

International Confederation of Childhood Cancer Parent Organisations (ICCCPO)

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“LOBBYING: Talking with Government and other agencies”

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Introduction

There are many, many cases worldwide where ‘Lobbying with Government and other agencies’ has proved to be the most the effective way to improve the outcome of children with cancer.

Advocacy and lobbying for causes we believe in are part of our everyday life and I am sure most people could relate a story of how they were directly or indirectly part of, or aware of, a successful lobbying cause.

The purpose of the parent’s workshop is to present some principles and considerations about how to lobby successfully. After discussion on the topic feedback will add additional information to this parent paper.

The aim is to prepare a source document that will be lodged on the ICCCPO website. Hopefully, this document will serve as a resource for those in the future who will wish to lobby to improve the outcome of children suffering from childhood cancer in their own countries.

This paper has been updated with feedback received at the ICCCPO Conference held in Mumbai, India, Oct/Nov 07. It is acknowledged that the principles and considerations contained in this paper are generic in context. That is, what will work in lobbying one country will not necessarily in another.

What is LOBBYING?

“direct communications with public holders and their advisers as part of an effort to influence a decision of government” *

(*Source – *“Improving the Non-Profit, Voluntary and Charitable Sector’s Effectiveness in Influencing Decisions of Government”* by Sean Moore pg 8, produced in 2005 for The Muttart Foundation, Canada. www.muttart.org)

What is ADVOCACY

“The act of speaking or of disseminating information intended to influence individual behaviour or opinion, corporate conduct, or public policy and law” *

* source as above - Sean Moore Pg 8

Childhood Cancer – Our Motivator to Lobby

Cancer is suffered by children worldwide. Cancer does not discriminate – it occurs regardless of race, colour, creed, sex, wealth, geographic location, etc

We don't yet know why cancer occurs in children. However, clever people are devoting their talents to research in order to find the causes of cancer and the cures. The researchers have achieved some considerable success. Research has been responsible for the dramatic improvement in child cancer survival rates in the past 60 years.

In New Zealand in the 1940s and 50s, for example, less than 5% of children with cancer survived. The survival rate some 60 years later is now around 80%.

However, in many countries of the world, children are still dying from cancer in situations where we know they could survive if they had access to current childhood cancer treatment protocols.

By way of comparison, in New Zealand as with many other developed countries, 100% of children with cancer will see a doctor and all will be treated. Of these, 80% will survive cancer. However, worldwide in total, it is assessed that only 20% of children with cancer will see a doctor.

In addition to lobbying in our own countries at a local level to improve the outcome for our own children, our lobbying should also be directed to redressing this dreadful shortfall for children in countries where there is no adequate cancer treatment for them. Many children who survive treatment for childhood cancer will live with the Late Effects of their cancer treatment for the rest of their lives. Late Effects may be wide ranging in nature and include the ability of the survivor to learn, see, hear, walk, run, have children, participate in the community.... and so the list goes on.

Research never stops in the quest for causes and cures of childhood cancers as well as to lessen the life long effects our children will suffer from after their cancer treatment is completed. These 'Late Effects' as we know them cause children and their families suffer.

Why Lobby? – Our Key Driver

In asking what the purpose of our lobbying is for, it is suggested that it is:

“To use the power of lobbying vested in parents and caregivers to achieve the best possible outcome for children suffering from cancer.”

This must surely be a matter very close to our hearts.

Lobbying – Starting the Process

To be effective in the treatment of childhood cancer, Health Professionals (HPs) and parents/caregivers need to work together in partnership. Combining the respective strengths of HPs and parents will provide the means to ensure the best possible outcome is achieved for children suffering from cancer.

In acknowledging the place of the HPs and the trust that is placed in them to treat and care for our children, we also need to acknowledge a limitation in their ability to lobby.

Firstly, HPs need all their energy and professional skills to help our sick children.

Secondly, HPs are employees and in most cases employees have limitations placed on their ability to lobby against their employers to advance a cause.

Employers of HPs are invariably the funders, or the managers, of funds for the cancer service being provided. Thus, in order to start the lobby trail, it is important to establish contact with those the HPs work for – that is, their employers who own or administer the respective hospitals, health boards and government departments

Some of you may be aware of the saying “He who pays the piper calls the tune.” In this case we need to lobby ‘the piper’ or those who control the purse strings.

Experience has shown it is the parents who can become powerful lobbyists and advocates in support of HPs needs. Our HPs will care for our children so long as they have the means to do so, and parents can provide the means through effective lobbying. We must always be looking to raise the profile for Paediatric Oncology. We lobby to seek recognition and funding to support skilled and dedicated HP staff, for better treatment facilities, for new equipment, for improved cancer treatment drugs, on-site facilities for parents, and for many other valid needs.

Naturally we must do this while being mindful of competing and perhaps equally valid claims made by those lobbying in support of groups supporting other children's illnesses.

Lobbying: First Steps

We lobby because constant improvement is needed to improve the outcome for children with cancer, and for our children's children.

The first step in building a strong lobbying plan is for, parents and HPs to identify and clarify the need – is it money, equipment, people, research, facilities that is needed? Narrowing the cause will help provide focus to the lobbying activity.

Some tips on effective lobbying

Focus and narrow the cause or purpose - Before lobbying commences for any specific issue, there needs to be a clear purpose. It is better that there will be a smaller gain for a narrow purpose than no gain at all because the aim was too wide or diverse.

