In memory of Lynn Faulds Wood

A big loss for cancer advocacy patients

Dear ECPC members,

A big loss for cancer advocacy patients: Lynn Faulds, UK TV presenter, groundbreaking journalist, Founder of European Cancer Patient Coalition in 2003 and President for seven years, left us last Friday. Cancer representatives of the 450 member organisations of ECPC are grieving for her passing.

After being diagnosed in 1992 with colon cancer, Lynn set up the very successful Lynn’s Bowel Cancer Campaign in the UK and later on, being a very active cancer patient advocate with unusual communication capacity, had the great intuition to raise awareness of the disease at European level to give voice to the cancer patients organisations operating in the then 28
Indeed in September 2003, at the European Cancer Conference (ECCO) in Copenhagen, Lynn, with the determined support of Kathy Redmond - editor of the magazine Cancer World of the European School of Oncology’s (ESO) - announced in a press conference the establishment of the European Cancer Patient Coalition, whose first 7 members were 2 from Germany and UK and one each from Austria, Ireland, Italy and Netherlands.

On that occasion she expressed her shock in discovering that there were so many inequalities in access to diagnosis, treatment and follow-up of cancer and that there was no knowledge of best practices across Europe. She then stated in her address:

“We hope that this new group will enable us to highlight some of these problems to policy makers, and empower patients. No-one with cancer should have to put up with sub-standard treatment just because they don’t know that there is anything better in another country, or even another region of the same country. To date there has been no fully representative body to which the European Commission, for example, could turn, and this has meant that they have often been given inappropriate advice by groups which are not able to see the full cancer patients picture. I was lucky to live and now I spend most of my time trying to save other lives from bowel and other cancers”.

The announced goals of ECPC were:
1) Nothing about us, without us,
2) Promote the fundamental rights of European cancer patients,
3) Increase cancer patients’ influence over European health policy,
4) Ensure timely access to appropriate prevention advice, treatment and care,
5) Promote the advancement of cancer research.

Lynn has been working very hard to realise what she had promised, bringing together cancer patients, health care professionals, scientists, scientific societies and politicians from across Europe to join the fight against cancer. She was instrumental in marshaling the collective voice of patients from the big cancer groups such as breast, colon, cervical, prostate, to the rarer cancers to speak with one voice. Under Lynn’s guidance, ECPC established a stable strong relationship with Members of the European Parliament and the European Commission. With the political support of Alojz Peterle, MEP and former Prime Minister of Slovenia, himself a cancer patient, ECPC set up one of the first European Parliament Interest Groups “MEPs against Cancer”. This group of politicians and cancer patients from across Europe not only advocated for the re-instatement of the Europe against Cancer programme, but also reached out to politicians and policy makers in different EU countries. Consequently the Slovenian government made Cancer their health priority when they held the EU Presidency chair of all EU Member States. ECPC contributed a chapter to the Slovenian Presidency publication “Responding to the challenge of cancer in Europe” – Cancer patients as partners for change.

Thanks to Lynn’s persistent work, ECPC was instrumental in re-instating the Europe against Cancer Programme, involving dedicated and devoted representatives of ECPC member
Francesco de Lorenzo, as a co-founder and past President of ECPC, would like to remind the most important achievement of Lynn: the European Parliament Resolution that allowed to establish, for the first time in Europe, a voluntary and very productive collaboration on cancer among Member States, through the approval of a Joint Action on Cancer Control, where ECPC represented the patients voice.

Unfortunately, Lynn decided to leave ECPC after 7 years of Presidency, due to conflicts within the Board and this meant a bad time for the Organization.

Under the Presidency of Francesco de Lorenzo in 2013, the new Board has worked as a team to rebuild the organization and unity was its flag. For ECPC’s 10 years celebration, Lynn was with us in Bucharest as the principal speaker in the Session: “Ten years of ECPC: Identifying the past and constructing the future”.

In the last 6 years ECPC played an essential role in Europe by effectively acting as the voice of cancer patients, committed to representing patients’ interest, raising awareness of the key issues that lead to disparities in cancer care, making practical recommendations to bridge the gap between cancer policy and cancer care practice, working closely with the European Commission on the Joint Actions against cancer: EPAAC, CanCon, JARC, iPAAC, ECIBC. These achievements are the ones that Lynn was envisioning in the press conference at the ECCO congress in 2003, when she announced the establishment of ECPC.

Today, under the stress that the covid-19 has placed on cancer care across Europe and threatens with acute disease and death the most frail cancer patients, the best that ECPC can do to honor Lynn’s memory is to work diligently and closely all together, members, Board and staff, for the five founding goals of ECPC that have been our beacon all these years.

Unity, mutual support, hard work, continuous learning and empowerment of our members are our guiding principles and the ones that will guide our steps in playing a major role in the Mission on Cancer and to help overcome the inequalities in cancer prevention, treatment, rehabilitation and survivorship care.

Kathi Apostolidis
President

Francesco de Lorenzo
Co-Founder, Past President and Chair of Scientific Committee

This is an updated version of the original text uploaded on 27th April 2020 on ECPC website.