



Patient association toolkit

Patient toolkit

Contents

1. Introduction	5
2. Getting started	6
a. How you would set up your support group?	6
b. Governance structure	8
i. Board composition	
ii. Voting and meeting rules	
iii. Standing committees	
iv. Incorporated versus unincorporated	
c. Mission statements	16
d. Membership structure	17
e. Aims and objectives	18
f. Policies and procedures	19
i. Accounting, fiscal and reporting procedures	
ii. Contracts	
iii. Personnel	
iv. Intellectual property	
v. Programs	
g. Checklist	20
3. Government relations and public policy advocacy	21
a. Ten principles to dealing with Government	22
b. Some of the challenges of dealing with Government	23
c. Some things to consider when establishing effective relationships with Government	24
d. Checklist	29
4. Media relations and communication	30
a. Media relations	31
b. The web and social media	36
c. Communicating with corporate sponsors	38
d. Communicating with supporters	41
e. Communicating with clinics/hospitals	43
f. Newsletters	45
g. Patient-led support groups	47
h. Coalition building with other like-minded patient organisations and professional groups	48
i. Education programs	49
j. Checklist	50

Patient toolkit

Introduction

Welcome to the patient association toolkit, developed by the International Consumer Support for Infertility (iCSi) group.

This patient toolkit has been designed to help patient organisations throughout the world effectively set up, run and manage the support they provide for patients in their own country. It is intended for this toolkit to be a resource for you in starting, growing, managing and developing your patient association.

We acknowledge that all patient associations are unique – as are the circumstances, legal requirements and cultural environments in which they operate. As such, this toolkit is not meant to be a definitive resource. Rather, it has been set up to raise issues for you to consider, evaluate and implement as they are relevant to your association.

The information contained in this toolkit has been provided by various patient associations from around the world. We thank them for sharing their knowledge and helping their colleagues in different countries.

Please use this toolkit and we'd be happy to hear your feedback and experiences. There is much that the collective iCSi community can share to make our individual efforts better and more effective for those people we represent ... patients requiring ART.



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Patient toolkit

Getting started

The early stages of any patient association are critical. How you establish the association, how it is structured, how you handle membership and the other groundwork that you do can be a key part to your success.

How you would set up your support group?

There are a number of ways of setting up your support group. The key to setting it up is support – how you will support the people who are representing but also how you will support yourself and other volunteers as you do the job of representing them.

There are a number of questions you may need to ask at this stage and these questions will help you make decisions on everything. Your responses to these questions will help guide everything from how you set up your event through to how you will talk to governments, approach the media, offer support and communicate with not just consumers but also psychosocial and medical professionals, doctors and clinics.

Setting up an organisation - UK

Olivia Montuschi is from Donor Conception Network in the UK. How did they set up their patient organisation?

“Setting up our organisation was quite a unique situation:

DCN or DI Network as we first named ourselves, was started by five families back in 1993. Two of the families were responsible for the writing of the My Story book for young children conceived by donor insemination. This book was published by a research trust attached to their clinic in Sheffield UK and an article about the book appeared in The Times newspaper late in 1992. The three other families, including my husband and myself, saw the article and wrote to the research trust saying that we were interested in being in touch with other parents who wanted to be open with their children. We were then invited to a meeting and the Network began.

We were very lucky in that all five families got on well together and between us we had the skills to start the organisation and respond to others - counsellor, lawyer, health visitor, teacher, business consultant, NHS administrator. For several years the five families took on the different functions of the organisation - editing a very simple newsletter, organising two national meetings a year and responding to letters and 'phone calls from other families. My husband and I had the 'phone line in our house- first of all our own home number but we soon had another dedicated line put in. We used a Post Office box, although it is rarely used these days because of increase in electronic communication. Between the four couples and one single woman all this was manageable on a very part-time basis for

Patient toolkit

many years. As I am the counsellor involved I did a lot of the telephone work, talking over things with would-be parents and those who had children already.

As far as governance is concerned, we had a constitution from the beginning setting out our aims and the legal responsibilities of the members of what we called the Steering Group. We sought charitable status very early on and were granted this. Until last year we did not have a formal Chairperson, preferring to run the organisation and meetings democratically with the role of Chair being passed around. Last year we appointed a Chair and we shifted our structure to have four Trustees who have legal and financial responsibility for the organisation and a Steering Group that consists of members representing the different family groupings and donation types within the Network. Their role is to advise the Trustees about the needs of these groups. The two groups meet together twice a year and are in contact by email at other times. The Trustees have regular phone conferences in between meetings. We do not have any 'outside' members of either of these groups. All are people who have been DCN members for over a year and most much longer than that. We have been very lucky in not having had the internal conflict that many small organisations suffer from.

Some tips to other patient organisations:

- *In-fighting can take up huge amounts of time and energy and is rarely of any value to those people the organisation has been set up to support.*
- *Respect for each other and different points of view has been present from the start and remains today. DCN is a broad church. We welcome anyone who is using donor conception of any sort for family addition or creation. Some people have quite strong feelings about some situations but because we are 'parent led but child focused' (soundbite!) we hope to keep everyone within the DCN family for the sake of the children. I would count this as one of our important successes. Be clear from the start about what you are doing and stick to it - or agree changes and then stick to them.*
- *We've had significant successes in attracting funding, particularly from government. The money has been mostly for the publications we are well known for and for workshops to help prepare people for DC parenthood and to help with talking. Prior to applying for funding we developed good relationships with our regulator, the HFEA and with relevant personnel in the Dept of Health.*
- *Managing those monies well and delivering high quality projects to budget and on time has only extended this respect.*
- *It's really important to have a good website and to make sure it is kept up to date.*
- *A group of people is better than just one individual or couple, but you do have to be clear that you share the same aims and respect for each other (you don't necessarily have to think exactly alike).*
- *An agreed governance structure is important together with charitable status.*
- *Don't start an organisation because you want support for yourself. Interestingly enough, most of the five families who started DCN, felt they were doing OK, they just thought it would be good to have contact with others.*
- *Being prepared to LISTEN to others is vital."*

Patient toolkit

Governance structure

Governance is a critical issue. When you are dealing with an issue such as infertility, there are many aspects to your work that will require transparency and a distance from the government, the pharmaceutical industry and the medical fraternity.

When you are seeking funding from corporate, pharmaceutical or government sources, they will be looking for a professionally-run organisation; one that is transparent in its dealings and responsible with its finances. Some patient organisations also seek tax deductibility status for donations. In this instance, you will be required to have a firm governance structure in place.

Good governance is more than just ‘jumping through hoops’ in order to appease supporters, sponsors or regulators. Good governance will enable you to continue your work in a way that is most beneficial free. It will enable you to rest assured that any issues that arise – whether they are financial or legal - will be adequately managed because you have the right structures in place.

The constitution

A constitution is the foundation for building an organisation. It should contain all the key agreements made by members on how the organisation will work. In law it is called the “founding document” and it is legally binding on the executive and members of the organisation. It should tell you the following:

- Why the organisation exists, its purpose and objectives
- Who the organisation’s key constituency and stakeholders are, who should benefit from its work
- How the organisation intends to work, its broad principles and the basic structures for decision making and getting the work done as well dealing with the finances and assets of the organisation.

The constitution or founding documents should be clear and simple so that members understand their rights and responsibilities, leaders understand their mandate and how to be accountable and members of the public understand why the organisation exists and how it operates.

Your constitution or founding documents will usually have detailed and clear sections on:

- The purpose of your organisation: why the organisations exists, who should benefit from your work and how they should benefit
- The objectives of your organisation: what it intends to achieve
- The type of organisation you are: for example not-for profit voluntary association

Patient toolkit

- The membership of your organisation: Who may become a member and the duties and rights of members. How you join and how members can resign or be expelled.
- The structures and main procedures of decision-making in your organisation:
 - annual general meetings and other meetings,
 - elections and appointments for the different structures of the organisation
 - their powers and functions,
 - who makes what decisions,
 - how the organisation is governed and how decisions are made
 - how it is organised to get the work done.
- The roles, rights and responsibilities of people holding specific positions and of the different structures: what different individuals or structures are responsible for, to whom they account.
- How the finances and assets of the organisation are controlled so that no money or resources that belong to the organisation can be abused or misused.
- Financial year and audit process that tell you when your annual financial account will be finalised and audited and who the report will go to
- Closing down the organisation: what process must be followed and what will happen to the money and assets of the organisation.

