

# A guide

to establishing a non-profit  
patient support organisation

By **Dr. Androulla Eleftheriou**

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*This booklet is inspired by patients' love for life and by the devotion and persistence of their parents for a brighter future.*

*It is dedicated to all patients and parents - members of the Thalassaemia International Federation and national thalassaemia associations worldwide, who paved the way for and who continue their struggle to establish equal access to appropriate healthcare and better quality of life for every patient with thalassaemia, across the globe.*

The Author  
**Androulla Eleftheriou**



# Foreword by

Her Excellency **Mrs. Photini Papadopoulou**

*Dear Readers,*

*Non-profit, non-governmental organisations (NGOs), particularly patient-driven ones, play a pivotal role in promoting and reforming health policies. Their contribution towards the improvement of medical and other care, as well as to patients' overall quality of life, has been immense.*

*Devotion, commitment, hardwork, voluntarism and sensitivity towards the alleviation of human pain are some of the most important elements of an NGOs work achieving their mission and fulfilment of their goals.*

*Indeed, patient-driven NGOs have a specific and vital role to play in directly and indirectly supporting patients and their parents/carers. Only well-structured and well-organised organisations, with clear visions and missions, are able to address the numerous challenges that are bound to appear, and to successfully develop the wide range of activities and services essential for the materialisation of their objectives.*

*In this context, I congratulate the Thalassaemia International Federation, members of the TIF Board, past and present, and members of national thalassaemia associations around the world. Despite their suffering, fears and uncertainty for the future, they found the courage and strength to support other patients, and their expertise and knowledge constitute invaluable tools for the promotion of other patient-driven NGOs.*

*I would also like to congratulate the author of this booklet, Dr Androulla Eleftheriou, TIF Scientific Director, for her genuine and deep respect for patients and for her invaluable contribution towards the promotion of the work and activities of TIF.*

*I am confident that this book will serve as a reference text helping patients worldwide to continue their struggle and to structure and organise their activities to effectively reach their goals.*

*“Better health and quality of life for everyone across the globe!”*

**Mrs Photini Papadopoulou**

Wife of the President of the Cyprus Republic  
President of the Cyprus Red Cross



# Message from

## the President of the Thalassaemia International Federation **Mr Panos Englezos**

This booklet is designed to provide helpful information and guidance on how to start up and promote your own non-profit non-governmental organisation, in aid of people with thalassaemia and their carers.

In compiling this book, every effort has been made to incorporate as much information as is relevant and useful. A key source of information has been long-standing successful patient/parent non-profit NGOs, international bodies such as TIF, and national patient/parent support groups that have achieved recognition or their work on a national and/or international level. A second valuable source has been a thorough literature review, revealing many important additional issues.

We hope this book will be of value to patients, individuals or groups interested in starting up a non-profit NGO, as well as offering useful tips to existing NGOs. The information contained here will also be of use to those working to promote national thalassaemia associations – a task at the heart of the Thalassaemia International Federation's (TIF) mission.

**With this publication, TIF hopes to greatly increase the number and strength of patient groups around the world. In the longer term, TIF aims to work with its partner patient organisations to establish powerful networks, maximising their individual impact through capacity-building, and enabling patients to advocate persuasively and effectively across borders.**

We hope this book will be distributed as widely as possible. We encourage readers to share it with friends and colleagues, and to translate it. Help us to make it as accessible, successful and effective a tool as possible.

I would like to take this opportunity, on behalf of TIF's Board, to thank Dr Androulla Eleftheriou, Executive Director of TIF, for her hard work in producing this extremely valuable publication. I would also like to acknowledge the contribution of Mrs Anastasia Neophytidou - TIF Scientific Collaborator, Dr Helen Perry – TIF Collaborating Editor, and past Board Members Costas Kountourou of the United Kingdom Thalassaemia Society and Merulla Steagull of Abrasta-Brazil for their significant contributions.

**Panos Englezos**



# About the Author

## Androulla Eleftheriou

Dr Eleftheriou obtained her graduate and postgraduate degrees (BSc Hons, MSc, PhD) from the University of London, in the fields of Biochemistry, Microbiology and Virology. She has been awarded a number of scholarships by the World Health Organisation and the Fulbright Commission. Her postdoctoral fellowship was completed at the Centre for Disease Control in Atlanta, GA, USA. Dr Eleftheriou has also recently obtained a Diploma in Business Management from the University of Leicester, UK.

From 1990 to 2006, Dr Eleftheriou served as head of the Virus Reference Centre of the Cyprus Ministry of Health – an institution she was closely involved in establishing. She is now the Executive Director of the Thalassaemia International Federation (TIF) Headquarter Offices, based in Nicosia, Cyprus, and Coordinator of its educational programme. In addition, Dr Eleftheriou regularly acts as a World Health Organisation (WHO) consultant on issues related to her field of expertise.

Through her work with TIF, Dr Eleftheriou has carried out numerous projects of local, national, regional and international scope, working closely with international experts, local physicians and thalassaemia associations worldwide. She is the author of several works published by TIF, as well as a number written in collaboration with the WHO and other international bodies on a wide range of scientific topics. Dr Eleftheriou is the Chief Editor of TIF Magazine, issued quarterly and distributed to 4,000 subscribers in more than 60 countries worldwide.



# Message from

the Vice-President of the Thalassaemia International Federation  
**Mrs Shobha Tuli**

*Dear Friends,*

Writing this message takes me back to the 1970s, when I heard the word “thalassaemia” for the first time, and when there was no thalassaemia association in India. As a parent of a child with thalassaemia, I remember the feeling of being alone—indeed, I was actually lost. This, I am sure, is exactly what thalassaemia patients and parents in other countries feel when they find themselves fighting the disease on their own.

NGOs have become extremely important in tackling a range of challenges associated with thalassaemia. In addition to helping those affected by the disease, they have had considerable success in bringing key issues to the attention of the medical profession, the general public, the media and government. They have proved that nothing is impossible. What matters to them is the cause! The dedication and hard work of many of those involved in NGOs have made them public figures - not because they wanted to be so, but because their actions have had such a profound impact.

The Thalassaemia International Federation is one of those organisations that need no introduction to thalassaemics, their parents and the very many NGOs working for thalassaemia around the world. TIF has proved that thalassaemia is a global problem requiring a global approach. TIF firmly believes in unity, and our unity lies in the strength we draw from our extended thalassaemia family across the globe.

Helping to establish thalassaemia associations, organising delegation visits, running workshops, medical conferences and bi-annual conferences, printing, translating and distributing essential material on thalassaemia, strengthening relations with the World Health Organisation (WHO) and other important organisations, and initiating new projects - all this and more has established TIF as a role model for national thalassaemia associations around the world.





Running an NGO is not an easy task. A strong thalassaemia NGO requires the involvement of patients and parents alike - indeed, there is no one better suited to running such an organisation than the ones who have experienced the pain and trauma of fighting thalassaemia.

My personal experience is that if our activities are transparent, our thoughts honest and our vision clear, a thalassaemia NGO can achieve anything, through sheer hard work and dedication. Believe me, nothing is impossible. But we must have faith in ourselves, and patience.

Together, everyone involved in the fight against thalassaemia has achieved an immense amount. But there is still a long way to go. While moving ahead we must not forget the hard times we have had - nor must we forget that the future is bright. And we must give thanks, too, for the great strides made in the area of treatment, with medical advances helping to make the lives of many patients more comfortable and more healthy.

Ultimately, we have knowledge, and we have hope. Let us commit ourselves to spreading the knowledge we have about thalassaemia, along with the hope - even conviction - that our future will be bright.

*Wishing you always the best.*

Warm regards,  
**Shobha Tuli**



# A word from the Author

**Dr Androulla Eleftheriou**

*Dear Friends,*

Patients need to have their voices heard, and their rights respected. They need to be given the opportunity to express and defend their position on all aspects of health policies.

In Europe and other parts of the world, health authorities have recognised the need to put the patient at the heart of debates over health care. In other countries, particularly in the developing world, the role of patients has yet to be fully accepted. But, encouraged by international health organisations - and very active and determined patients' groups - the message is spreading.

Patient organisations should become the natural point of reference for the European Commission, European and international health organisations and other interested stakeholders when they seek patients' views on policy. Patients' organisations need to co-operate closely in the formulation and implementation of joint projects with European and international health authorities, with a view to improving health outcomes and enhancing patients' quality of life. Only well-organised and well-networked organisations can ensure that patients have the strong voice they need in order to safeguard their right of equal access to quality health care.

Through my work with TIF I have had the opportunity to see how a national patient/parent support group can develop into a successful and influential international organisation. I feel extremely privileged to have worked closely with the Thalassaemia International Federation and, through it, with numerous other national patients' groups across the world. Coming from an entirely scientific background, I was completely overwhelmed by the tremendous impact non-governmental organisations can have in promoting national health services and public health policies.

I am extremely grateful to each and every one of the past and current Members of the Board of TIF who, over the years, have been an unlimited source of information and knowledge on the subject. I have learnt from them what incredible strength parents and patients can have when united with a clear vision and mission. And I have learnt from them the immense power and determination that patients and parents bring to efforts to protect their rights.



I hope that through this book, I have succeeded in committing to paper all the knowledge' and experience I have gained from them all and I hope that this will rise to the standard they would hope for. It is my wish that this publication will constitute a valuable guide for patients and parents in the process of establishing an NGO, or to those who wish to take their current organisation further.

I am particularly indebted to the President of TIF, Panos Englezos, with whom I have worked very closely over many years. He has been a wealth of information for me and I have learnt next to him how to listen, to appreciate, to be responsive and proactive, and how to be able to forgive and support people in pain, agony and fear for the future. I hope that this booklet provides the assistance and support to patients and parents that he has anticipated. I would finally like to acknowledge the valuable contribution of Mrs Anastasia Neophytou, a scientific collaborator of TIF, who helped with the compilation of the information and two past members of the Board, Merulla Steagull and Costas Kountourou, who have provided me with a first draft.

Last but by no means least, I would like to express my deep and sincere appreciation to Her Excellency, the wife of the President of the Cyprus Republic, Mrs Photini Papadopoulou, who shows great interest in and is extremely supportive of TIF's activities, and who very kindly accepted TIF's invitation to write the foreword to this book.

**Androulla Eleftheriou**



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# Introduction

Lester M. Salamon, of John Hopkins University, wrote in 1999 that the “**explosion in the number of non-governmental organisations** in the developing world could prove to be as momentous a feature in the late 20<sup>th</sup> century as the rise of nation state was in the late 19<sup>th</sup> century”. According to Salamon, we are in the midst of a “**global civil society revolution**” – a massive expansion of structured citizen activity outside the boundaries of the market and the state, with huge implications for citizens and nation-state alike.

The term civil society refers to the sphere of voluntary association and informal networks, in which individuals and groups actively promote the public good. Society as a whole can be broken down into three sectors: (i) the government, (ii) the private sector (including business) and (iii) civil society. The latter is distinguished from the public activities of government because it is voluntary, and from the private activities that occur through the market, because it seeks common ground between the sectors to secure public goods.

## “What is an NGO?”

Civil society is often described as the “third sector”, providing an essential link between citizens and the State and a countervailing power to the market. Non-governmental organisations (NGOs) are an essential element of civil society.

The term NGO has its origin in the years following 1945, when the United Nations sought through its Charter to differentiate between the participation rights of intergovernmental specialised agencies and those of international private organisations. Today the UN recognises an increasingly diverse range of bodies as NGOs.

