

# DEVELOPING AND SUSTAINING AN EFFECTIVE LOBBYING CAMPAIGN

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# Developing and Sustaining an Effective Lobbying Campaign

Brian O'Mahony

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## Introduction

Advocacy is defined as active support, especially for a cause. It generally involves arguing the case while trying to achieve a particular objective. A hemophilia organization can advocate for change with doctors, hospitals, health authorities, government officials, or politicians.

If through your advocacy efforts, you do not achieve or exceed your objective, or more public, media, or political awareness is needed, lobbying may be necessary.

Lobbying is the attempt to influence legislators in setting policy by taking a more active and wide-ranging approach than simply submitting a proposal or set of proposals. It generally requires the involvement of the media, politicians, and key people from your organization in an integrated strategy designed to ensure a positive response to your proposal and increase the chances of achieving your objectives.

Both advocacy and lobbying involve influencing what other people believe, think, and do in order to achieve an objective. Lobbying is more likely to be successful when many people are involved. It can be designed to set the agenda (proactive) or respond to someone else's agenda (reactive).

Lobbying is most effective when it:

- is based on facts, draws on practical experience, and offers proof for claims it makes;
- is carefully and strategically planned;
- involves and represents the group on whose behalf it is undertaken.<sup>1</sup>

Lobbying is usually least effective when it:

- is undertaken by an organization with no established reputation around the issue;
- is based on facts, nor supported by those on whose behalf it is undertaken;
- is poorly thought-out and unclear in what it is trying to achieve.

In an ideal world, a national hemophilia organization would have a clear vision of what it wants to achieve at a particular time. It would then sell its case to government, politicians, or senior health officials. After an appropriate interval, health officials or government ministers would meet with the organization. They would discuss what is needed and agree on how to meet the organization's objectives.

This rarely happens. It is more likely to occur in a country where:

- the economy is strong and hemophilia care is established as an integral part of the national health care system; or
- the organization has demonstrated its ability to lobby the government successfully in the past and, therefore, government officials are more likely to listen to suggestions from the organization and respond positively.

The reality is that, in most cases, the chances of success with government are higher if a carefully thought-out case is supported by political lobbying of key stakeholders.

There are various steps to putting together an integrated strategy for achieving your political objectives. Most successful advocacy and lobbying campaigns don't just happen but are carefully planned.

To make a good case for support, you must have a clear, rational purpose for trying to achieve your objectives and good data to support your request. A previous WFH monograph, *Making Your Case Effectively: A Guide to Government Relations*, sets out many of the requirements for

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<sup>1</sup> Adapted from *A Handbook on Advocacy: Child Domestic Workers: Finding a Voice*, by Maggie Black. Anti-Slavery International, 2002.  
<http://www.antislavery.org/homepage/resources/AdvocacyHandbookEng.pdf>

producing a good case for support and preparing for meetings.

This publication outlines the various steps in putting together an integrated lobbying strategy for achieving your aims politically.

### Defining your objectives

This is an internal process where, as a board and as an organization, you clearly define your objectives. You may be advocating for improvements in health care for hemophilia, or improvements to the treatment infrastructure. For example, you may be asking the government to:

- set up a hemophilia treatment centre (HTC) with a comprehensive care team;
- provide additional medical or HTC staff;
- fund home treatment with factor concentrates;
- provide an electronic patient record system.

Or, your objective may be related to replacement therapy, where you may be asking for:

- increased per capita usage of factor concentrate, specifying the amount needed to improve treatment for people with hemophilia;
- prophylaxis for children, or for all people with hemophilia;
- additional financial resources to provide recombinant products to replace plasma-derived concentrates;
- improved treatment for people with hemophilia who are infected with hepatitis C or HIV;
- compensation for members who were infected with hepatitis C or HIV.

Other aspects of hemophilia care for which political lobbying may be necessary are increased funding for the organization in general or in relation to provision of services, or for specific work such as outreach programs.

### Determining what is possible and achievable

When beginning a campaign on any issue, you must look at what is possible and achievable. Determine the level of knowledge and awareness of hemophilia and the support you have among politicians. If this is the first issue you have ever

campaigned on, and the level of public and political knowledge and awareness is very low, then you have to educate politicians, the media, and the public. Alternatively, if your organization has a strong and successful lobbying record, and there is a relatively high degree of understanding of the issues for which you are lobbying among politicians, you can assume a greater level of knowledge and proceed accordingly.

Any organization starting on a campaign must be aware of its own political strength, infrastructure, priorities, and key health issues.

You should also look at current changes in the healthcare system, changes which you can use to support your case.

*Example 1:* In Ireland, a report on centralization of major services in regional centres was implemented as a government priority. This was used by the Irish Haemophilia Society to gain support among politicians for comprehensive regional hemophilia treatment centres.

*Example 2:* In Mumbai, India, in 2003, the political motivation to help people with hemophilia by providing some clotting factor concentrates was justified in the context of the state government's AIDS prevention program. With the assistance of the WFH, hemophilia organization representatives were able to provide statistics on the relative risk of HIV from cryoprecipitate as opposed to clotting factor concentrates.

### Defining expected outcomes

The board should agree on both the objectives of the campaign and the political lobbying efforts necessary to achieve these objectives.

In any campaign, it is important for the board to first define:

- what the submission will ask for;
- the minimum result which is acceptable;
- the desired outcome;
- what total success would be.

If board members have different views on an issue, it is important that, once consensus has been reached, they stand behind the agreed upon objectives. It is damaging to the campaign if individual board members who do not agree with the campaign speak to politicians, media,

or the public in opposition to the agreed objectives. This should be avoided.

Write down what the board agrees to, so you can return to it later in the campaign when you wish to review your objectives, or if there is disagreement regarding the objectives. In a potentially long campaign, for example, on issues such as compensation for HIV or hepatitis C, it is important to write down agreed objectives at the beginning of the campaign. As the campaign progresses, realities change, perceptions differ, expectations shift. At a later stage, if there is disagreement about the objectives, you can refer back to the written notes from the meeting when the objectives were set.

The written document recording these objectives and the minimum result you expect should be kept confidential. It should not be circulated to politicians, health officials, journalists, or even to the wider membership of the organization. A document sent to every member of the organization has to be assumed to be in the public domain.

In most campaigns, you ask for more than you expect to receive in the hope of receiving, at least, the minimum acceptable outcome. You should also decide on your definition of success and failure in relation to the objectives. Success may not be entirely linked to achieving the minimum acceptable result. Bear in mind that, sometimes, even in failing to achieve the minimum acceptable result, raising the profile of hemophilia increases your ability to lobby politically as an organization. It may also result in a greater degree of respect for, or awareness of, your organization from politicians and the media. This heightened respect and profile may lead to subsequent submissions or campaigns being dealt with at a higher political and health official level.

Failure is not limited to not achieving their objectives. A bigger failure would be not to try in the first place. This would send the message that your organization is not active in defending the rights or promoting the goals of members.

### **Consulting with members**

Once you have defined your objectives, the next step is to inform your members of the campaign.

This may be in writing initially, but, for maximum support by members, meetings should be held where you set out:

- what you are doing;
- what you hope to achieve;
- what members can do to help;
- how you will keep them informed as the campaign develops.

This gives the members an opportunity to comment, hopefully constructively, on the campaign, and to agree to the objectives.