Constitutions are long-term decisions. They should be written so that they will not need to be changed throughout the life of an organisation. They should not need to be changed often, although they can be changed [amended] if members feel the need to make new agreements about the basic principles of the organisation. It is a major decision to change a constitution and the existing constitution should say when and how it may be done. Any changes should be publicised to members and the public [if relevant] and if you have registered your organisation, you will have to inform the bodies with whom you registered.

Constitutions should not be too detailed. They should record only those agreements that will remain true throughout the life of the organisation or until some major change happens. They should only record basic and long-term facts about the organisation that you will not need to change often. They should not, for example, include specific objectives that are only relevant for a short part of the organisation's life span. The objectives you include should be relevant to your long-term goal and purpose. The description of structures also should not be too detailed. It should not contain names or other specific details that will change as the organisation develops. Only the main structures and their functions should be covered, as you may want to change parts of the structure from time to time.

Using constitutions

The constitution is the key founding document of an organisation. It is a record of agreements on the basic principles of the organisation and is legally binding on all members. Constitutions are not like plans. They should not change regularly. The

Patient toolkit

Constitution records all those agreements that will be important for the whole life of the organisation. Constitutions play a key role at different times in the organisation's life:

- When you start an organisation, the process of developing a constitution helps members to develop clear agreements about the purpose of the organisation and how it will work.
- When members have developed the constitution, they can use it to register as a non-profit organisation. Registration gives the organisation rights, duties and privileges in relation to accountability, fundraising and tax. It also helps make sure everyone understands the responsibilities and obligations that go with being a non-profit organisation.
- When the organisation is up and running, the constitution is used by people inside and outside the organisation who want to understand the organisation's purpose, how it is governed and their responsibilities and rights.
- When there is tension or conflict in the organisation, the constitution guides members about how it should be dealt with in relation to key matters like accountability and finances. It also helps ensure solutions are appropriate to the purpose of the organisation.
- When an organisation is going to close, for whatever reason, the constitution indicates how this should be done and what should happen to the resources of the organisation.

Board composition

A board of directors or an overseeing body can provide enormous support to you as the facilitator of a patient organisation. Some patient organisations have established a board structure which is composed of the right people.

So if you do pursue a board structure, who is the best person to be represented?

The key when selecting a board to oversee your organisation is the word 'balance'. For a patient organisation, a good board will have a range of people who each bring individual skills to your organisation. They will have experiences that will enable them to have an insight into some of the issues that you face. They may have a career or work experience in an industry that will provide your organisation with significant input and a low cost.

For example, a board for a non-profit patient organisation in the field of infertility may have representatives from the following industries:

Patients (having patients on your board provides not just a breadth of experience from people who have been through their own infertility experience and can sympathise with your membership, it also makes a very strong statement to supporters, governments and even the media that your organisation is run by patients)

Patient toolkit

for patients)

Medical professionals *(you may face issues which require specific medical input and having a medical professional or professionals on your board will give you a medical perspective. The other benefit of having medical professionals on your board again - presuming they are the right people and are willing to contribute their time - may open doors for you with some medical circles)*

Counsellors and psychosocial professionals *(they have a very different perspective then medical professionals and some are experienced in groupwork and willing to support the establishment of a patient organization or help in running it)*

Nursing staff *(this group belongs to the 'medical fraternity' but they have a quite different perspective on patients and treatment than doctors or senior medical professionals)*

Other skills that individuals may have that may be useful for consideration when putting together the board to represent your patient organisation could include:

Legal skills *(there may be times when you can call on a board member to provide advice for a particular legal issue to ensure that you are complying with all regulations and managing your legal risk effectively)*

Accountancy/finance skills *(having someone on your board who understands finance and can advise you on the best way to maximize your financial resources can be very useful).*

Marketing *(people who understand marketing and communication can provide a clear voice and direction to help you with issues ranging from fundraising to communicating via the web).*

The media *(media relations is critical to the success of any patient organisation and having a board member who can advise on media issues or even be the media spokesperson if appropriate can be useful)*

Getting the right people on your board - Australia

Sandra Dill is the CEO of AccessAustralia, and has discovered one immediate benefit to having the right people on the Board:

"One of our board members is a media relations professional. She has often given advice to access as part of her board duties that have assisted us in responding effectively to media enquiries or generating publicity for AccessAustralia.

Having access to a media professional has been invaluable. She not only advised us on the right messages, but pointed us in the right direction of the right people to talk to. And using her contacts, and we were also able to find other media professionals that could assist us with our media coverage."



Patient toolkit

Voting and meeting rules

If you are going to have membership, one of the considerations is to decide the composition of that membership in whether or not your members have the right to vote.

Part of the governance structure required of you within your own country's legislation may mean you need to hold regular meetings every year to report back to your membership as to the performance of your question organisation. If that is the case you need to look at the legal implications of the voting rights of your members and how these meetings should be held.

Types of committees

You don't need to address all issues yourself. There may be issues or events that can be managed by a sub-set of the board, in a committee.

Types of committees

1. Establish committees when it's apparent that issues are too complex and/or numerous to be handled by the entire board.
2. For ongoing, major activities establish standing committees; for short-term activities, establish ad hoc committees that cease when the activities are completed. Standing committees should be included in the by-laws.
3. Committees recommend policy for approval by the entire board.
4. Committees make full use of board members' expertise, time and commitment, and ensure diversity of opinions on the board.
5. They do not supplant responsibility of each board member; they operate at the board level and not the staff level.
6. Committees may meet monthly (this is typical to new organisations, with working boards), every two months, or every three months; if meetings are not held monthly, attempt to have committees meet during the months between full board meetings.
7. Minutes should be recorded for all board meetings and for Executive Committee meetings if the ByLaws indicate the Executive Committee can make decisions in place of the board when needed.

How to developing committees

1. Ensure the committee has a specific charge or set of tasks to address, and ensure board members understand the committee's charge
2. Have at least two board members on each committee, preferably three
3. Don't have a member on more than two committees

Patient toolkit

4. In each board meeting, have each committee chair report the committee's work since the past board meeting
5. Consider having non-board volunteers as members of the committee (mostly common to nonprofits)
6. Consider having a relevant staff member as a member of the committee as well
7. Committee chairs are often appointed by the board chair; consider asking committees members for a volunteer for committee chair
8. If committee work is regularly effective and the executive committee has a strong relationship with the chief executive, consider having board meetings every other month and committee meetings between the board meeting.
9. The chief executive should service ex officio to the board and any relevant committees (some organisations might consider placing the chief executive as a member of the board -- this decision should be made very carefully)

Potential standing committees and their typical roles

The following descriptions are intended to portray various functions often conducted by standing board committees, i.e., committees that exist year round. Note that the following list is not intended to suggest that all of these committees should exist; it's ultimately up to the organisation to determine which committees should exist and what they should do.

Board Development: ensure effective board processes, structures and roles, including retreat planning, committee development, and board evaluation; sometimes includes role of nominating committee, such as keeping list of potential board members, orientation and training

Evaluation: ensures sound evaluation of products/services/programs, including, e.g., outcomes, goals, data, analysis and resulting adjustments

Executive: oversee operations of the board; often acts on behalf of the board during on-demand activities that occur between meetings, and these acts are later presented for full board review; comprised of board chair, other officers and/ or committee chairs (or sometimes just the officers, although this might be too small); often performs evaluation of chief executive

Finance: oversees development of the budget; ensures accurate tracking/monitoring/accountability for funds; ensures adequate financial controls; often led by the board treasurer; reviews major grants and associated terms

Fundraising: oversees development and implementation of the Fundraising Plan; identifies and solicits funds from external sources of support, working with the Development Officer if available; sometimes called Development Committee

Patient toolkit

Marketing: oversees development and implementation of the Marketing Plan, including identifying potential markets, their needs, how to meet those needs with products/ services/ programs, and how to promote/ sell the programs

Personnel: guides development, review and authorization of personnel policies and procedures; sometimes leads evaluation of the chief Executive; sometimes assists chief executive with leadership and management matters

Product/Program Development: guides development of service delivery mechanisms; may include evaluation of the services; link between the board and the staff on program's activities

Promotions and Sales: promotes organisation's services to the community, including generating fees for those services

Public Relations: represents the organisation to the community; enhances the organisation's image, including communications with the media.

