THE FIRST EUROPEAN COLORECTAL CANCER PATIENT CONFERENCE
24TH – 25TH JUNE 2011
BARCELONA
EXECUTIVE SUMMARY
Dear Colleagues and Friends

Established in 2005 europacolon is the first European organisation dedicated to colorectal cancer and it aims to unite patients, carers, healthcare professionals, politicians, the media and the public in the fight against the disease.

Our Mission:
“europacolon is committed to preventing deaths from colorectal cancer and improving the quality of life and support for those affected by the disease”

For many years it has been a dream of mine alongside the europacolon directors and our management team to host a colorectal cancer patient conference in Europe. europacolon has always believed that good cancer care starts with good cancer information and that well-informed patients are their own best advocates and invaluable partners for clinicians. Patients affected by colorectal cancer must be involved in decision making and have a range of support available to them.

It was therefore with great pride that on the 24th and 25th of June 2011 in Barcelona alongside the World Congress of Gastrointestinal Cancers we held the FIRST European Colorectal Cancer Patient Conference – ‘The Power of the Patient Voice – The Challenges, Collaboration & Change’ (CCPC 2011).

The main objective of the conference was to provide an opportunity for colorectal cancer patients and all other stakeholders to exchange knowledge, collaborate, and become better informed on all matters concerning colorectal cancer throughout Europe and the world today. The conference was well attended with over 130 delegates representing 20 countries globally and with over 30 NGOs, patient groups and medical organisations present. CCPC 2011 gave colorectal cancer patients, survivors and their families a platform to share their unique and inspirational experiences of living with colorectal cancer including the challenges they faced and how they were able to overcome these. What remained consistent throughout was the great desire amongst all stakeholders to build alliances and work together to reduce the overwhelming burden of the disease.

It is our expectation that this will be the first of many successful collaborations and I would like to take this opportunity to thank all those who attended and contributed towards the success of this event and supported our vision.

Jola Gore-Booth – Founder/Director europacolon
The World Journal of Gastroenterology (December 2009) stated that ‘colorectal cancer presents a serious public health care issue for the population of Europe.’

Colorectal cancer is the second most frequent malignant cancer in Europe – 412,000 people are diagnosed annually and 207,000 die of it. In 2003 the European Code against Cancer and the EU Council Recommendations specified that men and women over 50 years of age should participate in colorectal cancer screening. To date only 12 EU Member States have made any progress with implementing screening programmes and in many cases these are sporadic and diverse. In addition where screening is available whether population based or on request, compliance is still low. Colorectal cancer is highly treatable if diagnosed early. It is the most treatable of all the gastrointestinal cancers.

According to global colorectal cancer statistics available from GLOBOCAN 2008 published in June 2010 – deaths from colorectal cancer were estimated at 608,000 worldwide making the disease the fourth most common cause of cancer death.

Since its inception in 2005 europacolon has sought to make a difference to these statistics. To date it has established and partnered with 18 affiliate and associate groups across Europe, creating the beginnings of a European colorectal cancer community … one that is committed to coming together to instigate change! It is our intention that by 2016 there will be a colorectal cancer patient organisation in every European country.
Today europacolon has been accepted as the patient voice for colorectal cancer in Europe. Our sister organisation Global Colon Cancer also supports the vision of bringing together existing colorectal organisations, creating new ones where needed and uniting people all over the world in the fight against this killer disease.

The conference objectives aligned with the European Commission’s health initiative (EAACP) to reduce cancer incidence by 15% by 2020. The EU Health communication’s aim is that by 2013 every Member State should have in place a national cancer plan or strategy and 100% formal population screening. CCPC 2011 reinforced the urgency for the implementation of population screening and national cancer plans.

