



International Association of Jewish Genealogical Societies (IAJGS)

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STATEMENT FOR THE RECORD, HOUSE COMMITTEE ON WAYS AND MEANS, SUBCOMMITTEE ON SOCIAL SECURITY, WRITTEN COMMENTS ON PROVISIONS RELATING TO SOCIAL SECURITY ADMINISTRATION'S DEATH MASTER FILE, ALSO KNOWN COMMERCIALY AS THE SOCIAL SECURITY DEATH INDEX.

I. INTRODUCTION:

The House Committee on Ways and Means, Subcommittee on Social Security, held a Hearing on 2 February 2012, regarding the accuracy and uses of the Social Security Administration's Death Master File. The genealogical community was informed that no invitation to testify at the hearing would be forthcoming, but that we – the genealogical community – were invited to submit a statement. This statement is accordingly submitted.

II. IAJGS BACKGROUND & CONTACT INFORMATION:

The International Association of Jewish Genealogical Societies is the umbrella organization of 70 genealogical societies and Jewish historical societies worldwide whose approximately 10,000 members are actively researching their Jewish roots. We want to ensure that our members will be allowed continued and maximum access to these vital records. The IAJGS and its predecessor organization were formed in 1988 to provide a common voice for issues of significance to its members and to advance our genealogical avocation. One of our primary objectives is to promote public access to genealogically relevant records. In 2012, we are holding our 32nd consecutive annual International Conference on Jewish Genealogy (www.iajgs.org).

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Thank you for the opportunity to present the IAJGS concerns regarding the Subcommittee's proposed elimination or reduction of public access to the commercial version of the Death Master File (DMF), the Social Security Death Index (SSDI). For the purposes of this statement, we will be addressing access to the SSDI rather than the DMF, as the SSDI is the version that genealogists are permitted to access. We were surprised and disappointed that the genealogical community was not invited to participate at the February 2nd hearing. The genealogical community, an important stakeholder in the proposed legislation, had been working tirelessly with the Subcommittee staff since mid-November – providing information on genealogists' use of the SSDI and suggesting legislative language to deter identity theft while retaining public access.

It is ironic that a system that is used to prevent identity theft (by permitting employers, financial organizations, insurance companies, pension funds, and others the ability to check names against those deceased as reported on the Death Master File), [<http://www.ntis.gov/products/ssa-dmf.aspx>] is now being determined—inappropriately—as an instrument of identity theft.

We support the Subcommittee's intent to protect the residents of the United States from improper usage of their personal information, and to protect them from identity theft. But, rarely has it been documented that an individual's identity is violated by access to vital records or the SSDI; rather, the violations occur due to computer breaches from government and private enterprises. A 2009 study stated "in the last five years, approximately 500 million records containing personal identifying information of United States residents stored in government and corporate databases was [sic] either lost or stolen"¹. Many of these computer breaches have been well documented in the press.²

Genealogists Are Not the Cause of Identity Theft

We watched the February 2nd hearing and were disturbed by some of the misinformation and inferences that were given during the hearing. **Genealogists are not the cause of identity theft.** Thieves are the cause of identity theft. Financial institutions and government agencies have been hacked into numerous times and that has been documented^{1,2}, but was not mentioned during the hearing. Nor was there mention of returning to using non-computerized data to avoid the inevitable hacking that occurs daily in the 21st century. If we accept the continued use of computerized data, and the continued likelihood of hacking occurring to any given database at any time, then we must also accept that, occasionally, misuse of data will occur. It is not reasonable, Constitutional, or in the Nation's interests, to remove public documents from public access. For a real solution to this problem, see below "IRS Needs to be More Proactive."

As parents and grandparents there is nothing that we can adequately express to Mr. Agin, his wife, and the other parents of deceased children about their grief over the agonizing loss of their children. With all due respect, do we know for a fact that Mr. Agin's daughter's Social Security number was taken from the public SSDI?

Mr. Agin, in his reply to Chairman Johnson's question asking just that, said "**it was his personal belief** that someone who trolled blogs about sick children and then used the access of the SSDI on genealogical websites". He stated, while it was possible, he would like to believe it was not the case, that it was someone involved with the medical institutions where his daughter was treated--as they would have access to her Social Security number. **Neither the assumption that it was taken from a genealogical website or that his daughter's Social Security number was not stolen from one of the medical institutions where his daughter was treated are based on facts.** Unfortunately, medical identity theft, whereby medical employees have been found to steal patient's identification has become a growing business.³

Mr. Agin mentioned that 14 other parents of children who died from cancer reported that their children were also victims of identity theft. As noted above, many government and financial institutions have been victims of computer hacking and many hospital employees have been found to steal patients' Social Security Numbers. It is remarkable that the cancer victims were targeted—as the SSDI does not include cause of death. Therefore, it is equally possible that the Social Security number was stolen

from the medical institution, provider's office or an off-site medical records subcontractor by an individual or a computer hacker.

