



EDITORIAL

The last year has seen a number of activities and initiatives by the Association. After the very successful meeting held in Goiania in November 2006, IACR members were invited to Ljubljana in Slovenia for their 29th annual meeting, hosted by the National Institute of Oncology. As usual, the Executive Board met on the day before the meeting, the Association held its Annual General meeting on the final day. These will be my final meetings as President of the Association; Timo Hakulinen will also stand down as General Secretary, and we, with 4 regional representatives, will be replaced next September. The elections will take place in April-July.

On 28th October, a meeting of members from the African region was held in Cape Town, hosted by the South African Medical Research Council. The meeting followed the 3-day AORTIC conference, which many members were also able to attend.

A major collaborative project between the Agency and IACR *Cancer in Five Continents, Vol 9* - was concluded during 2006 and 2007 and members heard a report and were able to question the IACR representatives on the editorial board at the AGM in Ljubljana. The pdf version has been available via the IACR website since January 2008, and a printed version is promised. Plans were also presented to update the book "Cancer Registration: Principles and Methods".

The Association welcomed 9 new members during 2007, and finally, last but not least, a new Executive Secretary, Dr Maria Paula Curado, took over from Eva Steliarova-Foucher on 9th March, 2008. Maria-Paula is our fifth Executive Secretary since 2004, and we hope will be with us long enough to ensure some much needed stability for our secretariat. Our sincere thanks are due to Eva for her diligent work over the last 16 months.

Max Parkin, President

SCIENTIFIC MEETINGS

The 29th Annual Meeting of the International Association of Cancer Registries (IACR) was held this year in Ljubljana, Slovenia, 18 - 21 September 2007, with the participation of 41 countries. The meeting was hosted by the Institute of Oncology of Ljubljana in the very impressive surroundings of the old town.



Maja Žakelj had worked very hard with all the committees and put together a very comprehensive scientific programme and wonderful social events.

Presentations at the IACR meeting were on two themes: (1) "At the crossroad of traditions and new technologies in cancer registration" and (2) "The role of the cancer registry in cancer control". Invited speakers included Lynne Penberthy (USA) on the challenges and opportunities of automatic cancer registration, David Hill (AUS) on prevention programmes, and Antonio Ponti (ITA) on mammography screening. A special session, in the format of a round table discussion chaired by past-President Hans Storm (DEN), reviewed advantages and disadvantages of computerized sources of information. The verbal presentations sessions were complemented by a special 'Poster Presentation Session' organised by 5 moderators, which allowed authors to summarise the work displayed on their poster, and answer questions from the audience.

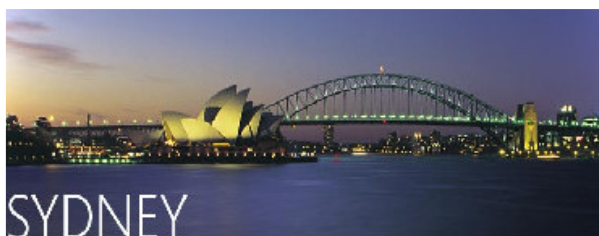
The Annual General (business) Meeting of the Association took place on 21st Sept, immediately preceding the closing ceremonies. This was the occasion for the Executive to report on activities of the Association in the preceding year (described elsewhere in this Newsletter), and for members to receive a financial report from the Treasurer. The two members nominated by the Association to serve on the editorial board of "Cancer Incidence in Five Continents vol IX" (Dr Brenda Edwards and Dr Hai Rim Shin) gave an account of their work. This was followed by a lively debate, and a resolution by members requesting the Editors to suppress in the final publication the categorisation of contributors into different classes of "quality". (After the meeting, the editors finally decided to remove the categories for each data. However, care should be taken in the interpretation of the data with asterisks as explained in the section of indices of data quality.)

The social activities gave everyone the opportunity to enjoy the Slovenian culture, with an evening at a Slovenian Inn and a gala dinner in the majestic dining room of the Union Hotel.

The conference was preceded by a **1-day course** on Cancer Mapping and Spatial Statistics in Cancer Epidemiology. The course was coordinated by Eero Pukkala and reached a record attendance of 70 students.

Following the meeting, on Friday 21st September, there was a one day meeting of the European Network of Cancer Registries.

The 30th IACR Meeting will be held in Sydney (Australia) from 18 to 21 November 2008, in conjunction with the Clinical Oncological Society of Australia (COSA).



The main theme will be 'Driving Improved Cancer Outcomes' and will include New Management Technique, Information, Research, Screening, Prevention and Education. The congress will focus on skin cancers, of concern in Australia. A conference website has been set up (<http://www.cosa-iacr.org>) with a link to the Association's website.

