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## GUEST MESSAGE

### THE CANCER REGISTRY: ITS PURPOSE AND USES

by Donald Maxwell Parkin <sup>1</sup>

#### CANCER REGISTRATION

Disease registers – inventories of newly diagnosed cases – have been used as a means of keeping track of the importance of several different diseases in the community, and how their distribution varies between different places, different subgroups of the population, and over time. Disease registers can supplement and extend the information we can get from vital statistics – records of deaths from specific diseases – as the latter deal only with fatal events, and death may be the outcome of a disease only in a minority of cases – even for many cancers. Registration of cancer has probably been the most successful and widely used form of disease registration. Cancer lends itself to the process, since it is a serious disease that almost always comes to medical attention, sooner or later, has a relatively clear definition, and generally occurs only once in the same individual. It is much more difficult to count cardiovascular events (such



**Patients waiting to be seen in the outpatient clinic of the Cancer Institute (W.I.A.) in Chennai, India. All cancer patients seen at the center are included in both the institutional registry and the population-based registry for Chennai.**

as myocardial infarctions or strokes), many episodes of which occur in sub-clinical form, with multiple events of the same disease in the same person, or congenital malformations, where definition is a problem, since most are trivial and may not even be noticed, let alone reported.

Cancer registration is a continuing process of systematic collection of information on individuals developing new cancers. The cancer registry (or rather, its staff) are responsible for collecting, processing, storing, analysing, interpreting and reporting data on the characteristics of the

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cancers and of the individuals affected. Hospital-based cancer registries are concerned only with the recording of information on the patients with cancer seen in one specific hospital. Their purpose is to contribute to patient care by providing readily accessible information on the patients seen at the institution over defined time periods, the treatment they received and its outcome. They also serve an administrative purpose and are useful in reviewing clinical performance of staff and deciding on present and future institutional needs. By contrast, a population-based cancer registry (PBCR) collects data on every subject with cancer in a defined population - usually, the residents of a particular geographical region (city, province or country). The cooperation of the medical



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**Views, comments and statements are not necessarily shared or endorsed by INCTR. All patients' photographs are published with their consent.**

#### Essential variables

- Personal identification: names (in full) AND/OR unique personal identification numbers
- Sex
- Date of birth: day, month, year
- Address: usual residence (coded)
- Incidence date (at least month and year)
- Most valid basis of diagnosis
- Topography (site) of primary cancer (ICD-O coded)
- Morphology (histology, ICD-O coded)
- Behavior (e.g., benign, malignant, in-situ, ICD-O coded)
- Source of information

#### Recommended variables

- Date of last contact (at least month and year)
- Status at last contact (at least dead or alive)
- Stage or extent of disease
- Initial treatment

**Table 1. Items of information collected by registries (from Jensen et al., 1991).**

profession and health care services within the region is vital to the success of cancer registration.

Since population registration involves head counts of new cancer cases occurring in a defined time period and relates this to a population of known size, it is possible to calculate the incidence rates of specific cancers for different subgroups of the population. Ideally, the registered cases can be followed up after diagnosis to find out which of them die from their disease, so that the survival rate for different cancers, at specified intervals after diagnosis, can be calculated.

The main sources of information for population-based registries include: (1) information from treatment facilities, such as cancer centers, hospitals, private clinics and hospices, (2) information from diagnostic services, especially pathology laboratories (3) death certificates from the vital statistics registration system. The way the data are collected invariably depends upon the local conditions; more and more it relies upon the transfer of computer files of patients from hospital administra-

tion systems, laboratory databases and population registers to the cancer registry. The amount of information on each cancer case collected by a registry is dictated by the purpose for which the registry has been established, but, in general, PBCRs collect only a limited amount of data for each patient. The basic minimum dataset is shown in Table 1.

It is essential to be able to identify individuals with cancer, not just the cancer itself (a few patients may have more than one cancer). Name, sex, date of birth (age) and address are essential identification items. Address is required for establishing the residence status, and for follow-up. Age is of great importance in the description of cancer incidence. The incidence date (date the cancer was detected) must be a definite, consistent and reliable point in time which can be verified from records. The most valid basis of diagnosis is of great interest in assessing the reliability of incidence rates; the minimum requirement for evaluation is differentiation between microscopic and non microscopic confirmation. The International Classification of Disease

for Oncology (ICD-O) coding scheme (Fritz et al, 2000) is used to describe the topography (site of primary tumor) and morphology (histological type). The topography of a tumor is the most important data item recorded and provides the main basis of tabulation of registry data. The fifth digit in the ICD-O morphology code describes the behavior of the tumor (benign, borderline, in situ, malignant). The optional (recommended) items in Table 1: clinical extent of disease (stage) before treatment, details of initial treatment and outcome in terms of follow up, are collected by most registries.

A PBCR must document its findings and conclusions in the form of cancer incidence reports and other special reports and articles in scientific journals that ensure dissemination of the information to users. A registry that simply collects and stores information serves no useful purpose – the data are only valuable if used for information, research, planning and evaluation, as described later. Registries with a wide portfolio of activities will tend to improve the quality of their routine statistics simply by utilizing the collected data, as well as by activating interest among collaborators (clinicians and researchers) in the daily registration procedures.

## THE HISTORY AND DEVELOPMENT OF CANCER REGISTRATION

The idea of recording information on all cancer cases in defined communities dates from the middle of the 20th century, and there has been a steady growth in the number of such cancer registries since. Originally, they were concerned primarily with describing cancer pat-

terns and trends, but provision of information on other aspects of cancer occurrence and on the control of the disease has developed progressively. This resulted initially from the need for information on the survival after cancer at the population level, and later to study the effects (value) of various aspects of services for prevention, early diagnosis, treatment and care. This template has been applied to a greater or lesser extent in various world regions, and the steady increase in the number of cancer registries attests to their value in cancer research and control. Figure 1 illustrates the growth in the number of cancer registries that are members of the International Association of Cancer Registries (IACR) between 1979 and 2006. These cancer registries cover around 21% of the population of the world, albeit with a rather uneven spread among the continents. Some entire national populations are covered; in smaller countries (e.g. Singapore, the Gulf States, the Nordic countries)

this is possible with a single cancer registry, but larger populations pose considerable technical and logistic problems, and there are few registries covering populations in excess of 10-15 million. National registries for the larger countries therefore rely upon input from independent regional registries (as in UK, Australia and Canada). In most countries, one or more cancer registries provide coverage of a sample of the population, although this is by no means random. Registry associations have grown up to deal with issues such as cross-notifications (of cancer patients resident in one area but treated in another), common definitions and coding, quality control procedures and staff training. There are many national as well as other groupings on a regional or linguistic basis (Table 2). Most registry associations hold training courses, sponsor joint research projects and hold scientific workshops and meetings. Almost all PBCRs are members of the IACR.

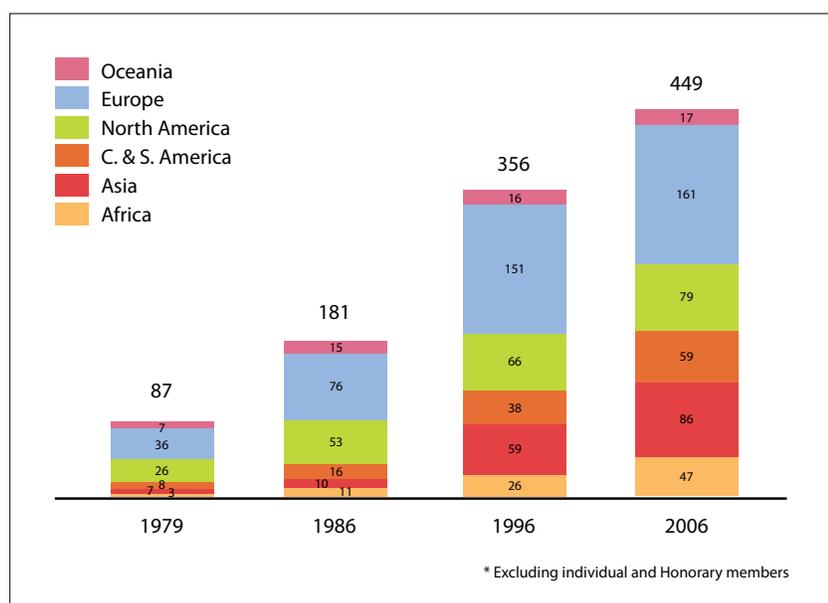


Figure 1. International Association of Cancer Registries - Membership\*.

