

# NETWORK

THE NEWSLETTER OF THE INTERNATIONAL NETWORK FOR CANCER TREATMENT AND RESEARCH



**Volume 6, Number 1, Summer 2005** — **Inside:** ARTICLE: Issues of the Stigma of Cancer - **8** - CASE REPORT: Cultural Aspects of Smokeless Tobacco Use and the Impact of Chewing Pan Masala in the Oral Cancer Scenario - **11** - FORUM: SOCHIMIO: People United Against Cancer in Cameroon - **15** - NEWS - **16** PARTNER PROFILE - **18** - PROFILES IN CANCER MEDICINE - **20**

## THE PRESIDENT'S MESSAGE

### LANGUAGE AND CANCER

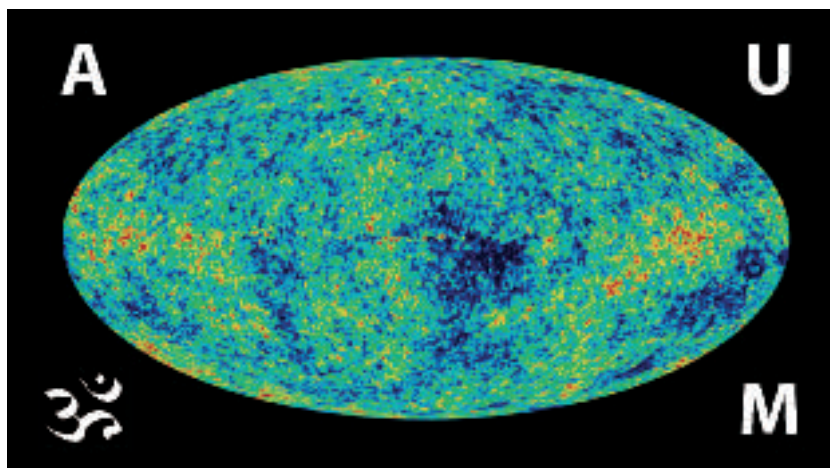
Part 1. Syntax and Semantics

by Ian Magrath

*You can make the sound of two hands clapping. Now what is the sound of one hand? Zen koan.*

*What cannot be heard by the ear, but by which the ear is able to hear - know That alone as Brahman and not this which people worship here. Kenopanishad.*

Most cosmologists believe that the potential universe, i.e., that which existed in the first  $10^{-43}$  seconds (Planck time, the smallest possible unit of time) cannot be known, but probably consisted of pure, undifferentiated energy at an extremely high temperature. Having no mass it could have no dimensions, and being one, its symmetry was perfect. Ancient Hindu philosophers reached a similar conclusion, if articulated in different words: Brahman (all of existence) was initially unmanifest. Being unmanifest, i.e., prior to spacetime, it was both incomprehensible and totipotential. The Upanishads (philo-



**Projection of the whole sky showing minute temperature fluctuations in the microwave background radiation as detected by the Wilkinson Microwave Anisotropy probe (WMAP) mission. Red spots are warmer, blue, colder. The satellite observatory reached its orbital position in October 2001. This map was released in February 2003. The inhomogeneity in the early universe is believed to have been the source of the cosmic structure we see today. Image: NASA/WMAP Science Team. AUM is shown in the bottom left corner.**

sophical explanations of the Vedas, the earliest sacred Hindu literature) recount how Brahman became manifest as a primordial vibration, Om or AUM (O, in Sanskrit is equivalent to the diphthong AU). Physicists have postulated that at the instant of manifestation ( $10^{-43}$  seconds), the perfect symmetry was broken by the separation of gravity from the exceed-

ingly hot universe. Further breaks in symmetry occurred as the universe rapidly expanded - perhaps, for a fleeting instant (known as inflation), faster than the speed of light. Such expansion was necessarily accompanied, according to the laws of physics, by rapid simultaneous cooling. Within a mere  $10^{-12}$  seconds (a thousand billionth of a second) the temperature

# NETWORK

had dropped to  $10^{15}$  Kelvin (K), allowing the emergence of the trinity of the three fundamental forces that, in the presence of the attractive gravitational force, led to the creation of matter. First, the *strong nuclear force* and the *electroweak* forces emerged, then the electroweak force separated into *electromagnetism* and the *weak nuclear force*. AUM is also a trinity. The Sanskrit letters Au, Uu and Mm represent the three elements of Brahman: Brahma, the creator, Vishnu, the preserver and Shiva the destroyer. The insights of the Hindu rishis (seers) who composed the ancient literature bear a remarkable resemblance to the law of conservation of energy and matter - everything that exists (implying preservation for a finite time-span) was created by the destruction (transformation) of something else.

The three elements of AUM are also known as *Satchitananda*: pure being (*Sat*), pure consciousness (*chit*) and pure bliss (*ananda*). Being is

that which is; bliss is not unlike the physicist's *symmetry*, but consciousness remains unexplained by modern science. However, quantum mechanical theory predicts that the quantum states of elementary particles or photons created simultaneously remain forever linked (*entangled*) such that the measurement of the quantum state of one will *instantaneously* determine the corresponding quantum state of the other no matter how separated the particles may be in spacetime. This has been confirmed in numerous experiments. Since all particles were entangled at the beginning of time, quantum mechanics is a non-local theory - i.e., it invokes a universal *awareness*, albeit, in everyday life the interactions of countless elementary particles mask their original coherence. In yet another remarkable parallel to modern science, the Upanishads describe individual souls, or *Jivatman*, as being fragments of the one great soul, or *Paramatman*.

The symbol for Om contains three curves (see picture), representing the three states of human consciousness: wakeful awareness of the universe, dreaming, or observing the universe from within, and deep sleep, in which the universe is fully absorbed into the mind, thereby eliminating all desire and creating a state of bliss. A semi-circle, representing *maya*, the illusion that lies between us and perfect understanding, separates the three curves of human consciousness from a dot, representing absolute consciousness. Absolute consciousness is seen to illuminate the other conscious states, but to achieve enlightenment (*moksha*), the Hindu adept must penetrate the veil of maya. In the world of modern science, physicists continue to pursue Einstein's goal of a uni-

fied theory able to definitively link gravity - a force which, his theory of general relativity states, derives from the large-scale structure of spacetime - to the remaining three quantum mechanical forces, which operate at the smallest possible scale (at which gravity has no impact). A unified theory - the physicist's Om - remains elusive, at least in mathematical terms, but the critical role of gravity (the only fundamental force which acts on all energy and matter) in the creation of the stars, the elements and, ultimately, life and human consciousness, provides a context in which the other three forces become meaningful. Om, then, might be seen as a qualitative representation of the concepts that physicists attempt to express in numerical terms in striving to lift the veil of maya separating them from a unified theory. Perhaps too, such a theory would also explain the phenomenon of entanglement, which is, after all, a form of universal consciousness. Such comparisons of science and eastern religious philosophy might seem spurious or contrived, but however different in outer guise, these two pathways are directed towards the same goal - that of reaching an understanding of the most fundamental question of all - the nature of being.

## A MANTRA MANIFEST

In 1900, Max Planck, in the course of his fundamental work on thermodynamics, developed an equation that fit well with experimental observation of the electromagnetic energy spectra emitted by *black bodies* at constant temperature (black bodies absorb all incident radiation and emit radiation in proportion to their temperature). Planck demonstrated that the total emitted energy, when

The logo for INCTR, with 'IN' in blue and 'CTR' in black.

### EDITORIAL STAFF

Ian Magrath, Editor

Marcia Landskroener, Managing Editor

Bénédicte Chaidron, Assistant Editor

Sophie Lebedoff, Tractor, Lay-out

### ADDRESS CORRESPONDENCE TO:

INCTR at the Institut Pasteur

Rue Engeland 642

1180 Brussels • Belgium

+32 2 373 93 23 • bene@inctr.be

www.inctr.org or to

NETWORK: INCTR Newsletter

c/o Marcia Landskroener

3817 McGinnes Road

Millington, Maryland 21651 USA

mlandskroener2@washcoll.edu

*The views of the authors expressed herein are their own and are not necessarily shared by INCTR.*

*All patients' photographs are published with their consent.*

# PRESIDENT'S MESSAGE

divided into equal portions, or *quantized*, in accordance with a constant,  $h$ , is proportional to the frequency of the radiation. The concept of quanta of energy was subsequently transformed by Einstein and others into the branch of physics now known as quantum mechanics. Almost 50 years after Planck formulated his equation, George Gamow (in 1948) predicted that if the universe had originated from a superhot point (a singularity) some 14 to 15 billion years ago, it ought to contain background radiation of the type emitted by a perfect black body. In 1963, while using an ultra-low background (cryogenic) radioantenna to probe the Milky Way at microwave frequency, Arno Penzias and Robert Woodrow Wilson unexpectedly detected low-level radiation that was the same in all directions. Initially interpreted as a technical malfunction, the "static" was subsequently identified as the *cosmic microwave background* (CMB) whose presence had been predicted by Gamow. Its energy spectrum was shown to fit precisely (the most exact fit ever observed) with the radiation spectrum of a black body predicted by Planck's formula at the observed temperature of 2.73K. The CMB is believed to have originated from the universe as it was some 300-400,000 years after its origin, by which time its temperature had cooled sufficiently (to 3000K) for electrons to associate with protons, forming hydrogen (and small amounts of lithium, deuterium and helium) and, in the process, drastically reducing the scatter of electromagnetic radiation. In effect, the universe became transparent in the process of creating the seed material from which galaxies of stars would subsequently form under the influence of gravity. The all-pervading

vibration of the CMB is seen to be a mantra manifest; Om, continuously chanted by the Universe itself, pointing towards its origins eons before. In the words of the Mundakopanishad, pointing the arrow of human consciousness, through meditation, to "that which is brilliant, smaller than small, that on which all worlds are founded and their inhabitants." To chant the word, or perhaps to experience the deep hum of the CMB vibrations converted into sound or light, is to be at one with the Universe. AUM, when uttered, begins at the throat, moves to the middle of the mouth, and ends at the lips. Hence, it is also considered to be the basis of all words, and of the sacred Sanskrit language in which the ritual hymns and prayers that comprise the Vedas were composed. All languages can, similarly, be traced back to the events that took place in the primordial universe some 14 or 15 billion years ago, to which the CMB bears witness.

