

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

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Background

- ❑ 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 2nd major cause of infant mortality
- ❑ Main source of bd data: birthing hospitals, pediatric and cardiovascular hospitals; high risk clinic and other agencies.



Purpose

- 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

- 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

- 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

- 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

- 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

- 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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