

**Appendix 6 – Patient Privacy Rights’ Application for *cy pres* Funds in *In Re: Google Buzz Privacy Litigation* (submitted to the Rose Foundation Mar. 14, 2011)**

**Application Coversheet**

1. Name of Applicant Organization and EIN Number

Patient Privacy Rights; EIN: 41-2131513

Type of organization:  501c(3)  Other - Please describe: \_\_\_\_\_

2. Contact Information:

Contact Person, Title Deborah C. Peel, MD, Founder and Chairman

Address PO Box 248

Austin, Texas 78767

Telephone 512-732-0033

Email dpeel@patientprivacyrights.org

3. Financial Information:

- (a) your organization’s overall annual 2011 operating budget

\$130,000.00 (+\$287,000 in kind) = \$417,000.00. For 2009: \$218,000 (+\$294 in kind) = \$512,000

- (b) total amount of money spent on Internet privacy or Internet education programs in 2010

\$115,819.00 (annual cash budget). For 2009: \$188,081 (annual cash budget).

- (c) total amount of funding your organization received, if any, in contributions from Google,

Inc. or the Google Foundation in 2010

None

- (d) amount of funding you are requesting from this Settlement fund

\$643,000.00 to be used over a 3 year period

***For questions 4 & 5, you may submit a narrative response up to 4 pages, BUT YOU MUST submit a brief description of no more than one paragraph. The coversheet must fit on one page.***

For six years, Patient Privacy Rights (PPR) has worked tirelessly to protect patient privacy and ensure patients have the right to control their personal health information, which is especially critical now that individuals’ sensitive health data is searchable and accessible online and via social media outlets, such as Google Buzz. Even though increased participation in online health platforms may put everyone’s privacy at risk, there is no other organization solely dedicated to studying Internet health privacy issues and effectively educating the public about the consequences of the loss of privacy protections and the need for solutions. We believe PPR has the potential to build and develop the world’s leading brain trust for Internet health privacy. To broaden the visibility of Internet privacy issues related to the widespread implementation of health information technology, PPR requests funding over the next three years to help expand its existing programs and help launch an innovative educational and policy program: the First International Summit on the Future of Health Privacy. The summit will be the first open public forum to successfully address the important health privacy issues that confront us in an increasingly connected world.

## **Narrative Responses for Questions 4 & 5**

4. Briefly describe any of your organization’s existing policy or education programs concerning Internet privacy issues – make sure to include the number of years you have had programming focused on Internet privacy.

According to Google and Bing, PPR is the top Internet resource for gathering information about patient privacy.

### **1. Existing Internet Privacy Education Programs**

- a. **Member/Public Outreach Program.** We consistently engage our members and the public on pressing Internet privacy issues. We provide numerous ways for consumers to educate themselves through our website, email alerts, and regularly occurring updates. Additionally, we engage our 12,000 members, more than 50 organizations in the bipartisan Coalition for Patient Privacy (founded by PPR), and our data base of over 3,000 specific journalists and media outlets through website access and the opportunity to offer input on a variety of Internet privacy issues. [6 years]
- b. **Online Privacy Destination Website:** [www.patientprivacyrights.org](http://www.patientprivacyrights.org) [6 years]
- i. Patient Privacy Toolkit: Offers downloadable forms and brochures that provide helpful privacy protection information for patients. [3 years]
  - ii. Personal Health Record Privacy Report Card: Informs consumers about the levels of privacy offered by different Personal Health Record companies on the Internet. [2 years]
  - iii. Privacy Risk Calculator: Helps consumers identify if their personal health privacy is at risk. [1 year]
  - iv. PPR/Zogby Privacy Poll: Identifies the public’s views on privacy, access to health information, and health information technology. [1 year]
  - v. Online English multi-media library—Supplies a rich collection of health privacy news and information. [6 years]
- c. **Bipartisan Coalition for Patient Privacy** [5 years]
- i. Privacy Principles Program: Educates consumers about our clear list of Internet health privacy principles, which standards for privacy-related legislation in Congress. The principles are updated periodically by the bipartisan Coalition for Patient Privacy. [5 years]
  - ii. Consistently recruits organizations and corporations that support restoring patient control over personal health data. [5 years]
  - iii. “Do Not Disclose” Campaign: Encourages individuals to join PPR in petitioning Congress to give patients control over health information in electronic systems. [2 years]
- d. **Privacy Speakers’ Bureau** [6 years]. We educate the public at numerous regional, state, national, and international conferences and events (details available upon request, or on our website, [www.patientprivacyrights.org](http://www.patientprivacyrights.org)). Events include, but are not limited to, industry conferences, major (health care?) provider and “think tank” conferences and events, Congressional testimony and briefings,
- i. Congressional testimony and briefings
  - ii. Federal testimony and events
  - iii. State legislatures (limited)
  - iv. Industry conferences
  - v. Major healthcare provider and ‘think tank’ conferences and events
  - vi. National consumer and advocacy organization conferences
  - vii. ABA and IBA conferences
  - viii. Privacy and consumer advocacy conferences
  - ix. Conferences at academic institutions

