



**Patient Advocates:**  
**A Powerful Nurse Practitioner Resource**  
August 8, 2013

For live audio, you must use your phone and dial (866) 513-4976; passcode: 6875187

# **James Dickens, DNP, NP, FAANP**

President

American Nurse Practitioner Foundation

CAPT, U.S. Public Health Service

Office of Minority Health, Region VI

Office of the Assistant Secretary for Health

U.S. Department of Health

and Human Services



# American Nurse Practitioner Foundation

## American Nurse Practitioner Foundation

- Formed in 1998
- First National NP Foundation in the US
- Focus on solutions to costly healthcare outcomes related to unmanaged Chronic Disease
  - Resources and Tools through Simply Health in Practice

Over \$1 million given in Scholarships and vital research grants to help overcome the impending shortage of Primary Care Providers and assist research efforts to improve patient care.

# American Nurse Practitioner Foundation

- Network NPs on domestic and global Humanitarian efforts.
- Connect NPs and Corporations for communication leading to better healthcare.
- Provide Global Care, starting locally.

The goal of the webinar is to link important advocacy messages to patient messaging and focus.

# Webinar Objectives

By the end of the webinar, participants will:

- Understand patient's rights and provider relationships
- Identify ways healthcare providers and patients can collaborate to create legislative change
- Understanding the role of the family caregiver
- Establish ways to focus on patient centered messaging while utilizing the healthcare provider

# Speakers

- **Regina Holliday**, caregiver, patient advocate and artist
- **Susan Hassmiller**, PhD, RN, FAAN,  
Robert Wood Johnson Foundation's Senior Advisor  
for Nursing & Director for the Future of Nursing:  
*Campaign for Action*

# Patient Advocate:

The **little things** that  
define the role of the patient and family  
caregiver



A presentation by Regina Holliday

# Disclosure Slide

I have presented or painted before these venues and companies:

A word cloud of various organizations and conferences. The words are arranged in a roughly circular shape, with some words being larger than others. The words are in a blue, serif font. The background is a light blue gradient.

University of New England Intermountain  
LeapFrog Arkansas Foundation for Medical Care  
Maine Association for Healthcare Quality Sharp Health Care HIMS ONC  
Kru Research Adventist Health Geisinger Health  
Hendricks Health Medstar CMS AHRQ HHS  
Health2conf HISA Academy Health Microsoft Puerto Rico REC  
America Case Managers Association ICSI NCVHS Linkage Cerner  
Disruptive Women in Medicine Avatar Genentech  
Health 2.0 ASHP Premier Quest AHIMA  
CHOP HDX Conference P2 Collaborative  
WHIT IHI TEDMED AHDI  
OCHIN  
Health Foo Camp Maine Quality Counts  
Bellin Health South Dakota REC eHealth Summit  
NPWF CorePoint Avera Genetic Alliance  
NIH OA Systems University Hospitals TMIT  
Korea Healthcare Congress  
California HIE Stakeholder Summit  
Collaboration Across Borders  
Stanford Medicine X Kaiser Permanente



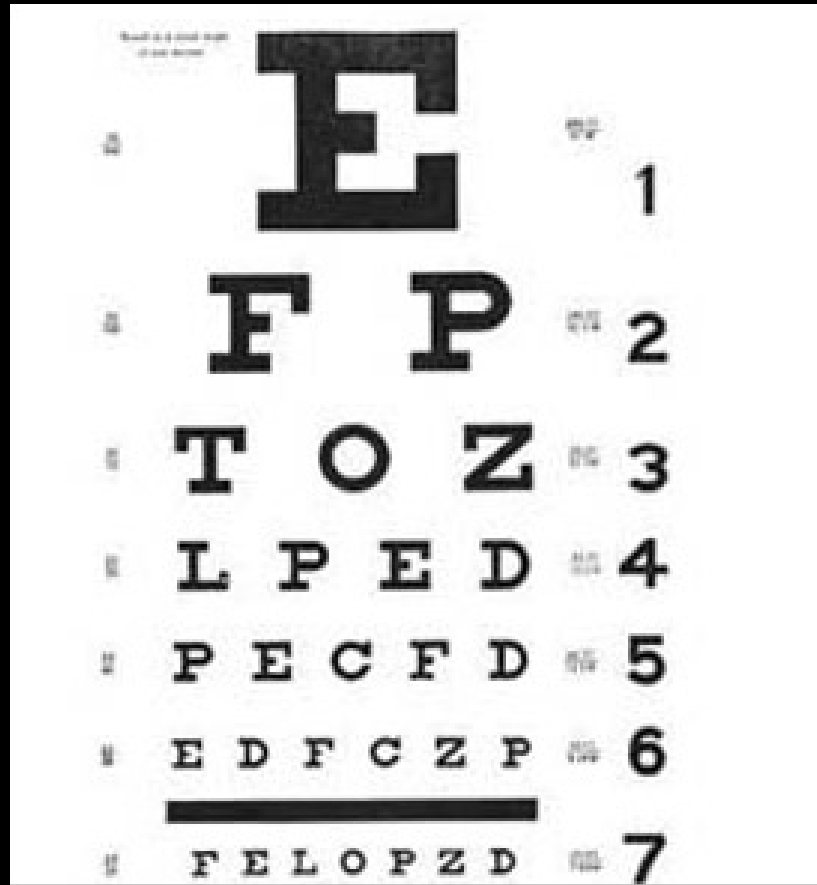
# Positives and Negatives



# Creative Thinking



Is this a clothespin or a bear trap?



