# Cancer in Canada



### Framing the Crisis and Previewing the Opportunity for Donors

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The authors dedicate this report to their parents, lost too early to cancer: Victoria Z. Greve, 1945-2004 Thomas H.Thomson, 1935-1992

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This report was created to answer the question of what has happened to the billions of dollars given in Canada in the name of cancer over the past couple of decades. Ci believes that with an understanding of what has happened in the past, we can best understand how to give with impact today.

For more information on how your donations to cancer charities can have impact, please visit our website at www.charityintelligence.ca or call 416.363.1555

#### **Executive Summary**

#### Cancer kills more Canadians, at younger ages, than any other disease.

Eighty percent of Canadians say they are concerned about cancer.<sup>1</sup> Charity Intelligence shares this concern, so we did what we do best: we harnessed the collective intellect and passion of our research analysts to examine Canada's cancer crisis, to help Canadian donors transform their concern into intelligent giving.

## Ci believes that rather than hoping for a "cure", funders should think strategically about how their donations can best change the cancer

**landscape.** "Cure" is a term that has had strong associations with cancer for as long as we can remember. Yet, oncologists and cancer researchers are generally of the belief that cancer, as a family of diseases, is unlikely to be "cured" in the way that infectious diseases such as polio and smallpox have been eradicated in the developed world.<sup>2</sup>

The best we can hope for is to transform cancer from a disease that Canadians die from to one that they can prevent or live with as a chronic condition, while mitigating the hardships associated with being a cancer patient or survivor.

In this report, Charity Intelligence takes a critical first step in helping donors who care about cancer: illustrating ways to optimize cancer research, identifying key levers in reducing cancer's tragic impact on Canadians, and highlighting the four cancers that are most desperate for donor support.

Cancer is a personal disease. The challenge for donors is to find funding opportunities that drive life-saving outcomes while matching each donor's personal connection to cancer. This report focuses on Ci's Top 10+. These are the cancers that rob the most years of life from Canadians: lung, colorectal, breast, pancreatic, non-Hodgkin lymphoma, brain, leukemia, prostate, ovarian, and stomach cancers, plus sarcoma, Terry Fox's cancer.

# Ci has identified four cancers that are underfunded relative to their deadly impact on Canadians: pancreatic, stomach, lung and colorectal.

These cancers represent an opportunity for donors to make real impact by filling a tragic funding gap.

As Canada's population ages, more Canadians will get cancer. Not all will survive. Palliative care will help cancer victims live out their lives in the greatest possible comfort, while reducing the burden on their loved ones and mitigating the escalation in Canada's health care costs.

Palliative care is a huge, growing, and currently unmet need that applies to all cancers. Funding palliative care is a key way for donors to make an immediate and measurable difference.

Ci hopes this report will enable Canadians to make cancer donation decisions with their heads as well as their hearts. At the time of this writing, there are 278 Canadian charities focused specifically on cancer. Each has its own unique approach to address cancer's multifaceted challenges. This report does not evaluate – or even identify – cancer charities for donors' consideration. That is the next step.

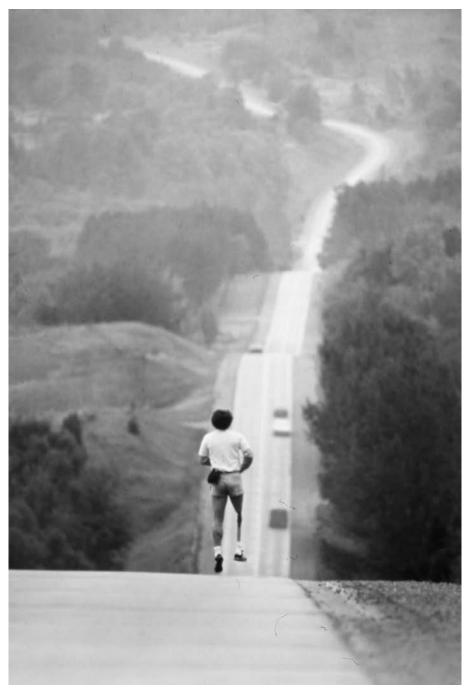


Photo: Spectrum Photofile

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#### I. Why Cancer Matters Most

In 2006, cancer surpassed cardiovascular disease<sup>3</sup> as the leading cause of death for Canadians.<sup>4</sup> The average lifetime risk of developing cancer is 45% for men and 40% for women. About one in four Canadians will die of the disease. In 2010, it is estimated that 76,200 Canadians died from cancer, representing more than a million potential years of life lost (PYLL) to cancer last year alone.<sup>5</sup>

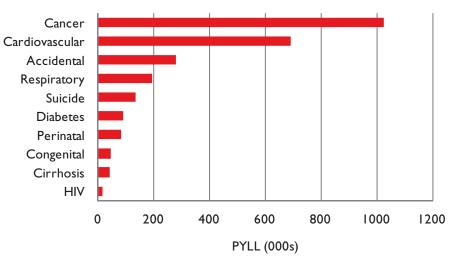


Figure 1: Potential Years of Life Lost (PYLL) by Cause

Cancer takes its victims at younger ages than cardiovascular disease, Canada's second killer. Cancer kills 41% of the two in five Canadians who die younger than 74 (the average age of death in Canada). That is twice the death toll of cardiovascular disease and four times the death toll of accidents and suicide among young Canadians. Cancer is the leading cause of death from disease among Canadians in every age range up to 84 years old.<sup>6</sup>

This is why the potential years of life lost is 50% higher for cancer than for cardiovascular disease, despite causing only 8% more deaths overall.<sup>7 8</sup>

Is it any wonder that Canadians identify cancer as their top health concern?

• Death in old age is inevitable, but death before old age is not. **?** 

 Sir Richard Doll, who proved the link between smoking and lung cancer

Source: Statistics Canada, 2004.

#### 2. Cancer's Changing Landscape

The first documented case of cancer was over 3,000 years ago. In that case, as in most cases of cancer through the early 20<sup>th</sup> century, cancer meant death.<sup>9</sup> Advances over the past century, and particularly the past 50 years, have made this less often the case.

There are four ways to characterize the magnitude of cancer's impact on Canadians' lives:

- **Cases** The number of people who develop cancer. Incidence is the number of cases per 100,000 Canadians.
- **Deaths** The number of people who die of cancer. Mortality rate is the number of deaths per 100,000 Canadians.
- **PYLL** The potential years of life lost to cancer, calculated based on deaths by age and life expectancy.
- **Prevalence** The number of living people who were previously diagnosed with cancer, including those currently in treatment and those no longer being treated.

#### Cases (Incidence)

The number of Canadian cancer cases has more than doubled over the past 25 years.  $^{\rm 10}$ 

The reason for the increase in the number of cancer cases is twofold: there are more Canadians, and Canadians are older. The Canadian population increased 30% over the past 25 years. During that same period, the number of Canadians aged 65 and over increased 41%, driving the average age of Canadians up by 33%.<sup>11</sup> Age is cancer's #1 risk factor. As Canadians live longer, more Canadians will get cancer.

Overall incidence rates of cancer in Canada, standardized to remove the effect of the aging population, have risen 6% over the past 25 years. This represents an average annual growth rate of only 0.2%.<sup>12</sup> This slight increase can be partly attributed to more frequent screening and improved detection methodologies, reflecting an increase in recognized cancer cases rather than an increase in cancer disease.

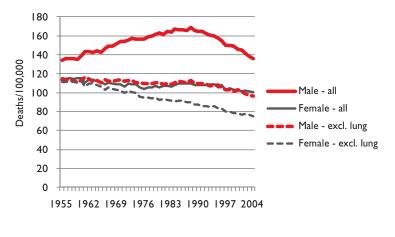
**C** Thus, for 3,000 years and more, this disease has been known to the medical profession. And for 3,000 years and more, humanity has been knocking at the door of the medical profession for a "cure".

– Fortune magazine, March 1937

#### Deaths (Mortality Rates)

Age-standardized mortality rates climbed steadily from 1950 until the late 1980s, then declined 15% between 1988 and 2004. However, in examining mortality rates, the dramatic impact of changes in lung cancer rates – discussed in the next section – must be looked at separately. Removing the effect of lung cancer, overall cancer mortality for women has declined steadily for the past 50 years, dropping 8% since 1988. For men, cancer mortality rates, excluding lung cancer, were flat from 1950 through the 1980s and have declined 18% since 1988.<sup>13</sup>

Figure 2: Canada's Cancer Mortality Rates



Source: World Health Organization. Age-standardized mortality rates for all cancers.

#### PYLL (Potential Years of Life Lost)

In 2004, Canadians lost more than one million potential years of life to cancer, a 15% increase over 10 years prior. Over that same period, the PYLL from cardiovascular disease increased only 9%. As Canada's population ages, increased cancer incidence will continue to put upward pressure on PYLL from cancer, mitigated by increased survival rates.<sup>14 15</sup>

#### Prevalence

There are an estimated one million Canadians (3% of the total population) living today who have been diagnosed with cancer in the past 15 years.<sup>16</sup> The prevalence of cancer is increasing dramatically as the result of higher incidence in Canada's aging population and improved survival rates. This trend threatens to stress our health care system and will require significantly higher levels of cancer care in coming years.

#### **Financial Cost**

The estimated cost of cancer to the Canadian economy in 2009 was \$22.5 billion. This total includes \$6 billion in direct costs of drugs, hospitals, and other social services required for cancer patients. The indirect cost, including the cost of mortality and long and short-term disability, totals \$14.5 billion.<sup>17</sup> The final component included is the amount of money given to charitable organizations working to help those with cancer. Cancer charities received an estimated \$1.9 billion in 2009, including \$1.3 billion from government sources and \$614 million from voluntary donations.<sup>18</sup>

To put these figures in perspective, the direct medical and social services costs of cancer represent 3.3% of Canada's health care spending.<sup>19</sup> The total estimated cost of cancer represents 1.5% of Canada's GDP.<sup>20</sup>

A 2005 assessment of future cost estimated that, based on current trends of incidence, PYLL and prevalence, cancer would cost the Canadian economy \$1.17 trillion over the next 30 years: 15% from direct health care costs and the balance from lost productivity, corporate profits and tax revenues. The underlying human drivers of these costs are the 5.9 million Canadians expected to develop cancer and 2.8 million Canadians expected to die of cancer, resulting in 13.3 million disability-adjusted life years lost and 38.2 million potential years of life lost due to premature death from cancer in those 30 years.<sup>21</sup>

#### Human Cost

Cancer is a human disease, with human costs. The PYLL metric captures the potential years of life lost to cancer – this is more than 15 years, on average, per Canadian who dies from cancer.<sup>22</sup> Fighting cancer is its own ordeal, including myriad doctors, tests, and procedures from diagnosis to staging to treatments that may include surgery, radiation, and/or chemotherapy. The ultimate goal is to achieve remission, or complete absence of cancer, however remission does not always constitute a "cure". Some patients who achieve remission will stay cancer-free only by continuing their chemotherapy treatments. Even survivors who are able to stop receiving treatment may have lasting complications and scars – physical, psychological, and emotional – that will be with them for the rest of their lives.<sup>23</sup>

Some patients will never achieve remission; their oncologists will merely try to control their cancer with effective treatments for as long as possible. Other patients will have cancer that was either so advanced at diagnosis or has stopped responding to treatments and has metastasized out of control. Those patients will require palliative care to keep them in the greatest possible comfort for the days, weeks, or months they have left to live.<sup>24</sup> Even lifesaving cancer treatments impose unique challenges. Surgery can be debilitating and have lasting ramifications such as a colostomy, infertility, or mental impairment. Radiation and chemotherapy may have side effects such as neuropathy, nausea, fatigue, anemia, blistering skin, and hair loss.<sup>25</sup> For childhood and young adult cancer patients, treatment side-effects can be long-lasting, including growth and developmental disorders and emotional and social integration problems.<sup>26</sup> Treatments also impinge on patients' lives, taking time and energy away from their normal activities, requiring travel to treatments, incurring out-of-pocket expenses, necessitating work disability leaves, and prolonging their involuntary "cancer patient" identities.

Finally, there are the costs to the friends and family members of cancer patients. Two thirds of these costs are in caregiving time, with the balance comprising medical and other out-of-pocket expenses.<sup>27</sup>

Canada's aging population presents a cancer-related health challenge. The corresponding opportunity is to transform cancer from a disease that Canadians die from to a chronic disease that they live with – while controlling the associated financial and personal costs.

Some cancers are closer to realizing this opportunity than others.



