

Give us speedometers.

Help us heed your advice.

**FDA Device Interoperability Workshop
January 25, 2010**

“e-Patient Dave” deBronkart @ePatientDave

How I came to be here today

- High tech marketing (TimeTrade Appointment Systems)
- Data geek; tech trends; automation
 - 2007: Cancer kicker
 - 2008: E-Patient blogger
 - 2009: Participatory Medicine, Public Speaker



**Patient is not
a third-person word.**

Your time will come –
you will care about this.

HealthLeaders

THE PATIENT OF THE FUTURE

Physicians suggest. Patients ignore. Technology alone won't bring them together. But a new relationship just might. p 18



Certifiable
Stroke Care p 33

The Art of
Balancing Risk p 47

Real-World
Bundling p 53

**I'm like JFK:
“They sank my boat”**

The Incidental Finding

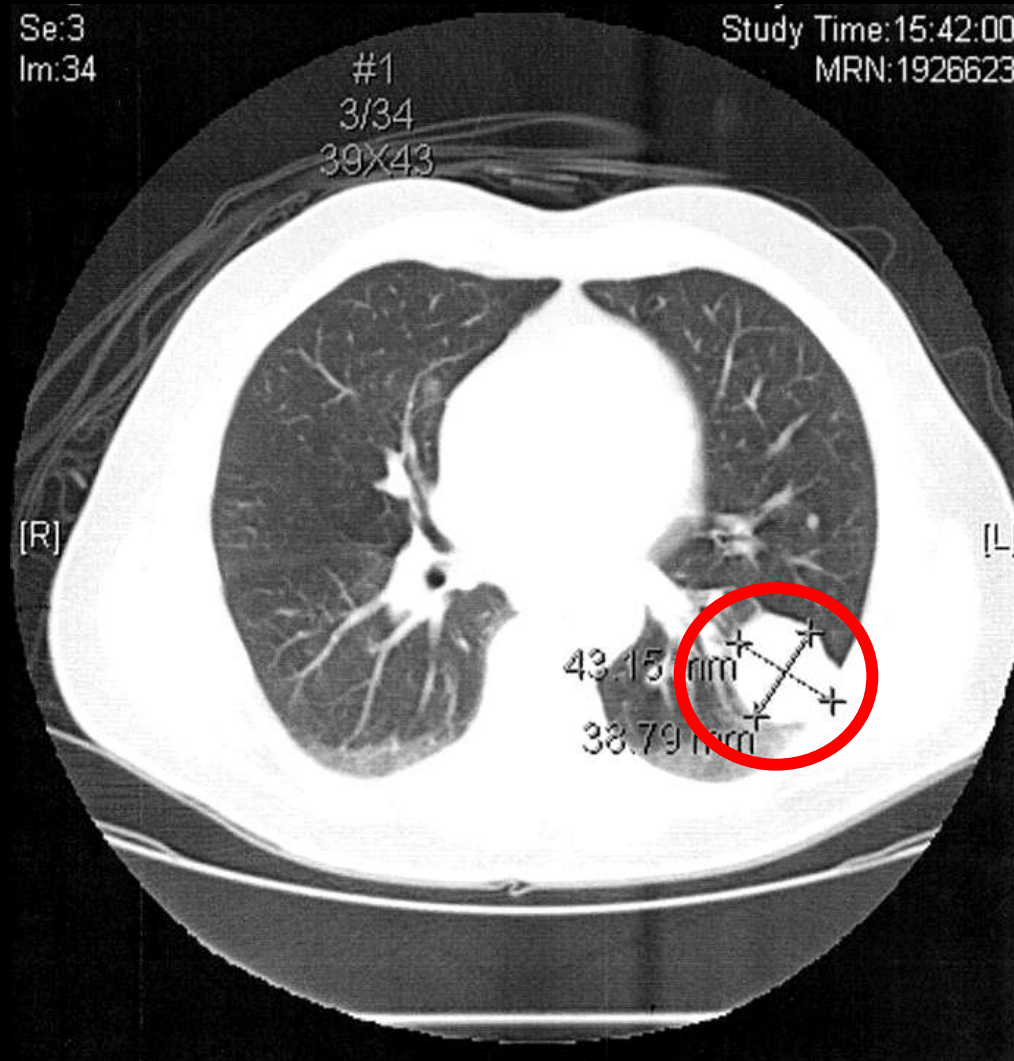
Routine shoulder x-ray, Jan. 2, 2007



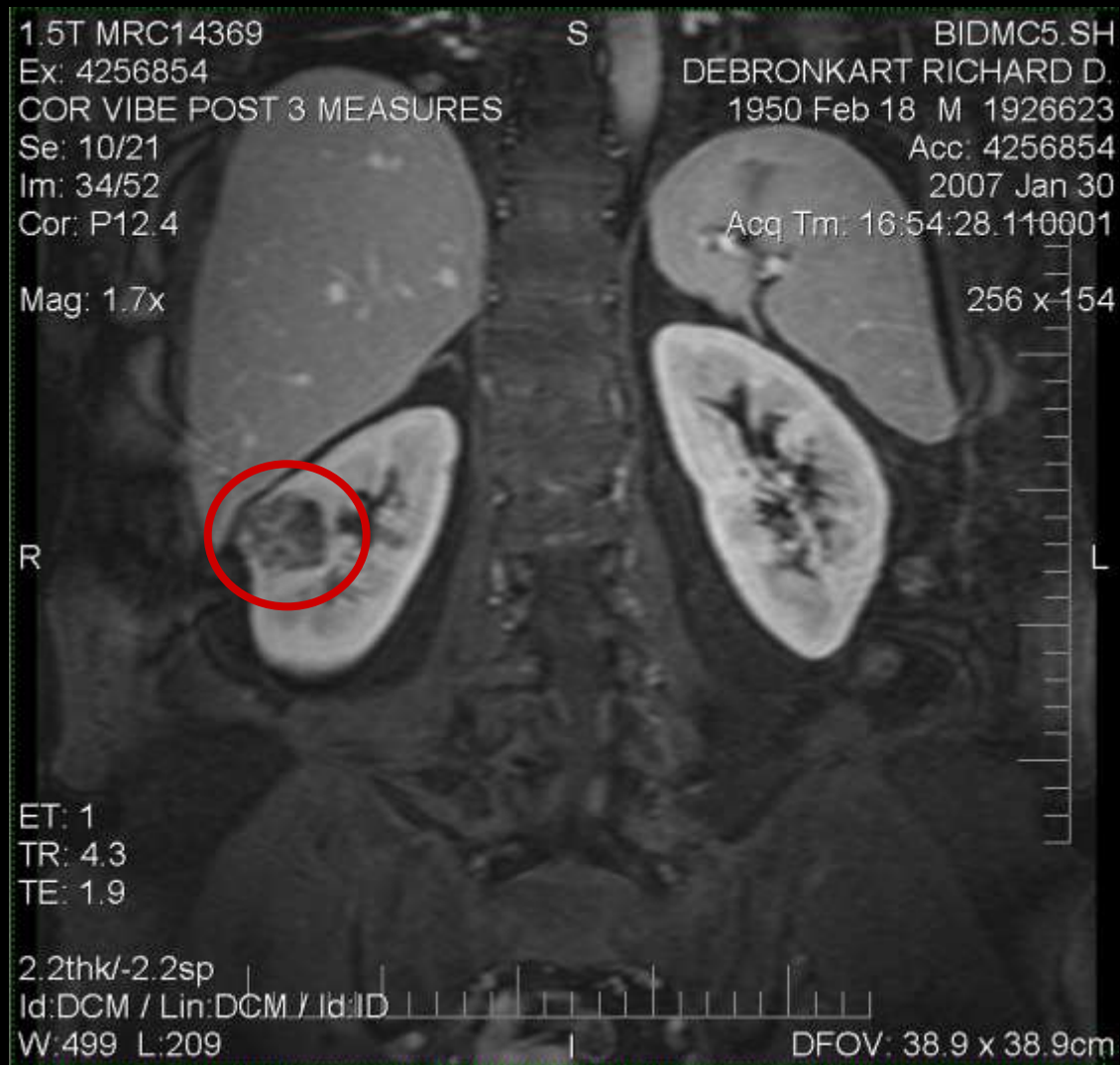
*"Your shoulder
will be fine ...
but there's
something
in your lung"*

Multiple tumors in both lungs

Where's This From??



Primary Tumor: Kidney



- 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](#)

E-Patient Activity 1: Researching my condition

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

FONT SIZE
A A A

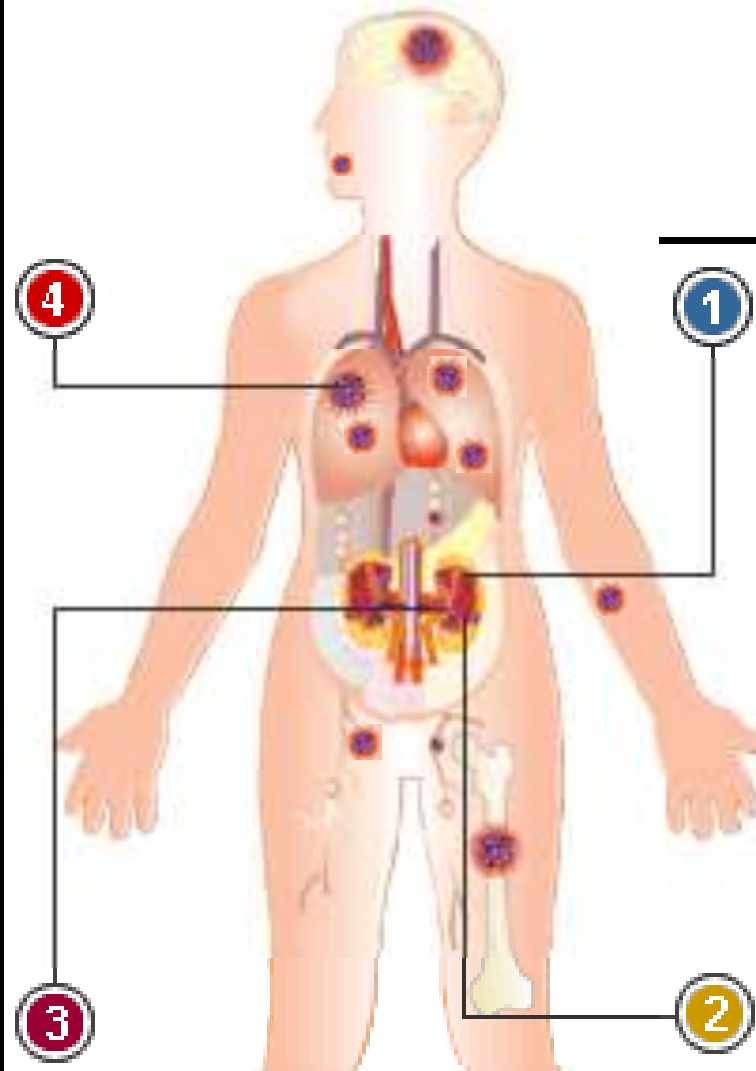
Stage IV renal cell cancer is defined by the following stage groupings:

