



18TH BIENNIAL MEETING OF
**THE EUROPEAN SOCIETY
FOR IMMUNODEFICIENCIES**
LISBON, PORTUGAL | 24-27 OCTOBER 2018

PID - FROM THE FETUS TO THE ELDERLY

LISBON



[KENES.COM/ESID](https://kenes.com/esid)

From a Parent Point of View: ADVISE TO PARENTS WITH SMALL CHILDREN

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Advise to parents with small children

HOW IS TO LIVE WITH A YOUNG KID WITH A PRIMARY IMMUNODEFICIENCY DIAGNOSIS?

BEFORE THE DIAGNOSIS



Uncertainty - Fear

180°
LIFE
CHANGES

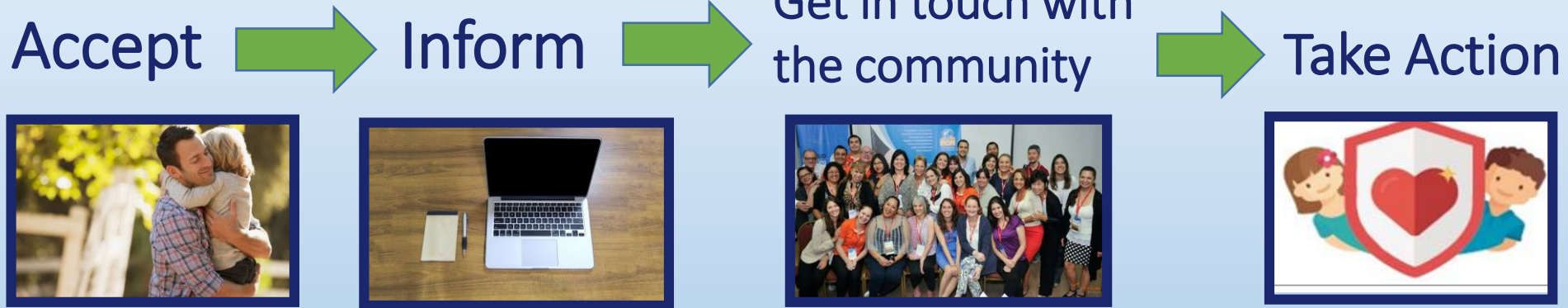
AFTER THE DIAGNOSIS



Big Challenge

Advise to parents with small children

✓ My experience in 4 steps:



Advise to parents with small children

✓ Accept:

- Overcome the shock
- It is Nobody's fault
- Embrace your new reality
- The Sooner the better



Advise to parents with small children

✓ Inform:

- Knowledge is power
- Ask your doctor all the questions
- Look for a second opinion
- Research: Organization's website
- Learn about the diagnosis, treatment, complications, care, prognosis.



Advise to parents with small children

- ✓ Get in touch with the community:
 - Look for a local organization
 - Speak with other patients/parents
 - Doctors, treatment centers, medical suppliers, insurance coverage ...



Advise to parents with small children

✓ Take action:

- There is always something you can do
- Participate with your local organization
- Push for the right changes
- Its gives a sense of purpose



Thank you