#### 3. One Disease With Many Types – Ci's Top 10+

Cancer is not one ailment. In fact, scientists often classify it as over 200 varied diseases,<sup>28</sup> all characterized by their intrinsic nature – uncontrolled growth of abnormal cells resulting from damage to the genes that regulate cell growth. The source of genetic malfunction varies by cancer type and patient age; generally, cancer results from a combination of an individual's genetic predisposition and the accumulation of genetic damage from exogenous factors over time. As the abnormal cells grow, they tend to invade other parts of the body in a process called metastasis. Metastasis into vital organs is the leading cause of death from cancer.<sup>29</sup>

Cancers are often named for the part of the body where they start.<sup>30</sup> The top six cancer types by mortality<sup>31</sup> – lung, colorectal (cancers of the colon and rectum), breast, prostate, pancreatic, and non-Hodgkin lymphoma – together account for over 60% of all cancer deaths.<sup>32</sup> The other four cancers with the highest PYLL – robbing the most years of potential life from Canadians – are brain, ovarian, and stomach cancers and leukemia. These 10 cancers, plus sarcoma, constitute Ci's Top 10+. Together, they represent approximately 70% of Canadian cancer cases, deaths, potential years of life lost, and prevalence.<sup>33</sup>

Why is sarcoma included? In 1980, a young sarcoma patient named Terry Fox captured the hearts of Canadians with his Marathon of Hope. Sarcoma's impact on Canadian cancer research and philanthropy has far surpassed its low incidence, because of the inspiring dream of one young patient.

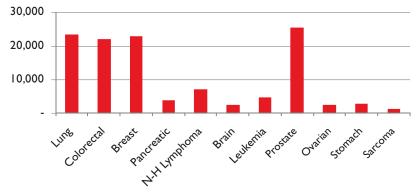
Each of these 11 cancers has a unique profile that drives its incidence, its mortality rate and the age at which it is typically diagnosed. These factors combine to determine its impact in terms of the potential years of life lost and prevalence in the population. The differences are depicted in the following pages.

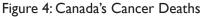
6 I believe in miracles... I have to. **9** 

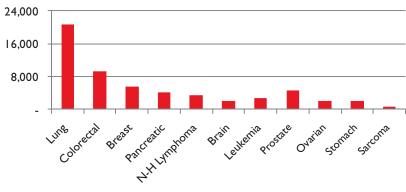
-Terry Fox

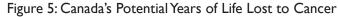
Lung, colorectal, breast, and prostate cancers have much higher incidence than other leading killers. With its high incidence and low survival rate, lung cancer causes 27% of Canadian cancer deaths. 39% of living Canadians diagnosed with cancer in the past 10 years had either breast or prostate cancer. Pancreatic cancer tells the inverse story, with more fatalities in a year than prevalence in the population.

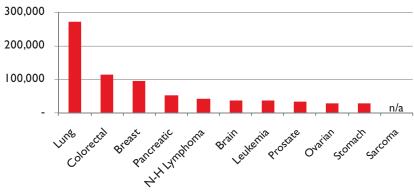
Figure 3: Canada's New Cancer Cases



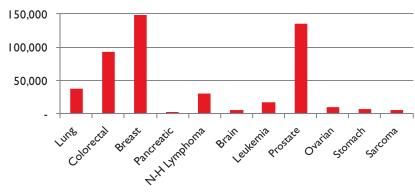






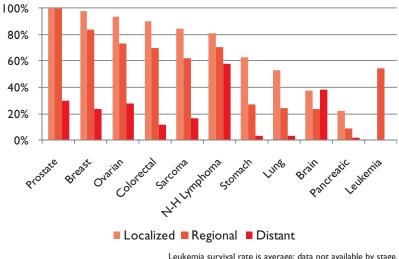






Source: Canadian Cancer Statistics 2008, 2009, 2010.

Mortality varies significantly by cancer type, due to several factors. Cancers diagnosed when they are still localized (prior to metastasis) can more often be contained and treated effectively. In addition, treatment options vary depending on the cancer type; some cancers have treatments that virtually guarantee survival if administered correctly, whereas some are without effective treatments even for localized cancer.<sup>34</sup>





Leukemia survival rate is average; data not available by stage. Source: SEER Stat Fact Sheets. U.S. Data 1999-2006.

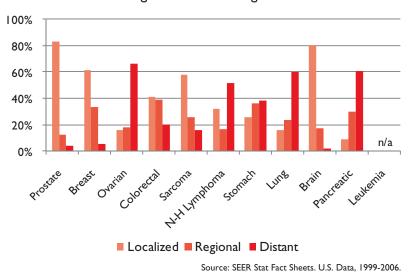


Figure 8: Percent of Cancers Diagnosed at Each Stage

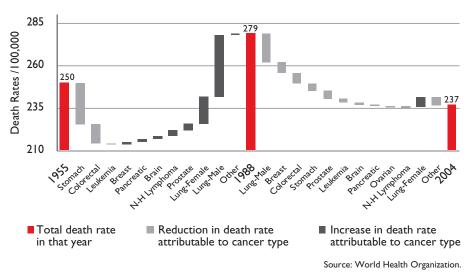
Prostate and pancreatic cancers illustrate how very different two diseases under the same cancer umbrella can be. In 2009, more than 6.5 times as many Canadians were diagnosed with prostate cancer as pancreatic cancer (25,500 vs. 3,900), but deaths from prostate cancer were only 13% higher than deaths from pancreatic cancer (4,400 vs. 3,900).<sup>35</sup> Pancreatic cancer is typically diagnosed late,<sup>36</sup> with few effective treatments even for localized cases.<sup>37</sup> Conversely, over 80% of prostate cancers are diagnosed early, with 100% survival rates.<sup>38</sup> In the case of prostate cancer, there are two fundamental types, characterized as "tigers" and "pussycats". Tigers are aggressive cancers, requiring treatment. However, the majority of prostate cancers are pussycats – slow-growing cancers that are likely to remain dormant and never be life-threatening. Pussycat cancers need to be monitored, but may never need to be treated. Tests are underway to determine which type of prostate cancer a patient has, but given the apparent predominance of pussycats, prostate cancer is deadly less often than other cancers.<sup>39</sup>

In contrast, all pancreatic cancers are ferocious tigers, stealthily spreading undetected, and almost impossible to treat.

#### What Causes the Differences in Cancer Outcomes?

Since they peaked in 1988, overall age-standardized cancer mortality rates have declined 15%.<sup>40</sup>

Figure 9: Canada's Cancer Mortality Rates Changes from 1955-1988 and 1988-2004



From 1955 to 1988, while stomach and colorectal cancer mortality rates dropped, huge increases in lung cancer rates caused the overall cancer mortality rate to increase. Since 1988, the decrease in male lung cancer mortality has been the most significant factor in the overall cancer mortality drop.

Before looking at the drivers of these declines for Ci's Top 10+ cancers, it's worth reflecting further on what drove cancer mortality rates to their 1988 peak: smoking-induced lung cancer. Between 1955 and 1988, lung cancer mortality rates increased by an alarming 212% – more than tripling its death toll.

The discovery that smoking is a leading cause of lung cancer was proven in 1954, but it was another 10 years before health hazard notices were required on cigarette packages sold in the U.S., later followed by Canada. It wasn't until 1988 that reductions in men's smoking habits finally led to declines in male lung cancer mortality rates. Lung cancer mortality rates in women, whose smoking habits peaked later, are still climbing.

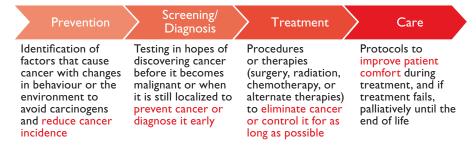
Overall rates of cancer mortality increased 12% between 1955 and 1988. Declines in mortality rates for male lung cancer and other cancers have led to a 15% reduction in overall cancer mortality rates since 1988. The resulting net decline in cancer mortality rates over the past half-century is 5%.

Without lung cancer, overall cancer mortality rates would have declined 10% between 1955 and 1988, and 24% – nearly one in four – since 1955. In the story of cancer, lung cancer has the dubious distinction of playing the mercurial lead; now, on to the full cast of characters.

Nearly all of Ci's Top 10+ cancers have seen mortality rates decrease since 1988; the only exceptions are female lung cancer and non-Hodgkin lymphoma.

All cancers share the same four levers along the cancer patient life-cycle: prevention, screening and diagnosis, treatment, and care. The first three levers decrease cancer incidence and save the lives of cancer patients. Differences in prevention, screening and diagnosis, and treatment define many of the differences in the Top 10+ cancers. The fourth lever, care, is what patients require when the first three levers have failed them.

Figure 10: The Cancer Patient Life-Cycle



For some cancers, the drivers of reduced mortality are clear; for others, there is ongoing research to resolve disputes over which levers are saving the most lives, and at what cost.

Based on the primary drivers of reduction in Ci's Top 10+ cancers,<sup>41</sup> Charity Intelligence attributes the reduction in overall age-standardized cancer mortality rates between 1988 and 2004 as follows: 52% prevention, 25% screening and 23% treatment. Taking lung cancer out of the equation, the balance would shift to 28% prevention, 40% screening and 32% treatment.

		Prevention	Screening/ Diagnosis	Treatment
	Change in mortality			
Lung – male	-30%	Reductions in male smoking rates		
Lung – female	+27%	Increases in female smoking rates		
Colorectal	-19%		Colonoscopy and Fecal Occult Blood Test screening	
Breast	-29%	Decreased use of hormone replacement therapy	Mammography screening	Adjuvant chemotherapy
Pancreatic	-7%	Reductions in male smoking rates		
N-H Lymphoma	+5%	Incidence increasing for unknown reasons	i	
Brain	-16%			Combined radiation therapy and chemotherapy treatment
Leukemia	-21%			New chemotherapy for some types of leukemia
Prostate	-27%		PSA screening effectiveness is in dispute	
Ovarian	-13%			New chemotherapy treatment options
Stomach	-41%	Reduced rates of helicobacter pylori virus and smoking		
Sarcoma	n/a			

### Figure 11:Top Reasons for Changes in Cancer Mortality Rates, 1988-2004

#### **Risk Factors and Prevention**

Epidemiological studies have attributed higher risk of cancer to myriad factors. Some of these, such as smokers having 20 times the risk of lung cancer as non-smokers, are clear mandates for preventative measures.<sup>42</sup> Others are harder to specify or have lower total impact. For instance, the lifetime risk of getting stomach cancer is only 0.9%. Smoking has been shown to increase stomach cancer incidence by 20% to 60%, such that the lifetime risk of stomach cancer in smokers increases, but still only to 1.1%-1.4%.<sup>43</sup>

It is also difficult to isolate the impact of a particular causal factor relative to others in causing cancer, and study design can wreak havoc on results. For instance, there have been reversals of thinking on the link between soy and breast cancer,<sup>44</sup> mobile phone usage and brain cancer.<sup>45</sup> In addition, many risk factors of cancer work in combination. For example, a hereditary predisposition to cancer may be triggered by the combination of smoking and alcohol consumption. This example could be triple counted in the statistics provided below. However, these factors do contribute to a significant proportion of cancer deaths in Canada.



**Smoking** To see the impact that effective prevention can have, the best example over the past 30 years has been the reduction in smoking by men. If smoking rates had not declined (from 50% in 1965 to 17% in 2008 among Canadians aged 15 and older)<sup>46 47</sup> and lung cancer incidence and mortality rates had stayed the same as they were in the late 1980s, there would be roughly 6,000 more Canadians with lung cancer today and

roughly 4,700 more deaths this year from lung cancer. Assuming an average cost per patient of \$50,000,<sup>48</sup> the annual savings from the reduction in lung cancer due to prevention is \$300 million.

Not everyone who gets lung cancer is a smoker. 13% of people diagnosed with lung cancer have never smoked.<sup>49</sup> However, smoking may still be a factor, as non-smoking spouses of smokers have a 30% greater risk of lung cancer than do spouses of nonsmokers and second-hand smoke exposure during childhood and adolescence is thought to increase incidence.<sup>50</sup>

The benefit of reductions in smoking, primarily on lung cancer rates among males, has demonstrated the ability for prevention campaigns, backed by solid data, to reduce the burden of cancer.<sup>51</sup> It is estimated that 30% of all cancer deaths in Canada could be caused by smoking.<sup>52</sup> Smoking accounts for an estimated 87% of all lung cancer deaths<sup>53</sup> and it also increases the risk of pancreatic, colorectal, stomach, and many other cancers.<sup>54 55 56 57</sup>

**Infectious Diseases** Pathogens cause up to 18% of cancers worldwide<sup>58</sup> and are responsible for roughly 8% of cancers in developed countries.<sup>59</sup> There are three main ways that these microbes increase the risk of cancer: they invade cells and interact with DNA, promoting mutations; they cause inflammation, which can also damage DNA; and they can compromise the immune system, making our bodies more susceptible to cancer. The helicobacter pylori virus causes an estimated 70% of stomach cancers.<sup>60</sup>

Nutrition and Fitness Over 30% of cancer deaths in Canada may be attributed to poor nutrition and fitness levels.<sup>61</sup> Body fatness significantly increases the risk of numerous cancers, including pancreatic, colorectal, and postmenopausal breast cancer.<sup>62</sup> Increased physical activity has been linked to a decreased risk of colorectal and breast cancer, and possibly prostate cancer.<sup>63</sup>

Significant diet-related factors that may decrease the risks of one or more types of cancer include various vegetables, fruits, and grains, while factors that likely increase the risk of cancer include red meats and processed meats, smoked foods, grilled or barbecued animal meats, and fats.<sup>64 65 66</sup> There is growing evidence that Vitamin D reduces the risk of some cancers, including colorectal and breast.<sup>67</sup> Alcohol (regardless of type) has shown to increase the risk of developing cancers of the breast and colon.<sup>68</sup>

**Hormonal Factors** Reproductive and hormonal factors contribute to an estimated 20% of cancers in Canada,<sup>69</sup> primarily breast, ovarian, and prostate. Exogenous hormonal factors that increase the risk of cancer include hormone replacement therapy (HRT) and oral contraceptives for breast cancer; conversely, oral contraceptives decrease the risk of ovarian cancer.<sup>70</sup> After the link between HRT and breast cancer was found and the use of HRT reduced, there was an immediate reduction in breast cancer incidence.

