

The Patient Story

a

presentation by
Regina Holliday

Johnny Strikes or Giant Strides?

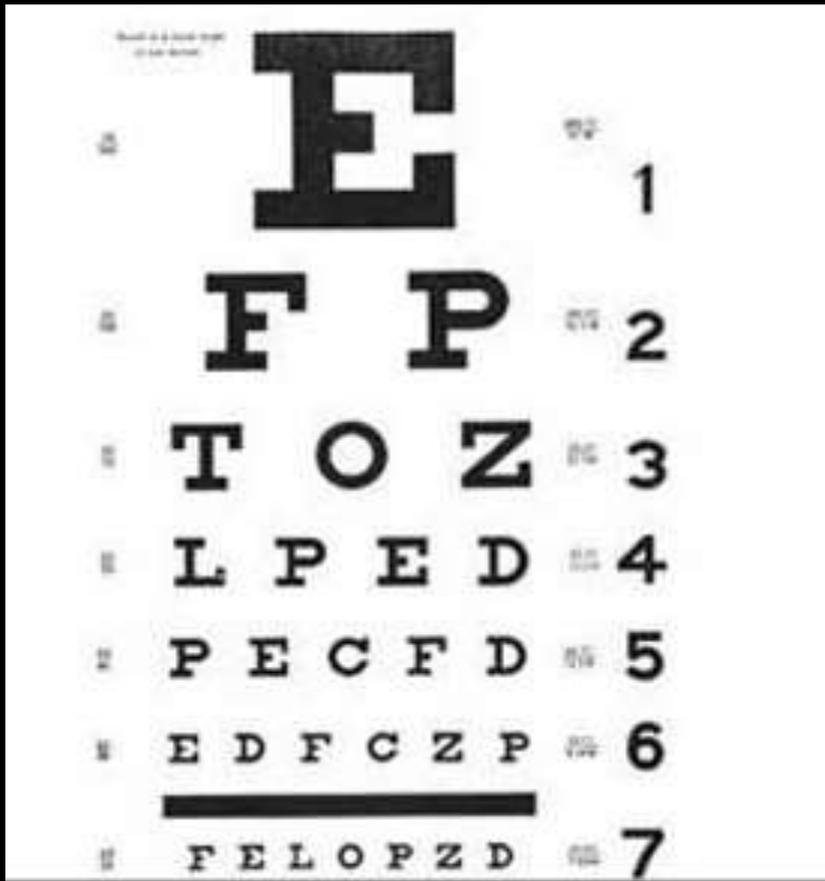




The Writing on the Wall

There was a little boy named Freddie who lived in Maryland and a little girl in Oklahoma named Regina.





Patient Reported Data



Compiled and Printed by
Creek County Guidance
Advisory Board

**Creek County Health
Department**

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When the abuse becomes too bad call this number.



We met in a scenic painting class at Oklahoma State University.

We would talk of Stephen King's Dark Tower.

We would fall in love.

Fred and I married, worked and played together for many years.

Fred continued his schooling and worked as video store clerk.



In 2005,
Fred would get a PhD in film studies
and would write his dissertation

About “Buffy the Vampire Slayer.”

In 1998,
Freddie III joined the family game

followed by
the littlest player Isaac in 2006.

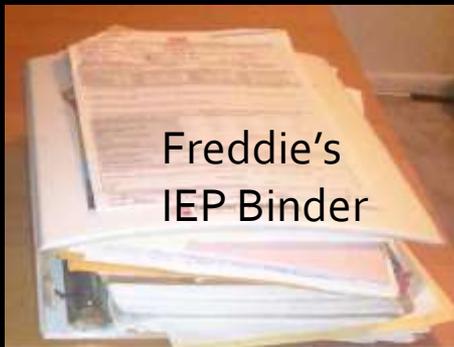
The Holliday Family Christmas 2007



Everything we ever wanted...

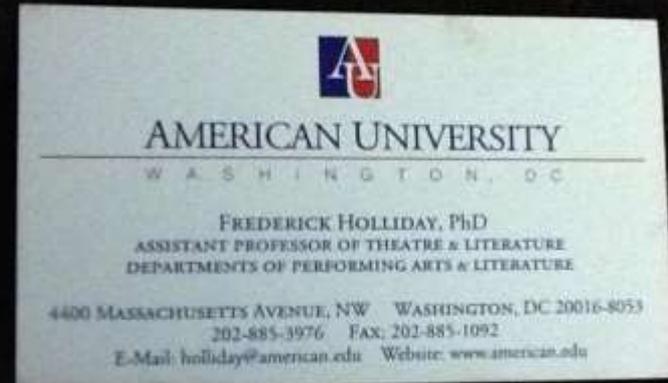
Resolutions January 2008:

1. Get Medical Insurance for the whole family
2. Get little Freddie into a special needs school
3. Fred gets a job in his field
4. Spend more time together as a family
5. Get a two bedroom apartment





Fred was happy with his new job.



But he was very tired,

He went to the doctor and was diagnosed with hypertension.



Frederick Holliday is already tired.

