



My son, Zachery, suffers from Neurofibromatosis (NF). I am asking for your support of two NF research programs in Fiscal Year 2018. The first request is for \$15 million in funding for the Army's NF Research Program (NFRP) in the FY2018 Defense Appropriations bill. The second request is for inclusion of report language on NF research at the National Institutes of Health in the FY2018 Labor-HHS-Education Appropriations bill.

NF involves the uncontrolled growth of tumors along the nervous system, which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer and death. NF is the most common neurological disorder caused by a single gene and is more common than muscular dystrophy and cystic fibrosis combined. However, because of NF's close connection to many common

diseases and disorders, such as cancer, learning disabilities, heart disease, memory loss, and brain tumors, research on NF stands to benefit 175 million Americans in this generation alone.

On the outside my son is a happy five year old who LOVES to smile and pretend he is a dinosaur, but inside his body is fighting what no person, let alone child should. He suffers learning disabilities that result in a severe speech and intellectual delay. Regular doctor visits and routine MRI's are necessary to monitor his NF progression and health. He receives almost 40 hours of therapies a week and the progress has been life altering for him.

I had never heard of Neurofibromatosis. If not for Zachery, it's possible I still would not know the disease. Nothing can be done to change what he has, but his story can be shared to bring awareness to NF. I am scared to think what his future holds. Nevertheless, I am honored to be associated with the NF Network, to inform people of Neurofibromatosis and bring families together. I have chaired five Central Florida NF Strong events. Each year I meet more Florida families that are impacted by NF attendance has grown over 150% from the 1st walk.

I believe in research and am grateful for the data and understanding that has already been discovered. I know more can be achieved, which is why I ask for the continued funding. My request is for support of the Congressionally Directed Medical Research Program for Neurofibromatosis in the amount of \$15 million for fiscal year 2018 and support language on NF research at the National Institutes of Health for fiscal year 2018 through the Labor, Health and Human Services, and Education Appropriations bill. The DOD's Neurofibromatosis Research Program provides hope. Continuing to invest in research and build on the successes of this program we WILL advance towards treatments and cures for NF and the numerous diseases associated with it.

Please join me and the more than 120,000 Americans living with NF and their families,

Sincerely,

Melanie P. Leach
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