Patient Reported Data is very important.



Compiled and Printed by  
Creek County Guidance  
Advisory Board

**Creek County Health  
Department**

Sapulpa (918) 224-5531  
Bristow (918) 367-3341  
Drumright (918) 352-9581

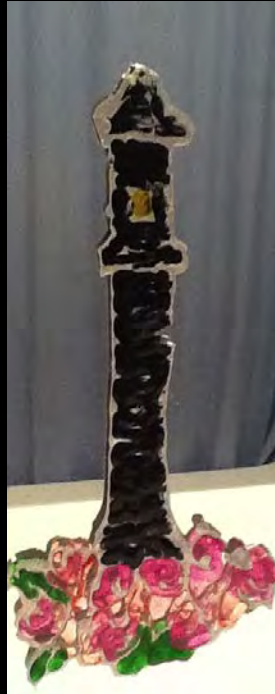
**HOTLINE NUMBERS**  
Can Help You With  
Your Problems!



**Helplines**  
**Pocket Reference**

When the abuse becomes too bad call this number.

Fred would meet Regina on a stage  
in a scenic painting class at Oklahoma State University.



We would talk of Stephen King's Dark Tower.

We would fall in love.

Fred got a Masters and then a PhD.

I would paint neighborhood murals.

I would teach art at a local preschool.

I would work in a toy store.





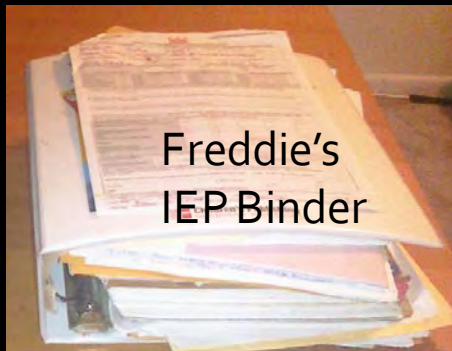
# The Holliday Family Christmas 2007



# Everything we ever wanted...

## Resolutions January 2008:

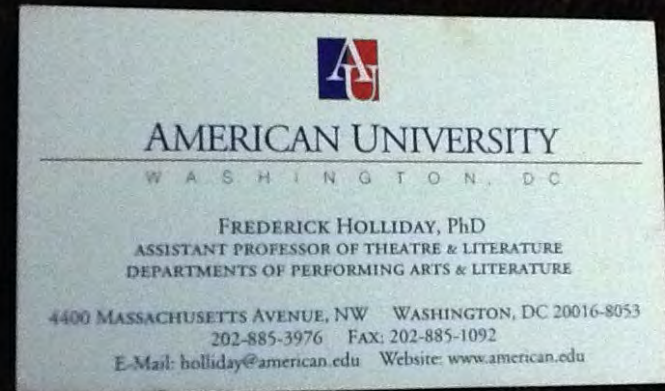
1. Get Medical Insurance for the whole family
2. Get little Freddie into a special needs school
3. Fred gets a job in his field
4. Spend more time together as a family
5. Get a two bedroom apartment







Fred was happy with his new job.



But he was very tired,

He went to the doctor and was  
diagnosed with hypertension.

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

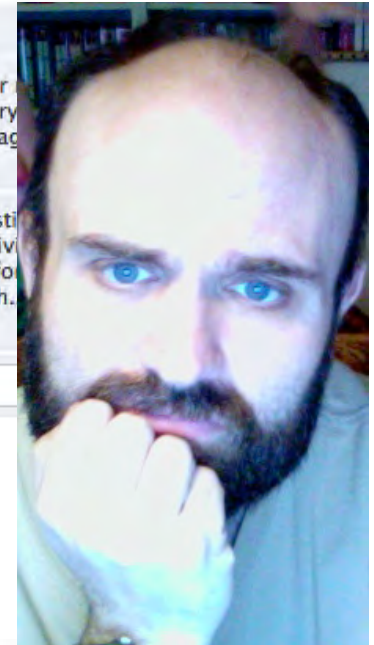
Status Lines...



**Frederick Holliday** is already tired.  
January 5, 2009 at 9:07pm · [Comment](#) · [Like](#)



**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 13<sup>th</sup>, 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 25<sup>th</sup> 2009  
for the administration of tests.



On March 27<sup>th</sup>, 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







“Go After Them,  
Regina.”

April 18, 2009



After waiting for **5** days for a transfer to another hospital for a second opinion,

We were sent with an out of date and incomplete medical record and transfer summary.