- ❖ 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)

The screenshot shows the ACOR.org website. At the top left is the logo for **acor.org** with the tagline "Association of Cancer Online Resources". To the right of the logo is a navigation bar with icons for Home, Dictionary, Help, and Site Map. Below the logo is a search bar with the text "Find a mailing list" and a "Search" button. The main content area is divided into several sections. On the left is a "WELCOME" section with the text: "ACOR is a unique collection of online communities designed to provide timely and accurate information in a supportive environment." Below this is another paragraph: "ACOR offers access to mailing lists that provide support, information, and community to everyone affected by cancer and related disorders." In the center is a vertical menu of navigation links, each with a play button icon. The links are: MAILING LISTS, SUPPORT & RESOURCES, TYPES OF CANCER, TREATMENT OPTIONS, CLINICAL TRIALS, PUBLICATIONS, PARTNERSHIPS, and HELP ACOR. The "SUPPORT & RESOURCES" and "TYPES OF CANCER" links are circled in red. On the right is a "News" section with a "News" header and three empty boxes. Below the header is a news article titled "Fat tissue-derived hormone leptin increases e-cadherin expression, obesity-breast cancer link noted" with a sub-headline "Being obese increases the risk of breast cancer in post-menopausal women, shortens the time between return of the disease and lowers overall ...". The article is dated "Apr 29, 2007" and has a "[Full Story]" link. Below the news section is a "What's New" section with the text "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
03/30/09 4:13 PM	E141R FOREARM (AP & LAT) RIGHT	APPROVED
03/30/09 4:13 PM	E221L FEMUR (AP & LAT) LEFT	APPROVED
03/30/09 4:13 PM	E212R HIP UNILAT MIN 2 VIEWS RIGHT	APPROVED
03/10/09 3:24 PM	Q992 CT CHEST W/O CONTRAST W/ONC TABLES	APPROVED
03/10/09 3:24 PM	Q995 CT ABDOMEN W/O CONTRAST W/ONC TABLE	APPROVED
03/10/09 3:24 PM	Q998 CT PELVIS W/O CONTRAST W/ONC TABLES	APPROVED
12/09/08 4:10 PM	Q992 CT CHEST W/O CONTRAST W/ONC TABLES	APPROVED
12/09/08 4:10 PM	Q995 CT ABDOMEN W/O CONTRAST W/ONC TABLE	APPROVED
12/09/08 4:10 PM	Q998 CT PELVIS W/O CONTRAST W/ONC TABLES	APPROVED
09/04/08 3:32 PM	Q411 CT CHEST W/O CONTRAST	APPROVED