## “How did it all start?”

The growing importance of civil society in the health sector is reflected in the WHO’s decision to establish a Civil Society Initiative (CSI), in June 2001 – a move no doubt encouraged by the fact that there are over 400 NGOs in regular contact with the organisation. CSI’s main objectives are to facilitate the more effective collaboration, exchange of information and dialogue with NGOs and civil society organisations (CSOs); to strengthen WHO’s support to Member States in their work with NGOs/CSOs on global, regional and national health issues; and to broaden dialogue and coordinated action with all civil society groups that have a legitimate interest in the work and goals of the WHO.

Beginning in Europe and more recently in the rest of the world, NGOs are increasingly appreciated for their role in fostering a sense of civic practice that can underpin better governance. **As the European Commission has observed: “NGOs can make an important contribution to the development of democracy and civil society in member countries.”**



NGOs are exceptionally diverse in size, scope and function. Ranging from tiny, single purpose organisations to complex institutions such as universities, foundations and social service entities, **NGOs play a key role in the delivery of services and in carrying out advocacy work.** Many reach the poorest and most disadvantaged, providing a voice to those otherwise rarely heard. NGOs may **represent people with disabilities or ethnic minorities, or they may address specific issues, ranging from the environment to world trade.** In terms of policy-making, many NGOs are linked at the local, national, regional and international (including European) level, and often offer expert input to policy-makers.

## “ Patient-driven NGOs ”

The effective promotion of public health requires an engaged populace and an active civil society. NGOs therefore have a critical role to play in promoting innovative policies, advocating on behalf of vulnerable populations, conceiving and lobbying for new policies and applying new service concepts.

At the same time, patient-driven NGOs have an important and particular role to play in supporting patients and their carers. They are informed on and aware of the issues that patients and carers face and are able to answer difficult questions. Perhaps more importantly, non-profit organisations are able to give **people the individual time and counsel that is often lacking in hospitals and other healthcare settings, particularly on issues of prevention, treatment and psychosocial care.**

Patient-driven groups are also an unparalleled source of information on a specific disease or diseases. Successful NGOs can develop unique expertise that can be exploited to the full in order to produce effective change – shifting and influencing consumer demand as well as national and international political priorities, furthering patients’ rights and a citizens’ empowerment agenda. For example, thalassaemia and haemophilia patient support groups have had considerable success in highlighting how organisations must change to better address issues of concern to patients and their families – issues such as patients’ rights, including the right to quality medical and psychological care and the importance of social integration. Such organisations have become experts in the delivery of unique services. And in doing so, they have become a model for others.

Patients’ organisations come in many forms. Small ones may be referred to as support groups or associations. Others, bringing together a number of smaller groups, are referred to as federations or alliances. Many such organisations are organised around a single disease in just one country.

Networks of patient organisations can link patients across borders, connecting patients around the world. Similarly, umbrella organisations can bring together organisations representing patients with a single disease, such as the **Thalassaemia International Federation (TIF)**, or groups representing related diseases, such as



the European Organisation for Rare Disorders (EURORDIS). **In either case, cross-border networks and national alliances are formed to meld the voices of thousands of individuals into one** – a voice that draws on the wealth of experience offered by each smaller organisation.

## “The role and contribution of patient NGOs”

Patient organisations pay particular attention to patients’ expertise, recognising the importance of patients and families as a source of information, expertise and empathy, and ensuring that services involve patients at all levels of corporate governance and service development, where possible. **The ultimate goal should be to provide validated, up-to-date and comprehensible information on all aspects of the disease to patients, families and the professionals working with them.**

**Patient/parent-driven NGOs are almost exclusively not-for-profit organisations. The difference between organisations such as these and for-profit NGOs is important: a not-for-profit patients’ NGO exists not to make a profit but to fulfil the mission for which it was established, through a blend of sound management, strong governance and by remaining clearly focused on results. Unlike a business or a for-profit organisation, no owner, stakeholder or trustee shares in the profits or losses of a non-profit NGO. These guiding principles have helped ensure that across the world, non-profit patient organisations have given a renewed sense of purpose to patients and their families, friends and carers.**

The following list highlights some key characteristics of non-profit NGOs, although it is important to note that many of the features mentioned will vary from country to country, according to local legislation governing the establishment and functioning of such organisations.

- (i) A non-profit NGO may qualify for exemption from a number of taxes, including corporate income tax;
- (ii) It may be able to receive grants and donations, and individual donors may be able to claim personal income tax deductions for their donations;
- (iii) Members of an NGO may be shielded from personal liability — probably the key benefit of non-profit incorporation. Board members, officers, and employees may be protected from liability for corporate debts or liabilities such as unpaid organisational debts or lawsuits against the organisation. An additional advantage related to the liability characterising non-profit NGOs is securing continuity of the non-profit NGO beyond the lifetime or involvement of the people who have established it — usually an attractive feature for donors, most of whom wish to fund a cause long-term;
- (iv) In forming a non-profit NGO, official documents are likely to be required to be prepared and submitted, which force Founders to be very clear about the organisation’s mission and objectives, and to develop with care and prudence operating rules and procedures for its functioning and for decision-making. This becomes particularly important for a non-profit NGO whose Board members may come from diverse interests, viewpoints, cultures and religions. Clear cut delegation of authority and specific lines of direction embodied in the articles of incorporation and the by-laws (internal regulations) will make the running of the organisation easier and less divisive.



Other miscellaneous benefits may include (i) exemptions from national taxes, (ii) lower postal rates on bulk mailing and (iii) cheaper advertising rates.

## “ Before setting up an NGO ”

At the same time, NGOs may face certain restrictions, such as (i) no remuneration for members of the Board, (ii) no political campaigning, (iii) no exemption from licensing, employment, safety, consumer protection and other laws that may require specific permits and registrations before operations begin, and (iv) no exemption from laws and regulations regarding social security, unemployment and any other taxes that may be related to employees.

Irrespective of national legislation, **devotion and determination on the part of its members, particularly the Board (see below) will be essential ingredients**, as an NGO takes on the considerable work load needed to meet its goals. Prior to setting up a non-profit NGO it is therefore prudent to **consult legal authorities on the relevant national legislation regarding the establishment and functioning of a non-profit NGO in your country.**

In principle anyone with an interest in a disease – usually a patient or parent/carer – can set up and/or be a member of the Board of a non-profit patient NGO. Typical exceptions include individuals:

1. **Under the age of 18;**
2. **Convicted of an offence involving deception or dishonesty;**
3. **Who are an un-discharged bankrupt;**
4. **Previously removed from the trusteeship of a charity for misconduct or mismanagement.**

The first and foremost prerequisite governing any decision to establish an NGO-patients group is a deep understanding of the needs of patients and parents – an understanding specific to the country and indeed the region in which the organisation is to be established.

## “ Useful Information prior to establishing a patients’ NGO ”

For a soon-to-be-launched NGO, it is helpful to have an all-round view of the context in which the new organisation will be born. A number of simple analytic tools can facilitate such an assessment, including PEST and SWOT (see below).

**PEST** is an acronym for the analysis of **P**olitical, **E**conomic, **S**ocial and **T**echnological factors, used to assess the environment facing a new or existing organisation. Although originally devised in order to better understand businesses, PEST analysis is a useful tool for understanding the position, potential and direction for non-profit NGOs.





PEST factors are generally external, and it is therefore useful to complete such an analysis first, before moving on to a second analysis, known as **SWOT** – an analysis of **S**trengths, **W**eaknesses, **O**pportunities and **T**hreats, which is based broadly on half internal and half external factors.

## “ What needs NGOs address in principle ”

Completing PEST and SWOT analyses is a simple process, but the best outcomes emerge from their application at various stages in the course of the development of an NGO, in workshop sessions with members of the Board in order to help develop a more targeted plan of action.

**In principle, non-profit patients' NGOs address three primary needs: (i) providing direct, personal support to individuals living with a disease and to their carers; (ii) promoting public awareness about a disease; and (iii) establishing close collaboration with relevant national and international actors in order to secure quality medical and other necessary care for member patients and their carers.**

At the same time, patient organisations are increasingly filling gaps in service provision. In the case of thalassaemia, for example, it has taken decades of great effort by patients and parents alike - often through national patient/parents' associations - to alert national health authorities (NHAs) to the need to recognise the disease as a huge public health threat, and to secure good standards of medical care and psychosocial support. In north European countries, where thalassaemia is extremely rare in indigenous populations, considerable work is still needed to effectively address a disease that nonetheless affects a large number of resident ethnic minority groups. However, **the much greater challenge lies in developing countries, where more than 80% of children with thalassaemia are born and where it is not rarity but limited resources, poor health infrastructure and competing health priorities that hinder progress.**

## “ Why set up a patients NGO? ”

Undoubtedly, patients can provide an important boost to efforts to tackle disease when they organise themselves into groups to demand their right to have their health needs met, or when they **seek to work with healthcare professionals, the bio-health and pharmaceutical industries, bodies such as the World Health Organisation (WHO), the scientific community or policymakers at the national, inter-governmental or international level, in an effort to ensure the delivery of high quality care to all patients, everywhere.**

It is hoped that TIF, through its newly published book “Patients' Rights”, will contribute significantly towards helping to inform patients around the world of their rights, and of ways in which they may organise themselves to secure the information they need, push for a legal framework governing those rights, and monitor and ensure their implementation.



# Starting from the beginning...

How to set up a non-profit patients' NGO – **First steps** (see also Appendix A)

Membership Strategy:

“Members are NGO “partners” in achieving goals”

Establishing a non-profit patients' NGO requires a full understanding of the key characteristics that will determine its success, including a Mission Statement, clear lines of accountability, adequate facilities, reliable and diverse revenue streams, and high-quality programmes and services (more detailed descriptions follow).

**Following the establishment of a clear mission and specific objectives, the next step in setting up a non-profit patient NGO is to identify members or ‘partners’.** The membership of such an organisation is a key consideration, because NGOs with strong, active members simply have more weight – they are taken seriously, their role is respected and they will find it easier to raise funds. In deploying the expertise of its members, NGOs demonstrate their wide support and technical capacities. Government officials, grant-making organisations and journalists are more interested in working with NGOs that can demonstrate broad-based participation, led by a high-profile Board of experts.

Almost all successful NGOs have developed some kind of membership strategy, through which the benefits of being a member are clearly set out. In the case of patient-driven NGOs, these may include:

- ▶ An active forum for the exchange of information, discussion and debate on all aspects of the disease;
- ▶ Regular briefings on developments in the medical and other aspects of care, with the support of international experts, including from the WHO;
- ▶ Opportunities for direct dialogue and discussion with national and international policy-makers;
- ▶ Opportunities to communicate personal views and experiences;
- ▶ Opportunities to integrate and develop collaboration with health professionals expert in the field, and with other NGOs directly or indirectly related to the disease;
- ▶ Receive free-of-charge publications and educational material, and;
- ▶ Facilitate or sponsor individual participation in educational events or projects.

At some point in the course of the development of an NGO, it may appear that one or indeed several members play a less active role in the organisation. Often this is more a case of some members being more vociferous than others. It is therefore important to ensure that all members, active or less active ones, feel a



sense of ownership – for example, by conducting regular surveys of individual members’ sense of needs and priorities.

In the case of patients’ associations for chronic hereditary diseases such as thalassaemia or sickle cell disease, finding members may be particularly difficult because patients and parents are not willing to disclose the health status of themselves or their children. While attitudes on this issue are changing in many parts of the world, the problem of stigmatisation remains substantial in many countries.

**Nonetheless, motivating patients and parents is the first, most important and most difficult step, requiring a high degree of commitment and devotion among those attempting to set up such an organisation.** And as the following quotes from thalassaemia patients and members actively involved in their national NGO indicate, the returns can be substantial.