January 5, 2009 at 9:07pm - Comment - Like

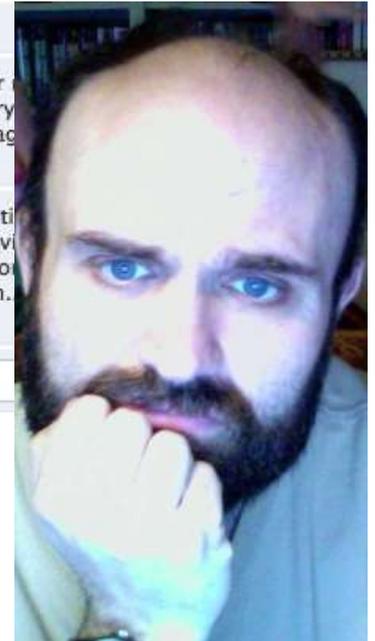
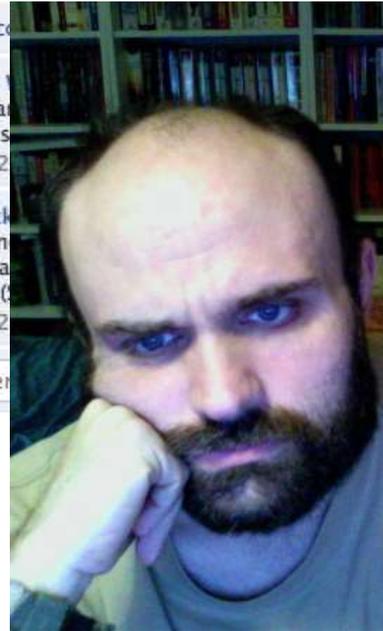
During the months of
January, February and
March of 2009,

Status Lines...



Frederick Holliday went and broke his darn rib! What a maroon!

January 27, 2009 at 5:47pm - Comment - Like



Frederick Holliday is simply giving up and just counting the days until this awful awful month is over.

February 12, 2009 at 5:57pm - Comment - Like



Frederick Holliday thinks grading while suffering severe back pain is no fun!

March 21, 2009 at 9:42am - Comment - Like



On Friday March 13th, We went to the ER because Fred was in so much pain .

We waited three hours before being sent home.

Fred was hospitalized on March 25th 2009
for the administration of tests.



On March 27th, he was told while alone that
he had “tumors and growths.”

He was scared and confused and did not understand.

His oncologist left town for the next four days to a medical
conference and was not reachable by phone or email.



What was the diagnosis? What were the treatment options? Would he get a pain consult?

Systems Error:

More than one bad doctor





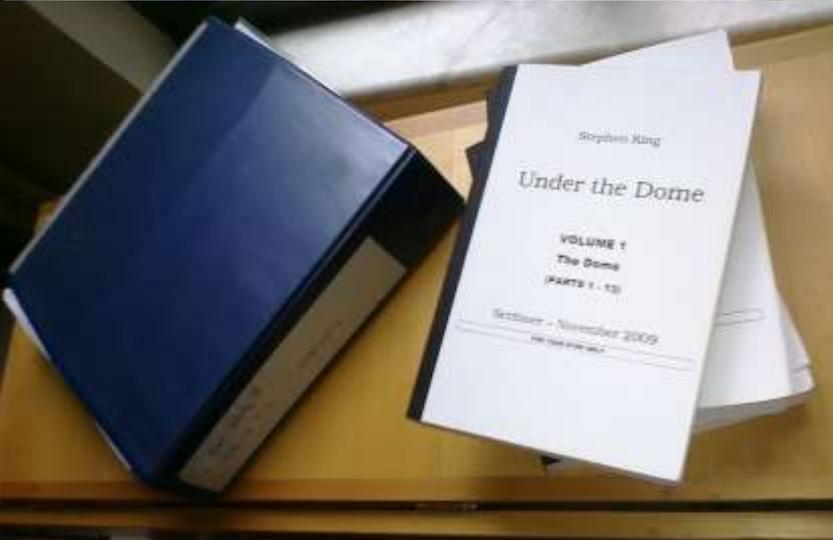
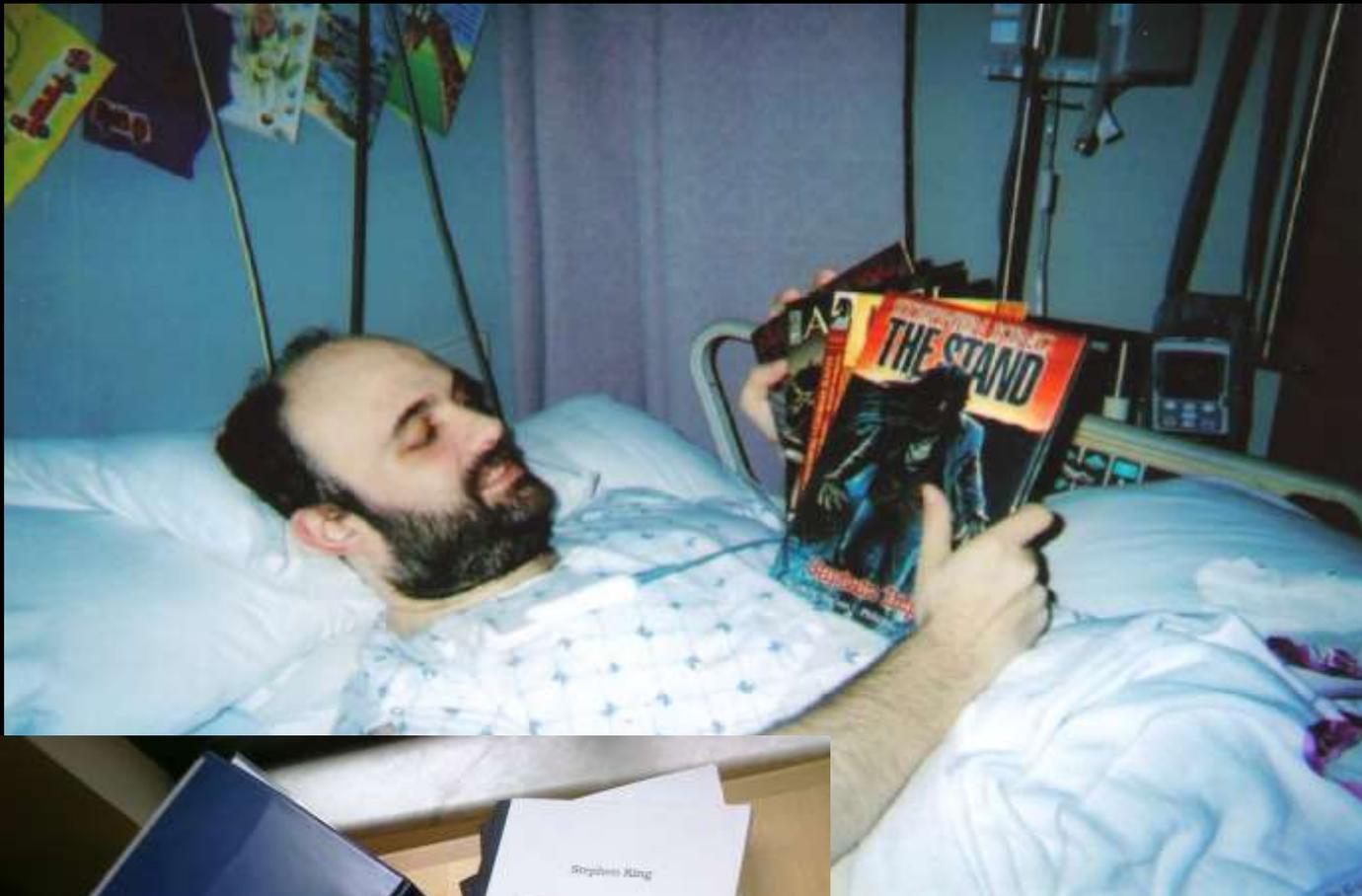
This is my husband's
medical record.

