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Registries in pediatric IBD

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Registries

- USA registries
- European registries
- Longterm registry (Centocor)

USA registries (1)

- **Pediatric IBD consortium (Heyman)**
 - Start 2000: prevalent and incident cases, \pm 1600 patients
 - 6 sites: San Francisco, Chicago, Atlanta, Houston, Philadelphia, Boston
 - Publications on:
 - Phenotype
 - IFX premedication and infusion reactions
 - Initial surgery risk in CD
 - Gender related phenotype and disease course
 - Age at onset-related phenotype and disease course
 - Racial/ethnic differences
 - Extraintestinal manifestations
 - Complications of CD

USA registries (2)

- **Pediatric IBD Collaborative Research Group (Hyams)**
 - Start 2002, consecutive incident cases < 16 years, ± 250 cases
 - in 18 Eastern US and Canadian centers
 - prospective registration by research nurses
 - Publications on:
 - Response to CS in UC
 - Response to CS and influence of IFX in CD
 - QoL (IMPACT) at diagnosis and 1 year follow-up
 - Lab tests at diagnosis
 - Perianal disease in CD
 - IFX maintenance in CD
 - Appraisal of PUCAI
 - IFX maintenance in UC

Europe (1)

- **EPIMAD (Colombel)**
 - Start 1988, pediatric and adult IBD, ± 500 pediatric patients
 - Population based inception cohort in Northern France
 - Interviewer practitioners collect data from pediatric gastroenterologists
 - Publications on:
 - Environmental risk factors in pediatric IBD
 - Incidence and disease location
 - Natural history of CD
 - Malnutrition and Growth in CD

Europe (2)

- **CEDATA (Buderus)**
 - Germany and Austria, start 2004, \pm 600 patients
 - Prevalent and incident cases, reported by pediatric gastroenterologists
 - Data on:
 - disease phenotype at presentation
 - first treatment

Europe (3)

- **SIGENP IBD Study Group**
 - Italian Pediatric National pediatric IBD register
 - start 1996, patients at diagnosis, \pm 1500 patients
 - all 40 ped gastroenterology centers in Italy
 - retrospective and prospective
 - Publication on:
 - Incidence and phenotype