## THE DANCE OF LANGUAGE

Human language in its broadest sense is a remarkable system of symbols, including gestures, sounds, and marks, made on almost any surface that are able to convey information, i.e., to represent a broad range of concepts and thoughts. Such concepts include everything we perceive around us, directly or indirectly, and the changes, or movements, that such "things" continuously undergo. Movement and change are fundamental aspects of language, which represents the dynamic world we live in and which itself is constantly changing. Change, the essence of being, was powerfully symbolized by Hindu philosophers in *Shiva Nataraja*, an image, usually in stone or bronze, that depicts Shiva performing the

cosmic dance of destruction and creation. Shiva Nataraja conveys the same meaning as that of the sacred syllable, AUM, and thus also represents the essence of language, which is movement. Speech begins with the movements of molecules within neurons - the material basis of the thoughts that language conveys. The resultant electrical impulses are transmitted via chemical "neurotransmitters" across synaptic junctions to the motor end plates, where they are converted into the complex dance

**Successful cancer control requires understanding of the syntax and semantics of target communities.**

of the numerous muscles needed to produce speech. The respiratory and laryngeal muscles cause the vocal cords to vibrate, producing a corresponding vibration in the column of air passing over them. The vibrating column of air is shaped by coordinated movements of the muscles of the pharynx, soft palate, mouth, tongue and lips. Consonants are created by constriction or closure of the vibrating air column somewhere in the vocal tract, resulting in an audible turbulence that begins and sometimes ends syllables, the central part of which is comprised of vowel sounds. The resultant sound units (*phonemes*) are combined and recombined to create syllables, words and sentences in a specific language. Only a small fraction of the sounds that can be made, and an even smaller fraction of their possible combinations, constitute meaningful speech. Voiced (and unvoiced) sounds are generally accompanied

# NETWORK

by movements of other parts of the face (e.g., eyebrows), as well as the hands, arms and even the entire body (body language) - movements that enhance meaning through the provision of emotional content. Pitch or intonation (part of the music of language), often in conjunction with special words such as amplifiers, interjections and expletives, are also used to add emotional content and in some languages (tonal languages), such as the variants of Chinese, Thai and Vietnamese, to distinguish different words. Intonation provides too, the approximate equivalent of punctuation. Speech and its graphic representation can be readily converted into other kinds of vibrations, such as electromagnetic waves, for propagation beyond the range of audibility - even beyond the planet.

The most fundamental classes of words are *nouns*, which designate "things", and *verbs*, which refer to the existence of such "things" and to their relationships and interactions in spacetime. Nouns and verbs may be considered, respectively, as the higher order equivalents of matter and energy, although nouns can represent much more than material objects, being also used to symbolize places, events and non-material "things" such as thoughts - even the fundamental forces! However, to the human mind, naming something (nouns are, in essence, the names of things) confers a material or quasi-material existence upon it, creating mental boundaries, however imprecise or even illusory they may be, for the thing named (e.g., chair, box, electron). Verbs relate to the changes that occur in "things" or to the visible actions that cause change rather than the underlying agents of change. Like matter and energy, which are

interconvertible, nouns and verbs blend into each other; whether a word is perceived as a noun or verb depends as much on the function it serves in a sentence as upon its own structure. Specific categories of actions (dancing, reading, etc.) are treated as nouns, while many nouns can be used as verbs (e.g., he *papered* over the cracks; she agreed to *chair* the meeting), although these details vary among languages. Many other parts of speech, whether words or phrases, can be used to create, modify or enhance meaning through the coupling of meaning units (*morphemes*), or the addition of descriptive elements.

## THE EVOLUTION OF LANGUAGES

Once a basic stock of words exists, new words and meanings can be created by the same processes that apply equally to atoms, molecules, genes, cells, objects and ideas - transformation and recombination. One form of transformation occurs when a word or phrase with a very specific meaning in the material world is used in a figurative or metaphorical sense (e.g., family *tree*, *high* spirits, *small* minded). Another is when the range of meanings of a word moves into a related but different realm. For example, the adjective *nice*, derived from the Latin word, *nescius*, meaning *ignorant*, has progressed in the course of its 700 years in the English language (which it entered via old French) from its initial sense of *foolish*, through *timid*, *fussy*, *fastidious*, *delicate*, *precise* and *delightful*, to its present most frequent meanings of *charming*, *tasty* or *subtle*, with occasional references to an earlier sense. The meaning of words often varies with context (e.g., *a nice shot*, *a nice person*, *a nice dis-*

*inction*), and composite words create new concepts often seemingly unrelated to the meanings of their constituent parts (e.g., *anteater*, *television*, *hardship*, *overcome*, *understand*), although some word elements (prefixes for example) - may have a relatively uniform influence on meaning (e.g., *belittle*, *bewitched*, *contemporary*, *concomitant*).

The richness of language has been greatly enhanced by the evolution of new languages through a process of variant pronunciation (*dialect*) analogous to genetic mutation. When populations are geographically separated, this may extend to the point of mutual unintelligibility - a process similar to the evolution of species, the hallmark of which is reproductive isolation. When previously separate populations come into contact again, there are many opportunities to borrow words - either complete with meaning, or to use in a different sense, often related; but in either case to expand the range of concepts that can be expressed. This horizontal cross-fertilization parallels the close cooperation that occurs among species in an ecosystem. The use of everyday Greek and Latin words in the creation of scientific terminology is a particularly dramatic example, but many modern languages, such as Urdu and Swahili, are comprised of words derived from several languages. English has also been greatly enriched by loan words. Syntactically a Germanic language, it is estimated that words from its original language family, Old English, Middle English, Old Norse and Dutch, account for only 25% of its vocabulary. More than half its vocabulary is of Latin (28%) or French (28%) origin and 5% from Greek (place names, other languages and words of unknown origin account for the rest).

# PRESIDENT'S MESSAGE

Languages contain specialized domains that have their own terminology and sometimes variant syntax, such that they are not accessible to all speakers - for example, legal, religious, literary or other domains. Mathematics is a special case, since its symbols have become essentially universal - i.e., have transcended language barriers. It comprises a set of words that symbolize numbers, the operations to which they can be subjected and the rules that govern such operations. Numerical description allows various characteristics such as size, distance, speed, frequency, intensity, even direction, to be expressed quantitatively and inter-relationships to be represented graphically (Figure 1), or, in the case of locations, *mapped*, i.e., plotted in correct spacial relationship on a two-dimensional surface. Maps can be used to indicate a broad

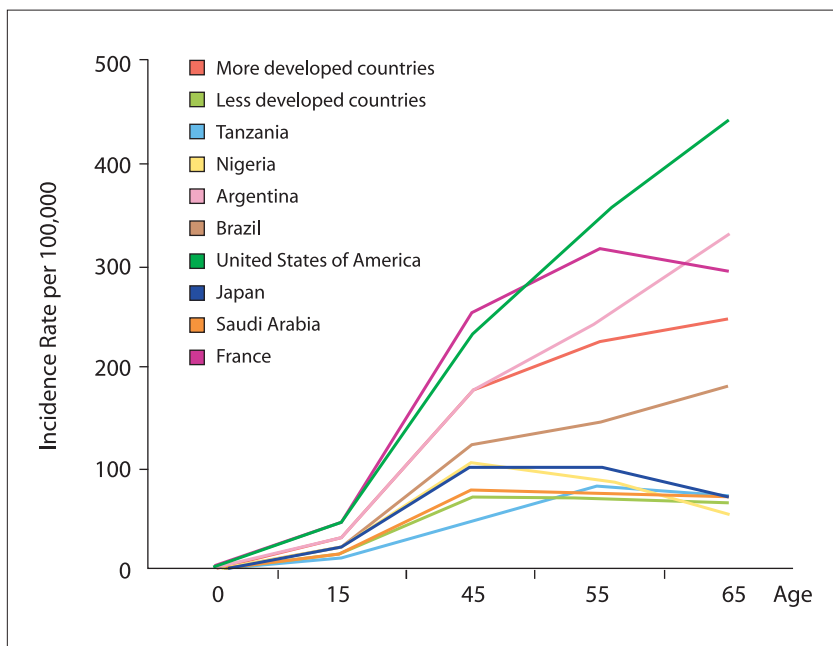
range of geographical relationships - including the distribution of diseases, such as cancer (Figure 2). The verb "map" is also used to express the relocation of non-geographical locations to other locations. Relationships, including rates of change, can be analyzed through the use of abstract or generalized numbers represented by letters (algebra) and even logical arguments can be expressed numerically. Remarkably, advanced mathematical techniques have permitted profound statements about the universe - such as the relationship between gravity and the structure of spacetime - to be concisely expressed as a small group of symbols.

