N E T W O R K

THE NEWSLETTER OF THE INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH

INCTR

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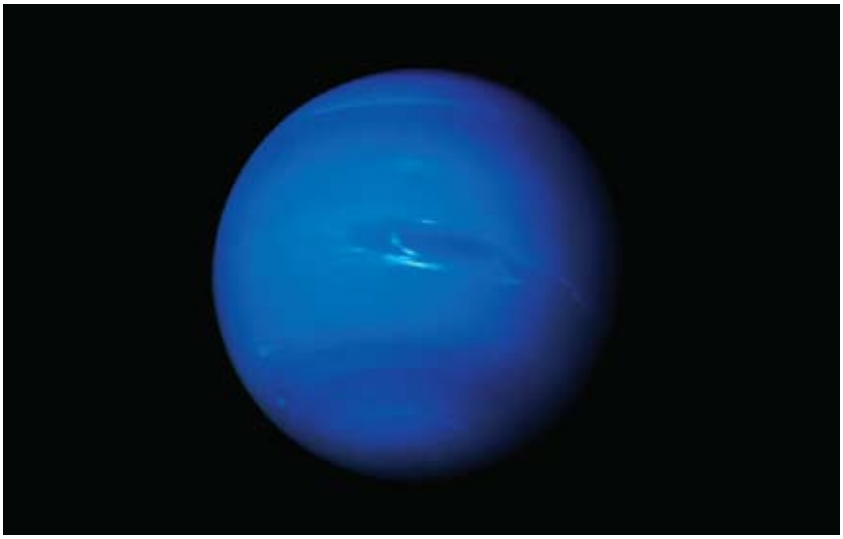
THE PRESIDENT'S MESSAGE

INFORMATION AND CANCER

by Ian Magrath

Information is defined as the degree of uncertainty which is resolved by the arrival of a signal. Robert Escarpit, 1978.

Why the great English poet, Dryden, entitled his poem about the year 1666, "Annus Mirabilis" (Year of Wonders), might not be immediately apparent. Bubonic plague had been raging in London since 1665 and in September the Great Fire of London broke out. It was, though, something of a miracle that only 16 people were believed to have died in the conflagration. The fire also brought an end to the epidemic of plague through the destruction of the most overcrowded districts, providing, at the same time, an opportunity to rebuild the city. Dryden also made much of the final victory of the English fleet over the Dutch after narrowly avoiding total destruction. He made no mention, however, of the remarkable scientific discoveries, that same year, of Isaac Newton. Newton had been sent home from Cambridge University shortly after receiving his degree in 1665 as a precaution against the plague. Prior to his return to Cambridge in 1667, he laid the foundations of calculus, developed new concepts of light and color, and began to formulate his laws of motion and gravity. 1666 was indeed an *annus mirabilis* for physics. Not surprisingly, some 240 years were to pass before this feat was equaled. In 1905, Albert Einstein published four remarkable articles in the physics journal *Annalen der Physik* which laid the foundations for atomic theory, quantum mechanics and relativity, and set the course for much of 20th century physics. Einstein's last article of the year showed the equivalence of mass



The planet Neptune, as seen by Voyager II. Neptune was discovered as a result of deviations in the orbit of Uranus from the path predicted by Newton's law of gravity - an example of scientific inference based on available information. Picture from NASA's open source website.

and energy through a relativistic derivation of the famous equation $E = mc^2$, where E stands for energy, m, mass, and c, the speed of light in a vacuum.

This simple equation might well be held to support the view of the seventeenth century Dutch philosopher, Spinoza, who believed in the unity of all that exists and that God and nature are two names for the same reality or substance. His particular brand of pantheism appealed to Einstein who wrote: "I believe in Spinoza's God who reveals Himself in the orderly harmony of what exists, not in a God who concerns himself with fates and actions of human beings." We can, of course, directly perceive both energy and matter, but perception alone provides little or no insight into the laws of nature to which Einstein was referring. This can be achieved only by scientific inquiry, although such inquiry also has its limits. We are unlikely ever to understand, for example, the nature of the ultimate "substance" that can be expressed either as matter or energy, or why it exists at all. Remarkably, however, the best minds are able to convey profound truths through the use of mathematical symbols, models or theories, which serve to increase our understanding of natural phenomena. The validity of such representations of particular aspects of reality can only be determined through repeated observation and/or experiment coupled to analysis of the data collected. But the collection of information and its analysis, or the derivation of a mathematical equation, require the expenditure of energy, and storage in a material context is essential to avoid rapid dissipation. Matter, already a vast repository of information in its composition, form, temperature and stored kinetic and potential energy, can be used in forms ranging from clay tablets to optical discs to store additional information for subsequent retrieval - again, by the expenditure of energy. Information, then, appears inherent to all that exists; some have argued that all that exists is information - *logos* - manifested as matter and energy.

INCTR

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REDUNDANCY AND SYMMETRY

One of the central problems of information theory - the discipline concerned with quantifying data and minimizing the space/time required for its transmission and storage - is that of noise. Making oneself understood in a noisy restaurant or aircraft can be difficult, but it is possible to separate the message, or signal, from noise. This process is aided by the rules of syntax, which create expectations in the mind of the listener, and by the redundancy of language - the message can still be accurately received even if some of it is garbled since normal speech includes elements in excess of the minimal amount of information required for understanding. Similarly, in written text, words may be misspelt or letters omitted but the recipient can still discern the meaning in the message. Redundancy allows computer text files to be compressed by as much as 60% without loss of information - into "zip" files, for example, that take up less storage space. The removal of redundancy is also essential to the creation of secure codes, and, conversely, its presence is helpful in deciphering unknown languages and ensuring that a message is accurately conveyed. Visual communication also includes redundancy; familiar objects may be readily recognized even if partially obscured. Similarly, simple sketches convey a great deal of information and even "stick people" and "smiley faces" (☺) can be used to communicate ideas. In the context of perception, the brain can often fill in missing elements.

Knowledge and understanding are intimately related to communication and it is apparent that the degree of certainty of a conclusion is increased, as with language and vision, by redundancy - i.e., by different types of supporting evidence. But at the same time, both knowledge and understanding are always, at some level, incomplete, although fortunately, perfect understanding is not necessary for the effective use of knowledge. Incomplete information can, of course, lead to incorrect conclusions or inappropriate generalizations, which may slow progress for centuries, but as information is

progressively accumulated a firm foundation on which understanding can be built is created.

The building of knowledge and understanding is a continuous process that extends across millennia and profits from the development of new tools for accumulating, storing and manipulating information. A central element of this process, linked closely to auditory and visual perception, is the brain's constant search for patterns and symmetries. This applies, for example, to our present understanding of the molecular genetic basic of carcinogenesis - an overall framework exists, but new pieces of the jigsaw puzzle are constantly being fitted into place. Broad conceptual outlines based on a considerable amount of information are often referred to as theories - for example, the theory of evolution and information theory. Belief in their validity is enhanced by their inherent symmetry, created by the supportive evidence, and defects in such patterns permit more focused research designed to fill gaps or resolve discrepancies. Incomplete mathematical symmetries, for example, led to the prediction of the existence of the planet Neptune and of several fundamental particles prior to their discovery.

TO BE OR NOT TO BE

Claude Shannon, an electrical engineer and mathematician, was greatly concerned with noise and redundancy. His Master's thesis in electrical engineering, submitted to the Massachusetts Institute of Technology in 1937, demonstrated that Boolean algebra and binary arithmetic (a "base-two" number system in which there are only two symbols (yes/no, on/off, present/absent or 1/0) could be combined to greatly simplify the use of electromagnetic switches (relays) used to route telephone calls. Boolean algebra deals with the logical manipulation of information contained in sets of objects, numbers or entities; The Boolean operators, AND, OR and NOT, are familiar to those who frequently search for publications relevant to their specific interests in sets of articles contained in databases such as PubMed. Of perhaps even greater significance, Shannon recognized that arrangements of electrical relays could be used to solve problems in Boolean algebra, which at its core is binary in nature since it can be reduced to making decisions about whether or not specific criteria are met.

