

No decision about us without us!

Patient representatives participate in open debate on patient safety issues and right to information at the European Parliament

Brussels, 15 November 2016. The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA), the Global Alliance for Patient Access (GAfPA) and representatives from several immunomodulated disease groups are gathering in the European Parliament for an open debate with Members of the European Parliament about patient safety and patient rights especially as it pertains to biosimilars and biologic treatments.

Patients will stress the importance of patients' right to information and knowledge as well as equal access to innovative drugs and health care in all EU member states. *"Patient empowerment is a strategic objective that will lead to a better knowledge of unmet needs and to reduce health inequalities in the EU. It is therefore crucial to include patients in the decision making processes ensuring optimal treatment plans and outcomes,"* said Martin Kojinkov, President of the European Federation of Crohn's and Ulcerative Colitis Associations. *"It is critical that policymakers hear the perspective of patients as they consider how to promote regulatory frameworks that will ensure access and prioritize patient safety and well-being"* said Brian Kennedy, Executive Director of Global Alliance for Patient Access.

Within the framework of patient safety EFCCA together with GAfPA organized an Advocacy Workshop on Patient Safety which took place in Barcelona on 4-6 February 2016. The meeting gathered over 60 representatives from immunomodulated disease groups such as Crohn's Disease, Ulcerative Colitis, Rheumatoid Arthritis, Ankylosing Spondylitis, Psoriasis, Hemofilia, Hidradenitis suppurativa as well as general patient associations.

The key messages emerging from the meeting will be presented at the European Parliament debate:

- **Switching from one drug to another:** This is a major concern expressed by patients and in some EU countries this is done without prior information to patients. It is essential to communicate with all relevant stakeholders (dispensing pharmacist, prescribing physician and patient) in order to optimize the outcome of the patient's treatment.
- **Tracing of a particular drug:** it is important to be able to trace back an administered drug in case there are some adverse effects.
- **Access to innovative drugs:** importance of increasing access to innovative drugs a costly but necessary treatment options. Initial high costs will outweigh overall economic costs of chronic disease patients in the long term.
- **Need for informing patients:** In order to empower them to be involved in the decision making and management of their conditions.

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About EFCCA

The European Federation of Crohn's & Ulcerative Colitis Associations is an umbrella organisation representing 33 national patients' associations. EFCCA aims to work to improve life for people with IBD and give them a louder voice and higher visibility across Europe and beyond.

About GafPA

The Global Alliance for Patient Access (GafPA) is a network of physicians and patient advocates with the shared mission of promoting health policy that ensures patient access to appropriate clinical care and approved therapies. GafPA accomplishes this mission through educating physicians and patients on health policy issues and developing education material and advocacy initiatives to promote informed policymaking.