



IPOPI 4TH REGIONAL ASIAN PID MEETING

19-20 NOVEMBER 2022
KUALA LUMPUR, MALAYSIA

an **IPOPI** event

CARE FOR RARE
GLOBAL ALLIANCE EDUCATIONAL SEMINAR



SUPPORTING ORGANISATIONS



SUPPORTED BY



Philippine Patient Organization for Primary Immunodeficiencies (PhilPOPI)

Speaker: Harris Baraguir



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- In 2019, PhilPOPI was officially registered with the Securities and Exchange Commission (SEC) as nongovernmental organization with six board members and 24 patient members
- SEC requires that an annual meeting be held to vote for the renewal or retention of officers and submit a report, including a financial statement
- The six board members elected in 2019 continue to lead the organization



SEARCH FOR



- Since 2019, the number of members is basically the same, some have been added but many could not be contacted after registering with PhilPOPI



LIST OF PATIENT MEMBERS 2019-2022

2019

- (1) Jerald Bacolod
- (2) Kevin Basanes
- (3) Juan Miguel Carag
- (4) Mathew Caidic
- (5) Kathniel Cuya
- (6) Francis Jay Estopa
- (7) Faith Corith Lim
- (8) Earvin Castro
- (9) Aleah Sanchez
- (10) Alessandra Sanchez
- (11) Theodore Sosoban
- (12) Cyene Yagdulas
- (13) Jerry Adolfo
- (14) Ivan Josh Alcaraz
- (15) Szandra Asistidio
- (16) Onyx Culala
- (17) Adrian Manzano
- (18) Alina Jane Nanat
- (19) Erik Viluan
- (20) Aiden Vilena
- (21) Maja Francisco *
- (22) Sabrina Hayalin*
- (23) Sophia Lao*
- (24) Adrian Ladiana*

2020

- (1) Jerald Bacolod
- (2) Kevin Basanes
- (3) Mathew Caidic
- (4) Juan Miguel Carag
- (5) Kathniel Cuya
- (6) Francis Jay Estopa
- (7) Faith Corith Lim
- (8) Earvin Castro
- (9) Aleah Sanchez
- (10) Alessandra Sanchez
- (11) Theodore Sosoban
- (12) Cyene Yagdulas
- (13) Max Moon

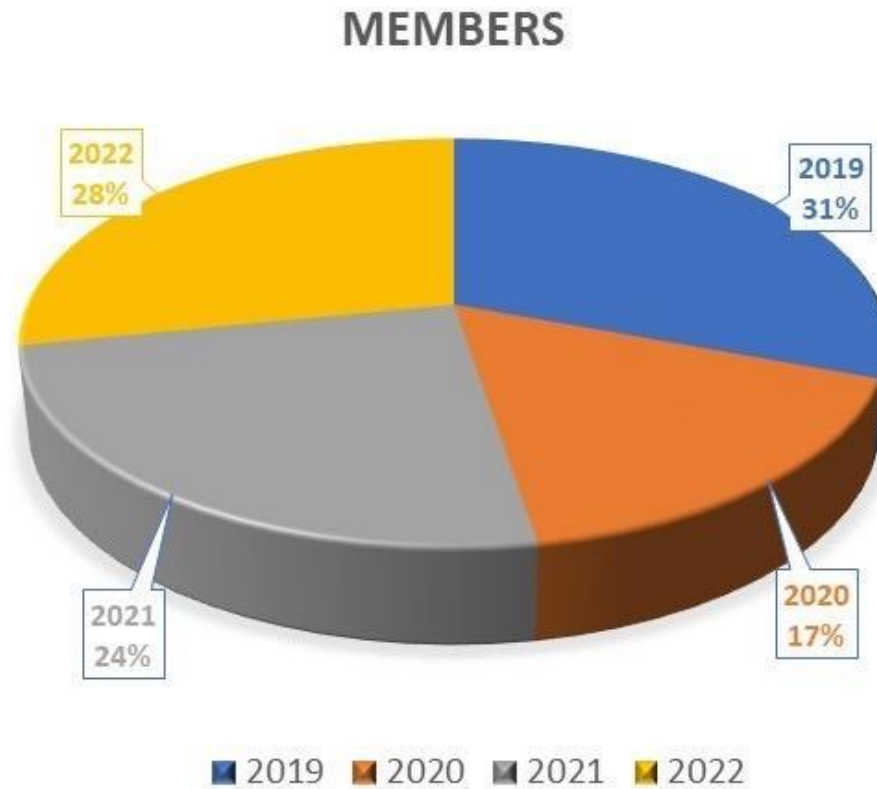
2021

- (1) Jerald Bacolod
- (2) Kevin Basanes
- (3) Harris Baraguir
- (4) Rohan Bolima
- (5) Mathew Caidic
- (6) Juan Miguel Carag
- (7) Earvin Castro
- (8) Maria Kathniel Cuya
- (9) Francis Jay Estopa
- (11) Willie Kampana
- (12) Faith Corith Lim
- (13) Aldrich Manaois
- (14) Max Moon
- (15) Andrei Salvador
- (16) Aleah Sanchez
- (17) Alessandra Sanchez
- (18) Theodore Sosoban
- (19) Cyene Yagdulas