Services

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

About Me

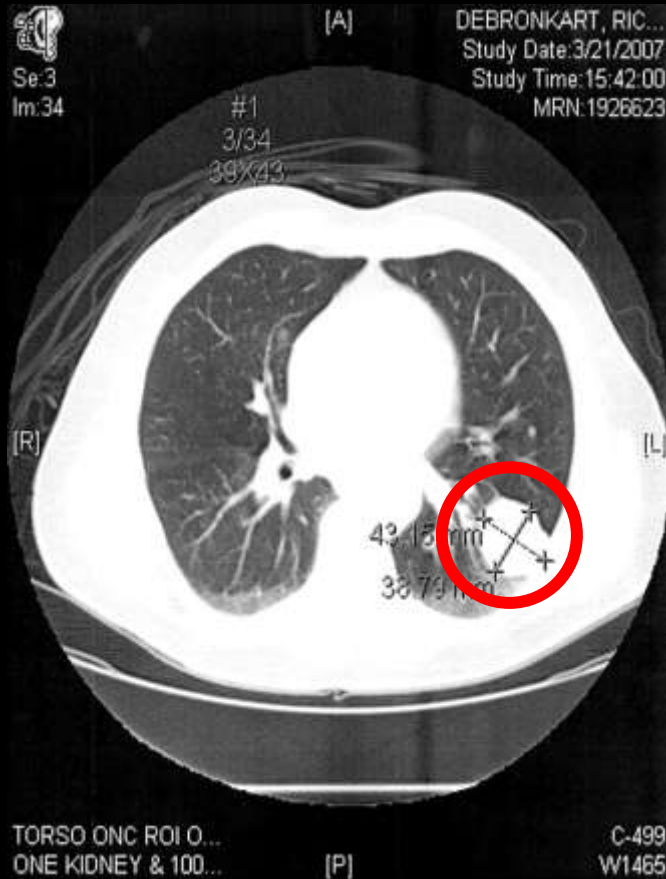
Records
Personal Profile

Support

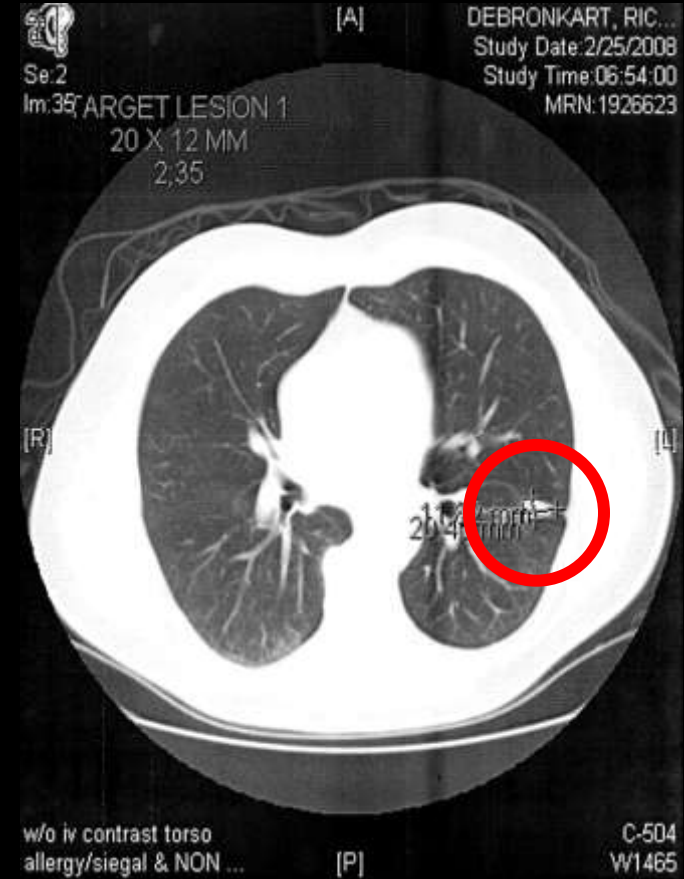
Tech Support
FAQ/Tutorial

The treatment worked.

Target Lesion 1 – Left Upper Lobe



Baseline: 39x43 mm



50 weeks: 20x12 mm



e-patients.net

because health professionals can't do it alone



*Doc Tom said,
“e-Patients are*

Equipped
Engaged
Empowered
Enabled”



e-patients.net

because health professionals can't do it alone



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

**e-Patients:
How They Can Help Us Heal
Healthcare**

Download the PDF (977 KB)

