

Cystic Fibrosis Worldwide

If we don't care who will?

STRATEGIC PLAN 2007 – 2012

Final Version

Contents Page

Vision	3
Mission	3
History of Cystic Fibrosis Worldwide	3
Current Operational Environment	5
Purpose of Strategic Plan	5
Structure of Strategic Plan	6
Use of the Plan	7
Key Activity Areas 1 – 6	8
Goal/Objectives/Strategies	9-21

VISION

All persons living with cystic fibrosis will have access to knowledge and appropriate care.

MISSION STATEMENT

Cystic Fibrosis Worldwide promotes access to knowledge and appropriate care to those people living with the cystic fibrosis and among medical, health professionals and governments worldwide.

HISTORY of CYSTIC FIBROSIS WORLDWIDE

Cystic Fibrosis Worldwide (CFW), formed after the merge of the International Association of Cystic Fibrosis Adults and the International Cystic Fibrosis (Mucoviscidosis) Association, is dedicated to improving quality of life and life expectancy for persons living with cystic fibrosis globally. CFW has 52 member countries with a number of members coming from developing parts of the world. With these new memberships comes an awareness of the desperate situation facing those who have cystic fibrosis, caregivers or medical professionals in developing countries.

Cystic Fibrosis Worldwide reaches out to these countries by working to help develop effective cystic fibrosis treatment and care. This includes helping to organize much needed medications, development, training and education of health care providers, parents and people with CF and spreading awareness of cystic fibrosis at the government and community levels. We seek to find people with CF who are living in countries where cystic fibrosis is thought to not exist and offer them hope for better tomorrows. It is our objective to find a solution that will bring long-term benefits to the existing persons with cystic fibrosis and to those people with CF who will be born in the future, leaving no people with CF behind. Until a cure is found, we will strive to provide humane situations for those who are currently suffering from cystic fibrosis globally.

CURRENT OPERATIONAL ENVIRONMENT

Target Population

The current target population is people with CF, families and medical/health professionals globally. A major effort is placed on reaching those suffering in countries that are currently without any resources to treat cystic fibrosis. Cystic Fibrosis Worldwide also provides services to people living with CF, family members and medical/health professionals in countries already having adequate care.

Funding

Cystic Fibrosis Worldwide is supported by membership fees, volunteer events, donations and grants from the Corporate and private sectors.

Cystic Fibrosis Worldwide Strategic Plan 2007-2012

Key Areas of Focus

Cystic Fibrosis Worldwide works in a number of areas.

1. Capacity building for Cystic Fibrosis Associations and Cystic Fibrosis Worldwide members;
Through the global network formed by the many Cystic Fibrosis Worldwide member countries and partners, newly formed Cystic Fibrosis Associations can access an international support group. Resources that develop infrastructure for long term sustainability and growth are made available.
2. A platform for education and the exchange of information globally;
Through vehicles such as the Cystic Fibrosis Worldwide Website, Newsletter and Conferences, we reach people in over 70 countries.
3. Global voice for Cystic Fibrosis people with CF;
Cystic Fibrosis Worldwide actively lobby's for improved care and access to necessary medication for people with CF globally.

PURPOSE OF THE STRATEGIC PLAN

Cystic Fibrosis Worldwide identified that a Strategic Plan was vital to provide the organization with direction for decision making over the next 5 years, plus a blueprint for action by the management team.

The need for a Plan lies in recognition of both the internal environment of the organization with its increased project-based mission, its aim for financial security and the external environment where decision makers, funding agencies and donors require ever increasing accountability.

STRUCTURE OF THE STRATEGIC PLAN

The Plan is being constructed via a series of consultative processes between the Executive Director, Board and staff members.

The Plan uses the following definitions:

Goals: the overall aims to which the organization aspires and that require a number of Objectives to achieve.

Objectives: measurable achievements via which the organization seeks to achieve its goals.

Strategies: actions needed to achieve the Objectives.

USE OF THE STRATEGIC PLAN

The Plan is to be a blueprint for the direction of the organization over the next five years and a guide for the work of the organization in each individual year.