I was told it would cost

73 Cents

per page

And we would have to
wait 21 days to get a copy.



“She must not have tried very hard to get the record.”
Comparing access to an unpublished book by
Stephen King
to accessing the
Electronic Medical Record
while hospitalized.



“Go After Them,
Regina.”

April 18, 2009



After waiting for **5** days for a transfer, we were sent with an out of date and incomplete medical record and transfer summary.

The new staff spent **6** hours trying to cobble together a record using a phone and a fax machine.

This is the **vital clinical information** from Fred's electronic medical record.



Medical Facts

Patient Frederick A. Holliday
 Age 39 years
 Wt. 189 lbs.
 Blood type O+

	Patient Vitals	Daily Normal For Ht/Wt
Blood Pressure	140/73	120/60
Hematocrit	30	38.0-4.0
Hemoglobin	8	12-16
White Blood Cell (WBC)	3	4.3-11
Red Blood Cell(RBC)	3	4.2-5.4
Platelet Count	100,000	150,000-450,000
Temperature	100	98.6
Sodium Level	124	135-145
Pulsox/O2 Sat. Monitor	89	98
Allergies		None

Injuries/Illness

Metastatic Renal Cell Carcinoma, Pathologic Break Left Hip, Pathologic Break Right Third Rib, Bed Bound

Bone Metastasis: Left frontal parietal skull, multiple ribs, lumbar spine L5 and S1, left ischium, left mid femur, sacrum, left femoral neck

Soft Tissue Metastasis: large right and left renal mass with bilateral growth across pelvic region, vena cava thrombosis, bilateral pulmonary nodules, right adrenal gland

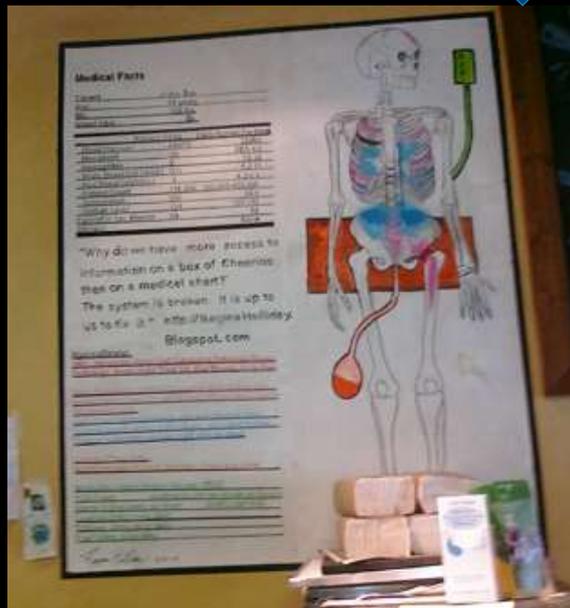
Urology: Place foley

Incontinent/sacral nerve damage: Check every three hours

Medication Administration Record (MAR)

PCA Pump continuous with ten minute on demand
Xanax 0.5mg every six hours 6:00/12:00/18:00/24:00
Lovenox 90mg twice daily 9:00/21:00
Prilosec 20mg once daily 6:00
Paxil 30mg once daily 9:00

Painted on the wall of Pumpernickel's Deli in Washington, DC.



Facebook as a Caring Bridge



Regina Holliday is home from the hospital ...Fred is getting lots of tests.

March 25, 2009 at 10:57pm · [Comment](#) · [Like](#)



Regina Holliday Thanks to everyone for your prayers, kind thoughts, and offers of help. We will let you know what is going on as soon as we know.

March 26, 2009 at 10:34pm · [Comment](#) · [Like](#)



Regina Holliday I am back from the hospital. No news today. seems like there are no test results available on Saturdays....

March 28, 2009 at 7:31pm · [Comment](#) · [Like](#)



Regina Holliday So people are asking questions of how this happened... If you are Facebook friends with Fred you can see posts going back into January about pain. All his posts are funny and light-hearted and there is a lot of banter between friends about how to deal with

April 1, 2009 at 12:38am · [Comment](#) · [Like](#)



Regina Holliday Fred is now on Antibiotics. The pain meds seem to be leaving his system and half the things he says now make sense. Tomorrow we go for the second set of MRI's. Pray for calm thoughts in small spaces.

