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14 **UNITED STATES DISTRICT COURT**
 15 **NORTHERN DISTRICT OF CALIFORNIA**
 16 **SAN FRANCISCO DIVISION**

17 FIRST UNITARIAN CHURCH OF LOS
 18 ANGELES, *et al.*

19 Plaintiffs,

20 v.

21 NATIONAL SECURITY AGENCY, *et al.*,

22 Defendants.

Case No: 3:13-cv-03287 JSW

**DECLARATION OF DEBORAH C.
 PEEL, MD, FOR PATIENT PRIVACY
 RIGHTS FOUNDATION IN
 SUPPORT OF PLAINTIFFS’
 MOTION FOR PARTIAL SUMMARY
 JUDGMENT**

Date: February 7, 2014
 Time: 9:00 A.M.
 Hon. Jeffrey S. White
 Courtroom 11 - 19th Floor

1 I, DEBORAH C. PEEL, MD, hereby declare:

2 1. I am the Founder and Chair of Patient Privacy Rights (“PPR”), a 501(c)(3) non-profit
3 foundation. The facts contained in the following affidavit are known to me of my own personal
4 knowledge and if called upon to testify, I could and would competently do so.

5 2. As a national health privacy advocacy organization, Patient Privacy Rights
6 Foundation educates the public about the elimination of health privacy and advocates for effective
7 privacy-protective laws and technical solutions that will restore trust in the patient-physician
8 relationship and electronic health systems, so patients will be willing to share sensitive health
9 information with physicians and other health professionals, and use electronic systems and data
10 exchanges.

11 3. The collection of our phone records by the government has (1) discouraged new
12 members, constituents, media, whistleblowers, and consumers from calling our office phone line to
13 seek information, help, and advice when their sensitive health information has been used or
14 disclosed; or discussing sensitive legal actions concerning corporate, state or federal government
15 violations of privacy; and (2) discouraged phone conversations with experts from other advocacy
16 organizations about collaborative efforts to hold industry or government accountable for privacy
17 health privacy violations, or to plan legal interventions at the state or federal level. The lack of
18 private phone calls has diminished the willingness of consumers, the media, members, and
19 whistleblowers to call PPR, creating a ‘chilling’ effect on key consumer services PPR offers, on
20 users’ and members’ associational rights, on whistleblowers willingness to speak, and on
21 collaborative advocacy efforts with other privacy and consumer organizations and experts and
22 actions such as lawsuits and campaigns to protect citizens’ rights to health information privacy.

23 4. I say this because of the following facts:

24 Patient Privacy Rights’ office line has been a key resource for consumers, members, the
25 media, and whistleblowers since 2006. Although our website offers resources and information,
26 phone calls are essential for discussion of sensitive matters concerning hidden use, disclosure, and
27 sale of the nation’s personal health information. PPR is a subscriber of Time Warner.

1 5. The Associational Tracking Program activities have harmed PPR because we have
2 experienced a decrease in communications from whistleblowers, members and users who would
3 have requested that their communications with Plaintiff remain secret.

4 6. PPR experienced a decrease in calls to our office phone line during the summer. For
5 example, prior to the revelations of NSA tracking, we received on average 40 calls per month. After
6 the NSA revelations became public, we received on average only 20 calls per month.

7 7. The NSA revelations have caused heightened attention to health data security
8 breaches and requests for help and resources to deal with breaches, but nevertheless have resulted in
9 a decrease in whistleblower calls. Since September, more people have expressed concerns to us
10 about health information security breaches.

11 8. Since the disclosure of the Associational Tracking Program, we can no longer assure
12 our members and constituents, as well as all others who seek to communicate with us, that their
13 communications to and with us can be kept confidential.

14 9. We make strong assurances of confidentiality of information shared with PPR in our
15 privacy policy, but clearly in light of NSA tracking, those assurances were false.

16 10. Moreover, the pattern of distortion and lawless conduct by the NSA, exacerbated by
17 the intense secrecy of its activities, have left us unable to reassure our members and the public that
18 additional forms of surveillance, as yet unconfirmed or actively denied by the government are not
19 also occurring, leaving us with no alternative forms of confidential communication.

