

Webinar ICORD, May 20, 2021

**ARE LAWS THE SOLUTION FOR RARE
DISEASES?
SITUATION IN COSTA RICA**

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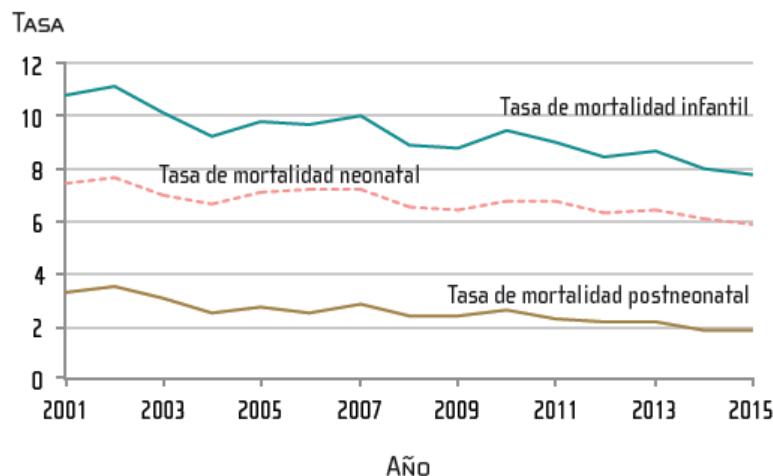


Population	→ 5 163 038
Life Expectancy	→ 80,6 años
Infant Mortality	→ 7.97 / 1 000
2nd Cause of infant death	→ Malformaciones congénitas
Total health investment	→ 9.3% PIB

GRÁFICO 2

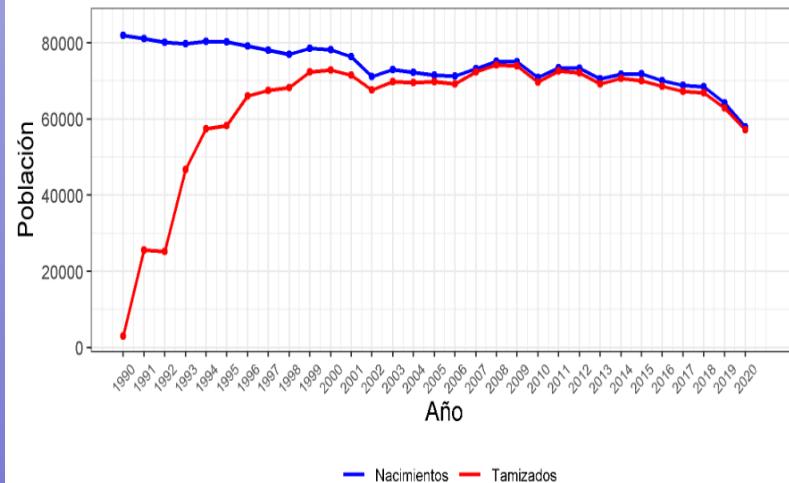
Tasas de mortalidad infantil, neonatal y postneonatal (por mil)

