NEUROFIBROMATOSIS: Tell-Tale Signs

Café-au-lait patches, 6 or more consult your Doctor
Message to our readers from NF Ireland
The Neurofibromatosis Association of Ireland exists for its members / patients and families affected by this complex genetic condition. Running the affairs of the association requires a commitment from a wide group of people not least our volunteers, the officers and committee, our fundraisers and the Health Professionals who look after the care and welfare of patients with NF. Therefore we are appealing to our members for support – join the committee, fundraise or just help out in whatever way possible.

Thank you
Officers NF Ireland

CALL THE HELPLINE
Tel: + 353 1 428 2858
to get in touch with a Genetic Counsellor.

Fortnightly Clinics are held at the Centre for Medical Genetics, Our Lady’s Children’s Hospital, Crumlin.

Brochures are available from the NF Clinic & NF Ireland covering all aspects of Neurofibromatosis.

Web Site: www.nfaireland.ie

Support NF Ireland Services – Fundraise / Join the Committee

The Neurofibromatosis Association of Ireland (NF Ireland)
Registered Charity CHY6657 &
Company Limited by Guarantee Ref. No. 299875
Telephone: + 353 1 872 6338
Genetic Counsellor Helpline: + 353 1 428 2858
INTRODUCTION

This brochure has been compiled to provide readers with a brief introduction to NF Ireland and how patients and their families can access the various services. Our most recent projects include the Neurofibromatosis Clinic, MDT medical team (Multidisciplinary Team), Genetic Counsellor Service, NF Brochures, new Web Site and Clinic Helpline. Members of the association officers and committee are particularly proud of what has been achieved by a small group of volunteers over the life of the association. We wish to acknowledge the support of Professor Green, Director, Centre for Medical Genetics, Professor Irvine and the Multidisciplinary Team at Crumlin for their assistance in raising the standard of medical intervention and care for those affected by Neurofibromatosis.

The association also recognise the guidance and support received from Dr Sue Huson, St Mary’s Hospital, Manchester, Professor Rosalie Ferner, Guy’s Hospital London, Professor Meena Upadhyaya, Institute of Medical Genetics, Cardiff University, the CTF (Children’s Tumour Foundation) New York, also the European and Australian support groups with whom we remain in contact.

Funding our services is an ongoing challenge for the association, in fact without the generosity of our sponsors, fundraisers and the HSE we could not survive. To that end we would like to pay a special tribute to those who have helped the association financially and for their belief in our work over the years.

Finally, I wish to acknowledge the work of the officers and committee and in particular the founding members who had the vision to start a support group. Also to those who volunteered their services for the past thirty years, a very special thank you.

Paddy Griffin
CEO, NF Ireland
April 2013
MISSION

NF Ireland is committed to securing an excellent medical service, accurate information, guidance, support and counselling services for all NF sufferers and their families also to promote research aimed at finding a cure.

Prof. Andrew Green
PhD, FRCPI, FFPath (RCPI)
Director, National Centre for Medical Genetics
Professor of Medical Genetics, University College Dublin
Consultant in Medical Genetics, Our Lady’s Children’s Hospital, Crumlin, Dublin 12 & The Children’s University Hospital, Temple Street, Dublin 1

Correspondence Address: National Centre for Medical Genetics, Our Lady’s Children’s Hospital, Crumlin, Dublin 12, Ireland
Tel: 353 1 409 6902, Fax: 353 1 456 0953
Email: andrew.green@olhsc.ie or andrew.green@ucd.ie
MDT (MULTIDISCIPLINARY TEAM)

**Prof. Andrew Green**
Geneticist

**Dr. Rosemary Watson**
Dermatologist

**Dr. Donal Brosnahan**
Ophthalmology

**Prof. Alan Irvine**
Dermatologist

**Dr. Grainne O’Regan**
Paediatrics & Dermatology

**Dr. Paula Kelly**
Orthopaedic Surgeon

**Dr. Michael Capra**
Oncologist

**Dr. David Coghlan**
Developments Paediatrics

**Plastic Surgeon**
TBA

**Neurologist**
TBA

**Multidisciplinary Team at OLCH Crumlin**

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**Professor Andrew Green,**
Director, Centre for Medical Genetics

**Claire Kirk,**
Genetic Counsellor

**Professor Alan Irvine,**
Consultant Dermatologist

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OFFICERS NF IRELAND

Patricia Nutty

Paul Fox

Jimmy Corr

Eddie Creevey
Neurofibromatosis Clinic & Service Overview

Services
• Clinics are held at: Dublin – Cork – Limerick – Galway.
• MDT – multidisciplinary team in place to deal with complex NF.
• Genetic Counsellor Service.
• Genetic Counsellor Helpline – Tel. + 353 1 428 2858.
• Web Site: www.nfaireland.ie
• NF Literature / Newsletter – Neuro News.

