Call for proposals:
RD/2002-1295/99/EG-SANCOG/4
01.11.2002 – 01.11.2004

Project:
Establishing a European Neurofibromatosis lay group network.
Health promotion, improving health information and knowledge for NF in Europe

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# 1. General information on the applicant

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<th>Name of applicant</th>
<th>European Federation for Neurofibromatosis Associations ivzw</th>
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<tr>
<td>Legal representative</td>
<td>Mia De Scheirder-Desmet</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>NF EUROPE ivzw</td>
</tr>
<tr>
<td>Address</td>
<td>Slachthuisstraat 73</td>
</tr>
<tr>
<td></td>
<td>9100 - Sint-Niklaas - Belgium</td>
</tr>
<tr>
<td></td>
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<td><a href="mailto:info@nfeurope.org">info@nfeurope.org</a></td>
</tr>
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<td>Registration number</td>
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<td>Contractual representative of the project:</td>
<td>DE SCHEIRDER-DESMET Mia</td>
</tr>
<tr>
<td></td>
<td>president NF EUROPE volunteer</td>
</tr>
<tr>
<td></td>
<td>Telephone: +32.495.22.55.08-</td>
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<tr>
<td>Project leader</td>
<td>Do SOCORRO COSTA De LEMOS Lúcia</td>
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<td></td>
<td>President APNF Lawyer, Lecturer University Lisbon,</td>
</tr>
<tr>
<td></td>
<td>Telephone: +351.21.934.39.59  Fax: +351.21.934.39.60</td>
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2. Summary of Aims and Achievements

2.1 To establish a European NF-network through linking the existing neurofibromatosis lay groups and to strengthen the collaboration among them. To investigate and evaluate the needs of people affected and their families. To integrate new lay groups from EC and other European countries and provide know-how and information.

2.1.1 “To establish an European NF-network through linking the existing neurofibromatosis lay groups and to strengthen the collaboration among them.”

**Achievements:**
From its establishment in 1999 NF EUROPE, due to its nature of being an umbrella organisation of more disconnected voluntary organisations, only functioned as a rather symbolic and loose conglomerate of some European NF-groups. The EC-program achieved permanent reinforcement of the organisation’s structural foundations, provided opportunities, ways and means to augment and embed collaboration among existing lay groups and developed activities and tools to enhance support, future networking and reaching out to young or new NF organisations. Timely business and planning meetings, workshops, training, a joint website and synchronised national activities are examples of the methods used to achieve this.

2.1.2 “To investigate and evaluate the needs of people affected and their families.”

**Achievements:**
Management of hereditary diseases and treatment of their consequences, is in many European countries, still the case of often strictly separately operating professionals and their institutions. Partitions, borders, exist between the health, the social and psychological professions preventing a “holistic” approach to dealing and living with NF. Basic assumptions on medical treatment and on handling psychosocial, emotional and occupational consequences of NF use the professionals’ premises instead of focussing on the cross-bordering needs and demands of people affected by NF and their families. During meetings and workshops, the apparent and all embracing needs of people affected and their families were listed, providing a starting point for actions to be undertaken by patient organisations themselves, and professionals at various units and institutions. The conclusion of the needs’ evaluation can be summarised as the necessity to develop multidisciplinary teams or units for the treatment, counselling and guidance of people affected and their families in which NF lay-groups are considered as equal partners with unique complementary activities and services using a comprehensive approach.
2.1.3 “To integrate new lay groups from EC and other European countries and provide know-how and information.”

**Achievements:**

At its establishment in 1999, some NF groups were reluctant to join just a loose young network because return on investments were not immediately noticeable and clear strategies on how to ameliorate the situation of people affected and their families and on how to strengthen the own organisation’s decisiveness through European collaboration were lacking. Moreover, transnational collaboration is expensive, in particular for voluntary lay-organisations.

At the start of the project NF lay groups from thirteen countries participated in NF EUROPE’s EC project. Almost immediately after the start, other NF lay organisations already expressed an interest to join the network and participate in the project. In the end five more countries joined the network. Also, in particular countries where no lay groups existed thus far, the project and network triggered the initiation of new lay groups who could put the manual on how to establish and maintain NF family support groups, developed through the programme, immediately into practice. They also profited from the already ongoing exchange of information.

2.2 To develop a volunteer training program in order to help people affected for better socialization and enable them to cope with the disease.

**Achievements:**

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.

On the other hand, in quite a number of patient organisations, 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 however they like to cut down on their commitment and involvement but are faced with the fact that active volunteers are scarce.

