

ANNEX 1.

Nomination of EC project staff – NF Europe board meeting nov.2002.

(see conclusion on page 4)

**NF EUROPE**

EUROPEAN FEDERATION FOR NEUROFIBROMATOSIS ASSOCIATIONS

November 8-10, 2002 – meetingroom Abingdon, Hotel Serwir - Sint-Niklaas Belgium

**6th BOARD MEETING**

**Present.**

Mia Desmet-president, , Anita Engstrøm-treasurer,  
Elisabetta Bissignani and Alessandro Evangelista - secretary  
Georg Poptodorov, Toril Rørdam, Karin Persson,

**Excused:** Pilar Muñoz,

**Meeting chair:** Mia Desmet

**Agenda: November 8**

1. Report Board Meeting Lisbon
2. Financial report
3. New members
4. Planning General Meeting Turku 2003 July 24-27
5. re-election board of directories
6. Planning scientific program Turku 2003 July 24-27
7. NF Summer camp for teens, Göteborg Sweden July 2004
8. News Flash
9. 2003, year of the disabled people
10. questions
11. items to discuss on request of the board members

**Agenda: november 9-10**

12. EC granted project: European NF network.
  - presentation EC project
  - discussion EC project
  - conclusions and strategies EC project,

**REPORT: Extract:**

**12. EC PROJECT**

This project will be very demanding. And we will need all the help we can get to achieve all items on the program. That's why about a year ago we did start looking for valuable people to strengthen the Belgian board and help us realizing this challenge, and now we can introduce here as members of the Belgian EC staff (suggestion to be considered by the board).

**Peter GIELEN**, Social worker,

Staf member for the International Information center on Self-Help and Health from 1984 till 1990.

A program from the World Health Association meant to investigate and promote European self help programs. In charge with different educational and training programs for volunteers, professionals and government members.

Since 1990, for about 12 years now staff member of Trefpunt Zelfhulp, (meeting point for volunteer groups) a support center created by the Government for self help and family support groups.

He is in charge with educational and international programs such as on the moment:



ANNEX 1.

- An EC project to promote and stimulate self help in Italy and Greece (partner groups from Italy, Greece, Austria, UK and Belgium)
- The European Network of Self-Help Supporters, collaboration between support groups in different European countries.
- different training programs in Belgium for self help organizations.

Did develop a draft educational program for our work shops (suggestion to be considered by the board).

**Frederik Van Genechten**, manager,  
software-engineer and ict-consultant (2000) - journalist, photo-journalist and media consultant (1997)  
-graphic designer and web-editor (1998) - manager of a press- and photo-agency and of a photo and design bureau (1999)

Did develop a financial plan for the EC project (suggestion to be considered by the board).

**Mia Desmet**,  
Educator, president of NF Kontakt, the Belgian NF association, and from NF EUROPE, European federatoin of NF associations,

Did develop draft materials to invite and motivate existing NF groups to join the program, to invite professionals to select and motivate students in medical and social programs to volunteer, and professionals in countries without NF groups to find volunteers willing to join and start up an NF family support group. (suggestion to be considered by the board).

**Gerlinda Braeckman**, project leader final grade school for reception and public relations,  
Was the main promoter of this discipline for about 8 years now, and in charge with the relationship between students and enterprisers.  
Was part of the committee in charge with the adaptation of the syllabus to the present situation

willing to 'volunteer' with the whole final grade class to organize our 1<sup>st</sup> work shop in Sint-Niklaas

**1. Final Application for Funding - Official Grant Agreement -**

Both copies provided in the meeting file

**2. Presentation of the Educational Program – Peter Gielen**

Copy provided in the meeting file

All member groups will have to select two volunteers before Christmas.  
it will have to be students from social, educational, medical or para-medical disciplines.  
Willing to subscribe a commitment for at least 3 years  
- Be available for at least 3 years on a row (2 for the work shops, 1 to pass on the information)  
(we did invite NF team doctors to look for students in medical, para-medical, or social disciplines)  
- They can make their final paper on NF based on the experiences in the groups.  
- Volunteers for the workshops are NOT board members but volunteers willing to participate in the training program and subscribe a 3 years commitment to help the local groups to organize (or re organize) their local family support groups.

Peter and Mia will line out the criteria and benefits for the students involved.



**ANNEX 1.**

This draft document will be mailed to all professionals supporting the local groups and we will invite them to select volunteers among their own students.

For the 1<sup>st</sup> work shop, planned on February 27 to March 2 in Sint-Niklaas, we will invite 2 volunteers plus a representative from each of the local boards in order to brief the starting volunteers on the needs and skills in their own local groups.

The second work shop will not be connected to the Scientific meeting in Turku because the rates are too expensive there to invite 32 extra participants, and the program as lined out already doesn't allow to add a work shop program anyhow.

But, as a part of our EC project, during the whole week end in Turku two members of the Belgian EC program crew will question both professionals and lay group representatives in order to map skills and needs of people affected and influence of NF on family life.

It was decided to organize the 3th work shop in one of the guest countries (Greece, Poland, Hungary, Czech Republic). Our presence there might help to focus press and officials attention on the needs of people affected with NF and hopefully bring the support they need to start up a family support group.

**All suggestions has been accepted by majority.**

**Peter Gielen has been invited to develop the educational program and run the work shops.**

**Mia Desmet has been invited to co ordinate the whole NF network project**

<b>3. Presentation of the Financial structure – Frederik Van Genechten</b>
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Copy provided in the meeting file

We can't deny that the previous project has been rejected, and the present one was slowed down, both due to difficulties related to the bank.

On Mrs. Aubin's advise I would suggest to create an additional bank account in Belgium, to simplify the procedures and to limit bank costs.

Participation from the different groups is limited to 30% of THEIR OWN COSTS.

Meaning the NF EUROPE office (= the Belgian NF group) is in charge with 30% of his own costs plus 30% of all costs other than travel and subsistence costs.

We will raise a part of this money from reductions and therefore do suggest to decide for group booking of all travel and subsistence costs for the whole duration of the program.

The largest part will have to be realized by gifts.

Since we will also have to pay all bills from here to prevent us for increased bank costs (217,00 € for organizing the Venice meeting) we do ask Anita to find out the most favorable procedure to transfer the EC money in large amounts. It's obvious that our Belgian treasurer will provide a detailed financial report on regular base to all board members.

1<sup>st</sup> payment: € 38.500,00 for adapting the office, rent of equipment for the 1<sup>st</sup> year, refund travel costs board meeting and 1<sup>st</sup> work shop is expected at about December 15. Mrs. Aubin did promise to speed up the procedures as much as she is able too.

This is a very demanding program, and we can't afford any mistake if we want a chance to renew our grant. I do realize each and everyone of you has plenty to do in his own group. Same here.

We therefore suggest to expand the Belgian staff.

Peter and Frederik, are willing to help us out for the duration of this program.

It's evident we will respect the decisions made here by the board and report about every step we make.

**All suggestions has been accepted by majority and Frederik Van Genechten has been invited to organize and run the financial part of the program.**



## ANNEX 1.

**4. adapting the existing office to European level**

Besides the usual office tasks, there is also the educational program and the work shops. So we did discuss the organization of the work shops with the school management of a training school for public relations here in Sint-Niklaas.

This way we hope to get a professional frame we can copy for further work shops.

Frederik and Mia will discuss a program with Gerlinde that will be interesting for both our office and the students involved.

The guidelines for managing the different aspects of NF in 10 languages is a detail that needs our special attention too. For this purpose Eva GERARD (translator 1<sup>st</sup> work shop in Leuven) is creating a translators pool.

**5. participation of the different groups**

Copy provided in the meeting file

It was decided in the previous board meeting in Lisbon NOT to include affiliated members or not member groups in this project.

**6. Planning 2002-2004: program to realize**

Copy provided in the meeting file

**7. Questionnaire Wolkenstein**

All board members has been invited to discuss the SF-36 in their own groups and send in suggestions for additional questions to Mia ASAP. (meeting Lisbon: October 18, 2001)

So far we didn't succeed to complete a model questionnaire to be discussed with Wolkenstein as suggested in Venice. It's rather difficult to realize a complete questionnaire within the given time left.

We therefore did suggest an alternative solution. Peter Gielen and his colleague will organize investigation among the group representatives and their scientific coaches during the Turku Meeting

**8. Public Awareness Campaign**

Since we do have the opportunity to benefit from the experience of a journalist and media consultant, and a complete class of future public relation professionals it was suggested to create a uniform campaign all over Europe.

A press conference will be integrated in the 1<sup>st</sup> work shop program.

A draft press release will be developed and provided in all listed languages, and a model announcement to be published in all different newspapers as well.

**9. questions and suggestions**

On Saturday afternoon and on Sunday morning the board members did discuss all details of the program.

The board of directories did subscribe all suggestions presented by the Belgian EC crew and did agree this crew will be in charge to realize the complete EC program.

There will be briefings at every step in the program, and reports to all board members every 3 months at least.

It was requested to approach local Government members to apply for support to cover the 30% due by the local groups. We will invite the doctors concerned to subscribe this request.



**10. steps to achieve from here**

**PART 1.**

1. an Extra edition of the News Flash with:  
announcement start of the program  
complete program to achieve  
task list for all member groups
2. send in the 1<sup>st</sup> interim report to obtain the next 40%
3. organize the international office in Sint-Niklaas (Mia)
- 3b. and the financial frame (Frederik) that will have to include refund the costs of this meeting asap.
4. complete the educational program (Peter)
5. compose a translator team (Eva)
6. organize the 1<sup>st</sup> work shop in February 2003 (Gerlinde)

**PART 2.**

- Public awareness campaign and Press meeting (Frederik)  
Scientific meeting – lay group program (Mia)  
Collecting data from groups and scientists (Peter)



## ANNEX 2

NF EUROPE NEWS FLASH ed. 16. NOV 2002

## Announcing the start of the European Network of NF-ASSOCIATIONS

**NF EUROPE NEWSFLASH**

Newspaper for member associations



Ed. no. 16 **TIME TO START WORKING !** November 2002  
EC PROJECT RUNNING FROM NOVEMBER 1 2002 TO NOVEMBER 30 2004

*Purpose: To offer all members the opportunity to get in touch by a monthly newspaper, each of them invited to send in his own page at latest every 25th of the month. There is no space limit, so please feel free to send in all messages or questions you want to share with the other groups. To easy access for each of you we kept the lay out as simple as possible. This is supposed to be YOUR newsletter, a tool all of you can use no matter what kind of programs you are using. If however there would be some problems please tell us.*

*Please do verify your own address and numbers*

**PART 1 Message from the Board**

Dear members.

Please be sure to remember November 1, 2002.

This date is a milestone in the history of our association.

Our request has been accepted, our program has been granted, the 1<sup>st</sup> payment is on our account.

Time to start working !

The board of directories did meet on November 8 to 10 to discuss the program and line out the steps to take from here.

**Aims of the program:**

1. To establish an European NF-network trough linking the existing NF 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. to develop a volunteer training program in order to help people affected for better socialization and enable them to cope with the disease.
3. To increase awareness about NF at a European level focussing on professionals, people concerned and the European society (organizing public awareness campaigns, designing a web page for disseminating contemporary information about NF)
4. To produce educational materials for people concerned (patients, social workers, teachers, and medical professionals).
5. Trough sharing experiences to investigate the medical and social needs of people affected and to create recommendations and guidelines for evidence based managing the various aspects related to NF.

