



October 19, 2017

New York City Department of Health and Mental Hygiene
Gotham Center, 42-09 28th Street, CN 31
Long Island City, NY 11101-4132

RE: Amendment to Provisions of Article 207 of New York City Health Code Regarding
Proposed Transfer Schedule of Birth and Death Records to DORIS

The International Association of Jewish Genealogical Societies (IAJGS) is very concerned with the changes for access to birth and death records being proposed by the New York City Department of Health and Mental Hygiene. Seventy-five percent of all immigrants to the United States during the turn of the century entered through Ellis Island.¹ Ellis Island estimates that close to 40 percent of all current U.S. citizens can trace at least one of their ancestors to Ellis Island.² A recent report cites over 37 percent of New York City residents were born in another country—more foreign born-immigrants live in New York City than any other city in the world.³ For that reason, access to New York City birth and death records can be crucial for New Yorkers, for all Americans, and those outside the United States. IAJGS has members worldwide who are interested in access to New York City birth and death records.

IAJGS respectfully requests the following guidelines for access be considered rather than what is currently proposed, namely:

- Access to birth records after 75 years (if the individual's death can be verified) or 105 years if no death date is verified.
- Access to death records after 50 years; or after 25 years to registered members of a genealogical society.
- Access to the index to death records after 25 years (providing the name, date of death, place of death, date of birth, and burial/cremation information).

There are many reasons for our opposition to the proposed guidelines as currently presented, and why we have put forward the alternative guidelines shown above.

Genealogists Are Not the Cause of Identity Theft

We understand that the impetus for the recommended lengthy embargo periods before accessing birth and death records centers around the concern about identity theft. The genealogical community condemns identity theft whether it is perpetrated against the living or the dead. Data breaches in business, government and medical arenas are the cause of identity theft, **not** genealogists. The most recent large data breaches exemplify this point, as indicated by the Equifax data breach affecting more than 145 million Americans and the Yahoo data breach, most recently estimated to exceed 3 billion people.⁴

There are no known instances where states with open records access have more identity theft than states with long embargo dates.

The proposed embargo periods of 125 years from date of birth and 75 years from date of death originate from the 2011 version of the Model State Vital Statistics Act which has not been approved by the U.S. Department of Health and Human Services. In fact, in January 2013, the U.S. Department of Health and Human Services promulgated final regulations on protected health information and privacy which now permit medical information about a deceased person to be released 50 years after the date of death.⁵ The 50-year embargo is consistent with the guideline we are suggesting rather than the proposed 75-year period. It is our understanding that the leadership team at that National Association for Public Health Statistics and Information Systems (NAPHSIS) is giving sympathetic consideration to revisiting the embargo periods specified in the 2011 version of the Model State Vital Statistics Act.

Informational Copies of Birth and Death Certificates

Except for heir research, holocaust restitution, probate issues, and forensic work, most genealogists do not require a certified birth or death certificate. Many jurisdictions offer an informational copy of a birth or death record for these purposes that are marked across the front of the record stating it is for information and not to be used for identification. Issuing this type of record will provide a further assurance that New York City vital records are not being used for fraudulent purposes. We ask that the New York City Department of Health and Mental Hygiene offer informational copies which would provide important details for genealogical and historical research, and not impose elongated embargo periods.

Informational copies and earlier release of birth and death records would be particularly useful for forensic work. The Department of Defense sometimes contracts with genealogists to identify next of kin of deceased military personnel. Genealogists also work with local, county, and state coroners to help find the next of kin of deceased persons to determine heirship and to provide proper family burial.

Family Medical Information

Genealogy assists researchers in tracing family medical traits that are passed on from generation- to- generation. Information included in birth and death records is critical to reconstructing families and tracing genetically-inherited attributes in current family members. Increasing numbers of physicians are requesting that their patients provide a “medical family tree” in order to more quickly identify conditions common within the family. Information on three generations is the suggested minimum. The US Surgeon General includes preparing a family medical history as part of the American Family Health Initiative⁶

There are many genetically inherited diseases, but for the purposes of this statement, we will just mention the *BRCA1* and *BRCA2* genes' mutations and breast, ovarian, stomach, prostate and pancreatic cancers.⁷ The following information is from the National Cancer Institute⁸.