“We can get all the support we need regarding medical and other care...”

“We get reliable information on new advancements in treatment...”

“We get the opportunity to participate in educational events, meeting other patients and parents and sharing experiences...”

“We do not feel alone anymore... Our NGO is our best friend, guide and supporter...”

“Our NGO keeps us interested and motivated to go on with our lives!”

“Our NGO is our second family. Through it we make new friends who share our problems and concerns...”

**Developing a clear communication strategy is essential to motivate passive members to become more active, but also to attract new ones.** A members’ newsletter and website, for example, are important communication tools (see reference to communication strategies later in this book). At the same time, NGOs would do well to cultivate a reputation for fairness, impartiality and discretion, as well as paying careful attention to the appearance, style and content of any information released for communication purposes.

The question of whom to invite to join a newly-established NGO will depend on the type of organisation envisaged. In the case of a patient/parent group, those involved should include primarily, if not solely, patients and carers - **patients working for patients**. Healthcare professionals, volunteers, government officials and business people may also be valuable partners, bringing in a variety of different skills and experience. However, their contribution and degree of involvement should be clearly defined and separate from those of patients and parents/carers.



## Steering Committee:

The **steering committee** is usually the first committee to be set up and should, if possible, involve only patients and/or carers. The **steering committee** is the key decision-making body in establishing and shaping the procedures to be followed in setting up and running the organisation. Its members should in no way gain personally from their involvement, and must be highly committed, motivated and visionary, and prepared to devote considerable time, energy and even money to establishing and managing the organisation. Ideally, steering committee members should between them have a range of experience, including in the areas of

- **Non-profit organisations**
- **Finance/ Accounts and**
- **Fund raising**

As an interim measure, steering committee members should also fill the roles of:



- Chairperson, to facilitate meetings
- Secretary, to take notes, write letters, etc.
- Treasurer, to manage income/funds
- Fundraisers, to raise money for the organisation

These individuals will also constitute the Board, until elections can be held according to the terms of the organisation's Constitution.

The focus of the first meetings of the interim Board must be to formulate and communicate the primary aim and objective of the organisation, laying a firm foundation for future activities.

The following simple – but by no means exhaustive – checklist can serve as a useful guide in the early stages, **although each patient's NGO will expand during the very early stages according to its available resources. In this context, a priority checklist should be prepared including the essential initial steps, such as those marked with an asterisk (\*) on the list shown below:**



1. \* Create a name and an emblem;
2. \* Define and draft, clearly and explicitly describing the charitable purpose of the organisation;
3. \* Recruit members – as many, if not more than, is required by law;
4. \* Employ or collaborate with individuals able to offer legal advice and guidance, prepare all documentation required to register an NGO, help in applying for tax-exempt status and, eventually, review your organisation's policies and activities;
5. \* Write a memorandum and provide a legal description of the organisation, needed in order to incorporate as a non-profit organisation;
6. \* Draft— an internal set of rules and regulations agreed by Members of the Board, specifying how the organisation and its Board will operate. These may be changed over time, according to the needs of the organisation, without need of a lawyer;
7. \* Open a bank account and employ or collaborate with an accountant to set up a basic book-keeping system, for your NGO;
8. \* Secure office space with a permanent, if possible address, and obtain necessary (basic initially) office equipment;
9. Recruit staff and prepare a personnel manual;
10. Establish a payroll system and procure necessary insurance coverage;
11. \* Develop a fundraising plan;
12. \* Initiate a plan for increasing participation in the organisation;
13. \* Invite health professionals to establish an advisory panel of experts – scientists and researchers involved directly or indirectly with your disease;
14. Initiate the establishment of a network of collaboration with external policy-makers, e.g. the European Union, the Council of Europe and the WHO (regional and headquarters), and identify any other national or international health-related organisations that could contribute in any way to your work;
15. Start identifying other national and international patient/parent NGOs related to your disease, or to other diseases/issues where collaboration may contribute slightly or significantly to your work, and;
16. \* Develop a budget and plan of action, to be adhered to faithfully and renewed every three years;
17. Monitor your outcomes, strengths and achievements, and identify your weaknesses.

NB — Please note that the terminology may vary according to the relevant national legislation binding non-profit NGOs.



# In detail

## 1. Create a name for your non-profit NGO.

Naming your non-profit NGO is not an easy task.

The name should describe the organisation's purpose and should preferably be one that will impress, is easy to remember and is not already being used by another business, organisation or group as a trademark or a domain name.

Naming an NGO at a relatively early stage is important, as it helps the organisation to get noticed as soon as possible.

Your first step will be to investigate what names are available, mainly through the internet, to ensure that your chosen name or names are not already in use. In this way, you may quickly eliminate names as well as checking for domain name availability. The national company registrar's office may also inform you, upon receiving your official application, whether your proposed name is in use by an NGO, nationally or internationally.

Other sources for such an investigation include the online service **Network Solutions**, through which users may search for organisation names, as well as for the suffixes used in domain names, such as '.com', '.gov', or '.edu'. The local phone book, trade publications and business directories are also useful sources to check, along with national trademark registries.

Finally, do not hesitate to seek professional help to save valuable time, particularly for your volunteers. Find out which agency handles trademark registries, for example, and seek their assistance or enquire how to conduct a proper search yourselves.

## 2. Vision and Mission Statements

“Public trust is an NGO's prime asset”

A vision and a mission statement, alongside statements of values and ethics, help establish the idea that even a new organisation, with limited resources, is serious and professional – and it demonstrates independence. Mission and

Vision statements provide an opportunity for an NGO to say what it stands for and – very importantly – to win respect across government, civil society and among potential new members.



**Vision and mission statements should articulate the essence of your organisation's beliefs and define its place and role in the community, society and the world.** They are essential towards establishing the long-term direction that will guide every aspect of an organisation's daily operations. More specifically,

**A vision statement** expresses an organisation's optimal goal and reason for its establishment and existence, while a mission statement provides an overview of the group's plans; tools and means by which it expects to fulfil those statements. As such they should include concise information regarding service areas, target audience and goals.

**A vision statement should be able to address questions such as:**



What values or beliefs guide our work?

What do we ultimately hope to accomplish?

**A mission statement** should feature on the organisation's publications and other messages to the public, so that, in effect, the mission becomes the organisation's "brand". It is therefore well worth coming up with a mission statement that is short and simple for people to understand and remember. And yet it must be tangible and applied seriously – not just as a publicity exercise.

**A good mission statement should stand the test of time. At the same time, however, it may be useful to establish a timetable for reviewing elements that include:**



whether the mission has been fulfilled either by the organisation or another entity;

whether the mission should be revised, and;

whether there is a desire or need to address new issues that might require a revised mission statement.

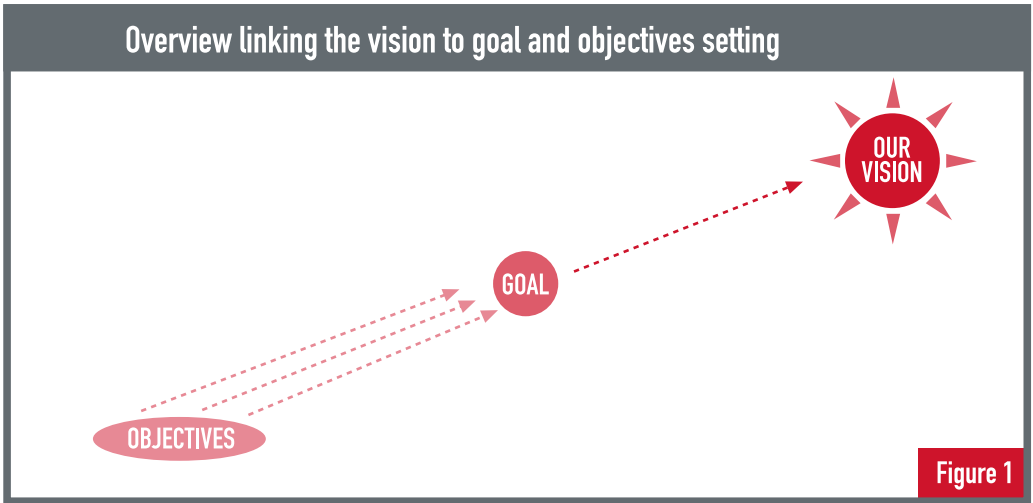
**A mission statement should provide clear and specific information on:**



What the plan of work towards the stated vision is, and for whose specific benefit the organisation exists



A well-defined mission statement that focuses energy and clearly outlines the NGO's purpose is also its best public relations tool, helping to attract the right partners, members, collaborators and friends and – very importantly – resources to your cause (see Figure 1).



## Code of Ethics:

The early adoption of a code of ethics is valuable, even if the NGO is still small and has limited resources. Having a clear statement on conflicts of interest, for example, means that such potential conflicts must be declared.

A code of ethics is one element of good governance and might include the following:

- ▶ The NGO should be accountable for its action and decisions, not only to its funding agencies but, very importantly and above all, to the people it serves, its staff, members and the public at large;
- ▶ The NGO should be transparent in all its dealings with government, the public, donors, partners and other interested parties





### | 3. Board Members - The Executive Arm

**“The Board of Directors is the official body promoting the NGO’s Vision and Mission”**

The board is responsible for promoting and implementing the decisions of the General Assembly, which is the NGO’s highest authority and is responsible for policy making. Board members are expected to act prudently and in the best interests of the organisation. They approve operating budgets,

establish long-term plans, and carry out fundraising activities.

Notwithstanding differences in national legal frameworks, the Board will have the following responsibilities:

- Developing and maintaining the NGO’s mission, values and annual plan;
- Fundraising — managing the NGO’s resources;
- Determining policies;
- Managing paid staff, and;
- Acting as ambassadors for the organisation and for its cause.

Finding appropriate, interested, motivated, visionary and committed Board Members can be a difficult task. Board Members should be interested in the organisation’s purpose, willing to work as part of a team, and be in a position to make financial contributions to the organisation or to find others who will.

In building an effective Board, it is essential to ensure that prospective members are volunteers and are explicitly told what is to be expected of them, before they are proposed for election. It is also crucial to ensure that they have an interest in promoting the rights of patients, i.e. as patients themselves or as the parent of a patient. Providing prospective members with an induction pack outlining the responsibilities and job description of Board members is very useful. The term length of Board Members varies from one NGO to another, but usually ranges from one to four years. In order to secure the strength of the Board, this period should preferably begin from the first General Meeting rather than the first steering committee meeting.



Where an NGO is led by a devoted Board and, in particular, a charismatic Chair, success is virtually guaranteed. Many people can learn and adopt good managerial skills but only a few possess the vision and innate qualities needed to drive a patients' NGO to success.

The Constitution of most patients' organisations stipulates a balance of patients and parents as Board Members, or indeed a patient-only Board. Some non-profit patients' NGOs may allow the participation of health professionals and/or influential individuals, in an effort to promote the NGO's mission and activities more effectively and widely.

Whatever the case, particular care should be taken to ensure that the Board does indeed truly, represent the interests of the patients for whom the NGO has been created. By extension, Board members should formulate the organisation's Constitution in such a way as to fully guarantee the rights of the patients they represent.

**The role of the lawyer:** It is essential to identify a lawyer, if possible on a voluntary basis, to support your NGO. Legal advice, guidance and coverage must be secured from the outset and for the duration of a non-profit NGO's lifetime.

A lawyer is essential, for example, in assisting the Board (i) to file articles of incorporation, (ii) to apply for tax-exempt status, (iii) to review the organisation's personnel policies, and (iv) generally to protect the interests of the organisation by addressing any other legal issues as and when they emerge.

