

The Northwell Health Firefighter Cancer Study is a unique opportunity to find out how many members of the volunteer fire service in New York State have developed or died from cancer. In addition to supporting presumptive cancer legislation to protect volunteer firefighters who develop cancer in the line of duty, this information will be invaluable for prevention and treatment programs that benefit firefighters.

Study Purpose

Cancer presumption for career firefighters has been established through research linking the risk of getting certain cancers to toxic exposures that firefighters encounter. Using the same methods, this will be the first study of cancer risk in volunteer firefighters in the U.S. The study will require an unprecedented level of participation and trust – from you and from every other volunteer fire department throughout New York State.

Study Data Sources

By law, cancer diagnoses and cause of death are recorded in every state. This information is available to researchers who have proven (1) that they are approved to do a research study that requires this information for individuals and (2) that they can protect the confidentiality and privacy of individuals' identities and health information.

- The Northwell Health Firefighter Cancer Study team is authorized to submit a list of names and other identifying information for individual volunteer firefighters -- active, former, or deceased -- to the agencies with the cancer and death records.
- These agencies are permitted to report any "matches" of cancer diagnoses and deaths with this list to the study team and won't do anything further with the list we submit. They do not keep the list, do not contact anyone on the list, and will not use the information for any other purpose.
- We are not asking for any personal health information, such as cancer diagnosis, from fire departments or from firefighters; the only health information we get comes directly from state and federal agencies with cancer and death records.

The Northwell Health Firefighter Cancer Study team is led by Dr. Jacqueline Moline, an occupational medicine physician who is the Chair of FASNY's Health and Wellness Committee and one of the founders of the World Trade Center Health Programs. The Study Director is Dr. Anne Golden, an occupational epidemiologist who was instrumental in obtaining the data for the Fire Department of New York that led to the first cancer presumption bill for career firefighters in New York State.

Partnership with Fire Departments throughout New York State

Your department's information is crucial to doing the best possible study for all the volunteer firefighters in New York State who are so deserving of comprehensive cancer coverage and programs.

We understand that making the roster of all your members is time-consuming and that releasing any personal information can seem very risky in this day and age. There is absolutely no room for error when protecting your firefighters' private information. We are obligated by the Ethical Research Board at Northwell Health and at the NYS Department of Health to ensure the confidentiality and privacy of all data we collect. We take this responsibility extremely seriously and have a strong track record of protecting workers and their data.

We pledge that our study team will use every data security precaution available, including:

- **NOT** requesting Social Security Numbers;
- never contacting individual firefighters or their families for any reason;
- using a research data storage system with the highest security protocols (REDCap, see FAQs for further information);
- only reporting completely de-identified data (no individual firefighters' or fire departments' names will ever appear in any report from the study); and
- not using or sharing the data for any other purpose

Thank you very much for being part of this important study.

Please contact ffcancerstudy@northwell.edu with questions or interest in participation.

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