Information from which no inference can be made is of no scientific value

Just one year before Shannon submitted his thesis, Alan Turing had described a theoretical machine that was, in essence, a programmable computer. He conceived of a simple tape (a memory device), a set of symbols (and blanks) regularly spaced along the tape, a means of reading, writing or erasing symbols, and the ability to move the tape one space at a time to the left or right according to a "table" of instructions. The machine could also keep track of its *state*, i.e., how far it had progressed through the table of instructions. The notion of using an appropriate algorithm (a set of defined instructions) that could be run on a simple machine was the immediate forerunner of the computer program. To bring the theoretical Universal Turing Machine (one capable of running any algorithm) into the realm of reality, a means of representing symbols that could be translated into a *language* appropriate to mechanical or electrical devices - a machine language - was required. Although not consciously pursuing this goal, Shannon's further work would provide just this.

After completing his PhD thesis Shannon joined Bell Laboratories, where he examined a question of considerable importance to the telephone/communications industry - how to ensure the highest possible information content in electrical signals transmitted in copper cables. A necessary prerequisite was a means of quantifying information. In his classic paper of 1948 entitled "A Mathematical Theory of Communication," Shannon laid the foundations of information theory. Building on his earlier ideas, he recognized that all information could be encoded in the form of a series of binary digits, which he referred to as *bits*. A bit answers a single, appropriately framed question, with either a yes or a no. Series of bits expand the number of questions that can be answered in such a way. Shannon recognized that a question with N possible outcomes can be answered with a string of $\log_2 N$ bits (log to the base two, since each bit was either a yes or a no). For example, three bits of information are required to distinguish among eight possibilities; N=8 and $\log_2 8 = 3$ ($8 = 2 \times 2 \times 2$). Each string indicates "yes" to one of the eight possibilities and "no" to the remainder (Table 1). The alphabet can now be seen as a set of 26 possible outcomes requiring 5 bits per letter to ensure distinction among each. More characters

111	000
110	001
100	011
101	010

Table 1. The eight possible configurations of three bits.

or symbols can be included by adding a few extra bits. For example, in ASCII code, the *American Standard Code for Information Exchange*, each of the included 128 characters/symbols (27 being the characters of the alphabet and the space, and ten, the digits 0-9), is encoded by 7 bits (log 128 = 7). Eight-bit standard codes (eight bits are referred to as a *byte*), which allow 256 characters to be encoded have also been developed, as well as more universal codes, such as *Unicode*, that allow text and symbols from all of the world's writing systems (scripts) to be represented and manipulated in digital format.

Binary codes also provide a universal means of measuring information content. Although the number of bits in a stream of symbols, such as may be found in a document or book, provides no more information than the total number of letters, bits can encode not only characters, but also the length and pitch of sound (as in speech or music), monochrome images and even color. Encoding a signal intensity for each pixel in each frame of a television or computer screen permits the digitization of images in which color is numerically represented in terms of the admixture of specific intensities of three colors, red, green and blue, abbreviated to *RGB* (Figure 1). This system also permits different monochrome intensities to be converted into color to improve visual impact.

It is important to recognize that information theory does not deal with meaning. Rather, it provides a method of quantifying message-carrying capacity. The size of an electronic file can be expressed as the number of bytes, or in thousand-fold increments of bytes, i.e., *kilobytes (KB), megabytes (MB), gigabytes (GB), terabytes (TB)*, etc. Technically, since we are dealing with a binary system, the closest number to 1000 is 2^{10}, i.e., 10 doublings, such that a kilobyte is sometimes considered to be 1024 rather than 1000 bytes and a megabyte either a million bytes, or 2^{20}, the equivalent of 1024^2. Which system is used makes, in practice, little difference. The speed of transmission of digitized information can also be readily expressed as the number of bits, most often kilobits (kB) or megabits (mB), transmitted per second. Interestingly, in order to assure the integrity of digitized information and a minimum of mistakes generated by hardware, a certain amount of redundancy has been incorporated into computer programs and transmitted messages. Examples include *parity bits*, which are binary digits that indicate whether the sum of the 1's in a stream of bits should be odd or even, and *checksums*, in which the bits are added up at intervals and the resultant sums stored and used to ensure that no changes have occurred in that part of the message during data storage or transmission.

SHANNON ENTROPY

Essentially singlehandedly, Shannon had developed a means of measuring information mathematically. He also realized that the amount of information that could be carried in digital form (i.e., in bits) is inversely proportional to the amount of redundancy. In an infinite series of 1's, for example, almost all of the message is redundant; the next digit is 100% predictable. Such a message could be very simply encoded as "always 1's." Conversely, a completely random stream of bits has no redundancy - it can only be represented by the actual sequence of bits since each successive bit has an equal chance of being a 1 or a 0. Although neither a completely predictable nor a completely random sequence of bits would convey any information, it is apparent that the capacity to carry information is closely related to the probabil-

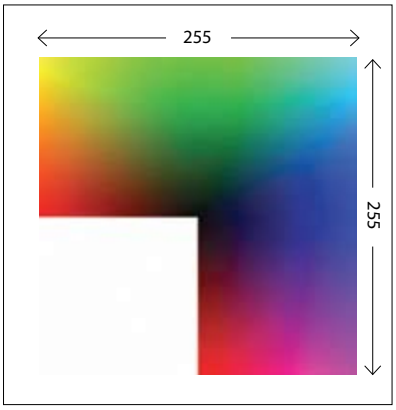

Figure 1. Numerical expression of color via red, green and blue (RGB) addition. Each of the 256 possible colors available here (each a point on the above colored area which has 255 points both vertically and horizontally) is specified by three numbers. Red is 255,0,0, green, 0,255,255 and blue, 0,0,255. Black is 0,0,0 and white 255,255,255. All other colors are various admixtures of RGB, i.e., three numbers between 0 and 255. A similar technique is involved in the quantification of intensity e.g., in imaging studies or scientific experiments. Image from Wikipedia Commons; author, Marc Mongenet.

ity of predicting the next element in a message - and increases with increasing uncertainty.

Remarkably, the mathematical expression for this "uncertainty" (log N) - in practical terms, the shortest sequence of bits required to transmit one message (or character) among all possible messages (or characters) - is identical to Rudolf Clausius's 1865 statement of the *second law of thermodynamics*. Clausius introduced the term *entropy* (from the Greek, *en*: inside; *trope*: turn or change), to mean the energy in a system that cannot be converted into work. He showed that in an isolated system not yet at equilibrium entropy will always increase over time, achieving a maximum value at equilibrium (when there is also maximal uncertainty about the original state of the system). In effect, the law refers to an initially heterogeneous system, with respect to its distribution of energy, moving towards maximal homogeneity. A simple example is a glass of water in a perfectly insulated container to which a piece of ice has been added. Equilibrium is reached when the ice has completely melted and the temperature of the water (its *macrostate*) has become uniform. Of course, the temperature of each of the molecules (equivalent to its motion), which comprise the *microstates* of this system, is not precisely the same. Rather, the molecules follow a distribution curve with respect to temperature, the majority clustering about the mean. Thus, the entropy of a system describes the dispersal of its energy content in statistical terms, and is equal to *k* log W, where k is Bolzman's constant and W corresponds to the number of different microstates in the system. The mathematician, John von Neumann, who made major contributions to the development of the electronic digital computer, recognized the similarity of the mathematical statement of Shannon's uncertainty function (in the binary system, $k = 1$) to the statistical mechanical basis of thermodynamics and suggested that Shannon's function should also be called entropy.

The second law of thermodynamics is of profound significance, since it expresses the process whereby, in open systems, mechanical work can be derived from energy. The model used by Clausius was a simple heat engine - a system in which the energy input, derived from combusted fuel, creates a difference in temperature between two reservoirs (containing water), causing molecules (steam) to flow from the hot to the cold reservoir - movement that can be readily converted into mechanical work. This, however, is an inherently inefficient process: more than 60% of the energy released from the fuel cannot be used to perform work but is dissipated, thereby increasing the entropy of the environment. The heat engine also provides a model for life itself. Energy used by living organisms, most of which derives ultimately from the sun, serves to maintain them (via work) far from equilibrium, and to allow for reproduction and evolution (and in human societies, for the creation of institutional structures). As with the heat engine, however, more energy is dissipated as heat than is available for work, such that the entropy of the environment, and eventually, of the overarching closed system, the universe, is increased—in conformity with the second law of thermodynamics. The notion of information entropy is also applicable to biological systems. For example, increasing the amount of information carried by the DNA of living organisms - increasing complexity in evolutionary terms, or biodiversity in the context of an ecosystem - equates to more information carrying capacity. And although information encoded in DNA is not binary in nature, information stored in the human brain probably is; ultimately, it rests upon whether individual neurons discharge or not. Nature also relies upon the security created by redundancy at many levels, ranging from molecular pathways to entire ecosystems. Ecosystems that contain more species are better able to withstand adverse environmental events. Life-creating energy, then, can also be seen to increase information entropy and the principle of the equivalence of energy and information is upheld.

