

World IBD Day Report 2018



EFCCA
European Federation of Crohn's &
Ulcerative Colitis Associations

Background

World IBD Day takes place on 19 May each year and unites people worldwide in their fight against Crohn's disease and ulcerative colitis, known as inflammatory bowel diseases (IBD). It is estimated that over 10 million¹ people live with inflammatory bowel diseases (IBD) however in many countries there are no official registries.

World IBD Day was created in 2010 by 5 founding members including the Crohn's and Colitis Foundation (US), the Crohn's and Colitis Foundation Canada, Crohn's and Colitis Australia, Crohn's and Colitis UK, ABCD (Brazil) and the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA). In recent years, EFCCA has been co-ordinating global campaigns to mark World IBD Day. Together with our founding members and other associate organisations we reach out to over 50 countries and growing.

Global campaign in 2018

In its eighth year of running World IBD Day is becoming an important global event which brings together patient associations, patient advocates, healthcare professionals, family, friends and other stakeholders to show their solidarity with the 10 million people that are living with IBD worldwide.

EFCCA has been coordinating the global campaign aimed at raising IBD awareness by illuminating famous landmarks in the colour of purple alongside the organisation of local events on either the 19th of May (the official date of World IBD Day) or around that date. In some countries the whole month of May has been used to raise IBD awareness.

This year has seen another successful campaign with a high degree of participation from our members and new countries joining the global campaign.



ACCU Bizkaya Group, Bilbao, Spain

Out of EFCCA's 36 member associations, 31 members participated in World IBD Day activities and in Europe alone there were over 250 famous landmarks lit in purple involving over 140 cities and regions.

The **World IBD Day website** has been an important tool in providing a unique platform for sharing activities that have taken place worldwide and for being a reference point to the international IBD community and those interested in the events. It has allowed us to promote the campaign through our social media channels and traditional media.

We have distributed over **5000 purple ribbons** worldwide which have been handed out free of charge at awareness raising events, doctor/patient meetings and other events aimed at promoting World IBD Day. The purple ribbon is the universal symbol of awareness and support for people living with IBD.



Triton Fountain, Rome, Italy

(1) Figures for US: Centers for Disease Control and Prevention (US) (2015), Europe: The burden of inflammatory bowel disease in Europe, Journal of Crohn's and Colitis Volume 7, Issue 4, 1 May 2013, Asia: Emerging Trends of Inflammatory Bowel Disease in Asia, Gastroenterol Hepatol (N Y). 2016 Mar; 12(3)

In relation to our EFCCA members, Italy and Spain saw a very strong participation in the illumination campaign and both the Italian IBD association, AMICI, and the Spanish association, ACCU España, were highly successful in mobilizing local patient groups to unite around the national and international campaign and organising local information events either in public spaces or more institutional acts in municipalities with the presence of local government officials. AMICI also prepared a World IBD Day promotional video that was being screened at the two main airports in Rome as well as received a medal from the Italian President, Sergio Mattarella, in recognition of World IBD Day.



World IBD Day events in France

The French IBD association, afa Crohn RC, mobilised many cities and regions to join the lightening campaign and also gathered support around the theme of IBD and physical activity. From sports clubs, dance competition to zumba, afa RCH Crohn made “France move” on that day (their slogan was: we move faster than the disease) in order to support research and the rights of IBD patients. Many Olympic athletes and other famous people in sports supported their campaign.

Some of our member associations opted for a different campaign format as they had found it difficult to arrange for famous landmarks to be lit in purple. For example in the Nordic countries, due to the long day light hours, it made no sense to highlight buildings in purple as it would not be visible, however they joined the worldwide celebrations through different activities aimed at raising IBD awareness, for example the Icelandic association, Crohn’s og Colitis Ulcerosa Samtökin (CCUS) organized a social media campaign posting every day leading up to World IBD Day pictures and personal stories of members

of the association together with many information events around IBD throughout the month of May.

Crohn’s and Colitis UK took advantage of the high media attention for the Royal Wedding between Prince Harry and Meghan Markle which took place on the same day as World IBD Day and organised a wedding theme around their awareness raising campaign. They encouraged their supporters to hold their own “royal tea party” or bake sale to raise awareness of IBD and funds for the charity.

All in all we have seen an amazing range of activities and events that show the creativity, eagerness and commitment of patient associations to make sure that we are visible and that we are heard! We recommend you to visit the www.worldibdday.org website to view country specific activities.

International dimension

IBD is unfortunately increasing worldwide over recent years and it is no longer a disease mainly observed in Europe, North America and Oceania. IBD incidence is rising in industrialized countries in Africa, Asia, and South America.

EFCCA has been collaborating traditionally with patient groups from North America, Brazil and Oceania but over the past few years we have been approached by other countries that are interested in raising awareness about IBD in their specific countries and to form part of an international network with the aim of exchange of information and being recognized nationally as part of a global movement.



World IBD Day events in India



Belarus joined World IBD Day for the first time this year

This year participation from non-EFCCA patient groups included 17 countries such as Australia, Azerbaijan, Belarus, Bosnia and Herzegovina, Brazil, Canada, Egypt, Hong Kong (China), India, Japan, Puerto Rico, Russia, South Korea, South Africa, Trinidad and Tobago and the USA. Newcomers to the campaign this year have been Belarus, Hong Kong, India, Japan, South Africa and Uruguay.

Added value for EFCCA and its members

World IBD Day for EFCCA and our patient associations is an excellent tool to gain visibility and to engage our supporters, be it volunteers, family members and friends or more institutional such as health care provider pharmaceutical industries and policy makers. Many of our member associations have been able to reach out to the public and become more visible through media (Television, radio, printed press), social media and public acts. Through the illumination campaign associations have also come in contact with municipal and regional authorities opening up ways for institutional visibility and potential for further collaboration. For example the 7 Canary islands in Spain have made an agreement to have most of the public buildings on the seven islands lit in purple on 19 May, this was organised in parallel with institutional acts and information events.

For EFCCA, World IBD Day also allows us to reach out to countries where there is no formal representation for patients with IBD. One of EFCCA's missions is to assist in establishing new associations in countries where they do not exist yet. Since we have started to mark World IBD Day we have been able to get in contact with groups

of patient, physicians and other stakeholders from countries where there are no formal representations of patient associations.

We are in discussions with several countries to see how we can collaborate in the creation of patient support groups and in ultimately improving the quality of life of people with IBD in those countries. For example the pharmaceutical company Janssen, (Mumbai office) were keen to celebrate World IBD Day in India. After discussions with them, they agreed to facilitate in the organization of several patient-doctors information seminars and we are now discussing a possible collaboration to help in the establishment of patient support groups in India.

World IBD Day 19 MAY #worldibdday2018 #unitedwe stand2018



Next steps

We are happy to see that World IBD Day is consolidating in nearly all of our member countries and is growing also in non-EFCCA member countries. For many of our associations the illumination campaign is an excellent tool to gain media visibility and to reach out to potential stakeholders in their efforts to advocate for people with IBD in their country.

For the 2019 campaign we would like to work with our members around the common theme of "Making the invisible visible". This theme is broad enough to allow our members to adapt their national agenda within that theme and it also allows those countries that would like to carry on with the illumination campaign to include it within their action.

You can find more detailed information about all the activities that took place this year on the following website: www.worldibdday.org. For other enquiries please contact: bella.haaf@efcca.org

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