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International Cancer News

From the Globe:

International Society of Cancer Chemoprevention Founded

After several years of thoughtful preparation and closely following the development of this new, rapidly growing field of oncology, an "International Society of Cancer Chemoprevention" (ISCaC) was founded on October 26, 1995 in Naples, Italy. Dr Michael Osborne, Director of the Strang Cancer Prevention Center (attached to Cornell University Medical Center), New York, U.S.A. and Dr Alberto Costa, Director of the European School of Oncology in Milan, Italy, were the driving forces for this move.

Some 30 international "Founding Members" attended the founding ceremony at the prestigious Grande Albergo Vesuvio in Naples, followed by a small international workshop on Cancer Chemoprevention on October 27, 1995 at the Istituto Nazionale Tumori-Fondazione Pasquale.

The specific aim of this new scientific society is to provide an international forum for the exchange of research data and educational developments in Cancer Chemoprevention, being defined as "any chemical intervention to inhibit the carcinogenic process prior to invasive disease" (based on the new constitution and by-laws of ISCaC). This apparently does not exclude "biotherapeutics" or "bioprevention" of cancer specifically (as long as these substances are defined as chemical substances), but it does exclude cancer vaccines etc.

The founding assembly elected Professor Umberto Veronesi, Milan, Italy, as its Founding President and named three Vice-Presidents for its major geographic areas: Dr Trevor Powles from London, U.K. (for Europe), Dr Michael Sporn from New York, U.S.A. (for the Americas) and Professor Hiroschi Kobayashi from Sapporo, Japan (for Asia). Dr Michael Osborne from New York will act as ISCaC's first Secretary General. Other elected officers of ISCaC comprise the chairpersons of four topical subcommittees: Dr Jack Cuzick, London, U.K. (for Epidemiology); Dr Gary J. Kelloff, Bethesda, U.S.A. (for New Agents); Dr Richard C. Moon, Chicago, U.S.A.; Dr Charles W. Boone, Bethesda, U.S.A.; and Dr Franca Formelli from Milan, Italy (for Laboratory Studies); Dr V. Ki Hong, Houston, U.S.A. and Dr Martin Lipkin from New York, U.S.A. (for Clinical Studies).

The new ISCaC society intends to embark on bi-annual international meetings on both sides of the Atlantic and in Japan, with potential annual workshops in between. There has been no decision yet over whether the society should establish its own scientific journal or become affiliated with an existing one in the field of cancer prevention

For information about ISCaC contact: Dr Michael P.Osborne, General Secretary of ISCaC, Strang Cancer Prevention Center, Cornell University Medical College, 428 E 72nd Street, Building 600, New York, New York 10021-4090, U.S.A.; Tel: +1 212 734 4953.

Hans-Jörg Senn
St Gallen, Switzerland

Quality of Life Around the Globe

Measuring quality of life as an outcome measure in health care is gaining momentum both in clinical trials and in clinical practice. Since this is a relatively new field of research, the need for professional exchanges between scientists active in this field is both greatly needed and warranted. It is for this reason that the International Society for Quality of Life Research (ISOQOL) was created in Brussels in the early spring of 1994. Last month, from October 14–17, this international association held its second meeting in Montreal, Canada. The conference was attended by more than 300 participants from countries all over the world, exceeding the expectation and for some sessions, the capacity of the location. Although sitting on the floor or standing in the corridor might not be the most pleasurable position, the diversity of subjects and the quality of the presentations compensated for this inconvenience. The aim of this scientific international association is to promote progress of the research related to the functional, psychological, and socio-economic repercussions of disease and its treatment. Although the society does not restrict itself to the scientific research of quality of life issues related to a specific disease, cancer always has and still receives major attention in this field, and not without reason. Oncological treatments can cause considerable side-effects in terms of morbidity, and cure is seldom guaranteed. In clinical practice, both the expected gains and losses have to be balanced against each other. Since survival or life-expectancy is often an unsatisfactory measure of outcome, quality of life has become an important issue in oncology. This was also reflected in the programme of the conference, with cancer receiving more attention than any other disease.

