

# Northwell Health-FASNY Study of Cancer in Volunteer Firefighters in New York State



Jacqueline Moline, MD

Anne Golden, PhD

Gina Arena, MA, Vincenza Caruso, BS, and Charles Purcell, BS

Northwell Health

Department of Occupational Medicine, Epidemiology, and Prevention

**Email us at:**

[ffcancerstudy@northwell.edu](mailto:ffcancerstudy@northwell.edu)

**Learn more at:**

<http://www.feinsteininstitute.org/ff-cancer-study/>

## Northwell Health Firefighter Cancer



### “All Hands” Needed to Combat Cancer in Volunteer Firefighters

The purpose of this study is to determine how many members of the ***Volunteer Fire Service in New York State*** have ***developed cancer and died from cancer*** over the past few decades. Your ***participation is crucial*** to getting you and your fellow firefighters the ***coverage and programs you deserve*** for prevention and treatment of cancer.

### How to Participate

1. Email [ffcancerstudy@northwell.edu](mailto:ffcancerstudy@northwell.edu) with the **email address** of the person from your department who will be completing the data collection forms
2. Use the link that will be emailed by the study team to open the online data collection form and upload:
  - a. **Your Fire Department Information**
  - b. **Personnel Information Files**

To learn more, visit: <http://www.feinsteininstitute.org/ff-cancer-study/>

If you have any questions about this study, please contact any of the following:

- ❖ Email [ffcancerstudy@northwell.edu](mailto:ffcancerstudy@northwell.edu)
- ❖ Project Coordinator - Gina Arena - 516-465-1944
- ❖ Research Assistant - Vincenza Caruso - 516-465-3196

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](mailto:ffcancerstudy@northwell.edu) with questions or interest in participation.

**Dr. Jacqueline Moline**  
**Chair, Occupational Medicine, Epidemiology and Prevention (OMEP)**  
**VP, Occupational Medicine, Epidemiology and Prevention**  
**Northwell Health**

**Researchers:**

Jacqueline Moline, MD and Anne Golden, PhD  
Department of Occupational Medicine, Epidemiology and Prevention  
Northwell Health, 175 Community Drive, Great Neck, NY 11021  
Office phone: 516-465-2639 or 516-465-3171  
E-mail: [agolden3@northwell.edu](mailto:agolden3@northwell.edu) or [ffcancerstudy@northwell.edu](mailto:ffcancerstudy@northwell.edu)

---

Your fire department is being asked to provide information for a research study being funded by the Firemen's Association of the State of New York (FASNY). The purpose of a research study is to answer specific questions. Participating in a research study is completely voluntary. Your department is free to decide whether or not it will take part in this research. Your department can also say 'yes' now, and change their minds later.

**Why is this research study being done?**

The purpose of this study is to determine how many members of the Volunteer Fire Service in New York State have developed cancer and died from cancer or other causes. Your fire department is being asked to take part in this study because you can provide the necessary information from your fire department personnel records.

**What will happen in this research study?**

If you agree to take part in this research, you will be asked to do two things:

- (1) Create a list of all past and present volunteer firefighters who served in your fire department going as far back in time as possible.
- (2) Provide the Northwell Health study team with the list of firefighters' identifying information (**\*required**):
  - complete name (last, first, middle initial)\***
  - date of birth\***
  - current street address, town or city, state, zip code\***
  - sex and ethnicity/race\***
  - status at fire department (active, inactive, exempt, or deceased)\***
  - date joined and date exempt/resigned at the fire department (and any gaps in service)\***
  - highest rank and position at fire department
  - membership with any other fire department and status as a career firefighter

**What will NOT happen in this research study?**

- Social Security numbers will NOT be obtained for any firefighters
- FASNY will NOT have access to any of the personnel records or any other information collected
- The information will NOT be used for solicitation or any other purpose
- The research team will NOT have any direct contact with individual firefighters or their families

**What are the risks of the research study? What could go wrong?**

There is a risk of loss of confidentiality of the information collected for this study. Procedures are in place to protect the information and we will do everything we can to keep it secure.

Please consult with your fire district manager or attorney about NY laws governing the release of personnel information that may affect your department.

The following reviewers may access the study data to make sure that this study is being done properly:

- Representatives from Northwell Health's Human Research Protection Program (a group of people that oversee research at this institution)

If you have any questions about this research, please contact the Principal Investigator at Northwell Health, Dr. Jacqueline Moline, at 516-465-2639 or the Program Director, Dr. Anne Golden, at 516-465-3171 or email [ffcancerstudy@northwell.edu](mailto:ffcancerstudy@northwell.edu). You can also call the Human Research Protection Program at Northwell Health at 516-465-1910.

