



Republic of the Philippines  
**HOUSE OF REPRESENTATIVES**  
Quezon City, Metro Manila

Eighteenth Congress  
First Regular Session  
**4348**



**HOUSE BILL NO.** \_\_\_\_\_

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Introduced by Representatives Fredenil H. Castro, Janette L. Garin, Loren B. Legarda, Michael B. Gorriceta, Lorenz R. Defensor, Braedan John Q. Biron, Raul C. Tupas, Teodorico T. Haresco Jr., Carlito S. Marquez, Emmanuel A. Billones, Ma. Lucille L. Nava, Julianne Baronda, Greg G. Gasataya, Gerardo P. Valmayor Jr., Leo Rafael M. Cueva, Francisco 'Kiko' B. Benitez, Juliet Marie De Leon Ferrer, Ma. Lourdes T. Arroyo, Genaro M. Alvarez Jr., Sonny "SL" L. Lagon, and Joseph Stephen "Caraps" S. Paduano

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**EXPLANATORY NOTE**

According to the paper "Nonmotor features in sex-linked dystonia parkinsonism" by Roland Dominic Jamora, Lourdes K Ledesma, Aloysius Domingo, Alvin Rae F. Cenina, and Lillian V. Lee published in 2014, XDP is an adult-onset, progressive, debilitating movement disorder that manifests with features of dystonia and parkinsonism. It was first described in 1976 as endemic to Filipino males from Panay Island (Philippines).

In a 2011 study, out of the four provinces of Panay Island, 23.7 persons out of every 100,000 of the population in Capiz, 7.7 persons out of every 100,000 of the population in Aklan, 0.8 for every 100,000 of the population in Antique, and 1.4 persons of every 100,000 of the population in Iloilo are affected by XDP.

As of June 2019, there are 251 XDP patients registered with Sunshine Care Foundation in Roxas City Capiz from all over Capiz, Iloilo, Antique, Aklan, Guimaras, and Negros Occidental. The foundation receives seven (7) to ten (10) new patients every month. Other XDP patients have been identified from parts of Luzon and Mindanao. Unfortunately, the exact number of XDP patients remains a challenging object of statistical research because many of those who are afflicted do not avail of basic medical services, or they and their families consider it a shameful curse, if not a malevolent punishment brought by fate.

It bears noting that as XDP progresses, the mental health of the patients is affected. In fact, one out of ten deaths of XDP patients is due to suicide. According to the paper "Suicidality among Patients with Sex-linked Dystonia-Parkinsonism

(XDP)” by Roland Dominic Jamora, Alvin Rae F. Cenina, Rosalia A. Teleg, and Lillian V. Lee published in *Acta Medica Philippina* in 2015: “One possible reason why suicide is prevalent in XDP patients is the nature of the disease. The diagnosis of XDP can be a family burden because of its genetic basis and the disfigurement it produces. This may lead the patient to withdraw or be abandoned, or hidden from others, leading to poor treatment and less than ideal living conditions. In addition, patients who have relatives with the same condition are very much aware of this situation. These patients may be more vulnerable to depression and suicide after observing the disease and its effects on their relatives.”

Families of XDP patients inevitably face financial pressures since the estimated cost in the management of XDP is shown to be thirty (30) times the average annual health expenditure of an average Filipino, according to the study “Cost-Analysis of the Different Treatment Modalities in XDP” by Ranel C. De Roxas and Roland Dominic Jamora published in *Frontiers in Neurology* on May 8, 2019. As such, available long-term treatments for XDP such as Deep Brain Stimulation is out of reach of the common people who have lost employment due to XDP.

This bill seeks separate and special funding for the establishment of the XDP CENTER OF THE PHILIPPINES TO SPEARHEAD RESEARCH AND PROVIDE ASSISTANCE TO PATIENTS OF XDP being a movement disorder unique to Filipinos for reasons still unknown due to limited research. The Center shall serve as a database for all XDP patients around the country for their proper monitoring and treatment and for the coordination of all research conducted to find cure for XDP.

Although the figures cited seem to reveal that the number of people afflicted by the disorder is much smaller compared with that of more widespread and more familiar diseases and ailments, a significant pro-active step is to arrest the spread of the condition, and address it with more lasting treatments made available as early as possible to Filipinos diagnosed with XDP.