Personal or general benefit? - There must be clarity in whether the lobbying will be for a singular or multi purpose cause. That is, lobbying is likely to be less effective if it is to support a personal crusade for a single child rather than of wider benefit for all children.

Funding – lobbying will most probably cost money so ensure the case has enough to be funded right through to a successful outcome

Realistic - The desired outcome of lobbying needs to be realistic, tangible and balanced.

Fair in context – The lobbying needs to be for an outcome that will be reasonable when placed in context with claims from other competing organisations who also seek recognition, funding and support

Reasonable - Lobbying must be framed in context of what reasonable people would ask for. Extreme stances or outlandish statements are not of the nature of reasonable people

Power of emotions - Remember to lobby and appeal to inner emotions as decision makers have children and families, too

Generate friends – Decision makers often have staff. To ease a staff member's load, find out who of the decision maker's staff will process your lobbying request and what the staff member will need from you, and in what format to make their job easier. Go the extra mile for them, and they might for you.

Use of contacts – Remember the saying "It is not what you know but who you know" so use wisely Parents/caregivers, families and friends who may have considerable influence in the community.

Official recognition – parents or groups could contact local/public administrators in order to be official recognised both at local and national levels so that in turn they may have the recognised authority to speak in support of the cause to lobby.

Sponsor pilot programmes – sponsoring short term pilot programmes can demonstrate to government agencies the ongoing need for service e.g. children's play therapists, art therapists etc

Lobbying: First consider getting HELP

There is no single solution, or 'right way' to get a successful lobbying outcome, but there are many avenues that will help gain a positive outcome.

Two important points are worth mention:

Bury egos - consider seeking help and advice from others to enhance lobbying. A solo passion for the cause may not be sufficient to round-out the case and sway the argument

Seek Expert advice - Consider seriously the place for expert advice such as retired MPs, pro bono Lawyers, retired or volunteer political staff, professional lobbyists, consultants, university specialist, philanthropists

Hierarchy for support - Graduated steps to get to the decision makers

Level 1 – begin networking

Friends, relatives, neighbours

Level 2

Childhood cancer survivors & Patients

Parents and families

Private health consultants

Local charities, church groups

Local Hospital Management – the Hospital CEO etc

Level 3

Local business, social bodies, charities, clubs (e.g. Lions, Rotary) educational institutes, local corporates, local bodies, local GPs, Educational staff, universities

Local Hospital Governance - the Hospital Board members

Level 4

Large scale national/international corporate bodies

Celebrities

Judiciary

The Media: Press/TV/Magazines/IT – judicious use

International NGOs e.g. ICCPCO

Level 5 – Government – local/state/national

Local municipal/City Councillors or Mayor

Local regional/State staff and elected/appointed representatives

Local Member/Representative of Parliament/Congress/Senate

Central/Federal Government – staff of Ministry/Department of Health

Central/Federal Government – Minister/Congressman/Senator

Central/Federal – Prime Minister/President

Some Principles in Preparing a Lobbying Strategy

Bureaucracy - Overcome personal blocks and barriers one may have against bureaucracy – a positive approach is needed at the outset in order to work for positive outcomes

Research - Research the background to provide depth to the case – time spent in preparation is never wasted

Prior information - Build on the past – don't start from scratch if there is earlier work already completed on the issue

Collaborate - Consider the value of collaboration, and support from other NGOs, charities, donor foundations and corporations

Depth - Involve and include other interested like minded supportive parties in order to prepare a well rounded collaborative effort e.g. HPs, parents, officials, staff, advisors etc

Best practice information - Ascertain national and/or international Best Practice standards – the web has limitless information and is free

Competition - Consider and compare your case against existing and likely competition from others for the same local & central government funding you seek

Context - Consider your proposition in the context of other political, policy and transparency issues faced by those your lobbying is trying to influence – try to understand their position and how they may react

Reasonable - Don't seek the impossible - ask for an outcome that makes it easier for the decision maker to say yes

Precedent - Consider the precedent this will set for the decision maker in relation to other charities – “if you were in their shoes, how would you decide ?”

Follow the process - Find out how the decision making process functions, follow the process and don't cut corners for fear of offending a potential in-house friend and supporter

One step at a time - Work through the established system but don't go 'political' too early – let the staff members do their work in reasonable time before you call on their boss

Avoid confrontation - Ensure lobbying is inspirational and aspirational rather than confrontational – ask for and propose realistic outcomes and solutions

Use the Press carefully - Consider the use of PR and the Press, but not before exercising 'proper' channels as reactionary decision makers on the back foot are less likely to decide favourably

Sincerity - Be flexible to change, open minded and responsive

Open to offers – Be prepared to consider counter-offers in order to gain a win-win outcome

Integrity - Exercise respect and tolerance, have patience

Perseverance - Don't give up at the first or subsequent knockbacks

Conclusion

The decision to lobby can be often be an emotive singular one. Emotion needs to be set aside as does the drive to 'do it alone'. The collective experience of a wide group of people who have empathy for the cause should be sought before beginning the quest for a better outcome.

This paper sets out to present some of the principles and considerations that may be considered before and during the lobbying process. Should readers hold or discover additional information, please contact ICCCPO Secretariat with a view to providing updates to this paper such that others may benefit.

The cause to lobby to improve the outcomes of our children with cancer is a very worthy cause to support. I wish you well in your lobbying endeavours such that your children and your children's children will benefit.

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