**Sun/UV Exposure** Skin cancer is the most prevalent cancer in Canada, but is not included in Ci's Top 10+. This is because more than 90% of cases are non-melanoma, which have an over 99% cure rate, compared to melanoma with an 89% 5-year survival rate.<sup>71</sup> The majority of melanomas are caused by excessive ultraviolet radiation from the sun or artificial tanning beds. Melanomas comprise roughly 1% of overall cancers in Canada.<sup>72</sup>

**Environmental and Workplace Carcinogens** Numerous cancers have been linked to environmental and workplace factors. These include indoor and outdoor air pollutants, and food additives and contaminants,<sup>73</sup> as well as workplace materials such as asbestos, arsenic, benzene, and radon.<sup>74</sup>

#### Screening and Diagnosis

Screening and early diagnosis can save lives by identifying a propensity for cancer before it starts, or diagnosing cancer when it is still at the localized stage.

The potential benefit of improved screening can be seen by examining the 5-year relative survival rates by stage of cancer. Data from the U.S. show that overall 5-year survival from the years 1999 through 2005 was 82% for cancers in the localized stage (confined entirely to the organ of origin), 63% in the regional stage (extended beyond the limits of the organ of origin, either directly into surrounding organs or tissues or into regional lymph nodes), and only 20% when the cancer had progressed to the distant stage (spread to parts of the body remote from the primary tumor). For most of the major types, detecting the cancer in the early stages has a dramatic impact on chances of survival. In fact, if screening were available to catch all cancers in the localized stage, cancer mortality rates over the 5-year time period would decrease 48%.<sup>75</sup>

Screening has led to dramatic reductions in deaths from colorectal cancer; the fecal occult blood test (FOBT) provides 15% to 33%<sup>76 77</sup> reduction in mortality and colonoscopy results in mortality reduction estimated in the range of 37%<sup>78</sup> to as high as 90%.<sup>79</sup> For every 1% increase in colonoscopy adoption, mortality decreases 3%.<sup>80</sup> Mammography has been a leading driver in reduced breast cancer deaths.<sup>81</sup>

The benefits of screening are not always so clear-cut. There is a current controversy in the area of screening for prostate cancer, regarding whether the prostate-specific antigen (PSA) test actually reduces mortality or not, and at what cost. The ERSPC study of 162,243 European men found a 5%-33% reduction in mortality resulting from the PSA test; however, for each death prevented, 1,410 men had to be screened and 48 men were treated unnecessarily based on false-positive results. This is largely because of the high incidence of indolent – or non-life-threatening – prostate cancers that may be found by the PSA test and treated unnecessarily. The PLCO study of 76,693 U.S. men found no difference in cancer incidence or mortality in the screening group versus the control group.<sup>82</sup>

6 It is to earlier diagnosis that we must look for any material improvement in our cancer cures. 99

> – John Lockhart-Mummery, British Journal of Surgery (1926-1927)

Another relevant topic related to screening is genetic predisposition. It is estimated that between 5% and 10% of cancers are caused by hereditary genetic mutations. The main cancers that show a hereditary link are breast, ovarian, prostate, and colorectal, but endogenous genetic mutations have also been tied to many other cancers. Genetic screening is possible in some cases where specific gene mutations have been discovered (e.g., BRCA1 and BRCA2 for breast cancer, as well as ovarian and prostate cancer to a lesser extent).<sup>83 84</sup> If the oncogene is found, the person may be able to prevent cancer through accelerated screening or even prophylactic procedures (removing the organ susceptible to the cancer). On the other hand, someone in a family with a high volume of genetically-linked cancer may get tested and find that she does not have the genetic predisposition, freeing her from unnecessary worry and procedures.

Evaluation of screening techniques must measure the effectiveness of the test in detecting cancer and reducing mortality, and weigh this against the cost, invasiveness, and other potential side effects of the testing protocol.



#### Treatment

Although Ci estimates that new cancer treatments account for only 23%-32% of the reduction in mortality since 1988, treatments are a critical lever in both saving and extending the lives of cancer patients. A U.S. study attributed 80% of the 3.9-year average increase in cancer survival to improved treatments. For a significant subset of breast cancer, leukemia and lymphoma patients, effective surgery, radiation and/or chemotherapy – alone or in combination – have transformed their prognoses from terminal to curable.<sup>85</sup> In many cases, treatments have added years or months to patients' lives between diagnosis and death.

For example, until recently, breast cancers that were positive for the Her-2 gene were among the most fatal and aggressive types of breast cancer. Herceptin, a chemotherapy developed between 1987 and 2003 in response to the discovery of the Her-2 gene, increases overall survival for these women by 33%.<sup>86</sup>

Treatments have also become more bearable for patients, in terms of side effects during treatment and long-term ramifications. Breast cancer provides an additional example that spans the last century. Between 1891 and 1981, in the era of the radical mastectomy, an estimated 500,000 women underwent surgical procedures that not only removed cancerous tissues from their breasts, but also removed the pectoral muscles, axillary nodes, chest wall, and occasionally the ribs, parts of the sternum, the clavicle, and the lymph nodes inside the chest, under the premise that cutting out more flesh around the breasts would make the cancer less likely to return. In 1927, a procedure combining a lumpectomy and radiation was developed for breast cancer that had not yet metastasized; however, it wasn't until 1981 that the results of a ten-year clinical trial showed that the rates of breast cancer recurrence, relapse, death, and metastasis were no different between women undergoing radical mastectomy, simple mastectomy, and lumpectomy followed by radiation. This finding saved countless future breast cancer patients from unnecessary pain and disfigurement.<sup>87</sup>

In the case of osteosarcoma (the bone cancer that Terry Fox died from), amputation of the affected limb used to be commonplace. With advances in surgical techniques, the usual surgery today involves a limb salvage/ sparing procedure; amputation is required in only 5% of cases. This provides a dramatically improved outcome for osteosarcoma patients, 56% of whom are under 20 years old.<sup>88</sup>

In the history of medicine, no significant disease had ever been eradicated by a treatmentrelated program alone.

Siddhartha Mukherjee,
 The Emperor of All Maladies
 A Biography of Cancer

#### Care

Whether a patient survives his cancer or dies from it, the calibre and type of care he receives is critical to his experience. There have been many advances in the last half century in the area of improving patients' physical tolerance of chemotherapy and radiation. More attention has been given to the need to support patients' psychological and emotional well-being through targeted activities and support groups.

Perhaps the most critical aspect in improving cancer patient experience has been in the advent of palliative care. A Canadian physician, Balfour Mount, first coined the term "palliative care" and opened Canada's first hospices for the terminally ill in Montreal and Winnipeg in 1975,<sup>89</sup> modeled after the world's first hospice, founded by Cecily Saunders in London, U.K. Following the opening of these hospices were rigorous clinical trials – of the same calibre as trials on curative treatment – on pain and pain relief that showed that opiates used on cancer patients did not cause addiction or deterioration, but rather relieved the cycle of anxiety, depression and pain. This was in stark contrast to previous thinking that medications to relieve pain and discomfort from cancer and cancer treatment would dilute the treatment efficacy or cause addiction.<sup>90</sup>

Even with recent reductions in cancer mortality, there is need for significant further improvement, particularly in those cancers that are taking the most life from Canadians. The necessary, initiating factors to effectively prevent, screen, diagnose and treat cancer, as well as to care for cancer patients, are research and development.

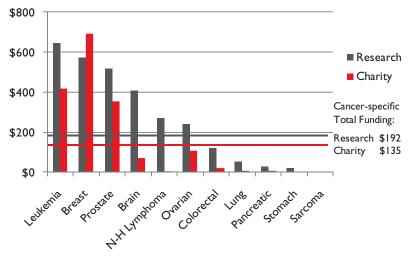


#### 4. Cancer Research's Unique Market Dynamics

#### Prevalence and Patient Age Drive Support

Canada's cancer research budget is approximately evenly split between general cancer research and research attributed to specific cancer types. Of research allocated to specific cancer types, 28% is dedicated to breast cancer research, 12% to leukemia, 9% to prostate, 8% to brain, and 7% each to lung and colorectal.<sup>91</sup>

Figure 12: Research and Charity Funding per Potential Year of Life Lost



Source: Canadian Cancer Research Alliance 2007, CRA 2009, Canadian Cancer Society 2010

If we look at cancer PYLL compared to the investment in research by type, leukemia, breast, prostate, and brain cancer research appear to be well-funded while stomach, pancreatic, lung, and colorectal cancer research appear to be underfunded.

This echoes the allocation of charitable donations to specific cancers. If the Canadian charities focusing on cancer are broken down by cancer type, 50% of charities cannot be classified by cancer type. The majority of the largest charities are broad-based, such that only 7% of cancer charity funding can be allocated to specific cancer types. However, from the amount that can be classified, a staggering 47% is donated towards breast cancer, 27% to children's cancer, 11% to leukemia (a cancer disproportionately impacting children) and 8% to prostate cancer, leaving less than 7% of cancer-specific charity funding for all other cancer types.<sup>92</sup>

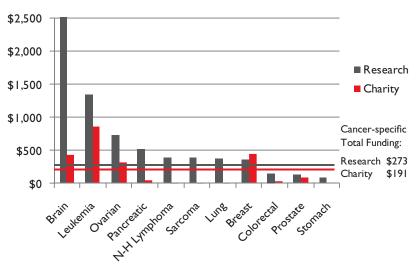


Figure 13: Research and Charity Funding Relative to Prevalence

Prevalence explains some portion of the distribution of research funding and donations by different cancer types. Because of the higher mortality rates of lung cancer compared to breast cancer, there are four times more breast cancer patients alive today in Canada than lung cancer patients. Research funding by prevalence is almost the same for lung cancer and breast cancer. Generally, research funding tracks prevalence, with the exception of the two largest children's cancers: leukemia and brain.

The 27% of cancer-specific charity funding that goes to children's cancer, plus that to leukemia and brain cancer, far surpasses any quantifiable measure of the impact of cancer on children.<sup>93</sup> Less than 1% of all cancers occur in children;<sup>94</sup> however, the poignancy of child cancer patients compels people to donate significantly to children's cancer charities.

The halo effect of cancer-specific research investment is that research initiated for a specific type of cancer is often beneficial for others as well. For instance, Gleevec is a chemotherapy that was initially discovered to treat chronic myeloid leukemia and has since been approved for a total of 11 separate indications involving seven different kinds of cancer.<sup>95</sup> Carboplatin and its predecessor, Cisplatin, were first developed to treat testicular cancer and are now front-line therapies for lung, ovarian, and head and neck cancers.<sup>96 97</sup> Smoking was first linked to lung cancer and has since been found to increase the risk of many other cancers, including pancreatic, colorectal, and stomach.<sup>98 99</sup>

• The medical importance of leukemia has always been disproportionate to its actual incidence.

> – Jonathan Tucker, Ellie:A Child's Fight Against Leukemia

Source: Canadian Cancer Research Alliance 2007, CRA 2009, Canadian Cancer Society 2009.

#### Canadian Cancer Research - the Most Cost Effective in the World

Each country's research and development efforts yield global results. Discoveries made by Canadian scientists are published in scientific journals and presented at international oncology conferences; scientists around the globe build upon these discoveries to develop treatments that are likewise published and presented – and vice versa. New discoveries that can improve prevention, screening, diagnosis, or treatment of cancer and care of cancer patients will improve patient outcomes worldwide, regardless of where the discovery takes place.