It is unfortunate that there have been no government efforts to study XDP’s cause and find its cure. Rather, a private institution in the country and private institutions abroad are the ones conducting and leading the research without the Philippine government’s support.

Moreover, although the Philippine Health Insurance Corporation (Philhealth) is improving on its benefit schemes for a defined set of services for a predetermined rate and is currently making great efforts to subsidize the needs of Filipinos, a number of diseases such as XDP are not covered by Philhealth; even Republic Act 10747 or the “Rare Disease Act of the Philippines” does not answer the needs of XDP patients.

XDP being a genetic disease attributed by studies to the Filipino race, particularly those who have roots from the Panay Visayas islands, efforts to find a cure for it deserve all the government support. Finding a cure for XDP is tantamount to bringing back to life the XDP patients, many of whom prior to the deterioration of their health, were productive, skillful, hardworking, and creative citizens of the country.



In view of all the foregoing, approval of this bill is earnestly sought.

JANETTE L. GARIN

LOREN B. LEGARDA

MA. LUCILLE L. NAVA

MICHAEL B. GORRICETA

BRAEDAN JOHN Q. BIRON

TEODORICO HARESCO JR.

GERARDO P. VALMAYOR JR.

FRANCISCO 'KIKO' B. BENITEZ

JULIET MARIE DE LEON FERRER

GENARO M. ALVAREZ JR.

JOSEPH STEPHEN "CARAPS" PADUANO

FREDENIL H. CASTRO

EMMANUEL A. BILLONES

JULIENNE BARONDA

LORENZ R. DEFENSOR

RAUL C. TUPAS

CARLITO S. MARQUEZ

GREG G. GASATAYA

LEO RAFAEL M. CUEVA

MA. LOURDES T. ARROYO

SONNY "SL" L. LAGON



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**AN ACT**

**RECOGNIZING X-LINKED DYSTONIA PARKINSONISM (XDP) AS A RARE FILIPINO DISEASE, CREATING THE XDP CENTER OF THE PHILIPPINES TO SPEARHEAD RESEARCH AND PROVIDE ASSISTANCE TO PATIENTS OF SAID DISEASE, AND PROVIDING FUNDS THEREFOR**

*Be it enacted by the Senate and the House of Representatives of the Philippines in Congress assembled:*

**SECTION 1. *Short Title.***- This Act shall be known as the "XDP Act of 2019";

**SEC. 2. *Declaration of Policy.*** - It is the policy of the State to protect and promote the right to health of the people, including the right of persons suffering from rare diseases to survival and full and healthy development as individuals through access to timely health information and adequate medical care. To this end, the State shall institutionalize a system that is comprehensive, integrative and sustainable and will facilitate collaboration among government and nongovernment agencies and organizations at the national and local levels, private sector, professional health

1 organizations, academic institutions, communities and families towards the provision  
2 of early and sustainable care of persons afflicted with the rare disease. The State  
3 recognizes the crucial role of research in defining health programs and activities to  
4 address the needs of patients with a rare disease.<sup>1</sup> In support of this policy, the  
5 establishment of the XDP Center of the Philippines aims to promote the welfare of  
6 Filipinos suffering from XDP and their families by providing them with readily  
7 accessible information about XDP and the medical care available to XDP patients and  
8 coordinating research efforts towards finding medical solutions for the disease.

9       **SEC. 3. *Definition of terms:***

10       a)     *X-linked Dystonia Parkinsonism (XDP)* is an adult-onset,  
11 predominantly male, inherited, debilitating, and progressive disease endemic in the  
12 Philippines manifesting as dystonia and parkinsonism, usually occurring during the  
13 third and fourth decades of life.

14       b)     *XDP Center* refers to the XDP Center of the Philippines created under  
15 this Act.

16       c)     *Director* refers to the director of the University of the Philippines –  
17 Philippine General Hospital (UP-PGH).

18       d)     *Ad hoc committee* refers to the body constituted to recommend the  
19 candidates for directorship of the UP-PGH.

20       e)     *Local health workers* refer to the midwives or nurses assigned in each  
21 barangay of each Local Government Unit in the Country.

