Ewings Cancer Foundation of Canada

5YR STRATEGIC BUSINESS PLAN
2014-2019
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1 WHO WE ARE & WHAT WE DO

The aim of the Ewings Cancer Foundation of Canada (ECFC) is to give all those who suffer from Ewing sarcoma real hope for the future with the opportunity to live long, happy lives spent fulfilling their dreams.

Our Vision

ECFC will grow to be a leading, volunteer-based national organization that contributes to the discovery of a cure for Ewing sarcoma cancer. In the interim, ECFC will lead the pan-Canadian action to improve the quality of life of those with the disease; through better care and services as well as more effective and less harmful treatments.

Our Mission

The mission of the ECFC is to help address the specific need for Ewing sarcoma research and the need for greater awareness of the disease. The Ewings Cancer Foundation of Canada is committed to educating the public on what Ewing sarcoma is and raising awareness among health care professionals with the goal of early detection.

Three core activities of ECFC:

- To support scientific research that will contribute to the discovery of better treatment and ultimately the cure for Ewing sarcoma cancer. Fundraising is organized and partnerships are formed with the goal of raising money and leveraging research dollars.

- Through targeted communications with key stakeholders and health care practitioners, we raise awareness about Ewing sarcoma cancer.

- Through active community outreach and participation we provide support and engagement platforms for the individuals, families, and communities affected by this disease.

What is Cancer?

Our bodies are made up of millions of cells, grouped together to form tissues and organs such as muscles and bones, the lungs and the liver. Genes inside each cell order it to grow, work, reproduce and die. Normally, our cells obey these orders and we remain healthy. But sometimes the instructions get mixed up, causing the cells to form lumps or tumours, or spread through the bloodstream and lymphatic system to other parts of the body. Tumours can be either benign (non-cancerous) or malignant (cancerous). Benign tumour cells stay in one place in the body and are not usually life-threatening. Malignant tumour cells are able to invade nearby tissues and spread to other parts of the body. Cancer cells that spread to other parts of the body are called metastases.

Canadian Cancer Society

What is Ewing Sarcoma?

Ewing sarcoma is a type of cancerous tumour that forms from a certain kind of cell in the bone or soft tissue. Other names for Ewing sarcoma are: Primitive Neuro-ectodermal Tumour (PNET), Askin tumor of the chest wall and Extraosseous Ewing sarcoma (tumour growing outside the bone). All of these names may be grouped into the Ewing sarcoma family of tumours (ESFT). Ewing sarcoma may be found in the bones of the legs, arms, feet, hands, chest, pelvis, spine or skull. It may also be found in the soft tissue of the trunk, arms, leg, head, abdominal cavity, or other areas. Ewing tumours often occur in teenagers and young adults. Signs and symptoms of Ewing sarcoma include pain and swelling near the tumour, a lump, fever, or a bone that breaks for no known reason. Treatment usually consists of chemotherapy, surgery and radiation.

National Cancer Institute
Our Strategic Plan

The Board of Directors at ECFC recognizes that focused strategic planning demonstrates fully transparent, committed leadership and accountability. The ECFC Board of Directors would like to ensure that ECFC can sustain growth and remain a relevant and trusted partner to clinical, research and patient communities. The ECFC Strategic Plan is a result of several focused discussions and sets a compelling roadmap for the Foundation for the next 5 years (2014-2019).

This roadmap builds on a broad scan of external environment and an assessment of internal strengths and weaknesses. Our strategic Plan builds on and reflects the Foundation's strong community presence and provides a foundation for partnerships as well as organizational development.

By aligning our daily activities with our long term vision, we can communicate what we aim to achieve and whom we would like to engage. By understanding what we need to do to achieve our goals we will be able to identify what resources and partnerships we will require. And finally, by setting clear and measurable goals we can monitor and adjust our activities.

Our Core Values

The ECFC is built on these main core values:

- Collaboration & Partnerships
- Enabling scientific discovery
- Accountability & Stewardship

These core values form the basis for maximizing ECFC research potential by leveraging funds and assist in delivery of specific value proposition elements allowing us to give back, in the most effective way, to the communities and individuals that support us.

ECFC keeps abreast of new and innovative scientific discoveries which are of utmost importance to those that support our research efforts.

ECFC is diligent in its efforts to maintain accountability and transparency in all activities it performs.
Our Stakeholders

ECFC works closely with a number of communities, partners, and stakeholders to deliver on its mission.

ECFC has a personal connection to the mission as all many of the Board members have been affected in some way or another by Ewing sarcoma.

Community support and volunteerism has been and continues to be an integral part of the ECFC’s success.

The ECFC Scientific Advisory Board is a key component to gaining trust and credibility across Canada.

Partnerships such those formed with C17 Children’s Cancer and Blood Disorders, allows us to be front and center to research that is going on specific to our mission.

Opportunities exist to establish a sustainable endowment fund and expand our efforts to new geographic locations. New partnerships are on the horizon, increased awareness and improved communications through various telecommunications and social media avenues with the aim of the ECFC become a trusted source of support for teens and young adults looking for help.

