



IPOPI
LATIN AMERICAN
PID PATIENTS'
MEETING

OCTOBER 19-20, 2023
MEXICO CITY, MEXICO

an **IPOPI** event

SESIÓN 7

COLLABORATION



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Abordar la transición de cuidados Addressing transition care

Moderadoras: Roberta Anido de Pena y Leire Solis

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Desafíos de la transición de cuidados en la atención de adultos con IDPs: perspectiva de una organización nacional

Transition Challenges in adult PID Care: Perspectives from an NMO

Héctor Amaya, El Salvador

Current Situation in El Salvador

- There is only one hospital in the country that provides attention and treatment for IDP patients.
- Our organization don't have information of adult patients been treated nor by private or public health institutions.
- Patients that reach 18+ years continues treatment at this hospital.
- Inmunoglobulin is part of the basic chart o medical products of the public health system.

The main difficulties identified by the patients

- Salvadorian health system don't have a formal protocol to address the transition of a patient from the child hospital to the adult health system.
- Differences in access to treatments between the public health system, social security and the private system.
- Lack of timely diagnosis.

The solutions presented by the doctors

- Advocate before health authorities for the establishment of a care protocol for the transition of young patients to the adult health system.
- Identify the most appropriate public care center to establish a care center for IDP patients, and advocate before health authorities for the establishment of a IDP patients care unit.
- Promote awareness among the medical community about the importance of timely diagnosis and treatment for IDP Patients.

Implementación de la transición de cuidados: reflexiones de una organización de pacientes

Implementation of Transition Care: Insights from an NMO experience

Gabriela Suárez Martínez, México

In 2009, the Latin American Society for Primary Immunodeficiencies (LASID) began a registry of patients diagnosed with PID, similar to that in Europe and the United States of America. Our country currently collaborates with 58 centers, and as of August 2023, 2,193 Mexicans with PID are registered. In Mexico, according to data from the National Institute of Statistics and Geography (INEGI), there is a population of 129 million inhabitants, and around 2,700,000 are born each year. girls and boys, of which 5,500 will have some type of PID, and 350 will have a lethal form.

https://www.senado.gob.mx/65/gaceta_del_senado/documento/56981

<https://lasidregistry.org/view/statistics/general/2023-09>

Unfortunately, in our country, medical care is insufficient to care for and diagnose people with PID. Even today, there are doctors who are unaware of this type of disease; consequently, the general population is unaware and ignorant of it. Furthermore, in Mexico there is no transition monitoring by these health institutions.

AMPIP provides free advice on social security to people who already have a diagnosis or a latent suspicion of suffering from PID, thereby facilitating access to health services. We have education programs to disseminate PIDs, through talks at different institutions and dissemination on our social networks.

The support is personalized, since each individual is different. We are generators of encounters with other people, doctor-patient, patient-caregiver, doctor-caregiver and patient-patient, so each of them requires a different temporal and spatial framework. We place people in the right place to request the treatment, medical care or studies necessary for each case. This work covers any stage of life, from neonates, infants, children, young people, adults and older adults, in addition to being open to caring for people with PID who, in addition to this, have some disability or complication derived from the disease itself.

AMPIP makes it possible for people with PID and their caregivers to not feel alone in this transition, providing them with psychological and thanatological care, recreational activities, and a mutual aid group in favor of their quality of life.

AMPIP strives to offer well-being to people with PID and their caregivers through three aspects: Physical, Psychological and social.

Q & A

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Taller: Abogar por los cuidados de transición

Workshop: Advocating for transition care

CONCLUSIONES CONCLUSIONS

Leire Solis

PAUSA PAUSE 10 min

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