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**International Association of Cancer Registries**

<http://www.iacr.com.fr>

**Association of Nordic Cancer Registries**

<http://ncu.cancer.dk>

**Australasian Association of Cancer Registries**

<http://www.aihw.gov.au/cancer/aacr/index.html>

**European Network of Cancer Registries**

<http://www.enrc.com.fr>

**Groupe de Coordination pour l'épidémiologie et l'enregistrement du cancer dans les pays de Langue Latine**

<http://www.grellnet.org>

**Gulf Center for Cancer Registration**

<http://www.gccr.org/main.html>

**North American Association of Central Cancer Registries**

<http://www.naacr.org>

**The Japanese Association of Cancer Registries**

<http://home.att.ne.jp/grape/jacr>

**Table 2. Some cancer registry associations.**

**CANCER REGISTRY USES: RESEARCH**

The original function of the cancer registry was to calculate rates of incidence, so that the risk of various cancers in different populations could be compared. Although this still remains their most basic role, the activities of cancer registries have developed far beyond this, to include studies of cancer cause and prevention. The registry may be a source of information on the importance of any risk factors relevant to the local population. At the very least, local researchers should be aware of the registry and the potential for using its database in approved research projects.

**DESCRIPTIVE STUDIES**

Descriptive studies use information from the registry database to examine differences in the incidence (or survival) of cancer, according to variables associated with place (of residence or of birth), time and personal

characteristics (sex, ethnic group, social status, etc). Classically, such descriptive studies are said to be “hypothesis generating” – providing clues to possible causes, to be followed up in studies that focus on specific risk factors.

Fig 2 shows time trends in cancer of the colon in two Asian populations, to illustrate the rapidly increasing risk of this disease, where previously it was relatively rare, compared

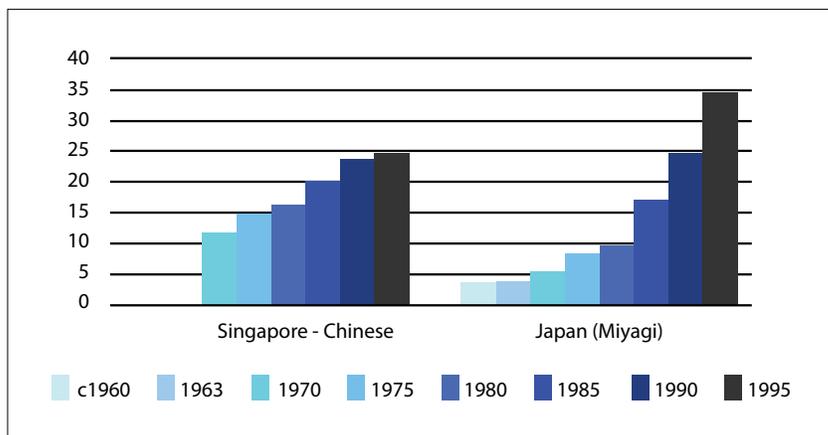
to the incidence in North America and Europe.

**STUDIES OF CAUSE**

Cancer registries are not involved in the majority of epidemiological studies of cause – except as a source of incidence rates for studies correlating incidence in different populations with prevalence of exposure to suspected risk factors (so-called “ecological” studies). Cancer registries have, however, been extensively used to follow up defined groups of individuals (“cohorts”) to detect the occurrence of new cases of cancer. They may involve linkage of pre-existing databases with the cancer registry (e.g. registers of specific occupations or of HIV-AIDS). A special example is the study of the risk of second cancers (in relation to the initial cancer and its treatment) – the interest here is in detecting commonality of risk factors (or susceptibility to them) or the adverse effects of treatment.

**EFFECTIVENESS OF INTERVENTIONS IN PREVENTION, EARLY DIAGNOSIS/ SCREENING AND THERAPY**

The effectiveness of new treatments for cancer has to be demonstrated



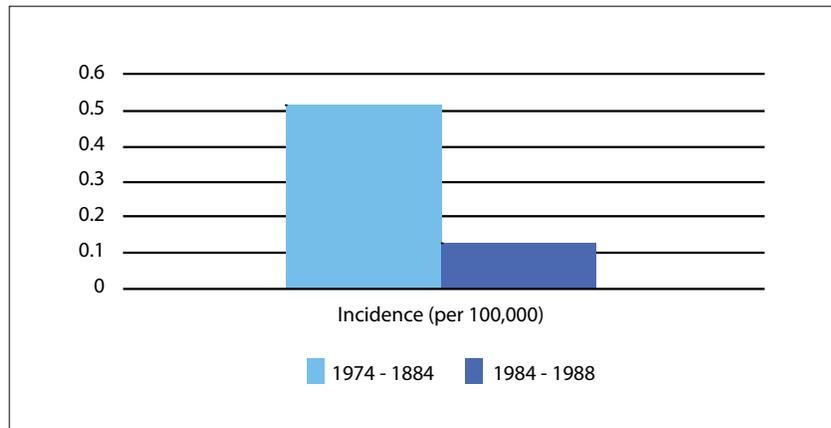
**Figure 2. Changes in incidence of colon cancer in men over a 35-year period.**

by means of a randomised controlled trial (RCT), before they are implemented in clinical practice. One might think that this is a reasonable condition to meet before other costly (or potentially harmful) interventions that aim to prevent cancer, or to detect it at an early stage (for example, by screening) are introduced. However, although sometimes the results of RCTs were available before widespread acceptance (e.g. vaccination against HPV in preventing precursors of cervical cancer, or mammographic screening for breast cancer), very often the benefit of a procedure was thought to be obvious, and no RCT evidence was available before widespread implementation (examples are most anti-smoking interventions, cytological screening for cervix cancer and PSA screening for prostate cancer).

The cancer registry has had a limited role in most RCTs. On the other hand, post hoc evaluation of already implemented programs has made wide use of cancer registration. This sort of research is the same as that involved in monitoring a prevention or screening program that was implemented after a proper appraisal of effectiveness, where we are concerned with the efficacy of the program in practice, rather than its theoretical effectiveness in the context of an RCT. Examples of use of cancer registries for the evaluation of programs that have already been implemented are given below.

### **CANCER REGISTRY USES: EVALUATION AND MONITORING PRIMARY PREVENTION**

The effectiveness of preventive interventions against cancer has rarely



**Figure 3. Incidence of liver cancer in children in Taiwan, born before and after introduction of vaccination against Hepatitis B.**

been evaluated by randomized controlled trials. We therefore have to judge their effectiveness by observation of established programs. This may involve comparing the incidence rates actually observed versus those expected (allowing for a time lag for the effects to emerge), where the “expected” rates are based on a prediction model of some kind. This approach has been widely used to evaluate the success of anti-smoking programs. An even more striking example is the dramatic effect on incidence of hepatocellular carcinoma recorded by the cancer registry in Taiwan, following the introduction of vaccination against hepatitis B in the 1980s, first to neonates born of HBsAg positive mothers, then, in 1984, for all newborns. By 1994, it was possible to compare liver cancer incidence in children aged 6-9 born before vaccination was introduced, and those born after (Chang et al, 1997). There was a fourfold difference (Fig 3).

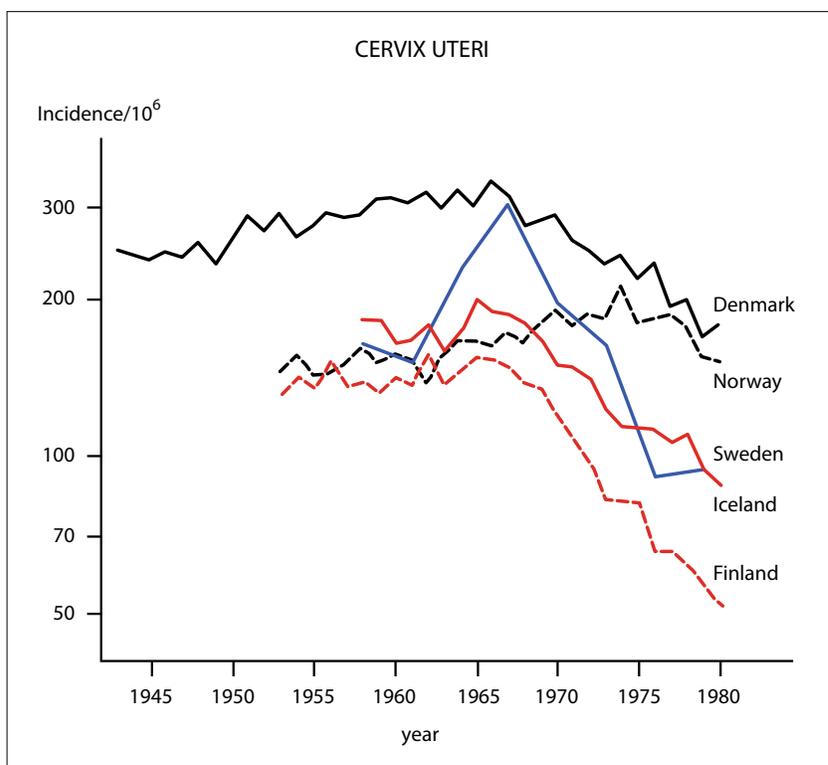
Another approach has been to compare incidence rates in areas with or without preventive programs, or with different intensities of intervention.