- e. **Media Inquiry Response Program.** We have developed a rapid response structure to address inquiries, inaccuracies, and misinformation about health privacy online. [6 years]

**2. Existing Privacy Policy Programs~**

- a. **Policy Monitoring Program.** We monitor state, federal, and international developments in Internet and health privacy policy. [6 years]

- i. Follow state hearings and proposed regulations (limited) [6 years]
- ii. Follow federal agency hearings and proposed regulations [6 years]
- iii. Follow Congressional hearings and review proposed and existing legislation [6 years]
- iv. Follow and review state and federal court decisions [6 years]
- v. Follow international developments in law and EU Data Directives (limited) [6 years]

- b. **Policy Response Program.** While our work at the federal level is currently well-developed, our state and international programs are at an earlier stage of growth. [6 years]

- i. Provide comments on state agency hearings and regulations (limited) [6 years]
- ii. Provide comments on federal agency hearings strategic plans, and regulations [6 years]
- iii. Provide comments on Congressional legislation and proposed drafts; work with Congressional bill sponsors [6 years]
- iv. Publicize and follow with opportunities to sign-on to letters of comment to the members of the bipartisan Coalition for Patient Privacy [6 years]
- v. Provide friend-of-court briefing expertise on health privacy legal issues [3 years]
- vi. Respond to key state, federal, and Supreme Court decisions by joining amici [5 years]
- vii. Publicize opportunities to sign-onto efforts to the members of the bipartisan Coalition for Patient Privacy [5 years]

**c. Policy Proposals and Formulation [6 years]:**

- i. Continue to develop policy with the Coalition for Patient Privacy and actively promote our privacy positions on Congressional, agency, and court decisions to the public and media.
- ii. Issue press releases, hold briefings for Congress and the media.

5. Briefly describe the particular program that funding from this Settlement would support and describe how it would benefit the Class by furthering policy or education concerning Internet privacy.

Consistent with current and anticipated funding for 2011, we expect to continue all programs as outlined above. Google Buzz cy pres funding would be used to support and expand existing operations and programs, as well as launch a critical new educational and policy program, the First International Summit on the Future of Health Privacy.

The Class, like the general public, commonly uses online tools and websites to seek information and communicate about their health. Individuals often use social media platforms to manage and collect information about their personal health, but they may not fully realize there are potential harmful results, such as job loss and credit discrimination, that can result from the absence of certain Internet privacy protections. PPR creates a counterpoint to corporations that seek to persuade everyone to share more personal information online without effective and necessary privacy protections. Without the safeguards and check points PPR recommends for health information, it's easy to see that health privacy can be easily violated. Our goal is to help the public understand the limitations of current technology and privacy laws and help restore the protections users expect in their online communications.

In order to achieve our goals, we plan to:

**1. Add a New Educational and Policy Program: the First International Summit on the Future of Health Privacy. Requested funding \$155,000.**

- a. In an effort to frame and influence the policy debate and emerging norms around health data privacy, PPR and the University of Texas' Lyndon B. Johnson School of Public Affairs have partnered to develop a Summit

entitled "The Patient's Right to Privacy: Does Health IT Have a Future Without It?" The Summit will take place at the Georgetown Law Center in Washington, DC on June 13, 2011, and will bring together key stakeholders, explicitly including patient and consumer voices, for an open and informed public forum on the future of health privacy in the Digital Age. There has been no public forum focused on education and debate about Internet health privacy challenges and solutions. PPR and the UT LBJ School of Public Affairs are ideal partners to convene a truly public forum. Computers, Freedom and Privacy will hold their annual conference June 14-16, 2011 in Washington, DC; they have designated the Summit as the official pre-conference meeting for their event. Beta summit website: <http://www.utexas.edu/lbj/healthprivacy>