The project therefore developed and conducted a training programme for new volunteers to safeguard the future of NF lay groups, prevent volunteer drop out, and improve the quality of service delivery and support. During training workshops and “home assignments” new volunteers learned how to run or contribute to their national NF-family support group thus offering emotional support, information and emancipation to people and families affected in their country.
2.3 To increase awareness about NF at a European level focusing on professionals, people concerned and the European society (organising public awareness campaigns, designing a web page for disseminating contemporary information about NF)

**Achievements:**
Part of the training program for volunteers was dedicated on how to set up public awareness campaigns in their country using the media, developing eye-catching events and promoting their organisation. During May 2005, a co-ordinated NF public awareness week aimed at professionals, politicians and the society at large will be held in each participating European country. A website introducing NF but particularly centred on the existence of support groups and professional help has been developed: [www.nfeurope.org](http://www.nfeurope.org)

2.4 To produce educational materials for people concerned (patients, social workers, teachers, and medical professionals).

**Achievements:**
An inventory of educational materials available in various countries and languages has been established. An overview of the most relevant materials can be found on NF-Europe’s website ([click: publications](http://www.nfeurope.org)). Particularly for support groups, a manual on how to start and maintain support groups was developed and translated. People interested in starting a group in their country, can receive a copy of the manual in their mother tongue at a simple request. Existing organisations use the manual as a guiding principal for their daily work and at turning points in the advancement of their organisation.

2.5 Through sharing experience to investigate the medical and social needs of people affected and to create recommendations and guidelines for evidence based managing the various aspects to NF.

**Achievements:**
Guidelines and recommendations for evidence based managing of NF have been established in close collaboration with leading experts on NF in Europe. They are translated into various European languages and will be made available and public through the respective national NF lay groups.
3. Description of activities, achievements, tasks, assessments and follow-up.

3.1 Description of activities and tasks

3.1.1 Adapting the existing office and widening the established NF network

The execution of such an ambitious programme was not obvious, at least not for a lay organisation purely relying on volunteer commitment and effort. It also challenged the knowledge and expertise, and the central office’s requisites at hand. It was therefore necessary not only to bring logistics and office equipment to a (semi) professional standard (extending means of communication, ICT, equipment) but also to seek support from experienced professionals to bring the content and organisation of the project to a favourable end.

Trefpunt Zelfhulp vzw, a Flemish, university based and government funded, self-help clearinghouse that has been supporting, training and guiding self-help groups and patient organisations in Flanders since 1982, agreed to carry out the volunteer training programme and assist in the development of the project materials. As a leading expert in the field of training and education for self-help groups and patient organisations among national self-help clearinghouses and support centres in Europe, Trefpunt Zelfhulp vzw can present ample experiences and excellent references.

Thinksmart bvba, a private firm specialised in ICT, organisation and finance, responded positively to NF-Europe’s appeal to offer expert guidance and consultation in these matters.

Employees of the two above mentioned ‘outside’ agencies together with NF-Europe’s chairperson were appointed ‘project staff’ at a special meeting of the Board of Directors. (annex 1) They were entrusted with the accountability to bringing the project to a good end. During this meeting aims, distribution of work, methods and finances were meticulously investigated as well as means, arguments and instruments to solicit participation of national NF lay groups in the project.

The actual launch of the project was the appeal to NF lay groups in Europe to participate in the project, to budget their participation, reserving finances and selecting new volunteers (see also 3.1.3.) who were able and willing to follow the training programme and committed to work for their respective NF lay group for at least three years. (annexes 2, 3.1, 3.2, 4, 7, 8, )

3.1.2 Evaluating needs

As mentioned earlier, the basic assumption of treating and managing NF is seemingly always a professional one. Also, when the functioning, results or methods of patient organisations or lay support groups are assessed, only professionals’ weights and measures are used in only the areas where professional expertise is at hand or already developed. In addition, treatment, consultation and guidance of people with NF and their families is often offered dispersedly with few connection between the various professional disciplines that can be involved.
NF-EUROPE advocates an “holistic” approach to treating NF and managing a life with NF, an approach that also should be reflected not only in the way the NF lay groups work but also in the development and extension of professional services and support. “Holistic” must not be understood as some kind of alternative medicine or voodoo treatment, but as an expression of the conviction that effective treatment, support and managing of NF can only be successful and beneficial when all aspects of the condition are envisaged and receive equal attention.

Drawing up an inventory of all the needs of people with NF and their families was essential to this project. The inventory serves as a guiding principle for the various national NF lay groups but also signalises professionals that NF is much more than a pure “medical” condition. In Bulgaria for instance, NF is largely approached as a purely medical problem; the Bulgarian NF association hence also only focuses on “medicine. The professionals as well as the lay group profited enormously from the introduction to the way all the problems surrounding NF, medical, social, psychological, occupational, …, are tackled in Belgium by multidisciplinary teams of experts and how this approach was triggered by the Belgian NF-association.