Incorporated versus unincorporated?

If you are not sure whether you want to incorporate your patient organisation as a non-profit corporation, there are a number of considerations you need to make.

Even though becoming incorporated requires some paperwork, it can be useful if the following activities apply to you:

When your association makes a profit from its activities

If your non-profit is already making a profit, or will make a profit, from engaging in its stated activities, your organisation could benefit significantly from incorporating. However, in order to realize the biggest benefits of incorporating as a non-profit, you must make sure that the money made is related to the charitable activities of your organisation. There may be tax implications.

When you are applying for funding

If your organisation does not have tax-exempt status, you may be excluded from applying for many public and private grants. Although you may be able to apply for and be granted tax-exempt status solely as an organisation or association, it will be harder to achieve the tax-exempt status that it would be if you incorporated. Getting tax-exempt status as an association requires that you prepare and adopt a complicated set of organizing papers and rules that govern the association's operation.

Patient toolkit

If you are looking for tax-deductibility status

When you incorporate your organisation as a non-profit corporation and are granted tax exempt status, gifts and donations that are given to your corporation can be deducted from the donors' income tax returns.

If you want to limit your personal liability from the organisation's activities

If it appears that your non-profit organisation may be the target of a lawsuit, or has the possibility of defaulting on future loans, you may want to consider incorporating to limit potential personal liability. Just like regular corporations, non-profit corporations can be sued. However, like normal corporations, the members and directors of non-profit corporations are shielded from the liability of the non-profit corporation. This means that you can shield your personal assets (cars, bank accounts, homes) by incorporating your non-profit organisation.

When your political activities could lead to lawsuits

As a general rule, non-profits can engage in very limited political activities. If want to limit your personal liability for any lawsuits that come from overzealous advocacy that takes your non-profit out of the safe political arena, you should incorporate. If you do not and your organisation is sued and loses, your personal assets may be at risk if the organisation's assets do not cover the monetary award.

Patient toolkit

Mission statements

Every organisation needs to have a direction. Without a direction, a patient organisation can focus solely on the short-term and not effectively manage longerterm issues such as legislative changes or changes to treatment all the medical process that directly impacts on its members.

A mission statement will encapsulate your patient organisations reason for its existence. It will help drive new directions, it will help keep you focused on current ones.

Some tips for writing your mission statement

- Bring in many perspectives. Get lots of input from the people you plan to serve, as well as from your board, staff, and volunteers. This will help you develop a broad base of support. You can get this input through meetings, surveys, or phone calls. Ask people what they think or need in regard to the area of services you plan to offer.
- Allow enough time. Time spent now will pay off later. So, don't rush the process. Provide time to reflect on the information you gather, to write an initial draft, to allow key participants to read it, and to make changes.
- Be open to new ideas. This is especially important for the founders of the organisation. You may have had tunnel vision while getting your organisation set up, but now it is time to get some fresh perspective. Be open to different interpretations of what you should be doing and new ideas about how to accomplish your goals. Use brainstorming techniques to ensure that all ideas come forward freely. You can winnow them down later.
- Write short and only what you need. The best mission statements are short and state the obvious. Your statement's length and complexity depends on what your organisation wants to do, but keep it as brief as possible. You should be able to use the statement frequently, so make it brief and succinct.
- Have a professional writer help you write your mission statement. A well-written mission statement can be the foundation for your organisation's marketing and branding program. But it should not be written in a way that only managers and insiders can understand. A good writer can help you avoid jargon and language that is stilted. The goal should be a mission statement that you are proud to display on your website and in your publications, and that everyone can understand and remember.
- Review your mission statement frequently. This is best done every 12-18 months.

Patient toolkit

Membership structure

Although a patient organisation can choose to have members who have voting rights, some decide not to adopt a membership structure and, in the interests of efficiency, leave the decision making up to the directors.

If a patient organisation does opt for a membership structure, the members participate in major corporate decisions. Specifically, the members have the exclusive right to elect directors, amend articles and bylaws and vote on a merger or dissolution of the corporation.

Members

Nonprofit organisations may have members that participate and provide input in terms of operating the organisation.

Your members may have the right to participate in the current and future activities of the nonprofit organisation.

However, it is not a necessity for a nonprofit organisation to have members as apart of its organisational structure.

Patient toolkit

Aims and objectives

Your aims and objectives will support your mission statement. It is important that you spend time listing the aims of your patient organisation and your objectives – what you want to achieve on behalf of the people you represent.

An organisation should be clear about its aims and objectives. Once aims and objectives are clear, it will be easier to agree on planned outputs, outcomes and impacts.

Aims

Aims are the changes that an organisation is trying to achieve.

Objectives

Objectives are the methods or the activities by which an organisation plans to achieve its aims. Objectives feed into the ‘what we do’ of the organisation and inform its outputs. Specific aims feed into the question of ‘why we do it’ and inform the organisation’s outcomes.

Outcomes

Outcomes are the changes, benefits, learning or other effects that happen as a result of your work. They can be wanted or unwanted, expected or unexpected. For example, your outcomes for infertile couples in your country could be:

- providing support information
- improved access to services
- being a voice for infertile couples in the media or government

Outcomes can occur in many places, so it is important to think through who or what your organisation is aiming to affect: what differences you are planning to make. For example, change could occur in:

- individuals accessing fertility treatment
- the wider community
- health organisations
- government policy

Patient toolkit

Policies and procedures

In keeping with the view that good governance will enable you to run smoothly and transparently, policies and procedures are a key part of your success. In the early stages, it you may be required to spend time developing the policies and procedures that will underpin your business, but in the longer term they will help to protect your patient organisation and ensure that it is running at its full capacity.

It is very important to have policies and procedures in place if you are intending to use volunteers or employ staff. These policies and procedures will help these people to ensure they are working towards the objectives you wish them to and they will provide a safety net for you if you are required to manage issues of performance from staff or volunteers. Types of policies and procedures that a patient organisation may require include:

Accounting, fiscal and reporting procedures

You will be required to have reporting procedures as an organisation that comply to your country's legislative requirements. It is important that you have policies and procedures in place to manage your accounts, incoming funds and outgoing expenses. If you take on sponsorship or funding from an external source, you will need financial policies and procedures in place to manage that money which is, after all, not strictly yours.

Contracts

When you sign a contract or legal agreement with anyone in business – whether that is a funding source, a supplier or a contract required to do a particular job for your organisation - you will be required to have policies and procedures in place to manage those contracts.

Personnel

Your staff will need to abide by the policies and procedures of your patient organisation. Ideally you would have a staff policies document (or even folder) which outlines the requirements of staff and how they go about their day-to-day tasks. This will significantly assist in your staff management but also in your risk management.

Intellectual property

As a patient organisation, if you develop intellectual property around a particular process or a program that supports your members, you will need to protect it through legal means. If you are employing staff or using volunteers and they are using your material, there needs to be something in place that says that they will respect the intellectual property of the organisation.

Programs

If you run programs or develop materials that directly help your members, they will need to be supported by policies and procedures as well.

Patient toolkit

Checklist

- ☒ Have you considered the governance structure of your patient organisation?
- ☒ Have you investigated your constitution?
- ☒ Is your board representative of the membership you are representing?
- ☒ Do you have a plan in place to attract new members to your board?
- ☒ Have you considered the voting rights of your members?
- ☒ Do you have a plan in place to develop and run committees from your board structure?
- ☒ Have you looked at incorporation as a way to establish your patient organisation?
- ☒ Have you written your mission statement?
- ☒ Have you clarified your aims and objectives?
- ☒ Do you have policies and procedures in place that will help provide a safety net from your patient organisation?

Patient toolkit

Government relations and public policy advocacy

with thanks to Estela Chardon from Concebir in Argentina

Dealing with the government is critical to the success of a patient association. Governments of many persuasions make legislative decisions that impact on your members – their access to treatment, the types of treatment that are available to them and the environment in which they can start or complete their families.