April 8, 2009 at 10:57pm · [Comment](#) · [Like](#)



Regina Holliday Fred is not doing well. I stayed all night at rehab center. We are looking at Hospice care. Issac is sick with 103 temp and a chest cough. I need to take him to the doctor today. I will post more info when I have it.

May 19, 2009 at 11:17am · [Comment](#) · [Like](#)

What's happening?

140

I am trying to talk with Christine Kraft and epatient Dave.

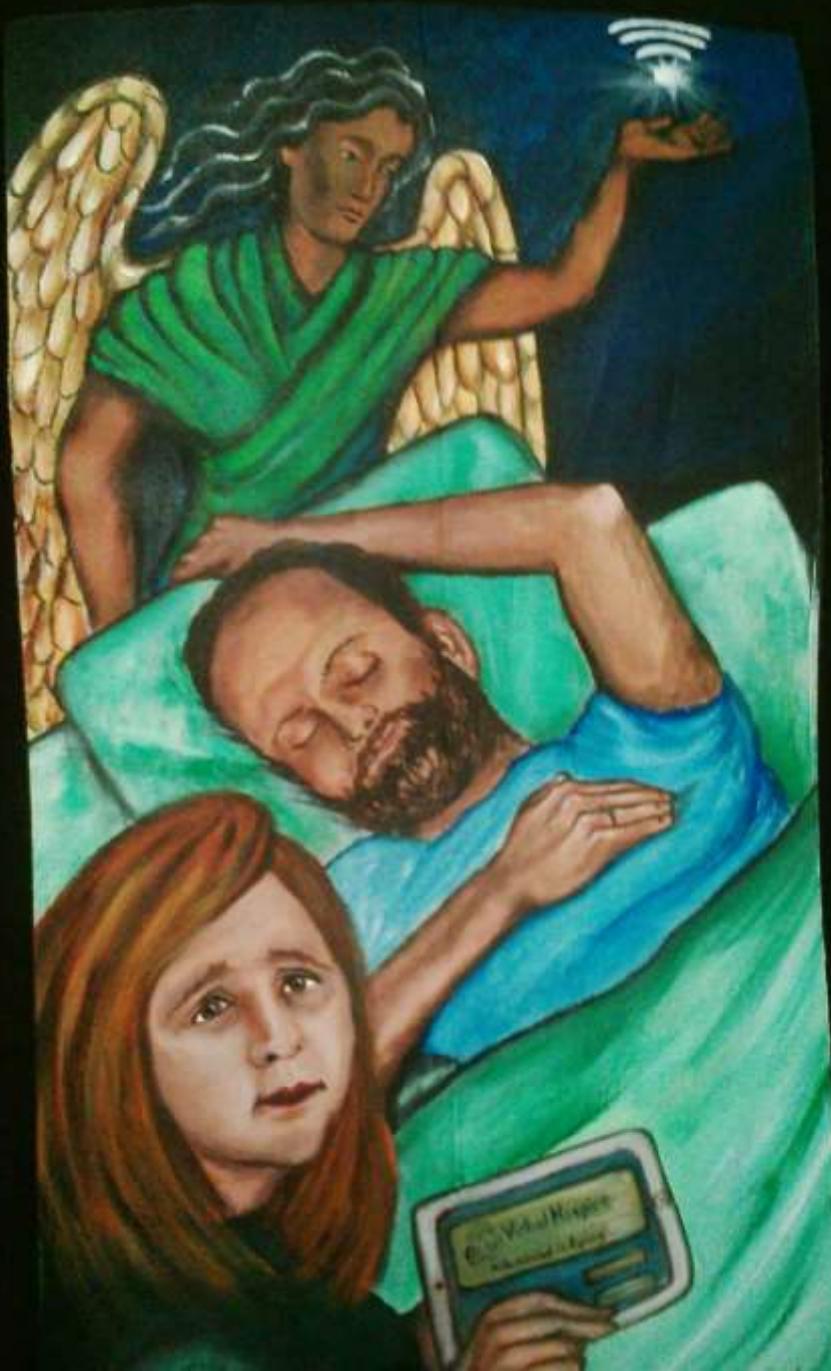


Why did we get more help and answers from
Social Media

than from our local hospital ?



You never really know which picture will be your last.



Going to Hospice.



