IBD in the Czech Republic: 2019

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Introduction

- **Czech IBD Working Group** (established 1996), a section of the Czech Society of Gastroenterology
- Founded by prof. Milan Lukáš
- Current head: Martin Bortlík
- Aims: education, guidelines, clinical research
- Cooperation with European Crohn´s and Colitis Organisation (ECCO) and other working groups and expert teams worldwide
- Cooperation with patients´organisation (Pacienti IBD)
Patients´ organization

- Conference and seminars
- Books for IBD patients
- Stand up for patients´ rights
- Social and legal consultancy
- Awareness of IBD, therapeutic options and early diagnostics in general population
- Cooperation with experts and civil service
- Clinical research and development of new therapies

1.068 members (as of May 09, 2019)
Epidemiology of IBD

East-west gradient

- **ECCO-EpiCom study**
  - 16 countries from West Europe & Izrael
  - 9 countries from East Europe

<table>
<thead>
<tr>
<th>Regional incidence rates</th>
<th>No of patients</th>
<th>IBD (95% CI)</th>
<th>CD (95% CI)</th>
<th>UC (95% CI)</th>
<th>IBDU (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All Western European centres</td>
<td>1259</td>
<td>18.5 (17.5 to 19.5)*</td>
<td>6.3 (5.7 to 6.9)*</td>
<td>9.8 (9.1 to 10.6)*</td>
<td>2.4 (2.0 to 2.8)*</td>
</tr>
<tr>
<td>All Eastern European centres</td>
<td>256</td>
<td>8.1 (7.2 to 9.2)</td>
<td>3.3 (2.7 to 4.0)</td>
<td>4.6 (3.9 to 5.4)</td>
<td>0.2 (0.1 to 0.4)</td>
</tr>
</tbody>
</table>

*Burisch J et al., Gut 2013*
Epidemiology of IBD

Czech Republic

• Incidence: 12.2/100,000/year
• Prevalence: ~55,000 IBD pts (0.5%)

Burisch J et al., Gut 2013; Dušek L et al. Gastroenterol Hepatol 2019
Epidemiology of IBD

Dušek L et al. Gastroenterol Hepatol 2019
Joint Projects

• Information for patients

• Quality of life with IBD

• IBD and Male Infertility – a Multicenter Study
Information for Patients

Everything You Always Wanted to Know About Biologicals in IBD

But Were Afraid to Ask
Information for Patients

ECCO/EFCCA Guidelines

Cooperation between physician, nurse and the patient

- Simplified guidelines
- Common language - comprehensibility
Quality of Life with IBD

Kvalita života pacientů s idiopatickými střevními záněty v České republice – multicentrická studie

Quality of life in patients with inflammatory bowel diseases in the Czech Republic – a multicentre study

Ďuricová D et al. Gastroenterol Hepatol 2018
Treatment Satisfaction and Adherence

• Fully satisfied – 85% pts

• Daily dosing: ≥2 – 57% pts

• Occasional non-adherence – 34% pts
  - adherence predictors: ↑age, being interested in IBD news

Ďuricová D et al. Gastroenterol Hepatol 2018
IBD and Work Activity

• Hiding IBD from employer – 23% pts

• Working with stress due to IBD – 38% pts

• Work limitation due to IBD – 43% pts

Ďuricová D et al. Gastroenterol Hepatol 2018
IBD Symptoms

Fatigue, weakness 66.4%
Diarrhea 61.6%
Abdominal pain 51.7%
Skin 24.8%
Bleeding 20.8%
PACD 13.6%
Aphthae 10.9%
None 9.0%
Eyes 8.2%
Arthritis, arthralgia 6.2%

Ďuriová D et al. Gastroenterol Hepatol 2018
And what about men?

- difficulties to beget
  - semen quality
  - need for IVF
- sexual life satisfaction
- voluntary childlessness
- others
„My name is D….. and I am an Irish Citizen living currently in the USA. I have recently been offered a teaching position in Prague and I am very excited for the opportunity to live and work in the Czech Republic."

„My treatment in the USA involves an infusion of Entyvio (vedolizumab)… I am finding it hard to find information about the availability of this drug in the Czech Republic. Can you tell me if Entyvio is being prescribed currently or is it only available to those on clinical trials?“

„I would love to take the position but am nervous that I will not be able to access this medication. Your help is greatly appreciated.“
Availability of biologic therapy in the Czech Republic

- 1998 – infliximab (CD), „expanded access programme“
- 2006 – infliximab (UC)
- 2007 – adalimumab (CD)
- 2012 – adalimumab (UC)
- 2013 – golimumab (UC), biosimilar infliximab (CD, UC)
- 2014 – vedolizumab (CD, UC)
- 2016 – ustekinumab (CD)
- 2018 – biosimilar adalimumab (CD, UC)

- Organisation of biological therapy for IBD:
  - till 2006 – individual prescription
  - since 2006 – specialized centers for BT
Don’t worry, the future is bright…
Thank you for your attention!

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