This publication is part of a program granted by the European Commission



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Ed. no. 16

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## List of participants

Group	Representative	Professional support
Belgium	Mia Desmet	Eric Legius
Denmark	Karin Persson	John Østergaard
Finland	Esko Olavi Kandelin	Minnaz Poyhonen
France 1	Anne Henrion	Pierre Wolkenstein
France 2	Jean Claude Lopez	Pierre Wolkenstein
Germany	Frank Wilke	Victor Mautner
Italy 1	Elisabetta Bissignani	Romano Tenconi
Italy 2	Luigi Meneguzzi	Romano Tenconi
Ireland	Patricia Nutty	Susan Huson
Netherlands	Peter vanden Ende	Arja Goeden, Bolder
Norway	Brit Ohrø	Arvid heiberg
Portugal	Lucia Lemos	Isabel Cordeiro
Spain	Pilar Muñoz Vilalobos	
Sweden	Anita Engström	Birgitta Rembeck
Switzerland	Barbara Kajori	Eugen Boltshauser
Bulgaria	Lidia Georgieva	Georg Poptodorov
Czeck Republic		Alena Petrakova
Greece	Katarina Avesi	Dacou Voutecatis
Hungary		Laslo Timar
Poland		Sergej Joswiac

## Time table:

1.	November 08-10, 2002	Board Meeting
2.	November 1 to December 31 - 2002	Adapting the existing offices to work on European level and to widen the established network
3.	November 1 to January 31, 2003	Creating a basic training program for participants from the different lay groups
4.	December 1 to February 28 , 2003	Designing a web page
5.	February 27- March 2, 2003	Organising a workshop for the selected participants to introduce them to the training program Preparing them to start it up in their own countries
6.	February – march 2003	Initial evaluation of the influence of NF on family and social life, as well as their medical and social needs
7.	February 28-March 2, 2003	Board meeting
8.	June - October 2003	Elaborating a unified program, efficient for lay groups in every European country
9.	May 2003 and May 2004	Public awareness campaigns
	July 25	General Meeting and re-election Board of Directories
10.	July 24 t e m 27 – 2003	Scientific NF meeting Turku Finland
11.	July 24, 2003	Board meeting
12.	September 19-21, 2003	Carrying out a second workshop for receiving feedback, assessment and adaptation of the training program for all involved countries
13.	May - October 2003	Collecting data from lay groups and starting the preparation of the educational materials for non-medicals (people affected, educators, social workers)
14.	November 2003 - September 2004	and for general practitioners and family doctors
15.	April 23-25, 2004	Carrying out a third workshop will finalise the educational programs and materials, which will be issued at the end of the project . They will be unified for Europe and translated in 10 languages.
16.	September - October 2004	Producing and distributing evidence based recommendations for managing NF.
17.	September 24-26, 2004	Board meeting



## Program to achieve by ALL participating groups

Before December 25, 2002	Select to volunteers to participate in the training program, according to the terms lined out below
February 27 to March 2	2 volunteers and 1 representative of the local board are participating in the 1 <sup>st</sup> work shop
May 2003 and May 2004	All groups are participating in the European Public Awareness campaign
July 24-27, 2003	Two board members from each member group are participating in the scientific meeting in Turku Finland
September 19-21, 2003	Two volunteers are participating in the second work shop
April 23-25, 2004	Two volunteers are participating in the third work shop

**For all those activities the International NF office in Belgium will arrange group booking for all participants involved. All groups concerned will receive an invoice covering only 30% of their own costs, all other costs will be covered by the EC grant.**

### General Meeting

And election of the new board of directories  
July 25, 2003 at 09.00 - Turku Finland

### Preliminary program

#### Thursday July 24

- 14:00 Registration
- NF EUROPE board Meeting
- 16:00 Opening of the 10th European NF Meeting
- Opening Session: Lessons learned from animal models for NF1 and NF2.  
Natural History of NF1.
- 18:30 Welcome reception and banquet: Turku City Hall

#### Friday July 25

- 09:00-12:00 Scientific session: NF1 and bones
- Lay group session: General Meeting (including board elections)
- 12:00-13:00 Lunch
- 13:00-16:00 Joint session Clinical aspects of NF1 and NF2
- 18:30 for both groups Dinner at the Castle of Turku

#### Saturday July 26

- 09:00-12:00 Scientific session: Cell Biology of NF1 and NF2.
- Lay group session: behavior disorder in children affected by NF  
Dr. Katarina Nikelson (to be endorsed)  
Atypical social behavior in youngsters with NF  
Dr. Markku Saino (to be endorsed)
- 12:00-13:00 Lunch
- 13:00-16:00 Scientific session: Molecular Genetics in NF1 and NF2
- for Lay groups: boat tour to Naantali, a small town about 20 km from Turku (Moominland, President's Summer residence, indoor spa, restaurants)

#### Sunday July 27

- 09:00-12:00 joint session: unusual cases of nF1  
Short report from lay group sessions  
Message from INFA  
Closing remarks
- 12:00 Lunch

During the Whole weekend there is a Medieval time style fair in the Cathedral area of Turku

**The International NF office in Belgium will contact you in a few weeks for group booking of travel tickets and participation cost for this meeting.  
70% of all cost for two participants from each member group will be covered by the EC grant.**

## **Election of the new NF EUROPE board of directories.**

According to the articles the Board of Directories is elected for 2 years, and has to be re elected on the 1<sup>st</sup> General meeting after this term.

Meaning we will have to elect a new board of directories on our next General Meeting in Turku.

**We hereby invite all Presidents of NF member groups to select among their representatives one candidate for the board of directories.**

### **Article 9.**

*The Board of Directors consists of the Chairman and the Directors, with a minimum of one individual affected by neurofibromatosis and one scientist. It will be elected by the General meeting. It will consist of three individuals at least, including the Chairman, up to 50% of the General Meeting, with no more than one participant per country.*

*The conditions for eligibility are as follows: two years of membership, at least, in the association to represent, ability to participate in English spoken discussions and a minimum age of 21 years.*

The board of directories is meeting at least once a year.

Please do contact us if your group is willing to send in a candidate for this elections, you will receive registration forms to complete.

### **Message to all member groups:**

Please don't forget to pay member fee for 2003, so your group will not lose the right to vote on the General Meeting in Turku next Summer.

**Member fee is still 25,00 € per member group**

### **Bank information:**

Account number:	1702866
Account name:	NF EUROPE
Address:	Sturegatan 3, 75314 Uppsala - Sweden
Bank company:	NORDBANKEN AB
Bank address:	Postbox 455- 75106 Uppsala – Sweden
Swift code:	NDEASESS
Currency	EURO

### **Electronic News Flash**

Several groups did request a printed version of the News Flash. No problem here unless the costs since of course mailing costs are the main part here. We don't have any other choice but asking 10,00 € extra for our NF EUROPE NEWS FLASH.

**So IF you do prefer a printed version, please do add 10,00 € on your annual member fee.**

Thanks for understanding.

**PLEASE YOUR SPECIAL ATTENTION FOR :**



### **The European Year of the disabled people"**

On 3 December 2001, the European Union adopted 2003 as the European Year of People with Disabilities. This decision has given an opportunity to disabled people across Europe to put disability rights at the top of the agenda for Europe and the Member States. We also hope that the European Year will also be celebrated in the countries of the European Economic Area and the candidate countries for accession to the European Union.

Thousands of activities and events will take place during the year in the different participating countries. They will be linked through a March through Europe which will start in Greece in January 2003, go through all the Member States of the European Union and will end in Italy in December 2003. Activities and events along the March at all levels in the Member States will be organised by the disability movement. The March will be supported by a campaign bus.

More information about the European campaigns and the different activities at national and local level will be available soon on this site.

We want you to get involved: sign up for the campaign and be the first to know how and where you can participate. We'll keep you posted! [More basic information on the Year.](#)

### **March route**

The events taking place in Europe in 2003 will be linked through a People's March through Europe which will start in Greece in January, go through all the Member States of the European Union and will end in Italy in December 2003.

The March is the European red thread linking as many activities at national and local level as possible. A specially designed EYPD bus will be travelling along the march route made up of your EYPD events.

The objective of the March is to link as many events as possible. Get on board ! Participate in the EYPD activities near you. Organise your own event and make it part of the March. Find out where the March is going and get on board. For more information on the bus and the events around it go to

[http://www.eypd2003.org/eypd/eypd/theyear/index\\_en.html](http://www.eypd2003.org/eypd/eypd/theyear/index_en.html)

**PART 2 coordinates from the member associations (in alphabetical order)**

**Belgium:** Full member of NF EUROPE since May 1999

**N.F.KONTAKT**

<b>Contact:</b>	<b>Address:</b>	Nijverheidsstraat 29, B 9100 Sint-Niklaas – untill September 15 Rode Kruisstraat 15, B 9100 Sint-Niklaas – from September 15
	<b>Tel.</b>	32.3.766.13.41
	<b>Fax.</b>	32.3.760.45.16
	<b>E mail</b>	nf@nfkontakt.be
	<b>Informant</b>	Mia De Scheider Desmet

Going beyond their own limits, that sure is what the Belgian NF Junior team did last Summer. As closing item on the educational program we took about 25 young people affected to the States for a real “survival trip”. The main challenge was to learn how to organise your life in spite of the limitations caused by NF.



Why to the States ? Simply because Peter Bellermann did show us the way in several previous camp programs.

Thanks to his advises our participants could question different scientist on NF in the Utah University, and we could book a five days rafting trip on the Colorado, covered by a marvellous team of volunteers specialised in accessible outdoors adventures.



But there was even more. We really did learn how one can live with limitations during our stay in the Navajo Tribe in monument Valley.

We have all been impressed by the testimony of our guides who really do love every single rock and pat in their territory, and by the difficult circumstances in which they have to raise their families. But none of them did complain. They really did surprise us as perfect hosts who did share everything with us and make us feel welcome. None of us will never forget the traditional dances, the talk by the campfire, the Sunrise above Totem Pole Valley...

We all felt sorry we had to leave, but there was one more item on the program, and we sure did save the best for last since Bryce Canyon is definitely the most beautiful corner in the world we ever saw. Too bad by that time the combination of tiredness and high altitude did cause problems for some of us.

Mia Desmet



**Bulgaria:** Associated member of NF EUROPE since May 1999:

**N.F.A.**

<b>Contact:</b>	<b>Address:</b>	PIROGOV Institute - Department of Neurosurgery 21, Tottleben blvd 1606 Sofia, Bulgaria
	<b>Tel.</b>	359 88 638 613
	<b>Fax.</b>	359 2 432 375
	<b>E mail</b>	NFW@omega.bg
	<b>Informant</b>	Dr. George Poptodorov-medical advisory board NF Europe



**Denmark** Full member of NF EUROPE since May 1999.

**Dansk Forening for NF**

<b>Contact:</b>	<b>Address:</b>	Droninggårds Ale 10 c / 1th., DK 2480 Holte
	<b>Tel.</b>	0045 45 41 15 80
	<b>Fax.</b>	0045 45 41 16 80
	<b>E mail</b>	karinpersson@mbox301.get2net.dk
	<b>Informant</b>	Karin Persson



**Finland**- Full member of NF EUROPE since August 1999.

**Suomen NF**

<b>Contact:</b>	<b>Address:</b>	Takomotie 27c 100 - SF 380 Helsinki
	<b>Tel.</b>	00358 9 55 33 18
	<b>Fax.</b>	00358 9 3087 753
	<b>E mail</b>	anne.leppala@kolumbus.fi
	<b>Informant</b>	Anne Leppälä



**ance 1- Blagnac** - Full member of NF EUROPE since June 1999.

**Association Neurofibromatose et Recklinghausen**

<b>Contact:</b>	<b>Address:</b>	3L, Rue Saint-Hilaire, FR 94210 La Varenne
	<b>Tel.</b>	0033 1 5596 2069
	<b>Fax.</b>	
	<b>E mail</b>	gerard.donadieu@psos.com
	<b>Informant</b>	G�rard Donadieu

Our Group follows its objectives:

One of the year strongest events is the NF Forum which has been held at Paris in April. This is the occasion to establish contacts between patients and doctors who talk about the latest news regarding research. Presentations about the cellular cultures in regards with mutations, animal based research, cerebral auditive implants for NF 2 patients. Moreover, an important part was dedicated to school medicine and learning difficulties concerning NF1 patients, patients assistance. It is too the opportunity to present the Association activity program for the on going year, association accountancy and the follow up of the researches involving association finances.

A lot of medical teams are now federate into a "NF network". It is important for doctors to meet regularly in order to share their knowledge and vision. It was in June at Nantes and the association is a real partner for doctors who paid a lot of attention to the association ideas, requests or comments. It has been decided during this meeting to launch a research program concerning pregnant women affected by NF1.

The Association is involved too into the organization of festive events such as "the Scully Marathon". Gillian Anderson fans had the opportunity May 11<sup>th</sup> in Paris to meet around their favourite films to raise funds for the NF. There will be many "Scully" organized in France in 2003 !

Almost each region has its own delegates; in Paris, June 23d, a full day animation, shows in Toulouse, in the Manche department. Some photographs have carefully realise photos of Association members during their everyday life. We equally plan to realize photos for medical purposes to be used in professional forums such as the Worldwide Dermatology Congress where we previously organised a stand. We consider too the opportunity to include pages in English in our Website.

A lot of ideas and projects !

G rard Donadieu



France 2 - Anais- Full member of NF EUROPE since June 1999  
**Ligue contre les neurofibromatoses**

<b>Contact:</b>	<b>Address:</b>	Chemin des Mésanges 2, FR 17540 Anais
	<b>Tel.</b>	0033 5 46 68 23 70
	<b>Fax.</b>	0033 5 46 68 23 70
	<b>E mail</b>	Ligue.Contre.nf@wanadoo.fr
	<b>Informant</b>	Jean Claude Lopez



Germany 1- Frankfurt Full member of NF EUROPE since September 1999.  
**Von Recklinghausen Gesellschaft e.v.**

<b>Contact:</b>	<b>Address:</b>	26, Kolberger Weg, D 65931 Frankfurt
	<b>Tel.</b>	0049 69 364 02 195
	<b>Fax.</b>	0049 69 364 02 197
	<b>E mail</b>	Von-Recklinghausen-Ffm@T-online.de
	<b>Informant</b>	Gabi Klaeser

One weekend in August the NF association in Frankfurt arranged a workshop for leaders of the regional NF Groups in Germany. There was a special workshop for the people with NF2.

A fairy-tale book was published in August. Children and adults with NF wrote the book. It contains more than 30 fairy-tales and it is absolutely wonderful.

We have also won a scholarship in a competition and at the moment we get advise from an expert and a coach to help us so our work for the association can be even better.

Frank Wilke was decorated by the Bundespresident for the great job he has done for the German NF association.

