

## A Donor's Guide to Cancer



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### introduction

Welcome to the new edition of the Donor's Guide to Cancer. Initially published in 2013, this updated version once again reflects the relentless passion demonstrated by philanthropists and foundations, and highlights innovations in cancer care and treatment.

In today's philanthropy landscape, cancer, like other non-communicable diseases (NCDs), represents a universal and tremendous challenge.

Cancer is the second leading cause of deaths globally and is affecting more people every year.

For whatever reason, cancer is perceived by some as a disease affecting only high-income countries, but in fact, two thirds of all cancer deaths occur in low- and middle-income countries (LMICs).

Over the past few years, both our organisations, the Union for International Cancer Control (UICC) and Bank Lombard Odier have joined forces to raise awareness, facilitate engagement and funding in this field. We are proud of the progress we have made, separately and together, to increase the knowledge of cancer and its causes around the world.

UICC, a global membership organisation, unites and supports the cancer community to reduce the global cancer burden, to promote greater equity, and to ensure that cancer control continues to be in the world's health and development agenda. It has successfully brought together a range of private donors, major cancer organisations, and corporations to support international and national players to make progress against the disease. UICC invests more than USD10m each year driving cancer control globally.

Since the creation of Lombard Odier more than 220 years ago, the families leading the bank have consistently been involved in philanthropy and have shared their experience with clients. Celebrating its tenth anniversary in 2018, Fondation Philanthropia facilitates clients' philanthropic engagement. The Foundation offers its donors a legal, financial and philanthropic framework for creating a bespoke project. It has already donated or committed over USD 30 million to the field of cancer, including research, prevention and for the improvement of patients' quality of life.





This is just one illustration how this illness, in spite of its multidimensional complexity, remains high on donors' giving agenda. As the field of oncology is undergoing a scientific revolution, we can expect a lot more philanthropic impact in the years to come.

Today, we make this guide freely available to any partners or philanthropists wishing to better understand the challenges the disease currently poses, and to help us improve the ways in which cancer can be prevented, detected early, and treated more successfully. The hope is that sound analysis will help focus philanthropic efforts and eventually make an impactful contribution to the solutions that human wisdom, progress and ingenuity will produce to reduce the number of deaths due to cancer over time.

We hope that this guide, intended as an initial step towards improving comprehension of the challenges, can inform and inspire would-be donors to make their own meaningful contributions to address a disease which affects us all.

With our deepest gratitude, we thank all contributors for this collective initiative.



**Dr Cary Adams**, Chief Executive Officer, UICC



Denis Pittet, Managing Partner, Lombard Odier Group. Ltd and President, Fondation Philanthropia

#### 1. Purpose of this guide

While this guide gives some basic information on cancer as a set of diseases, its intent it to provide a broad understanding of the current cancer landscape and to shed light on areas where there are gaps or support needed. We will touch on some of the basic aspects: prevention and early detection, the patient experience (including treatment, psychosocial support, survivorship and palliative care), advancements in research, and what is happening at a global level to address the growing cancer burden. Thanks to case studies from some major players, you will be able to understand where efforts are currently under way. The hope is that you will walk away knowing more about the status of cancer globally so that you can then make an informed decision to contribute to the progress against this devastating disease. This guide is not a scientific text, but attempts to bring some dense material to an understandable level.

As someone with the potential to help make strides in the fight against cancer, we understand you are interested in impact, and in knowing how your support can do the greatest good. There is a lot happening in the cancer space, so much so that it can be overwhelming.

This guide attempts to look at the impact-driven thematic areas where you can make a difference, and while you will no doubt see some overlap, we have structured the guide into the following broad themes based on your motivation as a donor:

- · Addressing the immediate needs of people living with cancer
- ▶ Building capacity to tackle cancer
- Getting to the root of the problem

Within each section there are sub-categories, and we will provide case studies of organisations working in these areas. We hope these case studies will speak to you on a personal level, and you will feel called to act.

#### 2. What is Cancer?

Cancer is a disease where cells in the body divide uncontrollably and then harm or spread into adjacent tissue. In fact, cancer is not one single disease, but a collection of many diseases where cells act in this way. Cancer starts with a single cell in which several genes have undergone changes (mutations). These mutations accumulate and start to cause problems.

Cancer can form in nearly any part of the body, including the blood. The body continuously replaces old, dead, or damaged cells with new, healthy cells. When there is a cancer, this healthy cell replacement is interrupted by abnormal cells, and damaged cells survive (and thrive) when they should die. Without something to interrupt this process, these unhealthy cells can keep dividing, and in most types of cancer can form masses of tissue called tumours.

When tumours are cancerous, which means they can spread into or invade nearby tissues, they are called malignant. In addition, these tumours can grow and spread throughout the body to form new tumours away from the original tumour, which is called metastasis.

It is possible for a tumour, however, to not be cancerous. These tumours, called benign, do not spread into or invade nearby tissues, and although they can be large and problematic, they are not generally life-threatening.

#### 3. What is the current burden?

Cancer is the second leading cause of death globally and is estimated to be responsible for 9.6 million deaths in 2018. Almost half of all new cancer cases, and more than half of cancer deaths occur in Asia, and one quarter in China alone.

Lung, prostate and colorectal cancers have the highest incidence amongst men globally, closely followed by stomach and liver cancers. However lung, liver and stomach cancers account for the highest rates of mortality. Lung cancer alone is responsible for about 1 in 5 of all cancer deaths. Prostate cancer has the second highest rate of incidence for men in developed and developing countries.

By comparison breast, lung and colorectal cancers are the most common amongst women, with cervical cancer following closely. In 154 countries breast cancer is the most commonly occurring cancer amongst women. Some countries have other cancer types as the most common in women, notably liver cancer in Mongolia and thyroid cancer in South Korea.

## addressing immediate needs

#### 1. Existing Treatment

As we have just learned, cancer is a complex group of diseases, and there is still much to understand about its development and evolution. As a result, a "multimodal" approach or combination of treatments is often used for people with a cancer diagnosis. Here is an overview of some of the most common types of cancer treatment methods available.

#### 1.1 Surgery

Surgery remains the mainstay of cancer treatment, and alone it cures about half of solid tumours (such as breast and colorectal, or any non-blood cancers). Despite advances in other treatment approaches, cancer experts believe that surgery will continue to play a fundamental role in cancer treatment. New technologies, such as robotic surgery or the use of tiny (laparoscopic) incisions to insert cameras and surgical instruments to perform image-guided operations, are no doubt making surgery even more effective, less invasive, and more precise.

#### 1.2 Radiation

Radiotherapy uses ionising radiation to destroy cancer cells and limit cell growth. Radiotherapy is recognised as an essential tool in the cure and palliation of cancer and is recommended in 52% of new cancer patients.

Radiation therapy uses high-energy radiation to shrink tumours and kill cancer cells by damaging their DNA. X-rays, gamma rays, and charged particles are types of radiation used for cancer treatment. The radiation may be delivered by a machine outside the body, or it may come from radioactive material placed inside the body near the cancer cells (internal radiation therapy, also called brachytherapy).



#### 1.2 Radiation (continued)

Radiotherapy works well and can be curative on tumours that are small and localised. For larger tumours, it is generally used after the tumour has been removed surgically to reduce the risk of cancer reoccurrence in the remaining tissue once the main tumour has been shrunk by chemotherapy or rendered more vulnerable to radiation by certain radio-sensitising drugs. However, for metastatic tumours that have spread to different parts of the body, radiation cannot be used. Although intending to be quite localised, side effects of radiation often arise from healthy tissue around the tumour being damaged during treatment.

There is another type of radiation treatment called proton therapy, which can be used on its own or in combination with other treatments. Protons are positively charged particles, which when sped up to a very high energy, can be used to kill cancer cells. Proton therapy beams protons to the specific tumour spot in the body, where they then deliver radiation. This method is different from conventional radiation because it stops as soon as it hits the target cells, which reduces the impact on surrounding tissue. This is an especially useful treatment method for tumours in sensitive areas, such as parts of the brain, but as a relatively new treatment, there is a lot left to learn about it.

It is important to keep in mind that the treatment modalities and outcomes will depend on the type and stage of cancer. We will talk more about early detection, sometimes referred to as "secondary prevention" later in this guide.

#### 1.3 Chemotherapy

The term chemotherapy simply means to use drugs to treat diseases; however, in popular usage, the word has long been synonymous, and all but exclusively used in regard to cancer treatment.

First used in the 1950s, chemotherapy uses drugs to destroy cancer cells by stopping or slowing their growth. Generally, a combination of drugs acting in different ways is used simultaneously to overcome the resistance of cancer cells to individual drugs.

Chemotherapy is different from radiation and surgery because it is not limited to a certain area. "Chemo" is often taken orally or intravenously and targets cells that are fast growing, and as a result, the medication goes through the entire system rather than just targeting the tumour. A benefit of chemotherapy is that it can work on cancer that is not localised to just one area. Unfortunately, other types of fast growing, but otherwise healthy cells are also harmed in the process. Examples of normal cells in the body that also divide quickly include the cells that line the mouth and intestines or cause hair to grow. The harm to these healthy, fast-growing cells can be a physically and psychologically painful side-effect of chemo.

New types and combinations of chemotherapy drugs, including drugs that target the cancer cells more selectively, have slightly reduced the severity of side-effects and have increased the proportion of cures for some types of cancer, notably childhood leukaemia and lymphoma, and, in adults, Hodgkin's disease and testicular cancers.

## Max Access Solution, a treatment access model of The Max Foundation

#### Background

The Max Foundation believes all people living with cancer deserve access to the best treatment, care, and support. Unfortunately, however, the existence of a treatment does not always result in access for patients who need it. To address this reality, the organisation facilitates access to life-saving oncology products for patients in low and middle-income countries, thereby decreasing premature mortality. Their historical focus is on Chronic Myeloid Leukaemia (CML), a rare cancer that remains deadly in neglected regions of the world even though effective treatments exist. The Max Foundation has brought together all the companies making medications for CML in what they call a "humanitarian pact" to improve treatment access for the disease. Max Access Solutions is the mechanism they use for getting oncology products to patients.