2001 - 2015



Evolución de la cobertura PNT

1990-2020



Fuente: base de datos Lab-PNT, INEC

GRÁFICO 3

Distribución porcentual de defunciones infantiles según causa de muerte

2010 - 2015

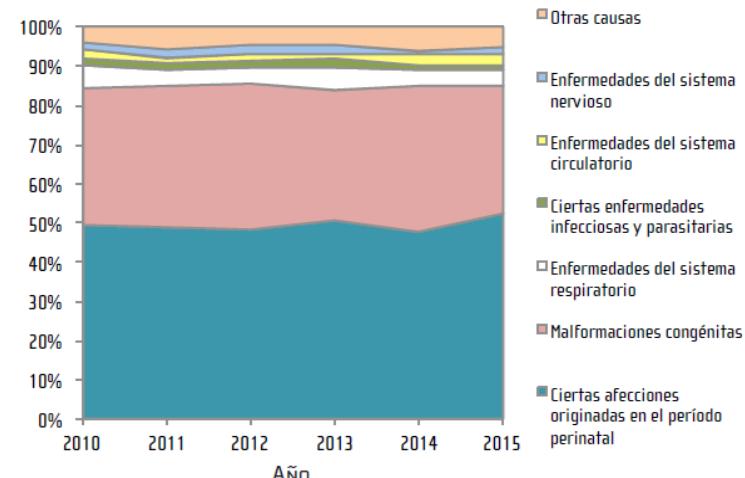
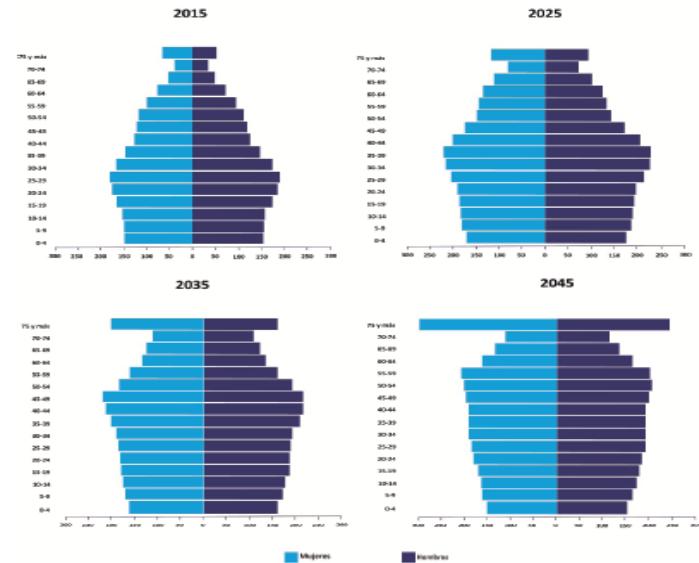


Gráfico 1. Estructura poblacional Costa Rica 2015, 2025, 2035, 2045



Fuente: tomado de la referencia (1).

Source: INEC, Boletín Semestral, Vol.1. Año 20 Mortalidad Infantil y Evolución Reciente, 2015.

Legal jurisdiction of the Costa Rican National Health System

- **Constitutive Law of the Social Security Health System.** Law 17 from Oct 22, 1943
 - Sickness
 - Maternity
 - Disability, Eld and Death
- **1956** Extension coverage for:
 - Wife
 - Offspring
 - Parents
- **1973 Universalization of the Social Security Health System.** Law 5349 from Sept 24, 1973
- **National Health Law.** Law 5395 from Oct 30, 1973
- **1977** Join to a single public health system
- **1983** Extension coverage to marginal and indigent
- **1990** Executive Order 40147 for the **National Newborn Screening Program**
- **1996 Law for Equal opportunities for disabled people** Law 7600
- **1998** Extension coverage for Schoolchildren and native americans
- **2002** Extension coverage for pregnant women and children under 1 year of age.

BASIC PRINCIPLES OF THE COSTA RICAN NATIONAL SOCIAL SECURITY HEALTH SYSTEM

- Public insurance**
- Universality**
- Solidarity**
- Obligatory**

Law for Universalization of the Social Security Health System. Law 5349 from Sept 24, 1973

Integración del Sistema Nacional de Salud

Ministerio de Salud (MS)

Caja Costarricense de Seguro Social (CCSS)

Instituto Nacional de Seguros (INS)

Instituto Costarricense de Acueductos y Alcantarillados (AyA)

Universidades e institutos, públicos y privados encargados de formar y capacitar a los profesionales y técnicos de salud.

Servicios de salud privados, cooperativas y empresas de autogestión que brindan servicios de promoción de la salud, prevención de la enfermedad, curación y rehabilitación de la salud de las personas.

Municipalidades

Comunidades

Fuente: basado en la referencia (38).

Asamblea Legislativa. Decreto Ejecutivo N°19276 Reglamento general de Sistema de Salud. Sistema costarricense de Información Jurídica 1989

Figura 1 Organización, funcionamiento y esquema de financiamiento del sistema de salud de Costa Rica