Dealing with governments in different countries is a very unique process. There are different cultural, legislative and social aspects that make a ‘one-size-fits-all’ approach quite difficult to apply to all governments.

But there are some key pointers that can benefit most patient associations.

Who do you contact in Government?

Dealing with the government necessarily implies getting in touch with different kinds of politicians. There are good ones who are always ready to help, but there are also others who can cause a lot of difficulties including:

- Politicians who are connected with the Catholic Church: they object to our ideas because of religious beliefs.
- Politicians who may be corrupted: they are always looking for personal benefit.
- Politicians who are inefficient: they make promises but do nothing.
- Politicians who may be ‘traitors’: they say something and then do something different.
- Politicians who may be unqualified, underqualified or misinformed: they don’t know about the issues, they don’t get informed but they still make decisions anyway.

The network of power sometimes turns into a labyrinth in which time and efforts are wasted and it is necessary to learn how to avoid them, how to find a way out or to give up a project when it gets stuck.

Sometimes it is better to wait and then “bring it up to the surface” at the right time.

Finally, being an NGO (not governmental organisation) it is necessary to be extremely careful so as not to get too close to any political party or any government official in particular.

We should contact everybody who is ready to listen to us.

Patient toolkit

Ten principles to dealing with the government

For more than 10 years, Concebir has developed some basic principles to deal with the authorities. Above all, it is necessary to mention that when we refer to the government we have to deal with officials from different areas:

- Health
- Women Assistance
- Consumers' Defence
- Human rights

The relationship is more difficult with judicial power. It depends on judicial actions in progress or the presentations made at the District Attorney's Office. We also contact representatives of the Chamber of Deputies in the Legislative Power. The relationship with the senators is even more complicated because it is composed by more conservative sectors.

All of this takes place at both national and municipal level.

This intricate framework of relationships with those in power calls for different strategies that can be summarized in these 10 principles of dealing with Government, as used by Concebir:

- 1- Ideals. In a material and individualistic world, it is possible for both parties to work in order to help the other, to give without expecting anything in return. Using your ideals as a way to deal with Government can be useful.
- 2- Credibility. Standing by the ideals and showing honesty and independence enables a transparent management which is fundamental at the moment of defending opinions. The Government's opinion of your value – and the support you provide to your members – is driven primarily by your credibility. You must be able to prove your credibility to Government partners.
- 3- Time and patience: What has been mentioned before can only be proved in the long run. Permanency and perseverance are essential. What we do can be compared to 'ants work'.
- 4- Being there: As far as it is possible, we try to participate in the most important activities connected with assisted reproduction and fertility. This implies going to TV programmes, speaking on the radio, talking to the press, meeting government officials, attending medical and scientific congresses, visiting universities and hospitals. Sometimes we achieve certain things, some other times we don't, but we never get discouraged.
- 5- Sowing Ideas: Creating opinion implies that ideas don't belong to anybody; they must

Patient toolkit

be spread no matter whose idea it is. The objective is that these ideas reach as many people as possible. More than once we happened to find a newspaper or scientific article with concepts that we had put forward to doctors, psychologists or politicians and which were later on presented as if they were their own. For us this is an accomplishment because it means that we are reaping what we sowed.

- 6- Set your priorities: There are many things to be done and all of them are connected but it is necessary to put them in order and establish priorities. If we expect to achieve absolutely everything, we may get nothing in return. Having clear priorities enables us to know what to ask for and which government official or area of government is in charge of it.
- 7- Homogeneous speech: It is absolutely necessary to achieve an internal consensus about basic concepts in such a way that when any member of the organisation takes part in a meeting, event, lecture or speaks in public, the message is coherent. You need to have one voice as an association, whether that's dealing with the media, Government or the public.
- 8- Don't try to convince: An aggressive attitude causes a defensive reaction which prevents reflection. Nothing is achieved in just one meeting. Putting forward an idea implies a process, it is something progressive and flexibility is required. While arguing, people stick to their opinions and this is just the opposite of what we are trying to get. Therefore, we get in touch with them with a relaxed attitude just trying to show a different point of view. It is worthwhile in the long run.
- 9- Being cautious: Politics is not our environment, we don't know the right codes, the internal framework of power and that is why sometimes mistakes have to be paid for. Risks must be considered because maybe they take measures that affect the activity or do any wrong action that may damage the prestige of the organisation.
- 10- Better nothing than something bad: It is better to be without a law rather than a law which is bad for your members. This is something to take into consideration when dealing with Government.

Some of the challenges of dealing with Government

The main challenge is to get a non-restrictive law contemplating some basic aspects, such as:

- That the difficulties to conceive are considered an illness, this requisite is the premise so that the cost of the treatments is covered by the health service.
- The need of cryopreservation of the non- transferred embryos so as to give flexibility to both the doctor and the patient and minimize the amount of transferred embryos by cycle. At the same time a clear definition of the destination of criopreserved embryos is required to prevent some of them from remaining in that state forever.
- As regards gametes donation we understand that it must be guaranteed that people

Patient toolkit

born through this technique can have access to the information about the donor when they are 18. In order to do that a Donors Register must be created.

- About a subrogated womb, Concebir doesn't have an unanimous position. So far, according to Argentine law it is considered that the mother is the woman who gives birth. Therefore, so as to contemplate this option, a previous modification of the Civil Code is needed.

Another challenge is to implement an uniform control system of assisted reproduction centers. At present the authorization is guaranteed by the Ministry of Health. The technical control of the proceedings and laboratory practice is carried out in some cases according to ISO norms and some others through the auditors of the LARA Network. We also consider that it is necessary to achieve a public diffusion of statistics updated by each center and that they can be available to patients.

Finally our most important challenge is the development of new patients organisations in Argentina and Latin America. We know it is hard work and it calls for great vocation and constant effort but we believe that we can encourage other patients to start their own associations.

At present, at Concebir we are training new leaders who can guarantee the continuity of the organisation, the best of our dreams and also real proof of the fertility of our work.

Some things to consider when establishing effective relationships with Government

Governments change

In any democratic system patient's associations must have contact with representatives of all political parties, so that accurate and current information provided by NGOs is accessible not only to officials and other government officials, but also all potential candidates for these charges.

The policy has different codes to the medical field

Patients are used to talking with health professionals (doctors, nurses, psychologists), so we learned to understand their language and their way of working. But to act on behalf of an NGO, you must interact with politicians, government officials and legislators and we must learn to manage in a different medium, so new languages and codes must be learnt to avoid mistakes.

Patient toolkit

It is important to note that in democratic systems, politicians need to be elected, and they are always attentive to the weight of public opinion and their prospective voters. Politicians seek votes, so we must show that infertility is a major issue in society and that specific policies are required - and will increasingly be required - to ensure reproductive health.

The Legislature works to a different time, and periods are marked by elections

Beyond the changes taking place in Congress as a result of the renewal of mandates of deputies and senators, on each elective period legislators will return to their provinces to sustain their political activity. Therefore at certain times of the year it may be difficult to obtain a quorum for some meetings, creating delays in the processing of bills.

In addition, each bill is in effect for a period beyond which it must again be presented again in case of failure discussed in the Chamber. Considering that laws relating to assisted reproduction are not usually the type of laws requiring immediate treatment, it is likely that the same project must be submitted on several occasions.

Finally, at each renewal of mandates, the representatives on each committee changes and sometimes it is necessary to start again from the beginning, explaining basic concepts that are essential for lawmakers to understand the complexity of an issue as important as human reproduction.

You must be patient and persevering

Leaders need to respond to endless complaints from different sectors of the population. Each of these are legitimate and with varying degrees of urgency. Often infertility is not considered as an urgent issue, even if governments understand that it is a priority or important, as they are often absorbed into other pressing situations.

This is why NGOs need to be patient and persevering. We must maintain our claims and actively support them, it is sometimes possible to find an alternative path within the government administrative system that allows us to achieve the same goals via a different route. Creativity and flexibility are needed to adapt in ways to streamline the paperwork and procedures required to achieve the objectives.

Dealing effectively and proactively with prejudices

Despite the long time since the July 25, 1978 (birth of Louise Brown) and the scientific advances achieved by reproductive medicine, it is likely that we still find many prejudices supported by different situations as such as ignorance, being attached to beliefs or religious dogma, economic interests, among others.

