ANNEX 10.1
Report work shops

10.1.1 Sint- Niklaas, Belgium – February 27 to March 2 - 2003

10.1.1.1 Program

Friday, February 28

Morning:	getting to know each other (volunteers only) Evaluation of needs and expectations in existing NF groups (represent. only)
Afternoon:	medical, psycho-social consequences of NF (Prof. E. Legius) (volunt. only)
Evening:	dinner in Sint-Niklaas

Saturday, March 1

Morning:	an introduction to self-help groups and patient associations (volunteers and representatives)
Afternoon:	"starting" a patient association (volunteers and representatives)
Evening:	Antwerp by night

Sunday, March 2

Morning:	evaluation and departure

10.1.1.2.Summary report

Introduction

There is sufficient evidence that in countries where patient organisations for neurofibromatosis (NF) are active, patients and their family are better informed and are therefore more able to cope with all the consequences of the illness. It is also clear that public and scientific interest in countries where patient organisations are well established, is higher, that patients and families involved are less isolated, that health professionals have more knowledge and understanding, and that the patients and families involved have more support and more opportunities to cope and deal with NF.
It can however not be ignored that differences among the many self-help groups and patient organisations in Europe exist: some are already in existence for many years, are well established and structured, have good contacts with professionals and policy, develop special programmes and particular services a.s.o. Others are just starting and developing, thinking about how to go about, how to reach members, how to organise and set up services.

Two concepts are fundamental to the overall aim of this project which is an initiative of the European Federation for Neurofibromatosis Associations (NF-Europe): to spread knowledge and experiences about all aspects of neurofibromatosis among members and to collaborate in order to ameliorate the situation of NF-patients all over Europe.
In light of the differential development of NF-organisations in Europe, the challenges (which at the same time should be considered as opportunities) the project faces are:

- To cover new grounds: starting NF-organisations in countries where they are now non-existent or embryonic; expanding of existing associations
- To re-think current practices and approaches: exchanging and streaming existing methods or approaches, developing new ones
- To create and underlying, supportive network of experience and practice
- To foster the continuity of associations in attracting and training new volunteers
- To use existing foundations of, on the one hand, self-help practice in Europe, on the other particular practice and experience of existing NF-associations.

Overcoming these challenges or seizing these opportunities, should lead to a solid, future oriented base for the functioning of NF-associations and groups, both new and old, in Europe and to the development of a "uniform" approach in managing groups and associations (taking into account cultural, political, social and other differences) in order to foster participation of NF-patients/families, thus ameliorating living conditions at large of people with neurofibromatosis.

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In quite a number of patient organizations finding and keeping active voluntary workers, is often quite troublesome. Associations are mostly started out of sincere personal commitment by a limited group of people who experience the problem themselves as a patient or a relative. They often perform a huge task in setting up the association from scratch, constantly and tirelessly taking up new tasks and challenges with admirable enthusiasm. At a certain moment they would like to cut down on their commitment and involvement but are faced with the fact that active volunteers are scarce. People who do candidate indeed often come with less commitment, are only willing or able to perform specific tasks and are also frequently more scanty with the time they want to put in. Since they in addition sometimes lack knowledge and experience, the founder-volunteer(s) often willy-nilly continue(s) to work, sometimes at the risk of burnout, in some cases associations are even discontinued because of the absence of appropriate succession.

NF-Europe acknowledges the challenge of continuity and succession of its patient associations. For the training-program of this project it therefore specifically chose to work with “new” volunteers in order to foster continuity for the medium range, to relieve the workload and in some cases to break through traditions or deadlocked habits. Each member association was therefore asked to select and delegate two “new” volunteers to the training program of this project. These motivated outsiders or newcomers committed themselves to follow the entire training program and to actively perform voluntary work at least for three years in the delegating NF-association or institution. The group of volunteers that in this way was put together, met for the first time in Sint Niklaas for the first of a series of training workshops. The mix in experience, education, theoretical and practical foreknowledge in NF and in patient organizations they presented, made thorough introductions to social and medical consequences of NF and to the background and functioning of patient organizations much-needed. This first workshop should therefore be considered as specific and fundamental first steps on which the next trainings will be grafted. Exceptionally – the next workshops will be for volunteers only – also representatives of national NF-associations attended parts of this first session.