## 4. Finances

**Establishing a system of checks and balances in the finances of an organisation contributes significantly to its transparency and credibility.** Finance work should be allocated to a specific individual in the office who is trained in book-keeping. The financial status of the organisation is presented to the Treasurer of the Board, who is responsible for closely monitoring the organisation's finances, at least every quarter. An annual audit should also be carried out by a nationally or internationally recognised firm, and presented to the Board for review prior to allocation of the following year's budget. Audited accounts are also presented at each General Assembly.

The Constitution should lay out, amongst other things, cheque-signing procedures and details of financial work, including who is to have authority over such issues. Each of these steps will help ensure that funds are properly invested and that there is transparency at every step and in every decision taken.



**In addition, non-profit leaders and managers should develop at least basic skills in financial management. Expecting others in the organisation to assume responsibility for financial management is not ideal.** An understanding of basic financial management practice, and how to generate, analyse and interpret financial statements, will help ensure an in-depth understanding of the financial condition of the organisation. Always bear in mind: transparency and properly-kept accounts are key indicators of the health of an organisation.

## Legal Documents:

The memorandum describing the objectives and mission of an NGO, as well as those articles encompassing procedural aspects such as participation, functioning and policies (see below) jointly make up the Constitution of an NGO, and constitute the official documents required to incorporate as a non-profit organisations. These include:

- ▶ a statement on how the Board of Directors was formed, when and how future Directors will be elected, an outline of the Board's authorities and duties, and the process for setting up committees and their powers;
- ▶ a statement defining who may become a member, qualifications, terms and conditions of membership; voting rights and the process for termination of membership;
- ▶ rules for preparing and submitting financial statements;
- ▶ a statement outlining how official meetings will be carried out, including: the notice to be given; the frequency; how decisions will be made; the required quorum for decision-making; and the requirements for proxy votes;
- ▶ a list of the activities of the organisation.

**In order to be officially registered, an NGO is generally required to provide all legal documents, originally signatures witnessed by an individual authorised to administer an oath, such as a lawyer. Any changes to these documents will require the consent of a General Assembly - the highest internal authority governing an NGO.**



# Non-profit NGOs

## Company, Club or Association:

NGOs usually register as a non-profit company, a club or an association. In each case, national legislation will outline the way in which the organisation can function and how it must establish accountability.

**The benefits of registering as a non-profit organisation usually include:**

- ▶ **Limited liability:** With limited liability, the volunteers involved with the organisation will not be forced to pay the organisation's debts nor can they be held responsible for other obligations, such as contracts, as long as they have carried out their duties in a responsible way.
- ▶ **Funding:** Many funding sources, such as foundations and certain government departments, will only fund an organisation if it is incorporated.
- ▶ **Recognition:** Incorporation enhances the credibility of an organisation by requiring some public accountability.
- ▶ **Legal rights:** Incorporation gives the organisation the right to:

**Own property;  
Obtain a bank loan;  
Sign a contract on behalf of the organisation, rather than its individual members.**

In the case of a club or an association, there may be less accountability to national legislation and thus more freedom of action than in the case of a company. However, committee members become financially liable for all transactions. Any group deciding to establish a non-profit NGO is advised to consult a lawyer familiar with the relevant national legislation, including the advantages, disadvantages, restrictions and accountabilities applicable to each type of NGO.

## Internal Regulations (IR):-

**These are of major importance since they specify how the organisation will be run and how the office will execute the decisions of the Board, in its efforts to achieve the mission and objectives of the NGO. These are not legal documents and do not constitute part of the Constitution of the NGO. IRs include preparation of the plan of action, office procedures and staff regulations, and can be changed by the Board or the General Assembly, as deemed necessary, or when specific needs arise.**



## Recruiting staff

It is essential for your organisation to have solid staff to carry out programmes and administrative functions. While volunteers can be helpful to an organisation, depending on the size of your budget, future donors may question the commitment of staff if you rely too heavily on volunteers. The consensus among founders is that paid staff is more reliable than unpaid volunteers.

**Finding competent staff for a non-profit patients/parents' NGO is more difficult than looking for staff for a government or for-profit organisation. Finding devoted, interested and motivated staff is extremely important, and in some ways it is even more challenging than recruiting Board Members. You will want senior staff to be charismatic, articulate, well-connected and organised. They will also need to be good managers, experienced fundraisers and have a firm understanding of the organisation's goals and ways in which they can be achieved.**

As you build up your staff, it is essential to foster an environment that will raise and sustain their interest and motivation. It is also important to have a clear, professional personnel manual, outlining policies related to quality of work overtime, annual and sick leave, health insurance and retirement benefits. While this document is not critical in the initial stages of setting up a non-profit organisation, it can prove extremely valuable when your staff begins to grow past the one-or-two-person stage.

**The quality of work provided by office personnel clearly reflects the level of the NGO and constitutes an important aspect contributing to its growth and promotion. High quality output contributes greatly to the credibility and reliability of an NGO since, in the majority of cases, the Board is a policy-making body while office staff is usually the executive arm.**



# Fundraising

## and Resources Strategy

Successful fundraising is a combination of science, art and luck. It means developing a public profile and reputation, where the NGO and its supporters are taken seriously and can get their foot in potential funders' door.

Resources come in a variety of forms, from good will to free accommodation to cash.

**A fundraising strategy is an integral part of any NGO's development process, and includes five critical factors:**

- ▶ **INDEPENDENCE** – However an NGO is funded, it is important to secure a reputation of keeping mission values and ethics firmly in mind;
- ▶ **DISTINCTIVENESS** – Your NGO should exert every effort to provide services that no other organisation offers, whether in the public or private sector. That will be the basis of your NGO's funding proposition;
- ▶ **SUSTAINABILITY** – Your NGO should be able to demonstrate that it is working towards a viable funding future, while asserting and protecting its independence and distinctiveness;
- ▶ **ETHICS** – Pursuing a fundraising strategy that conflicts with an NGO's mission may provide short-term benefits but it is ethically dubious and, in the long-term, the NGO risks losing its way. **Donations that can be shown to go against its mission or that make the organisation appear self-interested and cynical will damage the reputation and development of your NGO irreversibly.** This does not imply rejecting commercial funding, but it underscores the fact that such funding should be looked at dispassionately and with the mission, values and ethics of your NGO in mind;
- ▶ **ACCOUNTABILITY** – The receipt of financial support should commit the NGO to define how it will work with funders. For example, funders should be provided with reports on progress, whether they request this or not, in order to build a reputation of accountability and attention to detail. Funders speak to one another and reputations can be enhanced – or undermined – through informal feedback.

## RESOURCES:

Resources can come in various forms, other than financial described in more detail below. The time and experience of Board or other members and friends of the NGO, for example; donated meeting or office space; support in kind from other NGOs, national authorities or organisations such as the World



Health Organisation (WHO) are critical for any NGO, particularly a new one. It is important to always acknowledge such goodwill and to mention it wherever possible, including in Annual Reports.

Never underestimate people's willingness to get involved. Here are just a couple of thoughts from people who decided to support financially or in kind the fight against thalassaemia "... and never looked back".

*"I decided to help a friend whose daughter has thalassaemia. I made a commitment 10 years ago and have not looked back since!"*

*"I got involved in memory of a cousin who's no longer with us. I started because I admired his courage. I continue because his death hasn't dimmed that admiration."*

*"I do it for me and for my husband and for everything that lies ahead of us."*

*"I'm in this to support my sister. We've shared everything in our lives and my involvement with patients and the NGO ensures that we can keep doing that."*

*"I am keeping my son's memory alive."*

Fundraising is one of the most significant activities of a non-profit NGO. Health-related NGOs use funds to purchase and donate consumables or to cover the cost of treatment for members — a significant contribution such an NGO may make to its patient members. In the case of thalassaemia, for example, non-profit NGOs in many countries provide pumps, needles, filters and even drugs free-of-charge — in some cases to all patients, and in others to those patient members in need. On a number of occasions, thalassaemia NGOs have taken the lead in employing or supporting national health authorities to employ paramedical staff such as psychologists and/or sociologists, contributing greatly to the improvement of the quality of lives of their patients. Such activities make an NGO extremely useful to its members and attractive and worthwhile candidates for potential donors.

Furthermore, without a healthy financial status, there can be no proper staffing or adequate equipment for an NGO — both prerequisites to carrying out the work of the organisation.



In many countries, non-profits are required to register and obtain approval prior to conducting fundraising appeals. They are also required to produce a report on the outcome of fundraising efforts. Therefore all relevant legislation must be reviewed prior to any fundraising event.

## So, where does the money come from?

- Individuals are the largest source of funding for non-profit organisations in the US. According to Giving USA, individual giving to non-profits reached \$199.07 billion in 2005.
  - Corporations give in order to get exposure, publicity, community respect and market share. Their funding is more episodic, revolving around particular campaigns, events and projects. Corporate funding can be a good source of support for new initiatives, special programmes and special events.
  - Local and state governments will sometimes fund projects that benefit people in their jurisdiction. Examples are social service programmes, cultural resources and educational opportunities.
  - Foundations come in various sizes and types but their grants can be important and substantial.
- NGOs also plan their own fundraising activities, such as annual balls, sponsored marathon walks, collections in the streets, raffles, etc.

In addition to seeking outside support, it is of the utmost importance to develop an in-house fundraising program. Every NGO should eventually be in a position to seek both ongoing and episodic financial support.

Ongoing support is usually gained through:

- The Annual Fund, which appeals to a core group of constituents and is usually unrestricted in nature: i.e. it is available for one use and may represent a large percentage of the annual income of the non-profit NGO.
- Ongoing sales of products and services. Non-profits may organise annual social and educational events, open stores, produce and sell products, or provide services that can represent a substantial income stream.
- Multi-year grants. A grant-giving organisation such as a foundation may provide restricted funding for a particular project or programme. A grant covering one year, for example, can be considered ongoing support for the length of the grant. It is imperative, however, that this money is only used for the named project.





Episodic funding can come from foundation or corporate grants, special events, or a bequest. These funds may be for one purpose or devoted to several programmes.

Another type of fundraising is:

**Planned Giving:** This enables a donor to confer a gift at the time of his/her death, or at any stage of his/her life.

A good fundraising strategy will include a balance of the above techniques and sources. However, establishing unrestricted, ongoing funding, the most reliable type, is extremely difficult. Should effort to secure such funding fail, it is quite possible to grow through other sources.

## Publicity and Marketing: Multi-purpose tools:

Publicity:

**Becoming known is extremely important: publicity will enable your NGO to pass on its mission message to target groups** – in the case of a patient support non-profit NGO, to patients and their families - as well as to health authorities, health professionals and the wider community. In the case of a national thalassaemia association, one of the most important objectives is to raise awareness of the nature of the disease, its prevention and treatment, among as great a number of people as possible. In this context, members of a patients' non-profit NGO need to be constantly updated on all medical, scientific and research developments in the field, in order to be in a position to offer reliable information to anyone that wants it.

**In addition, becoming a credible, well-known non-profit NGO facilitates fundraising activities. All types of assistance and support are valuable for the growth and success of such an organisation, helping it achieve its goal and fulfil its mission.** Hence the tremendous importance of setting out a good, clear vision and mission statement right from the start, along with a well-thought out long-term plan of action.



# How does an NGO

## become known?

Becoming known is extremely important in (i) extending your message and achieving your mission, (ii) improving your membership recruitment, and (iii) increasing your fundraising activities.

### I. Website:

With the advent of the internet, there are many efficient ways of becoming more widely known.

