

## Privacy and Confidentiality: Where have we been? Where are we going?

---

P.Pearl O'Rourke, M.D.  
Partners HealthCare Systems  
Boston, MA.

## Privacy and Confidentiality

---

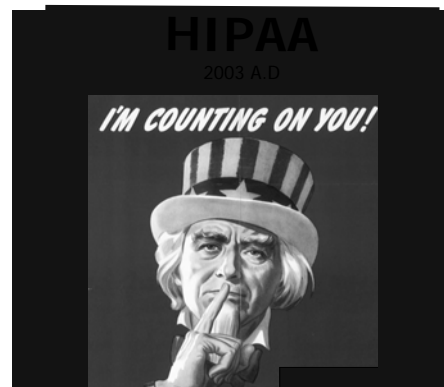
# HIPPOCRATES

## HIPPOCRATIC Oath

---

400 B.C.

"What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about."



## Responses to HIPAA

---

- Researchers:
  - I can no longer do clinical research
  - These regulations are killing me
  - What were they thinking?
- Patients:
  - It is still the status quo – I don't see any more protection
  - What were they thinking?

## So what are the facts?

---

- Balance between individual rights and public good
- Individuals' desire to have their information treated with respect and confidentiality
- Researchers' desire to be able to access info

**FACT:**

### Doctors need patient's full disclosure

---

- Optimal medical care requires honest and open communication between patients and physicians
- Patients who withhold information – or give incorrect information may receive inferior medical care
  - How often do you floss?

**FACT:**

### Patients demand privacy protection

---

- Patients trust that their information stops with their doctor
  - Not if your doctor uses the elevator!!!
- Patients often do not understand how their information is used in their care
  - Why do so many people handle my information?

**FACT?**

### My information stops with my Doctor.....right?

---

Medical Marketing Service advertises a database available...that includes the names of 4.3 million people with allergies; 923,000 with bladder control problems; and 380,000 who suffer from clinical depression ([www.mmlists.com](http://www.mmlists.com))

The 13-year-old daughter of a hospital employee took a list of patients' names and phone numbers from the hospital when visiting her mother at work. As a joke, she contacted patients and told them that they had been diagnosed with HIV. Wash.Post March 1, 1995, p A17

**FACT?**

### Computer technology provides excellent privacy protection

Eli Lilly inadvertently revealed over 600 patient e-mail addresses of those receiving reminders to take their Prozac (NYT, Jan 19, 2002, p. C3)

About 400 pages of detailed psychological records concerning visits and diagnoses of at least 62 children were accidentally posed on the University of Montana website (LA Times, Nov. 7, 2001, p. A1)

A doctor's laptop was stolen at a medical conference. The computer contained the names and medical histories of his patients. (Wash Post, Nov. 5, 2000, p. A1)

**Fact:**

### Patients want us to use their data

Mayo Clinic – 96% of 214,000 patients agreed to have their medical records accessible for research

J.Fam.Prac. 1998;47:361-5

**Fact:**

### Patients want us to use their data

Equifax-Harris Consumer Privacy Survey – 1996 – 1,005 adults

- 60% willing to provide criminal records (60%) vs 40% willing to provide medical records
- Use of medical info for research – assuming consent not feasible AND info would be kept confidential
  - **31% - NEVER ACCEPTABLE**
  - **39% - somewhat acceptable**
  - **18% - OK**

Fact:

## Patients want us to use their data

106 patients in doctors' offices

Opt-in or opt-out preference for consent:

28 (26%) – satisfied with passive notification  
and ability to opt-out at any time

78 (74%) – wanted opportunity to provide  
consent first

What should be in the consent?

57% wanted specific information

BMJ 2003;326:373

Fact:

## Patients want us to use their data

602 persons with serious genetic or other chronic  
medical condition asked:

"Medical researchers should be able to get  
my medical records without my permission  
if it will help them to do research that will  
advance medical knowledge."

- **31.1% agree**
- **13.6% neutral**
- **55.4% disagree**

J. Law, Med&Ethics 2003;31:429-33

## Need for TRUST

- System of privacy protections
- Review of all research
- Shadenfreude
- The simple lure of titillating information

## SCHADENFREUDE

SHAD-n-froy-duh

A malicious satisfaction in the misfortunes  
of others

## SCHADENFREUDE

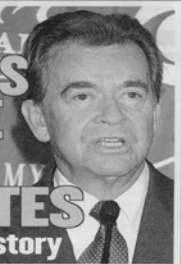
SHAD-n-froy-duh

A malicious satisfaction in the misfortunes  
of others

## The GLOBE

May 3, 2004

- Single issue literature review
- Exempt research



## DICK CLARK'S BATTLE WITH DIABETES - the inside story

**O**LD AGE may finally be catching up to America's oldest teenager - Dick Clark has revealed that he's developed diabetes.

Sources say the legendary 74-year-old producer and entertainer has kept his secret for a decade.