Removal of the SSDI from public access would not necessarily reduce the problem of fraudulent use of a Social Security number. As it will no longer be available as a reference check to many who use it as an identity theft deterrent, it may well increase identity theft.

Interest in Family History/Genealogy

Millions of Americans are interested in their family history; The Harris Interactive Poll taken in August 2011 found that four in 5 Americans have an interest in learning about their family history. The Poll also reported 73% of Americans believe it is important to pass along their family's lineage to the next generation.⁴ Genealogists doing U.S. research located both in and outside the United States rely on the Social Security Death Index.

Family Medical History

Genealogists use the Social Security Numbers (SSNs) to appropriately identify records of people when tracing **family medical history**, especially if the person has a common name: Sara Cohen, Tom Jones, Jose Martinez, Mary Smith etc. During the hearing, Mr. Pratt, representing the Consumer Data Industry Association (CDIA), mentioned CDIA had conducted a study and found some people with common names, i.e. Smith, also had the same last four digits on their Social Security number, validating why the complete Social Security number is necessary.

Genealogy assists researchers in tracing family medical problems that are passed on from generation to generation. Information included in birth, marriage, and death records is critical to reconstructing families and tracing genetically inherited attributes in current family members. The SSN is essential to make certain that one is researching the correct person. Increasing numbers of physicians are requesting that their patients provide a "medical family tree" in order to more quickly identify conditions common within the family⁵. 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 mention the *BRCA1* and *BRCA2* genes' mutations and breast and ovarian cancer. The following information is from the National Cancer Institute⁷.

"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. “

This form of breast cancer is something not unique to Ashkenazi Jews, as studies have demonstrated that this has also been found in the Hispanic communities in New Mexico and Colorado—who did not know they were descended from Sephardic Jews who had hidden their Jewish identity to survive the Inquisition in the 15th century. This is described in Jon Entine’s *Abraham’s Children: Race, Identity and the DNA of the Chosen People*, by the Smithsonian in their article, *The Secret Jews of San Luis Valley*, and *The Wandering Gene and the Indian Princess: Race, Religion, and DNA*⁸

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 in order 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). This is something both men and women need to be able to research—as either can be carrying the gene mutation. The SSDI is a critical tool in assuring researchers that the records they have located on possible ancestors are indeed the correct persons, especially when they have a common name.

We use this as only one example of inherited diseases that require the ability to research ancestry using a SSN—regardless of ethnicity.

Working with Coroners to Identify Deceased’s Next of Kin

People are going to their graves with no family to claim them. Medical examiners and coroners’ offices—frequently overstretched with burgeoning caseloads—need help in finding next of kin of the deceased. The deceaseds’ identities are known; it’s their next of kin that are unknown in these cases. Over 400 genealogists are now offering their volunteer services to help locate the next of kin for unclaimed persons. The identities of these people are known, but the government agencies are not always able to find the families, so they are literally unclaimed. It is a national problem with which coroners must cope. See unclaimedpersons.org

Working with the Military

There are literally tens of thousands of United States Veterans’ remains left unclaimed throughout the Nation. Sometimes decades pass while these remains are waiting to be identified as Veterans and given a proper military burial. Genealogists work with the military to locate relatives of soldiers who are still unaccounted for from past conflicts. By finding relatives, the military can identify soldiers using DNA, and notify the next of kin so the family can make burial decisions. While using DNA, the genealogists also need SSNs to help assure they are finding the correct person’s family⁹.

Genealogy as a Profession

While there are millions of people who actively study and research their family history as an avocation, there are many others who earn their livelihoods as professional genealogists. Professional genealogists use the SSDI to (1) help track heirs to estates, (2) find title to real property, (3) find witnesses to wills that need to be proved, (4) work on the repatriation projects [see Working with the Military], (5) track-works of art—including stolen art—and repatriation of looted art work during the Nazi era of World War II, and (6) assist in determining the status of Native American tribes and tribal members to prove—or disprove—that they are entitled to share in Tribal casino revenues.

IRS Needs to Be More Proactive

If the IRS were to routinely run Social Security numbers included in tax returns against the death index, they might avoid giving refunds to deceased individuals.

“Operation Rainmaker” (also known as Operation TurboTax), was a tax fraud operation in the Tampa Bay area. Law enforcement interviews specified that the IRS, while cooperating with other law enforcement officers, is not authorized to share information with local law enforcement departments, hampering efforts to protect their citizens. If the federal government is serious about addressing identity theft that uses a person’s Social Security number, then the IRS needs to be given legislative authority to share information with local, county and state law enforcement organizations. It was also stated that filing tax refunds for under \$10,000 will not get any attention. As “Operation Rainmaker” found the average tax fraud was about \$9,500, below the \$10,000 threshold¹¹. This is another practice that the Congress needs to review, as the criminals who are perpetrating this fraud know they will be undetected!