2022

- (1) Jerald Bacolod
- (2) Kevin Basanes
- (3) Harris Baraguir
- (4) Rohan Bolima
- (5) Mathew Caidic
- (6) Juan Miguel Carag
- (7) Earvin Castro
- (8) Rayne de Castro
- (9) Ramoncito Vinluan
- (10) Caleb Amora
- (11) Calvin Amora
- (12) Keith Blanco
- (13) Francis Jay Estopa
- (14) Theodore Sosoban
- (15) Cyene Yagdulas
- (16) Willie Kampana
- (17) Faith Corith Lim
- (18) Aldrich Manaois
- (19) Max Moon
- (20) Andrei Salvador
- (21) Aleah Sanchez
- (22) Alessandra Sanchez

PhilPOPI Members Yearly

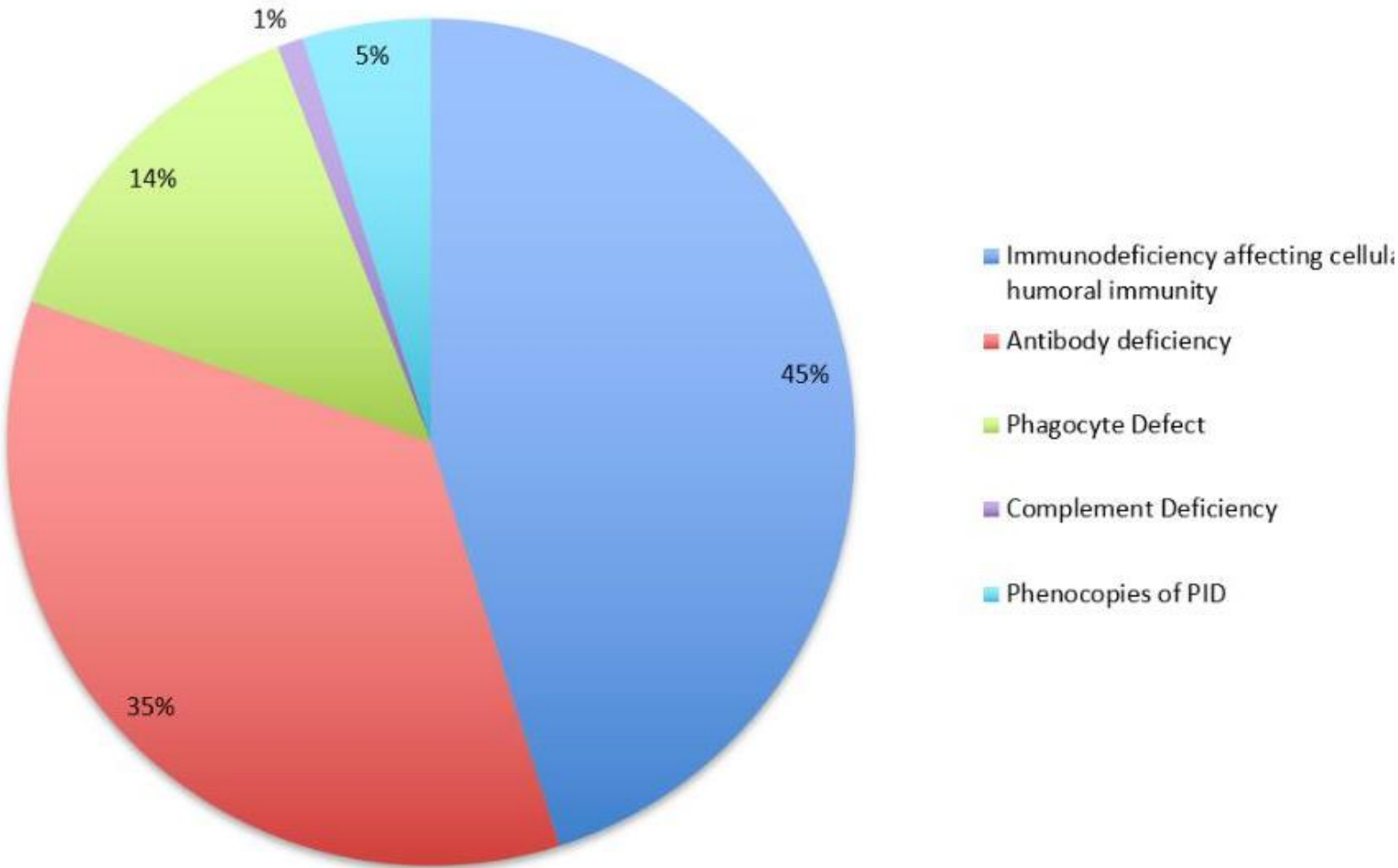


- PhilPOPI and PSAAI* are collaborating to reach out to PID patients and invite them to be members, as well as invite their friends and relatives to be volunteers to help with fundraising and other activities