Frank and Gabi



**Ireland**  
**NF Association of Ireland**

<b>Contact:</b>	<b>Address:</b>	Carmichael centre – North Brunswick Street, Dublin
	<b>Tel.</b>	00353 1 872 6338
	<b>Fax.</b>	003531 873 5737
	<b>E mail</b>	griffgriff@eircom.net
	<b>Informant</b>	Paddy GRIFFIN



Italy 1- Padova Full member of NF EUROPE since September 1999  
**LINFA - Lottiamo Insieme per le Neurofibromatosi**

<b>Contact:</b>	<b>Address:</b>	Clinical Genetics & Epidemiology Unit, Dep. Pediatrics, 3 Via Giustiniani, I 35128 Padova
	<b>Tel.</b>	0039 049 821 3513
	<b>Fax.</b>	0039 049 821 1425
	<b>E mail</b>	Tenconi@child.pedi.unipd.it
	<b>Informant</b>	Luigi Meneguzzi



**Italy 2- Parma ANF** Full member of NF EUROPE since July 1999

<b>Contact:</b>	<b>Address:</b>	7, Via dei Glicini, I 04013 Latina Scalo
	<b>Tel.</b>	00390 521 77 1457
	<b>Fax.</b>	00390 521 77 1457
	<b>E mail</b>	a.n.f.@neurofibromatosi.org
	<b>Informant</b>	Elisabetta Bisignani, Secretary NF EUROPE



**Italy 3 - Paolo Ballestrazzi Fund** affiliated member since April 2001

<b>Contact:</b>	<b>Address:</b>	Via Piedro Diacono 7, I 6079 Venafro
	<b>Tel.</b>	
	<b>Fax.</b>	
	<b>E mail</b>	
	<b>Informant:</b>	Palmina Giannini



**Luxembourg - INFA - International NF Association** affiliated member since April 2001

<b>Contact:</b>	<b>Address:</b>	c/o NNFF 95, Pine Street, 16 <sup>th</sup> Floor, New York, NY, 10005
	<b>Tel.</b>	212-344-6633
	<b>Fax.</b>	212-747-0004
	<b>E mail</b>	
	<b>Informant:</b>	Peter Beller mann-president INFA



**The Netherlands - NFvN – Neurofibromatoseverenigin,g Nederland** Full member since April 2001

<b>Contact:</b>	<b>Address:</b>	Mahatma Gandhistraat 11, NL 552 PA Den Haag
	<b>Tel.</b>	0031.070.39.75.168
	<b>Fax.</b>	
	<b>E mail</b>	PietJanJansen@zonnet.nl
	<b>Informant:</b>	Piet Jan Jansen



**Norway Norsk Forening for Nevrofibromatose** Associated member since September 1999.

<b>Contact:</b>	<b>Address:</b>	35 B Østli, N 3726 Skien
	<b>Tel.</b>	0047 3553 8093
	<b>Fax.</b>	<b>0047 3500 3710 Remember my name. The Fax is on my job.</b>
	<b>E mail</b>	toril.rordam@tts.telemax.no
	<b>Informant</b>	Toril Rørdam



**Portugal - APNF - Associação Portuguesa de NF** Full member since April 2001

<b>Contact:</b>	<b>Address:</b>	Rua Marquesa de Alorna 2 Atelier
	<b>Tel.</b>	0035 121 9343 959
	<b>Fax.</b>	0035 121 9343 960
	<b>E mail</b>	lucialemos.advg@iol.pt
	<b>Informant</b>	Lucia Lemos



**Spain** Full member of NF EUROPE since June 1999

**Asociacion Española de neurofibromatosis**

<b>Contact:</b>	<b>Address:</b>	7, Reina, E- 28004 Madrid
	<b>Tel.</b>	0034 91726 4823
	<b>Fax.</b>	0034 91 532 50 47
	<b>E mail</b>	asoc_nf@erasnas.com
	<b>WEB:</b>	<b>www.aeenf.com</b>
	<b>Informant</b>	Pilar Muñoz-Villalobos

"We have a Psychologist and since one year ago, that we have a small office, she is making group meetings. Till now we had a group for affected people and another for relatives, that meet once a month. This month she has begun to make also workshops and the first one will be about how to make a work interview. We have other ideas for workshops (parents of children with NF in school age; how to relax; how to laugh, ...). We had a stand in a Fair of Health in Albacete during 4 days last June. Since we started the association 5 years ago, we are working about how to get the Spanish Social Security system makes at least one joint speciality clinic in Spain. We had not being very lucky with the political time we had because during these last 4 years the system first was going to change, after was changing and after was just changed, so they just had to answer that was not the right moment. Now it is changed and we had meetings with some important people from the Sanitary system, and they asked us to make a report about what that will mean: organization, costs, etc. We are trying to make it and we want to take this opportunity to ask to the other countries NF associations to tell us about their systems, and how they have organized their NF expert groups in the clinical and genetics aspects (how many NF clinics in the country, how many experts, kind of genetics tests, if they have a clinical protocol, ...) any kind of information you think can be useful for us to convince the sanitary authorities we do need at least a small team of NF expert. Thanks in advance".

Pilar

*The Board of Directories send our colleague Pilar Munoz Villalobos our condolences and also express our deepest sympathy in de grief with the great loss of her beloved sister who passed away on November 8. We wish here all the courage she will need to help her beloved nephew to deal with this unbearable situation.*



**Sweden** Full member since September 1999

**NF-förbundet I Sverige**

<b>Contact:</b>	<b>Address:</b>	STURTEGATAN 3, SE 75314 Uppsala
	<b>Tel.</b>	0046 1836 7828
	<b>Fax.</b>	0046 1836 7218
	<b>E mail</b>	anita.engstrom@zeta.telenordia.se
	<b>Informant</b>	Anita Engström - Treasurer NF EUROPE



**Switzerland 1** - Associated member since September 1999.

**SNFv - Schweizerische NF Vereinigung**

<b>Contact:</b>	<b>Address:</b>	P.O.Box 753, CH 8037 Zürich
	<b>Tel.</b>	0041 1 363 8383
	<b>Fax.</b>	0041 1 363 8383
	<b>E mail</b>	bhans@smile.ch.
	<b>Informant</b>	Bernadette Hans





ANNEX 3

Invitation to participate in the project - draft materials to recruit volunteers

1. invitation to all existing NF Associations to sign inn and select volunteers



EUROPEAN FEDERATION FOR NEUROFIBROMATOSIS ASSOCIATIONS

ALBANIA  
ANDORRA  
AUSTRIA  
BELARUS  
BELGIUM  
BULGARIA  
CROATIA  
CZECK  
REPUBLIC  
DENMARK  
ESTONIA  
FINLAND  
FRANCE  
GERMANY  
GREECE  
HERZEGOVINA  
HUNGARIA  
ICELAND  
IRELAND  
ITALY  
LATVIA  
LIECHTENSTEIN  
LITHUANIA  
LUXEMBOURG  
MACEDONIA  
MALTA  
MOLDAVIA  
MONACO  
NORWAY  
POLAND  
PORTUGAL  
ROMANIA  
RUSSIA  
SAN MARINP  
SLOVAKIA  
SLOVENIA  
SPAIN  
SWEDEN  
SWITZERLAND  
THE  
NETHERLANDS  
THE UKRAINE  
TURKEY  
TURKMENISTAN  
UNTIED  
KINGDOM  
WHITE RUSSIA  
YUGOSLAVIA

Sint-Niklaas, December 1, 2002

Message to all NF EUROPE member groups

Dear all,

As promised we hereby include information to be used to select volunteers to represent your group in the work shops.

On page 1 a message for your scientific advisors, inviting them to support our invitation, Be sure to replace all red lines by your own group scientific advisors.

On page 2 a poster to advertise our project on bill boards in student houses, secretariat buildings and so on Be sure to replace all red lines by your national coordinates.

On page 3 detailed information on the project. Here again, replace the red lines by your national coordinates.

Be sure to send us names and addresses of your 2 volunteers as soon as possible.

Thanks for corporating,

For the EC project staff

Mia De Scheider Desmet

Office		Nijverheidsstraat 29	9100 St-Niklaas	Belgium	T. F. 32.3.766.13.41	nf.europe@nfkontakt.org
Presiden	Mia De Scheider	Lepelthoekstraat 78	9100 St-Niklaas	Belgium	Tel. 32.3.778.18.29	mia@nfkontakt.org
Secretary	Elisabeta Bisognani	Via Milano 21 b.	43100 Parma	Italy	Tel. 39.521.77.14.57	tabacchi_antonnicola@libero.it
treasurer	Anita Engström	Sturtegalan 3	74391 Storvreta	Sweden	Fax 46 18 36 72 18	anita.engstrm@telia.com



ANNEX 3

Invitation to participate in the project - draft materials to recruit volunteers

2. invitation to professionals familiar with NF to advertise our offer among their students



EUROPEAN FEDERATION FOR NEUROFIBROMATOSIS ASSOCIATIONS

ALBANIA  
ANDORRA  
AUSTRIA  
BELARUS  
BELGIUM  
BULGARIA  
CROATIA  
CZECK  
REPUBLIC  
DENMARK  
ESTONIA  
FINLAND  
FRANCE  
GERMANY  
GREECE  
HERZEGOVINA  
HUNGARIA  
ICELAND  
IRELAND  
ITALY  
LATVIA  
LIECHTENSTEIN  
LITHUANIA  
LUXEMBOURG  
MACEDONIA  
MALTA  
MOLDAVIA  
MONACO  
NORWAY  
POLAND  
PORTUGAL  
ROMANIA  
RUSSIA  
SAN MARINP  
SLOVAKIA  
SLOVENIA  
SPAIN  
SWEDEN  
SWITZERLAND  
THE  
NETHERLANDS  
THE UKRAINE  
TURKEY  
TURKMENISTAN  
UNTIED  
KINGDOM  
WHITE RUSSIA  
YUGOSLAVIA

Sint-Niklaas, December 1, 2002

Message to all members of our scientific advisory board

Dear **Doctor**,...

As discussed during our last scientific meeting in Venice we hereby appeal for your support as our scientific advisory board member to organize our new project granted by the EC commission for rare diseases.

Main goal of this project is to establish an efficient NF network offering advise and support to all people concerned across Europe, training volunteers for this purpose.

We hope for your help to advertise this opportunity among your students, and help us to select valuable volunteers for our training program.

In a few days your local NF group will send you a poster as well as detailed information on tis project. Please be so kind to warn us when you didn't hear from them in about 10 days from now, and then help us even more to find valuable volunteers to be trained to re enforce the existing NF family support group in your country.

Sure hope to meet again during the next Scientific meeting on NF in Turku Finland next Summer.

Kind regards,

Mia De Scheerder-Desmet  
president NF Europe

[mia@nfkontakt.be](mailto:mia@nfkontakt.be)

Office		Nijverheidsstraat 29	9100 St-Niklaas	Belgium	T. F. 32.3.766.13.41	<a href="mailto:nf_europe@nfkontakt.org">nf_europe@nfkontakt.org</a>
Presiden	Mia De Scheerder	Lepelhoekstraat 78	9100 St-Niklaas	Belgium	Tel. 32.3.778.18.29	<a href="mailto:mia@nfkontakt.org">mia@nfkontakt.org</a>
Secretary	Elisabeta Bisognani	Via Milano 21 b.	43100 Parma	Italy	Tel. 39.521.77.14.57	<a href="mailto:tabacchi_antonnicola@libero.it">tabacchi_antonnicola@libero.it</a>
treasurer	Anita Engström	Sturtegalan 3	74391 Storvreta	Sweden	Fax 46 18 36 72 18	<a href="mailto:anita.engstrm@telia.com">anita.engstrm@telia.com</a>



**ANNEX 3**

**Invitation to participate in the project - draft materials to recruit volunteers**

**3. Poster advertising our project to be spread in student homes and university secretariats**



**EUROPEAN FEDERATION FOR NEUROFIBROMATOSIS ASSOCIATIONS**

- ALBANIA
- ANDORRA
- AUSTRIA
- BELARUS
- BELGIUM
- BULGARIA
- CROATIA
- CZECH REPUBLIC
- DENMARK
- ESTONIA
- FINLAND
- FRANCE
- GERMANY
- GREECE
- HERZEGOVINA
- HUNGARY
- ICELAND
- IRELAND
- ITALY
- LATVIA
- LIECHTENSTEIN
- LITHUANIA
- LUXEMBOURG
- MACEDONIA
- MALTA
- MOLDAVIA
- MONACO
- NORWAY
- POLAND
- PORTUGAL
- ROMANIA
- RUSSIA
- SAN MARIN
- SLOVAKIA
- SLOVENIA
- SPAIN
- SWEDEN
- SWITZERLAND
- THE NETHERLANDS
- THE UKRAINE
- TURKEY
- TURKMENISTAN
- UNITED KINGDOM
- WHITE RUSSIA
- YUGOSLAVIA

**ORGANISING:**

A training program for establishing a European Neurofibromatosis lay group network in order to help people affected to break through social isolation and to cope with limitations caused by this disease

**LOOKING FOR:**

Two volunteers in each participating country  
Students or 'young' professionals  
in the areas of medicine or/and human services

**REQUIRING:**

Commitment to work for three years with an NF-association in **the volunteers country**.  
Fluent in English – access to the internet.  
Educational background in medicine or human services.  
Willing to participate in training courses abroad. ( Belgium, Greece, a.o.)  
Interested to work in "projects".  
Broad minded and with an interest in people with special needs.

