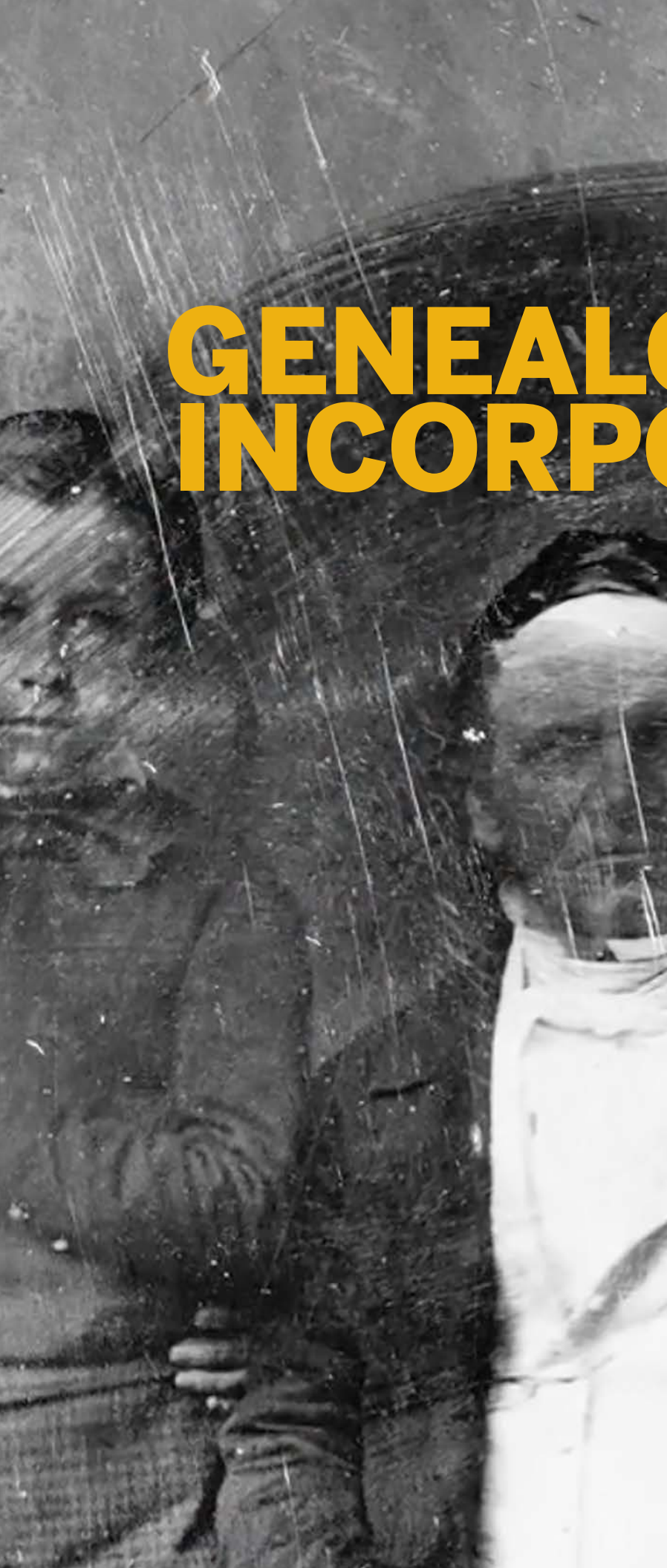




GENEALOGY INCORPORATED

“Who came before us?”

Seeking the answer to this question has made genealogy an exceedingly popular pastime in Canada.

Whether it's the discovery of a minor aristocrat, a political reformer, or even a small-time criminal, people are deeply invested in finding out more about the characters who populate their family histories and their countries of origin—if for no other reason than to have a good story to tell. Interest has also been primed by celebrity genealogies revealed on TV shows such as “Who Do You Think You Are?”

Previously a rather painstaking pursuit involving sending letters and making personal visits to archives, courthouses, churches, and libraries to request copies of records and information, genealogical research nowadays has gone viral thanks to the ease of conducting such research on the Internet.

Billions of marriage and death certificates, government census records, ship passenger lists, military histories, city directories, family photos and other data have been uploaded to the Internet by individuals, non-profit organizations, and for-profit genealogical companies. And the rush to digitize ancestral information shows no signs of abating.

But who owns this information? And who will protect it over time?

A documentary about genealogy finds a whole new set of privacy issues arises when personal information is added to online databases and aggregated. Below: Director Julia Creet and a series of production stills from the film.



FAMILY SECRET SPARKS DEEPER SEARCH

About a decade ago, spurred on by the desire to uncover a family secret, Julia Creet embarked upon her own ancestral quest. Searching for information about her mother, who had hidden her Jewish identity after surviving the Holocaust, Creet spent years combing through family archives and a trail of documents.

The more she probed, the more she began pondering the business of genealogy itself.