During the conference, various areas of quality of life research were addressed. Main topics included ethical and life span issues, determinants of quality of life, new measures, translation and valuation work on existing instruments, clinical studies, and health economics. The emphasis in this conference on cross-cultural differences was striking. For the first time in the short history of quality of life conferences, this subject was a very important issue and the most innovative issue to be discussed. Quality of life research has been developed and performed in mainly western societies. Although quality of life research in developing countries is still in its infancy, there is a growing interest in this issue and the number of studies that perform descriptive comparisons across cultures is rapidly growing.

However, as was apparent from the many oral and poster presentations, there are major cultural differences in the approach to disease and treatment, and therefore, before any instrument can be applied in quality of life evaluations, it has to be validated and tested within each country.

The message is also important for clinical cancer studies that are conducted in Europe. Although there is a long and strong history of co-operation with regard to the conduct of international clinical trials, there are also important cultural differences between the various countries in their approach to communication with and perceptions of patients on cancer issues. An appropriate measurement of the impact of disease and treatment on the quality of life ought to take into consideration the cultural background of patients and physicians.

3rd Annual Cochrane Collaboration Colloquium

One would think that our ability to carry out computerised searches would result in all information on cancer clinical trials being instantly available. Unfortunately, this is not the case, and large chunks of data have never been included on bibliographic databases or are not easily accessible. There is almost universal agreement that if the best and most current information about medical treatments were available more effective medical interventions would result. Put simply, good information can save lives. However, the computer is only a tool and unless the data is readily accessible, the information may only appear complete.There is, in addition, a need for appropriate unbiased quantitative synthesis of the data made available. The Cochrane Collaboration developed to stimulate production of complete databases of research and the synthesis of such data in systematic reviews. This rapidly growing group of clinicians, researchers, consumers and others met on October 4-8 1995 in Oslo, Norway.

From a modest beginning in October 1993, the Cochrane Collaboration now numbers over 1000 participants. There are currently Cochrane Centres in Australasia, Canada, Italy, The Netherlands, The Nordic Countries, The United Kingdom, The United States and the number continues to grow.

The Cochrane collaborative review groups currently address approximately 20 problem areas with an emphasis on producing results of randomised clinical trials. Researchers and editors are manually reviewing journals as far back as 1948, and are also on the alert for completed trials that have never beenpublished. The goal is: to create a register of all completed and continuing randomised controlled trials; to conduct systematic reviews; and to provide these to everyone through the Cochrane Database of Systematic Reviews by an on-line journal, the internet and on CD-Rom.

While this group is young and is still developing, the Cochrane Collaboration has already won considerable support from governments around the world.

The Cochrane Cancer Network is to be co-ordinated by Chris Williams (Cochrane Cancer Network, Institute of Health Sciences, P.O. Box 777, Oxford OX3 7LF, U.K.). This network provides a frame work for forming collaborative review groups to examine specific aspects of cancer care, and it is hoped that some unresolved questions can be answered through better use of the research data already available. Its findings will also act as a spur to further clinical trials.

Richard Sylvester, Brussels, Belgium
C. Williams, Southampton, U.K.

From Europe

Europa Donna — An Indpendent start

Europa Donna officially became an independent organisation at its recent second international conference in Vienna, although it will maintain close ties with the European School of Oncology (ESO). Until recently, the coalition functioned as an educational activity of ESO from which it received its basic financial support.

In Vienna, elections were held for president, vice-president, and board members — a formal leadership structure which has replaced the provisional six member working party that steered Europa Donna's course thus far. In addition, four expert subcommittees were set up to address issues related to medicine, patient care and support, information and education, and fundraising and public relations.

"By creating these subcommittees, we hope to harness various forms of expertise to the organisation", Gloria Freilich, Chairwomen of Europa Donna, said. "Within our membership, we can already see that there are people with an enormous amount to offer in each of these areas".

Among the participating countries, she added, "some have well-established breast cancer programmes, others are poorly resourced and eager for contact and information. There are those who feel they have so much to learn, and those who feel they have a lot to give. In fact, there's a crossover, because we all have a lot to learn as well as to give".