Canadian researchers have been pioneers in biological research related to stem cells, angiogenesis (the growth of new blood vessels to enable malignant tumour growth), metastasis (the spreading of cancer from one body part to another), genomics, and cancer cell signaling.<sup>100</sup> As part of the International Cancer Genome Consortium, Canada is leading research into pancreatic and prostate cancer.<sup>101</sup> Canadian researchers have driven prevention studies in tobacco control research and the impact of physical activity on cancer recurrence and quality of life. Among clinical research into new therapies, Canadian researchers' contributions are particularly noted in the area of patient care, including symptom control research, survivorship, and palliative care.<sup>102</sup>

Canada's research investment allocation reflects these strengths, with significant investments in place to continue its research achievements in biology, in etiology (causes of cancer) and prevention, and in treatment, including cancer control, survivorship, and care.<sup>103</sup>

In 2000, total non-corporate funding for cancer research in Canada was estimated at \$100-150 million per year; in 2006 it was \$400-600 million – a significant escalation.<sup>104</sup> Whereas U.S. state funding has been stagnant to decreasing in recent decades,<sup>105</sup> Canada has seen a recent increase in provincial funding, with \$80 million of 2006 funding coming from the Ontario Institute of Cancer Research and a further \$33 million coming from two BC foundations.<sup>106</sup>

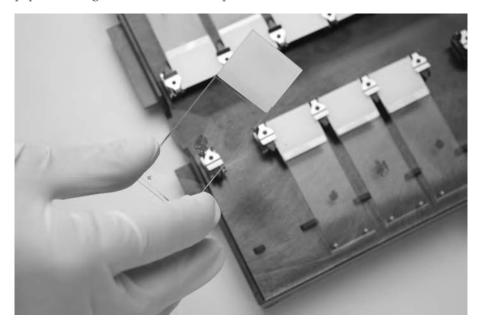
This funding increase has translated into a dramatic increase in research outputs. Between 2000 and 2008, the number of Canadian researchers publishing per year had risen almost 3-fold; Canada's share of the world's publications in cancer research rose from 3% to 4%. Canada ranks first in the world in terms of biomedical articles published per billion dollars spent, followed by the U.S.<sup>107</sup>

A standard metric of the impact of a research paper is the number of citations – in other words, the extent to which a paper's findings influence other researchers' work. Canada's impact exceeds its output, as it produced 14 of the world's 100 most-cited papers in 1998-2000 and 13 of the world's 100 most cited papers in 2006-2008. Canada has consistently

Generation of the set of the set

 Richard Klausner, U.S. National Cancer Institute Director, 1997 ranked  $3^{rd}$  or  $4^{th}$  in the world in terms of the number of citations per publication, behind the Netherlands, U.S., and sometimes the U.K.<sup>108</sup>

Canada is the most collaborative country in oncology research, with 50% of publications having a foreign author.<sup>109</sup> Cancer research publications resulting from international collaboration tend to be cited twice as often as those with exclusively Canadian authors.<sup>110</sup> Note that the increase in funding led to an increase in publications, but not in the number of Canadian papers among the 100 most-cited publications.



#### The Tension Between Profit and Progress

There are six distinct stages of cancer research and development that must happen before a treatment is ready to be tested on cancer patients in clinical trials.<sup>111</sup> Many potential leads are abandoned for every drug candidate that makes it to clinical trials, and still more before a drug is approved for patient use.

Estimates put the average cost of drug development in the range of US\$980 million<sup>112</sup> to US\$1.7 billion.<sup>113</sup> GlaxoSmithKline, one of the world's largest pharmaceutical companies, estimates that it takes 12 to 15 years and costs £500 million (C\$800 million) to develop a single new vaccine or medicine.<sup>114</sup> This process, especially at the clinical trials stages, is often funded by private corporations. Due to their fiduciary responsibility to their shareholders, these organizations invest primarily where the projected payback is substantial.

In 1998, the cancer drug with the highest ranking for worldwide pharmaceutical sales was Taxol, at #21 on the list, with sales of just over \$1 billion. In 2008, four cancer drugs ranked in the top 20 and five had sales of over \$3 billion.<sup>115</sup>

**6** Doing 'relevant' research is not necessarily doing 'good' research.

> James Watson, co-discoverer of the structure of DNA, to the U.S. Senate, 1969

The natural outcome of the cancer research process is that patentable treatments are pursued by the private sector with increasingly more expensive outcomes, and less profitable leads are ignored.

Several examples illustrate the challenge:

- It took five years of intensive lobbying by the scientist who discovered the dramatic impact of Imatinib (Gleevec) on chronic myeloid leukemia patients before its pharmaceutical company developer agreed to run a single, small clinical trial; the \$100-200 million cost of the trial was projected to eclipse the potential market value of treating only a few thousand patients.<sup>116</sup>
- A half-century-old diabetes drug named Metformin has shown promise for over five years in treating various cancers, including lung and breast.<sup>117 118</sup> Mount Sinai researchers in Toronto claim that they were not able to get clinical trials funded as Metformin is no longer patentable and would only command a price in the range of \$150 per year per patient compared to the average cost of \$65,000 for a course of treatment with newer cancer drugs.<sup>119</sup>
- Another off-patent compound, Dichloroacetate (DCA), has been used for years to help with metabolic issues in children. Researchers at the University of Alberta found that DCA is a promising anticancer agent;<sup>120</sup> however, they have struggled to get funding to perform clinical trials.

Metformin and DCA may prove to not offer any significant benefit to cancer patients, but treatments that show potential cannot be left to languish solely because they offer no profit potential. The dramatic results of Gleevec on patients with chronic myeloid leukemia and six other types of cancer are proof of the opportunity cost in terms of life years of ignoring promising treatments.<sup>121</sup>

#### Societal Return on Cancer Research Investment

Many new cancer treatments have been developed that extend lives to some degree, but questions are raised over the cost implications when a very expensive drug is developed that adds only a few weeks of life. A recently released study calculated the cost of a quality-adjusted life year (a year of life in perfect health) gained using chemotherapy to extend life among colon cancer patients at US\$99,100.<sup>122</sup> While this is within the generally accepted willingness to pay for a life year, concerns were made about the escalation of this figure over time. Advances in treatment should be measured primarily by their ability to extend lives, but also on their relative cost and side effects.

Because of the global benefits of cancer research, the ideal measure of return on investment would be to look at worldwide spend relative to worldwide change in cancer statistics – if such data were available. As the world's largest spender on health care and research (16% of GDP in the U.S. vs. 9% average in OECD countries and 10% in Canada),<sup>123</sup> the U.S. provides an illustrative model. Total non-corporate U.S. cancer research spending doubled from \$1.8 billion in 1971 to \$3.6 billion in 1997. By 2009, non-corporate U.S. cancer research spending had further tripled to between \$10.2-10.7 billion.<sup>124</sup>

A U.S. economic study showed that cancer survival increased by 3.9 years between 1988-2000, driven 80% by improvements in treatment, for instance in breast cancer and non-Hodgkin lymphoma. Changes in the probability of early detection were found to be less significant than improvements in survival at a given stage of disease. The study calculated the value of these improvements in survival at 23 million additional life years, providing \$1.9 trillion in value for patients. The corresponding cost of cancer treatments and research and development spending was \$433 billion. By this analysis, the value created for patients was over four times the research and treatment costs incurred. The share of value going to the patient, rather than to health care providers and pharmaceutical companies, ranged from 81%-95% and was rising over time.<sup>125</sup> Ci notes that this assessment understates the total value created by 1) focusing on survival rates rather than mortality rates, thereby ignoring the benefit of prevention, and 2) excluding the ongoing value for patients diagnosed after the study's conclusion.



Cancer treatment usually comprises some combination of surgery, radiation and chemotherapy; the variety of chemotherapy treatments includes cytotoxic (toxic to cancer cells), hormone therapy, immunotherapy, antibodies, tumour vaccines, gene therapy, and other novel techniques.<sup>126</sup> Given that different treatments are often administered in combination, it is difficult to isolate the impact of each different treatment element.

In cases such as Gleevec and Herceptin, new drugs have clearly and significantly extended the lives of cancer patients.<sup>127</sup> A study released in 2004 found the impact of cytotoxic chemotherapy on the 5-year cancer survival rate to be 2.1% in the U.S., and 2.3% in Australia. Although this is a small percentage improvement, for the 3,306 Americans and 1,690 Australians and who survived cancer because of cytotoxic chemotherapy, the impact is immeasurable.<sup>128</sup>

Other advances in treatment include chemotherapy regimens becoming less harsh, development of cancer drugs that are more highly targeted and effective, the application of chemotherapies developed for one cancer to another with positive results, and surgery that is less invasive and less disfiguring.

Research and development provide the tools to prevent, screen for and successfully treat and care for cancer and cancer patients; however, the tools don't work by themselves. Implementation of research findings and therapeutic developments has to happen on a local, provincial, or national scale.

#### 5. Canada's Cancer Report Card

Cancer is not a uniquely Canadian disease. Cancer is a global epidemic, causing 13% of all deaths worldwide.<sup>129</sup>

Of developed countries, Canada has one of the higher rates of both cancer incidence and mortality.<sup>130</sup> Compared to the U.S., Canada's cancer incidence rates are slightly lower overall, although they are higher for colorectal, breast, and prostate cancers. Mortality rates are more than 8% higher than the U.S. overall; colorectal cancer rates are 33% higher and prostate rates are over 17% higher in Canada.<sup>131</sup>

An important statistic in understanding how well Canada is combating cancer is the 5-year survival rate of cancer victims. A study released in the August 2008 issue of *The Lancet Oncology* showed that Canada had one of the highest rates of survival in the world among the cancers examined (breast, colorectal, and prostate). Another important finding was that there is much lower variation in cancer survival among Canadian provinces than among U.S. states or European countries. This suggests health care of a high standard in most areas in Canada.<sup>132</sup>

• ...there were the same old patients asking the same old questions again and again as though they had never been asked before: ...Will they cure me or won't they? What other remedies are there that might help?

-Aleksandr Solzhenitsyn, Cancer Ward

Although Canada lagged behind the U.S. by 10%, Canada's strong and consistent survival rate was heralded as a victory for our healthcare system.<sup>133</sup> However, an examination of mortality and incidence rates across countries points towards some of Canada's weaker areas. The ratio of mortality to incidence is not an actual measure of survival as the mortality of a given year is due to incidence from numerous prior years; however, this measure provides insights into Canada's cancer survival performance. While Canada does have a low relative mortality-to-incidence ratio for the cancers in the study – prostate, colorectal, and breast (ranking 2<sup>nd</sup>, 3<sup>rd</sup>, and 7<sup>th</sup> of 25 countries) – Canada fares much worse in the three remaining top-six killers, placing 14<sup>th</sup> in lung cancer, 13<sup>th</sup> in pancreatic, and 16<sup>th</sup> in non-Hodgkin lymphoma.<sup>134</sup>

#### Efforts are underway to rectify these challenges.

The Pan-Canadian Action on Cancer Control (CACC) developed a strategy in 2006 to maximize the development, translation, and transfer of knowledge and expertise across Canada in hopes of reducing fragmentation in the health care system and promoting the adoption of evidence-based best practices to save Canadians' lives and improve the experiences of cancer patients.<sup>135</sup> In response, in 2007 the Canadian government established the Canadian Partnership Against Cancer (CPAC) to co-ordinate pan-Canadian cancer control initiatives including prevention and treatment research, patient care, services, and support. On March 10, 2011, the government renewed its commitment to CPAC with another \$250 million in funding from 2012-2017, or \$500 million total from 2007-2017.<sup>136</sup> CPAC and other government bodies could be instrumental in leading coordination efforts. Canada's cancer charities, agencies and research universities are key stakeholders in executing this multifaceted strategy.<sup>137</sup>

#### This is where donors can create transformative impact.

#### 6. Donors' Opportunity for Impact

There are ample opportunities for donors to change the landscape of cancer: supporting underfunded cancers, resolving gaps in research and development funding, and implementing research findings for Canadians along the cancer patient life cycle of prevention, screening and diagnosis, treatment, and care.

Canada has 1,498 Canadian charities that have the word cancer in their general description of services; however, the majority of these organizations focus on an alternative cause with cancer as ancillary. Of these organizations, we have found 278 that focus specifically on cancer. These 278 organizations received donations and other fundraising revenue of \$614 million plus \$1.3 billion in government grants. Of the \$614 million, the top 10 organizations received 81% (including all of the provincial divisions of the Canadian Cancer Society as one). The largest organizations are typically

Generates History repeats, but science reverberates. The tools that we will use to battle cancer in the future will doubtless alter so dramatically in fifty years that the geography of cancer prevention and therapy might be unrecognizable.