**A website can be the gateway to an audience you didn't know you had – and a donor base you wish you'd had a long time ago. The internet is the way of the future, and every non-profit ought to have a website regardless of the size of the organisation. Some useful steps in developing your website include:**

- ▶ **Break down your organisation** into all of the parts you can think of. If your organisation is divided into departments, such as programme services, administration, management, development, community relations and accounting, take each of those departments and dissect them as well as you can. Remember, you are going to present each of these departments to the world. Literally. Even non-profits have the ability to set up informative and attractive websites.
- ▶ **Call for help. Go to your local university and find its web design/CIS/graphics design departments, and ask students if they want a project for their portfolios.** Tell them you will provide pictures and all the text required, if they will design your site.
- ▶ If this is not an option for your organisation, **employ someone to do the work for you.** Make expectations clear and deadlines enforceable.
- ▶ **Register your site.** Make sure that your cause or mission is registered with as many sites as possible. When someone is looking for anything even remotely related to your cause, your site should come up. This is a great way to get volunteers and donors.
- ▶ **Roll out your site to the general public and the media.** Write a press release as you would for any major event your organisation holds. Make sure the media and the general public are aware that they can go to your site and find everything they need to know about your organisation. Make sure a story about the site gets into your newsletter, so your donors know to check it out. Chances are, they will find out more there than anywhere else.
- ▶ **Change your look. Make sure that your website is regularly updated – at least twice a year –** and that all business cards, letterheads, newsletters and reprints of collateral material carry your web address. Remember, this is free advertising for your organisation.



## Let the world know who you are, and you will be rewarded.

Last, but not least, considerable care should be taken in the style and content of anything placed on the website. It should not disclose information for which special permission must be sought, it should not be written in a way that may insult or put in an awkward position any individual, government or company. Your lawyer and medical collaborators will be able to advise you as to which issues require special permission regarding scientific and medical articles or information. A specially-assigned member of staff should be responsible for posting new, updated information on the website, ensuring it remains a useful promotion tool for your non-profit NGO.

## II. Mass media:

Your organisation will only be able to help those people who are aware of its existence.

The most direct way to contact people is to enlist the support of key centres, using these contacts to help publicise your organisation and its work. Another means of reaching a broader audience is to issue regular press releases – a brief outline of events, activities, etc, sent to newspapers, radio and TV stations and medical journals. Begin with a press release about the launch of your organisation, using the opportunity to introduce the organisation to the local media and, through it, to the general public.

Consider appointing a press officer familiar with the media and how to compile and deliver a compelling story to different media audiences.

A successful communications strategy for the mass media includes:

- Clear definition of the webpage or pages to be transmitted
- Target your audience — with an eye to the public at large, but also institutions and the government
- Plan your programme carefully. Communication work makes demands on both time and resources. Plan a regular flow of information rather than focusing on occasional ad hoc announcements.
- Remember that television is a particularly powerful medium, and television news is one of the most trusted sources of information.
- When preparing a press release, use simple and consistent language intelligible to as large an audience as possible.
- When organising a press conference to mark a major event or to announce important news, plan well ahead and prepare a full set of materials as background information for journalists.
- Build good relationships with journalists. Be proactive, make yourself available, and where you are not in a position to answer a question, direct enquiries to people who are.



### III. Simple but effective correspondence:

**Promoting your organisation takes time and energy.** There are many ways that you can do this: **writing letters, talking to people you know, and making presentations at offices, clubs, hospitals, clinics, other organisations and schools.** Initially, the most effective promotion will be through contacts, so use your existing contacts to promote your organisation.

### MARKETING YOUR ORGANISATION:

*Differentiating your organisation*

*An effective marketing approach for your non-profit NGO will be to identify ways of differentiating it from other organisations.*

*Consider the following question that may be posed by potential donors: “Why should I help you instead of others?”*

You need to differentiate the services your organisation provides. When it comes to winning over supporters, you won't have much to communicate until you can answer the following questions:



What makes your non-profit NGO special or even unique?

What has your non-profit NGO got that others don't?

What do you offer your members and potential supporters?

How will you improve their lives?

It is important to remember that the **only product your organisation has to sell is the devoted, unbiased work and services it provides.** You can't just tell people that your **organisation is exceptional:** you have to prove it, so that people can see for themselves.

In order to survive, non-profit NGOs need to market their services to prospective supporters and prospective clients. In her article “*the 3 most effective non-profit marketing tools*”, Hildy Gottlieb highlights three virtually free techniques: writing, speaking and word-of-mouth.

### I. Writing

This can be in the form of articles for newsletters and local newspapers, or educational and awareness-raising material such as leaflets, booklets or books.



**Websites**, as previously mentioned, are another important outlet, acting as both a source of information for patient members and as a marketing tool. Websites are one of the easy ways to make your organisation stand out, highlighting the aspects that make it special.

A **quarterly or bi-annual magazine or newsletter** can also generate a great deal of interest, motivating members and potential supporters alike. Careful attention should be paid to ensuring that any publication is reliable, interesting and impartial, and consistent in style and format.

## II. Speaking

Identify charismatic, talented speakers **amongst your members**, who can capture the attention of the mass media. It is important to make clear to the audience that you are NOT there just to ask for money (a common fear provoked by non-profit NGOs), but to share with others what you know about a specific issue concerning the mission of your organisation.

Done well, speaking goes a step beyond writing. A good speaker provides a prospective supporter with a tangible sense of what an organisation is all about – how it helps and its significance for the wider community. Through speech, the listener is offered a direct way of sensing your organisation's approach, integrity and energy.

## III. Word-of-mouth

The word of a trusted friend or colleague can do wonders, opening doors to new prospects. Small initiatives can have huge pay backs. Yet few people really take advantage of this marketing tool. Consider taking one current supporter to breakfast each week. Chat about what's going on in your organisation, and seek their ideas, including people who might want to know about your non-profit NGO's work and activities.

**Be prepared to call anyone suggested by your friends and colleagues. Take them on a tour of your offices or ask to meet them at their convenience, to tell them about the work your organisation does.** When you do make contact, avoid asking for anything. What is important at this stage is to start building a relationship so that they know who you are. In the case of potential supporters, start to learn about their interests, and see if there are commonalities. Follow up with your new friends and bear in mind that collaboration is important. A thank you note for their time or an article that you thought they



might be interested in, are simple examples of ways to keep in touch. Keep them in your monthly/bi-monthly contact loop, and continue to follow up.

The more influential the person you meet, the greater the potential outcome. But always have in mind that **any help from anyone is help. And any help is greatly appreciated and ALWAYS contributes to the growth and promotion of an NGO.**

**Collaboration: The benefit of productive collaboration with others, particularly with well-established organisations, cannot be overstated. Productive collaboration provides an opportunity to learn; build on the experiences, connections and knowledge of others; and strengthen YOUR VOICE. Seek to establish as extensive a network of collaboration as possible between (i) government, (ii) national health authorities, (iii) national, European and international thalassaemia and other disease-orientated organisations (iv) national and international scientists and researchers working in your field, (v) industries producing or likely to develop drugs and/or consumables relevant to the disease in which you are interested and, (vi) other national and international organisations with common interests, such as (in the case of thalassaemia) those involved with blood, public health and humanitarian work.**

**OBTAINING GOVERNMENT SUPPORT** constitutes a major goal of any patient-driven organisation. This may be achieved by establishing a close and productive relationship that brings the organisation closer to health officials and policy-makers, to convince them of how big the needs in your area of expertise are, and to win their commitment to helping address them. In this context, updated educational materials, visual material, personal stories and reliable data will all help make the case for government support. Having such high quality informational material on hand will also save a good deal of resources over the longer term (for more details on securing government support, see Appendix A).

**A well-structured plan of action is required in seeking to establish government support. Although the policy-making process varies significantly from country to country, certain rules are common wherever you are. In order to effectively intervene in the policy-making process, knowing the decision-makers and being able to identify when and where to intervene in the process, how to do so and with whom, makes all the difference.**



The key to NGO's influence in lobbying is the provision of credible policy advice. Decision-makers give priority to evidence that helps them build their own case. In addition, the NGO may have other benefits to offer to politicians, civil servants and other policy-makers, such as legitimacy. NGOs are often in a position to act as bridge-builders when conflicts occur, and can serve as useful partners for ministries and politicians. However, getting the campaigning/lobbying balance right is extremely important – otherwise, an NGO runs the risk of harming their mission goals.

Monitoring results and the implementation of decisions taken in the course of meetings with government officials is extremely important. In addition, scheduling follow-up meetings before leaving keeps lines of communication open, giving you the chance to prepare and provide additional information.

In the case of thalassaemia, a disease that requires multi-disciplinary medical care, the establishment of collaborative relationships with government is an essential means of achieving the following goals:

- ▶ Raising awareness in the community;
- ▶ Educating patients/parents;
- ▶ Forming a medical advisory board and network of medical and scientific collaborators;
- ▶ Stimulating interest amongst scientific and medical communities;
- ▶ Promoting research to improve the treatment and quality of life of patients, and to find a final cure;
- ▶ Having a voice and making a contribution to the reforming and restructuring of health services at the national and international levels, and;
- ▶ Ensuring the promotion of patients' rights.

The establishment of networks with medical and scientific experts in support of an NGO's educational programme and awareness campaigns is extremely important. Of equal value is the development of networks with other patients' organisations, aimed at:

- ▶ Promoting common goals and objectives;
- ▶ Increasing rather than duplicating efforts;
- ▶ Learning from and sharing experiences and ideas, and;
- ▶ Advocating together, for a stronger voice.

In the same way, thalassaemia associations from different countries can achieve better results by working together to form a network, and through the Thalassaemia International Federation, to:





- Gain a stronger voice, building recognition at the regional and international levels;
- Make more efficient use of volunteers' time and resources;
- Attract wide public and government support, including funds, and;
- Address challenges collectively.

The value of collaboration with pharmaceutical companies should also not be underestimated. A close collaboration based on values and ethics leads to:



- Regular updates on new technological, medical and pharmaceutical developments;
- The opportunity to push for new developments;
- Additional sources of funding, and;
- A voice in and contribution to clinical trials.

**ACTIVITIES** – Activities are usually planned in the context of a three-year plan. These include **standard activities**, such as (i) updating information on websites, (ii) preparation and publication of newsletters, magazines or books, (iii) translation of educational material from national and international sources, (iv) encouragement, organisation or participation in blood drives, (v) keeping close contact with members and industry, and (vi) exerting additional pressure as deemed necessary.

**Sustainable activities and projects** include those planned according to the needs of patients in a city or country, and usually follow new developments in clinical management. The introduction of new medical advances, for example, the development of a new chelator or new monitoring equipment, requires the active involvement of NGOs in supporting patients through any medical or psychosocial effects of any changes.

### **Contribution of NGOs to the quality of life of patients they represent:**

**It is now widely accepted that thalassaemia, like other chronic diseases, has important psychological dimensions. The way in which patients and their families come to terms with the disease and its treatment will have a critical effect on patients' survival and quality of life.** It is precisely here that an NGO's most valued contribution to its members comes into play, by offering psychosocial support. An NGO can also help national health authorities to recognise the importance of and assist in restructuring policies on the provision of psychosocial support.





George Constantinou, a leading patient advocate, says:

**“I want to be an active member of the society I live in!”**

For people like him, patients’ NGOs have a responsibility to:



**Encourage patients to be optimistic about their future**

**Improve their life outside thalassaemia**

**Enable them to pursue their dreams – to be successful at everything from school to work, university, marriage, a family life – anything, in short, they may wish.**

Patients’ NGOs can also greatly contribute towards improving the social integration of their member patients, by collaborating closely with the medical community to provide, for example, evening clinics and transfusion sessions that better fit with a busy, normal life.