**OFFERING:**

Setting up or expanding lay groups for people affected with neurofibromatosis and their families in the volunteers country;  
Training courses on various organisational aspects, personal skills development, group dynamics and social skills in different European countries.  
Exchange of ideas, practice and support  
in an international network of highly motivated volunteers.  
A unique practical framework for further education and an opportunity to link theory and practice.  
A challenge to meet and work with patients and their relatives, crossing the boundaries of sometimes narrow professional education.  
Learning to collaborate and work with other professionals in their country, institutions, government agencies, a.s.o.

**project is running from December 1, 2002 to December 31, 2005**  
**1<sup>st</sup> workshop on February 27 to March 2, 2003**

**INTERESTED ?**

Please do contact  
**PLEASE DO COMPLETE HERE WITH YOUR LOCAL REFERENCES**  
Reference Doctors name and e mail,  
Local NF associations name, address, Tel. Nr. E mail address

**THIS PROJECT IS GRANTED BY THE EC**  
**AND PARTICIPATION IS FREE OF CHARGES FOR ALL VOLUNTEERS INVOLVED**

Office	Nijverheidsstraat 29	9100 St-Niklaas	Belgium	T. F. 32.3.766.13.41	nf.europe@nfbkontakt.org
Presiden	Mia De Scheinder	Lepelhoekstraat 78	9100 St-Niklaas	Belgium	Tel. 32.3.778.18.29
Secretary	Elisabeta Bisignani	Via Milano 21 b.	43100 Parma	Italy	Tel. 39.521.77.14.57
treasurer	Anita Engström	Sturtegalan 3	74391 Storvreta	Sweden	Fax 46 18 36 72 18
					mia@nfbkontakt.org
					tabacchi_antonnicola@libero.it
					anita.engstrm@telia.com



ANNEX 3

Invitation to participate in the project - draft materials to recruit volunteers

4. detailed information for students reacting on the posters.

Sint-Niklaas Belgium, December 1, 2002

Under a grant from the **European Commission**, Health & Consumer Protection Directorate General, the European Federation for Neurofibromatosis Associations: **NF-Europe** is establishing a European Neurofibromatosis lay group network.

This project is running from December 1, 2002 to December 31, 2005

Only two volunteers invited per member association.

**The aims of the project are:**

1. To establish a European NF-network, through linking the existing neurofibromatosis lay groups and strengthening 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. To develop a volunteer training program in order to help people affected for better socialization and enable them to cope better with the disease.
3. To increase awareness about NF at a European level focusing on professionals, people concerned and the European society.
4. To produce educational materials for people concerned (patients, social workers teachers, and medical professionals).
5. Through sharing experiences to investigate the medical and social needs of people affected and to create recommendations and guidelines for evidence based managing the various aspects related to neurofibromatosis.

In order to elaborate this project, NF-Europe and its member associations is offering a unique volunteering opportunity to students or "young" professionals in the areas of medicine and/or the human services. During three years they can help to establish new or strengthen existing NF-associations in their country thus putting theory into practice and learning about people behind disorders. (Participation free of charges for the volunteers involved)

The challenge

- Setting up or expanding lay groups for people affected with neurofibromatosis and their families in the volunteers country;
- Training courses on various organisational aspects, personal skills development, group dynamics and social skills in different European countries. (*1<sup>st</sup> workshop on February 27 to March 2, 2003*)
- Exchange of ideas, practice and support in an international network of highly motivated volunteers.
- A unique practical framework for further education and an opportunity to link theory and practice.
- A challenge to meet and work with patients and their relatives, crossing the boundaries of sometimes narrow professional education.
- Learning to collaborate and work with other professionals in their country, institutions, government agencies, a.s.o.

Requirements

- Commitment to work for three years with an NF-association in the volunteers country.
- Fluent in English – access to the internet.
- Educational background in medicine or human services.
- Willing to participate in training courses abroad.
- Interested to work in "projects".
- Broad minded and with an interest in people.

Youngsters willing to appeal for selection please do contact us for

- **More info or application:** PLEASE DO COMPLETE HERE WITH YOUR LOCAL REFERENCES
  - Reference Doctors name and e mail,
  - Local NF associations name, address, Tel. Nr. E mail address
  -

This document is part of a program funded by the European Commission



**List of people invited to collaborate:**

<b>Countries with NF association</b>	<b>representative</b>	<b>professional</b>
<b>NF EUROPE membergroups</b>		
Belgium	Marleen Gielen	Eric Legius
Bulgaria	Lidia Georgieva	Georges Poptodorov
Denmark	Karin Persson	John Østergard
Finland	Esko Olavi Kandelin	Minna Poyhonen
France	Anne Henrion	Pierre Wolkenstein
Germany	Frank Wilke	Victor Mautner
Italy	Elisabetta Bissignani	Romano Tenconi
Netherlands	Peter venden Ende	Arja Goeden Bolder
Norway	Toril Rørdam	Arvid Heiberg
Portugal	Lucia Lemos	Isabel Cordeiro
Spain	Pilar Muñoz Vilalobos	Carmen Valero Quiros
Sweden	Anita Engström	Birgitte Rembeck
Switzerland	Barbara Kajöri	Eugen Boltshauser
<b>Non NF EUROPE membergroups</b>		
Austria	Barbara Griesner Zittner	Katharina Wimmer
Ireland	Patricia Nutty	Susan Huson
UK	Roberta Tweedy	Susan Huson
<b>Countries without NF Associations</b>		
Czech Republic		Alena Petrakova
Greece		Dacou Voutecatis
Hungary		Laslo Timar
Poland		Sergius Jozwiac



ANNEX 3b

INVITATION to professionals in countries without NF family support groups so far.



EUROPEAN FEDERATION FOR NEUROFIBROMATOSIS ASSOCIATIONS

Sint-Niklaas, November 12, 2002

Dr. DACOU VOUTETAKIS,  
Dept. of Pediatrics  
UNIVERSITY OF ATHENS  
2, THIVON STREET  
GR 11527 GOUDI  
ATHENS - GREECE

ALBANIA  
ANDORRA  
AUSTRIA  
BELARUS  
BELGIUM  
BULGARIA  
CROATIA  
CZECH  
REPUBLIC  
DENMARK  
ESTONIA  
FINLAND  
FRANCE  
GERMANY  
GREECE  
HERZEGOVINA  
HUNGARIA  
ICELAND  
IRELAND  
ITALY  
LATVIA  
LIECHTENSTEIN  
LITHUANIA  
LUXEMBOURG  
MACEDONIA  
MALTA  
MOLDAVIA  
MONACO  
NORWAY  
POLAND  
PORTUGAL  
ROMANIA  
RUSSIA  
SAN MARIN  
SLOVAKIA  
SLOVENIA  
SPAIN  
SWEDEN  
SWITZERLAND  
THE  
NETHERLANDS  
THE UKRAINE  
TURKEY  
TURKMENISTAN  
UNTIED  
KINGDOM  
WHITE RUSSIA  
YUGOSLAVIA

CC. Dr. ALENA PETRAKOVA, Czech Republic  
Dr. LASLO TIMAR, Hungary  
Dr. SERGIUSZ JOZWIAK, Poland

To doctors in Greece, Czech Republic, Hungary and Poland,  
or colleagues active in the field of neurofibromatosis.

Dear Doctor,

As you probably remember we are really concerned about how to offer you all access to our international NF meetings, and how to help to start up a support group for people affected in your different countries.

In fact that was one of the main reasons to create NF EUROPE, European Federation for NF Associations.

I am really happy that the EC finally did decide to grand our project.

On November 1 we can start up an international program meant to offer information and support to all people affected all over Europe. During the 1st 2 years we will develop a support program and organize workshops in different European locations.

We will invite all of you to select one or two volunteers, for example students from social or medical disciplines.

They will be invited to join you to participate in the work shops and in the next scientific NF meeting that will be organized in Turku-Finland on July 24-27, 2003. All your travel costs of course covered by the EC grand.

For your own information, in this project our NF groups are covered by:  
for Belgium: Prof. Dr. Eric Legius, for Bulgaria: Dr. George Poptodorov, for Denmark: Dr. John Ostergard, for Finland: Dr. Minna Poyhonen, for France: Dr. Pierre Wolkenstein, for Germany: Dr. Victor Mautner, for Italy: Dr. Romano Tenconi, for Ireland: Dr. Susan Huson; for the Netherlands: Dr. Arja Goeden-Bolder, for Norway: Dr. Arvid Heiberg, for Portugal: Dr. Isabel Cordeiro, for Spain: Dr. Paschal Castroviejo, for Sweden: Dr. Birgitta Rembeck, for Switzerland: Dr. Eugen Boltshauser.

I guess many of those names are familiar and you will perhaps appreciate the opportunity to participate in this project with this list of outstanding European NF specialists.

If you 'r interested to join us, please contact me asap. I will mail you all information needed at once.

Looking forward to hear from you.

Kind regards

Mia De Scheider-Desmet  
president NF EUROPE

Office		Nijverheidsstraat 29	9100 St-Niklaas	Belgium	T. F 32.3.766.13.41	nf_europe@nfbkontakt.org
Presiden	Mia De Scheider	Lepelthoekstraat 78	9100 St-Niklaas	Belgium	Tel. 32.3.778.18.29	mia@nfbkontakt.org
Secretary	Elisabeta Bisignani	Via Milano 21 b.	43100 Parma	Italy	Tel. 39.521.77.14.57	tabacchi_antonnicola@libero.it
treasurer	Anita Engström	Sturtegatan 3	74391 Storvreta	Sweden	Fax 46 18 36 72 18	anita.engstrm@telia.com




**ANNEX 4**

**Fact sheets NF EUROPE member groups**


**PARTNER GROUPS in the European NF network**

**4.1 BELGIUM**

	
<b>country</b>	Belgium
<b>name of the association</b>	NF KONTAKT vzw
<b>address</b>	Slachthuisstraat 73, BE 9100 Sint-Niklaas
<b>Tel</b>	+32 3 766 13 41
<b>Fax</b>	-
<b>Email</b>	nf@nfkontakt.be
<b>URL</b>	<a href="http://nfvlaanderen.nfkontakt.be">http://nfvlaanderen.nfkontakt.be</a>
<b>president</b>	Mia DESMET
<b>Board members</b>	Adrienne POELEMANS Marleen HOUBEN Machteld VAN KERCKHOVE
<b>Amount of members</b>	About 600 affected member families
<b>Aims:</b> increase quality of life for families affected	
<b>Main activities:</b> Office in Sint-Niklaas: open for everyone needing information, offering support for families concerned and advice and training material for professionals. Volunteers are realizing the program including: <ul style="list-style-type: none"> <li>- News paper 4 times a year,</li> <li>- Discussion groups 2 or 3 times a year,</li> <li>- Scientific meeting on NF at least once a year,</li> <li>- Activities and discussion groups for different age groups,</li> <li>- Educational programs for Teens,</li> <li>- Information programs for teachers and educators</li> <li>- Summer Camps,</li> <li>- Various fund raising activities</li> </ul>	
<b>Recent realisations:</b> <ul style="list-style-type: none"> <li>- An NF family weekend,</li> <li>- a Public awareness day,</li> <li>- a training weekend for youngsters affected,</li> <li>- Publication "NF for kids who want to know all about it</li> <li>- and all activities requested as participants in the EC project.</li> </ul>	



**4.2 BULGARIA**

	
<b>country</b>	Bulgaria
<b>Name of the association</b>	Bulgarian Neurofibromatosis Association (NFA)
<b>address</b>	Department of Neurosurgery PIROGOV Institute 21, Totleben Blvd. 1606 Sofia
<b>Tel</b>	359 2 4344-375
<b>Fax</b>	
<b>Email</b>	gpoptodorov@omega.bg
<b>URL</b>	<a href="http://go.to/NFABulgaria">http://go.to/NFABulgaria</a>
<b>president</b>	Dr. George Poptodorov MD
<b>Board members</b>	
<b>Amount of members</b>	
<b>Aims</b> <ul style="list-style-type: none"> <li>• To support scientific investigations and research programs related to NF.</li> <li>• To collect and distribute up-to-date scientific information concerning NF.</li> <li>• To promote public awareness and spread information on NF.</li> <li>• To promote and improve contacts and effective collaboration among different medical specialties in order to ensure better management of the NF patients.</li> <li>• To build regional multidisciplinary teams of specialists and to provide an improved exchange of information between them.</li> <li>• To collect data about NF sufferers and their families in the country and to establish a national informational NF database.</li> <li>• To cooperate with other similar national and international organizations and institutions.</li> <li>• To act as a support group for affected people and their families, helping them to cope with the disease</li> </ul>	





**ANNEX 4**

- To provide genetic counseling for the affected patients and families.
- To provide help for social integration of disabled people.
- To promote contacts between affected people and their families.
- 
  
- To work on programs for increasing awareness of NF among patients, families, health and education professionals.
  
- To update on a regular basis a list of medical specialists concerned with NF (and keep informed the medical society and public) in order to provide patients and families affected by neurofibromatosis an improved access to better treatment.
- To refer affected people to regional NF multidisciplinary teams.