AFRICAN REGIONAL MEETING Cape Town, South Africa



A meeting of the African members of the Association (The AACR) was hosted by Ms Nthutu Somdyala of the South African Medical Research Council on 28th October 2007. This followed the biennial conference of AORTIC (African Organisation for Research and Treatment of Cancer), which was attended by all delegates, and during which the Association hosted a very well attended session on Cancer Registration in Africa. The regional meeting was the opportunity to review the current situation of members, and to consider solutions to the problems of support and funding, which have become especially acute in the last 2-3 years. The Association acknowledges the generous support on UICC and the US National Cancer Institute for this event

Executive Board – Elections and new appointments

Six positions will be vacant within the Executive Board of the IACR. A Nominating Committee chaired by David Forman has assembled the following list of candidates that have all accepted their nomination:

President: Brenda Edwards (SEER).

General Secretary: Freddie Bray (Norway); Henrik Møller (Thames, UK).

Regional – North America: Betsy Kohler (New Jersey, USA).

Regional – Africa: Charles Gombe-Mbalawa (Congo).

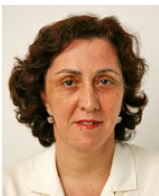
Regional – Europe: Sabine Siesling (IKST, Netherlands).

Regional – Asia: Hideaki Tsukuma (Osaka, Japan).

Regional-Oceania: Francine Baumann (New Caledonia)

Now, more nominations are expected from Voting Members. Each candidate must be affiliated with a Voting or Associate Member of the IACR, and the nomination has to be made by at least five voting Members for each candidate. Please, send your nominations by June 15 to the General Secretary of the IACR, Prof. Timo Hakulinen, e-mail: timo.hakulinen@cancer.fi. Each nomination should be also preferably accompanied by a one-page CV and a passport photograph of the candidate. Please, support democracy within the IACR by proposing many new candidates!

As part of the collaboration with IARC, the Agency nominates one of its staff to be Executive Secretary, of the Association. **Eva Steliarova-Foucher** was nominated for a 12 month period in December 2006. In February this year, IARC proposed that **Dr Maria Paula Curado**, the head of Descriptive Epidemiology Production Group at IARC, take over this function, and this nomination was endorsed by the Executive. Maria Paula took over on 9th March (Eva having kindly assured these duties in the interim). The members of the Executive Board would like to thank Eva Steliarova-Foucher for the dedication she gave to the job and her valuable contribution to the work of the Association, and to welcome Maria Paula to the Board.



Egil Engen has accepted to continue in his function of Treasurer until the conference in Sydney, at which time future arrangements will be reviewed.

Membership

We have been delighted to welcome nine new members during 2007 and two registries were upgraded from Associate Members to full Voting Members. The total membership is 679 from 110 countries

Honorary Members

IACR members who have made a substantial contribution to cancer registration, either nationally or internationally, are honoured by the Association during an award ceremony which takes place during the annual meeting. They are given a lifelong status as Honorary Member of the IACR in recognition of their work.

In 2007, this award went to **Prof Mati Rahu** and **Dr Tiiu Aareleid**. **Sharon Whelan** who had been awarded this membership in 2006 but had been unable to attend the Goiania meeting was presented with the award *a posteriori*.

Professor Mati Rahu has been a key person in establishing the nationwide Estonian Cancer Registry. His activities have played a major role in the dissemination of knowledge and state-of-the-art of cancer registration and modern epidemiology in the former USSR, and particularly in the Baltic countries. Dr Rahu graduated from the University of Tartu as a Medical Geographer. His PhD thesis "Occurrence of Stomach, Lung and Skin Cancers in Estonia (Statistics and Nosogeography)" (1976) was the first thesis focused on the cancer incidence patterns in Estonia. His main research areas are disease registration, cancer statistics, nosogeography and modern epidemiology. Mati Rahu's bibliography comprises about 170 scientific publications (including eight monographs/atlasses) and about 60 popular-scientific and related papers. Mati Rahu is among the authors of the Cancer Atlas of Northern Europe (2001). He has translated textbooks on modern epidemiology into Estonian and has made an important contribution to creating relevant Estonian terminology.

Tiiu Aareleid, also from Estonia has played an important part in the work of cancer registry in her country. Educated in Tartu University Hospital, Department of Neurosurgery, she worked with the Estonian Cancer Registry since its start in 1978. She served as the European Regional Representative at the IACR Executive Board for four years (2000-2004) and has been an active contributor and author in the EURO CARE project.