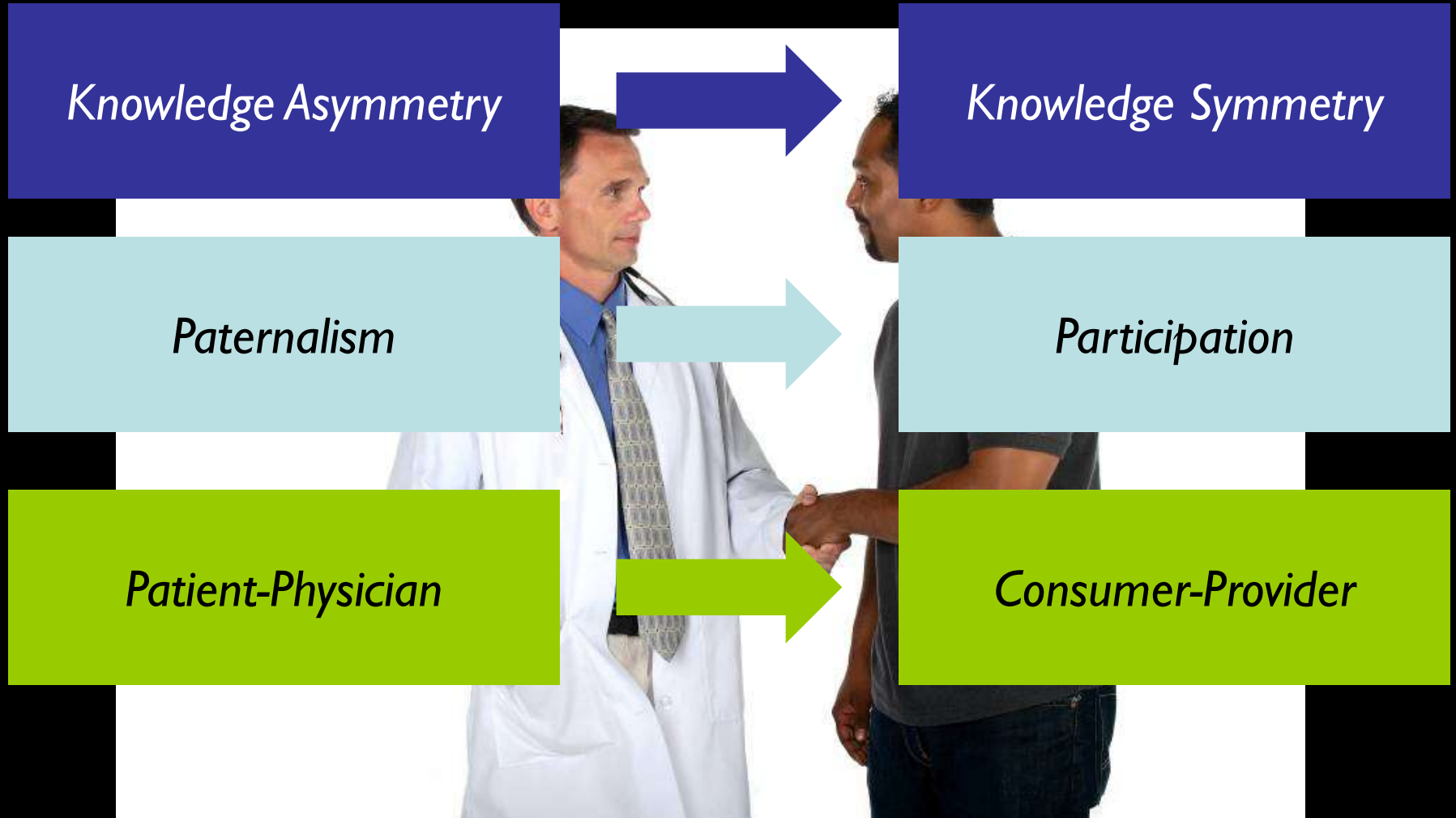
Read/Edit the Wiki Version

principles **3 Comments »**

EHRs/PHRs

Changing Nature of the Relationship

Author of this slide: Danny Sands MD, MPH





e-patients.net

because health professionals can't do it alone



“Physicians are coaches. Patients are players.”

by e-Patient Dave on December 31, 2008

I don't know who Stanley Feld is, but he just became my friend, with a terrific post on [doctor as coach](#), [patient as player](#). It starts:

4

tweets

retweet

“ *The role of patients with chronic diseases and their physicians must be clear to both patients and physicians. Physicians are*

A project of the

Society for Participatory Medicine

white paper

This resonates with what's become my favorite item from Chapter 2 of our white paper, *e-Patients: How they can help us heal health care*. Preliminary Conclusion #6, which is “The best way to improve healthcare is to make it more collaborative.”

the kidney cancer group on ACOR.org, taught me that increasingly cancer has become not an immediate threat to life but a chronic condition. Then, when I read *Anticancer: A new way of life*, an astounding idea came to my attention: cancer without disease.

e-Patients:

How They Can Help Us Heal Healthcare

“How can patients participate if they can’t see their information?”



2009: Society for Participatory Medicine

- “a cooperative model of health care that encourages and expects active involvement by all connected parties.”
- Led by a partnership of physicians and patients


Society for
**Participatory
Medicine**

Bringing together e-patients and health care professionals.

[Home](#) [Declaration](#) [Blog](#) [Journal](#) [Join Us](#) [Member](#)


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!](#)



Click to play video



**We publish
weight guidelines
and encourage
using a scale**

**What if we published
carefully researched speed guidelines
but no speedometers?**



How can we accelerate? Lessons from High Tech

- **Object-oriented programming**
- **Waterfall vs Agile**
- **Innovation flourishes
in a robust ecosystem**

Lessons from High Tech #1: Object-Oriented Programming

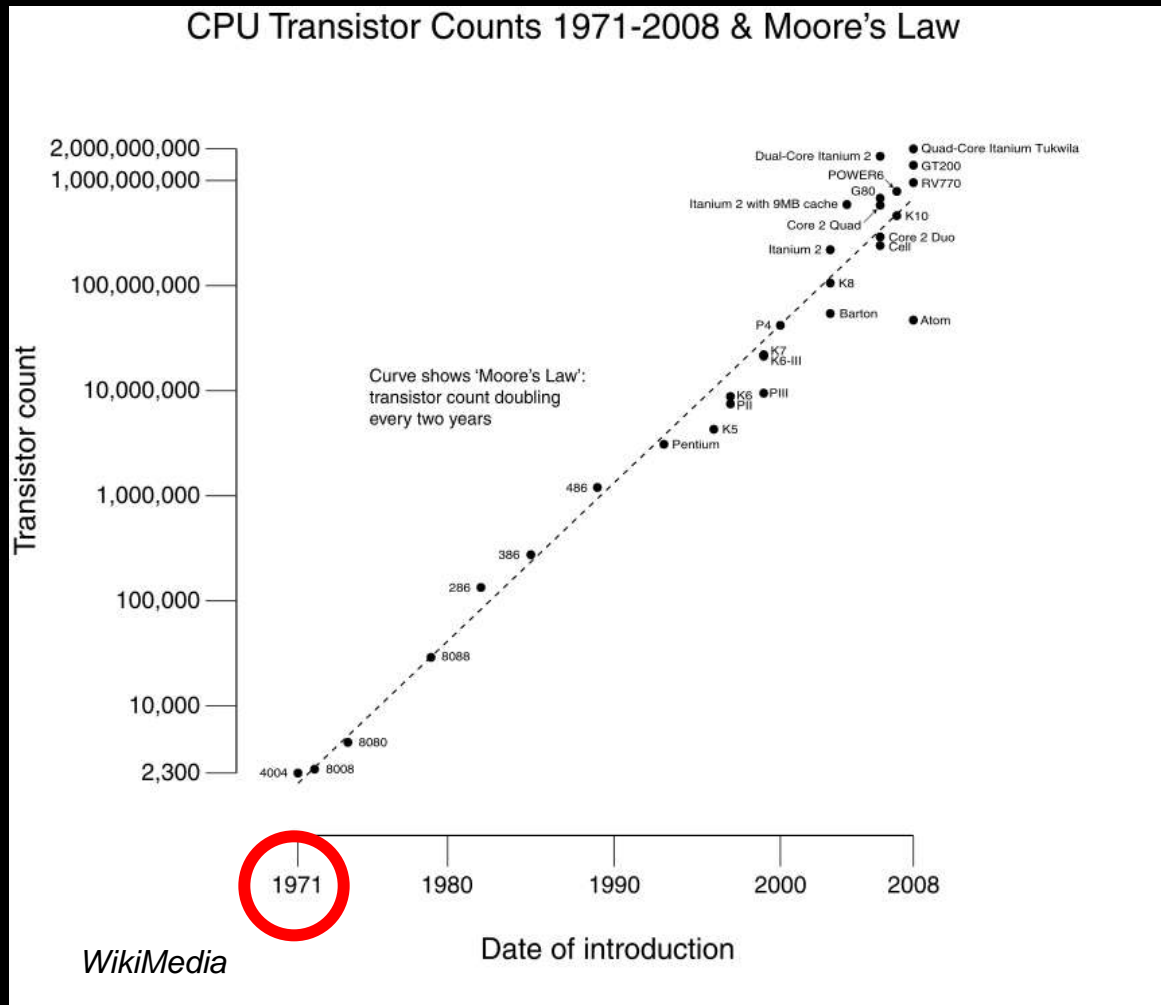
- Encapsulation
- Unit testing
- Test the interface,
not the internals
 - Lets people freely
develop new methods
without altering the
rest of the workflow