During the first workshop in Sint-Niklaas, representatives of NF groups as well as the new volunteers, listed “all” the needs of people with NF and their families. (annexes 5, 6) In addition they examined NF lay groups' contributions to solving or alleviating these needs or identifying ways of meeting these needs outside their organisations (medicine, policy, professional counselling, ...). At the same occasion board members of the different NF lay organisations evaluated strengths and weaknesses of their association, identifying areas where organisational improvements were necessary or exchange of expertises and approaches within the network should be fostered or incorporated in the project.

It goes without saying, that the needs and expectations of people with NF and their families were the constant guiding principles in all activities and products of the project.

3.1.3. Training program - workshops

As mentioned earlier, in quite a number of NF lay-groups, finding and keeping active voluntary workers is often quite troublesome. The lack of skilled and active collaborators often prevents groups to develop their full potential. In addition, cart pullers are often patient or relative themselves and are therefore often restricted in means, time and energy.

NF-EUROPE acknowledges the challenge of continuity and succession in its patient associations. For the training programme 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 dreadlock habits caused by “managerial anaemia”. As a condition to participating in this project, each NF-EUROPE member association was therefore asked to select and delegate two “new” volunteers to the training programme of the project. These motivated outsiders or newcomers committed themselves to follow the entire training programme and to actively perform voluntary work for at least three years in their delegating NF-association.
As an additional condition, these “new” volunteers should also carry an educational or professional background in the broad area of treatment and management of NF. Stipulating this condition was intentional: NF-Europe and the respective lay group was strengthened by particular professional knowledge; at the same time, the “professional volunteer” could serve as an instrument to dismantle the existing partitions between lay groups and professional in their institutions or workplace. “New” volunteers are for example lawyer, nurse, genetic analyst, surgeon or psychologist.

Volunteer advertisement and selection was conducted in close collaboration with genetic counselling centres or geneticists all over Europe.

(annexes 7, 8)

The purpose of the volunteer training programme was to establish a ‘solid’, forward looking base for the functioning of NF-groups and organisations, both new and old, in Europe and to develop a ‘uniform’ approach in managing and running groups/organisations (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.

Challenges and opportunities were to cover new grounds (starting NF-associations in countries where they are non-existent or embryonic – expanding of existing associations); to re-thinking current practices and approaches (= exchanging and streaming existing methods or approaches, developing new ones); to solve mutual problem areas; to creating an underlying, supportive network of experience and practice; and 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.

In sum, the training programme was designed to teach volunteers how to build, manage and expand an NF lay organisation. Themes of the programme were:

- About life and living in a self-help group / patient association (processes, influences, approaches and methods, …)

- ‘Starting and running a patient association (aims and objectives, recruitment, structure, group dynamics, fundraising, publicity, …)

- Skills (communication and interaction, leadership skills, public relations, conflict handling, decision-making, …)

- Ethics (privacy, confidentiality, loyalty, …)

(annex 9)

Training to new volunteers was offered during three workshops. The workshop in Sint-Niklaas (Belgium, February 17 – March 2, 2003) focussed on needs and expectations of people with NF and their families. Ample time was also dedicated to introduce genetic and medical information about NF to the volunteers. In Glyfada (Greece, September 18 – 21, 2003) emphasis of the training was laid on setting up and managing a new or young NF-association.
Volunteers were taught the ins and outs formulating a mission, aims and purposes, how to get organised and conduct public relations for their theoretically new NF lay-organisation.

In Krakow (Poland, April 23 – 25, 2004) there was no fixed training programme but a group assignment small working groups worked upon the entire weekend: 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 five specific objectives. Their work was constantly monitored and evaluated. The result of this “exercise” will, adequately revised and evaluated, serve as inspiration for local and national groups while developing their activities in the years to come.

(annexes 10, 11 12 )

3.1.4. Developing educational materials

The development of educational materials was one of the specific aims of NF-EUROPE’s EC-project. It can indeed not be ignored that differences among the various NF lay groups 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. In stead of forcing people to constantly re-invent the wheel, the project succeeded in bringing together, skills, knowledge and experience presently at hand at various places and developed new materials for lay NF groups to use during the different phases of their organisational development.

A manual on starting, running and maintaining NF support groups was elaborated, offering “old” and “new” groups guidelines on how to go about with issues such as publicity, collaboration, privacy, planning, giving information, and so on. It should be considered as a workbook with tips and advices, and as a tool to save time and work effectively and efficiently from the start. The manual is translated in each of the languages of the participating countries.