FELLOWSHIPS

The **Calum Muir Fellowship** was awarded to Ms. S Koyanda (Mumbai, India) (June 2007) who spent 4 weeks in BIOEPI, Padova, Italy. Another fellowship was awarded to Maria Aamir, from United Arab Emirates who will use the fellowship to receive training at the Thames Cancer Registry in London, under the supervision of Dr Henrik Moller in May 2008.

Application for this fellowship is available through our website. Contributions to the fund are also welcome.

When invoiced for your membership, please remember that your contribution to the Calum Muir Fellowship is very important for the training of colleagues to enhance the work in their own registry. Be generous!

Also note that a small fellowship is available through the **Constance Percy Memorial Fund** to support one or two members from low resource countries to attend the Annual Scientific Meeting of the Association. Applications must be made through the website to the IACR Secretariat.

WEBSITE

The IACR website can be accessed on:

www.iacr.com.fr

It contains a full list of members, and links to their websites. **Please check whether the information that the Association has about you is correct.**

The website is a forum for announcing activities of the Association, or any other information that is relevant or likely to be of interest to IACR members. Please do not hesitate to contact the secretariat (iacr@iacr.fr) if you would like to post an item.

CANREG

A new contact email-address for CanReg queries and support has been set up:
canreg@iacr.fr <<mailto:canreg@iacr.fr>>.

Version 5 of CanReg is currently under development and will be ready by the end of 2008. It will be released under an open source license and the main upgrades include a new database engine, more stable multi-user support, faster and more flexible networking capabilities and a revised graphical user interface.

NEWS FROM THE REGIONS

The following reports were presented by your regional representatives to the IACR Board Meeting on 17 September 2008.

ASIA

Presented by Surapon Wiangnon and Midori Soda



The report was based on a response to the questionnaire from 29 registries

- A number of registries complained that their data have been rejected from the IX volume of CI5 and about the way this fact was communicated to them.
 - All registries are determined to improve quality of data to meet CI5 requirements for the next volume
 - Access to death certificates, required to meet CI5 requirements for inclusion into the "A" category of the CI5 publication may be the obstacle difficult to overcome, since this does not depend on the registries.
- Another topic, considered important by the Asian registries is that of training of their staff.

- Accreditation of the registrars for trained staff would help to improve quality of cancer registration.
- Possibility of applying for Calum Muir Memorial Fellowship was evoked as a mean of improvement of qualification of the registration staff, although the funds available are relatively limited (~2 awardees per year from all over the world).
- An Association of Asian Pacific cancer registries would help to foster cancer registration in the region.

EUROPE

Presented by Marc Colonna and David Brewster



Southern and Western Europe

Marc Colonna presented the report, based on information from eight countries and four associations.

The highlighted activities included:

- Survival studies:
- Screening evaluation
- Registration techniques
- Regional incidence data publication

The registries also evoked several issues they are tackling at present:

- Privacy regulation about pathology registries pending in Italy
- Methodological supervision of analysis of time trends, geographical analysis, etc.
- Confidentiality of data, data protection and access to data
- Coordination of the different international cancer registry networks

Northern and Eastern Europe

David Brewster presented the report for this region, based on information from ten regional registries and two associations.

The most important issues are listed below:

- In Estonia, survival rate is difficult to quantify as the: access to death certificates is regulated by the Act on Personal Data which does not allow the access to individually identifiable death certificates.
- Scotland suggests the IACR lobby for laws making cancer a statutorily notifiable disease in all countries.
- Northern Ireland raised the issue of staff accreditation

IACR considered seriously the reports from Estonia, which is also an issue in other countries. To resolve the issue of the death certificates, IACR will take the following action:

Decision:

- Contact the relevant cancer registries where this is an issue
- Send a questionnaire to the European registries:
 - To map the situation of access to data and specifically death certificates and
 - To get proposals from the registries how IACR could help

Based on the response, approach the '29 Group' (Brussels) or Eurostat (Luxembourg) to seek EU help on the legality of the barring of access to the death certificates in European countries .