**As George Constantinou puts it,**

**– “Respect me, respect my time and respect my life!”**

**– For George, “The biggest barrier to my social integration is not really my medical condition, as my doctor says, but the way my doctor and everyone else structures my care, which promotes my disability and prevents me from being socially integrated.”**



# Planning Activities

Action plans identify the resources needed to accomplish an objective.

“If you don't know where you are going, you are sure to end up somewhere else”.

[Mark Twain]

Action plans identify the resources needed to accomplish an objective. Taken together, the action plans of an organisation allow management to determine how many objectives can be accomplished within the approved budget. If sufficient resources are not available, more must be found and allocated, and/or the objectives must be changed. At this point, decisions may be facilitated by an objective prioritisation process. It is far better to modify an objective in order that it can be accomplished, rather than encouraging unrealistic expectations.

**An organisation's objectives should be S M A R T:**

S	-	Specific
M	-	Measurable
A	-	Achievable
R	-	Relevant
T	-	Time-bound

Prior to initiating activities, particularly long-term, costly and demanding ones, it is essential to develop **strategic plans** and feasibility studies, including a careful assessment of needs and resources required. This will enable an organisation to assess its ability to initiate and see through any given project.



# What else can help our NGO

achieve its Mission? **A strategic plan**

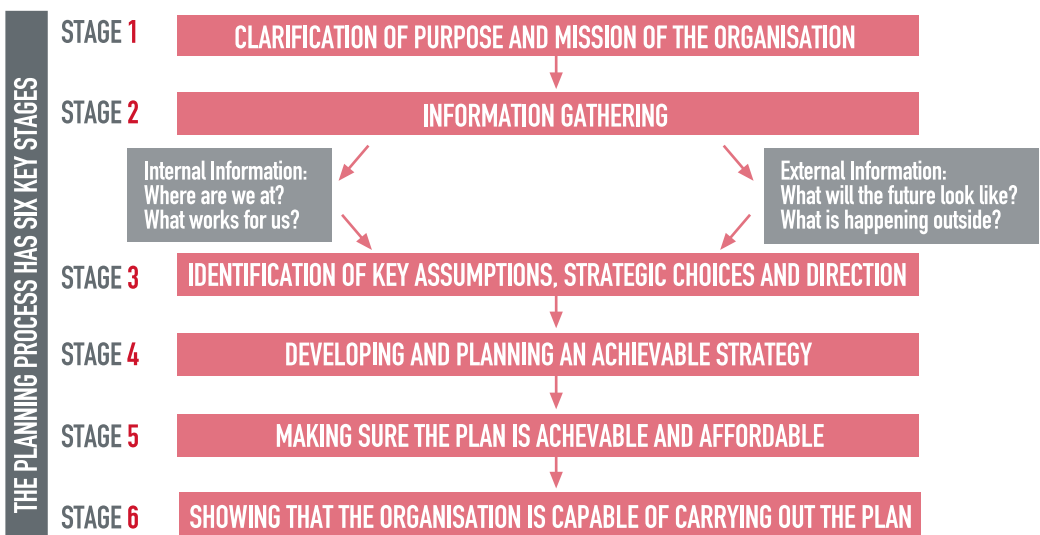
| A strategic plan is

- ▶ A disciplined effort to produce fundamental decisions and actions that shape and guide what an organisation is, what it does, and why it does it, and;
- ▶ A tool for the more effective management of a programme — one that needs to be used flexibly depending on circumstances. It provides a long-term view, establishing strategic aims for programmes and broad strategies to work towards achieving aims.

| A good strategy should be:

- ▶ As a document, no more than two pages long;
- ▶ Readable in less than 15 minutes;
- ▶ Understandable for all staff;
- ▶ Useful for guiding major future decisions, and;
- ▶ Valued and seen as important by all key staff

The figure below depicts the various distinctive stages of a preparation process (1-6), which may be the key to the successful execution of a plan of action (see also Appendix B).









# What else can help

patient-members of our NGO?

## I. Knowing their Rights

Always be up-to-date on the responsibilities of government authorities and the rights of patients, and identify ways to extend this information to each member of your NGO. **Patients will fight for what they know is right for them, and for what they are entitled to.**

In the case of thalassaemia, for example, patients have a number of rights specific to their disorder, in addition to their general rights as patients. These specific rights include:

-  To be transfused with safe, high quality blood
-  To have access to existing and any new iron chelator
-  To be clinically monitored by a multidisciplinary medical group
-  To have the opportunity to visit a centre of excellence for serious complications or a second opinion
-  To be provided with psychosocial support
-  To have a say in choosing their treatment regime

*(See TIF's publication on "Patients' Rights" - 2007)*

## II. Achieving Unity:

TIF's motto is:

**“Unity is our strength”**

Collective strength is needed to make an impact on governmental decisions — to influence governments to change policies, benefits, funding and laws to better meet the needs of citizens living with a chronic disease.

Umbrella federations or alliances of patient organisations can help by providing collective representation to authorities in government, drug regulatory agencies and other decision-making bodies, as well as by facilitating the sharing of knowledge and experience.

Umbrella organisations act as the voice of the disease community as a whole, persuading leaders of industry, science, healthcare and government, as well as national, regional and international health organisations, to change the world we live in, to make it a place where a person living with a disease in one country can enjoy the same quality of health care and living conditions as are available to people living elsewhere with the same disease.



## “Unity is essential, irrespective of the size of a patients’ NGO”

Most of today’s larger patient organisations began life as small, family-style groups. Over the decades, they have developed into organisations with greater stability and resources, more formal structures and a larger membership base.

Large organisations usually offer a wide range of services to parents of patients and to individual patients that go beyond those that can be provided by small organisations – services such as counselling, student scholarships, and support in becoming actively involved in patients’ social integration and in their professional development.

The funding of these groups is built on (i) fundraising events, (ii) grants from corporate sponsors (such as insurance or pharmaceutical companies), and (iii) in some countries, grants from national governments. Some patient NGOs with established reputations are well-known to government agencies and the medical and scientific world, and are listed, with full office contact information, in many directories.

### Smaller patients’ organisations tend to have “a family feel”

Leadership may be informal, members know one another personally, and there may be no office, with the organisation being run from the homes of devoted active members. Lack of money limits the kind of actions the organisation can undertake, such as publishing newsletters or sending representatives to conferences or launching advocacy campaigns with national, regional or international bodies.

Small groups may also lack members with expertise or professional skills in certain domains such as publishing, creating websites, fundraising, etc.

Also, small patient organisations tend to be volatile, and contact information such as an address, e-mail, or helpline phone number may shift often and suddenly. On the other hand, the human, personalised scale and very specific focus of small groups offer people living with thalassaemia the lifestyle support that larger, more formal organisations may not provide. Small organisations will always have someone who will listen and understand in that special way that only those experiencing the same disease can understand – someone whose life experience will be helpful in many practical ways.

There are numerous such non-profit patient organisations dealing with thalassaemia worldwide. Many have accomplished great things, drawing people together to solve problems, meet community needs and create valued collaborations. **In small organisations, the lack of professional staff is substituted by motivation, transparency, devotion and love, which become the characteristic ingredients for their success.**



# Discussion: Concluding points

A person living with a disease usually becomes an expert in that disease by necessity.

Patient organisations bring such expertise together, and are often able to advise a member better than a medical practitioner can. In the West, where thalassaemia is rare amongst indigenous populations, most health professionals have limited knowledge about the disease, including the availability of treatment and whether there are specialised centres or practitioners. At the same time, however, quality services for the treatment of thalassaemia are available in the West.

**Patient organisations collect and compile vital healthcare knowledge, directing members to the best specialist care currently available.** Although thalassaemia is not a rare disease in the majority of the developing world, patient/parent organisations in the developed and the developing world need to fight for the same objectives. The difference is that in one case a lack of information derives from limited demand, and in the other from a lack of health infrastructure, competing health priorities, and limited resources.

**Non-profit patient NGOs often develop collaborative relationships among professionals working in the field of their disease, or act as a link between professionals,** in order to create or promote "centres of reference" or "centres of excellence". These centres bring together leading specialists in the pathology, often in a multi-disciplinary approach, and offer the most advanced medical knowledge available on the subject. Because such centres are also a gathering point for significant numbers of patients affected by a specific disease, they also often carry out clinical trials and research.

Even mundane daily tasks can be difficult for those living with a disease. Non-profit patient NGOs provide a forum for members and newcomers to exchange tips and tricks they have learned – or invented – to cope with their disease.

**Non-profit patient NGOs provide a setting in which a person living with a disease can find others to talk about painful experiences, doubts and fears.** The sense of isolation and of not being understood that usually accompanies a rare disease is softened by meeting others who understand.

**Non-profit NGOs engage in collective work aimed at the prevention and better management of thalassaemia, and at creating a better world for the children of tomorrow born with the disease.**

**Non-profit NGOs also often actively support scientific and medical research in the field, by funding a research project, participating in clinical trials or undertaking advocacy and awareness campaigns to encourage scientists, universities and medical schools, governments or pharmaceutical companies to devote resources to research into the disease and its treatment.**



In recent years, patient-parent NGOs have taken a greater role as partners in the research process, commenting on research results, keeping researchers abreast of developments in the field, and acting as expert liaisons in promoting and shaping the direction of research into their disease.

Non-profit NGOs hold meetings and conferences, publish newsletters, magazines and websites, conduct fundraising campaigns, and reach out to the media in an effort to raise awareness of the disease and educate others about it.

The educational campaigns target a variety of audiences, including doctors and other healthcare professionals, the scientific community, social workers and policymakers.

## DO NOT FORGET who benefits from setting up an NGO

**Patients** and their **families** will and should directly benefit from the establishment of an NGO, in the following ways:

- By being given a central point for information and support, interacting with other patients, exchanging experiences, sharing feelings – fear, pain and isolation.
- By being updated on developments in their disease and its treatment, and having a source to answer their questions.
- By uniting and creating a strong voice, to lobby for changes in policies, to achieve optimal treatment for every patient and to help prevent new affected births.

## Your mission should be:

- Clearly defined, understood and shared by every member of the group
- It must **inspire**, but be **feasible**
- Engage the **heart**, but convince the **mind**
- Stir deep **passions**, but result in practical **actions**
- Guided by leaders, but **SHARED BY EVERYBODY**

**A mission statement can be as short as one sentence,  
and defined in one brief paragraph.**



## Remember that:

- ▶ All members have a **VOICE**
- ▶ All members know they will be **HEARD**
- ▶ All members should be aware of their **MISSION** and **RESPONSIBILITIES**

**Gaining the support of the mass media, opinion leaders and policymakers is ESSENTIAL**

## Always include in your organisational ethical principles:

- ▶ Confidentiality and use of information
- ▶ Anti-discrimination rules
- ▶ Conflict of interest
- ▶ Strive to be independent and autonomous
- ▶ Objectivity: ensure that advice remains objective and non-judgemental

“ All people, irrespective of age, race, nationality, religion or culture, should be entitled to a high standard of relevant health care ” - World Health Organisation, 1948.

“ Equal access to quality medical care for every patient with thalassaemia across the globe ” - TIF, 1986

## REFERENCES:

Information used in this booklet was obtained mainly from the First, Second and Third TIF National Thalassaemia Associations' Workshops, held in 2001, 2003 & 2006.