## Northwell Health Firefighter Cancer Study

# Frequently Asked Questions (FAQs)

### 1. Why is this study being done?

The purpose of this study is to determine how many members of the Volunteer Fire Service in New York State have developed cancer and died from cancer or other causes over the past few decades. 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. Your participation is voluntary, but a large study with input from every fire department will have the greatest impact on getting you and your fellow firefighters the programs you deserve.

### 2. Data Security: Will our department's information be safe?

**YES!** Information from fire departments will be collected by a secure web-based application called REDCap (Research Electronic Data Capture) and will be stored on secure Northwell Health servers. *REDCap is a HIPAA compliant website* used by many universities and hospitals to protect research information. **ONLY the members of the Firefighter Cancer Study team** have been granted access to the information sent through REDCap. We will take **EVERY** precaution to keep the information as secure as possible. (refer to the last page for more information about REDCap Security)

### 3. Why won't individual firefighters be contacted?

Fire departments are being asked to collect the information on behalf of their firefighters and send them to the **Firefighter Cancer Study team**. The study team will **NOT** have any direct contact with individual firefighters or their families. *No individual or fire department will be asked for information about which firefighters got cancers or died.* The study team needs to get that information directly from agencies that have complete and accurate information about cancer diagnoses (see #4).

### 4. How will the study find out which firefighters have cancer?

Cancer diagnoses for individual firefighters will be obtained directly from the NYS Cancer Registry which the New York State Department of Health uses to record every cancer in NYS residents. The NYS Cancer Registry will match the names and other information you provide to identify which members had cancer. *Your fire department does not need to indicate any cancer diagnoses or any other medical information, only the demographic information we request.*

### 5. Are you asking for our members' Social Security Numbers?

**NO!** We will **NOT** ask for Social Security Numbers.

### 6. What information is our department required to send?

Your department will be asked to enter the following information in the data collection forms in REDCap:

- a. Fire Department Information - general information about your department, Incident Type Report Summaries (the information that your department would report to NFIRS) for 2012-2016, and information for the department's contact person
- b. Personnel Information Files - basic demographic information for all past (inactive, exempt, and deceased) and present members of your fire department

### 7. How will we send you our fire department's information?

If you agree to participate in this study, you will be asked to provide the study team with a *single email address for your department*. The "contact person" who will provide the information for your department must have access to this email address. The link for the data collection forms will be sent in an email from [ffcancerstudy@northwell.edu](mailto:ffcancerstudy@northwell.edu) with the subject line: **"Northwell Health Firefighter Cancer Study."** *The email will contain instructions and the link for completing the data collection forms.*

There will be two options for uploading information:

- a. You can upload files from programs you have on your department computers that you use to manage rosters for your fire department.
- b. You can download the study's Excel spreadsheet to enter the information about your firefighters and then upload the Excel file.

#### **8. What types of files with our department's information can we upload?**

You can upload *any type of file* you have\*\*. If possible, please include all your information in a single file; however, you are able to upload up to 5 files on the data collection form. If you have more than 5 files, please contact Gina or Vincenza (see question 15 for contact information).

*\*\*We can also provide step-by-step instructions for downloading your files for some of the common personnel tracking/records management software systems upon request.*

#### **9. Do we need to submit all the information at one time? Can we start the forms and return later?**

You can save the forms with the information you've entered at any time and return later. You will receive an access code to use when you return to the forms. *Please save a copy of the code.* If you lose the code, contact the Project Coordinator, [garena@northwell.edu](mailto:garena@northwell.edu), to retrieve it. You may hit "save & return later" as many times as necessary; however, *once you hit "submit" for a survey, you will no longer be able to return to it.* Therefore, please make sure you've completed everything before you hit submit.

#### **10. Our department doesn't use a computer program or have electronic records of our rosters. How else can we send you the information?**

The study team's goal is to provide the simplest method for you to participate in this study. Please contact the team and they will be happy to work with you to find alternatives.

#### **11. What if we can't provide all the requested information?**

Some of the information is required because it ensures the best match to the NYS Cancer Registry; the data collection form shows which information is required. However, the study team can work with any amount of information you can provide. The more information you provide, the more data the study team will have to conduct a proper research study.

#### **12. How many years should we go back? Which rosters do we need to submit?**

The NYS Cancer Registry started recording cancers in 1976; therefore, cancers diagnosed before 1976 can't be used in the linkage. The further back in time you can provide rosters, the better for the study. If you can, submit the information for *every active, inactive, exempt, and deceased firefighter* who served in your department, *starting with the current roster and working back as far as possible.* The study team recognizes the difficulty of this request and will therefore work with any amount of information from your rosters you can provide.