22       f)     *Center Director* refers to the appointed person who shall head the XDP  
23 Center of the Philippines and shall lead the projects and initiatives of the Center.

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<sup>1</sup> Taken from RA 10747, the “Rare Diseases Act of the Philippines”.



g) *Advisory Council* refers to a group of medical specialists who shall assist the Center Director in the decision making process;

h) *Website Administrator* refers to the person chosen by the Advisory Council and approved by the Center Director to maintain and update the XDP Center's website, consolidate all information of XDP patients from local health workers around the country, and collate and compile all published paper on XDP from around the world;

i) *UP PGH Chief Accountant* refers to the highest ranking person in the accounting department of UP-PGH.

**SEC. 4. *Creation of XDP Center of the Philippines.*** - There is hereby created an XDP Center of the Philippines which shall be under the control and supervision of the Department of Health (DOH). It shall be based in the Philippine General Hospital, University of the Philippines, Manila (UP-PGH).

**SEC. 5. *Powers and Functions of the Center.*** - The XDP Center shall have the following powers and functions:

a) Consolidate and coordinate research activities, compile all research information regarding XDP, and collate data of XDP patients in the country;

b) Lead efforts to study the causes of XDP and find effective means for its prevention, cure and the alleviation of its effects;

c) Provide the public with access to current, reliable, and easy to understand information about XDP;

d) Enter into memoranda of agreement and receive grants from local and foreign funding agencies through the DOH upon the recommendation of the Advisory Council; and

e) Provide grants or aids to eligible XDP patients for their treatment or health care needs.

**SEC. 6. *Director of the XDP Center.*** - The XDP Center shall be headed by a Center Director who shall be responsible for the planning, implementation, and supervision of the programs and activities of the XDP Center.

**SEC. 7. *Functions of the Center Director.*** - The Center Director shall:

a) Set the programs and priorities of the Center upon the recommendation of the Advisory Council;

b) Approve grants or aids to persons eligible to receive such grants or aids under this Act, upon the recommendation of the Advisory Council.

c) Approve the amount of grant taking into consideration the needs of the patient, upon the recommendation of the Advisory Council.

d) Upon the recommendation of the Advisory Council, appoint the Center's personnel including the website administrator and the website assistant.

**SEC. 8. *Composition of the Advisory Council.*** - There is hereby created an Advisory Council, which is mandated to recommend policies and programs for the attainment of the objectives of this Act, composed of the following: (1) Director of the UP PGH as chairperson; (2) Executive Director of the National Institutes of Health (NIH) of the University of the Philippines as vice-chair; (3) the Executive Director of the Philippine Council for Health Research and Development (PCHRD) of the Department of Science and Technology (DOST); (4) the UP PGH Chief Accountant; (5) one neurologist specializing in movement disorder; (6) one psychiatrist who provides counseling to XDP patients; (7) one neurosurgeon who operates on XDP patients; and (8) a geneticist. The Director of the XDP Center shall act as the secretary of the Council. The Director of the UP PGH, the Executive

1 Directors of the NIH and PCHRD, and the UP PGH Chief Accountant shall be ex-  
2 officio members of the Advisory Council.

3 SEC. 9. *Functions of the Advisory Council.* – The Advisory Council shall:

4 a) Meet twice every quarter at the place and time approved by the  
5 majority of the members. The Center Director may convene the Advisory Council for  
6 a special meeting on urgent matters.

7 b) Recommend to the Center Director, through a majority vote, the XDP  
8 Center's priority research programs aimed at finding a cure for XDP, or other related  
9 research that will help XDP patients;

10 c) Recommend to the Center Director, through a majority vote, the XDP  
11 patients eligible to receive financial or other grants under this Act;

12 d) Recommend to the Center Director, through a majority vote, the  
13 amount of grant to the eligible XDP patient taking into consideration the financial  
14 capacity of the patient's family, urgency of the patient's health care needs, and other  
15 like criteria that may be determined by the Advisory Council;

16 e) Recommend, through a majority vote, who among the eligible XDP  
17 patients shall have priority in receiving the grant in accordance with the foregoing  
18 criteria; and

19 f) Recommend to the Center through a majority vote the information that  
20 shall appear in the Center's website.