Patient toolkit

If, when dealing with government representatives, we can detect in them these ideas, we must be able to recognize if they are supported by prejudices or ignorance, because if so, they should be modified by offering statistical information and research studies developed by recognized scientific societies. You can also organize conferences and meetings with different specialists in reproduction and provide updated material through publications or through the web.

However, in the case of prejudices based on religious beliefs, we must be respectful, accepting that each person has the right to govern their lives according to their beliefs, but we must demand, in countries where freedom of cult (religions) is respected, that laws are passed regardless any particular religious position about ART.

If those who oppose to a non restrictive ART law, do so according to their own economic interests that somehow could be affected by the enactment of modern laws providing equal access to the techniques, then you need to be careful and look for allies in other representatives of sectors who share your ideals and your ethics.

Apply to the Justice

When administrative or legal obstacles interfere with our work, as a last resort recourse you can apply to judicial mechanisms to ensure compliance with our rights and give effect to our claims, both individual patients and from the same NGO as a representative of a significant number of patients.

Resorting to the Courts

Since 2006, more and more couples started court proceedings to get prepaid medicine companies and social work cover their fertility treatments, and claiming that infertility should be considered a disease, as established by the World Health Organization (WHO). According to a survey published on the subject by the University of Buenos Aires School of Law and other institutions, comparing the first half of 2009 and the same period of 2010, submissions to judges increased 20%.

Of all the decisions surveyed in 2010, in 40% of the coverage was granted, of which the 78% provided comprehensive coverage and 22% is partially granted it: the cost is distributed among the subsystems of private services or social security and the complainant. Of all the decisions surveyed in 2009 shows that 63% of cases, injunctions were denied, but in 2010 there is the provision of coverage of 50% of claims.

Patient toolkit

Working with government - Argentina

In Argentina, Estela Chardon and Concebir have learned many things about dealing with government.



"Each patient association will have specific demands and requests for the government authorities regarding the implementation of ART, depending on each country's situation.

Objectives to be achieved should be identified, if possible, differentiating partial stages, to enable them to measure progress on management.

The main objective is to facilitate equal access to ART for all patients and ensure respect for patients' rights, people born through the techniques and potential donors or surrogates.

What successes have we had?

Through active participation in the legislative and executive CONCEBIR has achieved, through many years of effort, the following measures from the government:

- *1996: CONCEBIR presents to the Chamber of Deputies, the first Project for an ART Law written by patients and in this way a non-restrictive law is included in the debate.*
- *1996-2010: Participation in the Debates on Bills of RHA in Health Commission of the Chamber of Deputies and Senators of the National Congress.*
- *June 2004: CONCEBIR made a complaint to Secretary of Consumers Defense claiming the pre-paid medicine companies change their contracts, including coverage of pregnancy, childbirth and neonatal care resulting from assisted reproduction treatment. The Ministry of Consumer Protection issued a temporary injunction intimidates pre paid medicine companies to include coverage for pregnancy care, delivery and newborn care when it was conceived by ART as establishing the PMO (Compulsory Medical Plan) (case number S01: 0123950/04)*
- *2005: Presentation of the second CONCEBIR ART Bill*
- *2006: First claims (Appeal for Protection) by infertile patients seeking coverage for fertility treatments. The favorable rulings demonstrate the need for the enactment of a law regulating ART.*
- *2008: Presentation of the third CONCEBIR ART Bill*
- *2009: Presentation of the fourth CONCEBIR ART Bill. For the first time a RHA Project is approved by Health Commission of the Chamber of Deputies with a majority of votes. The first provincial laws that recognize infertility as a disease and ensure coverage of treatments are approved in the provinces of La Pampa (Resolution 450 / 09), Córdoba (Law 9695 / Res.178/09)*

Patient toolkit

- 2010: *At national level, the previous project could be improved and was approved again by majority opinion in Health Commission of Chamber of Deputies. This project included embryo cryopreservation and regulated gamete donation, recognizing the right of born to access donor information. It was passed to the Family and Childhood Commission and was approved.*
- 2010: *The Province of Entre Rios passed a law ensuring coverage of treatments (Res. 206/10) and on December 22nd the Province of Buenos Aires sanctioned a law recognizing infertility as a disease and ensuring coverage of fertility treatments for women between 30 and 40 years old (Law 14208/10).*
- 2011: *since the enactment of the Law of the Province of Buenos Aires until the month of June 2011 and 44 pregnancies were achieved and four new public hospital were fitted for the care of infertile patients. CONCEBIR was designed as a member of the Advisory Council which discusses the cases that fall outside the coverage provided by law.*

Patient toolkit

Checklist

- ☒ Do you have a list of key contacts in government?
- ☒ Have you established relationships with those contacts?
- ☒ Do you have a plan to regularly put your case forward to government authorities?
- ☒ Have you considered seeking help in dealing with government?

Patient toolkit

Media relations and communication

with thanks to David Rawlings from AccessAustralia

Communication is the lifeblood of a patient organisation. Your organisation will benefit greatly from regular communication to the various people who support you through sponsorship, support from the medical fraternity and the media.

The key to good communication is to ensure that your messages are right at all times and that you are communicating regularly. A good communications program for your patient organisation will typically run over a 12-month period and you will allocate time to regularly provide information to keep people.

This is often the one part of running a patient organisation that is the most hard to resource. Good communication takes time – writing and preparing materials takes time and money. Having an up-to-date website or social media outlet require significant investment of resources.

But the benefits are impressive. In this part of the toolkit, we will look at some of the ways you can communicate with those people who need to see the good work you are doing and we will draw from the experience of those who have faced similar challenges as you.

Patient toolkit

Media relations

The media is a key communication avenue for your patient organisation to get information to the wider community. Through media stories, you will be able to promote the good work that you are doing, raise issues that impact on your patient and members, lobby to change the government level or even address issues within the medical community.

A good media relations program is both proactive and reactive.

Proactive media relations

There are two key elements to a proactive media relations program that will benefit your patient organisation. The first of those is in the information you supply to the media through media releases or interviews, the second is the relationships you build with member representatives to get your information published.

Reactive media relations

At times the media may come to you looking for a response to a particular issue that impacts your membership. These opportunities are great times for your patient organisation to present itself to the wider community and be seen as an expert in the field of infertility.

The role of the media in your organisation

The media is an important avenue for us to reach the wider community, but it is important to understand what they are interested in what is important to them.

One of the key roles of understanding the media and how to relate to them is to understand the basic premise that the media not there to promote your organisation, your event or your cause. They are covering stories about issues that are important to their audience and once we realize that they are not an external promotional arm for us, we can help them to achieve what they want to achieve and in so doing, gather publicity for our organisation.

It is true that the media may only talk about infertility when its controversial (such as a woman in her 50s or 60s conceiving through IVF or when it's a celebrity pregnancy or both resulting from IVF). That is quite normal – but in so doing there are opportunities for your patient organisation.

Media training

Many organisations – not just patient organisations – benefit from receiving media training. You may wish to consider approaching a media professional in your country to help you

Patient toolkit

better understand how to react to the media, how to interact with the media-and also how to be proactive in gaining publicity. This is where having someone with a media experience on your board is critical.

Issues to media management

If you don't have the contacts or resources to undergo a media training then the following issues should be investigated in terms of how you respond to the media:

- Choosing the right spokesperson. The right spokesperson for your patient organisation may be you or it may be someone else with relevant experience in being interviewed. Ideally, they will be an empathetic to couples and infertility and come across as professional and polished.
- Interview subjects. Some patient organisations have a list of members or other infertile couples who are happy to speak with the media should an interview request arise. It is very important to have these interview subjects briefed and prepared well in advance so that you can respond quickly to media requests. One thing about media requests – they are always urgent. Another thing with media requests for interviews that you may need to consider is protecting your members privacy. There have been instances in the past where the media has sought an interview with a very specific subject – for example a single woman who has travelled overseas for surrogacy – and you will need to determine whether or not you will put forward someone for interview who may wish those details to remain private.
- Key messages. It is important that you and your patient organisation understand what your key messages are, so that in every media interview opportunity that you have few can ensure you are pushing the right message all the time and that is consistent.
- Media relations through media releases. One of the key tools at your disposal for a proactive media relations campaign is the ability to send out newsworthy items to media outlets as a media release. What makes for a good media release? Something that is timely, newsworthy, somewhat controversial or somewhat different. You may wish to issue renewed media release which responds to commentary that is already in the public forum on being discussed.
- A list of media contacts. Every organisation that responds to the media has a list of key journalists, producers or editors that it can forward information to. You may wish to consider preparing a list of the key media complex in your country so that when the story does arise or you are issuing a response to a public issue than information is getting straight to the people who need to get it.