 Siddhartha Mukherjee, The Emperor of All Maladies – A Biography of Cancer broad-based rather than cancer-specific in focus. This creates an interesting dichotomy – while 50% of cancer charities focus on specific cancer types, these only represent 7% of cancer charity funding, speaking to the fragmentation of the cancer-specific charity sector.<sup>138</sup>

#### Underfunded Cancers – Opportunity

- Think about cancer funding in terms of lives taken, rather than survivors
- Reallocate charitable donations to those cancers taking the most years of life from Canadians

Of the 7% of cancer-specific charity funding, a staggering 94% is donated to four areas: breast cancer, children's cancers, leukemia, and prostate cancer. This leaves only 6% of cancer-specific charity funding for all other cancer types.<sup>139</sup> Research funding is somewhat more evenly allocated, but there are still glaring examples of cancers in which funding falls far short of what their devastating impact would justify.

Pancreatic, stomach, and lung cancers have the lowest 5-year survival rates among Ci's Top 10+ cancers.<sup>140</sup> Colorectal cancer ranks second to lung cancer in both deaths and PYLL.<sup>141</sup> Collectively, pancreatic, stomach, lung, and colorectal cancers represent 46% of potential years of life lost to cancer in Canada.<sup>142</sup>

Yet, these four cancers collectively receive only 15% of cancer-specific research funding and 1.6% of cancer-specific charity funding. In terms of PYLL, they receive \$63 in research funding per PYLL and less than \$5 in charity funding per PYLL. Contrast these amounts with breast cancer, which receives a staggering \$575 in research funding per PYLL and \$691 in charity funding per PYLL.<sup>143 144</sup> In other words, Canadians donate 151 times more to breast cancer-specific charities per potential year of life lost than to the four most lethal cancers, combined.

Because of their high mortality rates, these cancers lack survivors to tell their stories and rally support. Ci suggests that Canadian donors consider cancer funding decisions in terms of the lives each cancer takes away, to increase the number of lives saved.

The appendix to this report contains profiles on Ci's Top 10+ cancers, including their unique characteristics, their toll on Canadian lives, their level of funding, and donors' opportunities for impact. Ci encourages donors to review these profiles and make informed decisions on which cancers to fund.

6 Incremental advances can add up to transformative changes. **9** 

- Siddhartha Mukherjee, The Emperor of All Maladies - A Biography of Cancer



X-ray images portray individuals inflicted with the four cancers most in need of funding: pancreatic, stomach, lung and colorectal cancers.

Donors who want to make a real difference in transforming outcomes for cancer patients can start by reallocating their donations from breast cancer, leukemia, and other cancers that are already well-funded to the four cancers where need matches opportunity: pancreatic, stomach, lung, and colorectal cancers. Hopefully, cancer research dollars will follow.

#### Cancer Research – Opportunity

- Support Canada's core areas of research strength
- Stem the funding gap in low-prevalence cancers
- Fund research directly, not through other charities

The greatest increases in cancer research funding have recently come from for-profit, industry investment. In the U.S., industry cancer research has been increasing by a 14% compound annual growth rate vs. 2.7% from government and charity sources.<sup>145</sup> For-profit institutions must necessarily pursue research that is most likely to yield profits based on treatment price, treatment duration, and number of patients.

It is critical that non-profit research institutions, including university-based research hospitals, continue to provide the widest breadth of research into biology, etiology, prevention and early detection, as well as qualitative aspects of cancer care. Non-profit research must also resolve the market failure where a treatment or prospect might otherwise be ignored due to lack of profit potential.

This is easier said than done, given the high cost and high risk nature of cancer research and limited resources available, but coordinated efforts are underway through CPAC and other bodies. Nevertheless, there is further opportunity for donors to demand coordination among research institutions to increase the calibre of research, and to fund research in Canada's core areas of strength and underfunded cancers.

For the largest cancer charities in 2009, 32% of spending went to fundraising and administrative costs, 30% went to grants for cancer research, and 34% went to direct programs.<sup>146</sup> Donors have the opportunity to increase the impact of their research contributions by 47% by donating directly to research institutions, rather than making donations to charities their own fundraising and administrative costs that in turn make research grants to institutions.

Research and development discoveries that stay in the lab are merely scientific ideas. For impact, they need to be implemented for patient benefit along the cancer patient life cycle.

#### Prevention – Opportunity

- Reinforce and reinvigorate the anti-smoking message
- Promote healthy nutrition and an active lifestyle

Success in prevention can be measured by the change in the target population of the etiological behaviour; for example, change in smoking rates. Although this is not done in isolation by cancer organizations (the fight to reduce smoking is largely affected by the Canadian Lung Association), charities working towards the prevention of cancer should be attempting to track their impact on the causal factors that they are targeting.

Despite all that is known about causes of cancer, Canadians are largely not living by the guidelines for prevention. Over half of Canadians do not eat the recommended amounts of fruits and vegetables,<sup>147</sup> 48% of the population is physically inactive,<sup>148</sup> 59% of Canadians are obese or overweight,<sup>149</sup> and 37% of Canadians over the age of 15 are frequent consumers of alcohol.<sup>150</sup> As well, despite the significant reduction from the strong anti-tobacco push, 17% of Canadians over the age of 15 still smoke.<sup>151</sup> Smoking rates have declined over the last decade, but these declines are inconsistent across age groups: between 1999-2009, there were declines of 9% to 14% among Canadians aged 15-44 but only 3% among smokers aged 45 and older. Preventing youth from smoking will have long-term impact, but smoking cessation is necessary for immediate impact on reducing related cancer mortality.<sup>152</sup>

Effective education and advocacy is needed to sustain and further progress on smoking habits and encourage other lifestyle improvements. There is a particular opportunity to educate Canada's First Nations, Inuit and Métis peoples, to reverse the trends of increasing age-adjusted incidence, latestage diagnosis, deaths from preventable cancers, and smoking-induced cancers.<sup>153</sup> • The history of Medicine is replete with examples of cures obtained years, decades, and even centuries before the mechanism of action was understood for these cures.

- Sidney Farber, chemotherapy pioneer

The link between smoking and lung cancer entices ideas of eradicating cancer through prevention. However, cancer existed long before tobacco smoking was in vogue – it is unlikely to go away, so there will continue to be a need for support further along the patient life cycle.



#### Screening and Diagnosis – Opportunity

- Maximize availability and adoption of colorectal cancer screening
- Educate doctors, nurses, and the public on cancer symptoms
- Develop and support more specific screening tests

The success of advocacy and education in promoting recommended screening protocols can be measured by the change in percentage of the target population that is screened. There is room for improvement. For instance, the combination of fecal occult blood tests (FOBT) and colonoscopies are the primary driver of reduced colorectal cancer mortality; however, only 40% of Canadians over the age of 50 report having a FOBT in the past two years or colonoscopy in the past five years, ranging from 28% in Quebec to 53% in Manitoba.<sup>154</sup> If colorectal cancer screening increased to 80% by 2013, it would save approximately 32,000 lives between 2013-2030 that would otherwise have been lost to colorectal cancer. This is an opportunity for charities to advocate the government for consistent screening guidelines and implementation, which don't currently exist.<sup>155 156</sup>

Likewise, proven screening methods need to be made broadly available and Canadians need to be educated about the need to take advantage of available screening. For instance, even where FOBT and colonoscopies are available, there is low patient adoption of these screening techniques to prevent colorectal cancer.<sup>157</sup>

Most cancers have symptoms which, if identified and evaluated early, can lead to early diagnosis. Charities can also help to educate physicians, nurses, and pharmacists to recognize cancer symptoms, accurately stage cancer, and develop effective treatment plans. Educating patients and medical professionals will increase diagnosis at the early, effective stages.

For instance, ovarian cancer is diagnosed after distant metastasis more than any other cancer type. Early stage symptoms – including pelvic or abdominal pain, bloating, difficulty eating, and/or urinary changes – are vague, and as a result, have historically been ignored or misdiagnosed as other ailments. A recent study found that 94% of women surveyed after ovarian cancer diagnosis had symptoms in the year prior to their diagnosis. New guidelines indicate that if any of these symptoms occur daily and persist for more than two to three weeks, a woman should see her doctor and get tested for ovarian cancer.<sup>158</sup> The hope is that these guidelines will drive more early-stage diagnoses.

There are also opportunities to improve the specificity of a cancer diagnosis in order to cater the treatment regimen for the specific cancer profile. One example is the development of a "tiger vs. pussycat" test for prostate cancer that would differentiate between malignant cancers requiring treatment and indolent cancers that can be left alone.

If all cancers were diagnosed at the localized stage, cancer mortality rates could go down by as much as 48% – an exciting prospect, but a significant challenge. In the meantime, and for cancers with high mortality rates even in the early stages, improved treatment options are the only hope of survival.

#### Treatment – Opportunity

- Improve approval and availability of high-impact treatments
- Participate in clinical trials

Development of a cancer treatment is only the first step in improving patient survival. All treatments have to be approved by Health Canada (whose timeliness has improved for cancer drugs in recent years). Even Health Canada approval does not ensure that a cancer therapy will be made available or covered by provincial health care authorities.<sup>159</sup> This is where patient advocacy can have huge impact. For instance, advocacy in the U.S. drove accelerated clinical trials and early FDA approval of Herceptin, the specific breast cancer drug that increases survival of patients with Her-2 positive cancer by 33%.<sup>160</sup>

There is also an opportunity for patients to help develop novel therapies by participating in clinical trials. Not only do trials lack adequate funding, they often lack the required number of patients. Educating patients about the benefits and importance of clinical trial participation can help overcome this hurdle. Cancer's reach is broad, but for each cancer patient, its impact is personal. Cancer patients deserve access to treatment that reflects the best available practices. In the tragic event that cancer brings a patient to the end of his life, palliative care will provide comfort and ease the burden on caregivers and the health system.



#### Care – Opportunity

- Increase the number of oncologists
- Increase the availability and accessibility of palliative care

Once treatments are approved, they need to be administered by specialist nurses and oncologists, the same oncologists who are required for prompt and accurate initial diagnosis of cancer to increase patient survival rates. At around one per 1,000 people, the number of general practitioners in Canada is the same as the average across 17 peer countries. However, the number of Canadian specialists per population is below the 17 country average, which may signal a shortage of oncologists to treat cancer – a gap that could be filled with more oncology placements within medical schools and oncologist certifications.<sup>161</sup>

Canada's relatively low variation in cancer mortality across provinces indicates that there aren't any gaping geographic discrepancies in availability of cancer treatment and care, although both could be improved in the Eastern provinces and Quebec where both incidence and mortality are higher. Generally speaking, the opportunities are national.

Because of Canada's aging population and improvements in cancer survival, the estimated number of Canadians living with cancer is growing at over three times the growth rate of the Canadian population.<sup>162 163</sup> Based on

current trends, in 2031 the number of Canadians who are cancer patients or cancer survivors will be 2.2 million, 2.5 times the estimated number of 900,000 in 2006.<sup>164</sup> This means that without significant improvements in the fight against cancer, cancer patients will become a more and more significant burden on the Canadian economy. Those diagnosed with cancer require information, care, treatment, and medical attention. The bulk of Canadian charitable dollars flowing towards cancer charities goes to educate and care for cancer patients.

While there are agencies across the spectrum of cancer care requiring funding, Ci highlights one area where both the need and the potential cost savings are significant: palliative care. Although the majority of Canadians do not wish to die in a hospital, 60% do,<sup>165</sup> while only 10% of the dying population requires hospitalization at the end of their life.<sup>166</sup> While investments in prevention, screening, and treatment all run the risk of showing no ultimate benefit to patients, investments in care typically provide an observable benefit.

To examine the potential impact of an investment in palliative care, we can look at the difference in cost between effective and efficient palliative care providers and the cost of an average death in hospital, multiplied by the number of patients who could make use of palliative care.

Two hospice charities that Ci recommended in 2009 offer world-class quality end-of-life care for under \$10,000.<sup>167</sup> Total end-of-life costs in hospital care are \$40,000 per death.<sup>168</sup> Of the estimated 76,200 cancer deaths in Canada in 2010, currently approximately 60%, or 45,700, die in hospital. The estimated number who actually require hospitalization is only 7,600, thus 38,100 patients could have a reduced cost of \$30,000 for a total savings of \$1.14 billion.

Of the costs incurred by Canadian caregivers in relation to cancer patients, caregiving time is substantial and this is where charitable organizations can play a key role. Combining the more cost-effective solution of specialized care over using hospital resources with the fact that Canadians would rather not spend their final weeks in hospital, palliative care is a vital part of helping Canadians in need.

...terminal care...is not merely the phase of defeat, hard to contemplate and unrewarding to carry out. In many ways its principles are fundamentally the same as those which underlie all other stages of care and treatment, although its rewards are different.

- Cecily Saunders, founder of the world's first hospice 

# Appendix: Ci's Top 10+ Cancer Profiles

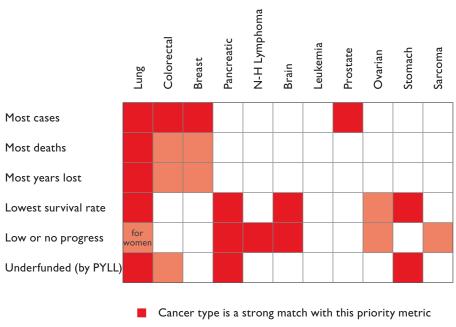
Charity Intelligence has developed profiles on the 10 cancers with the highest PYLL – these are the cancers that rob the most years of life from Canadians.