21 SEC. 10. *Qualifications of the Center Director and Advisory Council*  
22 *members.* - The Center Director shall be a Filipino citizen and a licensed physician.  
23 The Advisory Council members shall also be Filipino citizens and shall have among  
24 its members at least one (1) neurologist specializing in the field of movement



1 disorders who handles XDP patients, one (1) neurosurgeon who conducts surgeries on  
2 dystonia patients, and one (1) geneticist.

3 SEC. 11. *Selection of the Center Director and Members of the Advisory*  
4 *Council.* -

5 a) Thirty (30) days after the effectivity of this act, the ad hoc committee  
6 established in the UP PGH for the selection and recommendation of the candidate for  
7 Director of PGH shall be reconstituted to select and recommend the candidates for  
8 Director of the XDP Center and the non-ex-officio members of the Advisory Council.

9 b) Within sixty (60) days from its composition, the ad hoc committee  
10 shall recommend at least three candidates for Center Director from which the said  
11 official shall be selected. They shall also recommend at least three candidates for each  
12 non-ex-officio position of the Advisory Council unless the number of persons  
13 qualified for the position makes such requirement impracticable.

14 SEC. 12. *Appointing Official.* - The Director of UP PGH shall appoint the  
15 Director and the non-ex-officio members of the Advisory Council of the XDP Center  
16 within thirty (30) days from the submission by the ad hoc committee of the  
17 candidates.

18 SEC. 13. *Term of office of the Center Director and Advisory Council*  
19 *members.* - The Center Director and Advisory Council members shall serve for a  
20 term of three (3) years and may be reappointed for another two (2) terms, unless  
21 sooner removed for cause.

22 SEC. 14. *Quorum.* - Five (5) members of the Advisory Council present during  
23 each meeting shall constitute a quorum.

24 SEC. 15. *Website Administrator.* - There shall be appointed a website  
25 administrator who shall be a holder of a college degree in Information Technology or

1 related field and highly proficient in the use of computer graphics and presentation  
2 software. He shall be tasked with facilitating the Center's public information  
3 campaigns.

4 SEC. 16. *Functions of the Website Administrator.* – The Website  
5 Administrator shall:

6 a) Be responsible for creating, designing and maintaining the Center's  
7 website with the approval of the Center Director; see to it that the contents of the  
8 website are up to date and relevant; forward queries to the persons who have the  
9 expertise and know-how on the subject matter; and shall collate and compile  
10 published papers on XDP from around the world.

11 b) Make graphical representation of difficult medical concepts for easy  
12 appreciation and understanding of the public especially XDP patients.

13 c) Be responsible for creating an email address or any form of  
14 communication where the local health workers shall send their report of an XDP  
15 patient in their locality and, with the help of at least one assistant, collate all  
16 information from all the LGUs regarding XDP patients in the country.

17 d) Treat the information received from the local health workers about  
18 XDP patients with utmost confidence, only publish or report information, photos or  
19 videos of XDP patients with their express written permission or permission recorded  
20 in a video.

21 The Director of the XDP Center, the Director of the UP PGH, and the PGH  
22 Chief Accountant shall always have access to the user name and password of the  
23 Center's website.

24 SEC. 17. *Reporting.* - Every quarter, the Center Director shall submit a report  
25 to the Secretary of Health on the activities of the Center.

1           SEC. 18. *Information from Local Health Workers.* - The local health workers  
2 shall immediately report to the Center the names and addresses of XDP patients in  
3 their areas of responsibility. If the area is outside the coverage of the internet,  
4 reporting shall be made at least once a month, using the email address or means of  
5 communication provided by the Center for reporting. If the patient permits, through  
6 express written consent or consent recorded on video, the local health worker may  
7 take pictures or videos of the patient to be sent and evaluated by the Center. The  
8 Secretary of the DOH shall institute measures to ensure that local health workers are  
9 informed of their duty under this Act.

