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## GUEST MESSAGE

### TOWARDS AN INTERNATIONAL CANCER CONTROL PLAN: POLICY SOLUTIONS FOR THE GLOBAL CANCER EPIDEMIC

by Richard Sullivan<sup>1</sup> and  
Arnie Purushotham<sup>2</sup>

#### THE ECONOMIC AND PUBLIC POLICY CHALLENGE OF CANCER

Cancer has a devastating personal, social and economic impact on the global population. The figures provided by Ian Magrath are a stark warning that cancer specifically and non-communicable diseases (NCD) generally are a major and increasing burden on the health and wealth of nations. In the face of rapidly changing demographics – an aging and expanding global population – there is a critical need for public policy action at both national and supra-national levels. Chronic diseases including cancer, heart disease and diabetes account for more than 60% of deaths worldwide but less than three percent of public and private funding for global health. Excluding the huge impact of disability and years of lost life, cancer's economic toll was \$895 billion in 2008



**Building global cancer control: towards an integrated vision. Little Tower of Babel, Pieter Bruegel the Elder. Museum Boijmans Van Beuningen, Rotterdam.**

— equivalent to 1.5% of the world's gross domestic product<sup>(1)</sup>. Cancer is a direct public health threat to economic development; preventive measures, as well as the healthcare programs and systems needed to manage cancer using resource-level-appropriate control measures, is a basic necessity,

not a luxury. Cancer cuts productive lives short and has a major impact on essential social structures, e.g. through female mortality due to breast (developed countries) and cervical (mainly low/middle income countries) cancers. Kevin Murphy and Robert Topel at the University of Chicago have estimated

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that a 10% reduction in cancer mortality would be worth more than four trillion USD to the global economy, of which more than half of this will fall on low/middle income countries (LMC)<sup>(2)</sup>.

Public policy measures for global cancer control are not a zero sum game with other critical domains – population and nutrition – and diseases, e.g. HIV/AIDS, unipolar depression, maternal and child health. In other words, controlling cancer does NOT need to be at the expense of these other areas. Rather, 1) cancer and NCDs need to be integrated into all the major horizontal actions and, 2) all aspects of cancer control plans – from prevention to health systems design and research priorities – should be part of proper health systems planning. Cancer is a global issue and whilst developed countries have only had to deal with an epidemiological transition from

acute to chronic diseases, the reality for LMCs is one of the double and, even triple burden of disease, i.e. the need for health systems that can deal with a disease burden that stretches from infections to chronic disease and Group III causes (accident, conflict, etc). This is a unique and wholly untested situation for cancer control that will need novel ways of superimposing and integrating cancer prevention and management systems and programs onto other disease areas. Furthermore, achieving good outcomes in cancer control at low cost is entirely achievable with the correct prioritization of cost-effective modalities and care pathways (e.g. the state of Kerala in India and Costa Rica)<sup>(3)</sup>.

National cancer control programs (NCCP) and engagement with global prevention frameworks such as Framework Convention on Tobacco Control (FCTC) are now part of the normative socio-political structure of developed countries. However, the degree to which emergent market economies (EME) have implemented well-validated NCCP is highly variable and outcomes for many types of cancers in many countries remain unacceptable in light of the knowledge of what can be achieved. Substantial variations in cancer outcomes due to deprivation in EME with otherwise low index of inequality (Gini), for example, are unacceptable<sup>(4)</sup>. Models for cancer systems reform as well as public-private partnerships and research funding forums (e.g. Institut National du Cancer <http://www.e-cancer.fr/>) are not the rate-limiting factor to delivering cancer public health policies for developed countries. Numerous approaches to excellence in service delivery, research and education/training abound, along with a spectrum of options for their organization based on center or network models<sup>(5)</sup>.

In developed countries the key public policy issues center around over-regulation, the relative lack of supra-national funding for research, the escalating cost (and cost-effectiveness issues) around cancer care and the orphanization of key domains such as cancer surgery and prevention relative to cancer medicines<sup>(6)</sup>. However, taking a global perspective, in spite of these significant issues for cancer in developed countries, outcomes, are excellent compared to those in LMC. It is these countries that will be the key to global cancer health in the coming decades (Figure 1).

One of the critical challenges to G20 and all countries committed to cancer control is to understand the myriad partnerships, global actors and initiatives currently at work. Beyond country-specific efforts there are a plethora of partners from the WHO Non-Communicable Disease division and the International Atomic Energy's cancer program (<http://cancer.iaea.org/index.asp#content>) through to umbrella / advocacy organizations – e.g. the Union for International Cancer Control (<http://www.uicc.org/>), patient groups and trans-national research organizations e.g. International Prevention Research Institute (<http://www.i-pri.org/>) and the International Network for Cancer Treatment and Research (<http://www.inctr.org/>). There are a bewildering number of organizations, interconnected in a myriad ways and through a variety of horizontal and vertical programs to form what amounts to a cancer public policy nexus. Are all these organizations necessary? Almost certainly they are. The challenges of country-specific cancer control and supra-national program require a multitude of different alliances, perspectives and knowledge. However, current partnerships can be obscure and ad hoc; there is,

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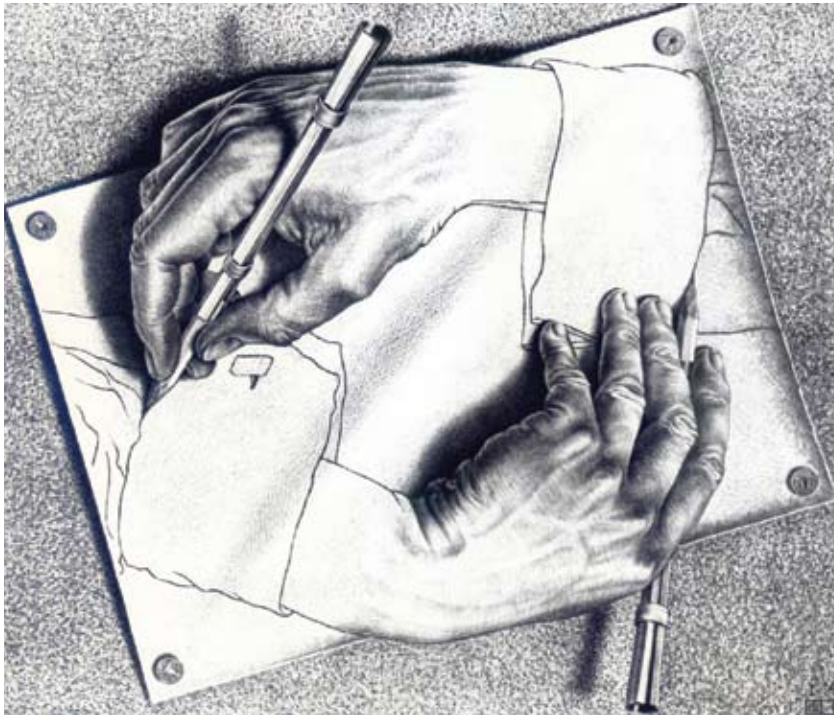


Figure 1. Internal consistency in cancer public policy is essential. *Drawing Hands. MC Escher.*

for example, a need to constantly challenge the status quo with new policy approaches that bring in new players. Important opportunities for enhancing global cancer control could be managed by World Bank NCD programs<sup>(7)</sup>. Although these organizations all have heterogeneous goals, operating patterns and histories, the one common feature is that in their efforts to support cancer control in LMC, the available funding is a drop in the ocean in comparison to what is provided by and for cancer public health in developed countries. This massive funding gap is now a critical public and economic health threat.

### THE SOCIAL DETERMINANTS OF CANCER

The human ecology of cancer and its control is at least as complex, if not more so than any aspect of the biomedical science of oncology. This policy domain, first described in the 1920's

by Roderick McKenzie, encompasses all the complex dynamic spatial and sustenance interrelationships within which human society is organized and through which cultural forces act<sup>(8)</sup>. Thus cancer control is seen not as a collection of molecular and cellular processes but as a result of multi-dimensional processes that bring to bear such values and concepts such as equity, distributive justice, access and sustainability. By its nature this is a hugely challenging area for cancer public policy and one that is frequently neglected, in part because of its intrinsic challenge but more so because it forces a dialogue about political ideology and the prioritization of expenditure and efforts in cancer control. If, for example, it is so abundantly clear that countries and global institutions are failing to address the growing burden of cancer in LMC, despite a plethora of documents, finely worded declarations, learned articles and

other assorted policy paraphernalia, what are the root socio-political causes of this "second translational gap", i.e. turning knowledge about the solutions to cancer control into real change on the ground?

In framing the human ecology of cancer it is essential to develop public policy that is convergent and complementary with existing direction articulated by the Commission on Social Determinants of Health<sup>(9)</sup>. By mapping them onto existing public policy that covers the full spectrum of health and well-being, policies that specifically address cancer control can be developed into coherent strategies with real chances of implementation, rather than ad hoc documents unlinked to core national and supra-national social policy-making. One of the critical failings time and time again is the development of public policy and actions around inequality and cancer outcomes that are completely dissociated from the actual lifestyles and concepts of individual responsibility that give rise to the situation in the first place. Before even setting the policy agenda for the social determinants of cancer, there needs to be an explicit political mechanism that stitches cancer into the various vertical political silos of social policy – for example education and urban planning.

### INEQUALITY AND CANCER

Inequality in cancer remains one of the most fundamental issues that both developed and LMC societies struggle to address. Here cancer reflects the broad problem of health inequality – one that has been globally recognized since the 1978 Alma Ata declaration that saw health promotion as a system that acted on the underlying economic, social and political causes of poor health. For LMC this dream of Primary Health Care was shattered by the



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**Figure 2. Globalization of cancer risk. Worldwide, increasing numbers of children are being targeted by the tobacco industry.** Reproduced from <http://children.foreignpolicyblogs.com/page/3/>

imposition of a series of market-orientated models and decades of structural adjustment programs following the Washington consensus that all but put social health to the sword. Against this background, the combined effect of poor governance and inequality has ensured that in many LMC, the huge gaps in cancer outcomes between the affluent and the deprived are deeply entrenched. Furthermore, because of the double burden of disease, many health programs in these settings focus exclusively on Group I (infectious disease, maternal mortality etc) without recourse to thinking how to map on specific cancer control and other NCD control measures. Because of the tight relationship between cancer outcomes and cumulative life experience, generic measures to address inequal-

ity from the start of life will, over time, enhance cancer control. A diagnosis of cancer is not only a personal tragedy but is often a financial disaster for patients and their dependents as well. Such individuals will either not present for treatment, present too late and/or only complete primary treatment without follow-up. In terms of gender equity the impact of cancer on women has a dramatic knock-on effect to the health and economic productivity of their families. Some 64% of all illiterate adults are women (an estimated 495 million worldwide)<sup>(10)</sup> and this directly impacts on the ability to deliver effective cancer control; the stigmata of cancer for women in many societies leads to substantial social disruption. Policies that directly work to address gender equity will, coupled to early

detection and good universal cancer management systems, ensure directly the improvement of the health and wealth of families as a whole. The seemingly entrenched deprivation gaps manifested in developed countries also need urgent attention. For developed countries like the USA<sup>(11)</sup> and the UK<sup>(12)</sup>, the public policy solutions are clear; they simply lack socio-political motivation.

## HEALTHY ENVIRONMENT

The human environment is constantly changing. Over three quarters of the population in developed countries are urbanized and LMC are catching up fast with 40.9% occurring in cities. In the latter, however, some 43% of the urban population live in slums (UN-HABITAT 2003 data). The rural-urban environ-

ments have a dramatic effect on the full spectrum of health. On the one hand, there has been chronic under-investment in rural medical infrastructure<sup>(13)</sup>, thus there are few treatment options in this setting. On the other hand, urbanization is a "pro-cancer" environment that promotes "nutrition transition" – high consumption of fats, energy dense and highly processed foods – and thus, coupled to less physical activity, leads to obesity which, after tobacco usage (Figure 2), is one of the most important cancer risk factors. Poor environmental conditions can also exacerbate poor cancer outcomes due to the triad of deprivation-elderly-ethnic minority. Each feeds back and re-inforces poor outcomes. Public policy solutions aimed at tackling urban planning, rural support and access, rural-urban migration and the natural environment would all have positive long-term effects in terms of both prevention and the outcomes in cancer.