If you are lobbying for an issue that is in your strategic plan or annual priorities, you may not need to hold separate meetings to inform your members. A general letter to members, informing them what your objectives are and what you intend to do, and/or some specific articles in your newsletter or publications should be enough.

### **Planning the campaign**

#### **Developing a budget**

This is essential, especially if it is going to be a relatively long campaign. For a short campaign, a well-resourced organization may be able to absorb the costs into their general budget. For a longer or more complex campaign, or for a campaign being undertaken by an organization with very limited resources, it is important to estimate the budget required before the campaign starts.

Setting a budget will prevent a situation where other important programs or activities are hurt by having their funding re-allocated to the campaign. It will also avoid a situation where the campaign has to be halted or delayed because of lack of funds. Delay can cause a loss of crucial momentum and increase the possibility of failure.

For a long or complex campaign, costs may include:

- travel by staff and volunteers to meetings and/or regions around the country;
- hosting frequent press conferences;

- hosting special events (meetings, rallies, protests);
- employing additional staff or replacement staff, if existing staff are working on the campaign;
- employing a professional lobbyist or public relations person.

When setting your budget, examine the relative importance of the issues to your overall organizational objectives. Look at the cost in relation to the duration of the campaign. A higher cost may be preferable if it leads to a better chance of a positive outcome in a shorter period of time.

*Example:* In 2005, New Zealand allocated a sizeable budget to allow for an intensive five-month campaign on hepatitis C. This was more cost effective than setting a smaller annual budget on the issue for several years, as this type of lower intensity lobbying is rarely successful.

Having a specific campaign budget also allows you to inform the members of your financial needs, and can be used to encourage them to raise funds. Alternatively, you may wish to organize specific fundraising events for the campaign.

### **Determining human resource needs**

Look at staff available and re-assignment of existing staff with required skills from less important areas of work for the duration of the campaign. Determine what volunteers are needed and who is available. Volunteers (members) may be needed to help with logistics, write to and meet local politicians, and attend campaign events. Involvement of clinicians may be required if the campaign focus is a medical resource or treatment issue. Look at the time available and maximize its use.

### **Determining the probable duration of a campaign**

It is important to discuss the duration of a campaign before you start. For instance, your campaign may be time limited. You may be trying to ensure that it will be completed by the time an election takes place.

The duration of a campaign will depend not only on general factors such as when the next

government election may be called. It will also depend on how vital the issue is to your organization and where the issue lies in relation to your priorities and the time period.

In estimating the duration of the campaign, consider that it:

- may be geared to a specific end point such as an election, or may be open-ended with a defined periods of high activity and less intensive activity;
- should be set relative to the priority the organization attaches to the issue;
- may be affected by the people, finances, and resources available;
- should be a carefully planned campaign.

It is easy to fall into the trap of putting together a submission for the government and then beginning a lobbying campaign on an issue, without any clear idea of how long it may take to resolve the issue successfully. The longer this goes on without a clear strategy on the part of the organization, the more likely it is that fatigue and exasperation will set in. Expectations will shift and the issue will increasingly take up staff's energy and commitment. This will impact negatively on the general work of the organization.

If you do not have clear objectives and a clear, broad timeline in mind, you run a real danger of losing other programs or activities, and alienating members who would not benefit from the campaign.

At the end of the expected time period, in the absence of a resolution, you should review your entire campaign. In some cases, it may be necessary to cut your losses if a campaign has taken up more time, resources, and energy than you are prepared to put into it. With no sign of a successful outcome, it may be time to stop the campaign.

*Example 1:* The U.K. Haemophilia Society spent several years and a lot of time, effort, and resources campaigning for hepatitis C compensation. It eventually resulted in success when people with hemophilia with hepatitis C were granted compensation in 2003. However, during the long campaign, the issue of ending it had been discussed.

**Example 2:** In Ireland, an extension of the hepatitis C compensation scheme to allow for additional compensation for people with HIV was agreed at Parliament. The issue had not been dealt with by Parliament earlier, and the upcoming election, and specific lobbying of politicians, resulted in the legislation being passed. It was the last piece of legislation that went through before Parliament dissolved for a general election in 2002. Those involved were aware that this was the ideal moment to achieve the objective. The objective was achieved within a defined time limit: before the general election. However, if success had not been achieved before the election, it would have been necessary to re-examine how much time, effort, and energy was put into this issue on an ongoing basis.

**Example 3:** A similar campaign for compensation and treatment for people with hemophilia with hepatitis C in New Zealand went on for several years as a low-key campaign. With the knowledge that a general election was to take place between July and September of 2005, the campaign was restructured to make a maximum effort leading up to the election. The Haemophilia Foundation of New Zealand (HFNZ) achieved its objective. In addition, respect for the organization among politicians and the media grew. This shows that leverage increases, the closer you get to an election, and decreases after the election.

### Assigning roles

The board should decide on the roles that various people will take on in the lobbying campaign. Analyse the skills of the volunteers and staff that are available. Particularly important is the assignment of the person who will lead the campaign, making decisions on a day-to-day basis and determining the method for liaising with the board.

It is also important to agree on the selection of the spokesperson(s). It is not necessarily the president, chairman, or chief executive officer who will be the best spokesperson for the campaign, or even the sole spokesperson. However, this is most often the case, together with other volunteers or staff who have demonstrated skills or abilities in dealing with the media. No other representatives from the organization should speak to the media on these issues without clearing it first with the coordinator and spokesperson(s) of the campaign.

### Setting timelines

When setting timelines for the campaign, consider the urgency with which the resources are required. Timelines can be dictated by events, such as an upcoming election, where you want to maximize the political opportunity to achieve your objectives.

### Identifying key officials and politicians

It is very important to identify the key officials and politicians who can influence the outcome of your campaign.

Find out which government and health officials are responsible for the area on which you are lobbying. More importantly, find out which of these officials, if any, can make decisions. This will usually be clear from their job titles. Some countries publish a directory of key politicians and government officials, including their job titles. Understand the relative importance of the job titles within the bureaucracy you are dealing with.

**Example:** In Ireland, the chief civil servant in a government department is designated as the secretary general but is usually referred to as the “secretary” of the department. This could be seen as a relatively unimportant post when, in fact, the opposite is true.

Know the identity of the health minister. You also need to know the identity and specific areas of responsibility of any junior or deputy health ministers. Find out who are the health spokespersons for the opposition parties or members of the government or parliamentary health committee.

Be aware of the relative importance of members of each assembly in a bicameral system (government with two chambers, or houses, such as the House of Commons and House of Lords in the U.K., or the Congress and Senate in the U.S.A.) and their responsibilities.

**Example:** In the U.S.A., a senator is more influential than a congressman. In Ireland, a member of Parliament is more influential than a senator, as the Senate in Ireland is the lower house of Parliament.



### Understanding the political and electoral system in your country

Different political systems mean that decisions are made at different levels. In many countries, the national government and parliament are the decision-making bodies. The role of the prime minister versus the role of the president, king, or other head of state must be understood. The role of the government versus the parliament varies with the degree of oversight (and in a real sense, the size of the government majority).

The role of the federal versus state government must be understood in countries with a federal system such as the United States. Likewise, the role of the national versus provincial government must be understood by countries such as Canada. In these countries hemophilia organizations have to lobby at both national/federal and provincial /state levels.

This concept is also relevant to the 25 member states of the European Union where National Member Organizations have to become more aware of and better at lobbying at both national and EU levels.

