

# Chilean National Childhood Cancer Program



**Dra Myriam Campbell B.**  
**Coordinadora Nacional**  
**PINDA- MINSAL**  
**OPS Febrero 2017**

# Highlights of Chilean Public Health

1952

Cancer  
7 th  
cause of  
death in  
Chile

**NATIONAL HEALTH SYSTEM** was established by Law # 10.383 to take care and promote health of the workers and their families  
**MINISTRY OF HEALTH** programmes, coordinates and controls the activities

1978

5 Hospitals create the Chilean national pediatric oncology group ,  
**GOPECH**, with common protocols

1981

Cancer  
2nd  
cause of  
death in  
Chile

Private Institutions (ISAPRES) were developed to give health care to their affiliates

1986

Cancer  
2nd  
cause of  
death in  
Chile

The **NATIONAL CANCER COMMITTEE** was established with members from the scientific societies, universities, private and public system.

# Structure of Chilean Health Care System

Funding	General Taxes	Health –Specific Tax
	<p>National Health Care Fund</p> <p>FONASA –A-B-C. (80%)</p>	<p>Private Health Insurance</p> <p>ISAPRES (20%)</p>
Provider	<p>Public Health Care System</p> <p>Primary Care Center</p>	<p>Private Health Care Centers</p>

# Epidemiological situation

## Infantil mortality decline

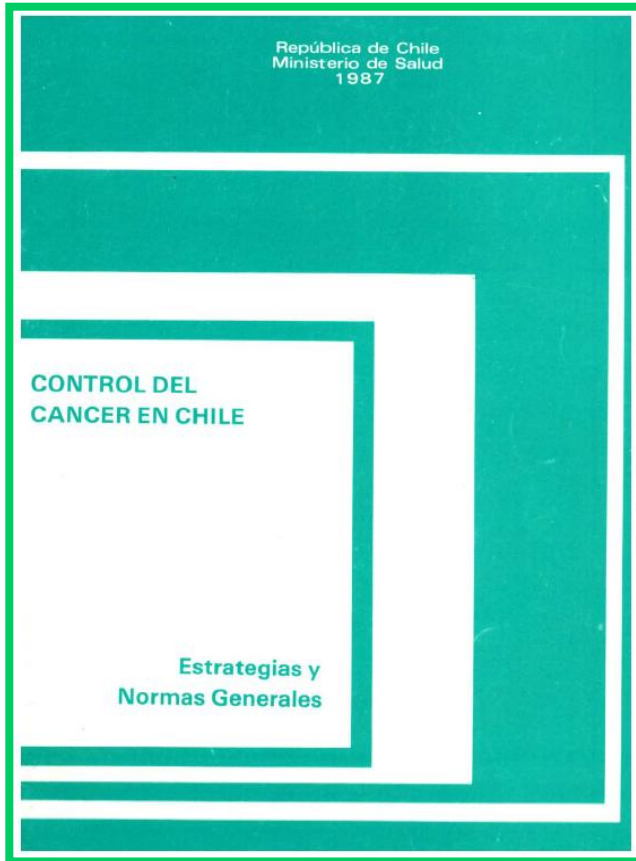
1970 82,2 x 1000 newborn  
1986 19,1 x 1000 newborn  
(2014 7,2 )

## Death due to cancer < 15 years

1970 0,8%  
1985 2,3%

Cancer : Second cause of death > 5 years  
(preceded by accidents )

1986 Ministry of Health (MINSAL) creates the  
National Cancer Committee



**1987 Strategies and General Guidelines to Control Cancer in Chile**

**1988 MINSAL initiated Antineoplastic drugs Program PANDA - PINDA**

# National Committee for Cancer



**1988**

Public Health System Beneficiaries

12 Centers + national network

13 protocols, drugs 100% free

Financial support US \$ 500.000

# GOPECH results 1978 - 1986

**878 patients treated**

Protocol	78	82
5y EFS	%	%
ALL	19	36
Hodgkin Lymphoma	74	81
Non Hodgkin Lym.	35	46
Wilms Tumor	60	74

Pediatría (Santiago), vol 31, 1988

# PINDA protocols 1988

Leucemias y Linfoma no Hodgkin	BFM
Tu Células Germinales	MAKAI
Neuroblastoma	SIOP
Tumor Wilms	NWTS III
Osteosarcoma	St'Jude
Sarcoma de Ewing	St'Jude
Sarcoma PB	IRS III
Linfoma Hodgkin	Chile (EORTC, Stanford)
Histiocitosis	Chile-Soc. Int. Hist
Retinoblastoma	Brasil (Pratt)



# General Committees

## DISEASES COMMITTEES (1988)

Protocol evaluation and results analysis

Contact with original groups

Periodic presentation of results

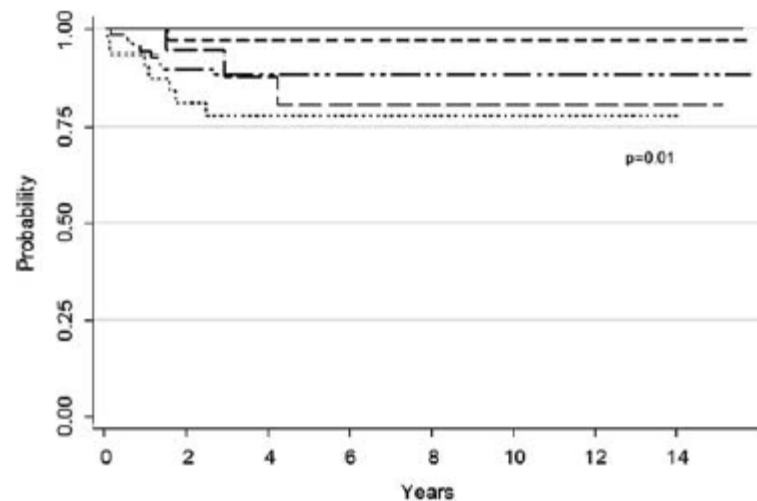
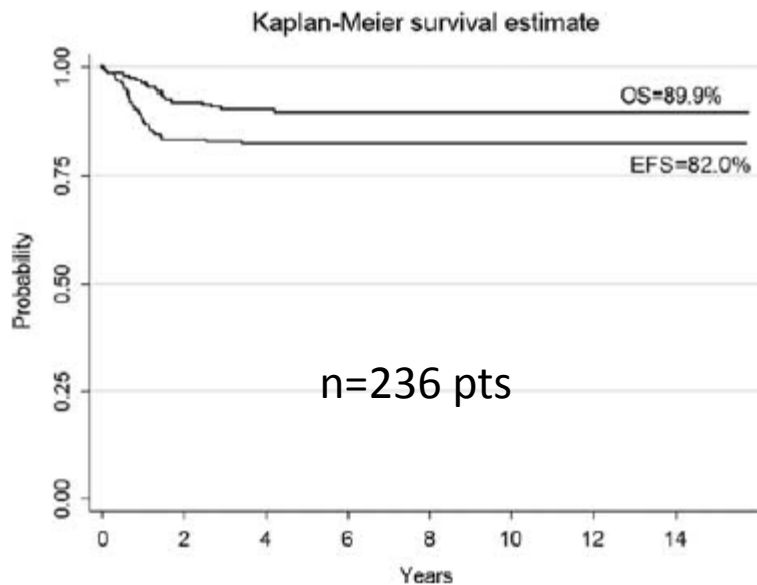
Publication

Renewal of trials every 4-6 years

Multidisciplinary - Case discussion

# Results of Therapy for Wilms Tumor and Other Malignant Kidney Tumors: A Report From the Chilean Pediatric National Cancer Program (PINDA)

*Pilar Joannon, MD,\* Ana Becker, MD,† Paola Kabalan, MD, MMed,‡  
Emma Concha, MD,§ Victoria Beresi, MD,§ Carmen Salgado, MD,||  
Pilar Martínez, MD,¶ Paola Olate, MD,# Mónica Arriagada, MD,\*\*  
Felipe Espinoza, MD,†† Mónica Varas, MD,‡‡ Pablo Benavides, MD,§§  
Miguel Valero, MD,||| and Mauricio Reyes, MD,¶¶*



# Nurses (1992)

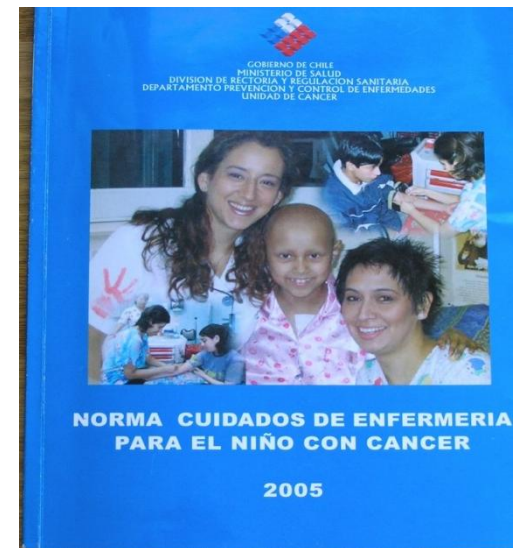
✓ Nursing handbook

✓ Nursing teaching in pediatric oncology

Jornadas Técnicos Paramédicos

✓ Investigation:

- Patients categorization according to level of dependence
- Aloe vera use in clinic
- Infection management



# Infectology (1994)

Febrile neutropenia guidelines

Multiple research and publications

Vaccination program in cancer

Air and water studies in oncology units

“ Prospective, multicenter evaluation of risk factors associated with invasive bacterial infection in children with cancer, neutropenia, and fever “

**J Clin Oncol 2001 ; 19 : 3415 – 3421**

“Prospective evaluation of a model of prediction of invasive bacterial infection risk among children with cancer, fever , and neutropenia”

**Clin Infect Dis 2002 ; 35 : 678 – 683**

“Early hospital discharge followed by outpatient management versus continued hospitalization of children with cancer, fever, and neutropenia at low risk of invasive bacterial infection”

**J Clin Oncol 2004; 22: 3784-3789**

Consenso: Manejo racional del paciente con cáncer, neutropenia y fiebre.

**Rev Chil Infectol 2005; vol 22 : S81-S113.**



# Hospital Schools (1999)



# Progressive Expansion

1992 : ALL Relapse

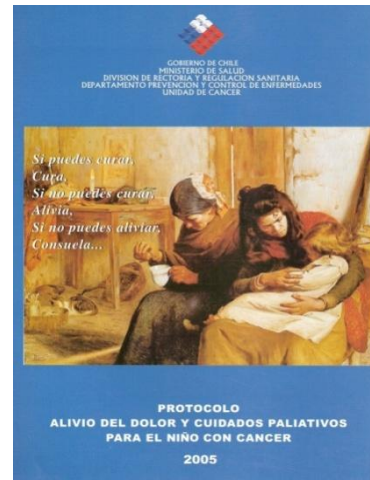
1996 : CNS Tumors

1998 : AML and Solid Tumors relapse trials

1999: Bone Marrow Transplant Program

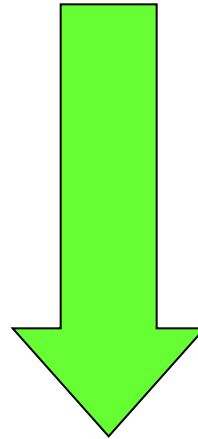
2003: Palliative Care and Pain relief

2007 : **All types of cancer in children**





DRUGS PROGRAM



CHILDHOOD CANCER  
PROGRAM

# National Cancer Program

## OBJECTIVE

- **To decrease cancer associated mortality**  
Through prioritized interventions of proven quality  
Including promotion of health to palliative care  
Within a functional network
- **To ensure equity, continuity, resolution & satisfaction**  
With impact indicators and scheduled assessments

# ERICE Statement

## I-BFM-SG ELTEC

La meta a largo plazo respecto a la cura y cuidado del niño con cáncer es que el / ella lleguen a ser adultos resilientes, activos y autónomos con una calidad de vida óptima respecto a la salud y que sean aceptados por la sociedad al mismo nivel que sus pares.

