

# Regional clinical priorities in PID treatment: Europe

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# The 4 questions

- Which diagnosis tools/options are available in your region for which PID symptoms?
- Which treatments are available for which diagnosis?
- Main barriers and opportunities?
- Availability of national/regional registries

The answer: all is there –  
The challenge: inequality  
(mostly due to government support y/n)

# Europe: what's in a name?

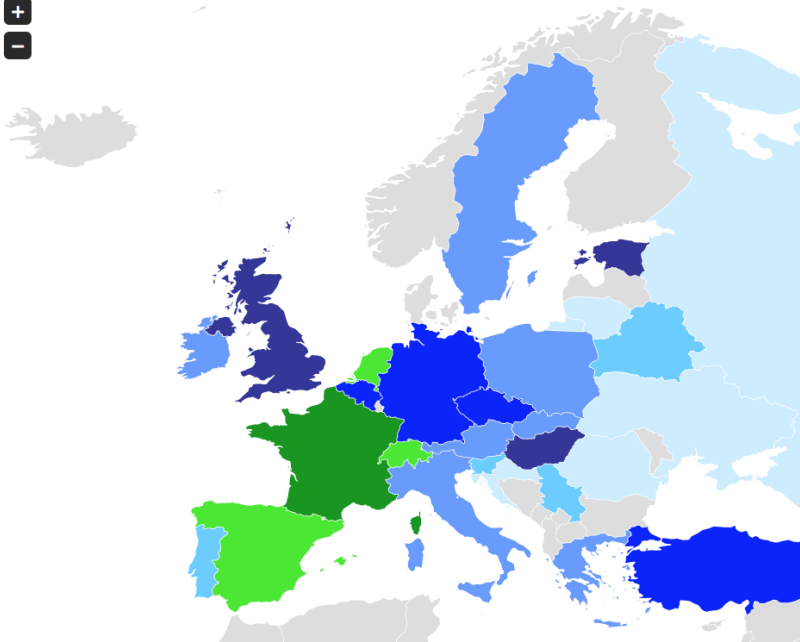
(Move mouse over map for more details (Country, number of living patients, prevalence))

## Color legend

$n = 0$	$0 < n < 0.5$
$0.5 \leq n < 1$	$1 \leq n < 2$
$2 \leq n < 3$	$3 \leq n < 4$
$4 \leq n < 5$	$n \geq 5$

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# Inequalities

1. Diagnostics: availability of NGS – NBS introduction – centers under pressure if not supported by government

2. **Treatment discrepancies:**

IgG

- Romania: EU country!
  - IVIG treatment scheduled when product (mixtures) available – companies withdrawing products!
- Moldavia: still i.m. Ig treatment

Monoclonals very unequally available (and reimbursed)

HSCT and GT availability and accessibility

# Challenges ahead

- Stringent reimbursement rules in some countries >> European rules
- IgG as an immunomodulatory treatment >> IG privileging
- Price setting differs per country - inequality in availability>> equal price settings
- Monoclonals, Anti-virals, HSCT and GT
- Treatment and its reimbursement may depend on “proof” >> stress on awareness, (molecular) diagnostics and screening

# Opportunities

- ESID to work on striding against inequality in diagnostics and treatment
- IPOPI: NATIONAL PATIENT ORGANIZATIONS' REINFORCEMENT – PATIENT EMPOWERMENT
- ERN: share – care – cure: will it be more than an acronym?
- Focus on national registries reporting to regional registries  
e.g. CEREDIH - ESID Registry > moving politics by numbers!
- Creation and support of strong national and international patient organizations > lobbying at the government level