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April 7, 2013

Mitch Greenlick, Ph.D. Chairman, Oregon House Health Care Committee Oregon State Capitol 900 Court St. NE H-493 Salem, OR 97301

Re: HB 2093

Dear Chairman Greenlick, Vice Chairs Keny-Guyer , Thompson and Members of the Oregon House Health Care Committee:

The International Association of Jewish Genealogical Societies (IAJGS) appreciates your interest in updating the Oregon Vital Statistics provisions. However, we have concerns about Oregon adopting provisions in HB 2093 of a proposed 2011 Model Vital Statistics Act that have not had any public hearings including input from the genealogical community. The United States Department of Health and Human Services (DHHS) has not adopted this model. In fact, in April 2012 they put the 2011 revision "on hold". A working group, put together by the Centers for Disease Control and Prevention/National Center for Health Statistics consisting primarily of state and local vital statistics executives, was formed in 2009 to update the Model Act and after distributing a draft to vital records officers for comments in 2011, reported out their work as the 2011 Revision in May 2011. At best, it is premature for Oregon to try to adopt a revision to their vital statistics statute for a revision that is not yet federally approved and may, at some point in the future, if the DHHS decides to review and hold public hearings, make substantive changes to the 2011 revision.

Our objection is specifically to Section 32. ORS 432.115 (4) which will close vital records for 125 years for births, 75 years for deaths, and 100 years for marriages, which is an unjustified increase in every category. No rationale has been voiced by the proponents of these elongated wait periods above the current Model Vital Statistics Act adopted in 1992 and operating in Oregon for decades without causing problems.

Currently, Oregon's Vital Statistics Act restricts the public from accessing vital records for 100 years from date of birth and 50 years from date of marriage or death. Nothing in HB 2093 supports the necessity of changing the current waiting periods. The US census is released every 72 years –still less than the current Oregon birth release of 100 years. You may ask why family historians need birth records if we already have access to census records. Family

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historians need to have a primary document to ascertain that they are researching the correct person—a census will not provide date nor specific location of the birth, nor necessarily the parents—all critically important to prove the record is of the correct person. This is especially relevant for those with names that are more common, such as Sara Cohen, Tom Jones, Jose Martinez and Mary Smith. The language from the 2011 proposed Model Statistics Act will close vital records for 125 years for births, 75 years for deaths, and 100 years for marriages, which is an unjustified increase in time to access these records. While we would prefer immediate access to such vital records, we are requesting that at a minimum, the elongated wait periods of 125 from date of birth, 100 from date of marriage and 75 years from date of death not be adopted.

Genealogists Want Access To Vital Records And Are Not the Cause of Identity Theft

Family historians believe access to records is critical. It is too easy now to claim that records should be closed in the name of security; however, if records are to be closed further, it is important that they be closed for justifiable reasons. Closing records can have real consequences. Family historians know what a valuable resource birth, marriage and death records are in their research. They are often the key documents that enable them to construct their families. We understand that some are concerned that access to vital documents might result in identity theft. 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}

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 state's interests, to remove public documents from public access.

Identity theft of the recently deceased is a serious problem. Increasing the timeframe for access to the death records of people who have been dead longer than 50 years will have no effect on identity theft or fraud. In fact, we believe that making death information widely available works to prevent identity theft and fraud. Making sure that official databases, such as the Social Security Death Index (SSDI), are updated quickly with death information and ensuring that creditors consult these databases will better prevent this fraud. Congress is currently addressing increased security measures that should be, **but have not been** taken by the IRS, to prevent identity theft measures that will aid the public. Closing access to vital records is not the answer!

Why Access to Vital Records Is Important

Family Medical History

Genealogy/family history 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. Accessing birth, marriage and death records are essential in making 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 family.³ Information on three generations is the suggested *minimum*.⁴ The US Surgeon General includes preparing a family medical history as part of the American Family Health Initiative ⁵. IAJGS Statement on HB 2093 Page 3 April 7, 2013

There are many genetically inherited diseases, but for the purposes of this statement, we will mention the BRCAI and BRCA2 genes' mutations and breast and ovarian cancer. The following information is from the National Cancer Institute ⁶.

"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. 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^{7.}

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. Being able to access vital records in a time sensitive period 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.

IAJGS Statement on HB 2093 Page 4 April 7, 2013

We use this as only one example of inherited diseases that require the ability to research ancestry using vital records—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 deceased's 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 <u>unclaimedpersons.org</u>

Compassionate Genealogy --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 vital records to help assure they are finding the correct person's family⁸.

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 these records 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 Compassionate Genealogy-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.

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.⁸ Genealogists doing U.S. research located both in and outside the United States rely on being able to access birth, marriage and death records.

We respectfully request that you do not adopt the language for wait periods as currently proposed in HB 2093 and at a minimum leave the current Oregon statutory language of 100-years for birth and 50 years for marriage and death as is, or reduce those wait times even further.

IAJGS Statement on HB 2093 Page 5 April 7, 2013

The IAJGS is the umbrella organization of 72 genealogical societies worldwide (of which two members are located in Oregon) whose approximately 10,000 members are actively researching their Jewish roots.

Please do not hesitate to contact me through the various contact points listed on the top of page one.

Sincerely,

Jan Meisels aller

Jan Meisels Allen IAJGS Vice President Chairperson, IAJGS Public Records Access Monitoring Committee

cc: Tyler Larson

| 1. | http://www.idtheftcenter.org/ITRC%20Breach%20Report%202013.pdf |
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| 2. | http://www.boston.com/metrodesk/2013/03/15/virus-accesses-salem-state-university- |
| | database-containing-personal-information-for- |
| | thousands/SFzoX7Cihtbm984ToweiaN/story.html |
| | http://www.usatoday.com/story/news/nation/2012/10/26/hacker-south-caroling-social- |
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| | http://www.nctimes.com/news/local/article_3b98ce38-f048-597e-9a76- |
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| | http://www.washingtonpost.com/politics/tricare-military-beneficiaries-being-informed-of- |
| | stolen-personal-data/2011/11/23/gIQAcRNHtN_story.html |
| 3. | Mayo Clinic staff: "Medical History: Compiling your medical family tree," |
| | http://www.mayoclinic.com/health/medical-history/HQ01707 |
| 4. | http://www.jogc.com/abstracts/full/201007 Obstetrics 5.pdf; |
| | http://www.aafp.org/afp/2005/0801/p441.html |
| | http://www.geneticalliance.org/ksc_assets/pdfs/manual/chapter_3.pdf |
| 5. | https://familyhistory.hhs.gov/fhh-web/home.action |
| 6. | http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA |
| 7. | 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. |
| 8. | http://www.aarp.org/relationships/genealogy/info-06-2011/genealogy-tips.html |
| | http://www.familiesforforgottenheroes.org/Genealogist.htm |
| | |

9. <u>http://corporate.ancestry.com/press/press-releases/2012/01/ancestry.com- partners-with- historical-society-of-pennsylvania-to-bring-the-states-rich-history-online/</u>

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