# What is the "+"?

In 1980, a young sarcoma patient named Terry Fox captured the hearts of Canadians with his Marathon of Hope. Ci couldn't profile the cancers that most impact Canadians without including sarcoma – a cancer whose impact on Canadian cancer research and philanthropy has far surpassed its low overall incidence, because of the inspiring dream of one young patient.

Each of these cancers has a unique profile based on its incidence rate, how deadly it usually is, and the age at which it is typically diagnosed.

Cancer is a personal disease, and we tend to connect to the cancers that have impacted our lives – or the lives of our loved ones – in some way. Ci's Top 10+ cancer profiles will help Canadian donors understand each cancer's life impact and identify opportunities for donors to give intelligently – and save lives.



#### Figure A1: Potential Donor Priorities and Fit with Different Cancer Types

Cancer type is a moderate match with this priority metric

	Prevention	Screening/ Diagnosis	Treatment	Care
Lung	\$\$	\$\$	\$	\$\$\$
Colorectal	\$	\$\$\$	\$	\$\$\$
Breast		\$		\$\$\$
Pancreatic	\$\$\$	\$\$	\$\$\$	\$\$\$
Non-Hodgkin Lymphoma	\$\$	\$	\$	\$\$\$
Brain	\$		\$\$	\$\$\$
Leukemia			\$	\$\$\$
Prostate		\$		\$\$\$
Ovarian	\$	\$\$	\$	\$\$\$
Stomach	\$	\$\$\$	\$\$	\$\$\$
Sarcoma	\$	\$	\$	\$\$\$

# Figure A2: Opportunities for Donor Impact

\$\$\$ Very high opportunity for donor impact – highest priority need

- **\$\$** High opportunity for donor impact
- Moderate opportunity for donor impact
   Limited or no opportunity for donor impact

# Lung Cancer in Canada

Lung cancer has the dubious distinction of being the cancer that kills the most Canadians. In 2009, 20,500 Canadians died of lung cancer, shortening victims' lives by an average of 13 years. Lung cancer kills more Canadians than the next three cancers combined; over one quarter of all Canadian cancer deaths are from lung cancer. In 2009, 23,400 Canadians were newly diagnosed with lung cancer, and lung cancer caused 272,800 potential years of lost life in Canada.<sup>6</sup>

Smoking cigarettes is the largest cause of lung cancer – smokers have 20 times the risk of lung cancer of non-smokers.<sup>7</sup> Lung cancer mortality more than tripled between 1955-1988, driven by the smoking culture of the mid 20<sup>th</sup> century. The decline in men's smoking rates from 50% in 1965 to 17% in 2008 has driven great reductions in lung cancer incidence and mortality.<sup>8</sup> <sup>9</sup> Women, whose smoking peaked later than men's, are still waiting for their odds to improve.

Not everyone who gets lung cancer is a smoker. 13% of people diagnosed with lung cancer have never smoked.<sup>10</sup> Smoking may still be a factor, as non-smoking spouses of smokers have a 30% greater risk of lung cancer than spouses of non-smokers and second-hand smoke exposure during childhood and adolescence is thought to increase incidence.<sup>11</sup> Regardless, these unlucky victims are tarred by the public impression that they caused their own cancer.

Lung cancer has relatively low survival rates even for those few patients who are diagnosed early; for the 60% who are diagnosed with distant metastasis, 5-year survival is only 3.5%.<sup>12</sup> New imaging techniques are being evaluated to help diagnose early-stage lung cancer that would not appear on an X-ray. If successful, these could save thousands of lives.<sup>13</sup>

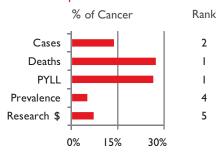
# Donor opportunity for impact – High

Although lung cancer causes 27% of cancer-related deaths, it gets only 7% of cancer-specific research funding, and 0.1% of cancer donations. This gap between lives lost and funding presents an enormous opportunity for donors to save and improve lives.

Prevention With the dramatic link between smoking and lung cancer, continued advocacy and education have the greatest potential to save lives.
Screening Effective tests for identifying early-stage cancer in high-risk populations could increase survival of these patients by more than 15 times.
Treatment Lung cancer is one of the most fatal cancers, even for cancers diagnosed at the localized stage. For lung cancer patients, hope for survival will come from treatment improvements, which will require research funding.
Care Until incidence decreases and treatments improve, the 84% of lung cancer patients who do not survive will benefit from improvements in palliative care, living out their shortened lives in the greatest possible comfort.

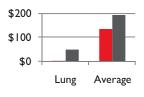


Relative Impact<sup>1 2</sup>



Deaths and PYLL from lung cancer are over twice as high as the next most deadly cancer.

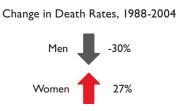
#### Funding per PYLL<sup>123</sup>



Charity Research

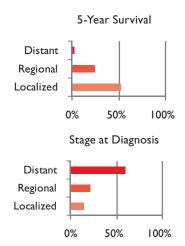
Lung cancer is one of the least funded cancers per PYLL.

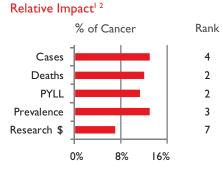
#### Trend Analysis<sup>4</sup>



Reduced smoking by men led to dramatic mortality reductions; hopefully women will follow.

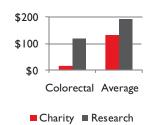
#### Stage Analysis<sup>5</sup>





Colorectal cancer represents roughly I in 8 cancer cases, deaths, PYLL and surviving patients in Canada.

Funding per PYLL<sup>123</sup>



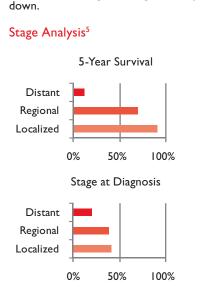
Colorectal cancer receives only 1 in 15 cancer dollars.

Change in Death Rates, 1988-2004

Effective screening is driving mortality

-19%

#### Trend Analysis<sup>4</sup>



90% survival for the 39% of patients diagnosed early.

# Colorectal Cancer in Canada

Colorectal cancer (cancer of the colon and/or rectum) represents about 1 in 8 cancer cases and cancer deaths. In 2009, 22,000 Canadians were newly diagnosed with colorectal cancer and 9,100 Canadians died of the disease, causing 115,300 potential years of lost life in Canada.<sup>14</sup>

Colorectal cancer risk increases with age; more than 90% of people diagnosed with colorectal cancer are over 50 years old. Colorectal cancer tends to run in families. One in 5 colorectal cancer patients have 2, or more, close relatives who have been diagnosed with the disease. Lifestyle also has an impact, with higher risk of colorectal cancer for people who are obese, inactive or with diets high in red and processed meats. Risk is lower for active people and for those who consume high amounts of fruits, vegetables and other high fibre foods.<sup>15</sup>

Colorectal tumours develop from polyps. If polyps are removed while they are still benign, colorectal cancer is preventable. Even if a polyp has become malignant, if it is found prior to metastasis, the cancer is likely to respond to treatment.<sup>16</sup>

This is why screening has the potential to dramatically reduce deaths from colorectal cancer. Estimates of the reduction in mortality from screening tests range from a 15%-33% reduction from the fecal occult blood test (FOBT)<sup>17 18</sup> to a 37%-90% reduction from colonoscopy.<sup>19 20</sup> Experts estimate that for every 1% increase in colonoscopy adoption, mortality decreases by 3%.<sup>21</sup> However, only 40% of Canadians over the age of 50 report having a FOBT in the past 2 years or colonoscopy in the past 5 years.<sup>22</sup>

#### Donor opportunity for impact – High

Colorectal cancer is underfunded relative to its impact in causing 1 in 8 Canadian cancer deaths. Generally, prevalence is a key driver of cancer funding; colorectal cancer is one of the only cancers whose funding is only half of what its prevalence would predict.

Research has already provided the solution for most colorectal cancer patients: screening saves lives. Now, we just need to make sure that timely, effective screening is available to Canadians, and that Canadians over 50 adopt regular screening as part of their medical routine.

**Screening** Colorectal cancer is among the most preventable and treatable cancers, if caught early. Advocacy and education are critical to increase access to FOBT and/or colonoscopy screening, and to encourage Canadians over 50 to get tested regularly.

**Care** For the 35% of colorectal cancer patients who do not survive, improvements in palliative care will help them to live out their shortened lives in the greatest possible comfort.



# Breast Cancer in Canada

Breast cancer is the most pervasive cancer among Canadian women. Based on current lifetime risk, 1 in 8 Canadian women will get breast cancer in their lifetime, with the risk increasing with age. Men also get breast cancer, with 1% the incidence rate of women. In 2009, 22,900 Canadian women were newly diagnosed with breast cancer and 5,400 women died of the disease, causing 95,000 potential years of lost life in Canada.<sup>23</sup>

There are nearly 150,000 Canadian women alive today who were diagnosed with breast cancer in the past 10 years.<sup>24</sup> This dynamic survivor network has mobilized more funds for breast cancer than for any other cancer, driving dramatic improvements in screening (diagnosing the cancer at early, more treatable stages) and treatments (more effective, less disfiguring surgeries and targeted chemotherapies based on the cancer's specific genetic or hormonal characteristics).<sup>25</sup> As a result, age-adjusted death rates from breast cancer have declined by nearly a third since 1988 – a virtuous cycle that has created more survivors and generated more funding.

With its 89% 5-year survival rate, breast cancer is heralded as one of cancer's great success stories. Breast cancer research has had a halo effect on other cancers that benefit from its treatments and scientists who learn from its success.

# Donor opportunity for impact – Very Low, due to saturation and past success

Breast cancer is the most funded cancer – receiving 28% of all Canadian cancer funding, despite representing fewer than 10% of cancer deaths or PYLL. Breast cancer receives 3 times the average of the other 9 top killers: more than \$10,000 per breast cancer death. With 45 charities focused on breast cancer and high support from general cancer charities – and the resulting high survival rates – breast cancer has a low funding need relative to other cancers.<sup>26</sup>

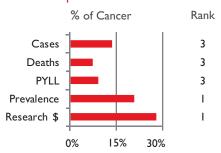
Still, for those who want to fund breast cancer, there are opportunities to donate with impact.

**Screening** Early diagnosis of breast cancer is the greatest determinant of survival. There is still room for improvement related to screening. Opportunities include refining the frequency and type of screening tests used, based on patient risk factors, and more effective screening options for younger women who have high false-negative rates from traditional mammograms and high false-positive rates for MRIs.

**Care** For the 11% of breast cancer patients who do not survive, improvements in palliative care will help them to live out their shortened lives in the greatest possible comfort.

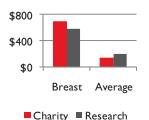


Relative Impact<sup>1 2</sup>



Highest prevalence due to its high incidence and survival.

#### Funding per PYLL<sup>123</sup>



Breast cancer has over 10x the funding per PYLL of lung cancer.

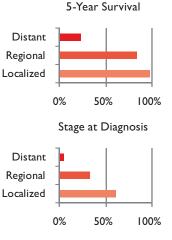
# Trend Analysis⁴

Change in Death Rates, 1988-2004

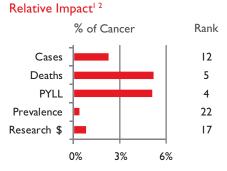


Early detection and improved treatments have dramatically reduced mortality.

# Stage Analysis<sup>5</sup>

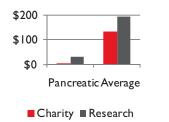


93% of patients are diagnosed before distant metastasis, leading to breast cancer's high 89% overall survival rate.



Pancreatic cancer kills most of its mercifully few patients.

#### Funding per PYLL<sup>123</sup>



Despite its brutally high mortality rates, pancreatic cancer gets very little funding.

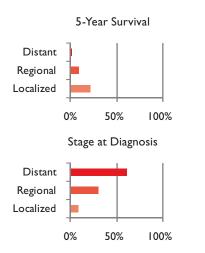
#### Trend Analysis<sup>4</sup>

Change in Death Rates, 1988-2004



Reduced smoking is the likely driver of the modest decline in mortality for men.

#### Stage Analysis<sup>5</sup>



Survival rates are bleak, no matter when it is diagnosed.