## SOCIETY AND CANCER

The culture and structures of societies play a critical role in how cancer is perceived, what action is taken to prevent and alleviate suffering, and the socio-political priority assigned to implement the required public policies. "Social system influences... may account for as much (if not more) of the variation in health and/or illness statistics as do environmental influences, or even the attributes and lifestyles of individuals"<sup>(14)</sup> and numerous facets of these systems – the role, position and liberty of women, the social stigma of cancer, perceptions of the causes of cancer, taboos in seeking help outside the "in-group", etc – contribute to the global burden of cancer but at a local level. The heterogeneous nature of the global society makes broad public policy particularly difficult, especially when it

challenges entrenched culture. Policies aimed at promoting and supporting grass roots advocacy for cancer control are absolutely essential and the only effective means of changing, long term, cultural artifacts that promote cancer and poor outcomes. Political governance woven into the fabric of societies is also a critical determinant of cancer control, and indeed in delivering universal health. Political governance needs to be held to account by national advocates in civil society and, where the formal sector of the economy is weak and government limited, community health insurance schemes need to be initiated to provide social health protection. Policies to provide sickness funds can also help mitigate the social consequences of cancer and defray catastrophic expenditures as a result of this.

## FINANCE AND MARKET RESPONSIBILITY

Cancer control relies upon an adequate supply of services and material resources. For many countries, the free market has failed to deliver not least because economic growth remains so low that even with the political will to mobilize 15% or more in taxes from the domestic economy the absolute level of per capita income is too low for this to be an effective sum. Part of the solution, particularly for the better financed middle income countries, lies in fiscal transfers to directly support cancer control in higher burden, greater "at-risk" regions and better economic management (budgeting, payment contracting, etc). For upper low income countries where cancer is becoming a significant public health threat, there are a variety of basic strategies, articulated by the WHO Commission on Macroeconomics and Health, that would directly support cancer control, for example pre-payment schemes and community

finance programs that would support families hit by a diagnosis of cancer<sup>(15)</sup>. This is particularly important. In India, for example, some 86% of women and 83% of men employed in areas outside the agricultural sector are in informal employment<sup>(16)</sup>. Over 45% of this group with a diagnosis of cancer will have catastrophic expenditure, with around a quarter being pushed below the poverty line (2004 data)<sup>(17)</sup>. How governments work with the private market is hugely challenging and no easy public policy solutions exist. Little information is available to measure private sector performance and pricing but, it is clear that tighter federal oversight is required. For very different reasons, developed countries also need to challenge the role of the market as the cost of cancer control continues to go up. The glass ceiling has already been reached, and in some cases breached. A continual price increase for cancer control in high income countries is simply not affordable and public policies targeting cost-effectiveness and driving greater value from services are essential.

## GLOBALIZATION OF CANCER RISK. NEW POLICIES FOR PREVENTION

It is widely acknowledged that too little is done to prevent cancer. Data indicate that less than 4% of the overall annual public global research budget is spent on this area and the contribution from private sectors is also tiny. The major risk factors for cancer as well as other non-communicable diseases are absolutely clear. Tobacco usage remains far and away the most dangerous risk to health, but it is being chased by a combination of obesity and alcohol usage, particularly in developed countries. In LMC the threat from infection-related cancers, e.g. hepatitis B and liver cancer, and of course human papilloma

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virus (HPV) and cervical cancer, a particular threat for women, continues its upward march, even in the face of new eradication programs centered around vaccination (which, at best, will require decades before creating a measurable effect). In both developed and LMC, especially in the latter, a combination of aging demographics coupled with increasing exposures to pro-cancer environments and lifestyles will have a critical socio-economic impact. It is now crystal clear that few, if any, LMC will, on the basis of their current out-of-pocket driven healthcare systems, be able to cope with the financial impact of managing cancer without driving down incidence through preventative measures. Although challenging, prevention remains the only serious option for controlling the long-term impact of cancer, and indeed wider afield the impact of other chronic diseases such as CVD and diabetes. The control of viral and bacterial-induced cancers by vaccination and other approaches remains a critical quest for public policy in cancer prevention. Although many global initiatives have been launched to conquer the threat of infectious disease through vaccination, major success has been elusive, not least because by themselves vaccines are a small component of the overall health system, and in many cases present their own issues in terms of costs and the logistics of deliverability. Nevertheless, within a program that is based on real understanding of the social context of the community to be engaged and with appropriate health system strengthening in parallel, vaccination remains an important part of the preventative repertoire. However, global vaccination programs are not a magic bullet and even where, for example, in cervical cancer vaccines have been developed, it still may be more cost-effective to utilize

a non-vaccine approach to prevention which, in any case, will be required for the foreseeable future.

While there are many international documents outlining important strategies in cancer prevention, the practicalities and logistics are left to the individual countries. Even within the country, it may be unclear who has the responsibility for cancer prevention. Given that tobacco smoking, obesity and alcohol consumption are major drivers of cancer incidence worldwide, a national strategy lacking coordination with other countries seems doomed to fail. Studying these major risk factors one by one it is clear that they are driven by global - not local or national - phenomena. As one market for these products shrinks, another one is opened up. Particular examples include:

- The tobacco industry turning to the big markets in India and China.
- The international food industry changing societies' diets with calorie dense, poor quality food-stuffs, creating a global "Westernization" cultural change with fast food and less physical activity.
- A westernized lifestyle regarding alcohol intake where, for example, women are targeted as a high use consumer group.

The disconnect between the globalization of pro-cancer commodities and the relative nationalization of prevention within a cancer control setting is a major issue. Social determinants also play an integral role in the complex adaptive system health behaviors but with few public policies addressing the demand side of pro-cancer commodities. The globalization of markets, behaviors, population and development are having a profound effect on the supply and demand of pro-cancer commodities such as tobacco

and alcohol. By itself globalization is not the issue. The expansion of global markets has provided major benefits for human development; however, the same mechanisms have been co-opted to increase exposure in LMC to tobacco. Furthermore we know that where countries experience economic shocks from global downturns without recourse to the benefits of local/national sustainability plans, the social stress and disintegration of cohesive, health-promoting networks forces many into serious pro-cancer, anti-health behaviors such as increased tobacco usage and alcohol consumption<sup>(18)</sup>.

What can and should be the focus for public policy? For developed countries there is simply no longer any excuse not to put in place the full raft of public health measures to combat the most pernicious risks, such as alcohol and obesity. Furthermore, there is an urgent need to support more research into the most appropriate measures and means to combat these cancer risks stratified by the various complex sub-populations within countries. Beyond the Framework Convention on Tobacco Control a suite of public policy measures – tobacco taxation, restrictions on smoking, health information and counter-advertising, bans on advertising and promotion, and smoking cessation treatments – are available<sup>(19)</sup>. There is also a clear political governance role for helping to rein in the movement of these pro-cancer commodities and supply chains to LMC. Most major corporations are based in the developed world in one way or another and concerted action to prevent them from "globalizing" these pro-cancer commodities is necessary. In addition and considering the harm posed by tobacco to public health in general in comparison with other drugs<sup>(20)</sup>, perhaps countries

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should consider taking the route that the Kingdom of Bhutan has and ban tobacco sales completely.

Can we call on Adam Smith's invisible hand to suggest that counter-forces can and will come into play against the tyranny of anti-health commodities? Whilst most cancer prevention public policy has focused on the demand-side, the case for changing human behavior is more complex and potentially less tractable. Should we perhaps take a more enforced top down approach to the supply-side in the name of public health? Aside from the practicalities, political philosophy is sharply divided between the pro-free market of Hayek and Friedman and the need for Sen-like distributive justice. A bottom up approach seems too slow and top down too political. Thus we are left with civil society, philanthropic funders, advocacy and patient groups to hold policy-makers to account and agitate and educate within their communities. Is this the correct solution or are FCTC-like public policy the only avenue for real improvements to the prevention agenda? An attractive, but long term policy approach is to incorporate prevention into the education stream, particularly for women, as part of a health for tomorrow program. Adding health to the basic universal curriculum as part of the Education for All objective would be a huge step forward in cancer prevention and life-long health<sup>(10)</sup>.

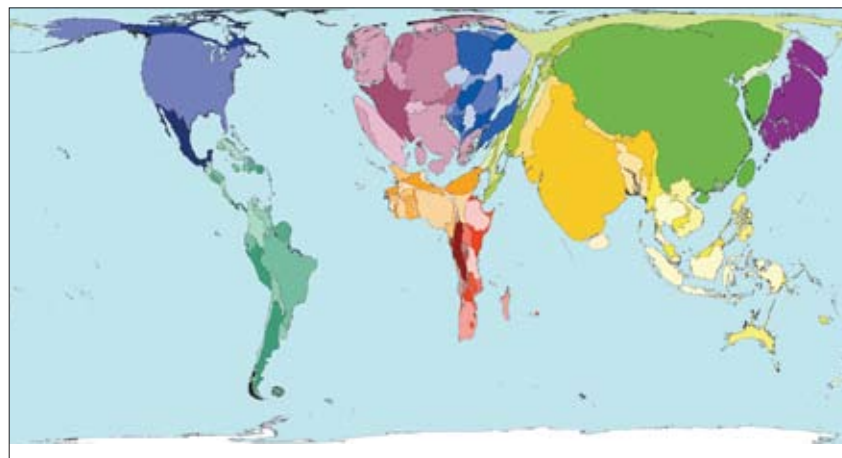
Perhaps we have recourse in a belief in the self-correcting nature of human societies. However, major changes in human society have only taken place under substantial environmental pressure<sup>(21)</sup> and the ever increasing fissioning of social groups suggests that a wait-and-watch approach will fail. Public policy in cancer prevention could, however, take much more notice of what we

have learnt about the evolution of human behavior from our evolutionary adapted environment. As Robin Dunbar at the University of Oxford has eloquently put it, "Primate societies [and that includes humans] are implicit social contracts. Like all social contracts, their stability and functionality depends on the members trading off short and long term benefits"<sup>(22)</sup>. In societies with short life expectancies and a higher proportion of life spent disabled, prevention makes no sense to the individual. However, even in societies that have fully undergone the demographic and epidemiological transition, major portions of these societies are increasingly at risk from pro-cancer behaviors. While social conformity and good health behavior can always be imposed by punitive action on backsliders<sup>(23)</sup>, there are limits to which such action can really enforce social cooperation. Social cooperation is far more effective when individuals act willingly because they all voluntarily sign up to the communal project. Mechanisms that create a sense of communality in cancer pre-

vention are thus more likely to result in the required levels of altruism than the use of top-down social control<sup>(24)</sup>.

### INTERNATIONAL CANCER CONTROL PLANNING (ICCP)

How are we to address global cancer control when, even today, we are faced with some basic truths that we have failed to adequately deal with the most simple of public health measures? As a recent *Lancet* editorial starkly put it, "adequate sanitation is the most effective public-health intervention the international community has at its disposal. Yet 40% of the world's population still lacks access to a toilet"<sup>(25)</sup>. The answers lie not in trade-offs with other facets of global health but in formulating a new paradigm that constructs programs, systems and public policy that is inclusive and coherent with the variety of needs on the ground. Cancer is a part of a cross-sectoral approach that will have many commonalities with the control of other NCD, but will also need very specific vertical programs. Likewise, the much needed call for the inclusion



**Figure 3. World mapping of absolute number of cancer deaths. Territories are sized in proportion to the absolute number of people who died from cancer in one year. Malignant neoplasms (cancers) caused 12% of all deaths worldwide in 2002, an average of 1144 deaths per million people per year. Adapted from Worldmapper.org (data as of 2002). International Classification of Diseases-10 codes: C00-C97.**



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of cancer as a Millennium Development Goal<sup>(26)</sup>, and this partial recognition by the recent UN General Assembly to work towards a high level meeting of the General Assembly<sup>(27)</sup>, is a positive international response. Nevertheless it is still a long way from a tangible adequately-funded global cancer action plan. G20 leaders could do much to catalyze this. This should and will require careful thought. Donors should be willing to ask the hard questions as to whether proposals will lead to better cancer public policy and, through this, better control. Different countries, regions and even domains of cancer control (surgery, palliative care, etc) will need bespoke vertical action and as these are evolved (Figure 3), the need to weave them horizontally with cancer control as a whole and wider into health will be a serious intellectual and logistical challenge. There is plenty to guide G20 leaders including the analysis of Official Development Assistance (ODA) policies as well as the lessons learnt from other global health (mis)adventures. Multilateral coordination is the ultimate goal but confidence-building steps between donors, advocates and national leaders will be required for a full International Cancer Control Plan.