Haupt R et al : Long term survivors of childhood cancer: Cure and care  
European Journal of Cancer 1778-80,2007

**MINSAL**  
**DIPRECE división de prevención y control de enfermedades**

**Departamento de Cáncer**

**PINDA**  
**Coordinador Nacional**

**Comisión Directiva**

**Comités Generales**

**Enfermería- Infectología  
Patología - Radioterapia  
Químicos - Cirugía  
Psicólogos-Servicio Social  
Trasplante MO  
Cuidado Paliativo y  
Alivio Dolor  
Odontólogos**

**Comités de Protocolos**

**30 Protocolos**

**Coordinadores Centros**

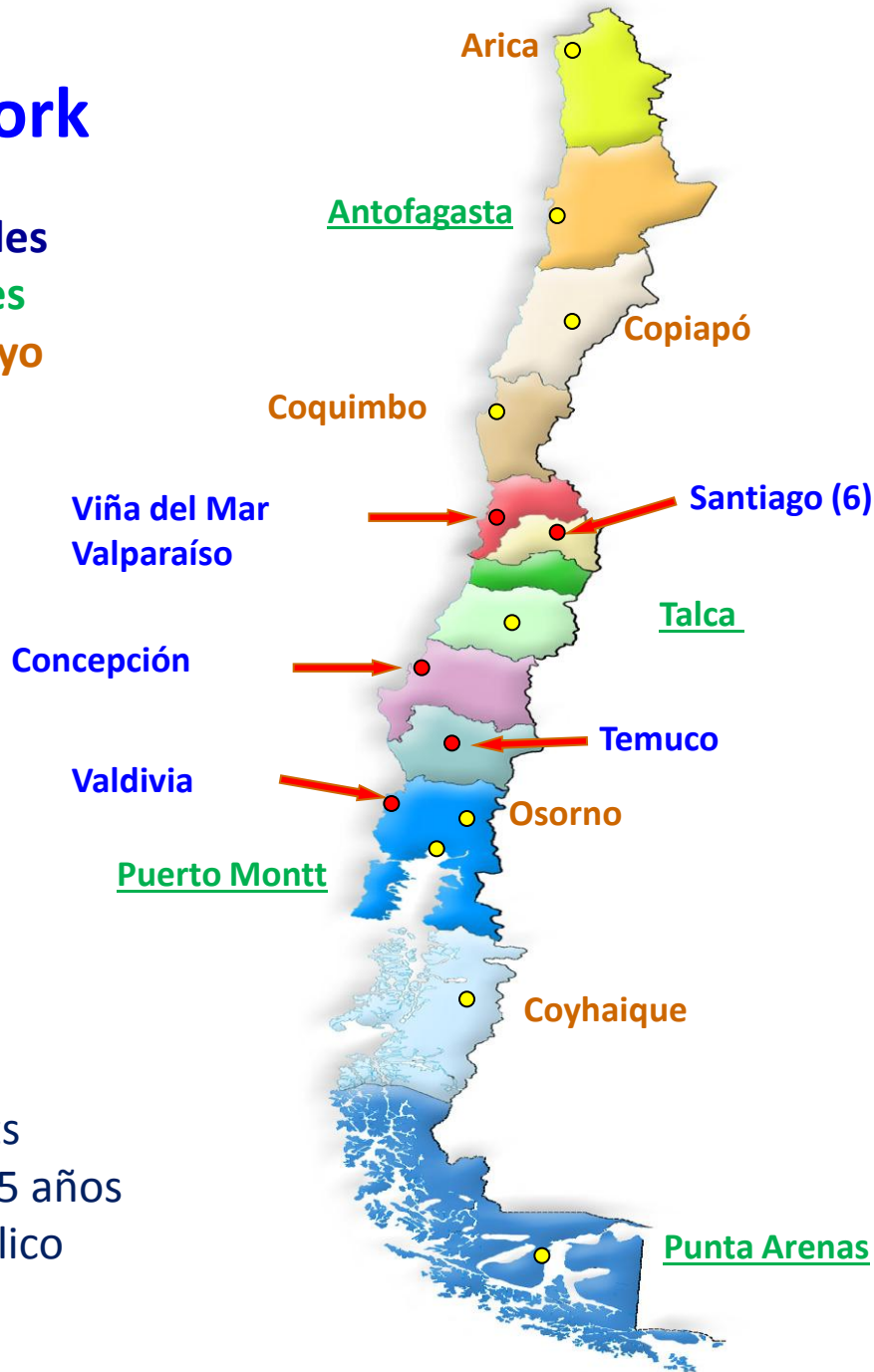
**Red Nacional**  
**11 Centros Integrales  
4 Centros Parciales  
5 Centros Apoyo**

# PINDA Network

11 Centros Integrales

4 Centros parciales

5 Centros de apoyo



~ 17 millones hbts

~ 3,5 millones < 15 años

80% Sistema Público

## Macroredes:

Radioterapia

Lab: INM-ERM-CG

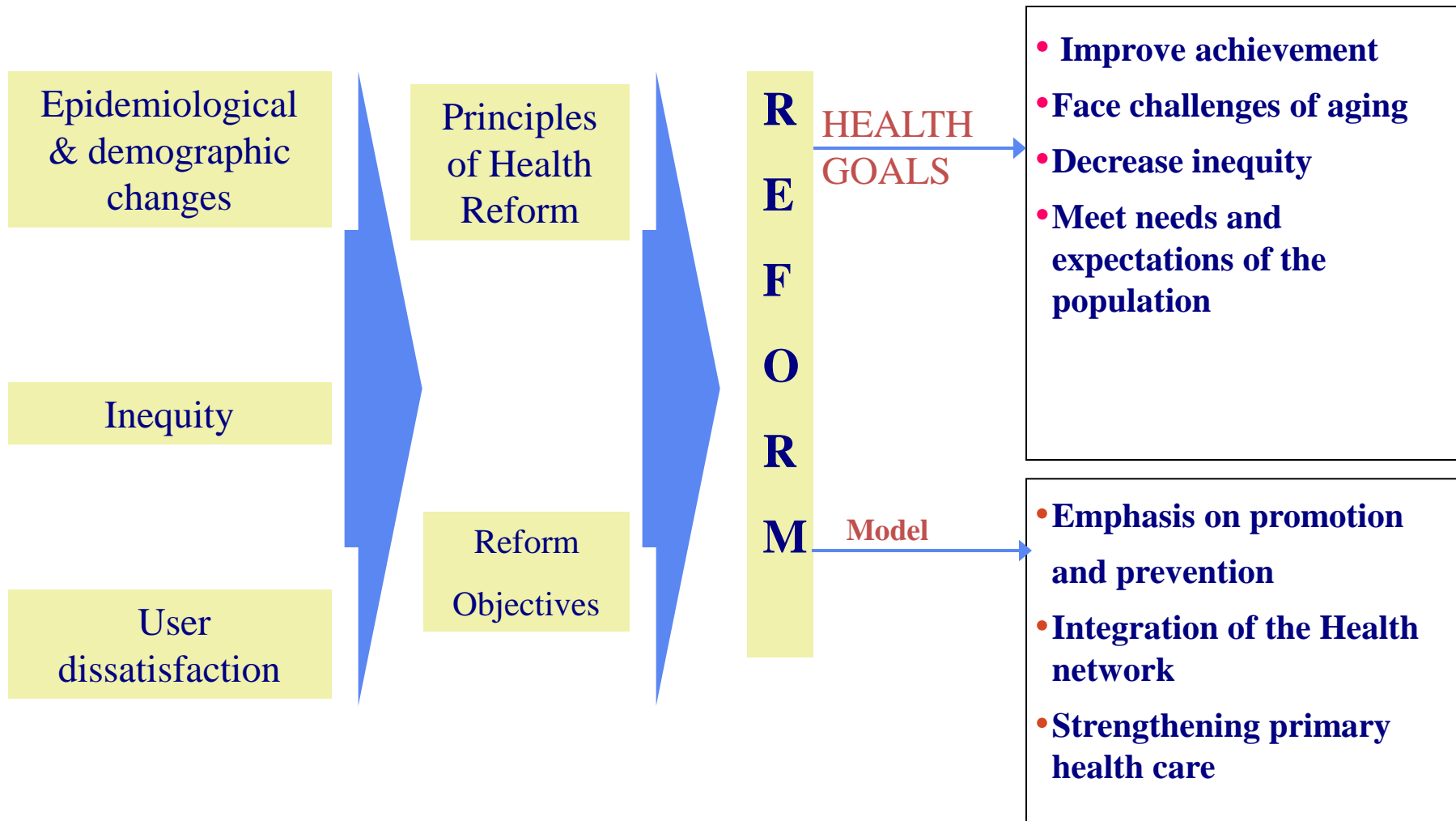
Neurocirugía

Trasplante

Osteosarcoma

Retino intraocular

# Chilean Health Reform



# Highlights of Chilean Health system

**2002**

Cancer  
2nd  
cause of  
death in  
Chile

Starts the **Health System Reform**

**2002**

Cancer  
2nd  
cause of  
death in  
Chile

**PINDA** was chosen as pilot for the new system

**2005**

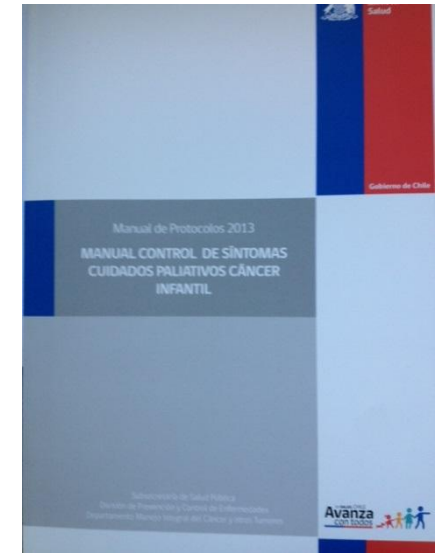
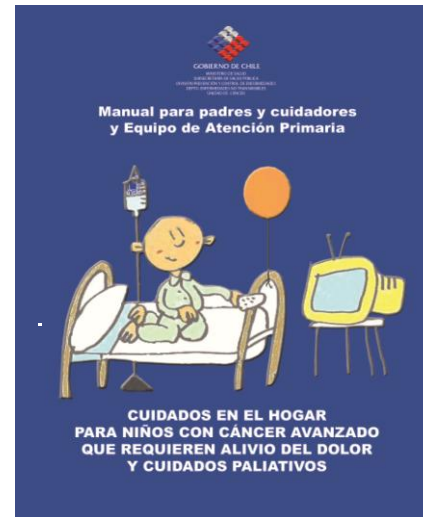
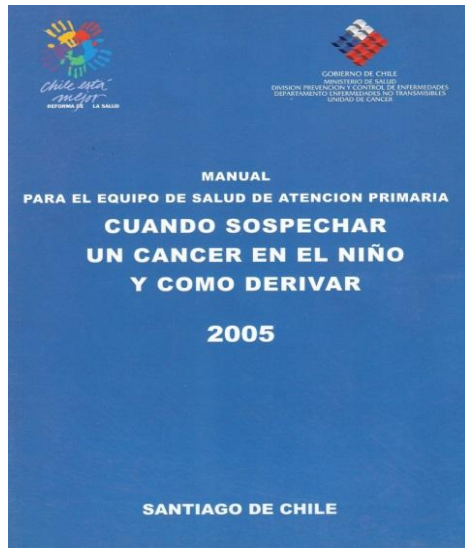
Cancer  
2nd  
cause of  
death in  
Chile

**2005** goes into effect the new **Health Authority Act** & the law for **Explicit Health Guarantees (GES)**.  
**Childhood Cancer** was included “VII 2005 decreto N° 170”.

