

CVID in Motol Hospital - data extraction -

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Patients' Characteristics

Number of patients	24
Familiar cases	3
Males	17
Females	7
Age (years)	
mean	28,7
max	65
min	5
Age of 1st symptoms	
mean	17,7
max	50
min	1

Patients' Characteristics

- Increased no. of infectious diseases requiring antibiotics
 - respiratory tract, paranasal sinuses,...
- Approx. 3 infectious episodes per year
- Increased incidence of autoimmune diseases
 - Crohn (2), ITP (4), Hashimoto's thyroiditis (1), IDDM (1)
- IgA deficit (11)

Treatment

- **Approx. each 4 weeks ambulatory IVIG application**
- **Mean dose: 170 mg/kg**
- **Mean IgG level: 4.8 g/L**

Case Report

- Male, born 1994
- Since 1995 recurrent RTI, 1996 mastoiditis, 2x chicken pox
- Allergy, atopic eczema
- Since 2004 treated in Motol
- in 2006 Crohn disease diagnosed
- Current treatment
 - Remicade, Imuran, Pentase, IVIG (transition to SCIG)

Ig (g) 12

10

8

6

4

2

0

Crohn

2003

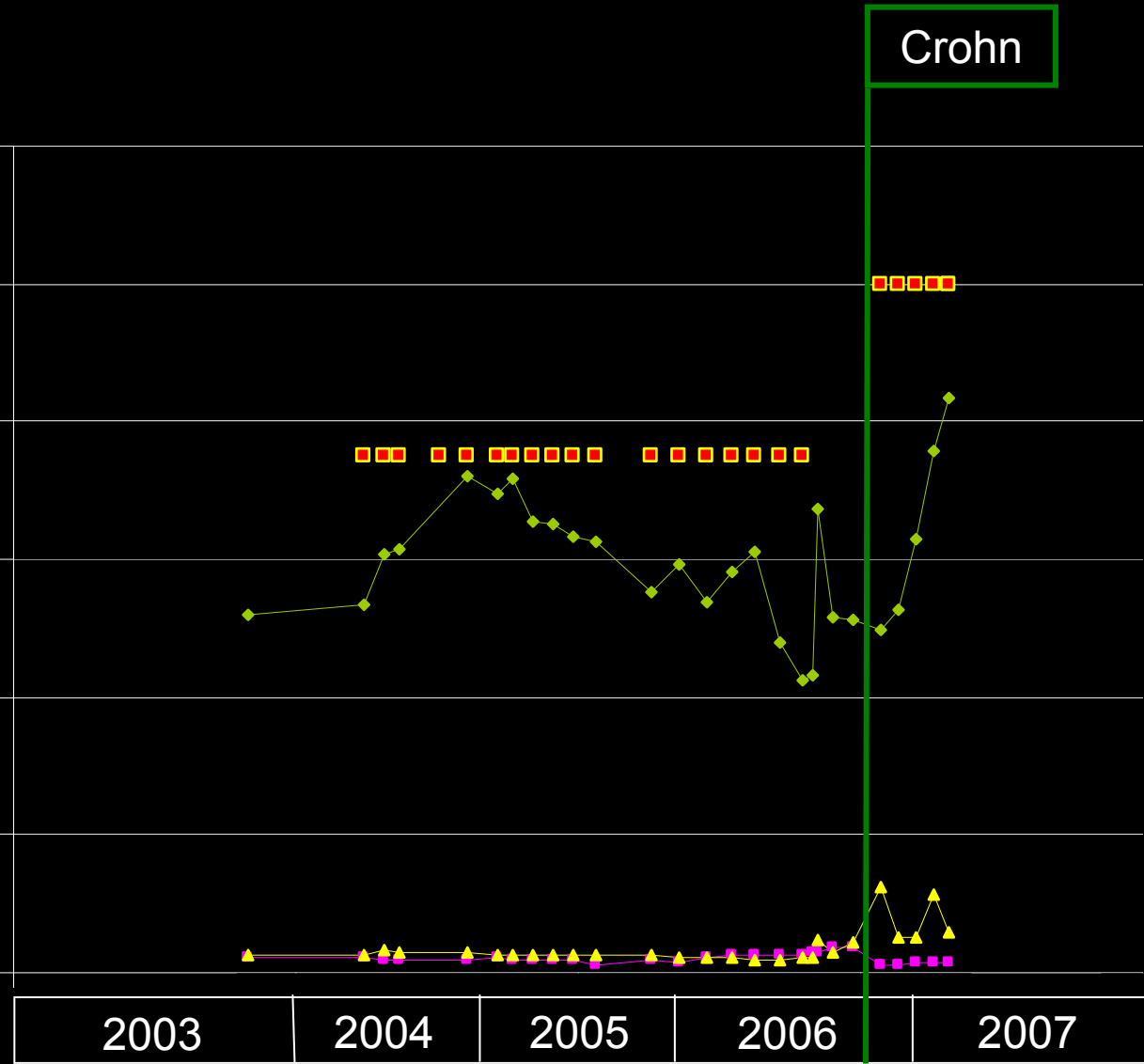
2004

2005

2006

2007

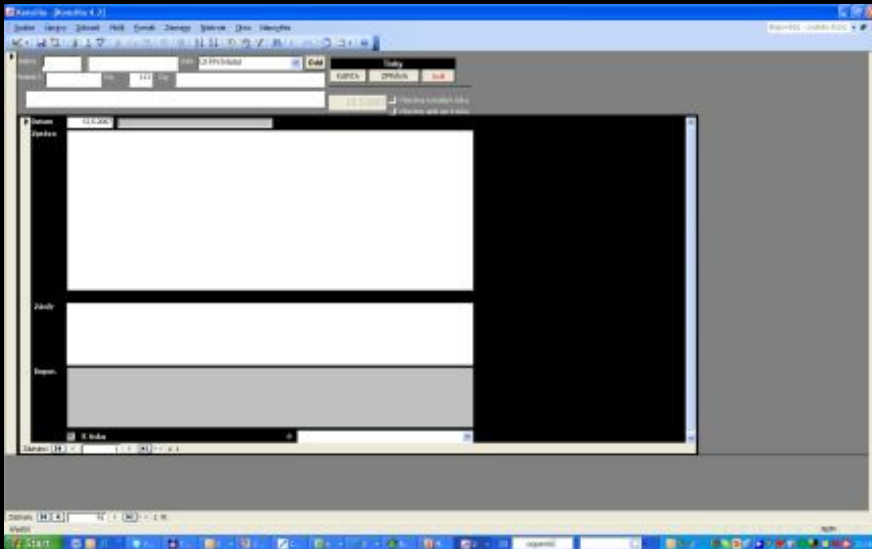
- ◆— IgG
- IgA
- ▲— IgM
- Substitution



Data extraction

- advantages:
 - data collection
 - improvement in patients' care
- constraints:
 - paper documentation, transition to electronic patient chart
 - time demanding
 - data on 24 patients = 170 hours = 7 hours/patient
 - online upload

Local x Online



ESID CVID-subregistry

USER ID: 127
Login: czech3 cadm
PATIENT ID:
none selected

Menu:

- Core Dataset
- Core Laboratory
- Percentiles
- Diagnosis & Etiology
- History & Add Diagnosis
- Quality of Life & Clinical Inv.
- Additional Investigation
- Immunisations & Serology
- Core & Extended Laboratory
- Sample & Biopsy & Surgery
- Therapy & Adverse Events
- SF36 Survey
- Normal Ranges



Welcome to: ESID CVID-subregistry

Provided by: European Society for Immunodeficiencies, CwebRD

WHAT IS YOUR EXPERIENCE?