**Recent realisations:**



**4.3 DENMARK**

<p><b>DANSK FORENING FOR</b> <b>Neurofibromatosis Recklinghausen</b></p>	
<b>country</b>	Denmark
<b>Name of the association</b>	Dansk forening for Neurofibromatosis Recklinghausen
<b>address</b>	Dronninggårds Allé 10C, 1.th. , DK 2840 Holte
<b>Tel</b>	-45 4570227010 / -45 45411580
<b>Fax</b>	-45 45411680
<b>Email</b>	karinpersson@mbox301.get2net.dk
<b>URL</b>	www.nfrecklinghausen.dk
<b>president</b>	Karin PERSSON
<b>Board members</b>	Vice President Henning Oettinger Traesure: Sven Burlin Sek: Lene Lind Board Members: Jytte Johansen Anni Bundgaard Peter Hogue Jørgen Juel Pedersen
<b>Amount of members</b>	465
<b>Aims:</b>	To support people and families with NF, to spread knowledge about the disease, surport scientific research in its prevention and treatment.
<b>Realisations:</b>	Short overview of your activities:



**ANNEX 4**

IN 2004 the ass. held annual meeting with scientific lectures, we attempted a fair for handicap, course for young people: How to reply for job. Our youth group had a trip to Legoland, and a Christmas Meeting, the ass. had 2 weekend trips to (badeland), a course for parents, the youth group had a trip to Lego Land, the local groups have held some meetings.


The ass. have attempted many meetings with ministries and other ass. for handicapped.

In 2005, we are going to have annual meeting with scientific lectures, attempt a fair for handicap, a course for our elder members, a big family course and a course for our young members,

We have 3 local groups and a youth group



**4.4 FINLAND**

	
<b>country</b>	Finland
<b>Name of the association</b>	Suomen neurofibromatoosiyhdistys ry
<b>address</b>	PL 1096, FI-00101 HELSINKI
<b>Tel</b>	+358 6 417 5179
<b>Fax</b>	+358 6 417 5179
<b>Email</b>	toimisto@nf-yhdistys.org
<b>URL</b>	www.nf-yhdistys.org
<b>president</b>	Esko Olavi Kandelin
<b>Board members</b>	Mrs Kaisu Kandelin (secretary) Mr Martti Komu (treasurer) Mrs Tuula Huhtiniemi Ms Anne Leppälä (vice president) Mr. Hannu Havanka Mr. Pertti Kallio Mrs Minna Lehtonen Mrs Mirella Rautanen
	Aprox. 450
<b>Aims:</b> - give fact of NF to people, who have NF, their relatives, and familiars and people, who works with NF - information meetings to general public - to give aid to NF families and give chance meet people in same condition on camps and course - aim at developing nursing and tracking system - aim at developing medical research of NF - international co-operation with national NF associations in Europe	
<b>Recent realisations:</b> Statutory meetings twice in year (on spring and on autumn)	



**ANNEX 4**

Problem: Finland is very large country. We have long distances to meeting points. For example from Helsinki to North Finland or from Karelien to Helsinki is 700-800 km and it takes time and money to travel. If you must travel by bus/ train, it is problem to take it:

On weekends you have problems or it can be „mission impossible%” to travel by public traffic!

Also in „Country of thousands lakes%” distance between two cities via Milky Way it can be 20 km, but via main road distance is 80 km or more! Of course you must change buses two three times in that case!

In meetings in less than 10 members! Twice we have had on autumn cruise from Turku to Stockholm. This is our new popular tradition!

We have planed local clubs to ours association. Now we have founded three clubs. Many who have NF, will never herd about us and NF. And many members of NF-Finland will be only member, but will do nothing for us. In the clubs are only 2-3 active members.

Once year we have family camp. Last year it was in South Finland, on this year it will be in North Finland. So all members has change be with it. On the week end are NF-doctors telling about NF.


On this year we have planed new brochure one for adults and one for youth on simplified language. Also we will send own brochure for doctors to all hospitals and health care centre in Finland. To this project we have got 10.000 • financial support from Finland,s Slot Machine Association (RAY)

We have now some local groups in provinces. They can meet as they will!

In local groups are only 2-5 active persons. For youth we have not their own groups.



**4.5 FRANCE**

	
<b>country</b>	France
<b>Name of the association</b>	Association Neurofibromatoses et Recklinghausen
<b>address</b>	34 vieux Chemin de Grenade, FR 31700 Blagnac
<b>Tel</b>	+33 561 300 337
<b>Fax</b>	
<b>Email</b>	ass.neurofibromatoses@wanadoo.fr
<b>URL</b>	<a href="http://www.anrfrance.org">http://www.anrfrance.org</a>
<b>president</b>	Anne HENRION
<b>International contacts</b>	Bernard BABU – 41, rue d'Iéna FR 44000 NANTES bernardbabu@wanadoo
<b>Amount of members</b>	apr. 1000
<p><b>Aims:</b></p> <ul style="list-style-type: none"> <li>- information about the disease ( to members, doctors in general, para-medics, teaching professions, the public at large ) ;</li> <li style="padding-left: 20px;">- support and help to the ill and their families ;</li> <li style="padding-left: 20px;">- stimulation of all initiatives to improve the knowledge, the diagnosis, the prevention, the research, the cure about these ailments.</li> </ul> <p><i>(NB: for those purposes the association has been recognised nationally of 'public utility' since may 3, 2004.)</i></p>	
<p><b>Prior activities:</b></p> <p>preparing the yearly congress, this year in NANTES :</p> <p>" journées nationales NF" MARCH 18 and 19, 2005</p> <p>first day about information on medical research plus discussion groups with psychologists, second day more about the life of the association. These 'journées nationales NF' are open to all interested people, (ill people, members, doctors, ...).</p>	



**past/future activities:**

There are **2 levels of action** : national and local :

\* **national level** : initiatives to make for the creation of the NF FRANCE national medical Network and of the setting up of interdisciplinary teams in a large number of hospital centers equally spread out on the whole territory + actions for the recognition by the Health Ministry in Paris of : the disease itself, the number of ill people, their difficulties in their every day life ("life quality") - and the recognition of NF centers (called "centers of reference" in an official document dated beginning of december 2004).

Organization of Yearly medical days which are "a yearly reference" for all our members enabling them to meet the experts and be informed about the progress in research. (last year it took place in PARIS.)

Recognition of 'public utility' which is conferred by the State to the associations when they can prove the remarkable rigour of their finance management and strict follow up of statutory objectives.

\*\* **local and national levels** : advice and information to members, generalist doctors, information via written and audio-visual media.


Writing and sending to all members a quarterly "bulletin de l'association" entitled : NEUROFIBROMATOSES.

\*\*\* **local level** : organisation of friendly meetings 2 to 4 times a year with discussions and exchanges on the subjects connected to their daily experience of the disease; organisation of money-raising activities during the year to publicize the disease and collect money ( sporting events in particular) : more of these will happen in may, month of neurofibromatoses.

10/ NB: youth groups depend on each region, and 3 discussion groups are particularly appreciated on the first day, friday p.m., of the yearly congress, with doctors and psychological help. A report is published in the 'bulletin'.



**4.6 GERMANY**

	
<b>country</b>	Germany
<b>Name of the association</b>	Von Recklinghausen-Gesellschaft e.V
<b>address</b>	Von-Recklinghausen-Gesellschaft e.V. Im Klinikum Ochsenzoll Langenhorner Chausse 560 D - 22419 Hamburg
<b>Tel</b>	H.040-1818 87 2822 F. +49 69 / 36402 - 195
<b>Fax</b>	H. +49 040-5277462 F +49 69 / 36402 - 197
<b>Email</b>	E-mail:H- info@von-recklinghausen.org F-mailto: von-Recklinghausen-Ffm@t-online.de
<b>URL</b>	(1) <a href="http://www.neurofibromatose.de">http://www.neurofibromatose.de</a> (2) <a href="http://von-recklinghausen.org">http://von-recklinghausen.org</a> (3) <a href="http://www.nf2.de">http://www.nf2.de</a>
<b>president</b>	Prof. Dr. med. V.F. Mautner
<b>Board members</b>	Frank Wilke (Vicepresident) Rainer Swiderski (Treasurer)
<b>Amount of members</b>	Aprox. 1480
<b>Aims:</b> (1) Healing/Successful treatment of Neurofibromatosis (2) Clearing up affected people, their relatives, medical professionals and society (3) Publishing of information material e.g. brochures (4) Improvement of medical and psychological care (5) Supporting for science an research (6) Supporting for social integration of affected people	
<b>Prior activities:</b> (1) <i>The Von-Recklinghausen-Gesellschaft e.V. offers affected people to get in contact to an</i>	

This document is part of a program funded by the European Commission





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*interdisciplinary health-care-center, which is specialised on Neurofibromatosis to discuss the further therapeutical proceeding with the NF-doctors.*

(2) The Von-Recklinghausen-Gesellschaft e.V. offers affected people the chance of social integration through getting in contact with other affected people. Affected people shall live as far as possible self-dependent. This requires the offer of seminars with topics concerning the handling of the disease.

(3) The Von-Recklinghausen-Gesellschaft e.V. has enabled some scientific researches especially concerning learning difficulties of NF1-children and molecular genetic causes of NF2.

(4) The Von-Recklinghausen-Gesellschaft e.V. makes intensive efforts on raising money from private sponsors and government to finance their activities and tries to win persons, who are well-known in the public life, for patronages.

**Subdivisions:**

The Von-Recklinghausen-Gesellschaft e.V. is a federal association, which

- > currently is organized in round about 20 regional groups seated in
- > different parts of Germany and one national NF2-group. They all offer a
- > wide palette of activities. In these groups there are working round
- > about 50 contact persons, which are trained by special seminars to get
- > fit on their job, to be on the side of their fellow



**4.7 GREECE**

<b>country</b>	Greece
<b>Name of the association</b>	NF guest group
<b>address</b>	Tritonos 66-68, P.Phalilro, HE17561 Athens
<b>Tel</b>	+302 10 981 49 28
<b>Fax</b>	-
<b>Email</b>	kpapadi@otenet.gr
<b>URL</b>	-
<b>president</b>	
<b>Board members</b>	
<b>Amount of members</b>	
<b>Aims:</b>	
<b>Recent realisations:</b> Katerina PAPANIMITRIIOU and colleagues looking for help to start a family support group	



**4.8 IRELAND**

	
<b>country</b>	Ireland
<b>Name of the association</b>	Neurofibromatosis Association of Ireland registered charity CHY 6657
<b>address</b>	Carmichael Centre, North Brunswick Street, Dublin 7
<b>Tel</b>	01– 8726338
<b>Fax</b>	01– 8735737
<b>Email</b>	nfaireland@eircom.net
<b>URL</b>	<a href="http://www.nfaireland.ie">http://www.nfaireland.ie</a>
<b>president</b>	Patricia Nutty
<b>Board members</b>	Jimmy Corr, Secretary Eddie Creevey treasurer 6 Committee Members 6 Volunteers CEO - Paddy Griffin
<b>Amount of members</b>	
<p><b>Aims:</b> <b><u>Information &amp; Research</u></b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Provide information on Nf. to Patients, Doctors, Consultants and Teachers also to promote awareness and an understanding of the problems encountered with the disorder.</li> <li><input type="checkbox"/> To organise seminars to disseminate information/progress on research into Nf.</li> <li><input type="checkbox"/> To organize public awareness campaigns.</li> </ul>	



**ANNEX 4**


- ❑ To provide advocacy and the provision of information.
- ❑ To source information on specialised medical services yet unavailable in Ireland.
- ❑ To encourage scientific research that might lead to a cure.
- ❑ To provide financial aid where possible towards research.

**realisations:**

- *24-hour Help Line*
- *Counseling Service*
- *Respite*
- *Bi-monthly Newsletter "Neuro News" (500 copies distributed countrywide)*
- Procuring & circulating literature / Information Packs on Nf.
- Information Evenings.
- Awareness Programme focused at Nf. families and Health Professionals.
- Home and Hospital visits.
- Referral service to medical services and other support groups
- Information/promotion of research into finding a cure
- Linking patients and families together to overcome the feeling of isolation
- Attending meetings of associated bodies.
- Administrating Grant Aid from the State Sector and other bodies



**4.9 ITALY A.N.F.**

	
<b>country</b>	Italy:
<b>Name of the association</b>	A.N.F. Associazione Neuro Fibromatosi -onlus - ITALY
<b>address</b>	Via Milano, 21/B - 43100 Parma - Italy
<b>Tel</b>	+ 39/0521-771457
<b>Fax</b>	+ 39/0521/771457
<b>Email</b>	<a href="mailto:associazione@neurofibromatosi.org">associazione@neurofibromatosi.org</a> <a href="mailto:a.n.f.@neurofibromatosi.org">a.n.f.@neurofibromatosi.org</a>
<b>URL</b>	<a href="http://www.neurofibromatosi.org">http://www.neurofibromatosi.org</a> >
<b>president</b>	Corrado Melegari
<b>Board members</b>	Michele Palomba, vice-president Mariastella Eisenberg, vice-president Giuseppe Porcu, councillor and secretary Adelia Frigè Moioli, councilor Antonello Corbetta, councillor Felice Mostacci, councillor Marzia Cassani, councillor Michela Corradini, councillor Michele Curatolo, councillor
<b>Amount of members</b>	Aprox 1500
<p><b>Aims:</b></p> <ul style="list-style-type: none"> <li>- divulge the knowledge of the NF, uniform and improve the diagnostic-welfare Procedures, support studies and researches , promote the cooperation within medical, biological and social sphere, support the international contacts and the exchanges among similar associations</li> <li>- organize two yearly meeting for the members</li> <li>- open new branches in the Italian regions</li> <li>- print and diffusion of information material of the NF and on the assistential center</li> </ul>	



- print and diffusion of a Newsletter, a wishing card and a tee-shirt with the logo of our Association;
- direct participation in the Tribunale del Diritto del Malato, in Telethon, and in Meetings, Congresses and Conferences dealing with our pathology.