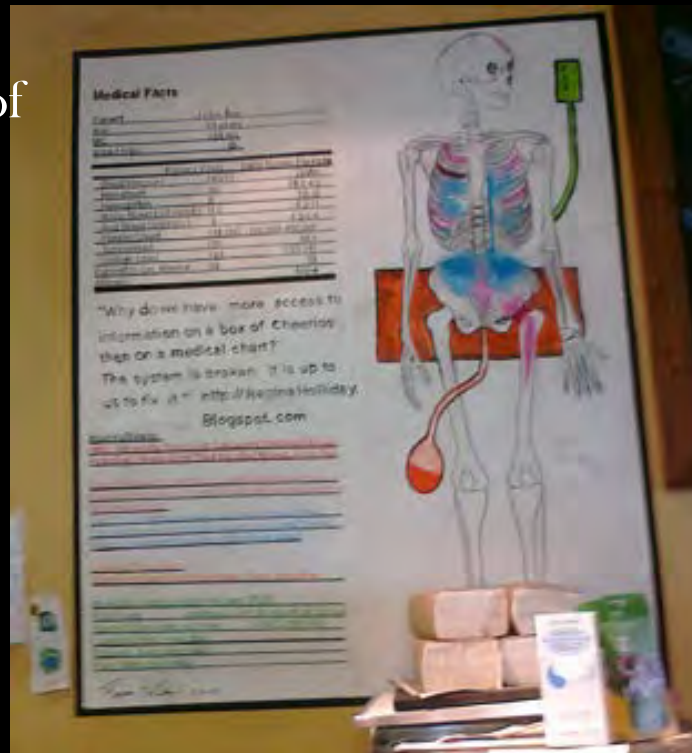
The new staff spent **6** hours trying to cobble together a current medical record Using a telephone and a fax machine.

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



Presented in the style of  
the Nutrition Facts Label.

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



## 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



# 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. It 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 post are funny and light-hearted and there is a lot of banter between friends about how to deal wit

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.

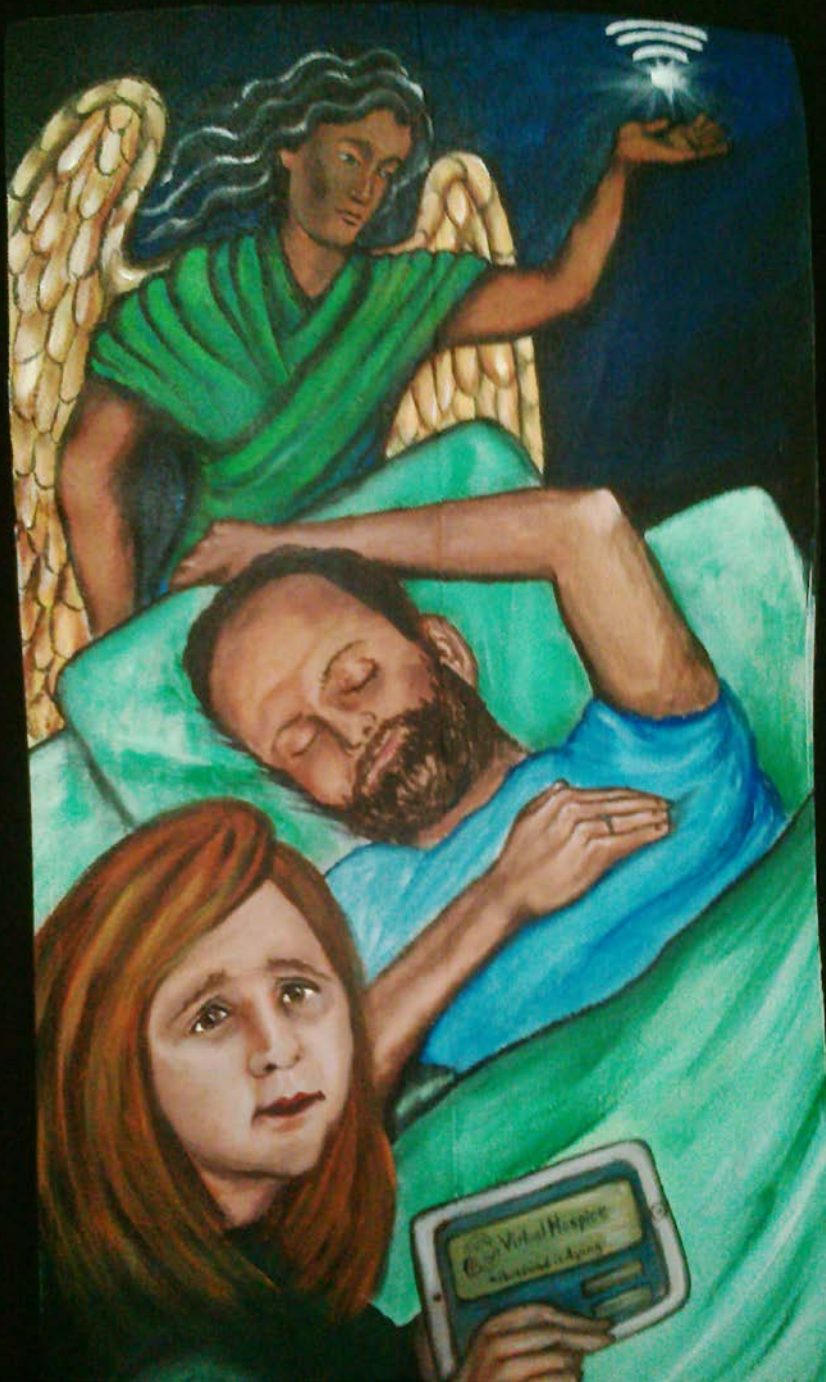


Why did we get more help and answers from  
**Social Media**  
than from our local hospital ?

Within one day were in email contact  
and then spoke on the phone.

By ten o'clock May 4<sup>th</sup> 2009, I was  
talking on the phone with Dave's  
Oncologist about my husband's cancer.





Going to Hospice.



We fulfilled our final 2008 resolution on June 11<sup>th</sup> 2009.

