

**IMPROVING QUALITY OF CARE  
IN RARE DISEASES  
THROUGH PREGRADUATE  
MEDICAL EDUCATION  
EXPERIENCES FROM FACULTATIVE CLASSES  
ON CYSTIC FIBROSIS**

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# PRESENTATION PLAN

1. Medical Education in EU regulations on Rare Diseases
2. Bologna Process and Medical Education in Europe
3. Aspects of Rare Diseases in Medical Faculty Curriculum in Poland
4. Facultative Classes on Cystic Fibrosis as a possible way to improve Quality of Care in a rare disease
5. Joint Projects to raise Awareness and improve Quality of Care – cooperation with Patients' Organizations
6. Conclusions



# EU REGULATIONS ON RARE DISEASES

## MEDICAL EDUCATION (PRE- & POSTGRADUATE)

- **COUNCIL RECOMMENDATION of 8 June 2009 on an action in the field of rare diseases (2009/C 151/02):**
  - THE COUNCIL OF THE EUROPEAN UNION (...)  
HEREBY RECOMMENDS THAT MEMBER STATES:
    - 17. Gather national expertise on rare diseases and support the pooling of that expertise with European counterparts in order to support:
      - (a) **the sharing of best practices on diagnostic tools and medical care as well as education and social care in the field of rare diseases;**
      - (b) **adequate education and training for all health professionals to make them aware of the existence of these diseases and of resources available for their care**
      - (c) the development of **medical training** in fields relevant to the **diagnosis and management** of rare diseases, such as **genetics, immunology, neurology, oncology or paediatrics;**



# BOLOGNA PROCESS

## ASPECTS RELEVANT IN THE FIELD OF MEDICAL EDUCATION

- Currently **47 signatory countries** since 1999
- Opportunity for raising **standards and convergence** across Europe
  - Quality
  - Diversity
  - Innovation
  - Resources
- **Mobility** for students and staff
- **Transparency** of qualifications:
  - Comparable **degrees**, three-cycle structure (e.g. bachelor-master-doctorate) – difficult to implement in M.D. programmes...