Although initially controversial, the relationship between thermodynamic and information entropy is now much more widely (but not universally) accepted. Indeed, it has been suggested that thermodynamic entropy is a particular application of *inference* and information theory. Inference, or inductive reasoning, is simply the process of drawing a conclusion on the basis of the evidence, i.e., the available information. Microstates in thermodynamic systems comprise, in essence, the information which determines the macrostate (inference) of the system. Both thermodynamic and information entropy are based upon probabilities, such that the precision of the macrostate, or conclusion, is greater when

the number of microstates, or bits of information, is high. Population-based cancer registration, for example, is generally undertaken only for populations in excess of a million to ensure that calculated incidence and mortality rates are accurate, while controlled clinical trials must include sufficient numbers of randomly selected patients for any difference observed to achieve statistical significance. Inference, combined with imagination, is a primary element of the scientific method and as such is essential to effective health interventions including cancer control. Information from which no inference can be made is of no scientific value, although this may simply reflect an insufficiency of information that can be overcome in the course of time.

DIGITAL DEVELOPMENTS

Shannon and Turing, between them, had provided the mathematical basis for the development of the digital computer and microchips. These have greatly extended our ability to store and manipulate information of all kinds and have also provided insights into human cognition. Along with telephony and radio communications, the invention of the Internet in the 1970s (a system of linked computer networks using a common protocol for the transmission of signals) and the World Wide Web (www) two decades later, which links documents via *hypertext*, i.e., by "clicking" on highlighted text, have permitted everyone with access to a suitably equipped computer, no matter where they are, to communicate almost instantaneously with anybody else in the world via sound, text and images and thereby

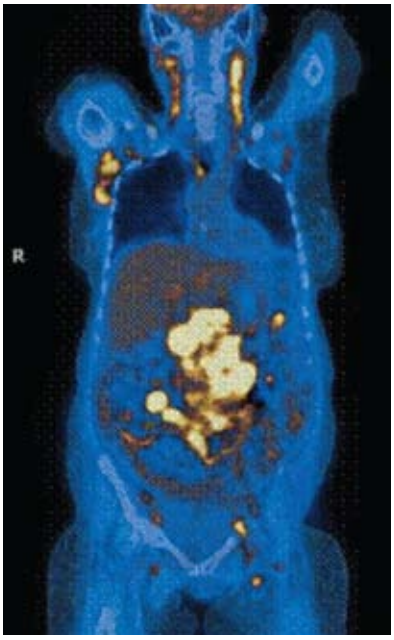

Figure 2. Superimposed images of computerized tomograph, a radiographic technique in which anatomical structure is digitized, permitting two or three dimensional reconstructed images, and PET scanning, in which functional imaging is based on uptake of radioactively labeled glucose. The intensity of uptake is digitally converted into color. Image reproduced by kind permission of Jorge Carasquillo.

to have historically unprecedented access to, and the ability to share, stored information. A semantic web, in which communication will more closely resemble human language, is presently under development. In the fields of medicine in general, and cancer in particular, digital electronics is essential to, or enhances the functionality of, a broad array of equipment for the investigation, monitoring and treatment of disease as well as storing, analyzing and disseminating (e.g., via the *Web*) data required for routine patient care or research (Figure 2). Computers have helped promote increased communication efficiency through the need to standardize case report forms in research and standardized reporting formats for the results of investigations, both of which reduce redundancy. Unwanted redundancy, or noise, abounds elsewhere - e.g., in the form of gratuitous computer *printouts* and computer *spam* and *viruses*. Computers and appropriate software, however, effectively used, can reduce errors and treatment toxicity, e.g., by the use of computerized prescribing or by improving the therapeutic ratio of radiation therapy (conformal planning and beam intensity modulation). In the context of research, the accumulation, analysis and use of evidence pertinent to hypotheses framed, leads to ever more efficient interventions, although many factors, including personal integrity and volition, technical skills and discipline as well as political and commercial considerations, influence the efficiency of this process. Of critical importance is the accuracy of stored data elements. Here, too, computerization can aid quality assurance. For example, electronic databases usually include a set of *business rules* that ensure that specific data elements fall within a predetermined range, or are consistent with values elsewhere in the case record.

DIGITAL DISPARITIES

While high-income countries move towards ever greater access to information as a consequence of ever faster speeds of data transmission and ever smaller storage spaces for ever large quantities of information (several gigabytes can be stored on a key ring), low

Resource	Comment	Website
Open Source	Education re: open source software	http://www.opensource.org
UNESCO	Information and communication site	http://unesco.orghttp://portal.unesco.org/ci/en
Development Gateway Foundation	Portal for world wide sharing of knowledge and information	http://topics.developmentgateway.org
Open University (UK)	Resources for students and educators	http://www.open.ac.uk/openlearn/home.php
MITOpenCourseWare	All MIT courses online	http://ocw.mit.edu/index.html
Johns Hopkins School of Public Health OpenCourseWare	Free courseware in Public Health	http://ocw.jhsph.edu
Wikipedia (on line encyclopedia)	Users contribute or modify articles	http://wikipedia.org
Wikipedia Commons	Free content images and sound	http://commons.wikimedia.org/wiki/Main_Page
eGranary digital library	Provides digital educational resources for institutions lacking Internet access	http://www.widernet.org/digitallibrary
World Health Organization	Information on global health	http://www.who.int/en
UICC	Information on global cancer control	http://www.uicc.org
IARC	Epidemiologically focused resources	http://www.iarc.fr/ENG/Databases/index.php
US National Library of Medicine	Health information and databases	http://www.nlm.nih.gov/hinfo.html
National Cancer Institute (USA)	Comprehensive cancer information	http://www.cancer.gov
Alliance for Cervical Cancer Prevention	Comprehensive information on the early detection of cervical cancer	http://www.alliance-cxca.org

Table 2. Selected list of open resources available on the World Wide Web.

and middle income countries, barely able to summon the energy requirements for the creation and maintenance of dissipative societal and institutional structures, have much more limited access to information - whether digital or not - and therefore, to education and training. The Web is likely to play a major role in alleviating this disparity as computers become smaller, cheaper and more portable, network connectivity improves and *open source* (i.e., created by the community for the community) software, goods and services, coupled to electronic *commons*, i.e., public information sources with relaxed copyright provisions, continuously expand (Table 2). Web-based education, training and communication will help to overcome obstacles created by limited human resources and the high cost of transportation (financially and environmentally) and telephony. Free access to the latest biomedical information via online journals will play a role in continuing education, while the ability to contribute directly to such information will encourage participation and a sense of ownership. The establishment of international and national networks will greatly enhance the sharing of "domain-specific" information, such as that needed to improve health and control cancer, creating electronic communities of practice through which information can be translated into action able to reach the most physically and financially isolated communities.

1948 might well be added to 1666 and 1905 as an *annus mirabilis* for science, for this was the year in which Shannon laid the foundations of information theory, leading to new analytical approaches and insights relevant to disciplines ranging from biology to astronomy. Even the advances made in Einstein's *annus mirabilis* can be recast in terms of information theory, considered by some to be the third pillar of 20th century physics, alongside relativity and quantum mechanics. At a social level, a more equitable global distribution of information would do much to reduce the world's present inequities and heighten the sense of a global community. Whether or not this will be accomplished depends largely upon how much energy - human and otherwise - is put into the effort. ■

NETWORK

INCTR'S WEB PORTAL

A web portal, as the name implies, is a single point of access to a set of linked applications, available via the World Wide Web (www), that are of interest to a range of users. Portals then, unite users who share a common, overarching interest (e.g., the mission of INCTR) within which their roles and functions may be very different, and lead to much more effective communication and collaboration. The applications available via the portal have a consistent look and feel with regard to the way in which information can be accessed or functions executed, such that users are not even aware that they are using multiple different applications. Portals provide access to electronic work spaces or sites, each designed for a different user group, one of which may be the general public. In this sense they provide "horizontal" mobility, i.e., from one user group (or site) to another and "vertical" mobility, to the various elements within the group site. Each of the portal sites is entered via its own "home page" and contains a set of applications that permit the uploading and downloading of information relevant to the user group, as well as group activities, such as discussions or surveys. Group members may be anywhere in the world, the sole criterion for access to the portal being access to the Internet – broadband is essential for uploading and downloading files in a realistic timeframe.