**Acitivities:**


*We have organized from 1993 up to the date , 4 NF National Congresses, we organize banquets, collect funds and shows to spread the NF knowledge*

*We have been conferred in our town some important awards*

*We are preparing a project dealing with the learning difficulties of the children with NF.*




**4.10 ITALY LINFA**

	
<b>country</b>	Italy
<b>Name of the association</b>	LINFA, Lottiamo Insieme per la NeuroFibromatosi - ONLUS
<b>address</b>	C/o Dipartimento di Pediatria Cattedra di Genetica, - Via Giustiniani, 3 IT 35128 Padova-
<b>Tel</b>	+049.8213513
<b>Fax</b>	+049.8211425
<b>Email</b>	associaz.linfa@libero.it
<b>URL</b>	www.associazionelinfa.it (under construction)
<b>president</b>	Longo Daniela
<b>Board members</b>	Boscaro Dario, Rossi Eclio, Busatto Giorgia, Mazuoli >>Cinzia, Fantinato Ivana, Martellato Marika, Piantella Giovanna, Wailant Emilio.
<b>Amount of members</b>	Aprox 200
<b>Aims:</b> Help the people concerned about NF.	
<b>Recent realisations:</b>  We write the periodic Linfanews, we finance one researcher on the NF, in the month of may we organize the annual assembly of member,s etc.	



**4.11 NETHERLANDS**

	
<b>country</b>	The Netherlands
<b>Name of the association</b>	NFVN, Neurofibromatose Vereniging Nederland
<b>address</b>	Gondel 27-37 8243 CP Lelystad
<b>Tel</b>	0320 0 227017
<b>Fax</b>	
<b>Email</b>	p.jjansen06@freeler.nl
<b>URL</b>	<a href="http://www.neurofibromatose.nl">http://www.neurofibromatose.nl</a> (under construction)
<b>president</b>	Michel AARTS
<b>Board members</b>	Tally Vink, Hans Bruggeman, Petra Veldman, Monique Schuijlenburg, Rene Hamburg, Piet Jan Jansen, Nina Hlillegers and Gerard Janson
<b>Amount of members</b>	Aprox 900
<p><b>Aims:</b> making neurofibromatose more known, giving people with NF possibilities to meet other people with NF, making information about NF available for those who are interested.</p>	
<p><b>realisations:</b> The activities we have to meet these aims are once a year a lecture about medical aspects of NF, we also try to have a lecture about social problems people affected by NF are confronted with. We are trying to hold two of this meetings in a year. The youth group meets four times a year by one of the youth at home and onwe a year we organize a weekend for them. On these occasions they talk with each other about their problems and they have a lot of fun together. This year we start with two new groups, one for the older people with NF we organise a day where they can met and to together and go out together as a number of them don't fin it ease to go to the zoo on their own because everybodt stares at them. The second group we start this year is for the sibblings of people affected by NF, as they see that the brother or sister with NF get more attention.</p>	





**4.12 NORWAY**

	
<b>country</b>	Norway
<b>Name of the association</b>	Norsk Forening for Nevrofibromatose
<b>address</b>	Asgaarden 10, 3179 Åsgårdstrand
<b>Tel</b>	33 08 14 50
<b>Fax</b>	
<b>Email</b>	atique@online.no
<b>URL</b>	<a href="http://nevrofibromatose.com/">http://nevrofibromatose.com/</a>
<b>president</b>	Britt Ohrø
<b>Board members</b>	Leif Bjarne Gjessing, Secretary Tove Granum, treasurer Terje Øgreid Bjørrg Ranheim, Anette Gjessing Tonje Sollie Kristin Haukeland
<b>Amount of members</b>	482
<p><b>Aims:</b></p> <ul style="list-style-type: none"> <li>• to advise, inform and assist anyone who has neurofibromatose and their families</li> <li>• to spread information about NF to hospitals and other relevant institutions</li> <li>• to inform government agencies about the special problems NF can cause</li> <li>• to establish contact with similar organisations in other countries</li> </ul> <p>Every year about 15 children is born with NF in Norway. All in all in excess of 1000 persons has been diagnosed with NF1 and about 20 with NF2. If you are one of these, or you are related to one of them you can join our organisation. Here you and your relatives can recive information, help and advice from others in the same situation. Both the nationwide and the local organisations has activities you can take part in.</p> <p>As with other rear conditions, knowledge about NF is often poor among medical professionals, schools and health and social services. NFFNF can help with information and guidance.</p>	
<p><b>Recent realisations:</b></p> <p>Summer camp for youth group, Winter camp for the Youth group, they are planning and taking care of things to do themselves - the board in the Youth group, Summer camp in Sweden, our volunteers was there as leaders of the group; Week-end for adults with NF-diagnosis, travel club Region week-end gathering, and for NF-2 as well courses for members - how to manage daily living and co-operation with our comprehensive center Frambu</p>	

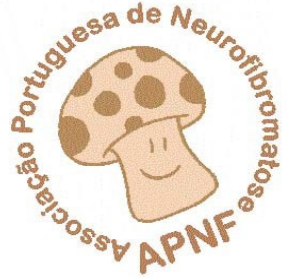


**4.13 POLAND**

<b>country</b>	Poland
<b>Name of the association</b>	NF POLSKA (start January 2005)
<b>address</b>	Babimost 66-110 ul. Rynek 20/10
<b>Tel</b>	+48 68 351 2302
<b>Fax</b>	+48 68 351 2302
<b>Email</b>	asoc_nf@eresmas.com maciej.kmiecik@nfpolska.com
<b>URL</b>	www.nfpolska.com (under construction)
<b>president</b>	Maciej Kmiecik
<b>Board members</b>	
<b>Amount of members</b>	
<b>Aims:</b>	
<b>Recent realisations: just started</b>	



**4.14 PORTUGAL**

	
<b>country</b>	Portugal
<b>Name of the association</b>	APNF, Associação Portuguesa de NF
<b>address</b>	Rua Marquesa d'Alorna, nº2, Atelier, Bons Dias, 2675-781 Ramada, Odivelas,
<b>Tel</b>	+351 219 34 39 59
<b>Fax</b>	+351 219 34 39 60
<b>Email</b>	apnf@iol.pt
<b>URL</b>	
<b>president</b>	Lúcia Lemos
<b>Board members</b>	Secretary – Cidália Mira Treasurer – Cristina Rodrigue Other representatives: Isabel Cordeiro, Elisabete Gomes
<b>Amount of members</b>	
<p><b>APNF's major aims:</b></p> <ul style="list-style-type: none"> <li>- To promote all activities related to the medical, social and educational support of all NF affected individuals;</li> <li>- To guide all NF affected individuals and their relatives in:             <ul style="list-style-type: none"> <li>- early diagnosis</li> <li>- medical support</li> <li>- educational support</li> <li>- social support</li> <li>- genetic counselling.</li> </ul> </li> </ul>	



**APNF's previous activities:**


- Annual patient and relatives' meetings;
- Promotion of awareness regarding NF and the association along with the media (TV, radio, newspapers, magazines)
- Meetings with government representatives as well as with representatives off all the political parties;
- Promotion of awareness regarding NF and the association at Universities and Nursing Schools;
- Participation in the EC-Project for the NF Associations worldwide;
- Individualized support to patients and their families whenever necessary;
- Guidance towards specialized healthcare professionals when requested by patients or their families;
- And others more related to the association's internal functioning.

**APNF's prior activities:**

- Move the association's headquarters to a new address donated by the by the local representative of our government
- Raise funds to allow the previously mentioned moving of the headquarters;
- The 3<sup>rd</sup> APNF's National Encounter in Lisbon;
- The European NF Meeting in 2007 in Portugal (Lisbon)



**4.15 SPAIN**

 <p>Asociación Española de Neurofibromatosis</p>	
<b>country</b>	Spain
<b>Name of the association</b>	Asociación Española de Afectados de Neurofibromatosis
<b>address</b>	Reina, 1, ES 28004 Madrid
<b>Tel</b>	91 726 48 23
<b>Fax</b>	91 532 50 47
<b>Email</b>	asoc_nf@eresmas.com
<b>URL</b>	<a href="http://www.aeenf.com">http://www.aeenf.com</a>
<b>president</b>	Pilar Muñoz Villalobos
<b>Board members</b>	Carmen Jiménez Caro (Vice-president), Carlos Vargas Martínez (Treasurer), Teresa Jiménez Jiménez (Secretary)
<b>Amount of members</b>	1166
<b>Aims:</b>	
<p>Recent realisations:</p> <p><b>ACTIVITIES DEVELOPED DURING 2004 BY THE SPANISH NF ASSOCIATION</b></p> <ul style="list-style-type: none"> <li>• Celebration, on January 24<sup>th</sup> of the seventh national meeting. At this time we had censused 1.111 affected persons. As usual we dedicated the first part of the meeting to the professionals related with NF. They told us the news and answer all our questions. This year, beside our clinic and genetic assessors, Dr. Ignacio Pascual Castroviejo &amp; Dra. Carmen Valero, assisted, as invited, four doctors that let us know the news in their specialities.</li> <li>• Between March 19<sup>th</sup> to 22<sup>nd</sup> the two voluntaries from the association assisted to the 3er voluntary works held in Cracovia (Poland). These works are held as part of the project of the European Federation of Associations of NF, subsidized on the 70% by the European Union</li> <li>• On the 29<sup>th</sup> of May, the president and genetic assessor assisted to the general meeting of the Portuguese nf Association</li> <li>• We have continued with the distribution of the book edited in May 2000 under Dr's Castroviejo coordination. This is the first book edited in Spanish and 14<sup>th</sup> professionals from Medicine and Genetic camps have contributed to its development besides Dr. Castroviejo. Actually we have distributed 2000 copies between paper and CD format</li> </ul>	



## ANNEX 4

- We still count with the collaboration of Carmen Valero, our Psychologist, and under her direction are held sessions of auto help groups and individual sessions in Madrid as well as by telephone with members of the Association from anywhere from Spain
- We have signed a collaboration agreement with Ramón y Cajal hospital and Caja de Madrid for two years, which can be extended if all parts are interested and we can afford it. The agreement covers a project of investigation “*Genetic study on the variability of expression in NF 1: mosaicism and modification genes. Design of a protocol for molecular diagnosis of the illness*” The project is directed by Dra. Concha Hernández, representing the hospital, and Dra. Carmen Valero for the association.
- We have elaborated and distributed to association members and more than 200 doctors 4 Informative papers (numbers 24 to 27) covering news related with our illness and as well a report of our activities. The papers were made in March, June, September and December
- We have distributed about 10.000 triptychs that explain the illness
- About 160 explicative leaflets have been distributed to the new families that have got in touch with us for the first time, not only from Spain but from Spanish speaking countries. The leaflets have been given as well to professionals and students of medicine, psychologist, social workers, etc.
- The president of our association belongs to the Board of Management of the European federation of Neurofibromatosis associations that was funded in Ulm (Germany) with representatives from the following countries: Bulgaria, Belgium, United Kingdom, Sweden, Ireland, Switzerland and Norway. This Board met on year 2002 in Sint Niklaas (Belgium) and in July in Turku (Finland). There a new Board was elected, being the Spanish candidature to become a member the most voted.
- We have facilitated information and help to persons and nf associations from Spanish speaking countries: Uruguay, Chile, Argentine, Mexico, Costa Rica, Colombia, Perú, ..., and so to programs in Spanish realized by associations in Italy, United States, ...
- We have sent information and appeared some times in press, television, and radio (in international, national and local areas)
- We held a Web site ([www.aeenf.com](http://www.aeenf.com)) for which we have a subvention from “*Fundacion Telefónica*” and have had many visits to it. We have received and answer a media of two mails per day from our e-mail: [asoc\\_nf@eresmas.com](mailto:asoc_nf@eresmas.com).
- We have sent all the documents required to continued being an Public utility association (according with 2001 laws)
- We have held meetings en Health Ministry and Madrid Community in order to obtain a reference unit for our illness. Up to the moment with no results
- The association has a small office in Madrid sited in Avda. América nº 4 1º A, where we can work and have activities and meetings
- The fourth youngster coexistence was held with a trip to London in September.
- We are elaborating the first affected census that is made in our country. On December 31<sup>st</sup> we were 1.111 persons
- We have collaborated with a group of Italian doctors in a project to evaluate, in a European level, quality of the welfare and health attention received by affected person with rare illness (nf among them)
- “*Fundación Real Madrid*” offers, from time to time tickets for our members to assist to social or sport events
- Last May, on the international Museums day some of our members participate on experimental archaeological works organized by a local museum
- Assistance to working tables organized by the office of the patience defender from Madrid Community held in Madrid on April 19<sup>th</sup>, 21<sup>st</sup>, 22<sup>nd</sup>, 27<sup>th</sup> 28<sup>th</sup> and 29<sup>th</sup>, in order to elaborate “*the Card of rights and owes for patience and users of the health system*” for Community of Madrid
- Request to the Community of Madrid for the declaration of two of our projects: the elaboration of the first census elaborated in Spain of people affected of NF, and the project of investigation on the laboratory of Molecular Genetic made at Ramón y Cajal Hospital. Both of them were rejected because they could not been set as congress, meetings, etc
- Organization of a play of theatre for the association’s kids, their brothers, sisters and friends, in the Holy Kings celebration. The play was King Lion and was made by group Tomateleon on the 10<sup>th</sup> of January




**ANNEX 4**

- Neurofibromatosis was included in the program of Medicine as a free configuration material for the University of Sevilla. Our Genetic assessor Dra. Carmen Valero was invited to participate in the part dedicated to rare illness and give a conference entitled "Neurofibromatosis: a rare illness, a common illness"
  - On the 26<sup>th</sup> of October the president and the Genetic Assessor assisted to a popularizing talk over Neurofibromatosis organized in the Medicine University of Cordoba by the association
  - One of our members, Rosa Suarez, is collecting information about the learning disabilities that about a 40% of children with NF 1 suffer. She is giving talks in schools and universities of Madrid
- 
- To obtain funds and spread the knowledge over our illness and association we have organized the following activities all along 2004 year:
    - The selling of Christmas lottery
    - A free market held in the lobby of an underground station in Madrid, freely gave by the Madrid underground on December 17<sup>th</sup> and 18<sup>th</sup>
    - The selling of T shirts and jumpers with prints elaborated for our association for the very popular humorists Gallego y Rey, Ricardo y Nacho and Gorka.
    - The selling of the book "*Neurofibromatosis*"
    - The Celebration of the 3<sup>rd</sup> Scully Marathon. On April 23<sup>rd</sup> and 24<sup>th</sup>.