# Quality Managements Commitments

## Primary Care : Information & Education

- Cancer suspicion and referral
- Palliative Care



Quando sospechar cáncer.....  
Aprendizaje autogestionado  
2012



**¿HA VISTO UNA LUZ BLANCA  
EN EL OJO DE SU HIJO(A)?**  
(Un brillo como ojo de gato en un niño menor de 3 años)

**Puede ser cáncer de ojo,  
si lo atiende a tiempo,  
es posible salvar su vista y su vida.**

En su consultorio le informarán cómo derivarlo a un centro PINDA (Programa de Cáncer Infantil), más cercano y/o a la consulta de un especialista (Oftalmólogo), lo más rápido posible para descartar un retinoblastoma.

[www.minsal.uvirtual.cl](http://www.minsal.uvirtual.cl)



# Quality Managements Commitments

## **PINDA Centers :**

- Improve quality of diagnosis and stratification:  
Acces to CT scan, MRI and molecular biology technics
- Treatment and follow up according to stablished trials  
(up to 25 yeras)
- Team and protocols for Palliative Care and Pain Relief



## Guías Clínicas AUGE Leucemia en menores de 15 años

Noviembre 2014

Subsecretaría de Salud Pública  
División de prevención y Control de Enfermedades  
Departamento Manejo Integral del Cáncer y otros Tumores



## Guía Clínica Linfoma y tumores sólidos en menores de 15 años

2015

Subsecretaría de Salud Pública  
DIPRECE  
Departamento Manejo integral de Cáncer y otros Tumores



**CUÁNDO SOSPECHAR UN CÁNCER  
EN EL NIÑO Y COMO DERIVAR**

# Management Commitments

## Opportunity

### 1.- REFERENCE from Primary Care

For a child with suspected cancer:

it ensures attention within **7 working days** in a PINDA Center

### 2.- DIAGNOSIS & STRATIFICATION

From enrolment in PINDA Center : **Leukemias 7 working days.**

**Solid Tumors 30 working days.**

### 3.- TREATMENT & FOLLOW-UP **at least 10 years**

(IdDO 1002905)

# APRUEBA GARANTÍAS EXPLÍCITAS EN SALUD DEL RÉGIMEN GENERAL DE GARANTÍAS EN SALUD

Núm. 3.- Santiago, 27 de enero de 2016.

## LISTADO DE PRESTACIONES ESPECÍFICAS

ANEXO DECRETO  
RÉGIMEN DE GARANTÍAS EXPLÍCITAS EN SALUD  
2016

Cáncer infantil  
Pag. 155 -214



Redes de Atención  
Ges y No Ges  
2016

### c. Protección Financiera:

N°	Problema de Salud	Tipo de Intervención Sanitaria	Prestación o Grupo de Prestaciones	Periodicidad	Arancel	Copago %	Copago \$
14.-	CÁNCER en personas menores de 15 años	Diagnóstico	Confirmación y etapificación cáncer en menores de 15 años	cada vez	1.686.090	20%	337.220
		Tratamiento	Tratamiento tumores solidos cáncer en menores de 15 años	por tratamiento completo	6.357.160	20%	1.271.430
			Tratamiento leucemia cáncer en menores de 15 años	por tratamiento completo	7.312.830	20%	1.462.570
			Tratamiento linfoma cáncer en menores de 15 años	por tratamiento completo	5.628.910	20%	1.125.780
			Trasplante de médula autólogo	cada vez	33.517.400	20%	6.703.480
			Trasplante de médula alógeno	cada vez	67.789.590	20%	13.557.920
			Quimioterapia cáncer en menores de 15 años	mensual	746.280	20%	149.260
			Radioterapia Cáncer en menores de 15 años	por tratamiento completo	958.750	20%	191.750
			Tratamiento radioyodo	por tratamiento completo	196.560	20%	39.310
		Seguimiento	Seguimiento cáncer en menores de 15 años	por control	91.230	20%	18.250

4. ALIVIO DEL DOLOR Y CUIDADOS PALIATIVOS POR CÁNCER AVANZADO .....	77
4.1. TRATAMIENTO .....	77
4.1.1. Tratamiento Integral y Cuidados Paliativos por Cáncer Avanzado.....	77
4.1.2. Tratamiento Integral por Alivio del Dolor pacientes sin cáncer progresivo .....	78

c. Protección Financiera:

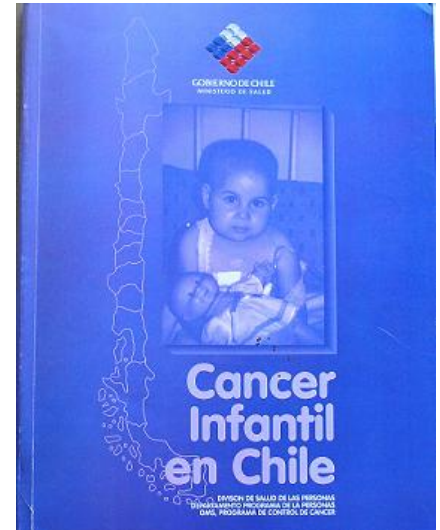
N°	Problema de Salud	Tipo de Intervención Sanitaria	Prestación o Grupo de Prestaciones	Periodicidad	Arancel	Copago %	Copago \$
4.-	ALIVIO DEL DOLOR Y CUIDADOS PALIATIVOS POR CÁNCER AVANZADO	Tratamiento	Tratamiento integral y cuidados paliativos por cáncer avanzado	mensual	94.450	20%	18.890
			Tratamiento integral por Alivio del Dolor sin cáncer progresivo	mensual	39.180	20%	7.840

## AUGE 14

CANCER INFANTIL - TUMORES HEMATOLÓGICOS						
Servicios de Salud	LINFOMA					TPH (Trasplante Medula Osea)
	HÓDGIN		NO HÓDGIN		Seguimiento	
	Diagnóstico	Quimioterapia	Diagnóstico	Quimioterapia		
Arica	H. Luis Calvo Mackenna, M. Oriente	H. Luis Calvo Mackenna, M. Oriente	H. Luis Calvo Mackenna, M. Oriente	H. Luis Calvo Mackenna, M. Oriente	H. Juan Noé, Arica * / H Luis Calvo Mackenna, M. Oriente	
Iquique	H. Luis Calvo Mackenna, M. Oriente	H. Luis Calvo Mackenna, M. Oriente	H. Luis Calvo Mackenna, M. Oriente	H. Luis Calvo Mackenna, M. Oriente	H. Luis Calvo Mackenna, M. Oriente	
Antofagasta	H Leonardo Guzmán, Antofagasta * / H. Luis Calvo Mackenna, M. Oriente	H Leonardo Guzmán, Antofagasta * / H. Luis Calvo Mackenna, M. Oriente	H Leonardo Guzmán, Antofagasta * / H. Luis Calvo Mackenna, M. Oriente	H Leonardo Guzmán, Antofagasta * / H. Luis Calvo Mackenna, M. Oriente	H Leonardo Guzmán, Antofagasta * / H. Luis Calvo Mackenna, M. Oriente	
Atacama	H. Roberto del Río, M. Norte	H. Roberto del Río, M. Norte	H. Roberto del Río, M. Norte	H. Roberto del Río, M. Norte	H. San José del Carmen, Copiapó* / H. Roberto del Río, M. Norte	
Coquimbo	H. Roberto del Río, M. Norte	H. Roberto del Río, M. Norte	H. Roberto del Río, M. Norte	H. Roberto del Río, M. Norte	H. San Pablo, Coquimbo * / H. Roberto del Río, M. Norte	

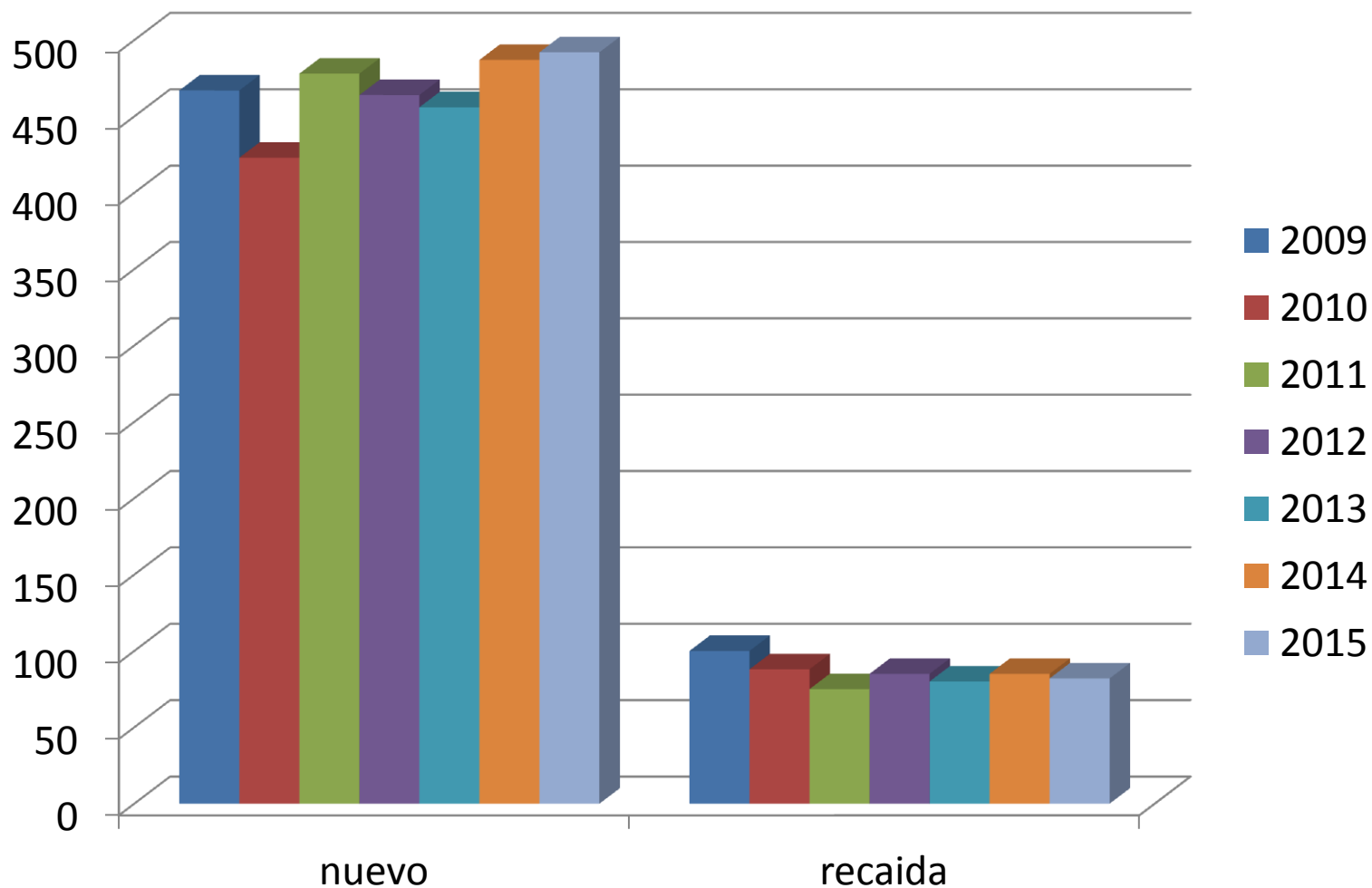
# Results Evaluation

- XXX National PINDA meetings
- International Meeting 1998 y 2004
- BFM 2012 meeting & 8º Leukemia symposium
- Annual reports
  - SLAOP - GALOP
  - SIOP
  - BFM