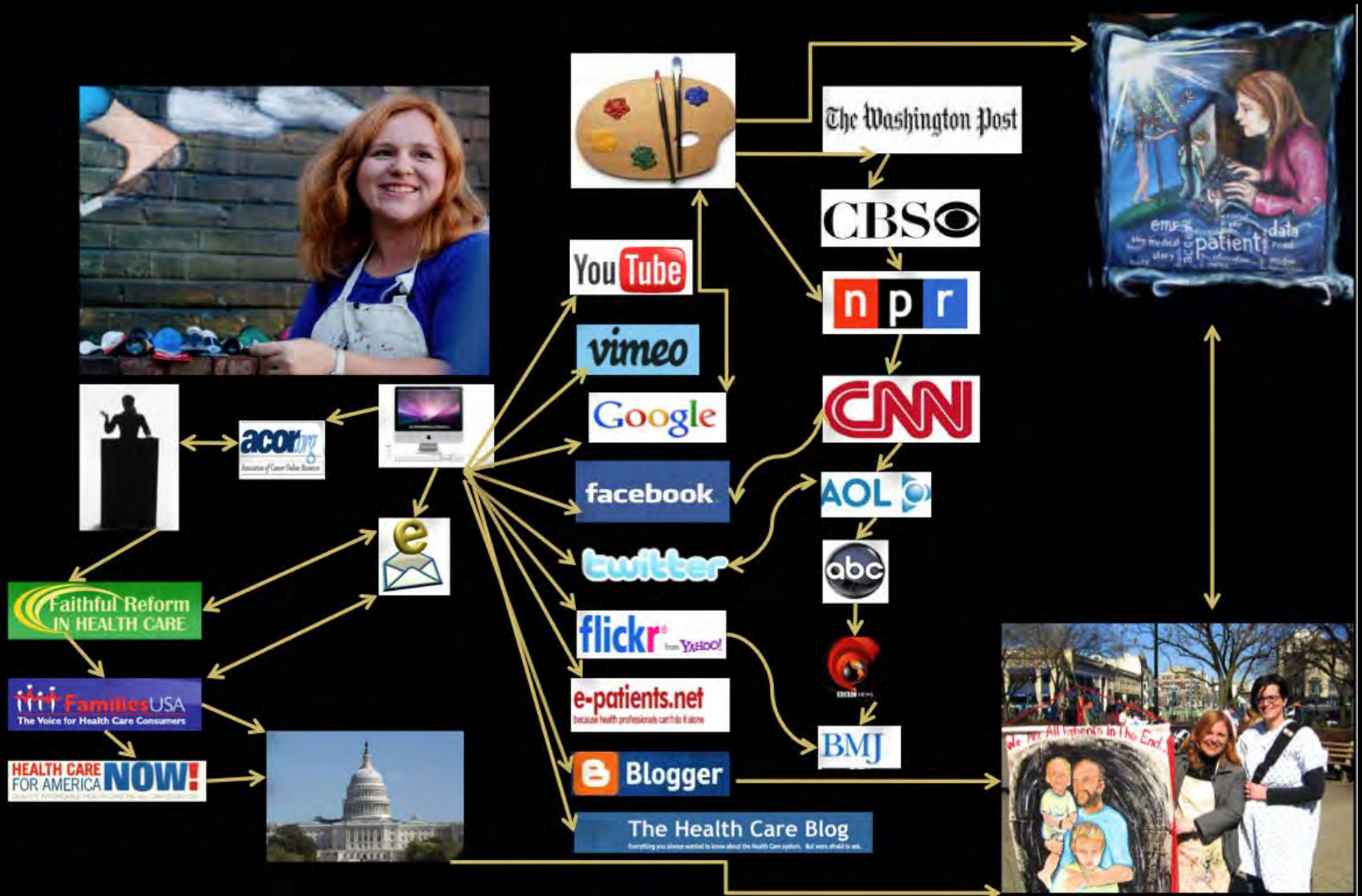
We moved into a two bedroom apartment so I could care for Fred in home hospice.



He died six days later on June 17<sup>th</sup>, 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 20<sup>th</sup> 2009 we dedicated the mural,

“Where do we go  
from here?”



# *How about a report card for Hospitals?*





How would you  
define  
Meaningful Use?

Here is the real meaning of  
the “I” in HIT.