A portal is much more interactive than a standard website. It permits users (those, at least, who are given, through passwords, the necessary privileges) to themselves modify (or customize) both the home pages, create new elements, including document and picture libraries, and modify the content of the various applications that can be accessed from the home page. Documents can not only be uploaded or downloaded, but may also be edited by members of the group who have *contributor* or *administrator* privileges (*readers* may not modify or contribute content). Modifications to documents are automatically tracked, and automatic e-mail alerts allow group members to know when modifications have been made. While editing documents, users are able to send e-mails to the entire site user group or to selected members. Site administrators can create new work spaces, e.g., for selected users or previously existing groups in order to work on a particular document or meeting and portal administrators are able to create entirely new sites as and when necessary.

The INCTR portal is constructed with Microsoft Share Point Portal Software and generously provided to INCTR by Capital Technology Information Services, Inc. The portal home page can be reached via INCTR's web site, http://www.inctr.org/, or directly, e.g., by including the home page in the list of "favorites" in the user's own web-browser. The main home page provides a broad range of information, including lists of events, announcements, contact lists, links to other organizations and open source materials, such as data bases and medical books, and document and picture libraries. The main document library, accessible from the Quick Launch Bar of the home page, contains INCTR progress reports and the INCTR Charter as well as several PowerPoint presentations. The main picture library contains a large number of downloadable digital photographs taken at various events, such as strategy group meetings and annual meetings. From the main home page, users can access, again, via the Quick Launch Bar, INCTR's programs, strategy groups, committees etc. (see picture). Branches can be accessed by clicking on the appropriate part of the world map, or via the branches and offices link. Returning to the home page is always just a mouse click away.

An administrative site, accessible to INCTR staff, includes INCTR's main data base of contact information as well as various working documents and the INCTR calendar. The latter, accessible to INCTR staff anywhere in the world, ensures that everyone is informed about future events, which can also be listed in chronological order rather than in a standard calendar view, so that all INCTR activities are documented. Each office or branch site has its own calendar, document and picture libraries, such that with a few mouse clicks, INCTR staff can check on events that will or have taken place on the other side of the world (as long as, of course, information is kept updated). INCTR staff also have working sites for annual meetings and NETWORK.

Public sites, such as the Education and Palliative Care sites, provide a great deal of information. Almost all of the presentations of the last two INCTR annual meetings are available from the Education site, as well as PowerPoint presentations on the staging of several cancers, while an electronic version of INCTR's palliative care guidelines (also accessible via INCTR's conventional website, via the Palliative Care program) can be consulted or downloaded.

The Members Forum site should prove to be of particular interest to INCTR members who may both contribute content and download pictures, presentations and documents. In the course of time, it is hoped that this site will develop into a valuable resource – in essence a "community of practice" where members can engage in discussions on topics of their choice, create or respond to surveys and find a range of educational materials. INCTR would value suggestions from members as to how the Members Forum can be made more valuable – but of course they also can play an important role in this process themselves, by simply uploading materials likely to be of interest to other members. Since most INCTR members are not used to this form of interaction, it is anticipated that it will be some time before this site is widely and regularly used. Members should contact INCTR for further information.

Of course, while INCTR's Web Portal is already a valuable tool, for various reasons, including poor Internet access, uncertainty as to how to use the portal, or difficulties relating to variability in software and hardware throughout the world, only a small proportion of INCTR's members and collaborators presently use it regularly, although it has already become a valuable tool for INCTR staff. As with all worthwhile endeavors, some investment is required to gain maximal benefit. INCTR has, therefore, created guidelines to the use of the portal that have been sent by e-mail to all INCTR members and are available in the main document library. We would greatly appreciate feedback on both the portal and guidelines.

As technological advances continue at a rapid pace, it is expected that the portal will become ever more easy to use, and ever more valuable, helping to ensure that our colleagues in the remotest corners of the world no longer feel isolated, but are able to stay in touch as readily as if in the next room! ■

Ian Magrath, INCTR, Brussels, Belgium and Raj Shah, CTIS inc., Rockville, USA

THE NURSE'S ROLE IN ONCOLOGY: AN ESSENTIAL ELEMENT OF CANCER CONTROL IN LOW AND MIDDLE-INCOME COUNTRIES

Can we hope to improve cancer care in developing countries without paying attention to the training and continuing education of health care teams (doctors, nurses, pharmacists, technicians and many others)? Clearly not! And although each team member has an important role, that of the nurse is often not given the emphasis it deserves. Nurses tend to have much more limited responsibilities in low-income countries compared to high-income countries – to a considerable degree a consequence of male-dominated societies.

Yet nurses, who are in much closer contact with patients than are doctors, are responsible for the delivery of many of the medical interventions necessary for effective treatment; their day-to-day observations are critical to the identification of potential problems, including treatment toxicities, and their role as communicator and intermediary between doctors and patients has an important impact on the effective delivery of care and measurement of its outcome. For nurses to be maximally effective team members in the care of the cancer patient, they should, like doctors, receive oncology specialty training. Unfortunately, there is limited available information on the number of oncology nurses and the quality of oncology nursing in developing countries and few formal training programs in such countries. Given the demonstrable shortage of gen-

eral nurses in developing countries (who are sometimes outnumbered by doctors) it is clear that few are available to work in cancer units. Among other factors identified as impeding nurses' involvement in cancer care are: the lack of specialist doctors in charge of training and support, the traditional exclusion of nurses from decision making at most of levels in the health system, the undervaluing of the nursing role and the lack of continuing educational opportunities. Changing the present situation will be difficult, but not impossible. The development of oncology-specific education for nurses, as long as it is associated with appropriate recognition, including higher income, is the primary requirement. The enhanced role of nurses should lead to improved communication between doctors and nurses, a greater role in decision making and at the same time, a reduction of the work load of doctors. Appropriately trained nurses can perform many routine procedures, have a larger role in ensuring that necessary investigations are performed, provide necessary information to patients (and to doctors) and even, in some circumstances, prescribe particular medications.

INCTR recognizes the importance of the patient perspective in the fight against cancer and believes that beneficial actions are possible even when human and material resources are severely restricted. Education is central to this goal and nursing education, given their closer relationship to patients and pivotal role in the oncology team, has a high priority. While each country may be different in its oncology nursing needs and its willingness to accept an enhanced role for nurses, a core curriculum based on essential knowledge for all oncology nurses should not be difficult to develop. In order to move forward, however, it is essential to know where one presently stands. The present article is the first of two parts. The present article is the first of two parts. We begin with a review of current oncology nursing programs in Latin America, with a special emphasis on pediatric oncology. Part Two, focusing on INCTR initiatives in cancer nursing in Morocco and Niger, will appear in the next edition of Network.

PART ONE. PEDIATRIC ONCOLOGY NURSING IN LATIN AMERICA

(Julia Challinor, RN, PhD[1])

"More than 85% of pediatric cancer cases occur in developing countries that command less than 5% of the world's resources" (Yaris, Mandiracioglu, & Buyukpamukcu, 2004, p. 240). Yet in some of the poorest developing countries there is only one trained pediatric oncologist, in others, none. In such situations, nurses, who provide coverage 24 hours a day and seven days a week, have a critical role in enabling the complex treatment for children with cancer to be delivered in a timely manner. Although the number of physicians required to care for children with cancer is much smaller than the number of nurses, the current global flight of trained nurses to more developed countries leaves understaffed units with overworked nurses (WHO, 2006). For example, in the Dominican Republic with a population of nine million, five professional oncology nurses and eight nursing assistants work in the sole pediatric cancer unit, comprised of 16 inpatient beds and an outpatient unit.