# MEDICAL CURRICULUM IN POLAND

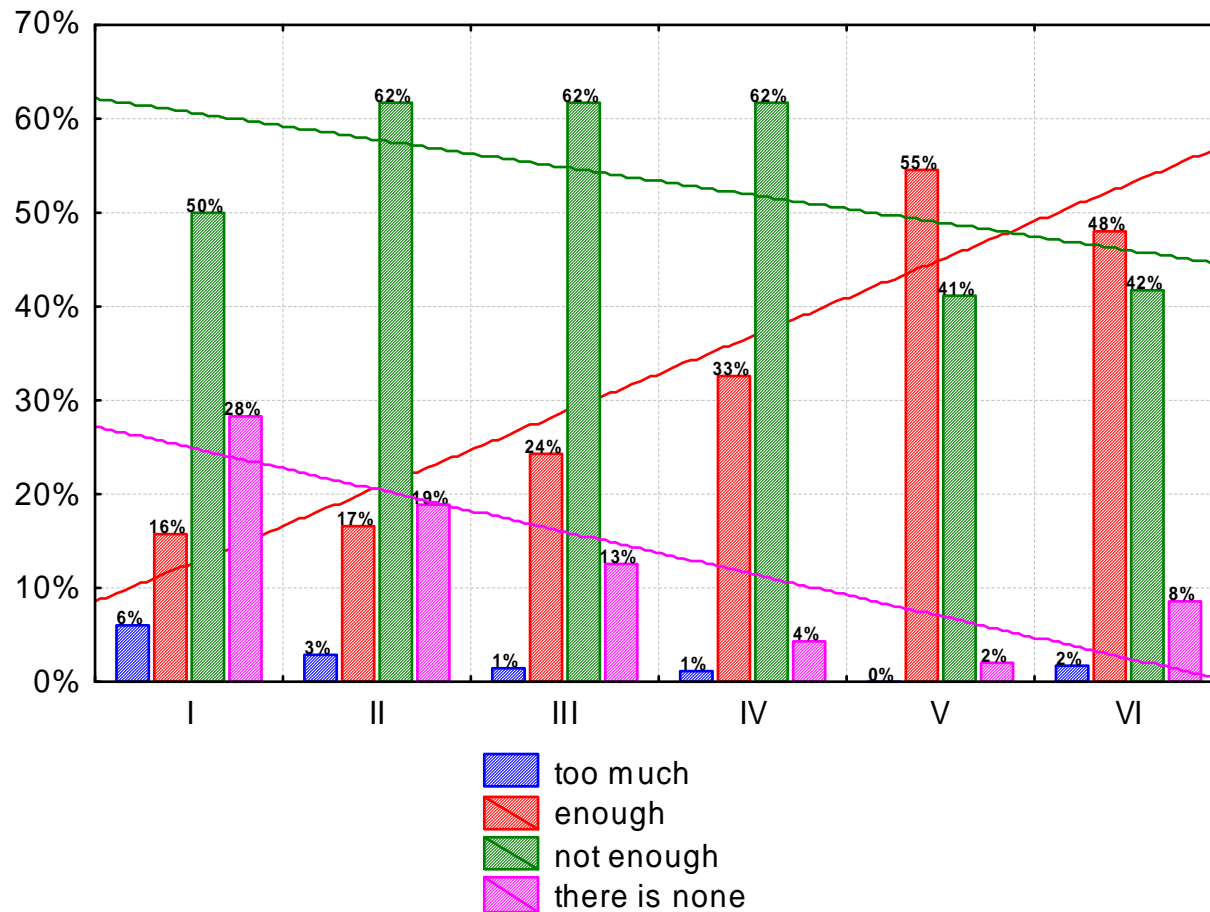
## ASPECTS OF RARE DISEASES

- Every **medical specialty** has its **more** and **less common** diseases, **including** also **very rare**
- ... but where M.D. students **learn most** about **rare diseases** (3 main subjects...)?
  1. **Biochemistry** – „enzyme-centric” approach...
  2. **Genetics/Medical Genetics** – focus on genetic basis & symptoms, not necessarily treatment...
  3. **Paediatrics** – very wide field...



# FACULTATIVE CLASSES ON CF IDEA

- „Do you think there is enough information on CF during the course of study”?



# FACULTATIVE CLASSES ON CF DESIGN

- Students may **choose** facultative classes each year (1-4 ECTS points depending on year)
- CF facultative classes available initially for III-VI year students, now III-IV
- About **50 students participate** each year since 2005
- **One week – integrated approach, all aspects!**
- **Lectures** given by specialists in the following aspects of CF: **pneumonology, gastroenterology, ENT, genetics, psychology, nutrition, CF complex care, role of NGOs**
- **Clinical practice** – history taking and examination



# FACULTATIVE CLASSES ON CF

## POSSIBLE IMPACT ON QUALITY OF CARE IN RARE DZS

- **Higher awareness and better knowledge among future medical professionals:**
  - **effects will be visible in their future work**
  - **decreasing time** between first **symptoms** and the **final diagnosis**
  - **patients initially present to General Practitioners** - young doctors often work part-time in GP / family medicine / ER – they may help in recognizing symptoms and referring patients to specialists
  - **involving medical professional** in rare diseases -related projects (research / awareness / social / policy-making)