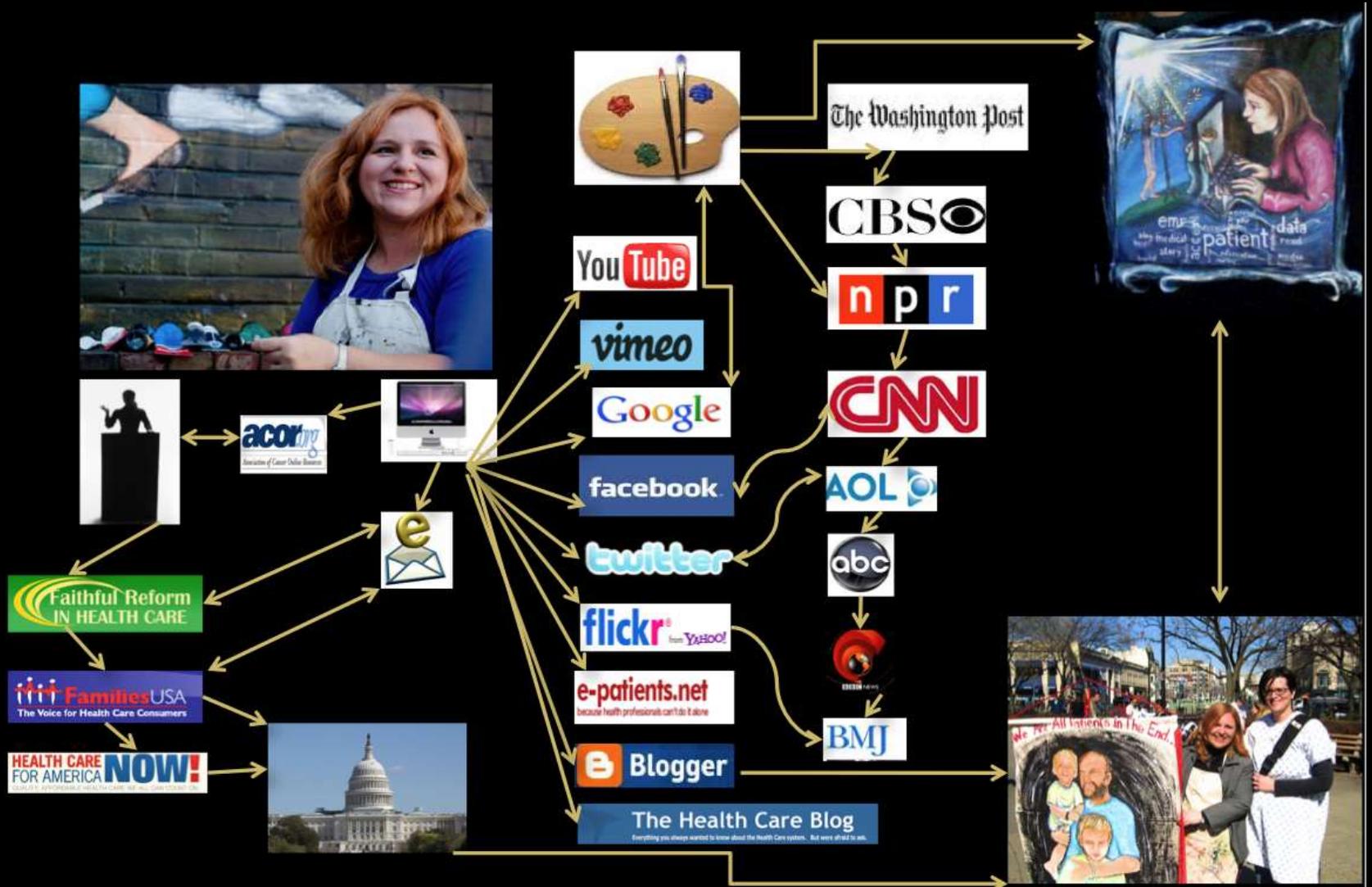
We fulfilled our final 2008 resolution on June 11th 2009.

We moved into a two bedroom apartment so I could care for Fred in home hospice.



He died six days later on June 17th, 2009

Painting Advocacy meets Social Media



This is the painting *73 cents*.



This is the vital patient story, the social history , the sacred heart of Fred's

ELECTRONIC MEDICAL RECORD.



On Tuesday, October 20th 2009 we dedicated the mural,

“Where do we go
from here?”

Next Steps: Why not paint open access hospital data sets...



...in front of said hospital?



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HCAHPS Visualization

Short [Eidolon Films](#) 3 years ago / via [Vimeo Creative Commons License](#)

Artist Regina Holliday paints outside the George Washington University Hospital, depicting HCAHPS and interacting with the people that pass by.

Music by Paul Harris

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THE SUNLIGHT LABS ANNOUNCES DESIGN FOR AMERICA WINNERS

Contest awarded designers for creative ways to visualize data, government documents and congressional procedures

o Special Honorable Mention for Best Use of Health Data: Street art about community health data by Regina Holliday (<http://reginaholliday.blogspot.com/2010/05/to-apples-by-regina-holliday.html>)

process transparency and redesigning government.

"The Design for America winners prove that we can analyze and contextualize government information in ways that are truly meaningful—when that government data is made available to us all online," said Clay Johnson, director of Sunlight Labs. "With about 72 entries, the design community stepped up and showed amazing ways for us to view the work of government and imagine new ways for the government to serve citizens."

Search

Sort by: random

Ideas matching: "Toilet"



[click for full image](#)

Would you eat off a toilet seat?

As a pre-school art teacher, I know school cleanliness standards and would never ask students to eat off a changing table. When my husband was hospitalized, I found out the standards were not the same in hospitals and nursing homes, patients do this. The hand tray table is used for food service, prep space for incontinence and prep space for wound dressing materials. In this painting spread awareness of this "unmentionable" problem. I hope to increase patient safety outcomes in our most compromised areas.

by: Regina Holliday | Aug 22, 2010

189 people like this.

CHANGING + FEEDING TRAY = HOSPITAL TRAY TABLE



Why not paint about the need for better hygiene practices and then enter that painting in an online vote competition?

2 year study at Primary care settings of Beth Israel Deaconess Medical Center, Geisinger and Harborview