The role of local or regional government also varies and the dynamics must be understood by any hemophilia organization.

National Member Organizations undertaking a lobbying campaign should consider the following factors, especially if the campaign is planned in the period leading up to an election:

- frequency of elections (indeed, the absence of elections or of a real democratic system in some countries);
- the number of constituencies or electoral districts;
- the strength of the various political parties;
- potential “swing” constituencies which could have an undue effect on the outcome of an election.

### Developing a media list

Create a list of all media contacts, including:

- all national newspapers and television and radio stations;
- health and political correspondents from major national newspapers and radio and television stations;

- regional newspapers and radio and television outlets;
- medical press and relevant internet sites.

Add to the list as you develop relationships with journalists, and update it regularly. These lists should be an ongoing resource during and after the campaign.

## Preparing your submission

### Gathering all supportive data

To build a good case you need data to support your arguments. Data can be gathered from a number of sources:

- general statistics: the WFH collects global data on hemophilia and related bleeding disorders from over 90 countries and also has general data available in advocacy sheets, monographs, and other publications available from its website ([www.wfh.org](http://www.wfh.org)). You may contact the WFH with individual requests for data.
- treatment guidelines: guidelines from the WFH, the Medical and Scientific Advisory Council (MASAC) of the U.S. National Hemophilia Foundation, or the U.K. Haemophilia Centre Doctor’s Organisation (UKHCDO) are good sources of information on treatment.
- Compensation: the WFH and the European Haemophilia Consortium (EHC) have data on compensation for HIV and hepatitis C.

You should also get detailed information from other countries where a similar objective was achieved. The WFH and EHC data can act as a guide to the countries you should contact.

### Developing alliances with other groups representing people with hemophilia

*Doctors and healthcare workers*

If your campaign issue concerns medical resources or directly impacts on the hemophilia treatment centre (HTC), consult with healthcare workers at the HTC in preparing your submission. It is vital that your hemophilia organization and the lead doctor work together if, for example, the proposal is for more resources to the HTC, the appointment of an additional senior doctor, or improved or

increased amounts of replacement therapy. The treatment centre director can write supporting documents which can be sent in separately to the government, or he/she can work with you to ensure that the HTC's views are put across as part of the main submission.

It should be clear in your submission that the organization and the senior doctors have co-operated in its production, and are jointly agreed on the objectives of the campaign and the contents of the document. The point to remember here is not whether the doctors and the hemophilia society send in a joint submission or two separate submissions (both are acceptable). The key point is to ensure that the hemophilia society and the doctors agree on the objectives and that, if there are two submissions, they agree on the broad concept of what is required.

Separate detailed letters or supporting documents from doctors can strengthen your submission and increase the likelihood for a successful lobbying initiative. If done co-operatively, the effort can yield good results.

*Example:* In 1997, provision of recombinant products for all people with hemophilia in Ireland was a joint effort where the national hemophilia director (the leading clinician) sent a detailed submission to the Department of Health, and the Irish Haemophilia Society (IHS) then met with the minister of health and senior officials with a separate submission on the issue. Politically, success was achieved.

*If co-ordination had not taken place, the following could have occurred:*

- *The submission from the clinician would have gone through normal channels, which would have delayed a decision considerably. In addition, department of health officials would have had to determine if the request for recombinant products had the approval of the national hemophilia organization.*
- *If the IHS had proceeded without the letter and submission from the clinician, then a decision could not have been made at the meeting, as the government officials would have had to check if the IHS had the support of the clinician.*

*Other organizations representing the interests of your members*

If you are campaigning for a potentially divisive issue (such as HIV or hepatitis C compensation) and there are other organizations outside of the national hemophilia organization which represent the views of people with hemophilia, you should try to get their support. At the very least, ensure that they do not oppose your objectives in this area.

In a situation where more than one organization lobbies a politician claiming to represent the interests of people with hemophilia, and where these organizations have opposite views on how an issue should be resolved, then the politician will probably ignore both organizations or use the views of one organization to discredit or neutralize the other.

*Example:* In 1994, both the U.S. National Hemophilia Foundation and the Committee of Ten Thousand, an organization representing people with hemophilia with HIV, separately lobbied Congress on issues related to HIV. However, since there was some co-ordination between the two organizations and they were lobbying for the same objectives, this did not create a problem.

### **Writing a clear, strong submission**

Prepare your submission based on your consultations, research, and an assessment of what is possible and achievable. It should be sharp and to the point, containing the key arguments with data and examples to back them up, as well as the reasons for granting your request. Make sure that your submission contains accurate data with enough detail to justify granting your objectives but not so much detail as to make it too time-consuming for politicians and senior health officials to read.

Politicians and senior health officials can easily read a submission of up to 10 pages. A submission of 10 to 20 pages is acceptable if it includes some of the key supporting documentation or data. Keep detailed, back-up documentation in reserve, but do not include it in the main submission.

Be aware of arguments and data that can be used to counter your position, and prepare a rebuttal to this data, if required. However, you

do not have to set out and refute the arguments against your case in the submission.

### **Consulting with your board**

The proposal may be written by your chief executive officer (CEO), chairman, and/or president, but input and agreement on the submission by the board is vital.

### **Sending your submission**

When your submission has been finalized and approved, it should then be sent to the appropriate politician or government official with a specified time in which to reply. A “reply” here should mean a substantial reply and not merely an acknowledgment of receipt of the document.

At this time it is also advisable to prepare a one-page summary for other politicians, journalists, and for your members and supporters.

### **Meeting with the minister**

Meetings to discuss your submission or major concerns should involve high level officials who report directly to, and make recommendations to, the relevant government minister. In some cases, a preliminary meeting with a more junior official just to go over the issues may be required. These meetings can often take place on an unofficial basis. However, there is usually little point in having a successful meeting with a sympathetic junior official. It will not advance the campaign much, unless as an introduction to an agreed-upon meeting with a more senior official who has decision-making powers, or, indeed, with the minister directly. (Refer to Identifying key officials and politicians, on page 5.)

### **Preparing for the meeting**

When preparing for a meeting with the minister or senior officials, make sure that you have the correct documentation that you wish to distribute. Decide who from your organization will attend the meeting. In some cases it is helpful if a representative from the WFH, or a known international expert, can attend the meeting with you. This can increase the importance of the meeting for the officials or the government minister. It can add much-needed support to your case and be very useful when

briefing the media, as it gives the media another angle on the story.

Before the meeting, also decide who will speak on which specific topic. For example, the leader of the organization could cover the issues from a factual point of view. If there is a specific medical issue, perhaps the HTC director could be present to cover this aspect. A carefully selected person with hemophilia, or a person affected by the specific issue which you wish to address (prophylaxis, HIV, hepatitis C), could be asked to speak from a personal point of view.

### **Stating your case effectively**

Be prepared, be brief, be clear. State your case factually and support it by telling personal stories.

Being aggressive is always going to be counter-productive. There have been examples in the hemophilia community of activists being physically aggressive or abusive to politicians. This is going to be counter-productive to achieving your aims. If the meeting becomes too emotional or accusatory, then you may have damaged your chance of success or of obtaining a further meeting with the minister.

You should bring a person who can take minutes of the meeting. At the end of the meeting, you should ask for a decision within the specified time and, if subsequent meetings are to take place, try to schedule them within the specified time and at the same or higher level.

