

ONE HUNDRED FIFTEENTH CONGRESS  
**Congress of the United States**  
**House of Representatives**

COMMITTEE ON ENERGY AND COMMERCE

2125 RAYBURN HOUSE OFFICE BUILDING  
WASHINGTON, DC 20515-6115

Majority (202) 225-2927  
Minority (202) 225-3641

June 20, 2018

Mr. Gary Knell  
CEO  
National Geographic  
1145 17th Street NW  
Washington, DC 20036

Dear Mr. Knell:

We write to you to try to work together to address privacy protections for consumers. As you know, recent privacy violations involving companies that have access to customer data, including MyHeritage, Equifax and Facebook, have increased consumers' fears about losing control of their personal information. Cooperation between government and industry can avoid potential problems for consumers.

Genetic testing companies hold a unique position due to the type of personal information being collected. Breaches of consumer personal information at a company like yours could cause serious problems for customers. We would like to discuss our concerns with your company so that your customers know their data is protected and so we can address the potential problems in advance.

Direct-to-consumer genetic testing services promise consumers the ability to learn information about themselves, such as ancestry and health risks. We are sure you agree that given the intrinsically personal nature of this service, consumers using genetic tests deserve to know that their information is stored securely and that their privacy is being protected.

We believe that to protect the privacy of your customers, how your company stores, uses, shares, and sells the data that is collected through physical samples should be clearly communicated to consumers. Sharing genetic information with third parties could have

unforeseen or unintended consequences for your customers, including discrimination based on individual's genetics.<sup>1</sup>

Storing genetic information without proper safeguards poses unique and serious risks to consumers, including identity fraud.<sup>2</sup> In the event of a data breach, consumers cannot change their genetic data the same way they can change a compromised password or replace a credit card. Moreover, researchers have demonstrated that even when genetic data is anonymized, individuals may be identified from their genetic profile – demonstrating that the privacy and security of genetic data have consequences not only for your customers but also for their genetic relatives.

We want to better understand your privacy policy, what measures the company takes to secure information it collects from consumers, how the company uses this information, and whether and how the company shares information with third parties. Specifically, we would like to better understand how your company addresses the following questions:

1. How does your company store and secure the personal information and physical samples that it collects and retains?
  - a. Please describe in detail all personal information, including genetic information, that is collected from users and all personal information that is retained by your company. What non-genetic information is collected from users (e.g., names, addresses, email addresses, telephone numbers, dates of birth, Social Security numbers, credit or debit card information, etc.)?
  - b. Please describe in detail the retention policies of your company with regard to customer personal information, including genetic data and physical samples. If retention times are different for physical samples or for different types of information, please provide the retention times for each.
  - c. If the company destroys user data and physical samples at any time, please describe in detail all measures that are taken to ensure this material is destroyed securely.
  - d. Please list the titles of all employees within your company that have access to users' personal information, including physical samples. What limitations, if any, does the company place on the ability of its employees to access and use

---

<sup>1</sup> See, e.g., *Thanks to Genetic Testing, Everyone Could Soon Have a Pre-Existing Condition*, Slate (May 18, 2017); *The Privacy Delusions of Genetic Testing*, Forbes (Feb. 15, 2017); *If You Want Life Insurance, Think Twice Before Getting a Genetic Test*, Fast Company (Feb. 17, 2016).

<sup>2</sup> *Only a Click Away—DTC Genetics for Ancestry, Health, Love...and More: A View of the Business and Regulatory Landscape*, Applied & Translational Genomics (2016).

customer data and physical specimens?

- e. Please describe in detail your company's security policies and procedures, including physical security of customer's physical samples and security of customers' personal information. Please describe in detail all assessments your company undertakes to identify reasonably foreseeable risks to the security of its users' personal information and all breach response plans and policies.
2. Please provide copies of your company's privacy policies and terms and conditions and other similar documents establishing the rights of your customers. Please describe how users are informed of these policies.
  - a. Please describe in detail all options customers are provided regarding the collection, use, sharing, and selling of their personal information including physical samples. Please list with specificity all provisions are customers given the option not to consent and still use the service you company provides.
  - b. Please list all provisions of your company's privacy policies and terms and conditions or any other document in which customers are provided with the option to withdraw their consent and describe how and when such options are presented to customers.
  - c. Are users required to resolve disputes with the company through arbitration as a condition of using the company's services?
  - d. How are users informed of the changes to the privacy policies and terms and conditions? How is consent for the changes acquired?
  - e. Please specify the provision of your company's privacy policy or terms of service or any other document that describes what happens to customers' personal information including physical samples if the company is sold or enters into bankruptcy. Does the company treat user data as an asset that could be sold or transferred during restructuring?
  - f. Please specify the provision of your company's privacy policy or terms of service or any other document that describes how the company stores and protects genetic information including physical samples and how long such information and samples are kept.
3. Please describe in detail all purposes for which your company uses genetic information collected from customers, including providing services directly to the customer from whom the information was collected. Please specify the provision of your company's privacy policy or terms of service or any other document that expressly informs its

customers that their genetic information may be used for other purposes?

4. Please describe with specificity all customer personal information, including physical samples, that is shared with or sold to affiliates and third parties.
  - a. Please list all types of affiliates and third parties with whom you share or to whom your company sells customers' personal information, including physical samples. Include the purpose for which each of these entities have such access and how they use such information and physical samples. And please specify the provision of your company's privacy policy or terms of service or any other document that explains such information to your customers.
  - b. Please provide copies of all contract and other documents, in redacted form if necessary, that describe all requirements, obligations, or limitations placed on third parties with whom you share or to whom your company sells customers' personal information, including physical samples.
  - c. Is customers' personal information, including physical samples, whether anonymized or in any other form, shared with or sold to affiliates or third parties for research purposes? Please specify the provision of your company's privacy policy or terms of service or any other document that expressly informs customers that their information is shared, sold, or used for research purposes. Please describe in detail how is user consent acquired for such use.
  - d. Is customers' personal information, including physical samples, shared with or sold to affiliates or third parties for marketing or advertising purposes? Please specify the provision of your company's privacy policy or terms of service or any other document that expressly informs customers that their information is shared, sold, or used for marketing or advertising purposes. Please describe in detail how is user consent acquired for such use.
  - e. Please describe with specificity how your company controls and monitors affiliates' or third parties' access and use of customers' personal information including physical samples.
  - f. Does the company reserve the right to share or sell customers' personal information, including physical samples, to other parties? Please specify the provision of your company's privacy policy or terms of service or any other document that expressly informs customers that their information may be shared, sold, or used with unknown third parties in the future. Please describe in detail how is user consent acquired for such sharing or selling of their personal information.

Mr. Gary Knell  
June 20, 2018  
Page 5

Your assistance in this matter is greatly appreciated, and we look forward to receiving a response by July 5, 2018. If you have any questions, please contact Healthcare advisor to Congressman Loeb sack, Katie Murray, at [katie.murray@mail.house.gov](mailto:katie.murray@mail.house.gov) at (202)-225-6576, or Lisa Goldman, of the Democratic Committee staff, at (202)-226-3400.

Sincerely,

A handwritten signature in blue ink that reads "Frank Pallone, Jr." in a cursive style.

Frank Pallone, Jr.  
Ranking Member

A handwritten signature in blue ink that reads "Dave Loebsack" in a cursive style.

Dave Loebsack  
Member of Congress