Most developing countries lack supportive care and multidisciplinary teams that include nutritionists, pediatric oncology pharmacists, intravenous teams, nurse educators, palliative care teams, social workers, etc. Therefore, these responsibilities are devolved to the pediatric oncology nurses who are already struggling with high patient-to-nurse staffing ratios. Needless to say, many aspects of total care are, of necessity, neglected. As an example, in El Salvador, there is one nutritionist for 300 children hospitalized in the one pediatric hospital, Hospital Benjamin Bloom, in the capital, San Salvador. This is the only referral center for children with cancer (30 beds) in a country with a population of 6.9 million and chronic malnutrition rates of 19.5% for first graders and 18.5% for children less than five years of age (World Food Program, 2007).

Other aspects of the limited resources of developing countries also increase the workload of oncology nurses. In Bolivia, for example, and several Central American countries, nurses are expected to prepare as well as administer chemotherapy. This is a consequence of the shortage of pharmacists in the country and the lack of funds to hire a pharmacist specifically for pediatric oncology. In Nicaragua, one nurse mixes all inpatient chemotherapies four hours a day, Monday through Friday for up to 30 hospitalized patients while the outpatient nurse mixes and administers chemotherapy for approximately 40 patients a day during the week. In some countries, such as the Dominican Republic, pharmacists earn less than a professional nurse so that the lack of a pharmacist adds to the cost of the chemotherapy preparation and reduces the time available for direct

Blanca Nieves Maradiaga preparing chemotherapy at Hospital Escuela in Honduras.

nursing care. Another example arises from the limited use of central venous access catheters in developing countries, largely because attempts to do so have resulted in unacceptably high infection rates and correspondingly higher mortality rates. This means that a great deal of time is spent in establishing intravenous access – which becomes more difficult as time goes by and veins are damaged by the administered drugs.

The level of parental education is often low in developing countries, due to poverty. In Nicaragua, 82% of people live on 1 dollar a day or less and 36% of the population cannot read or write. The literacy rate in Guatemala is 70.6% overall and 63.3% among women who bring their children to the public hospitals for treatment. In addition, 40% of the population does not speak Spanish, or speaks Spanish as a second language, their first being one of the 23 officially recognized Amerindian languages (CIA Factbook, 2007). This greatly complicates the task of the pediatric oncology nurse in teaching parents how to care for their child during treatment for cancer. However, severe understaffing leaves little time for nurses to listen to and address the specific needs and anxieties of the family while trying to ensure that the child will be in a safe home environment when discharged during treatment.

Palliative care is a constant concern for nurses caring for children with cancer in developing countries. Unfortunately, a significant number of children in most developing countries are diagnosed in the late stages of their disease and there is no hope for cure. As stated by the International Atomic Energy Agency, "For most of the developing world, the reality is overstretched health systems, where few cancer patients are screened, diagnosis comes too late or treatment is just not available" (International Atomic Energy Agency, 2003, p.13). However, limited access to morphine as well as inappropriate medical or cultural concerns about addiction can be obstacles to appropriate pain control. The low consumption of opioid analgesics for the treatment of moderate to severe pain, especially in developing countries, which account for only some 6% of global morphine consumption, continues to be a matter of great concern to the International Narcotics Control Board (International Narcotics Control Board, 2005, p. 25). There are few home palliative care programs in developing countries and therefore no support for the family when the terminally ill child is discharged from hospital.

The inclusion of nurses in the multidisciplinary team, which is generally the case in the more developed countries, is still rare in the less developed countries. This has a negative impact both on the nurses and the entire care team; without an equal opportunity for continuing education nurses will remain as undervalued and constrained partners in the fight against childhood cancer, while their omission from the multidisciplinary team can result in overlooking information important to the patient's welfare. Nurses are more likely to be from similar socio-economic groups as the patients and often privy to personal family information that is not shared with the physician. Those countries where they have been identified as an important partner in care and given the opportunity to excel as a result of continuing education programs and international twinning (partnership) and networking programs have demonstrated a decrease in the abandonment of therapy before its completion and higher cure rates, e.g., in El Salvador, Honduras, Guatemala, and Nicaragua. Strong international partnerships that include pediatric oncology nurses will ensure a stable nucleus of these dedicated, essential health professionals which can be expanded to serve both present and future needs. Providing continuing education for oncology nurses while training more, and simultaneously improving their local professional opportunities in order to reduce their desire to emigrate once trained are important, but frequently overlooked, aspects of cancer control. ■

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References available on www.inctr.org

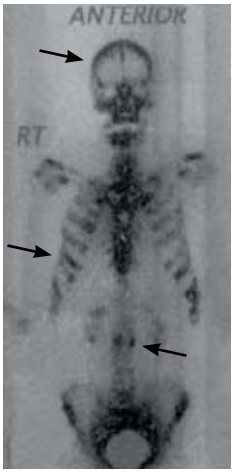
A CASE OF HEPATOCELLAR CARCINOMA IN EGYPT

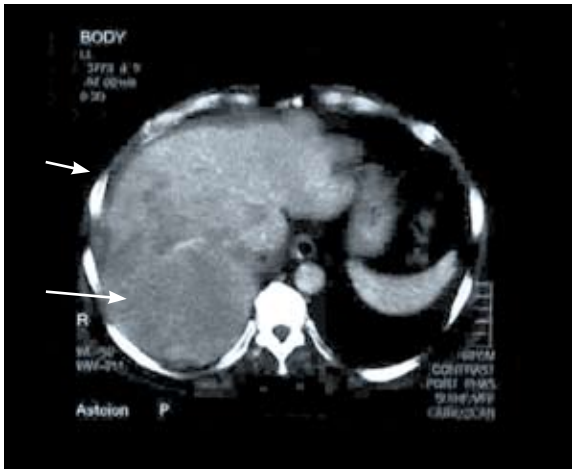
Mr. E.S. is a 68-year-old male patient known to have had hepatitis B infection and liver cirrhosis since 1995. During regular follow-up in September 2004, abdominal sonography showed a right focal hepatic lesion. Spiral computerized tomography (CT) of the abdomen, performed on September 26, 2004, revealed the presence of liver cirrhosis as well as a focal hepatic lesion in the posterior segment of the right lobe of the liver, measuring 2.1 x 2.7cm. There was evidence of portal hypertension, although the portal vein was patent, and cholecystitis associated with gall-stones. Serum alpha-fetoprotein (AFP) was 110 ng/ml (normal is up to 13.6 ng/ml). The patient underwent laparotomy on October 31, 2004, at which time three lesions were identified in hepatic segments II, III, and VIII. The lesions in segments II and III were resected and that in segment VIII was destroyed by radiofrequency ablation. Pathological examination showed features of mixed cirrhosis and hyperplastic nodule formation as well as hepatocellular carcinoma. Spiral CT of the abdomen performed two months later, on December 12, 2004, revealed that the previously ablated segment VIII hepatic lesion had been adequately ablated and now showed central necrosis and no enhancing tissue. AFP on December 11, 2004 dropped to 20 ng/ml.

The patient was followed uneventfully until March 2005, when a routine abdominal sonography revealed two new focal lesions on the right side of the liver. A spiral CT of the abdomen and measurement of AFP (151 ng/ml) confirmed the relapse. Chemo-embolization with cisplatin was undertaken on August 28, 2005.

By October 10, 2005, AFP was elevated to 610 ng/ml. Magnetic resonance imaging (MRI) of the abdomen showed no evidence of residual activity within the lesion but the patient started to complain of bone pain, especially in the thoracic region. A bone scan, performed on December 3, 2005, showed uptake of isotope in multiple osseous lesions in the right occipito-parietal region, several ribs and the upper thoracic vertebrae. The patient was given three doses of systemic single-agent doxorubicin (50 mg/m^2 every 3 weeks). CT of the abdomen and pelvis on February 15, 2006 showed no change in the right hepatic lesion. However, serial AFP measurements had shown a progressive increase in January and February, reaching 1540 ng/ml on February 13, 2006.

In view of this, a decision was made to stop doxorubicin. On July 18, 2006, the patient was started on Xeloda (an oral agent converted to 5-fluorouracil in the body) at a dose of 2 gm/m^2 for 14 days every 3 weeks. The third cycle was completed in early September 2006. Re-evaluation showed a markedly elevated AFP and CT of the abdomen and pelvis on 18 September 2006 showed an increase in the size of the right hepatic lesion and new lesions in the left lobe of the liver. The physician-in-charge decided to stop further specific therapy and to give only best supportive care. Figures 1 and 2 show disease progression observed at the time of the last follow-up in March 2007 although the patient's performance status was excellent.





