

**Patient**

~~Consumer~~ **Engagement**  
**on the Hoof**

*as seen by the hoof*

**“e-Patient Dave” deBronkart**  
**@ePatientDave**

facebook.com / ePatientDave  
LinkedIn.com / in / ePatientdave  
dave@epatientdave.com

# How I came to be here today

- High tech marketing
- Data geek; tech trends; automation
- 2007: Cancer kicker
- 2008: E-Patient blogger
- 2009: Participatory  
Medicine,  
Public Speaker
- 2010: Full time

A photograph of a man in a dark suit and patterned tie speaking at a podium. The podium has a sign that reads "Medicine 2.0". The man is gesturing with his right hand. The background is dark.

Medicine 2.0

WWW.HEALTHLEADERSMEDIA.COM SEPTEMBER 2009 \$8.00

# HealthLeaders

## THE PATIENT OF THE FUTURE

Physicians suggest. Patients ignore. Technology alone won't bring them together. But a new relationship just might. p16



Certifiable Stroke Care p 33

The Art of Balancing Risk p 47

Real-World Bundling p 53

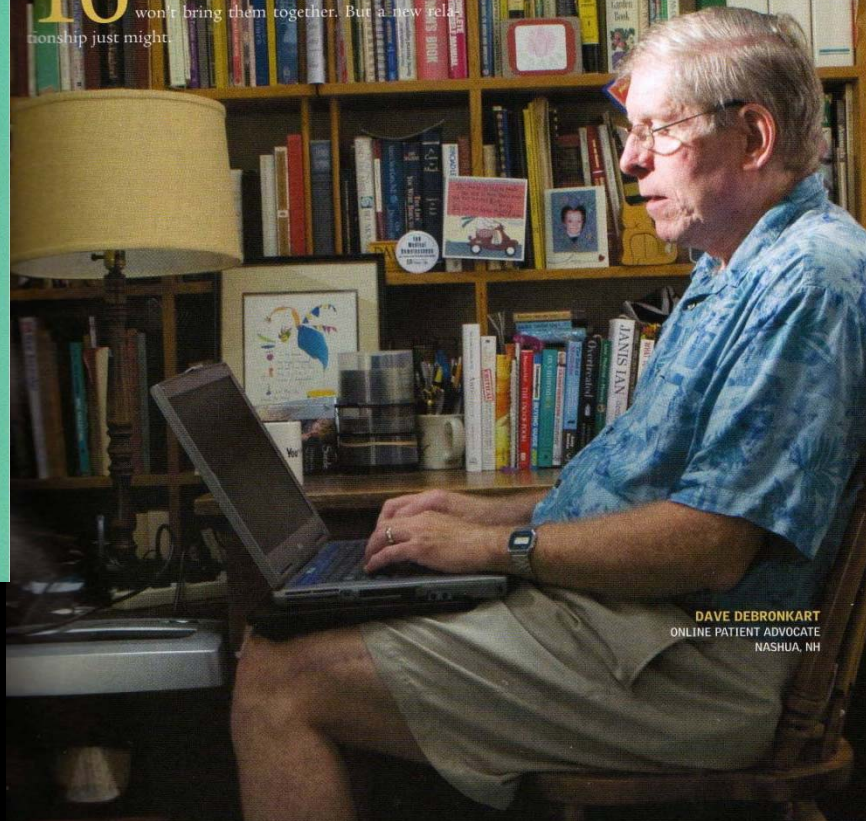
VOLUME XII NUMBER 9

# SEPTEMBER 2009

CONTENTS

### COVER STORY

**16** The Patient of the Future Physicians suggest. Patients ignore. Technology alone won't bring them together. But a new relationship just might.