### **SCREENING AND EARLY DETECTION**

Cancer registry data have been widely used for evaluation and monitoring of screening programs. The effectiveness of screening can only be correctly judged by the extent to which the objective of reduced mortality (or reduced incidence, for cancer of the cervix) is achieved. Thus, screening for cervix cancer aims to reduce incidence of invasive cancer; this is the aim of oral cancer detection programs also. Other screening programs (e.g., breast, large bowel), which aim to detect cancers early, do not reduce incidence. Their objective is to decrease the number of deaths.

Ideally, information on the screening status of individuals from a suitable database can be linked to that of the cancer registry in order to study outcome for individuals with different intensities of screening exposure. The simplest study design is the cohort study, in which occurrence of disease (incidence or mortality, as appropriate) is compared in screened vs. unscreened individuals with the objective of deciding the decrease in risk which might plausibly be ascribed to screening. Studies such as these

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**Figure 4. Trends in incidence of cancer of the cervix in the five Nordic countries.**

were used to study the potential benefit of cytological screening in preventing invasive cancer of the cervix or mortality from gastric cancer, programs whose effectiveness has never been demonstrated in an RCT. The problem with these studies is that individuals who agree to take part in screening programs are not at the same risk of disease as those who do not, so a lower incidence in those screened may be due to the intervention itself, or to the type of person who chooses to have it.

If screening is known to be able to reduce mortality from cancer (for example, mammography screening for breast cancer), the so-called “intermediate endpoints” - such as tumor size, stage and survival- may be used to monitor the screening process. The cancer registry is

essential here, providing information on the screened population and also on the ‘expected’ distribution of cancers by stage or incidence rates (overall, by age group and/or by stage), that would have been expected in the absence of screening. Linkage of the cancer registry and the screening program allows calculation of incidence rates of interval cancers (detected between screenings) and incidence of advanced cancers. The incidence of interval cancers (detected between screenings) is useful in making decisions about the appropriate intervals between tests, and incidence of advanced cancers provides an indication of the probable benefit in terms of mortality.

More usually, there is no information on the screening status of individuals, and population-level

analyses are used. The simplest are time trends in incidence, for cancers where screening should prevent invasive cancer, such as in the cervix. Fig 4 shows perhaps the most celebrated example – the trends in incidence in the Nordic countries following the introduction of population screening (Iceland, Finland, Sweden), its partial implementation (Denmark) and postponement (Norway) - Hakama et al, 1991.

Detection of cancers in an early stage by screening will lead to improved survival, whether this results in reduction in mortality (the goal of screening), or is simply due to advancing the date of diagnosis (lead time bias) or differential detection of slow-growing tumors (length bias). But, improved survival can also result from patients presenting earlier with their disease. During 1996-1999, health personnel in Sarawak, Malaysia, were trained to improve their skills in early detection of cancers of the nasopharynx, breast and cervix, and, at the same time, a public education program was carried out to raise awareness of these diseases, and their early signs and symptoms (Devi et al, 2007). Fig 5 shows the results; for both breast and cervix cancer, the percentage of cases presenting in late stages (III and IV) showed marked declines.

## **SURVIVAL AND QUALITY OF LIFE**

While cancer control aims to reduce deaths from cancer, the effect of cancer control activities on mortality will often be quite delayed. Changes in survival from cancer will usually be evident much sooner. Differences in survival rates (between populations or over time), as measured by cancer registries are the result of many

factors other than the effectiveness of treatment. The methods of data collection and analysis, tumor characteristics (histology, stage, method of detection) and patient characteristics (age, sex, ethnicity, socio-economic status and lifestyle) also affect survival at the population level, as measured by cancer registries. The study of survival gives an indication of the possible role of the process of care, and not simply the effectiveness of a specific treatment. International comparisons of survival, such as those of EUROCARE group<sup>1</sup> (Fig 6) have influenced policy making for cancer treatment services in several countries, e.g. the U.K. and Denmark.

## CLINICAL CARE

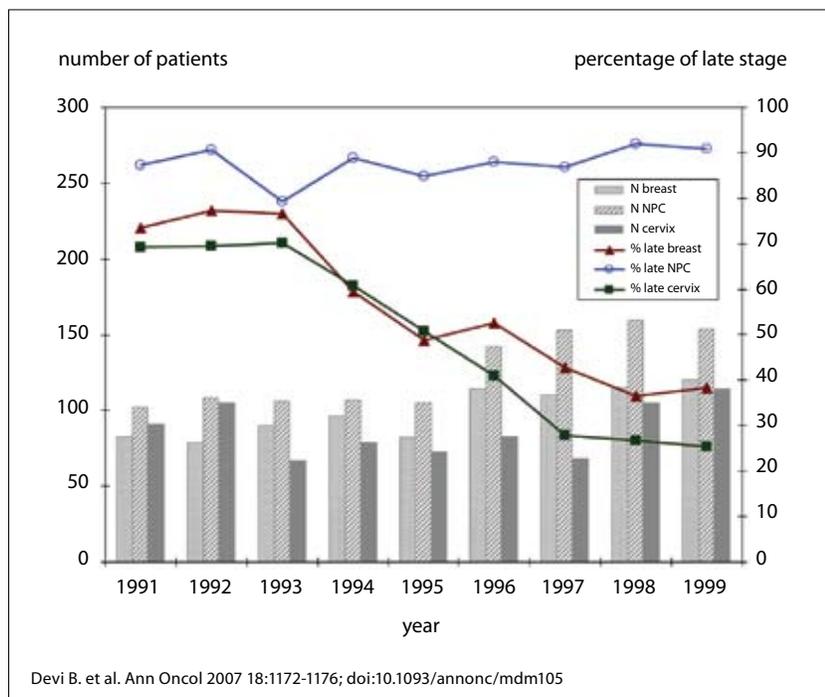
In the past, research on the quality of clinical cancer care, leading to the development of management guidelines, has been based on the study of clinical case series, often in randomized trials. But series such as these are not at all typical of cancer patients in clinical practice, who are older, with other coincident diseases. Thus, in recent years, increasing attention has been paid to examining variations in the process of care for the cancer patient between different providers or different groups of patients (clients), and cancer registries have proved very useful in this role. For example, they can be used to study the location (e.g. type of hospital) of treatment for specific cancers, and the specialty and case load of individual clinicians treating cancer patients. Although these are indirect indicators of quality of care, they have been shown to be important in determining outcome. Simple measures such as delay in diagnosis, or in receiving appropri-

ate treatment, provide information on equity and access, as well as potentially influencing outcome. Auditing the nature of the therapeutic procedures actually performed may also be possible – for example, in monitoring the proportion of early breast cancer cases receiving breast-conserving surgery followed by radiation therapy (Edwards et al, 2005).