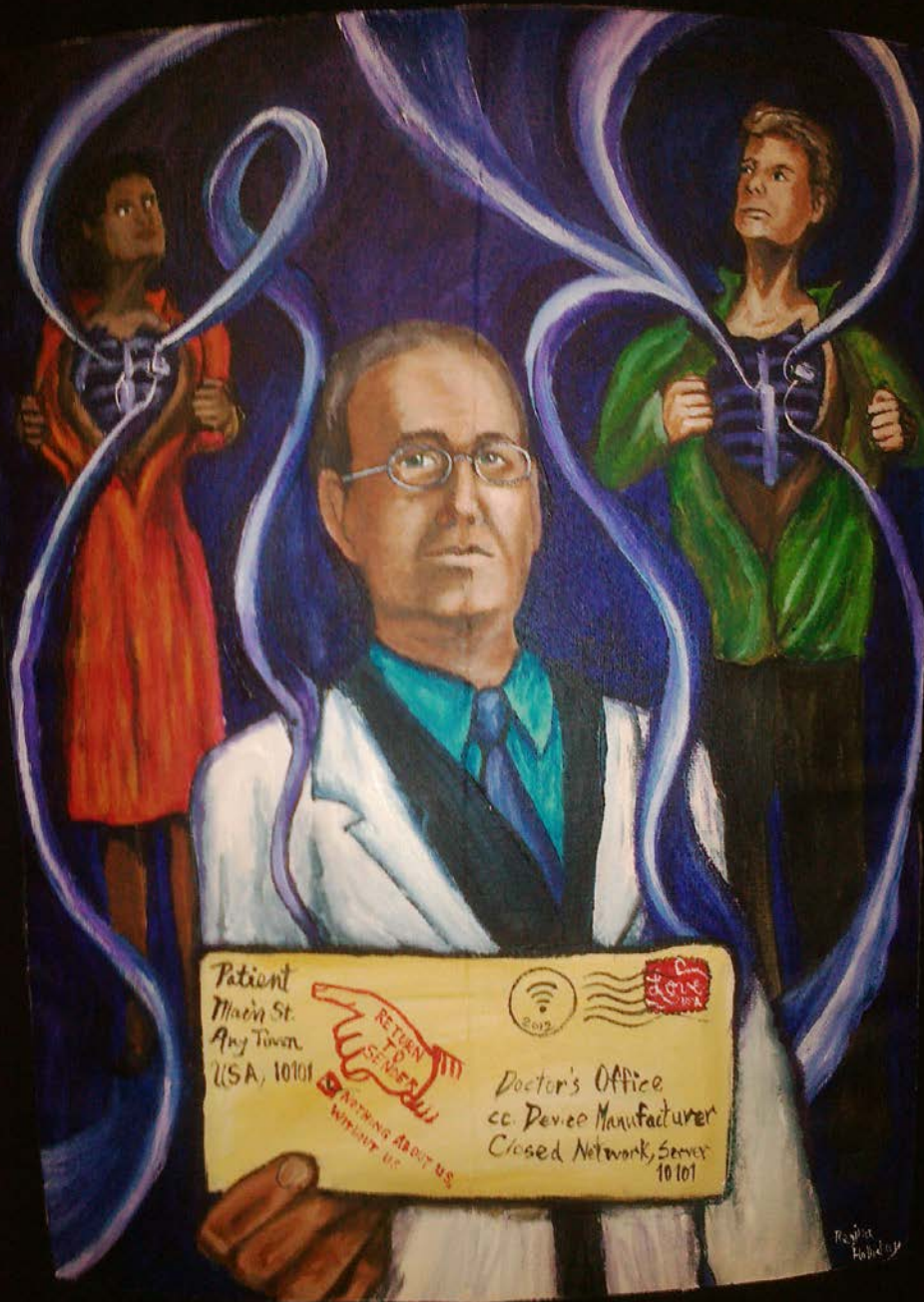






There may be set backs on  
Our way to patient data access.,

but  
we  
will  
prevail.



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.





Inside of every EMR there is a patient story,  
And sometimes it is told by Betty of Bellin Health.



# Blue Button: More than app for veterans.



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.