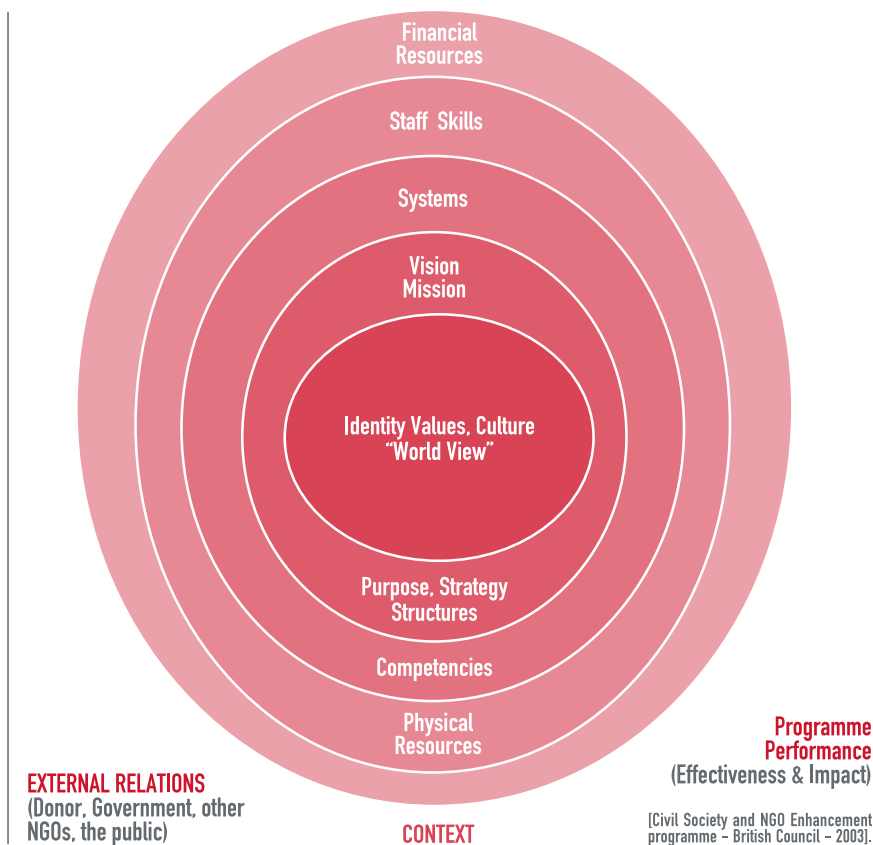
Additional information was obtained from the 'Civil Society and NGO Enhancement programme' - an educational course run by the British Council in Cyprus [14-17 March 2003].





# Appendix A:

## THE INGREDIENTS FOR A SUCCESSFUL NON-GOVERNMENTAL ORGANISATION (NGO)



### THE ONION SKIN MODEL

- The outer layer of the "onion skin" represents the physical and financial resources an NGO needs —money, buildings, vehicles, equipment.
- The next layer holds the human skills required to carry out the NGOs activities — individual staff competencies and abilities.
- The next layer holds the structures and systems (such as monitoring, evaluation, personnel and financial management systems) needed to make an organisation work.
- The next layer holds the vision, purpose and strategy of the NGO — what it wants to achieve and how.
- Right at the heart of the NGO is its identity, values, beliefs, culture, motivation and theory of development.



The benefits of this model are that it shows clearly how all these different components of an NGO are **inter-related**. There is a need for **coherence and consistency** between these different components and an understanding that if you work on one component, it will have ramifications for the rest of the organisation. The “fit” between the different components has to be good.

The “onion-skin model” also clearly demonstrates that **the heart of the organisation is pivotal**. There is almost a **hierarchy of capacities**. Unless the inside layers are adequate, there is little point in trying to address problems in outer layers. Increasingly, issues of NGO values and attitude (which were previously almost taken for granted) are becoming major concerns within both the NGO and the donor communities. Raising funds for or giving money to an organisation that does not have the right motivation from within is at best a waste of money and at worst destructive. Improving the resource base without having integrity and honesty in an organisation may also prove counter-productive. NGO staff needs a sense of ownership and commitment to development. Otherwise, the NGO will be ineffective, however wonderful its goals and systems. Furthermore, we see many instances of authoritarian and alienating leadership styles, even while espousing rhetoric about destructive decision-making, creating a destructive organisational culture that contradicts and undermines NGO goals of “empowerment”.

As well as such “heart” issues, NGOs need other core capacities. For example, while many NGOs are strong on their vision for a better world, fewer are able to integrate these with a focused purpose and realistic strategy for making a difference. NGOs constantly fall into the trap of being unable to say no in the face of a bottomless pit of need. While they try and do more and raise more resources, they actually spread themselves too thinly to have any impact. NGOs need a clear sense of where they want to be in the future, but many tend to operate with a very short-term perspective which sometimes fails to see beyond their own immediate survival, leaving them in a strategic vacuum and reducing their development effectiveness.

It is obvious that unless the core of an organisation is in shape, there is little point in generating more financial resources or even training staff. Yet this is all too often what we try and do.

The model also serves to show that the **complexity of NGO capacities increases as you move towards the centre of the onion**. It is often easier to solve the problem of a lack of financial resources than of self-serving values or an unclear purpose. Indeed, NGOs themselves often struggle to analyse their needs beyond their immediate resource deficiencies, and yet their most serious and long-term problems are much more deep-rooted than that and not easily solved just through the outside injection of funds.



## ORGANISATIONAL LIFE CYCLE

### STAGE IN LIFE CYCLE

#### INFANCY

The organisation has been born! Only very basic policies/systems are developed at this stage. The non-governmental director's office (*NGDO*) lacks experience (*no track record*). It is opportunity driven. Very vulnerable to changes in the external environment.

#### ADOLESCENCE

Finds many more opportunities for diversification, but has little experience of prioritising. Everybody knows what everybody else is doing – good communication. Each person shares responsibilities with others – very participatory.

#### PRIME

Strong 'results orientation'. A balance of self-control, flexibility and responsibility has been reached. Institutionalised vision and creativity in all its work. Strategic approach is strong: knows what it is doing, where it is going and how to get there.

#### MATURITY

Still strong, but losing flexibility and creativity. Takes fewer risks and becomes unwilling to change. Provides fewer incentives for visionary thinking. New ideas are received without enthusiasm. Lower expectations for growth. Starts focusing on past achievements instead of future visions. End of growth period and start of decline (watch for signs to take corrective measures).

#### ARISTOCRACY

Greater proportion of budget spent on administrative control systems. Emphasis on how things are done rather than what and why things are done. Low internal innovation. Decline of performance. Formality at the expense of functionality.



**EARLY  
BUREAUCRACY**

Much conflict: focus on internal battles. Emphasis on who caused the problem rather than what to do with problem.  
Members do not feel responsible for what is happening.  
Performance declines. Concerns are not directed for growth of organisation but for survival of self-interested individuals.

**BUREAUCRACY**

Nothing of any importance gets done. Dissociates itself from its environment and focuses mostly on itself.  
Makes it difficult for outsiders (*especially constituents*) to gain access.  
Only remaining systems are administrative rules and regulations.  
Members know the rules, but do not remember why they exist – they only answer “it is a policy”.  
Unless revived death is imminent.

**LIVING DEATH**

Organisation expires (*either quietly in its sleep, or painfully, if members are not prepared to move on*).



## CRITERIA

### 1. STRUCTURE

BREADTH OF CITIZEN PARTICIPATION  
DEPTH OF CITIZEN PARTICIPATION  
DIVERSITY WITHIN SOCIETY  
LEVEL OF ORGANISATION  
RESOURCES

### 2. ENVIRONMENT

POLITICAL CONTEXT  
BASIC FREEDOMS AND RIGHTS  
SOCIO-ECONOMIC CONTEXT  
SOCIO-CULTURAL CONTEXT  
LEGAL ENVIRONMENT STATE-CIVIL SOCIETY RELATIONS  
PRIVATE SECTOR — CIVIL SOCIETY RELATIONS

### 3. VALUES

DEMOCRACY  
TRANSPARENCY  
TOLERANCE  
NON-VIOLENCE  
GENDER EQUALITY  
POVERTY ERADICATION

### 4. IMPACT

INFLUENCING PUBLIC OPINION  
HOLDING STATE AND PRIVATE CORPORATIONS ACCOUNTABLE  
RESPONDING TO SOCIAL INTERESTS  
EMPOWERING CITIZENS  
MEETING SOCIETAL NEEDS



# Appendix B:

## “How to Obtain Government Support”

*Dawn F. Adler, MA – presented during the course of the 3<sup>rd</sup> International Workshop for National Thalassaemia Associations/Federations – held in Nicosia, Cyprus, on 12<sup>th</sup> -13<sup>th</sup> November 2006.*

Forming a thalassaemia association requires commitment, dedication and support. The Thalassaemia International Federation (TIF) workshop presenters provided helpful suggestions, examples and tools. Though each country has their own specific and varying levels of need, it is important to use the knowledge provided and embrace how it will assist in the attainability of your association's goals.

The following is an overview of what was presented. It is important to look at these goals as a foundation on which to form an association:

- ▶ Establish a community of patients and parents
- ▶ Organise patients, parents, medical providers, friends, family and the community committed to forming an association
- ▶ Establish a mission and goals based on need
- ▶ Establish the role of fundraising
- ▶ Acknowledge the importance of collaboration with relevant parties

No matter if you are from a developed country or a developing country, one of the most relevant parties your association needs to seek support from is government – all levels, from local government officials and agencies to state/regional governments to national governments.

The purpose here is to present ideas and suggestions as to how associations can obtain government support. The outline is broad-based, in order to give you the opportunity to determine what may be relevant for your country and the unique needs of your association.

Obtaining government support is particularly important since it will be based largely on the needs of your association, and those needs will change over the years. First and foremost, you must establish a relationship, which is an ongoing process. Another level of need is education. This includes educating the government about thalassaemia, including prevention and intervention, and then using their support and resources to help educate the people of the country. Securing financial support from government – an obvious need – may be easier in some countries than others. It is important to understand how the government supports various organisations and what your association needs to do to enhance its chances of competing for a piece of the pie. Lastly, obtaining government support is essential for those living with thalassaemia, in order to secure access to quality health care.

Attaining and maintaining government support takes time, patience, dedication and persistence. The first step is to make contact. You can do this by writing



letters, making calls, using connections or the connections of those in your community, as well as by creating a campaign. Education on thalassaemia, trait carrier awareness and blood donation drives are all examples of a campaign. Making contact can also be achieved by getting local leaders involved.

The next step is to set up a meeting. Even though it may take time to arrange an appointment, there are a number of things to keep in mind once the meeting is set. Bring at least one patient and one parent to share their story. People respond to other people's needs when they hear and see for themselves. Another important person to bring is a provider. They can help discuss the medical needs and answer questions related to care. Be prepared to educate and provide real numbers and statistics of the situation in your country. Government focuses on numbers, statistics and saving money.

While in the meeting your goal is to help them understand and convince them how big the need is in your country. Some suggestions include having visuals, which may include pictures and charts. As mentioned, provide personal stories and illustrations of hardship. Bring educational materials, including books and brochures about thalassaemia. Another way you can convince them is by showing them. Invite them to the medical centre/clinic where children with thalassaemia are treated. Bring the issues and needs to life through the senses of seeing, feeling, hearing and smelling.

