

## **EUROPE FIGHTS AGAINST IBD – inflammatory bowel disease Paris 4 - 8 October 2006**

**Breaking the silence ... Briser le Silence** was part of the challenge taken up by EFCCA delegates and the members of AFA in early October when they were together in Paris at the time of EFCCA's 16<sup>th</sup> Conference and General Assembly and the Association Francois Aupetit's First National IBD- MICI Day to raise awareness of the difficulties of living with IBD.

EFCCA delegates from 20 countries came to Paris not only for their General Assembly but to help raise the tempo across Europe in the fight against IBD, to discuss wide-ranging issues and to encourage vital research.

Initially EFCCA representatives joined one of a series of evening discussion groups at the Hospital St Antoine in Paris and on Saturday 7 October joined AFA's major event at the Cite des Sciences, Paris La Villette to support Association Francois Aupetit members in their week long series of events.

During EFCCA's General Assembly held at the Forest Hill Hotel La Villette the Slovenian Crohn's and Colitis Patients Association became the 23<sup>rd</sup> national Crohn's and colitis patient association to be elected to membership and we are delighted to welcome them to the EFCCA family.

Among the decisions taken at the first GA following registration in Belgium of the amended statutes, delegates confirmed the "modernisation" of the EFCCA governance and management structure which included the introduction of 5 new Standing Committees to encourage greater year round involvement of delegates: Healthcare : European Affairs : Communication : Development : Finance. All except Finance met during the Paris days and results were fed back to all EFCCA delegates towards the end of the Assembly.

The EFCCA Treasurer in presenting the calendar Year 2005 accounts confirmed a satisfactory financial position and as a result the year 2006 Budget was tabled without the need for an increased annual subscription. Both were approved together with the Year 2007 outline Work Plan.

It was announced during the GA that for the first time EFCCA have also published their Annual Report (for Year 2005) for external use and to aid transparency. The Annual Report together with the Executive Committee's report about the first nine months of 2006 and a number of other interesting articles can be found in the pages of the **October EFCCA Newsletter No 25, which is available and also in PDF format for download from the website at: [www.efcca.org](http://www.efcca.org)**

Delegates heard also at the GA about the positive work of the EFCCA Youth Group, took a decision to post summarised information about Travelling with IBD on the EFCCA website and to have a fact sheet/leaflet available for those without web access, subject to generating sufficient funds to extend beyond the first year to establish a "Brussels" office with part time admin support, and dealt with a number of other issues taken from the EFCCA Executive Committee Report.

Following discussions in Paris EFCCA will also move further forward with its feasibility project about establishing an EFCCA European IBD (Patients) Research Foundation to provide a research fund for those wishing to donate funds for multi country research - so important today in the fight against IBD. It was also agreed in principle to the setting up of an

EFCCA supporter group, European Friends of IBD although in both cases the organisation names have not been confirmed.

As a new venture towards the end of each Assembly day interesting outreach sessions were provided:

- The first a very interactive non-promotional, non-biased session was provided by an industry representative about the general subject of Clinical trials, which produced many questions and the need for an easily understandable fact-sheet to assist patients and families through this complex subject.

- On day two a presentation by given by Professor John Frederick Colombel, the Vice President of ECCO about the work of the European Crohn's and Colitis Organisation, in which EFCCA is already represented. It was agreed following the ECCO presentation and constructive discussion that EFCCA should seek to set up a joint working party to see how the two organisations might co-operate. Meanwhile as a first step to offer to partner with ECCO in a project about Information to IBD Patients Guidelines, given the increasing interest of the European authorities in this subject area.

The Chairman also reported that an Oral Presentation was being made during the Berlin Year 2006 UEGW scientific programme about the results of first EFCCA Pan European IBD Study carried out in year 2005 with the assistance of 7 member associations.

On Le Nuit Blanche - the night when nobody sleeps and our last night in Paris - EFCCA delegates joined the AFA members and their organising team for a celebration at which EFCCA Chairman Rod Mitchell thanked our hosts, the AFA Board and their financial supporters for making it possible for EFCCA to be in France.

In talking together earlier in the day in La Villette Rod Mitchell on behalf of EFCCA and Patrick Riaudet the President of AFA both pledged to raise the tempo in their respective organisations plans to see how more resources can be discovered and used for IBD Research to find cause and cure. At the same time importantly they also agreed to work with other member associations to "break the silence and taboo ... surrounding these often debilitating life long conditions and to help those peoples diagnosed with Crohn's and colitis to cope with their everyday lives as very many still feel socially isolated through their bowel condition.

Departing after a successful General Assembly and the AFA IBD Awareness events, as always EFFCA would like to acknowledge and thank their very many IBD friends who help in so many ways. Without our active Member Associations, Delegates and Medical Patrons , the Board and Executive Committee and Industry supporters much of the EFCCA work across Europe and beyond would not be possible. The vibrant meeting in Paris heralded a new beginning in some ways for EFCCA which is looking forward to the future with renewed enthusiasm and confidence and with special thanks to the many volunteers Europe-wide, who give so freely of their time in helping to make all this possible.

### **Year 2007 Diary**

***Since the Paris days the Falk Foundation have kindly agreed to support EFCCA's " Year 2007 Conference and General Assembly" in Sevilla, Spain from 21 – 25 March.***

***During part of that time the Falk Foundation are holding the Falk Intestinal Inflammation and Colorectal Cancer Symposium. Details about the Falk Symposium can be obtained via: [www.falkfoundation.de](http://www.falkfoundation.de)***

*More information about the EFCCA days in Sevilla can be obtained from the EFCCA Secretariat: [micke.lindholm@pp.inet.fi](mailto:micke.lindholm@pp.inet.fi) although the General Assembly is a closed meeting for the delegates of the EFCCA member associations.*