# Prototype Consumer Reporting System for Patient Safety,

*When the abuse becomes too bad call this number.*

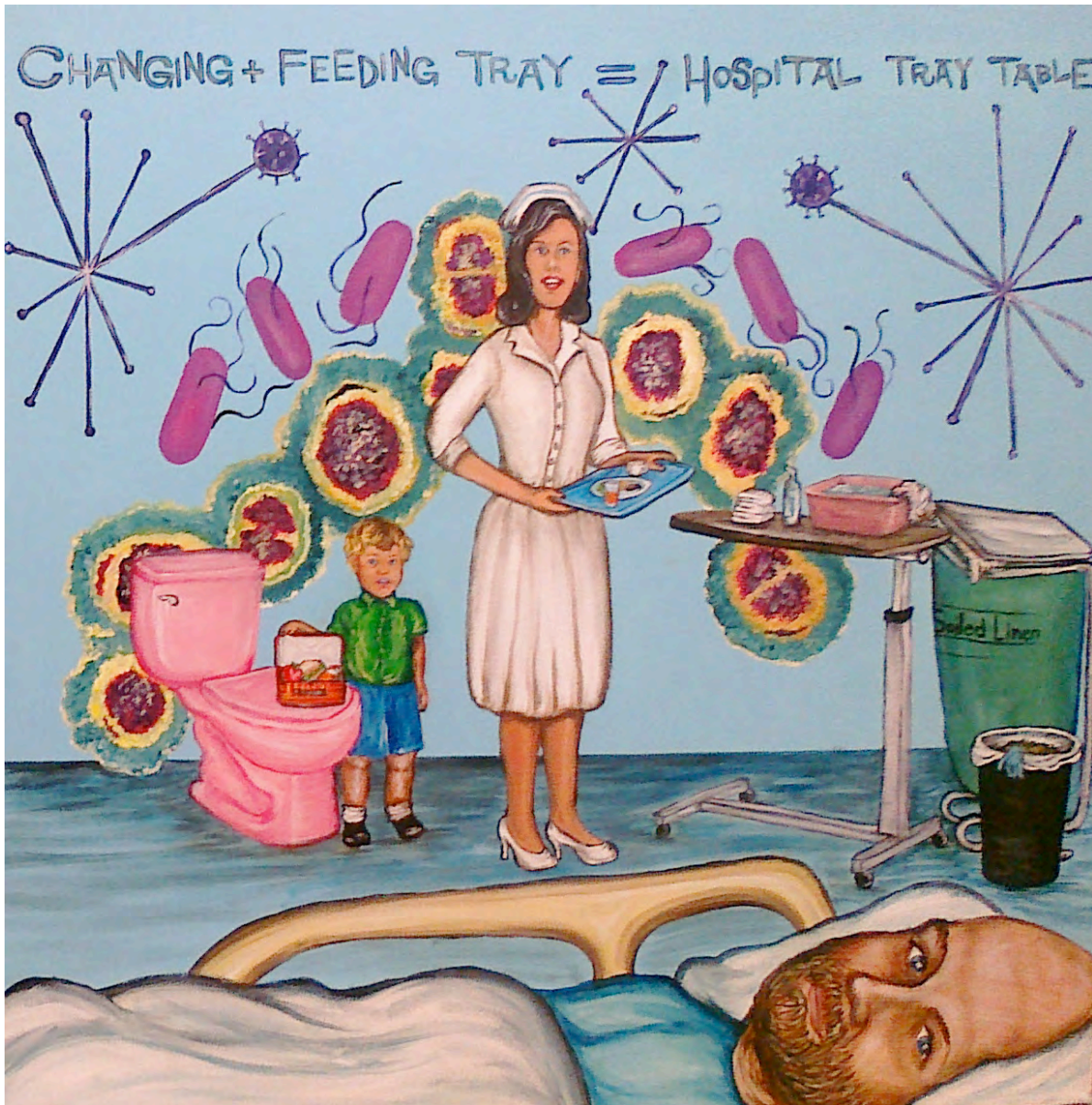




What happens to user experience when designers like  
**Michael Graves** design wheelchairs?







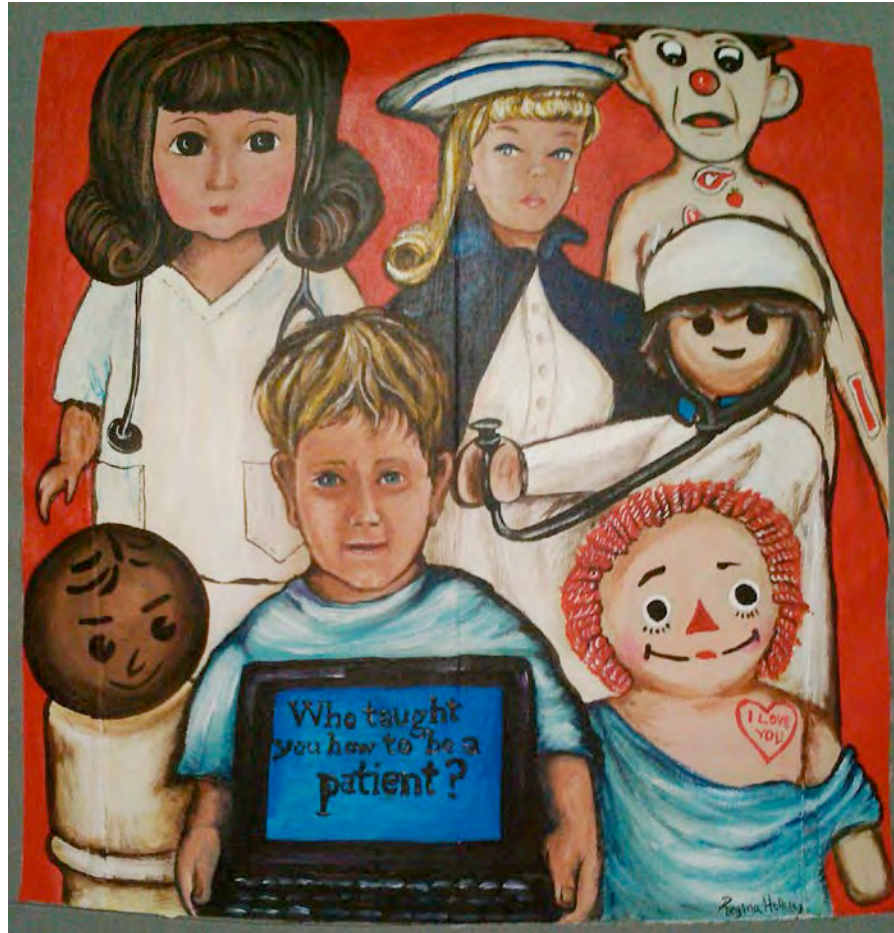
The little things...

How do you use  
Your bedside tray table?

If a child's toy can figure any item in the world in 20 questions, why  
Can't we have CPOE and CDS in every hospital and family practice?