# Pancreatic Cancer in Canada

Pancreatic cancer is the deadliest type of cancer. Despite representing only 2% of Canadian cancer cases, it causes over 5% of Canada's cancer deaths and potential years of lost life. There are fewer people living in Canada who were diagnosed with pancreatic cancer in the past 10 years than there are deaths from this disease in any single year. **In 2009, there were 3,900 new cases of pancreatic cancer in Canada and 3,900 Canadians died of it, resulting in 52,500 potential years of lost life.**<sup>27</sup>

Little is known about pancreatic cancer – what causes it, how to screen for and diagnose it, or how to treat it.<sup>28</sup> Smoking increases pancreatic cancer risk, and likely caused the 13% increase in age-adjusted mortality between 1955 and 1988. The decline in men's smoking rates from 50% in 1965 to 17% in 2008 has driven modest recent declines in pancreatic cancer mortality for men.<sup>29 30</sup> Women, whose smoking peaked later than men's, may reap a similar benefit from changed smoking habits.

Pancreatic cancer develops "silently", without obvious symptoms until after the cancer has metastasized.<sup>31</sup> It has dismal survival rates even for the 9% of patients who are diagnosed early. Pancreatic cancer survival is only 23% when the cancer is still localized; for those diagnosed after distant metastasis, less than 1 in 50 survive for 5 years.<sup>32</sup> A leading Toronto oncologist shared his belief that the few people who survive metastatic pancreatic cancer were actually misdiagnosed and survived another cancer.

#### Donor opportunity for impact – Very High

Although pancreatic cancer causes 5% of cancer-related deaths and PYLL, it gets only 0.8% of cancer-specific research funding, and 0.1% of cancer donations. This gap between lives lost and funding presents an enormous opportunity for donors to save and improve lives.

**Prevention** Reduced smoking levels will help, but much still remains unknown about the causes of pancreatic cancer. Epidemiological research could resolve this mystery and generate leads for effective treatments.

**Screening** Even if caught early, the 5-year survival rate is only 23%. Still, that is over 10 times higher than survival once the cancer has metastasized to distant organs, justifying investment in research related to screening options.

**Treatment** Pancreatic cancer is the most fatal cancer, with limited success in treating even localized cases. For pancreatic cancer patients, hope for survival hinges on treatment improvements, that will require research funding. **Care** In the absence of effective treatments, over 94% of pancreatic cancer patients will lose their lives to the disease. Those victims and their families will benefit from improvements in palliative care, allowing them to live out their shortened lives in the greatest possible comfort.



# 43

#### Non-Hodgkin Lymphoma in Canada

Non-Hodgkin lymphoma is a cancer of the lymphatic system, a series of lymph vessels that run alongside blood vessels. Non-Hodgkin lymphoma generally affects people over 60 years old, in contrast to Hodgkin's lymphoma, which is more often found in adolescents and young adults.<sup>33</sup> **In 2009**, **7,200 Canadians were newly diagnosed with non-Hodgkin lymphoma and 3,200 Canadians died from it, causing 42,500 potential years of lost life in Canada.**<sup>34</sup>

Among Ci's Top 10+ cancers, non-Hodgkin lymphoma exhibits the most uniformity in terms of its relative number of cases, deaths, PYLL and prevalence – it represents 4% of cancer impact in each case. Its research funding outweighs its relative impact, perhaps because its outcomes are not improving.

Incidence of non-Hodgkin lymphoma has doubled over the last 50 years, for unknown reasons. As a result, despite modest improvements in treatment techniques, mortality is increasing.<sup>35</sup> Half of patients are diagnosed after distant metastasis has occurred; fortunately the 58% survival rate for these patients is unusually high.

The only confirmed risk factor of non-Hodgkin lymphoma is having a weak immune system. Non-Hodgkin lymphoma has more than 30 different subtypes, each of which has its own prognosis and treatment regimen. Other determinants of treatment regimen are the age of the patient, other health factors, and the types of symptoms he exhibits.<sup>36</sup>

#### Donor opportunity for impact – Moderate to High

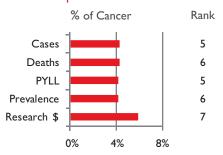
Non-Hodgkin lymphoma has substantial research funding per PYLL, but almost no charity support. For all that is known about its 30 subtypes, the reason for its increasing incidence is a mystery to cancer researchers – one whose solution could enable prevention and save lives.

Prevention Given how little is known about non-Hodgkin lymphoma's causes, or why its incidence is increasing, the greatest opportunity for donors lies in identification of risk factors to drive prevention and decrease incidence. Treatment Until incidence decreases, improved treatment regimens will be critical to increasing survival rates.

**Care** For the third of non-Hodgkin lymphoma patients who do not survive, improvements in palliative care will help them to live out their shortened lives in the greatest possible comfort.

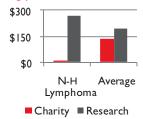


Relative Impact<sup>1 2</sup>



Non-Hodgkin lymphoma has high uniformity of relative impact and support metrics.





Research funding is typical of its impact; donations are very low.

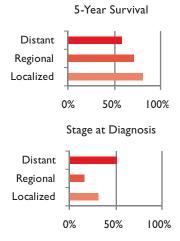
#### Trend Analysis<sup>4</sup>

Change in Death Rates, 1988-2004

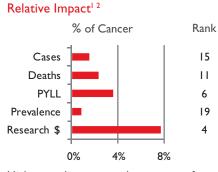


Incidence doubled since 1955, driving increased mortality.

#### Stage Analysis<sup>5</sup>

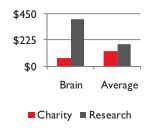


Survival is relatively high, at 67%, with little variation based on when it is diagnosed.



High mortality rates and young age of onset drive brain cancer's high PYLL.

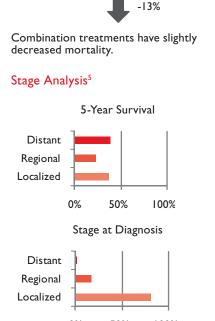
Funding per PYLL<sup>123</sup>



Brain cancer has very high research funding relative to PYLL, and the highest, relative to prevalence, of any cancer.

Change in Death Rates, 1988-2004

#### Trend Analysis<sup>4</sup>



0% 50% 100%

Even for the 80% who are diagnosed early, only 38% survive 5 years. In this case early diagnosis doesn't help.

# Brain Cancer in Canada

Brain cancer tends to strike at younger ages than most, and is the second most diagnosed cancer in children and young people. Because of its young age of onset and dismal survival rates, it has the highest ratio of potential years of life lost relative to incidence of any cancer – higher even than pancreatic and lung cancer. In 2009, 2,600 Canadians were newly diagnosed with brain cancer and 1,750 Canadians died from it, causing 37,200 potential years of lost life in Canada.<sup>37</sup>

Brain cancer refers to malignant tumours that develop in the brain. It does not include benign brain tumours, that may cause complications but are not cancerous. It also does not include metastatic brain tumours, which are other types of cancer (most often lung, breast, kidney and metastatic melanoma) that metastasize to the brain.<sup>38</sup>

Although there are several suspected causes of brain cancer, none have been proven. Most notably, there is no proven link between cell phone use and brain tumours.<sup>39</sup> Brain cancer is usually diagnosed when it is still localized. However, this does not translate to improved outcomes as it does with most cancers. Treatment for brain cancer may include some combination of surgery, radiation and/or chemotherapy, with increased risks and challenges depending on where the tumours are located.<sup>40</sup>

#### Donor opportunity for impact – Moderate

Brain cancer gets the most research funding relative to prevalence of any cancer. It takes many more years of life away from Canadians than its incidence would predict – because it inflicts patients younger, and has lower survival rates. There is very little charity funding for brain cancer, presenting an opportunity for donors to support a cancer whose patients currently have very little hope of survival.

Prevention Little is known about what causes brain cancer. Epidemiological research could resolve this mystery and generate leads for effective treatments.
Treatment Only pancreatic cancer has lower survival rates than brain cancer for early-diagnosed patients. For brain cancer patients, hope for survival hinges on treatment improvements, that will require research funding.
Care In the absence of effective treatments, 65% of brain cancer patients will lose their lives to the disease. Those victims and their families will benefit

from improvements in palliative care, allowing them to live out their shortened lives in the greatest possible comfort.



# Leukemia in Canada

Leukemia is a cancer that has long been associated with children. It is the most common cancer type diagnosed in children; however, it is 10 times more common in adults than in children and youths.<sup>41</sup> **In 2009, 4,700 Canadians were newly diagnosed with leukemia and 2,500 Canadians died of it, causing 36,600 potential years of lost life in Canada.**<sup>42</sup>

Leukemia affects Canadians of all ages, with median age at diagnosis ranging from 13 for acute lymphocytic leukemia (ALL) to 72 for chronic lymphocytic leukemia (CLL). Survival rates differ substantially based on the sub-type of leukemia, from 24% for acute myeloid leukemia (AML) to 78% for CLL.<sup>43</sup>

Leukemia is cancer of the blood cells, and is the only type of cancer that does not form discrete tumours. As a result, it cannot be treated by surgery or radiation.<sup>44</sup> Leukemia was the target of pioneering early chemotherapy research in the mid-20<sup>th</sup> century and continues to play a key role in driving cancer drug development.<sup>45</sup>

Imatinib (Gleevec) is a recent example of leukemia-driven innovation. Prior to the development of Gleevec in 2001, chronic myeloid leukemia (CML) had median survival of 3-6 years. With Gleevec, a targeted therapy with few side effects, more than 90% of patients were alive 4 years after diagnosis. Gleevec's impact extends to 6 other cancer types that have also seen significant response to this new drug.<sup>46</sup>

For childhood and young adult leukemia patients, treatment side effects can be long-lasting, including growth and developmental disorders, as well as emotional and social integration problems.<sup>47</sup> These challenges bridge treatment and care, and are an area of opportunity for donor impact.

# Donor opportunity for impact - Low, due to donor saturation

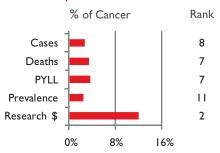
Leukemia is second to breast cancer in terms of both research and charity funding, despite ranking 7<sup>th</sup>-11<sup>th</sup> in terms of its relative impact on Canadians. Given its role in leading chemotherapy innovation, this is the area that deserves continued focus, though it may already be well-funded.

**Treatment** The success of Gleevec in CML gives hope that other leukemias will achieve similar results from chemotherapy. Ideally, other new treatments will also benefit other cancers, as in Gleevec's case. Minimizing long-term side effects, especially in children and young people, should be a consideration in drug development for leukemia.

**Care** Young leukemia patients often endure lifelong side effects and ramifications of their early treatment, and would benefit from long-term care related to these challenges. Those 46% of patients who don't survive leukemia will benefit from improvements in palliative care, allowing them to live out their shortened lives in the greatest possible comfort.

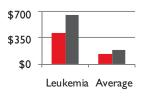


Relative Impact<sup>1 2</sup>



Leukemia is most notable for its high funding relative to either PYLL or prevalence.

# Funding per PYLL<sup>123</sup>



Charity Research

Leukemia is the  $2^{nd}$  most funded cancer type.

# Trend Analysis<sup>4</sup>

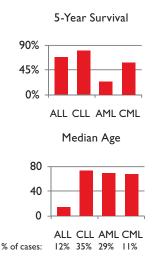
Change in Death Rates, 1988-2004



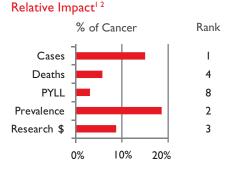
Treatment improvements have driven reduced death rates.

#### Stage Analysis: not available

# Survival and Age at Diagnosis<sup>48</sup> for 4 Most Common Leukemias

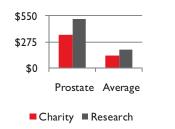


Patient profiles and survival rates vary between sub-types.



Prostate cancer's high prevalence is driven by high incidence and survival.

Funding per PYLL<sup>123</sup>



Driven by prevalence, prostate cancer has high funding relative to its PYLL.

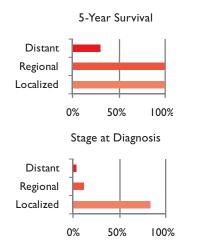
#### Trend Analysis<sup>4</sup>





Though screening has mixed reviews, it is often credited with reduced mortality rates.

#### Stage Analysis<sup>5</sup>



Patients with localized or regional cancer have unprecedented 100% survival rates.

#### Prostate Cancer in Canada

Prostate cancer is the most diagnosed cancer in Canada, representing 15% of all cancer cases despite only affecting the male half of the population. In 2009, 25,500 Canadian men were newly diagnosed with prostate cancer and 4,400 died from it, causing 33,200 potential years of lost life in Canada.<sup>48</sup>

The greatest driver of prostate cancer is age – only 9.5% of cases are diagnosed in men younger than 55. As the population ages, incidence will increase. It is estimated that 1 in 6 men will be diagnosed with prostate cancer at some time in their lives.