National Groups affiliated with Europa Donna often sponsor programmes or hold events that address particular needs and concerns of women in their country. For example, the Israeli Cancer Society set up workshops in which sisters and other close female relatives of women with breast cancer met with doctors to discuss genetic aspects of the disease. In Italy, the group ANDOS arranges for patients in hospital to be visited by volunteers, to meet for social and recreational activities, and to be fitted for breast prostheses. And the Russian group Nadezhda, funded by collections carried out by children in that country, provides support, information, and rehabilitative care in the face of limited resources.

The dissemination of accurate and understandable information will continue to be a priority for Europa Donna. The coalition has published its own brochures in Italian and English, and hopes to find funding to have them translated and printed in other languages. In addition, Europa Donna serves as a clearing house for breast cancer information from a variety of sources, and local groups often distribute the literature through doctors' offices, pharmacies and other sites.

Like breast cancer advocates in the United States, the leaders are keenly aware that political pressure must be applied to push their agenda forward and to secure better funding for early detection, treatment and research. In fact, the overall goal of Europa Donna, as stated in publicity materials, is "to focus attention on breast cancer and move European Parliaments to take action against the disease."

"We need them to treat breast cancer as the important major threat to life and health that it is," Freilich added. "Not enough resources have been put into that."

Besides pressing for more resources in individual countries, Europa Donna plans to lobby the Parliament of the European Community to fund international breast cancer programmes including educational initiatives and collaborative research projects. At the Vienna conference, a drive was launched to collect millions of signatures from all participating countries — a scaling-up of the original plan to collect one million, Freilich said.

"We are designating March 21 as Europa Donna Day, and women will be out in the streets on that day gathering signatures. They will be boxed by each country, then taken to Strasbourg as a petition to the European Parliament."

Aside from calling for additional funding for breast cancer research in general, Europa Donna has not yet taken any specific positions on the directions and priorities of the research agenda, as some U.S. groups have. However, Freilich said the coalition will probably take a more focused approach in this area after consultation with scientific advisors. "I think we have to review what breast cancer research is doing in Europe, and what needs to be done, with a group of experts in the field. Then we will decide what we're going to push for."

A major activity at the Vienna meeting was the teaching of advocacy skills, enabling delegates to go home armed with the tools for change. While American women have already forced the medical establishment to grant them a more active role in treatment decisions, many European countries have retained more traditional attitudes toward the doctor–patient relationship.

As stated by Freilich, "Women on the whole have not been terribly vocal or prepared to push for improvements, but I think the raising of awareness has begun," she said. "There is an enormous amount of latent pressure, of potential power out there. It just needs pulling together and pushing forward, shifting into the next gear – and into the next century."

Tom Reynolds
London, U.K.

European Cancer Patients Need to be Better Informed

In many European countries, research shows that a majority of doctors would not tell a cancer patient the truth about their diagnosis unless specifically asked. The thorny issue of whether and how to give patients information, including those enrolling in clinical trials, was the focus of a special session of the European Oncology Nursing Society (EONS), facilitated by an educational grant from Rhône-Poulenc Rorer.

Nearly 300 cancer nurses from 16 countries, attending ECCO 8, Europe's largest joint medical/nursing cancer meeting, heard how external influences, such as European Parliament's promotion of patients' rights, will have significant implications for health professionals in this area.

"Health professional are being increasingly forced to re-evaluate the way in which they communicate with their patients", said Kathy Redmond, President of EONS. "It's important that we, as nurses, into whoes domain this issue clearly falls, should put the effective delivery of patient information at the top of our agenda, and champion its value as an important therapeutic intervention".

Pat Webb, U.K. lecturer in palliative care, pointed out that in most European countries, North and South, cancer is still regarded as a death sentence. : "Information," she said, "belongs to patients, but "ownership" of the information is often attributed to doctors, and,in some cases, nurses may be barred from giving information."

U.K. European Parliament Member, Mel Read, Vice-President of a parliamentary health pressure group, outlined the European Parliament's position on patients' rights. This includes the patient's right to self-determination and the right to clear and understandable information.Speaking about the situation in Greece, Dora Paraskevopoulou, President of the Hellenic Mastectomy Society, described how it was still possible for a women to wake up after what she thought would be minor surgery, to discover that she had lost a breast. A breast cancer survivor herself, Dora spoke movingly about how, in her case, cancer had been a liberating experience, offering the opportunity to view her life in a more meaningful way.