“I started getting the sense that many, many people were doing genealogical research and that there was a whole other context to this enterprise,” explains Creet, an Associate Professor of English at Toronto’s York University. “I started to wonder: If I’m part of the genealogical ‘zeitgeist,’ are my motivations purely individual or are they being driven by larger forces?”

These nagging questions sparked a deeper investigation into the reasons for genealogy’s exponential growth, and eventually inspired Creet to make a documentary film: *Data Mining the Deceased*.

Made with funding support from the Office of the Privacy Commissioner of Canada’s Contributions Program, the film documents Creet’s quest to unearth the genealogy industry’s key players and examine their motivations. Along with thorny questions about racial identity, the film raises concerns about the ownership and privacy of personal data, particularly the merging of genetic and genealogical information.

“I didn’t start out looking at privacy issues, but it quickly became apparent that there were tensions even within my own family. Not everyone wants family secrets to become public,” explains Creet. “A whole new set of privacy issues arises when personal information is added to online databases and aggregated. When you connect that information to genetic information, what you’re

“Not everyone wants family secrets to become public... A whole new set of privacy issues arises.”

giving away is much more valuable than what you’re getting in return.”

ICELAND’S FAMILY TREE

The film initially follows Creet to Iceland, which has the most complete genealogical database in the world. Records have been kept since the ninth century, shortly after the isolated island was settled.

Iceland’s situation drew worldwide attention when, starting in the 1990s, private genetics company deCODE sought to link DNA research to Iceland’s national health system population resources, with the aim of discovering genetic risk factors for common diseases.

The company also provided funding to accelerate the digitization of Icelanders’ genealogical records, and asked for volunteers to donate their DNA. It later received a 12-year licence from the government, along with permission from the country’s data protection authority, to access nationalized medical records. Although that access was later revoked after a public outcry, tens of thousands of records had already been transferred to the company.

“Iceland is a canary in a coal mine. When deCODE started braiding genetic information with genealogical information, privacy issues started to surface. Some people started to object to their medical history becoming part of a

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privately owned database,” states Creet, noting that deCODE has since been sold to US biotech giant Amgen, further complicating issues of data ownership.

“Few people read the fine print,” Creet continues, “but when you give your DNA to a private database, they have complete proprietary rights. They can aggregate it, sell it to other companies, and sell it for research—by non-profit institutions or for-profit companies.”

BILLIONS OF RECORDS NOW ONLINE

Even when non-profit databases are created by volunteers guided by a religious mission, corporate interests may eventually become involved, as Creet discovered when she began unpacking the relationship between the Mormon Church’s free FamilySearch database and ancestry.com, owned by Ancestry, “the world’s leading family history brand.” The site has two million paying subscribers who can access over 16 billion records.

Mormons believe they should offer baptism to dead relatives. To help members trace their family tree, the Church of Jesus Christ of Latter-day Saints (LDS) has amassed about thirty times the amount of information held by the Library of Congress—and new records are continually being added. FamilySearch now contains an estimated one-quarter of the human race’s genealogical information. Using the site’s substantial records, the church aims to build a family tree of as many people in the world as possible.

In the film, Creet interviews executives from FamilySearch and co-founders of Ancestry, revealing strategic partnerships between the two. Over the years, numerous LDS databases have been sold to Ancestry. In one recent deal, FamilySearch agreed to release one billion international digitized genealogical records online over five years for Ancestry subscribers.

When Creet broaches the subject of privacy with Ancestry’s co-founders, they admit it’s “at best a gray area.”

“I think there’s protection for living people...,” states one former Ancestry executive, “I’m not sure there is any movement or any effort to try to protect any records that pertain to people who are no longer living.”



Building a family tree using online databases can put your privacy at risk.

Ancestry is now charging users to submit their DNA to “uncover your ethnic mix, discover distant relatives, and find new details about your unique family history with AncestryDNA.” The company recently sold access to its DNA database to Calico, a genetic company backed by Google, which intends to examine genetic patterns in people who live long lives.

A CAUTIONARY TALE

“Most people who purchase these services do not read company privacy policies beforehand,” Creet says. “Private companies are accumulating vast amounts of vital information. Much of that information is donated by users and then bought and sold. We really have no idea how the information will be used, but it could have implications for insurability and employability. We’ve all seen how an old Facebook post can come back to haunt you.”

Ultimately, Creet’s film is a cautionary tale for anybody undertaking genealogical research. Her advice for individuals pursuing their family histories? “If you want to guard your privacy, stay away from online databases. Ask other family members about your shared ancestors. After two or three generations, the stories are mostly fiction anyways.” 

Julia Creet can be contacted at creet@yorku.ca.

To inquire about screening Data Mining the Deceased, please contact the film’s distributor at www.vtape.org or info@vtape.org.

LEARN MORE

View a synopsis of the report and clips from the film: <http://past-productions.apps01.yorku.ca/need-to-know/synopsis/>