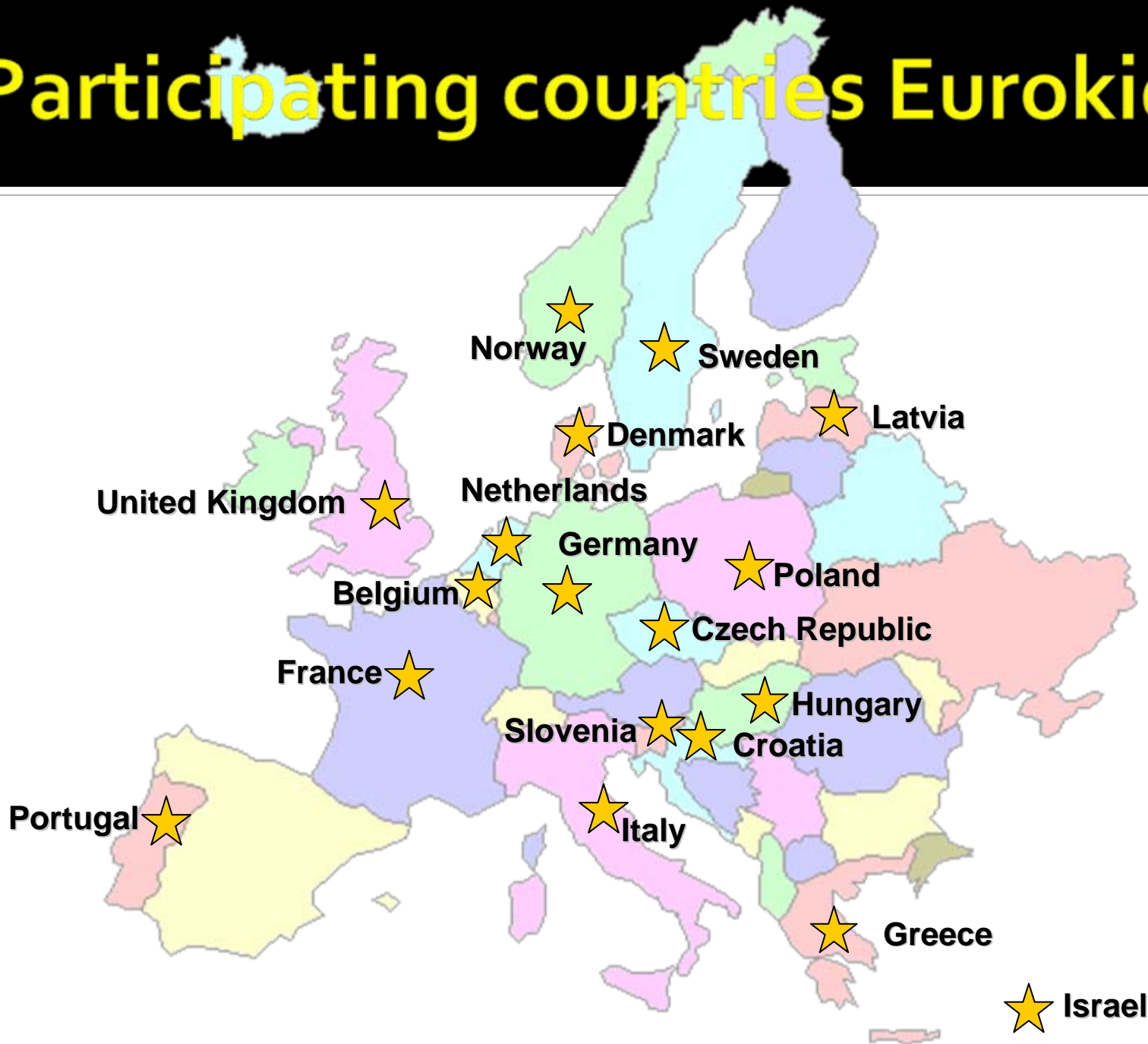
Europe (4)

- EUROKIDS (Escher)
 - Web-based registry of ESPGHAN IBD working group
 - in 18 European countries and Israel
 - incident cases < 18 years, registration at diagnosis
 - Start 2004, ongoing, now \pm 3000 patients
 - Continued registration of new patients
 - Open for new participants, new countries
 - Data on:
 - Diagnostic work-up
 - Disease location in CD
 - Disease location in UC and IBD-U
 - Height and weight at diagnosis
 - Colitis in the very young