## CONCLUSIONS

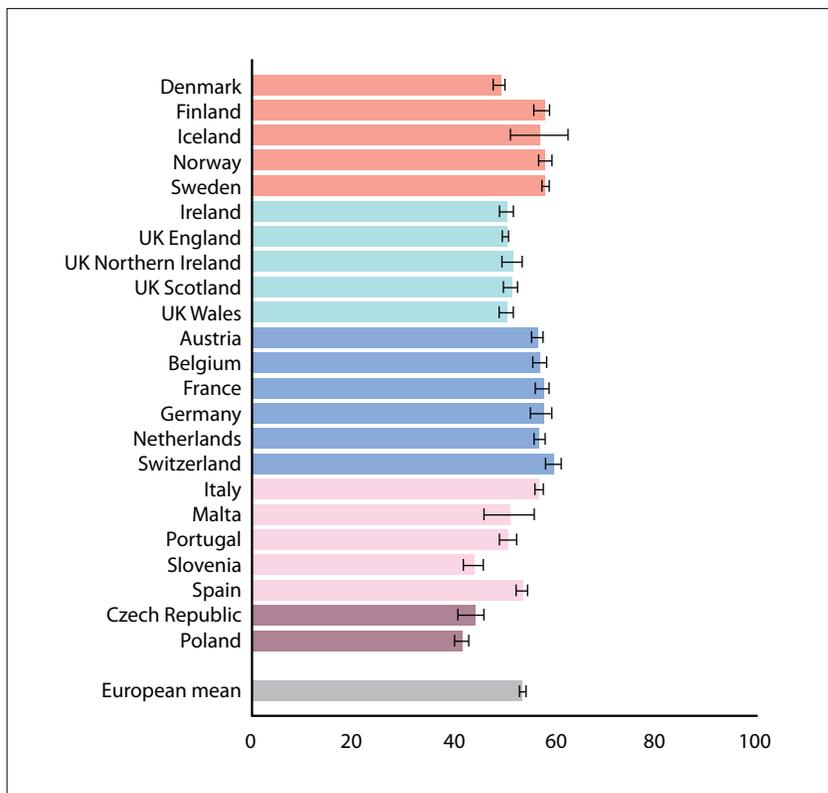
The policy of the World Health Organization is to encourage as many as possible of its member states to develop comprehensive national cancer control programs (NCCPs), as the most efficient method of reducing their cancer burden (WHO, 2002). Planning and evaluation of cancer control

needs a surveillance system, and, although mortality statistics (from vital registration systems) can provide much important information, the scope and utility of surveillance is greatly extended by the presence of one or more population-based cancer registries (PBCRs). For planning purposes, a PBCR does not need to cover the entire national population, although for many epidemiological studies this is highly desirable. Coverage of a sample of the population is adequate for many purposes. Ideally, the sample would be a reasonably representative one (as was done with the Surveillance, Epidemiology and End-results (SEER) program in the United States, which now currently covers about 26% of the national population), but even partial,



**Figure 5. Percentage of patients presenting at late stage for nasopharyngeal cancer (NPC), breast and cervix in the Department of Radiotherapy and Oncology (DRO), Sarawak General Hospital (SGH) (1991-1999). Reprint with permission of the Annals of Oncology and the authors (from Devi et al., 2007).**

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**Figure 6. Age-adjusted 5-year relative survival from cancer of the colon & rectum (males & females), by country, with area-weighted mean European relative survival. Horizontal bars show 95% confidence intervals (from Berrino et al., 2007).**

non-random coverage can provide adequate estimates of the national situation, although the sometimes marked heterogeneity of populations in developing countries may necessitate careful planning as to the siting of cancer registries, and significant differences in different populations may be found.

The resources required to operate a PBCR for a limited population (for example, a city or province) are quite modest, comprising, as well as a medical director (part-time with their usual duties), one or two trained data clerks, a personal computer, expenses for office supplies and transport. The benefits, in terms of providing essential information in formulating the cancer control plan,

as well as in monitoring its success, means that all countries introducing a cancer control program should attempt to include a PBCR as part of the cancer surveillance program of their NCCP. ■

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## OBSTACLES TO EDUCATING PATHOLOGISTS AND RETAINING THEM IN THEIR COUNTRY OF ORIGIN

Pathology diagnostic services have made significant progress in recent years. The tests are not only specific but also more sensitive. The use of techniques such as immunohistochemistry has led to new insights into the cellular origins of tumors and provides information relevant to both diagnosis and optimal treatment. Consequently, pathologists, at least in most developed countries, are expected to meet stringent training, management and quality-assurance standards.

Unfortunately, most developing countries are unable to take advantage of the progress made because of their severe limitations in human resources, leading, in the case of pathology, to too few laboratories — many of which are understaffed. A trained pathologist requires at least nine years of undergraduate and postgraduate education. If the training is of poor quality, or well-trained pathologists do not practice in their countries of origin, this could (and does) have a major negative impact on cancer control and the many other areas of health where pathological plays an important role in diagnosis.

The obstacles to the effective training of such a specialized body of physicians in countries with limited resources are numerous and have diverse and complex causes. The most important of these are addressed in this article.

### SHORTAGE OF INSTITUTIONS AND STAFF

The indicators relating to the availability of health system resources

show significant shortages in the number of physicians, laboratory workers and funding in developing countries (Table I). Yet these are the essential prerequisites for the establishment of a credible pathology service. Pathologists working in these countries are therefore very few. Tanzania has some 16 pathologists for a population of approximately 40 million; Ghana had only six trained pathologists in 2006 while Laos had just one. Even in relatively more developed countries like Pakistan or India, the number of pathologists per capita is a small fraction of that in, for example, the United Kingdom. The shortage of pathologists creates a vicious cycle; not only are institutions understaffed, but the quality of the services is substandard. In some training institutions (e.g., university affiliated), a pathologist might have to handle more than 10,000 biopsies a year. This enormous work load will inevitably affect his or her other duties, such as teaching or research.

Professional institutions such as colleges of pathologists do not exist in most developing countries, such that pathology training, such as it is, is organized by non-pathologists. Even if small, academic bodies of pathologists are better able to plan and supervise training for pathologists.

Opportunities for continuing edu-

cation and further specialization are limited. The institutions that grant a diploma in pathology or certify an individual as having met the requirements for practice do not generally require participation in continuing education programs for continued certification. Pathologists, therefore, rarely remain up-to-date with respect to the progress being made in their field. As a result they are unable to take advantage of new diagnostic tools, even when these are financially feasible, leading to loss of credibility and frustration.

The availability of professional journals and access to teaching materials is generally poor. Although the advent of the Internet has improved the situation somewhat, the type of high speed access required is not always available and may be costly. Moreover, there is a well-recognized gap in the availability of information on the Internet and its utilization.

### NATURE OF PATHOLOGY TRAINING

The training provided in many institutions is generally similar to that given in more developed countries. This not only makes such institutions appear more “modern” but is also attractive for those who wish to enroll in the institution – often because after successful completion of their training

Country	Physicians per 10,000 population	Lab Health Workers per 10,000 population	Per Capita Expenditure on Health (US \$)
Australia	25	4	3181
UK	23	3	3064
USA	26	23	6350
India	6	<1	36
Nigeria	3	<1	27
Pakistan	8	<1	15

(WHO HEALTH STATISTICS 2008)

**Table 1. Health systems resources availability.**

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they are more likely to find opportunities abroad. This means that the prevalent diseases and conditions in the country are generally underemphasized. As a result, those who stay in their own country find themselves bewildered and unable to cope with on-the-ground realities.

Autopsies are an essential requirement for training a pathologist yet medical autopsies are rarely performed. This deprives the trainees of a very valuable means for learning and confirmation of the diagnoses they made in the course of the patient's disease – in some ways, this is similar to the loss of patients to follow-up after treatment.

## **UNATTRACTIVE AND HIERARCHAL SERVICE STRUCTURE**

The structure of pathology services is generally unattractive and financial remuneration is a fraction of what a trained pathologist could command in an affluent country. A qualified pathologist in Pakistan would normally receive approximately \$7,000 per annum. Although the cost of living is less, this still compares extremely poorly with the average earnings of a pathologist in USA, which on average is \$223,000.

Frequently, newly trained pathologists working for the government are posted to a small hospital in an area distant from a major city, leading to professional and social isolation with poor chances of further advancement. There is little money even for routine services, let alone academic work or research, and access to the limited available funding is tightly controlled by the local bureaucracy. If an enterprising pathologist were to try and arrange his own resources, this could create major difficulties

with his administrative superiors. This system has evolved over decades and in the absence of radical government reforms is likely to persist for the foreseeable future. Given political instability, such reform is highly unlikely to be a priority of governments. The lack of security in some rural regions also adds to the poor quality of life and provides an added deterrent to those who might otherwise rise to the challenge of providing improved pathology services in outlying areas.

## **BRAIN DRAIN**

The reasons that persuade pathologists to leave their own countries are numerous and complex. The serious negative impact of the continuing exodus, however, is only too obvious in developing countries. Although fewer in terms of the absolute numbers of migrants, the poorest countries tend to be the worst affected, although as countries try to improve their educational programs, this is likely, for a time, to lead to pathologists being more readily able to acquire jobs in other countries. According to a report, in Zimbabwe in 2006, out of 145 senior registrars, only 36 were still working in Zimbabwe, and there were only 72 specialist consultants instead of the predicted 189. There were only two specialist pathologists out of the eight required even to staff the existing programs and a serious shortage of senior pathologists. A deficit in State Certified Medical Laboratory Technicians was estimated to be in the region of 89%, further impairing the ability of pathologists to practice efficiently.