Information & Research
• To provide information on NF to Patients, Doctors, Consultants and Teachers also to promote awareness and an understanding of the problems encountered with the disorder.
• To organise seminars to disseminate information/progress on research into NF.
• To organise public awareness campaigns.
• To provide advocacy and the provision of information.
• To source information on specialised medical services yet unavailable in Ireland.
• To encourage scientific research leading to a cure.
• To provide financial aid where possible towards research.

The Community
• To bring sufferers of NF together in order to overcome the feeling of isolation.
• To maintain liaison with like-minded organisations and the medical professionals nationally and internationally.
• Provide continued support to the Neurofibromatosis Clinic.
• Provide links between sufferers and health professionals to their mutual benefit.

Family Support
• Association to underwrite a Genetic Counsellor’s salary.
• To develop activities to increase quality of life for affected families.
• Conduct Respite Weekends for NF families with a focus on children and young adults.

Fundraising
• To organise and support fundraising activities to realise these aims.
• To lobby Government and State Bodies to provide financial support towards mutually agreed goals of the NF association.
Policy Development

- To make a positive contribution to the policy-making decisions of the HSE and other State Bodies.

Neurofibromatosis Clinic

*The Neurofibromatosis Clinic complimented by the services of a Genetic Counsellor and the MDT team combine to provide a quality health care service for patients and their families.*

Neurofibromatosis Clinic

Dublin clinics are held every 2 weeks on a Monday afternoon between 1:45 and 5:45pm. They are based in the National Centre for Medical Genetics, Our Lady’s Children’s Hospital, Crumlin, Dublin 12. Appointments are for 1 hour. Patients are offered a consultation with Professor Andrew Green or another Consultant Clinical Geneticist in order to confirm the exact diagnosis. Once a diagnosis of NF has been established patients and families can meet with the NF Genetic Counsellor to discuss the genetic basis of the condition, how it arose in the family, risks to and implications for other family members and arrangements for follow-up care. Relevant literature and links to support organisations are also provided.

How to make an appointment

How to make an appointment / what’s required e.g. GP / Consultant referral letter

Referrals are accepted from consultant clinicians or GP’s by way of written referral letter to the National Centre for Medical Genetics, Our Lady’s Children’s Hospital, Crumlin, Dublin 12. This may be in order to establish an initial diagnosis in the family or parents may be concerned that subsequent children in the family are also affected. Review appointments are available for adults who were diagnosed as children and who wish to now discuss their diagnosis, ongoing health care and implications for having children of their own. For families who have already been seen by genetics it is possible to make an appointment by phoning 01 409 6902 and quoting the genetics reference number which is on the top of all our correspondence.
Who coordinates follow up medical intervention / appointment dates, scans etc?
Children with NF1 will be referred to a consultant paediatrician and consultant ophthalmologist for yearly review. Current care guidelines will also be sent to each of these clinicians and to each GP in order to encourage best practice. GP’s will be asked to organise yearly health checks and blood pressure monitoring for all affected adults and to make appropriate referrals should other health concerns arise. Breast Mammogram Screening for women aged 40-50 years will be recommended.

Referral Service for Adults

How the Clinic operates, doctors in the loop, follow up monitoring?
Adults with NF1 will also be seen in the NF Clinic and where necessary will be referred on to the relevant specialists where the patient is presenting with a complex problem. e.g. NF1 adults with brain tumours are generally looked after by the Beaumont Neurosurgery team. Also Cork has Neurosurgery, and they also look after NF1 patients there.

Neurofibromatosis Type 2
NF2 is generally a teenage and adult disease. Neurosurgery and ENT in Beaumont jointly manage the care of these patients. However, a number of these cases are referred over to Manchester, which is best practice.

Genetic Counsellor Service
Our Genetic Counsellor sees patients by appointment at the National Centre for Medical Genetics, Our Lady’s Children Hospital, Crumlin, Dublin 12. To speak to our genetic counsellor or to make an appointment call the helpline below.

Genetic Counsellor Helpline: Tel. +353 1 428 2858
Our Genetic Counsellor responds to all Helpline enquiries – a telephone answering service is available outside office hours or when the office is unattended. Note: There is no charge for the above service.

Doctors & Specialist Service accessible outside Dublin
In order to reduce the travelling burden for those families who live outside Dublin, NF clinics are also held throughout the year in Cork, Limerick and Galway.
Doctors & Specialist Service accessible at the Crumlin Clinic for complex aspects of NF (MDT Clinic)
When NF1 patients present with complex needs a multi-disciplinary approach is possible. Links have been built with a number of consultants within the Dublin Hospitals and a multidisciplinary team of Consultants have come together specialising in paediatric dermatology, endocrinology, neurology, ophthalmic surgery, orthopaedic surgery, oncology, neurosurgery and plastic surgery. Appropriate arrangements are in place for certain problems e.g. children with NF1 who have brain tumours are jointly managed by Crumlin Oncology and Temple Street Neurosurgery. Clinics have been developed in line with best practice.

