

Republic of the Philippines  
**HOUSE OF REPRESENTATIVES**  
Quezon City

**EIGHTEENTH CONGRESS**  
First Regular Session

House Bill No. 3564



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*Introduced By Representatives* **EMMANUEL A. BILLONES**

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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 THEREOF

**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 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, this according to the study "Cost-Analysis of the Different Treatment Modalities in XDP" by Ranhel 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 its 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 the 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, this bill is earnestly sought.

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

**Section 1.** Short Title.— This Act shall be known as the **XDP Act of 2019**;

**Section 2.** Declaration of Policy.—

- a. The state shall promote a just and dynamic social order that will ensure the prosperity and independence of the nation and free the people from poverty through policies that provide adequate social services, promote full employment, a rising standard of living, and an improved quality of life for all;<sup>1</sup>
- b. The state shall protect and promote the right to health of the people and instill health consciousness among them<sup>2</sup>
- c. The state shall adopt an integrated and comprehensive approach to health development which shall endeavor to make essential goods, health, and other social services available to all the people at affordable cost. There shall be priority for the needs of the underprivileged sick, elderly, disabled, women, and children. The State shall endeavor to provide free medical care to paupers.<sup>3</sup>

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<sup>1</sup> Section 9, Article II

<sup>2</sup> Section 15, Article II

<sup>3</sup> Section 11, Article XIII

- d. The State shall establish a special agency for disabled persons for rehabilitation, self-development and self-reliance, and their integration into the mainstream of society.<sup>4</sup>

**Section 3. Definition of terms:**

- a. *XDP* is an adult-onset, predominantly male, inherited, debilitating, and progressive disease endemic in the Philippines manifesting as dystonia and parkinsonism, usually occurring during the third and fourth decades of life. Majority of patients initially present with focal dystonia becoming generalized, eventually progressing to parkinsonism presenting tremors, slowness of movement and gait instability within five years of onset. Due to its presentation, patients have decreased quality of life and shortened life span. Its diagnosis is a burden not only to the patient but also to the family because of its stigma and genetic nature. (“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)
- b. *UP PGH* refers to the University of the Philippines Philippine General Hospital
- c. *Director* refers to the director of the UP PGH.
- d. *Ad hoc committee* refers to the body constituted to recommend the candidates for directorship of the UP PGH;
- e. *Local health workers* refers to the midwives or nurses assigned in each barangay of each Local Government Unit in the Country
- f. *XDP Chairperson* refers to the appointed person who shall head the XDP Center of the Philippines and shall lead the projects and initiatives of the Center for a term of three years and may be reappointed for another two terms;
- g. *Advisory council* refers to medical specialist who shall assist the Chairperson in his decision making process;
- h. *Website administrator* refers to the person chosen by the advisory council and approved by the chairperson to maintain and update the XDP Center’s website, and consolidate all information of XDP patients from Local Health Workers around the Country, and to collate and compile all published paper on XDP from around the world;

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<sup>4</sup> Section 13, Article XIII

- i. *UP PGH Chief Accountant* refers to the person in the accounting department of UP PGH who has the highest position.

**Section 4.** Creation of XDP Center of the Philippines.— there is hereby created an XDP Center of the Philippines that shall consolidate, coordinate, and compile all research regarding XDP and shall collate data of XDP patients in the country. It shall be based in Philippine General Hospital, University of the Philippines, Manila.

**Section 5.** Selection of Chairperson and Advisory Council. —

- a. Thirty days from the effectivity of this act, the ad hoc committee established in the UP PGH for the selection and recommendation of the candidate for Director of PGH shall be reconstituted to select and recommend the candidates for chairperson of the Center and his advisory council.
- b. Within sixty days from its composition, the ad hoc committee shall recommend at least three candidates for Chairperson position from which the chairperson shall be selected. They shall also recommend at least three candidates for each position of the advisory commission unless there are no person eligible for the post.

**Section 6.** Appointing Officials. —

- a. The Director of UP PGH shall appoint the Chairperson and the members of the advisory council of the XDP Center.
- b. Within thirty (30) days from the submission of the ad hoc committee of the candidates, the Director shall announce his/her choice of the chairperson and the advisory council.

**Section 7.** Qualifications of Chairperson and Advisory Council members.— the chairperson and advisory council members shall be a neurologist specializing in the field of movement disorders who handles XDP patients, neurosurgeon who conducts surgeries on dystonia patients or a geneticist.

**Section 8.** Qualification of Website Administrator. — the website administrator shall be a graduate of Information Technology or related fields. In addition he/she should know how to make graphics to help better inform the public of the activities of the Center.

**Section 9.** Functions of the Chairperson—

- a. With the help of the advisory council, he/she shall set the priorities of the Center in terms of research.



- b. With the help of the advisory council, he/she shall also approve the persons eligible to receive the money provided as grants in this Act.
- c. With the help of the advisory council, he/she shall approve the amount of grant to the person eligible taking into consideration the needs of the patient;
- d. With the help of the advisory council, he/she shall choose the Center's personnel including the website administrator and his/ her assistant.

**Section 10. Functions of the Advisory Council—**

- a. They shall meet twice every quarter in the place and time approved by the majority of the members. The Chairperson may call on the advisory council for a special meeting on urgent matters.
- b. They shall assist the chairperson, through a majority vote, in prioritizing research to find a cure to XDP, or other related research that will help XDP patients;
- c. They shall recommend to the chairperson, through a majority vote, the persons eligible to receive the money provided as grant in this Act.
- d. They shall recommend, through a majority vote, to the chairperson the amount of grant to the person eligible taking into consideration the needs of the patient;
- e. They shall recommend, through a majority vote, who among the eligible patients shall receive the grant first.
- f. They shall recommend, through a majority vote, to the Chairperson the information that shall appear in the Center's website.