The introduction of PSA testing in the 1980s dramatically increased the number of diagnosed prostate cancer cases (but not necessarily prostate cancer incidence). The PSA test has a high rate of "false positives", such that of the 10% of men who have high PSA levels, only 3 in 10 will have prostate cancer. The test also misses some cases – of the 90% who test normal, 2 in 90 will actually have prostate cancer, despite testing negative. As a result, PSA testing leads to unnecessary treatment for some (with associated side effects), and potentially missed treatment for others.<sup>49</sup>

Even an accurate prostate cancer diagnosis may not be life threatening. Scientists have identified two fundamental types, characterized as "tigers" and "pussycats". Tigers are aggressive cancers, requiring treatment. However, the majority of prostate cancers are pussycats – slow-growing cancers that are likely to remain dormant and never be life-threatening. Pussycat cancers need to be monitored, but may never need to be treated. Tests are underway to determine which type of prostate cancer a patient has, but given the apparent predominance of pussycats, prostate cancer generally has a better prognosis than other cancers.<sup>50</sup>

# Donor opportunity for impact – Low, due to donor saturation and high survival rates

As a charitable cause seeking donations, prostate cancer benefits from being the most prevalent men's cancer. It has a very low funding need, and the predominance of indolent cancer types gives it the highest survival rate of all cancers.

Still, for those who want to fund prostate cancer, there are opportunities to donate with impact.

Screening Effective tests to differentiate between "tigers" and "pussycats" will increase the treatment benefit to patients with aggressive cancer and minimize unnecessary treatments for those whose cancer may never be life-threatening. **Care** For the small percentage of prostate cancer patients who do not survive, improvements in palliative care will help them to live out their shortened lives in the greatest possible comfort.



# Ovarian Cancer in Canada

Ovarian cancer is the most lethal women's cancer. Although its incidence is only one-ninth that of breast cancer, its high mortality rate means that it kills one-third as many women as breast cancer does. In 2009, 2,500 Canadian women were newly diagnosed with ovarian cancer and 1,750 died from it, causing 28,600 potential years of lost life in Canada.<sup>51</sup>

Ovarian cancer is often called "the disease that whispers" or the "silent cancer", developing without specific symptoms until the cancer has metastasized well beyond the ovaries. It is diagnosed after distant metastasis in 66% of cases – more than any of the other cancers in the top 10+. Of those patients, only 28% survive for 5 years.

Risk factors for ovarian cancer include age, genetic predisposition in 5%-10% of cases, and hormone-related factors that are often beyond women's control. The key to ovarian cancer survival is thought to lie in screening and early diagnosis; however, current tests are not accurate or specific enough to reliably diagnose ovarian cancer in the general population.<sup>52</sup>

Early stage symptoms – including pelvic or abdominal pain, bloating, difficulty eating, and/or urinary changes – are vague, and as a result, have historically been ignored or misdiagnosed as other ailments. One study found that 94% of women surveyed after ovarian cancer diagnosis had symptoms in the year prior to their diagnosis. New guidelines indicate that if any of these symptoms occur daily and persist for more than 2-3 weeks, a woman should see her doctor and get tested for ovarian cancer.<sup>53</sup>

Ovarian cancer treatment usually comprises surgery, chemotherapy, and sometimes radiation. Chemotherapy options have improved, from one drug in the 1960s to 30 currently approved drugs, however survival is still low once the cancer has metastasized to distant organs.<sup>54</sup>

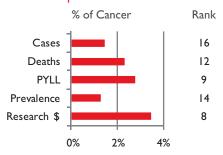
# Donor opportunity for impact - Moderate to High

# Ovarian cancer is moderately funded, but there is still room to improve outcomes through research into screening and treatment, as well as education of symptoms.

Screening Educating women and their doctors about ovarian cancer's vague and persistent symptoms should increase the likelihood that women will be tested and diagnosed earlier. Research efforts to find an inexpensive and accurate screening test for the general population could save thousands of lives. Treatment Ovarian cancer has benefitted from drugs developed for other cancers. Funding trials to test efficacy of current treatments in ovarian cancer patients could increase survival even for those patients with advanced disease. Care For the 54% of ovarian cancer patients who do not survive, improvements in palliative care will help them to live out their shortened lives in the greatest possible comfort.

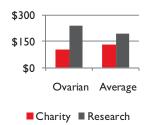


Relative Impact<sup>1 2</sup>



Ovarian cancer's typically late diagnosis drives its high death toll and low prevalence.

# Funding per PYLL<sup>123</sup>



Ovarian cancer benefits from a halo effect from breast cancer's highly-funded research.

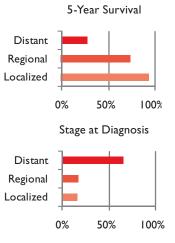
# Trend Analysis<sup>4</sup>

Change in Death Rates, 1988-2004

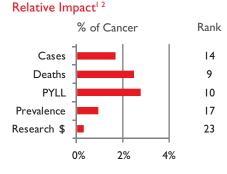


The slight decrease in mortality is attributed to improved treatments.

# Stage Analysis<sup>5</sup>

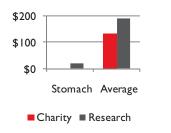


With 66% of patients diagnosed late, over half of ovarian cancer patients die within 5 years.



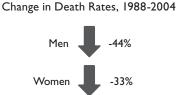
Stomach cancer ranks  $10^{\rm th}$  in terms of Canadian PYLL.

# Funding per PYLL<sup>1 2 3</sup>



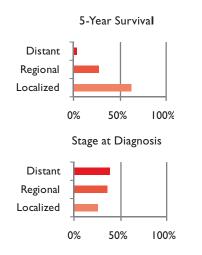
Stomach is the least funded of Ci's Top 10+ cancers. There is no dedicated stomach cancer charity in Canada.

#### Trend Analysis<sup>4</sup>



Decreased incidence has driven reductions in mortality.

#### Stage Analysis<sup>5</sup>



Stomach Cancer in Canada

Stomach cancer, also called gastric cancer, is the second most frequent cause of cancer death worldwide, though less common in Canada.<sup>55</sup> In 2009, 2,900 Canadians were newly diagnosed with stomach cancer and 1,850 died from it, causing 28,100 potential years of lost life in Canada.<sup>56</sup>

The main cause of stomach cancer is the helicobacter pylori virus. With the increase in food refrigeration and hygiene, and decreased consumption of salted, smoked, and cured foods, stomach cancer incidence and mortality have decreased dramatically in Canada.<sup>57</sup> Smoking cigarettes has also been linked to stomach cancer and the decline in men's smoking rates from 50% in 1965 to 17% in 2008 has likely contributed to reduced stomach cancer mortality in men.<sup>58 59</sup>

Prevention is the first line of defence for stomach cancer. When diagnosed early, surgery provides a relatively high likelihood of survival. However, in two-thirds of cases it is diagnosed late. In some cases, stomach cancer is without symptoms in the early stages; even when patients have symptoms, they may misattribute them to other GI-related issues. Although radiation and chemotherapy may help, there is no reliable second line treatment once the cancer has metastasized outside the stomach.<sup>60</sup>

# Donor opportunity for impact – Very High

Stomach cancer receives the least research funding relative to its impact of any of the Top 10+ cancers. Although we know how to prevent it, and prevention is happening, research and education are needed to diagnose stomach cancer early enough to treat it effectively in patients, and improve treatments for patients with distant metastasis.

Stomach cancer shows a significant gap between lives lost and funding that presents an opportunity for donors to save and improve lives.

**Prevention** Stomach cancer should benefit from continued improvements in food hygiene and reduced smoking.

**Screening** Education about the differences between stomach cancer symptoms and other GI-related issues could encourage people to see their doctors about symptoms, and help doctors identify the need for tests. This will help more cases to be diagnosed at the localized, treatable stages.

**Treatment** For stomach cancer patients diagnosed in later stages, hope for survival will come from treatment improvements, which will require research funding.

**Care** For the 74% of stomach cancer patients who do not survive, improvements in palliative care will help them to live out their shortened lives in the greatest possible comfort.



Stomach cancer is often diagnosed late, with dire outcomes.

# Sarcoma in Canada

Sarcoma is cancer that invades the body's connective tissues, such as nerves, muscles, cartilage, fat, and bone. It disproportionately affects young people, causing 13% of cancer cases in people younger than 20 years old.<sup>61</sup> **In 2005, 1,342 Canadians were newly diagnosed with sarcoma and 517 Canadians died from the disease.**<sup>62</sup>

Sarcoma is not one of the 10 cancers known to take the most years of life from Canadians. Ranking only 20<sup>th</sup> in incidence among cancer types, its PYLL isn't even measured. However, its unparalleled impact on the Canadian cancer landscape illustrates the power of patient advocacy.

Terry Fox was 18 when he was diagnosed with bone cancer and had his leg amputated. In 1980, he embarked on a Marathon of Hope, running a full marathon distance daily in his effort to run across Canada and raise money for cancer research. After 143 days and 3,339 km, the cancer metastasized to his lungs, forcing him to cut his journey short. In the 30 years since he lost his life, his journey has inspired nearly \$500 million in donations for cancer research through annual Terry Fox running events.<sup>63</sup>

Had Terry Fox been diagnosed 20 years later, there would only be a 5% chance that his leg would be amputated. He more likely would have had surgery to remove the cancerous portion of his bone, combined with improved chemotherapy and/or radiation treatments with low risk and few side effects.<sup>64</sup> He might still be alive today.

The causes of sarcoma are unknown, although bone sarcoma rates differ by race, with Ewing's sarcoma six times as common in white children as black children. Bone cancer rates peak near the time of the adolescent growth spurt in the mid-teens. Sarcoma is usually treated successfully when diagnosed early; however, given its tendency to affect young people, it can be misdiagnosed as an athletic injury, leading to late diagnosis and poor outcomes.<sup>65</sup>

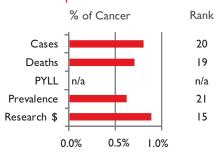
# Donor opportunity for impact – Moderate

Sarcoma is relatively well funded with some strong treatment options. However, there is still modest potential to reduce incidence and mortality across all levers.

Prevention Etiological research into the incidence differences between white and black children could provide insights to fuel prevention, screening or treatment. Screening Education about sarcoma symptoms relative to athletic injuries could help drive early diagnosis, catching more cases at the localized, treatable stages. Treatment For sarcoma patients diagnosed in later stages, hope for survival will come from treatment improvements, which will require research funding. Care For the 33% of sarcoma patients who do not survive, improvements in palliative care will allow them to live out their shortened lives in the greatest possible comfort.

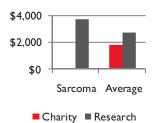


Relative Impact<sup>1 2</sup>



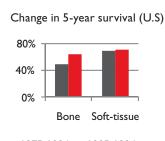
Sarcoma's role in driving cancer support belies its low incidence.

# Funding per PYLL<sup>123</sup>



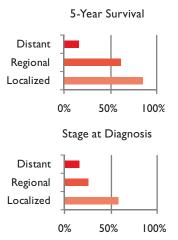
Excludes the Terry Fox Foundation, which supports cancer research generally.

# Trend Analysis<sup>66</sup>



■ 1975-1984 ■ 1985-1994 Survival has improved for bone cancer since Terry Fox had it.

# Stage Analysis (soft tissue only)67



As with most cancers, late diagnosis means low survival.

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# Authors



Greg Thomson holds a BA in Economics from Queen's University and an MBA from Harvard University. Greg is Director of Research at Charity Intelligence. He is also an owner and CFO of Women's Post Media with experience in strategy consulting.

Greg's father was diagnosed with colon cancer in 1987. Determined to take responsibility for his own treatment, he changed his diet and his lifestyle, and traveled to meet various experts in alternative therapies. While he was able to make the most of his last years, Tom succumbed to his cancer five years later at the age of 57.

The year after his father's death, Greg embarked on a round-the-world bike trip to raise funds for cancer research. Seventeen years later, his work at Charity Intelligence led him to wonder just what had happened with the funds that he raised in memory of his father. This report is partly a result of that question.



Karen Greve Young holds a BA from Harvard University and an MBA from Stanford University. Her work experience includes strategy consulting and finance. She has volunteered extensively for the U.K.'s Institute of Cancer Research and other non-profits in Toronto, London, UK and San Francisco.

Karen's mother had every symptom of ovarian cancer for several months before massive abdominal swelling finally led to her late-stage diagnosis. She had no idea that her fatigue and digestive issues were early symptoms of ovarian cancer. Four and a half years later, she passed away at age 58.

As many do, Karen transformed grief into action. She has chaired events to increase awareness of silent cancer symptoms and raise money for cancer research. She and her mother co-wrote a book about their experience as cancer patient-mother and carer-daughter that will be published in summer 2011. Karen hopes that Ci's Cancer in Canada report will inform donors about how they can most effectively help transform cancer from a disease people die from to one they survive.



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