### **Developing the campaign: creating momentum**

Your organization, in putting together any lobbying campaign, will have to deal with politicians, media, members, other associations, and the public.

### **Getting members involved**

Once your submission has been drafted, it is useful to organize a meeting of the members, if this has not already taken place, to outline the campaign.

With bigger or more divisive issues – such as compensation, or provision of prophylaxis or recombinant products nationally – you must ensure that members are well informed and will

support the campaign. You need to send a letter to members and publish articles in your newsletter.

In a larger country, you need to brief your chapter leadership, local groups, or provincial leadership. Ideally you would organize meetings in the major cities and geographical regions of the country, and accompany your local, provincial, or chapter leadership to the meetings.

In a smaller country, encourage your members to attend open meetings in the major cities, again using a travelling show approach.

At these meetings set out what you hope to achieve – *not* the minimum goals that you would accept, as you do not want this made public. Give as many of your members as possible the opportunity to attend these meetings (perhaps by holding the meetings on weekends) and to hear the organization's objectives and how they may be achieved.

These meetings give you the opportunity to identify members who have good ideas and suggestions, and who are willing to help, either nationally or in their local areas. You will also identify individuals who disagree with the objectives or methods of the campaign, and then can work to bring them within the consensus, explaining why and how you wish to proceed.

These meetings can be used as an opportunity to identify and motivate volunteers who will help with the campaign. You can set out what you would like to ask of members and what help they can give during the campaign. The involvement of members can include the following:

- Providing logistical and practical help from stuffing envelopes and photocopying for a mailing to all politicians, to providing logistical support in organizing local meetings.
- volunteering to speak to politicians or the media about how they are personally affected by the issue if the objectives of the campaign can be conveyed through their personal stories. This can be either anonymously or publicly. Care must be taken here to protect the member and to

ensure that those chosen can help by integrating their personal stories into the objectives of the campaign.

- contacting all elected government officials. This is most effectively done by having all members contact the politician in their constituency or district. You can send a form letter to members and encourage them to send it to their local representative, who will usually copy the letter to the health minister. In this way, not only are the politicians made aware of the issue on a local level, but the volume of letters forwarded to the minister increases the minister's awareness of the relevance of the issue.
- visiting the constituency clinic of their local politician to lobby for the objectives of the society. They can illustrate the hemophilia society's case using their personal stories. They may be accompanied by a senior person from the hemophilia society who can explain the campaign objectives nationally and try to enlist the support of the politician. It is even better if this meeting is attended by several members from the constituency. The politician will be acutely aware that these members and their families are all potential votes.
- attending society meetings to be briefed regularly in the course of the campaign. These meetings are also an opportunity to invite politicians and get more media coverage. The agenda can be used to explain a change in strategy or convey a particular message to politicians or the media. At these meetings, a speaker from abroad, who can contrast the government's poor response with a better response elsewhere, can be used to provide a new angle for the media.
- taking part in campaign events.

*Examples: In Ireland, many members of the Irish Haemophilia Society were involved in canvassing from door to door for IHS candidates standing for election. In Bulgaria, many members took part in a silent protest outside Parliament. A similar protest was held in Venezuela.*

### **Involving other politicians and key influencers**

A copy of the submission should be sent to the health spokesperson(s) for the other parties in the country. A copy should also be distributed

to all members of an all-party committee on hemophilia, if such a committee exists.

*Example:* Currently in the U.K. there is an all-party group of members of Parliament at Westminster who are interested in hemophilia issues and who are briefed by the hemophilia society. In Ireland, the Irish Haemophilia Society used the establishment of an all-party committee to help achieve HIV compensation in 1991.

A copy of the submission should also be sent to the chair of the government or parliamentary health sub-committee, if such a body exists, and to all members of the committee. They can then be contacted to examine the feasibility of holding hearings on your issue. A summary of the submission, which incorporates the key points and is limited to no more than two pages, should be prepared and circulated to all interested politicians.

To maintain momentum following the meeting with the minister, you can encourage opposition party politicians to set down questions for the minister for health to answer. For opposition health spokespersons, you can provide additional data, such as key points for their speeches, specific points which they can use in television or radio debates, or comments about health care or other issues. Use panel discussions and television programs involving politicians to raise the issue.

*Example:* There was a Question & Answer program on the National Irish Television station in 1991. At the time, IHS was campaigning for compensation for people with hemophilia infected with HIV. A member of the IHS attended as part of the audience, and asked a prepared question of the deputy health minister. The deputy minister's reply, in relation to the government's dealings with the IHS, was totally inaccurate. This inaccuracy was then used by the IHS as the focus of a news story the following day. The story rapidly led to direct involvement with the minister for health and the government, and the settling of this issue in a manner satisfactory to the IHS.

### Using ties with other organizations

Make sure that other organizations in related areas are aware of what you wish to achieve with your campaign, and can give you their

support where possible. A briefing document prepared for politicians could be circulated to other organizations with like interests: those advocating for disability issues, or for people affected by HIV, liver disease, or for other medical issues. You could network with organizations or other voluntary bodies dealing with hematological conditions. Other more general organizations, such as rotary clubs, can also be enlisted to give support. Find out if any of your members are members of organizations who could support your campaign.

*Example 1:* In Ireland in 1991, there were a number of families in the farming community whose children had hemophilia. The IHS had the mothers speak to the Irish Country Women's Association, a very strong and cohesive organization representing farming families. At the time, this organization had a lot of influence on some of the politicians because of its very large number of members. It supported the campaign in writing, and this was very useful in the lobbying campaign.

*Example 2:* In New Zealand in 2005, the hemophilia society there had a very large and effective fundraising network of about 100,000 individuals. These people were informed of the campaign and were asked to mention the issue to politicians who called or visited their homes canvassing for votes during the general election.

*Example 3:* In Bulgaria, the hemophilia society worked in co-operation with other organizations also lobbying for more government funding for medicines.

### Raising general public awareness

Contact with the general public during a campaign is minimal (unless you run candidates in an election, in which case they will be individually canvassing in the constituencies where the candidates are standing for election). You might, in rare situations, interact with the public at events such as a silent protest.

Most public knowledge of hemophilia and awareness of the issue on which you are campaigning will come from media coverage of the campaign.

## Media strategy: maintaining momentum

For any given campaign, your organization should have a planned media strategy and be capable of dealing with the unexpected. At the initial stage, you should prepare a good media briefing on your submission.

Sympathetic media coverage is vital to getting public support. Similarly, such media coverage will often increase your access to politicians which in turn can generate news, leading to more media coverage which can lead to increased public awareness of the issue and, hopefully, sympathy.

### Giving interviews

#### *Identifying spokespersons*

Choose people to deal with the issues on an ongoing basis. This will include representatives of the organization to address the factual issues and other members willing to tell their personal stories. If you have members who are willing to speak publicly about their own situations (for example, having a child with hemophilia, being infected with HIV or hepatitis C, or looking to the potential benefits of prophylaxis), you will need to prepare them carefully before they are ready for interviewing by the media.

*Example: In New Zealand, during the campaign for hepatitis C treatment and compensation, a man with hemophilia and hepatitis C agreed to speak publicly. His ability to explain the reason for the campaign in the context of his personal experience was a major asset to the organization.*

Members must be informed before doing any media interviews that their privacy and confidentiality may be affected.