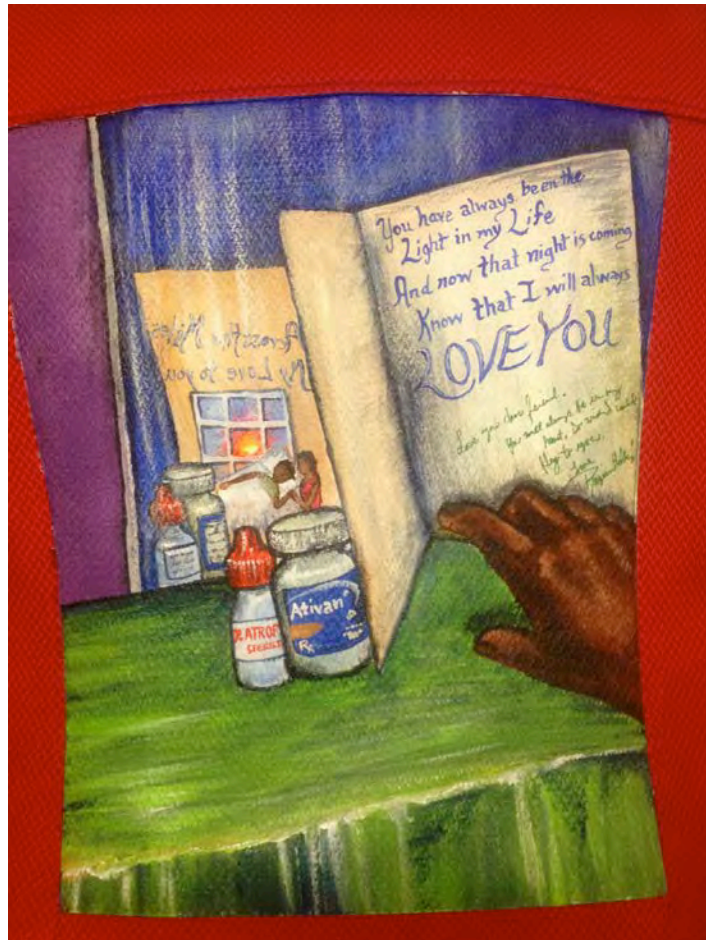
Who taught you how to be a patient?

"During this hospital stay, how often was your pain well controlled?"



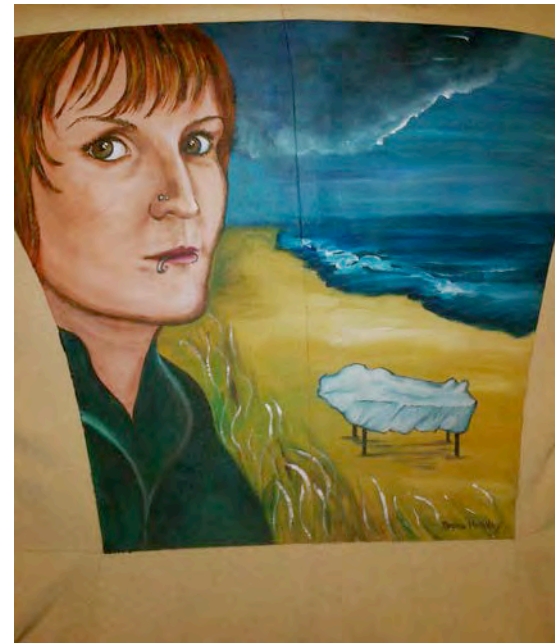
HAPPY FACE - SAD FACE SCALE





Why can't we ask Hallmark to make hospice cards?

Would that help us talk about end of life?





# Welcome to the Walking Gallery.



## Telling the patient story one jacket at a time.





Freddie grows beyond peering through a door crack to walking in a Gallery.



Isaac grows up.

He joins the gallery as an artist.  
His jacket is named "Feelings."

In this year's jacket he focused  
on diabetes care.





Standing out and looking different,  
Can be uncomfortable or frightening.

But is often needed for advocacy.

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

~ @ReginaHolliday



**Susan B. Hassmiller, PhD, RN, FAAN,**  
RWJF Senior Advisor for Nursing and  
Director, Future of Nursing: *Campaign  
for Action*





# Campaign Vision

**FUTURE OF NURSING™**  
Campaign for Action

All Americans have access to high-quality, patient-centered care in a health care system where nurses contribute as essential partners in achieving success.



