

WHAT IS NF?

The term "NF" generally refers to a group of complex genetic disorders. They include neurofibromatosis type 1 (NF1), NF2-related schwannomatosis (NF2-SWN), and schwannomatosis (SWN). While all three types of NF are genetically distinct and have different characteristic tumors, they share the common feature of causing tumors and can lead to various complications. Additionally, the severity of symptoms and the specific manifestations of these disorders can vary significantly from person to person, even within the same type of NF.

HOW COMMON IS NF?

NF1 is the most common of the NF conditions, affecting approximately one in 2,500. NF2-SWN affects around one in 25,000, and other schwannomatosis types affect around one in 40,000. Together, these disorders affect at least 1 in 2,000 people or approximately 4 million worldwide.

WHO CAN BE BORN WITH NF?

Since these disorders are not always inherited, anyone can be born with an NF disorder. People with NF usually have a 50% chance of passing it on. These disorders affect all races and genders equally. You probably know someone with an NF condition.

HOW CAN YOU HELP?

- Be supportive and understanding of people with NF.
- Go to www.nfmidwest.org and learn more about these conditions and the different ways people may be affected.
- Donate to NF programs and research.
- Volunteer and get involved.

HOW CAN RESEARCH BENEFIT EVERYONE?

Programs to support people with NF, and research for treatments and cures are severely underfunded. Also, because of close connection to many common conditions, such as cancer, learning disabilities, heart disease, memory loss, and brain tumors, research on NF stands to benefit 175 million Americans.

Because NF/ research also benefits those without NF, the support you give will eventually help someone you love.

NF PROGRAMS & RESEARCH

NF Midwest works to improve the lives and futures of children, adults, and families impacted by NF/SWN disorders and ensuring that No One Fights Alone!

Our focus and foundation is on C.A.R.E.S. (Clinics, Awareness, Research, Education, and Support) in the states of Illinois, Indiana, Iowa, Kentucky, Wisconsin, and Missouri.

This includes, but is not limited to:

- Support programs
- Dedicated support coordinator
- Website for education, support and awareness
- Research grants and support
- Advocacy for federal funding
- Clinic support
- Educational events and material
- Camp for kids with NF
- Scholarships for adults with NF
- Awareness materials and events

NF Midwest raises most of its money through fundraising. Receiving no direct government support, we rely on corporations, foundations, and individuals for funding.

The children, adults, and families with NF need your support. Please give what you can whether, it's your time, money, wisdom, or by spreading the word.

We need you to care and to join us in this fight. If you'd like to help or learn more, go to www.nfmidwest.org



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FACES OF NF



No One Fights Alone
www.nfmidwest.org





Everyone with NF is
AFFECTED DIFFERENTLY.
These are SOME of the challenges they
may face.

- Internal and skin tumors
- Learning disabilities
- Attention deficit disorder
- Chronic pain
- Spinal issues
- Migraines
- Seizures
- Facial disfigurement
- Poor fine motor skills
- Poor gross motor skills
- Bone deformities
- Orthopedic issues
- Vascular Issues
- Scoliosis
- Amputation from tumors or bone abnormalities
- Loss of function or removal of organs due to tumors or other complications
- Depression
- Complete or partial hearing loss
- Complete or partial loss of sight
- Cancer
- Paralysis
- Precocious puberty
- High blood pressure
- Discrimination
- Dural ectasia
- Speech problems or delays
- Hydrocephalus
- Loss of balance
- Loss of life