## **INTERNAL BRAIN DRAIN**

Although not publicized as much, the desire of trained personnel to work in major urban centers leaves large areas

in low- and middle-income countries without any pathology cover. This is despite of the fact that in many countries, the candidates for training from less developed regions of the country are granted incentives. Yet few choose to serve the regions from which they came after completing their training (a parallel to the international brain drain). In Tanzania for example, out of 16 or so pathologists, 13 serve in the capital city, Dar es Salaam. In Ghana, in 2006, all trained pathologists in the country were working in the capital city, Accra. As a consequence, the diagnosis of a malignancy in peripheral areas could take weeks or months.

## **WHAT NEEDS TO BE DONE?**

Humans have emigrated for times immemorial for reasons that were not dissimilar to those operating today. It will take decades, if not more, to change the situation. Improvements are predicated upon substantial changes in the material and cultural environment. This will take a great deal of time. However a number of steps can be proposed to stop the continuing slide and to materially improve the situation.

## **ESTABLISHING AND IMPROVING INDIGENOUS INSTITUTIONS**

Although financial considerations are significant for emigrants, they are not the only reason that professionals wish to practice in other countries. The ability to improve and develop professionally is also a major reason. Some institutions in developing countries have provided a good academic environment with reasonable financial packages and have been successful in attracting qualified natives who migrated to return, while retaining more of those trained locally. All

consultant pathologists working at Shaukat Khanum Memorial Hospital in Lahore, Pakistan, for example, have had additional training abroad, mostly in the USA and UK. A similar situation is seen at the Aga Khan University in Karachi.

A number of institutions in developed countries, such as the College of American Pathologists and the University of Calgary, have developed plans through which trained pathologists spend a variable period of time in these institutions. Such collaboration can help to improve available services – as long as trainees are not tempted to return to the high-income countries. A more sustainable program is one in which permanent facilities are established in developing countries in collaboration with local governments. During the 1960s, Indiana University helped establish a postgraduate program at the Basic Medical Sciences Institute in Karachi. More than a hundred pathologists have passed through this training program, and in turn, trained hundreds more, which has improved the quality of pathology throughout Pakistan.

### CHANGES IN TRAINING

Thought should be given to training programs in pathology. It may be more useful, for example, to aim for shorter training courses covering all essential aspects of the major disciplines of pathology. This approach to emphasizing generalist training has several strengths. More pathologists can be trained and their deployment more flexible. Such pathologists will have more knowledge of the common conditions they will encounter, particularly in peripheral areas. After working in rural regions for some years, they will have developed valuable experience in pathology as

a whole and some of them could receive more advanced training in the sub-specialty of their choosing. The same approach could be employed for technologists.

Training must be in tune with the conditions faced in everyday practice and the available resources. Training in the use of manual equipment (which tends to be more reliable and more readily maintained) and special emphasis on the prevalent diseases is important. In order to achieve this, it is essential for pathologists in developing countries to establish their own academic and professional institutions, such as Colleges of Pathologists, which should also be given more control over the national pathology curricula. Such institutions could also have a major role in accreditation and continuing education.

### SOUTH-SOUTH COOPERATION

There are a number of world-class institutions in developing countries (Fig. 1). There should be more cooperation among them in deciding upon curricula and the actual provision of training in-country. Such training is far less expensive, should be adapted to the local or regional needs, and is not as likely to lead to migration as training abroad. In this regard, INCTR has helped train health professionals from Afghanistan and Nigeria in India and Pakistan. Such efforts should be more extensive and better organized.

### TELEPATHOLOGY

The digital revolution has transformed the way pathology is practiced all over the world, including in the developing countries. Telepathology, in which diagnoses are made in other countries to which pathology images of sections are transmitted, is already providing a

service in the Solomon Islands, where there are no pathologists. Several software systems are available and openly accessible (i.e., at no cost). In *Virtual Slides*, the microscopic images seen from a microscope attached to a computer can be moved remotely from any computer connected to the Internet. In iPATH, libraries of images can be created for training purposes, and digital images uploaded to a password-protected website for consultation purposes. Many pathologists, including those recently retired from senior positions in high-income countries, would be willing to give some of their time to endeavors of this kind, which require no travel and minimal cost. Digital technology could knit far flung areas into a network and provide a better and reliable output. It will become an increasingly valuable component of continuing medical education and will be especially useful for countries like Afghanistan, Iraq and African countries, which are presently drastically underserved. In this context initiatives like Open Educational Resources Cancer Community (OERC) (<http://teachingcommons.cdl.edu/oerc/>) could be very useful.

It is vital for the provision of reliable pathology services in developing countries to have well-trained pathologists who remain in their own countries or return home to work. However, many obstacles will need to be overcome before this goal can be achieved. There are no shortcuts, but the solutions are clear: the establishment of more academic institutions producing more and better trained pathologists and the provision of better working environments. ■

*Manzoor Ahmad  
College of Pathologists  
Rawalpindi, Pakistan*

# NETWORK

## MEDICAL KNOWLEDGE INSTITUTE OFFERS BEADS OF HOPE

They may appear to be simple strands of beads, but these hand-crafted pieces of jewelry are powerful weapons against poverty, ignorance and disease. The multi-hued bracelets are the fruits of a grass-roots campaign to empower HIV-infected women in South Africa to make better health decisions for themselves and their children, while providing them marketable skills and financial independence. According to Harold Robles, co-founder and president of Medical Knowledge Institute (MKI), the YOELL® Collection may be the catalyst communities need to stop the cycle of HIV infection, violence against young women, and despair. He has seen the transformation in women who come to the MKI's Health Information Centers in the townships of South Africa. And he is delighted to have launched a sustainable economic enterprise that partners local artisans with European designers and marketing experts. International sales of the YOELL® Collection — offered through the most exclusive shops of Holland, the United Kingdom and Germany — raise the funds that support and sustain MKI projects while providing incomes to women who would otherwise be jobless.

Dr. Robles, a native of the Netherlands known for his international humanitarian work, has devoted his life to promoting healthcare education and information as a human right. As a boy, he became fascinated with the work of Albert Schweitzer, the Nobel

Peace Prize laureate who worked as a medical missionary in Africa. More than twenty-five years ago, with the support of Dr. Schweitzer's daughter Rhena, Dr. Robles founded the Albert Schweitzer Institute for the Humanities in the state of Connecticut, USA. Dr. Robles dedicated the work of his nonprofit organization to alleviating suffering and injustice in the world, and



**A South African woman models the beads made by the HIV-infected women who visit Dr. Robles' clinics.**

*Photo by Patricia Steur for MKI.*

to creating a more equitable and sustainable future for our planet and its inhabitants.

Through this humanitarian agency, he provided aid to the people of war-torn Balkans; organized health education programs in underserved countries; established mother and child health clinics throughout Albania and introduced Albania's first child development center in that country's capital city; evacuat-

ed seriously injured children from Bosnia for life-saving medical treatment; championed humane living conditions for orphans in Georgia; created, at the request of former President Michael Gorbachev, the International Trust for Children's Health Care in Russia to provide medical care for children with leukemia; provided dental care for 150,000 refugee children in Belgrade; and, in partnership with the Soros Foundation and other agencies, brought medical equipment, pharmaceuticals and medical supplies to more than 20 developing and transitional countries.

Dr. Robles retired as president of the Schweitzer Institute in 1998 and returned to the Netherlands, where he now directs his humanitarian work toward Africa. In 1999, he co-founded, with the support of his best friend Dr. Peter Bittel, the Medical Knowledge Institute a nonprofit organization associated with the World Health Organization and the United Nations and dedicated to the premise that healthcare is a human right, not a privilege. The programs of MKI are designed to improve the quality of healthcare and to promote humanitarian values through education and public health programs. Among the initiatives of the MKI is an HIV/ AIDS training program aimed at preventing vertical transmission of the virus in South Africa. This project, conducted in collaboration with the International Confederation of Midwives, the VU Medical Center in Amsterdam and the Dutch Red Cross, is aimed at informing and educating midwives and healthcare workers on how to prevent the transmission of HIV/AIDS from mother to child.



**Dr. Harold Robles and community members celebrate the opening of the MKI Health Information Center in Khayelitsha, a township in South Africa.**

It is here in South Africa, at MKI's Health Information Centers, that something extraordinary is happening. Mothers are being educated about child development and childhood illnesses, their daughters' safety and welfare, domestic violence and preventable diseases, including AIDS. Even more remarkable, women infected with HIV are being empowered to do something for themselves, their families and their communities.