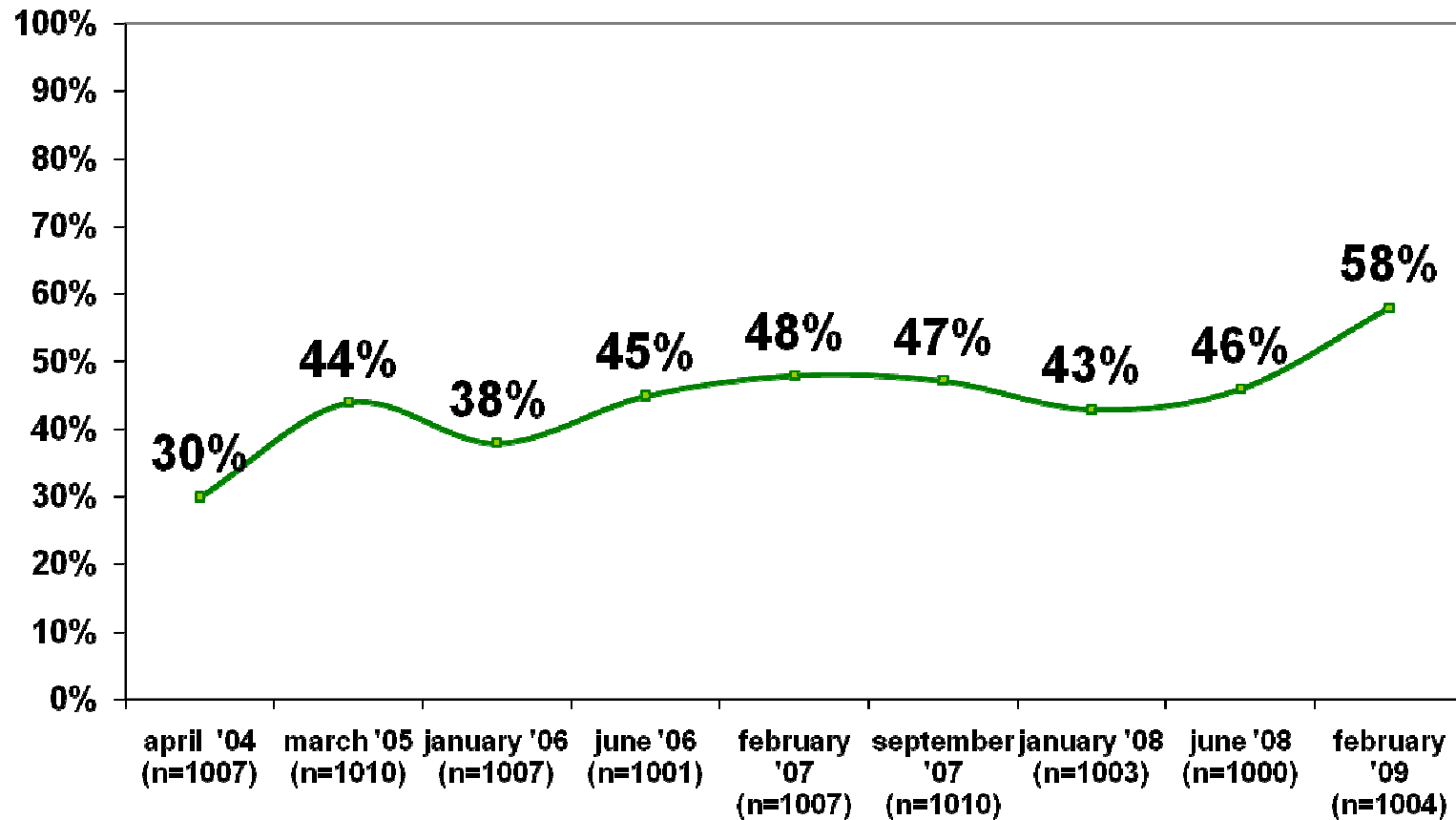


# PROJECTS TO INCREASE AWARENESS ROLE OF NGOS / PATIENTS' ORGANISATIONS

- **CF awareness campaign – National CF Week** (Polish Cystic Fibrosis Foundation MATIO, Krakow, Poland)
  - **Adressed to general public:** posters / TV / radio / Internet / press / volunteering activities / consultations with specialist
  - **In 2004 – combined with lectures for medical students** at 8 out of 11 medical universities in Poland – „Defeat CF” student project organized in cooperation with IFMSA-Poland
- **Outcome:**
  - **Steady increase in awareness** („have you heard about CF?”) over the years
  - **Students who participated in lectures – better results in CF-knowledge questionnaire**



# PROJECTS TO INCREASE AWARENESS ROLE OF NGOS / PATIENTS' ORGANISATIONS



- public awareness poll (Millward Brown SMG/KRC) – „Have you heard about CF?“ – data courtesy of Polish Cystic Fibrosis Foundation MATIO