**Section 11. Composition of the Advisory Council.** — The advisory council shall be composed of the (1) Director of the UP PGH as chairperson (2) Executive Director of NIH as vice-chair, (3) the Executive Director of the Philippines Council for Health Research and Development (PCHRD) of the Department of Science and Technology (DOST), (4) one neurologist specializing in movement disorder, (5) one psychiatrist who provides counseling to XDP patients, (6) one neurosurgeon who operates on XDP Patients, (7) a geneticist, (8) and the UP PGH Chief Accountant. The Chairperson shall serve as the member-secretary of the Council. The Director of the UP PGH, the Executive Director of the NIH, PCHRD, and the UP PGH Chief Accountant shall be the ex-officio member of the advisory council.

**Section 12. Quorum.**— Five members of the advisory council present during each meeting constitute a quorum.

**Section 13. Reporting.** -- Every quarter, the Chairperson shall submit a report to the Secretary of Health of the activities of the Center

**Section 14. Functions of the Website administrator.** —

- a. The website administrator shall be responsible for creating, designing with the approval of the Chairperson, and maintaining the Center's Website. He/she shall see to it that the contents thereof are up to date and relevant. He/she shall also forward queries to the persons who have the expertise and know how to answer the questions. He/she shall collate and compile published papers on XDP from around the world.
- b. He/she shall be able to make graphical representation of difficult medical concepts for easy appreciation and understanding of the public especially XDP patients.
- c. The website administrator shall also be responsible for creating an email address or any form of communication where the local health workers shall send their report of an XDP patient in their locality. He/she shall have at least one assistant and together, they shall collate all information from all the LGU regarding XDP patients in the Country.
- d. The website administrator and his/her assistant shall treat the information they receive from the Local Health Workers about XDP patient with utmost confidence. They shall only publish photos or videos of the XDP patients with express written permission or permission recorded in a video.
- e. The Chairperson, the UP Director, and the PGH Chief Accountant shall always have access to the user name and password of the Center's website.

**Section 15. Function of the Local Health Worker.** — The Local Health worker shall immediately report to the center the XDP patient in his/her area. If his/or her area is outside the coverage of the internet, he/she shall report at least once a month, using the email address or means of communication provided by the Center for reporting. If the patient permits, the local health worker may take pictures or videos of the patient to be sent and evaluated by the Center. The local health worker shall see to it that the consent given by the patient be recorded in the video.

**Section 16. Budget.** —

- a. The XDP Center shall have an annual budget of One Hundred Million Pesos (P100,000,000.00) to be sourced from the share of the government from Pagcor and PCSO. This budget shall be adjusted to account for inflation.



- b. The Center shall use  $\frac{1}{3}$  of its budget for research to find the cure for XDP,  $\frac{1}{3}$  for the maintenance medicines of the XDP patients and the grant of long term pain alleviation such as Deep Brain Stimulation (DBS), or any surgical procedure that will benefit the patient, its maintenance, and other procedures determined by the advisory council as effective and poses no significant danger to the patient. But in no case shall the grant exceed One Million Eight Hundred Thousand pesos (P1,800,000.00) per patient. And the last one third of its budget shall be used for its operation, training, and information dissemination throughout the country. The chairperson with the help of the advisory council through a majority vote may realign the budget for operations of the center to research and long term alleviation of XDP patients as he deems fit.

**Section 17. Remuneration. —**

- a. The Chairperson shall receive a remuneration of One Hundred Thousand pesos (P100,000.00) a month from the budget of the Center.
- b. The Advisory committee shall not receive any remuneration from the Center but each shall receive a per diem of Ten Thousand Pesos (P10,000.00) per meeting.
- c. The foregoing remuneration shall in no way be considered as double compensation.
- d. The chairperson and his/her advisory committee are also allowed to continue to practice their profession. But this provision does not apply to the UP PGH Chief Accountant
- e. The Chairperson and his/her advisory committee shall decide on the salary of the employees of the center keeping in mind the wages received by government employees.
- f. Their remuneration shall be adjusted to account for inflation.

**Section 18. Signatories. —** The Chairperson and the PGH Chief Accountant shall be the signatory for the release of all funds from the Center.

**Section 19. Independence of the Center.—** the XDP Center shall operate independently from UP PGH. Its chairman and the members of the advisory committee cannot be removed unless he/she has served his term.

**Section 20. Oversight Function.—** Congress shall exercise an oversight function in the conduct of the operations of the Center.

**Section 21. IRR.** — Within sixty (60) days from the announcement of the Chairperson and the members of his/her advisory council, the chair and his advisory council shall convene to promulgate the Implementing Rules and Regulations of this Act.

**Section 22. Interpretation.** — All doubts in the interpretation and implementation of this Act, including its IRR, shall be resolved in favor of the XDP patient.

**Section 23. Separability Clause.** — If any part or provision is held invalid or unconstitutional, the remaining parts or provisions not affected shall remain in full force and effect.

**Section 24.** Nothing in this Act disqualifies the XDP patient from availing of the benefits provided by RA 11223 or the Universal Health Act, RA 7277 or Magna Carta for Persons with Disability as amended by RA 10754 or An Act Expanding the Benefits and Privileges of Persons with Disability (PWD), RA 10747 or The Rare Disease Act of the Philippines, and other laws.

**Section 24. Effectivity Clause.** -- This Act shall take effect fifteen (15) days from the date of publication in full in at least two (2) national papers of general circulation.

Approved,