DAVE DEBRONKART  
ONLINE PATIENT ADVOCATE  
NASHUA, NH

**I'm like JFK:  
“They sank my boat”**

# The Incidental Finding

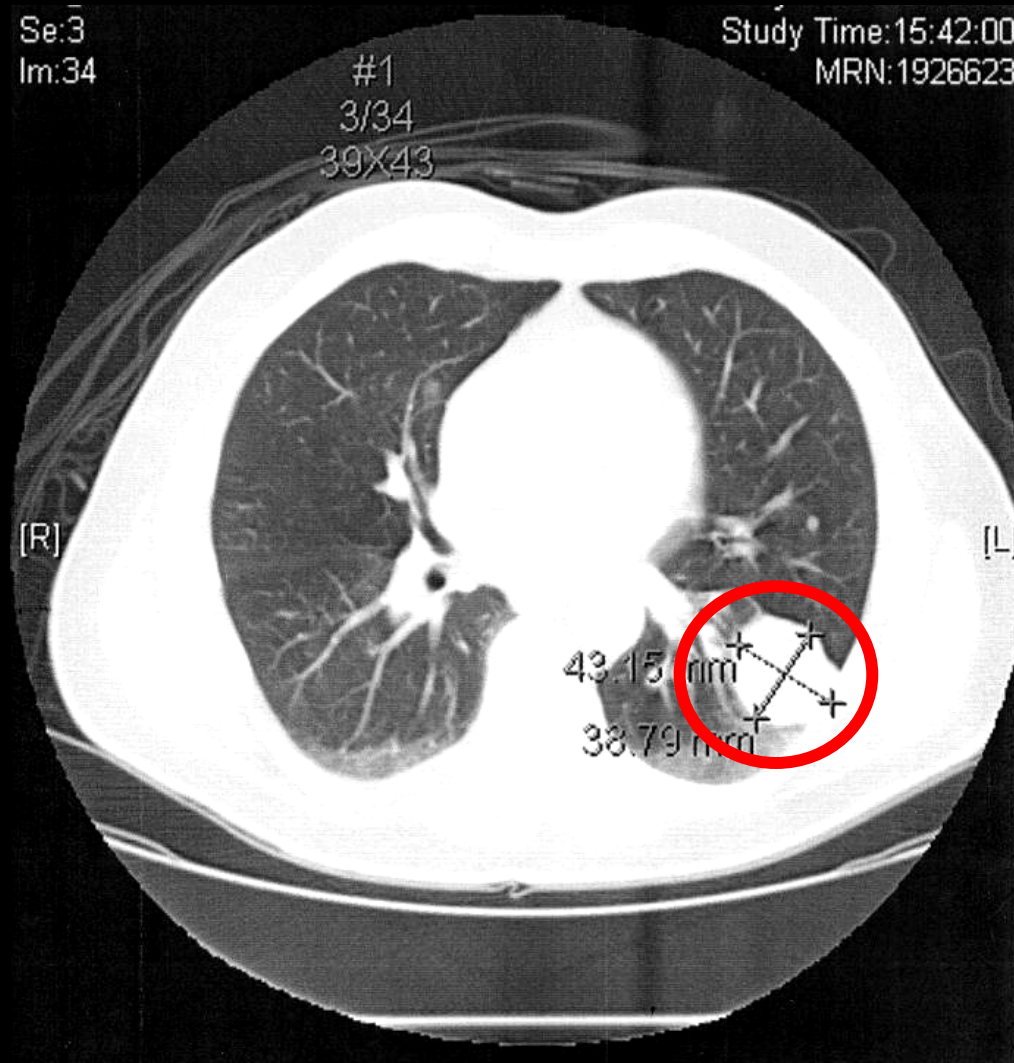


*Routine shoulder x-ray  
Jan. 2, 2007*

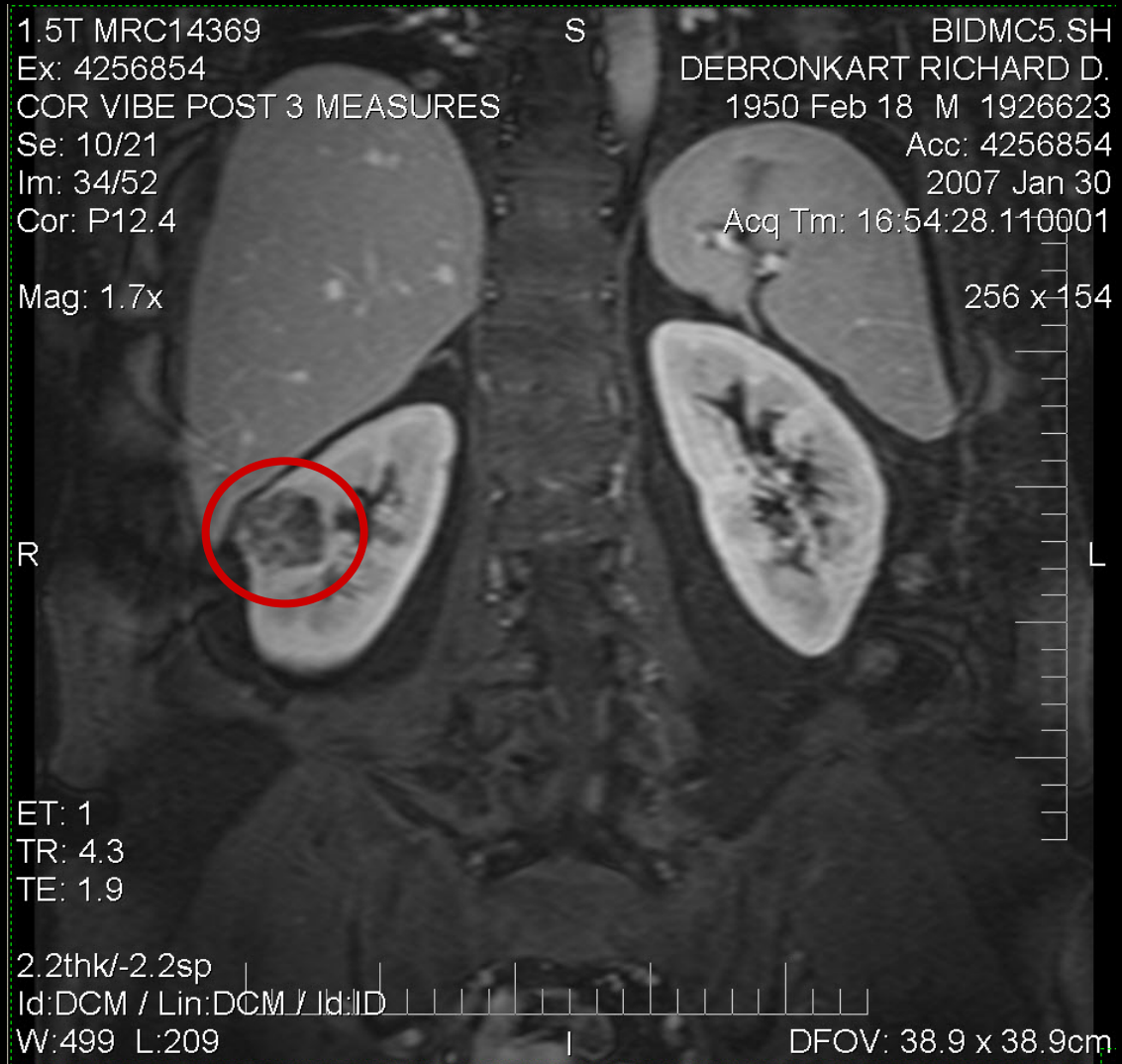
*“Your shoulder  
will be fine ...  
but there’s  
something  
in your lung”*

