

NEWSFLASH

February 2007

Message from the ENCR secretariat: New Era, New Attitude, New Ways.....

Greetings from the IARC secretariat of ENCR! My name is Lydia Voti and I was recently hired in the post of scientist to support the ENCR activities. New at IARC, but rather old timer in the field of cancer registration and epidemiology I am delighted and honoured to be joining this group. I have been following the developments of our field in Europe for years, hoping to come back and work here one day. And the opportunity came in 2007.

Coming from Greece and having worked for about 12 years at a state-wide cancer registry in the US, I have come to understand the differences and appreciate the strengths of cancer registration practices in the old and new continents. I have also been on both sides of the fence: collector of data from registries and contributor of data to national and international data repositories. I have also been member of workgroups shaping standards for registries but also representative of registries debating some of the standards adopted by umbrella organizations. My hope and wish is to capitalize on all that and contribute to the starting of a new era in the secretariat of ENCR. **Please join me in this effort: let's shape ENCR together and turn it to a body that supports, respects, caters to the needs of cancer registries and advances cancer research in Europe.**

As for the Newsflash, let it be a participatory forum for exchange of news, ideas and opinions. I am looking forward to a close collaboration with all of you and I hope to meet you in person at the ENCR general meeting, which is held in Ljubljana, September 18-20, 2007 in conjunction with the 29th IACR meeting (www.iacr2007.si).

Save the Date!

September 18-20th, 2007
IACR annual meeting, Ljubljana, Slovenia

Other related tentative dates:

- Posting of ENCR general meeting topics on the website: March 15th, 2007
- Call for abstract submission to the IARC secretariat : April 1st to May 31st, 2007

Your briefing from the 34th Steering Committee meeting, January 30-31st 2007, Lyon:

Dr. Boyle opened the meeting welcoming the members, shared his thoughts about ENCR and stated the priorities of the Agency. He called the committee to

focus on re-establishing funding for ENCR through FP7 and emphasized the fact that output from ENCR was a pre-requisite to claim any EU funding.

The meeting started with a roundtable discussion where all members were asked to share their thoughts and suggest improvements in the collaboration between Registries, the Steering Committee (SC) and IARC. Dr Autier's vision for ENCR is to become the intermediary body, facilitating the collaboration between IARC and the registries. He emphasized the instrumental role of the steering committee in the pursuit of this goal. Dr. Storm welcomed the idea, emphasizing that the registries need to be respected in order to come aboard and stated that the steering committee has to carefully decide on the core deliverables (EUCAN, Newsflash, courses, data standards etc.) and devise a process to establish the collaboration required to produce them.

1. FP7- ERA-NET

Markus Pasterk of IARC gave a short presentation on FP7-funded ERA-NET. The SC discussed several possible schemes and proposals. Dr Autier emphasized the fact that IARC can contribute only if the SC commits to this project. Dr. Storm stated that the ENCR will dissolve without funding from FP7. Drs Storm, Møller and Bray committed to work on this issue and produce a working draft by March 23rd, 2007.

The SC agreed on the theme: **Cancer registries supporting cancer control**. Data quality and comparability, data exchange and analysis, integration of screening and clinical care were the main objectives of the proposal. The SC will devise a link between several institutions that fund cancer registries, with the IARC being one of them. Depending on the final scheme, registries will be contacted and requested for collaboration and participation.

2. EUNICE

Dr Autier gave the SC members background information on EUNICE and informed them that the European Council asked IARC to deliver a report on screening activities in the European Union (current state, effectiveness and recommendations). Dr Autier asked the SC for assistance in involving ENCR members in the compilation of the report. The issue of measuring screening effectiveness and how to use the registries for that purpose was also discussed. Dr. Autier offered to organize a separate meeting on that, inviting all stakeholders.

3. EUROCIM

Registries were asked for contribution of data for EUROCIM-2, CI-5 and EUROCARE-4 during the same call, through the 'ENCR Gateway data submission 2006'. Dr Voti presented the response rate for EUROCIM and

tables summarizing the variables collected by each registry. The members of the SC felt that the format of the invitation as well as miscommunication of the idea of the 'GATEWAY' may have confused the responders. Dr. Møller asked to contact all registries that contributed data to CI-5 but not to EUROCIM-2 to verify their intent, especially if the registries had contributed the additional data required for the study. (**Please give us some feedback on this issue!**). It was also agreed to send separate letters to responders and non-responders requesting corrections and data respectively.