For both prevention and early detection, the critical factors will be the social determinants of health, fit-for-purpose technologies and the requisite infrastructure (this includes manpower and training). Other domains of cancer control also need strong international public policy. The Palliative Care Access program from the INCTR and WHO policies on this area have created a strong advocacy movement which can be built on. Likewise, the efforts of the IAEA in bringing radiotherapy provision to many LMC countries is a model start. However, we have yet to see a concerted effort and advocacy around

surgical oncology or indeed around how LMC are going to access essential cancer medicines. There is a critical need for new public policies in both these areas. Furthermore, there needs to be recognition of the fallacy of trying to translate clinical guidelines and/or systems from developed countries to LMC. International Cancer Control Planning is not amenable to one-size-fits-all. Dealing with, for example, the complexities of orthodox and traditional approaches and systems used by most LMC for cancer treatment requires a deep understanding and empathy with the socio-cultural norms of these societies in order to develop the most effective systems and programs. Increased institutional cooperation would be a major step forward. Cancer centers in developed countries can provide faculty, funding and other support for networks and centers in LMC. The relationships should be reciprocal; developed countries have much to learn in terms of novel cost-effective management techniques but more importantly from the critical issues under which much of the world operates when developing their cancer control plans.

Research is vital and absolutely integral to ICCP. Many developed countries take their responsibility to fund cancer research seriously but in practice do not always do so. Data gathered during the European Cancer Research Managers Forum (ECRM) project identified major shortfalls in many countries<sup>(28)</sup>. More seriously though are, a) the imbalance between different domains of research, and b) the lack of funding to support research regarding controlling the cancer burden in LMC. In the latter case our current estimates from the Centre for OncoPolicy indicate that less than 2.7% of global funding goes to cancer research specifically relevant for LMC.

This is an astonishing 97/3 gap. On the former issue, cancer research funding has been extremely generous towards fundamental biology and drug development, and far less so towards many other crucial areas. Proactive measures to stimulate and fund research in prevention, early detection, childhood cancers and cancer surgery, to name but a few, are needed. Improvements in global cancer outcomes require research across the full spectrum. Data on the challenges and priorities for the public sector for global health, including cancer<sup>(29)</sup>, are now readily available and whilst totals have risen, the distribution of contributions has not changed significantly<sup>(30)</sup>. There is a strong case both for the creation of a Global Cancer Fund and for increased corporate responsibility and national research funding organizations to support work outside their borders. The building blocks and tools are there to construct an international cancer control plan; so too are the builders. It is, as in so many cases, now simply a matter of will. ■

References available at [www.inctr.org](http://www.inctr.org)

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2. Arnie Purushotham, Director of Kings Health Partners Integrated Cancer Centre and Professor of Breast Cancer, King's College London and, Guy's and St. Thomas' NHS Foundation Trust, London, United Kingdom.

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## INCTR'S CHALLENGE FUND



The INCTR Challenge Fund started life simply as "The Challenge Fund"; a charity established by individuals allied to the European School of Oncology (ESO). Registered as a UK charity (Charity 1079181) in January 2000, the Challenge Fund supported cancer research projects in countries outside the EU such as Georgia and Yemen.

In 2008 the responsibility for managing the charity was transferred to INCTR's UK Office, with Mark Lodge (Executive Director INCTR UK) appointed as the charity's first Director. Soon afterwards the charity changed its name to become the INCTR Challenge Fund and a new Board of Trustees was appointed to reflect the charity's new mission: to raise awareness about the impact of cancer in developing countries and to support INCTR's international capacity building programs.

The charity currently supports two key INCTR programs: the INCTR Palliative Access (PAX) program and the INCTR Burkitt Lymphoma Program. Grants from the INCTR Challenge Fund have enabled PAX members to travel to Nepal and work with local health care professionals in building capacity for the palliative care of terminally ill patients and improving access to pain-relieving drugs. INCTR's Burkitt Lymphoma Program provides treatment costs and training for health care staff treating children suffering from the most common type of childhood cancer in Equatorial Africa. This is a cause close to the heart of two of the charity's strongest supporters:

Geoff and Jayne Niblett, the parents of Christopher Niblett, himself a victim of Burkitt Lymphoma.

Christopher was a fit and healthy young man training to become a teacher in the UK. He loved to participate in sports and completed the London Marathon in 2000. First diagnosed with Burkitt Lymphoma in August 2005, Christopher remained extremely positive throughout his illness, stating that when he was better he would like to help all the young children in Africa who, like himself, were suffering from Burkitt Lymphoma but were not receiving the treatment available to him.

Sadly, Christopher was never able to carry out that wish as he died in July 2006. A memorial fund was set up in his name. Every year the Christopher Niblett Memorial Fund organizes several fundraising events (including a Barn Dance, an Open Garden, the annual Craft Fair and a charity football match) and donates the proceeds to the INCTR Challenge Fund. (The dates of the 2011 events will be advertised on the Challenge Fund website.) To date, £37,500 has been raised, of which £32,250 has been given to the INCTR to help treat African children with Burkitt Lymphoma. A plaque commemorating Christopher's memory hangs above one of the hospital beds in the children's ward at the Ocean Road Cancer Institute, Dar-Es-Salaam in Tanzania, where many of these patients are treated.

Other volunteers have also helped the INCTR Challenge Fund raise funds for the INCTR BL program. Matthew Hutchinson, a bone cancer survivor, walked 10 miles across the Derbyshire Dales with a new prosthetic implant in his left femur. Seven volunteers have pledged to run marathons or half marathons in 2011 to raise funds for the charity, including Glenn Colville, serv-

ing with the Rifles Regiment, Jos Busby, a computer support expert working with Kaspersky's Labs, and Isabella Peres, who is studying for her Ph.D. in neurology at Reading University.

Donations are raised through the charity's website [www.challengefund.org](http://www.challengefund.org) where visitors can read about the charity and its latest activities and donate through Charity Choice. The INCTR



**Jos Busby training for the London Marathon 2010.**

Challenge Fund also uses the JustGiving website (<http://www.justgiving.com>) to help its marathon athletes achieve their fundraising targets. Both sites enable the charity to raise extra revenue through the UK Government's "Gift Aid" scheme. Gift Aid will provide an additional 25% on top of donations made by most UK taxpayers.

The INCTR Challenge Fund works with volunteers from the UK and other countries, helping them raise money and awareness by supporting their participation in fundraising events. If you would like to host an event on behalf of the charity, please contact Mark Lodge at [enquiry@challengefund.org](mailto:enquiry@challengefund.org). ■

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## WORKSHOP REPORT: "WHAT CAN WE LEARN FROM AFRICA?"

**Certosa di Pontignano,  
Siena, May 7 - 8, 2010**

This workshop, held in the beautiful former monastery Certosa di Pontignano, just outside Siena, Italy, was a follow-up to an assessment visit by a team of five experienced hematopathologists, comprising the INCTR Pathology Program, from Europe and the USA (Leonie Ayers, Nina Hurwitz, Lorenzo Leoncini, Naresh Kikkeri and Martine Raphael). The team visited histopathology departments in East Africa (Uganda, Tanzania and Kenya) during the Autumn of 2009 to perform a central pathology review of all patients who had been entered into INCTR's study 03-06 on Burkitt lymphoma. This study includes both HIV+ and HIV- patients and is ongoing in all three of the countries visited, as well as in Nigeria. The team also assessed the facilities, knowledge and experience in each of the centers visited by reviewing over 400 consecutive lymphoproliferative lesions seen at these institutions. Although nearly all cases had been examined and analyzed by basic histological techniques in the reporting laboratory, cases that could not be diagnosed, or in which there was lack of agreement among the pathologists, were studied by immunocytochemistry and molecular techniques in the laboratories of the visiting pathologists. All cases were classified according to the WHO classification 2008. While the visits themselves permitted assessments of the needs for accurate diagnosis in the African centers (one of the most important being immunohistochemistry), it also

became clear, during discussions among the pathologists examining slides together, that a follow-up workshop would be of considerable educational value to all. Accordingly, Professor Lorenzo Leoncini arranged for such a workshop in Siena to take place in May 2010.

The goals of the Siena workshop were to permit the sharing of experience of the visiting hematopathologists with pathologists from different backgrounds and countries across the globe. Additional experts with particular expertise in lymphoma pathology, and with the latest World Health Organization classification were invited to discuss the diagnosis of specific entities and to attempt to devise a way of improving diagnostic skills and knowledge among African pathologists who largely, at present, do not have the tools to diagnose all cases according to the WHO. Clearly, accurate diagnosis is an essential requirement for providing appropriate treatment and conducting meaningful clinical research. The meeting included participants from Africa, India, Europe and the USA. Each expert presented an overview of the pathology of one or more lymphoma subtypes and discussed the most challenging African cases, illustrating pitfalls in lymphoma diagnoses and how to avoid them.

After introductory remarks by Ian Magrath, INCTR, Bruxelles, Belgium, and Mostafa Nokta, NCI - Bethesda, USA about the work of the INCTR and NCI in the context of Burkitt lymphoma in Africa, Shaheen Sayed, from Nairobi, Kenya, talked about the feasibility of using the WHO lymphoma classification in the context of diagnostic practices in Africa, offering a pathologist's perspective. Her conclusions were that even with a pathologist-population ratio of 1 to 800,000 in Kenya, it is not only necessary but

possible to ensure good clinical practice in at least the major laboratories, which could become centers of excellence that would participate in education, training and research, and international collaboration.

One of the most challenging diagnostic difficulties throughout the world is the differential diagnosis of diffuse large B-cell lymphoma (DLBCL) and Burkitt lymphoma (BL). Martine Raphael, from the University Paris Sud, France, highlighted this in her presentation entitled "Intermediate cases between BL and DLBCL are likely to be a real disease entity: a lesson from African cases".

These cases, with histopathology intermediate between BL and DLBCL are included in the 2008 WHO classification, although they are known, on the basis of several studies, to represent a somewhat heterogeneous group at a molecular level. The INCTR study has demonstrated that intermediate forms are frequent in African patients. They are known to be very aggressive tumors and there is much need for further studies to determine whether they differ in clinical features and treatment outcome from BL and DLBCL.

Naresh Kikkeri, from Imperial College London, UK, discussed "How to make a diagnosis of BL with a limited panel of antibodies." The essentials necessary to formulate a diagnosis of BL are not based merely on morphological features. He proposed a scoring system based on five immunostains (CD10, BCL2, CD38, CD44, Ki-67) that would permit distinction between BL and other high grade lymphomas. This approach should be applicable in countries with limited resources.

The importance of HIV-associated lymphomas and of atypical lymphoproliferative disorders in HIV-positive patients in the developing world was addressed by Leonie Ayers and Ethel

Cesarman; cases were presented by participants from Tanzania and Nigeria.

Additional presentations included "New insights of the pathogenesis of infection driven Lymphoma," by Lorenzo Leoncini, whose analysis of microRNA from 400 patients suggested that there is a correlation between the presence of infection and concurrent neoplasia.

Anita Borges, from Bombay, India, spoke on "Malignancies mimicking lymphomas – how to differentiate these from lymphomas by morphol-

table discussion during which practical recommendations were made for improving lymphoma diagnosis in Africa and for adapting the WHO classification of lymphoma for the practice of lymphoma pathology in developing countries. It is imperative to bridge the gaps between developing and developed countries. Though there are no magic answers for an issue of this magnitude, twinning between institutions in the developed countries and developing countries is likely to contribute to both immediate and

oped countries, but is used in Africa because of its low cost. Unfortunately, the quality of the material obtained by this means is often inadequate to make a diagnosis. Another important problem is the frequently poor quality of the histology in cases where biopsies are performed, and the complete lack of immunohistochemistry and other supportive investigations considered by experts to be absolutely necessary for a correct diagnosis to be made. Because of these limitations and also a lack of continuing education, the current WHO classification is not generally used to diagnose lymphoid malignancies in sub-Saharan Africa. Telepathology, as already employed by the Italian NGO Pathology oltre Frontiere, and by INCTR (iPath), can be a useful tool in linking pathologists in different continents, thereby providing additional capacity for consultation and further technical improvements in low-resource settings (see last edition of NETWORK).

