Integration of Rare Diseases in the Philippine National Health System

Second High Level Event of the NGO Committee for Rare Diseases
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Topic Coverage

- Milestones
- PSOD’s contribution to the passage of the Rare Diseases Act
- Salient features of the Rare Diseases Act
- Provisions on the pending Universal Health Care Act impacting implementation of the RDA
- Persons With Rare Diseases Claim: Our to Right to Life
Milestones

1990’s: Early case findings of PWRD

2006: Formation of PSOD

Republic Act 9288
Newborn Screening Act of 2004

Republic Act 10747
Rare Diseases Act of the Philippines 2016

2019: Consolidated UHC Bill submitted for signature
PSOD’s Contribution to the Passage of the RDA

Rare Disease Medicine Access Program 2011, 2013 and 2018

Ground level lobbying for the passage of RDA

Member of the Technical Working Group
Salient Features of the Rare Diseases Act

Policy Declaration: The RDA mandates that persons suffering with rare disease have the right to survival and full and healthy development through access to timely health information and adequate medical care that is:

<table>
<thead>
<tr>
<th>COMPREHENSIVE</th>
<th>INTEGRATED</th>
<th>SUSTAINABLE</th>
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<tbody>
<tr>
<td>➢ NBS continuity care nationwide</td>
<td>➢ Public Educational and Information campaign by the DOH</td>
<td>➢ PhilHealth Benefit Package for RD</td>
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<td>➢ Telegenetics</td>
<td>➢ Committed collaboration among stakeholders</td>
<td>➢ Fiscal Incentive</td>
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<td>➢ Rare Disease Registry</td>
<td>• NIH</td>
<td>Exemption from all taxes and customs duties of donations for:</td>
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<td>➢ Rare Disease Management Program</td>
<td>• FDA</td>
<td>• Rare Disease Research</td>
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<td></td>
<td>• DILG/DePED</td>
<td>• Maintenance of Registry</td>
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<td>• Purchase of Orphan Drugs &amp; Orphan Products</td>
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Twin Legislation

6 Newborn screening centers
14 Continuity clinics
Provisions in the pending UHC
Integrating the RDA Act

No one will be left behind
Health Technology Assessment
Expanded source of funding
PWRD Claim: Our Right to Life

Sustainability

Collaboration

DOH & Allied Government Agencies

NIH-IHG

PSOD

Private Sector & Biopharma
Someday soon, with our collective help, patient families can feel… “No disease is rare for someone you love”.

Because everyone has a right to life... ...and a right to a quality life.
Maraming Salamat
Thank You

Philippine Society for Orphan Disorders, Inc.
Acknowledgement for Rare Disease Act

Patients, their families and all its donors and sponsors

Geneticists and other health professionals
For further information, contact:

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