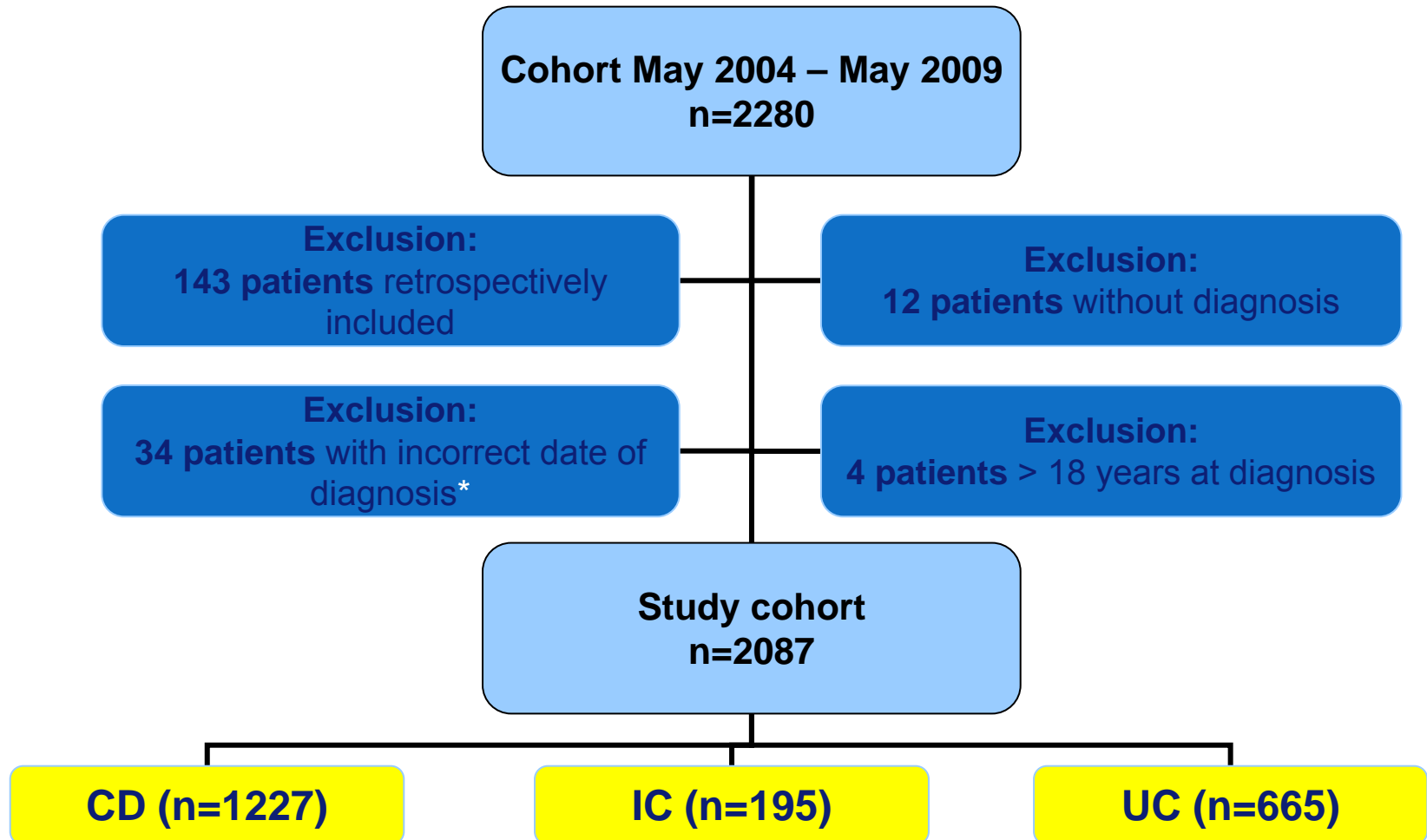
Methods – Eurokids database

- Initiative of IBD working group of ESPGHAN
- Start May 2004 with 21 centres in 12 countries
 - now 18 countries
- Prospective registration of newly diagnosed IBD patients
- Data entry:
 - 2004 – 2006: electronic forms sent by email
 - 2006 – now: web-based registry
- Coordination in Rotterdam, The Netherlands