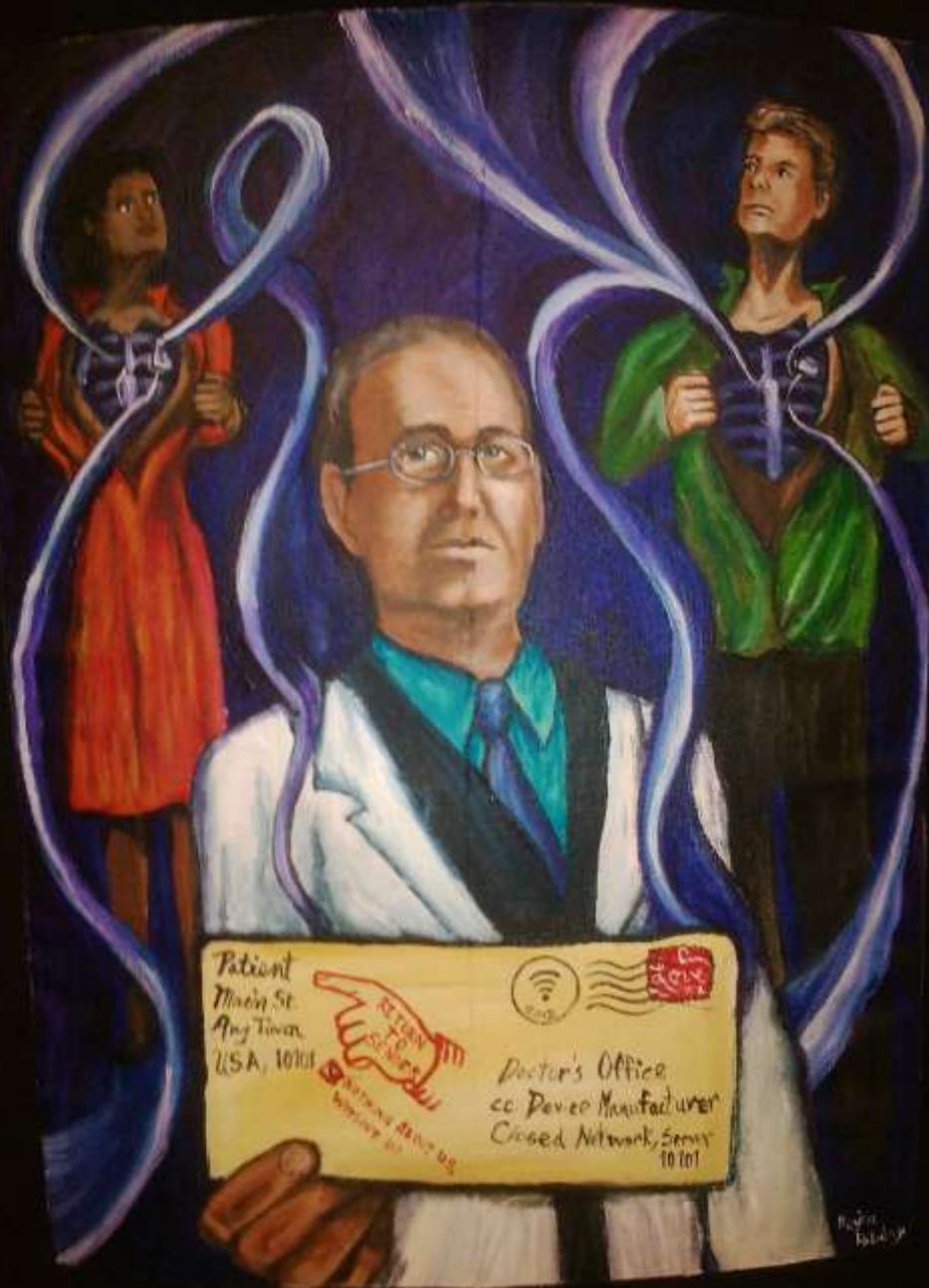
90% patients responded they understood what they had read & were not bothered by it.

1-2% were concerned/offended by the contents of the notes

87% of those patients enrolled in this study did check the notes.

Doctors said the study either only added a modest increase in work or that it was negligible.

80% Patients claimed greater adherence to medication protocols due to access to the notes.



All over the world, patients
Are demanding their data.

They are demanding access
to the data from their doctors,
from their hospitals,
and from the devices
inside of their bodies.





Adverse Childhood Experience Survey

@boltyboy

Welcome to the Walking Gallery.



Telling the patient story one jacket at a time.

448 unique members of the Walking Gallery
have joined wearing 496 jackets.

The Walking Gallery is promoted heavily
using the free tools of

social media.



The more stickers that are out there the more important it seems.
The more important it seems, the more people want to know what it is.
The more they ask they ask each other.

It gains **real power** from **perceived power**. -Shepard Fairey



#



 **Nancy Shute** @nancyshute 8m

.@reginaholliday If you look right now you're the "photo lede" on the home page at npr.org! #thewalkinggallery

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Artist's brush with health care, creates medical murals

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Posted: Jul 15, 2013 4:02 PM EDT
Updated: Jul 15, 2013 10:46 PM EDT

By Sherri Ly, @SherrLyFox5 - blo



WASHINGTON, DC - With each stroke of her paint brush, Regina Holliday reveals a story. She works meticulously, on each painting and the meaning behind it. She started with painting murals on walls. Now she's expanding her canvas to something much bigger. The DC artist turned her talents into a passion for better health care. She created The Walking Gallery, spreading the message worldwide on people's backs. She is working on a mural for a doctor, who struggled as a medical student to get enough sleep. There's an hourglass in the middle. "It doesn't stop and the time is running out," she explains.



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United States Of Outrage: NSA, IRS Overreach Sparks Bipartisan Ire

Some issues, like NSA surveillance, can scramble the ideological fault lines.

- 'Nobody is Listening to Your Telephone Calls,' Obama Says
- 'Profound Questions About Privacy' Arise

Maggie Starbuck/NPR

Two Big Waves In The Labor Pool

Friday's employment report offers a snapshot of an economy that's treading water, analysts say.

Salt, Flies, Pickled Tongues: A Perfect Great Salt Lake Swim

Open water swimmers endure blisters and brine flies to swim in the Great Salt Lake in Utah.

An Artist's Brush Reveals Tales Of Struggle And Survival

There's a story to tell about every family's encounters with the health care system. Artist Regina Holliday brings those secret stories to life in her Walking Gallery. Some of the tales are tragedies, but many are blazes of enduring hope in the face of suffering and loss.