# Multiple tumors in both lungs

## Where's This From??



# Primary Tumor: Kidney



# E-Patient Activity 1: Researching my condition

- Purpose of This PDQ Summary
- General Information
- Cellular Classification
- Stage Information
- Treatment Option Overview
- Stage I Renal Cell Cancer
- Stage II Renal Cell Cancer
- Stage III Renal Cell Cancer
- **Stage IV and Recurrent Renal Cell Cancer**
- Get More Information From NCI
- Changes to This Summary (03/10/2008)
- More Information

## Related To

- [All Cancer Topics](#)
- [Bladder Cancer](#)
- [Brain Cancer](#)
- [Cervical Cancer](#)
- [Healthy Living Calendar](#)

## Renal Cell Cancer Treatment (PDQ®) - Stage IV and Recurrent Renal Cell Cancer

FONT SIZE



*Stage IV renal cell cancer is defined by the following stage groupings:*

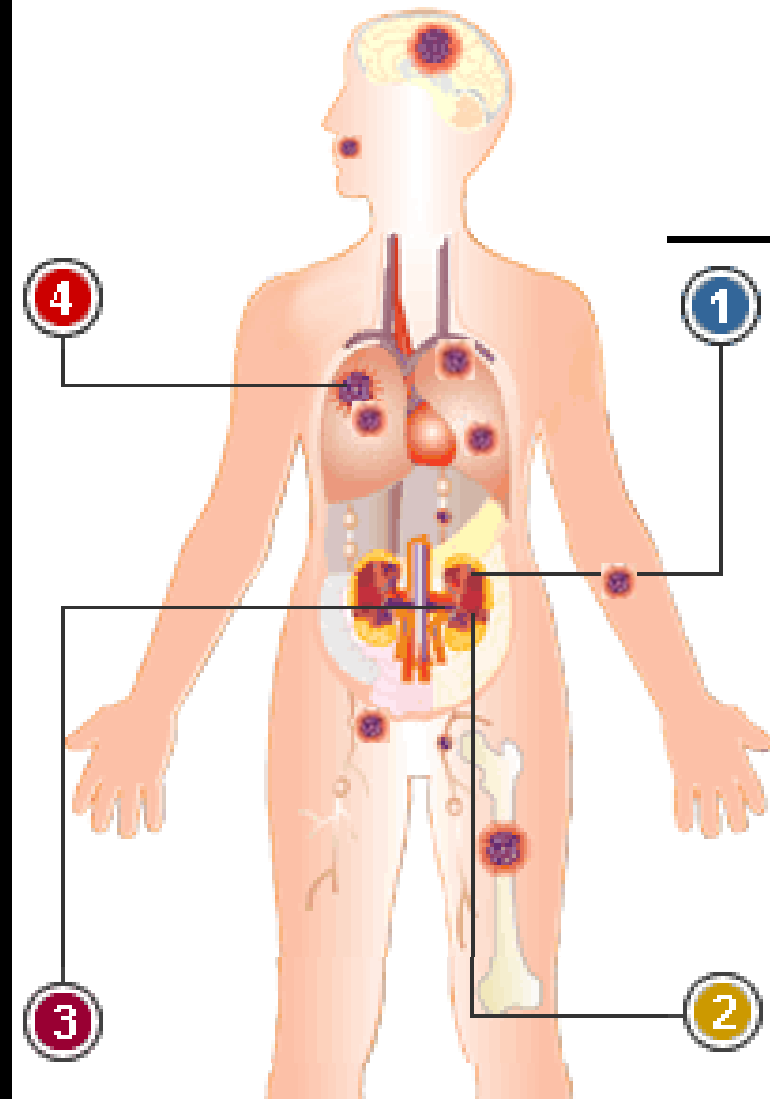
- ♦ T4, N0, M0
- ♦ T4, N1, M0
- ♦ Any T, N2, M0
- ♦ Any T, any N, M1

The prognosis for any treated renal cell cancer patient with progressing, recurring, or relapsing disease is **poor**, regardless of cell type or stage. Almost all patients with stage IV renal cell cancer are **incurable**. The question and selection of further treatment depends on many factors, including prior treatment and site of recurrence as well as individual patient considerations. Carefully selected patients may benefit from surgical resection of localized metastatic disease, particularly if they have had a prolonged, disease-free interval since their primary therapy. Because of early reports of success, progestational agents have been administered to patients with metastatic renal cell cancer, but the response rates have been disappointingly low; therefore, no rationale



# Classic Stage IV, Grade 4 Renal Cell Carcinoma

Illustration on  
the drug company's  
web site



**Median Survival:  
24 weeks**

# E-Patient Activity 2: “My doctor prescribed ACOR” (Community of my patient peers)

**acor.org**  
Association of Cancer Online Resources

The free online lifeline for everyone affected by cancer & related disorders

Home Dictionary Help Site Map

Find a mailing list Search

## WELCOME

Association of Cancer Online Resources

ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment.

ACOR offers access to mailing lists that provide support, information, and community to everyone affected by cancer and related disorders.

- ▶ MAILING LISTS
  - ONLINE COMMUNITIES
- ▶ SUPPORT & RESOURCES
  - COMMUNITIES WITH CANCER
- ▶ TYPES OF CANCER
  - BY CANCER TYPE A-TO-Z LIST
- ▶ TREATMENT OPTIONS
  - CURRENT TREATMENTS
- ▶ CLINICAL TRIALS
  - EXPERIMENTAL TREATMENTS
- ▶ PUBLICATIONS
  - CANCER-RELATED BOOKS
- ▶ PARTNERSHIPS
  - ALLIANCES & FRIENDS
- ▶ HELP ACOR
  - DONATIONS & VOLUNTEERS

## News

### Fat tissue-derived hormone leptin increases e-cadherin expression, obesity-breast cancer link noted

Being obese increases the risk of breast cancer in post-menopausal women, shortens the time between return of the disease and lowers overall ...  
Apr 29, 2007  
[\[Full Story\]](#)