Report according to program

Thursday evening session: Presentation of the project’s aims and purposes (volunteers only)

During this first introductory session, the overall aims and purposes of the project were presented (see introduction) as well as the themes and subjects of the entire training program for volunteers. Especially highlighted were the expectations towards the volunteers as well as their expectations towards the project and program. Also, some practicalities and “rules of the game” were addressed.

Friday morning session B: Getting to know each other (volunteers only)

This entire session was dedicated to get to know one another, to get rid of the initial discomfort and nervousness that characterizes new groups and to create a pleasant yet productive atmosphere. Among other warming up and acquaintance exercises, “name games” were played, couple interviews where partners assessed personal interests and backgrounds, education, trivia a.s.o. and were then asked to present their conversation partner to the entire group, etc.
During a discussion in small groups, volunteers were asked to list their motivation to volunteer, what they would like to learn during the course of the training program, their expectations and fears in this regard on a personal level, when this training could be considered a success, and finally, what they ideally would like to achieve with the organization they are volunteering for. At random, some of the remarks were:

> Motivation: getting to know and work with people from all over Europe, to complement theoretical education with practice, to work with and for the people only known to me from laboratory work, ameliorating professional skills with practical skills, to learn from multiple experiences, to help people with NF and their organizations, …

Learning experience: to learn more about personal and social consequences of NF, how to set up an NF-association in Poland, social and group skills, increased knowledge of NF, how to motivate people to join an association, how to set up activities and services for youngsters with NF, how to work more effectively and efficiently in the NF-association, how to communicate with professionals, …

The training is a success, achievements: when new associations can profit from the experience of older ones, when personal growth is achieved, when goals are clearer and things are more planned ahead in our association, when professionals are more involved in the patient association, when an organization has been set up in our country, when we can better assist local organizations and families, …

Friday morning session B: Your organization through a looking glass (representatives)

While volunteers were getting to know each other, the representatives of national NF-associations during a simultaneous session, performed a sort of SWOT-analysis of their respective organization. By means of an open questionnaire, they listed the plus points and minuses with regard to 1. aims, objectives and methods, 2. membership, 3. assignment of tasks, 4. recognition, 5. achievements and 6. ameliorations/changes.

The results of this analysis will prove useful in customer-tailoring the training program for volunteers to the needs of the organization they will be working for, or, in other words, to set priorities for the work ahead in developing and expanding the organizations in particular countries. The analysis will also be useful and used to determine fields and areas where particular organizations are successful. In these areas they can serve as models to be followed. It will also be used to determine fallow grounds, uncharted working areas that NF- associations are not covering thus far but should be covered in order to achieve their overall aims.

A first review of the questionnaire with regard to “aims, objectives and methods” shows that the larger part of existing NF-associations do state to have clear aims, but surprisingly, only few of them are able to really list them. Apparently it is difficult to concretize what is often only in the heads of a few highly committed members. Communication about aims and methods with relevant outsiders or ordinary members seems absent. It is also apparent that aims and objectives are only seldom revised or at least evaluated. This leads to the assumption that quite some associations do things because they “ feel they just have to do something” but without concrete planning or methodology. As for hindrances in the achievement of aims and objectives, lack of money and active involvement or participation as well as practical obstacles are often mentioned. Finally, respondents note that the methods they use are probably not always efficient and effective.