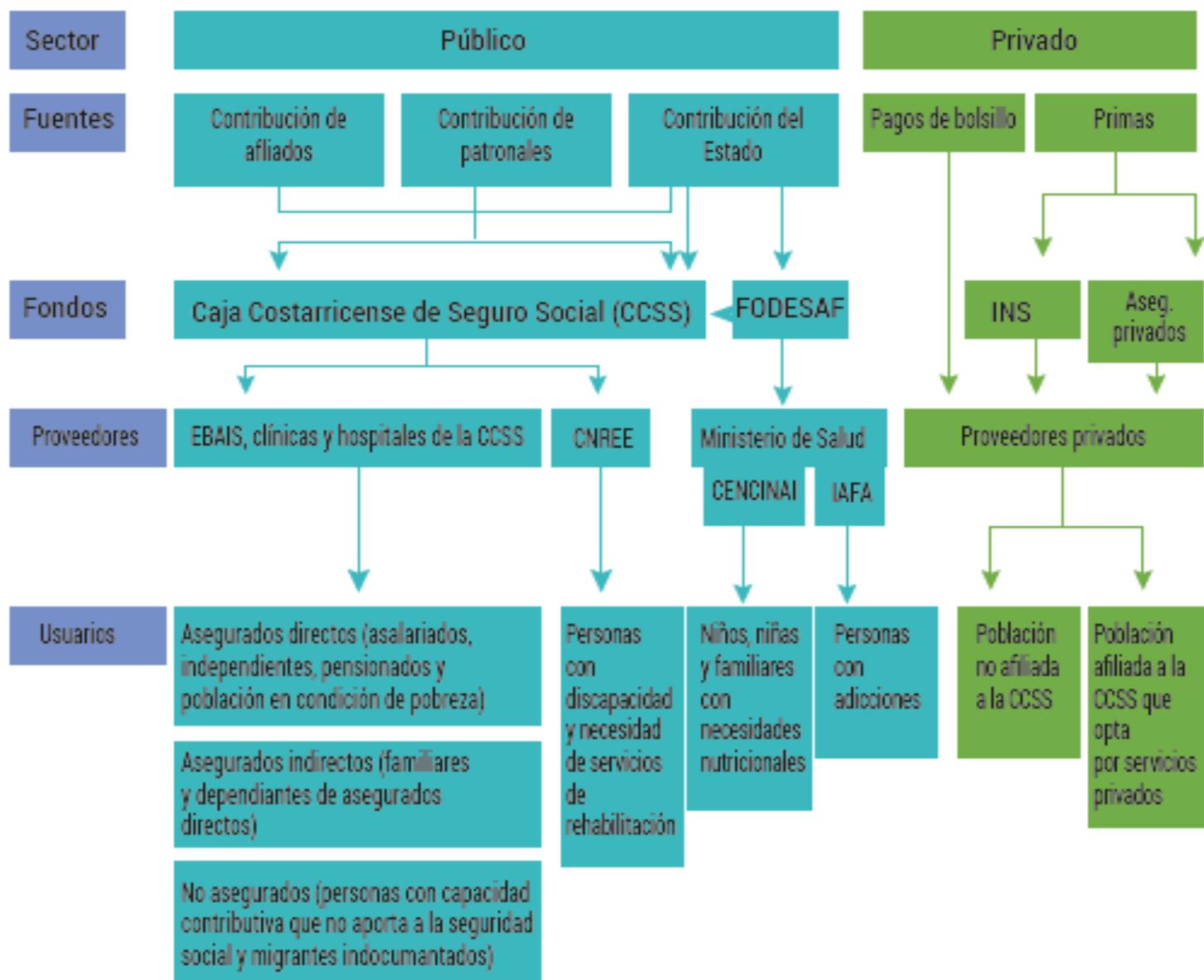