Their Max Access Solution for CML addresses all sides of the issue to increase availability of life-saving treatments as prescribed by treating physicians. Through this initiative, people diagnosed with CML in the lowest income economies can gain access to any approved treatment indicated for their disease – treatments otherwise available only to patients in high income countries, or those with means to travel. Max Access Solution for CML marks an exciting opportunity for the global cancer community to come together in a proof of concept model that could be adapted, giving us hope to deliver similar complex care for other cancers.

#### **Project description**

The Max Access Solution represents a new model for humanitarian access to treatment where an international NGO acts as the clearinghouse for products sourced from multiple manufacturers and then channels them to validated cancer centres for individual patients.

First, the distribution is developed with supply chain actors then, through other multisectoral partnership agreements, the project provides support with patient tracking, planning and forecasting, diagnostics, professional training, and patient education and support.

From a cancer control perspective, Max Access Solutions is innovative in its focus on access to treatment. Often cancer control programmes focus on system strengthening but neglect access to the actual treatment until the local economy is ready to sustain it. However, the Max Access Solutions model not only saves the lives of patients in need of treatment today, but also promotes the notion that access to treatment creates cancer survivors, thereby increasing awareness of the needs of cancer patients.

#### Project steps taken:

- Identification of all oral treatments approved for CML and available to patients diagnosed in high income countries;
- Identification of supportive care needed to successfully treat the disease;
- Mapping of stakeholders for successful implementation: civil society, physicians and national cancer centres, government institutions, international distributors and shipping companies, drug and diagnostic manufacturers, etc.;
- Development of collaborative agreements with each partner; and
- Establishment of a manufacturer to patient validated supply chain into each country/ cancer institution following international regulations.

## Max Access Solution, a treatment access model of The Max Foundation

#### **Outcomes & Learning**

In the first two years of implementation Max Access Solutions delivered more than 700,000 required daily doses of cancer medication and 2,500 molecular diagnostic tests to more than 10,000 patients in 68 countries. To date, it has established a validated supply chain spanning 90 cancer institutions with 226 oncologists and haematologists and has worked with a wide range of partners across the care continuum.

### Project model



#### **Intended Continuation**

Measures of long-term impact of the project include:

- Increased survival
- Strengthening of health systems
- Establishment of validated end to end supply chain

A key outcome of their Max Access Solution for CML is the creation of systems and impact measurements, with the long-term vision of expanding the model to other cancers.

#### Tips for donors

Max Access Solutions are funded by companies who participate in The Max Foundation's "humanitarian pact" who provide grant funding, and through fundraising from private donors and the community at large. Donors interested in this type of model can help diversify the sources of funding at all levels of support.

#### www.themaxfoundation.org



 $a\,member\,organisation\,of\,UICC$ 



#### 2. Patient experience



#### 2.1 Psychosocial support & survivorship

A cancer diagnosis is a major life disruption that can have significant impacts beyond one's physical health. Secondary symptoms of the disease can be linked to side effects of treatment, as well as huge challenges associated with navigating the primary cancer diagnosis. Depression, anxiety, fatigue, stress and many more symptoms can plague those living with cancer and their caregivers. Patients who do not receive adequate support to meet basic needs (such as the ability to pay for treatment, transportation to treatment or emotional support groups, leave from work, etc.) face significant hurdles to successfully completing their cancer treatment. For people living with cancer, theirs is a daily struggle which requires holistic support. The same is true for their loved ones who fight by their side against the disease.



Even post-treatment, returning to "normal" life can be a major challenge, because survivorship can present many challenges, both physical and emotional. Almost without exception, cancer treatment will damage some normal tissue and the immune system. Modern medicine in general and cancer treatment in particular, is imperfect. Unfortunately, patients do not always receive enough information up front to fully understand potential lasting adverse effects such as infertility, susceptibility to other diseases, and the significant emotional toll of the disease. Cancer survivors have likened the experience to that of living on top of a trap door—wanting to fully live their newfound life, but often overwhelmed by the feeling of not knowing when the door may open again. This can be a time of finding a "new normal", rather than trying to return to a life that is now fundamentally different. Long-term psychosocial support may be an important part of recovery for many people post-treatment.

The types of support programmes addressing these needs, often referred to as psychosocial support, look at the psychological, emotional, social and often logistical needs of someone as they navigate their diagnosis. Indeed, these programmes allow patients and their families to ensure they are getting the most out of their treatment by making the external barriers more manageable. Examples include support groups, financial assistance, transportation, complimentary medicine, aesthetics, nutrition counselling, meditation and yoga, and adapted exercise programmes, among many others.

## Australia's first online prostate cancer community

#### Background

Prostate cancer is an important public health issue and a major challenge for the health system, and Australian society. It is the most common cancer in Australia for men. There are more than 200,000 men living after a diagnosis with prostate cancer in the country and 80% of these men will be long-term survivors. Many men live with ongoing physical, emotional, sexual, and practical concerns that often are not identified or addressed.

Face-to-face peer support groups have existed for several decades as a valuable community-led approach, to connect people with cancer experiences and access support. The Prostate Cancer Foundation of Australia (PCFA) has affiliation with over 170 support groups across Australia. However, with increased access to the internet, online support has begun to emerge as an alternative mode of delivery. The challenge for PCFA was to develop a safe and secure platform allowing individuals from the broader prostate cancer community to connect whereby reducing the isolation and burden often felt by those coping with this disease. Whilst recognising the value of traditional face-toface interactions in the community, PCFA wanted to make an alternative way of accessing information and support. Given that men can find it difficult to ask for help, PCFA sought to explore ways to empower those diagnosed with prostate cancer and make it easier to reach out to others.

#### **Project description**

From 2011 to 2014, Cancer Australia provided approximately USD \$2.9m seed funding to PCFA to provide national, evidence-based, self-management information and resources and psychosocial support for those affected by prostate cancer. One of three deliverables of the programme was the development of an internet-based platform with discussion boards and evidence-based resources to facilitate communication between the established support group networks.

The program was designed to connect peers through a community forum, a video gallery, and a research blog. A scientific writer was engaged to provide concise summaries of the latest research and communicate emerging trends in diagnosis, treatment and management of the disease. A framework was established to ensure security of member's information, ethical organisational online practice and respectful interaction between members. In June 2016, PCFA's Online Community was made publicly available. In addition, an online newsletter was added in May 2017 to connect with activities occurring at a local grassroots community level.

#### **Outcomes**

Even without formal launch or promotion, membership of PCFA's Online Community is over 2 800. From May 2017, membership grew by an average of 106 users per month.

Community members primarily identify themselves as having been diagnosed with prostate cancer (61%), followed by being a partner or carer (19%) and working in a health sector (11%).

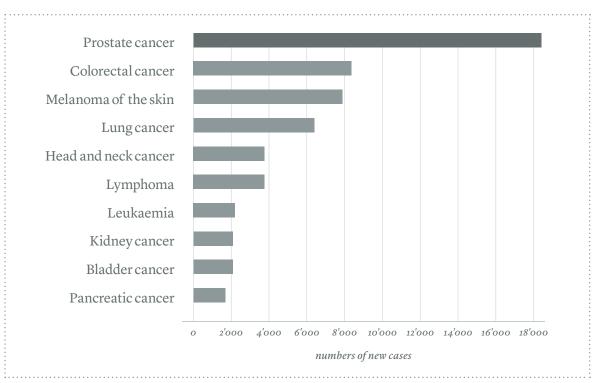
While the programme cannot meet every psychosocial need, it has provided an avenue of support for people whose information or preferences are grounded in online interaction. Interestingly, multiple discussions have been posted on the issues facing younger men and their families, a group particularly vulnerable to higher distress during diagnosis and treatment. The programme addresses isolation and the gap of trustworthy information available.

# Australia's first online prostate cancer community

"I like the fact that in this forum we remain anon[ymous] so we can share things. It's a tough journey especially for those of us under 50... We have to talk about our experience for that is the only way in which we can help each other enjoy this journey.

- a forum participant

#### Most common cancers diagnosed, Australia, males, 2014



Data source: Australian Institute of Health and Welfare

#### Tips for donors

Ongoing development and sustainability of PCFA's Online Community aligns with the organisation's mission, to broaden engagement with and support to the Australian community. With additional funding key areas to consider are how the use of artificial intelligence could enhance usability, incorporating live streaming for different purposes (webcasts or support group meetings), and voice interaction to enhance engagement. Donors interested in this type of cutting-edge online psychosocial support will find many other organisations focusing on specific cancers, geographic, or demographic groups.

www.pcfa.org.au www.onlinecommunity.pcfa.org.au



a member organisation of UICC

#### **OTIUM Centre**

#### Background

In Switzerland, more than 100,000 people have been diagnosed with cancer within the past five years and around 37,000 new cases are registered each year, making cancer the second most common cause of death in the country. Although medical progress now makes it possible to cure one out of two cancers, the fact remains that the scope of this disease far exceeds the medical framework. Indeed, hospitals cannot meet all of patients' needs, not only in terms of physical and psychological health, but also in terms of emotional and social well-being. People living with cancer and their loved ones need a place to come together to address all their needs, because cancer affects much more than one's medical health.

#### **Project description**

In this context, the OTIUM Foundation's mission is to improve the life of people living with cancer in Geneva, during and post-treatment, to create synergies and work with all the existing players to lesson stress and improve overall outcomes of one's cancer journey. OTIUM offers, care, advice and support in a warm and welcoming environment to patients and their families. The centre focuses on nutrition and alternative forms of therapy, including relaxation, yoga, mindfulness and meditation, psychotherapy and aesthetics. The latter are not intended to replace medical treatment, but to work in harmony with it, in order to help patients live better with and after cancer treatment.