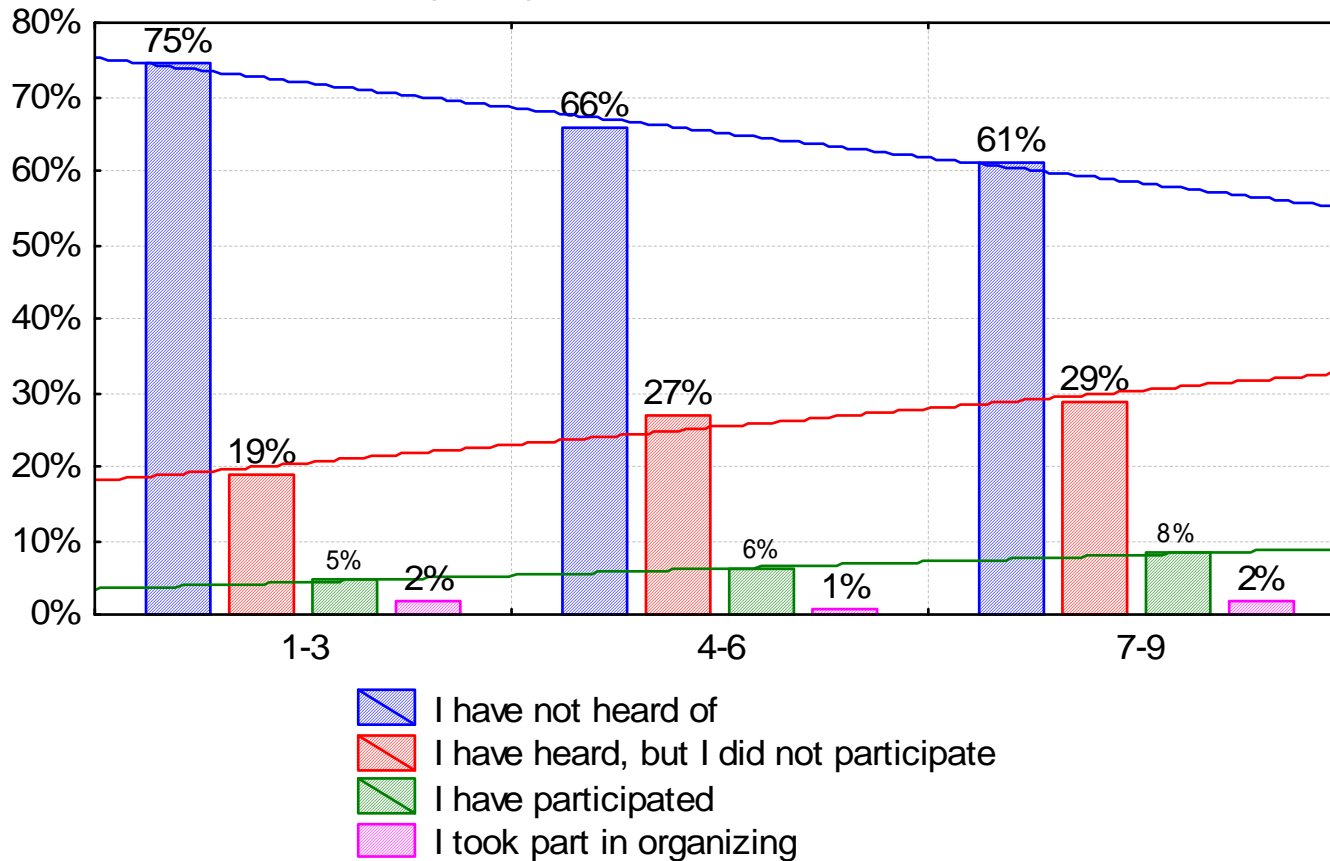


# PROJECTS TO INCREASE AWARENESS ROLE OF NGOS / PATIENTS' ORGANISATIONS

"I have not heard of" trendline =  $-0,068*x+0,79$

"I have heard, but I did not participate" trendline =  $0,049*x+0,16$

"I have participated" trendline =  $0,019*x+0,026$



- 2005 – evaluation of knowledge about CF among medical students (n=935) and participation in „Defeat CF” project



# CONCLUSIONS

- **Medical education is crucial in the field of rare diseases – to make professionals aware of existence and resources available in rare diseases**
- **Facultative classes are a novel way of improving quality of care in rare diseases in a long term**
- **NGOs and rare diseases patients' organizations may effectively work for increasing awareness = educating the general public as well as people affected by rare diseases and their families**