Figs 1 and 2. Disease progression at the time of the last follow-up (March 2007).

COMMENT

Hepatocellular carcinoma accounts for over 650,000 deaths worldwide every year and nearly always arises in a setting of pre-existing liver damage, particularly cirrhosis, from viral hepatitis or alcohol. Only in rare patients, particularly in developing countries, is tumor sufficiently limited for complete surgical resection and a chance for cure. In appropriate settings liver transplantation may be performed. In spite of the poor prognosis in most patients, the disease can often be effectively controlled by a number of approaches, as illustrated by the present case. ■

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ST. JUDE CHILDREN'S RESEARCH HOSPITAL

Most people know of St. Jude Children's Research Hospital as one of the premier institutions in the United States for treating children with cancer. The nation's third-largest health charity, St. Jude supports cutting-edge clinical research in pediatric oncology, while accepting and treating patients without regard to the family's ability to pay. Fewer know that since 1992, under the direction of Dr. Raul Ribeiro, St. Jude has extended its compassionate reach into the international arena.

Bone marrow transplant at Calvo McKenna, Santiago, Chile.

International Outreach now has or is in the process of developing partner sites in 16 countries: Brazil, Chile, China, Costa Rica, El Salvador, Ecuador, Guatemala, Honduras, Ireland, Jordan, Lebanon, Morocco, Mexico, Russia, Syria and Venezuela.

Dr. Ribeiro, a native Brazilian, went to St. Jude on a fellowship program in the mid-1980s and then returned to practice pediatric medicine in his hometown of Curitiba. In 1990, he was invited back to St. Jude, where he helped to launch a "twinning" program that matches St. Jude doctors in the U.S. with their counterparts abroad.

"This program began with a request from a mother of a child with acute myeloid leukemia," recalls Dr. Ribeiro. "She and her husband had brought the child to St. Jude from El Salvador. She came to us and told us that her son was lucky, but that other kids in El Salvador were dying of cancer. She asked if there was anything we could do for children who could not come to the U.S."

The Board of St. Jude agreed to support a pilot program in El Salvador. Within the first three years, doctors had improved the cure rate for acute lymphoblastic leukemia (ALL) from 5% to 50%. Between January 1994 and December 1996, complete remission was achieved in 82.4% of ALL patients. "With the resources we would spend to treat one child in the U.S., we could treat 100 children in El Salvador," Dr. Ribeiro recalls. "In 1999, based on the success of this model, the Board approved the principles of the international twinning program and agreed to expand into other countries."

The main objectives, he says, are to increase the cure rate and to help the twin institution achieve sustainability. "As the program develops, we help them develop fundraising strategies, we train physicians and nurses, and we develop protocol-based therapies. We work with the community to assure that patients and their families have a place to stay, and we work with the hospital to improve infrastructure. We don't invest in buildings or buy medication. But once we have demonstrated that it is possible to cure cancer, we make alliances with the government to extend our model to other medical centers."

St. Jude's approach varies, of course, according to the geopolitical and economic situation of each country. In Nicaragua, for instance, funding may come from European sources but, in Brazil, funding is locally generated.

Dr. Pui and Dr. Ribeiro with physicians, patients and parents at Shanghai Children Medical Center.

"One reason our international programs are successful is that we require the pediatric oncologist to be fully dedicated to cancer patients. St. Jude supplements his salary, so we avoid having very well-trained oncologists treating ear infections," Dr. Ribeiro says.

For each country, St. Jude appoints one U.S.-based physician as medical director of the international pro-

gram; he is the "twin" of a physician abroad. Eight or nine other St. Jude physicians devote up to 50% of their time to the twinning program.

Three nurses are assigned to training, an administrative director helps keep order, and a volunteer coordinator helps place field workers. "About thirty percent of all college students have said they want to participate in international humanitarian volunteer work," says Ribeiro. "This is a great resource for our twinning programs."

Some twinning units have developed into training centers. Guatemala's center has matured enough to sponsor a fellowship program. Thanks to a partnership between St. Jude and Hospital Calvo McKenna, the Chilean public health system now has a bone marrow transplant unit—the cost of the transplant procedures has been paid by the government.

In Lebanon, St. Jude has partnered with the American University of Beirut to build a pediatric cancer clinic. "We're doing very well there," he says. "Fundraising from the Gulf region has been very successful, and about 100 new patients a year are being served."

In accordance with its mission, St. Jude Children's Research Hospital still accepts newly diagnosed patients from abroad to its U.S. facilities, but the twinning programs promote a local solution. "Whether a child from another country wants to come, or whether he or she is too sick to come, we try to offer an opportunity for that child. In practice, we can better fulfill our mission if we can refer them to a facility closer to their own home." ■

Marcia Landskroener for INCTR

A CERVICAL CANCER PREVENTION TRAINING FACILITY IN LIMA, PERU

Uterine cervical cancer is the first or second cause of cancer related mortality in many Latin American countries. Affecting women of reproductive age, it represents a serious public health problem. Unfortunately, there is a shortage of personnel qualified to fight against this potentially lethal but preventable disease, especially through secondary prevention (screening for early lesions). In spite of serious efforts to establish nationwide cervical cancer screening programs in many Latin American countries in the last three decades, there has not been a significant reduction in mortality. In exploring the reasons for this it has become clear that there is a great need for the education of health professionals in the management of cervical cancer in order to improve our ability to combat this disease in the region, particularly through secondary prevention.

As a result of discussions between the International Agency for Cancer Research (IARC) and the Instituto Nacional de Enfermedades Neoplasicas, in Lima, Peru (INEN), it was decided to establish a training facility that would serve Spanish speaking Latin American countries, based at INEN, a referral center for the entire country that manages 1200 new cases of cervical neoplasia per year.

The concept of a "Latin American School for Cervical Cancer" was developed in 2004 and implemented later that year, through a collaborative agreement between INEN and IARC. A training curriculum, and educational materials were completed by the end of 2004. Training is being conducted primarily at the Gynecologic Oncology Department of INEN, where classical and alternative primary and secondary prevention modalities are extensively practiced as well as surgical management of early invasive disease. The goal is to "train the trainer", promoting a "cascade effect" that would result in ever more rapid augmentation of the national capacity for the control of cervical cancer.

Dr. Carlos Santos with two of his trainees.

At this point, INCTR became an important component of this joint effort, offering not only collaboration but economic support for foreign trainees. INCTR was the link between INEN and the Instituto Oncologico del Oriente Boliviano from Santa Cruz de la Sierra, which is committed to improving its cervical cancer screening program. The first trainee from Bolivia arrived in November 2005. Five Latin American professionals have been trained since then over a period of 16 months, as follows:

Dr. Sobeyda Lopez, from Honduras, learns to use the analytic tools of colposcopy.

- Ingrid Hurtado, MD, Gynecologic oncologist from Santa Cruz Cancer Center, Bolivia; one month

- Miss Etelvina Franco, secretary from Santa Cruz Cancer Center, Bolivia, trained in Cancer Registry related procedures and documentation; one month

- Reynaldo Rocha, MD, Ob/Gyn from Hospital Municipal de Yapacani, Santa Cruz, Bolivia, in charge of the Cervical Pathology Unit; three months

- Lismar Bianco, MD, Ob/Gyn from Merida, Venezuela; three months

- Sobeyda Lopez MD, Ob/Gyn from "Enma Romero de Callejas" Cancer Center, Tegucigalpa, Honduras; three months

The "Escuela Latinoamericana de Cancer de Cervix" has conducted two colposcopy courses in partnership with The American Society for Colposcopy and Cervical Pathology (May 2005) and The Sociedad Peruana de Obstetricia y Ginecologia (February 2007), and has produced its first educational tool, an *Atlas of Colposcopy*, also the first of its kind in Peru.

The School offers courses designed for different professionals involved in cervical cancer management, from Ob/Gyns to policy makers, including non-medical health promoters and screening providers.

