



EFCCA
powered by people

European Federation of Crohn's and
Ulcerative Colitis Associations

Registered Brussels, BELGIUM
Reg. number 459814543

Secretarial address
Gropmorsvagen 28
10520 Tenala FINLAND

IBAN : GB18ALEI 72025062835489
BIC : ALEIGB22

www.efcca.org

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European Commission
Attn Ulla Narhi
DG Enterprise & Industry Unit F2 "Pharmaceuticals"
45 Avenue d'Auderghem, Office 10/93
B-1049 BRUSSELS, Belgium

PUBLIC CONSULTATION – Legislative proposal about Information to Patients

Dear Ulla,

Meeting the needs of people with long-term Crohn's and colitis (IBD) is high on our agenda. As part of EFCCA's overall strategy to improve the quality of life of patients of all ages and their families/carers, one of our prime aims is to work for improvements in the area of Information to patients, their healthcare including access to new medicines.

In seeking improvements to the development and availability of Information EFCCA has maintained an interest for some time in the subject of information to patients and the differing views of stakeholders, including the European citizens. So we are pleased to see the new proposals and that the current consultation involves all stakeholders, including patients and society at large.

Founded in 1990 the European Federation of Crohn's and Ulcerative Colitis Associations – EFCCA is currently comprised of 23 member national Crohn's and colitis' patient associations. It works for and with the member organisations and other related healthcare stakeholders and for the > 1.3 million diagnosed with chronic inflammatory bowel disease (IBD) cross Europe. We maintain contact with similar patient groups in other parts of the world. The numbers newly diagnosed continue to rise and give us some cause for concern. Please see also www.efcca.org

Through EFCCA's membership of both the International Alliance of Patients Organisations – IAPO and the European Patients Forum – EPF we have been involved in the current consultation process. **We support the IAPO and EPF's formal responses as submitted.**

In all that has been said it must though be remembered that people with chronic illnesses like inflammatory bowel diseases (Crohn's and colitis) and also many of the families and other people who support and care for them will continually seek information about how both new and different treatments might help their condition and/or how their daily lives might be improved.

They will rightly use all means of accessing that information and that will include where accessible "pulling" **information** from pharmaceutical Patient Information websites.

Citizens and consumer organizations do not always fully understand the needs of people with acute or chronic illnesses as they try to cope with their daily living in the short or long term, so very often have a different view.

Like many of the associations who have responded we believe that patients need good quality, objective, reliable and non-promotional information on medical products and treatments, which should be validated and standardized across the EU member states.

While the current Commission initiative can help this aim, the EC proposals do not cover the envisaged "bigger picture" as highlighted in the EPF response. In the patient-centred information strategy we also believe that DG Sanco should also be involved, given the White Paper Together for Health.

There is a need to take account of the current work and outcomes of the Pharmaceutical Forum, which includes the Information to Patient strand.

We already have new Medicine information systems for the public being developed/introduced by EMEA at the EU level in which the PCWP (Patient & Consumer Working Party) is actively working, so in this time of limited resources consideration should also be given to how the relevant outcomes of the present initiative can be incorporated into the European Medicines Agency systems and particularly its website. However that IT facility should be much more user friendly and much better publicized. The Commission's Health Portal could be available too with some modifications and of course the needs of member states considered too.

A formal European quality standard / content trust mark applicable to all providers of patient information should be urgently developed.

We thank the Commission for this opportunity to respond, in our case on behalf of those people with inflammatory bowel disease (IBD) of all ages and look forward to seeing the overall results of the consultation.

The EFCCA Board together with our IBD member associations and Medical advisers will be active either alone or in co-operation with other umbrella groups, the EPF and IAPO, as the results unfold and as we see confirmation of the next steps in the Commission and Parliamentary process.

We look forward to receiving the acknowledgement confirming that you have received this letter, which is being sent via e-mail.

Yours sincerely

Rod Mitchell

Chairman EFCCA