Communication, of course, is not confined to human language, and similar principles governing effective communication can be seen at all levels of being. Gravity itself, to which

all matter and energy is subject, may be the most fundamental form of communication in the universe: its attractive force is ultimately responsible for the continuous creation of the elements. Life is dependent upon complex interdigitating molecular pathways in cells, intercellular communication and at the most complex levels, interactions among species in ecosystems and individuals in communities. Human language can be seen to be a further development of the host of communication systems in animals, plants and fungi, at molecular, cellular or organism levels. A crucial evolutionary step towards this higher level system of communication was the emergence of nervous systems of sufficient complexity to allow deliberation. Existing systems of communication could then be adapted to the sharing of thoughts - an ability that greatly enhances the possibility of concerted effort, resulting in improved efficiency in everyday activities, as well as the ability to capitalize on rare, but potentially immensely valuable ideas that might occur in only one brain in the course of many centuries. Such momentous thoughts, like novel metabolic processes (photosynthesis or aerobic respiration), could have an enormous impact on survival and once "captured" - i.e., disseminated to many individuals - can be further developed, sometimes in the course of millennia.

## SYNTAX AND SEMANTICS

Language is seen to be an extraordinarily flexible tool which takes the possibilities inherent in social behavior a quantum leap forward. But in order to create meaning, the symbolic elements of language must be combined according to specific



**Figure 1. Graphic representation of breast cancer incidence rates in different age groups. There appears to be a disproportionately low incidence in women above the age of 45 in less developed countries as well as Japan. One possible explanation is that there are different risk factors for pre- and post-menopausal breast cancer. Graph created with Globocan 2002.**



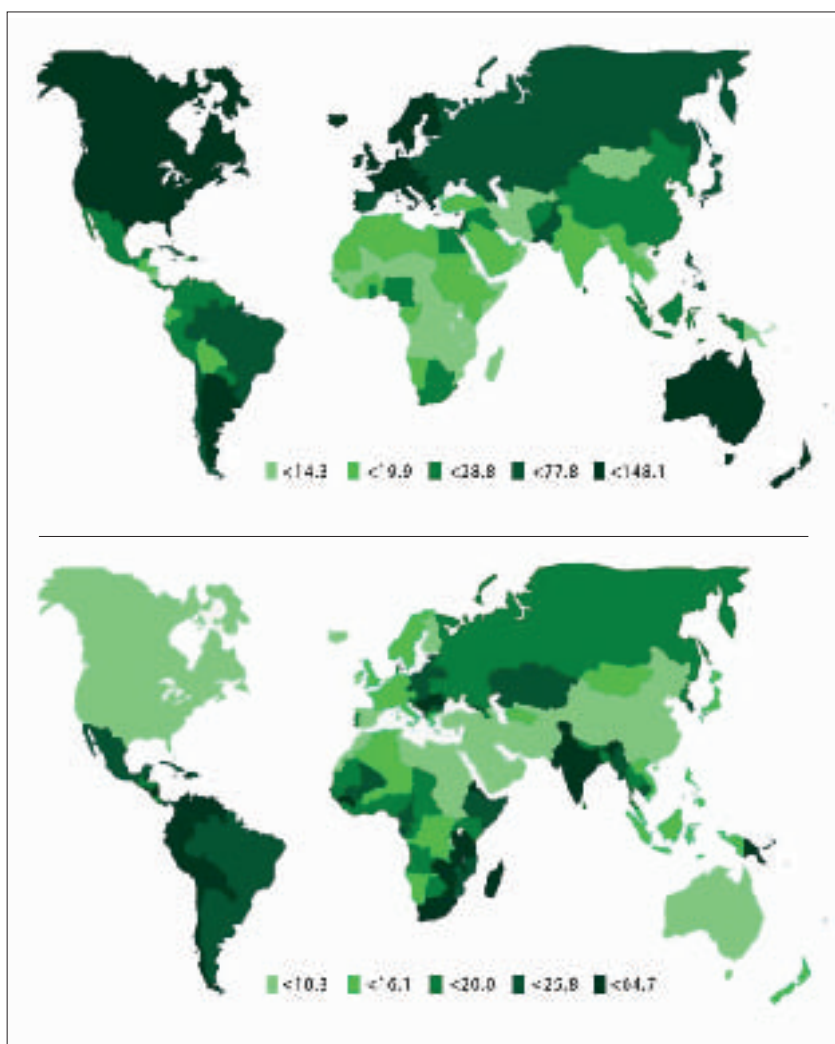
# NETWORK

rules. This is not unique to language - nothing can effectively function in the absence of relevant structure. In human language, the classification of words into categories (*taxons*) and the grammatical rules that govern their meaningful sequential arrangement is known as syntax (*syn* Gk. = with or together). The basic rules of syntax

and its relationship to semantics are almost certainly genetically encoded and must have emerged with the genetic changes associated with the physical ability to speak. The details, however, including the symbols used for words (or more precisely, *lexemes*, the smallest unit of structure) and the precise way in which parts of speech

are meaningfully combined, was left to the interaction of the newly developed nervous system with the world in which it found itself - hence the thousands of existing languages and, doubtless, millions of extinct languages. The existence of a "hard coded" *universal grammar* means that any healthy child is capable of learning the language or languages to which he or she is exposed, while persons sufficiently fluent in multiple language are able to translate from one to another - i.e., to use other words and syntax to convey the same meaning. Perhaps "culture" - the syntax and semantics of communities - is derived from a similar but more general set of universal rules. If so, there may be no better time than childhood to instill healthy patterns of behavior, which may persist throughout life and significantly impact upon the incidence of many diseases, including cancer.

*Semantics*, the study of meaning in the context of language, is derived from the Greek for "significant meaning" (*semantikos*); *sema* means a sign. Complex meaning is built up by combining words (or more precisely, *morphemes*) in a grammatically correct manner. Meaning can be destroyed completely, or modified, by errors or changes in individual words or in the syntax of strings of words. But correct syntax does not guarantee precise meaning, for meaning is context-sensitive (as exemplified by example of "nice," above). Even syntactically correct sentences may contain no meaning, or contradictory meaning (as, for example, in the sentence "this statement is false") or may be nullified by succeeding sentences. Achieving the highest precision in meaning, or "constructing" the intent of existing laws, accounts for much of legal practice. And since languages and culture undergo continu-



**Figure 2.** Map showing geographical variations in the crude incidence of breast cancer, A, and cancer of the uterine cervix, B. Higher incidence is indicated by darker green. The map tells us that, overall, the incidence of both cancers varies with socioeconomic status, but in opposite directions. The incidence of breast cancer increases, while that of cervical cancer decreases, with socioeconomic status. This phenomenon can also be seen in different socioeconomic groups within countries. This raises a series of questions relating to "why." Maps created with Globocan 2002.

# PRESIDENT'S MESSAGE

ous change, the meaning of ancient law, or lore, may, with time, become increasingly imprecise and open to interpretation - a problem compounded by the specialized language included in sacred texts or legal documents. These problems apply within a culture or language; how much more likely is misunderstanding among different cultures with different languages? These issues loom larger as the world becomes increasingly connected through efficient transportation and electronic systems. Unfortunately, a large fraction of humanity is left out of this process, and major efforts will be required if the less integrated members of national and international societies are not to be considered "alien" - the "default" setting derived from instinct. Those interested in cancer control (whether national or international) must recognize that the most meaningful interventions are likely to be associated with efforts to understand the syntax and semantics of the target communities.

## CANCER IN CONTEXT

Cancer is a set of diseases in which the progeny of a "founder" cell behave inappropriately - i.e., continuously multiply, fail to die, and encroach upon forbidden territory. It derives ultimately from the malfunctioning of specific molecular pathways consequent upon misinformation derived from the cell genome. Such misinformation results from damage to the cell genome, the likelihood of which depends upon the context - i.e., the genetic background and the lifestyle and environment of the individual. The syntax of the language of life, spelled out in the genomes of living organisms, must be protected from corruption in order to preserve its semantics. Cancer is more likely to occur when the molecular

**Table 1. Some of the levels at which genetic factors may influence the impact of environmental carcinogens<sup>1</sup>.**

| LEVEL OF PROTECTION                        | GENETIC FACTORS   |
|--|---|
| Behavior <sup>2</sup>                      | Acquisition of culture, language, character, intelligence |
| Absorption                                 | Efficiency of absorption                                  |
| Liver metabolism (detoxification)          | Efficiency of detoxification                              |
| Intracellular processing in "target" cells | Intracellular metabolism                                  |
| Neutralization of free radicals            | Concentration of protective molecules                     |
| Repair of DNA (genetic) damage             | Efficiency of excision-repair enzymes                     |

(1) Exposure is heavily influenced by legislation, concentration of the carcinogen in the individual's environment (occupation, lifestyle), protective measures actually taken (influenced by learned behavior and literacy, personality, available safety measures etc.), and cumulative duration of exposure.  
 (2) Behavior is heavily influenced by community structure, family, environment and education.

pathways which protect the whole individual, the tissues and organs and the information encoded in the genome itself, are either intrinsically less efficient or, in the case of target cells, damaged through the actions of environmental agents (Table 1). At the level of society, context derives from the political structure and accumulated legislation as well as numerous other cultural elements, including religion and lifestyle (which varies greatly, even within the same society). All of these elements, which are heavily dependent upon language, are relevant to cancer, and may influence the likelihood of exposure to cancer risk factors, the time to diagnosis, access to effective anti-cancer therapy, follow-up and palliative care.

The advent of writing and electronic communication, particularly the World-Wide Web, have permitted enormous amplification of the possibilities inherent in language, bringing ideas to an ever more extended community where they can be modified or developed to the benefit of all. At the same time, however, the for-

mer cultural system of discrete tribal units has largely given way to complex multinational, multicultural and multilingual communities, creating a crisis of allegiance and issues of hegemony at national and global levels. In the modern era it is easier for communities to share ideas and build upon them in domains in which the intellectual component still outweighs issues of power, influence and economics. These include the arts, science and medicine. It is essential that the ideas inherent in these domains are protected and nurtured by their advocates, just as the genome protects its own integrity without stifling its evolution. For these are ideas of great majesty and beauty whose origins reach back to the beginning of time, a beginning invoked by the sacred syllable AUM and its scientific counterpart, the CMB. And just as their origins and existence are in language, so too is their preservation dependent upon language - as indeed, is that of the human race itself. ■

Part II. Reading the Signs will follow.