Dr Gertrud Grahn of the University of Lund in Sweden, endorsed the view that patient information "can help transform the experience of suffering from cancer into an experience of living with cancer". Dr Grahn presented a programme – six years in the making – which was designed in close collaboration with cancer patients and their families. The programme, Learning to Live with Cancer, represents one of the first attempts to provide comprehensive answers to the questions patients have. The programme, developed in Sweden, is currently being translated in three other European languages.

Kathy Redmond
EONS-Press Conference
ECCO 8, Paris, France

From the Countries

U.K. – Providing Information – A Vital Part of Cancer Care

BACUP, the British Association of Cancer United Patients, recently celebrated its 10th Anniversary. Co-incident with this important milestone has been the appointment of a new Chief Executive, Jean Mossman. Jean brings to her new post the experience of 9 years as former Secretary to the United Kingdon Co-ordinating Committee on Cancer Research. BACUP's 10th Anniversary celebrations culminated in a gala reception at St Bartholomew's Hospital, London, on Thursday 9 November 1995, attended by Her Royal Highness, Princess Alexandra. As part of its anniversary labours, BACUP also produced and published a series of recommendations on how information and support should be provided for cancer patients.

Started in October 1985, BACUP was the brain-child of a young physician, Dr Vicky Clement-Jones, who graduated from Cambridge University with a double first and who was conducting medical research at St Bartholomew's Hospital, London. After Dr Clement-Jones had been diagnosed as suffering from ovarian cancer, she became appalled at the lack of information and support available for cancer patients in the U.K. She decided that an organisation that met the supplementary needs of cancer patients, as district from their medical treatment, was required and accordingly BACUP was born. Over the past 10 years BACUP has grown and now provides several services, all of which are free of charge, to people affected by cancer. These include not only the patients themselves but also their families and friends.

Three major areas of support are provided by BACUP. Face to face counselling is available in London and Glasgow with each person allowed up to eight counselling sessions. Such a service can reach only a small number of people and a major means of support is provided via the telephone helpline. This service, which is staffed by trained cancer nurses, receives approximately 38,000 enquiries every year and provides information on a variety of topics ranging from how different cancers are treated, to how mothers can arrange child-care during treatment. BACUP also provides a series of publications on cancer topics. There are 46 different booklets, which cover diverse tumour types, different treatments and difficulties of living with cancer, as well as 50 fact sheets on rare tumours and specific treatment regimens. Although BACUP is primarily a British Charity, many of these booklets have been translated and now are used throughout Europe. The major complaint of callers to the information service has been that physicians and medical staff have not provided appropriate information nor has it been given in a sufficiently supportive manner To address this problem, BACUP held a workshop in June 1995 to develop guidelines for the provision of information and support for those whose lives are affected by cancer. These guidelines were launched in the U.K. on the 8 November 1995 and a summary of these recommendations is detailed below. The provision of information and support for cancer patients constitutes a vital part of cancer care and one where BACUP has established a National and International role. Those interested in further details should contact Jean Mossman, Chief Executive, BACUP, 3 Bath Place, Rivington Street, London, EC1A 2JH, U.K.

The Right to Know - Summary

People affected by cancer have a right to clear, accurate, up-to-date information and considerate and confidential support.

Information

The following types of information should be available as needed and wanted:

- medical (diagnosis, treatment options and their implications, prognosis)
- access to healthcare professionals (including out-of-hours, second opinion)
- practical, social and financial sources of help
- effects on relationships and sexual health, and coping with them
- complimentary therapies

Presentation

- information presented wherever possible in the most suitable formats (including verbal, written, audio- or video tape)
- suitable expression and language, taking into account ethnic and other minority groups and different levels of understanding
- presented with skill: honestly, clearly, kindly and confidentially

Delivery

- timing and content to suit the person affected by cancer
- at each stage in the illness (diagnosis, treatment, remission, relapse or recurrence, terminal or cure stages)
- varying locations (home, GP's surgery, clinic, hospital)
- in a comfortable and private environment
- by appropriate personnel (doctor, nurse, information professional, other patients).