“A woman's risk of developing breast and/or ovarian cancer is greatly increased if she inherits a deleterious (harmful) *BRCA1* or *BRCA2* mutation. Men with these mutations also have an increased risk of breast cancer. Both men and women who have harmful *BRCA1* or *BRCA2* mutations may be at increased risk of other cancers.

The likelihood that a breast and/or ovarian cancer is associated with a harmful mutation in *BRCA1* or *BRCA2* is highest in families with a history of multiple cases of breast cancer, cases of both breast and ovarian cancer, one or more family members with two primary cancers (original tumors that develop at different sites in the body), or an Ashkenazi (Central and Eastern European) Jewish background.

Regardless, women who have a relative with a harmful *BRCA1* or *BRCA2* mutation and women who appear to be at increased risk of breast and/or ovarian cancer because of their *family history* [emphasis added] should consider genetic counseling to learn more about their potential risks and about *BRCA1* and *BRCA2* genetic tests.”

The likelihood of a harmful mutation in *BRCA1* or *BRCA2* is increased with certain familial patterns of cancer [emphasis added]. These patterns include the following for women of Ashkenazi Jewish descent:

- **Any first-degree relative diagnosed with breast or ovarian cancer; and**
- **Two second-degree relatives on the same side of the family diagnosed with breast or ovarian cancer.”**

People who have had members of their families diagnosed with breast cancer need to know whether past family members may have also died from this disease, in order to determine if it is inherited. **Both current and future generations need to have this information** to make decisions about whether to prophylactically remove both breasts and ovaries (which can mean the difference between early detection and treatment versus possible early death). Information needs to be available for both men and women as either can carry the gene mutation. Timely access to birth and death records is essential to assuring researchers that the records they have located on possible ancestors are indeed the correct persons, especially when they have a common name.

The example above is but one sample of the thousands of genetically-inherited diseases that by giving access to birth and death records in a timely fashion could save lives of current and future generations. Providing an individual with information as to potential medical issues they may have inherited allows for the opportunity to take proactive measures. For this reason, access to an individual’s cause of death is extremely important for those tracing and understanding their medical history relative to genetically-inherited diseases.

Why Genealogists Should Have Access to Records in a Timely Manner

In the proposed rule, the Department specifically requests feedback from genealogists about adopting a 50-year rule for death records rather than the proposed 75-years. We strongly encourage the 50-year rule be adopted for the following reasons:

- Genealogists are **NOT** the cause of identity theft.
- Genealogists have legitimate, professional and life-saving reasons to have timely access to birth and death records. The embargo periods being proposed are unnecessarily long and may cause accelerated health issues or premature death.

- Genealogists that belong to a genealogical society, with proof by letter from the society or membership card, should be afforded earlier access to birth and death records—such as 25 years.
- Informational, non-certified, birth and death records should be made available and are not useable for identity purposes.

IAJGS respectfully and strongly encourages the New York City Department of Health and Mental Hygiene to reduce the proposed embargo periods for birth and death records to those mentioned on the first page of this letter.

The International Association of Jewish Genealogical Societies is the umbrella organization of 75 genealogical societies and Jewish historical societies worldwide whose approximately 10,000 members are actively researching their Jewish roots. In the New York City- Long Island region, we have five member societies who collectively represent approximately 1,400 genealogists with interest in the New York City area records. The IAJGS was formed in 1988 to advance genealogical study, to elevate research standards and to provide a common voice for issues of significance to its members. Our societies' members include both professional and hobbyist genealogists. In 2017, we held our 37th consecutive annual International Conference on Jewish Genealogy (www.iajgs.org). One of our primary objectives is to promote public access to genealogically relevant records.

If you have any questions, please feel free to contact us at the email addresses listed below.

Sincerely,



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¹ <http://www.tabletmag.com/jewish-life-and-religion/246347/inside-ellis-islands-immigrant-hospital>

² <http://www.history.com/topics/ellis-island>

³ https://www.huffingtonpost.com/2013/12/19/new-york-city-immigrants_n_4475197.html

⁴ <https://www.nytimes.com/interactive/2017/your-money/equifax-data-breach-credit.html>

<https://www.wired.com/story/yahoo-breach-three-billion-accounts>

⁵ <http://www.gpo.gov/fdsys/pkg/FR-2013-01-25/pdf/FR-2013-01-25.pdf> page 5576 section 160.103. and see pages 5613 -5614 section 164.502(f)

⁶ <https://familyhistory.hhs.gov/FHH/html/index.html>

⁷ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4521499/>

⁸ <http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>