GDPR (General Data Protection Regulation) Guidelines for Coffey y-DNA Project

I am Fred Coffey, and I am co-administrator of the Coffey DNA Project on Family Tree DNA (FTDNA). I am primarily focused on the y-DNA test results. The other co-administrator is Tim Peterman, whose primary interest is autosomal DNA results. We work together.

In response to the EU data protection laws, known as GDPR (General Data Protection Regulation), our testing service FTDNA and many other companies have decided to apply the same rules to their business. FTDNA have issued a new set of "Group Project Administrator Terms & Policies". To remain as an administrator, I needed to acknowledge that I accept those policies. I have done so.

The heart of the policy is that you have a "Right to be forgotten". You can request that your data in any institution applying GDPR be removed.

It is important that you understand what access rights I have as an administrator. The various access levels for me are "Minimal", "Limited", and "Advanced". Only in a very few rare cases do I have "Advanced", and that has been negotiated directly with the participant. But here is what FTDNA says about the other two:

<u>Minimal:</u> provides the administrator(s) the ability to utilize tools, specifically built for administrators, that allow the administrator to view certain results in relation to how you match other project members. The administrator will not have access to any of your myFTDNA pages under this access level.

<u>Limited:</u> In addition to the capabilities given in "Group Access Only," Limited Access grants the administrator the ability to visit your personal myFTDNA pages to view Genetic Information along with certain Personal Information that may support project research.

In the past, I have had Limited Access to our DNA Project participants information, and for present members that will remain so unless the participant chooses to switch to Minimal. A few have done so, and that raises some issues to be discussed below.

New members will be encouraged by FTDNA to select "Limited". This should be preselected in the drop-down menu.

FTDNA hosts Group Platform and Pages in their internal system, including the ability to group members' results into subgroups. This allows members to see how they fit into the Project. But it shows only the sample numbers of the participants. I have made very little use of this system.

What you need to know is that I am operating what they call "<u>Externally Hosted Group Project Pages</u>". They do not encourage this, but it is acceptable provided I agree that "it must follow the same standards as the FamilyTreeDNA hosted pages". I expect to do so.

For my Coffey Project Pages, I have always collected additional information direct from users. FTDNA guidelines now are explicit that "If you collect content and information directly from users, you make it clear that you (and not FTDNA) are collecting it, and you must provide notice about and obtain user consent for your use of the content and information that you collect.

Regardless of how you obtain content and information from users, you are responsible for securing all necessary permissions to reuse their content and information."

For new members I expect to often ask for additional information. I have always, and will continue, to describe how I will use the information I collect on the external Coffey Project Web Pages, and I always ask the participant for his permission to do so. Only a very few have declined, and those are not shown. And I will promptly remove any information or discussion that a participant requests that I remove.

Current members are encouraged to visit the following link to our web page. Then examine the "Genealogy" and the "Data" links to see what information might be included about yourself. If you see a problem let me know (<u>FredCoffey@aol.com</u>), and your data and analysis will be removed:

http://www.coffey.ws/FamilyTree/DNA/

FYI, the major difference vs FTDNA pages is that I show the name of the participant and I show as best I can how his genealogy fits into the big Coffey/Coffee picture. I think that is fundamental to explaining how the various families fit together and to encourage discussion. I never show the email address of a participant.

A few of our current members have CHANGED administrator access from Limited to Minimal. Be aware that limits my ability to look at your results and discuss or ask, or answer, questions. I prefer to generally have Limited Access, but that choice is up to the participant.

However existing members should be aware that I have already used my old Limited capability to extract information for use on the external Coffey Project Web Pages. I will keep that previously extracted information in place, unless the participant specifically requests that I remove it.

As a separate activity, the Coffey Cousins Clearinghouse publishes quarterly newsletters, and I am often active in writing therein about DNA analysis. Sometimes that discussion may make it possible to learn more about a DNA participant than can be learned from our DNA web page, including sometimes his email or mail address. Usually the DNA participant is also an active participant in the discussions and is delighted to have that discussion. For future newsletters, we will take great care to assure that we clearly have the DNA participant's explicit permission to discuss his DNA and to report his email address. However, I consider all previous newsletters to be "public", and these newsletters are sometimes collected in public libraries. I will not be able to retroactively remove information.

<u>How to Change Your Access Permission:</u> Log onto your FTDNA home page. Click on "<u>Manage Personal Information</u>". Click on "<u>Preferences</u>". Click on "<u>Project Preferences</u>". Find the Coffey project, and click on "<u>Edit</u>". Change preference as desired, then "<u>Accept</u>". Then "<u>Confirm</u>".

Comments or questions are welcome.

Fred Coffey