#### *Staying on message*

Staying on message means delivering the key campaign message without getting sidetracked. Spokespersons must make clear, concise points and illustrate them with examples. For any interview or meeting, spokespersons should have a particular message or number of messages that they want to put across. They should prepare well for television or radio interviews. They must stay on message and not allow the interview to go off on too many

tangents without returning to the key messages which they wish to put across.

Spokespersons must be able to stay on message even while telling their own highly personal stories. They should place their personal stories in the context of a wider campaign. Make sure that, when members are telling their personal stories to the media, a representative of your organization is always present or willing to give support.

#### *Maintaining professionalism*

In any dialogue with politicians or the media, whether on television, radio, or in public debate, it is good for the organization's spokesperson(s) to be forceful and decisive. Being rude and personally insulting to the politicians is counter-productive. It may well result in a severe loss of respect for your organization's position, and a decrease in public support for your campaign.

The correctness of your cause will be better served by upholding the dignity of the membership through respecting the fine line between forceful, dynamic campaigning and unnecessary aggression. Arguing with, or contradicting, the politician in a public or media debate is productive and appropriate tactics, whereas being personally insulting is not.

#### *Dealing with difficult questions*

The spokesperson(s) should prepare for difficult questions and also have a ready response to contrary views. It is very important to know who else will be on the interview; there may be a government spokesperson or a person with a contrary view. With a radio interview, you have more scope for using some briefing notes which you've brought with you. This is certainly the case if the interview is done by phone, rather than in studio. It is also important to know if the interview will be live or edited. If the interview is live, you can get your message across knowing that it cannot be edited. However, this also means that you have to get every point you wish to make across on your first take. You do not get a second chance. There is also no opportunity to correct a mistake.

With an edited interview, there may be an opportunity (depending on the good will of the journalist) to correct a mistake that you have

made or to give a more concise and clear answer where you had previously given a convoluted answer. However, the final outcome depends on the journalists and their editing of the segment. For this reason, a live interview is preferable, but the importance of being aware of the clear key messages you wish to get across cannot be overstated.

### **Changing or adapting your message when appropriate**

In a campaign which takes more than a couple of weeks you will have different messages or a different emphasis that you want to communicate to the media on any given day or week. It is important for the spokesperson(s), and any member who is speaking publicly on the campaign, to adapt to the new message. At different times you may bring in international experts to reinforce the message: for example, you may wish to show that the WFH supports the campaign, or you may want to use experts to boost or change the direction of the campaign at a particular time.

*Example: In Argentina in 2003, the Fundación de la Hemofilia was lobbying the government to restore funding for the treatment centre it operated. They used the visit of a WFH delegation marking the 50<sup>th</sup> anniversary of the Fundación as an opportunity to organize a press conference attended by the country's vice-president. The presence of the WFH delegation helped to increase media attendance. The messages expressed to the vice-president and the attending media were well co-ordinated and helpful to their cause. The press conference, and the impression made on the vice-president, led to a meeting the same day with the health minister, and, in turn, to further positive media coverage and an eventual positive outcome to the campaign.*

It is also important not to use all your ammunition at once. If your campaign issue is very complex, you may want to release portions of the information to the media at different times, so that the story remains fresh and new for the media. For example, when the government calls an election campaign which has a duration of up to six weeks, you do not see government members issuing all of their policies in their various areas (health, education, defence etc) at the one time. They very deliberately release this information over a period of time to

ensure maximum media coverage and freshness, and they get their message across. Your organization should do the same.

### **Keeping the media interested**

Your organization must understand the dynamics of media coverage. Journalists will generally cover the factual issues which are being raised (statistics, information, etc.), and will then want to cover some personal stories to reflect a human interest angle. The coverage may then swing, depending on the length of the campaign, between the factual and the personal.

For example, following the initial submission, further factual coverage can determine, and report on, whether there was a government response. If a submission has been sent to government, or questions have been tabled to government, or comment has been made inviting a government response, then the government response can be used to start another news cycle on the issue. The press can then be briefed on your organization's view of the government response. At the same time, the personal views of some of your members can be given.

Alternatively, if the government does not respond, government members can be criticized for a lack of response and a response can then be demanded. For this reason, when a submission is sent to government, a detailed response should be requested within a specific period of time and you should be ready to re-activate media interest at that time.

Additional personal stories can be given out on a gradual basis. Also, the personal angle of the reaction of the government's indifference, or response to, the campaign may be covered.

### **Ensuring local coverage**

It is also important to include local newspapers and radio stations in the campaign coverage. They may often look for local angles and you can certainly give them local statistics in relation to the number of people in that area who have hemophilia, or the limited resources at a local treatment centre. Depending on the availability of members who can stay on message, you may also be able to provide newspapers or radio

with a local person with hemophilia to interview.

### **Dealing with politicians in the lead-up to a general election**

If your campaign is taking place leading up to a general election, you can use this to your advantage by keeping in mind the following tactics.

#### **Involving the opposition**

- brief opposition health spokespersons and key politicians;
- ask the opposition parties to include a commitment to resolving the issue to your satisfaction in their election manifesto. If that party forms the next government, or is part of a coalition which forms a government, it puts you in a strong position to resolve the issue to your satisfaction;
- get letters of support from opposition spokespersons in relation to your issue. The letter of support may be crucial if that opposition spokesperson subsequently becomes minister for health, or a member of the incoming government.

*Example: In New Zealand, the Haemophilia Foundation obtained a letter of support for compensation for hepatitis C from an opposition politician, in 1999. In 2000, this politician became Minister for Health and the letter was crucial in resolving the issue during the 2005 election campaign.*

#### *Organize meetings*

Organize meetings with groups of politicians. These should be attended by as many of your members as possible. Use the meetings to allow some of the members to tell their personal stories to humanize the issue. Explain the issues to the politicians and make sure that they understand the need for positive resolution to the campaign. If they are sympathetic following this meeting, make sure that media people are available so that the politicians can state their public support for your campaign.

One tactic useful in relation to these meetings is to have a guest speaker from abroad – either a representative from the WFH or perhaps a representative from a hemophilia society which has achieved a successful resolution to the issue

on which you are campaigning. This adds another dimension to the meeting for politicians and media. It can be used to generate additional media coverage, comparing your government's response to that of another country where the issue was resolved.

You can also attend public meetings organized by government politicians, and raise your issue at these meetings. If you are doing this, ensure that local members of your organization attend.

#### **Working at a local or constituency level**

Ask local councils or authorities to pass a motion to call on the government to grant your requests; then ensure that the motion is sent to the government.

During an election campaign, target key constituencies, for example, the constituencies of the prime minister or health minister, or marginal constituencies where campaigning on the issue would cause some concern for the government. Having identified these constituencies, you could then:

- organize public meetings and invite all the politicians who are running in that constituency to attend;
- ensure that local radio and television stations and journalists are briefed after the meeting.

#### **Tailgating the minister**

Another potential tactic is to tailgate the prime minister or health minister. This means that, wherever the prime minister or health minister goes to campaign in the course of a general election, your organization has representatives there who can discuss the issue, attend public meetings, and raise the issue with local journalists and radio and television stations.

#### **Running candidates**

Your organization could run candidates in marginal or key constituencies. This is an extreme measure which requires a lot of commitment from specific individuals and should not be taken on unless the organization is willing to put in major effort. The objective here is not to get elected but, rather, to raise the profile of the issue so that local politicians in



these marginal or key constituencies would make it a higher priority for the government.

