

Patient comes first

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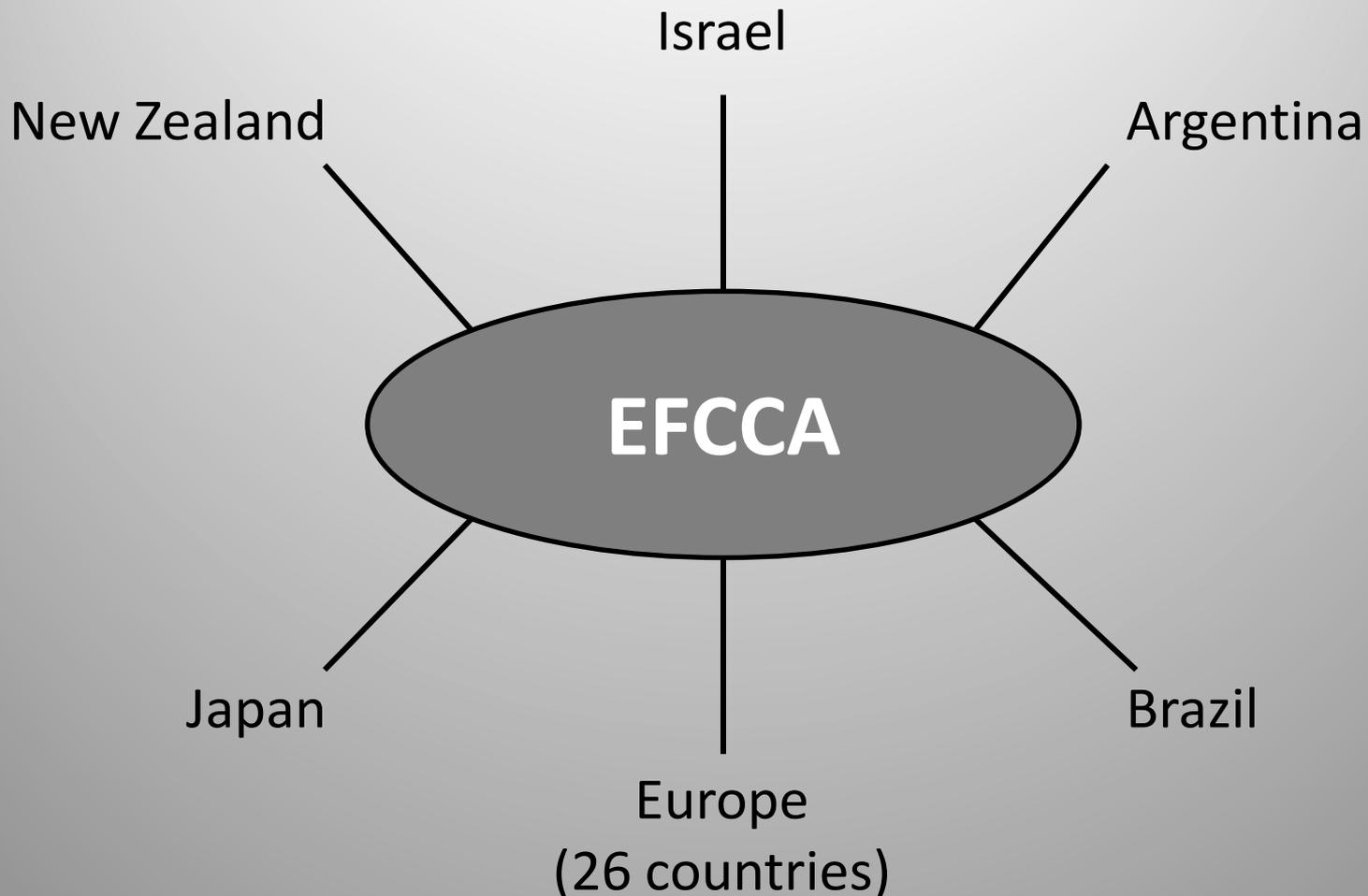
EFCCA