Patient toolkit

Working with the media - Argentina

Estela Chardon heads up Concebir in Argentina and has a wealth of experience in dealing with the media.



"CONCEBIR is, in Argentina, the most experienced and prestigious association that represents patients. We have made significant notes on all media (newspapers, magazines, radio, TV and web), both general and specialized information. We call each year to a wide conference on the occasion of our Annual Congress and for the past three years ago do with another patient association meetings in different provinces in which the diffusion is also performed in the local press.

Becoming a reputable organization, to which the media come to know the position of patients, is the result of many years of hard work. Our association has introduced some important topics of discussion - long before they were raised by society and even by specialists. Creating interest on the subject of infertility and ART is one of the most powerful means of drawing the attention of society and Governments - that's why NGOs have to deal with media.

An NGO needs to spread its activities as widely as possible to ensure patients know of the benefits offered by the association. Social networks and publishing information on the web is one of the most dynamic ways of communicating and can be accessed on your own. However TV, radio, newspapers and magazines offer access to different kinds of audiences, so the relationship with journalists is a part of our daily work.

In my opinion, there are seven keys to media management:

- 1. Have strong ideas: all members of your association who have contact with the media should be trained to convey certain basic and fundamental concepts in a few sentences, so as to consolidate a basic and homogeneous message (including vision, mission, principles of the NGO). Any time a staff member communicates with the media, he should attempt to repeat these 'strong ideas' into the message he is transmitting, creating and maintaining a framework that defines the NGO and allowing journalists to describe and define it easily.*
- 2. Time is money: when dealing with journalists it is crucial not to forget that "time is money", both in radio or TV. Available time is always short, so the message must be clearly defined and simple in order to minimize distortion. If we allow the journalist to decide how to reduce the content of information, we run the risk of losing an important part of our message, so it is always desirable to develop a very short introduction and then provide all the supplemental material.*
- 3. Risk of the "yellow press": at times the media communicate with an association for news that will generate an impact on their readers (eg errors in the clinics, older mothers, multiple births, etc). Deciding whether to provide information or not depends on your policy, although it is possible to*

Patient toolkit

use the interest for the news to convey a message of interest to your members. It will depend on the communication abilities of the spokesperson to avoid getting into irrelevant debates. When dealing with media known for a “yellow” reporting style, you should evaluate the risks of offering a distorted picture of the association. When the medium contacting us does not deserve our respect, it may be better not to give an interview to avoid damaging your image.

- 4. Focus and direct the message to the appropriate channels: for each message to be transmitted there will always be a privileged medium in which they should focus, for example when it comes to technical information - where recipients are professionals - we can concentrate our efforts on publishing in different journals or in certain scientific programs. In the case of an open conference to disseminate to the community, is likely to be more effective publication in mass media such as newspapers or radio and TV. To evaluate the effectiveness of dissemination you need to keep track of how people access and communicate with the association, including understanding how each member learned about you and your activity.*
- 5. Find press material of interest: journalists are usually interested in the most shocking and current issues, but a lot of valuable information can be transformed into 'news' if it is properly presented. Bringing updated statistical material, surveys and information, campaigns aimed at specific issues, is one of the ways to achieve media interest. When the media contacts us to deliver an expert opinion on any news related to infertility, is an excellent opportunity to publicize our activities and invite listeners to come by offering support and information.*
- 6. Maintaining systematic contact with the media: to make sure that the media would provide information about your association or help you to spread certain activities (conferences, meetings), you can maintain contact with journalists in different ways. These communications will help journalists consider you a current and reliable source of information and will turn to you at any time they need to work in the area of human reproduction. Ideas for contact include:*
 - Publish a newsletter and send it frequently*
 - Send press releases or information about a specific topic related to infertility*
 - Perform statistical studies on infertility (eg. age of women at their first consultation, opinion of patients about embryo cryopreservation and donation of gametes etc.)*
 - Develop abstracts of the most important treaties in different congresses and national and international conferences*
 - Provide testimonials from patients who have been successful or who wish to share their experiences*
- 7. Do not get disappointed: many times, despite having offered updated, interesting and relevant information, the article or piece of news is not published for various reasons beyond our control. In such cases, avoid disappointment and keep going because at least we have got the relationship with the journalist to whom we can go another time. A goal to remember is that the more contact you have with the press more likely to have spread our activities.*

Patient toolkit

What advice would you pass on to other organizations?

- *Respect and recognition arises from work and effort. Excellence and professionalism are crucial when conveying information and helping to form opinion on issues that are often controversial.*
- *It takes a long time to achieve respect and it can be lost easily with any inappropriate action of the NGO. Only qualified and trained members should have access to the media, and contents should always be agreed upon and discussed internally by the mechanisms provided within each association.*
- *If one of the objectives of the NGOs is access to as many patients as possible, the media is one of the most direct. It is essential the evaluation of the results of each media campaign to choose the most effective and optimize the resources of the NGO.*
- *Social networks and websites are increasingly important, so the spread should be diversified among the traditional channels and new options via the network.*

Patient toolkit

The web and social media

The Internet has opened a number of opportunities to communicate with not just your membership but with your wider society. The web means we can now communicate quickly and efficiently to hundreds of thousands of people in an instant. Online communities (such as Facebook) mean you can tap into groups of people who are meeting online.

Every patient association needs to have addressed how they will be using the web and social media on a number of fronts.

A good website and a presence in social media is an important part of communicating with your members in the 21st century. It is also a great way to build communities online, to spread your reach and influence beyond your physical capability to meet with people, a chance to reach people quickly and effectively and a way to collect market research information at minimal cost.

The two questions to ask yourself is a patient organisation are: what do people see when they visit our website and what feelings they get about the work we are doing and secondly, if we establish a social media presence, what do our members get out of it?

Your website

There are two facets of your website that require your attention – the design and content.

With the design, you need to ensure that your patient organisation's branding and personality shine through – that people visiting your website you feel that you are in the people business and representing members with genuine issues and concerns.

Some patient organisations, in an endeavour to save money, head down the path of producing a website themselves or choosing a free web design option. While that saves money, the counterbalance to that argument is the fact that these websites often reflect the amount of money that has gone into it and do not represent a patient organisation well. On the web, it is definitely a case of getting what you paid for - and if often looks like it.

That is not to say that your patient organisations website needs to be designed with a significant financial budget. But there are considerations that need to be made in terms of how the website appears. This is particularly important if you are hoping to attract members to your organisation through your website.

With the content, the best websites are regularly updated, have good information that will help people and will provide clear contact details so that your members, prospective members or the media are able to contact you easily. This is another thing to add to your timetable – the regular maintenance of your website.

Patient toolkit

How often should a patient organisation update its website? As often as it has good information to upload. However at a minimum, it is recommended that you update your website at least monthly – so that people who come to your website on a semi-regular basis see something new each time they arrive.

Ideas for your website

- If financial resources are an issue, have you considered approaching a design company to become a sponsor of your organisation and supplied website services at no cost or a reduced cost?
- Do you have the capacity to update your website yourself, saving significant ongoing costs in terms of updating your website?
- Are there members who can contribute information or content to your website, reducing the amount of information you are required to produce yourself?
- If you are holding events, have you considered videoing them and then using that footage as content to be uploaded to the website?

Providing information

A patient association's website can be a good repository of information for members, but also for prospective members. Some of the ways that a patient association could use its website to deliver its information includes:

- Fact sheets: in which you talk about a particular issue and provide advice in terms of how to manage it. This advice could come from doctors, medical professionals, alternative health professionals or counsellors.
- Media releases: your website could be a good place to publish media releases. This gives journalists easy access to your media statements, but also allows members and prospective members the chance to see that you are proactive with the media.

