

# **Puerto Rico Birth Defects Surveillance System: Efforts for reporting prenatal diagnostic data**

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Diana Valencia, MS  
Department of Health, San Juan, PR



Estado Libre Asociado de Puerto Rico  
Departamento de Salud



# Background

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- ❑ PR BDSS was established in 1995
- ❑ Active surveillance since 1999
- ❑ Since 2004 a law requires every health facility to have a log book for birth defects and to report all cases to the PRDOH
- ❑ ~ 51,000 live births each year
- ❑ Birth defects 2<sup>nd</sup> major cause of infant mortality
- ❑ Main source of bd data: birthing hospitals, pediatric and cardiovascular hospitals; high risk clinic and other agencies.



# Purpose

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- 1999 collaboration with the University of Puerto Rico Hospital's (HOPU) high risk clinic
  - Tertiary hospital
  - Receives referrals from all clinics and hospitals across the island
  - Two of the three perinatologist in PR practice in this clinic



# What we do

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- Since 1999, every prenatal diagnosis of an NTD is referred to us for follow up.
- Verify dx
- Enter information into a data base different than the BDSS data base
- Follow up until delivery
- Transfer case with all documentation to data entry of BDSS



# What we do

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- The family is contacted and offered:
  - Counseling services
  - Referrals to the spinal bifida association
  - Participation in a molecular study
  - Referrals to other community services as necessary
- Printed educational material is mailed
- Follow up is given until time of delivery



# What we do

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- Currently we offer the same service for:
  - Gastroschisis / omphalocele
  - Limb defects
  - Oral clefts
  - Trisomies
  - Conjoin twins

# Prenatal referrals for 2006

Birth defect	Cases referred prenataly
NTD	53% (20/38)
Gastroschisis	39% (7/18)
Omphalocele	17% (1/6)
Down Syndrome	11% (6/56)
Limb defects	10% (1/10)
Trisomy 18	13% (2/15)
Trisomy 13	36% (4/11)
Conjoin twins	100% (1/1)



# What we do

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- A total of 42 prenatal cases were referred to our System
- All cases were counseled and referred to agencies in the community according to the needs of the parents and the patient
- Some have not been born yet





# What we do

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- Prenatal data is not entered into the BDSS data base until
  - The baby is born (alive or dead)
  - The diagnosis is confirmed
  
- We are expanding our collaboration to other high risk clinics



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