*Example: In Ireland in 1991, during the course of a campaign for HIV compensation, the Irish Haemophilia Society (IHS) ran four candidates in four Dublin constituencies in the local elections. As the Society was running four candidates under the banner of the IHS, it also received some free television airtime to promote the general campaign on which the four candidates were running. These candidates were successful in raising the profile of the issue locally. Therefore, they increased the level of concern in these carefully selected constituencies and among government candidates in these constituencies. The government candidates then raised the issue with the government party, because they were under pressure over the issue. The issue was successfully resolved for the IHS. One of the four candidates came within seven votes of being elected. Government came to the negotiating table and a successful outcome was achieved.*

## **Conclusion**

Lobbying to achieve the major objectives of your organization is a difficult, complex, and multifaceted set of tasks. If carried out with skill, perseverance, and knowledge of the political and media systems, lobbying can help the organization to achieve their objectives and raise their profile to the extent that future lobbying efforts are even more likely to be successful.

## APPENDIX 1: LOBBYING CHECKLIST

### Objectives

- Has the board has defined and agreed on objectives?
- Has the board agreed on exactly what will be asked for, the optimum outcome, and the minimum acceptable outcome?
- Has the board defined success and failure?

### Resources

- Have you determined the budget for the campaign?
- Have you determined the human resources needed, including staff, volunteers, and clinicians?
- Have you determined the probable duration of campaign?
- Have you identified who will lead the campaign?
- Have you identified who will be the spokesperson(s)?
- Have you set a timeline for the campaign?
- Have you identified key officials and politicians, including
  - officials with responsibility in the area in which you are campaigning;
  - officials with decision-making powers;
  - hierarchy of officials in the department.
  - government ministers and junior ministers (senators, congressmen);
  - opposition health spokespersons for each party;
  - members of a government health committee and their party affiliations;
  - politicians who have spoken on hemophilia in the past (can be word searched from many parliament records);
  - key politicians at national and regional/state level (for example, members of EU Health Committee);
  - members who reside in key constituencies, such as the prime minister's and health minister's (can be

used for access to politicians at a local level)?

- Have you compiled a media list of:
  - national newspaper, television, and radio contacts;
  - health and political correspondents from major national newspapers, radio and television stations;
  - contacts in regional newspapers, radio, and television outlets;
  - contacts in the medical press and from relevant internet sites.

### The submission

- Have you gathered necessary data, including:
  - internal data, reports, and statistics;
  - comparative data from other countries;
  - global statistics and guidelines on treatment and treatment products;
  - compensation data;
  - other sources, such as journals, experts?
- Have you developed alliances with other groups representing people with hemophilia, including:
  - HTC staff;
  - Other organizations that represent the views of people with bleeding disorders?
- Have you prepared a clearly written, well-argued submission for government?
- Has the board approved the submission?
- Have you defined counter-arguments which may be used to refuse your requests, and prepared data and arguments to refute them?
- Have you prepared a one-page summary for other politicians, journalists, and your members and supporters?

## APPENDIX 2 –CASE STUDIES

### Case study 1 - Bulgaria 2005

#### Supply crisis in the beginning of 2005

In early 2005, there was an unexpected problem concerning the lack of regular supply of factor concentrates. The announcement of the tender procedure for delivery of coagulation factor concentrates was delayed by more than two months. When it became clear that the tendering procedure had not been started within the normal time period, the Bulgarian Hemophilia Society questioned those in charge. The Society received no satisfactory answers to their questions about the reasons for this delay.

One of the formal explanations was that, because of the large group of 11 different diseases, the procedure included a range of medicines offering a lot of alternatives; thus, the decision was complicated and needed more time.

The explanation didn't clarify anything. It was becoming obvious that there was no good will to rely on for any adequate response or understanding. The Society sent an official letter to the health authorities, pointing out the serious dangers that such a delay could cause for people with hemophilia. The letter was supplemented with exact data about the current stock of available products, and by the projection of whether the demand could be met in the forthcoming period.

The Society's board organized a large open meeting and invited friends and supporters, most of them experts in different fields, mainly public relations. These people got together to discuss the best strategy to use.

At the same time, letters with a brief description of the problem and request for support were sent to friends and colleagues abroad at the EHC and WFH. The response was very quick. Dr. Hubert Hartl, chair of the EHC, and Mark Skinner, president of the WFH, sent letters to the minister.

Other patient organizations were contacted and it was agreed to coordinate efforts. As a result, it

was possible to address different political committees in Parliament, as well as its Health Commission.

It was very important to run an effective media campaign – most of the leading TV and popular newspapers showed increasing interest in the problem. Very soon, the subject became a leading item in most of the mass media, because the problem extended to a large range of patients nationally. It was no longer possible to ignore. With help from its friends, the society recorded a very successful audio spot which would touch listeners and send a warning message to the minister of health. It was produced and aired for free by three radio stations at the same time.

In collaboration with other patient organizations, the Society held a silent street protest in front of the Ministry of Health. Many media representatives attended. Finally, representatives of the Society were invited to a meeting with the responsible deputy minister. This was followed by a large public press conference.

In this way, under pressure, health authority representatives took responsibility and promised to solve the problem within a short time period. They officially announced that a tender procedure would be started. It was decided to organize an exceptional and urgent delivery of factor to meet patient needs during the tender procedure, a period of at least two months.

#### Conclusions

- The Bulgarian Hemophilia Society spent a lot of energy to reach a goal that should be something very common and normal in a well-developed society.
- It gained valuable experience, and learned important lessons.
- It took part in establishing a new association of 15 different patient organizations. As a result, the Society formulated and submitted several suggestions to the new leadership of the Ministry for:
  - development of a new separate tender procedure for purchasing of clotting factor concentrates, with a designated budget;
  - inclusion of representatives from the Society, or those with medical expertise

- from the society, in the structure of the tender commission;
- development of the existing patient registry system into an integrated information system for management of treatment and supply in all regional centres;
  - Continued trend to increase planned quantities, in order to reach at least the European norms of 2.0 IU per capita in the next year.

*Jordan Nedevski*

### **Author's comments**

This campaign is a very good example of working effectively with other organizations. All the organizations that needed a reliable tender procedure for medications, within a short period of time, united to form a coalition to lobby on the issue to government and media. This gave the media different angles, conditions, and personal stories to cover. The use of a key contact in the media to arrange free advertisements for the campaign was very effective. Normally, you would not run advertisements, as they are expensive and in some countries media will not run "political" advertisements. However, in this case there was no cost, and the repetitive impact of the advertisements was very useful. The silent vigil at Parliament was dignified and effective as it gained a measure of sympathy from politicians and coverage in the media.

## **Case study 2**

### **UK Haemophilia Society campaign for hepatitis C compensation**

#### **History and strategy**

In 1993, the trustees of the UK Haemophilia Society decided that, while there had been recognition for people with hemophilia infected by HIV receiving compensation through the Macfarlane Trust, nothing had been done to assist those infected by hepatitis C. The trustees considered how the campaign should be directed to try and persuade the government that this should be put right. It was decided to focus on the moral issue of people being infected in exactly the same way from contaminated blood products, with one group receiving compensation and the other not.

At that time, there had only recently been a test for hepatitis C, previously diagnosed NA/NB, so the Society decided to appoint a hepatitis C worker, Mandy Cheatham. She would carry out a survey of hemophilia treatment centres and members, to find out the course and outcome of the disease. These results were used by the Society and supporting members of Parliament (MPs) to lobby not only for compensation but for better treatment as well. Some patients had access to interferon and, later, interferon and ribavirin. This was largely rectified by pressure from the Society with support of the media, and supporting MPs.

