

# NF Network Advocacy Program

## Neurofibromatosis (NF) Fact Sheet



"When I look in the mirror, I don't see NF. I only see my big bright smile and my mischievous eyes looking back at me."



Facial Paralysis  
Spinal Tumors

Chronic Depression  
Skin Tumors  
Learning Disabilities

Adrenal Tumors  
Organ Tumors  
Cancer

Cardio-Vascular  
Abnormalities  
Skin Tumors



Plexiform Tumor

Deafness  
Balance Issues  
Vision Loss

G.I. Issues  
Eye Tumors  
Precocious Puberty

Brain Tumor

### NEUROFIBROMATOSIS

- ♥ NF is a highly variable and unpredictable genetic disorder of the nervous system that affects almost every organ system in the body. NF causes tumors to grow along nerves including in the skin, just below the skin, and in the brain and spinal cord.
- ♥ Complications of NF can include brain and spinal tumors, benign and malignant tumors, severe pain, bone abnormalities, blindness, deafness, cardiovascular disease, muscle weakness, disfigurement, and psychosocial disabilities such as learning disabilities and autism, and in some cases death.
- ♥ NF occurs worldwide in all races, ethnic groups and both sexes and can appear in any family. Half of all affected people inherit the disorder, the other half arise spontaneously through mutations in the NF genes.
- ♥ NF affects more than 100,000 Americans; this makes NF more prevalent than Cystic Fibrosis, hereditary Muscular Dystrophy, Huntington's disease and Tay Sachs combined.
- ♥ There is no known treatment to stop the growth of these tumors and there is no cure.

### NF RESEARCH PROGRAMS

- ♥ NF research has been funded by Congress through the Congressionally Directed Medical Research Programs (CDMRP) at the Department of Defense since 1996, and through the National Institutes of Health (NIH).
- ♥ Funded research has determined that the NF gene controls pathways which are directly related to pain, nerve regeneration, wound healing, inflammation and blood vessel growth, bone growth and repair, orthopedic abnormalities, amputation, learning disabilities, behavioral and brain function, tumor growth, and many forms of cancer, affecting over 175 million Americans, including members of the military.
- ♥ NF Clinical Trials Consortium significantly accelerates the clinical trial process by recruiting patients from 25 clinical sites with an operational center to analyze data.
- ♥ Continued Congressional funding through the CDMRP and NIH is vital in funding pre-clinical and clinical trials and finding a treatment and cure for NF and its related disorders.

### WHAT WE ARE SEEKING IN FY 2020

- ♥ **Defense Appropriations Request:** Support \$15 million in funding for the Army's NF Research Program (NFRP) in the FY 2020 Department of Defense Appropriations bills.
- ♥ **Labor HHS Appropriations Request:** Support the inclusion of report language on NF research at the National Institutes of Health in the FY 2020 Labor, Health and Human Services, Education Appropriations bill.