(annex 13)

Information on all aspects of NF is crucial to people affected and their families. Information offers insight, makes people less dependent of professionals, and initiates the development of coping strategies. Practically every NF lay group tries to inform people affected and their families. The quality of the information offered (brochures, folders, the internet) however differs widely, being sometimes obsolete or incomplete. During this project, information materials of participating lay groups were listed and evaluated according to standards presented during the training workshops. Materials satisfying these standards were listed on NF-Europe’s website and the member pages. With this, NF-Europe wishes to make sound information accessible to all NF suffers and their families throughout Europe, preferably in their own language. It goes without saying that when medical or other specialised information is involved, nationally or internationally acknowledged experts served as reviewers of the information and materials concerned.

(annex 14)
The internet being a major source of information nowadays, the project developed a website offering an overview of NF-associations in Europe, medical information, sources of help a.s.o. This website is not intended to double the work of already existing ones. It serves as a tool to guide people to an NF group in their country, to find information in their language so that little time is lost to tackle the medical, social or psychological problems. The website is also instrumental as a communication and network tool for NF-Europe as a whole and as a signing board for professionals, policy makers and society as a whole.
(annex 15, www.nfeurope.org)

3.1.5. Evidence based recommendations
In the course of this report, it has already been said several times that guidelines on how to treat the medical consequences of NF and how to manage its psycho-social effects, differ according to the point of view of the professional expert involved. During the international scientific NF congress in Türku (Finland, July 24 – 27, 2003) meetings between persons with NF, their relatives and international experts on NF, laid the foundations for elaborating evidence based recommendations on how to treat and manage the consequences of NF. These important recommendations that start from the needs of patients and their families, are used now as standards for taking care of newly diagnosed persons thus saving them not only time, but also useless or non-effective interventions, misinformation, and also prevent misdiagnosis, or –treatment and offer future oriented “holistic” support for persons affected and their relatives.
(annex 16)
3.2 Description of Achievements

3.2.1 Expanded network and stronger co-operation between groups
At the start of the project NF lay groups from thirteen countries participated in NF EUROPE’s EC project. Almost immediately after the start, other NF lay organisations already expressed an interest to join the network and participate in the project. In the end five more countries joined the network. Also, in particular countries where no lay groups existed thus far, the project and network triggered the initiation of new lay groups.
Thanks to regular meetings during workshops and training, responsibles of lay groups and volunteers could personally meet and build co-operation. Communication between lay groups increased; they learn about each other’s projects and progress through the website, they exchange written materials (some translated into their own language) and work according to a “central” agenda” (e.g. with respect to the public awareness campaign 2005).
Thanks to the EC-project, the credibility of NF-Europe as a serious, reliable and knowledgeable partner in the management of the consequences of NF increased with professionals. It can be observed that professionals now contact the lay groups while earlier this was quite the opposite and exceptional.

3.2.2 Mapping of needs and expectations
For the first time in NF-Europe’s existence, the needs of people with NF and their families are pointed out, not founded on professionals’ premises, but taking the patients and their families as a starting point. The inventory of needs and expectations is used as a future road map for the activities of the lay groups. It also serves as an orientation point for professionals clarifying that living with and managing NF is a matter seeking balances between medical, psychosocial and occupational interventions. It also maps virgin territories in the management and treatment of NF such as occupation/job and social relationships.
(annex 6)

3.2.3 More solid operational basis of the different groups
It was gratifying to see that during meetings and training, volunteers and responsibles of groups were constantly comparing what their organisation did and how it did it. It can now be observed that programmes, methods and approaches are being copied or at least adapted and that cross-pollination is spreading.
It can also be observed that the “new” volunteers are almost everywhere taking up their role and responsibility and work according to guidelines and recommendations that were communicated and trained during the training programme.
Some “new” volunteers have taken up seats in the board of their organisation and have already expanded their lay initiative beyond the initial personal, individual (self-centred) ambitions of the founders.
The “new” volunteers are young people, skilful in communication, the Internet and languages. A younger age combined with enthusiasm and motivation, seems to enhance commitment and pulls lay groups ahead. The professional background and skills these volunteers brought along, also reflects positively on the development of the lay groups and especially on their societal range. The “new”, young volunteers, credible because of their professional background, also seem better equipped to pull down the boundaries between patients and professionals.

As a whole, NF lay groups, thanks to the opportunities offered by the projects and to the involvement of new volunteers, are starting to function in a more structured manner, devising working plans aimed at the medium term in stead of working quite by accident or by inspiration of the moment. Although voluntarism is still the basis of involvement in the lay groups, the concept of “management by objectives” is being introduced, raising effectiveness and efficiency.

3.2.4 Indirect result: efficient lay groups – better management of NF

There is sufficient evidence that in countries where patient organisations for neurofibromatosis are active, patients and their families 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.