"It is important that we empower people to take care of their own healthcare issues," says Dr. Robles, "because there are so few doctors — one for every 190,000 people in Africa. We have to empower the local people, especially the women. The future of the African continent is in their hands."

He describes the YOELL® jewelry venture as a project that started by accident three years ago. "A

colleague board member and I felt that we had to do something for the many HIV/AIDS infected women coming to the centres for workshops," Dr. Robles explains. "So we taught them to make bracelets out of recycled beads. We put them on the payroll and started selling the bracelets abroad. Half of the proceeds supports the clinics, and the other half goes to them. These women are living in shacks, but they all have bank accounts where their money is being deposited. Now we are sending famous Dutch designers to Africa to teach them to refine their craft."

Along with their beading mastery, the South African women who earn certificates through workshop training are also passing along their newfound knowledge. In a country where orphaned adolescent girls commit suicide because they confuse the onset

of menstruation with fatal internal bleeding, MKI's Knowledge4Health Network sustains a grass-roots model of information sharing that can save lives.

"South African children are not dying of AIDS," says Dr. Robles. "They are dying of curable diseases. If a child were to die of diarrhea in Holland, the authorities would close that clinic. Nelson Mandela, the former president of South Africa, is constantly imploring the international community to do more on health education. Education is the most powerful weapon we have to change the world."

MKI currently operates four Health Information Centers in South Africa and hopes to increase that number to ten before the end of next year. The women employed are producing 500-700 bracelets a month, and the demand is growing with new markets opening in the United States. MKI's achievement have recently been recognized by a nomination for the Gates Global health Award.

Since meeting INCTR President Ian Magrath at an oncology symposium in London, Dr. Robles anticipates introducing lessons about cancer prevention into his public health workshops.

"We will promote prevention and early diagnosis of breast cancer by offering simple education," Dr. Robles says. He is also interested in INCTR's palliative care initiatives for AIDS patients and will discuss this with Ian Magrath while they are exploring a working relationship between INCTR and MKI. ■

*Marcia Landskroener for INCTR*

# NETWORK

## AGA AMCC IN PARIS

The annual general meeting of INCTR's French branch, the Alliance Mondiale contre le Cancer (AMCC) took place in Paris on 26<sup>th</sup> March. Sabine Perrier-Bonnet, project officer, gave a report of her activities in the last year and proposed activities for the next year. The AMCC is a founder member of the International Cancer Network created by the French Ministry of Foreign Affairs and the Ministry of Health and has signed an agreement with the French League against Cancer. These partnerships have led to meetings and workshops in Niger and Burkino Faso in tobacco control, nursing oncology and palliative care. ■

## A DAY DEDICATED TO CANCER IN MONTPELLIER

Sabine Perrier-Bonnet of AMCC organized a cancer day for French speaking health professionals at the Val d'Aurelle cancer center in Montpellier on 11<sup>th</sup> April, 2008. Presentations regarding ongoing activities and future plans of the participating organizations were made by Prof. Dubois, Director of the Cancer Center, Dr Henri Pujol, former director of the French national League against Cancer and presently director of the league for the Montpellier region, Sabine



Sabine Perrier-Bonnet, Binta Bourgoïn (Côte d'Ivoire) and Guy de Thé at the «Cancer Day».



Elisabeth Dupont presents INCTR activities in Montpellier.

Perrier-Bonnet and Prof. Guy de Thé of AMCC and Elisabeth Dupont of INCTR. The meeting was attended by some 50 persons. ■

## UICC BOARD MEETING

A Board Meeting of the International Union Against Cancer took place on 27<sup>th</sup> April in Lugano. Dr Magrath attended as INCTR's liaison to the UICC. ■

## MEETINGS RELATING TO BREAST CANCER CONTROL IN MOROCCO

Earlier this year, INCTR signed an agreement with the Association Lalla Salma against Cancer (ALSAC) to collaborate on the development of a breast cancer control program in Morocco. This was promoted by the Brussels Capital Region Government, specifically by the Centre d'Informatiques pour la Région bruxelloise (CIRB) with whom INCTR has met on several occasions in this context. On 29<sup>th</sup> April, it was agreed, with Dr Sorin Ciocca and Mrs Roselyne Goossens from the Brussels Capital Region to hold a subsequent meeting with representatives of AMCC and ALSAC. This took place on 12<sup>th</sup> May. Dr Andre Grivegnée, a mammography specialist from the Jules Bordet Cancer Center in Brussels, who had participated, with CIRB and ALSAC,

in a recently completed pilot project to assess the feasibility of double reading of digital mammographs transmitted to Brussels from Rabat, discussed the results of this project and Dr Anthony Miller, an expert in the early detection of breast cancer described ongoing studies of screening by clinical breast examination in Egypt, Sudan and Yemen in studies sponsored by the European School of Oncology. Dr Alberto Costa, Director of the European School of Oncology participated by telephone. The participants discussed plans for developing a program for the early detection of breast cancer by clinical examination in community health clinics in Rabat, Morocco, in which screen-positive patients would be referred to gynecological hospitals for diagnosis and those found to have breast cancer referred to the National Oncology Institute in Rabat for treatment. INCTR will work with ALSAC on the documentation and management of the project through the development of a comprehensive data base. ■

## DR PATRICIA SCANLAN VISITS INCTR, BRUSSELS

Dr Scanlan, a pediatrician with training in international health and pediatric oncology is an INCTR Medical Officer who is presently stationed in the Pediatric Department of the Ocean Road Cancer Center in Dar es Salaam. Dr Scanlan visited INCTR on 13<sup>th</sup> May to discuss past work and future plans with respect to INCTR's ongoing collaborations with the Ocean Road Cancer Center (ORCI), Directed by Dr Twalib Ngoma. Dr Ngoma also directs INCTR's Tanzanian Office. Dr Scanlan has worked with local staff to develop standard proce-

dures for nurses and doctors in the care of pediatric patients and to train junior staff in their application. Ongoing collaborative projects between ORCI and INCTR include the treatment of Burkitt lymphoma (Principal Investigator (PI), Dr Jane Kaijage) and the development of improved palliative care services both at ORCI and in other parts of the country (PI, Dr Msemo Diwani). It is hoped to initiate additional projects in the treatment of selected pediatric solid tumors (e.g., Wilms' tumor) as well as to develop, with pediatric oncologists from other low and middle income countries, an INCTR handbook of pediatric supportive care for use by medical and nursing staff who care for children with cancer. ■

#### **DR FRASER BLACK AND DOUG ENNELS VISIT INCTR BRUSSELS**

A new edition of a palliative care handbook, written by INCTR's PAX (Palliative Care Access) team is also in production. In addition to expanding the range of symptoms covered by the book, this edition will provide more information on pediatric palliative care and psychosocial support. During a visit to Europe, Fraser Black, Co-director of PAX and Doug Ennels (PAX psychosocial worker) visited INCTR's offices (26<sup>th</sup> May) to work with INCTR staff (Bénédicte Chaidron) on the next edition of the handbook. Publication is planned for late 2008. ■

#### **OPEN EDUCATIONAL RESOURCES FOR CANCER**

INCTR has agreed to become a member of a group of organizations, including i-Bharti Health, which are

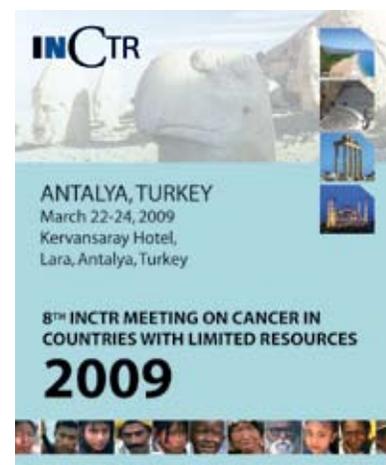
collaborating in the development of a web portal that will make freely available a broad range of information about cancer. A particular focus will be cancer in low and middle income countries, whose special needs are generally overlooked in available educational materials. The William and Flora Hewlett Foundation, which supports web-based open educational resources, has a strong interest in the project and is willing to consider providing financial support. A meeting of the group took place in Chicago on 29<sup>th</sup> May 2008. Attendees included representatives of the European Society for Medical Oncology, the National Cancer Institute (USA), (including the Director of the Office of International Affairs, the Director of Outreach, Cancer Expert Corp and a senior staff member from the Cancer Biomedical Informatics Grid program), the Washington Cancer Institute, i-Bharti Health, Giunti Labs, the William and Flora Hewlett foundation and INCTR. At this meeting a decision was made to move forward with the project and various strategies were discussed. Updates will be provided in future newsletters. ■

