## EMBARGOED FOR RELEASE UNTIL10:30 A.M. EST, OCTOBER 18, 2007

CONTACT:
Ashley Katz
Patient Privacy Rights
(512) 732-033 or (512) 897-6390
akatz@patientprivacyrights.org
www.patientprivacyrights.org

## 47 State & National Organizations, Health IT Companies Join Forces to Demand Consumers Regain Control of their Personal Health Records.

The Tipping Point for Health IT is not about funding or even bureaucracy: it's about PATIENTS trusting that their most personal information will be protected.

Washington, DC – The bi-partisan Coalition for Patient Privacy is back on the steps of the Capitol urging Congress to restore basic privacy protections; only this year they have doubled their membership and included health IT corporations, big and small. As everyone races to build electronic health records systems without ironclad federal privacy protections, the ACLU, AIDS Action, the American Association for People with Disabilities, American Conservative Union, Family Research Council, Patient Privacy Rights, Consumer Action, Microsoft Corp., Inc. and many more ask Congress to step to the plate and set national privacy standards. Three-fourths of the American public want Congress, not unelected bureaucrats or the whims of the market, to ensure our right to health privacy is protected in electronic systems and yet we still have no Federal statutory right to health privacy.

Read the Coalition for Patient Privacy's letter (link).

The letter to Congress will be revealed at a press conference Thursday, October 18, 2007 at 10:00 a.m. EST in the Rayburn House Office Building, Room 2456. "Today the Coalition for Patient Privacy has transformed the debate on privacy and health IT: a major multinational technology corporation, Microsoft, has joined the American people in urging Congress to build ironclad privacy protections into electronic health systems up front" said Dr. Deborah Peel, Founder of Patient Privacy Rights. "The false arguments that consumer control of access to health information is too expensive or will obstruct the flow of health information have been laid to rest. Privacy--every American's right to control access to personal health information---is the key to building a successful electronic health system."

Congressman Edward J. Markey will join the Coalition as they advocate for strong privacy protections at the press conference. "The great Irish poet William Butler Yeats once wisely observed, 'In dreams begins responsibility.' The dream of a nationwide, seamless,

effective health IT system is enticing. Let us hope that we can realize this dream. But today Congress has a responsibility to ensure that patients' personal medical secrets are not put at risk in the process. If we fail to build in tough privacy principles and strict safeguards, we run the risk that the dream of health IT will turn into a nightmare. I look forward to working with my colleagues in Congress, and privacy leaders such as Dr. Peel, to craft legislation that both promotes the use of health IT while also preserving patient privacy," said Representative Ed Markey (D-MA), a Co-Chairman of the House Privacy Caucus.

Frank Torres, Director of Consumer Affairs, Microsoft added: "Microsoft joins the Coalition for Patient Privacy in urging Congress to include basic privacy protections for electronic health records in any health IT bill it considers. Such protections are needed to ensure the creation of a health IT eco-system that consumers can trust. We can empower people to lead healthy lives, while putting them at the center and in control of their health information."

The letter is being released at a crucial time as the Senate and House are preparing to consider legislation that will establish an Electronic Health Information Network. The Wired for Health Care Quality Act (S. 1693) pending in the Senate provides for a national electronic health information system and does <u>not</u> recognize or protect Americans' right to health privacy. In fact, the bill authorizes the Secretary of Health and Human Services to issue standards eliminating the individual's right to health privacy without even providing an opportunity for public comment.

"Medical care is one of the most intimate, personal services in every individual's life. It is an art form requiring complete honesty and absolute confidence in the good intentions and discretion of the attending physician. Infringements on that relationship are among the most destructive things the state can possibly do to its citizens," said William Westmiller, National Chairman, Republican Liberty Caucus. "Every patient has a right to absolute privacy and totally confidential treatment, just as fundamental as the right to their own life," Westmiller said.

Despite the intent of the Health Insurance Portability and Accountability Act (HIPAA) and its "Privacy Rule", the current regulations leave all Americans' personal health information completely vulnerable and exposed. State laws, common laws and the Constitution are there for protection. Yet the HIPAA "Privacy Rule" is really a "Disclosure Rule" that authorizes more than 4 million entities to use and disclose an individual's health information. This disclosure is without the individual's consent and over their objections. "All Americans have a right to privacy, and that right doesn't stop at the doctor's office door. Medical privacy is a mystery to most Americans. After signing their HIPAA forms, most Americans don't think about what happens to their information, and worse, most would be shocked to know that their most

personal information is not as safe as they would hope. Congress must ensure that Americans' medical information will not be used without their consent and that their privacy rights will not be trampled, whether their health information is kept on paper or electronically" said Michael W. Macleod-Ball, American Civil Liberties Chief Legislative and Policy Counsel.

"If Congress is going to force health IT on the American people with their foolish mandates, subsidies and grants, then at the very least there needs to be privacy protections included as well as the ability for sane citizens to opt out," added the National Director for the Liberty Coalition, Michael Ostrolenk.

As we move toward one of the most important elections in the nation's history, all Americans should ask political candidates a simple question: 'Do you believe we as Americans have a right to health information privacy, and if so, do you believe that right should be recognized and protected in any national electronic health information system?' "This is not a partisan issue: the right to health information privacy is a fundamental right of all Americans recognized in Constitutional law, standards for the ethical practice of medicine and the physician-patient privilege. The voters should know where the candidates stand on this critical issue," said Jim Pyles, Principal in health law firm of Powers, Pyles, Sutter & Verville, P. C..

The Coalition for Patient Privacy first formed in 2006 and represents millions of Americans. Dr. Peel leads the Coalition and is the founder of Patient Privacy Rights, a national consumer health privacy watchdog organization based in Austin, TX.

## **Background Material**

The elimination of consent for health records

2006 activity by the Coalition for Patient Privacy

The millions of individuals and entities who legally have rights to your personal information

## The Coalition for Patient Privacy includes:

**AIDS Action** 

American Association of People with Disabilities

American Association of Practicing Psychiatrists

American Chiropractic Association

American Civil Liberties Union

American Conservative Union

American Psychoanalytic Association

Association of American Physicians and Surgeons

Bazelon Center for Mental Health Law

Bob Barr (former Congressman R-GA)

Citizens for Health

Citizen Outreach Project

Clinical Social Work Association

Consumer Action

Consumers for Health Care Choices

Cyber Privacy Project

Doctors for Open Government

Ethics in Government Group

Fairfax County Privacy Council

Family Research Council

Free Congress Foundation

Georgians for Open Government

Gun Owners of America

Health Administration Responsibility Project, Inc.

The Liberty Coalition

The Multiracial Activist

Microsoft Corporation, Inc.

The National Center for Transgender Equality

The National Coalition for Mental Health

Professionals and Consumers National Whistleblower Center The Natural Solutions Foundation

The New Grady Coalition

Pain Relief Network
Patient Privacy Rights Foundation

Privacy Activism

Privacy Rights Now Coalition

Private Citizen, Inc.

Just Health (California Consumer Health Care Council)

Republican Liberty Caucus

The Student Health Integrity Project (SHIP)

TexPIRG

Thoughtful House Center for Autism

Tolven, Inc.

Tradition, Family, Property, Inc.

Universata, Inc.

U.S. Bill of Rights Foundation

You Take Control, Inc.