

Our Mission

Advocure is a working advocacy group for the NF2 international community.

Recent advances in our understanding of NF tumorigenesis and signal transduction have taken us into the era of translational research whereby it is possible to screen and identify existing drugs or compounds that act on key targets, potentially curing both NF1 and NF2.

Advocure is an international coalition committed to ensuring the rapid translation of this knowledge into targeted therapy for the NF community.

Advocure will monitor relevant research and drug developments world wide and lobby to achieve our goal of expediting much needed systemic therapy for this devastating Central Nervous System (CNS) disorder.



Recruitment

As outlined in our mission statement, Advocure is a volunteer parent/patient advocacy group with a core of office bearing members, and other rotating members from our international community. If you are a patient or have a family member with NF2 and are interested in volunteering please contact us below.

Contact Us

P.O. Box 4118
Clearwater, FL 33758-4118
USA

contact@advocurenf2.org

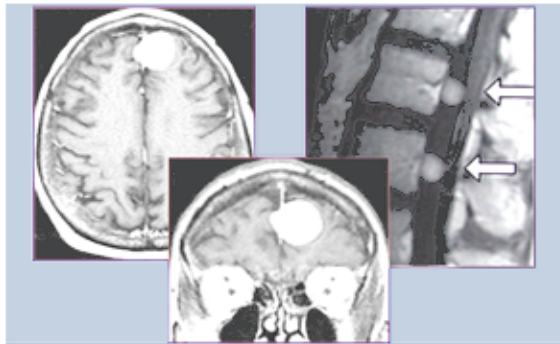
www.advocurenf2.org

Neurofibromatosis type 2

What is NF2?

Neurofibromatosis type 2 (NF2) is distinguished by multiple brain and spinal tumors, commonly causing deafness, severe balance problems, facial nerve paralysis, and also sometimes spinal cord compression, swallowing difficulties, and loss of mobility.

Optic nerve tumors, certain types of cataracts, and eye function complications from surgeries may also cause loss of vision or blindness.



Top Questions Commonly Asked.....

Q: Are there any research centers that specialize in NF2?

A: While there are many NF clinics, the two pre-clinical research centers specifically for NF2 are at the House Ear Institute (HEI) in Los Angeles and the NF clinic at the Massachusetts General Hospital (MGH) in Boston.

cont....

Q: Is there any effective systemic treatment to stop progression of disease once you have been diagnosed with NF2?

A: No, but some groups are working on it. At the present time only surgery and radiation are routinely available to treat tumors when they become problematic. However, this in itself becomes a serious risk over time if it is necessary for you to have multiple procedures, as is often the case.

Q: Are there any clinical drug trials for NF2?

A: Currently there are none. But there are some NF2 patients trialing drugs, and also some NF2 patients on other clinical trials. Advocure has set up an email forum called "Trial Talk" for these patients to freely correspond on these matters. To join, please visit our website. Also, with the growing interest in our community in naturally occurring compounds as a means to control tumor growth, Trial Talk has been expanded to include those 'trials' these compounds as well.

Q: Are there any prenatal and genetic tests for NF2?

A: Yes. For details please consult with your physician or genetic counselor. Genetic testing centers and prenatal options are listed and described on the Advocure NF2, Inc. website.

cont....

Q: How early can a child show symptoms of NF2?

A: As early as birth, but more commonly in the teens. The importance of seeing a Neuro-ophthalmologist who is familiar with NF2 cannot be underestimated in the diagnosis of children. Often eye symptoms are one of the earliest presenting symptoms for a NF2 mutation, in particular, juvenile posterior subcapsular cataracts.

Q: How many different kinds of tumors can a NF2 patient have?

A: All patients with NF2 develop bilateral vestibular schwannomas (VS), sometimes mistakenly referred to as Acoustic Neuromas (AN). However, most patients will also develop multiple Central Nervous System (CNS) tumors, most commonly meningiomas and schwannomas. Finally, some patients may also develop CNS ependymomas, astrocytomas, and gliomas.