# PINDA : New cases and relapses /year 2009-15



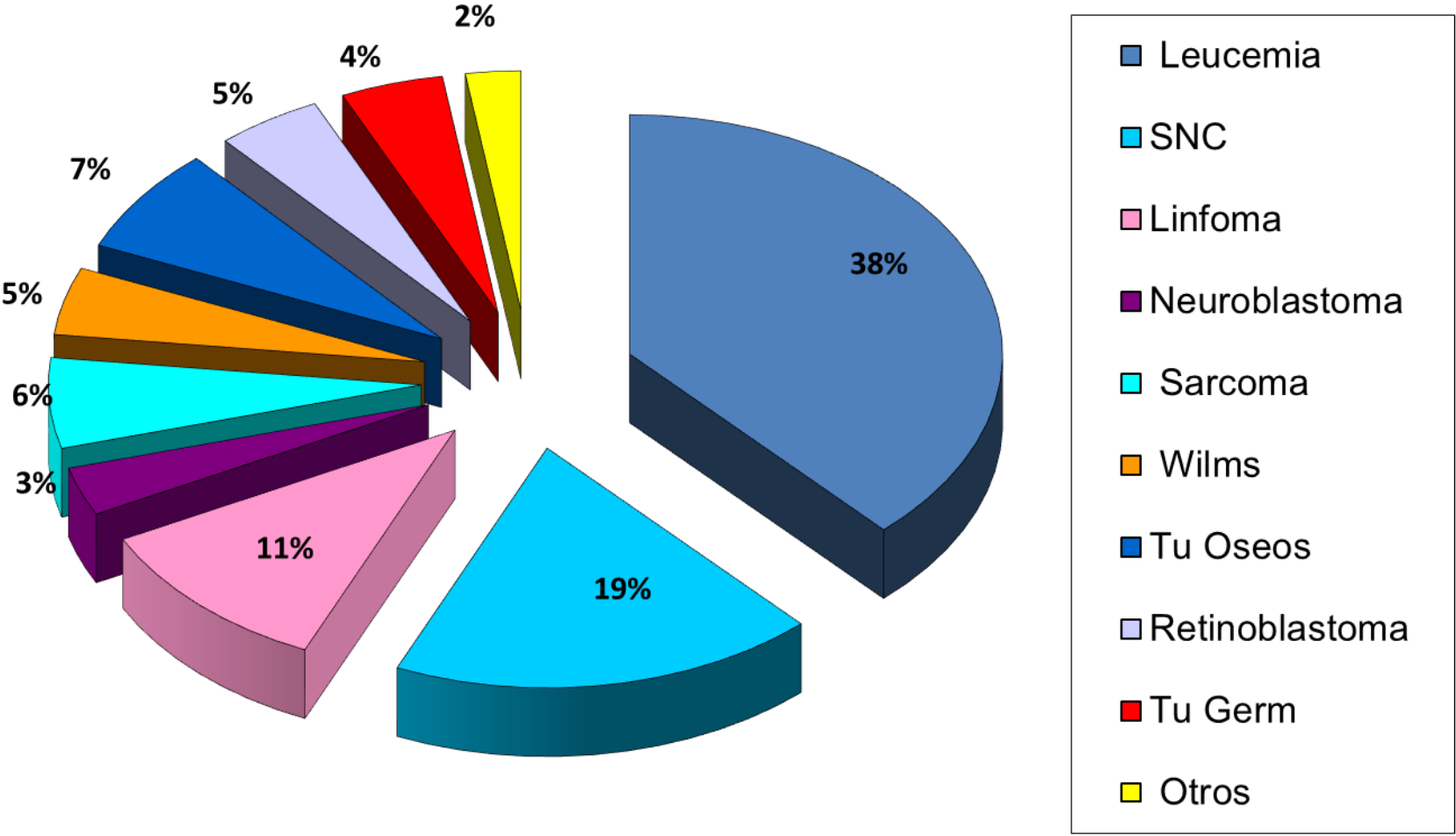
Mediana 467 casos nuevos- 82 recaídas

# PINDA Observed Cancer Incidence

- Median cases per year 

New	467
Relapse	82
- Observed incidence  
     $\approx 14$  cases x 100.000 < 15 años

# Distribution by types of cancer



# PINDA Results

n = 4279

## SLE 5 años (%)

<b>Protocolo</b>	<b>88</b>	<b>92</b>	<b>96</b>
Linfoma Hodgkin	83	95	96
Retinoblastoma	77	91	93
Tumor Wilms	81	85	89
Linfoma linfoblástico	52	67	86
Linfoma Burkitt	68	71	76
Leucemia linfoblástica	60	67	73
Sarcomas PB	45	52	73
Leucemia Mieloide	30	36	50
Recaídas LLA	-	16	32

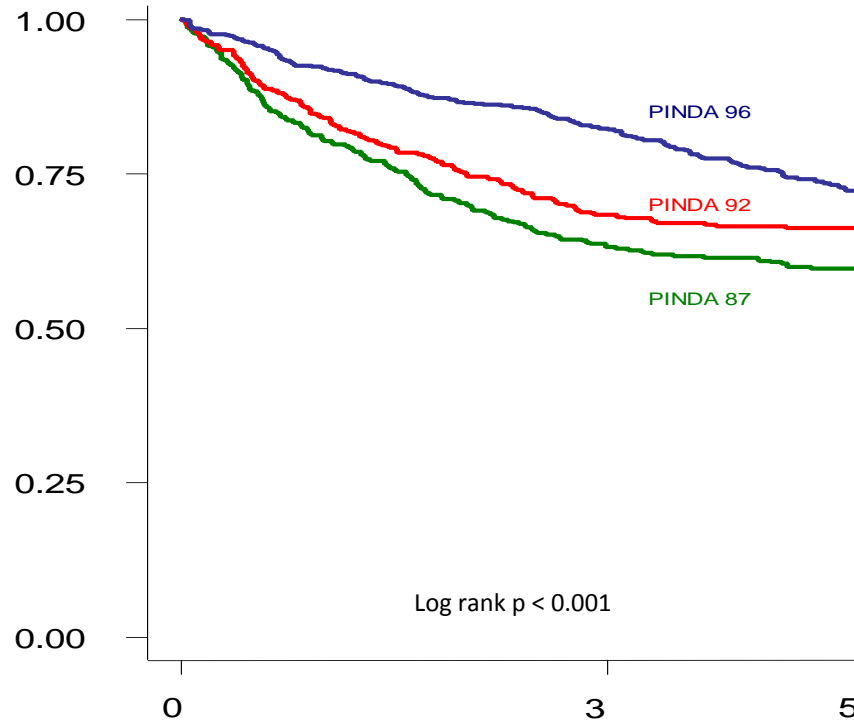
# Development in ALL

- 1988, BFM 86 adapted
- 1996 I-BFM-SG member
- MR Randomised trial
- ALL-IC-BFM 2002,all RG randomised
- ALL-IC-BFM 2009 all RG randomised
- Morphology
- Immunophenotype
- Cytogenetics
- Molecular Biology
- MRD by Flow cytometry

# ALL PINDA 87, 92, 96

## 5 years EFS

n = 1550



LLA PINDA 87 = 0.60, ES= .02 (n = 425, 167 eventos)

LLA PINDA 92 = 0.67, ES = .02 (n = 407, 136 eventos)

LLA PINDA 96 = 0.73, ES = .02 (n = 723, 197 eventos)