It also became apparent in Mr. Agin’s case that the IRS assumes the first person filing is the “legitimate” filer and by inference, the second filer is the fraudulent party. The IRS needs to amend their practice when the filing involves a deceased child, to require some verification to determine which is a valid filing.

Unfortunately, since the IRS advocated electronic filing of tax returns, one unexpected consequence is the remarkable increase in tax identity theft.

Support For Efforts to Cease Identity Theft

- If income tax returns were electronically compared to the Master Death File, matching cases could be flagged for special processing, and the person attempting to create a tax fraud could be stopped before the fraud occurs.
- A parent’s social security number should be required when filing a tax return for any minor. It is an extremely rare occurrence that a minor child would not be listed as a dependent on the parent or guardian’s tax filing. If the minor dies, the IRS could have a procedure to flag any filings without the parent’s social security number, again preventing the fraud. Draft legislative language was provided to the Subcommittee staff on January 24, which would facilitate just this prevention of identity theft perpetrated on children. The *National Taxpayer Advocate’s Report to Congress for 2011* specifically highlights the benefits of the IRS Issued Identity Protection PINs¹⁰ and suggests that taxpayers should be allowed to turn off their ability to file tax returns electronically. Any family that suffers a death could elect to turn off the electronic filing ability.
- Criminal penalty statutes for those who fraudulently use Social Security Numbers, including, but not restricted to, those who misuse their positions (e.g., hospital, medical institution and office personnel, financial and credit card organizations personnel, prison corrections officer, college or university registrar etc.)

For the reasons stated above:

- genealogists are **NOT** the cause of identity theft;
- genealogists have legitimate, professional and life saving reasons to have immediate access to the SSDI; and
- proactive measures are needed to prevent identity theft and vigorously pursue and punish the **TRUE** identity thieves,

IAJGS respectfully and vehemently encourages the Subcommittee to continue the commercial version of the Death Master File, known as the Social Security Death Index, to be available to the public.

On behalf of the International Association of Jewish Genealogical Societies we appreciate the opportunity to submit our comments, and for the occasion to bring to the Subcommittee's attention the many services the genealogy community performs for local, **state and federal government offices**. We look forward to working with the Subcommittee and staff to find an accommodation that provides genealogists with immediate access to the SSDI.

Respectfully submitted,



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Chairperson, IAJGS Public Records Access Monitoring Committee

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- ¹ <http://www.identitytheft.info/breaches09.aspx>
- ² http://www.boston.com/business/articles/2008/03/18/grocer_hannaford_hit_by_computer_breach/
http://www.nctimes.com/news/local/article_3b98ce38-f048-597e-9a76-47321d114326.html
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http://www.washingtonpost.com/politics/tricare-military-beneficiaries-being-informed-of-stolen-personal-data/2011/11/23/gIQAcRNHtN_story.html
<http://sundayherald.com/news/heraldnews/display.var.2432225.0.0.php>
- Copes, H., and Vieraitis, L.M. (2009). Understanding identity theft: Offenders' accounts of their lives and crimes. *Criminal Justice Review*, 34(3), 329-349
- ³ <http://consumerist.com/2010/03/id-theft-ring-used-hospital-records-for-300k-shopping-sprees.html>;
http://articles.sun-sentinel.com/2010-11-11/health/fl-hk-holy-cross-id-20101110_1_identity-theft-ring-patient-files-emergency-room
<http://www.miamiherald.com/2011/12/07/2536190/miami-va-hospital-employee-charged.html>;
- ⁴ <http://corporate.ancestry.com/press/press-releases/2012/01/ancestry.com-partners-with-historical-society-of-pennsylvania-to-bring-the-states-rich-history-online/>
This survey was conducted online within the United States by Harris Interactive via its QuickQuery omnibus product on behalf of Ancestry.com from August 5-9, 2011 among 2,950 adults ages 18 and older
- ⁵ Mayo Clinic staff: "Medical History: Compiling your medical family tree,"
<http://www.mayoclinic.com/health/medical-history/HQ01707>;
- ⁶ <https://familyhistory.hhs.gov/fhh-web/home.action>
- ⁷ <http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>
- ⁸ Abraham's Children: Race, Identity, and the DNA of the Chosen People. Jon Entine, Grand Central Publishing, New York, N.Y. 2007
<http://www.smithsonianmag.com/science-nature/san-luis-valley.html>
The Wandering Gene and the Indian Princess: Race, Religion, and DNA. Jeff Wheelwright. WW Norton & Co. New York, NY, 2012.
- ⁹ <http://www.aarp.org/relationships/genealogy/info-06-2011/genealogy-tips.html>
<http://www.familiesforgottenheroes.org/Genealogist.htm>
- ¹⁰ <http://www.irs.gov/pub/irs-pdf/p2104.pdf>
- ¹¹ <http://www.youtube.com/watch?v=gpgTFO7nMBk>