What is Noonan Syndrome?

Noonan syndrome (NS) is a variably expressed, multisystem disorder with an estimated prevalence of 1 in 1,000 - 2,500 births. It is nicknamed the "Most Common Rare Syndrome You've Never Heard Of". People with NS may experience bleeding issues, congenital heart defects including hypertrophic cardiomyopathy and/or pulmonary valve stenosis, lymphatic abnormalities, small stature/growth issues, feeding and gastrointestinal issues, failure to thrive, hypertelorism, learning disorders, autistic tendencies, unexplained chronic pain, connective tissue disorders, auto-immune disorders, chiari malformation, hypotonia, ptosis, skeletal malformations, chiari malformation, laryngomalacia, tracheomalacia, opthamology issues, orthopaedic issues, oncology issues and much, much more. Because of the variability in presentation and the need for multidisciplinary care, it is essential that the condition be identified and managed comprehensively.




How can we help?

The Noonan Syndrome Foundation is the leading 501c3 non-profit, Noonan Syndrome organization. Our mission is focused on raising awareness, educating the public and healthcare providers, building community through social media and providing informational support services to the community. We are also centered on finding life-saving and effective medical treatments for people with NS by supporting research initiatives. Please contact us via our website, e-mail or Facebook.

www.teamnoonan.org · info@teamnoonan.org · Facebook: Noonan Syndrome Foundation