Med Ped Oncol,1999;33:88-94

Pediatric Blood Cancer 2004; 43:17-22

Lancet 2007;369:123-31

# I- BFM- SG LLA RM 95 : pulses Vcr/ Dexa

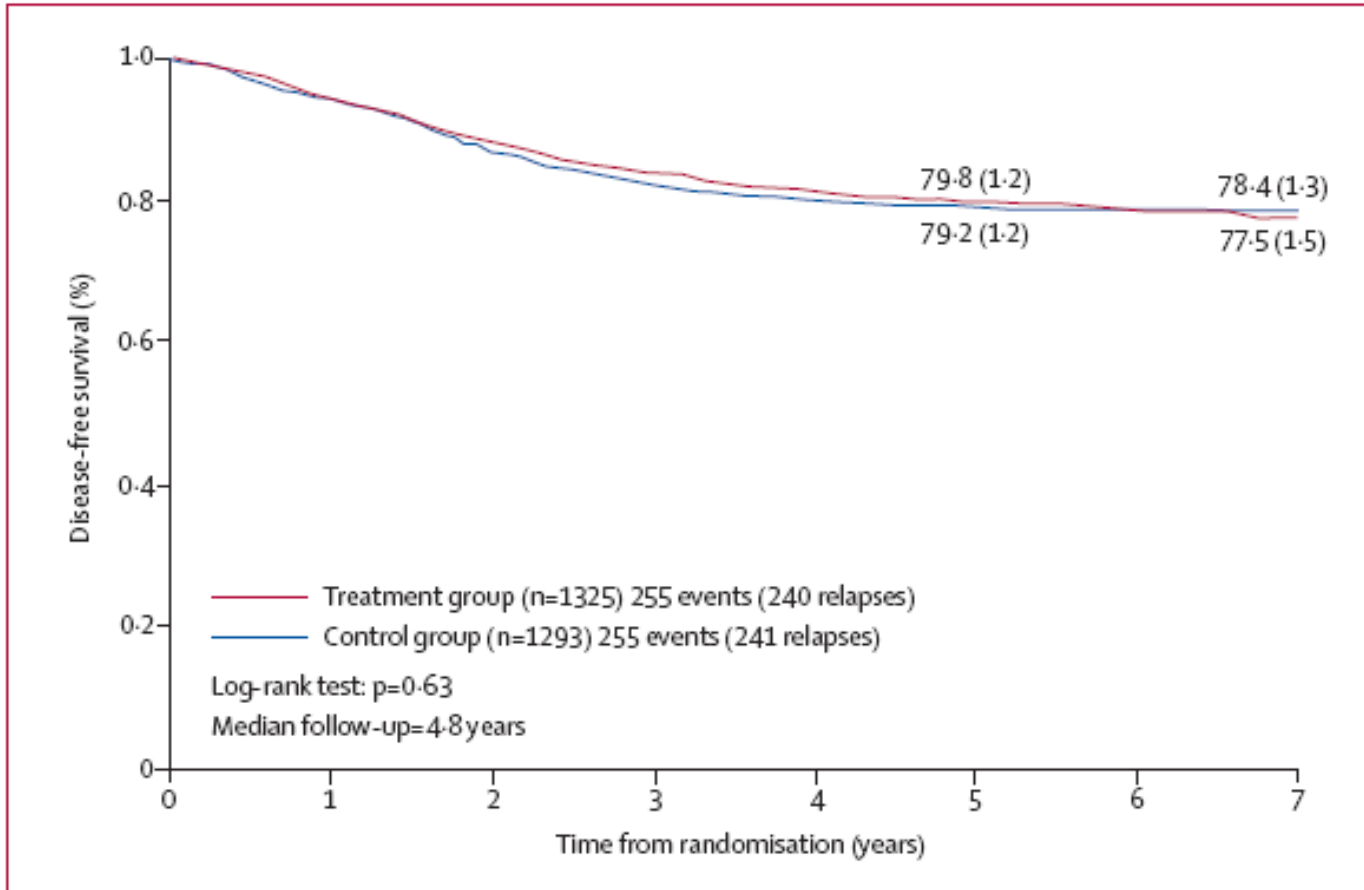
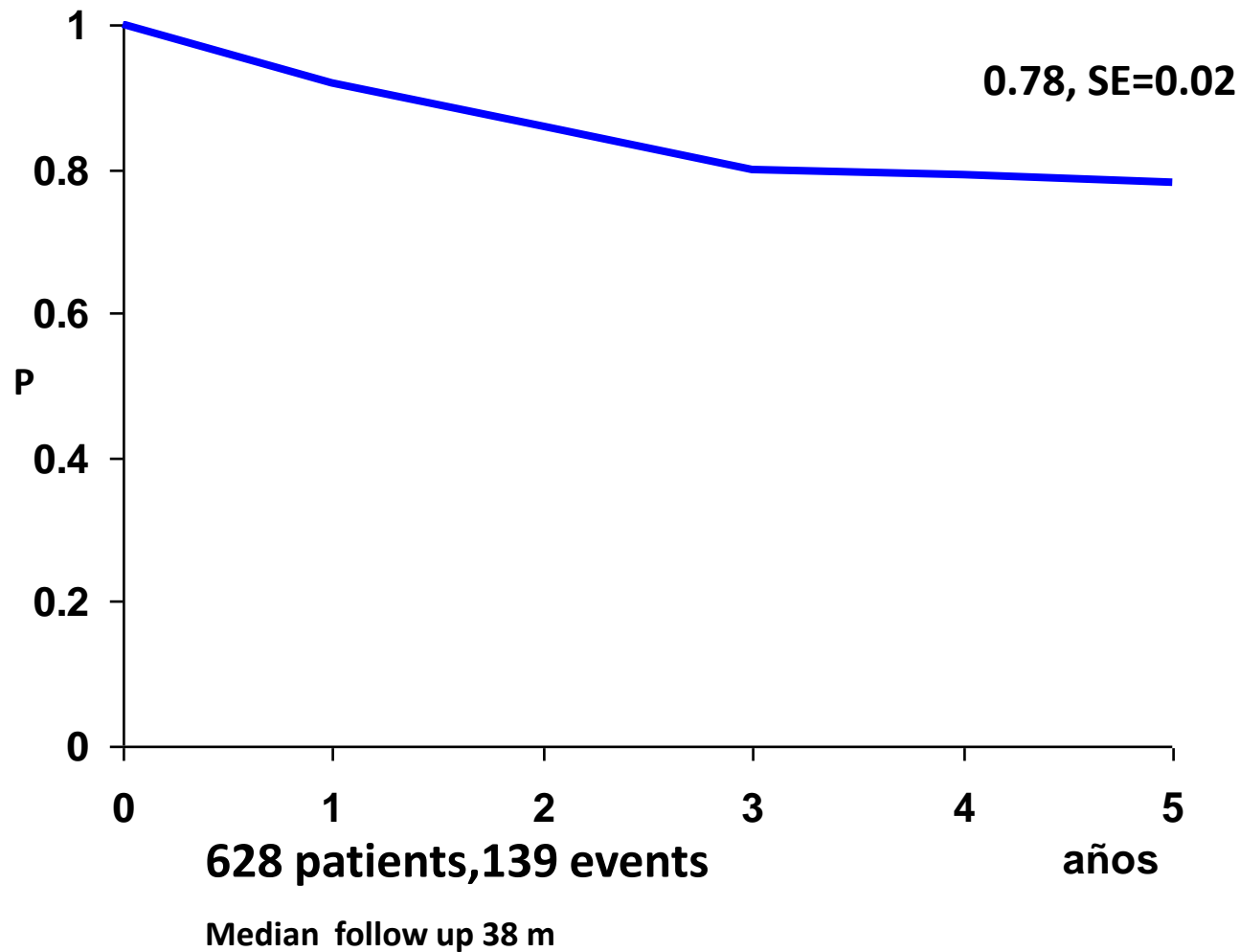


Figure 3: Disease-free survival curves in treatment and control groups

BFM, A, AEIOP, Czech R, Hungary, EORTC, GATLA, **PINDA**

# ALL-IC-BFM- PINDA 2002

n= 5060 from 15 countries





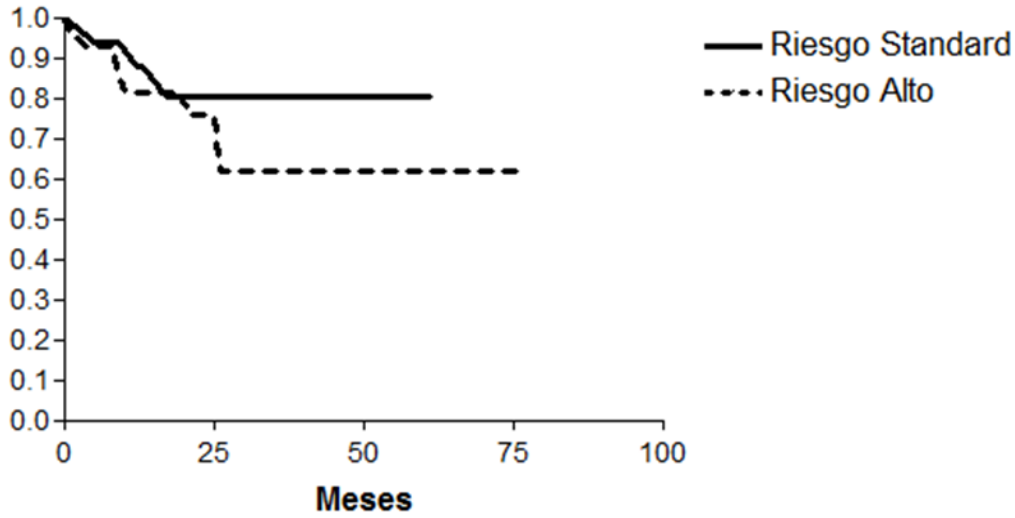
# Active trials

n = 3000

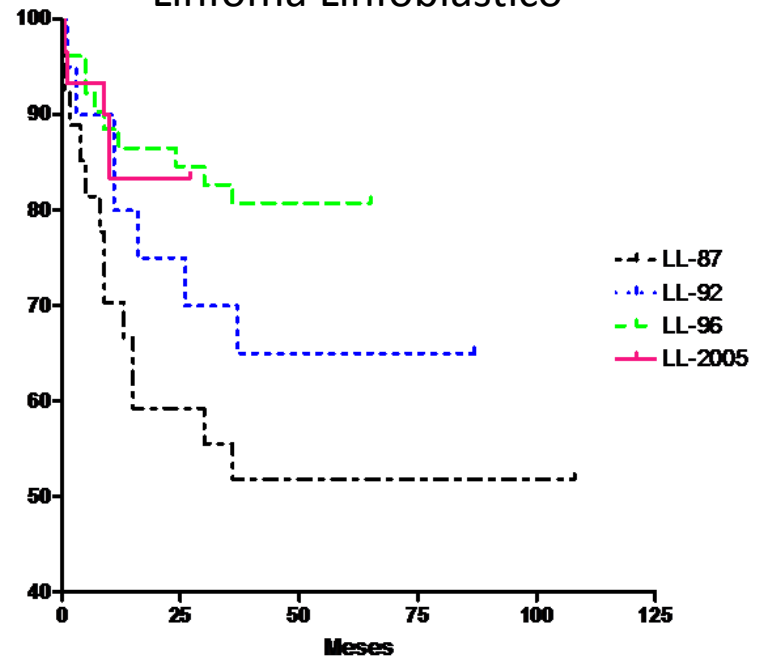
± 78% SLE/ST

Tu Germinal no SNC	95
Linfoma Hodgkin	92
Tumor Wilms	89
Linfoma linfoblástico	87
Retinoblastoma	87
Osteosarcomas	78
Sarcomas	73
Meduloblastoma	67
Leucemia Mieloide	50

