

1 IN 3,000 PEOPLE
IS BORN WITH
NEUROFIBROMATOSIS.

WITH YOU, FOR YOU!

OUR MISSION

APNF's mission is to mitigate, as much as possible, the impact of neurofibromatoses (NFs) on the lives of those affected by these diseases.

THESE ARE APNF'S PILLARS:

- Support patients, family and caregivers
- Raise awareness
- Contribute to the discovery of a cure for NF, generating evidence with clinical and scientific basis
- Contribute to create a multidisciplinary center in Portugal for the treatment of these diseases



WE ARE HERE

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APNF

Associação Portuguesa
de **Neurofibromatose**

SUPPORT LINES

EDUCATION

(EMAIL: EDUCACAO@APNF.PT)

- Monitoring/development workshop of possible compromised skills: improve communication / oral/written comprehension
- Argumentation skills: thoughts clarification and their articulation
- Decision process
- Reading assessment
- Animal-assisted reading sessions (in partnership with Cães&Livros - R.E.A.D. Portugal)

PSYCHOLOGY

(EMAIL: PSICOLOGIA@APNF.PT)

- Psychological assessment
- Individual appointment (children/young people and caregivers)
- Psychological intervention appropriate to the person's needs
- Family support and counseling
- Psychological support for caregivers

APNF promotes awareness/training sessions in schools, aimed at teachers and operational assistants in which NF is presented and framed within the greater theme of learning/development difficulties that can affect school-age children.

MULTIDISCIPLINARY MONITORING

Neurofibromatosis impact patients' lives at different levels – family, academic, social and professional – and a regular and multidisciplinary medical follow-up is recommended.

MEDICAL REFERENCE APPOINTMENTS

Hospital Dona Estefânia

Neurocutaneous Syndromes
multidisciplinary appointment
for pediatric age

consulta.neurocutaneos@chlc.min-saude.pt

Instituto Português de Oncologia Francisco Gentil (Lisboa)

Appointment for adulthood and pathology
tumor in pediatric age
(eg. optic glioma, plexiform neurofibroma)
consneuro@ipolisboa.min-saude.pt

NF IN PORTUGAL

~40 NEW CASES PER YEAR

~4.000 PEOPLE LIVE WITH NF

~500 SCHOOL-AGE CHILDREN

ABOUT NEUROFIBROMATOSIS

Neurofibromatosis (NF) is the name given to a set of three rare genetic diseases: NF1 (the most frequent), NF2 and Schwannomatosis.

These diseases, with genetic origin, can be transmitted **hereditarily** or arise *de novo*, due to a **spontaneous mutation** (each possibility occurs in 50% of the cases). NFs may affect anyone, regardless of people's age, ethnicity, gender or family history.

All predispose to the appearance of benign tumors of the nervous system, which require high monitoring.

NFs are chronic diseases and there is no cure so far.

An affected person is already born with the disease. **NF it's not a lifelong condition, nor is it contagious.**

Some signs or symptoms may appear at an early age, others only later.

NF1 has a clinical diagnosis and the patient should be referred to a **multidisciplinary specialized team.**



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