ECFC Continues to Improve in the Following Areas:

Strategic Relationships
- Build stronger relationships with pediatric hospitals across Canada
- Formalize recruitment strategy for volunteers complete with volunteer recognition program
- Define specific value proposition for potential corporate donors / sponsors
- Define an integrated communication & outreach strategy that supports development of awareness in targeted communities of interest

Helping Eliminate Barriers to Success
- Helping promote fair and equitable sharing of national cancer research funds so as not to be lumped into the same “cancer” bucket.
- Fully understand the impact of the Privacy Act with regards to sharing of information and reporting of statistics, etc.
- We are lumped into “cancer” bucket, but not all specific cancers get funding
- Competing diseases and competing research priorities

Better Understanding and Management of the Disease Profile
- Young adults are less likely to receive sympathy than kids
- Teenagers are affected, but they don’t have large money to contribute to fundraisers
- It is a spontaneous, very aggressive disease
2 WHERE WE ARE HEADING

To ensure that we will be able to work on these priorities, a set of enabling strategies have been identified and defined to provide a clear roadmap of activities for the next 5 years. This roadmap is a snapshot, which we will monitor, review and adjust as needed.
3 OUR FUNDRAISING GOALS

How do we raise money

Challenge
Cancer research is expensive - cancer cells for just one experiment can cost from $300 to $500. Cancer research is time-consuming – it can take years to complete a single study before the study enters into a human clinical trial.

Goal 1: To organize ECFC events and to partner with others to establish a sustainable annual funding opportunity.

To meet this goal we will run:
- ECFC annual events in various communities
- Events conducted with strategic partners & collaborators
- Events organized on behalf of ECFC by our numerous community volunteers

The Type of Research We Fund

Challenge
Because so much about Ewing sarcoma is still unknown (origin of disease, genetics, severity indicators, accurate reportable statistics, advanced treatment options, etc.), we need to have a balance between funding research that covers all aspects of the disease from front to back. This involves collaboration with scientists, clinicians and statisticians.

Goal 2: To help stimulate new research interests that will help bring focus to develop better understanding of the Ewing sarcoma cancer - whether for scientific cure or delivery of care.

To meet this goal ECFC offers funding to Canadian researchers interested in a range of scientific research projects – from basic microscopic bench top lab research to macroscopic quality of life and population-based statistical research. The ECFC commits to funding using a balanced approach. By partnering with organizations such as the C17 Council for Children’s Cancer and Blood Disorders, the ECFC can leverage research dollars more effectively, network with the most appropriate researchers, and promote innovative discoveries and clinical research right here in Canada – all of this benefitting those patients with Ewing sarcoma, and their families.
How We Allocate Funds

**Challenge**

There is a significant amount of research going on worldwide and the ECFC must collaborate where possible and take care not to duplicate research efforts being done elsewhere. This requires ECFC being diligent about knowing what research is going on and where.

**Goal 3: To fund scientific research that meets criteria for excellence and addresses identified priority areas.**

To meet this goal ECFC builds trust through accountability. Funding will be awarded to recipients that are highly qualified and reputable in medical research. Our application process is overseen by our Scientific Advisory Board, including reporting back on results.

We work with our Scientific Advisory Board to identify priority research topics specifically related to Ewing sarcoma and then select projects that will help address them.

In general, because our grants are small, we fund specific individual researchers rather than research teams or groups.

4 **OUR AWARENESS GOALS**

According to the Canadian Cancer Society statistics, an estimated 191,300 new cases of cancer will be diagnosed in 2014 in Canada. Of that, more than one-half will be lung, colorectal, prostate and breast cancers. There are an estimated 80 new Ewing sarcoma diagnoses in Canada each year, with an age-standardized incident rate of 2.7 per 1,000,000 for those 0-14 years of age and an estimated 140 new diagnoses in Canada each year, with an age-standardized incident rate of 3.9 per 1,000,000 for those 15 – 29 years of age.
**Challenge**

Often there is a delay in diagnosis due to the fact that Ewing sarcoma can often mimic a benign condition (such as a sports injury) in children, teens and young adults. Once the disease has spread beyond the primary site, it makes it more difficult to treat and the prognosis of survival drops significantly from 75-80% to less than 30% in 5 years. Early detection is vital.

**Goal 4: To provide health professionals as well as families with relevant and trusted information and resource lists regarding symptoms of Ewing sarcoma cancer.**

To meet this goal ECFC has been providing communication material to family physicians. We also work with various health practitioners to identify how best to provide information.

**5  OUR GOALS FOR SUPPORT AND ENGAGEMENT PLATFORMS**

**Challenge**

It’s often overwhelming for families both newly diagnosed and those undergoing a relapse to know where to go and who to speak to for support and how to obtain referrals and information on available clinical trials.

**Goal 5: Engage and reach out to communities**

- Make available on the ECFC website a list of Frequently Asked Questions (FAQs) related to Ewing sarcoma.
- Provide links on the ECFC website links to reputable cancer and sarcoma-specific websites
- Provide available articles and lists of clinical trials available for those with limited options for treatment

**6  MONITORING & MEASURING PROGRESS**

With specific goals we can set targets and track where we are. Goals will be reviewed annually and evaluated to monitor both successful achievements and shortcomings. This will allow the ECFC to keep on target and move in a forward direction. Where shortcomings occur, goals will be readjusted and priorities and strategies reinforced for the next review period.