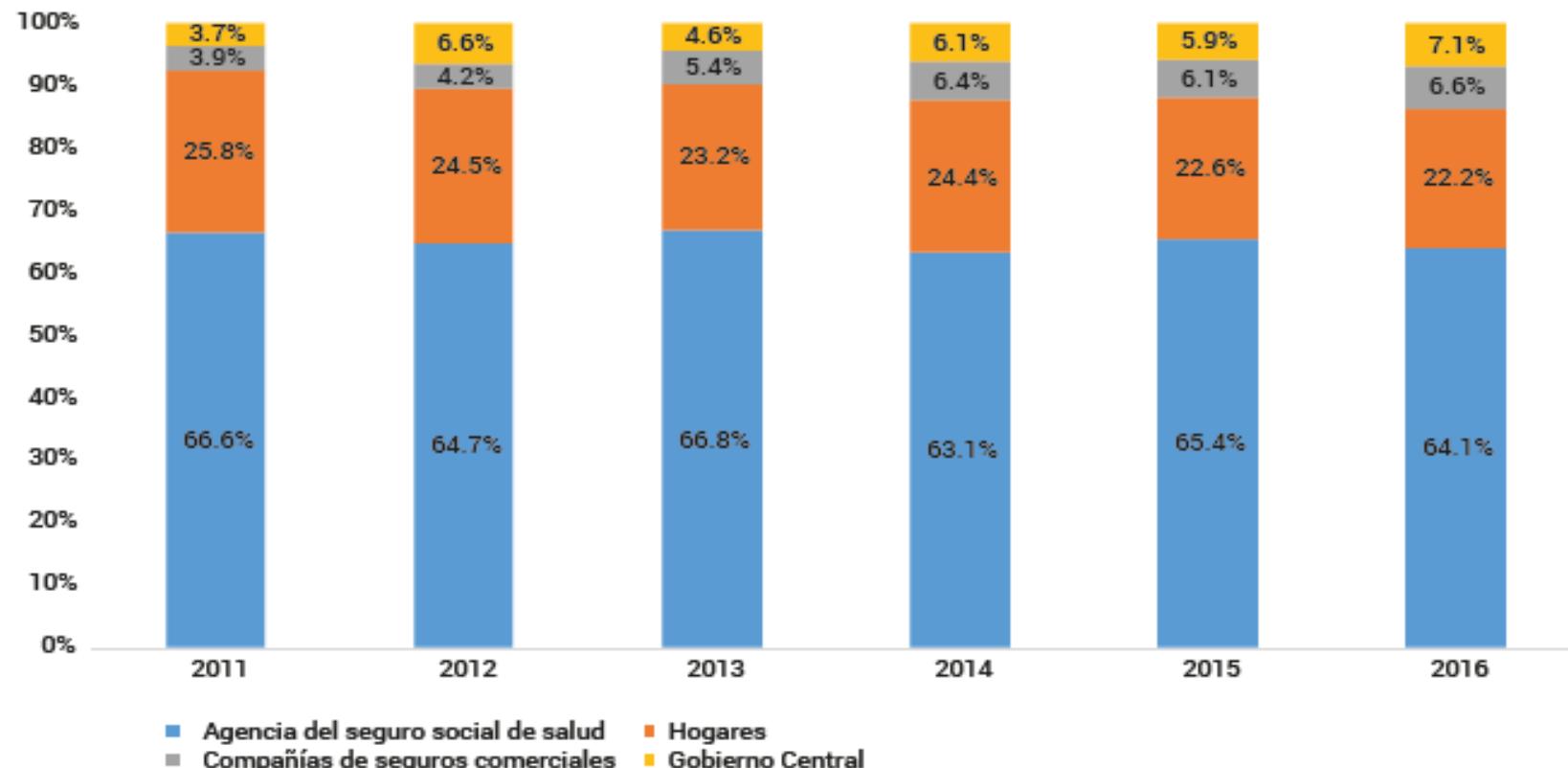