- IBD 11, Prague, 14th November 2013 -

EFCCA

- Since 1993
- Umbrella organization representing 28 national IBD patients' associations and three associate members outside Europe
 - Improving life for **100,000** active members
- EFCCA'S mission and values
 - Exchange of information, raising public awareness, empowering patient associations, assist in establishing new associations, encouraging research of IBD

EFCCA: Global challenge



+ Co-operations:

Australia (Australian Crohns and Colitis Association [ACCA]), Canada (Crohn's and Colitis Foundation of Canada [CCFC]) and US (Crohn's and Colitis Foundation of America [CCFA])

EFCCA / 2

- Activities and projects
 - World IBD Day on May 19th
 - Catch Your Dream Summer camp
 - IMPACT survey
 - World Symposium on research funded by patients
 - EU / EC initiatives
 - EMA (PRAC / PCWP)

IMPACT

- Developed by EFCCA to obtain an international European perspective of impact of IBD on patients' lives
- Nov 2010-Aug 2011; 4990 responses from 25 countries have been analyzed
- 70% are satisfied with their treatment plan, BUT:
 - 24% felt they did not have adequate access to specialists
 - 53% felt they were not able to tell the specialist something important and 65% wished they were asked more probing questions; the quality of communication in consultations needs to be improved

IMPACT

- 40% felt IBD prevented an intimate relationship; 34% felt IBD caused one to end
- 74% have taken time off work in the last year due to IBD
- 21% have suffered discrimination at work; 25% have received complaints or unfair comments
- 52% felt unable to perform to their full potential in an educational setting
- 96% felt tired, weak, and worn out in daily life during a flare-up; 83% also during remission
- Majority had IBD symptoms (urgency, pain, bleeding) at least once a week also in remission

IBD 2020

- June-August 2013, 5003 participants, 6 countries
- Around half of the patients state that the overall quality of their IBD care is either “very good” or “excellent”

BUT:

- Aims of care rarely discussed: 50% say no health care professional discussed with them main goals or priorities in caring for their condition(s)
- 72% say that no health care professional helped make a plan that could be carried out in daily life
- Need for improving quality of care in IBD!

Similar results and... not...

- IBD 2020 result of not having enough discussion shows that care is therapy-oriented and the overall impact of IBD on patient's life is often forgotten
- IMPACT results show the overall impact of IBD on social life, relationships, work, education, symptoms also in remission

Limits

- Quality of care often concentrates on quality of services, therapy, desired health outcomes, effectivity and timeliness of care
- These are important aspects – but an important outcome, the patient's quality of life, can sometimes be forgotten.
- Instead of concentrating on therapy alone, is it possible to concentrate on the individual with his/her individual needs ?

Which approach do we have ?

- Economy
- Structure of trials and drug-development
- NHS
- Guidelines
- Lack of time
- Lack of resources (also human)
- The patient himself

Leads to the risk of a “therapeutic-focused” approach

From therapeutic-focused approach...

- Not only evidence-based, but also patient-based
- “Think outside the bowel” - the patient is more than his/her illness
- Not only health care personnel, but also patients must be more aware of their role

...to patient-focused approach

- Patients are the ones to refer to when you need “first-hand” information
- A patient with a long history of IBD has a lot of experience and knowledge; book knowledge is not the equivalent of a patient’s subjective feelings and long experience with IBD

Is the involvement “safe”?

- Yes... but it has some conditions:
 - Decisions must be made in cooperation with patient and health care professional, both must listen to one another
 - If it is based on a real cooperation based on trust; patients will be more compliant if there is a trusting environment with the health care professional
- e.g. EMA

What you can practically do?

- Cooperate with us
- Develop with us new strategies
- Informing newly diagnosed (and not only) and their family about the existence and the work of our National Associations
- Lobbying with us

Take home

- Patients should come back to the center of OUR common work
- This approach could lead to a better allocation of the actual limited resources
- This approach could work only in the context of an open, honest and mutual cooperation