- b. We expect to have 250 attendees listen to national and international experts, moderated panels, and key lawmakers lay out urgent issues and challenges, then participate in breakout groups to identify and prioritize key privacy issues and an agenda going forward.
- c. Expected summit outcomes include:
  - i. The development of a network/brain trust of health and Internet privacy experts.
  - ii. The identification of solutions -- policies, business practices, and technologies -- that encourage the legitimate access, use, and control of personal health information.
  - iii. Work groups to reconvene throughout the year on key issues.
  - iv. The publication of a summary of sessions and the actions they called for as a resource for the public, the media, policymakers, and industry.
  - v. Summit proceedings and video.
  - vi. A recommended strategy of next steps for the United States on how to make health privacy a reality.
  - vii. Explore plans for the next summit.
- d. The outcome of this meeting is critically important for state and federal policymakers who are working to develop America's future health information infrastructures and exchanges. The Summit will also be invaluable for health care consumers, who are eager to understand and be involved in what options they have for protecting their personal information. The Summit is of particular relevance to the youngest generation of consumers, who have grown up with the Internet, are assumed to have different conceptions of privacy than adults, and whose entire health histories will become digitally available to more and more people in an increasingly connected world. Funding would be used for staffing, travel, communication, and publications.

## 2. ***Expand and Update Existing Internet Privacy Education Programs~***

- a. ***Expand Member/Public Outreach Program.*** Our goal is to increase PPR membership from 12,000 to 24,000 members in Year 1, then increase those numbers by an additional 25,000 for the two subsequent years. Additionally, we intend to increase our PPR data base of reporters, journalists, and media groups from 3,000 to 5,000 over the following 2 years.
- b. ***Expand Bipartisan Coalition for Patient Privacy Membership.*** We would like to increase the Coalition's membership from its current 50 member base of organizations to 100 over the next 3 years.
- c. ***Update and Expand Online Outreach***
  - i. Privacy Principles Program: Evaluate and develop new key privacy principles with the bipartisan Coalition for Patient Privacy in light of evolving information regarding industry practices and technology developments.
  - ii. Review and update Patient Privacy Toolkit, Personal Health Record Privacy Report Card and Privacy Risk Calculator.
  - iii. Repeat PPR/Zogby Privacy Poll.
  - iv. Hire a Director to manage and expand English multi-media library of health privacy news and information so that it includes an increasing number of key health privacy documents and white papers, video presentations from leading experts on health privacy, and relevant speeches from Congress and the Administration.
  - v. Add a Director of new social media to improve communications outreach.

- d. **Formally create and oversee a Privacy Speakers' Bureau. Focus on providing speakers to more consumer organization conferences, academic institutions, state legislatures, and international institutions and conferences.**

### **3. Expand Privacy Policy Programs~**

#### **a. Expand Policy Monitoring Program**

- i. Oversight of State hearings and regulations—Add staff to develop and disseminate consent and privacy expertise urgently needed as states receive significant funding to exchange health data online. This will help counteract the tendency of new programs to eliminate or reduce state privacy protections.
- ii. Oversight of Federal agency hearings and review of proposed regulations—Add technical and policy staff to monitor and analyze all federal agencies and advisory committees. Consumer analysts and technical experts are in short supply compared to industry experts.
- iii. Oversight of Congressional hearings and legislation reviews—Add staff in DC to attend all hearings.
- iv. Oversight of State and Federal court decisions—Add expertise by hiring part time legal expertise
- v. Contribute US public perspective to International developments in law and EU Data Directives—Add funds for staff travel to key EU conferences and forums.

#### **b. Expand Policy Response Program**

- i. Provide comments on state agency hearings and regulations – Add staff to offer expertise on state Health Information Exchange (HIE) and consent issues and laws, and develop a new online sub-site for state resource materials.
- ii. Provide comments on federal agency hearings strategic plans, and regulations – Add part time DC policy analyst to attend all hearings and travel funds to allow existing staff to travel to DC more often.
- iii. Provide comments on Congressional legislation and proposed drafts, work with Congressional bill sponsors---Add part time DC staff and travel funds for existing staff.
- iv. Publicize opportunities to sign-onto letters of comment to the members of the bipartisan Coalition for Patient Privacy--- DC staff could work closely with existing coalition member organizations, as well as work to expand the coalition.
- v. Continue to support friend-of-the court briefs on health privacy as requested when consistent with mission.
- vi. Respond to key state, federal, and Supreme Court decisions by joining amici--add expertise via hiring PT legal expertise.
- vii. Publicize opportunities to sign-onto efforts to the members of the bipartisan Coalition for Patient Privacy ---PT DC staff could work closely with existing coalition member organizations and to expand the coalition.

#### **c. Expand Media Policy Outreach**

- i. Hire a Director of Media to promote coalition privacy positions on Congressional and agency decisions and court decisions and send press releases about letters of comment and amici and expand Media Policy Inquiry Response Program.