Tabla 6 Costa Rica: porcentaje del gasto total en salud, según actor, periodo 2011-2016

Descripción	2011	2012	2013	2014	2015	2016
CCSS	67,9%	68,5%	68,0%	67,2%	68,9%	69,6%
Hogares	25,3%	24,0%	22,3%	23,7%	21,9%	21,4%
INS	3,2%	3,5%	5,2%	4,1%	4,4%	4,0%
Ministerio de Salud 1/	3,3%	3,7%	3,7%	3,6%	3,6%	3,4%
Seguros Privados	0,3%	0,4%	0,7%	1,4%	1,3%	1,6%
Monto total	1.785.369	1.879.451	2.027.482	2.199.889	2.354.980	2.422.927

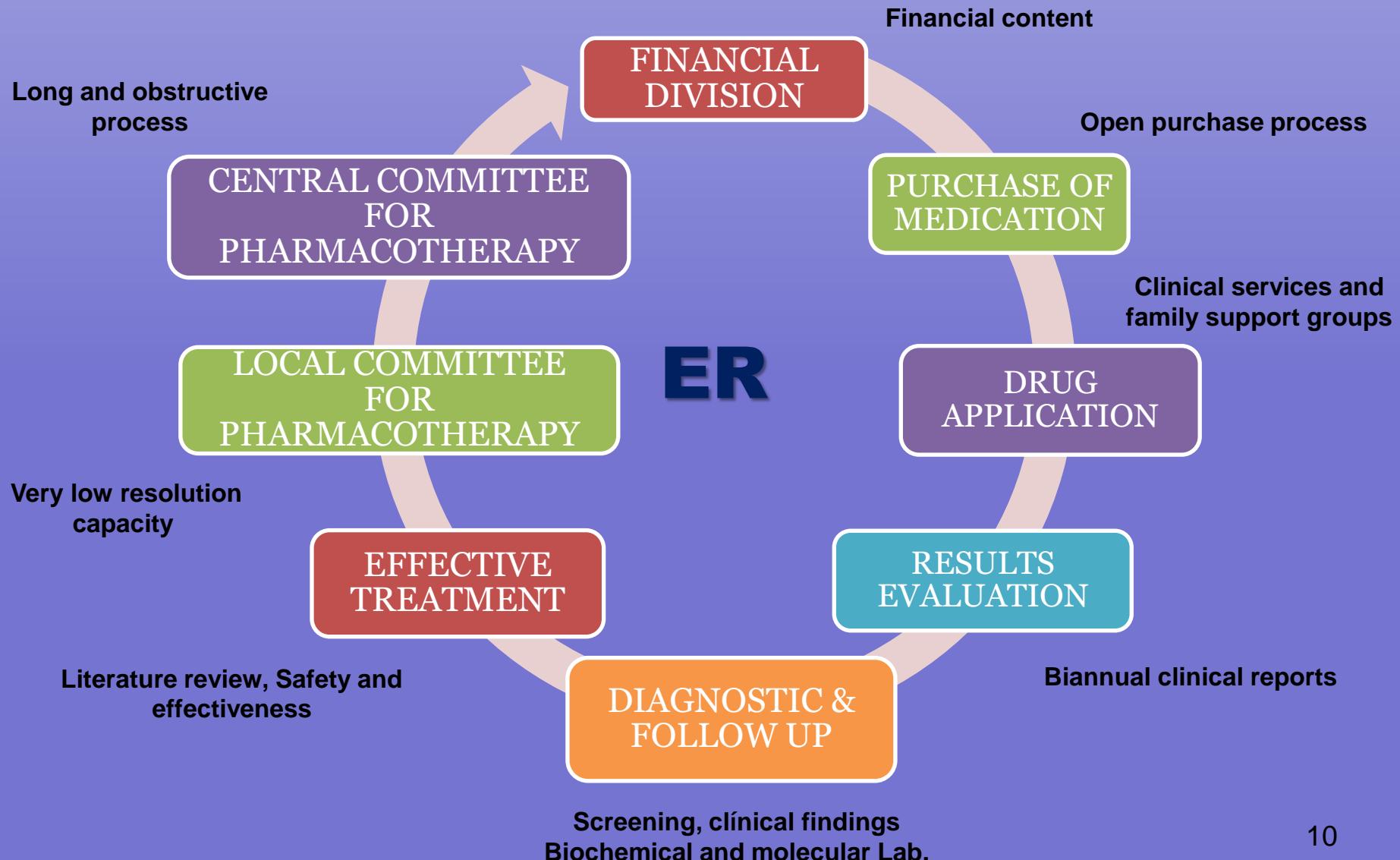
Fuente: tomado de la referencia (58).

Gráfico 4 Costa Rica: agentes de financiamiento en salud y su aporte como porcentaje del gasto total en salud, periodo 2011-2016



Fuente: tomado de la referencia (53).

ORPHAN DRUG APPLICATION PROCESS FOR RARE DISEASES IN COSTA RICA



ARE LAWS THE SOLUTION FOR RARE DISEASES?

- **Yes** they are a requirement for a legal definition of the health system
- **Yes** they are needed to define health institution responsibilities
- **Yes** they are needed to define the society commitment for individuals with rare diseases and their families
- **Not** necessary for diagnosis
- **Not** necessary to determine the ideal medical therapy
- **Not** functional without financial support
- **No** need for new laws if the system is already well defined

Facilitating factors to achieve therapies for rare diseases in Costa Rica

- Existence of a Constitutional Court
- Active Office of the Ombudsman
- Presence of organized pressure groups
- Presence of Adult Rare Diseases Clinic
- Active healthcare groups
- Negotiation margins for state/pharmaceutical purchases
- Dynamic local representatives from pharmaceutical providers

Some difficulties for adequate rare disease therapy in Costa Rica

- Not enough advanced diagnostic molecular tests
- High cost of therapies
- Not enough pharmaceutical representation in the local market
- Lack of healthcare groups interested in managing rare diseases nationwide
- 8000 Rare Diseases

HOSPITAL NACIONAL DE NIÑOS

San José, Costa Rica



CENTRO PARA LA PREVENCION DE DISCAPACIDADES (CPD)

