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**International Association of
Jewish Genealogical Societies (IAJGS)**
41 Aldridge Ave, Edgware, Middlesex, HA8 8TA United Kingdom
Tel: +44 20 89585249
www.iajgs.org

29 August 2013

The Honourable Ivo Opstelten
Minister of Security and Justice
Ministry of Security and Justice
Schedeldoekshaven 100
2511 EX The Hague
Netherlands

Re: European Union Proposed Data Protection Regulation

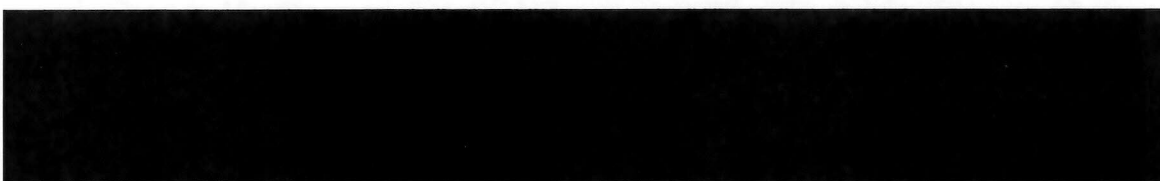
Dear Minister Opstelten

I am writing on behalf of the International Association of Jewish Genealogical Societies [IAJGS] an umbrella organization of 73 Jewish genealogical organisations whose combined membership is approximately 10,000 individuals. Of our member organisations, seven are located within Europe and six within the current members of the European Union [Belgium, Denmark, France, Germany, Great Britain and Sweden]. In addition, many members of our societies outside of Europe research their family history in one if not more of the current 28 European Union member Countries.

We understand and agree that the European Union 1995 Data Protection regulation needs to be updated to recognize the phenomenal effect that the Internet has had on our ability to access information since it was first developed. At the same time, we concur that individuals have certain rights to the protection of their identity and privacy.

I am writing to ask for your consideration in advising your country's European Council member of *certain concerns* we have regarding the proposed regulation as currently drafted. We ask that the regulation be modified to address our concerns and failing that, that the regulation vote be: not approved. Our major concerns are:

1. 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. Access to vital records—historical as well as current—is essential in making certain that one is researching the correct person. Increasing numbers of physicians are requesting that their IAJGS Letter on European Union Proposed Data Protection Regulation
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patients provide a "medical family tree" in order to more quickly identify conditions common within the family. It is critical to be able to trace back, not only straight-line, but also by collateral lines² which afford the individual as well as future generations to measure probability and historical medical occurrences and take appropriate preventive action as required.

There are many genetically inherited diseases, but for the purposes of this statement, we mention the *BRCA1* and *BRCA2* genes' mutations and breast and ovarian cancer. The following information is from the [US] National Cancer Institute³.

"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) [emphasis added] 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.⁴

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.

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2. "The right to be remembered." Many family historians are still trying to find out about their lost relatives from the Holocaust. Not only do we need to help people trace those who were lost or murdered during the Holocaust but also those persons trying to reunite members of their original family by first finding out their original roots. This is especially true for those such as the Hidden Children from World War II. These children were given to families or convents by doomed Jewish neighbors. Now many of them wish to trace their Jewish lineage and in some

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cases to find their own identity. Others have been helped to identify family members—sometimes half- siblings—children of a father's first wife, for example who perished in the Holocaust. Quoting from an article in the Free Press of Côte St. Luc (Canada) about Jewish Records Indexing—Poland [JRI-PL]:

" We have been able to reunite families separated by the Holocaust all over the world', said Diamond [Stanley] noting that unlike other European countries affected by the Nazis, some 80 percent of Poland's records were saved. The database has also been used by people looking to reconstruct their family history for medical and genetic purposes. ...

But the most heartwarming thing obviously is when people who thought they had no cousins because they were the only child of a family of survivors, learn that they do have a family, such as first and second cousins. ...and that has happened so many times its beyond belief. It doesn't take more than one generation, particularly if families are separated by geography and time for families to become totally unaware of each other...

Working with the original registers, JRI-PL has completely indexed may towns and cities throughout Poland, putting information online and giving people the opportunity to scroll through their history⁵.

Recently, UNESCO added the Yad Vashem Pages of Testimony repository to their World Register, UNESCO's Memory of the World Program which "raises to a global level the awareness and the imperative of preservation of, and access to irreplaceable documentary heritage in various parts of the world."⁶

The European Union wholeheartedly supports Holocaust Memorial Day each year but this event extends beyond remembering those who perished to reconnecting the living whose families were shattered.

Too many Europeans were lost during the Holocaust—Jews and non-Jews alike. And while our references are to those with Jewish genetic diseases and the Holocaust, these two examples of genealogical issues are relevant to all regardless of their ethnicity. Their records may be the only remaining evidence of their existence. To not be able to continue their memory even if it is only through their existing records is akin to having them die again. It is imperative that these victims of the Holocaust not be forgotten but be remembered by permitting continued access to the vital records that many organizations have started to include on the Internet or would be permitted to be on the Internet following the 100-year embargo placed by European Union of such records.

While we agree the individual has certain civil liberties, and there needs to be some data protection, we believe the data protection regulation as proposed goes too far. We request

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that protection should be balanced with public access to certain types of records for compelling reasons such as those stated above: tracing family medical history and Holocaust victims' "right to be remembered". The two individual "rights" are not mutually exclusive. Some flexibility needs to be included in the document along with the delivery of the individual's fundamental rights. The potential for an impossible situation is brewing with the proposed individual's decision to have their data removed once it on the Internet.

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Thank you for your consideration of our issues.

If you have any questions, I would be most willing to try to answer them.

Sincerely,



1. Mayo Clinic staff: "Medical History: Compiling your medical family tree,"
<http://www.mayoclinic.com/health/medical-history/HQ01707>
2. In genealogy, a collateral ancestor is someone related but not in your direct line such as an aunt, uncle, cousin. They are a branch on the family tree, when going back far enough on the ancestral tree they merge into a common ancestor.
http://wiki.genealogytoday.com/collateral_line.html
3. <http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA>
4. 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>
5. The Free Press of Côte St. Luc (Canada) News Montreal 13-August-2013
<http://www.freepresspaper.com/pdf/FP-2013-08-12.pdf> page 16
6. http://www.yadvashem.org/yv/en/pressroom/pressreleases/pr_details.asp?cid=797

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