- "I am convinced that people living with cancer speed up their recovery if they are able to better manage their treatment.
  - Linda Kamal Director of Otium Foundation
- "Medical treatment in hospital and holistic additional care complement each other. The offer brought by the OTIUM Centre meets a real need. My patients often tell me about the additional therapeutic support they seek to complement the oncology treatment. Offering these therapies under one roof is a real bonus for patients.
  - Dr Angela Pugliesi-Rinaldi Head of the Oncology department at La Tour Hospital

#### Tips for donors

A family with a long philanthropic tradition initiated this project and established this operational foundation. Given the compelling mission of the Centres, local private and institutional donors joined the initial stages, mostly by word of mouth, to secure the set-up costs. Once the centres are operational, gifts of all sizes will support the running costs and the replenishment of a fund covering fees for users with insufficient health insurance. Additional public funding might also come in at a later stage, but private donor support is key during the proof-of-concept stage of such a project.

www.centre-otium.ch





#### 2.2 Palliative care

The World Health Organisation (WHO) and the Worldwide Palliative Care Alliance define Palliative care as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain". While not unique to cancer, palliative care is an essential aspect of the patient experience for those suffering from life-threatening illnesses. Relief of pain however, remains a critical component of holistic care, as pain is the cause of serious suffering in about 80% of cancer patients.



Attenuating the symptoms of a disease is the primary aim of palliative medicine. Contrary to popular belief, palliative medicine is not confined to patients in the terminal stages of a disease but is and should be used at any stage to ease the pain and the collateral effects of treatment. Moreover, in recent years, its scope has expanded to include relief not only from physical pain, but also from suffering and distress in all areas of a patient's life—mental, emotional, social, etc.

It is also possible to combine palliation and curative treatment. Several palliative approaches and technologies have been developed to make chemotherapy safer and more tolerable such as so-called "anti-emetic" drugs can reduce the nausea and vomiting associated with chemotherapy.

A small number of medications, no longer under patent, can control pain for almost 90% of all people with cancer pain, including children. The use of these to reduce pain, as well as specific efforts to manage patient distress are integral to specialised palliative care services.

WHO considers opioids an essential medicine for pain management, but despite this there are unacceptable disparities in worldwide use of opioids for the treatment of pain, with high-income countries consuming 93% of the world's morphine supply while 70% of deaths from cancer occur in LMICs.

Up to 58% of patients in palliative care experience significant levels of emotional distress, which affects their quality of life and alleviation of physical symptoms including pain, as well as physical and social functioning. Likewise, cancer pain is often linked to high levels of psychological distress, including higher levels of depression, anxiety and fear.

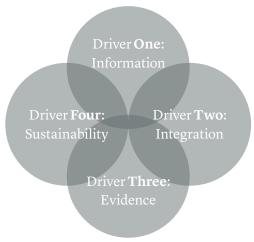


## The Pain Free Hospital Initiative (PFHI) in 3 African countries (Botswana, Ghana and Uganda)

#### **Background**

Although there is evidence that pain is one of the most distressing symptoms in people with cancer, it remains a neglected aspect of care, specifically in many African countries. Unbearable pain can contribute to increased mortality and unnecessary suffering, thereby diminishing the quality of life of people living with cancer and their families. Pain relief is therefore central to effective cancer care. However, there is a general lack of knowledge and skills among health care workers to assess and manage pain, and ignorance on the part of key players charged with making pain medicines available and accessible.

#### APCA strategic drivers: The interaction



Access to palliative care for all in Africa

A Donor's Guide to Cancer

#### **Proposed solution**

To address this problem, the African Palliative Care Association (APCA), in collaboration with the American Cancer Society (ACS) implemented a 3-year (2015-2018) Pain Free Hospital Initiative (PFHI) in seven hospital sites across three African countries (Botswana, Ghana and Uganda) using existing knowledge, evidence and internationally recognised guidelines to train health care workers.

The primary intended outcome of PFHI was to reduce needless suffering. Project indicators were: changes in knowledge and attitudes of health care workers on pain assessment, and management and monitoring of opioid consumption. Monitoring these outcomes was achieved through supporting in-service training; measuring patient pain intensities and morphine consumption trends. To ensure ownership of the initiative, APCA worked with contacts in local institutions who tailored activities and schedules based on their facility's needs and context. Before the training, project sites obtained data on average patient pain scores as a baseline, which was then used to measure change by comparing average pain scores taken at intervals following the training. Regular tracking of opioid consumption trends was also measured for each site against an initial baseline.

#### **Outcomes**

In achieving its ultimate goal, the initiative resulted in a reduction in patient pain scores. At the Uganda Cancer Institute (UCI), over a period of 11 weeks the average pain scores for four wards reduced from 3.6 to 0.9 out of 10, and at Gulu Regional Referral Hospital in Uganda, the average pain score improved from a baseline pain score of 5.8 to 3.8 out of 10 in 9 months.

In total, 1968 people (1465 health care professionals, and 503 hospital support staff) across the seven project hospitals were trained on pain assessment and management. In all project countries the demand for oral morphine has increased due to greater awareness and knowledge of health care workers.

The facility-led approach promoted ownership and adaptation of the project into the local context, as well as the institutionalisation of pain assessment and management. In Ghana for example, pain is now one of the hospital vital signs indicators.

#### **Intended continuation**

In all three project countries, there are plans for expansion. The Palliative Care Association of Uganda has replicated PFHI in other public hospitals with initial technical support and orientation by APCA and ACS. In Botswana, the Ministry of Health has considered the replication of this project in another six hospitals, with a long-term plan of covering all hospitals. Meanwhile Ghana has extended it to more than 20 health facilities.

The PFHI project has proved that challenges of pain management for cancer patients can be addressed through awareness, capacity building and on-going technical support.

#### Tips for donors

It is often difficult to meet the increased demand for morphine and to access pain medications. It would therefore be valuable to expand the project by building the capacity of legal opioids prescribers and other key players in the medicines supply chain. The adaptation of the local production of oral liquid morphine used in the management of moderate to severe pain by countries such as Botswana also presents a critical solution for ensuring the accessibility to affordable pain relief. It costs approximately US\$ 25,000 for a country to initiate the local production of oral liquid morphine.

#### www.africanpalliativecare.org



a member organisation of UICC

## capacity building and infrastructure

#### 1. Training cancer professionals

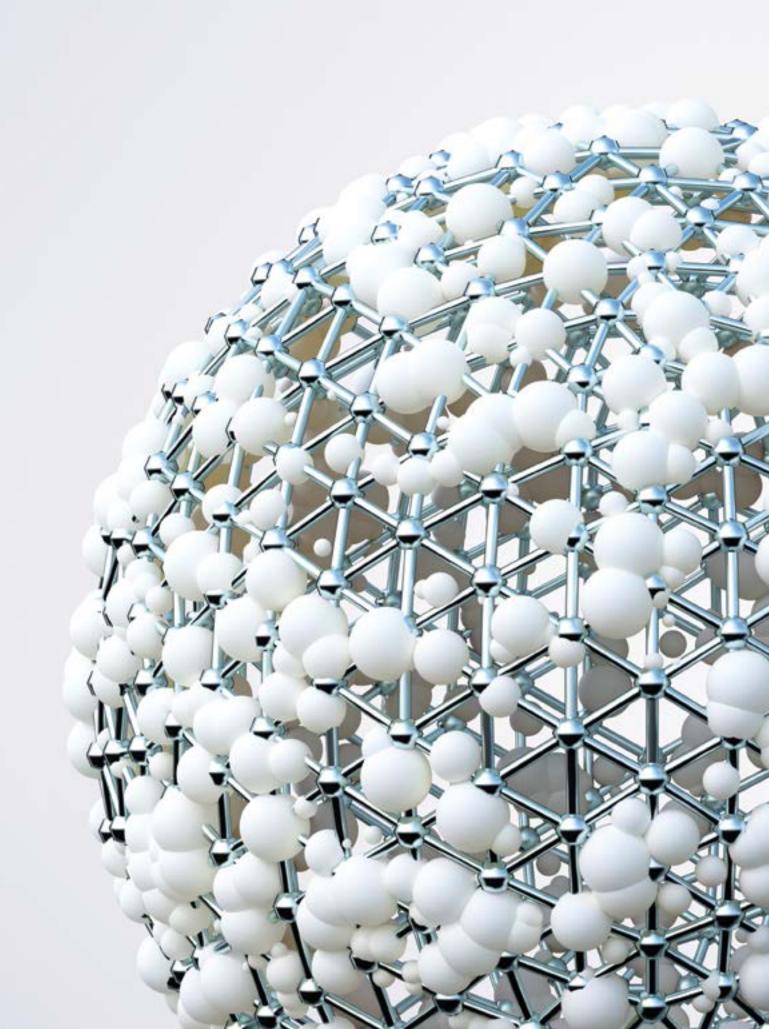
It is clear from all the forecasts that the future burden of cancer will fall mostly on countries that are less able to cope with it.

The International Agency for Research on Cancer (IARC) estimates that more than 70% of the growth in cancer incidence and mortality will occur in LMICs in the next two decades. If we are to improve the conditions of cancer care worldwide, then we should be aware that investing in the capabilities of the cancer community in these areas is a global imperative.

Global attention to infrastructure, capacity building, and training of cancer professionals are some of the biggest areas of need, where short-term impact is possible. Investing in an organisation's capacity building plans means improved skills, competencies, and greater impact. Ultimately the hope is that this investment will translate into improved quality of life for patients and even more lives saved.

To address this need, UICC has been developing a suite of new training and education approaches purposed to meet the needs of its members. Each designed and delivered with and through its members addressing the stark inequities that exist.

While UICC's work has often focused on members in developing countries, as guided by their will to ensure regional equity, building on existing structures, maximising resources and sharing information are essential in oncology no matter the resource setting, there are examples of this happening around the world.



## Romandie Oncology Network: how sharing information and expertise can build capacity

#### **Context**

The population of French-speaking Switzerland represent around 2 million inhabitants, which is equivalent of the catchment area of a typical cancer centre. In a traditionally decentralised country, it makes sense for treatment centres and oncologists to build a critical mass of patient cases to reach a scale that is clinically efficient and allows information and data sharing.