The School's plans for the near future are focused on expanding its training capabilities, developing alliances with specific general hospitals and reaching out to rural regions whose populations are particularly deprived and at high risk (e.g., in the Peruvian Amazonian jungle), in order to create an integrated national program. We also intend to explore the role of virtual education (distance or e-learning). Besides being a regional training center for Latin America, the School will soon serve as the main training facility of the recently launched Peruvian Uterine Cervix Cancer Control Plan under the umbrella of the National Cancer Control Plan. In this context and consistent with INCTR's interests, it will work to establish community-based clinics that will provide services for defined regions and measure outcomes, such as the increase in the proportion of women in the target population screened and the role of innovative tools such as telecytology and telecolposcopy. ■

Dr. Reynaldo Rocha, from Bolivia, studying at the Peruvian School.

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Instituto Nacional de
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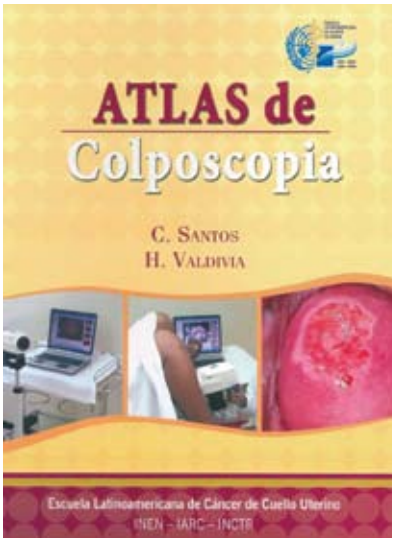
Lima, Peru

NETWORK

A NEW COLPOSCOPY ATLAS

One of the reasons of the almost uniform failure of secondary cervical cancer prevention (i.e., screening for early lesions) in the developing world, and specifically in Latin America, is the lack of trained personnel. In this regard, education appropriate for various levels of health professionals,



from those responsible for screening to highly specialized oncologists, is a priority. An essential component of this process is the availability of adequate educational material.

Colposcopic evaluation is a very important step in the investigation of women with positive cytology (ASCUS or worse), in order to confirm or exclude the presence of preinvasive disease, to rule out invasion, to determine the size and distribution of lesions, and what is more important, to guide biopsies. Information provided by colposcopy is also critical for selecting the most appropriate therapeutic modality. Although extensive educational materials relating to colposcopy already exist, most relate to the more developed world and do not address aspects of cervical pathology that are peculiar to Latin America. For example, severe cervical inflammatory diseases are common in the region, making differential diagnosis more difficult, although a recent report suggested that the mean size of CIN at the time of diagnosis is larger in Peru than in industrialized countries, making lesions, at least in theory, easier to detect. In addition, such books, and often the procedures and instruments described, are too expensive for the majority of professionals in the region.

One of the main objectives of the "Latin American School for Cervical Cancer Management", a regional training facility founded at the Instituto Nacional de Enfermedades Neoplasicas in Lima, Peru, under the sponsorship of IARC and INCTR, is the development of appropriate educational materials. With this in mind, a bank of digital colposcopic images was collected in the course of a year and used as the basis for the creation of an *Atlas of Colposcopy*, which has just been published. This is the first text of its kind in Peru and has two advantages – it includes images of pathological conditions of the uterine cervix prevalent in the region and is affordable for the vast majority of health professionals interested in colposcopy. This useful tool will contribute significantly to capacity building for the fight against cervical cancer. Additional educational tools are to be developed in the near future. ■

AGREEMENT WITH CAMEROON MINISTRY OF PUBLIC HEALTH

On April 6th a Convention between INCTR and the Minister of Public Health, Urbain Olanguena, was signed, establishing a partnership in furthering efforts to control cancer in Cameroon. A national cancer control committee (Comité National de Lutte contre le Cancer, CNLC) has already been created under the chairmanship of Professor Anderson Doh and a national cancer control plan developed. INCTR will establish a branch in Cameroon, to be directed by Dr Paul Ndom, and assist the committee in achieving specific high priority goals in the context of this plan. Particular emphasis will be given to training and education for health professionals in the areas of the early detection and treatment of cancer. ■

Signing ceremony in Yaoundé, April 6th.

ADVANCED PALLIATIVE CARE WORKSHOP IN NEPAL

A workshop on advanced palliative care took place in Kathmandu, Nepal from 10th to 16th April. The meeting was jointly organized by INCTR's Nepalese Branch, NNCTR / INCTR, and the BP Koirola Memorial Cancer Hospital, and there was active participation by INCTR's palliative care team. Representatives from 15 hospitals or hospices in the region, as well as the Nepali Ministry of Health, the Nepal Health Research Council, the Nepal Oncology Society, the Nepal Nursing Council, the SARC Oncology Society and other local organizations

attended. The workshop covered a broad range of topics including local and regional palliative care services, symptom control, psychological support, palliative care nursing, the role of radiation therapy and surgery, education and research. Local and regional organizations provided their experiences and perspectives. ■

MEETING IN VIENNA ON BREAST CANCER

INCTR staff attended a meeting in Vienna from 27 to 28th April to discuss collaboration in breast cancer treatment with members of the International Atomic Energy Agency (IAEA) Division of Human Health and representatives from many developing countries. ■

EVENTS IN TANZANIA

In the last week in May, a series of meetings and expert visits took place in Dar es Salaam, Tanzania. INCTR's palliative care team undertook a site visit at the Ocean Road Cancer Institute (ORCI) to discuss plans for developing the small existing palliative care program directed by Dr. Msemo and provide training of ORCI staff. Discussions were also held with International Atomic Energy Agency (IAEA) members regarding the integration of radiotherapy with palliative care services. An IAEA workshop on Evidence-Based Radiation Therapy, in which INCTR also took part, was held simultaneously.

On 25th May, a meeting was held with the Deputy Minister of Health of Tanzania, Dr. Twalib Ngoma, Director of ORCI, INCTR representatives and members of the IAEA PACT (Program of Action for Cancer Therapy). The purpose was to present a report on a previous imPACT mission entitled "Planning for Comprehensive Cancer Control in Tanzania" to the Deputy Minister on behalf of IAEA PACT partners (including the African Region of WHO, the American Cancer Society, INCTR and the International Agency Against Cancer) who have agreed work with colleagues in Tanzania to implement the plan. The Deputy Minister of Health accepted the plan and pledged her support, and that of the Minister of Health, with respect to its implementation. ■

THE CHRISTOPHER NIBLETT MEMORIAL FUND

The INCTR is greatly indebted to Chris Niblett, in whose name a Memorial fund was set up to raise money for the INCTR's continuing clinical trials in African Burkitt Lymphoma.

Chris was a trainee geography teacher and keen footballer, hoping to run the London Marathon for the second time, when he was diagnosed with Burkitt Lymphoma at age 25, in August 2005. Following a second recurrence, he was referred to Professor Ama Rohatiner at St Bartholomew's Hospital, London. It was through her that Chris found out about the INCTR and, more specifically, the work being done to treat patients with Burkitt Lymphoma in Africa. Chris was deeply moved by the fact that so many young children were suffering from the same illness, but in much poorer circumstances. Before Chris, sadly, died of his illness, he had planned to organize a charity football match on his recovery and, although he was not able to do so, his friends and family fulfilled this wish for him. The match was played between four teams and was refereed by ex-England international player, Gary Mabbutt.

However the fundraising has not stopped there. Since the football match, money has been raised through a whole host of events, including a night of music, a sponsored run, a guided London tour, book sales, cake sales, clothes sales, collections at all the family's respective schools (Chris's parents are both teachers) and individual donations.

Christopher Niblett (picture provided by his family).

The INCTR is very grateful for all that has been done. Remarkably, £9000 has already been raised with further events still being planned. The money is being used to buy the chemotherapy for children being treated for Burkitt Lymphoma in Nigeria and Kenya.

Chris was a warm and friendly young man with a great sense of humor, whose popularity has ensured this continuing interest in the fund. It is a fitting testament to the generosity of a young man who, though very ill himself, was able to think of others. ■

NETWORK

FAKOUS CANCER CENTER

HISTORICAL BACKGROUND

The Arab Republic of Egypt is famous for its ancient civilization and some of the world's oldest and most significant monuments and artifacts. The Nile Valley has supported human habitation for at least 5,000 years. Today, Egypt is the most populous country in the Arab world, with nearly all inhabitants concentrated along the banks of the Nile River. This means that approximately 99% of the population occupies only 5.5% of the total land area.

The Fakous Cancer Center.

