



NF Network Advocacy Program

Frequently Asked Questions

Question: What are we seeking in Fiscal Year 2020?

Answer: **Defense Appropriations Request:** \$15 million for the Army's Neurofibromatosis (NF) Research Program through the Army Research, Development, Test and Evaluation (RDT&E), Medical Advanced Technology account in the FY2020 Department of Defense Appropriations bill (Line 31, PE # 0603002A).

Labor HHS Appropriations Request: Increased funding for Neurofibromatosis research at the National Institutes of Health (NIH). Specifically, we are requesting that NF specific report language be included in the Office of the Director Account in the FY2020 Departments of Labor, Health and Human Services, and Education Appropriations bill.

Question: How is Neurofibromatosis research funded?

Answer: Through several institutes at the National Institutes of Health (NIH) and through the Department of Defense.

Question: When did the Department of Defense start funding Neurofibromatosis Research?

Answer: The Congressionally Directed Medical Research Program (CDMRP) was established within the U.S. Army Medical Research and Materiel Command in 1993. The Peer-Reviewed Neurofibromatosis Research Program (NFRP) was established in 1996.

Question: Who stands to benefit from NF research?

Answer: Approximately 175 million Americans stand to benefit from NF research

- **Cancer** (65 million)
- **Heart Disease** (including hypertension) (50 million)
- **Learning Disabilities** (35 million)
- **Memory Loss** (at least 25 million)
- **Brain Tumors** (at least 30 thousand)

Question: Are research efforts duplicated by NIH and DOD?

Answer: No, the Department of Defense offers awards to fill gaps in ongoing research and compliments initiatives sponsored by other agencies, such as NIH. The Department of Defense's Neurofibromatosis Research Program (NFRP) and the National Institutes of Health research programs work in harmony with each other and have proven to be an excellent partnership to advance NF research. NFRP funding often allows researchers to explore new ideas and gather quality data making successful research more competitive in the larger science arena at NIH.

Question: How are NFRP funds awarded?

Answer: Funds are awarded through a competitive two-tier review process and are not targeted for a specific site. As such, the Neurofibromatosis Research Program (NFRP) is a national program with grants awarded to researchers all over the world.

Question: How much money has the Department of Defense received for NF research?

Answer:	FY1996	\$8 million
	FY1997	\$8 million
	FY1998	\$9.8 million
	FY1999	\$11.5 million
	FY2000	\$15 million
	FY2001	\$17 million
	FY2002	\$21 million
	FY2003	\$20 million
	FY2004	\$20 million
	FY2005	\$25 million
	FY2006	\$17 million
	FY2007	\$10 million
	FY2008	\$8 million
	FY2009	\$10 million
	FY2010	\$13.75 million
	FY2011	\$16 million
	FY2012	\$12.8 million
	FY2013	\$15 million
	FY2014	\$15 million
	FY2015	\$15 million
	FY2016	\$15 million
	FY2017	\$15 million
	FY2018	\$15 million
	FY2019	\$15 million
	TOTAL	\$347.85 million

*\$8 million was appropriated in FY1992

Question: What NIH institutes have conducted NF research?

Answer: National Cancer Institute (NCI), National Institutes of Neurological Disorders and Stroke (NINDS), National Institute of Child Health and Human Development (NICHD), National Eye Institute (NEI), National Institute on Deafness and other Communication Disorders (NIDCD), National Human Genome Research Institute (NHGRI), National Center for Research Resources (NCRR), National Heart, Lung, and Blood Institute (NHLBI), National Institute of Mental Health (NIMH), National Institute on Aging (NIA), National Institute of General Medical Sciences (NIGMS), National Center for Advancing Translational Sciences (NCATS), and the Office of the Director (OD).