Joining other communities

The growing number of social media outlets and forums on the Web means there are more and more people seeking information, support and ideas from the wider web community on issues such as infertility. There are many forums on which couples who are struggling to conceive talk about their experience and share with others. There are groups on social media outlets which are gathering places for couples seeking adoption, for example.

Your patient association needs to have looked at these opportunities and to have identified whether or not it has the time and resources to manage this. But this is a real opportunity and a way for you to spread the message reasonably quickly and efficiently.

Patient toolkit

Communicating with corporate sponsors

Communicating with your corporate sponsors and those who support you financially is critical.

Sponsorship is not a donation. Sponsorship is a relationship based on a financial transaction made in support of the work you are doing. One of the best ways to view corporate sponsors and the ways you need to communicate with them is to see them as a partner in your work. They need to know what you are doing with their money and you should continue a conversation with them to highlight your successes.

Tips on communicating with corporate sponsors

- Make it a habit to regularly communicate with your corporate sponsors. Even a short email on a regular basis will ensure that the lines of communication are kept open.
- Always communicate your successes, regardless of size. There are significant benefits to regularly reporting to corporate sponsors of the good work you are doing.
- Thank them for their support in the context of the work you are doing. Remind them that it is with their support that you are able to achieve what you are achieving.
- Establish more than one contact. It is important with a corporate sponsor that you know more than one person at the organisation – what would happen if your key contact left the organisation? It is critical that you have more than one contact that you can go to in case of people leaving or even simply going on holidays.
- Find out from them what information they require from you. Part of their reporting processes to their management may be requirements to justify their sponsorship. As the organisation receiving funding, you need to ensure that you are making this job easy for them.
- Use the conversations with your corporate sponsor as a way to market yourself. Many corporates have newsletters, magazines or publications in which they trumpet their own success. There may be opportunities for you to piggyback on their communication and promote your patient organisation to your corporate sponsors customers, for example.
- Establish a regular reporting schedule. Part of any sponsorship arrangement with a corporate entity will require regular reporting. It is important that you establish what these requirements are and make sure that you fulfill them.

Patient toolkit

How do you approach sponsors? - Canada

Beverly Hanck is the Executive Director of the Infertility Awareness Association of Canada. What has she learned about approaching sponsors?



"These days there is no question as to how valuable the web is in terms of communicating with anyone, not only supporters. You can always ask your pharmaceutical companies for a certain amount of money to have their logo and a link on your web site. At www.iaac.ca you will see the pharma's logos on the home page; over time the cost of this has increased to \$20,000 annually for this privilege. We have set up a program whereby the clinics have a membership in our association. Membership details are as follows:

Gold Level Sponsorship (\$10,000 annually)

- *Listing on the web site.*
- *Charitable tax receipt.*
- *Acknowledgement as a Gold Level Sponsor published in the spring issue of CREATING FAMILIES.*
- *Receive an award honouring association with IAAC. This keepsake will be presented at the annual CEAS meeting.*
- *Referrals to the clinic from the 1-800 support line.*
- *A link to the Clinic's website from the IAAC Website will be created.*
- *Two full pages of 'colour' advertising space in CREATING FAMILIES (valued at \$3,000) including design, preparation and printing.*
- *Annual subscription to the CREATING FAMILIES magazine with 100 copies of each of the quarterly issues delivered to the clinic (valued at around \$2,400)*

Silver Level Sponsorship (\$5,000 annually)

- *Listing on the web site.*
- *Charitable tax receipt.*
- *Acknowledgement as a Gold Level Sponsor published in the spring issue of CREATING FAMILIES.*
- *Receive an award honouring association with IAAC. This keepsake will be presented at the annual CEAS meeting. Displaying this plaque in your reception area will symbolize your dedication and commitment to your patients.*
- *One full colour 1/2 page advertising space in CREATING FAMILIES including design, preparation and printing.*
- *Referrals to the clinic from the 1-800 support line.*
- *A link to the Clinic's website from the IAAC Website will be created.*
- *Annual subscription to the CREATING FAMILIES magazine with 100 copies of each of the quarterly issues delivered to the clinic (valued at around \$1,200)*

Patient toolkit

Some tips to other patient organisations:

- *Keep in mind the clinics are making lots of money; \$5,000 or \$10,000. is the cost of one or two treatments, respectively.*
- *Be clear about what you are offering – you need to show value to your potential sponsors.*

Patient toolkit

Communicating with supporters

Your supporters need to hear from you. While they may be members and you may be supporting them on their own infertility journey, you need to be in regular contact with your supporter base.

What is the best way to keep in contact with people? This will largely depend on the make up of your supporter base, the channels they use to communicate and how often they want to medication from you.

Tips on communicating with supporters

- Make your communication regular. Many patient organisations communicate once a month to ensure that the supporters have regular updates of the work they are doing.
- Make your communication updates about people. While it is true that you are an organisation, when you are working in the field of infertility you are effectively representing a large group of people. What stories can you pass on about people's experiences that would benefit your supporters?
- Ask them for help. One of the challenges of running a patient organisation is the issue of resources and time. Many patient organisations are run by a single person or a very small group of people. Could your communication with your supporters ask for their input? Is there a particular job or a task that they could do to you. For example, if you are approaching government about lobbying a legislative change, could you communicate with your supporter base in membership to ask them to write letters to the members of Parliament to give your case larger numbers of people behind you.
- Ask them for their stories. Regular communication requires significant investment in developing the communication messages. Could you ask people to supply information about their infertility journey, their perceptions of the treatment they are receiving or their feedback to proposed government changes?

Communicating with supporters - Israel

Ofra Balaban is the Chairperson of Chen Fertility Patients Association in Israel. What has she learned about communicating with supporters?

"In 25 years of experience I have learned to divide our supporters into three groups:

1. *The first group is the patients group that may pay a member's fee and sometimes when they succeed in their treatment they will donate more than a member's fee. One issue with this group is that they*

Patient toolkit

are random and in Israel most of the patients with family and friends related to infertility will not be involved and do not pay.

- 2. The second group of supporters is the pharmaceutical industry. They have commercial reasons to assist and support an association that may promote their products. In this case you should prepare a budget with projects and contact the companies at least a year before so they may insert you to the budgetary plan. None can be on immediate basis. Another important thing is to keep good relations with the managing director or other person that decided about the annual support. On the other hand you should keep in mind be aware not to become the company speaker.*
- 3. The third group of supporters is the supporters who join you out of sympathy. They may have heard about your association's activities and wish to donate as they like it. These donors are the best but their support cannot be planned in advance. You should know the budgetary timing (ie end of year or in some countries is March 31). Also learn first on the company product or availability cash flow of the company. Their mentality is also an important key. Many companies are willing to donate but some of them will agree to donate materials or services and other only cash.*

Some tips to other patient organisations:

- Communicating with the above three groups is different for each group. But, it is always in personal relations that really make a donor to donate to your association.*
- If you keep a donor's list, contact them every year, be open with them about your projects and show your thanks even in public if they agree to it – that's the key.*
- It is a full-time job to get finances as donations or fund.*
- Be aware that it might take more than two years until you contact will be fruitful.”*

Patient toolkit

Communicating with clinics/hospitals

Your members – as people on their own infertility journey – are regular patients of fertility clinics and hospitals. Therefore it is important that your patient organisation is regularly communicating with these same institutions.

Some tips on communicating with clinics and hospitals

- Provide them with printed promotional materials for their waiting rooms. While patients are waiting for appointments, they are sitting in waiting rooms and may spend their time reading all looking at your promotional material. It may seem a simple idea, but you need to ensure that your presence is in the waiting room where these patients can access it.
- Links with clinics and hospitals. Some clinics and hospitals are open to the approach of distributing information to their patients beyond the waiting room. They may have a team of counsellors who are happy to recommend your group as a source of information or very simply promote your web site as a place where couples dealing with infertility can go to find information, connections with others or support.
- Educate their staff. There is some benefit for your patient organisation by educating nursing and counselling staff of the services that your patient organisation provides. If you can generate and then develop advocates for your organisation within a hospital or clinic that will help you with the growth of your organisation.