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In health care reform, art keeps patients in the picture

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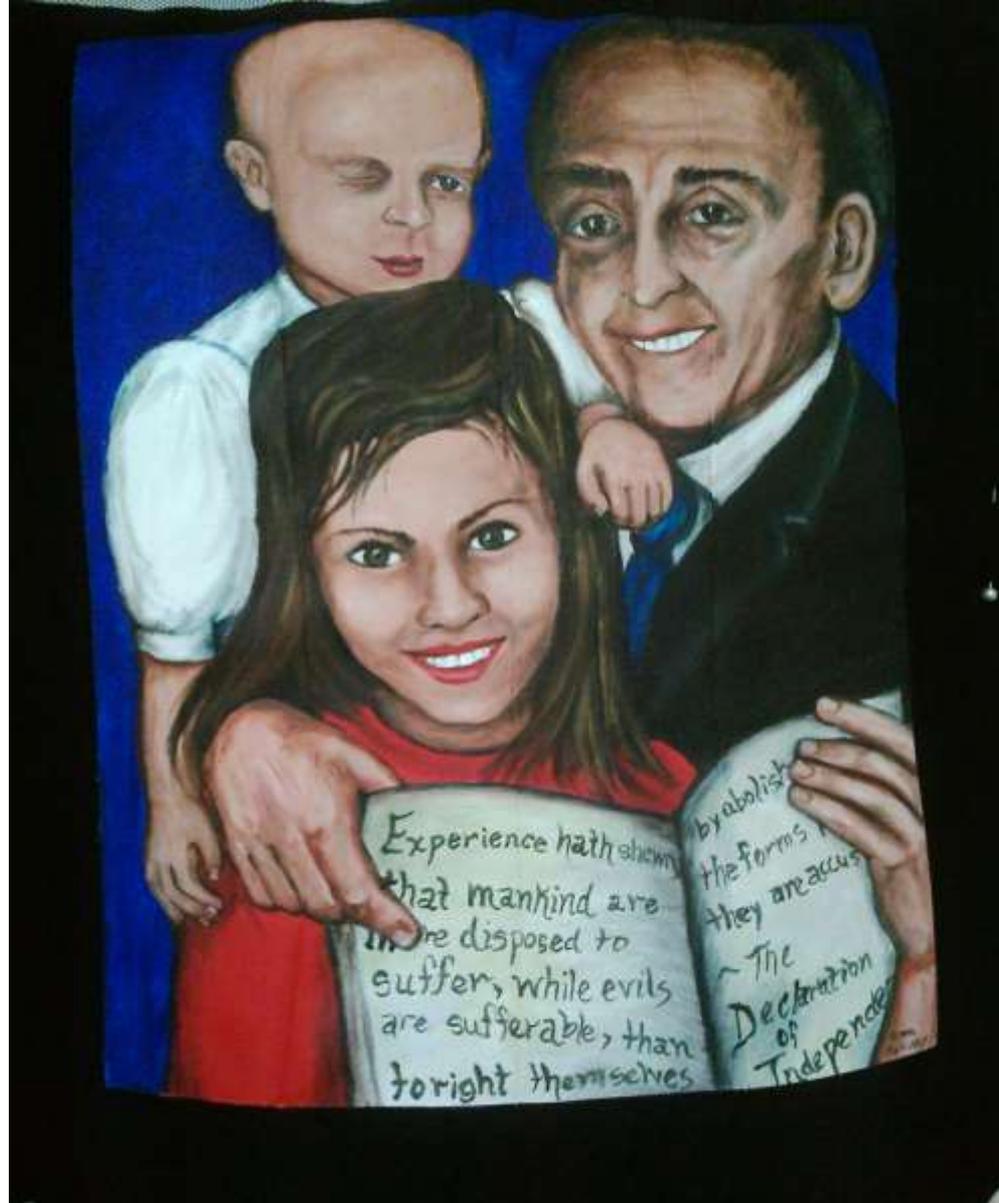


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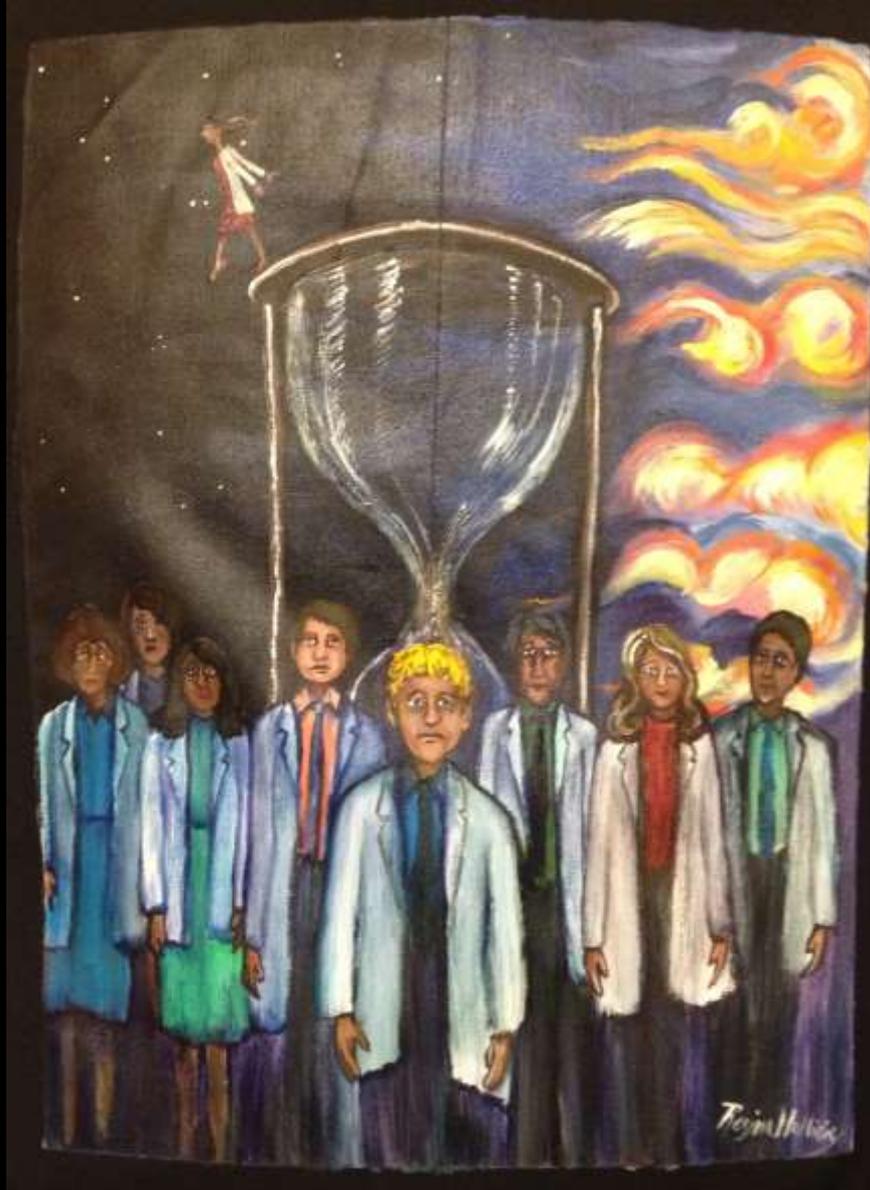
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[Comments](#)