# NETWORK

## ISSUES OF THE STIGMA OF CANCER

As we are aware, humans are gregarious beings, actively shaping the evolvement of the social and physical environment, mapping out behaviors observed, making varying interpretations of their lives and communicating these ideas through communities. All this encompasses a society's culture (Swain et al., 1993). Any deviation from the norm is a sign of potential marginalization from mainstream society. Cancer poses a threat to social inclusion, thereby creating a stigma and leading to stereotyping.

As Hunt (1998) states: *An impaired or deformed body is a difference that hits everyone hard at first. Inevitably it produces an instinctive revulsion, has a disturbing effect. Our own first reaction to this is to want to hide ourselves, to attempt to buy acceptance on any terms, to agree uncritically with whatever is the done thing.*

Cancer is considered a personal tragedy. Especially so in breast cancer where (according to Hahn, 1986): *...widespread aversion towards women with breast cancer may be the product of both aesthetic anxiety, which rejects marked deviations from "normal" physical appearances, and of an "existential" anxiety which may find a projected risk of rejection* (Hahn, 1986, p. 125). Is this inclusion or exclusion?

### STIGMA THEORY BY GOFFMAN

According to Watson (2003), impaired people are marginalized by virtue of their impaired body. Social interaction is a combination of environmental behavior, people-to-people encounters, the media and one's own thoughts. A person's

physical appearance allows society to categorize him or her. Goffman (1968) terms this a social identity. "Normality" is an assumption conceptualized by society. People with a physical impairment are considered to be unable to achieve full humanness. By definition, stigma dehumanizes the person, therefore creating discrimination and hence reducing their opportunities in life.

The person living with cancer has to make extra effort to justify her status as an ordinary, human and worthy individual, but the reaction of society may dispute this struggle through an unconscious act of exclusion.

### MYSTIFYING CANCER

For many with cancer, marginalization or rejection is disastrous. It causes despair and seclusion, which in turn widen the gap and produce further rejection and stereotyping. One becomes literally alienated by the social attitudes encountered daily. Such prejudice and discrimination can be initiated by cancer survivors themselves. Demystification of the concept of being victims in the eyes of society can help to show that cancer is just another disease, and that one can bounce back to living again after treatment is completed. It can be difficult to form a constructive relationship if cancer survivors are bitter and hostile to the surrounding community. If the social environment is oppressive and characterizes patients with cancer as victims, then inevitably that is the way cancer survivors see themselves. If the answer lies in the survivor changing his or her own mindset, then they must discover the mechanisms by which an inner source of strength and

support from peers and loved ones can be rediscovered. Rebuilding self-esteem in an environment that continues to be prejudiced can be a challenging task. It is essential to undergo transformation from victim to survivor.

### THE CHINESE CULTURE AND CANCER

The Chinese largely view illness as a punishment for sins committed in a past life by the ill person or the person's parents. Therefore, they visit temples or Taoist priests to pray, to perform rituals to ascertain the cause of their ill health and to find solutions to their problems. (Liu, 2005).

Guilt and fear are generally present in the person with cancer and the family, in part due to misunderstanding and a lack of knowledge. The stigma attached to the condition generates fear of being exposed to criticism and disgrace.

Some myths about cancer cause social isolation of the person with cancer within the household. Utensils, clothing and other belongings of the cancer survivor are frequently separated from those of other family members. Younger children are not told that daddy or mummy has cancer thinking that they are "sparing the children from agony" not realizing that this action contributes to the child's fears. Women with cancer tend to avoid physical contact (such as hugging) with their child, believing that the child, as a consequence, will not miss his/her mother when she dies. One woman was proud to reveal to her doctor that she had kept her cancer at bay by not having any sexual contact with her husband for the past 10 years.



## THE SOUTH ASIAN CULTURE AND CANCER

The South Asians believe that life-threatening disease or a disability is caused by the sins committed by parents, ancestors or extended family members, or by the patient in a previous life. In some communities it is believed that the mother committed the sin during pregnancy (Sotnik & Hasnain, 1998).

Being resigned to the belief that it is *Karma* (destiny, based on one's actions), or God's will, or even that the person is cursed with cancer, is a frequent way in which South Asian communities deal with the social impact of the disease.

Traditional Tamilian and Ceylonese Tamil communities are fearful of revealing whether a woman has cancer. Matrimonial prospects for their daughters and sisters are reduced. Hence the woman with cancer is blamed for being the bearer of the 'dreaded disease' into the family.

Muslim women fear that their husbands may take additional wives or divorce and remarry, the traditional belief being that a woman with cancer is unable to perform wifely duties.

## THE CANCER LANGUAGE

Language can be very powerful. Social stigmata associated with cancer are so deeply engrained that derogatory terms are commonly used without taking into consideration the psychological impact it can cause on a cancer survivor. Remarks such as *"This problem is spreading like cancer"* can be rather disturbing for those of us who are living with cancer.

## INSURANCE COVERAGE

Insurance companies (in circum-

stances where health insurance exists) leave people with cancer in the lurch as they are considered unproductive and at high risk for serious illness.

## DIMINISHED JOB OPPORTUNITIES

Job opportunities are diminished when an adult is diagnosed with cancer. Many Asians have actually indicated that they do not want their employers to know that they have cancer for fear that they may be dismissed or have markedly reduced career development prospects. There was one incident where a woman refused to stay away from work even during her chemotherapy on the spurious grounds that she had pressing deadlines.

## THE UNSPOKEN

Nobody wants to talk about what most have no knowledge of. The narrations of others with cancer and their survival journeys are spiced up with mysteriously interesting anecdotes.

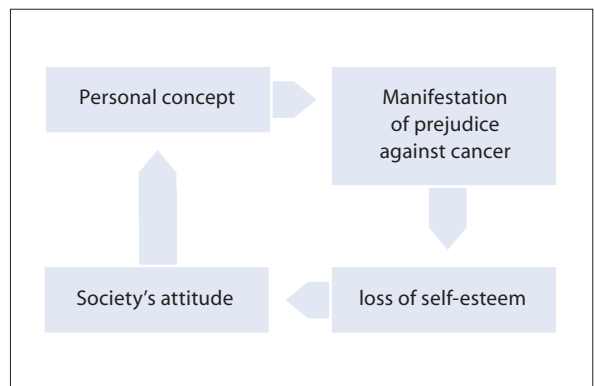
## DEATH AND DYING

To many, the diagnosis of cancer indicates the end of life and thoughts turn to death and dying with the sudden realization that death is lurking around the corner. However there are social expectations that prevent people from speaking about death or anything to do with dying. Community members believe that they do not want the cancer survivor to feel terrible or cause any GRIEF although talking about death in normal everyday conversation may eventually result in RELIEF.

## DILEMMA OF FRIENDS

To speak or not to speak about it, or whether to make a big deal of it, or to ignore it are the cross-roads where, as stated by Linda Richman in 2001: *When you get cancer people do not know how to respond.... There is a sense of uneasiness. Old friends stop calling – they could not cope with the reality – strange, it is not they who have cancer – it is I. People do not know what they are supposed to do – speak about it, make a big deal of it or ignore it.*

## VICIOUS CIRCLE



## WHY DOES STIGMA PERSIST ?

People fear 'differences,' 'the future,' 'the unknown,' and therefore, stigmatize those who embody such characteristics. According to Ainsley et al. (1986): *People fear differences, fear the future, fear the unknown, and therefore stigmatise that which is different and unknown. An equally important issue to investigate is how stigmatisation may be linked to the fear of being different.*

The cancer survivor has to examine his or her own attitude towards the disease. The uneasiness displayed by society could also be the result of ignorance, fear and lack of familiarity rather than prejudice, cancer usually being considered synonymous with death and dying.

# NETWORK



"Reach to recovery" is a concept where women with breast cancer experience are trained to give emotional, practical and informational, non-medical support to newly diagnosed women to help them cope and deal with life after breast cancer. Contact Reach to Recovery International if you are keen to set up a reach to recovery group in your community: [ranjit@myjaring.net](mailto:ranjit@myjaring.net). For details refer to: [www.uicc.org](http://www.uicc.org)

## KNOWLEDGE IS POWER

It is essential to be in touch with scientific knowledge and the latest research on cancer. This kind of proactive approach helps the survivor and the surrounding community to be open to change, to be realistic and to accept evidence-based results.

## TRANSFORMING CANCER SURVIVORS FIRST

Dickinson, in 1977, stated that: *Patients must be allowed to come to terms, they must grieve and mourn for their lost... body part... lost looks and be helped to adjust to their lost body-image. Anyone who has not had a... similar experience... is unable to understand the horror of the situation.* (Dickinson, 1977)

The transformation of a victim to a survivor is a triumphant victory. Yet a death has occurred; and it is critical that this death is acknowl-

edged. *The body and mind have undergone major alterations. It is not the same body. A new self has risen from the ashes of the old body and mind* (Seymour, 1989. P.122). This is the turning point from the "poor me" status to "I shall live for as long as I can."