4. European Cancer Observatory (ECO)

Dr. Autier informed the SC of the EU commitment to enhance cancer research competitiveness. Additionally, he emphasized the need for reliable data for decision making and suggested to put EUCAN and Cancerpole under the same umbrella. Dr Møller will integrate the ECO within the ERA-NET application.

5. IACR Annual Meeting, Ljubljana, September 18-20th, 2007

The content of the ENCR general meeting, which will be held in conjunction with the international meeting, was discussed. Dr Møller suggested having invited, contributed papers and an ENCR business meeting. Dr. Storm proposed 'confidentiality' as a potential topic. A workgroup responsible for the agenda of the ENCR meeting was formed. Dr Steliarova-Foucher briefed the SC members on the spatial statistics course offered prior to the meeting. ENCR and IARC were going to jointly fund this course. Dr Autier will revisit the budget and report on this issue by the next SC meeting.

6. ENCR Website

Dr Bray provided IARC staff with the desired updates of the website, he reminded however that it needs to be rebuilt and he suggested using the Finnish cancer registry web site as a template. The IARC secretariat is working on finalizing the updates by February 28th.

7. Cancer Statistics Update (Factsheets)

Dr Autier suggested producing fact sheets suitable for more lay audience and/or geared towards policy makers. Dr. Voti will send templates for consideration to the SC committee by March 25th. **Your ideas in the formulation and production of the FactSheets are very welcome!!!**

8. Study of Mariana Beltran: Evaluation of breast cancer screening

Dr Autier emphasized the need to produce stage-specific incidence rates and suggested surveying the registries to gather information on the staging schemes they use. The CONCORD study offers information on this issue but if further information is needed then a protocol will be developed and the registries will be surveyed.

9. New business

a) HAEMACARE

Dr. Moller informed the SC that the HAEMACARE Work Package 3 (responsible R. Sankila) will organize a European meeting on the standardizing the terminology for diagnosis and grouping of haematopoietic and lymphoid neoplasms and their coding and presentation

by the cancer registries in Europe. If this workshop bears fruit, the WP will present its conclusions to the ENCR, to be formulated into ENCR recommendations. Dr Lutz will be attending the workshop and will inform the SC of the workshop outputs.

b) Accreditation

There is interest in establish an accreditation system for European registrars. Dr Storm pointed out that the heterogeneity of language and circumstances involved with cancer registration in Europe poses a problem. However, the SC encourages the initiative and asked the interested individuals to keep the SC informed of the results of their efforts to establish accreditation.

c) Cancer in Europe

Dr Boyle asked the SC to reflect on a European cancer conference, with data usage and research topics. Potential date: December 2007. The members of the SC will reflect on this and will discuss at the next SC meeting.

d) Maastricht Cancer registry: request for EUROCIM data for study on oesophageal cancer

The Maastricht Cancer Registry has applied for EUROCIM data to repeat a study (published) on esophageal cancer. This study was very well received by the SC. Dr Dirx, who applied originally for the data wanted to know what is the most recent data set they could use for the study and if their protocol is satisfactory. The SC informed them that as EUROCIM is not finalized yet the V2.4 database should be used, unless they can afford to wait for an update. Regarding their protocol, they were requested to base it on the Vancouver authorship rules (Uniform requirements for manuscripts submitted to biomedical journals. International Committee of Medical Journal Editors. Ann Intern Med 1997; 126:36-47).

Next Steering Committee meeting

Lyon, 11-12th of April, 2007.

Would you like to be part of the editorial team? Your participation to the Newsflash and to the Cancer FactSheets (coming soon...) is highly desired and appreciated! Please email your ideas/news/articles to encr@iarc.fr

When you speak we listen...

If you need a listening ear for your thoughts or concerns about ENCR, please do not hesitate to call me at +33 4 72 73 84 35, or email me at votil@iarc.fr. Constructive criticism and suggestions of solutions to problems are very welcome!

For all correspondence with the ENCR Secretariat please use encr@iarc.fr. The mailing address remains the same:

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