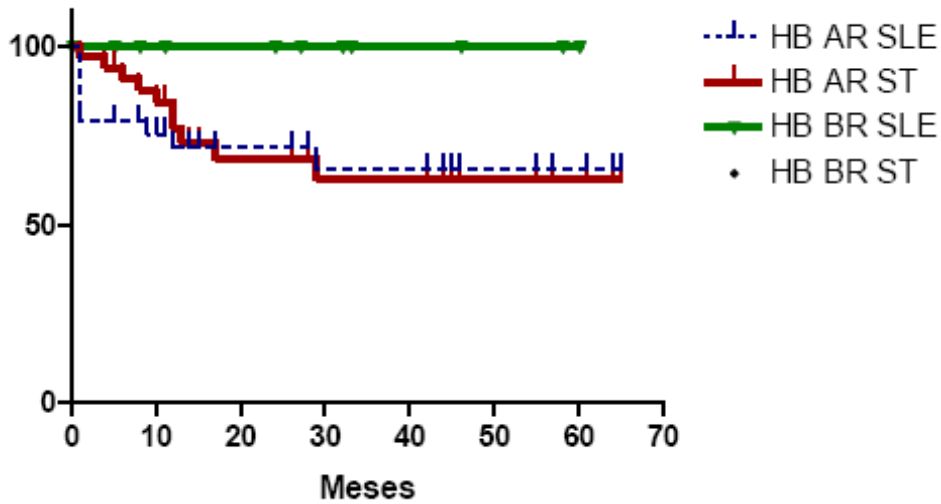
### Medulloblastoma SLE 2007-2013



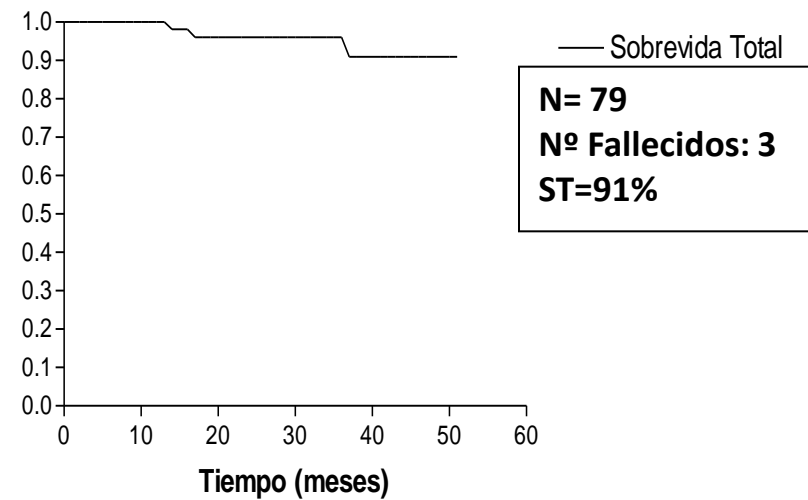
### Linfoma Linfoblástico



### Hepatoblastoma



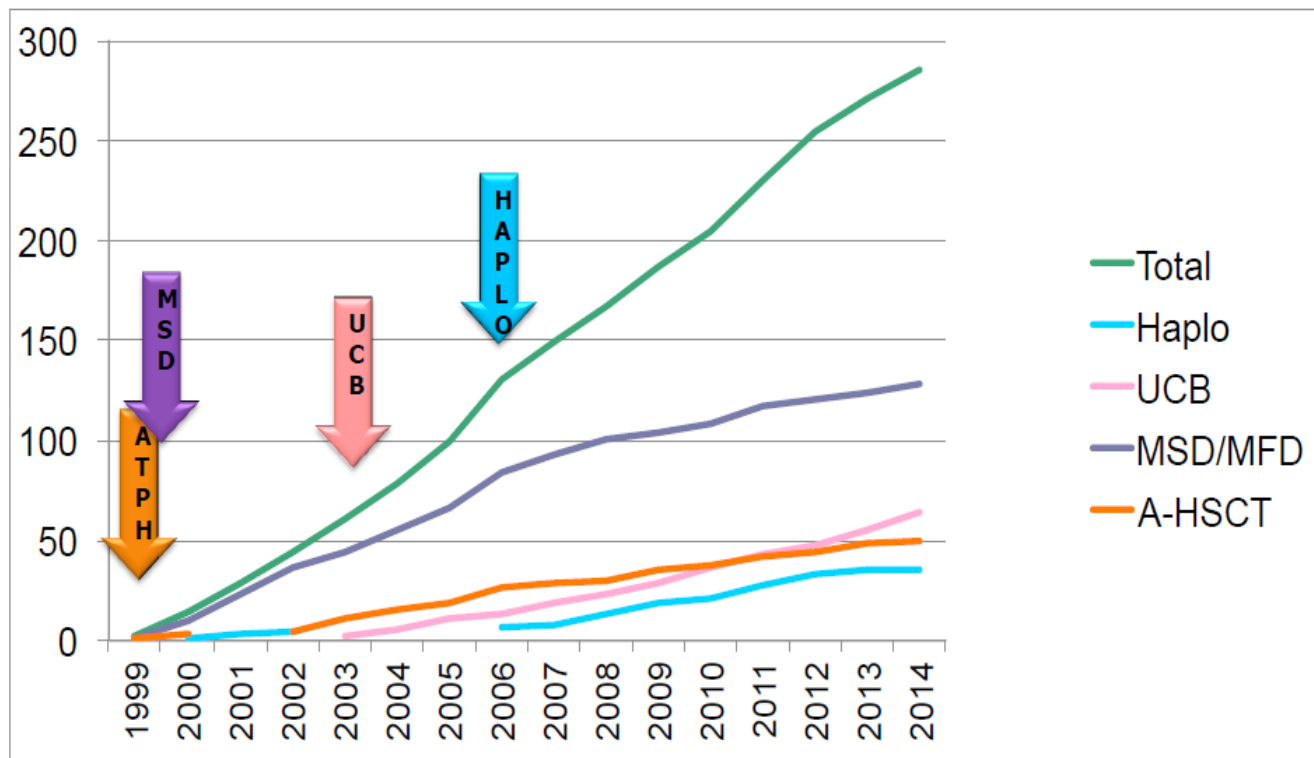
### Linfoma Hodgkin



# Bone Marrow Transplant Unit

## H L Calvo Mackenna

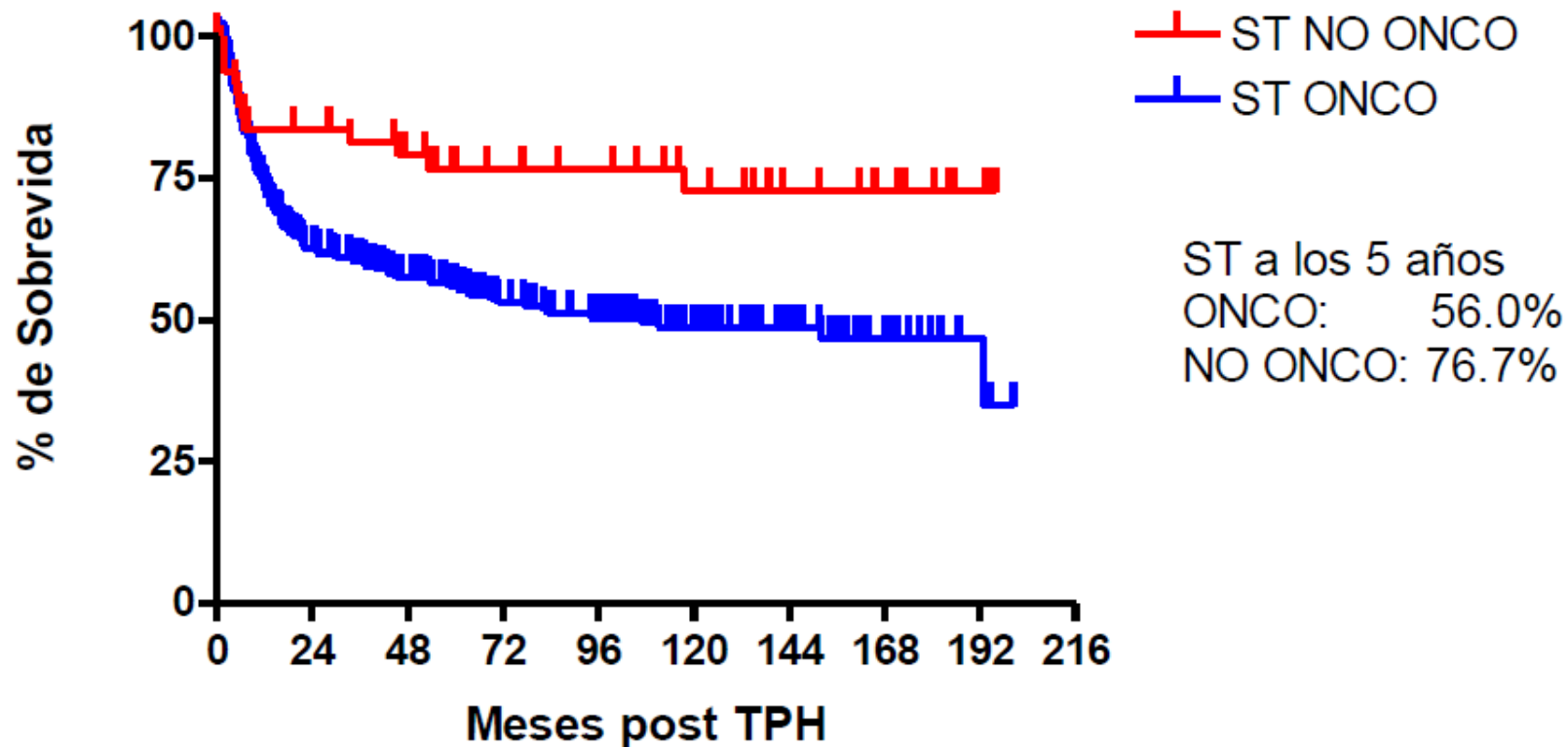
Actividad de Trasplante  
1999 – 2016



# Bone Marrow Transplant Unit

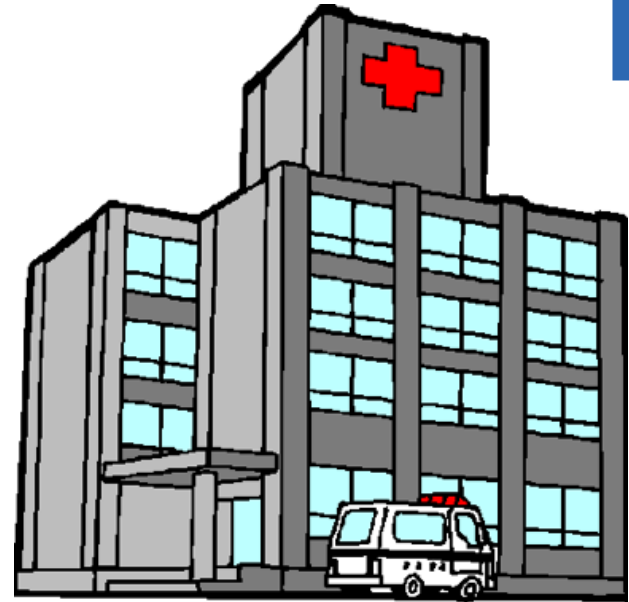
## H L Calvo Mackenna

**Sobrevida Total**  
**n=318 trasplantes**  
No Onco: 49 Onco: 269





**Trained Staff**



**INFRASTRUCTURE**



**Technology – Equipment**  
**ICU**  
**Centralized Blood Banks**  
**Specialized Labs**

# International BFM SG members (1996)

- ALLIC BFM2009
- INTERFANT 2006
- ESPHALL
- Myeloid Leukemias
- Lymphomas
- BMT trials
- Ambiguous leukemia

# Participation in other Groups

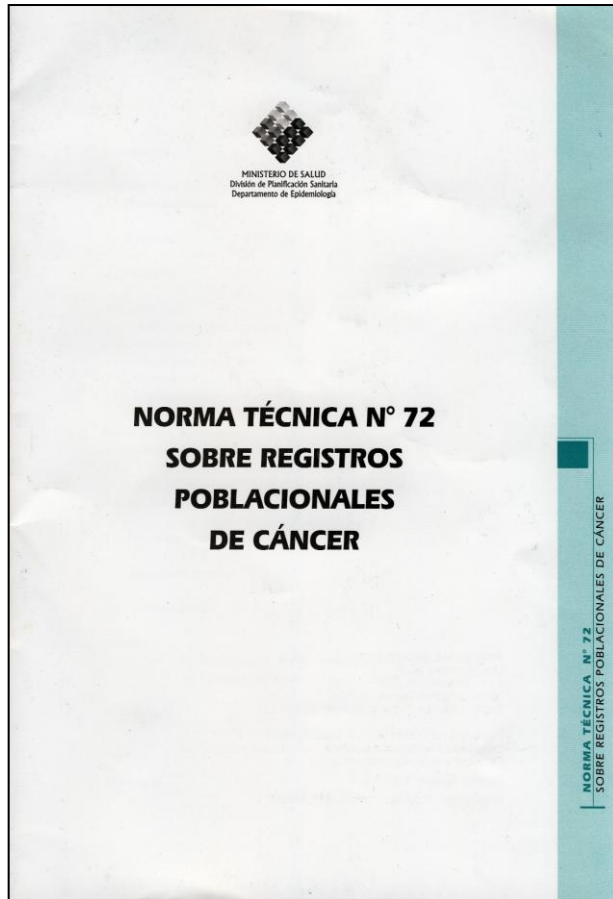
- Hospital St'Jude Osteosarcoma 99.  
Pediatr Blood Cancer 2008;50: 1143-46
- SIOPEL IV Hepatoblastoma
- GALOP Ewing Sarcoma  
Unilateral Retinoblastoma
- Toronto Intraocular Retinoblastoma