The better NF lay groups are organised and the better the quality of their activities, information, or support, the better people affected by NF in the respective countries are able to deal with the unfortunate challenges NF poses. (annex 24) This project resulted in more active and knowledgeable lay groups. It therefore can be expected that more people with NF and their families receive better support and information. Since the project stimulated the initiation of new groups in other countries, the supposition that in these “new” countries people with NF and their families also now receive adequate support and information, is probably not far from the mark.

3.2.5 Improved attention for research and collaboration with professionals

During the international scientific NF congress in Turku, representatives from the lay groups could evaluate the most recent evolutions and insights in research and were able to meet all renowned NF scientists worldwide. At this high profile meeting, NF-Europe, thanks to the EC-project, could present itself as a trustworthy and capable partner in managing NF and supporting patients and families. The presence of lay groups at this important scientific meeting is meaningful since patients and relatives could collect first hand information, discuss it with scientist and almost immediately spread new insights, methods and techniques to their membership.
In addition, patients and their families pointed at important gaps in the present research on NF, among other things to the fact that professional occupation for youngster with NF is a tangible question that certainly deserves scientific attention. Scientific insight and data could then be used to convince governments and policy makers to undertake positive action in areas that are, as far as NF is concerned, still uncharted.

Organisers of the Turku-congress, officially acknowledge the presence, contributions and insights of lay organisations. As a result, ample occasion will be offered for lay organisations to contribute – in stead of merely attend – the next international scientific NF congress to be held in Göteborg 2005. (annex 22)

Finally, as a result of the Turku-meeting it must be said that thanks to the mediation of NF-Europe, famous international NF-experts were willing to give a boost to new lay groups in a.o. Poland, Turkey and Greece, that had difficulty in their country to be taken serious by the professional world and policy.

3.2.6 The NF-Europe website

It is obvious that in these days of computer and Internet communication, presence in the Internet is essential. NF-Europe’s website is meant as a starting point for people looking for information in their language and seeking contact with other people with NF and their families in their country. It is also used as a working tool for NF-Europe and its member groups, not only offering free web space, but also ameliorating and streaming information of all kinds: co-ordination, joint projects, organisational matters, campaigning together (NF awareness week) a.s.o.

Website headings a.o. are: events and meetings, publications, country specific information and materials, a.s.o. (annex 15)

Delivering content for the country specific divisions of the website was part of a home assignment that the “new” volunteers had to fulfil in between training workshops. (annex 10.4)

Offering information and support through the Internet and evaluating information according to the HON-code and the recommendations formulated by Eurordis, was taught at the training workshop in Glyfada (Greece)

3.2.7 Manual

Following the project’s aim to ameliorate national organisations’ functioning, safeguard their future and foster the development of new NF groups throughout Europe, the project produced a manual on setting up and developing a NF self-help group.

It brings together approaches on how to start and run a NF self-help group. Its contents stems from knowledge, experience and advises from both ‘old’ and ‘young’ groups and is intended as a grip for future groups and a tool for already existing ones.

The brochure is organised along traditional lines.
If one starts at the beginning and reads through to the end, one can learn the basics of organising and sustaining a NF self-help group. It is NF- Europe’s best effort at saving people from having to say, “If I had only known about this before!”.

The manual is translated in several European languages and will be supplemented as new information becomes available.

The manual differs from existing “handbooks” on other lay groups or patient organisations as it specifically focuses on organisational problems that are NF-specific. It also goes further than existing, general manuals in that it provides customer tailored information for lay groups in stead of popularised management information that only seldom meets the real needs of patient organisations and lay groups.

(annex 13)

3.2.8 Evidence based recommendations on NF1

Although NF1 is among the most common genetic disorders, patients and their families often loose too much time before the correct diagnosis is made and adequate treatment and counselling started. Lack of knowledge and experience from the side of general practitioners, school nurses, and professional educators are some of the causes of this deficiency. As with every serious condition or illness, early detection is crucial in order to prevent possible negative consequences, identify co-morbidity or to initiate early support or timely counselling programmes that tackle such NF related issues as learning disabilities or attention deficit hyperactivity disorder.

The different members of the scientific advisory board of NF EUROPE and other scientists specialised in NF therefore developed recommendations and guidelines on diagnosing, treating and managing NF.

The guidelines are based on published clinical evidence and expertise. They are meant as an introduction to a very complicated disorder, are aimed at general practitioners, nurses, professional educators, a.s.o. and should foster early diagnosis and treatment. Among other things, the value of these guidelines is, that they start from a patient’s perspective, focussing on crucial health, educational and psychosocial issues instead of pure scientific knowledge.

