

**My Own Medicine:  
Lessons Learned En Route to  
Remission**

**Geoffrey Kurland, M.D.  
Children's Hospital of Pittsburgh**

# Disclosures

- No financial conflicts of interest, unfortunately...
- This talk will have a tangential discussion of off-label drug use
- There will be no mathematics, equations, etc.
- The opinions contained in this talk are my own...

I WONDER WHERE WE  
GO WHEN WE DIE.





PITTSBURGH?



5-17

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YOU MEAN IF WE'RE  
GOOD OR IF WE'RE BAD?

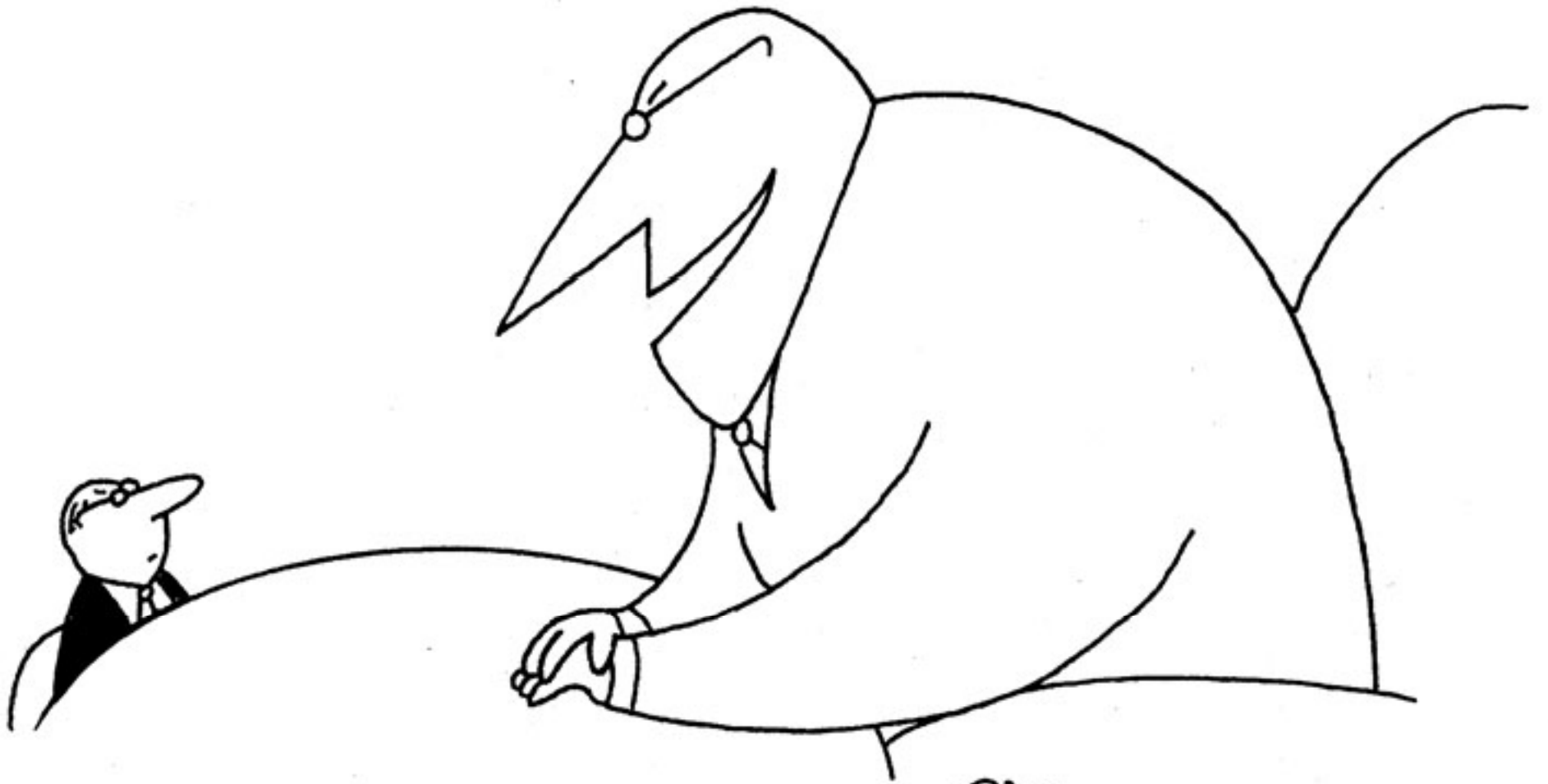


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NEIBSON

Who is this guy?

...and what is he  
qualified to speak about,  
anyway?



