

Rare Diseases, situation in Costa Rica

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Costa Rica

extension: 51 000 square kilometers
population: 5 163 000 inhabitants
currency: colon (615 per \$1)
life expectancy: 80.6 years
infant mortality: 7.97/ 1000
health expenditure: 9.3% of GDP
annual deliveries: 57 000/ year



Existing local legislation and policies

- **1949**. Health is a **right**, according to the Costa Rican Constitution
 - **1990***. Heel prick screening test. Started out with a small No. of conditions, it grew to 29 and is **currently performed for 51**.
 - **1996***. Law of Equal Opportunities for Persons with Disabilities
 - All pregnant ladies, all babies <1yr., all school children, all indigenous, individuals, **are covered regardless**
 - **NO SPECIFIC RDs LAW YET!**
- *significant work of Dr. M. Saborío

Current areas of activities

- Active lab. at the Center for Prevention of Disabilities (National Children's Hosp- Heel prick) to Dx RDs
- Ongoing meetings of various stakeholders at Congress-woman Valladares' office, to write a legislation proposal
- Creation of diseases Associations (pts., families, physicians, others)
- Participation in different forums (RD day, PH day, biomedical research, ICORD, etc.)
- Legal counseling

Current pt's associations in CR

- Hereditary angioedema
- Asociación Prana de CR.
- Anasovi
- Multiple sclerosis Assoc.
- Spinal muscular atrophy Association
- Ehler Danlos Association
- Pulmonary hypertension Association

Barriers, or Obstacles

- Lack of knowledge of national burden of RDs
- Low physician recognition of pts with RDs. (GPs)
- Inadequate distribution/ number of specialized human resources
- Inadequate means (infraestructure, labs or equipment) to make a Dx
- Limited CCSS list of medications for RDs.
- Long and cumbersome national process to register meds.
- High cost of many indicated meds.
- Low interest in research in general and in RDs particularly

Challenges ➤ eventual solutions

- To establish research programs (which diseases?, how many pts.?, how bad?, personnel availability, etc.)
- To introduce necessary curricular changes in health careers
- To determine referral centers for specific diseases (already occurs in Peds, and in 1 adult hosp.)
- Implement a well rounded and funded RDs legislation
- Attend international forums to share info and directions