**4.16 SWEDEN**

	
<b>country</b>	SWEDEN
<b>Name of the association</b>	<b>NF-förbundet i Sverige</b> Org.nr: 893202-0905
<b>address</b>	Sturegatan 3 SW 753 14 Uppsala,
<b>Tel</b>	+46 18 36 72 18
<b>Fax</b>	+46 18 36 78 28
<b>Email</b>	anitaengstrom@bredband.net
<b>URL</b>	www.nf-forbundet.se
<b>president</b>	Anita Engström, Uppsala
<b>Board members</b>	Barbro Svedell, treasurer, Sala Inga-Lill Ehelenius-Öhman, Luleå Viktorija Andersson, Västerås Åke Håkansson, Växjö Daniel Degerman, Stockholm Mattias Ekholm, Stockholm
<b>Amount of members</b>	600 members
<b>Aims:</b> <ul style="list-style-type: none"> <li>• improve quality of life</li> <li>• promote research</li> <li>• circulate NF-information to members and society</li> <li>• connecting people with NF</li> </ul>	





**Prior activities:**

- NF-bladet - Newspaper 4 times a year
- Helpline
- Meetings
- Support, networking
- Family and youthcamps

**Recent realisations:**

2003- started up regional divisions in 5 different parts of the country

2004 - arranged the International NF Youth Camp in Skara

Annual Meeting and Family Camp in Luleå

2005- February - Meeting at Sea Stockholm - Mariehamn

July: hosting the 11th european NF-meeting in Göteborg

August: FamilyCamp and Annual Meeting, Rättvik, Dalarna

Plus Meetings in the different regions.


In the end of 2005 we will have more then 10 regional divisions.

**subdivisions:**

The Swedish NF-ass. have started up seven regional divisions since 2003 and one division for youth and one parents network.



**4.17 SWITZERLAND**

	
<b>country</b>	Switzerland
<b>Name of the association</b>	Schweizerische Neurofibromatose Vereinigung
<b>address</b>	Postfach 753, CH 8037 Zürich,
<b>Tel</b>	56 1 363 83 83
<b>Fax</b>	56 1 363 83 83
<b>Email</b>	bhans@hispeed.ch
<b>URL</b>	<a href="http://www.neurofibromatose.ch/">http://www.neurofibromatose.ch/</a>
<b>president</b>	Barbara Cajöri
<b>Board members</b>	Brigitte Fischer Vice president Eugen Boltshauser Prof. Dr. Hedy Angst Lea Bodenmann Walter Gehrig Monika Reisel
<b>Amount of members</b>	
<b>Aims:</b> helping people affected in any possible way	
<b>Recent realisations:</b> Newspaper twice a year A web site wit chatbox and discussion room A Meeting for youngsters A family pick nick A final grade paper on quality of life for people affected by NF And more	



**new NF EUROPE MEMBER GROUPS (not participating in the project)**

**4.18 AUSTRIA**

<b>name of the association</b>	NF Austria
<b>address</b>	Dollnergasse 2/4, 1190 Wien
<b>Tel</b>	+41 01 3686 689
<b>Fax</b>	+41 01 3698 007
<b>Email</b>	nf3ges@atnet.at
<b>URL</b>	

**4.19 TURKEY**

<b>name of the association</b>	Nörofibromatozis Türkiye
<b>address</b>	Banu Anlar MD Hacettepe University, Sıhhiye Ankara
<b>Tel</b>	312 305 5000
<b>Fax</b>	-
<b>Email</b>	banlar@hacettepe.edu.tr
<b>URL</b>	<a href="http://www.nf.hacettepe.edu.tr/link.htm">http://www.nf.hacettepe.edu.tr/link.htm</a>

**4.20 UK**

<b>name of the association</b>	The Neurofibromatosis Association
<b>address</b>	Quayside House, 38 High Street KT11HL Kingston/Thames
<b>Tel</b>	+20 8439 1234
<b>Fax</b>	+20 8439 1200
<b>Email</b>	nfamark@zetnet.uk
<b>URL</b>	<a href="http://www.nfa.zetnet.co.uk">http://www.nfa.zetnet.co.uk</a>



<p><b>BELGIUM:</b>            Group: NF KONTAKT            Address: Nijverheidsstraat 29/16            B-9100 Sint-Niklaas            Tel. +32.3.766.13.41            Fax. +32.3.766.45.16            E mail: nf@nfkontakt.be            URL: http://nfvlaanderen.nfkontakt.be            President Mia DESMET            Represented by Marleen GIELEN            Scientific advisor Prof. Dr. Eric LEGIUS            Center for Human Genetics – Leuven</p>	<p><b>BULGARIA</b>            Group: NFW-Bulgaria            Address: 21 Tottleben Blvd. 21            BG 1616 Sofia            Tel. +359.88.638.613            Fax. +359.2.432.375            E mail: U1005@omega.bg            URL:            President: Georg POPTODOROV            Represented by: George POPTODOROV            Scientific advisor Dr. Lidia GEORGIEVA</p>
<p><b>DENMARK:</b>            Group: Dansk Foreninge for NF            Address: Dronninggårds Alle 10c - 1th            DK 2480 Holte            Tel. +45.45.41.15.80            Fax. +45.45.41.16.80            E mail: karin.persson@mbox301.get2net.dk            URL: http://www.nfrecklinghausen.dk            President: Karin PERSSON            Represented by:            Scientific advisor Dr. John ØSTERGAARD            Skejby Hospital – Aarhus</p>	<p><b>FINLAND:</b>            Group: Suomen Neurofibromatoosiyhdistys            Address: Paavonkatu 4 a1            FI 60200 Seinäjoki            Tel. 00358 6 4175 179            Fax. 00358 6 4175 179            E mail: kaisu.kandelin@kolumbus.fi            URL: http://www.nf-yhdistys.org::            President Esko Olavi KANDELIN            Represented by: Minna LEHTONEN            Scientific advisor Dr. Minna POYHONEN            Väestöliitto – Helsinki</p>
<p><b>FRANCE:</b>            Group: 1 Association pour la NF            Address: Vieux Chemin de Grenade 34            FR-31700 Blagnac            Tel. +33.5.61.30.03.37            Fax. +33.5.61.30.03.37            E mail: ass.neurofibromatoses@wanadoo.fr            URL: http://nf.fnet.fr            President: Anne HENRION            Represented by : Gérard DONADIEU            Supported by: Dr. Pierre WOLKENSTEIN - Dermatology            HENRI-MONDOR - F-94010 CRETEIL            CEDEX</p>	<p><b>FRANCE:</b>            Group:2 Association contre les neurofibromatoses            Address: 2 CHEMIN DES MESANGES            FR 17540 ANAIS            Tel. +33. 5 46 68 23 70            Fax. +33. 5 46 68 23 70            E mail: Ligue.Contre.nf@wanadoo.fr            URL:            President: Jean Claude LOPEZ            Represented by :            Supported by:</p>
<p><b>GERMANY:</b>            Group: von Recklinghauser Gesellschaft            Address: LANGENHORNER Chaussee 560            D-22419 Hamburg 62            Tel. +49.40.5271.2344            Fax. +49 40 5271 2932            E mail: Von-Recklinghausen-FfM@T-online.de            URL:            President Victor MAUTNER            Represented by: Frank WILKE            Scientific advisor Prof. Dr. Victor MAUTNER            Univ. Hosp. Hamburg - Klinikum.Nord            Ochsenzoll</p>	<p><b>ITALY:</b>            Group: 2 LINFA            Address: 3, Via Giustiniani,            I 35128 Padova            Tel. +39.049.821.3513            Fax. +39.049.821.1425            E mail: Tenconi@child.pedi.unipd.it            URL:            President: Luigi MENEGUZZO            Represented by: Prof. Dr. Romano TENCONI            Supported by: Unidate Pediatrica.Univ. Padova</p>



<p><b>GERMANY:</b>                  Group: von Recklinghauser Gesellschaft                  Address: LANGENHORNER Chaussee 560                  D-22419 Hamburg 62                  Tel. +49.40.5271.2344                  Fax. +49 40 5271 2932                  E mail: Von-Recklinghausen-FfM@T-online.de                  URL:                  President Victor MAUTNER                  Represented by: Frank WILKE                  Scientific advisor Prof. Dr. Victor MAUTNER                  Univ. Hosp. Hamburg - Klinikum.Nord                  Ochsenzoll</p>	<p><b>ITALY:</b>                  Group: 2 LINFA                  Address: 3, Via Giustiniani,                  I 35128 Padova                  Tel. +39.049.821.3513                  Fax. +39.049.821.1425                  E mail: Tenconi@child.pedi.unipd.it                  URL:                  President:                  Represented by: Luigi MENEGUZZO                  Supported by: Prof. Dr. Romano TENCONI                  Unidade Pediatrica.Univ. Padova</p>
<p><b>ITALY:</b>                  Group: 1 ANF                  Address: Via Milano 21b                  I 43100 PArma                  Tel. +39.512.77.14.57                  Fax. +39.512.77.14.57                  E mail: a.n.f.@neurofibromatosi.org                  URL: http://www.neurofibromatosi.org/                  President: Elisabeta BISIGNAN                  Represented by: Elisabeta BISIGNANI                  Scientific advisor Prof. Dr. Romano TENCONI                  Unidade Pediatrica.Univ. Padova</p>	<p><b>The NETHERLANDS:</b>                  Group: NFVN                  Address: Mahatma Ghandistraat 11                  NL 2552 PA Den Haag                  Tel. +31.70.39.75 168                  Fax.                  E mail: p.jjansen06@freeler.nl                  URL: http://www.neurofibromatose.nl                  President: Peter VAN DEN ENDE                  Represented by: PietJan JANSEN                  Scientific advisor Dr. Arja DE GOEDE-BOLDER                  Sophia Kinderziekenhuis – Rotterdam</p>
<p><b>NORWAY:</b>                  Group: Norsk Forening for NF                  Address: Østli 25 b                  NW 3726 Skien                  Tel. +47.35.53.80.92                  Fax.                  E mail: <a href="mailto:sroerdam@c2i.net">sroerdam@c2i.net</a>                  URL: http://nevrofibromatose.com                  President: Brit OHRØ                  Represented by: Toril RØRDAM                  Scientific advisor Dr. Arvid HEIBERG                  Frambu Helsecenter</p>	<p><b>PORTUGAL:</b>                  Group: APNF                  Address: Rua Marquesa D'Alorna 2 Atelier                  P Ramada                  Tel. +351.219.34.39.59                  Fax. +351.219.34.39.60                  E mail: <a href="mailto:lucialemos_adv@iol.pt">lucialemos_adv@iol.pt</a>                  URL:                  President: Lucia COSTA DI SOCORO LEMOS                  Represented by: Lucia COSTA DI SOCORO LEMOS                  Scientific advisor Dr. Isabel CORDEIRO                  Hospital Santa Maria Unid. De Genética-                  Lisboa</p>
<p><b>SPAIN:</b>                  Group: Asociación Española de NF                  Address: Reina, 7                  28004 Madrid                  Tel. +34.91.726.48.23                  Fax. +34 91.532.50.47                  E mail: <a href="mailto:asoc_nf@eresmas.com">asoc_nf@eresmas.com</a>                  URL: http://www.aeenf.com                  President Pilar MUÑOZ VILLALOBOS                  Represented by: Pilar MUÑOZ VILLALOBOS                  Scientific advisor Dra. Carmen VALERO QUIRÓS</p>	<p><b>SWEDEN:</b>                  Group: NF-Föreninge i Sverige                  Address: Sturegatan 3                  SE 75314 Uppsala                  Tel. +46.18.36.78.28                  Fax. +46.18.36.72.18                  E mail: <a href="mailto:anitaengstrom@bredband.net">anitaengstrom@bredband.net</a>                  URL: http://www.nfforeningen.com                  President : Anita ENGSTRÖM                  Represented by: Anita ENGSTRÖM                  Scientific advisor: Prof.Dr. Birgita REMBECK                  Psychiatric Clinic Mölndal</p>