## MULTIPLIER EFFECT

In their daily interactions, persons living with cancer can educate others by communicating their experience in coping with cancer. The adoption of initiatives of this kind by all cancer survivors could help to change the attitude of society. But first, cancer survivors have to rebuild a healthy relationship with society, which is, no doubt, a long and tedious task. Once accomplished, society can be educated about cancer and the possibility of leading a meaningful life after cancer. Such

a communication process at the level of individuals can create a positive multiplier effect through "spreading the word." ■

Ranjit Kaur, Reach to Recovery International, Geneva, Switzerland

## REFERENCES

Ainsley S., Becker G. and Coleman L. (1986). *The Dilemma of Difference: A Multidisciplinary View of Stigma*. Plenum Press, New York.

Dickinson M. (1977) *Rehabilitating the traumatically disabled adult*, *Social Work Today*, Vol 8, No. 28, p.12.

Goffman, E. (1968) *Stigma*. Pelikan, Harmondsworth.

Hahn H. (1986) "Public support for rehabilitation programs: the analysis of US disability policy," *Disability Handicap and Society*, Vol 1, No. 2).

Hunt P. (1998) *Stigma: The experience of disability*. Chapman, London.

Liu G.Z. (2005) 'Best Practices: Developing Cross-Cultural Competence From a Chinese Perspective.' In Stone JH. (ed) *Culture and Disability: Providing Culturally Competent Services*. Sage, California.

Richman L. (2001). *I'd rather laugh: How to be happy when life has other plans for you*. Warner Brothers Inc, New York.

Seymour W. (1989). *Bodily Alterations*. Allen and Unwin, Sydney.

Sotnik P. & Hasnain R. (1998). 'Outreach and service delivery to the Southeast Asian populations in the United States.' in T.S. Smith (Ed) *Rural rehabilitation: A modern perspective*. Bow River Publishing, Arnaudville, LA.

Swain J., Finkelstein V., French S. and Oliver M. (Eds). (1993). *Disabling Barriers - Enabling Environments*. Sage, London.

Watson N. (2003) 'Daily denials: The routinisation of oppression and resistance.' in Riddell, S. and Watson N. (Eds). *Disability, Culture and Identity*. Sage, London.

# CASE REPORT

## CULTURAL ASPECTS OF SMOKELESS TOBACCO USE AND THE IMPACT OF CHEWING PAN MASALA IN THE ORAL CANCER SCENARIO

The dentist was astonished to find that a 21-year-old engineer, groomed well in a middle-class family and about to join a famous IT firm in the city of Bangalore, could not open her mouth even to permit an impression tray with alginate. She had come to him to improve her facial appearance with orthodontic treatment. She had been using pan masala for the last eight years, even as a school girl; three-four packets a day!

In India, tobacco is chewed in several forms. The predominant varieties are Mainpuri tobacco, Mawa, Khaini, Mishri, Gattipodi, scented tobacco, and Jafna tobacco, although there are many more. Any type of tobacco chewing habit is an accepted social norm in Indian society. Let us consider why pan chewing, unlike smoking and drinking, is an accepted social behavior among all classes. The habit of *Thamboola Charavana* (chewing of betel leaf with areca nut, also known as betel nut, both derived from the Betel Pine, *Semen arcae*, and spices) has been prevalent in India for more than 3000 years. **Ashtanga Hridaya**, a basic book on Ayurveda, the ancient system of medicine in India, lists the ingredients for *Thamboola Charavana* as betel leaf, areca nut, camphor, copra, cardamom, cloves, nutmeg and slaked lime<sup>1</sup>. This book also states that *Thamboola Charavana* will reduce bad breath and increase the secretion of gastric juices. **Manusmrithi**, the Magna Carta of ancient India,



Figure 1. *Thamboola* with tobacco (current practice).



Figure 2. Indian Pan Masala brands.



# NETWORK

states that it is the duty of the wife to give *Thamboola* to her husband after every meal.

Chewing of betel leaf with areca nut and other spices (e.g., masala) used to be a harmless habit. The Portuguese introduced tobacco into India and it became a commercial commodity by the middle of the 17<sup>th</sup> century. Narahari, an Ayurvedic physician who lived during the time of the Mogul Emperor, Akbar, used tobacco broth for the first time for

gargling, to treat bad breath and gum diseases<sup>2</sup>. Gradually, tobacco became more frequently used as an ingredient of *Thamboola* Charavana. Today tobacco is a home remedy for tooth ache. As time passed, the more expensive spices in *Thamboola* were replaced by tobacco by the poor man, who used it to dull the pangs of hunger. (Figure 1)

Until recently, pan was disbursed by pan *wallas* (delivery boys) fresh from pan shops, which were found

all over the country even in the remotest corner. In this form of pan, tobacco, betel nut and slaked lime were packed in one or two fresh, tender betel leaves and consumed immediately. Such pan was wet, difficult to distribute on a large scale and inconvenient to carry. The solution was to use a dry mixture of lime, betel nut, tobacco other spices and flavoring agents without betel leaf, which could be easily packed in separate sachets and tins in varying quantities, depending on the requirements of the consumer. This form of pan is known as pan masala. Other psychotropic substances like gambir, bhang and ganja may also be found in particular brands of pan, but the composition is generally kept as closely guarded secret. All of these ingredients are hazardous to health. Pan masala was shown to be mutagenic by Bagwe et al (1990)<sup>3</sup>, Polasa K. et al (1993)<sup>4</sup> and Patel R.K. et al (1994)<sup>5</sup>. Studies conducted by the Regional Cancer Centre (RCC), Trivandrum, in collaboration with the John Hopkins University, Baltimore, USA, by Babu Mathew and P.P. Nair in 1996 on 22 brands of pan masala has shown that 19 brands were highly mutagenic. The results are shown in the table below.

Analysis of various samples of pan masala at the National Institute for Occupational Health (NIOH) showed the presence of heavy metals such as nickel, cadmium, lead and pesticides in many samples<sup>6</sup>. Polycyclic hydrocarbons and traces of habit-forming substances were also found in some samples.

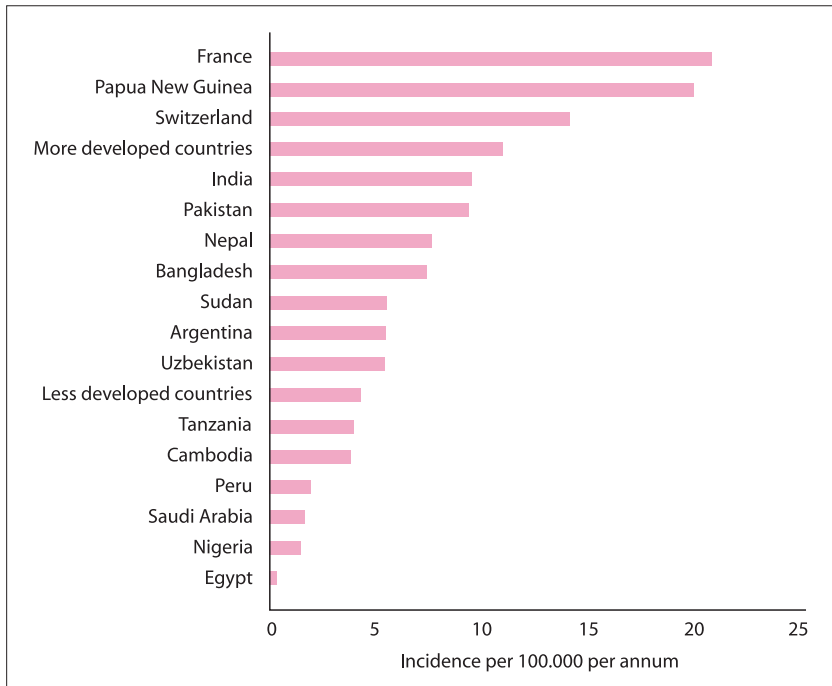
The massive advertising campaigns aimed at youth in higher income brackets have increased the sale of pan masala. There are more than 12 brands of pan masala with annual

| SOURCE / BRAND                                | SOSIP <sup>(A)</sup> | RELATIVE ACTIVITY (UNITS) <sup>(B)</sup> |
|---|----------------------|--|
| Raja Chap Khaini                              | 66                   | 0.73                                     |
| Moolchand Superb Gutukha                      | 114                  | 1.25                                     |
| Rahat   | 270                  | 2.97                                     |
| Vimal   | 397                  | 4.36                                     |
| Badshah                                       | 321                  | 3.53                                     |
| Superfit                                      | 9                    | 0.09                                     |
| Tara  | 159                  | 1.75                                     |
| Pan Parag #1                                  | 763                  | 8.38                                     |
| Panking                                       | 210                  | 2.31                                     |
| Manikchand                                    | 1249                 | 13.73                                    |
| Mahak   | 888                  | 9.76                                     |
| Yamu  | 343                  | 3.77                                     |
| Jubilee                                       | 189                  | 2.08                                     |
| Talab   | 113                  | 1.24                                     |
| Rajdarbar                                     | 371                  | 4.08                                     |
| Crane   | 383                  | 4.21                                     |
| Kuber   | 367                  | 4.03                                     |
| Kamla Pasand                                  | 133                  | 1.46                                     |
| Kanchan                                       | 137                  | 1.51                                     |
| Tulsi   | 277                  | 3.04                                     |
| Zatpat  | 41                   | 0.45                                     |
| Pan Parag #2                                  | 100                  | 1.09                                     |
| 4-Nitroquinoline Oxide<br>(Reference Mutagen) | 91                   | 1.00                                     |

(A) Expressed as the SOS inducing potency (SOSIP)  
 (B) Expressed as the relative activity in units. One unit is expressed as the SOSIP of 1µg of 4-Nitroquinoline Oxide, the standard reference direct-acting mutagen.