### What's New

Please Note: Mar 26, 2007 Update: We have started

# E-Patient Activity 3: Reading (and sharing) my hospital data online



Welcome to the Personal Health Website of Richard Davies  
deBronkart

• Sign Out

Home

Records of Richard Davies deBronkart  
[Security Audit]

Help

BIDMC

MyEntries

Problems

Reports

Meds

Allergies

Visits

X-rays

Labs

Micro

Date	Exam	Status
<a href="#">03/30/09 4:13 PM</a>	E141R FOREARM (AP & LAT) RIGHT	APPROVED
<a href="#">03/30/09 4:13 PM</a>	E221L FEMUR (AP & LAT) LEFT	APPROVED
<a href="#">03/30/09 4:13 PM</a>	E212R HIP UNILAT MIN 2 VIEWS RIGHT	APPROVED
<a href="#">03/10/09 3:24 PM</a>	Q992 CT CHEST W/O CONTRAST W/ONC TABLES	APPROVED
<a href="#">03/10/09 3:24 PM</a>	Q995 CT ABDOMEN W/O CONTRAST W/ONC TABLE	APPROVED
<a href="#">03/10/09 3:24 PM</a>	Q998 CT PELVIS W/O CONTRAST W/ONC TABLES	APPROVED
<a href="#">12/09/08 4:10 PM</a>	Q992 CT CHEST W/O CONTRAST W/ONC TABLES	APPROVED
<a href="#">12/09/08 4:10 PM</a>	Q995 CT ABDOMEN W/O CONTRAST W/ONC TABLE	APPROVED
<a href="#">12/09/08 4:10 PM</a>	Q998 CT PELVIS W/O CONTRAST W/ONC TABLES	APPROVED
<a href="#">09/04/08 3:32 PM</a>	Q411 CT CHEST W/O CONTRAST	APPROVED

Services

- Mail
- Prescriptions
- Appointments
- Referrals
- Google Health NEW
- Microsoft HealthVault NEW
- Links
- Account Statement

About Me

- Records
- Personal Profile

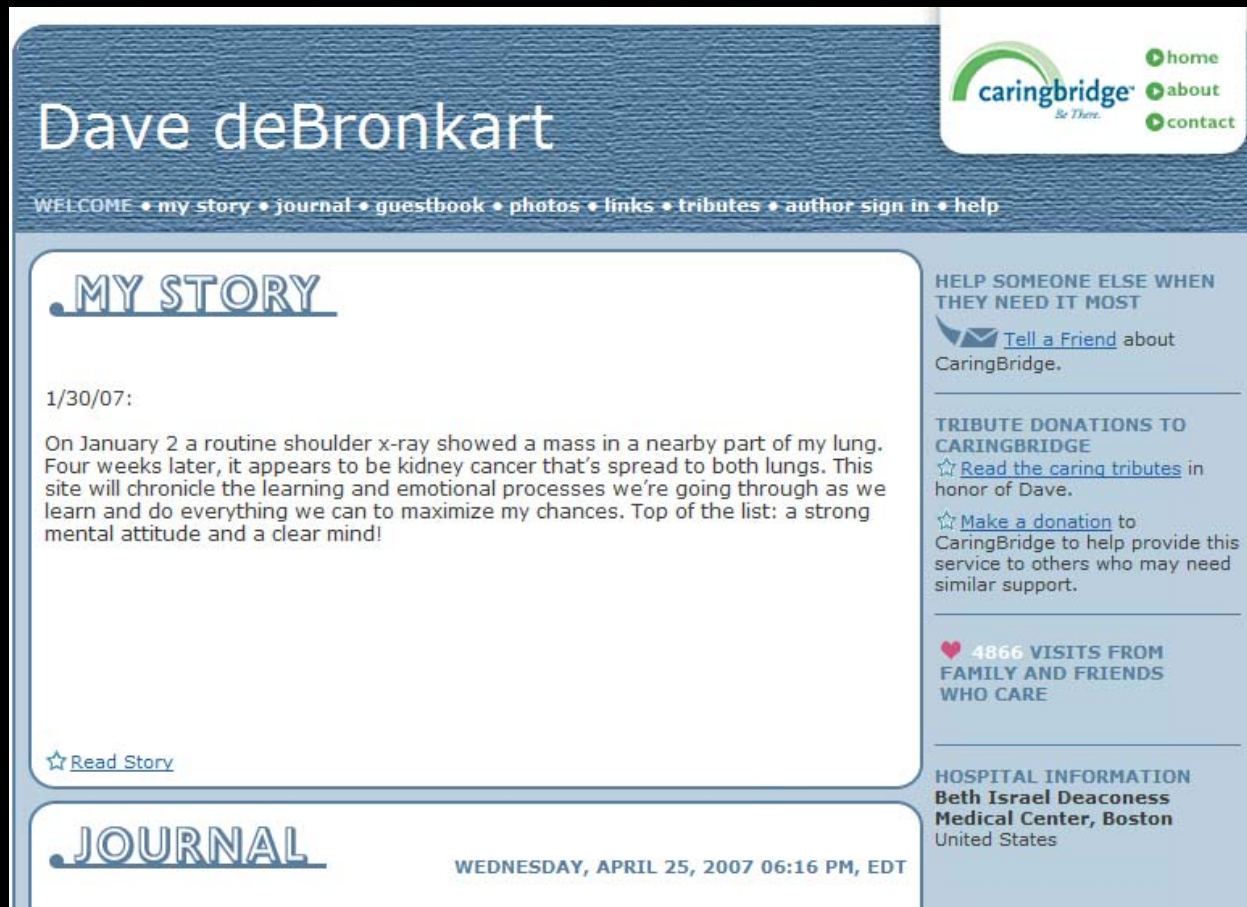
Support

- Tech Support
- FAQ/Tutorial

# E-Patient Activity 4:

## My own social support network

(CaringBridge.org - family and friends - journal & guestbook)