At this stage of the campaign, however, a division developed among the members about how compensation might work. Some mono-infected people stated that those who had received compensation for HIV infection should not be eligible for further assistance. Obviously, those co-infected with HIV and hepatitis C felt the opposite. From this developed another campaign outside the control of the Society. The Department of Health used this to argue that, if those infected could not agree, it was hard for them to provide any possibility of assistance.

#### **The need to unite**

The Society, despite media and political support provided by several debates in Parliament, remained stuck with this position for some time. With the appointment of a new Chief Executive,

Karin Pappenheim, and some changes in the board, the Society took a new look at the campaign and the seeds were sown for a more successful outcome.<sup>1</sup>

As well as increased deaths from those mono-infected, co-infection was causing the deaths of so many infected by HIV, even with better drugs and treatment for the condition. The trustees and members of the Society now backed the campaign, not only for hepatitis C compensation, but also for the provision of recombinant clotting factor. They also backed a public inquiry to investigate why these disasters had been allowed to happen.<sup>2</sup>

It was necessary to employ professional lobbyists, Weber Shandwick, despite the huge costs which heavily depleted the Society's resources.<sup>3</sup>

From this point, the campaign gained momentum with more support from a newly created All-Parliamentary Group of MPs headed by Michael Connarty, MP. The Society was greatly indebted to its president, Lord Morris, for his enormous commitment in raising countless debates in the House of Lords, and questions in the House of Commons directed to the prime minister and secretary of state for health. Also helpful was the inquiry into hepatitis C infection in Scotland, headed by Lord Ross, which was commissioned by the minister of health, Malcolm Chisholm, for the devolved Scottish Parliament.<sup>4</sup>

The Carpet of Lilies demonstration at Westminster was perhaps the highest profile event. Several hundred lilies were brought to Parliament. Each lily represented a person with hemophilia who had died of hepatitis C. The lilies were viewed by a group of some 40 MPs with the media in attendance.<sup>5</sup>

A surprise announcement was made by John Reid, Secretary of State for Health, in August 2003, creating the Skipton Fund – probably influenced by the decision in Scotland – to make financial recompense.<sup>6</sup>

### **What worked**

The U.K. Haemophilia Society needs to acknowledge the valuable involvement of the

press and TV who brought the issue to public attention, and brought pressure on the government. Much of this was generated by the Society, advised by Mark Weaving of Myriad Public Relations and Weber Shandwick. It involved the work of the staff, trustees, and a small but passionate patient group who gave interviews, wrote to MPs, and attended local and national meetings – a huge amount of time and dedication, much of it demanding great effort and commitment to force a conclusion. Some 50 members of the Society took an active role in the campaign at some point.

It was a long hard struggle and the Society still has to keep vigilant to deal with other problems such as vCJD, the cost of recombinant treatment, and the issue of widows not receiving compensation. The Society also awaits the report, believed to be due very soon, from the Lord Owen Review, addressing the question of why the UK did not become self-sufficient in blood in the late 1970s.

*Chris Hodgson*

### **Author's comments:**

<sup>1</sup> This is an example of the problems caused by lack of agreement among members of a national hemophilia organization with regard to the objectives of a campaign. The government, health officials, and media may take advantage of the disunity to discredit the aims of the campaign.

<sup>2</sup> Where there are clear, agreed objectives, chance of success improves. The fact that members affected by hepatitis C were willing to lobby MPs and speak to the media was crucial in maintaining interest in and momentum of the campaign.

<sup>3</sup> The resources required for a campaign, both in terms of time and finance, can be very considerable and easily underestimated. The campaign took 10 years from 1993 to 2003 with varying degrees of activity in that time.

<sup>4</sup> This case study is also an example of the importance of understanding the political dynamics in a country. In the U.K., devolution had occurred and Scotland, Wales, and Northern Ireland and they were granted

separate parliaments. The Scottish parliament set the precedent which was followed by Westminster for the entire U.K. The reasons that Scotland paid compensation first may be due to a wish to demonstrate its parliamentary independence, coupled with very active lobbying by the Scottish group of the U.K. Haemophilia Society.

<sup>5</sup> The Carpet of Lilies was an example of a planned campaign event which achieved its objectives in relation to generating political and media interest. The politicians are more likely to attend if they know there will be media coverage and the media are more likely to attend if they can be assured that a large number of politicians will attend.

The campaign resulted in payments of £20,000 to £40,000 to each person with hepatitis C, and the provision of recombinant products to all persons with hemophilia.

The U.K. Society is stronger in terms of both its political and media profile as a result of this long and arduous campaign.

### Case study 3

#### New Zealand campaign for hepatitis C treatment and financial compensation

##### The issue

Super heat-treated products were in use in the U.K. from 1988 but were not fully available in New Zealand until 1993. The technology for screening donated blood was available by 1989 and doctors, and the then Haemophilia Society (now Haemophilia Foundation of New Zealand, HFNZ), had long been urging the government to adopt more robust screening and viral inactivation techniques. Even so, products manufactured from screened plasma only became available in NZ in 1993.

It is thought that around 700 New Zealanders contracted hepatitis C (HCV) from blood. A further 172 people with bleeding disorders contracted HCV from therapeutic products. To compound the disaster, people with hemophilia:

- were excluded from lookback programs intended to identify recipients of donated blood, thus alerting them to a range of potential health issues;
- found it extremely difficult to access treatment for HCV;
- were denied access to statutory lump sum compensation by a legislative change;
- were denied compensation for loss of earnings and reimbursement of medical expenses.

##### Development of the campaign

When, in 1992, HFNZ began to campaign for financial compensation, they did not anticipate a 13-year struggle. Initially, the main goal was lump sum compensation (for loss of enjoyment of life), earnings compensation (for being unable to work), and reimbursement of medical expenses. At this stage, treatment was not an issue, as many people with hemophilia were not aware they were infected. In the early days, HFNZ focused largely on parliamentarians, and several members of Parliament (MPs) gave their support by tabling questions in Parliament and speaking out in the media.

By late 1992, the newspapers were full of debate about the "Bad Blood Scandal." Around this

time 125 people with hemophilia filed claims for High Court proceedings against the Crown.

For HFNZ, the mid-1990s were dominated by legal activity as lawyers gathered evidence, prepared cases on behalf of members, communicated with government officials, and built up a media profile. By this time, many members were feeling more angry than ever and ready to make their feelings known to a wider public through less bureaucratic means. In 1999, members staged a two-month vigil outside the parliament buildings in Wellington. A large scale "Wall of Shame" was created, with photos and personal stories of families affected by the tragedy. The media took a great interest in the issue, and public awareness was high. In August, opposition health spokesperson Annette King sent a message of support pledging that, when in government, her party would seek to bring about "a fair and speedy settlement."

The following year, the Labour Party came to power, and with it, a newly appointed minister of health, Annette King. In April 2000, an offer of compensation was made, but the qualification criteria were such that only three people of the 175 people affected could prove their eligibility.

The campaign continued. Members now identified their key priorities as access to top quality care, an apology from government, and a lump compensation sum of NZ\$50,000 to all of those affected. The minister was advised that legal action would be withdrawn only if these conditions were met.

