

United States Senate

WASHINGTON, DC 20510

March 17, 2016

Chairman Roy Blunt
Senate Appropriations Subcommittee on
Labor, HHS, Education
Washington, DC 20510

Ranking Member Patty Murray
Senate Appropriations Subcommittee on
Labor, HHS, Education
Washington, DC 20510

Dear Chairman Blunt and Ranking Member Murray:

We write to thank you for your past support of Neurofibromatosis (NF) research and to request your subcommittee's support in Fiscal Year 2017 for the inclusion of the attached report language on NF research in the Labor, Health and Human Services, Education Appropriations bill.

NF involves the uncontrolled growth of tumors along the nervous system, which can result in terrible pain, disfigurement, deformity, deafness, blindness, brain tumors, cancer and death. NF is the most common neurological disorder caused by a single gene and affects more people than Cystic Fibrosis, hereditary Muscular Dystrophy, Huntington's disease and Tay Sachs combined.

With your continued support and a relatively small Federal investment, NF has become one of the great success stories of the current revolution in molecular genetics, improving our understanding of the human body. Indeed, current research in NF has implications for many other diseases and disorders, including cancer, hearing loss, learning disabilities, heart disease, memory loss, brain tumors, and vision loss.

Since the discovery of the NF gene, researchers are now on the threshold of developing a treatment and cure for this terrible disease, as well as for many other disorders connected to NF affecting over 175 million Americans in this generation alone. It is important that we continue to build upon these exciting advances by encouraging numerous institutes at the National Institutes of Health to continue to expand their NF research portfolios.

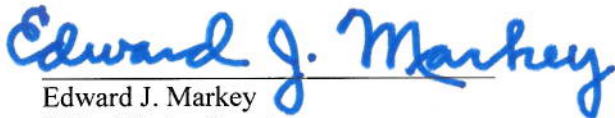
Thanks you for your attention to this request and for your continued support of NF research.

*National Institutes of Health
Office of the Director*

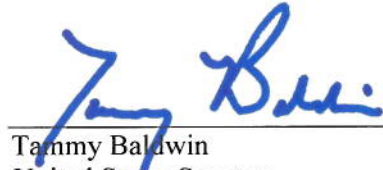
Neurofibromatosis [NF] – The Committee supports efforts to increase funding and resources for NF research and treatment at multiple NIH Institutes, including NCI, NINDS, NIDCD, NHLBI, NICHD, NIMH, NCATS, and NEI. Children and adults with NF are at significant risk for the development of many forms of cancer; the Committee encourages NCI to increase its NF research portfolio in fundamental basic science, translational research and clinical trials focused on NF. The Committee also encourages the NCI to support NF centers, NF clinical trials consortia, NF preclinical mouse models consortia and NF-associated tumor sequencing efforts. Because NF causes brain and nerve tumors and is associated with cognitive and behavioral problems, the Committee urges NINDS to continue to aggressively fund fundamental basic science research on NF relevant to nerve damage and repair. Based on emerging findings from numerous researchers worldwide demonstrating that children with NF are at significant risk for autism, learning disabilities, motor delays, and attention deficits, the Committee

encourages NINDS, NIMH and NICHD to expand their investments in laboratory-based and clinical investigations in these areas. Since NF2 accounts for approximately 5 percent of genetic forms of deafness, the Committee encourages NIDCD to expand its investment in NF2 basic and clinical research. NF1 can cause vision loss due to optic gliomas, the Committee encourages NEI to expand its investment in NF1 basic and clinical research.

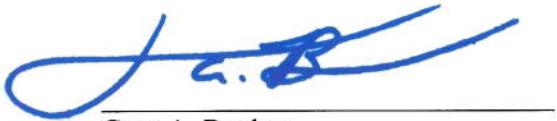
Sincerely,



Edward J. Markey
United States Senator



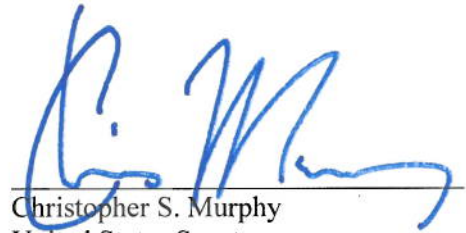
Tammy Baldwin
United States Senator



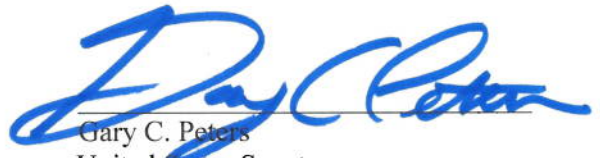
Cory A. Booker
United States Senator



Kirsten Gillibrand
United States Senator



Christopher S. Murphy
United States Senator



Gary C. Peters
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