10.1.2. Glyfada Greece – September , 2003

10.1.2.1 Program

Thursday, September 19, 2003 – evening session

Welcome
Getting re-acquainted
Outlining this weekend's course
Practicalities and arrangements

Friday, September 19, 2003

Session I	starting an NF-group:	formulating a mission, aims and purposes
Session II	starting an NF-group:	getting organised (setting up a core group, finding members, formulating an offer, recruiting members)

Saturday, September 20, 2003

Session III:	public relations for self-help groups (theory)
Session IV	public relations for self-help groups (practice: press release, devising a folder, using the internet, working with the media, hindrances and pitfalls)

Sunday, September 21, 2003

Session V: Closing
Home assignment(s) = 1. compiling an public relations grid of your NF-group (describing pr-instruments and target audiences);
Departure

10.1.2.2 .Summary report

The purpose of the three day workshop in Glyfada (Greece) was to let the NF-volunteers into the secrets of how to set up an NF-group. Some volunteers indeed work for already existing organisations; but when looking at laying dawn the foundations of a hypothetical new group, lots of principles and working methods that are or can be used for the development of already existing groups also pass in review.

Starting from the mission statement: "The association is committed to securing excellent medical services, accurate information, guidance, support and counselling services for all NF-sufferers and their families and also to the promotion of research aimed at finding a cure for the condition" and from the general aims and purposes of a NF-group that were elaborated during the first workshop, participants were given the assignment to describe and elaborate in detail the start of a new NF-group: how to establish a core group or steering committee of like-minded people (it's not a good idea to start a self-help group all by yourself) and how to recruit the first members. Participants a.o. had to design a rudimentary folder, write a press release and devise a public relations grid (pr-instruments combined with target audience).

Reviewing the small group work was alternated with "theoretical sessions" on public relations: principles, preconditions, review of pr-instruments that are affordable for self-help groups (folders, brochures, posters, press conference) and working with the media. Since the internet by many self-help groups is viewed as the ultimate solution for solving organisational problems such as lack of money, collaborators or adequate communication channels, ample time was spend on reviewing the possibilities, but certainly also the pitfalls of running an internet-based self-help group on NF.

The last session of this second training workshop was spend to address effective and efficient working methods that could be used to meet the need for emotional and social support of NF-sufferers and their families: organising and running discussion groups and individual counselling. Unfortunately, the time was too short to practise individual listening and responding skills or to exercise leading a discussion group.

As a home assignment, participants were asked to elaborate a detailed public relations grid of their organisation, listing the various audiences they come across and all the materials used to give information on NF and on the functioning and activities of their organisation. This assignment served a double purpose: rendering new volunteers insight in the organisational network of their NF-group; providing the project's staff information to include in the country-specific section of NF-Europe's website.

10.1.3. Krakow Poland – April 22-25 , 2004

10.1.3.1 Program

There was no fixed programme in Krakow, just a time table to follow indicating breaks and meals. Participants worked the entire weekend in small groups on an assignment: a fictitious NF-group that after an initial start-up year, in its next years was expected to develop activities, produce informational materials, find money a.s.o. in order to achieve 5 specific objectives. Their work was constantly monitored and evaluated. In between, participants where given extra assignments, simulating unexpected events that are bound to occur while operating a NF-self-help group

10.1.3.2. Summary report

Group assignment: "describe what you will do during the next working year to reach the following objectives:

1. <u>By the end of the working year, membership of NF-families should be doubled; proportionately, attendance at activities and use of services should be increased.</u>

Background: Your organisation counts 249 members (210 + 39) today. Only six percent of the estimated number of people with NF in your country has joined so far. There are however already people calling upon your organisation without becoming a member (and paying a fee). A larger number of members will increase your credibility, influence, and income; more knowledge about perceptions, experiences, and difficulties surrounding NF will become available. In all, more members could increase the strength of your association in several fields. At a personal level, knowing that you are working hard for a considerable number of people is more rewarding and indeed helps to stay motivated.