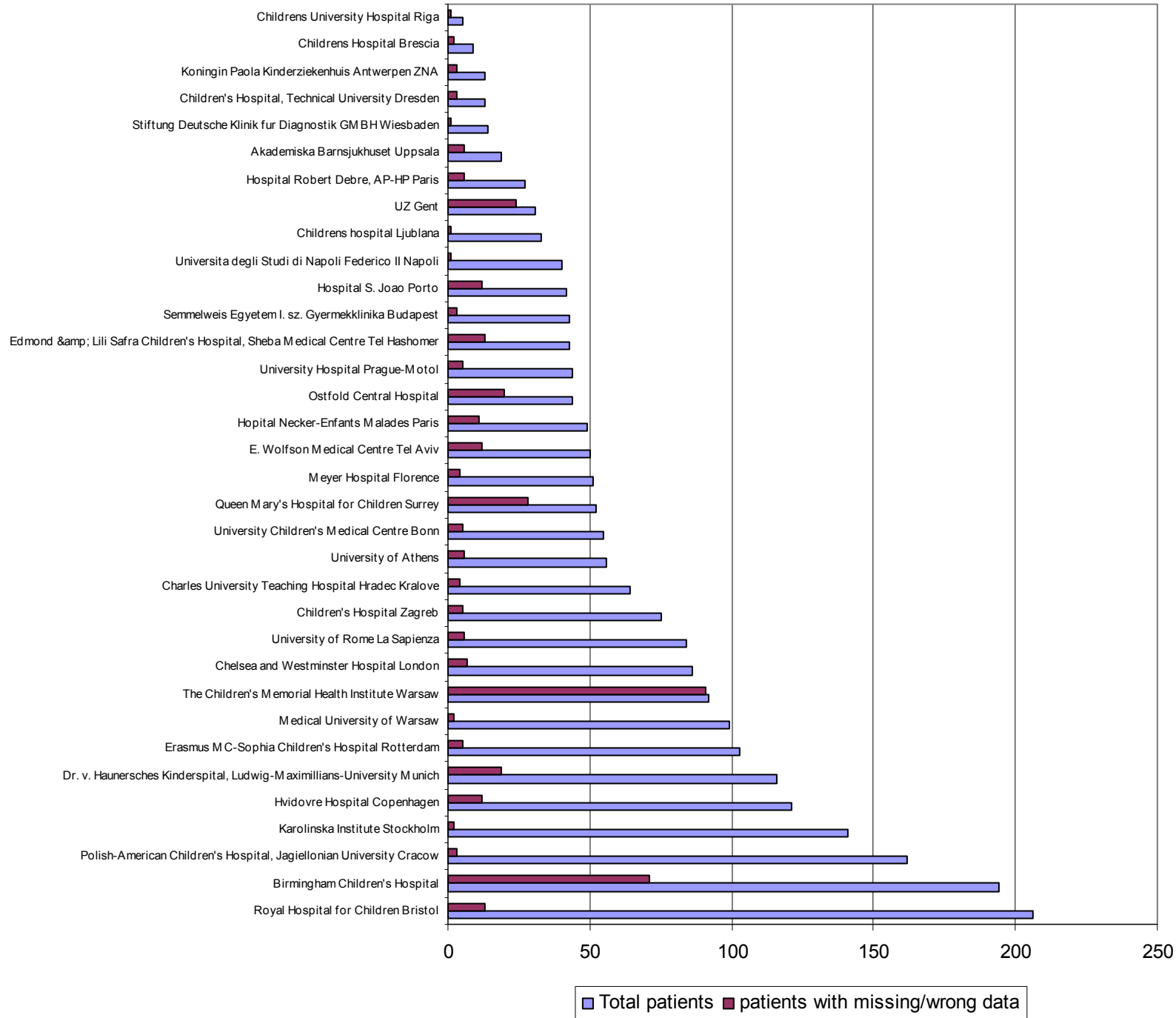
Participating countries Eurokids



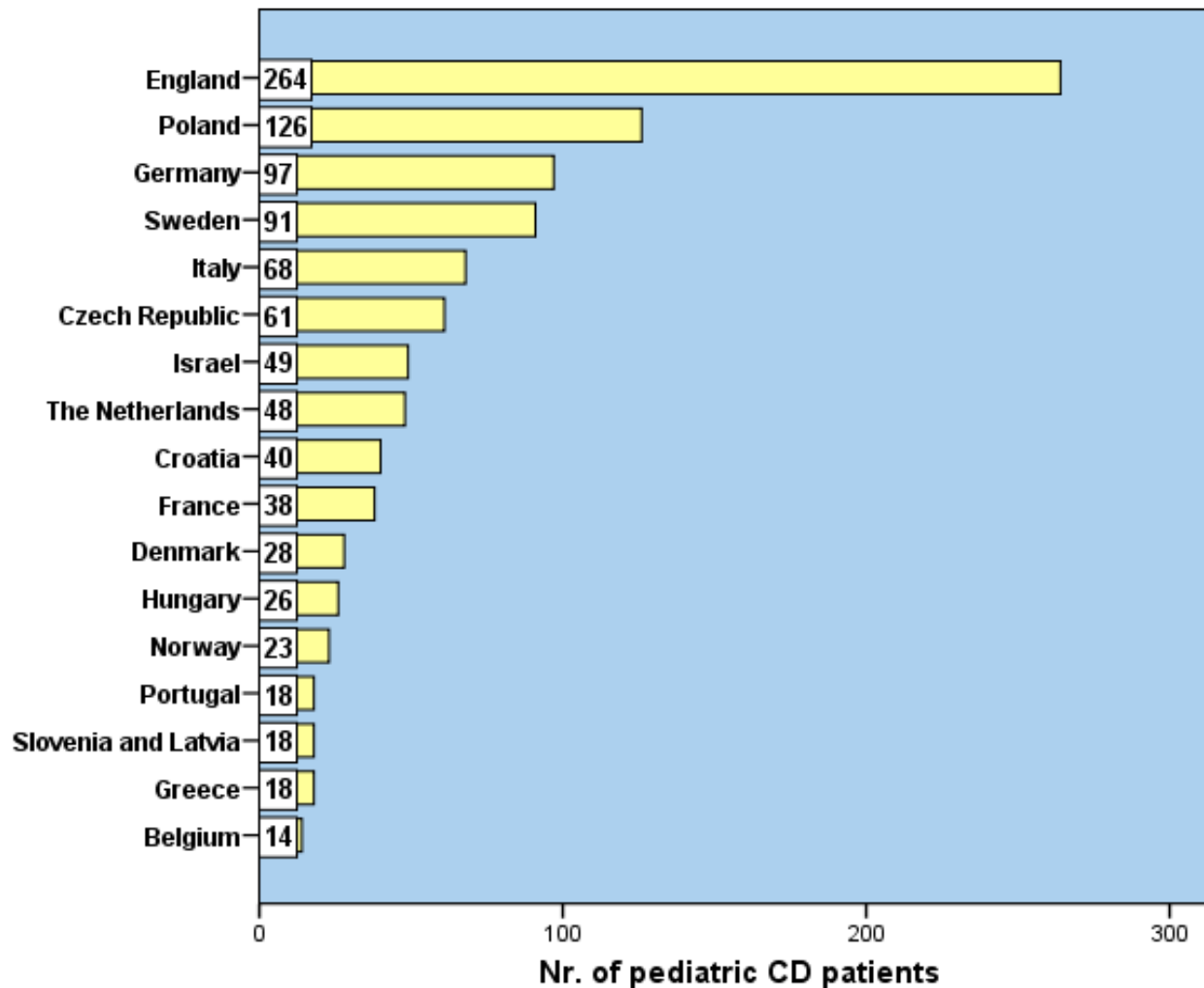
Eurokids May 2004 – May 2009



* Date of diagnosis > 1 month after date of registration



Eurokids: CD patients in participating countries



Eurokids: CD patients (n=1227)