10           SEC. 19. *Appropriations.* – a) For the first three (3) years after the effectivity  
11 of this Act, the XDP Center shall have an annual budget of One Hundred Million  
12 Pesos (P100,000,000.00) to be taken from the share of the national government from  
13 the incomes of Philippine Amusement and Gaming Corporation (PAGCOR) and  
14 Philippine Charity Sweepstakes Office (PCSO) as provided under their respective  
15 charters. On the fourth and succeeding years, the annual appropriation shall be  
16 included in the General Appropriations Act (GAA).

17           b) The Center shall use one-third ( $\frac{1}{3}$ ) of its budget for research to find the  
18 cure or treatment for XDP, one-third ( $\frac{1}{3}$ ) for the maintenance medicines of the XDP  
19 patients and the grant of long term pain alleviation such as Deep Brain Stimulation  
20 (DBS), or any surgical procedure that will benefit the patient, its maintenance, and  
21 other procedures determined by the Advisory Council as effective and poses no  
22 significant danger to the patient, but in no case shall the grant exceed One Million  
23 Eight Hundred Thousand pesos (P1,800,000.00) per patient, and the last one-third  
24 ( $\frac{1}{3}$ ) for its operation, training, and information dissemination throughout the country.



1           SEC. 20. ***Donations to the Foundation.*** - The Center is hereby authorized to  
2   solicit and receive donations, grants, contributions, gifts or endowments, through the  
3   DOH, from all sources foreign or domestic, and whether government or private, without  
4   need of securing a permit, approval or registration. Notwithstanding any provision of law  
5   to the contrary, all grants, contributions, gifts or endowments received by the Center  
6   pursuant hereto, shall be exempt from income, donor's and all other kinds of taxes, and  
7   shall further be deductible in full for purposes of computing the maximum amount  
8   deductible for tax purposes under the National Internal Revenue Code, as amended.

9           SEC. 21. ***Remuneration.*** - a) The Center Director shall have the same salary  
10   grade and monthly compensation as a University Professor of the University of the  
11   Philippines.

12           b) The Advisory Council members shall not receive any remuneration from  
13   the Center but each shall receive a per diem of Ten Thousand Pesos (P10,000.00) per  
14   meeting, or an amount equal to one-tenth (1/10) of the monthly compensation of the  
15   Center Director, whichever is higher.

16           c) The foregoing remuneration shall in no way be considered as double  
17   compensation.

18           d) The Center Director and the non-ex officio members of the Advisory  
19   Council are also allowed to continue to practice their profession.

20           e) The Center Director and the Advisory Council shall decide on the salary of  
21   the employees of the Center keeping in mind the wages received by government  
22   employees.

23           f) Their remuneration shall be adjusted to account for inflation.

24           SEC. 22. ***Signatories.*** - The Center Director and the PGH Chief Accountant  
25   shall be the signatories for the release of all funds from the Center.

1           SEC. 23. *Independence of the Center.*- the XDP Center shall operate  
2 independently from UP PGH.

3           SEC. 24. *Implementing Rules and Regulations.* - Within sixty (60) days from  
4 the appointment of the Center Director and the members of the Advisory Council, the  
5 Advisory Council shall convene to promulgate the Implementing Rules and  
6 Regulations of this Act.

7           SEC. 25. *Interpretation.* - All doubts in the interpretation and implementation  
8 of this Act, including its IRR, shall be resolved in favor of the XDP patient.

9           Nothing in this Act disqualifies the XDP patient from availing of the benefits  
10 provided by RA 11223 or the Universal Health Act, RA 7277 or Magna Carta for  
11 Persons with Disability as amended by RA 10754 or An Act Expanding the Benefits  
12 and Privileges of Persons with Disability (PWD), RA 10747 or The Rare Disease Act  
13 of the Philippines, and other laws.

14           SEC. 26. *Repealing Clause.* - All laws, decrees, executive orders, and other  
15 laws including their implementing rules and regulations inconsistent with the  
16 provisions of this Act are hereby amended, repealed or modified accordingly.

17           SEC. 27. *Separability Clause.* - If any part or provision is held invalid or  
18 unconstitutional, the remaining parts or provisions not affected shall remain in full  
19 force and effect.

20           SEC. 28. *Effectivity.* - This Act shall take effect fifteen (15) days from the  
21 date of its publication in full in at least two (2) national papers of general circulation.

22           Approved,