#### **Project description**

In 2017, in French-speaking Switzerland, a network was formed for the collection and sharing of data during a weekly molecular tumour board meeting. This network brings together oncologists from hospitals and clinics, as well as specialists (pathologists, bio-informaticians and genomics experts).

- "This is a win-win situation. Patients have the opportunity to access the most advanced technologies, in particular when joining a clinical trial. Meanwhile oncologists in private practices can access innovations developed in the university hospitals.
  - Professor George Coukos, Head of the Oncology Department of CHUV (Centre Hospitalier Universitaire Vaudois) and Director, Lausanne Branch,

Ludwig Cancer Research.

- "More than 150 different molecules are available to tackle cancer and about 20 new ones are added annually. Managing these changing parameters is near impossible for an individual physician. The Network allows private and academic oncologists to work collaboratively and to handle complexity better than they could on their own.
  - Professor Pierre-Yves Dietrich, Head of the Oncology Department of HUG (Hôpitaux Universitaires de Genève).

#### **Outcomes**

Thus far over 400 patients have benefited from this multidisciplinary analysis of their files, and as a result half were able to join a clinical trial or benefit from off-label use of a treatment and more than 500 genomic analysis helped finetune treatment options. Measures of success of this model will look at treatment outcomes down the road.

#### Tips for donors

Originally jointly funded by two grantmaking foundations (Fondation FAMSA; Fondation Philanthropia), the project will require additional support after its initial 3-year trail period. Institutional donors interested in making a commitment of a few years can support the additional human resource needs of the clinical teams (data managers, clinical nurses, research assistants) and reinforce the technical infrastructure provided by public funding.

www.chuv.ch www.hug-ge.ch



## Increasing Access to Breast Cancer Treatment at the Community Level through Mobile (mHealth) Solutions

#### Background

In many LMICs, an inadequately prepared and insufficient nursing workforce exists, specifically in cancer care. Successful cancer care requires a team approach, and knowledgeable oncology nurses play a crucial role in a functioning team. The goals of reducing cancer incidence, improving survival, and providing better palliative care cannot be met without the efforts of these nurses. Oncology nurses who work in the community and at the bedside can deliver needed patient, family, and community education; implement early detection programs; administer treatments; identify complications; provide palliative care; and lead and collaborate on clinical research.

In the Kenyan health care system, primary health care providers such as nurses often have very little training in cancer diagnosis, control, or prevention. There is an enormous deficit in the capacity for cancer management in Kenya, thus the majority of patients present in advanced stages of disease when few options remain. With the rise of cancer in the LMICs with a limited oncology community, efficient and effective ways of building capacity of the health professionals on oncology requires application of innovative approaches such as e-/ m-learning in the delivery of the training materials.



#### **Project description**

Amref Health Africa developed Leap, which is an innovative, scalable, and integrated mobile platform that offers continuous training opportunities, peer collaboration, real time evaluation reports, and strengthened supervision. Leap employs an appropriate mobile learning pedagogy to train via mobile phone, thereby enabling users to complete topics at their own pace and with their own mobile devices from anywhere.

This project has two main functions:

#### 1. Training of healthcare professionals:

The project converted the existing national breast cancer curriculum into mobile topics (mTopics) that train the front-line community health workers (CHWs) on breast cancer care (diagnosis, treatment and prevention) using the innovative mHealth platform.

#### 2. Data collection to improve diagnosis and referral:

The household community health reporting tool is improving accuracy, timeliness and completeness of data at the community level by facilitating real-time data collection and submission on breast cancer, as well as other cancers and NCDs. Through the referral module within the tool, any suspected cases can be referred for treatment by CHWs. The mobile application captures data for important project monitoring and evaluation metrics. Importantly, it verifies the completeness and validity of data before submission, tracks change of address to enable accuracy of population estimations related to cancer screening and incidence, and has the ability to store data offline.

## Increasing Access to Breast Cancer Treatment at the Community Level through Mobile (mHealth) Solutions

#### **Outcomes**

So far, the project has converted the National Integrated Curriculum on cancer care into 10 mTopics that have been used to train 500 CHWs in cancer care control and management.

The project increased and improved household/community level data collection and management on cancer care through the community health reporting tool.

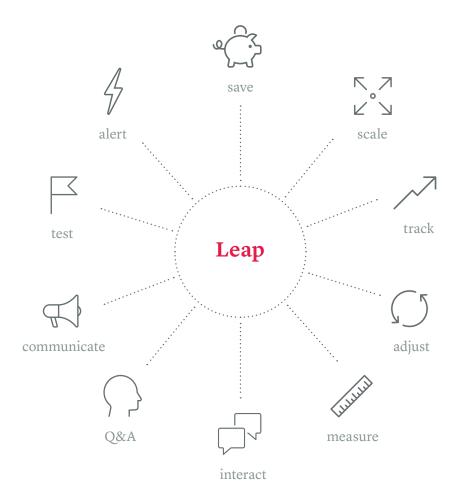
Implementation challenges have included poor mobile network coverage and language barriers, but the digital breast cancer curriculum has garnered important professional validation through its accreditation as continuing education for health care workers.

#### Tips for donors

Leap stems from a cross-sector partnership comprised of the Ministry of Health, Amref Health Africa, Accenture, Safaricom, MPesa Foundation, and Mezzanine, bringing together core capacities required in the development of a sustainable mHealth platform.

With additional funding Leap could be scaled up by training more nurses, other affiliated health workers across Kenya and beyond to other African countries. Institutional donors interested in this region and its access to state-of-the-art care could fund such programmes, in complement to the core funding. It would cost roughly US\$300,000 to set up Leap in a new country, train 500 HCWs, and support for one year. This includes digital content development for 10 mTopics.





#### 2. Advocacy

Investing in cancer control, from prevention to treatment and care, can bring about important changes in disease burden by reducing cancer-related illness and death. It is estimated that increased annual international funding of USD \$18 billion globally on prevention, earlier detection and improved care for cancer patients could save three million lives per year by 2030 and yield an additional US\$200 billion based on healthy lives and employee productivity saved.



#### What is cancer control advocacy?

Advocacy for cancer control is a strategic process designed to influence governments, decision makers and other key stakeholders through the effective use of evidence, to reduce the global cancer burden, to promote greater equity, and to ensure that cancer control continues to be in the world's health and development agenda. UICC has played a key role in advocating for global attention being paid to cancer. UICC unites the cancer community through its members and partners by building upon key international agreements, such as:

- The United Nation's Sustainable Development Goals (SDGs);
- The Global Action Plan on NCDs 2013-2020, which includes overarching objective to reduce premature mortality from NCDs by 25 percent by the year 2025;
- The World Cancer Declaration, which calls for a major reductions in premature deaths from cancer, and improvements in quality of life and cancer survival rates; and
- The 2017 Cancer Resolution, which provides a framework for countries to take action on cancer by identifying policy opportunities to scale-up access to prevention, diagnosis, treatment, and care services.

Going forward, these documents form a basis for advocacy work to ensure that these global goals and targets translate into national action.

To learn more about UICC's work and how investing in cancer control can bring about important changes in the disease burden by reducing cancer-related illness and death, please visit www.uicc.org.



### "Smoke Free Spaces" campaign

#### Background

Smoking is a major health concern in France where over 13 million people smoke daily, and tobacco kills 73,000 people each year. Amongst people aged 15 to 75, the proportion of daily smokers rose from 27% to 29.1% between 2005 and 2010, despite new tobacco laws.

It is most worrying that amongst 17-year olds, the number of smokers rose from 28.9% in 2008 to 31.5% in 2011. Every year 200 000 teenagers take up smoking in France. The country's average age to start smoking is just 14 years, with some of the highest numbers of young smokers. Smoking during adolescence can lead to the development of profound modifications to the central nervous

system, beyond being a major risk factor for cancer and other NCDs later in life.

Because four out of five smokers take up the habit before the age of 18, reducing the prevalence of smoking in France must be seen as protection of young people by reducing their exposure and in turn to prevent them from becoming regular smokers. France's recent National Programme for Tobacco Reduction aims to ensure that children born in 2014 become the first "tobaccofree generation" as adults in 2032. To achieve this ambitious goal, change must happen at all levels to de-normalise tobacco consumption in public places and reduce the number of young people who take up smoking.





#### **Project description**

Launched by the French League against cancer, the Smoke Free Outdoor Spaces campaign works in partnership with municipalities for the establishment of smoke-free outdoor public places.

The League encourages and supports the creation of outdoor spaces without tobacco, awarding a label to cities that commit to tobacco control and to the health of their citizens. This measure aims to create smoking restrictions for areas mainly visited by children, such as playgrounds, schools, beaches, gardens and parks.

Thankfully, public opinion is evolving. A survey of the French Alliance Against Tobacco in 2014, found that public support for smoke free spaces is very high: 83% of respondents support a smoking ban in parks, 72% on beaches and 84% in playgrounds and in front of schools.

#### **Outcomes**

The Smoke Free Spaces campaign has already seen some promising results. After implementation in Strasbourg and La Ciotat, satisfaction surveys found 97.8% supportive opinion in Strasbourg's parks and 75% satisfaction on La Ciotat smoke-free beach.

In the six years since initial implementation the campaigns reached nearly 980 Smoke Free Outdoor Spaces in 300 French cities. This project associates the lobbying capacity of the local committees of the League with the national coordination for development and enhancement of national regulation.

#### **Intended continuation**

This type of initiative relies heavily on political buy-in and collaboration with the relevant Government Ministries to be successful. With this in mind and after the success of the campaigns thus far, the French League against cancer launched "Smoke Free City" to ensure that it is maximising the current political openness and support of the French Ministry of Health. Because this campaign involves public spaces it has had to have strong partnerships with local authorities.

