



**A PROCLAMATION DECLARING MAY 2018 AS NEUROFIBROMATOSIS
AWARENESS MONTH**

WHEREAS, The Children's Tumor Foundation and Neurofibromatosis awareness organizations around the world are observing May as World Neurofibromatosis (NF) Awareness Month to educate the public about this rare genetic disorder; and

WHEREAS, Although over 100,000 Americans are living with NF and 1 in every 3,000 births is diagnosed with NF, it is still relatively unknown to the public; and

WHEREAS, NF affects all populations equally, regardless of race, ethnicity or gender; and

WHEREAS, NF causes tumors to grow on nerves throughout the body and also can affect development of the brain, cardiovascular system, bones and skin; and

WHEREAS, the disorder can lead to blindness, deafness, bone abnormalities, disfigurement, learning disabilities, disabling pain, and cancer; and

WHEREAS, NF is more prevalent than cystic fibrosis, Duchenne muscular dystrophy, and Huntington's disease combined; and

WHEREAS, The Children's Tumor Foundation proudly celebrates 40 years of providing patient and family support, driving research, expanding knowledge, and advancing care for the NF community, this year reflecting on the many key advancements in NF research that can be traced to the Foundation; and

WHEREAS, much remains to be done in raising public awareness of NF to help promote early diagnosis, proper management and treatment, prevention of complications, and support for research.

NOW, THEREFORE, BE IT PROCLAIMED, by the Town of Superior, Colorado, that the Mayor and Board of Trustees, in recognition of this important initiative, do hereby proclaim the month of May 2018 as "Neurofibromatosis (NF) Awareness Month."

IN WITNESS WHEREOF, I have hereunto set my hand this 14th day of May, 2018.

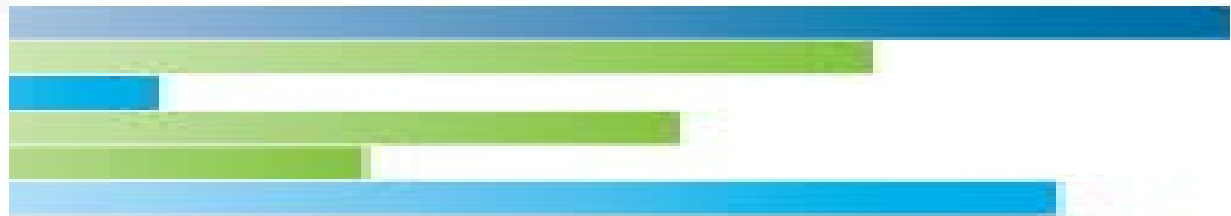



Clint Folsom, Mayor

Neurofibromatosis and The Lynn Family

Town Of Superior, Colorado

May 2018



What is Neurofibromatosis?

- Neurofibromatosis (NF) is a genetic disorder that causes tumors to grow on nerves throughout the body and can lead to blindness, bone abnormalities, cancer, deafness, disfigurement, learning disabilities, epilepsy, and excruciating and disabling pain.
- NF is comprised of three distinct disorders: NF1, NF2, and schwannomatosis.
- NF affects one in every 3,000 people, more than cystic fibrosis, Duchenne muscular dystrophy, and Huntington's disease combined.
- May is NF Awareness Month; May 17 is NF Awareness Day

E

Today: 10 years old, finishing
4th Grade at Kohl Elementary,
and a wonderfully happy and
energetic kid

ynn

- Diagnosed with
- Diagnosed with
 - Seizures controlled
- 7 Brain MRIs
- 1 Spinal MRI
- Surgery for
- Several multiple seizures (May 5)
- Several Neuropathies
- Severe developmental delay

2017 Children's
Tumor Foundation "NF
Hero" - Colorado

...lies (inc. April 30-
...nors)

How Our Family is Helping

- Children's Tumor Foundation Volunteer Leadership Council



What is CTF?

- The Children's Tumor Foundation is a not-for-profit organization dedicated to finding effective treatments, via research funding, for the millions of people worldwide living with NF
- In addition to benefiting those who live with NF, this research is shedding new light on several forms of cancer, brain tumors, bone abnormalities, and learning disabilities, ultimately benefiting the broader community.
 - Accordingly, NF research may benefit an additional 100 million Americans (i.e. 65 million with cancer and 35 million with learning disabilities).



April 30 2018

Denver City & County Building



THROUGH RESEARCH

Thanks to the Mayor Folsom and the Town of Superior Council Members for the discussion of the NF Awareness Proclamation, and for your time this evening!

www.ctf.org

www.nfnetwork.org

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@childrenstumor

Facebook/childrenstumor

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