Just a word of warning: some patient organisations report some friction between clinics and their patient organisation. You may find that some clinics do not want contact with your patient organisation and would prefer to provide all information to their patients which is branded with their own clinical or hospital's name.

Working with hospitals and clinics - Japan

Akiko Matsumoto is the Executive Director of the FINE, the Fertility Information Network in Japan. How does FINE collaborate and communicate with hospitals and clinics?

“We work in an alliance with hospitals and clinics in Japan. Of course, it does not mean we collaborate with all infertility clinics in the nation. The range of our alliance is partial and the area of our work is limited, but it is growing little by little. In this section of the toolkit, we will introduce some areas of our achievements, hoping that sharing our experience can help your new organization steadily develop.



Patient toolkit

The most significant area of our work in which we ask hospitals and clinics for cooperation is collecting signatures in order to make a petition to the government asking for “Restructuring the way to utilize governmental subsidiaries”. We send a kit of paperwork necessary for the signature gathering once in a year by postal mail and ask hospitals and clinics for cooperation.

This year was the fourth year since we started this system. Unfortunately, the petition has not yet taken up in the Diet deliberations, but we are encouraged to continue this work next year. As compared to the first year, the number of cooperative clinics has increased.

More and more clinics have recognized our organization through this action. We believe this is the positive outcome of our low-key but steady efforts. They are now showing more interests and understandings in other areas of our work. Some of them asked us to speak at their lecture meetings or allowed us to give out our brochures in their clinics.

Although the number is still small, there are clinics offering supports for our events.

To summarize, what we believe the key to success of our actions is as follows:

- *The actions should benefit both patients and medical professionals (Signature gathering-Petition to government – extended and improved subsidiaries and system)*
- *The action is regularly taking place every year, though it is low-key and hard work.*
- *We always enclose a record of our actions and achievements as well as Charter of our organization so that people can understand our purposes correctly.*
- *We show our positive attitude to infertility issues and treatments.*

We hope the examples of our activities will be of any help to you!”

Some tips to other patient organisations:

- *There should be always agreements and disagreements in the needs of patients and medical professionals. So it is very important to carefully find out where the both parties’ needs agree and to attempt to collaborate as much as possible where it is relevant.*
- *Listening to medical professionals’ voices mean a lot to you. If you have a chance, we urge you to listen to their candid opinions and “gather” their needs as much as possible. To that end, you also need to develop the kind of receptivity or system to receive voices of patients, in order to get a clearer picture of exactly what they are wanting.*

Patient toolkit

Newsletters

Newsletters are a great way to regularly and professionally keep in contact with your membership and supporters. They enable you to show the best of your organisation.

What are some of the considerations for developing and running in a newsletter?

- Production schedule – how often can you sustain the production process of a newsletter?
- The right format – will you be posting your newsletter to people or will it be emailed?
- The right content – what will you say in your newsletter? Do you have good photographs to go with your articles? Will you allow people from outside your organisation to provide information – such as doctors talking about latest techniques in IVF or counsellors providing advice on how to deal with a particular life issue?

Communicating with supporters through newsletters - Canada

Beverly Hanck is the Executive Director of the Infertility Awareness Association of Canada. What has she learned about communicating with supporters through newsletters?

“Many people challenged our publishing of an actual hard copy magazine – as it is an extreme amount of work – but CREATING FAMILIES has become our flagship. I am prepared to allow anyone in any country to reprint the articles; over 300 articles are available on our website (www.iaac.ca) and downloading them is free. The articles cover all the new and relevant medical treatments available and there are many personal stories as well.



The patients love the magazine - they are distributed through the clinics and handed out for free as they are part of the clinic's membership.

The magazine certainly keeps us going. Through clinic memberships and allows pharmaceutical companies to pay for full-page advertising, we raise nearly \$50,000 annually. We have other, more occasional advertisers who bring in more money.

Subscriptions are available on line. We print about 10,000 copies but they are likely read by at least 15,000-20,000 patients.

This also contributes beyond just the financial side of things. The coverage we get with our articles

Patient toolkit

means we are now the undeniable voice of the patients in Canada.”

Some tips to other patient organisations:

- *Never give up; the infertility patients need us very badly. If we are hounding governments for funding - it is the right thing to do, if we are educating the patients - it is the right thing to do – do not stop and do not accept no for an answer!*
- *Essentially you have to make up your mind what you want to see, put your head down and keep ploughing through the challenges.*
- *I would be happy to share/discuss any questions that any of the international patient organizations may have - they are at liberty to email me any time.*

Patient toolkit

Patient-led support groups

Support groups are a fantastic avenue for your members to get together, share a common journey, commiserate with people who understand what they are going through and deal with problems in a group rather than in an isolated one.

There are two ways you can go with support groups and the patient organisation:

Support groups managed by your organisation

Some organisations manage and run support groups. They are the ones who are regularly arranging events, advertising them to members and ensuring that the right speakers are presenting information to members.

Pros: you can guarantee the quality of the information presented, you have control over these support group in the direction goes in and it's another angle to your support that you offer

Cons: it's very labour-intensive

Support groups overseen by your organisation

A less resource-intensive way of running support groups is to encourage them to be generated by your membership base and then for your patient organisation to oversee them. You may be providing them with information or the ability to advertise to the wider membership, but ultimately they are run by the patients themselves.

Pros: it is less labour-intensive, you are able to run more than one support group because you are not having to manage each one

Cons: you lose control over the group which may be an issue if the group is meeting under your name

Patient toolkit

Coalition building with other like-minded groups

When you are working by yourself or with a small group of people to run your patient organisation, there is significant benefit in building relationships with other like-minded groups. One of the things you may discover is that other like-minded groups working in the non-profit sector are as under-resourced as you and therefore there are opportunities for you to support each other and potentially work together to maximize the time and money you have available.

Which organisations could you link with?

You may find some benefit in linking with other groups including:

- Representative groups of other health conditions related to infertility – such as polycystic ovary syndrome groups or survivors of prostate cancer
- Groups that represent people in specific sections of the infertility journey – including adoption or donor conception
- Community groups that are a collection of people who decided to have children later in life.

With these relationships, you may find you are sharing resources but also members. These coalitions also extend the range of services you can offer as an organisation and through reciprocal arrangements with these groups you can offer far more services than you are physically capable of providing.

Patient toolkit

Education programs

One thing that is common to many patient organisations is the fact that they are working within an environment of little knowledge of fertility issues. Some patient organisations find they educating are their members, the media, government or corporate supporters about the infertility experience. Is there room in your patient organisations communication strategy to include an education program?

Education programs can take a number of different forms:

- Education programs in the media. You may take some time and resources to develop a program which runs in the media to educate the wider community about the impact of infertility. There may be some value in trying to gain media coverage about the struggle that some couples go through to conceive.
- Education trends in schools. Another opportunity for you may be to produce materials that educate teenagers about their own fertility. Some patient organisations report that sex education in schools and their country relates solely to contraception. Is there an opportunity for your organisation to present the factors of infertility to a younger group of people?
- Education programs in the community. You may find that arranging for people to speak at information nights regarding health or family or lifestyle is a good way to educate the wider community about the infertility experience and the numbers of people who will experience it. You may find that speaking at these information nights uncovers prospective members or enables you to make contact with her bee health community.

Patient toolkit

Checklist

- ☒ Have you considered a media relations programme?
- ☒ Do you have resources available to conduct media training?
- ☒ Is your ad website adequately providing information to your membership and others?
- ☒ Have you investigated social media as a way to communicate with members and address their communities online?
- ☒ Do you have a program in place for communicating regularly with your corporate sponsors question mark
- ☒ Do you know the porting requirements of your corporate sponsors are you adhering to them?
- ☒ Do you have a communication plan to commit a regularly with your supporters?
- ☒ Have you considered how you will regularly keep in contact with clinics and hospitals?
- ☒ Are you running a newsletter as a way of communicating with your supporters and members?
- ☒ If you are running a newsletter, have you evaluated its effectiveness?
- ☒ Are there opportunities for you to build coalitions or relationships with other like-minded groups?
- ☒ Have you considered the best way to your patients to be supported in support groups?
- ☒ Our education program is a way for you to educate the wider community that infertility issues in your country?