**NORTH AMERICA
(USA AND CANADA)**



Two reports were presented separately for Canada (Heather Bryant) and the USA (Lynn Ries)

Canada

- Collection of data on staging, with the initial focus on the four most common diagnoses (breast, lung, colorectum and prostate). The more advanced registries train the less advanced. Manitoba is collecting stage for all registered patients.
 - Enhancing data quality and comparability, facilitated by a devoted nationwide committee
 - Earning a continuous contribution of quality data to the annual report of the Statistics Canada
 - Standardised implementation of changes in coding of multiple primaries
 - Preparation for certification of cancer registrars, specifically for Canada
 - Ever increasing use of data, bringing about:
 - Work on the rules for access to data and central evaluation of proposals by researchers from outside cancer registration area
 - Work on the input from Canadian CR to the Cancer Control Planet, the web-site concentrating relevant information existing within USA and Canada.
- <http://cancercontrolplanet.cancer.gov>

USA

- The following were the main points:
 - Information on funding of Central Cancer Registries (more info on www.naaccr.org)
 - A new set of Multiple Primary Rules has been adopted for registrations as from 2007 to promote standardized use across the USA (see. <http://www.seer.cancer.gov/tools/mphrules>)

- Efforts to standardize Collaborative Staging data (collected since 2004) have been reported.
- All non-malignant brain tumours are reportable in the USA since 2004.
- Number of collaborative publications:
 - Annual Report to the Nation
 - United States Cancer Statistics: 2003 Incidence and Mortality
 - Implementation Guidelines (new rules for standardized data collection)
 - Cancer Statistics Review (including long-term time trends)
 - Cancer in North America, with a possibility for researcher to apply for access to data.
- Enforcement of Data Standards:
 - Volumes on data standards (www.naaccr.org)
- Emphasis on education and training, including modules available on-line, some of them free of charge through the web-sites of the following organizations: SEER, COC, NCRA, CDC, NAACCR.

SOUTH AND LATIN AMERICA



Presented by Eduardo Laura

A questionnaire had been circulated and 16 registries responded, as follows:

- All countries responded to the questionnaire. Registries are active in all, except for Bolivia, where the registry is inactive because of lack of financial support.
- Twelve out of 16 responding registries stated that they have economic difficulties.
- Eight out of 16 find it difficult working with health professionals who do not understand the importance of cancer registration, which translates into difficulties to obtain the data from primary sources.
- Only 5 out of 16 registries receive financial support from their provinces, 8 receive mixed financial support 1 only from an NGO and 1 does not receive any financial support .
- All registries agreed that a South American Association of Cancer Registries would be useful for their work and for promotion of their mission in their countries.
- Only 4 considered that their countries have consistent cancer control programmes (with defined objectives and adequate financial support).
- Eight registries are involved in research projects.
- Five follow IARC/IACR recommendations.
- Six consider their output very satisfactory and ten moderately satisfactory

In conclusion, cancer registration does not receive due support from the governments of South American countries. IACR could help to improve the situation of the Latin American registries by promoting their mission with the registries.

AFRICA

The following are extracts of the report of the meeting of African members in Cape Town (28th October, 2007), prepared by Dr SS Manraj



In the absence of Prof Ekanem, Dr S S Manraj from Mauritius was appointed Chairman of the Meeting.

1. Roberto Zanetti (UICC) began proceedings with a presentation on **“Computer Systems for Cancer Registration”**. He made a review of various computer systems namely the CANREG Software of IARC (Lyon), other software (Abstract Plus) and finally the various fully comprehensive commercial ones available in USA/Canada (AUTOCODE). He also mentioned of the project of IARC of developing CANREG 5 which was announced during last UICC meeting.

2. N. Somdyala presented **“Methods of case finding in rural areas”** giving practical details on problems and challenges in developing a rural PBCR namely the poor state of medical records in certain hospitals/health institutions particularly the private ones and lack of commitment and collaboration from medical staff.

3. Eric Chokunonga made a presentation on **“Follow up studies of survival in Africa”**.

4. Dr Ogunbiyi talked about the **“Problems of estimating population at risk”** giving as example Lagos whose population was estimated by different agencies /institutions with wide variation.

5. Mrs H. Roussow presented the **Paediatric Cancer Registry in South Africa”**

6. Dr Max Parkin made a presentation on **“Publishing registry results”**. He made an update on all cancer registries now existing on the African Continent. However, few of them possess the quality standards that will ensure their inclusion in “Cancer in Five Continents”. Discussions took place on whether a different format might be used for publishing registry results from Africa, and what such a publication might include.

7. A final group discussion was on the topic of **“Support to cancer registries in Africa”**. AACR members unanimously mentioned about the lack of support by IARC (Lyon), and the substantial increase in response time for help with CANREG4. They hoped that the situation will improve with the

development of CANREG 5. Dr J. Harford of NCI talked about the notion of “donor fatigue”. He urged African cancer registries to send application for funding to NCI through joint collaborative partnerships with American institutions. Success of certain twinning arrangements (e.g. Benghazi cancer registry, Libya with Modena, Italy, and the MECC collaboration etc) was noted. However personal contacts and dedication played a great role in sustainability of such partnerships. Possibility of tapping global funds and other development funds to support cancer registries and eventually cancer control programs was proposed bearing in mind that cancer causes globally, more morbidity and mortality than HIV/AIDS, tuberculosis and Malaria (ATM) combined.