- Welcome to your new (limited) membership
- We'll tell all contributors we're return to financing benefit
- Thanks so much for being in Louisiana
- Sorry! Brad and Lacey students missing out on selective coverage

[STORY](#)



The big picture changes by the stories we share.

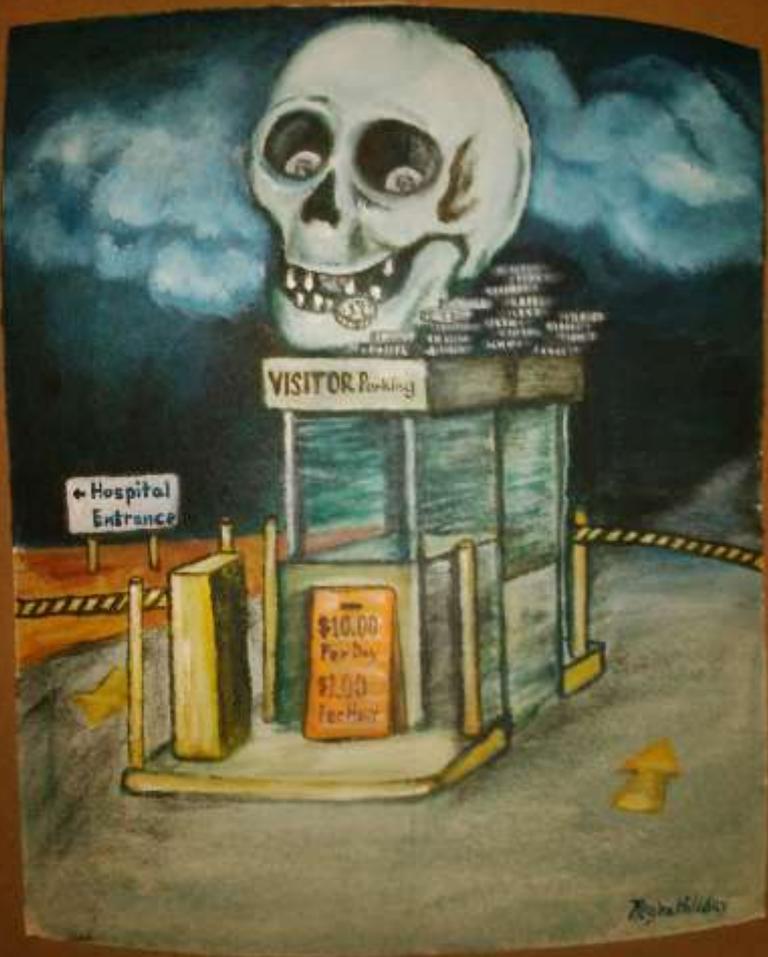


“Shift”
Nick Van Terheyden



“Is she okay?”
Jess Jacobs





Be the change you wish to see.



e-patients.net

because health professionals can't do it alone

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E-PATIENTS.NET > GENERAL > REGINA HOLLIDAY IS NOT SPECIAL!

Regina Holliday is not special!

Gilles Frydman | October 5, 2010

I'm sure that got your attention! But that is exactly Regina's message: **We are all patients . Both collectively and individually we are the most important and the most silent stakeholder of the healthcare system.**

16

6

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To discuss the expanding role of the patient please join us at the [Patients 2.0 session](#) to plan the next phase of action for patients, citizens and other people passionate about improving healthcare, working both online and face to face. Regina will be there!

Of course Regina is a spectacular and obviously very special human being, amazingly multi-talented, able to create unique and powerful distributors of great wisdom, either through her art, her powerpoint presentations or her straight talks. Of course she has helped shape the national conversation about patient empowerment and individual access to one's own health data. She is, notwithstanding her great humility, a true mover and shaker. But most importantly, we must all be listening to what she is telling us and be able to forget her genius for an instant and conclude that, in fact she is not special at all. She just said it again, in a tiny comment on Dave's [latest post](#) about his experience becoming a professional patient:

I disagree with the comment that at some point we stop being "patients." **We are all patients, and some of us are e-. But this is the role we must all take up in points throughout our life**

Welcome



Participatory Medicine is a model of cooperative health care that seeks to achieve active involvement by patients, professionals, caregivers, and others across the continuum of care on all issues related to an individual's health. Participatory medicine is an ethical approach to care that also holds promise to improve outcomes, reduce medical errors, increase patient satisfaction and improve the cost of care.

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A



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A

You can take a negative and turn
it into a **POSITIVE.**