It was felt that the goal of this meeting - to share the experience of the visiting hematopathologists with pathologists from different backgrounds and different sites across the globe - was successfully met. Furthermore, this meeting provided an excellent opportunity to plan future clinical and research studies in lymphomas through collaboration between the more and less developed countries. ■

*Lorenzo Leoncini  
INCTR Pathology Program  
Karin Schurfeld  
University of Siena  
Siena, Italy*

*The meeting was sponsored by  
Istituto Toscano Tumori, NCI,  
Menarini Fondazione Monte dei Paschi  
and the Università di Siena.*



**Participants in the Siena Workshop.**

ogy, with or without a limited panel of immunostains." She impressed upon the audience the fact that not everything that looks like a lymphoma is a lymphoma. The importance of a correct diagnosis was also highlighted in a talk entitled "Therapeutic implications of the incorrect diagnosis of malignancies mimicking lymphoma", given by Emanuele Zucca of Bellinzona, Switzerland.

The meeting ended with a round-

lasting improvements in diagnostic accuracy, through capacity building, consultations and both direct and indirect technology transfer.

The INCTR-sponsored study of lymphoma cases from various institutions highlighted several remediable problems. A major problem is the current practice of basing lymphoma diagnosis on fine needle aspiration cytology alone in a large proportion of cases, a practice that is not acceptable in devel-

# NETWORK

## E-LEARNING: INCREASING EDUCATION WITHOUT THE BURDEN OF TIME OR MONEY



In today's society and current economic climate, time and money are probably two of the biggest issues we face when having to make a decision. The conclusions are often the same: either we don't have enough time or something is too expensive. All too often, we don't have enough of either! When it comes to further education or attending conferences and meetings, we find ourselves having to renounce opportunities for continuing education or keeping up with ongoing research because of our busy schedules and tight budgets.

But in today's technological era, these two problems can surely be overcome. The ever-increasing use of the Internet has meant that our world has seemingly become smaller and smaller. We communicate with people in other nations as if they were sitting in the office next door, often building strong relationships with people whom we never actually meet. This new way of working has meant that our lives have become somewhat impersonal; we lack physical contact with others. We are frequently stuck behind a computer screen for hours every day. However, the advantages of the technological boom seem to

outweigh the disadvantages and even though we may prefer face to face contact, using technology can enhance the frequency of interactions, which are no less valuable, and indeed, need not and do not completely replace face-to-face meetings.

E-learning is just one of the many benefits that the cyber generation has given us and the concept is simple. Rather than attending a traditional course/seminar requiring time off work and the cost of travel and accommodation, by simply turning on the computer you and many others who may be spread across the globe can attend simultaneously online – eliminating those two burdensome problems of unproductive time and the cost of travel!

In 2008, the European School of Oncology (ESO) in collaboration with Nature Reviews in Clinical Oncology, and with the issues of time and money very much in mind, decided to launch its own e-learning project. With its motto at the forefront "Learning to care," ESO designed a weekly webcast format that would keep oncologists up to date with the latest news and views in the world of cancer and at the same time would give them the opportunity to interact with an expert on a given subject without having to leave their homes or place of work.

Now, oncologists from around the world log into the e-eso.net website every Thursday at 18:15, Central European Time, where they are able to view a live webcast called an "e-grandround" in which a chosen expert addresses a hot topic in the field of cancer via a short presentation, including slides. Taking part in the webcast is also a selected discussant. Whilst viewing the webcast, the participants are able to send questions to the discussant, and these are then put to the expert, creating a live and interactive discussion.

It took a long time (the program is in its third year) to find a time and day that would work well for everyone - viewers may be just finishing work in Europe, on a lunch break in the United States, just finishing dinner in Africa, or on a night shift in Japan, but so far the chosen time seems to be the best compromise, and attendance has grown.

One of the things that makes ESO's e-learning program so appealing to cancer clinicians is the fact that these weekly e-grandrounds are held without any commercial sponsorship and are free of charge to the participants. All that is required from those wishing to view a session is to complete a simple registration form that literally takes two minutes. From that moment onwards participants are able to view as many e-grandrounds as they want.

Obviously not everyone is available at 18:15 on Thursdays, so each session is recorded and available online for at least six months. What's more, all ESO's e-grandround sessions are CME and ESMO-MORA accredited, meaning that the program has been recognized for its high quality value both from scientific and didactic points of view. In order to obtain a CME certificate, participants can follow either the live or recorded session, after which the system asks them to complete an evaluation form. Then they are directed to a multiple-choice test of five questions. To pass the test and obtain the certificate, the participant has to attend the session and answer four out of the five questions correctly. The certificate is then released electronically and the participants can log into their account on the e-ESO site and track their certificates.

As well as the official certification, ESO has created its own e-learning quiz called the Mastermind quiz, with the idea of making learning fun. The Mastermind quiz uses the same five multiple-choice questions from the



CME test, the difference being that here “time” is an important factor. The winner is the participant who answers the most questions correctly in the shortest time. Each week the names of the top three participants from the previous week’s e-grandround are published on the e-ESO website and at the end of the year the participant who scored the best throughout the year receives a prize. In 2010 the Mastermind prize was awarded to Mher Kostanyan, a surgical oncologist from Yerevan in Armenia. A regular viewer of the e-grandrounds, Mher participated in the quiz 72 times in total and finished first four times. On learning that he had received the Mastermind prize, Mher said that “ESO e-grandrounds are very informative and useful for me. I get up-to-date information which is relevant to my work and practice.” He doesn’t need to leave Armenia to gain access to this information, he doesn’t have to spend any money, and he can choose whether and when he wishes to take part in a session.

The e-grandround program has been a great success. ESO has held more than 130 e-grandrounds to date on a variety of subjects. There are more than 2900 registered users on the site from more than 100 different countries, proving that distance is not a limiting factor.

In 2010, ESO decided to extend its e-learning program with the introduction of a new type of webcast,



called e-oncoreviews. The format is the same but the focus is different. While e-grandrounds focus on hot topics, e-oncoreviews have been designed to offer a balanced and comprehensive overview on a specific topic, be it a tumor type, a type of therapy, or a diagnostic or therapeutic approach. Some e-oncoreviews are organized in collaboration with the School's sponsors, whilst ESO-organized sessions are held in cooperation with Nature Reviews in Clinical Oncology and Critical Reviews in Oncology-Hematology and remain CME and ESMO-MORA accredited. E-oncoreviews are held on the first Tuesday of each month at the same time, 18:15 (Central European Time).

Beginning in 2012, ESO's e-grandrounds will also be used by the University of Ulm in its online MSc in Advanced Oncology. Students on the online MSc will be required to

view e-grandrounds as part of the curriculum, bringing even more academic recognition to the ESO program.

ESO's E-sessions have become part of an oncologist's calendar, the time and day of the week are now regularly scheduled into people's diaries, the same participants are often seen again and again, and new participants are joining each week. Often, presenters comment that they enjoyed taking part in the session because they found them more interactive than the usual presentations they attend, so maybe we need to start viewing e-learning as a form of education that breaks the traditional barriers of communication and not one that limits us to an impersonal way of life. ■

*Corinne Hall  
The European School of Oncology  
Milano, Italy*



For further information on e-ESO sessions and the full program for 2011 please visit [www.e-eso.net](http://www.e-eso.net)

## **E-grandround**

>> every Thursday, 18:15 - 19:00 (Central European Time)

## **E-oncoreviews**

>> first Tuesday of each month, 18:15 - 19:00 (Central European Time)

# NETWORK

## **PEDIATRIC ONCOLOGY IN TANZANIA – THE REWARDS OF PARTNERSHIP**

Pediatric malignancy and its treatment have evolved dramatically over the last 50 years. At the beginning of the 1960s the situation was hopeless worldwide. Treatment options were extremely limited and the vast majority of children died. However, since then, protocols and oncology services have been developed and refined

This success story has not been reflected in resource-poor settings where up until recently priorities have been focused on delivery of basic health care and combating infectious diseases. Resources have not traditionally been available for non communicable disease (NCDs) such as cancer, in part because of its markedly lower incidence compared to infectious diseases and other acute illnesses, and in part because of the complexities of therapy and lack of persons knowledgeable about cancer.



**Ocean Road Cancer Institute, Dar es Salaam.**

through clinical research, such that treatment successes of up to 90% for some of the more common childhood cancers are now routine. This remarkable achievement is reported from all oncology centers in resource-rich countries. Quite why the majority of children with cancer were entered into clinical trials, which is not the case for adults, is unclear, but may relate to the relative rarity of these tumors, such that pediatric oncologists were under much greater pressure to share experiences and patients for clinical studies.

These global phenomena have raised interest in the area of NCDs in general, cancer being one of the four that account for 80%, globally, of all NCDs and is perhaps numerically more important among the NCDs of children. At least 80% of all pediatric cancers occur in developing countries. These countries have populations with much greater proportions of children and fewer elderly persons, such that age-structure alone could account for the greater proportion of children with cancer, but cancer in general has been

increasing as a consequence of greater exposure to the known risk factors that are still causing an increase in cancer incidence throughout the world, and exposure to which often begins in childhood, while various infections that cause cancer in childhood (e.g. HIV) or later in life, such as HPV, are becoming less of a problem due to the development of vaccines and antibiotics. As a result, throughout the continent of Africa, oncology facilities have appeared, offering cancer screening, simplified chemotherapy schedules, radiotherapy and surgery for both cure and palliation. However, research in these centers is minimal - specialists are attempting to address this very real need using lessons learnt in the more affluent regions of the world. Much of this knowledge is globally applicable, but circumstances and populations are so different in countries with limited resources that research in these countries is essential if optimal prevention and treatment programs are to be developed.

The International Network for Cancer Treatment and Research (INCTR) was established in 1998 to assist these initiatives in resource-poor countries. The vision of the founders was to provide cancer care support and expertise within the controlled context of treatment trials and protocols where the urgent need for cancer treatment programs had been highlighted by local partners.

Tanzania is a typical resource-poor country with a human development index of 152/179 in 2009. 44% of the population is under the age of 14 years. Dar es Salaam, which in Arabic means "haven of peace," was the original capital and remains the largest city with a population of over 2.5 million. However, 80% of the 37.5 million total population are farmers living in remote rural areas, making health care delivery a real chal-



**Dr. Trish Scanlan with two cancer patients.**

lenge. It is estimated that each year in Tanzania, there are approximately 2000 new cases of childhood cancer. Most of these children die without access to appropriate treatment.

As an initial bold step in the creation of an effective national cancer strategy, the Tanzanian government has pledged to provide all cancer-related services free of charge to all her citizens. The importance of this initiative cannot be underestimated. Cancer care is complicated. Hospital costs include admission fees, various and repeated investigations and of course treatment and supportive care. Removing these fees has done much to make universal cancer care access feasible even in the context of the poor in Tanzania. Since 1982 this care

has been coordinated through the Ocean Road Hospital (now the Ocean Road Cancer Institute (ORCI) in Dar es Salaam, the national and first cancer care facility in Tanzania.

Further progress was made in 2004 when pediatric oncology officially began with the opening of the first dedicated pediatric ward. The same year, the INCTR Burkitt Lymphoma trial commenced. This trial has improved two-year survival in BL patients from 15% to 73% in six short years at ORCI.

Following these admirable first steps and to ensure ongoing progress in pediatric oncology, in 2006 a study was begun to identify additional areas needing support and development. Over the following years solutions to these highlighted needs were sought,

implemented and subsequently evaluated for effectiveness.