Some things that could be considered:

- How to locate potential members (who knows where to find them)?
- Which instruments/channels to choose to conduct a membership campaign?
- Costs
- Timing and strategy
- How to 'convince' people (attractiveness, appeal of your association (a good offer))
- Consequences of growing membership?
- Possible links with other targets?
- …

2. <u>Specific activities and services for youngsters (children, adolescents and young adults) will be arranged.</u>

Background: Most of the time it is always parents attending meetings and activities, which contact you over the phone for information or a personal talk. You therefore only reach younger patients indirectly. Your organisation however also wants to matter for them and offer solutions for the problems they encounter (learning and perhaps other disabilities, dependency, employment, …)
the things they worry about (friends, recreation, feeling, 'abnormal' or an 'outsider'...) and offer 'customer-tailored' information.
You want to set up activities and services that are beneficial and of interest for the 'youngsters' right now, but are also future-oriented, offering them sound foundations for life.

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Some things that could be considered:

- "attractive" activities and services linked to youngsters needs and expectations
- "beneficial" services and activities for youngsters
- Costs
- Timing and strategies, means
- Practicalities
- Scale
- …

3. A national awareness day will be organised

Background: Traditionally, each year beginning of May, in several countries in Europe a public awareness campaign on Neurofibromatosis is being organised. It is a one day activity aimed at catching the attention of the public at large, policy-makers, and the broad professional field on the consequences of NF and the needs of people affected. Getting in the picture, putting neurofibromatosis on the map, inevitably means using the media. The final outcome of the awareness day should be to get as much attention for NF as possible.
There is no specific theme for this awareness day laid down (yet?)

Some things that could be considered:

- How to make it newsworthy (an interesting "message", approach, event)
- How to "approach" the media
- Timing and strategy
- Costs
- Content
- Consequences
- …

4. People with NF (and their families), people at risk, and relevant professionals will be more fully informed about the medical, genetic and psychological aspects of NF.

Background: Providing recent and correct information on various aspects of NF is for most associations of crucial importance. Thus far you had a half-day symposium, there is a rudimentary newsletter and 1 sheet leaflet.

Information for people affected and their families is indeed important to gain control over their situation, to come to terms with consequences, to learn to handle them and to cope. In sum, solid information arms people, makes them less dependent of professionals and offers them the possibility to choose. Patient associations also often offer their members (and others) practical information by bringing experiences and models of good practise together for the profit of others.
Associations wish to inform various audiences: their members, carers, educators, and professionals, people at risk a.s.o. The information aimed at "outsiders", is often about gaining understanding and developing a special approach for the particular needs of people with NF.

Some things that could be considered:

- Instruments
- Validity of information
- Accessibility
- Target audiences
- Timing and strategy
- Completeness, comprehensiveness
- Costs
- …

5. The association will secure a more solid operational foundation

Background: Reaching the above targets without “solid” foundations are impossible. You are therefore looking for a healthy, future-oriented structure, reliable sources of income, a supportive network, committed volunteers and helpers, perhaps secretarial offices, professional staff (?) a.s.o.

More solid operational foundations will safeguard the future, since the association as such becomes less dependent on individual’s sometimes unstable commitment. Tasks and responsibilities can be delegated or split up (which could prevent burnout or oligarchy), specific expertise could be attracted, a.s.o. It goes without a saying that a solid financial base will also prove very helpful.

Some things that could be considered:

- How could the future organisational chart of your association look like?
- What is needed to achieve this?
- Where to find it?
- How to get it? (strategies and possibilities, instruments)
- Costs
- …

10.1.3.3. Evaluation:

Participants were not just asked to brainstorm and simply list ideas. They were forced to elaborate various aspects in great detail: budgeting, sketches of folders, elaborated descriptions of information materials, and the full planning of an NF-awareness day a.s.o.

During report back in plenum, plans, ideas and concepts were put to the test and critically reviewed in terms of efficiency, effectiveness and realism.

The results of this exercise will be, adequately revised and evaluated, serve as inspiration for local and national groups while developing their activities in the years to come.

All these training workshop was conducted by a well experienced staff member of Trefpunt Zelfhulp vzw, a university based support centre in Flanders (Belgium) a.o. specialised in offering training to various self-help groups. It seemed that such targeted training is not widely available to self-help groups in Europe, let alone for self-help groups in particular.