The screenshot shows a user profile on CaringBridge.org. The header includes the user's name, 'Dave deBronkart', and navigation links: home, about, and contact. A secondary navigation bar lists: WELCOME, my story, journal, guestbook, photos, links, tributes, author sign in, and help. The main content area is divided into two sections: 'MY STORY' and 'JOURNAL'. The 'MY STORY' section contains a dated entry from 1/30/07 describing a medical diagnosis of kidney cancer and the user's positive outlook. Below the story is a 'Read Story' link. The 'JOURNAL' section shows the date 'WEDNESDAY, APRIL 25, 2007 06:16 PM, EDT'. On the right side, there are three informational boxes: 'HELP SOMEONE ELSE WHEN THEY NEED IT MOST' with a 'Tell a Friend' link; 'TRIBUTE DONATIONS TO CARINGBRIDGE' with links to 'Read the caring tributes' and 'Make a donation'; and '4866 VISITS FROM FAMILY AND FRIENDS WHO CARE'. At the bottom right, 'HOSPITAL INFORMATION' for Beth Israel Deaconess Medical Center, Boston, United States is provided.

**Dave deBronkart**

home about contact

WELCOME • my story • journal • guestbook • photos • links • tributes • author sign in • help

### MY STORY

1/30/07:

On January 2 a routine shoulder x-ray showed a mass in a nearby part of my lung. Four weeks later, it appears to be kidney cancer that's spread to both lungs. This site will chronicle the learning and emotional processes we're going through as we learn and do everything we can to maximize my chances. Top of the list: a strong mental attitude and a clear mind!

[☆ Read Story](#)

HELP SOMEONE ELSE WHEN THEY NEED IT MOST

[Tell a Friend](#) about CaringBridge.

TRIBUTE DONATIONS TO CARINGBRIDGE

[☆ Read the caring tributes](#) in honor of Dave.

[☆ Make a donation](#) to CaringBridge to help provide this service to others who may need similar support.

♥ 4866 VISITS FROM FAMILY AND FRIENDS WHO CARE

HOSPITAL INFORMATION  
Beth Israel Deaconess  
Medical Center, Boston  
United States