As predicted, access to care or delayed presentation was one of the most serious problems identified, with patients waiting on average seven months from initial symptom awareness to starting appropriate treatment. The methods considered to combat this problem included a national cancer awareness campaign to highlight the early warning signs of childhood cancer – lymphoma/leukemia and retinoblastoma to begin with; establishing links with referring doctors and regional hospitals to open regular lines of communication; finding novel ways to assist families with travel and other hidden costs (such as loss of earnings while at the hospital); and considering moving the



# NETWORK

children's oncology facility from ORCI to the University Hospital (MNH) where most children spend a great deal of time while the diagnosis is confirmed. All of these plans are now underway.

On the children's ward at ORCI, additional challenges were identified, including diagnostic difficulties, lack of comprehensive staging, no established treatment or supportive care protocols, a lack of surgical access to ICU care and a basic lack of essential chemotherapy. Medical and non-medical disposable items were regularly out of stock and modern automated equipment was generally lacking from laboratory services.

Only those children enrolled in the INCTR BL trial were consistently given all prescribed chemotherapy and this was the only full protocol in use on the ward at that time.

Staffing shortages, both nursing and medical, were deemed an urgent priority. Children were regularly left without any nursing care for long periods of time, especially over night, such that essential treatments were not possible - including the administration of IV fluids, blood and antibiotics.

Accurate diagnosis and staging has been identified as extremely important and care is now taken to complete these steps prior to the initiation

of any definitive treatment. External laboratories assist where hi-tech or even basic investigations are unavailable in-country.

The key improvements to care in the last three years include: the provision of all chemotherapeutic agents and all supportive care drugs free of charge to all patients, the application of internationally recognized treatment and supportive care protocols, the introduction of 24-hour nursing care and basic nutritional support for all children and caregivers. This has only been possible thanks to the combined generosity of hundreds of companies, institutions and private individuals. In the last three years, INCTR has played a key role on the clinical side of these changes. Children in Crossfire (CiC), another non-government organization, has also made a major difference through its championing of children's cancer in Tanzania. CiC has been central to effective change in many ways through committing to support non-clinical needs for the children, including running the children's school (in partnership with the Tanzanian government), fundraising and coordinating support for much of the clinical changes on the ward and raising childhood cancer awareness at local, national and international levels. It is the partnership between the Tanzanian government and these two complementary organizations that has allowed such rapid progress.

Recently the children's facility space itself was deemed insufficient for the demand. Regularly two or three children share a bed. In 2005, approximately 150 new children were seen. By 2009 this figure had risen to 330. In fact, thanks to the success of recent initiatives, this situation has become significantly more serious with on average 50-60 inpatients now cared for in this space originally designed for a maximum of 17 patients.



**Space availability makes it sometime necessary to share a bed!**



To begin addressing this issue, a brand new ward facility has been designed and renovated at the MNH. There are also imminent plans to build a “home-away-from-home” facility. This hostel facility will provide not only accommodation and food for long stay patients and their families but also space to provide classrooms for the children, health education and income generation for parents. The hostel will eventually be managed by the newly established parents' support group. It is hoped that this group will take on many non-clinical responsibilities including parent education, advocacy and fundraising.

But improved access and quality of care is only important if it leads to improved survival in the children treated. The number of children accessing the service has increased by 220% from 2005 to 2009. One-year overall survival has improved from 25% in 2005 to 60% in 2009, so in clear, measurable terms the situation is improving dramatically. Individual cancers have improved at different rates: for example, the one-year survival of acute lymphoblastic leukemia has improved from 0.5% in 2005 to 50% in 2009 and retinoblastoma from 15% to 45%. These results fall far below the average in resource-rich settings but they are moving in the right direction.

Following these meaningful changes to oncology care at the children's ward at ORCI, the time has come to once again look nationally. Tanzania requires more than one pediatric oncology facility in order to fulfill its promise to provide cancer care to all children who need it. The distances are vast – parents can travel three to four days and cross national borders just to reach Dar es Salaam. The provision of care to all children would need at least five or six specialist centers throughout the country.



**Children can have fun even during treatment.**

As a result, all interested partners are currently designing a National Pediatric Oncology strategy for the next five years. It is proposed that the ORCI/MNH facility remain the center of excellence for children's cancer in Tanzania and possibly in East Africa. It will adopt an educational role, developing curricula for both nursing and medical sub-specialty training. It will also generate public awareness material and continue to act as the primary focal point for national awareness campaigns regarding children's cancer.

It will cooperate with other university centers around Tanzania and assist in the establishment of sister pediatric oncology centers in these hospitals. Bugando Hospital in Mwanza has already made great progress in establishing a second facility for children's cancer. It is hoped that this local initiative can strengthen the partnership with the national facility in Dar es Salaam and that other university hospitals will soon follow with similar programs. The Tanzanian

government and both international organizations – INCTR and CiC – as well as many other local groups and individuals, are committed to making this strategy a viable reality for all Tanzanian children.

This stepwise model is feasible and manageable in resource-poor settings. Tanzania started with a national governmental commitment and vision, leading to the establishment of a local facility requiring International NGO partnerships for strengthening and progress and finally the design of a realistic national pediatric cancer care plan. It is working in Tanzania. It could work in similar resource-limited circumstances elsewhere in the world.

Children's cancer is curable no matter where the child is born. Tanzania is working to make this statement a reality. ■

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Matthew Banks  
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# NETWORK

## PALLIATIVE CARE IN PAKISTAN – THE ROLE OF INCTR

As the incidence of cancer continues to increase in the developing world, an urgent need for palliative care services is emerging, outpacing even the need for cancer treatment, since most patients present with advanced, and in most cases, incurable disease.

The World Health Organization (WHO) defines palliative care as improvement in the quality of life of patients “through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual<sup>1</sup>.” In developing countries, money allocated to public health programs has been spent largely on the prevention and treatment of infectious diseases and malnutrition. Hence, palliative care has remained a neglected discipline. Studies have shown that only about 6% of all palliative care services are located in Asia and Africa, which account for 80% of the world’s population, and their main focus, to date, has been in HIV-infected patients<sup>2</sup>.

The situation in Pakistan is consistent with the global pattern. Pakistan is a low to medium income developing

country with a growing population of approximately 180 million (Fig 1) and an annual economic growth rate of 2.03%. The population is young with 37% less than 15 years of age, and a literacy rate of less than 50%. 36.45 million live below the poverty line<sup>3</sup>.

Cancer is one of the major health care problems in Pakistan. In the absence of a national population-based cancer registry, the precise incidence, mortality rates, number of new cancer cases and number of deaths annually in Pakistan are not known. However, according to WHO estimates, as many as 61,624 incident cases and 42,624 cancer deaths occur annually in males and 75,095 incident cases and 43,188 deaths occur annually in females. In children too, cancer is now recognized as an important cause of morbidity and mortality. Based on the data from the Karachi Cancer Registry, it is estimated that approximately five to six thousand children develop cancer every year in Pakistan with survival rates varying between 20-60%<sup>4</sup>.

Although Pakistan has a National Cancer Control Plan in place, it is poorly implemented, especially with regard to the development of palliative care services and morphine availability. In fact, palliative care was only included in the second phase of the implementation of

the plan (due to begin in 2009)<sup>5</sup>. As a result, most patients who present with advanced disease, in need of palliation from the start, face abandonment when terminally ill and usually die with poorly controlled pain.

In a recent publication mapping global levels of palliative care development, the International Observatory on End-of-Life Care categorizes Pakistan as a Category 3 country (Localized hospice-palliative care provision)<sup>2</sup>.

## ISLAM AND PALLIATIVE CARE

Palliative care has not been a difficult concept to introduce in Pakistan. For most Muslims, care of the dying is considered an important responsibility of the family, friends and extended community. Death is preferred at home surrounded by loved ones and prayers. Based on religious precepts, the concept of ‘do not resuscitate’ is easily accepted by most Muslims.

## MORPHINE AVAILABILITY

This continues to remain one of the biggest problems in the implementation of good pain control, especially for terminally ill patients. Morphine is still not freely available, even at the major centers that treat cancer; supply is sporadic and there is no support from the government to improve its availability. Though Pakistan still lags behind other developing countries in the use of narcotics, oral morphine has become available in tablet form along with some other expensive agents such as Fentanyl (Fig 2).

## PALLIATIVE CARE SERVICES

In the last 10 years, palliative care services have slowly evolved in Pakistan. This has occurred mainly as awareness of cancer has increased in the medical community along with help from international organizations such as INCTR and APPNA, amongst others,

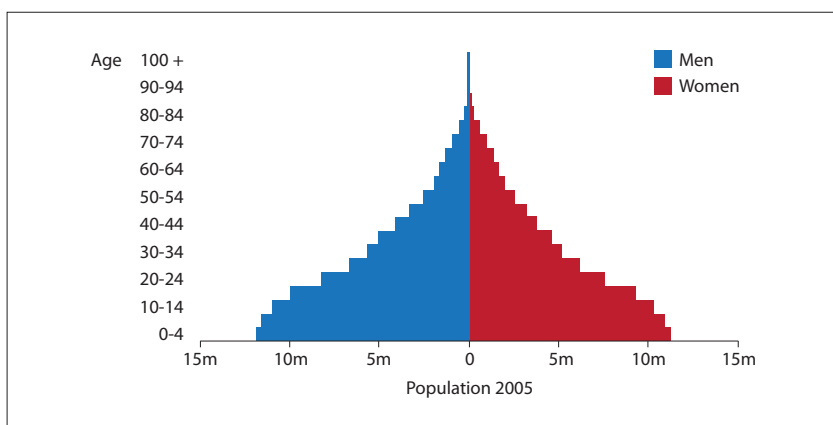


Figure 1. Population pyramid for Pakistan (m = millions).



Question time with Stuart Brown and Aziza Shad during the palliative care workshop.

that have focused their initial efforts mainly on training and education in palliative care.

Palliative care programs, including pain services, are rapidly developing in large city hospitals that treat patients with cancer. For example, fairly well developed palliative care services exist at the Shaukat Khanum Memorial Cancer Center (SKMCC) in Lahore, and the Aga Khan University Hospital in Karachi. There are pain management teams primarily consisting of anesthesiologists at some private hospitals, an increasing number of hospices scattered all over the country, and slowly improving home care and pediatric palliative care services.

## 1. SHAUKAT KHANUM MEMORIAL CANCER CENTER (SKMCC), LAHORE

The palliative care program was initiated in 1997, run primarily by a nurse, with a focus on bereavement support. With the addition of a physician trained in palliative care in 2008, Dr Haroon Hafeez, it has grown significantly. The team now consists of four physicians, a nurse and a psychologist. It runs an active clinical service that provides inpatient and outpatient care and consultations for adults and children. Between October 2009 and October 2010, 1800 patients were seen in the outpatient

clinic and 700 inpatient consultations were performed. A 24-hour telephone helpline is available 365 days a year. For end-of-life care, the Liverpool Care Pathway has been followed since 2009. Home care and hospice care, however, are not well developed. Morphine is available, although supplies are limited.

Educational activities include a monthly video conference with St Francis Hospice, UK, where challenging cases are discussed, a monthly palliative care journal club, training courses for physicians and nurses and international palliative care symposia. Future plans include the development of satellite centers in other cities where the bulk of patients come from, community education, a palliative care fellowship program with Cardiff University and the formation of a national palliative care association that advocates for the availability of morphine and the development of palliative care services throughout Pakistan.

## 2. AGA KHAN UNIVERSITY HOSPITAL, KARACHI

The palliative care program at the Aga Khan University began in 2003. Presently, it is a comprehensive home-based palliative care and end-of-life care program. The team, which consists of a nurse specialist, social worker and a generalist, works with the primary oncologist and

family physician to provide care. This includes daily home visits, nutritional support including tube feeds and parenteral nutrition, central line care, ostomy and catheter care and pain management with oral or intravenous morphine infusion pumps and fentanyl patches. Outpatient pain clinics are run by anesthesiologists and oncologists. Pediatric palliative care is not well developed. Educational activities include training seminars, primarily for nurses.

## 3. PEDIATRIC PALLIATIVE CARE

This continues to remain in the early stages of development. Although awareness for pediatric palliative care has increased significantly, the services have not grown. There are currently two recognized pediatric palliative care programs in the country, both of which have occurred through affiliation with INCTR directly or indirectly; the Children's Cancer Hospital, Karachi and the Children's Hospital, Lahore, both started small in-patient palliative care units in 2008.