**Table 1. Relative Mutagenic Activities of Pan Masala Assessed by the Superoxide Scavenging (SOS) Microplate Assay (SOSMA).**

## CASE REPORT



Bar graph showing the crude annual incidence rate of oral cancer in males of all ages in selected countries. Average incidence rates for more and less developed countries are also shown. Graph created with Globocan 2002.

turnover of more than 2 000 million Indian rupees. (Figure 2)

To create a taste for pan masala in later life, children are encouraged to use certain substances as mouth fresheners, e.g. Pan Pas, from Pasand Vardhan, which may not contain tobacco but are surrogates for pan masala. As they reach adolescence, children start chewing pan masala and are thus exposed to the risks of chewing tobacco, which they continue throughout their lives. Hence parents and teachers should dissuade children from using such substances.

From the epidemiological evidence, it is clear that oral precancerous changes occur in pan masala chewers much earlier than in conventional betel chewers. This is because of the absence of betel leaf in pan masala. In conventional pan, the carotenoids present in the betel

leaf act as free radical quenchers (anti oxidants), thereby reducing the toxicity of tobacco and areca nut<sup>7</sup>. High pan masala consumers among men include bus, taxi and auto-rickshaw drivers, watchmen, painters and carpenters. Women consumers are mostly office workers.

During the last decade, researchers and clinicians have become increasingly aware of a new disease called localized oral submucous fibrosis (OSF) in adolescent pan masala users<sup>8</sup>. In older betel chewers more generalized OSF due to betel chewing occurs. The classical OSF seen in conventional betel nut chewers is a disease characterized by blanching of the oral mucosa, inability to tolerate spicy food, difficulty in opening the mouth and difficulty in protruding the tongue. The elastic nature of the oral mucosa is gradually lost.

This is due to stimulation of collagen growth in the submucosa and prevention of collagen breakdown as a consequence of exposure to an alkaloid, arecoline, as well as tannins and flavonoids, all present in areca nuts. The other pan masala-related oral lesions are leukoplakia, erythroplakia and pigmentary changes. (Figure 3)

Conventional betel nut chewers with OSF, leukoplakia and erythroplakia develop squamous cell carcinoma within 10 to 15 years. In our experience, precancerous localized OSF seen in pan masala users more rapidly undergoes malignant transformation.

The reported prevalence of OSF in Gujarat in 1967 was 0.16%. A resurvey in the same area by the same team in 1998 showed that the prevalence had increased to 3.36% - almost 20 fold<sup>9</sup>. A prevalence survey of three colleges in Trivandrum city, Kerala, by Babu Mathew et al in 1996 showed that 7.6% of the boys and 5.2% of the girls were pan masala users<sup>10</sup>. The recent reports from Bhopal showed a prevalence of 1.98% OSF among teenage school children in Bhopal city<sup>11</sup>. In the pre-cancer registry of RCC, there are 23 teenagers with OSF due only to pan masala use. Hazare and Goyal from Nagpur have calculated the relative risk of developing OSF in pan masala users, demonstrating a direct



Figure 3. Pan-chewing teenager with OSF and Leukoplakia.



# NETWORK



**Figure 4. Pan-chewing teenager with cancer of tongue.**

proportional increase in the disease with the increased frequency of pan masala consumption.

Other reported health hazards of pan masala are anxiety, irrational fear, depression, desperation, introvert behaviour, forgetfulness, loss of temper, mental derangement, suicidal tendencies and impotence. Anybody who consumes this product with gutka for the first time may have a momentary loss of consciousness. There was a report of sudden death in a teenager from Kasargode District in Kerala, who tasted pan masala. The cause of death was confirmed on autopsy as anaphylactic shock.

There are very few reports of successfully overcoming addiction to pan masala which may be more difficult than alcoholic detoxification or giving up smoking.

The use of pan masala can be controlled by a three-pronged strategy. There should be proper health education and awareness-raising of the economic, social and health hazards of pan masala. There should be proper legislation to control the production, storage, distribution and sale. Advocacy activities to make this

habit an unacceptable social practice may also be effective in controlling its use. Voluntary organizations in the colleges, such as the National Service Scheme (NSS) and National Cadet Core (NCC) and scouts and guides in schools, may work to reduce pan masala use. Religious organizations are often active campaigners against pan masala.

No meaningful federal legislation has been introduced relating to the control of pan masala in India, although some states (Tamil Nadu, Andhra Pradesh, Goa, etc.) have banned the sale of pan masala and the Allahabad High Court has banned it in Uttar Pradesh. Students should boycott sports and cultural activities sponsored by pan masala companies. The federal government is now thinking of introducing a bill to control this menace.

We wish to narrate a tragic drama that was staged in our clinics two years ago. Noushad from Malappuram, Kerala, a 12<sup>th</sup>-year standard student, was referred to RCC for an ulcer on the tongue. He was 16 years of age. OSF was diagnosed in association with an ulcer on the left margin of the tongue (Figure 4). On questioning he confessed that he had been consuming ten packets of pan masala a day for the last six years. First given free to him by his neighbour, a shop-keeper, Noushad later bought or stole it. A biopsy of the ulcer was reported as squamous cell carcinoma and the patient underwent treatment at RCC, Trivandrum. Even during treatment he could not resist pan masala and in spite of all possible measures, we could not save this young man. ■

*M. Krishnan Nair and Babu Mathew, Amrita Institute of Medical Sciences, Kerala, India*

## REFERENCES

1. Babu Mathew, *Cultural Aspects of Tobacco Chewing Abstract Book XI World Conference on Tobacco or Health Vol, 2, Page 288. 2000*
2. Babu Mathew. *Pan Masala, a prelude to oral cancer epidemic in South East Asia. International Journal of Cancer Supplement 13, Page 80. 2002.*
3. Bagwe A.N., Ganu U.K., Gokhale S.V. and Bhisey R.A. *Evaluation of Mutagenicity of Pan Masala, a chewing substitute widely used in India. Mutation Research 1990; 241: 349-54.*
4. Polasa K., Babu S and Shenolikan I.S. *Dose dependent genotoxic effect of Pan Masala and areca nut in the salmonella typhimuricum assay. Food chem. Toxicol 1993;31: 439-42.*
5. Patel R.K., Trivedi AM, Jaju R.J., Adhvaryu S.G. and Balan DB. *Ethnol Potentialities the Clastogenicity of Pan Masala and in vitro experience. Carcinogenesis 1994; 19:2017-21.*
6. *National Institute of Occupational Health. Toxicological evaluation of Pan Masala. Annual Report of National Institute of Occupational Health (ICMR), Ahmedabad 1989-90. Page 60-66.*
7. Lahiri M. and Bhide S.V. *studies on Possible Protective effect of plant derived phenols and the vitamins precursors –  $\beta$  carotene and  $\alpha$  tocopherol on 7,12, dimethylbenz (a) anthracene induced tumour initiation events. Phytotherapy Research 1994: 8: 237-40.*
8. Babu S., Sesikiran B. and Bhat R.V. *Oral fibrosis among teenagers chewing tobacco areca nut and pan masala letter. The Lancet - 1996 348: 692.*
9. Gupta.P.C., Sinor P.A., Bhosle R.B. *Oral Submucous fibrosis in India: A New Epidemic National Medical Journal of India: 1998:11: 113-116.*
10. Sannyal (Personal Communication Dr. Babu Mathew) 2004. *Prevalence of Oral submucous fibrosis in school children of Bhopal city.*
11. Hazare and Goyal OSMF. *Areca nut and Pan masala use. A case control study National Medical Journal of India, 1998:11: Page 299.*

## SOCHIMIO: PEOPLE UNITED AGAINST CANCER IN CAMEROON



Like most oncologists in Africa, Dr. Paul Ndom, chief of Medical Oncology Service at Yaoundé General Hospital in Cameroon, has learned to be creative in finding solutions for managing cancer in his country.

Faced with poor cancer drug availability and a lack of medical equipment needed to diagnose and treat cancer - to say nothing of the high cost of those medical resources - Dr. Ndom enlisted the power of people united in a single cause to bring about change. In February 1999, the French-trained medical oncologist launched SOCHIMIO, a not-for-profit association intended to ease both the economic and psychological burdens of cancer treatment.

Dr. Ndom, president of the organization, outlined several objectives: 1. to collect drugs and medical equipment and put them at the disposal of cancer patients; 2. to reduce the cost of cancer treatment in Cameroon; 3. to facilitate exchanges between cancer survivors and those undergoing treatment; 4. to give psychological support to cancer patients; 5. to collaborate with associations or people with similar objectives.

Seven years later, SOCHIMIO can point to several accomplishments. Cancer patients who are members of SOCHIMIO can buy their drugs at a 50% savings from SOCHIMIO's "Social Pharmacy" rather than from private pharmacies - which are not regularly supplied with cancer drugs. A Center for Counseling, Information and Education on Cancer supported by SOCHIMIO promotes open dialogues among patients and others

seeking information about cancer. Educational programs at the Center, which opened in 2003, stress the importance of cancer screening and early diagnosis, promote healthy lifestyles, and provide information about specific cancers and AIDS. The Center organizes screening and early diagnosis campaigns in outlying areas, and refers identified cancer patients to specialized cancer centers. SOCHIMIO also supports cancer research in a limited way, providing some financial assistance to medical doctors for the collection of epidemiological data and to nurses who need specialized training.

Gradually, the organization is gaining greater visibility, with the opening of satellite offices in Cameroon's main provincial towns. Memberships are on the rise as the organization recruits health professionals and interested citizens, whose membership dues help subsidize the cost of drugs for cancer patients. Augmenting its relationship with Yaoundé General Hospital, Dr. Ndom has established ties with Cameroon's National Committee for the Fight Against Cancer and is working with other partners to secure project funding. Ongoing capital projects call for the purchase of equipment and Internet facilities for the Center, and for computer equipment in the Social Pharmacy.

