

THE ROLE OF **PATIENT GROUPS**

6TH PID FORUM

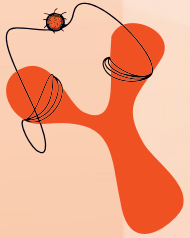
PID PRINCIPLES OF CARE

PRESIDENT

RICARDO PEREIRA



THE PORTUGUESE
ASSOCIATION OF
**PRIMARY
IMMUNODEFICIENCIES**

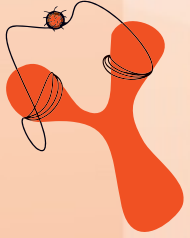


INTRODUCTION

- Ricardo Pereira
- Software Engineer
- President of the **Portuguese PID Patient Group**

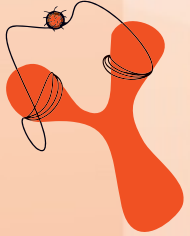
Diagnosis

- X Linked Agammaglobulinemia (XLA)
 - 3 years old
 - Immunoglobulin (IgG) for life



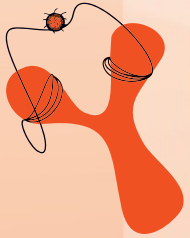
EXPERIENCE

- Normal life with **burden**
 - Work:
 - Job interviews
 - Days off
 - Travel:
 - Health insurance
 - Medical prescription (immunoglobulin, needles, syringes, ...)



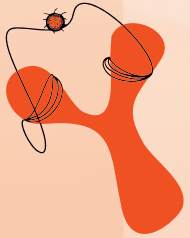
ACCEPTANCE

- Born with a Primary Immunodeficiencies (PID)
- Obstacles while a teenager
- Importance of a **Patient Group**
 - Accessible
 - Guidance
 - Support
 - Awareness
 - Gathering
 - ...



PATIENT GROUP

- Portuguese Association of PID (**APDIP**)
 - Members with PID knowledge
 - Met the group in 2003
 - Small and closed
- Joins **IPOPI** in 2010
 - APDIP reboot
 - New elections (*"I want to be part of it"*)



MISSION

- Be present
- Be updated
- Collaborate with health professionals
- PID Awareness for our society

30/12/2014 23:28

Olá Ricardo! Sou mãe dum menino de 3 anos que sofre do mesmo problema k o Ricardo. Há 1 ano que lhe foi diagnosticada a agamaglobulinemia e um turbilhão de dúvidas permanecem. Gostaria muito de trocar ideias e de encontrar (nem que seja p facebook)um grupo de pessoas que me compreendam...porque agora ja consigo expressar e encarar doutra forma este nosso problema...

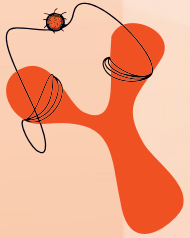


Re: Pedido de aconselhamento

☆ [redacted] To: APDIP ▾

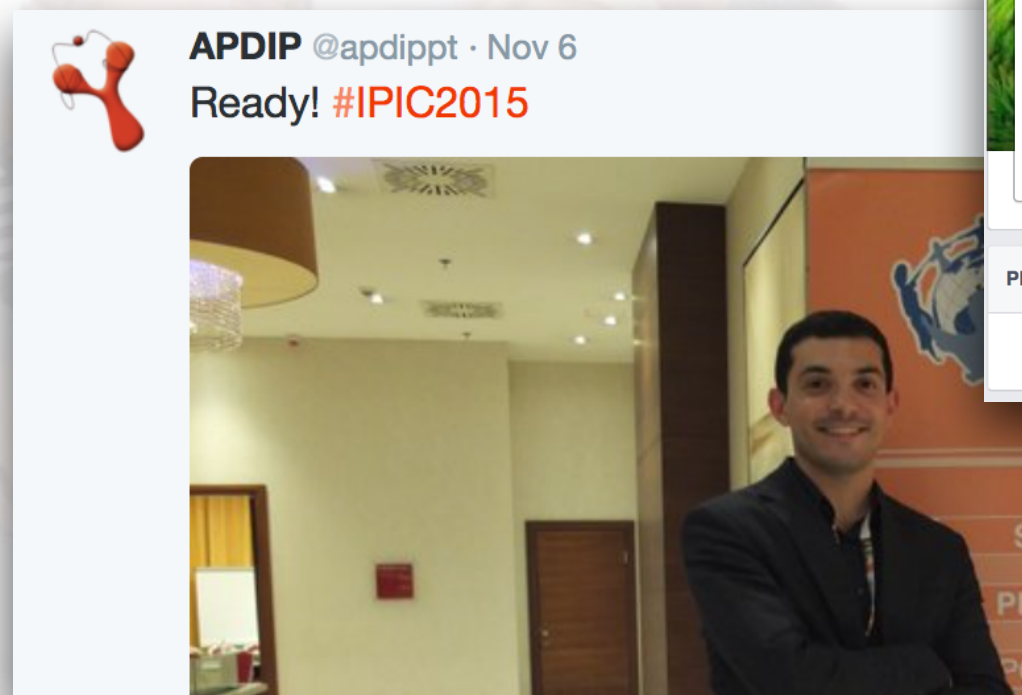
Boa tarde,

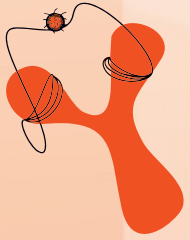
Muito obrigada pela rápida resposta. A minha área de



MISSION

- Online page: **www.apdip.pt**
- Facebook: **facebook/apdippt**
- Twitter: **twitter/apdippt**
- YouTube: **soon**

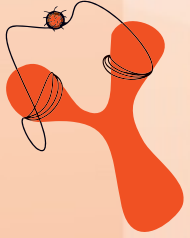




EVENTS

- **Share experiences:** Family Day

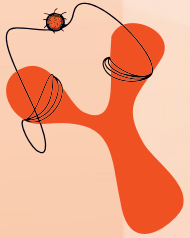




EVENTS

- **Gathering:** Walk for Health





EVENTS

- **Awareness:** National TV news



Thank you