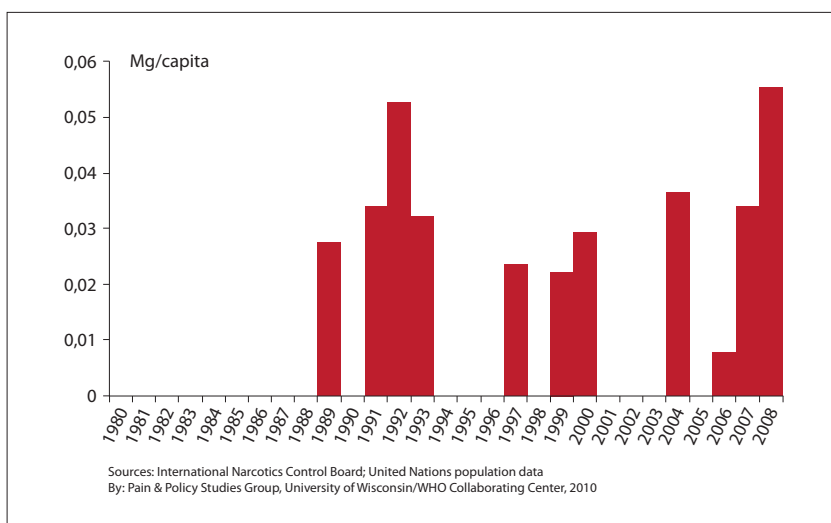
### • Children's Hospital, Lahore

The unit at Children's Hospital, Lahore, was established with a grant awarded by "My Child Matters" in 2008 with mentorship provided by Dr Aziza Shad. Although the psychosocial aspect of the program has developed significantly, lack of trained personnel, insufficient supply of morphine and absence of outreach continue to remain major problems.

### • Children's Cancer Hospital, Karachi

The Palliative Care Program at the Children's Cancer Hospital was initiated immediately following the First Palliative Care Workshop, held in Karachi in February 2007, a joint venture of the Pakistan Society of Pediatric Oncology (PSPO) and INCTR. Since then, it has developed into a small but viable program, run by a physician and social worker, with a two-bed inpatient

# NETWORK



**Figure 2. Mg/capita Consumption of Morphine in Pakistan, 1980-2008.**

unit, availability of parenteral and oral morphine, tramadol and other analgesics, outpatient care for all children with relapsed or advanced disease and psychosocial services for families. Future plans include the addition of a trained nurse and psychologist.

## ROLE OF INCTR IN DEVELOPMENT OF PALLIATIVE CARE SERVICES

INCTR is actively involved in the establishment of pediatric palliative care services in Pakistan, through various approaches to training and education. The following list includes activities that have taken place in the last two years:

1. In 2008, the first Palliative Care Symposium sponsored by INCTR and supported by OIA, NCI was held in Karachi, Pakistan. This served as an incentive for the development of two pediatric palliative care programs in the country.
2. INCTR members have been actively involved in subsequent palliative care workshops in Pakistan, most recently in Lahore at the Annual SKMCC Cancer Symposium, where a full day was dedicated to palliative care. The focus of the workshop was pain and symptom management and ethical issues arising in the context of palliation. Drs Stuart

Brown and Aziza Shad of the INCTR PAX Program helped in the development of the content of the workshop, as well as participating in it.

3. Mentorship for both pediatric palliative care programs is provided by Dr Aziza Shad. Based on the initial success of the palliative care initiative at the Children's Hospital, Lahore, the "My Child Matters" steering committee has extended the award for a third year.

4. In 2008, INCTR officially partnered with APPNA (Association of Physicians of Pakistani Descent in North America) to initiate a program introducing palliative care all over Pakistan. This program is moving ahead and will include training workshops and the introduction of palliative care to the medical and nursing school curricula.

## FUTURE INCTR INITIATIVES

INCTR plans to continue to expand its activities in palliative care in Pakistan. In particular, its activities will be focused on:

1. The National Palliative Care Association which is in its final stages of incorporation. It will serve as the platform for advocacy relating to palliative care services in Pakistan through lobbying the government for the provision of support and

the improved availability of morphine. Members of the INCTR PAX Program will serve as advisors to the association.

2. An INCTR-supported palliative care workshop will be held in Karachi in March 2011, in conjunction with the Pakistan Society of Clinical Oncology.

3. Capacity-building in palliative care will continue through the joint INCTR/APPNA initiative.

- a) The first Web-based Palliative Care seminars will begin in March 2011.

- b) Together, INCTR and APPNA continue to successfully lobby for introduction of palliative care training modules in medical, nursing and pharmacy school curricula.

4. Through the Middle East Cancer Consortium (MECC) / INCTR initiative, physicians and nurses from Pakistan will now be invited to training workshops conducted by MECC.

## CONCLUSION

The need for palliative care is gaining awareness in Pakistan. INCTR continues to provide support in the form of education and training. In spite of the success of efforts to date, many patients who need palliative care still do not receive it: the role of INCTR in establishing palliative care services needs to be expanded, with a special emphasis on children. ■

References available at [www.inctr.org](http://www.inctr.org)

Aziza Shad, INCTR USA

Georgetown University Hospital

Washington DC, USA

Shamvil Ashraf

Children's Cancer Hospital

Karachi, Pakistan

Zehra Fadoo and Ahmed Naqvi

Aga Khan University Hospital

Karachi, Pakistan

Haroon Hafeez

Shaukat Khanum Memorial Cancer Center

Lahore, Pakistan



## BURKITT LYMPHOMA WITH CUTANEOUS INVOLVEMENT IN UGANDA

An 11-year-old boy was admitted at St Mary Hospital Lacor, Gulu, from a remote village in Northern Uganda. The boy had fallen from a bicycle some months before and had since then been complaining about left lower limb swelling.

The mother first took him to a nearby regional hospital where a left tibia osteomyelitis was diagnosed and a sequestrectomy was performed. After the operation his general condition deteriorated. The mother brought the child to Lacor where he was admitted to the surgery department.

The boy appeared febrile (T38.5°) and wasted. He also had splenomegaly and lymphadenopathy in the neck (7x6 cm). The major finding was oedema of the lower left limb and a septic ulcerating soft tissue mass, measuring 15x7 cm, in the distal third of the leg. He also had left inguinal lymphadenopathy (3 cm). The left tibial x-ray revealed osteolytic bone infiltrates with a periosteal reaction. The abdominal ultrasound showed multiple hypoechoic masses in the splenic parenchyma (biggest 3.5 x 3.9 cm). The chest X-Ray was normal.

Because the surgeon suspected a malignant process, a skin biopsy was performed. The sample was composed of epidermis and dermis associated with some sub-cutaneous tissue. Microscopic analysis revealed diffuse infiltration of the dermis and subcutaneous tissue by a homogenous population of small to medium-sized round cells of lymphoid appearance.

Considering the peculiar site of the tumor, an immunohistochemical study was needed to achieve a final diagnosis and rule out a soft tissue high grade sarcoma. This analysis is

not routinely available at Lacor due to the (relatively) high cost of histochemical reagents and the specimen had to be sent to Italy for a complete immunohistochemical analysis. APOF (an Italian NGO whose name corresponds to "Pathologists without Borders") collaborates with the Lacor Hospital in supporting our pathology laboratory. Results were as follows: the malignant cells were positive for CD19, CD20, CD10 and BCL-6 and negative for CD5, BCL-2 and TdT. Ki67 was strongly positive on almost 100% of the cells. These findings were entirely consistent with Burkitt lymphoma. The overall process took several weeks and the final diagnosis was obtained more than one month after the patient's admission to Lacor and many months after the symptoms commenced.

Once the diagnosis was made, the patient was transferred to the pediatric oncologic unit. Despite the advanced stage of the disease and the delay in diagnosis, specific treatment was initiated using a combination of cyclophosphamide, vincristine and methotrexate intravenously as well as intrathecal methotrexate and cytarabine. He had a rapid response to therapy and he achieved complete remission. He comes regularly for follow-up.

### DISCUSSION

This case highlights the difficulties of recognizing, diagnosing and treating cancer in a poor, rural setting like Northern Uganda. Here, the vast majority of the people still live in mud-huts within small villages with no access to running water or electricity. There is limited access to hospitals due to bad road conditions and the absence of affordable public transportation. Not surprisingly, people resort to traditional medicine

or take the advice of unqualified personnel at a community pharmacy. Even healthcare units, however, often lack the necessary knowledge and facilities to diagnose and manage cancer.



**Ulcerative leg lesion.**

This is unfortunate since many leave as it was cancers, if correctly and timely diagnosed, are curable. The most common cancers in Uganda are cervical and breast cancers in females, and Kaposi's sarcoma, prostate and esophagus for males. For children, non-Hodgkin's lymphoma is the most prevalent cancer, with Burkitt lymphoma accounting for the majority of cases.<sup>1-2</sup>

Cancer is a growing concern in Uganda. According to our institution-based experience pediatric cancers are of increasing importance in terms of frequency, morbidity and mortality, especially among children between 5 and 15 years of age.

Between 2008-2010, Lacor Hospital observed 448 cases of pediatric cancer: 54% Burkitt lymphomas, 23% other lymphomas, 6% acute lymphoblastic leukemia ALL; 6% Sarcoma; 6% Wilms tumor and a small number of very rare tumors. There is only one cancer institute in the country, but distance and cost of treatment are prohibitive for most patients, so

# NETWORK

that many die without ever receiving therapy. Others may receive therapy at one of the hospitals that treats selected cases of cancer. Lacor Hospital, for example, has treated lymphomas, as well as a few other childhood tumors, including Kaposi sarcoma in AIDS patients, since the 1970s. Chemotherapy is provided free for patients with these types of tumor. In 2010 Lacor Hospital became part of the INCTR Burkitt's Lymphoma strategy group and began using the INCTR protocol. APOF sends pathologists to the hospital in order to assist in training and education of African pathologists and technicians.

The diagnosis of cancer requires knowledge and expertise. While a well-equipped pathology lab is key, clinicians are responsible for deciding when and how a biopsy should be done, and surgeons need to be familiar with the appropriate preservation of specimens for microscopic analysis. The clinician, whether before or at the time of operation, must also be sufficiently experienced to recognize or suspect "atypical" cases similar to the one presented.

Although Burkitt lymphoma can frequently involve extranodal sites, cutaneous involvement is very rare.<sup>4,5,6,7,8,9</sup> Cases of cutaneous Burkitt's lymphoma have resulted from tumor seeding after a surgical procedure<sup>6</sup> or local invasion of rapidly enlarging underlying tumors<sup>4,5</sup> but may also occur unassociated with recognized predisposing factors or tumor arising from deeper tissue. This patient's soft tissue and cutaneous Burkitt lymphoma was initially misdiagnosed as osteomyelitis with cellulitis and treated surgically, which does not provide adequate therapy for Burkitt lymphoma. This contributed to the late arrival to the specialized unit at Lacor hospital.

## CONCLUSIONS

Although in countries like Uganda it is not feasible to have every health care unit capable of diagnosing and treating cancer, efforts should be made to create common pathways of referral, in increasing awareness among clinicians and eventually in disseminating information about the availability of the treatment in various parts of the country. This would help patients

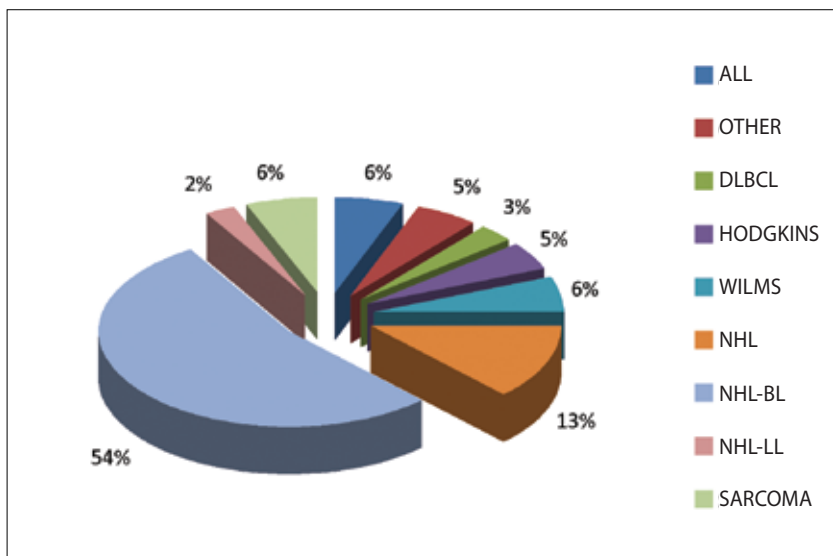
reach the most suitable specialized centers and ensure that patients are diagnosed and treated at the earliest possible time.