The legal process and campaign moved ahead slowly in the face of government insistence that those who were eligible had been compensated (three people). HFNZ continued to research the background to the issue, lobby parliamentarians, and keep reporters updated. Members continued to write letters to their MPs expressing their shock at the government's indifferent dismissal of the consequences of this avoidable disaster.

By the end of 2004 HFNZ had organized years of research into a single document presenting clear evidence against the government. As part of this process the media was fed information

and kept informed of the issues and ongoing consequences for those affected.

### **The 2005 campaign**

In April 2005, at a conference for people with hemophilia and hepatitis C, members directed the HFNZ to pursue a fair and equitable compensation and welfare package – leveraging the period before the election in September. The campaign now entered its final phase, guided by hands-on support from visiting experts Brian O'Mahony and Raymond Bradley.

Accompanied by Brian and Raymond, the HFNZ conveyed this resolution to the minister of health at a meeting with her director general. Although resistant to suggestions that the issue had not been adequately resolved, the director general agreed to consider a submission detailing a possible settlement. Brian and Raymond quickly prepared such a document, drawing on overseas models and their new-found understanding of the New Zealand legal and political system.

Just days later, following a press conference, the submission was delivered to the Ministry of Health in Wellington by HFNZ members. The delivery was captured by the news media and provoked a storm of national publicity. HFNZ requested that the Ministry provide a "meaningful response" within 14 days and officials withdrew to consider their reply – under the watchful eyes of HFNZ and the national media.

HFNZ now appointed a small team dedicated solely to the campaign, and allocated a specific campaign budget for expenses such as travel and printed materials. The team planned a three-pronged approach aimed at applying pressure on government directly, via Parliament, and in the media.

Two weeks later, a response from the Ministry of Health focused entirely on the scientific details of the issue and required a complex and detailed response, including the testimony of medical and scientific experts. On the advice of Brian and Raymond, scientific debate with the Ministry was sidelined while the HFNZ concentrated on applying pressure through the media and Parliament in the pre-election period.

Years of research and painstaking detail were boiled down to five key messages that could be readily fed to the media. Reporters were cultivated and kept updated. Members shared their personal stories in the media so the public could see the human consequences of a bureaucratic disaster. MPs were lobbied via a series of bi-monthly “newsletters”, with the simple aim of keeping the issue alive and increasing its political value in the run up to the election. Three major opposition parties committed active support, which gave the HFNZ hope for the post-election period, as well as enhancing its bargaining position with the current government in the meantime.

With 14 days to go before the election, the previously confident Labour government was starting to become concerned about its poll ratings. But still there was no sign of a settlement. Feeling bleak and discouraged, the HFNZ quickly put together a leaflet slamming the government for its record of broken promises and lack of compassion towards vulnerable citizens. The leaflet featured health minister Annette King and her “promise letter” of August 1999. Members were encouraged to deliver the leaflet in person to their MP. Distribution with local newspapers in key constituencies was arranged. The news media pricked up its ears again. Aware that the threat held more power than its actual execution, the HFNZ held its breath and debated whether to fire its last missile.

The evening before the first print run was scheduled, an HCV spokesman attended a public meeting chaired by Annette King in her Wellington electorate. He showed her the leaflet and let her know that it would be delivered to every home in her electorate immediately prior to the election. Annette King told our spokesman, “This thing has to be sorted,” and asked him to meet with department officials the following day to hammer out a settlement.

The next day, the HFNZ met with the director general of health and her advisory team, who had been directed to facilitate a swift and final conclusion. The Ministry not only agreed that further compensation was necessary but also moved from its position that nothing was wrong with HCV services to a wide acknowledgement

that services were in urgent need of upgrade. A settlement was drafted, with some modifications agreed over the next few days. By the end of the week, a treatment and welfare package had been formally agreed by both parties, and the HFNZ was thrilled to tell members that they could expect financial and medical assistance once the administration had been completed.

### **The major strategies and tactics used**

**Research:** HFNZ was sure that the facts were not known to the organization, the public, or government officials. Therefore, a major task was to establish the facts and find evidence. As part of this process media interest grew and some journalists began digging for evidence as well.

**Mobilizing members:** Surveys of people with hemophilia and HCV were revealing some desperate situations, so HFNZ decided to run a conference covering treatment and compensation. Specific members were selected to tell their personal stories to the media.

**Distilling information:** Expert campaigners Brian O’Mahony and Raymond Bradley showed HFNZ how to distil a considerable volume of information into five main points which could be fed to the media and public and grasped easily.

**Campaign targets:** The campaign applied pressure on the government via three pressure points - Parliament, the media, and the Ministry of Health. The three activity streams were worked in parallel and supported each other.

- Parliament – In N.Z., opposition parties are essential to support either of the major parties in power. With this in mind, we committed significant resources to getting commitment from the smaller parties.
- Media / public – Relationships were developed with TV, radio, and press journalists. Releases were issued regularly and information was dressed up as “new.” Events were used to encourage media interest, such as the delivery by hand of the submission to the Ministry of Health.
- Ministry of Health – The submission and information-sharing process continued with the Ministry of Health as HFNZ’s



relationships with key officials developed and negotiations intensified. The impending election was used positively by HFNZ.

**Timing:** The timing of campaign activities was carefully managed and activity increased as the general election approached. This proved to be vital to the eventual outcome.

### The outcome

An exchange of letters, post-election, has assured HFNZ of:

- a commitment to quickly enhance HCV services throughout the country;
- access to earnings compensation and reimbursement of expenses;
- an apology to be made by the prime minister;
- lump sum compensation to be reinstated;
- reimbursement to HFNZ for expenses;
- an ongoing contract with HFNZ to care for members with hepatitis C.

### Lessons learned

- Establish and stay with the facts.
- Sound bites are more powerful than information.
- Recognize that the facts will only provide a basis for solution. The solution will be influenced by political, media, and administrators.
- Know what members want/need.
- Get resources of people and dollars committed by the national organization.
- Be professional in negotiation.
- Re-evaluate direction from time to time but between evaluations stick to the script.
- There are downstream impacts:
  - a national Haemophilia Management Group has just been formed to manage hemophilia services in NZ. HFNZ has been appointed to the board;
  - HFNZ has developed a reputation as a fearsome and strong negotiator because it is usually better informed.

*Mike Carnahan*

### Author's comments

HFNZ had worked long and hard to secure better treatment and financial provision for their members with hepatitis C. They had compiled

an admirably comprehensive data bank. The 2005 campaign was deliberately timed to take advantage of the national election. Key messages were chosen. The data was summarized into a 12-page submission. Specific spokespeople were chosen by HFNZ and key messages were selected for dissemination during the campaign which was to last from three to five months. The board and members were united in agreement on the objectives. In dealing with politicians, the campaign was an example of:

- effective briefing of, and declarations of support from, opposition politicians and leaders of small parties based on an understanding of the political system in the country (coalition government likely);
- effective use of experts from abroad;
- targeting key constituencies and politicians (in this case, the minister for health);
- tailgating a politician. I have no doubt that, if it were not for the leaflet which could have embarrassed the health minister at a public meeting and in the media, negotiations would still be proceeding at a snail's pace as opposed to concluding in one week.

In giving the minister sight of the leaflet, HFNZ gave the government an opportunity to settle the issue. They demonstrated both strength and decorum and avoided a possible counter-productive strategy while increasing respect for the organization as a group who should not be easily dismissed by government.