#### **COLLABORATION WITH ASCO**

Melissa Adde, who directs INCTR's Clinical Trials Office, has provided advice and educational materials on data management for use by the American Society for Clinical Oncology (ASCO). ASCO will use these materials in a variety of educational events designed for low and middle income countries. Melissa participated in an international telephone conference relating to this program on 2<sup>nd</sup> June. ■

#### **PRE-MEETING WORKSHOP ORGANIZED IN CONJUNCTION WITH THE 10<sup>TH</sup> ICML**

A workshop on "Epidemiology and Management of Lymphoma in Developing Countries: Challenges and Opportunities for International Collaborations" was held on June 4<sup>th</sup>, immediately prior to the 10<sup>th</sup> International Conference on Malignant Lymphoma (ICML) in Lugano, Switzerland. The workshop was jointly organized by Drs Zucca and Cavalli, primary organizers of the 10<sup>th</sup> ICML, and Drs Ama Rohatiner and Magrath of INCTR. It was sponsored by UICC, ESMO and ESO. The workshop was very successful and a number of pathologists agreed to form collaborative groups to address education and training of pathologists as well as to conduct studies on the epidemiology of lymphomas in low and middle income countries. A report of the meeting will be submitted for publication. In the course of the main meeting, the results of INCTR's ongoing treatment study in African Burkitt lymphoma were presented by Dr Muheez Durosinmi, the PI in one of the participating institutions in Nigeria. ■



For more information see [www.inctr.org](http://www.inctr.org)

# NETWORK

## COMMENT ON "ADVANCED BREAST CANCER IN YAOUNDÉ, CAMEROON"

(Published in *Network* - Vol 7,  
Number 4, Winter 2007-08)

This tragic case of pregnancy-associated breast cancer in a 26 year old woman illustrates the challenges of delivery proper multidisciplinary cancer care in low and middle income countries (LMCs). First, it should be emphasized that this case would be difficult in the best of circumstances and resources. At the point that cancer was definitively diagnosed at the end of her 1st trimester of pregnancy, she already had a locally advanced cancer – an 8cm mass eroding through skin (T4). The recommendation for induced abortion and neoadjuvant systemic therapy was correct and appropriate, although the necessity for abortion can be debated. Neoadjuvant chemotherapy with adriamycin and Cytoxan beginning in the second trimester of pregnancy can be safely delivered and is considered the standard of care in the United States. Unfortunately, the disagreement between patient and her clinicians regarding pregnancy termination led to delay in the initiation of systemic therapy for 3 - 4 months. It cannot be determined in retrospect whether prompt initiation of systemic therapy without therapeutic abortion would have changed the final outcome. Of note, the cancer continued to progress despite of systemic therapy, suggesting that this cancer was particularly aggressive and drug resistant. Furthermore, it cannot be determine whether the premature delivery resulted from the systemic chemotherapy or from the progressive cancer itself. Only a few weeks

after the delivery, hepatic metastases were diagnosed, illustrating the unremitting progression of disease and suggesting that the cancer may have played a role in the loss of the fetus. A second delay occurred after loss of the pregnancy when locoregional therapy with surgery and radiation was refused, whereby the possibility



### CASE SUMMARY

A 26 year old law student detected a breast lump in July 2005, which was eventually excised (February 2006) and reported as a fibroadenoma. In May 2006 she developed another large mass (8cm) in the same breast. Needle aspiration led to a diagnosis of breast cancer. The patient, however, was 14 weeks pregnant and declined a recommended termination. Chemotherapy was delayed until September 2006, and led to spontaneous delivery. The infant survived only one day. One month later an ultrasound examination suggested hepatic metastases. More chemotherapy was given and mastectomy recommended. The patient, however, declined surgery and resorted, instead, to traditional remedies. The tumor progressed, and in late December additional chemotherapy was given. She did not return for follow-up until June 2007 when local disease was very advanced (shown here). She was treated by mastectomy and radiation therapy, but in vain: local recurrence rapidly occurred in association with ascites. The patient was given palliative care.

for local control of disease was lost leaving palliation of symptoms as the only treatment option.

What learning points can be gleaned from this terrible situation? At the core of this treacherous case is failed communication between the patient and her oncology team at the earliest point in her disease's course when a positive impact of therapy would be most likely to have had success. The medical team appears to have believed that abortion was a necessary prerequisite to the provision of care, an option that the patient was unwilling to accept. This disagreement caused an interruption of care during which her cancer progressed. The patient's decision appears to have been based information received from her community suggesting that traditional medicine with local remedies and prayer could be as effective as systemic chemotherapy, surgery and radiation therapy. Thus, the critical importance of public education about the value of early detection and effectiveness of modern treatment cannot be over-emphasized. From the professional side, there may have been a role for professional education regarding the use of neoadjuvant chemotherapy during pregnancy and also about communication with patients regarding methods of gaining patient trust. Had this patient conversed with a breast cancer survivor at the time of diagnosis, her trust might have been achieved earlier in the course of disease. While this case has had the worst possible outcome, future efforts directed at public and professional education could lead to - benefits for future cases. ■

*Benjamin O. Anderson, Breast Health  
Global Initiative, Seattle, USA*

# LETTER / PARTNER PROFILE

## ST. MARY'S HOSPITAL LACOR

One of the best hospitals in all of East Africa is a sprawling complex in northern Uganda that treats more than 280,000 patients annually. Founded by an international society, Comboni Missionaries in 1959 as a 30-bed maternity unit, St. Mary's Hospital Lacor has since grown to be Uganda's third largest hospital – a de facto referral hospital - with a reputation for quality service delivery and for addressing the medical and social needs of the poor. Lacor Hospital is well respected for providing health care with a human face as well as for excelling in areas of specialized medical service.

Lacor, a private not-for-profit hospital, currently has 476 beds and operates three peripheral health centers in Amuru, Opit and Pabo, each with an additional 24 beds. The hospital employs 556 staff, of which 23 are medical officers of various ranks, and 269 are nursing and paramedical staff.

The hospital has experienced phenomenal growth, particularly in recent years, yet has always managed to respond to increasing and changing patterns of demand without compromising professional standards and core values. Key to this achievement has been an implicit strategy of continuous monitoring and adjustment, as well as a commitment to the development of its staff, reinforced by a set of core values reflected in the hospital's mission statement. The hospital's achievements are all the more remarkable given the instability and strife that has characterized northern Uganda for the past 20 years as well as some of the challenges that the hospital

has been faced with - most notably the Ebola outbreak from October 2000 to February 2001, which took the lives of 12 staff members including the director designate, Matthew Lukwiya, as well as the passing away of the hospital's founders and visionary leaders, Lucille and Piero Corti.

Since its founding, Lacor Hospital has earned a reputation for being

ning war. Professionalism, compassion, integrity and accountability are the shared values that are quickly transferred to every new member of the hospital.

### CHALLENGES AHEAD

Uganda is plagued by health problems including high rates of malaria, HIV/AIDS, tuberculosis, malnutri-



St. Mary's Hospital Lacor, Gulu, Uganda.

among the best health care providers in the country. This is a perception shared by nearly all stakeholders, from government officials and local opinion leaders to the public at large. Among Lacor's strengths are a dedicated workforce, functional infrastructure, committed partners and a good working relationship with local and central government. The hospital is also valued for the contributions it has made to creating employment and training opportunities, and for the provision of security and humanitarian assistance during periods of unrest in northern Uganda. Lacor was considered a safe haven during Africa's longest run-

tion, infant mortality and maternal mortality. These health concerns are multiplied in the north because of the political unrest, including a higher HIV prevalence rate (9.1 percent) than in the south.

At Lacor, medical staffers are working diligently to keep up with the demand and safeguarding the hospital's mission and reputation. With a five-year strategic plan now in place, Lacor is considering how best to:

- Maintain and improve service levels
- Clarify comparative advantages and complementarities within the larger health care delivery system, while retaining the capacity to respond to emerging needs

# NETWORK

- Secure and sustain human and financial resources
- Determine the appropriateness of expansion and the introduction of new services, and
- Strengthen relationships and interactions with stakeholders and partners to ensure understanding, identify opportunities and secure resources.

## CANCER IN UGANDA

Cancer is a growing concern in Uganda, though its importance as a health problem is masked by the overwhelming prevalence of infectious diseases and trauma. There is one cancer institute in the country, but unfortunately, the distance from home and cost of treatment



**Patients and family members enjoying the Ugandan sunshine while the hospital wards are fumigated.**

are prohibitive for many cancer patients. There are other hospitals that treat selected cases of cancer. Lacor Hospital, for example, treats mainly childhood lymphomas and other childhood cancers as well as Kaposi sarcoma in AIDS patients. The most common cancers in Uganda are cervical and breast cancers in females, and Kaposi's sarcoma, prostate and esophagus for males, in that order. For children, non-Hodgkin's lymphoma is the most prevalent cancer, most of which is Burkitt lymphoma.