- The PhilPOPI brochure is being updated in line with new terminologies – as part of awareness campaign
- PSAAI continues to monitor the number of PID patients seen by immunologists
- *Philippine Society for Asthma, Allergy and Immunology



This data is now being updated.....

**PIDs seen by PSAAI-certified Immunologists, 1990-2019
(102 patients)**



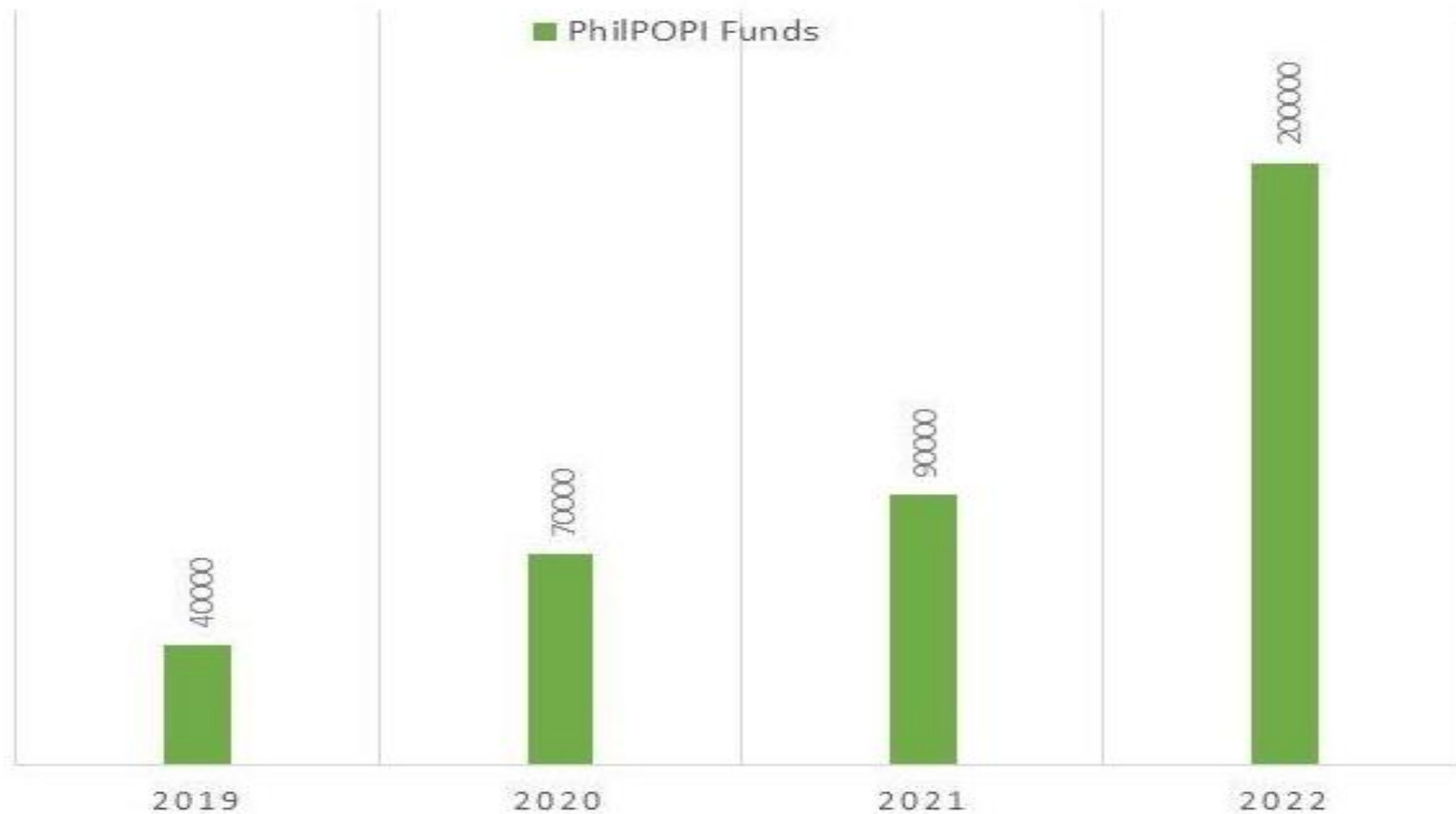
FUNDS



- With support from IPOPI and PSAAI, fundraising activities have provided sufficient funds to manage the organization
- Fundraising can be optimized with more volunteers