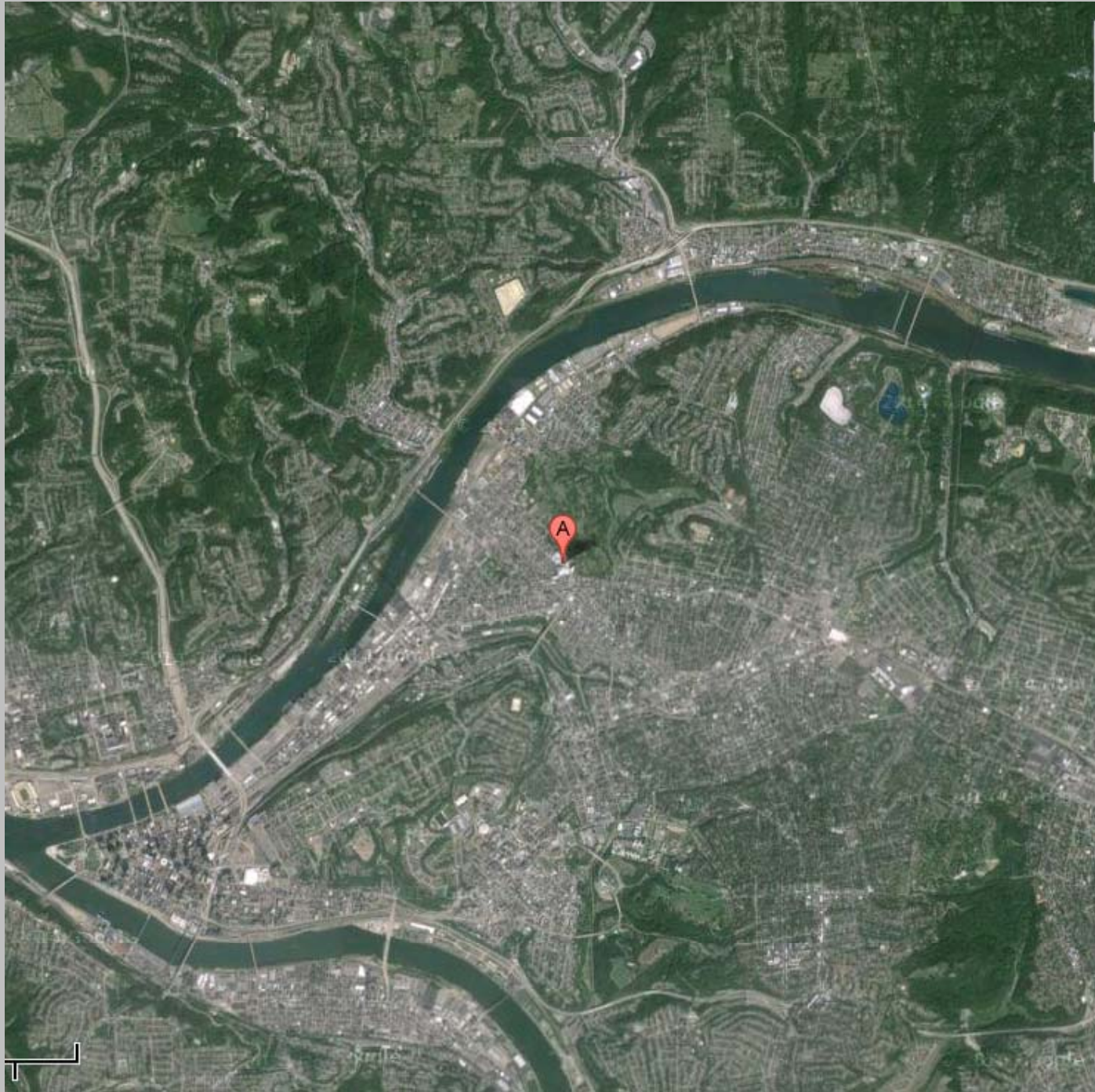
*C. Barzotti*

*"I hope you don't think that you have a monopoly on ethics."*

• •







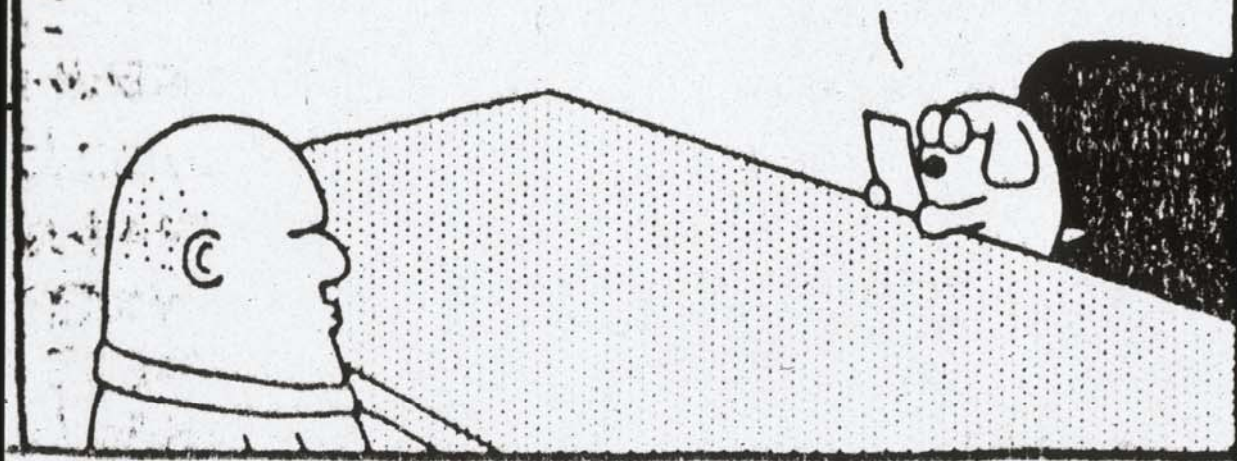




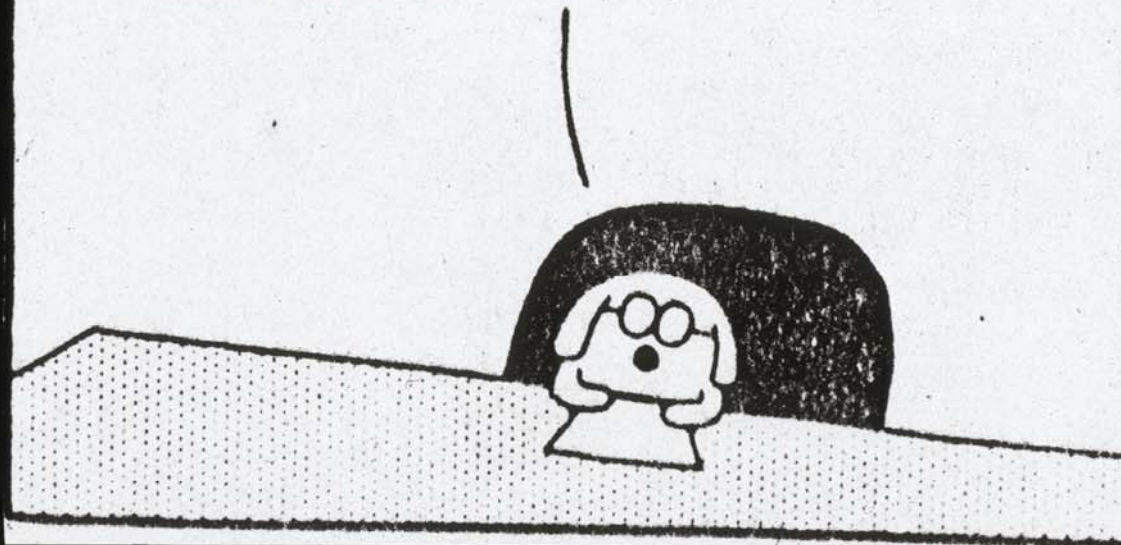


DOGBERT, CAREER COUNSELOR

ACCORDING TO YOUR  
OCCUPATIONAL PREFERENCE  
TEST, YOU LIKE TO REMOVE  
VITAL ORGANS FROM  
HELPLESS PEOPLE.



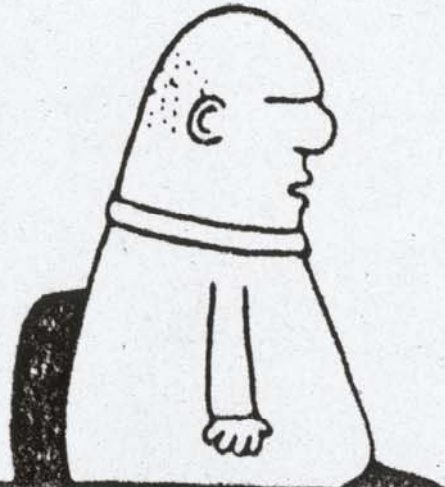
THAT NARROWS THE  
CAREER CHOICES TO  
DOCTOR. OR SERIAL  
KILLER. DO YOU GET  
ALONG WITH OTHER  
PEOPLE?





OTHER PEOPLE  
ARE INSIGNIFI-  
CANT INSECTS.