Even in an institution like Lacor Hospital where lymphomas have been treated for many years, the diagnosis is still a challenge because of the lack of specialists and the high cost of equipment. Immunohistochemical analysis is crucial in the differential diagnosis of some type of cancers especially for differentiating between sarcomas and lymphomas and defining subtypes of these tumors. Not only is the procedure costly, however, but the reagents are often unavailable. This causes added delay in initiating treatment and sometimes clinicians must make judgement calls as to whether they should initiate treatment with the available information in hand, changing therapy, if necessary, after receiving additional information from material referred to another institution, or can afford to wait for more precise diagnosis. Burkitt lymphoma grows sufficiently rapidly that patients can, and have died while awaiting diagnosis. At the least, they will develop more disease while awaiting the detailed report, lessening their chances of cure.

In conclusion, the scientific community could benefit by identifying common algorithms for the differential diagnosis of cancers which may include a limited panel of affordable antibodies selected for their relevance to tumors in which morphological distinction can be difficult. ■

References available at [www.inctr.org](http://www.inctr.org)

Valeria Calbi  
Michael Mowanda  
Martin Ogwang  
St Mary Hospital Lacor  
Gulu, Uganda



Distribution of pediatric oncologic cases at St Mary Hospital Lacor, 2008-2010.

# PARTNER PROFILE

## TATA MEMORIAL CENTRE, MUMBAI, INDIA<sup>1</sup>

### HISTORY

Tata Memorial Hospital (TMH), inaugurated on February 28, 1941, was founded by the house of Tata, one of the leading industrialist families of India. It was later given to the Government of India, and since 1962 has been operated by the Department of Atomic Energy. TMH was merged with the Cancer Research Institute (CRI, Est. 1952) in 1966, under the banner of Tata Memorial Centre (TMC), although both names remain in use. TMC's third arm was a Clinical Research Center (CRC) established in 2005. TMC is the national comprehensive cancer center for prevention, treatment, education and research in cancer and is recognized as one of the leading cancer centers in this part of the world. In order to fulfill its objective of providing the highest standards of patient care, the center has been continuously upgrading its administrative structure and its use of technology in order to deliver optimal cancer care as well as conduct research and education at a globally competitive level. As the premier cancer center in the country, TMC provides leadership for the national strategy for cancer control.

### THE PROBLEM

India is seeing a major increase in cancer patients and the disease is likely to double or triple its numbers over the next 20 years. This is due to various factors including population growth, increasing longevity and changing lifestyles, particularly the urbanization of rural India. Much of the true increase in incidence that has occurred is due to a few subtypes of cancer (e.g. breast and lung). As per Globocan figures (IARC 2008), 948,900 new cases of cancer were diagnosed

in 2008 with an age-standardized rate of 98.5 cases per 100,000 persons per year in India (as compared to 326.1 for Denmark and 300.2 for the USA).

Over 65% of cancers in India are tobacco related, breast cancers or cervical cancers, which are either highly preventable and/or can be diagnosed early by simple screening techniques.

nosis and another one million cancer patients will show progression of disease within five years of diagnosis.

### CLINICAL CARE

Surgery remains the basic approach to treatment, especially for patients with solid tumors. Nearly 6300 major surgical procedures are performed annu-



**TMH is the largest comprehensive cancer center in the subcontinent with approximately 600 beds. More than 43,000 new patients visit this center every year, of which nearly 2000 are children < 18 years of age. More than 60% of patients are treated free of charge or at a nominal charge. [www.tatamemorialcentre.com](http://www.tatamemorialcentre.com)**

In spite of this, the number of cancers is increasing every year and to make matters worse, 70% of newly diagnosed patients have advanced disease by the time they reach cancer centers such as TMC, such that they are incurable. This is partly because of lack of adequate number of comprehensive cancer centers with good infrastructure and well-trained human resources, as well as to a lack of medical insurance in India, such that most patients have to pay "out-of-pocket" – which, for the most part, they simply cannot afford. As a consequence, more than 50% of newly diagnosed patients in India will die within 12 months of diag-

ally in 20 state-of-the-art operating theatres at TMC. Wherever possible, conservative organ-sparing surgery is performed. Nearly 6000 patients are treated with radiotherapy each year with equipment that includes state-of-the-art technology. At TMC there are five cobalt units, six linear accelerators, two high dose brachytherapy units, several treatment planning systems with computerized tomographic (CT) stimulators, and two Image Guided Radiotherapy units with Helical Tomotherapy (IGRT). The radiology department is equipped with ultrasonography, mammography, CT-Scanners, MRI equipment and

# NETWORK

## OVERVIEW OF PEDIATRIC ONCOLOGY SERVICES AT TATA MEMORIAL HOSPITAL

Largest and oldest, most comprehensive Pediatric Oncology Program in the country. More than 1600 new patients (< 15 years) registered every year.

The team consists of Pediatric Medical Oncologists, Pediatric Radiation Oncologists, a Pediatric Onco-Surgeon, Orthopedic Oncologists, a Pediatric Neuro-surgeon, Pediatric Onco-Pathologists, a Pediatric Palliative Care expert, Medical Social Worker, Clinical Psychologists, a Rehabilitation expert and other allied disciplines. Patients are seen in the Pediatric Disease Management Group (DMG).

There is a separate Leukemia and Lymphoma clinic (the only one of its kind in India); a Pediatric multidisciplinary solid tumor clinic; a Pediatric Neuro-Oncology program; a Pediatric BMT Program; After Completion of Therapy (ACT) clinic for long-term survivors (the only of its kind in India); a Pediatric Social Service Unit; Pediatric rehabilitation services; Pediatric Palliative Care services; Pediatric Nutrition services; Non-formal education for children; a Pediatric data-management team; a Pediatric infection control team and a Pediatric volunteer group.

With the help of various voluntary organizations and the hospital Medical Social Service department, nearly 70% of the children are treated almost free of cost. Also their other needs, such as the requirement of blood and platelet donors, food, accommodation, etc, is also taken care of. Jiv Daya Foundation, USA, is helping us build capacity by supporting many of the above non-medical personnel.

Patients are treated according to various indigenously developed protocols, including the modified versions of protocol MCP-841 (ALL) and MCP-842 (NHL) which were developed specifically by Dr. Ian Magrath for developing countries. The outcome of children treated on protocols is as good as that of many high-income countries.

has excellent interventional radiology facilities. The nuclear medicine department has access to the latest isotopes for nuclear imaging and possesses two Positron Emission Tomography-CT units. All the clinical data and reports are directly entered into the Hospital Information System and so are immediately available. The radiology films can be accessed on computers in the clinics through the standard system for transmitting high quality images, known as PACS. This online data can also be accessed from home by the staff. TMH is equipped with an excellent microbiology laboratory, a pathology laboratory with immuno-histochemistry facilities, a hematology laboratory (with automated cell counters and flow cytometers), a cytogenetics laboratory and molecular biology laboratory. All the laboratories are

accredited by an autonomous body established by the Indian Government called the National Accreditation Board for Testing and Calibrating Laboratories.

Nearly half the patients visiting TMH go through the Medical Oncology department. In addition to various solid tumors, TMH treats the largest number of leukemia (both myeloid and lymphoid) and lymphoma patients in the country. The department also has a seven-bed Bone Marrow Transplant unit where approximately 50 transplants are performed every year (allogenic; autologous, unrelated; cord blood).

TMH was the first to introduce the concept of joint (multidisciplinary) clinics in India in the 1980s, and in 2009, TMH was the first oncology facility in the country to introduce the concept of Disease Management Groups

(DMG). The groups presently include adult hemato-lymphoid neoplasms, bone and soft tissue tumors, breast cancer, gastro-intestinal tumors, gynecological cancer, head and neck cancers, neuro-oncological tumors, thoracic cancers, urological cancers, pediatric hematological and lymphoid tumors and pediatric solid tumors. The aim of this "division of labor" was to ensure a team approach and provision of care in accordance with evidence-based standards and access to the full range of potential therapies for all patients, together with involvement of patients in decisions about their care, aiming for better outcomes and increased patient satisfaction. At the same time, this will also help in the advancement of science.

The strategy for early diagnosis, treatment, rehabilitation, pain relief and palliative care has been established as a comprehensive and multidisciplinary approach; a total cancer care program. There is an active medical social worker department which looks after the social, financial, travel and accommodation needs of the patients. Additionally, several voluntary non-governmental organizations (NGOs) have been working with TMH to help patients deal with the implications of the successive stages of their disease management. More than 40 individual volunteers also provide help in the out-patient departments and clinics.

## ACADEMIC PROGRAM

Training, education and career development of the next generation of cancer care professionals (doctors, nurses and paramedical staff) and cancer scientists has been an important mission of the Tata Memorial Hospital. TMC is a recognized training center for cancer education and research by national and international organizations such as WHO, IAEA and UICC, it remains



## PARTNER PROFILE

the largest single point provider of trained manpower in cancer health for the country. The educational effort at TMC is directed towards providing a holistic and conducive environment to training cancer care workers and researchers from across the country. The best standards of patient care are incorporated and delivered as a part of a dynamic curriculum in all areas of oncology practice. All the post-graduate degree programs are recognized by the Medical Council of India and are now conducted through the Homi Bhabha National Institute (HBNI) which has university status. Every year about 140 post-graduate students register with the center for masters or doctorate level courses. Approximately 400 students undergo training every year in medical and non-medical fields in long and short term courses.

### RESEARCH

While technology in cancer research has undergone a sea change during the 70 years of our existence, the ethos for research has remained undiluted at the center. Even before the end of the second world war, research findings of clinical, epidemiological and experimental animal research conducted at TMH were reported in leading international journals.

In 1997 the Hospital Scientific Review Committee (HSRC) and Human Ethics Committee (HEC) were created for facilitating, formalizing and monitoring high-quality medical and scientific research in the center. These were amongst the first few such organized institutional bodies for medical research in the country. The Data & Safety Monitoring Committee (DSMC) is the subcommittee of the HEC that ensures compliance to the highest scientific and ethical standards and the safety of human participants in clinical trials.

Establishment of the Clinical Research Secretariat (CRS) and the DAE Clinical Trial Centre (DAE-CTC) complimented these efforts by providing a research environment, as well as the necessary infrastructure, including human resources (data management and statistical support) and funding for clinical and translational research. The TMC Research Administrative Council (TRAC) was constituted in 2008 to maintain and improve all aspects of research - basic, translational and clinical - at TMC.

While contemporary clinical research has always been our forte, incremental gains in the quality, quantum and spectrum of clinical research are becoming increasingly evident with over 110 clinical publications in international PubMed indexed journals annually. In the last decade, the clinical research at TMH has evolved from publishing case series to conducting prospective phase I to III clinical trials and translational and public health research programs. Clinical investigators at TMH have been increasingly involved in initiating and participating in collaborative multicentric national and international studies as equal partners.

### COMMUNITY OUTREACH

Education and prevention, vital weapons against cancer, are fully used by the department of preventive oncology. TMC played a leading role in establishing Nargis Dutt Memorial Cancer Hospital at Barshi (450 km. away from Mumbai) in 1983, where the Bill and Melinda Gates Foundation supported the International Agency for Research in Cancer to perform a "Collaborative Project on Cervical Cancer Prevention" and has now shown that through simple techniques, the rate of cervical cancer can be significantly decreased. TMC also established a Rural Cancer Registry at Barshi. Building on the above experiences and achievements, TMC with the BKL Walawalkar Hospital, Dervan (300 km from Mumbai), set up a model rural comprehensive cancer control program in the Ratnagiri and Sindhudurg districts of Western Maharashtra in 2003. The TMC-Rural Outreach Program (TMCROP) has succeeded, overall, in fulfilling the objective of ensuring good quality cancer surgery, diagnosis and treatment services for poor and marginal populations locally and creating a model for resource-poor countries. The blueprint



**Pediatric Outpatient Department.**

# NETWORK

of the district cancer control program has been featured in the UICC Manual on "Cancer Awareness, Prevention and control: Strategies for South Asia" set to become a model cancer control program, which can be adopted in similar low-resource settings in other parts of the world.