20 11. Patient Privacy Rights works to protect the public's fundamental Constitutional, state
21 and federal rights to health information privacy. We work to inform the public about how the
22 healthcare industry and government violate patients' rights to health information privacy. We offer
23 technical and legal solutions to enable the benefits of technology while eliminating current
24 technology-caused harm from hidden health data surveillance, collection, disclosure, sale, and
25 misuse. 40-50 million patients per year delay or avoid essential treatment or hide information to try
26 and protect the privacy of their health data because they know health data is used to damage
27 reputations, jobs, credit, and more. The lack of health information privacy causes bad health

1 outcomes. At the same time, patients cannot obtain electronic copies of health data or obtain a
2 ‘chain of custody’ to track the hidden flows of their health information. *See* theDataMap.org¹, a
3 project PPR supports to map the hidden flows of health data inside and outside the US. As the
4 nation’s leading health privacy advocacy organization, PPR has over 20,000 members in all 50
5 states. PPR leads the bipartisan Coalition for Patient Privacy, representing 10.3 million US citizens
6 who want to control the use of personal health data in electronic systems. In 2007-2008, PPR led
7 development of the PPR Trust Framework, 75+ auditable criteria² to measure how effectively
8 technology systems protect data privacy. The Framework can be used for research about privacy
9 and to certify health IT systems. Since 2011, PPR has convened the ‘International Summits on the
10 Future of Health Privacy’,³ co-hosted by Georgetown Law Center. In 2012, PPR proposed a 5-year
11 plan to move the US health IT system from institutional to patient control over health data in
12 *Information Privacy in the Evolving Healthcare Environment*.⁴ As a privacy organization, PPR tries
13 to hold itself to the highest privacy standards and practices. PPR promised users and members that
14 any information shared with PPR would remain private. Our online privacy policy states, “We do
15 not share, sell, rent, or lease your email address or any personal information. EVER.” The
16 revelations that the NSA collects and stores all phone calls and metadata violates PPR’s members’
17 and users’ expectations that their phone conversations with our staff were private and would not be
18 disclosed.

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25 ¹ theDataMap.org

26 ² <http://patientprivacyrights.org/wp-content/uploads/2013/04/%C2%A9-2010-to-2013-PPRs-Trust-Framework-Brief-Summary-and-Auditable-Criteria.pdf>

27 ³ <http://www.healthprivacy-summitl.org/events/2013-health-privacy-summit/event-summary-1bfa9be80d364092aead1a8803377fa8.aspx>.

28 ⁴ <http://ebooks.himss.org/product/information-privacy-in-evolving-healthcare-environment44808>.

1 12. Specifically, the key consequences of NSA surveillance on the public and Plaintiff's
2 members are:

3 a. Phone and email surveillance has made whistleblowers afraid to report government
4 and industry health privacy violations to PPR because all calls, metadata, and emails are being
5 collected and stored by NSA.

6 b. Knowledge that telephonic communications are monitored has forced our employees
7 and members to restrict what they say over the telephone about privacy violations, legal advocacy,
8 and work related to litigation or legal defense committees.

9 c. NSA surveillance forces us to convene in-person meetings to discuss sensitive
10 matters. This is very difficult for PPR because our office is in Austin, Texas and we serve the entire
11 country. PPR must rely more on more time-consuming and costly face-to-face meetings or attempt
12 to find and purchase technology so we can hold private conversations.

13 d. PPR must revise its privacy policy.

14 e. PPR must advise callers that phone calls and metadata are not secure, ask for limited
15 information and ensure timely deletion of any notes of the calls.

16 f. PPR's effectiveness and credibility depend on being able to interview people with
17 direct knowledge of violations of health information privacy rights, including victims, witnesses,
18 perpetrators, whistleblowers, or knowledgeable bystanders such as government officials or industry
19 employees, other advocacy organizations, and lawyers and other civil society partners. PPR is
20 concerned that many of these parties will fear contacting our office knowing that the NSA logs all
21 calls and metadata.

22 I declare under penalty of perjury under the laws of the United States of America that the
23 foregoing is true and correct. Executed on October 29, 2013, at Austin, Texas.

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27 DEBORAH C. PEEL MD