<p><b>SWITZERLAND:</b> Group: SNFV Address: P.O.BOX 753 CH 8028 Zurich Tel. +41.1.363.8383 Fax. +41.1.363.8383 E mail: <a href="mailto:bhans@smile.ch">bhans@smile.ch</a> URL :<a href="http://www.neurofibromatose.ch">http://www.neurofibromatose.ch</a> President BarbaraCajöri Surbekstr.37 CH 3006Bern Email <a href="mailto:b.cajoeri@bluewin.ch">b.cajoeri@bluewin.ch</a> Represented by: Brigitte FISCHER Supported by: Dr. Eugen BOLTSHAUSER Kinderspital Zurich, CH 8032 Zürich E mail: <a href="mailto:boltsha@kispi.unizh.ch">boltsha@kispi.unizh.ch</a></p>	
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**MEMBER GROUPS  
JANUARY 2005**

<p><b>AUSTRIA</b>  <b>Full member since July 2003</b>                      Group: NF- Austria                      Address: Dollnergasse 2/4                      AU 1190 Wien                      Tel. +43 01 3686 689                      Fax. +43 01 3698 007                      E mail: nf3ges@atnet.at                      URL: www.atnet.at/nf                      President : Barbara GRIESSNER ZITTNER                      Represented by:                      Scientific advisor:                        Volunteers:</p>	<p><b>BELGIUM:</b>  <b>Full member since May 1999</b>                      Group: NF KONTAKT                      Address: Slachthuisstraat 73                      B-9100 Sint-Niklaas                      Tel. +32.3.766.13.41                      Fax. -                      E mail: nf@nfkontakt.be                      URL: http://nfvlaanderen.nfkontakt.be                      President Mia DESMET                      Represented by Marleen GIELEN                      Scientific advisor Eric LEGIUS, Prof. MD - CHG KULeuven                      Volunteers: Ophèlie MAERTENS MD                      Nahalie GODERIS</p>
<p><b>BULGARIA`</b>  <b>Associated member since May 1999</b>                      Group: NFA-Bulgaria                      Address: 21 Tottleben Blvd. 21                      BG 1616 Sofia                      Tel. +359.88.638.613                      Fax. +359.2.432.375                      E mail: U1005@omega.bg                      URL: http://go.to/NFABulgaria                      President: George POPTODOROV MD                      Represented by: George POPTODOROV                      Scientific advisor Dr. Lidia GEORGIEVA                        Volunteers Emilova Stoyanove BRANIMIRA MD                      Maria GEORGIEVA MD                      Todorov Dimitrov SVETOSIAV</p>	<p><b>DENMARK:</b>  <b>Full member since May 1999</b>                      Group: Dansk Forening for NF                      Address: Dronninggårds Alle 10c - 1th                      DK 2480 Holte                      Tel. +45.45.41.15.80                      Fax. +45.45.41.16.80                      E mail: karin.persson@inbox301.get2net.dk                      URL: http://www.nfrecklinghausen.dk                      President: Karin PERSSON                      Represented by:                      Scientific advisor John ØSTERGAARD MD                      Skejby Hospital – Aarhus                      Volunteers: Malene JESSEN                      Hans Peter GADE</p>
<p><b>FINLAND:</b>  <b>Full member since August 1999</b>                      Group: Suomen Neurofibromatoosiyhdistys                      Address: Paavonkatu 4 a1                      FI 60200 Seinäjoki                      Tel. 00358 6 4175 179                      Fax. 00358 6 4175 179                      E mail: kaisu.kandelin@kolumbus.fi                      URL: http://www.nf-yhdistys.org.:                      President Esko Olavi KANDELIN                      Represented by: Minna LEHTONEN                      Scientific advisor Dr. Minna POYHONEN                      Väestöliitto – Helsinki                        Volunteers Martti KOMU                      Pertti KALLIO</p>	<p><b>FRANCE:</b>  <b>Full member since June 1999</b>                      Group: 1 Association pour la NF                      Address: Vieux Chemin de Grenade 34                      FR-31700 Blagnac                      Tel. +33.5.61.30.03.37                      Fax. +33.5.61.30.03.37                      E mail: ass.neurofibromatoses@wanadoo.fr                      URL: http://nf.fnet.fr                      President: Anne HENRION                      Represented by : Bernard BABU                      Supported by: Dr. Pierre WOLKENSTEIN - Dermatology                      HENRI-MONDOR - F-94010 CRETEIL                      Volunteers: Pascal SOULARUE                      Nadia BILLAULT</p>



<p><b>GERMANY:</b>  <b>Full member since september 1999</b>                  Group: von Recklinghauser Gesellschaft                  Address: Ohmstrasse 62                  60486 Frankfurt am Main                  Tel. +49.69/36402 195                  Fax. +49 69/36402 197                  E mail: von-Recklinghausen-Ffm@t-online.de                  URL:                  President Victor MAUTNER MD                  Represented by: Frank WILKE                  Scientific advisor Victor MAUTNER Prof MD                  Klinikum.Nord Ochsenzoll                  Volunteers: Martin SHULD                  Martin KREBS</p>	<p><b>GREECE:</b>                  Group: -                  Address: Tritonos 66 - 68, P.Phailiro                  17561 Athens                  Tel. + 310 981 49 28                  Fax. +                  E mail: kpapadi@otenet.gr.                  URL                  President                  Represented by: Katerina PAPANIMITRIOU                  Supported by:                  Volunteers:</p>
<p><b>IRELAND:</b>  <b>Full member since July 2003</b>                  Group: NFAI                  Address: Carmichael Centre, North Brunswick                  Street,                  Dublin 7 - Ireland                  Tel. +353.1.872.63.38                  Fax. +353.1.873.57.37                  E mail: nfaireland@eircom.net                  URL: http://www.nfaireland.ie                  President Patricia Nutty                  Represented by: Paddy GRIFFIN                  Scientific advisor William Reardon MD                  Volunteers: Patricia NUTTY                  Majella NASIR</p>	<p><b>ITALY:</b>  <b>Full member since July 1999</b>                  Group: 1 ANF                  Address: Via Milano 21b                  I 43100 Parma                  Tel. +39.512.77.14.57                  Fax. +39.512.77.14.57                  E mail: a.n.f.@neurofibromatosi.org                  URL: http://www.neurofibromatosi.org/                  President: Corrado MELEGARI                  Represented by: Corrado MELEGARI                  Scientific advisor Prof. Dr. Romano TENCONI                  Unidade Pediatrica.Univ. Padova                  Volunteers: Alessandro EVANGELISTA                  Eugen DEMA</p>
<p><b>ITALY:</b>  <b>Full member since September 1999</b>                  Group: 2 LINFA                  Address: Dipartimento pediatria cat. Di genetica                  3, Via Giustiniani,                  I 35128 Padova                  Tel. +39.049.821.3513                  Fax. +39.049.821.1425                  E mail: associaz.linfa@libero.be                  URL: www.associazionelinfa.it                  President: Daniella LONGO                  Represented by: Luigi MENEGUZZO                  Supported by: Prof. Dr. Romano TENCONI                  Unidade Pediatrica.Univ. Padova                  Volunteers: Elena RAFFAGNATO                  Marika MARTELLATO</p>	<p><b>The NETHERLANDS:</b>  <b>Full member since April 2001</b>                  Group: NFVN                  Address: Gondel 27-37                  8243 CP Lelystad                  Tel. +31.320 0 227017                  Fax.                  E mail: p.jjansen06@freeler.nl                  URL: http://www.neurofibromatose.nl                  President: Michel AARTS                  Represented by: PietJan JANSEN                  Scientific advisor Dr. Arja DE GOEDE-BOLDER                  Sophia Kinderziekenhuis – Rotterdam                  Volunteers: Hans BRUGGEMAN                  Monique SCHUIJLENBURG</p>





<p><b>NORWAY:</b>  <b>Associated member since September 1999</b>                      Group: Norsk Forening for Nvrofibrmatose                      Address: Østli 25 b                      NW 3726 Skien                      Tel. +47.35.53.80.92                      Fax.                      E mail: <a href="mailto:brittohr@online.no">brittohr@online.no</a>                      URL: <a href="http://nevrofibrmatose.com">http://nevrofibrmatose.com</a>                      President: Brit OHRØ                      Represented by: Toril RØRDAM                      Scientific advisor: Dr. Arvid HEIBERG                      Frambu Helsecenter                      Volunteers: Anne RØRDAM                      Øvind HANTHO</p>	<p><b>POLAND:</b>  <b>Appealing for membership</b>                      Group: NF Polska                      Address: Babimost 66-110 ul.                      Rynek 20/10                      Tel. +48 66 351 2302                      Fax. +48 68 351 2302                      E mail: <a href="mailto:asoc_nf@eresmas.com">asoc_nf@eresmas.com</a>                      URL: <a href="http://www.nfpolska.com">www.nfpolska.com</a>                      President: Maciej KMIECIK                      Represented by: Dr. Krystyna CHRZANOWSKA                      Scientific advisor: Dr. Sergiusz JOSWIAK, Ped Neurology                      Children's Mem. Health Inst of Warsawa                      Volunteers: Pavel DEPTULA                      Maciej KMIECIK</p>
<p><b>PORTUGAL:</b>  <b>Full member since April 2001</b>                      Group: APNF                      Address: Rua Marquesa D'Alorna 2 Atelier                      P Ramada                      Tel. +351.219.34.39.59                      Fax. +351.219.34.39.60                      E mail: <a href="mailto:apnf@iol.pt">apnf@iol.pt</a>                      URL:                      President: Lucia COSTA DI SOCORO LEMOS                      Represented by: Lucia COSTA DI SOCORO LEMOS                      Scientific advisor: Dr. Isabel CORDEIRO                      Hospital San Maria Unid. De Genética-                      Lisboa                      Volunteers: Andreia FIGUEIREDO NUNES                      Cidália MIRA RIBEIRO</p>	<p><b>SPAIN:</b>  <b>Full member since June 1999</b>                      Group: Asociación Española de NF                      Address: Reina, 7                      28004 Madrid                      Tel. +34.91.726.48.23                      Fax. +34 91.532.50.47                      E mail: <a href="mailto:asoc_nf@eresmas.com">asoc_nf@eresmas.com</a>                      URL: <a href="http://www.aeenf.com">http://www.aeenf.com</a>                      President: Pilar MUÑOZ VILLALOBOS                      Represented by: Pilar MUÑOZ VILLALOBOS                      Scientific advisor: Dra. Carmen VALERO QUIRÓS                      Volunteers: Rosa SUÁREZ GONZÁLEZ                      Pilar ORTI</p>
<p><b>SWEDEN:</b>  <b>Full member since september 1999</b>                      Group: NF-Förbundet i Sverige                      Address: Sturegatan 3                      SE 75314 Uppsala                      Tel. +46.18.36.78.28                      Fax. +46.18.36.72.18                      E mail: <a href="mailto:anitaengstrom@bredband.net">anitaengstrom@bredband.net</a>                      URL: <a href="http://www.nf-forbundet.se">http://www.nf-forbundet.se</a>                      President : Anita ENGSTRÖM                      Represented by: Anita ENGSTRÖM                      Scientific advisor: Prof.Dr. Birgita REMBECK                      Psychiatric Clinic Mölndal                      Volunteers: Robert MALMSBORG                      Olav-Thomas UTSI</p>	<p><b>SWITZERLAND:</b>  <b>Associated member since September 1999</b>                      Group: SNFV                      Address: P.O.BOX 753                      CH 8037 Zurich                      Tel. +41.1.363.8383                      Fax. +41.1.363.8383                      E mail: <a href="mailto:bhans@smile.ch">bhans@smile.ch</a>                      URL: <a href="http://www.neurofibromatose.ch">http://www.neurofibromatose.ch</a>                      President: Barbara Cajöri                      Represented by: Brigitte FISCHER                      Supported by: Dr. Eugen BOLTSHAUSER                      Kinderspital Zurich, CH 8032 Zürich                      Volunteers: Monika REISEL                      Brigitte FISCHER</p>



<p><b>TURKEY</b> <b>Appealing for membership</b> Group: NF Nörofibromatozis Turkiye Address: Ardiçlievler, Safir 60/2 34850 Bahçeşehir -Istanbul Tel. +90 532 211 18 18 Fax. + E mail: engin_bay@superonline.com URL President Represented by: Engin BAYRAKTAR Supported by: Banu ANYAR MD  Volunteers: Engin BAYRAKTAR Gulseren BAYRAKTAR</p>	<p><b>UK</b> <b>Full member since July 2003</b> Group: The Neurofibromatosis Association Address: Quayside House, 38 High Street UK – KT11HL Kingston on Thames Tel. +20 8439 1234 Fax. +20 8439 116107 E mail: nfaceo@zetnet.uk URL: www..nfa.zetnet.co.uk President : Clare Webb Represented by: Scientific advisor: Susan HUSON  Volunteers:</p>
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