Dijkstra:

- Father of structured programming ("A Case Against the GOTO Statement")
- Turing Award winner in 1972

What changed? Moore's Law.



The penalty
for changing
your mind
dropped
dramatically.

Flexibility
became
affordable.

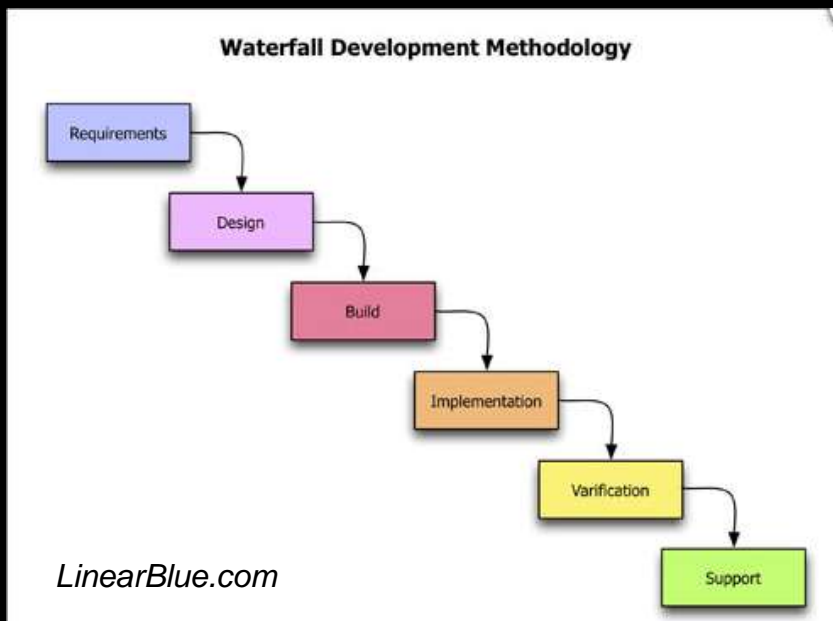
Lessons from High Tech #2: Agile replaces Waterfall

- **Waterfall**

- Decide what you want, and plan it. Efficient.
- Allows optimizing.
- “Make up your mind!!”

- **Agile development**

- You can't figure it out in advance anymore. Deal with it.
- Besides, things change so fast, the target moves.
- So: get started and adapt as you go along.
- **KEEP YOUR OPTIONS OPEN.**



Lessons from High Tech #3: Rich ecosystems → innovation





■ *e-Patient Dave* says:

September 17, 2009 at 1:13 pm (Edit)

I want innovation at a rate that resembles the rate of improvement in cell phones and iPods: I want to think, in 2011, that the healthcare tool I started using in 2009 is, well, “that’s SO 2009,” just the way many people think about their cell phones.