PHILPOPI FINANCES 2019-2022

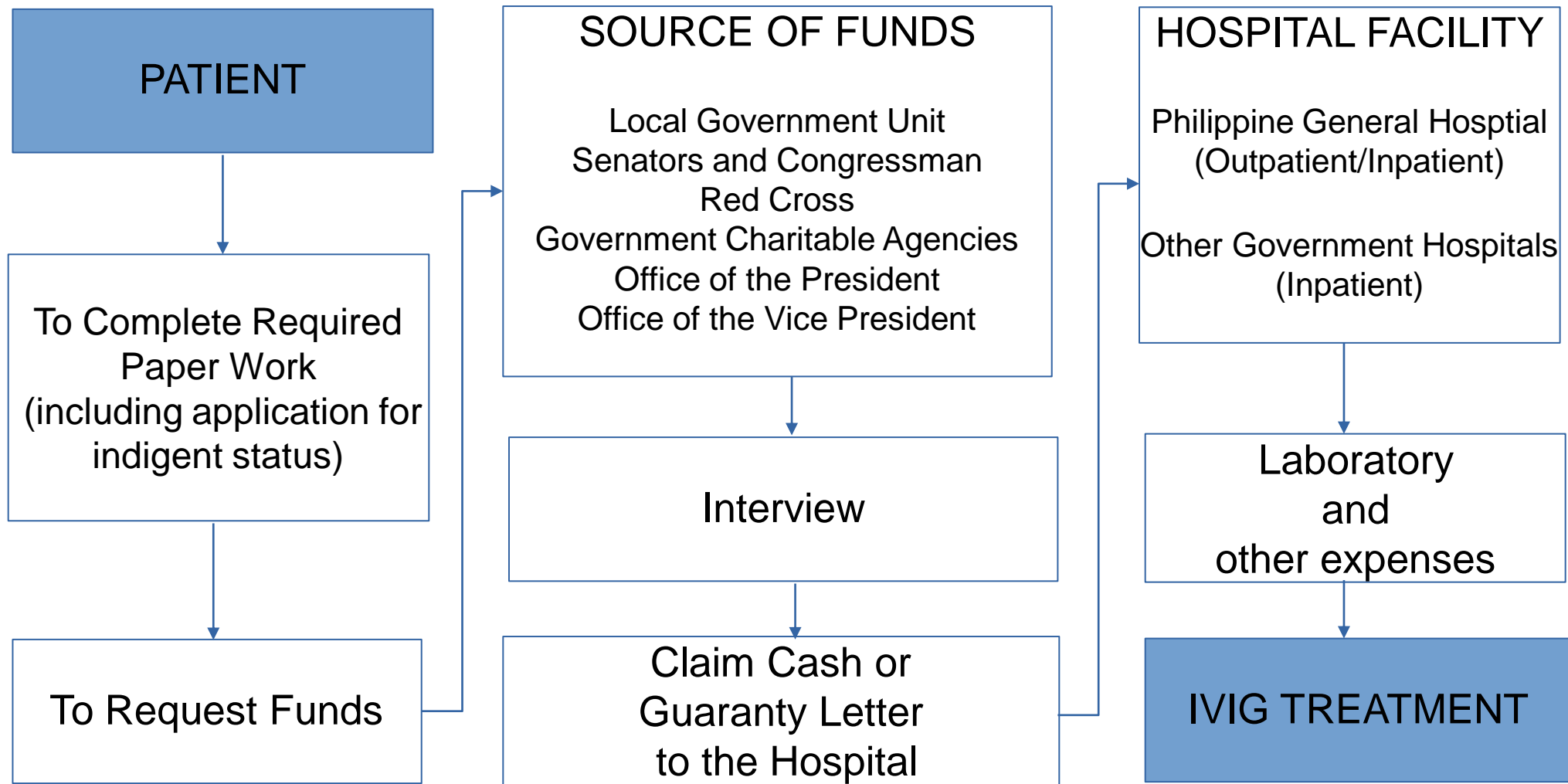


MEDICAL ASSISTANCE



- The current process to request for medical assistance from the government can be difficult
- Patients scramble to approach different individuals and agencies hoping to be accommodated for assistance from government hospitals, which can be very irregular and even inaccessible if the hospital is too far from where the patient lives





- PhilPOPI and PSAAI are pushing for a streamlined process to help patients obtain uninterrupted regular medical assistance such as IVIG infusion
- PhilPOPI and PSOD* continue to discuss with the Department of Health and the Philippine Health Insurance to provide a special benefit package for rare diseases
- *Philippine Society for Orphan Disorders





•THANK YOU!



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