



**INGID  
Meeting  
Florence, Italy**

**LIVING WITH A PID**

**Jose Drabwell  
President  
5 October 2012**



**FLORENCE 2012**

**THANK YOU**



# FLORENCE 2012



- **AGE 3 – DIAGNOSED WITH POLIO**
- **unable to walk**
- **heavy metal callipers**
- **heavy brown boots**
  
- **AGE 5 – HOSPITALIZED WITH CHRONIC CYSTITIS**
- **kidney rinsing**
- **lots of medication**
  
- **14 DAYS LATER – SEVERE CHICKENPOX**



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**AGE 8 – CALLIPERS CAME OFF, but heavy boots stayed**

**AGE 11 – NORMAL SHOES AND BIKE**



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- **SCHOOL YEARS**
  - continued cystitis
  - many chest infections
  - steenpuisten (boils?)
  - Asiatic flu
  - lots of diarrhoea
  - anaemia



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- **AGE 18 – AU-PAIR IN THE UK**
- **AGE 22 – MARRIED AND 2 CHILDREN**
  
- **HEALTH ISSUES WORSEN**
- **Bronchitis**
- **Pleurisy**
- **Constant diarrhoea**
- **Non-stop coughing**
- **Breast benign growth removed**
- **Skin problems**



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- **LUNG EMBOLISM – warfarin/ heparin**
- **EXTREME TIREDNESS**
- **SLEEPLESS NIGHTS, constant coughing and diarrhoea**
- **DIAGNOSED WITH ASTHMA**
- **OPERATION ON NOSE TO CLEAR CATARRH**
- **IRRITABLE BOWL SYNDROME**
- **BLOCKED TEARDUCTS – ANOTHER OPERATION?**
- **RECEDING GUMS**
  
- **HYPOCHONDRIAC**



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**2 PNEUMONIAS WITHIN ONE MONTH  
FINALLY DIAGNOSED WITH A CONDITION!**

**HYPOGAMMAGLOBULINEMIA**

**Now classified as CVID**

**SIMPLE AND CHEAP BLOOD TEST**

**18 YEARS SINCE DIAGNOSIS**



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- **INTRAVENOUS IMMUNOGLOBULIN**
- **CHRONIC CONDITION**
  
- **NEW LEASE OF LIFE**
- **QUALITY OF LIFE**
  
- **LOSS OF MANY YEARS THROUGH ILL HEALTH**
- **UNNECESSARY MEDICATION AND OPERATIONS**



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- **SINCE DIAGNOSIS:**
- **LIVING LIFE TO THE FULL, every day, every hour, every minute, every second**
- **RAISING AWARENESS FOR PID WORLDWIDE together with all PID stakeholders**
- **WORKING FOR MORE AND QUICKER DIAGNOSES FOR CHILDREN AND ADULTS**



# FLORENCE 2012



- THANK YOU TO INGID
- THANK YOU TO ALL THE NURSES
- FROM ALL THE PID PATIENTS
  - ACROSS THE WORLD
- INCLUDING ME