#### Tips for donors

The French League against cancer financially supported this campaign, using funding received mostly from private donations. The material expenses for this initiative are low, but its major costs are human resources associated with advocacy work. Donors ready to commit to medium or long term, at ease with funding human resources and wishing to bring change in a community they cherish, can make a crucial difference to the impact of such a campaign.

#### www.ligue-cancer.net



 $a\,member\,organisation\,of\,UICC$ 

## getting to the root of the problem

#### 1. Prevention

We have a lot left to learn about cancer, but progress occurs in leaps and bounds, as we understand what causes some cancers. For this guide, we will look at cancer prevention and early detection.

What do we currently know about what causes cancer?

Cancer is part of a category of diseases referred to as non-communicable diseases (NCDs), which cannot be transmitted from person to person like a virus. However, several infectious agents, such as the hepatitis B virus (HBV), human papillomavirus (HPV), and helicobacter pylori bacteria, may cause some cancers. Together, they account for 18% of cancer cases worldwide and up to 26% cases in LMICs. Many of the most common cancers in developing countries, such as cancers of the liver, stomach, and cervix, are caused by infections. We currently have vaccines for the viral infections that cause cervical cancer (HPV vaccine) and liver cancer (HBV vaccine). These two cancers alone account for nearly 10% of worldwide cancers. By increasing the availability and use the existing vaccines, more lives can be saved.

However, there is a range of other cancer risk factors. Heredity brings some predispositions for cancer, but it is important to stress that what is inherited is a tendency to develop a specific cancer, not the actual cancer per se. Parents may pass on to their offspring genes with potentially cancer-leading mutations: people with these mutations have a 'head start' on the cancerous process, as a mutation that can contribute to cancer is already present in every one of their cells. However, only about 5% to 10% of all cancers are the direct result of inherited gene mutations.

In fact, this is good news because there are many factors that we can take control of to try to mitigate our risk of developing cancer.

Biological risk factors include age, gender, ethnic origin, skin complexion and hereditary pre-disposition. Age is clearly the most important unavoidable risk factor: in the United States, for example, about 77% of all cancers are diagnosed in people aged 55 and older. However, there are many avoidable risk factors, and it is estimated that around 4 in 10 of all the world's cancers could be prevented.



#### 1.1 Primary prevention

Over the last decades, research has identified a variety of factors that increase or decrease the risk of developing cancer. In about 40% of cancer cases, these factors are linked to lifestyle or personal choices, so in principle nearly half of cancers could be prevented by avoiding these risk factors.

In addition to infections, these risk factors include:

Tobacco use, the most devastating risk factor, is estimated to account for 22% of all cancer deaths worldwide. Multiple studies have shown that male smokers are about 23 times more likely to develop lung cancer than non-smokers are. Smoking is accountable for 90% of lung cancer cases. Other than lung cancer, tobacco is associated with least a dozen other types of cancer, including cancer of the throat, mouth, nasal cavity, oesophagus, stomach, pancreas, kidney and bladder.

Overweight and obesity, insufficient physical activity and unhealthy diet are, next to exposure to tobacco, the most influential avoidable risk factors. Overweight and obesity, resulting from poor diet and physical inactivity, are linked to at least 13 different types of cancer. In the United States, evidence suggests that about one-third of cancer deaths in 2012 were related to obesity, physical inactivity and unhealthy diets. Importantly, trends suggest that if nothing is done, then overweight and obesity could overtake smoking as the most significant risk factor for cancer in our lifetimes.

Alcohol use is associated with cancers of the mouth (oral cavity), liver, pharynx, larynx, oesophagus, breast and colorectum.

According to a recent study, alcohol is accountable for 44% of upper aerodigestive tract cancers, 33% of liver cancers and 17% of colorectal cancers in men.

#### Excessive exposure of skin

to sunlight (ultraviolet radiation) causes skin melanoma, to which fair-skinned, blue-eyed people are particularly prone. Some studies show that about 65% to 90% of melanomas are caused by exposure to ultraviolet light.

**Environmental and occupational exposure**, including urban air pollution,
smoke from indoor use of solid fuels, asbestos,
radon, pesticides and other toxins present in
consumer goods (including building materials,
food and drink), are estimated to account
for 2 to 4% of cancer deaths.

"In most cases it isn't a single food or nutrient that makes a difference – there are no magic bullets. The important thing is what you eat and drink, your weight and how active you are through your lifetime. In fact, around 40% of cancer cases could be prevented by reducing exposure to cancer risk factors including diet, weight and physical inactivity. The World Cancer Research Fund Cancer Prevention Recommendations provide a blueprint people can follow to reduce their risk.

#### - Dr Kate Allen

Executive Director, Science and Public Affairs, World Cancer Research Fund International, a member organisation of UICC



### 1.2 Secondary prevention: early detection

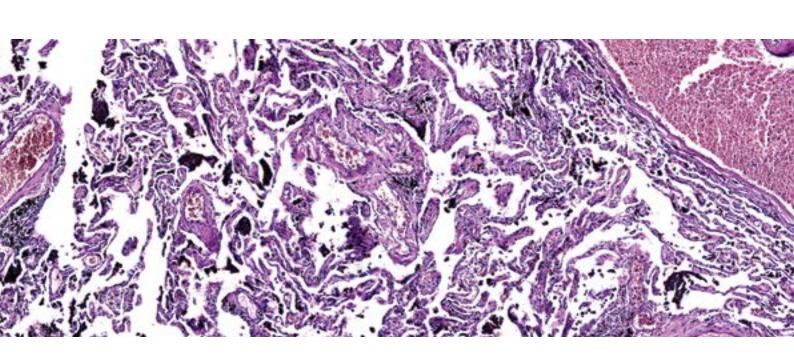
Today, it is widely acknowledged that the earlier a diagnosis of cancer is made, the more likely the chances of successful treatment will be.

In fact, many experts consider early detection the most promising and most feasible means for reducing cancer deaths. The question is: how early is early in relation to the progression of cancer? The answer is that it varies from person to person, but it is true that many cancers take years, or even decades to develop from a single mutant cell to a fully blown metastatic cancer. Although we do not know just how wide the window of opportunity is, we can employ various methods to detect malignancies at an early enough stage to effectively treat to cure. Some research suggests that at least half of all cancer deaths could be prevented if detected earlier.

Regular check-ups and screenings by healthcare professionals can result in the detection and removal of precancerous growths (for example for cancers of the cervix, colon and rectum), as well as diagnosis of cancers at an early stage, when they are most treatable. Detecting and diagnosing cancer early can be done using several different techniques and examinations.

"The Indonesia Cancer Foundation's (ICF) work is focused around a belief that many cancers can be cured if detected at an early stage. ICF continuously promotes early detection of cancer and ensures cancer patients undergo timely proper medical treatment. We believe that our initiatives in Indonesia will reduce mortality rate due to cancer.

- Professor Dr Aru W Sudoyo ICF Chairperson, a member organisation of UICC



#### These include:

#### Physical examination and patient history:

Understanding the signs and symptoms of cancer, especially when one has a family history, is important for early detection. For example, if one notices unusual skin blemishes, lumps, or other unusual symptoms, these are worth sharing with a general practitioner so they can make an assessment.

#### Laboratory tests:

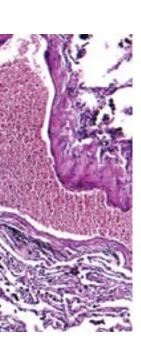
If there is a reason to suspect cancer, doctors may order laboratory tests or a biopsy. These procedures test samples of tissue, blood, urine or other substances in the body to check for cancer cells or markers.

#### **Imaging procedures:**

An imaging test is a technique used to see what is going on inside the body. Imaging procedures send forms of energy (x-rays, sound waves, radioactive particles or magnetic fields) through the body. The changes in energy patterns made by body tissues create an image, which can help to identify abnormal tissues, such as cancer.

#### Genetic testing:

Genetic testing (also called DNA-based testing) is one of the newest and most sophisticated techniques used to determine the likelihood of a person developing cancer. These tests analyse genes, chromosomes or proteins to help predict the risk of disease and identify carriers. More than 1,000 genetic tests are available for many different diseases, including breast, ovarian, colon, thyroid and other cancers.



Although techniques and procedures have progressed greatly in recent decades, it is important to note that limitations and challenges still exist. At a population level, only certain cancers are amenable to screening, particularly breast, cervical, colorectal and oral cancers. For other cancers the screening tests that exist have not proved to be reliable or to have a demonstrated impact on reducing cancer deaths.

Also, false results are possible with some screening tests. Screening results can sometimes appear abnormal, even though there is no cancer present, or negative, even where tumours are present. Increasingly, these tests need to fulfil criteria relating to sensitivity, specificity and availability of effective treatments to be considered potentially worthwhile. The physical and psychological pros and cons should be weighed before undergoing a particular screening test, and global guidelines exist to support this decision.

In the case of more aggressive cancers still beyond our ability to treat, early diagnosis may not improve chances of survival. Early diagnosis would, however, help patients and their caregivers gain access to supportive and palliative care.

Lastly, screening and diagnostic testing require financial, technological and logistical resources that can be beyond the means of LMICs. Frequently countries with weak health system or inadequate resources are likely to have limited early diagnostic capacity and ineffective or absent national screening programmes.



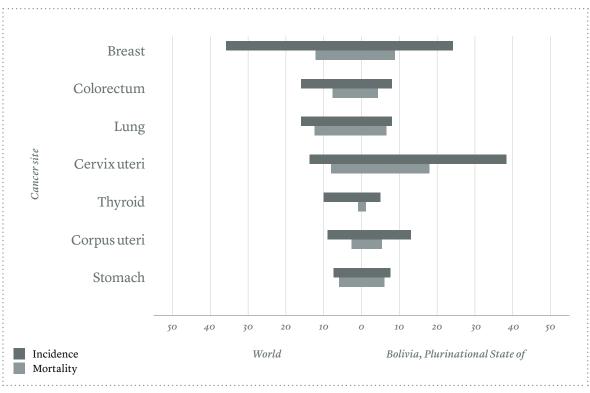


### IPPF/WHR & CIES: Saving Women's Lives in Bolivia

#### Background

Cervical cancer is the fourth most frequently occurring cancer among women around the world, and is the most frequently occurring cancer in Bolivia, with approximately eight new cases diagnosed per day. In a region with some of the world's largest structural and gendered health, wealth, and social disparities, millions of women and girls are estimated to have an unmet need for modern contraception and many lack even basic access to quality sexual and reproductive healthcare. For a cancer that is otherwise easily preventable and highly treatable, early and regular cervical cancer screening and treatment services are also practically inaccessible for many.