#### **13. Who will have access to the information we provide?**

The members of the **Firefighter Cancer Study team** will be the **ONLY** people with access to the information you provide. The information will be stored on secure Northwell Health servers for the study period. There are strict limits on how we can use your information; these limits are enforced by the boards that oversee research at Northwell Health and at the New York State Department of Health. *The study team is obligated to keep the information safe and only use it for the purposes of this study.* The information will NOT be shared with FASNY and will NOT be used for solicitation or any other purpose.

#### **14. What are the risks of participating in this study?**

There is a risk of loss of confidentiality of the information collected for this study; while this risk is possible, the highest priority is keeping your information safe. Northwell Health provides research information technology (IT) procedures and training to ensure that the study team does everything it can to keep the information secure, including password protections and log-in restrictions to files and Northwell Health computers. Representatives from Northwell Health's

Human Research Protection Program (a group of people that oversee research at Northwell Health) will make sure this study is being done properly.

**15. What are the risks of sending information on behalf of our members?**

Please consult with your fire district manager or attorney about NY laws governing release of personnel information that may affect your department.

**16. Will we get results about our fire department?**

You will not receive results about your specific fire department. The study may report cancer rates among firefighters by county, but not for individual municipalities or fire departments.

**17. Who do we contact if we have questions?**

You can contact any member of the research team with any questions or concerns you have by emailing [ffcancerstudy@northwell.edu](mailto:ffcancerstudy@northwell.edu).

For questions regarding participation and completing the data collection forms, contact:

- Project Coordinator: Gina Arena – 516-465-1944 – [garena@northwell.edu](mailto:garena@northwell.edu)
- Research Assistant: Vincenza Caruso – 516-465-3196 – [vcarusos2@northwell.edu](mailto:vcarusos2@northwell.edu)

If you have a research-related question or concern, contact:

- Principal Investigator: Dr. Jacqueline Moline – 516-465-2639 – [jmoline@northwell.edu](mailto:jmoline@northwell.edu)
- Program Director: Dr. Anne Golden – 516-465-3171 – [agolden3@northwell.edu](mailto:agolden3@northwell.edu)

For questions regarding protection of research participants or other concerns about this study (refer to Northwell Study ID #16-848), contact:

- Human Research Protection Program at Northwell Health – 516-465-1910

## **REDCap Survey and Database Security**

To help protect and secure the data stored in REDCap's back end database, the software application employs various methods to protect against malicious users who may attempt to identify and exploit any security vulnerabilities in the system. Such methods will be described here in technical detail.

In REDCap, all incoming data gets intentionally filtered, sanitized, and escaped. This includes all data submitted in an HTTP Post request and all query string data found in every URL while accessing REDCap, among other modes through which user-defined data gets submitted in the application. Server environment variables that are vulnerable to forgery by users are also checked and sanitized. All user submitted data is properly filtered for any possibly harmful markup tags (e.g. <script>) and is then escaped before ever being displayed on a web page within the application. SQL queries sent to the database server from REDCap are all properly escaped before being sent. If any values used in an SQL query originated from user-defined values, they would have already been sanitized beforehand as well, as described above. User-defined data used within SQL queries also have their data type checked to prevent any mismatching of data types (e.g. making sure a number is really a number). These processes of sanitization, filtering, data type checking, and escaping all help to protect against methods of attack, such as Cross-Site Scripting (XSS) and SQL Injection. To specifically protect against Cross-Site Request

Forgery (CSRF), which is another method of attack, REDCap utilizes a "nonce" (a secret, user-specific token) on every web form used in the application. The nonce is generated anew on each web page as the user navigates within REDCap during a session.