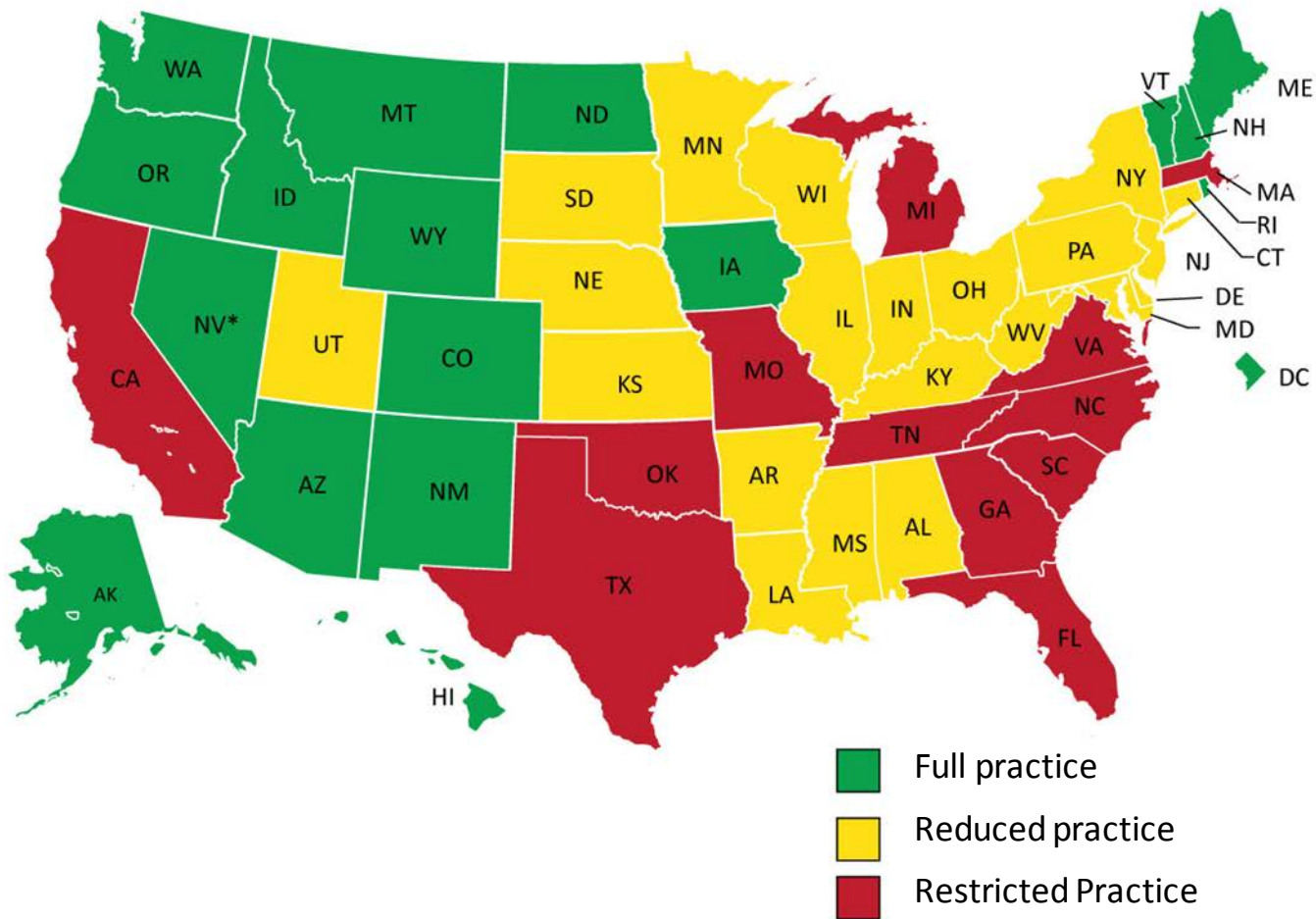
Robert Wood Johnson Foundation



# Jody's Patient's Story

- Bedridden patient who was diagnosed with wound.
- Needed visiting nursing services.
- Took week to receive authorization from physician's office.
- Patient's wound became larger and took longer to heal.

**FUTURE OF NURSING™**  
Campaign for Action





# Focus on Patient

**FUTURE OF NURSING™**  
Campaign for Action

NP's focus on **Describe:**  
qualified **How** patients are  
comp **Identified** barriers by outdated  
are **Scope of practice**  
vs



# Patient-focused Messaging

- NPs more likely to serve in underserved and rural areas.\*
- NPs comprise significant portion of safety net providers.\*
- NPs can help to provide primary care to 25 million Americans who will become eligible for care in 2014.\*\*



Sources: \*See Charting Nursing's Future, June 2013. Available at:

[http://www.rwjf.org/content/dam/farm/reports/issue\\_briefs/2013/rwjf405378](http://www.rwjf.org/content/dam/farm/reports/issue_briefs/2013/rwjf405378)

\*\*CBO estimate, May 2013. Available at: <http://www.cbo.gov/publication/44176>

## The State Op-Ed: “Nurses Can Help Solve Pending Care Crisis”

- Describes implications of crisis: longer waits, more ER crowding and more expensive primary care.
- Explains how NPs can help improve access to care.
- Mentions barriers, despite evidence supporting APRN practice.
- Calls on policy leaders to remove barriers so South Carolinians can get care they need.



# Patient-Centered Messaging

## Legal Barrier

- APRNs need formal agreement with collaborating physician to diagnose, treat and prescribe.
- Some physicians charge prohibitive fees.

## Your Message

- Patients can face care delays when collaborating physician is not available.

# Patient-Centered Messaging

Regulatory  
Barrier

- Some Medicare regulations do not allow APRNs to admit patient to hospitals, lead medical homes or sign orders for home health services.

Your  
Message

- Patients who have good relationship with APRN will be examined by strangers.

# Patient-Centered Messaging

Regulatory  
Barrier

- Medicaid won't reimburse APRNs for certain codes or pharmacy supplies.

Your  
Message

- Restrictive reimbursement practices can force patients to pay out-of-pocket or find different provider.



# Patient-Centered Messaging

Regulatory  
Barrier

- Some state Medicare and private health insurance companies don't recognize APRNs as primary care providers.

Your  
Message

- Excluding APRNs can limit the supply of available clinicians in a time of growing demand.

# Patient-Centered Messaging

Institutional  
Barrier

- Some hospitals' medical staff bylaws prohibit APRNs from admitting patients or performing certain procedures.

Your  
Message

- Patients may have to wait for treatment even if a qualified APRN is available.

# Campaign Resources

**FUTURE OF NURSING™**  
Campaign for Action

Visit us on the web at  
[www.campaignforaction.org](http://www.campaignforaction.org)



about us

who's  
involved

campaign  
progress

state action  
coalitions

evidence

community

the  
challenge

Transforming  
Health Care for  
the 21st Century

our  
progress



<http://facebook.com/campaignforaction>



[www.twitter.com/campaignforaction](http://www.twitter.com/campaignforaction)





Press \*1 on your telephone key pad to ask a question  
OR  
Use the “chat” feature to send the host/presenter a question.



Email Questions to [foundation@anp-foundation.org](mailto:foundation@anp-foundation.org)

Visit us at [www.anp-foundation.org](http://www.anp-foundation.org)

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