## Estimated age-standardized incidence and mortality rates (World) in 2018, females, all ages



Data source: GLOBOCAN 2018 Graph production: Global Cancer Observatory (http://gco.iarc.fr)

#### **Project description**

International Planned Parenthood
Federation/Western Hemisphere Region
(IPPF/WHR) is a leader in the movement
for sexual and reproductive health and
rights in the Americas and Caribbean.
IPPF/WHR works with many partner
organisations in the region to ensure
universal access to sexual and
reproductive healthcare, promote
comprehensive sexuality education, and
fight for sexual and reproductive rights.

CIES (Centro de Investigación, Educación y Servicios) is an IPPF/WHR member association and a leading provider of sexual and reproductive health (SRH) services, education and advocacy in Bolivia. A long-time provider of women's cancer screening and treatment services, CIES is keenly aware of the need to reach more women with life-saving care.

Working together, IPPF/WHR and CIES designed a secondary prevention intervention to increase access to cervical cancer screening and treatment services, aiming to ensure that all women have access to newly available hybrid-capture HPV DNA testing (careHPV), cytology (pap smears) and/or Visual Inspection with Acetic Acid (VIA), as recommended per clinical guidelines.

These methods allow for more sensitive and accurate screening results earlier in the carcinogenic process before cervical cancer can develop, and at longer intervals, which avoids over-screening and improves cost-effectiveness. For these reasons, HPV DNA testing is preferred over pap smears as the screening method of choice. Critically, all positive cases of cancerous or precancerous lesions are immediately treated or referred. The approach included promoting the new testing services at CIES' fixed clinic locations and bringing services directly to rural and hard-to-reach, geographically and economically vulnerable populations via mobile health units (MHU).

The project was implemented in a series of stages, bringing in all relevant stakeholder groups. It included partnerships with the Ministry of Health and a manufacturer providing the testing equipment; a communications and awareness campaign to promote the new screening technology and encourage uptake; training in new technologies to build institutional capacity; and evaluation and monitoring throughout.

### IPPF/WHR & CIES: Saving Women's Lives in Bolivia

#### **Outcomes**

CIES saw a gradual increase in the number of women who accessed new cervical cancer services including hybrid-capture HPV testing in the five-month period this project was implemented from March to July 2016, reaching a total of 2,346 women.

The project also highlighted several useful lessons and opportunities to address some of the traditional socioeconomic and geographic barriers experienced by women in accessing SRH care, among them:

- Better results are achieved when providing a combination of direct services and education, working at both clinic and community levels and including MHUs.
- Subsidising service costs for economically disadvantaged clients increases uptake among poorer populations.
- Comprehensive care and user satisfaction are improved with immediate delivery of testing and treatment services.
- Bolivian women are most familiar with pap smears as a screening method. Significant effort will be required to encourage acceptance and uptake of any new screening technology.

The intervention was designed to be sustainable from the start, borne out by the organisation's full integration of the new and expanded screening technologies and protocols within fixed clinics and MHUs. CIES is planning additional efforts to further promote awareness around the availability of all screening and treatment options, and the need for early, regular screening. In 2017, CIES provided 373, 468 cervical cancer related services.

#### Tips for donors

Financial support for this project comes from several foundations and development agencies, ensuring that 100% of services are subsidised for those who could not otherwise afford them. With additional funding IPPF/WHR hopes to build upon the successes and lessons learned in this project and continue similar work in cervical cancer prevention, screening and treatment in Bolivia and in the region.

www.cies.org.bo www.ippfwhr.org



a member organisation of UICC

#### 2. Research

Cancer research is a vast and complex field. To give you a small taste of what is out there, here we focus on three main areas:

- Basic research understanding how cancer works.
- Translational research turning research into solutions for patients.
- Clinical research testing those solutions in clinical practice.

There are a multitude of sub-specialties within each of those sections, and our aim is not that you walk away an expert, but rather that you gain a more comprehensive overview of what is happening in cancer research. It is important to note that each area plays a unique role in the process of gaining knowledge, to understanding how it can be used to save lives.

#### 2.1 Basic research

Basic research (also referred to as pure or fundamental research) is just that: the research that aims to increase understanding of the fundamental principles underlying cancer growth, and its ability to kill healthy cells.

Basic research does not have an immediate effect on the way we treat patients, but instead provides us with the important breakthroughs required to better understand how we can prevent, diagnose or treat cancer.

According to many, cancer-related basic research is burgeoning: some speak of "a new era of cancer medicine", or of being "at a defining moment in our ability to conquer cancer". Progress is certainly being made, largely thanks to new breakthroughs and technologies developed over the past decade. For example, probing the genetics of cancer cells has become a cornerstone of current cancer research, and owes much to the Human Genome Project, which was completed in 2003 after identifying all the 20,000 to 25,000 genes in human DNA. Similarly, technologies such as nanotechnology have provided a leap forward, allowing researchers to explore and manipulate cancer-related molecules that are important during the earliest stages of the disease progression.

Basic research currently revolves around three main approaches:

- 1. **Genomics**, or the study of genetic material.
- 2. **Epigenetics**, the study of how various external factors can change how our genes function.
- 3. **Proteomics**, or the study of proteins associated with certain tumours (called biomarkers).

While quite distinct, these three areas are complementary, and are all seeing huge strides forward in recent years.

#### **Genomics:**

Genomics involves the study of genetic material and the mapping of the different genes that make up the genome (the complete set of genetic material of an individual). In the context of cancer, genomics allows the tracing of a "blue print" of each tumour for improved understanding in how to fight it. In fact, each cancer has a genome sequence, or blueprint, that is specific to it, irrespective of its location (lung, breast, etc.). If we identify subclasses of cancers according to their genome sequence, rather than their location, we can focus on treating and preventing these cancers accordingly.

#### **Epigenetics:**

Epigenetics looks at how other external factors can impact how cells read our genes, which is to say, ultimately how a gene is turned on or off. These factors do not change the DNA itself. We have learned that genes alone are not enough to explain how cancer arises. It is becoming clear that the chemical "packaging" on which genes sit can also determine how cells function and potentially evolve into cancer cells. This area of research, known as epigenetics, is a recent addition to the body of knowledge on cancer, and is becoming increasingly important. According to the International Agency for Research on Cancer, epigenetics is "one of the most rapidly expanding fields of modern biology, with enormous implications on our thinking and understanding of biological phenomena and diseases, especially cancer".

#### **Proteomics:**

This is the study of proteins, and more specifically proteins typically associated to certain tumours, known as biomarkers, that can be useful to diagnose cancer, predict a response to a drug, or predict the aggressiveness of a cancer. Understanding proteomics enables the identification and classification of cancers, not according to their genetic modification, but the complex interactions they have with the cells and tissues around them over time.

### Cancer Research UK Grand Challenge

#### Background

Historically, the research community has functioned in silos, with laboratory groups working on narrow topics of research and communicating only within their field. But no single team, organisation or country is going to beat cancer on its own. To ensure that cancer research builds on what's already known, these barriers must be replaced with a spirit of collaboration and knowledge-sharing. Moving beyond traditional funding approaches, rising above national agendas and collaborating with researchers from other disciplines will bring fresh ideas and new perspectives to the table, while the ongoing technological revolution will facilitate communication and speed up research.



#### **Project description**

Through Grand Challenge, Cancer Research UK (CRUK) is shaking up traditional ways of funding by bringing together international, multidisciplinary teams of the world's best researchers to solve some of the toughest problems in cancer.

Working with researchers and patients worldwide, an independent Scientific Advisory Panel of leading scientists set challenges which, if addressed, will change the face of cancer research and transform outcomes for patients.

CRUK has called on international researchers from all disciplines – including academia, technology and business – to respond with innovative and ambitious approaches to tackling one of these problems. First, the teams submit an expression of interest, outlining their proposed team and approach. These are reviewed by the panel and the shortlisted teams receive seed-funding to develop full applications. Three months later, the teams submit full applications and are interviewed by the panel.

Grand Challenge is the biggest cancer research grant in the world. The winning team, or teams, are awarded up to US\$26m over five years to carry out their pioneering research.

#### **Outcomes**

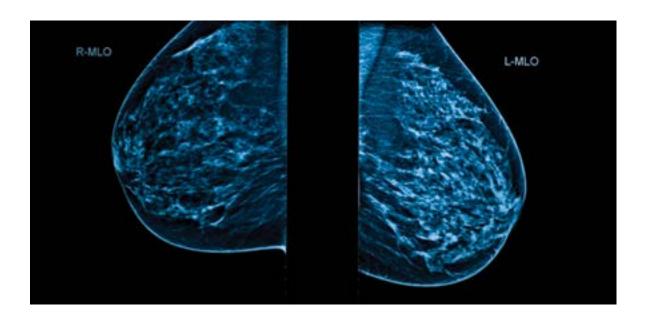
The first round of Grand Challenge was launched in October 2015. In total, 57 ideas were submitted from scientists across 200 institutes, spanning 25 countries and uniting more than 400 researchers. The panel shortlisted nine teams; however, the proposals were so compelling that they felt it would be a missed opportunity to fund only one. Thanks to new collaborations with other organisations and philanthropists, in February 2017 CRUK announced that four teams would together receive more than US\$91m over the next five years.