In recent years, Egypt has given high priority to the provision of public health services, with an emphasis on preventive care. Yet despite the government's commitment to improve the coverage and quality of health care delivery, health facilities and staff are concentrated in urban areas, particularly Cairo and Alexandria. The National Cancer Institute in Cairo and regional cancer centers conduct most cancer control activities in Egypt.

THE INSTITUTION

The Fakous Cancer Center was established as a nonprofit rural cancer center to address a growing need for cancer medicine in the Egyptian Delta region. Before it opened in the governorate of Sharkeya, residents lacked ready access to health care and quite a large percentage of the population suffered from cancer which, consequently, had a high mortality rate, particularly among women and children. Before 1987, the only option for patients from the region was to travel to the National Cancer Institute in Cairo, 120 kilometers away, for care. Under the leadership of Sherif Omar, a professor of surgical oncology affiliated with NCI-Cairo, chairman of the medical committee in the Egyptian parliament at that time (and now chairman of education and the scientific research committee), a group of friends and patrons established a charitable foundation, The Philanthropic Medical Society, in order to create a free cancer clinic in Fakous City (pop. 667,000). The philanthropists later expanded their efforts, with the help of the Al Ahram daily newspaper, to raise the funds needed to build the first nongovernmental cancer center in Egypt.

When the free clinic opened in Fakous, doctors received more than 80 patients a day, many of whom needed surgery, postoperative care, diagnostic testing and treatment facilities that the clinic could not provide. The Philantropic Medical Society therefore agreed to try to raise funds to build a cancer center in

Item	Consultants	Specialists & Residents	Total
Surgery	7	8	15
Anesthesia & ICU	2	2	4
Radiology	3	2	5
Pathology Laboratories Chemotherapy, Radiotherapy	3	2	5
Pediatric Oncology	7	3	10
Internal Medicine	2	-	2
Urology	2	1	3

All consultants are MD and/or FRCS. All residents had Master Degree (MSc).

FCC employs 94 staff, including 45 physicians, 32 nurses and 17 technicians.

Fakous City and, within a year, the foundation had raised more than $1 million USD. Of that sum, more than half was earmarked for medical equipment.

In 1990, the Fakous Cancer Center was erected on the site of an old cattle market covering 1,000 square meters on a piece of land totaling an acre in size. The idea for the new facility was to integrate tertiary services with the primary health care facilities, and consideration was given to the physical, social and spiritual needs of the patients. The surrounding gardens and an aviary bring a sense of peace and serenity to the medical facility, which admits about 100 patients a month.

The hospital's administration also fulfills an important role in the social fabric of the community, offering jobs and job training to men and women alike. The facility employs 247 persons, including 94 medical staff, and is sensitive to gender issues that often marginalize the women of Egypt. When cancer devastates a family and leaves orphaned children, FCC steps in to help provide for them; more than 1,200 orphans of cancer fatalities have been assisted thus far.

In 2006, FCC embraced the UICC's World Cancer Campaign initiative, "My Child Matters," working to detect, diagnose and treat children with cancer among the population of eight villages and slum areas in central Fakous. All pediatric patients receive required laboratory tests and medications free of charge. Other outreach projects focus on creating awareness about childhood cancer and breast cancer through public and professional education. FCC has trained 45 "pioneer" social workers to conduct home visits. The initiative has reached 10,000 women in the area. In February 2007, FCC sponsored its first professional training program, addressing 45 primary health care physicians on the importance of early detection.

Today, the 52-bed Fakous Cancer Center collaborates with a number of national and international organizations, including INCTR. With many of its physicians trained at NCI-Cairo, and with an efficient cancer registry in place, FCC has become recognized as a research center capable of participating in national initiatives pertaining to cancer control. ■

Dr. Sherif Omar, founder and chairman of the Board of Fakous Cancer Center, contributed to this article, prepared by Marcia Landskroener for INCTR.

UNITS

Radiotherapy
Radiodiagnosis
Pediatric Oncology
Histopathology
Clinical Pathology Laboratory
Dialysis – five machines
Lectures and Seminars Hall
Rehabilitation/Pain Clinic
Data Registry

RESOURCES

Total Beds	52
Cobalt Radiotherapy units (2D Planning System)	1
Rehabilitation/Pain Clinic	
Data Registry	

PATIENTS SEEN

New cancer patients (2005)	986
Pediatric cancer patients (2005)	22
Total outpatients (2005)	16,815

TRAINING WORKSHOPS

- Organization of Congresses
- Health Management in non-governmental organizations
- Quality control in health services
- Management of health projects
- Institutional evaluation and capacity building
- Result-based management and information systems
- Customized quality management

CURRICULUM OF PHYSICIAN TRAINING

- Leukemia
- Lymphoma
- Solid tumors
- BMT
- Palliative treatment and pain management
- Blood products
- Oncological Emergencies
- Statistics, epidemiology, genetics
- Management Guidelines and supportive care

Nearly sixty percent of the 250 persons employed at the FCC are women.

PROFILES IN CANCER MEDICINE

UNVEILING BREAST CANCER

Dr. Salwa Boulos is leading a grassroots effort to educate the women of Cairo about breast health. Since 2000, Boulos, the sole breast radiologist at the Italian Hospital in Cairo qualified to read mammography film, has been sending teams of social health educators into areas of the city in a door-to-door campaign to improve women's chances of detecting and surviving breast cancer. In the first year of the pilot project, more than 4,000 women between the ages of 35 and 65 were invited to participate in the study, designed to evaluate the role of clinical breast examination as a primary screening modality. Under the auspices of the Ministry of Health and Population in Cairo, the study confirms that breast screening detects a high rate of breast cancer—about 8 per 1,000 at the first examination and 2 per 1,000 among those who appeared for re-screening. The second phase of the study is now underway, bringing to 15,000 the number of women contacted.

Dr. Boulos studied medicine at the University of Cairo and did post-graduate work in mammography in Milan. When her cousin was misdiagnosed and died of breast cancer at age 44, Dr. Boulos was determined to focus her energy on a disease little regarded in a male-dominated culture. As a female physician, Dr. Boulos was able to gain the trust of her patients, teaching them to perform self-examinations and, if indicated, to undergo mammography and treatment.

Her clinic has the financial support of the wife of the former Italian Ambassador to Egypt, Vittoria Aloisi de Larderel, who was impressed that Dr. Boulos was pioneering breast cancer detection and treatment in that country.

Dr. Salwa Boulos is training physicians devoted to women's breast health.

"She wanted to do something for Egypt," Dr. Boulos says, "so we developed this project that trains social health workers and young doctors to screen women for breast cancer." If the woman has a lump or a family history of breast cancer, she is referred to Dr. Boulos's clinic for further evaluation and treatment. The program operates under the umbrella of Challenge, an organization established by the European School of Oncology (ESO) with whom INCTR is establishing a collaborative program, and Mrs. Aloisi who, together with ESO, covers the entire cost of screening, diagnosis and treatment.

"We are beginning to see higher levels of cooperation among our target population, with respect to annual visits and taking tamoxifen, an important part of the follow-up care regimen, and we are starting to get some support from local businesses," says Dr. Boulos, who is helping to transfer this program to Yemen, Sudan and soon, to Lebanon, by training doctors and social workers from those countries in breast examination, needle and core biopsy, and the proper use of instrumentation. "One of the fruitful things is the Euro-Arab School of Oncology, established last year in Cairo in collaboration with ESO," she says. "Because we share language and culture, we can more easily train the next generation of doctors and technicians to work with the resources we have."

Scarcity of resources and rampant illiteracy are on her list of challenges, but her biggest obstacle, she says, is a male-dominated society that hinders diagnosis and treatment for its women.

"I lost a wonderful patient because her husband wouldn't let her be treated," Dr. Boulos recalls. "When she was finally brought to me and she took off her veil, I could see the cancer had metastasized up to her neck. It was too late to save her. She died."

Dr. Boulos also struggles to explain complicated medical procedures to the illiterate. "Many don't understand the difference between biopsy and surgery. One young patient couldn't quite grasp how she woke up with a reconstructed breast."

Still, she fights the good fight and dreams of a not-too-distant day when her clinic works hand-in-hand with the Egyptian government, the Minister of Health and the National Cancer Institute to enhance women's health. ■

Marcia Landskroener for INCTR