The smiling face behind TV's American Bandstand has Type-2 diabetes and has battled the disease for about

organs - particularly the heart, kidneys and eyes.

"Diabetes is a leading cause of heart attacks," says Dr. Rizza, who has not treated Clark. "you need to take care of yourself in order to manage the disease."

"It seems that Mr. Clark is lean and fit for his age, so obesity may not be a factor in his case. As we age, our pancreas sometimes can't handle the job and



"He says he wants utter privacy in death - just as he's demanded in life."

The Godfather star has been suffering from congestive heart failure. Once tipping the scales at nearly 400 pounds, he now weighs about 265, uses a wheelchair to get around and relies on an oxygen tank to help him breathe. He's had other heart problems and just last year was diagnosed with hepatitis C.

Along with his physical woes, Brando is also still despondent over the death of his daughter Cheyenne. She hanged herself in 1995, a few years after her half brother Christian shot to death Dag Drollet, her fiancé and father of her baby.

For a while, Brando talked about having his Hollywood Hills home sealed off after he died, entombing him with his possessions like an Egyptian pharaoh. But that idea didn't sit well with the authorities, not

• Kelly Ripa's son had to be treated by a plastic surgeon after gnashing his head at school...the wound needed stitches...three on the outside and four on the inside."

## KELLY RIPA'S NIGHTMARE

### Son injured in freak accident

KELLY RIPA's son had to be treated by a plastic surgeon after gnashing his head at school.

The Livel co-host and her soap star hubby Mark Conmusio took no chances after a school nurse first treated little Michael, 6, following his fall in the enclosed rooftop playground.

"They have playtime on the roof, and he ran and he fell," says Kelly, who was called to the school immediately after the April 15 accident.

She and Mark arrived in the nurse's office to see that Michael had a Band-Aid covering the injury. Reveals Kelly, "I know he must be fine because he says, 'Can we get a toy after this?'"

Still, she decided to call Michael's doctor. She adds, "Our pediatrician says that since it's on the face you have to go get plastic surgery."

Mom-of-three Kelly says it was just as well, because the wound needed stitches. "He had three on the outside and four

33-year-old stunner told Livel viewers couldn't resist the opportunity about getting some work done on while they were there.

On the drive across town to the co-surgeon's Manhattan office, she says Mark, "I'll have a little freshen up in there."

As the doc was examining Michael



## GLOBE EXTRA Robert Pastorelli

# MURPHY BROWN STAR'S OFFICIAL AUTOPSY REPORT

ACTOR Robert Pastorelli's autopsy disclosed a bombshell revelation - the 50-year-old star was missing organs - indicating he may have been secretly suffering from an incurable disease, say experts.

The Los Angeles County coroner's report concludes that the 49-year-old star, who played longtime doctor Elton on Murphy Brown, died from an accidental drug overdose, but it also reveals his gallbladder, spleen, appendix and parts of his small and large intestines were missing.

Pastorelli's business manager Carlos Mangera told investigators the actor's medical history included three-decades of hepatitis B and a long-standing gastrointestinal problem for which he was operated on two years ago.

Famed forensic pathologist Dr. Cyril Wecht, coroner of Allegheny County, Pa., reviewed the report and told GLOBE the actor was "suffering from the incurable Crohn's disease."

"The absence of so much of the digestive tract was unusual for him,"

It's been unclear but had been reported since his girlfriend Charlene Jonovich killed herself in 1989.

Charlene, mother of Gianni, blew her brains out in front of Pastorelli during an argument at his home.


GLOBE previously reported that the L.A. District Attorney's office was considering reopening the case to determine if Pastorelli, who had been raising Gianni, was the shooter.

The autopsy says the 6-foot-2, 198-pound actor's death at his Hollywood Hills home March 8 was due to an accidental overdose of heroin and cocaine.

He was originally found by his personal assistant on the toilet, slumped over, says the official L.A. coroner's report. "She found a syringe in his right arm."

The New Jersey native was fully dressed in black pants, belt, socks, underwear, a white tank top and brown shoes.

On the bathroom sink counter was a sport with dark wood and a




### THE MYSTERY OF HIS MISSING BODY PARTS

## The GLOBE

May 3, 2004

- Actor Robert Pastorelli's autopsy disclosed a bombshell revelation...missing organs - indicating that he may have been secretly suffering from an incurable disease..."
- "...liver destroying Hepatitis B...and incurable Crohn's disease
- Supported by photocopies of the autopsy and toxicology reports

## The GLOBE

May 3, 2004

- Weird Al's parents die from carbon monoxide poisoning
- John Lennon's father had cancer
- Monaco's Princess Caroline once suffered from alopecia
- Nia Vardalos "started undergoing fertility treatments."
- Queen Latifah "looks like she's put on about 20 pounds..."

## **FACTS**

Maintaining confidentiality  
is difficult.

Maintaining the public's  
trust may be even more  
difficult.