

NF2 Information Sources

The websites and organizations listed below are offered for the purpose of providing patients, families, and friends with information and resources that may be helpful in understanding NF2.

Neurofibromatosis, Inc. P.O. Box 6884, Chicago, IL 60666. Phone: 800-942-6825 or 630-627-1115; Fax 630-627-1117 Website: www.nfinc.org To contact our NF2 representative, e mail Marie.Drew@nfinc.org Provide support and information. A new patient packet, or Hospital Packet is available upon request.

Advocure P.O Box 4118, Clearwater, FL USA 33758. Website: www.advocurenf2.org This advocacy group is dedicated to monitoring relevant research and drug developments, and lobbying to achieve the goal of finding a cure for NF2. Under the link “Understanding NF2” there are articles giving an accurate overview of NF2 as well as some of the controversies that enter into treatment options.

NF2 Crew – website is www.nf2crew.org This is an online support and sharing group for persons with NF2 and/or their family members. More than 300 members span the globe. Included on their website are many links to useful information. To join the NF2Crew, the address is: NF2Crew-subscribe@yahoogroups.com or contact jennetteb@gmail.com

Acoustic Neuroma Association (ANA) – 600 Peachtree Parkway, Suite #108, Cumming, GA 30041. Phone 770-205-8211. Website is: www.ANAUSA.org Most people in this organization have only a unilateral (one) acoustic neuroma (or vestibular schwannoma) and only a small percentage have Neurofibromatosis 2. However AN people experience many of the same post-op problems, such as balance, eye closure, facial nerve damage, etc. Just be aware that statistics cited are DIFFERENT for a unilateral acoustic neuroma than for someone who has Neurofibromatosis 2.

Association of Late Deafened Adults (ALDA). Their address is ALDA Inc. 8038McIntosh Lane, Rockford, IL 61107. Phone 866-402-2532, and website is www.alda.org This organization serves those who became deaf or hard of hearing later in life for a variety of reasons. Members share the same problems of not fitting into either the culturally deaf or the hearing world. At their annual national meeting, all methods of communication are provided – sign, captioning, etc. The motto of ALDA is: “Whatever works”.

National Institute of Neurological Disorders and Strokes (NINDS) – www.ninds.nih.gov/disorders/neurofibromatosis/detail_neurofibromatosis.htm#57363162, Or just type in NINDS, go to “Disorders”, click on NF/neurofibromatosis. This is a government site that provides extensive information about NF2. For information about radiation, click on the link: www.IRSA.org/acoustic_neuroma.html listed under NINDS Organizations.

Children’s Tumor Foundation (CTF) formerly the National Neurofibromatosis Foundation – 95 Pine Street, 16th Floor, New York, New York 10005 Phone 800-323-7938. Website is www.ctf.org