- Mean age at diagnosis 12.5 years
- Mean diagnostic delay 5 months

- Ethnicity 86% Caucasian
- 1st degree family history in 10.6%

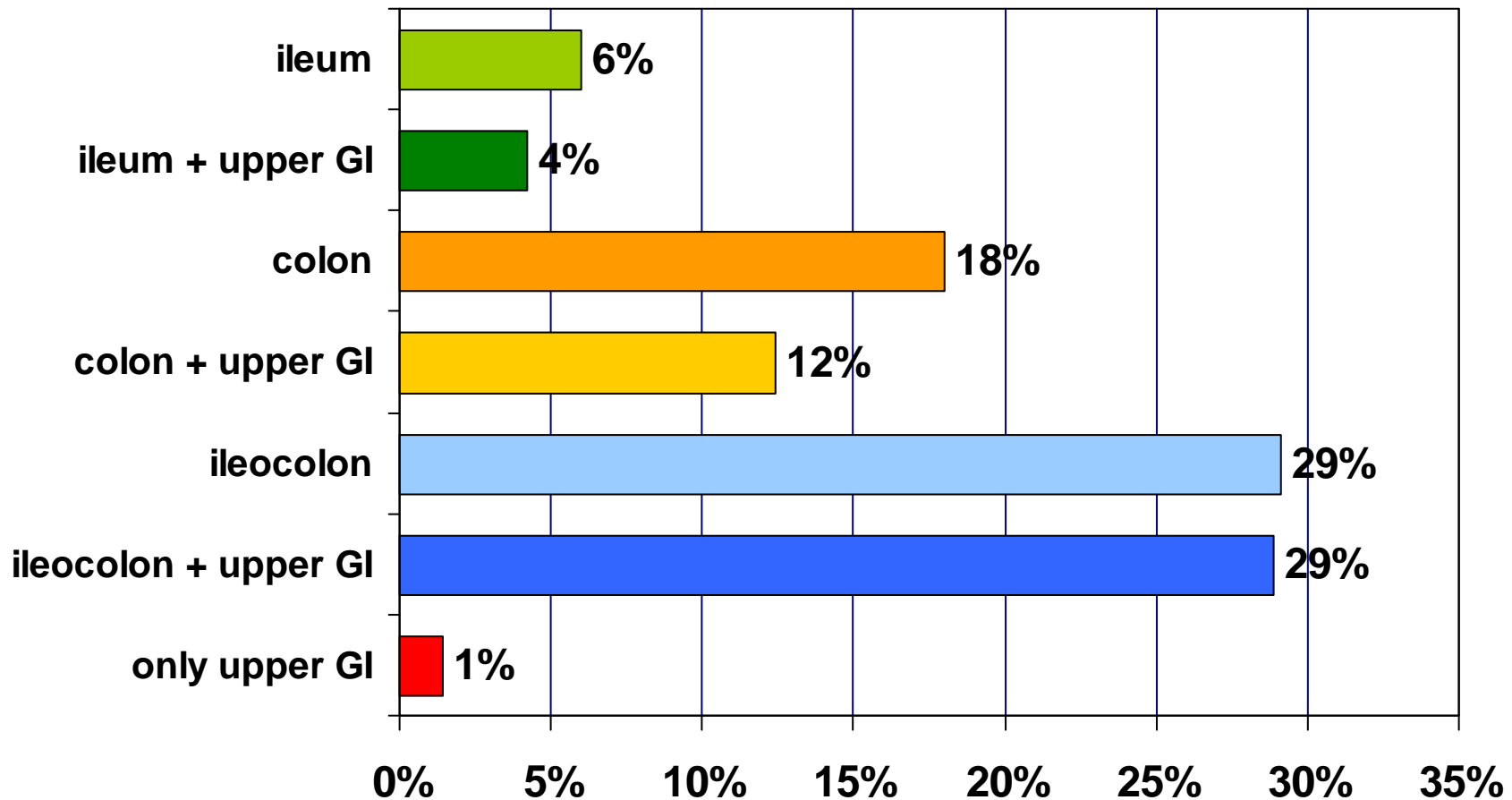
- Extraintestinal symptoms in 18.3%
- Perianal disease in 9.1%
- Stenosis in 13.6%

Eurokids:

Diagnostic work-up in CD (n=1227)

- 57% had complete Porto work-up
 - = upper GI + ileocolonoscopy + small bowel imaging
- 88% upper GI endoscopy
- 88% colonoscopy
 - 70% terminal ileum
- 70% imaging of small bowel (SBFT, MRI)
- 95% terminal ileum visualised
 - by endoscopy or radiology

Eurokids: Disease location in CD



N=990

Longterm registry

- Centocor; FDA and EMEA mandate
- USA (start 2007?)
- 6 European (start 2009) countries
- Europe 10-15 sites
 - France, Italy, Germany, UK, Belgium, Netherlands
- 5000 patients, 20 year follow-up
 - 2000 Crohn's disease, IFX treated
 - 2000 Crohn's disease, not IFX treated
 - 1000 ulcerative colitis/unclassified