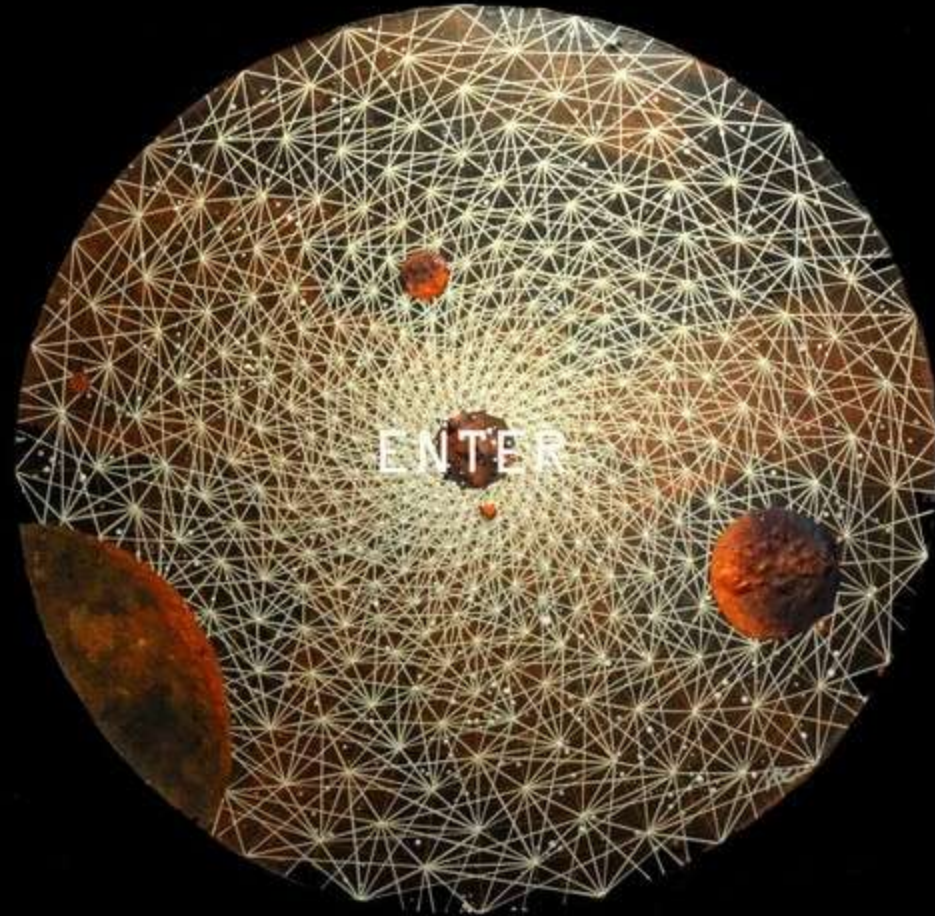
Lessons from High Tech #4: Combinatorial Explosion

Scenario:

2,000 models of Dell PC

1,000 models of HP printer

- To test each in isolation:
3,000 tests to do
- To test all combinations:
2 million tests



Do the math.

Compare...

- Testing 2,000,000 combinations,
- vs 3,000 individual items, is...

667 times more work

- Budgetary impact
- Time (months/years)

Drastic impact on innovators' payback;
impedes innovation and consumer benefit

**We can't get there in time
doing it that way.**

**I want modern
mash-ups.**

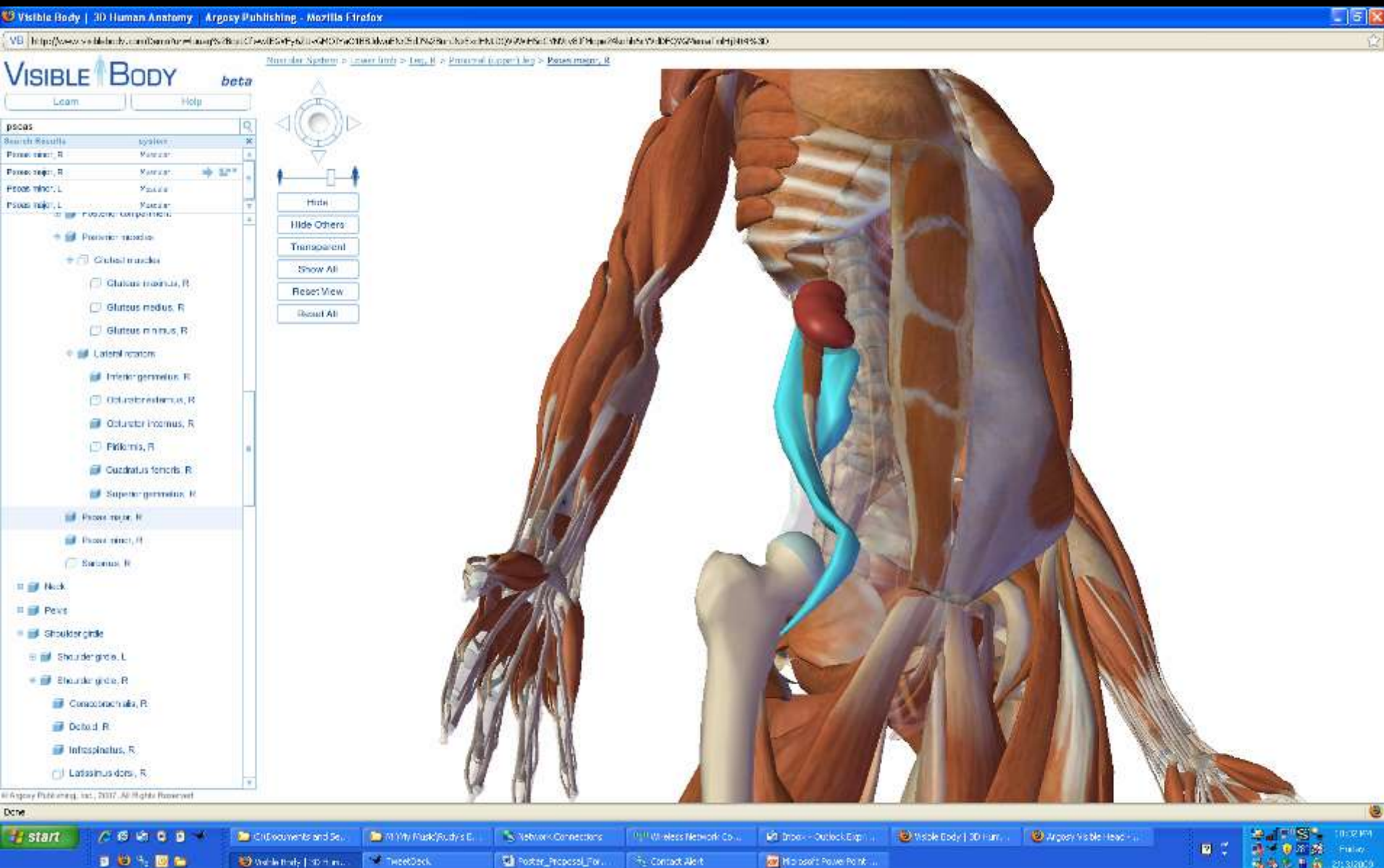
Old School (literally)



