



APIP

3.1 MILLONES
de habitantes



What we have?

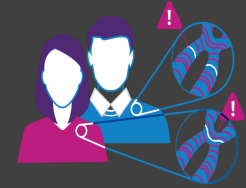


APIP members – 118-137



SCID – 1-60,000

(<http://pcnpr.rcm.upr.edu/>)



Newborn screening since 2015

100% (28 hereditary conditions)



PID patients registry – Not available



Diagnostic Test -

Peripheral Blood, Genetic Tests and Rare Disease Test



THEMES



PART #1

CRISIS HAPPEN



How to work or manage an event that was not planned or contemplated?

PART #2 – DEAL WITH CRISIS



What we did to connect with our group again?



**NATURAL
DISASTER**



**HURRICANE
MARIA**

Anoche

September 19, 2017

Hoy

September 20, 2017

HURRICANE MARIA

NATURAL DISASTER



First months

- Hard to get food, water and gas
- 95% Without power
- Chaos to get medical services
- 15% airport operation



Three to Six months later

- 50% Schools open
- 50% Banks open
- 50% Government services open



First year

2,975 - Official deaths by government

4,645 - Harvard University Study

1% - Without power

Things that happen and that
are outside your control

LASID CONGRESS

COMMITMENT

LOSE VALUABLE
INFORMATION

TEAM WOK

14 DAYS LATER

INVITATION

BEAUTIFUL COUNTRY

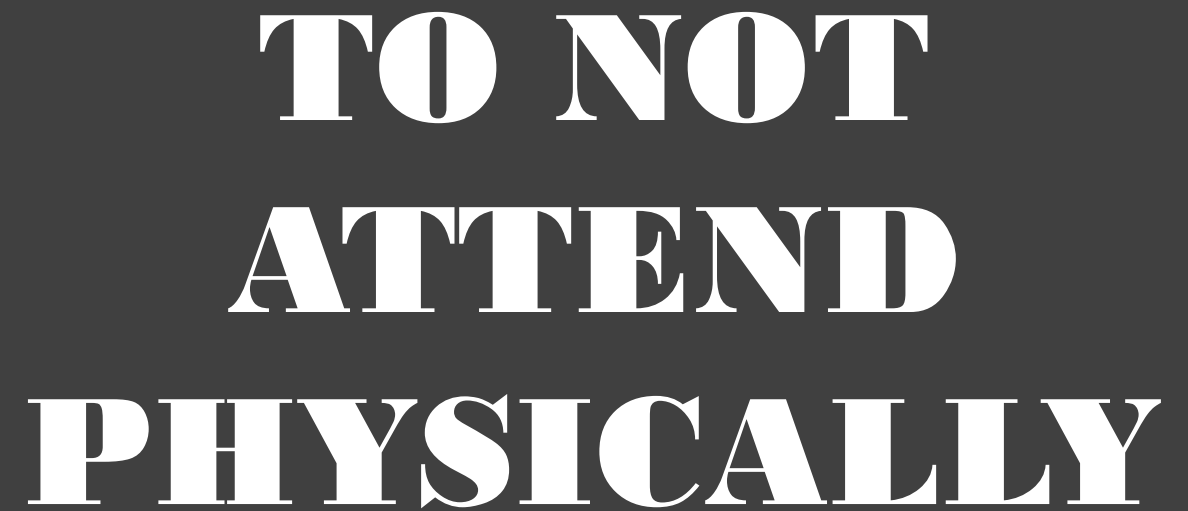
IPOPI FAMILY

SPEAKERS

**CONNECTIONS
EFFORTS**

IDEAL GROUP





LASID
Latin American Society for Immunodeficiencies
Sociedad Latinoamericana de Inmunodeficiencias

HOW IT WAS POSSIBLE



- **AVAILABLE TECHNOLOGY**
 - **MOBILE PHONE**
 - **LAPTOP**
- **DO NOT BE AFRAID OF DIFFICULTIES**
 - Charge the computer and cell phone at the mall, after 3 hour line.
 - Fishing for internet signal in the only available area, close to the tower of a communication provider.
 - Made the recording inside of the closet because it was the only quiet place to do it, due to all of the noise generated by the power plants.



Latin American Society for Immunodeficiencies



PART #2

Phases I **COMMUNICATION** **PROBLEM**

APIP COLLEAGUES

- **Are they alive?**
- **Still in the island?**

OUR PARTNERS

- **Treatment Centers**
- **Pharmaceuticals**
- **Doctors**

VISITS

- **Provide moral support**
- **Identify basic needs**

Phase II **ACTION PLAN** **WPIW' 18**

COMMUNITY

EFFORTS



STRATEGIC

ALLIANCES

**PUBLIC
RELATIONS
EFFORTS**

OUR COMMUNITY

EFFORTS #1:

- MEDIA TOUR
- DOCTOR VISITS
- PROMOTE THE EVENTS



EFFORTS #2:

- GIVE FOOD
- WATER
- MEDICINES



FOOD & MEDICINES



EFFORTS #3: APIP COLLEAGUES... OUR REASON WHY



BLACK OUT



PUBLIC RELATIONS

EFFORTS #4:

DIGITAL MEDIA FACEBOOK

Alliances

- Government
- Other NMO
 - Di George Foundation
 - Respiratory Disease Foundation



WPIW'18 – PICTURE CONTEST WINNER

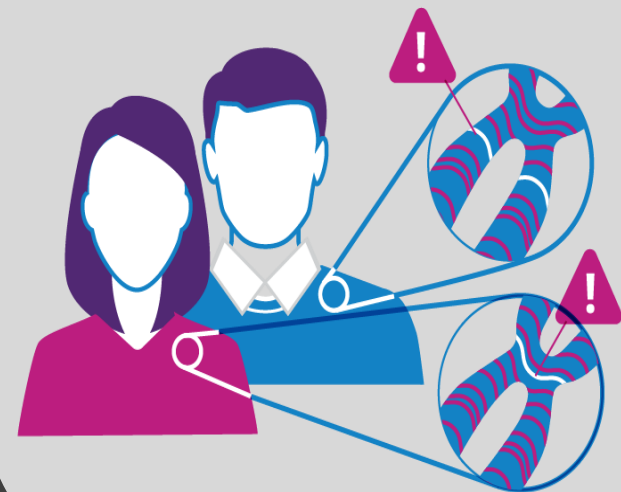




**THE APIP FAMILY IS
MORE IMPORTANT
THAN ANY
NATURAL
DISASTER...**



THE BOOK



THE BOOK OF PRIMARY IMMUNODEFICIENCIES in many of our countries is being written today, our commitment is to put a grain of sand so that our brothers, children, grandchildren and unborn relatives have the opportunity and access to treatment that many of us did not have.



THANKS