The conference was supported by cancer survivors and their families, clinical colorectal cancer experts and key opinion leaders across Europe and the world. A supportive statement from Professor Jose’ Martin Moreno – Director of the World Health Organisation (Europe) echoed and emphasized our vision for a co-ordinated and united front on fighting colorectal cancer. The keynote speakers included MEP Pavel Poc (Czech Republic), Suzanne Lindley (US) Co Founder Beat Liver Tumours and europacolon’s Medical Director Professor Eric van Cutsem who all reiterated the importance of creating a united colorectal cancer community. We were also honoured to have a representative from LIVESTRONG presenting at the conference. The wonders of technology permitted us to webstream the conference allowing audiences across the globe to unite with us.
CCPC 2011 addressed six main topics:

1. Recent & Future Advances in Colorectal Cancer Treatment
2. Investing in Colorectal Cancer Prevention and Control
3. Patient Rights
4. Sharing Best Practice
5. Challenges in Health Policy at EU Level and in Member States – The importance of Lobbying
6. Importance of Patient Advocacy

Speaker presentations provided an overview of existing strategies and actions in the current field of colorectal cancer health promotion, prevention and control from colorectal cancer experts and patient advocacy groups. Also included were presentations of inspiring experiences from cancer survivors and families of those who have suffered from colorectal cancer – these proved most profound and passionate and gave patients and families a voice to convey their perception of the challenges they faced. The programme included 20 minute ‘Question and Answers’ sessions after each set of presentations to facilitate discussion and interaction with delegates.
The overall consensus was that for future events smaller workshops and breakout sessions should be made available. This would give all present an opportunity to voice their opinions and experiences in a more intimate manner to strengthen and enhance the patient voice.

Our PR agency reports that media coverage of CCPC 2011 was a huge success, they disseminated information via 120 separate routes/mediums globally in the week that followed. For full details of headlines, medium and links to each article please see our full report which will be available in October 2011 on our website.

The subject of a universal symbol for colorectal cancer was strongly debated. Three different designs were presented – a blue ribbon submitted by Belgium, the digestive man symbol submitted by the UK and the colorectal cancer star from the US. Opinion was divided amongst the delegates with the digestive man appearing to be the winner. However the debate continues as cost elements have to be taken into consideration and of the three the most cost effective to reproduce on a mass scale is the blue ribbon – the jury is still out! europacolon is keen to establish an agreed symbol and to work with the European Parliament/WHO in order to formalise March as European Colorectal Cancer Awareness Month (ECCAM).
ECCAM was launched in the European Parliament by europacolon in March 2008. It has been adopted across most of Europe as the month for colorectal cancer however this as yet has to be given official approval.

As a result of this hugely successful meeting and continual encouragement from so many present, europacolon will commit to hosting ‘CCPC – The Patient Voice’ biennially with the intention of a ‘CCPC – Extending the Reach’ conference for the Central / Eastern European countries each alternate year that follows.

CCPC 2011 has contributed towards the establishment and development of many successful new alliances and partnerships. All outcomes, key messages and conclusions will enable europacolon to continue with a comprehensive programme of activities to achieve our overall mission of preventing deaths from colorectal cancer.

A full report on the conference to include: presentations, photos and CD will be available at www.europacolon.com and via social networks by the end of October 2011.
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The following organisations have given a statement of support for the Conference. The statements can be viewed at www.europacolon.com/CCPC
europacolon would like to thank everyone who contributed towards the success of this First European Colorectal Cancer Patient Conference.

The conference proved without doubt that the European colorectal cancer community is wholly committed to working together in saving lives from this highly treatable disease through prevention and control and to effecting the much needed changes in access to best treatments, care and support for colorectal cancer patients, their families and carers …

… because life matters!

We dedicated this conference to the memory of those who have inspired and motivated the work of europacolon

Emir Cizmic europacolon Bosnia
Leslie Dobolyi europacolon Hungary
Lidija Vidmar Andrejasic europacolon Slovenia
Angel Gracia europacolon España
Dave Miners who was the inspiration behind europacolon

europacolon … because life matters

www.europacolon.com/CCPC

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