



The global organisation working to improve the quality of life for people  
with primary immunodeficiencies.

# **IPOPI EU POLICY FORUM**

## **NEW BORN SCREENING FOR SEVERE COMBINED IMMUNODEFICIENCIES**

European Parliament  
Brussels, 15 June 2011

Jose Drabwell  
President



The global organisation working to improve the quality of life for people  
with primary immunodeficiencies.

---

**Parent Perspective**

**Child Perspective**

**Doctor Perspective**



The global organisation working to improve the quality of life for people  
with primary immunodeficiencies.

## PARENTS PERSPECTIVE

**Joy of having a baby** - *“she was our first child. I held her in my arms and she looked absolutely beautiful”*

- **Initially healthy baby, then terribly ill** – *“he was just two months old and he was transferred to our local hospital for 5 months”*

**Desperation** – Despite treatment not getting better

**No diagnosis** - Other possible syndromes, but not the correct ones

**No treatment** – *“Nothing could be done – died one month later”*

**Entire family affected** – *“fear of the unknown”*

**Possible Economic affect on the family** - One or both parents might have to help in the care of looking after the ill child..



The global organisation working to improve the quality of life for people  
with primary immunodeficiencies.

## **PARENTS PERSPECTIVE**

- **Newborn screening**
- **Diagnosis**
- **Bone Marrow Transplant**
- **Treatment**
- **Future siblings**
- **Hope**



The global organisation working to improve the quality of life for people  
with primary immunodeficiencies.

## CHILD'S PERSPECTIVE

- No ill health
- No suffering
- Do sports
- Be normal
- Grow and flourish



The global organisation working to improve the quality of life for people  
with primary immunodeficiencies.

---

## DOCTOR'S PERSPECTIVE

We have just heard Bobby Gaspar's presentation !!



The global organisation working to improve the quality of life for people  
with primary immunodeficiencies.

---

**Rare but curable**

**If treated at a very early stage**

**Newborn screening essential**

**. Safeguard future generations**



The global organisation working to improve the quality of life for people  
with primary immunodeficiencies.

---

## **LUCIANO VASSALLI AWARD**

### **RECOGNITION OF YOUNG PEOPLE**

**THOMAS ANDERSEN – 2008**

**ISAAC ANTILLA - 2010**



VAC1



The global organisation working to improve the quality of life for people  
with primary immunodeficiencies.

---

Thank you

## Slide 9

---

**VAC1**

Valued Acer Customer, 09/06/2011