Peter Chambers
London, U.K.

France — 50th Anniversary of FNCLCC

Fifty years ago on the first of October 1945, General Charles De Gaulle, President of the provisory government of the French Republic, signed an ordinance legalising the status of Cancer Institutes. Today, the twenty French Cancer Institutes constitute an exceptional national network although the size of each centre varies widely from Villejuif (one of thelargest Cancer Centres in Europe) to some small local centres.

Supported by Public Health Insurance, Cancer Institutes play an important part in the organisation of the fight against cancer in France. The ordinance of 1945 defined the goals of the Cancer Institutes as:

- Prevention, diagnosis and treatment of cancer
- Long-term follow-up of therapeutic results and side-effects
- Research and aetiology, prophylaxis and treatment of cancer
- Teaching of cancer specialists and related disciplines

Multidisciplinary is the keyword of cancer institutes. All practitioners and equipment needed for diagnosis and therapy of cancer are offered to the patient at the same site. Each therapeutic decision results from the co-operation of various disciplines. The same spirit is equally found in the fields of clinical and biological research. Therefore, some scientific and medical research teams belonging to official structures, such as INSERM and CNRS, are hosted in several Cancer Institutes, providing the opportunity for good interaction between the laboratory research and clinical practice.

The "Fédération Nationale des Centres de Lutte Contre le Cancer (FNCLCC)" represents the twenty Cancer Centres, and has launched a medical and scientific policy. Since 1975, data on diagnosis, treatment, and follow-up of 380 000 cancer patients have been collected in a common database. The FNCLCC is also the promoter of 32 phase II or III trials and participates in several projects with the French League Against Cancer. Two of these are particularly important: the first consists of a telematic teaching programme in oncology for the practitioner, using the Minitel electronic mail system; the second is funding scientific programmes, mainly in the field of clinical research. Once a year, the FNCLCC organises a meeting on oncology with the "Société Française du Cancer", mainly promoting the contribution of young scientists and clinicians. In 1993, the FNCLCC initiated a comprehensive review of international literature references to establish: (a) consensus statements and standard of treatment policities; (b) alternative options considered by the experts as acceptable treatment; (c) recommendations on diagnosis and therapeutic procedures considered as good medical practice by the oncology community. This work, supported by the French Ministry of Health and the French League Against Cancer, is also part of a three year telematics project "Action" supported by DG XIII of the EC for the period 1995–1998. French Cancer Institutes are a dynamic component of oncology, not only in France but also inter-nationally and especially in Europe.

J. Rouëssé, Paris, France
J. C. Horiot, Dijon, France

Awards/Appointments

First Director General of EORTC

Professor Françoise Meunier was recently appointed as Director General of the EORTC. She will concentrate on fundraising with the Foundation and external affairs (matters with the EC, Cancer Leagues, NCI and the Industry) and remain as Director of the EORTC Data Centre.

Dr Patrick Therasse has been provisionally appointed as Deputy Director of the Data Centre.

This promotion reflects the immense commitment and dedication that Françoise Meunier has shown since her commencement with the EORTC Data Centre 4 years ago.

New Director of Research and Development in U.K. Department of Health

Professor John Swales has been appointed Director of Research and Development for the Department of Health.

Professor Swales will take up the post on 1 January 1996 when Professor Sir Michael Peckham moves on. Professor Swales has been Professor of Medicine at Leicester University since 1974. He was educated at Cambridge University and Westminster Medical School, and has held many national and international appointments including, currently, chairman of the Culyer Implementation Group on R & D in the NHS, and chairman of the Trent RHA Research and Development Strategy council.

Erratum

The European Journal of Cancer **Volume 31A, Issue 11 (1995), pp. 1729.** ***International Cancer News, Article: From the Journal***

The European Journal of Cancer would like to apologise to Dr Jon Pritchard for the error in his qualifications in the above article of the journal.

Dr Jon Pritchard's qualifications should read – Dr Jon Pritchard, FRCP, not Dr Pritchard, FRCPath as published.