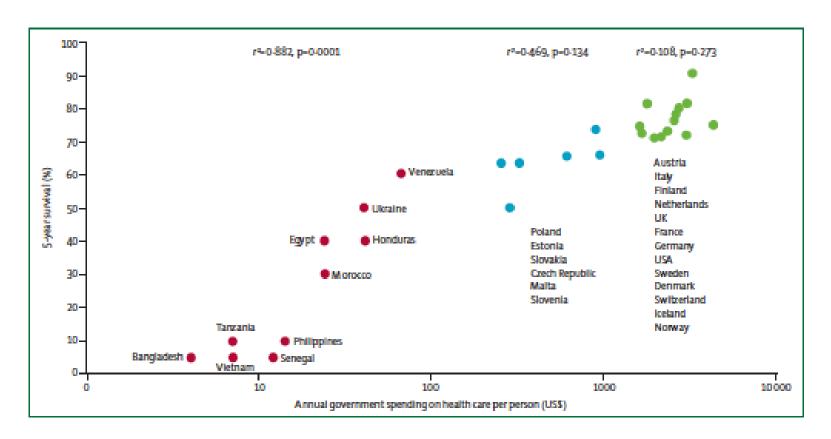
Intersections between Human Rights Approaches and Childhood Cancer

Thiago Luchesi
Advocacy Advisor, Child Survival and Health
Save the Children International



17 - 18 November | Istanbul, Turkey
Effective International Collaboration

Health Inequities or Discrimination?





The hard question

Why for other priority diseases that affect developing countries (e.g. HIV/AIDS), the world has established concrete targets and used these goals to drive progress?

Why this has not been the case for cancer?



Challenges to overcome

- Individual family, community, national poverty
- Other overwhelming societal priorities
- Natural and man-made disasters
- Lack of cancer incidence registration
- Lack of awareness /perceptions of incurability
- Lack of access to diagnosis/treatment
- Lack of palliative care
- Lack of trained staff/ability to retain staff
- Infrastructural problems e.g. transport



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So, where do we start?





Why child rights

- Legally binding obligations
- Needs-based and service-delivery approaches to development have failed to reach the most deprived children
- Authorities might not be sensitive to the needs of poor and other marginalized groups



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Why child rights

Focus on Universality and Non-discrimination: « Reach the furthest behind first »





AVAILABILITY AND ACCESSIBILITY OF SERVICES



Why child rights

- We talk about DIGNITY (and Palliative Care)
- PARTICIPATION of patients and family members in decisions affecting their lives is encouraged

ACCEPTABILITY AND QUALITY OF SERVICES



The best interests of the child

We care about children's physical, emotional, social and educational needs, age, sex, relationship with parents and caregivers and their family and social background.





The right to survival and development

States have the obligation to ensure the survival, growth and development of children, including the physical, mental, moral, spiritual and social dimensions

of their development





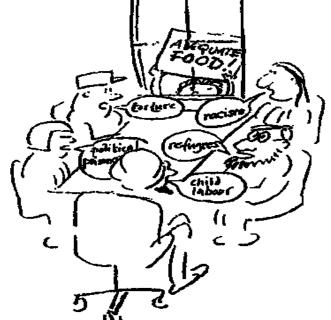


A right's based approach is also about...

Progressive realization (no retrogressive

measures accepted)

Minimum core obligations







A right's based approach is also about...

ACCOUNTABILITY











Advocacy and Campaining work!

The example of



 Can the mouvement around Universal Health Coverage help?





Thank you