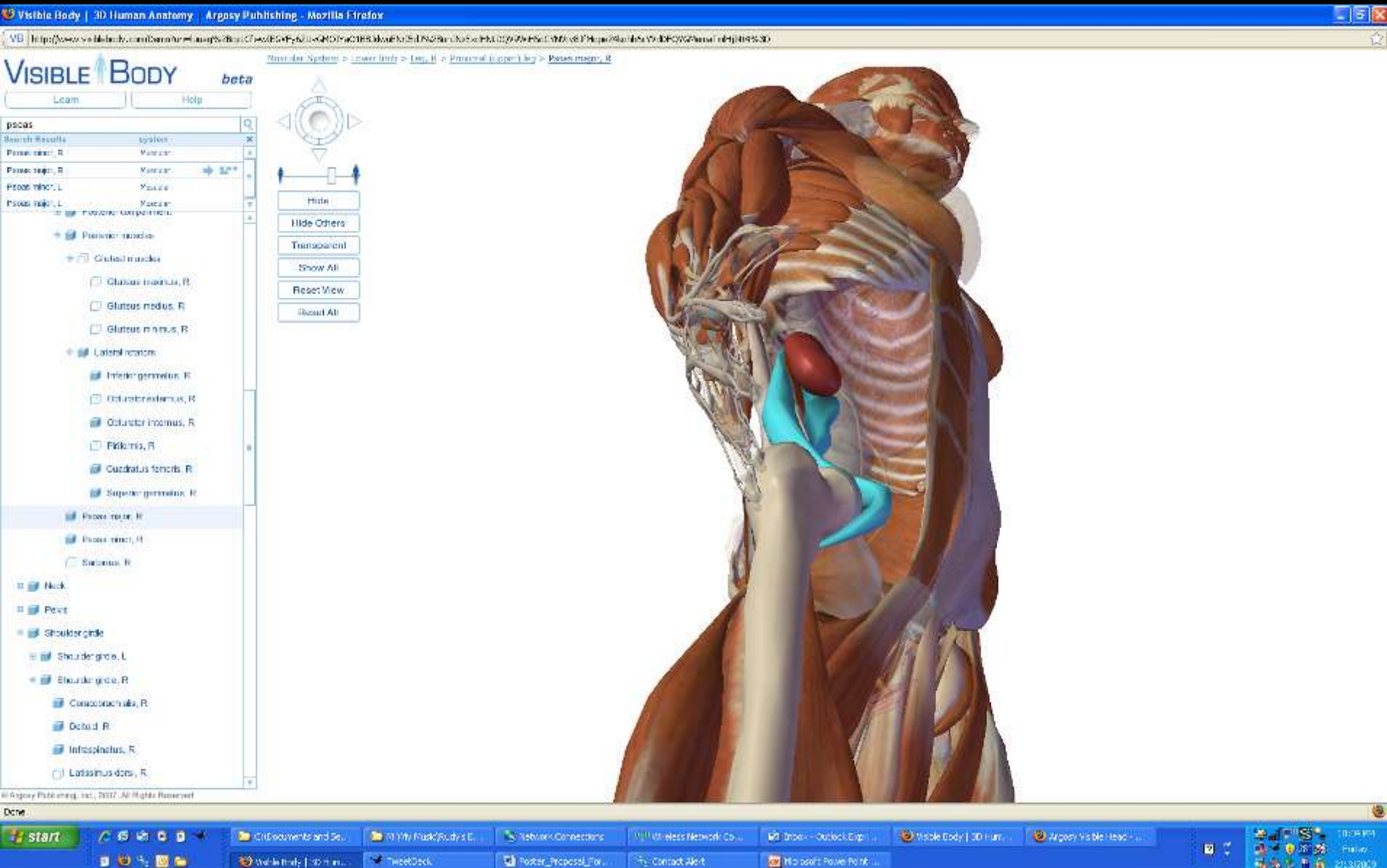
Modern: psoas muscle

(My kidney tumor was encroaching on it)

my rendering on VisibleBody.com



Why not “Google Earth for my body”?



Don't Leave Me This Way



Give us speedometers.

And tachs.

And pressure gauges.

Empower and Enable.

Help us heed your guidelines.

I can do a lot better
if I know *how* I'm doing.

Help us heed your guidelines.

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