The Neurofibromatosis Association of Ireland Ltd. (NF Ireland)

The association comprises of a management committee of volunteers who have a close personal involvement with the disorder either through their family or their professional work.

The Neurofibromatosis Association
In 1985 four people came together in Cork and elected to set up a support group for neurofibromatosis called PHONE. The name was subsequently changed to “The Neurofibromatosis Association of Ireland” (NF Ireland), a registered charity CHY6657 and company limited by guarantee ref. no. 299875.

From the outset the aim of the association was to bring families together to address the feeling of isolation and help them cope with their NF. This has been achieved by:

- Supporting patients & families,
- Raising awareness of the condition,
- Providing quality information and literature,
- A neurofibromatosis clinic,
- Setting up a MDT team of Doctors to deal with the more complex aspects of NF,
- A counselling service,
- Clinic helpline,
- Supporting research,
- Conference, seminars & respite weekends.
NF Ireland Head Office:
The association have their office at the Carmichael Centre, North Brunswick Street, Dublin 7. Tel: + 353 1 872 6338. Web: www.nfairland.ie  Email:nfairland@eircom.net

The association administer and fund the following services:
- Genetic Counsellor salary
- Administrator services
- Procurement & printing of literature
- Web site maintenance
- Office accommodation
- Insurance
- Phone & postage charges
- AGM & open days
- Conferences / speakers engaged in research
- Awareness campaigns – local radio & press
- Benevolent fund
- Respite weekends
- Seminars
- NF conference & meetings abroad
- Design & printing
- Bank charges / accountancy fees
- Newsletter – neuro news

Funding Our Services

Apart from a small HSE grant, funding the wide range of services provided by NF Ireland depends on voluntary donations, fundraising events and sponsorship. Absorbing the salary of our Genetic Counsellor, the cost of sourcing & printing literature, administration, accommodation costs, etc. places immense pressure on those charged with conducting the affairs of NF Ireland. Unfortunately the HSE are not prepared to fund a Genetic Counsellor’s salary at this time.

Don’t leave it to others to look after your medical needs
Rarely people with NF sail through life without the need for medical intervention. Often it’s at this time that patients turn to the association for information, advice or counselling. Whether the problem involves a child or adult, access to the Clinic or Multidisciplinary team who understand the complications is paramount. Members therefore must not
lose sight of the important role played by NF Ireland in securing services at the clinic and to realise even that the smallest contribution can help underpin medical intervention in the long-term.

Funding Opportunities
Cycling events, women’s mini marathon, church gate collections, quizzes, cake sales, bag packing & collections are proven ways of fundraising. Relatives and family friends may well consider leaving money in their “Will”, the opportunities for funding association services are endless.

Supporting Research
Unfortunately NF Ireland finances does not extend to contributing towards research, however the advantage of providing a platform for scientists engaged in research to share ideas and collaborate has been recognised. In 2008 the association spent in excess of €98,000 hosting the European Scientific Meeting in Killarney, subsequently financial assistance was provided towards CTF and Istanbul meetings also scientific meetings in Manchester and Cardiff.
Literature

Listed below are brochures & leaflets available at the Clinic or by contacting NF Ireland directly – for those who require a complete set of brochures there is a €25 charge to cover printing and postage. The once off payment also includes one year’s membership of NF Ireland.

NF Brochures:
- Overview of Neurofibromatosis Type 1
- A Guide for Educators
- Learning & Cognitive Difficulties
- Neurofibromatosis Type 1 for Teens
- The Child with Neurofibromatosis Type 1
- Talking to Your Child
- Readers 100 Questions Answered

Leaflets
- NF1 Review Checklist for Children & Adults
- Neurofibromatosis – A Brief Introduction
- Schwannomatosis
- Contact Form

Clinical Guidelines for Managing NF1
- For Adults
- For Health Professionals

Neurofibromatosis Type 2 Brochures
- For Families
- For Health Professionals

Handbook
- NF Ireland Handbook
Neurofibromatosis can affect patients in many different ways and therefore may require the intervention of any of the following who specialise in: paediatrics, dermatology, endocrinology, neurology, ophthalmic surgery, orthopaedic surgery, oncology, neurosurgery and plastic surgery.

A wide range of medical intervention is available through the NF Clinic & the MDT (Multidisciplinary Team) for complex cases.

The association welcome enquiries from patients, their families, health professionals, those involved in research, health care, people with an interest in NF or who may require information / literature on the condition.
DISCLAIMER

Every care has been taken to ensure the accuracy of the information contained in this brochure. The NF association cannot however accept responsibility for errors or omissions, but where such are brought to our attention the information will be amended accordingly. The author and publisher accept no responsibility for any loss, damage, injury or inconvenience sustained or caused as a result of information supplied in this brochure. It is recommended that anyone who has concerns about Neurofibromatosis first speak to their doctor.