In addition to the above, TMC also runs an Urban Outreach Program in the slums of Mumbai for "Early Detection of Common Cancers in Women in India" through an RO1 grant from National Institutes of Health, USA – a prestigious award that is uncommonly made to a foreign center. Beginning in 1997, it involved a cluster randomized study of cost-effective screening strategies and health education for the prevention of breast and cervical cancers among the socio-economically disadvantaged women residing in the slums of Mumbai. Over 150,000 women have been evaluated and followed up in the study, the results of which demonstrated a significant down-staging of both breast and cervical cancers. There is ongoing surveillance and the final results of this path-breaking study are expected in the next few years.

TMH has always used its expertise to help build cancer centers in different parts of the country. The latest is Tata Cancer Hospital in Kolkata. TMC has also trained doctors, nurses and other paramedical personnel from other regions, so that they can return to their own areas and develop oncology programs locally.

In 2002, a telepathology service was established starting with the rural Cancer Hospital at Barshi. This service is now utilized by several other hospitals as well. A telemedicine service facility was set up linking Dr. B. Barooah Cancer Institute at Guwahati and the BKL Walawalkar Hospital at Dervan, Chiplun in 2005. Six hospi-

tals in the North East and regional cancer centers were later connected. Today TMH can be accessed by over 30 centers for telemedicine consultations and CME broadcasts.

## INTERNATIONAL COLLABORATION

International collaboration for manpower training in advanced techniques, including frontier areas of translational research have resulted in high impact research that has improved the care of Indian cancer patients.

In partnership with the International Agency for Research on Cancer, World Health Organization (IARC-WHO), Lyon, France and Center for Global Health Research (Canada), Tata Memorial Centre is trying to understand the reasons for the low incidence of cancer in rural India compared to urban areas and western populations. A large cohort of about 200,000 individuals residing in Barshi Tehsil of Solapur District in rural Maharashtra is being evaluated in partnership with IARC to characterize and study life-style factors, rural-urban differences, genetic factors etc with respect to cancer incidence. This study will help to determine those aspects of our life-style that have historically led to low cancer incidence and hence can be preserved and propagated in future generations.

The India-Oxford (INDOX) partnership is a unique global resource to support the advancement of new anti-cancer therapeutics from the laboratory into the clinic. INDOX's aim is to conduct high-quality research into causes of cancer in India, its prevention and cost-effective treatments, thereby reducing morbidity and mortality. Tata Memorial Centre is one of the leading partners in INDOX.

Tata Memorial Centre has started to collaborate with George Washington

University (GWU), USA and Oxford University, UK, in order to establish a Global Cancer Genomic Consortium. This will bring together cancer biologists, oncologists and physicians from the three leading institutions to investigate the causes and associations of various types and subtypes of cancers along with the therapies that are likely to be effective in treating these diseases. There is also a provision for transfer of technology and capability in areas of bioinformatics and computational biology.

Other high-value collaborations such as the International Sarcoma Kindred Study in partnership with Dana Farber Cancer Center, USA, Royal Marsden Hospital, UK, University Claude Bernard, France and Peter McCallum Cancer Centre, Australia will shed light on the fundamental questions of cancer causation and control.

Additionally TMC has also developed a partnership with one of the world's leading cancer centers, the MD Anderson Cancer Center, Houston, Texas, USA, as its sister institution. TMC also works with the International Atomic Energy Agency (IAEA) through the PACT (Program of Action for Cancer Therapy). TMC is an active member of INCTR initiatives, through which it helps develop protocols for the treatment of childhood cancers and participates in other cancer control programs.

## ADVANCED CENTER FOR TREATMENT, RESEARCH AND EDUCATION IN CANCER (ACTREC)

ACTREC, located in the beautiful natural surroundings in Kharghar, New-Mumbai (32 km from TMH), is a unique center dedicated to basic, translational and clinical research in cancer. Its two arms are the Cancer Research Institute and the Clinical Research Center.

# PARTNER PROFILE

## CLINICAL RESEARCH CENTER (CRC)

This 60-bed, state-of-the-art, multi-disciplinary clinical facility devoted exclusively to translational and clinical research in cancer was commissioned on March 30, 2005. The clinical activities at CRC emphasize childhood cancers, cancer genetics and the evaluation of cost-effective or indigenous technology. With an active pharmacology department, it has the necessary infrastructure to conduct Phase I studies. All efforts have been made to seamlessly integrate clinical services, clinical research activities as well as staff members in CRC at ACTREC and the Tata Memorial Hospital. ACTREC played an important role in the development of an indigenous teletherapy unit "Bhabhatron" which is in use in various centers in India and abroad. The Bone Marrow Transplant (BMT) unit was moved from TMH to ACTREC and commissioned on 14th November 2007. Fifty-two transplants were performed last year and the transplant-related mortality in the first 100 days has been a low 4-5%.

## LOOKING INTO THE FUTURE

Private initiative backed by focused governance and the long-term vision of the Department of Atomic Energy have been a unique feature of TMH. The result is there for all to see and to be inspired by. The new 14-story Homi Bhabha Block is ready to be inaugurated. This block will house tumor site-specific clinics, 75 additional beds, a minor theatre complex, day care beds, academic offices, seminar rooms for post-graduate education and a tele-medicine center. With the formation of DMGs, we hope that both clinical and basic science in the field of cancer will advance more rapidly. Two new buildings are being built in the ACTREC complex. One will house the "Center for Cancer Epidemiology", which will help

	TMH Mumbai, India	MDACC Texas, USA*	TMH Mumbai, India Pediatric Services	SJCRH Memphis, USA**
<b>New Patients</b>	31, 909	29, 157	2, 048	~ 400
<b>In-Patient Beds</b>	530 ***	512	~ 60 (no fixed number)	78
<b>Faculty</b>	117	1400	~ 20 (some shared)	119
<b>Clinical Fellows</b>	144	927	~ 10 (no fixed number)	~ 45
<b>All Employees</b>	2503	16, 840	--	3, 300
<p>* MDACC: MD Anderson Cancer Center, Texas, USA.  ** SJCRH: St. Jukes Children's Research Hospital, Memphis, USA.  All figures are not exact figures but are extrapolated from data available from the website of the Institution.  *** Another 70 beds will be added in the coming months.</p>				

**Table. Some numeral comparison of TMH with centers in the USA.**

us to perform large-scale locally relevant studies and research in the field of cancer epidemiology. The other is for research in basic and radiological sciences. In the next phase, the important task of imparting effective cancer care to all, irrespective of their social or economic background, can be met with the help of increased participation of those who are motivated to give generously to society. TMC is planning to build a separate facility for the most vulnerable cancer patients, women and children. This demonstrates that TMC is not only concerned with scientific progress but also with the social responsibilities of the health profession.

In the final analysis, an institution is judged by the quality of the staff. Our eminence is entirely due to their unquestioned and total dedication to the cause of fighting cancer. TMC will not rest on past achievements, splendid as they are, but will continue to give succor to cancer patients, offer them the best chance of cure, of a high quality life, and relief from pain, in continuing a tribute to the vision and

dedication of those who have guided the destiny of the institution throughout the many years of its existence. ■

*Shripad D. Banavali*  
Tata Memorial Centre  
Mumbai, India

*1) This article is longer than most partner profiles, since it illustrates progress made in the course of a decade – see original partner profile on TMH in the Volume 2, Number 3 Edition of the INCTR Newsletter/Magazine published in Winter 2001. It also illustrates what is being achieved in the successful emerging economies and emphasizes that in at least some parts of the world, dramatic changes are being made in the ability of at least the best centers to combat cancer through a broad range of cancer control activities.*

News items for the September quarter can be found at:  
<http://www.inctr.org/media-center/news-and-events/>

# NETWORK

## PROFILE IN CANCER MEDICINE

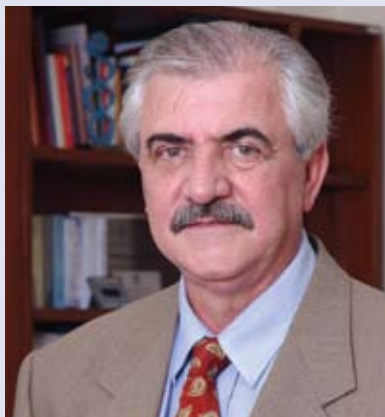
### CANCER AS A PUBLIC HEALTH PROBLEM

As one of the leaders of the successful implementation of the Unified Health System in Brazil (SUS), an advanced health public-funded system, Dr. Luiz Antonio Santini has focused on public health in the last decades of his career.

Previously he served as Nova Friburgo's Municipal Secretary of Health, as National Institute for Medical Care and Social Security Regional Superintendent for the state of Rio de Janeiro, and as Chairman of the Administration Board of the Vital Brazil Institute Center for Research, Development and Production of Biopharmaceuticals, Pharmaceuticals and Technology to Health.

Much of Santini's acquired professional experience as a thoracic surgeon and in clinical education was collected at the Fluminense Federal University. As Director of the College of Medicine, he implemented a pioneer project for the integration of health services with the academic field. He also headed the emergency service of the Antonio Pedro University Hospital at the Fluminense Federal University.

As Director General of the Brazilian National Cancer Institute (INCA) since 2005, he was one of the mentors of the National Cancer Control Policy launched by the Ministry of Health, which considered cancer a health priority. INCA has been developing a countrywide Cancer Control Network, where governmental and non-governmental organizations are joining hands to help raise awareness of cancer, to reduce cancer burden, and to ensure the best possible quality of life for patients undergoing treatment. His efforts to set up a new participative management model at the Institute have been widely recognized.



**Luiz Antonio Santini**

Headquartered in Rio de Janeiro, INCA is the branch of the Ministry of Health of the Federal Government in charge of supporting the design and implementation of cancer control policies for the whole country, covering the entire continuum of cancer, from prevention through early detection, treatment, and palliative care, besides education, surveillance and research. INCA's hospitals improved their standards in the last four years and have been accredited by the Joint Commission on Accreditation of Healthcare Organizations.

INCA runs the National Register for Bone Marrow Donors and the Umbilical Cord Blood Bank Network. After a series of mobilization campaigns the number of people who joined the National Register has increased from 60 thousand in 2005 to more than 1.5 million donors in the past five years. The National Register in Brazil became the third largest bone marrow bank in the world. Also the Cord Blood Banks, a network of 13 banks funded by the Brazilian Development Bank, now covers every Brazilian region.

A matter of concern for Dr. Santini was to identify the best strategies and practices to be applied in approaching cancer as a public health problem that affects Brazil

as well as other nations, developed or developing. He encouraged INCA to play a leading role at national and international levels. On his initiative, the second International Cancer Control Congress was held by INCA in Rio de Janeiro to establish, develop and enhance population-based cancer control plans. More than 545 participants from 47 countries, especially from Latin America, gathered for the second ICC, which established a basis for a new phase of global and regional cooperation.

As a result of the Congress, the Latin America and the Caribbean Alliance For Cancer Control was created in 2008 to set up new forms of joint effort among its members for the sharing of common programs, projects and experiences. Ever since, more regional collaborative relationships focusing on a broad range of mutual interests have been fostered. For example, the Ibero-American Network of Tobacco Control was set up to coordinate common tobacco control actions among the member states regarding their efforts to adopt the initiatives and regulations established by the WHO Framework Convention on Tobacco Control.

Another important initiative for international cooperation is the U.S.-Latin America Cancer Research Network, which presently includes the governments of Argentina, Brazil, Chile, Mexico, Uruguay and the USA. The current pilot project focuses on advanced breast cancer and Dr. Santini leads the Brazilian research centers in this network.

In addition to his responsibilities, Dr. Santini serves also on the Board of Directors of the UICC (Union for International Cancer Control). ■

*Luiz Antonio Santini, INCA  
Rio de Janeiro, Brazil*