### Cancer Research UK Grand Challenge



## Dr Jelle Wesseling is preventing unnecessary breast cancer treatment

Dr Wesseling, from the Netherlands Cancer Institute, and his team are focusing on a condition called ductal carcinoma in situ (DCIS). This is where women have abnormal cells in the milk ducts of their breast, which have not yet developed the ability to spread into surrounding tissue. Not all women with DCIS will go on to develop breast cancer, but doctors can't yet tell which women have the most risk, meaning that some women with DCIS undergo hospital visits, surgery, and even chemotherapy and radiotherapy when they don't actually need it. The team is using large and unique collections of DCIS samples to study the condition in more detail to try to provide a way of identifying the women who may go on to develop breast cancer. Their aim is to spare women unnecessary treatment, reduce anxiety and preserve quality of life, while still ensuring that the women who need treatment get it. This group was granted a Grand Challenge award because the scale of the work and the data analysis involved are unparalleled in the field of cancer research. To fund this team, CRUK partnered with the Dutch Cancer Society, pooling resources to enable this large-scale research to happen.



#### **Intended continuation**

In June 2017, CRUK launched round two of Grand Challenge with a refreshed set of eight challenges. In response, the panel received 134 submissions from the global research community. The panel shortlisted the 10 most impressive projects and the successful team, or teams, will be revealed in early 2019.

#### Tips for donors

Grand Challenge is CRUK's innovative solution to beating cancer on a global scale by bringing together the world's brightest minds to answer critical questions. Forward-thinking philanthropists fund the awards because they want to be involved in significantly accelerating progress in cancer research. With further financial support, CRUK could fund more awards and answer more of these big questions faster.

CANCER RESEARCH UK

a member organisation of UICC

#### 2.2 Translational Research

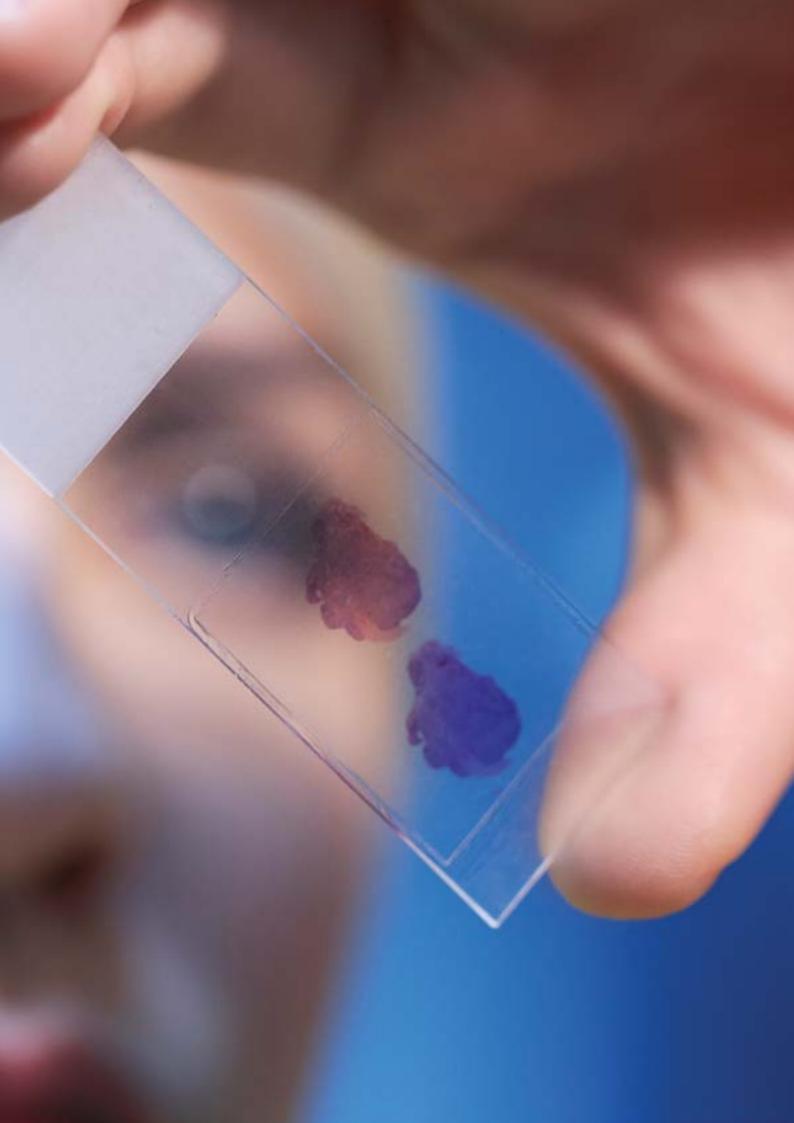
Translational research is the link between breakthrough basic research, and practical improvements in patient care. The past decade has seen unprecedented interest in translational cancer research.

Indeed, as the wealth of knowledge and information produced by basic researchers pours in, it must be made "actionable" and transformed into concrete tools, treatments, and procedures that will be able to save lives.

To this end, translational cancer research explores ways of applying cutting-edge scientific discoveries to new approaches to cancer prevention and treatment.

At the same time, it aims to ensure researchers keep the pressing needs of cancer patients at the forefront of their work by reducing the time it takes for a promising research finding or concept to be tested, prior to being used on patients.





## **Champalimaud Foundation Pancreatic Cancer Programme**

#### Background

According to the WHO, pancreatic cancer claimed more than 330,000 lives in 2012, with 68% of deaths occurring in developed countries. This cancer accounts now for more deaths in the US than breast cancer and is projected to become the second leading cause of cancer death by 2020. Since most patients present with metastatic disease at diagnosis, the 5-year survival rate is only 5%. Up to now the treatment options for patients with pancreatic cancer are limited.

Over the last half century, it has become well established that cancers can be targeted by a person's immune response. Cancer treatments that target the immune system, rather than the cancer cells themselves have proven immensely effective, particularly in some patients with metastatic melanoma or Hodgkin lymphoma. However, these approaches have not had the same success to date in pancreatic cancer. The important challenge is therefore to see if new immunotherapy approaches can achieve lasting clinical responses in patients with pancreatic cancer.

#### **Project description**

Immunotherapy approaches, and in particular specialised T-cell based therapies, which target the immune system, have resulted in some remarkable clinical responses in patients with metastatic cancers. T-cells are white blood cells which attack foreign, diseased or cancerous cells, and are an important component of the immune system response.

The clinical efficacy (the measure of how well a treatment succeeds in achieving its aim) of innovative targeted immunotherapies appears to depend on the ability of T-cells to recognise mutated versions of proteins in the host cell.

Manipulating the T-cell response to these mutated proteins is the basis for new immunotherapeutic responses in pancreatic cancer. Yet for several potential reasons, including the particular tumour microenvironment in pancreatic cancers that can restrict the infiltration of T-cells, the immune response against pancreatic cancer cells appears to be suppressed. This suppression is thought to be an early event in patients with pancreatic cancer; and therefore, increasing T-cell infiltration is a strategy that could potentially improve the response in pancreatic cancer patients.

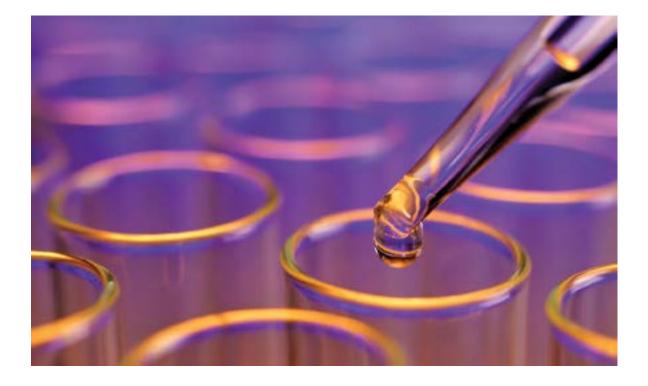
The long-term project has a clear and defined clinical approach: to expand tumour infiltrating T-cells (TIL) products to patients with locally advanced or metastatic pancreatic cancer. This is currently a clinically unmet need concerning immunotherapy with TIL for patients with pancreatic cancer, which must be addressed. Specifically, it is important to better understand the tumour microenvironment in order to improve outcomes using combination therapies, develop superior TIL products, test their local delivery of T-cell products, and seek out "genetic blueprints".

## **Champalimaud Foundation Pancreatic Cancer Programme**

#### **Outcomes**

In a recent clinical study, members of the Champalimaud team successfully expanded TIL from a patient with recurrent and rapidly progressing glioblastoma (a form of brain cancer), leading to tumour regression. This approach led to the increase of healthy T-cell products and enabled the treatment of the tumour within the patient.

Patients with pancreatic cancer or fibrosarcoma metastatic in the lung were treated in the same way, specifically, TIL were expanded in 40 out of 40 patients with pancreatic cancer, and results indicate the potential for increased survival in pancreatic cancer patients.



#### Next steps

The Champalimaud Immuno-Surgery Unit (within Immuno-Oncology Programme) is working on translational research projects to further improve therapy options and efficacy.

Early results suggest that TIL therapy is more cost-effective and potentially more efficacious than currently available options for pancreatic cancer treatment. The aim of the project is to offer patients with pancreatic cancer an additional line of therapy using similar/related T-cells. Successful translational efforts with other modes of T-cell therapies will expand the repertoire of immunotherapeutic approaches. Each patient within the Champalimaud Pancreas Programme receives detailed genetic and immunological analysis, including the prospective TIL harvest and expansion in the context of standard diagnostic or therapeutic procedures for potential future therapies. This enriches clinical practice and enhances health care solutions, as new developments in academic medicine are integrated into patient care.

This project is in partnership with: Krankenhaus Nordwest, National Cancer Institute USA, Zellwerk GmbH, and IGR, Paris, France.

#### Tips for donors

The idea of the Champalimaud
Foundation began in the mind of
a Portuguese entrepreneur, a successful
industrialist and financier, António de
Sommer Champalimaud, who left a
legacy after his death in 2004 to create
an international project in the field of
biomedicine. He appointed the former
Portuguese Minister of Health, Leonor
Beleza, as President of the Foundation.
Donors wishing to learn how they can
support the work of the Foundation can
contact them directly through
the website below.