The elected Board of Directors has the responsibility to prioritize within each key area of activity, the strategies to be executed in each year, then to allocate appropriate resources and a budget for achieving those strategies. This in turn will formulate the annual Business Plan.

KEY ACTIVITY AREAS

We have identified six major activity areas of the organisation:

Key Activity 1 – Capacity Building for Cystic Fibrosis Associations globally

Key Activity 2 – Educate parents, people living with cystic fibrosis and Medical/Health Professionals in the treatment and care of cystic fibrosis

Key Activity 3 – Provide local and international policy and political support to Cystic Fibrosis Associations and people living with cystic fibrosis

Key Activity 4 – Act as a Key Source of international cystic fibrosis information and resources

Key Activity 5 – Support cystic fibrosis clinical care development with a focus on developing countries

Key Activity 6 – Business Management/ Development

KEY ACTIVITY AREA 1 – Capacity Building for Cystic Fibrosis Associations globally

Goal 1

Cystic Fibrosis Worldwide supports capacity building for Cystic Fibrosis Associations internationally.

Objective 1:

Encourage the creation of national Cystic Fibrosis associations that support programs that work to improve the lives of persons with cystic fibrosis.

Strategies:

- Develop Governance frameworks (By-Laws, registration)
- Develop strategic plan templates (business and fundraising plans)
- Support organisational/board development (lobby for parent and community support)

Objective 2:

Develop sustainability for newly formed Cystic Fibrosis Associations

Strategies:

- Develop international network (Cystic Fibrosis Worldwide members, partners and WHO)
- Develop network for families from developed countries to “adopt” families from developing countries
- Educate board members and volunteers (How to write grants, hold events and find corporate funding)
- Support association workshops, meetings and conferences

KEY ACTIVITY AREA 2 - Educate parents, people living with cystic fibrosis and Medical, Health Professionals in the treatment of cystic fibrosis

Goal 2

Administer global education programs that incorporate analysis and evaluation of each country to make programs specific and targeted to achieve a favourable outcome.

Objective 1:

Disseminate education among medical professionals, parents and persons living with cystic fibrosis to ensure appropriate treatment. Reinforce clinical and home therapy and care by training collaboratively i.e. parents – physiotherapists, persons with cystic fibrosis, nutritionist, whenever possible.

Strategies:

- Analyse at least 2 countries per year
- Run educational workshops for persons with cystic fibrosis, parents and medical/health professionals on a needs specific basis.
- Encourage the development of multidisciplinary teams
- Evaluate outcomes from education program
- Operate a granting program for health care providers to obtain an enhanced knowledge of cystic fibrosis centre

Objective 2:

Support the development of appropriate treatment models.

Strategies:

- Evaluate information collected during the analysis
- Collaborate with local medical/health professionals to develop appropriate treatment plans
- Encourage the involvement of health ministries and opinion leaders to assist with the sustainability of the treatment plans

KEY ACTIVITY AREA 3 – Provide local and international policy and political support to Cystic Fibrosis Associations and people living with cystic fibrosis**Goal 3**

Be a leader in political and policy support for persons living with cystic fibrosis globally.

Objective 1:

Develop a network with partners in the cystic fibrosis global community such as Cystic Fibrosis Worldwide members, international working groups and the World Health Organization to bring awareness of cystic fibrosis and the needs of persons with cystic fibrosis at the local and international levels in government, health and public sectors.

Strategies:

- Lobby to have necessary medicines for cystic fibrosis included on the WHO necessary drug list
- Assist in the development of a global registry to bring awareness of the prevalence of cystic fibrosis
- Facilitate epidemiology studies among large populations in areas where cystic fibrosis is thought to not exist or is considered rare

- Support regional projects to increase awareness and support for persons living with cystic fibrosis

Objective 2:

Lobby governments and private sectors of individual countries to ensure support for persons living with cystic fibrosis.