## CANCER TREATMENT

Lacor established a cancer treatment ward in the 1970s. Because of financial constraints and other unavoidable circumstances, the radiotherapy unit built for the ward was shut down in 2000. Presently, Lacor Hospital is focusing efforts on cancers that can be treated largely with chemotherapy, surgery or a combination of the two. Patients who require radiation therapy are referred to the radiation therapy department at Mulago Hospital in Kampala, where the Uganda Cancer Institute is also located.

## MISSION STATEMENT

The Mission of the Hospital is to provide health care to the needy and to fight diseases and poverty for every sick person regardless of ethnic origin, social status, religious or political affiliation. The Hospital seeks to promote the access to health care for the weakest social groups, like women, children, people in destitute financial conditions, and people affected by chronic diseases. The Hospital advocates a comprehensive, integrated and sustainable action on health, including treatment, prevention and training of health workers.

While Lacor does have a hospital-based Burkitt lymphoma registry, there is only one population-based cancer registry in Uganda, also in Mulago Hospital, which collects data only from Kampala.

## CANCER PREVENTION

Hospital officials are discussing whether to offer vaccination against human papilloma virus for cancer of the cervix. It presently performs pap smear screening and is planning to institute a second screening method: visual inspection of the cervix using acetic acid (VIA).

## COLLABORATION WITH INCTR

In northern Uganda, Burkitt lymphoma is endemic. Lacor Hospital is interested in joining hands with INCTR to implement INCTR's treatment protocol for African Burkitt lymphoma. After an initial meeting with INCTR representatives at the AORTIC Conference, Lacor Hospital took part in discussions at the Burkitt Lymphoma Conference in Kampala in February 2008. INCTR sent an expert to the center to assess its sustainability in delivering Burkitt treatment in accordance with the INCTR protocol. Ethical approvals and other administrative processes are underway and chemotherapy drugs will be sent to Lacor Hospital with an anticipated start date of the program early in 2009.

## OTHER COLLABORATIONS

The Division of Cancer Epidemiology and Genetics of the National Cancer Institute, USA, has established a collaboration with Lacor, the major aim of which will be to study the epidemiology of Burkitt Lymphoma, and in particular, the possibility that genes that confer resistance to malaria could modifying the risk for the development of Burkitt lymphoma.

The international organization known as Pathologists without Borders is helping Lacor Hospital by sending pathologists on a rotational

# PARTNER PROFILE

## HOSPITAL SERVICES

Lacor is a general hospital offering a limited number of specialized services.

The hospital has the following departments:

- Surgery - including a burns unit, ICU and orthopedics
- Obstetrics and gynecology
- Pediatrics - comprising general pediatrics, cancer treatment (Burkitt ward), isolation ward and malnutrition ward
- Medicine - general medicine and tuberculosis ward
- Public health
- Dental unit
- Radiology - X-ray and ultrasonography

All of these departments are headed by specialists.

## INSTITUTIONAL RESOURCES

Total Beds	476
Beds devoted to cancer care (Burkitt ward)	10
Staff Physicians <i>(8 specialists, 15 general practitioners, 2 specialist expatriates)</i> We also have 13 doctors currently undertaking internships	25
Nurses	140
Dedicated oncology nurses <i>(3 pediatric specialist, 2 dedicated to Burkitt treatment, 2 palliative care nurses)</i>	7
Oncologists	
• Medical	2
• Radiation (but our unit has been closed since 2000)	1
Pathologist <i>(on rotation from Pathologists without Borders. In the event of a gap in coverage specimens are sent to the Department of Pathology at Mulago Hospital, Kampala for processing and diagnosis)</i>	1
General and specialist surgeons	3
CT Scanner	None
MRI	None
Radiotherapy machines	
• Cobalt radiotherapy unit <i>(the possibility of reestablishing a radiotherapy unit is under discussion with the Ugandan Ministry of Health)</i>	closed down since 2000
• Linear Accelerator	None

## PATIENTS PER YEAR

Outpatients	267,253
Inpatient admissions	37,371



**Children's ward.**

basis to the hospital in order to assist in training and education of African pathologists and technicians and to assist in upgrading pathology services. This effort is assisted by the Italian province of Bolzano which is also providing funding to re-equip the pathology laboratory and to support staff exchanges.



**Graves of the hospital founders (Dr. Lucille Teasdale, a Canadian surgeon and her husband, an Italian, Piero Corti) and also of Dr. Matthew Lukwiya, Medical Superintendent, and other staff members who died in the epidemic of Ebola fever.**

## FUNDING

At present, the hospital does not have specific funding for cancer treatment; rather funds made available by donors are used to cover general operating costs, including cancer treatment. Funds are presently insufficient to provide full cancer services. ■

*Martin Ogwang, Lacor Hospital, Gulu, Uganda*

# NETWORK

## PROFILE IN CANCER MEDICINE

### A QUESTION OF WILL

Paul Ndom, medical officer at Yaoundé General Hospital in Cameroon, confronts challenges every day that would defeat all but the most faithful of physicians. In this African nation, poverty is the most crippling malady.

Dr. Ndom, a 1983 graduate of the Yaoundé School of Medicine, was a general practitioner working in the obstetrics/gynecology unit at Yaoundé University Teaching Hospital when he began seeing women with cancer. Not only did the patients have to raise the money to buy the chemotherapy drugs, they had to buy the water buckets they used as emesis basins.

"It was heartbreaking. The chemotherapy was so difficult, I thought there should be a better treatment for them," recalls Ndom, who went to France to study oncology in 1989. He spent the next seven years abroad, turning down a good job offer to return to Cameroon. In January 1996, Dr. Ndom was named head of the medical oncology service at Yaoundé General Hospital. It would now be up to him to devise ways to convince patients that they can benefit from cancer treatment, find inexpensive solutions to treating cancer patients, and to somehow find the money and staff needed to keep the cancer unit in operation. – well trained health care providers frequently migrate to better paid jobs in other countries. On any given day, within a three-hour stretch, Dr. Ndom will see 35 patients, 80% of whom are in the late stages of their disease. Most of them are poor.

Like other African nations, Cameroon is facing a cancer epidemic. Cancer



**Dr. Paul Ndom is director of the INCTR's branch office in Cameroon.**

doctors battle public misconceptions (some believe that cancer is a disease induced by witchcraft) as well as those of many health workers that delay diagnosis, eliminating, for most, the possibility of cure, and struggle to find the resources required to improve the situation. For those such as Dr. Ndom, it becomes a question of sheer will.

"My message to medical students is that cancer patients in Cameroon need treatment, but there are not enough doctors here to treat them and that this is a problem that cannot be solved for us. Sometimes it seems as though the rest of the world has closed its eyes and ears to what is happening in Cameroon. So it is up to us to continue to do what we can to improve the situation."

Dr. Ndom, the director of INCTR's branch office in Cameroon, feels the added responsibility of being Cameroon's first qualified medical oncologist — a physician who will not achieve cure in 80% of his patients because of their advanced disease. "I have to be an example," he says, "a role model for the young doctors who are unfamiliar or unreceptive to medical oncology. They see medical oncol-

ogists as working with patients who are going to die and worry about making a good living, since poor patients have no money."

He takes satisfaction in knowing that he is relieving the pain and suffering of his patients. There are also moments of jubilation – as when a former patient visits to show off her new baby. "Sometimes you see that your work is of benefit, even if results are not as good as in higher income countries, and the patients appreciate the progress we have made in spite of the severe limitations in resources."

Dr. Ndom is cautiously optimistic about that progress. On the continental stage, he has been one of the primary facilitators of the EuroAfrican congresses on oncology, and he recently completed his term as President of the African Organization for Research and Training in Cancer. Locally, his oncology unit is well known for providing good palliative care. He has one young doctor working with him, and another student who wants to pursue a rotation in oncology. The non-governmental organization he established in 1999, Solidarity Chemotherapy Association (Sochimio), provides cancer drugs and support to cancer patients, and offers public educational programs. Sochimio's Center for Counseling, Information and Education organizes screening and early detection campaigns in outlying areas (most notably for cervical cancer).

He has done much with so little. He imagines what he could do with a little more. ■

*Marcia Landskroener for INCTR*