Setting up such a project, with the creation of a large philanthropic vehicle, requires careful fiscal and strategic planning. It would typically involve a build-up phase with a range of specialist advisers. An initial scoping study should inform them on the best strategy to adopt. For the philanthropic vision to deliver on its promise, foundations like these should also have guaranteed resources, with a multi-million dollar endowment, invested in the long run.

www.fchampalimaud.org



a member organisation of UICC

#### 2.3 Clinical Research

Clinical trials are one of the final stages of the complete cancer research process.

Whereas translational research seeks to make discoveries applicable, clinical research tests the application of those techniques, drugs or procedures intended to prevent, detect or treat diseases.

In cancer research, a clinical trial is designed to show how a certain preventive approach, a new diagnostic test, drug or surgical procedure can affect the people receiving it. Although participating in these trials does not guarantee patients a better chance of survival, it does represent an important contribution to the body of cancer knowledge and the overall fight against the disease.

It generally takes 12 to 18 years from the time a breakthrough discovery is made until a new drug reaches your pharmacy. It can take years for the discovery to be used to produce a candidate drug, and once developed the drug must be fine-tuned and first tested for safely and effectiveness on animals or in vitro. Only when the candidate drug has received approval from the relevant national authorities, the comprehensive and rigorous journey through the many phases of clinical trials may commence.



These trials are conducted according to a progressive step-by-step sequence, each with a distinct goal, as described below.

#### Phase I:

The first set of trials is conducted on approaches that appeared promising after extensive laboratory research, animal testing, and the filing of an application with the national drug authorities. The purpose of this phase is to focus on determining the safety and side effects, as well as the proper dosage of the drug. Only a small number of people (usually a couple of dozen) are needed to take part in these studies. Participants are patients who volunteer, generally because other treatments are no longer effective for them.

#### Phase II:

A somewhat larger group, roughly 100-300 people, is involved to further investigate safety, dosages, and to get a preliminary idea as to whether the approach has a positive effect against the cancer.

#### Phase III:

These trials, which usually involve hundreds or even thousands of volunteers, compare the new approach with the best standard approach, and this is the final phase before the national drug authorities' approval. Some people enrolling in this type of trial are randomly chosen to receive the new treatment, whilst others will be offered the standard treatment (control group). The purpose of this type of trial is to determine whether the new treatment is more beneficial than the standard therapy or indeed, if it adds any benefit at all.

If all these steps are successful, the approach can then be submitted to the country's regulatory authorities that make the final decision whether to allow the drug or procedure to be used on human subjects or not. The fourth and final step, once the drug or procedure is being used, involves surveillance of the population to detect any side effects that could justify withdrawal of the drug.



# The gut microbiota on cancer immunotherapy: from biomarker to modulation

#### Background

Immunotherapy represents a breakthrough in oncology. The immune system of patients living with cancer is often altered and weakened. Immune checkpoint inhibitors (ICI) is a new class of drugs that re-awaken the immune system to kill cancer cells. ICIs provide unparalleled clinical results in advanced non-small cell lung cancer (NSCLC), melanoma, and renal cell carcinoma (RCC). Unfortunately, a significant proportion of patients still exhibit resistance. Therefore, new biomarkers to predict response and methods to safely enhance ICI efficacy (the measure of how well a treatment succeeds) are urgently needed.

#### **Project description**

A research group at Gustave Roussy, Paris, led by Professor Laurence Zitvogel first unravelled the unexpected association between the trillion bacteria that colonise our gastrointestinal tract collectively known as the gut microbiota and ICI efficacy in 2015. To solidify this observation, they launched a project at Gustave Roussy to collect faeces of cancer patients on immunotherapy. They initially collected faeces from 153 metastatic NSCLC and RCC patients treated with an ICI and the composition of the patient's microbiome (the genetic material of the gut microbiota) was then analysed. They also reviewed patients' medical records to identify those individuals that received antibiotics because, although antibiotics are known to eradicate pathogen bacteria, they can significantly alter the composition of the gut microbiota by also killing good bacteria in the gastrointestinal tract.

#### **Outcomes**

The results of this study demonstrated that antibiotics use before starting immunotherapy had a negative effect on patients' clinical outcomes. Subsequently, the research team (including Dr Bertrand Routy, and Dr Lisa Derosa) established that a patient's response to ICI could be determined by the makeup of their particular gut microbiota, and specifically identified a bacterium, which was more abundant in patients with a favourable response. Moreover, they were able to confirm this association in a pre-clinical mouse model. Two independent groups also validated the key role of microbiota in melanoma patients receiving ICI.

#### **Intended continuation**

To prove the clinical relevance of the gut microbiota as a novel biomarker for cancer immunotherapy, they have launched a large multicentric international study where they collect microbiota from NSCLC patients receiving ICI in 14 hospitals in France and 3 hospitals in Canada. The discovery of bacteria capable of increasing clinical benefit of ICI will help in the development of a novel therapeutic concept, whereby treatment of cancer can be improved by the modulation of gut microbiota. They are planning to start clinical trials to administer bacteria with immunotherapy. Targeting microbiota in cancer will most likely change the concept of immunooncology and push the frontiers of personalised medicine even further to improve patient care.

This experience with more than 300 participants in various clinical trials demonstrated a strong interest from the patients to enrol in this type of ancillary study and reached a compliance level above 90%.

#### Tips for donors

This project receives funding from Gustave Roussy, Fondation Philanthropia PhD in oncology programme, RHU Torino Lumière, Centre Hospitalier de l'Université de Montréal and the start-up onco-microbiome company EverImmune. The PhD programme allows Gustave Roussy to attract talented young medical doctors, engineers, or pharmacists and provide them with a three-year mentoring and research experience, an above-market compensation and a higher employability upon graduation. The programme costs EUR 150'000 for three years per student. Through such a programme donors can directly contribute to quick and tangible results: the production of breakthrough research, the development of an international network of oncology specialists and the strengthening of Gustave Roussy as a training centre.

www.gustaveroussy.fr



#### Fondation Philanthropia-PhD in Oncology at Gustave Roussy Cancer Campus: 2013-2018



→ 608 applications - 22 laureates



3 year training in major field of translational research



cost per student €150'100 over three years



- medical doctors, pharmacists, engineers in biology
  - 20 mentors
  - even male/female split
  - ▶ 15 French/ 7 foreign
  - → 100% have since found a research position

## conclusions and next steps

Thank you for taking the time to learn about the current state of cancer control and care. In this pivotal moment in the progress against cancer, we hope you found the information contained in this guide to be compelling and enlightening. As you have now realised, the needs are as great and as complex as the challenge before us. It can be difficult to understand the priorities when there are so many worthy projects and immediate needs. We hope you are walking away with a newfound awareness of the complexity of the problem, but also a sense of encouragement about the progress being made to tackle this disease. There is still a long way to go, but your contribution could shorten the time to defeat cancer and make you part of a global movement working together towards the same goal.

Having now read about the challenge and some of the key issues, is there an area where you feel yourself called to get involved or to know more about? If so, we hope you explore the websites of the organisations featured to continue learning about the important work already happening in cancer control, and to examine if there are ways you feel called to act.

- Rosetrees is a family charity applying its successful business skills to find and fund the best ideas in about 400 cutting edge medical research projects. Having gained experience running a property and finance business, the family chose a charitable trust as vehicle to materialise their philanthropic ideas. Today, 25% of Rosetrees's donations are in oncology, with a specific focus on the UK research community. A team of 12 works together to find, fund and follow the best medical ideas, advised by some of the UK's leading scientists. Life enhancing treatments follow, which benefit patients, enhance researchers' careers and leave us as the donors, fulfilled. It's win/win-try it!
  - Richard Ross, Chairman of Rosetrees
  - www.rosetreestrust.co.uk



#### Next steps with Lombard Odier Philanthropy Services

You may feel overwhelmed by all the options, but we are here to discuss your aspirations and help guide and connect you with the relevant partners. Based on our expertise in advising clients who wish to make a difference in the movement for a cure, better treatment and disease management and support, we at Lombard Odier Philanthropy Services recommend you take these steps:

- **Define your philanthropic objectives** set your priorities in terms of topic, but also geographic scope, mode of intervention and impact. This will help you find the niche that is relevant to you and the targeted issue.
- **Develop your giving strategy** in this field like in many, there is no small donation. Decide if you wish to help strengthen the means of action (capacity building), focus on providing more care, research or services, or promote their outcome.
- Marry passion with power of data try to balance the passion you feel for the cause witha databased approach. It will help you select the right programme or project.
- Collaborate and co-finance remember that in the case of cancer, joining forces with others and co-financing are crucial. This may be important when measuring the impact of scientific research for a drug or of a prevention campaign for HPV.
- Share learning and achievements share what you learn with other like-minded donors and learn from them. Your advisor can help widen your circle of contacts in oncology or in the cancer community as a whole.
- Asset management strategy if in charge of a grant-making foundation focused on cancer or not, discuss with your Board the opportunity to invest the capital in companies or funds that support the cancer challenge.

Philanthropy Services | +41 22 709 99 40 | philanthropy@lombardodier.com/www.lombardodier.com/philanthropy



The Union for International Cancer Control (UICC) is dedicated to taking the lead in convening, capacity building and advocacy initiatives that unite and support the cancer community to reduce the global cancer burden, to promote greater equity, and to ensure that cancer control continues to be a priority in the world's health and development agenda.

The organisation's rapidly increasing membership base of over 1100 organisations in more than 160 countries, represents the world's major cancer societies, ministries of health and patient groups and includes influential policy makers, researchers and experts in cancer prevention and control. UICC also boasts more than 50 strategic partners. To learn more please visit www.uicc.org | partnerships@uicc.org

#### Glossary

LMICs: Low and Middle Income Countries as defined by the World Bank

using the Gross National Income as a primary benchmark

**NCDs**: Non-Communicable Diseases

**UICC:** Union for International Cancer Control

WHO: World Health Organization

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