In some countries where the incidence and certainly the non-medical consequences of NF are still largely underestimated due to lack of scientific or medical interest, patients and their families can use these guidelines to put pressure upon their medical community and governments to develop and finance adequate treatment and counselling programmes.

(annex 17)
3.2.9 Inventory of materials and network analysis

Another home assignment for volunteers in between training workshops was to draw up an inventory of educational and informational materials used in their originating NF association. These materials were evaluated according to standards put forward during the training courses. Thus an overview of accessible but at the same time correct materials was compiled and made available through the Internet (either through the NF-Europe website or the member pages.

The network analysis of NF lay associations that was drawn up for each country, is intended for patients and their relatives so that they are able to find adequate treatment, counselling and information quickly. In addition, doctors, educators, professionals in the field of psychosocial problems are offered an instrument to contact NF-experts in their country. For countries where medical interest or political willingness to tackle NF and its problems is lacking, the analysis of countries that use a highly developed multidisciplinary approach must be seen as an example of good practise that should be replicated. (annex 19)

3.2.10 Improvement of lay groups offers and activities

The regular meetings, workshops, training and the involvement of “new” motivated volunteers, for certain lay groups meant a fresh start. Exchanging ideas and approaches, learning techniques and gaining insight in issues such as public relations, membership recruitment, or spreading information effectively, inspired these groups to further develop and even expand their activities. Some groups that thus far only focussed on emotional support through discussion groups, started pressure group activities. Others that were only spreading information, initiated activities for adolescents with NF aimed at finding a job, starting social relationships and living on their own. Still others that were only striving to motivate governments and professionals to offer treatment and support, discovered and recognised the valuable complementary contribution to managing NF that patient organisations have to offer.

Here again, the project offered suggestions and information to volunteers willing to assist people affected by NF during various activities. (annex 21)
3.3 Assessment and follow-up

3.3.1 Assessment

Assessment through a questionnaire to distinguish the improved medical and social care supply on NF as well as the increase of professional's and society awareness about NF in the participating countries, as stated in the grant agreement, proved impracticable. Effects on the medical and social supply will only be visible in the medium range and depend from the means, motivation and results of NF-Europe’s member organisations. However, the start of new NF lay-groups in Poland and Turkey and the interest expressed by Polish and Turkish doctors and other professionals relevant for NF to join NF’s scientific network, can serve as some proof that this project is indeed awakening attention and interest.

The underlying premises of this EC-project is, that strong NF lay associations can really make a difference in attaining interest from the medical community and politics. Effective associations are also able to offer support and help people affected and their families to cope better, and in the long run offer patients and their families a qualitatively better life. This last premises was confirmed by a small qualitative research conducted by the sociological department of the KU Leuven (Belgium)/annex 20).

Beneficial effects of being a member of a NF-association were investigated through literature research and interviews with members of various NF-associations. The research a. o. shows that the following aspects of belonging to an NF association that are, according to members, most helpful are: the group cohesiveness, instillation of hope and universality. Helping factors in NF associations are: giving support, imparting information, conveying a sense of belonging, communicating experiential knowledge and teaching coping methods. In addition, NF association produce five change-oriented skills that help members to achieve life-altering goals: identity transformation, empowerment, insight, re-framing, and formation of a new way of life.

One of the most striking results of research about the effects of belonging to a patient organisation in general is that the quality of life increases. The research also revealed this effect in NF associations.

And finally the research also showed that the way in which people look at NF, determines the way of coping with it. European NF organisations show that they fight the perception of some parts of the society who look at NF patients as helpless and pitiful. Important is how the illness is viewed and how it is incorporated into one’s self-image: are we ill or do we have an illness? NF patient organisations try to convince their members they aren't just somebody affected by NF, but first of all a person with qualities and capabilities as anyone else, unfortunately also affected by an illness, namely NF.
3.3.2. Follow-up

This EC funded project offered NF-Europe and its member organisations to develop sound foundations for the future. Initiatives and activities that were developed with the financial aid of the Commission will be continued:

- The website will be expanded and constantly updated (annex 15)

- The manual, list of materials and publications as well as joint activities will be developed even and also after the official end of the funded project (annexes 13, 14, 8.2, 19)

- Many of the “new” volunteers are still active in their originating associations, taking up leading roles, inspiring other collaborators and planning to do this even longer than the agreed 3 years. (one year longer than the duration of the training project!). (annex 3.1 pag.3)

- New associations receive support and information from NF-Europe and from members of its medical and scientific board.

- NF-Europe’s organisational structure is ameliorated and expanded; some of our member associations are even planning to delegate their “new” volunteers in the European Federation.

