

EVENT PRESS RELEASE

CONTACT INFORMATION:

Neurofibromatosis Network

Contact: Ashley Sola
Events and Marketing Coordinator

Office: 630-510-1115

Cell:

Email: asola@nfnetwork.org



FOR IMMEDIATE RELEASE

[Headline: Together We Are #NFStrong - NF Network Rallies Community for the inaugural #NFStrong 5K]

[Omaha, NE] – For the first year ever, the Neurofibromatosis (NF) Network has brought together individuals from all over the country to support and celebrate the NF community. This year, the #NFStrong 5K for Neurofibromatosis will commence at the Walnut Creek Grange Shelter on Sunday, September 25th, 2022. We are excited to host a hybrid event – both in-person and virtual – to allow for members of our community to participate in any way they feel comfortable.

Neurofibromatosis is a rare genetic disorder that causes tumor growth on nerve endings throughout the body. Neurofibromatosis, or NF, affects one in every 2,500 births and shows no bias against age, race, or gender. Currently there is no cure for NF and very minimal treatments, our mission is to continue not only advocating and searching for a cure, but also building community by raising awareness and spreading hope.

The Boardman #NFStrong 5K is led by Jessie and Paul Patterson. Inspired by Paul and their 3 children who all have NF2, they are excited to bring awareness to the Omaha area and connect with others in the NF community - parents, families, and individuals alike!

Our #NFStrong events take place in communities nationwide. These inspiring events create strong bonds that build a supportive NF community. The goal of these strong communities is to rally together and become one great voice in finding effective treatments and an eventual cure for NF. These events are a great way to involve family and friends, meet others who are affected by NF, and raise awareness of this disorder as we continue research for a cure.

This year's event is sponsored nationally by Alexion Pharmaceuticals. Their mission is to transform the lives of people affected by rare diseases and devastating conditions by continuously innovating and creating meaningful value in all that they do, and they're making real progress, **every day**. Learn more about Alexion at www.alexion.com/our-company/about-us.

Join the NF Network on September 25th in Walnut Creek Grange Shelter and enjoy a day of family fun with the NF community. Check-in and walk up registration begin at 9:00am and the Family Walk and 5K Run begin at 10:00am.

Sign up early and receive an early bird discount on in-person adult registration. The In-Person 5K is \$20 through August 13th. After August 13th the In-Person 5K is \$25. Registration for children is always discounted - \$3 for 3 years old and under and \$6 for 4-11 years old. ALL registrants who sign up for the In-Person 5K through August 13th will receive a FREE #NFStrong t-shirt! Registration for the Virtual 5K is just \$10 to participate, with t-shirts available for purchase through August 13th. To sign up today, visit www.nfnetwork.org. We can't wait for you to join us!

NOTICE FOR ALL REGISTRANTS - By attending this event, you and your guests voluntarily assume all risks related to exposure to COVID-19 and agree not to hold the organization, the venue, the event presenter, or any of their affiliates, directors, officers, employees, agents, contractors, or volunteers liable for any illness or injury.

The NF Network is a non-profit 501(c)(3) organization and was founded in 1988 by a group of people who were in some way affected by neurofibromatosis. We are the leading national organization advocating for federal funding for NF research and building and supporting NF communities. The NF Network's goal is to eradicate the health issues, pain, isolation and uncertainty that the diagnosis of NF inflicts. The NF Network provides opportunities for local NF organizations to share experiences. The network is a dynamic and growing open space for shared resources, development of new tools, and creation of innovative programs. It brings together groups from around the country to speak as one voice on national issues.

Our mission is to *"find treatments and a **cure** for neurofibromatosis by promoting scientific research, improving clinical care, providing outreach through education and awareness, while offering hope and support to those affected by NF. "*



###