# Specialists training

- Pediatric Hematoncologist U de Chile (2 years)  
3 places/year
- Nurse Pediatric Oncologist  
U Católica (1 year)  
3 places/year
- Training nurses in Palliative Care and Oncology  
(4 months)



# Childhood Cancer National Registry RENCI



- Developed by Minsal with the support of PINDA and Fundación Nuestros Hijos
- According to Standard Technic Standard N° 72
- Based in IARC and ICCC-3

# RENCI : Childhood Cancer. Incidence per year 2007-2011

Año de Incidencia (diagnóstico)	Total		
	Nº	%	Tasa (*)
2007	506	21,0	132,7
2008	512	21,3	135,7
2009	456	19,0	121,8
2010	426	17,7	114,5
2011	504	21,0	136,1
Total	2404	100,0	128,2

**85% treated in PINDA**

\*Tasa x millon

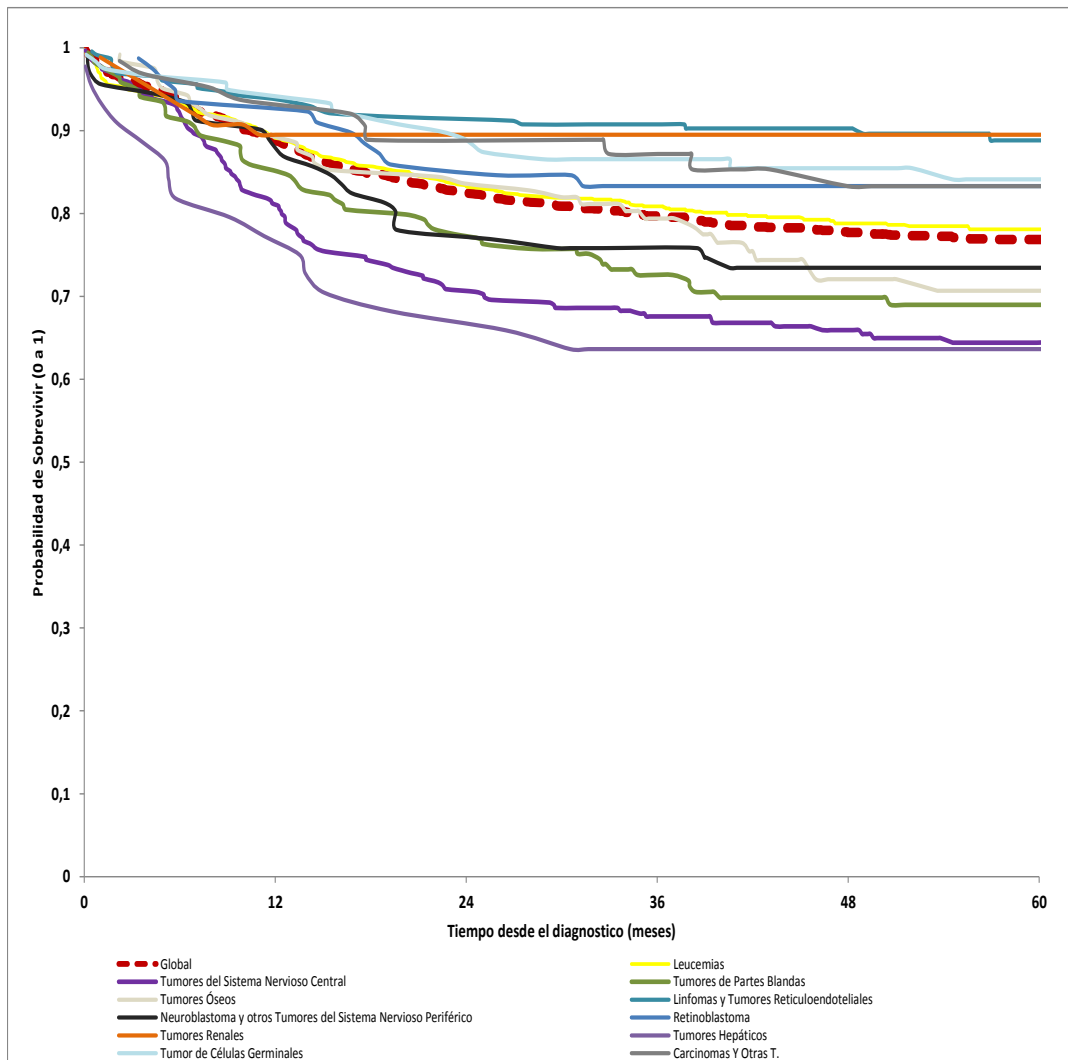
# Incidence by type of Cancer

RENCI 2007-2011

Grupos de Cáncer		Nº Casos anuales	%	Tasa por millón
I	Leucemias	193	40,1	51,5
II	Linfomas y Tumores Reticuloendoteliales	48	9,9	12,7
III	Tumores del Sistema Nervioso Central	76	15,8	20,3
IV	Neuroblastoma y otros Tumores del SNP	20	4,1	5,2
V	Retinoblastoma	16	3,3	4,3
VI	Tumores Renales	19	3,9	5,0
VII	Tumores Hepáticos	9	2,0	2,5
VIII	Tumores Óseos	26	5,4	7,0
IX	Tumores de Partes Blandas	34	7,1	9,1
X	Tumor de Células Germinales	24	5,0	6,4
XI	Carcinomas y Otras tumores Epiteliales	13	2,6	3,4
XII	Otros tumores malignos no especificados	3	0,7	0,9
	Total	481	100,0	128,2

# Survival by type of Cancer

## 2007-2011



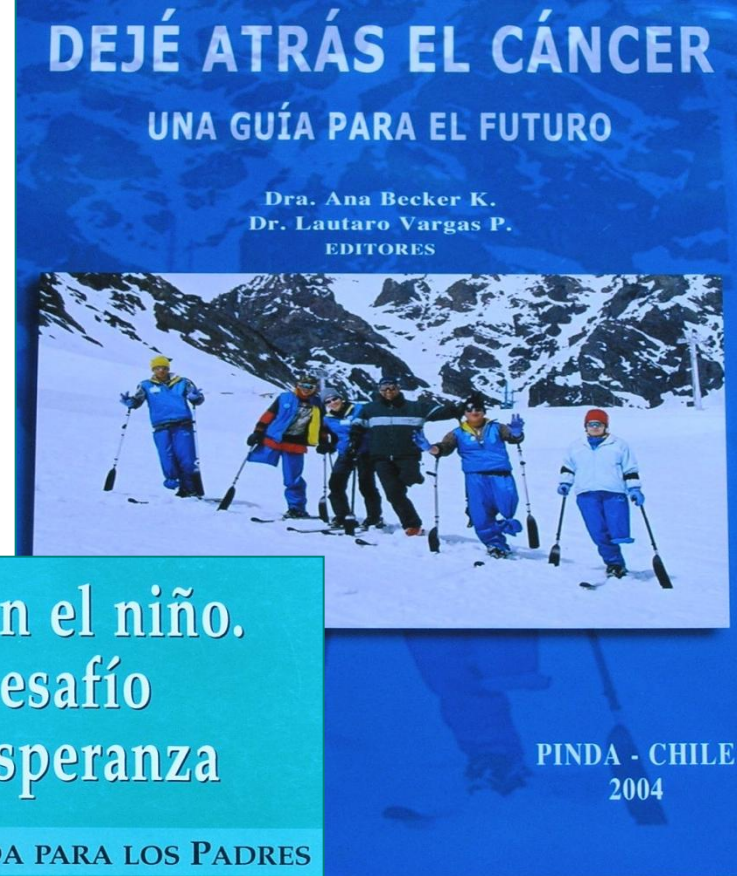
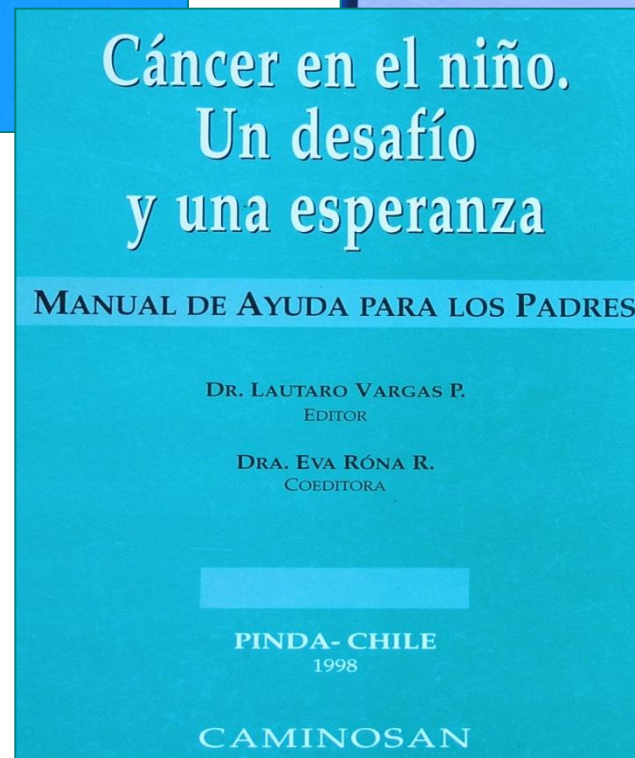
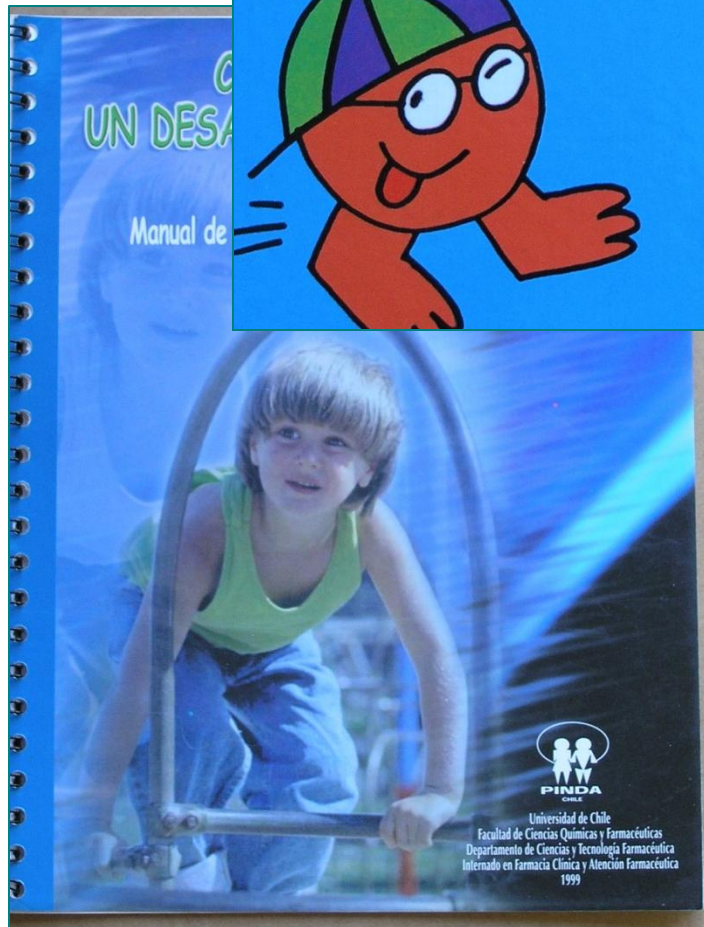
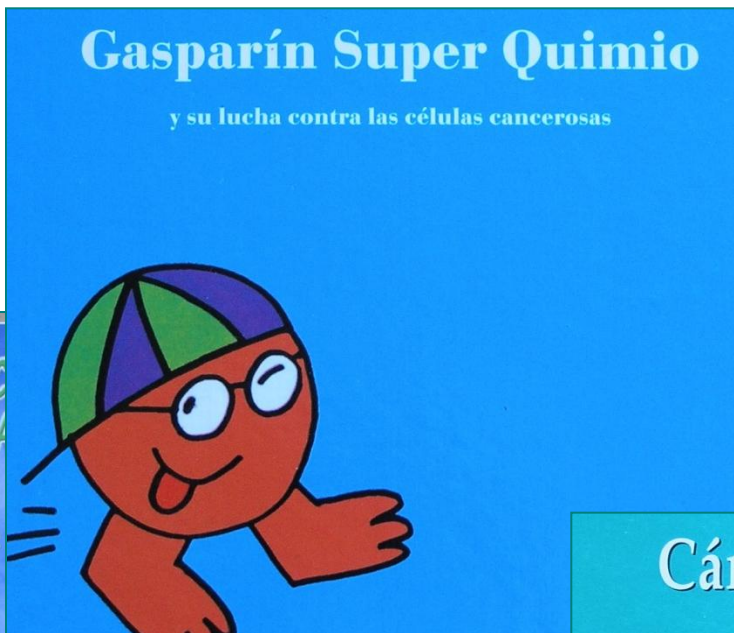
Sobrevida por grupos de cancer (ICCC v3)		
	60 meses	
	Prob (%)	IC 95%
VI Tumores Renales	89,5	(80,8 - 94,4)
II Linfomas y Tumores Reticuloendoteliales	88,8	(83,7 - 92,4)
X Tumor de Células Germinales	84,1	(75,8 - 89,8)
V Retinoblastoma	83,3	(73,0 - 90,0)
XI Carcinomas y Otras tumores Epiteliales	83,3	(71,1 - 90,7)
I Leucemias	78,1	(75,2 - 80,7)
<b>Global</b>	<b>76,9</b>	<b>(75,0 - 78,6)</b>
Neuroblastoma y otros		
IV Tumores del Sistema Nervioso Periférico	73,5	(63,1 - 81,4)
VIII Tumores Óseos	70,7	(61,1 - 78,3)
IX Tumores de Partes Blandas	69,0	(61,2 - 75,5)
III Tumores del Sistema Nervioso Central	64,4	(58,6 - 69,6)
VII Tumores Hepáticos	63,6	(47,7 - 75,9)