### JOURNAL

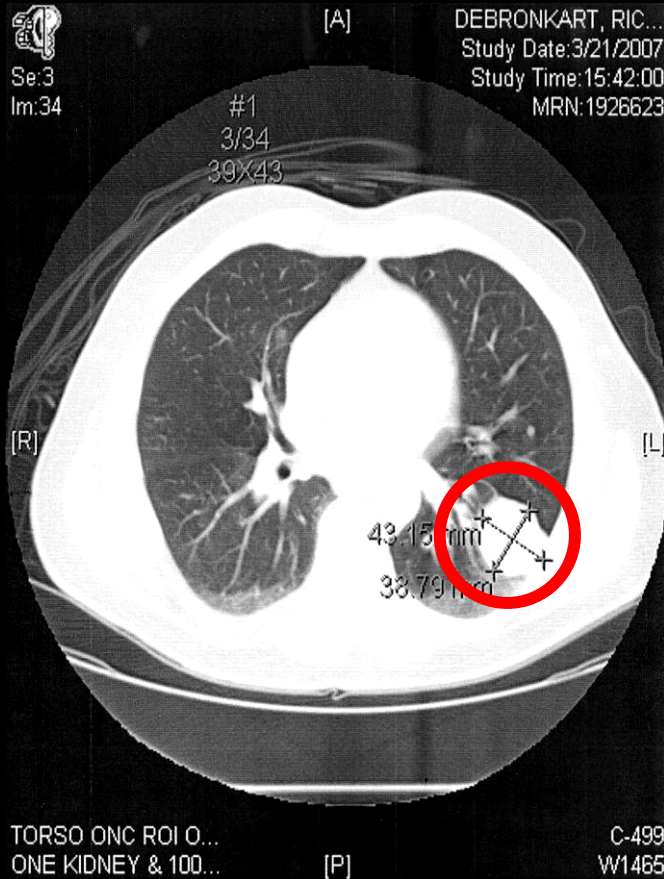
WEDNESDAY, APRIL 25, 2007 06:16 PM, EDT

# Finally, a Symptom (6 weeks post-x-ray)

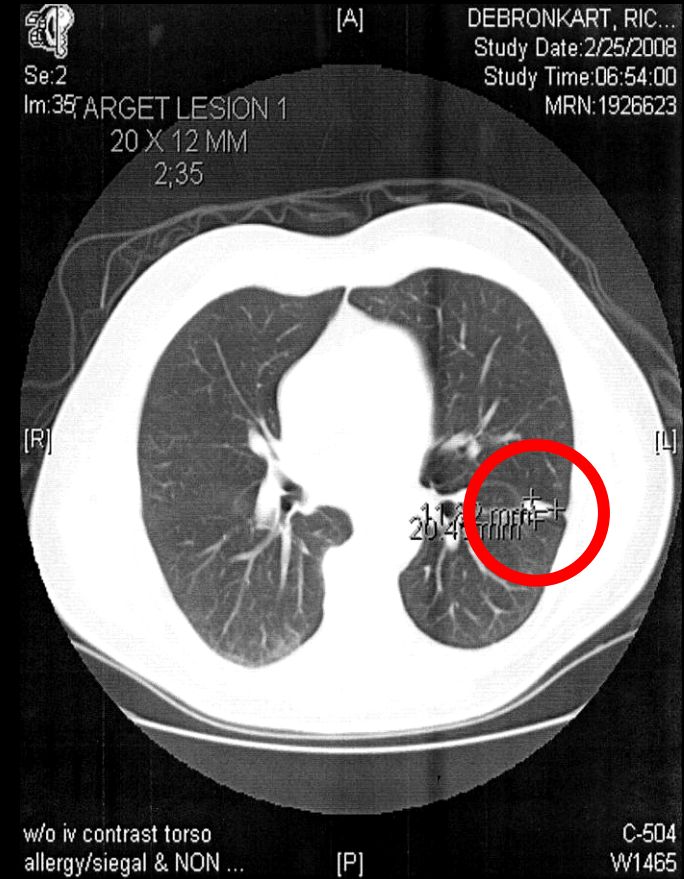


# Surgery & Interleukin worked.

## Target Lesion 1 – Left Upper Lobe



Baseline: 39x43 mm



50 weeks: 20x12 mm

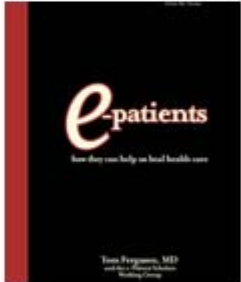


John Sharp,  
Cleveland Clinic:  
“If you have not read  
the e-Patient White  
Paper, you do not  
understand the future  
of medicine.”



Search this website...

white paper



How They Can Help Us Heal Healthcare

Download the PDF (977 KB)

Read/Edit the Wiki Version

principles 3 Comments »

EHRs/PHRs



**e-patients.net**  
because health professionals can't do it alone



Doc Tom said,  
“e-Patients are

↑  
e-Patients.net founder  
**E**quipped  
Tom Ferguson MD

1944-2006  
**E**ngaged

**E**mpowered

**E**nabled”



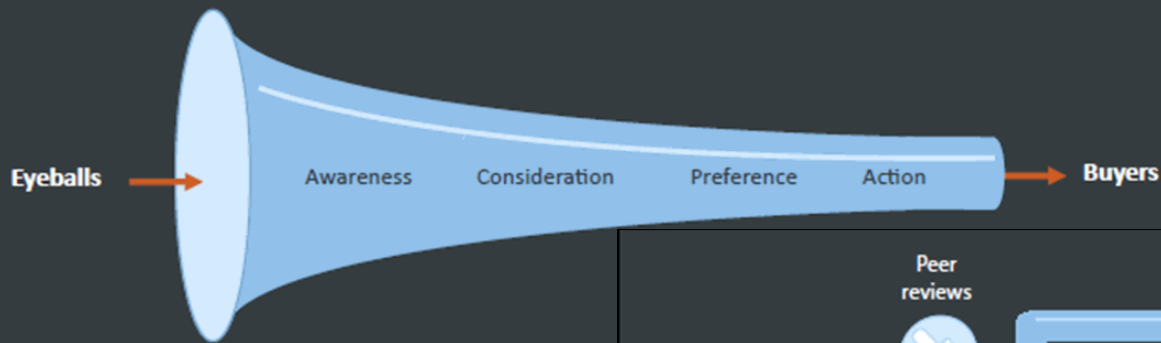
**A radical proposal:  
The “producer-consumer”  
paradigm is erroneous  
in today’s world.**

**Networked patients  
are producing value,  
not just consuming.**

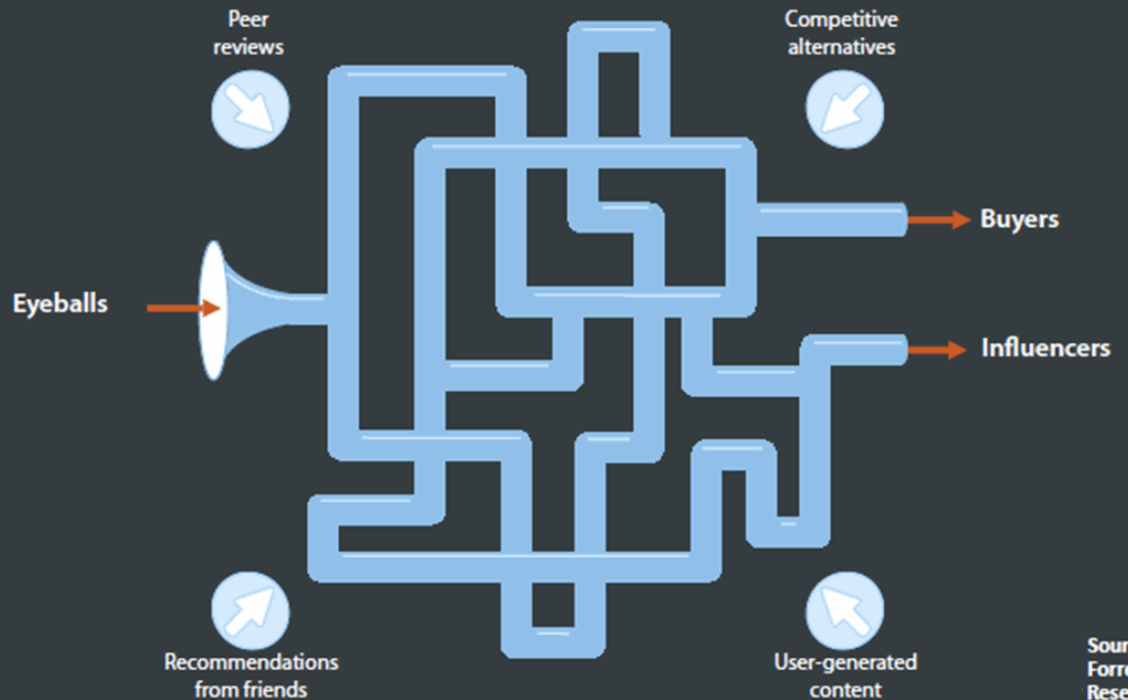
# Cluetrain Manifesto, 1999: “Markets are Conversations”

