Who is Neurofibromatosis Northeast?

We are a non-profit health organization that has advocated for those with neurofibromatosis since our founding in 1988. Our vision is a world where the burden of the genetic disorder known as neurofibromatosis (NF) does not exist. We seek to accomplish this vision through advocacy, raising awareness, and providing support for those affected by NF and allied disorders.

Our Vision: A world where the burden of neurofibromatosis does not exist.

Our Mission: To bring hope to those affected by neurofibromatosis and allied disorders.

NF Northeast is involved in every aspect of the NF journey. Our primary focus is providing resources to those affected by NF in the form of mentorship programs, scholarships, educational opportunities, online support communities, and more. We are also committed to finding treatments—and a cure—for NF by supporting medical research through our grant programs. We are proud to advocate for federal NF research funding by lobbying Congress on a national level.

Ultimately, NF Northeast is dedicated to creating a community of hope and support for patients, families, and all those affected by neurofibromatosis. We are here to help everyone navigate their journey with NF.

We are proud to serve Pennsylvania, New Jersey, New York, Connecticut, Rhode Island, Massachusetts, Vermont, New Hampshire, and Maine. However, we are committed to helping any NF patient regardless of where they live.

Contact Information

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For more information, scan the QR code above or visit www.nfnortheast.org

Follow us on social media!

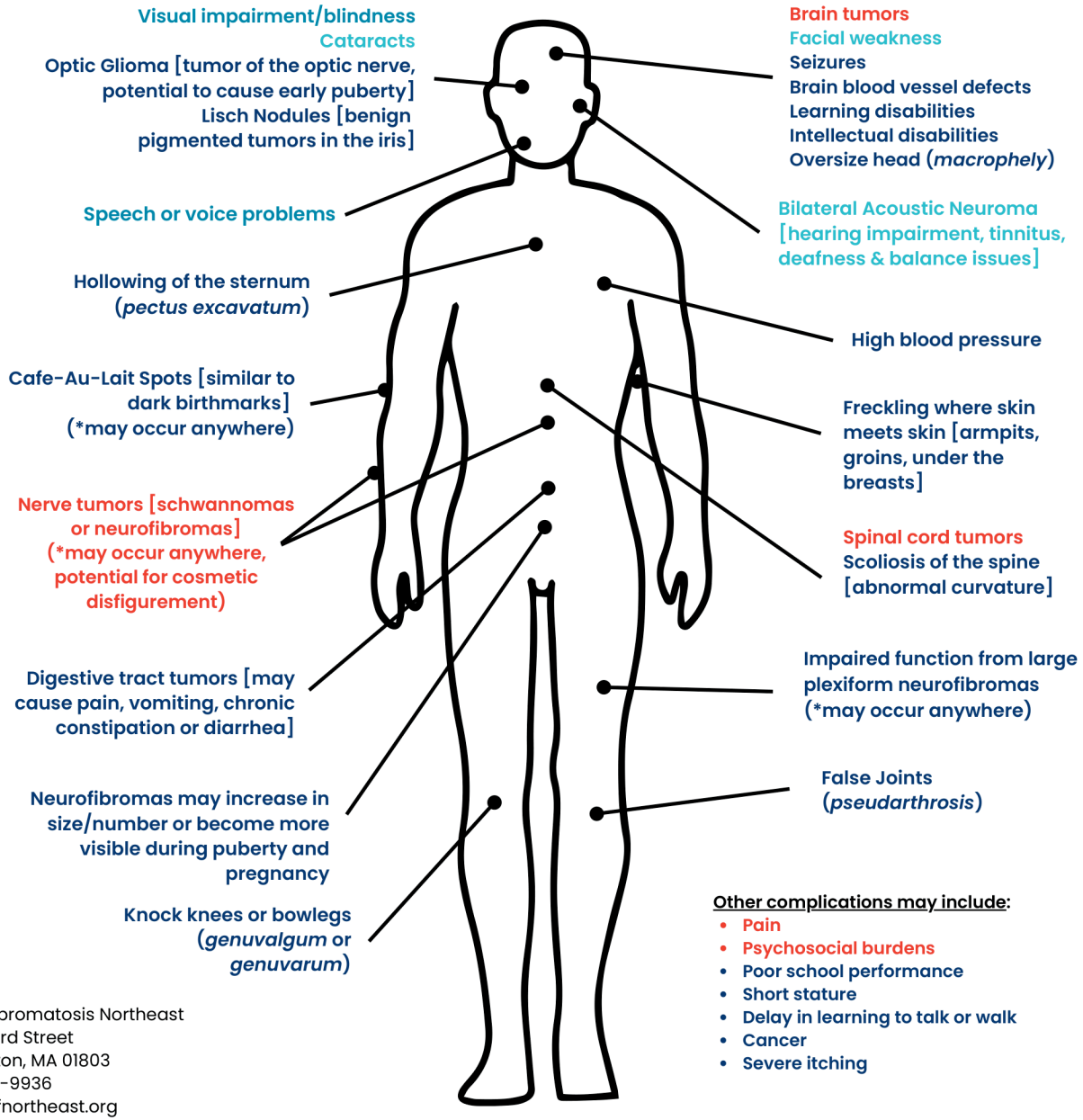
NEUROFIBROMATOSIS NORTHEAST

the organization with heart

Improving the lives of patients living with Neurofibromatosis Type 1 (NF1) NF2-Related Schwannomatosis (NF2) & Schwannomatosis (SWN)

NF Northeast

HOW NF CAN AFFECT THE BODY



Other complications may include:

- Pain
- Psychosocial burdens
- Poor school performance
- Short stature
- Delay in learning to talk or walk
- Cancer
- Severe itching

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NF Northeast

Potential Symptoms For:

NF1 Patients | NF2 Patients | NF1 & NF2 Patients | NF1/NF2/SWN Patients

What is neurofibromatosis?

- Neurofibromatosis (NF) and schwannomatosis (SWN), pronounced neuro-fibroma-tosis or schwa-noma-tosis respectively, are genetic disorders of the nervous system that cause tumors to form on the nerves anywhere in or on the body at any time. There are multiple subtypes with distinct clinical symptoms, including NF1, NF2-related schwannomatosis (formerly called neurofibromatosis type 2), and other kinds of schwannomatosis.
- NF affects all races, ethnic groups, and sexes equally. NF impacts three times as many people as muscular dystrophy, cystic fibrosis, Huntington's disease, and Tay-Sachs disease combined.
- NF is associated with pain, deafness, vision impairment, disfigurement, neurological challenges, learning disabilities, and cancer.
- Symptoms vary tremendously between the three allied disorders, and within individual patient cases. A range of mild to severe symptoms is possible, with the potential for additional health complications to develop over time.
- There is currently no cure for neurofibromatosis or schwannomatosis.

More than 100,000 Americans are living with neurofibromatosis, and it affects over 2 million people worldwide.

Symptoms can differ greatly in occurrence, severity, and age of appearance between patients. This makes NF difficult to identify and diagnose. If NF is suspected, genetic testing is typically the most appropriate way to diagnose it.