# Foundations and Volontiers

- Support children and families
- Recreation activities
- Support Oncology Units
- Shelters
- Support hospital Schools
- Support investigations



GOBIERNO DE CHILE  
MINISTERIO DE SALUD



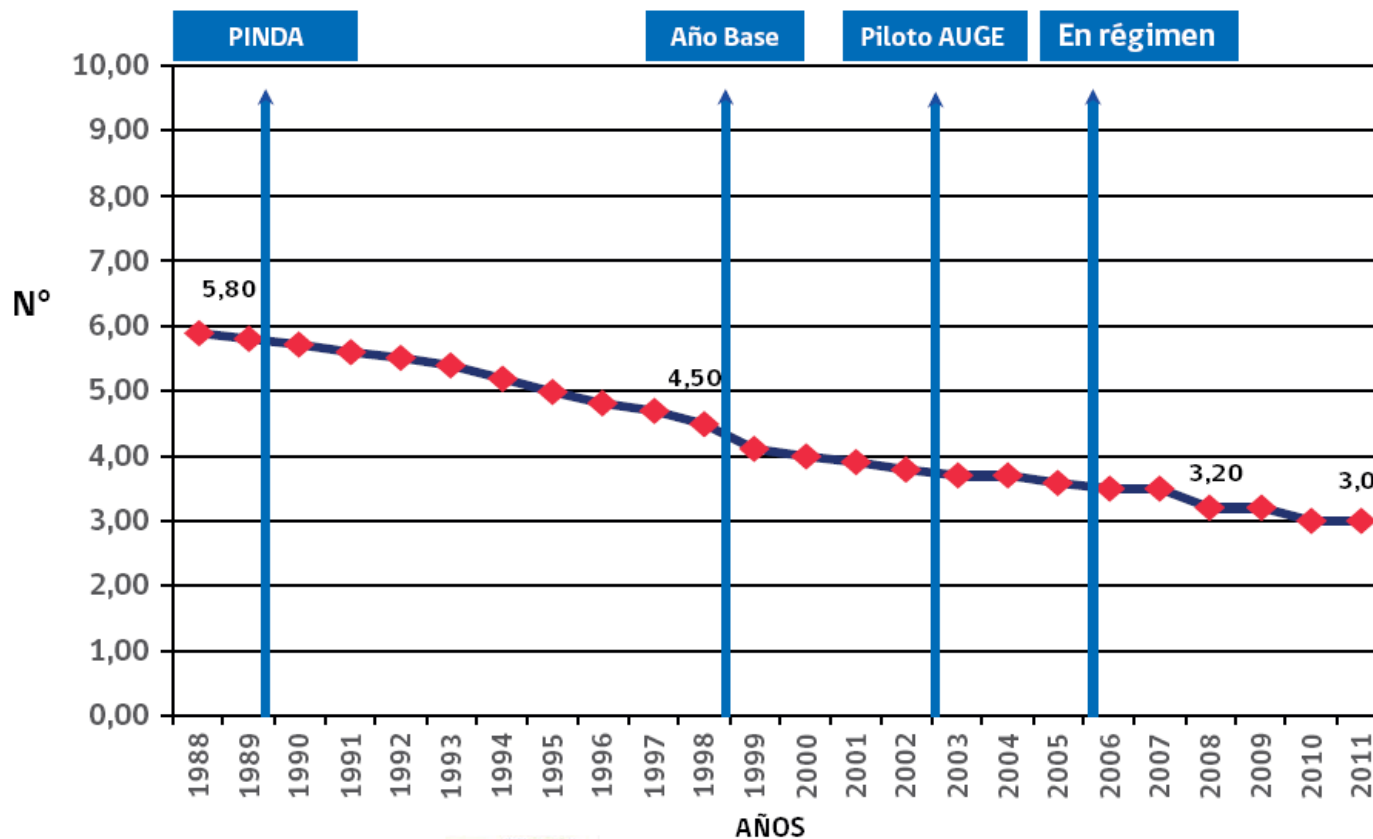
**Education: child, family & care givers**

# European standard 2011

## to take care children with cancer

- Every patient should receive the best possible treatment
- Specialized centers, multidisciplinary trained team ensures better survival
- Create a center with > 30 cases per year
- Pain Relief and Palliative Care
- Follow up, late effects
- Cancer Registry
- National and international networks

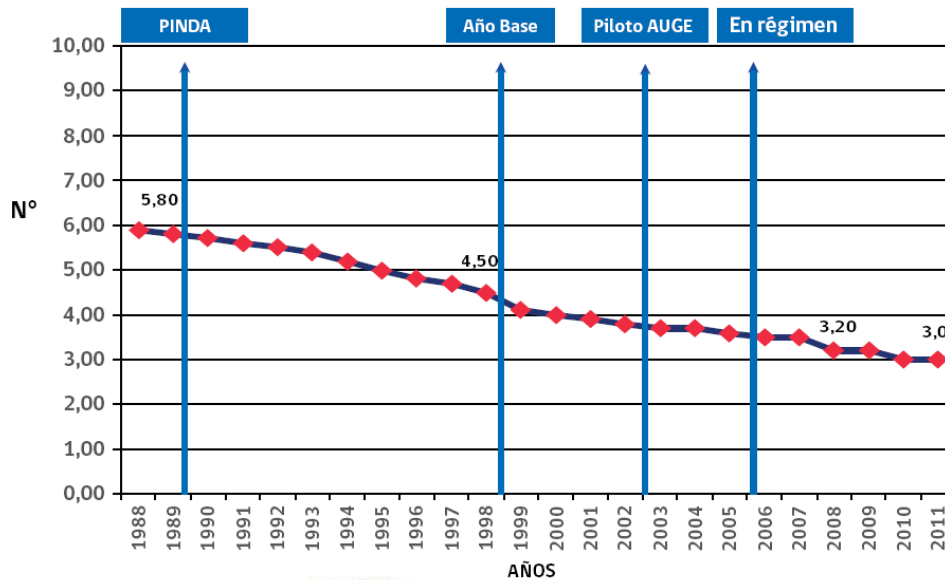
# Childhood Cancer Mortality rate





# Strategic Objectives of the Cancer Program 2011-2020

✓ Mortality rate reduction 5%



	Año 2012	Año 2013
# Deaths	150	125

✓ Improve Survival over 78%

# Gaps, Challenges and Opportunities for Improvement

## Strengths

- Integral Cancer Program, with legal and financial support
- Specialized centers with trained multidisciplinary teams. .
- Clinical Guidelines guide the best therapeutic recommendation
- Protocols with proven effectiveness
- Quality control standards
- Monitoring and evaluation according to annual and long term indicators – Pediatric cancer Registry

## Weaknesses

- > 15 years not included
- Biobank still is a proyect
- Short access to latest generation images
- Implementation of new diagnostic techniques
- Lack of research support
- Protocols with pending publications.
- Wages not in line with the market
- Lack of specialist retention program (multidisciplinary)

# Gaps, Challenges and Opportunities for Improvement

## Opportunities

- Continuous improvement of the program
- Dissemination of results at national and international level.
- The knowledge of the results allows to implement new interventions
- Permanent interest in working on a successful health program
- .

## Threats

- Training of specialists depends to a large extent on the education sector rather than on the health sector
- Fragility of the care network to maintain quality standards.
- .Risk of migration of specialists to the private sector

# Key external actors for the development of PINDA

- Internacional BFM Study Group (I- BFM –SG)
- St’Jude Research Hospital

ROL :Sharing knowledge and experience to improve diagnosis and treatment of children with cancer

- Hospital Vall d’ Hebron ,Barcelona
- Hospital for Sick Children Toronto, Canada

ROL : Train subspecialists to improve diagnosis and treatment of children with cancer

# Support needed to continue development of PINDA

1. Partnerships for the improvement of the professionals who collaborate in the maintenance of the current quality standards.
2. Support in the creation of the Pediatric Biobank, currently in the process of generating legal regulations. Training of professional team, generation of collaborative research in LA and others.
3. Generation of Bone Marrow donor registry , in alliance with LA, USA, Europe.
4. Registry of Childhood Cancer: training in coding and publication of results in IARC
5. Support to support other countries to generate a Childhood Cancer Program

# Conclusions

- ✓ PINDA has diminished childhood cancer mortality
- ✓ To improve we need to augment the transnational trial collaboration
- ✓ We offer our collaboration with other countries



**Muchas gracias**