30 years ago the “marketing funnel” was this:

(Graphics by Forrester)



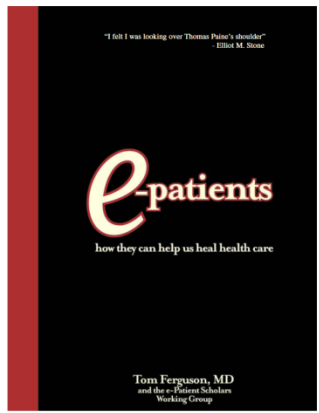
Today's buyer progresses like this:



**To overlook this**

(by not training and harnessing  
this highly motivated resource)

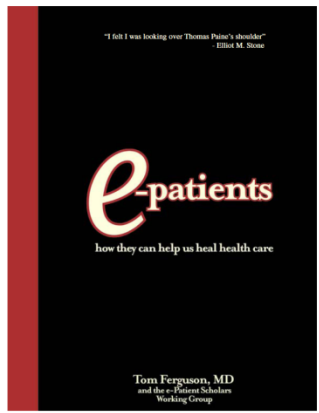
**would be to squander a  
substantial resource  
at a time of great need.**



# Dr. Lindberg: 400 years

“If I read two journal articles every night,  
at the end of a year I’d be 400 years behind.”

It’s not humanly possible to keep up.

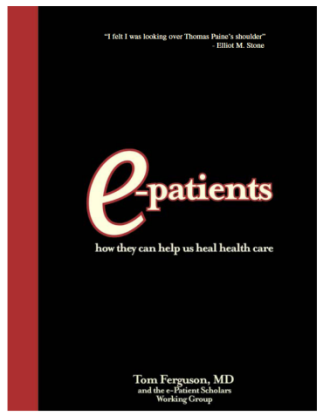


# The lethal lag time: 2-5 years

The time it takes after successful research is completed before publication is completed and the article's been read.

During this time,  
people who might have benefitted can die.

Engaged patients have all the time in the world  
to look for such things.



# Death by Googling: Not.

*(Dr. Gunther Eysenbach, Europe)*

*Compare with*

**“To Err is Human”**

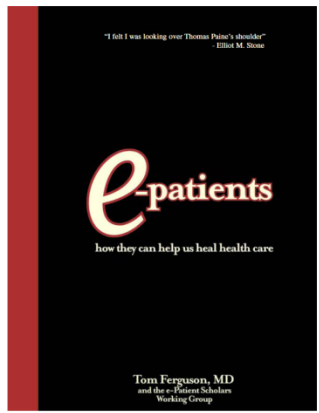
"I felt I was looking over Thomas Paine's shoulder"  
—John M. Swasey

# e-patients

how they can help us heal health care

Tom Ferguson, MD  
and the e-Patient Scholars  
Working Group

**“Arguably it’s  
more dangerous  
not to google  
your condition.”**



**“We modestly suggest that these conclusions are no more 'anti-doctor' or 'anti-medicine' than the conclusions of Copernicus and Galileo were 'anti-astronomer.’”**



# Participatory Medicine

The screenshot shows the homepage of the Society for Participatory Medicine. At the top left is the logo, which consists of three interlocking circles in blue and green, followed by the text "Society for Participatory Medicine" and the tagline "Bringing together e-patients and health care professionals." To the right of the logo is a search bar with a "Search" button. Below the logo is a navigation menu with links for "Home", "Declaration", "Blog", "Journal", "Join Us", "Member List", and "About Us". A quote is displayed: "Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners." Below the quote is a "Welcome" section with a paragraph of text and a small image of two hands shaking. To the right of the text is a sidebar with sections: "The Society" (with links to Declaration, About Us, Journal, and Join Us), "The Journal" (with a link to About the Journal), "White Paper" (with a link to e-Patients: How They Can Help Us Heal Healthcare), "Founding Organizations" (listing The Boston Foundation and The Douglas Drane Family Fund), and "Forums" (with links to e-Patient Stories, General Discussion, and Medical Records & Technology). At the bottom of the main content area is a video player with a play button and the text "Click to play video". The video player has a progress bar showing "00:00 / 00:00" and a volume icon. Below the video player is a caption: "Our two founding core initiatives are the e-patients.net blog and the Journal of Participatory Medicine."

**Society for Participatory Medicine**  
Bringing together e-patients and health care professionals.

Home Declaration Blog Journal Join Us Member List About Us

*Participatory Medicine is a movement in which networked patients shift from being mere passengers to responsible drivers of their health, and in which providers encourage and value them as full partners.*

## Welcome

Participatory Medicine is a cooperative model of health care that encourages and expects active involvement by all connected parties (patients, caregivers, healthcare professionals, etc.) as integral to the full continuum of care. The 'participatory' concept may also be applied to fitness, nutrition, mental health, end-of-life care, and all issues broadly related to an individual's health.

The Society was founded to learn about and promote Participatory Medicine through writing, speaking, social networking, and other channels. [Join us!](#)

**The Society**

- A Declaration of Participation
- About Us
- Journal of Participatory Medicine
- Join Us

**The Journal**

- About the Journal

**White Paper**

- e-Patients: How They Can Help Us Heal Healthcare (PDF, 977 Kb)

**Founding Organizations**

- tBf The Boston Foundation**  
INNOVATION. INFORMATION. IMPACT.  
The Douglas Drane Family Fund

**Forums**

- e-Patient Stories
- General Discussion
- Medical Records & Technology

Click to play video

Internet TV for Doctors

00:00 / 00:00 Volume

Our two founding core initiatives are the [e-patients.net](#) blog and the [Journal of Participatory Medicine](#).

“A movement in which networked patients shift from being mere passengers to responsible drivers of their health, and providers encourage and value them as full partners.”