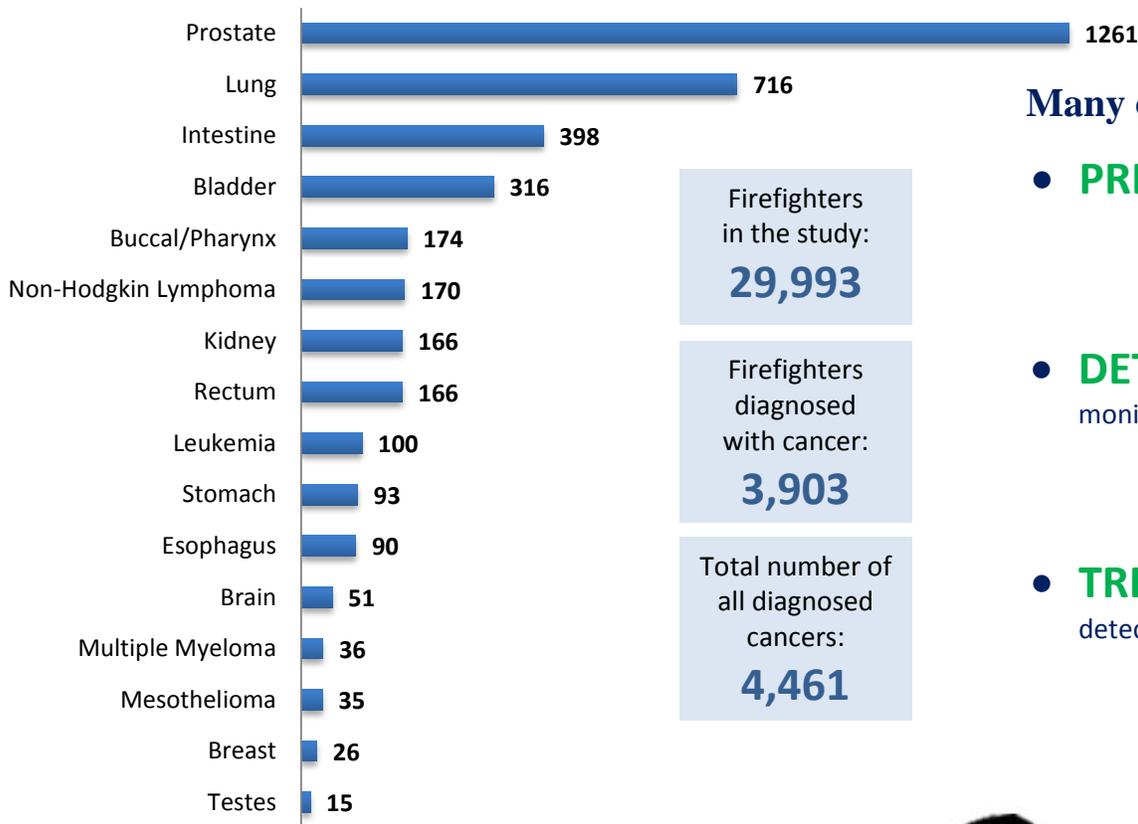
Many institutions that have installed REDCap have made use of enterprise-level web application security scanners, such as HP Webinspect and Acunetix, to scan and test REDCap's security and its ability to withstand various methods of attack. REDCap has performed very well in such instances. Any partner institution that wishes to scan REDCap using security scanning software is free to do so without the consent of Vanderbilt University or REDCap developers so long as the particular instance of REDCap being scanned is their own and not hosted by another institution. If an institution decides to perform a security scan of REDCap and finds any medium- to high-risk security issues that are directly REDCap related, they are encouraged to contact the REDCap developers at Vanderbilt so that such issues can be addressed. More information is available at <https://projectredcap.org/REDCapTechnicalOverview.pdf>

# FIREFIGHTING AND CANCER

## The facts you should know

### Cancer Incidence from the NIOSH Study of Career Firefighters

Observed values in a pooled cohort of firefighters from San Francisco, Chicago and Philadelphia (1950-2009)



Firefighters in the study:  
**29,993**

Firefighters diagnosed with cancer:  
**3,903**

Total number of all diagnosed cancers:  
**4,461**

Many of these cancers are:

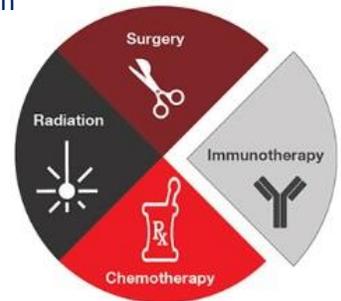
• **PREVENTABLE**



• **DETECTABLE** through monitoring and screening



• **TREATABLE** with early detection



Source: Daniels RD, et al. *Occup Environ Med* 2014;71:388-397

### NY State Senate Bill S1411B

#### Cancer Presumption for NYS Volunteer Firefighters

Signed by Governor

2017-2018 Legislative Session

#### Coverage for cancers affecting the:

- ✓ Lymphatic System
- ✓ Hematological System
- ✓ Digestive System
- ✓ Urinary System
- ✓ Neurological System
- ✓ Breast or Reproductive system
- ✓ Prostate
- ✓ Melanoma

View the bill at:

<https://www.nysenate.gov/legislation/bills/2017/s1411/amendment/b>