Strategies:

- Support persons living with cystic fibrosis who are experiencing segregation or human rights violations because of cystic fibrosis (letters to officials, information translated in local languages and access to renowned opinion leaders)
- Lobby for access to medicines and appropriate treatment for all people with cystic fibrosis
- Utilize the member network and partnerships with international cystic fibrosis working groups and scientific bodies to ensure appropriate care levels are achieved

KEY ACTIVITY AREA 4 - Act as a key source of international cystic fibrosis information and resources

Goal 4

Provide a platform for the exchange of information eliminating language barriers and opening lines of global communication among parents, people with cystic fibrosis and health care providers in the management of cystic fibrosis.

Objective1:

Offer a public forum via the Cystic Fibrosis Worldwide website and newsletter that relays current information and facilitates access to professionals to share knowledge, experiences and the latest developments

Strategies:

- Maintain a multi-language website (Forums, Publications, member updates, Press Releases, conference news)
- Deliver the Cystic Fibrosis Worldwide newsletter 3 times per year
- Develop a program for an annual seminar to be held in conjunction with Cystic Fibrosis Worldwide meetings

Objective 2:

Develop member networks

Strategies:

- Produce a member newsletter quarterly
- Produce online updates and information via email
- Offer ways for members to participate or partner in programs

KEY ACTIVITY AREA 5 - Support cystic fibrosis clinical care development with a focus on developing countries

Goal 5

Provide a network able to assist in the development of clinical care and specialized treatment of cystic fibrosis in countries without appropriate care facilities

Objective 1:

Support the development of specialized cystic fibrosis care centres in existing hospitals that will be maintained by domestic health care programs and local donors

Strategies:

- Assist in the development of a sustainable program
- Lobby government, opinion leaders and decision makers for support of cystic fibrosis care
- Utilize networks to assist collection of equipment, supplies and funding to establish clinics
- Evaluate the program outcomes to ensure continuous improvement

Objective 2:

Improve daily care for people with cystic fibrosis to increase quality of life

Strategies:

- Facilitate the supply of necessary equipment for daily care
- Develop a model to train medical/health professionals to work towards establishing home care
- Develop home treatment plans with people with cystic fibrosis, parents and medical professionals
- Lobby for support of home care for people with cystic fibrosis

KEY ACTIVITY AREA 6 – Business Management/Development

GOAL 6

Cystic Fibrosis Worldwide effectively manages its resources and continues to develop strategies to improve governance, policy and operations of the organization.

Objective 1:

Develop an annual plan based on the strategic plan that will engage the Board, members, staff and stakeholders in collaborative action to aid persons living with cystic fibrosis.

Strategies:

- Develop an annual budget for the operations of Cystic Fibrosis Worldwide
- Develop business plans and budgets for each project
- Develop an organizational chart
- Develop and review governance policies/procedures as necessary

Objective 2:

Develop strategies that enable the implementation of the strategic plan

Strategies:

- Increase staff
- Increase global awareness
- Develop a Board recruitment/selection process to ensure necessary skill sets are available

Objective 3:

To facilitate and manage the acquisition, development and growth of all resources to maintain the viability of Cystic Fibrosis Worldwide

Strategies:

- Develop and implement policies for financial administration of the organisation
- Follow sound financial management procedures in gaining and distributing funds
- Allocate funds and resources in line with the identified priorities and objectives of Cystic Fibrosis Worldwide
- Provide direction to and support to all human resources of the organisation
- Negotiate with funding agencies for expansion of budgets
- Explore and access a range of government and business funding programs and other appropriate sources for monies to expand options for the benefit of members

Objective 4:

To attract and maintain highly skilled staff and volunteers

Strategies

- Attend to the engagement and management of appropriate staff/volunteers in line with the developing objectives of the organization
- Ensure staff/volunteers roles are guided by clear and comprehensive job description statements
- Provide a safe and professional working environment for all staff
- Identify staff training needs through performance appraisals and provide access to professional development
- Provide appropriate benefits for staff such as competitive wages, health insurance, pensions etc.
- Recognize staff and volunteer efforts

Final Version