- Member groups has been urged to organize similar public awareness campaigns during the same period in May 2005 along guidelines put together and forward by NF-Europe’s network (annex 18)

- The scientific NF meeting to be held in Göteborg 2005 will host a special, joined session dedicated entirely on collaboration between NF lay groups and medical professionals and scientists (annex 22.2)

- The evidence based guidelines on diagnosing treating and managing NF1 will be presented to the Ministries of Health of NF-Europe’s member associations at the occasion of the upcoming NF awareness campaign in May. (annex 18.2)
3.4 Evaluation of the results

NF-Europe is a conglomerate/association of voluntary organisations with limited financial resources but lots of ambitions and plans. NF-Europe is all about joining forces of national, sometimes small and powerless organisations focussing on a rare disease. In this field, collaboration is essential to grow, gain visibility and attain credibility from outsiders and medical professionals. It is clear that in some European countries the support and information offered to patients with NF and their relatives by NF-patient organisations is of a high standard. The European dimension offers ‘less able’ associations the opportunity to learn and profit from these achievements thus avoiding pitfalls and growing pains, profiting from the experiences and achievements of others. On the other hand, ‘new, young’ organisations sometimes force the older ones to reflect on their original foundations that sometimes are blurred because of organisational dynamics or opportunistic choices.

Without this European programme it would never have been possible to achieve the objectives, involve professionals and recruit volunteers. (testified by several NF related professionals – annex 24) The programme is also of tremendous value in overcoming important hurdles such as language difficulties, streamlining communication and fostering the network as a whole.

EC-funds also render credibility and legitimacy to the project’s aims and objectives, approaches a.s.o. Thus, involvement and collaboration are easier to attain.

Ending or diminishing negative consequences of rare diseases can only be achieved on European scale. National perspectives are often to narrow, knowledge scattered. That’s why the European dimension of this project added value to this social utility.

The main long term effects that can be expected is a well trained volunteer network, co-operating on an international level to increase the quality of life for people affected and all people concerned (family members, educators, social workers, health care workers,…).

NF-Europe was created to act as a permanent functioning network, but the result of this project is valuable not only for our own members but also for other groups concerning rare disorders with similar problems: because patients and families are complementing professional care and support (self-management, self-reliance, participation, …); because the volunteers in this program are trained to increase quality of life and independence for all people affected by a genetic disease; because the outcomes of our programmes will be useful also in the longer term.

Some of the long-term effects are already visible.

- Portuguese doctors asked for advise to increase the effect of a public awareness campaign in Portugal, and decided to organise an international scientific meeting on NF in Lisbon.

- The volunteers are now directly involved in the daily organisation of the family support groups in most of our member countries. As a result this input of younger people, fresh energy and new pathways already increased the results of the existing groups.
In co-operation with local scientists, the Polish volunteers started a new NF association that was officially registered in January 2005.

Different member groups are working together to organise activities, such as a training weekend for youngsters from Netherlands and Flanders (the Dutch speaking part of Belgium), an information day on NF in France and the Walloons (the French speaking part of Belgium), and a “Scandinavian” NF weekend.

Private Internet chat boxes for specific subjects created more efficient communication between the different member groups.

The website makes it easier to distribute information an distribute leaflets, booklets, pdf’s between the different country groups and in the future directly to patients, families, professionals, politicians, a.s.o.

After our presentation in the closing session of the Scientific Meeting in Turku, scientists contacted us for information about how to start up a family support group in their home country.

As a result of our presentation at the international scientific meeting in July 2003, representatives from the scientific group suggested to include in the next congress program (Göteborg, July 2005) a joined session dedicated entirely to more efficient collaboration between the scientists and lay group representatives.

The manual on starting and developing an NF-support group will be distributed widely among family support group representatives, scientists and other medical professionals in Göteborg 2005.

The recognition of needs of people with NF, fostering social inclusion (ending isolation, offering a network, raising self-esteem and self-confidence) educated patients and families are definitely the added value of our project in its global social environment.

In running this programme, NF-Europe however also had to cope with some problems:

For voluntary organisations, such as NF-Europe, it is discouraging and difficult to cope with the own financial contribution to the entire budget. It is very difficult to raise 30% of the budget especially when contributions in kind are not envisaged. Member organisations are poor themselves, sponsors in the field of NF are very hard to find, especially on a European level, because NF is a rare and therefore unknown disease and on top not to be cured by any drug available on this moment . This limited financial capacity forced us to downsize the outset of the programme.

Since we had to convince member organisations to invest time and financial means in this valuable but expensive programme, and they at their turn had to communicate with their national responsibles, the time between the call and the deadline was rather short.

We also underestimated the workload with regard to reports, accounts, a.s.o.
Nevertheless, we are proud that, as a voluntary association with limited time, restricted financial means, energy and specific administrative knowledge, we achieved the aims of this project.

