

What the DOH is doing for Rare Disease and its Role in the Proposed Act

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Officicer-in-Charge

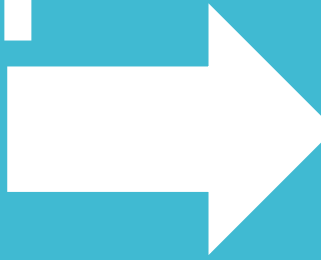
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Department of Health



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**What is the DOH Currently
Doing for Patients with Rare
Diseases?**



Under the DOH's National Comprehensive Newborn Screening Program (RA 9288):

What DOH is currently doing for rare disease patients

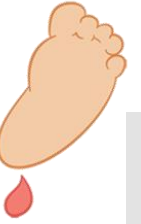
1. Ensure every newborn has access to NBS
2. Establish and integrate a sustainable newborn screening system in the public health delivery system



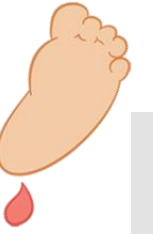
What DOH is currently doing for rare disease patients



Under the DOH's National Comprehensive Newborn Screening Program (RA 9288):



3. Ensure all health practitioners are aware of the advantages of NBS and their responsibility in offering newborns to undergo NBS
4. Ensure parents recognize their responsibility in promoting the child's right to health and full development within the context of responsible parenthood, by protecting their child from preventable disabilities and death through NBS

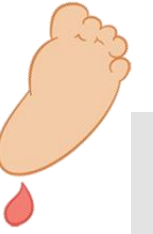


What DOH is currently doing for rare disease patients



Under the DOH's National Comprehensive Newborn Screening Program (RA 9288):

- Screening for 3 out of 6 rare diseases currently in NBS panel of disorders (PKU, Gal and MSUD)
- NBS part of Philhealth newborn care package

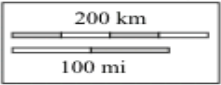


What DOH is currently doing for rare disease patients



Under the DOH's National Comprehensive Newborn Screening Program (RA 9288):

- Referral and treatment network for management and care of patients
- **Continuity Clinics** for per region equipped to facilitate continuity of care of patients confirmed with heritable (including rare) conditions



11 Continuity Clinics in operation

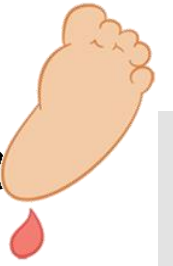
Continuity Clinic MAP

- Ilocos Training and Regional Medical Center, Region 1
- Cagayan Valley Medical Center, Region 2
- Jose B. Lingad Memorial Regional Hospital, Region 3
- Baguio General Hospital and Medical Center, CAR
- Philippine General Hospital, NCR
- Gen. Emilio Aguinaldo Memorial Hospital, CALABARZON
- Bicol Regional Training and Teaching Hospital, Region 5
- West Visayas State University Medical Center, Region 6
- *Vicente Sotto Memorial Medical Center, Region 7*
- *Eastern Visayas Regional Medical Center, Region 8*
- *Zamboanga City Medical Center, Region 9*
- Northern Mindanao Medical Center, Region 10
- Southern Philippines Medical Center, Region 11
- Cotabato Regional Medical Center, Region 12

What DOH is currently doing for rare disease patients



Under the DOH's National Comprehensive Newborn Screening Program (RA 9288):



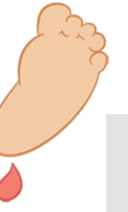
In the pipelines:

- Genetic Counseling will be available in all regions;
- A Telegenetics Referral System to be utilized by the NBS Continuity Clinics and Birth Defects Continuity Clinics where subspecialists are not available in the hospital;

What DOH is currently doing for rare disease patients



Under the DOH's National Comprehensive Newborn Screening Program (RA 9288):



In the pipelines:

- Expanded newborn screening coverage to cover 26 diseases (from 6); 25 of the 26 diseases in the Expanded NBS are rare.

What DOH is currently doing for rare disease patients

1.2 →

Under DOH National Center for Pharmaceutical Access and Management

- Rare Disease Medicine Access Program granting Php 11 million for 2 years (2012, 2014) for the ff:
 - P10 million for enzyme replacement therapy/treatment of 2 Gaucher Disease patients for each year
 - P1 million for patient navigation

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**What is the Role of the DOH in
the Proposed Rare Disease Act?**

What is the Role of the DOH in the proposed Rare Disease Act?

2.1 →

As Lead Agency in implementation:

- Establish the Technical Working group for the Rare Diseases;
- Develop the implementing rules and regulation for the implementation of this Bill within one hundred eighty (180) days from the enactment of the Law;

What is the Role of the DOH in the proposed Rare Disease Act?

2.1 →

As Lead Agency in implementation:

- Coordinate with the National Institutes of Health for the technical assistance in the implementation of the Act;
- Coordinate with all government and non-government agencies that will be involved in the implementation of the Act;

What is the Role of the DOH in the proposed Rare Disease Act?

2.1 →

As Lead Agency in implementation:

- Designate referral centers in strategic location in the country for the timely and sustainable medical management of persons afflicted with rare disorders;
- Organize a pool of medical specialists who will be responsible in the diagnosis and management of persons afflicted with rare disorders and their families; and
- Allot budget for the implementation of the law.

Goal:
**Inclusion of Rare Diseases in the Universal Health Program
by integrating in the delivery of health services**