SOCHIMIO's relatively limited resources are derived from membership fees, members' contributions and proceeds from services provided.

"This is an association with a lot of compassion for cancer patients, but with very little money," says Dr. Ndom. "The Centre for Counseling, Information and Education on

Cancer is one of SOCHIMIO's greatest achievements, which deserves to be especially mentioned. Its mission is to promote constructive exchanges about cancer."

The Center holds monthly informational sessions, organizes public



**Dr. Paul Ndom is the leading champion of SOCHIMIO, a non-profit organization he established to provide cancer drugs and useful information to patients in Cameroon.**

conferences on specific topics, and offers visitors informational literature and media broadcasts. About 1,200 people visit the Center each year.

SOCHIMIO is a grassroots initiative that brings solace and physical comfort, as well as medicine, to cancer patients. Somehow, SOCHIMIO manages to provide what is needed.

And sometimes, what is most needed is hope. Dr. Ndom offers the annual Christmas celebration as an example. "This is an opportunity for former cancer patients and those still under treatment to come together to pray, to eat, to dance and to rejoice together."

At a recent celebration, cancer survivors stressed the importance of follow-up care, and members organized a march through the city of Yaoundé to raise public awareness of cancer and its cost. For more information, visit [www.sochimio.org](http://www.sochimio.org). ■

*Marcia Landskroener for INCTR*

# NETWORK

## 1<sup>ST</sup> INTERNATIONAL CONFERENCE ON PEDIATRIC ONCOLOGY

The First International Conference on Pediatric Oncology, held jointly with the Third International Oncology and Nuclear Medicine Conference, took place on July 8–10<sup>th</sup> in Karachi, Pakistan. The Pediatric Oncology Conference was a collaborative effort between Pakistani oncologists and INCTR and was supported by the Office of International Affairs of the National Cancer Institute, USA. Dr Aziza Shad, the recently appointed Director of INCTR USA and also the Director of Education for Pediatric Oncology worked closely with Dr Shamvil Ashraf, the Chairman of the Pediatric Oncology Organizing Committee in the planning of the program. The conference brought together experts from many different countries to provide training for young physicians, nurses and

data management personnel who have an interest in pediatric cancer. Delegates and speakers from India, Bangladesh, Nepal, Afghanistan, Oman, Saudi Arabia, Jordan, Iraq, Canada, UK, USA and Pakistan participated in the meeting.

The topics addressed during the three day meeting included leukemia, retinoblastoma, brain tumors, adolescent cancers, translational research, infections in the immunocompromised host, peripheral stem cell transplantation, and the late effects of therapy. A special session devoted to palliative and supportive care was included in the conference program. The Director and Co-Director of INCTR's Palliative Care Program, Drs Stuart Brown and Fraser Black respectively, gave presentations on how to organize palliative care services in developing countries, INCTR's efforts to create palliative care guidelines appropriate for developing countries and

pain management in terminally ill patients. "Meet the Expert" sessions as well as a Tumor Board to discuss a pediatric cancer, Wilms' tumor and an adult cancer, colon carcinoma were held.

During the meeting, discussions regarding the formation of a Pakistani Society of Pediatric Oncology were finalized, and the inauguration of the society announced.

INCTR had an active role in two pre-conference workshops – Oncology Nursing and Research Methodology.

### PRE-CONFERENCE WORKSHOPS

#### • RESEARCH METHODOLOGY AND MEDICAL ETHICS

This pre-conference workshop was held on July 7<sup>th</sup>. The objective of the workshop was to educate and motivate practicing physicians, scientists, post-graduate and medical students to undertake research, particularly in cancer. Dr Asim Belgaumi from the King Faisal Specialist Hospital in Riyadh, Saudi Arabia, and Dr Shad chaired the workshop. The session began with a presentation on "Child Health Research in Developing Countries; A Luxury or a Necessity" from Dr Zulfiqar Bhutta of the Aga Khan University Hospital. He presented the global picture of childhood survival and mortality and discussed the importance of child health research and its role in improving childhood survival. Other topics presented during the workshop included ethics in medical research, study design, roles and responsibilities of the members of the research team, and the importance of data management. About 100 participants including foreign and Pakistani delegates attended the workshop.



Faculty of the 3<sup>rd</sup> International Oncology and Nuclear Medicine Conference and 1<sup>st</sup> International Conference on Pediatric Oncology.



#### • ONCOLOGY NURSING WORKSHOP

The workshop on Oncology Nursing, organized by the Nursing Department of the Aga Khan University Hospital in Karachi was held on July 7 and 8<sup>th</sup>. Sixty-eight nurses from different parts of Pakistan involved in the care of patients suffering with cancer attended the workshop. The two-day workshop was comprehensive and many relevant issues related to cancer nursing were presented and discussed, among them, communication skills, counseling, pain management, nutrition in cancer, nursing care of patients and their families, ethical issues in end-of-life care and quality of life. ■

### PALLIATIVE CARE TEAM VISITS TANZANIA AND UGANDA

#### TANZANIA

The INCTR Palliative Care Team – Dr Stuart Brown, Dr Fraser Black, Doug Ennals (social worker) and Virginia LeBaron (RN), and Sabine Perrier-Bonnet from INCTR's French Branch, Alliance Mondiale Contre le Cancer, conducted a palliative care educational workshop at the Ocean Road Cancer Institute in Dar es Salaam on June 15-16<sup>th</sup>. The goal of the workshop was to provide palliative care education appropriate to the region in terms of culture, needs and resources. It was also an opportunity for the INCTR Palliative Care Team to gain an understanding of initiatives in palliative care that are presently on-going in the region. Over 40 participants included physicians, nurses, social workers, psychologists, counselors, health care advisors, program coordinators, data managers and researchers. Some of the participants were from



**Palliative Care workshop participants (Ocean Cancer Road Institute Tanzania).**

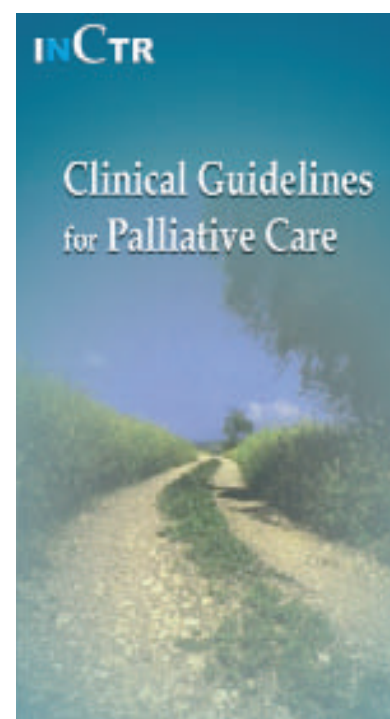
non-governmental organizations, including the Tanzania Palliative Care Association. As per the meeting evaluation, the presentations were found to be beneficial to the work of the participants. Of particular value were discussions of pain assessment, symptom management (including pain, dyspnea, nausea and vomiting) as well as the importance of assessing and regularly re-assessing symptoms and the correct use of opioid analgesia. Two special topics were included: the problems and approaches to the assessment and management of pain in pediatric patients and palliative care of patients with HIV/AIDS.

In addition to the educational workshop, Sabine Perrier-Bonnet and Virginia LeBaron led a morning seminar for the ORCI nurses regarding chemotherapy administration and primary cancer prevention. The purpose of this seminar was to demonstrate how to safely prepare and administer chemotherapy, to review the nursing management of the side effects associated with chemotherapy and to discuss primary cancer prevention. Twenty-five nurses and one physician attended this seminar.

#### UGANDA

The INCTR Palliative Care Team met with the Executive Director of the African Palliative Care Association

(APCA), Dr Faith Mwangi Powell in Kampala, Uganda on June 22 and then with Hospice African Uganda (HAU) and the Mildmay Center on the 23<sup>rd</sup>. The purpose of these meetings was to learn more about the missions, objectives and activities of each of these organizations and to discuss ways in which INCTR could work with them in expanding palliative care services, which are desperately needed in Africa (for cancer as well as HIV). Particularly important were discussions on how to develop the training and education programs required for such an expansion and how to identify and overcome obstacles to opioid availability and use. ■



**INCTR Palliative Care Staff in conjunction with colleagues in developing countries are in the process of preparing a web based Clinical Guidelines for Palliative Care.**

# NETWORK

## CHILDREN'S WELFARE TEACHING HOSPITAL, IRAQ

In the last decade the health status of the Iraqi people has suffered serious setbacks. The unfortunate circumstances of wars and economic sanctions have damaged many aspects of life in Iraq, with adverse effects on physical health,



The Medical City Complex, Baghdad.

nutritional status, psychological well-being and the rising incidence of communicable and non-communicable diseases including cancer - this after substantial progress had been made in improving survival rates for children with both acute and chronic diseases. The challenge of delivering effective health care has been made more difficult by limited investment in clinical facilities and the severe damage done to existing facilities in recent times.

Children's cancer accounts for a higher percentage of cancer in developing countries than in high-income countries due to the greater proportion of children in poorer nations. Iraq is no exception in this regard. Unfortunately, given the complexities of diagnosis and treatment, children with cancer have greater needs, which often cannot be met. In this report, the situation at the Children's Welfare Teaching Hospital (CWTH), part of a medical city complex in Baghdad, and in particular, the situation with childhood cancer, will be described in order to illustrate the problems faced.