- We built a solid foundation for networking between existing and starting family support groups on NF. Annex 4.21

- We developed a manual containing guidelines how to set up a new lay group and how to optimise the functioning of existing groups. Annex 13

- National groups found new volunteers, safeguarding the future of their organisation and preventing burnout or downsizing. Some volunteers from our project team have already taken up full responsibility as a board member.

- After years of uncertainty and professional’s dispute, finally evidence based recommendations for managing NF are now available in all countries involved in their national language. Annex 17

- In Switzerland one of our volunteers – a student on the neuropsychiatry department of the Zurich University- started a research project based on the results of this project to evaluate influence of NF on social life.

- In all, The EC-project proved of extremely valuable help to put neurofibromatosis on the “map” and so increase quality of life for all families involved.
5. Further objectives

With NF-Europe we need to focus more on developing strategies and approaches aimed at increasing the self-reliance of people and families with NF and to implement these widely. The overall objective has always been to offer youngsters with NF better opportunities by informing educators, teachers, peers, employers, colleagues and so on, of their capabilities and limitations.

Patients with NF in general dispose of a more than average IQ. Still their capabilities are often underestimated because they combine physical defects and non-verbal learning disabilities. As a consequence they are often considered as mentally handicapped and referred to special schools and programs far beneath their capabilities and talents. Later in life, by lack of education, they seldom find a proper job and are forced to live on social security benefits. Proper information can prevent this. Appropriate education, leading to satisfying normal employment offers people with NF the possibility to lead a full life despite the illness and its physical consequences.

Since the number of people with NF is proportionally low, only co-ordinated actions from voluntary groups and sympathetic expert professionals on a European level can lead to necessary changes and attention at national policy levels.

In order to develop a project on supporting youngsters with NF in their daily life, we set our hope on the project’s prolongation for a few years for follow up, to coach the volunteers while sharing the training results with colleagues and to establish a firm financial base for the activities and objectives of the network. Unfortunately, the criteria and prerequisites as formulated in the current EC funding scheme are impossible to meet for “poor” organisations that are exclusively relying on volunteer commitment and engagement. Nevertheless, the initial results of this project will also prove helpful in the area described above, for every national association involved (new trained collaborators, materials, …). We’re grateful to the commission for offering us this grant and opportunity. And so are undoubtedly the patients and families that are already now benefiting from belonging to a solid NF association somewhere in Europe.
6. Annex

1. Extract report board meeting – nomination of EC project staff.
2. Presentation of the project – NF EUROPE News Flash Nov 2002
3. Invitation to participate in the project
   3.1. Draft materials to recruit volunteers
   3.2. Request for professionals in countries without NF groups
4. Fact sheets NF EUROPE member groups
   4.1. Belgium
   4.2. Bulgaria
   4.3. Denmark
   4.4. Finland
   4.5. France
   4.6. Germany
   4.7. Greece
   4.8. Ireland
   4.9. Italy ANF
   4.10. Italy LINFA
   4.11. Netherlands
   4.12. Norway
   4.13. Poland
   4.14. Portugal
   4.15. Spain
   4.16. Sweden
   4.17. Switzerland
   4.18. Austria
   4.19. Turkey
   4.20. UK
   4.21. a. Member lists 2002
   4.21. b. Member lists 2005
5. Sample training materials - Your organization through a looking glass
6. Needs and expectations of people affected
   6.1. Overview
   6.2. Sample investigation materials - Frequent asked questions about NF
7. List participating groups
8. Samples documents of commitment
   8.1. Affidavit
   8.2. Letter of commitment participating groups
   8.3. Letter of commitment volunteers
9. Training program
10. Work shops
   10.1. Report
   10.2. Samples ppt presentations
   10.3. Samples work shop assignment (Krakow)
   10.4. Samples home assignments
11. Participants lists training program
12. Sample evaluation by the participants
   13.1. Full Eng. version
   13.2. Sample of translation in 10 languages
14. Sample inventory of group materials
15. Website - screen shots
16. Scientific meeting 2003 Turku:
   16.1. Participants list
   16.2. Scientific program
   16.3. Lay group program
   16.4. Report scientific presentations
   16.5. Sample report local publication
17. Evidence based recommendations
18. Public awareness campaign
   18.1. Sample suggestions
   18.2. Suggestion letter to government members
19. List of publication – based on home assignments
20. Report - Effects of being a member of a NF patient organisation
21. Sample volunteers information
22. Scientific meeting July 2005 Goteborg,
   22.1. Invitation
   22.2. Program
23. Full financial report
24. Testimonies from NF specialised professionals
25. Photoreport
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