## Low-Tech Models of Participatory Medicine: The Astounding Results of Group Prenatal Care

by e-Patient Dave on November 1, 2009

A signal moment in the history of this blog was the arrival in late summer of a new ally, the birthing movement, represented by Amy Romano, the blogger at [Science and Sensibility](#), the Lamaze International blog.

15  
tweets

retweet



white paper

Here's her next – a scientifically controlled study that demonstrates how being an engaged patient produces **life-altering improvements that no physician intervention has achieved**. The results **span all demographic boundaries** and **didn't involve a bit of technology**. It's exciting; please help scrutinize.

*Guest post by Amy Romano, Science and Sensibility*

In the process of reposting on my [blog](#) the [archives](#) of research summaries I wrote for a Lamaze e-newsletter from 2004-2008, I came across this summary of one of my all-time favorite randomized controlled trials. (Yes, I'm a nerd and have favorite RCTs.) I thought there was no better place to repost it than here, on e-Patients.net.

Reading this summary almost 2 years after I wrote it, I am struck by **how important it is to the emerging Participatory Medicine movement**. As you read it, keep in mind:

- The “intervention” – a participatory model of group prenatal care known as CenteringPregnancy – is **the only prenatal intervention known to reduce the risk of preterm birth** in mixed-risk populations. Preterm birth is one of the

How They Can Help Us Heal  
Healthcare

 [Download the PDF](#) (977 Kb)

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recent posts

**Note: If you include handhelds,  
the digital divide disappears.**

Cell phones leapfrog drinking water

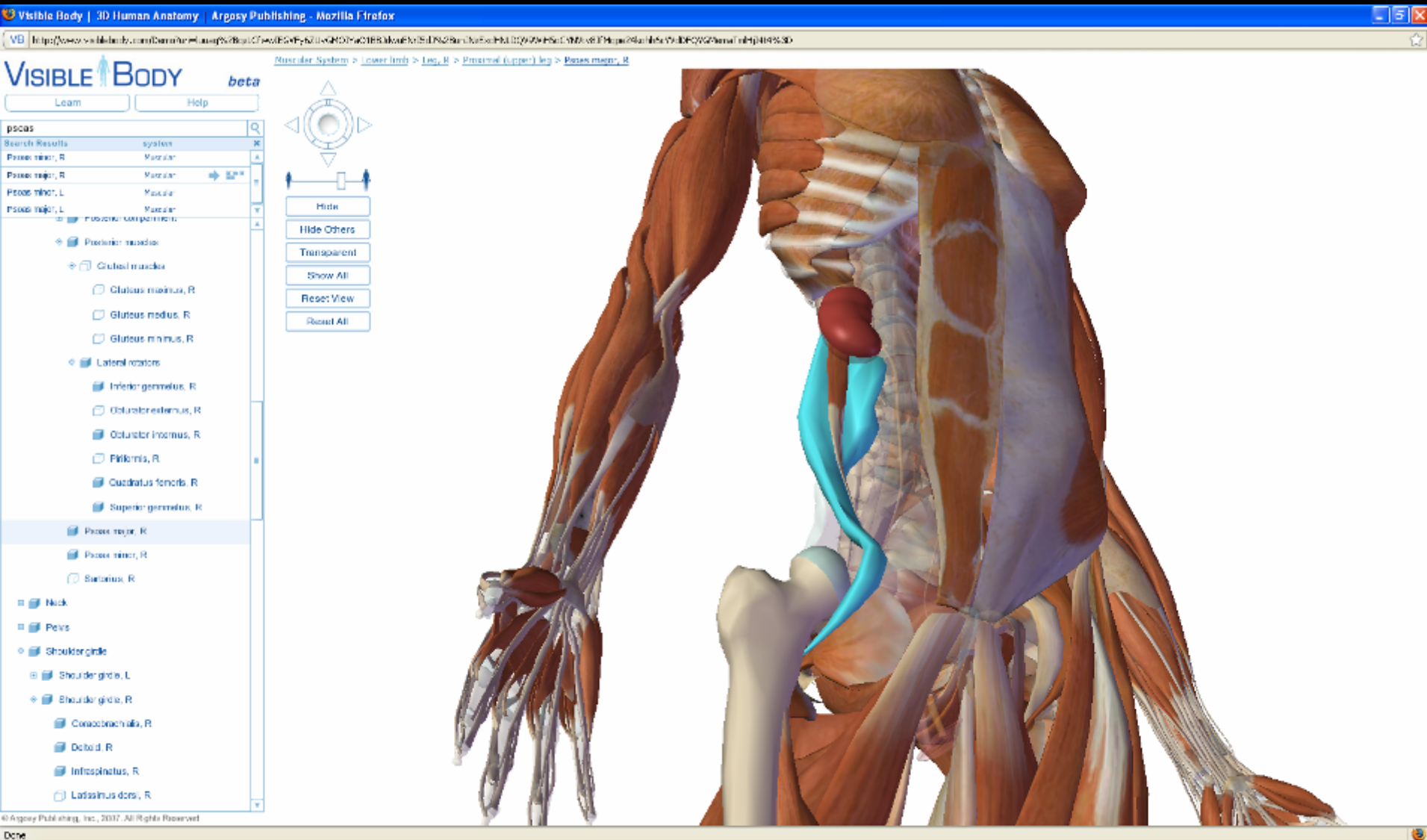


<http://thapz.blogspot.com/2008/04/cell-phones-leapfrog-drinking-water.html>

# Psoas muscle

(My kidney tumor was encroaching on it)

my rendering on VisibleBody.com







**e-patients.net**  
because health professionals can't do it alone



**E**mpower

**E**ngage

**E**quip

**E**nable

e-Patients

**Patient**

~~Consumer~~ **Engagement**  
**on the Hoof**

*as seen by the hoof*

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**dave@epatientdave.com**