OCEANIA

The report was not available at the time of print.



AUTOMATION IN CANCER REGISTRATION

The Automation in Cancer Registration Working Group has been meeting monthly via teleconference. They first had to grapple with what is automation as applied to the cancer registry and registration processes. One long term goal of the working group is to publish international data standards, and the short term goal is to document for each data item, its definition, purpose, and source. There would be a cross walk among countries for each similar data item. The starting point is data standards documentation from ENCR and NAACCR. Registry functions will also be documented. The group is deciding which registry functions should be included in their discussions. After a format is established, registries will be contacted to supply information for this ambitious project. There are several countries represented in the working group, but more international representation especially from Asia, South America, Africa, and Oceania is desirable. If you are interested in joining, please send a note to Lynn_Ries@nih.gov.

CANCER IN FIVE CONTINENTS (CI5) VOL. IX

Cancer in Five Continents (CI5) Volume IX presents incidence data from populations all over the world for which good quality data are available. Submissions were received from 313 cancer registries. Table 1 shows the percentage of submissions that were accepted for publication. The final volume includes data from 300

populations, 225 cancer registries and 60 countries (increases of ,respectively, 40%,21% and 5% over Volume VIII).

Table 1: Cancer registry populations' data submitted to CI5 Volume IX for the period 1998–2002

	Submitted	Accepted
Countries	80	60
Registries	313	225
Populations	406	300

The geographical coverage of CI5 Volume IX by continent is shown in Table 2.

Table 2: Geographical coverage by country, registry and population group

	Countries		Registries		Populations	
	Subm	Accp	Subm	Accp	Subm	Accp
Africa	14	5	16	5	16	5
South&Central America	11	8	29	11	29	11
North America	2	2	58	54	136	118
Asia	18	15	77	44	84	50
Europe	30	29	120	100	123	100
Oceania	6	4	13	11	18	16
Total	80	60	313	225	406	300

Note: The sum of the individual countries is greater than the total, reflecting the fact that some countries are present in more than one continent

The share of the world population covered in this volume is 11.6%, distributed as follows: Africa: 8.8 million (1.1%), South and Central America: 23 million (4.4%), North America: 258.5 million (83.6%), Asia: 152.3 million (4.1%), Europe: 238.8 million (32.8%) and Oceania: 23.0 million (75.7%) (Table 3).

Table 3: Geographical coverage in CI5 IX (1998-2002) by number of population and continents

	Number of population (million)		
	Overall	Submitted	Accepted
Africa	784.0	61.8	8.8 (1.1%)
South and Central America	519.0	67.5	23.0 (4.4%)
North America	309.0	257.2	258.5 (83.6%)
Asia	3682.0	258.6	152.3 (4.1%)
Europe	729.0	292.7	238.8 (32.8%)
Oceania	30.4	24.9	23.0 (75.7%)
Total	6053.4	962.7	699.9 (11.6%)

FORTHCOMING EVENTS

International Course on introduction to cancer registration and its application to cancer epidemiology - Seoul, Republic of Korea, 22-27 September 2008

The course is organised by IARC and the National Cancer Centre in the Republic of Korea and its aim is to provide an intensive introduction to the methodology of cancer registration, to use cancer registry data, and to provide instruction in epidemiological methods that are appropriate to this purpose. More information is available the following website: http://www.iarc.fr/ENG/Training_Course. You can also contacting the Courses Programme (IARC) by e-mail (cor@iarc.fr) or by phone on (+33) 472 73 80 72)

The deadline for application is 31 July 2008

2008 IACR Annual Meeting: Sydney, Australia – 18-20 November 2008 (see above for details)

2009 IACR Annual Meeting: New Orleans, USA – June 2009

2010 IACR Annual Meeting: Japan

IACR CONTACT INFORMATION UPDATE

We are striving for an updated contact database. A form will be attached to the invoices with the details we hold on our database. Please complete and return the form to us to inform us of contact information changes at your registry. Send all new contact information to iacr@iarc.fr, or to the IACR Secretariat, 150 Cours Albert Thomas, 69372, Lyon Cedex 08, France. You can also reach us at: +33 (0)4 72 73 84 17