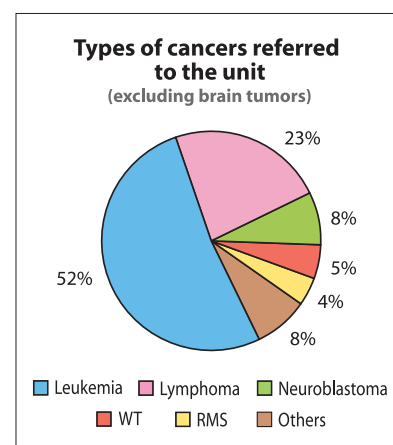
CWTH is a tertiary care center established in 1984; maintenance was last carried out in 1989. The hospital is recognized by the Iraqi Commission for Medical Specialization for the training of post-graduate students for the National Board in Pediatrics. The clinical facilities of this 240-beds hospital include general pediatric wards and specialist units for hemato-oncology, neonatology, emergency medicine, pediatric surgery and respiratory care. The pediatric oncology ward was established in 1984; today it includes two medical oncologists, three fellows, two hemato-pathologists, four interns alternating every two months and fourteen nursing staff (versus five before 2003). We have an outpatient department and chemotherapy daycare (ten beds), but no bone marrow transplant unit.

Our infrastructure is damaged at the level of the most basic facilities. Electricity, sewage, water and communications systems, while improving, remain below the standard required for safe and effective health care. The support services, including the clinical chemistry laboratory, blood transfusion, radiology and pharmacy departments, are operating below capacity and to questionable safety standards, with a continued lack of maintenance. Information systems and warehousing facilities necessary for the distribution of medicines have progressively deteriorated. We do not have a radiotherapy department. While there is a national radiotherapy institute that provides services for the entire country, this facility has a long waiting list (which can be as long as six months or even more). Most radiotherapy is delivered by Cobalt<sup>60</sup> machines from an earlier era; a single linear accelerator is out of order most of the time.

Chemotherapy is administered by resident doctors because we do not

have dedicated oncology nurses. We are not equipped to insert and maintain indwelling intravenous catheters. The paucity of diagnostic capability, both quantitative and qualitative, imposes major limitations on diagnostic accuracy and jeopardizes appropriate therapy. Palliative care is nonexistent due to morphine being unavailable, while less effective analgesics are available only in small quantities. In addition, there are no social workers or cancer support groups. Infection is the most frequent cause of morbidity and mortality because of the children's poor nutritional status, lack of an infection control policy and the high rate of parent illiteracy.

We see 260 new childhood cancer cases per year, excluding brain tumors, with a monthly average of 500 patients seen in the outpatient department and approximately 30 inpatients treated each day. Leukemia is the most common neoplasm, followed by lymphoma. Currently our unit is implementing western protocols modified to make them feasible in the context of the local situation. Our unit provides care to patients from various parts of the country. It is one of two centers for childhood cancer in Baghdad.



We do not have a functional data management system so that the data



## PARTNER PROFILE

regarding cancer rates in Iraq are somewhat sketchy, although Iraq established a population-based cancer registry in 1976. The cancer unit registry is kept manually by the pediatric oncologists running the unit. We have a limited access to medical libraries and the latest research because of the intellectual embargo from the international medical community. Internet access is minimal. There is always a significant delay between the disease manifestation and referral to us because of delays in diagnosis, or the problems of transportation faced by families who live in distant provinces. We lose a relatively high fraction of patients to follow-up because of economic and security problems or military operations in their regions, causing difficulties in assessment of long-term survival in patients who have completed treatment.

Since 2003 the care of children with cancer has been supported by a number of organizations, including INCTR. INCTR, sponsored by the Office of International Affairs of the NCI, took primary responsibility for developing pediatric oncology workshops designed to identify problems faced by Iraqi pediatric oncologists and to provide relevant updates and continuing education with respect to the care of children with cancer. The strategy focuses on providing assistance to pediatric oncology teams currently practicing in Iraq, including educational updates offered through workshops. To date, three workshops have been held. The first workshop was held at the King Hussein Cancer Center (KHCC) in Amman, Jordan, in April 2004. Dr. Aziza Shad, Chairperson of INCTR's subcommittee on pediatric oncology education, designed a program focused primarily on pediatric leukemia, lymphoma, and supportive and palliative care. A follow-up meet-

ing was held in Cairo, Egypt, in October 2004 as part of INCTR's annual meeting. We also participated in the First International Oncology and Nuclear Medicine Workshop and the First International Conference on Pediatric Oncology (a workshop focused on research methodology and management of common pediatric cancers), held on July 8-10, 2005 in Karachi, Pakistan, a meeting also conducted in collaboration with INCTR's Pediatric Education Subcommittee. Our participation in these workshops and conferences, with exposure to internationally accepted current practices, encouraged us to implement improved patient management practices in our daily work. It has also provided us with access to expert consultants when we have difficulties in management, enhances our links with international institutions, and encourages a multidisciplinary approach to the management of childhood cancer. The value of this support is reflected in a decrease in overall mortality rate from 20.8% in the year 2000 to 10.9% in 2004.

Other international organizations are also providing aid. A recent collaboration with the hematology unit of La Sapienza University in Rome, supported by an Italian non-governmental organization known as INTERSOS, has been a rewarding experience. One specific outcome has been the design of a modern treatment protocol for the management of Iraqi children with acute promyelocytic leukemia. The treatment protocol for this leukemia, which has a relatively high incidence and mortality in Iraq, includes the use of a retinoid drug (ATRA) provided by INTERSOS; professional consultation is provided via televideo linkage. We have seen survival rates improve from less than 10 percent to more than 80 percent in treated cases.



**Dr. Salma Al-Hadad and staff.**

International Medical Corporation (IMC) funded a partial reconstruction of the pediatric unit in 2004, providing a children's playroom and internet connection. IMC also supported a six-week training program for five doctors and five nurses at KHCC. Japan-Iraq Medical Network (JIM-NET) is coordinating a program that provides chemotherapy medicines, infection control materials, a teaching microscope, infusion pumps, centrifuges, etc., as well as training at KHCC for a doctor, a nurse and a bacterial culture technician. At a workshop in Amman in September 2005, JIM-NET evaluated the support and medical situation in Iraq, and made recommendations for establishing a cord blood bank in Iraq.

Our requirements for improving patient care include improved infrastructure and human resources and more equipment and medicines, which should be made available through a government drug delivery system. We need to further develop our educational programs and research collaboration with other cancer centers in order to catch up with modern care and preferred treatment protocols after a long period of isolation from the outside world and, consequently, an inability to keep up with and implement medical advances. ■

*Contributed by Salma Al-Hadad and Mazin Al-Jadiry, CWTH, Baghdad, Iraq*

# NETWORK

## PROFILES IN CANCER MEDICINE

### PAKISTAN'S PIONEER ONCOLOGIST CHANGES MEDICAL CULTURE

Zeba Aziz, the first medical oncologist to practice in her native country of Pakistan, had personal reasons for entering the field of cancer medicine. When she was a student at the Fatima Jinnah Medical College in Lahore, her father developed chronic myeloid leukemia. At that time, bone marrow transplantation was available only in more developed countries. Her father traveled to England for treatment, and was away from his family for 18 months and died there.

"We lost out on precious time," she says. "He was only 42. That's when you make relationships with your children. It's important that families not be torn apart by cancer."

Dr. Aziz's father encouraged her to pursue medical research rather than clinical practice alone. And he wanted her to work in Pakistan rather than move permanently out of the country. After completing postgraduate training in the United States - at SUNY Downstate Medical Center and St. Vincent's Hospital in New York - she returned to Pakistan in 1987 with board certification in internal medicine and the subspecialties of hematology and medical oncology. Today she is Professor and Head of the Department of Medical Oncology at Allama Iqbal Medical College at Jinnah Hospital in Lahore.

"When I returned to Pakistan, there was no concept of medical oncology," she says, "and it was difficult to develop. I encountered a lot of resistance. It has taken 12 years to establish Medical Oncology as a subspecialty."



**Dr. Zeba Aziz**

What keeps her going, she says, are her patients, her students and the support of her husband and children. She also feels tremendous satisfaction in knowing she has brought important medical advances to her homeland.

Still, there are tremendous challenges. Illiteracy and poverty top the list, along with the government's lack of attention to health care issues.

"How can people travel for cancer treatment, if they don't have money to eat?" she asks. "If we provide them with medical care that is not constrained by financial issues, they do as well as anyone else."

Oncologists in Pakistan also battle common misperceptions about cancer - that homeopathic medicines are preferable to standard medical care, and that cancer is not curable. The use of complementary medicine is common due to its easy access and low cost. The patients she sees at Jinnah are too often in late stages of the disease. Because the cost of mammography is prohibitive, she has launched initiatives to encourage clinical breast

examination and breast self-examination in the hope of diagnosing the disease before it becomes advanced.

As a member of INCTR's Breast Strategy Group, Dr. Aziz is conducting clinical trials that survey breast cancer risk factors, and is working on the development of a treatment protocol for locally advanced cancer. With INCTR's help, she is also endeavoring to develop a professional educational program in partnership with Egypt and Tunisia.

Despite the rising incidence of breast cancer in developing countries, she says, 70% of patients have no identifiable risk factors. And no public health policies are in place to enhance awareness that would lead to early detection and treatment. Even at the professional level, cancer education needs to be improved. Medical oncology is not yet part of the curriculum of Pakistan's medical schools. "A lot of patients don't come because doctors don't refer them," she says. "More education is needed, and the government needs to step in, in order for us to achieve more."

As a teacher, Dr. Aziz is succeeding in training physicians. But the research culture she dreams of has not yet materialized. "The research environment is so poor - there is no reward or recognition. That's where I feel I've failed. They haven't gone abroad and seen what I've seen - that evidence-based medicine is key to ensuring good quality medical practice. The ability to question things and to develop your own data is critical. That is where INCTR can help and is helping." ■

*Marcia Landskroener for INCTR*