Money and how to hold on to it is the most important thing to the government. Remember that you are not the only one asking for assistance. Your association needs to stand out. The best way to do that, aside from the approaches discussed thus far, is by showing how government support will actually save money in the long run. Examples include explaining how testing of the blood supply will produce healthier patients by preventing blood-borne diseases. Another important money-saving issue is iron chelation. Convince them that providing patients with access to means of removing iron from their bodies will decrease the incidence of other expensive health complaints such as heart problems and diabetes. Able and productive citizens are also important to government in regards to the economy and development of the country. In the case of thalassaemia, a high quality, continuously updated healthcare system will equal able and productive citizens who happen to have thalassaemia.

Establishing and maintaining relationships is the key to any successful business or non-profit, whether an organisation or an individual. Form a partnership with the government. Emphasise that they are an important stakeholder in thalassaemia in their country through outreach and awareness programmes, as well as through programmes aimed at prevention and quality of life. It is now the end of your hard-won meeting with your government official. Do not leave until you ask for a follow-up meeting. In doing so, you gain their



commitment – and government officials, especially elected ones, usually try not to back out of a commitment. You are also keeping the line of communication open and highlighting the association's commitment to the partnership as well. A follow-up meeting or connection will also give your Association the opportunity to provide any additional information or statistics in the process of educating the government.

The Thalassaemia International Federation (TIF) is made up of country representations from all over the globe. Each eligible voting country is required to have a thalassaemia association representing its thalassaemics. It is important not to reinvent the wheel. Look to neighbouring countries with similar government systems and other national thalassaemia associations or blood-disease related groups such as sickle cell anaemia. TIF is a primary support mechanism with immense knowledge and connections. TIF has close relationships with various medical providers as well as working closely with the WHO and its regional offices. Those relationships can provide contact information in your country, and provide your association with educational and medical literature explaining thalassaemia, its care and prevention in a number of languages.

Government support is important for various stages in the growth of associations, in both developed and emerging countries. Examples include Cyprus, protesting for equal standards of care for all of Cyprus, not just one medical centre. Currently in the United States, an association is lobbying for insurance coverage and funding and grants through the National Institutes of Health (NIH), and the United Kingdom association has partnered with its government to establish thalassaemia screening guidelines.

Developing a national thalassaemia association is a lot of work and requires dedication, commitment and assistance. The government can be a vital support mechanism, not only in establishing an association, but in the education, prevention and care of people with thalassaemia in your country. Our hope is that these main points will provide a foundation for national thalassaemia associations to reach out to their respective governments for support.

- ▶ **Understand your government**
- ▶ **Establish a Mission Statement and Goals**
- ▶ **Adopt standards of care**
- ▶ **Awareness-raising campaign**
- ▶ **Communication**
- ▶ **Build partnerships**
- ▶ **Effect policy change/legislation**
- ▶ **Ask for support from TIF and other national thalassaemia associations**
- ▶ **BE PERSISTENT!!!!**





## About thalassaemia

The haemoglobin disorders, sickle cell anaemia and thalassaemias contribute significantly to the global toll of birth defects. Although these disorders occur most frequently in tropical countries in which malaria was or still is a major killer, they contribute to mortality and disability in many other countries because of population migration. Approximately 7 percent of the world's population is a carrier for haemoglobin disorders, and between 300,000 and 500,000 infants with the severe, homozygous forms of these diseases are born each year, about 80% in developing parts of the world. Of these, more than 70% have sickle cell disease and the rest have major thalassaemias (World Bank, 2006). Thalassaemia, the disease on which the Thalassaemia International Federation focuses its work and activities, is a severe disorder of the blood requiring lifelong blood transfusions and iron chelation therapy.

Despite the availability of effective treatment, 50-80 percent of children with sickle cell anaemia and 50,000-100,000 children with  $\beta$ -thalassaemia die each year in low- and middle-income countries. Survival is frequently associated with disability caused by anaemia, haemolytic crises, stroke, infection and other complications. Weatherall et al recently documented the significant contribution of the haemoglobin disorders to the global tally of disability-adjusted life years (DALYs) (Weatherall, 2006).

## About the Thalassaemia International Federation

The Thalassaemia International Federation (TIF) was established in 1987 with the mission to promote the establishment of national control programmes for the effective prevention and appropriate clinical management of thalassaemia, in every affected country of the world. TIF, a Federation “umbrella”, is comprised of 98 national thalassaemia associations from 60 countries, representing hundreds of thousands of patients worldwide.

TIF has been in official relations with the World Health Organisation (WHO) since 1996, and has developed an extensive network of collaboration with scientific and medical professionals from more than 60 countries around the



world, as well as with other national and international health bodies, pharmaceutical companies and other disease-orientated patients' organisations.

TIF's educational programme is one of its most important and successful activities. It includes the organisation of local, national, regional and international workshops, conferences and seminars, and the preparation, publication, translation and free distribution of leaflets, magazines and books for health professionals and patients/parents, to more than 60 countries.

For more information, visit our website:

[www.thalassaemia.org.cy](http://www.thalassaemia.org.cy)



# Thalassaemia International Federation (TIF) Publications:

1.	“Blood Safety Kit” (1999) <ul style="list-style-type: none"><li>• In English</li></ul>
2.	“Guidelines to the Clinical Management of Thalassaemia” 2000 <ul style="list-style-type: none"><li>• Translated into 6 languages</li></ul>
3.	“Compliance to Iron Chelation therapy with Desferrioxamine” 2000 — Reprint 2005 <ul style="list-style-type: none"><li>• Translated into 4 languages</li></ul>
4.	“About Thalassaemia” - 2003 <ul style="list-style-type: none"><li>• Translated into 11 languages</li></ul>
5.	“Prevention of Thalassaemias and Other Haemoglobinopathies” Volume I (2003) <ul style="list-style-type: none"><li>• Translated into 2 languages &amp;</li></ul>
6.	“Prevention of Thalassaemias and Other Haemoglobiopathies” Volume II (2005) <ul style="list-style-type: none"><li>• In English</li></ul>
7.	“Patients’ Rights” 2007 <ul style="list-style-type: none"><li>• In English</li></ul>
8.	“A guide to the establishment and promotion of non-government patients/parents’ organization” 2007 <ul style="list-style-type: none"><li>• In English</li></ul>
9.	“Guidelines to the Clinical Management of Thalassaemia” Second Edition - 2007 <ul style="list-style-type: none"><li>• In English</li></ul>
10.	“Thalassaemia Major and Me” — Children’s Book — 2007 <ul style="list-style-type: none"><li>• In English</li></ul>
11.	“About - $\beta$ - thalassaemia” — 2007 <ul style="list-style-type: none"><li>• In English</li></ul>
12.	“About - $\alpha$ - thalassaemia” — 2007 <ul style="list-style-type: none"><li>• In English</li></ul>
13.	“About sickle cell disease” — 2007 <ul style="list-style-type: none"><li>• In English</li></ul>



# Thalassaemia International Federation

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Board Member

Cooley's Anemia Foundation



# Patients' Websites

PanEuropean Blood Safety Alliance:

<http://www.pbsalliance.org>

Interactive Groups for discussion on MSN:

<http://groups.msn.com/thalassemiapatientandfriends>

Thalassaemia Community Forum

<http://www.thalforum.ca>

Patient Information UK

<http://www.pifonline.org.uk>

Sickle Cell Society

<http://www.sicklecelldisease.org>

Impact Children

<http://www.impactchildren.org>

Patients' views

<http://www.patient-view.com>

European Patient Forum

<http://www.europeanpatientsforum.org/>

International Association of Patients' Organisations [IAPO]

<http://www.patientsorganizations.org>

European Organisation for Rare Diseases [EURORDIS]

<http://www.eurordis.org>

Cooleys Anemia Foundation

<http://www.cooleysanemia.org>



# Useful Links

[www.ukts.org](http://www.ukts.org)

The United Kingdom Thalassaemia Society

[www.tvs.org.au](http://www.tvs.org.au)

The Australian Thalassaemia Association

[www.abrasta.org.br](http://www.abrasta.org.br)

Associação Brasileira dos Talassemicos

[www.chroniccare.org.lb](http://www.chroniccare.org.lb)

The Chronic Care Centre – Lebanon

[www.penthal.org](http://www.penthal.org)

Penang Thalassaemia Society – Malaysia

[www.thalassemicindia.org](http://www.thalassemicindia.org)

Thalassaemics India – New Delhi – India

[www.fundatal.org.ar](http://www.fundatal.org.ar)

Thalassaemia Association of Argentina – ‘Fundatal’

[www.tta.org.tw](http://www.tta.org.tw)

Taiwan Thalassaemia Association (TTA)

[www.talasemi.org](http://www.talasemi.org)

Thalassaemia Federation of Turkey

[www.ama.org.pk](http://www.ama.org.pk)

Abbotonians Medical Association

[www.thalassaemiaindia.org](http://www.thalassaemiaindia.org); [www.thalassemiaindia.org](http://www.thalassemiaindia.org)

National Thalassaemia Welfare Society – India

[www.fondazionegiambrone.it](http://www.fondazionegiambrone.it)

Fondazione Italiana “Leonardo Giambrone” per la guarigione dalla Talassemia

<http://erasmeinfo.ulb.ac.be/globule/index.htm>

Association Belgo Méditerranéenne de Lutte Centre la Talassemie

[www.thalassemie.nl](http://www.thalassemie.nl)

Oscar Nederland – Netherlands

[www.thalassaemia.org.hk](http://www.thalassaemia.org.hk)

Thalassaemia Association of Hong Kong

[www.tam.org.my](http://www.tam.org.my)

Persatuan Thalassaemia – Malaysia

[www.thalassaemia.org.pk](http://www.thalassaemia.org.pk)

Thalassaemia Society of Pakistan

[www.thal.psu.ac.th](http://www.thal.psu.ac.th)

Thalassaemia Foundation of Thailand

[www.cooleysanemia.org](http://www.cooleysanemia.org); [www.thalassemia.org](http://www.thalassemia.org)

The Cooley’s Anaemia Foundation

[www.thalassemia.ca](http://www.thalassemia.ca)

Thalassaemia Foundation of Canada

[www.thalassaemia.cdc.net.my](http://www.thalassaemia.cdc.net.my)

The Sarawak Thalassaemia Online – Malaysia

[www.thals.org](http://www.thals.org)

The Bangladesh Thalassaemia Foundation

[www.clubrainbow.org](http://www.clubrainbow.org)

Club Rainbow Thalassaemia Major Support Group – Singapore

[www.avlt.it](http://www.avlt.it)

Associazione Veneta Per La Lotta Alla Talassemia (AVLT)



# Travel Advice

## Advice to patients traveling on holiday or business:

1. Having chosen your destination and decided on the length of stay:
  - Identify the nearest treatment destination:- TIF can provide you with this information. Therefore contact TIF Headquarters stating your destination and you will receive the full contact details of the nearest treatment centre;
  - Ask your own doctor for an updated medical report stating the expected date of your next transfusion, blood group accompanied by information regarding adverse reactions during blood transfusions, any antibodies identified and your iron chelation pattern;
  - Send the report in advance to the centre at destination;
  - Enquire about possible costs;
  - Consider travel and health insurance.
2. Take enough medicines and other supplies to cover the period of travel. Buying medicines such as chelating agents may be difficult. Pack your medicines carefully in your hand-luggage.
3. Enquire, through your doctors, about any vaccination requirements at destination. Get vaccinated well in advance. Discuss anti-malarial prophylaxis, if necessary with your doctor — some agents may not be suitable for patients with haematological problems, so a suitable drug should be chosen for you.
4. If traveling to a high altitude destination, a high Haemoglobin level may be required, so get transfused before starting off. When you arrive, give yourself time to acclimatize before getting too active.

For further information please visit - **WHO** - <http://www.who.int/ith>

Visit TIF's Website  
for more patient-related sites



# How to contact TIF

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