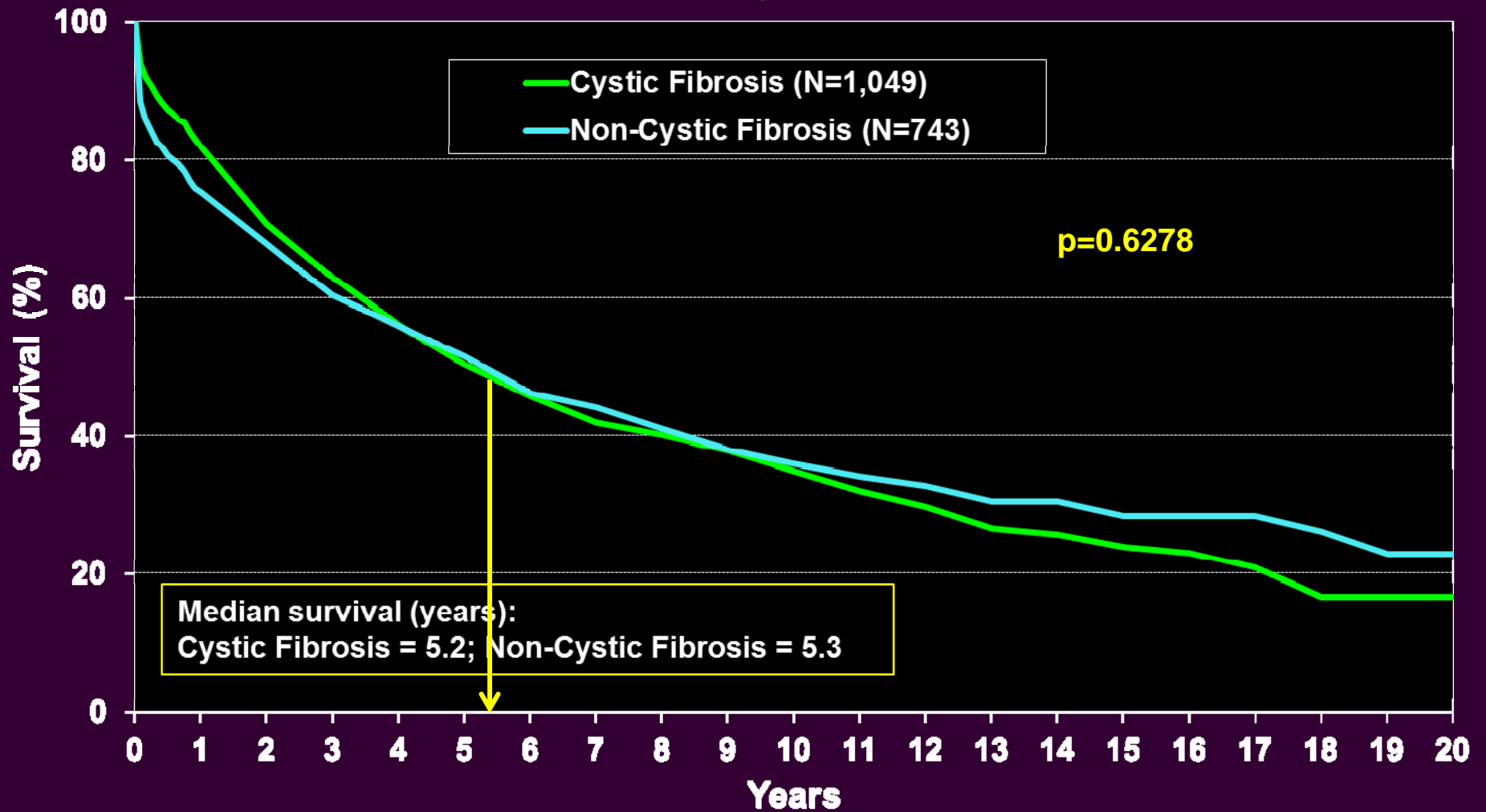
WE'LL HAVE TO  
GO TO A  
TIE-BREAKER  
QUESTION.



# A few of my "qualifications"

- Physician
- Former long distance Runner (...as if that qualifies me for anything...)
- Survivor of leukemia
- Current "battler" of prostate cancer

# Pediatric Lung Transplants Kaplan-Meier Survival by Diagnosis (Transplants: January 1990 – June 2013)











**M Y O W N M E D I C I N E**

A D O C T O R ' S L I F E A S A P A T I E N T

**G E O F F R E Y K U R L A N D , M . D .**

# **My Own Medicine**

## **A Doctor's Life as a Patient**



**Geoffrey Kurland, M.D.**

**Now available on Kindle and Nook!!**

# How Does a Single Description of a Medical Experience "fit" with this Conference/Talk?

- This is an example of "Narrative" in Medicine...
- It relates "what happened" in a way that links the reader to the author's (=patient's) feelings, thoughts, and actions.
- It gives a glimpse of a set of patient-physician relationships with teaching (and possibly "ethical") considerations...

"Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged...to identify ourselves as citizens of that other place."

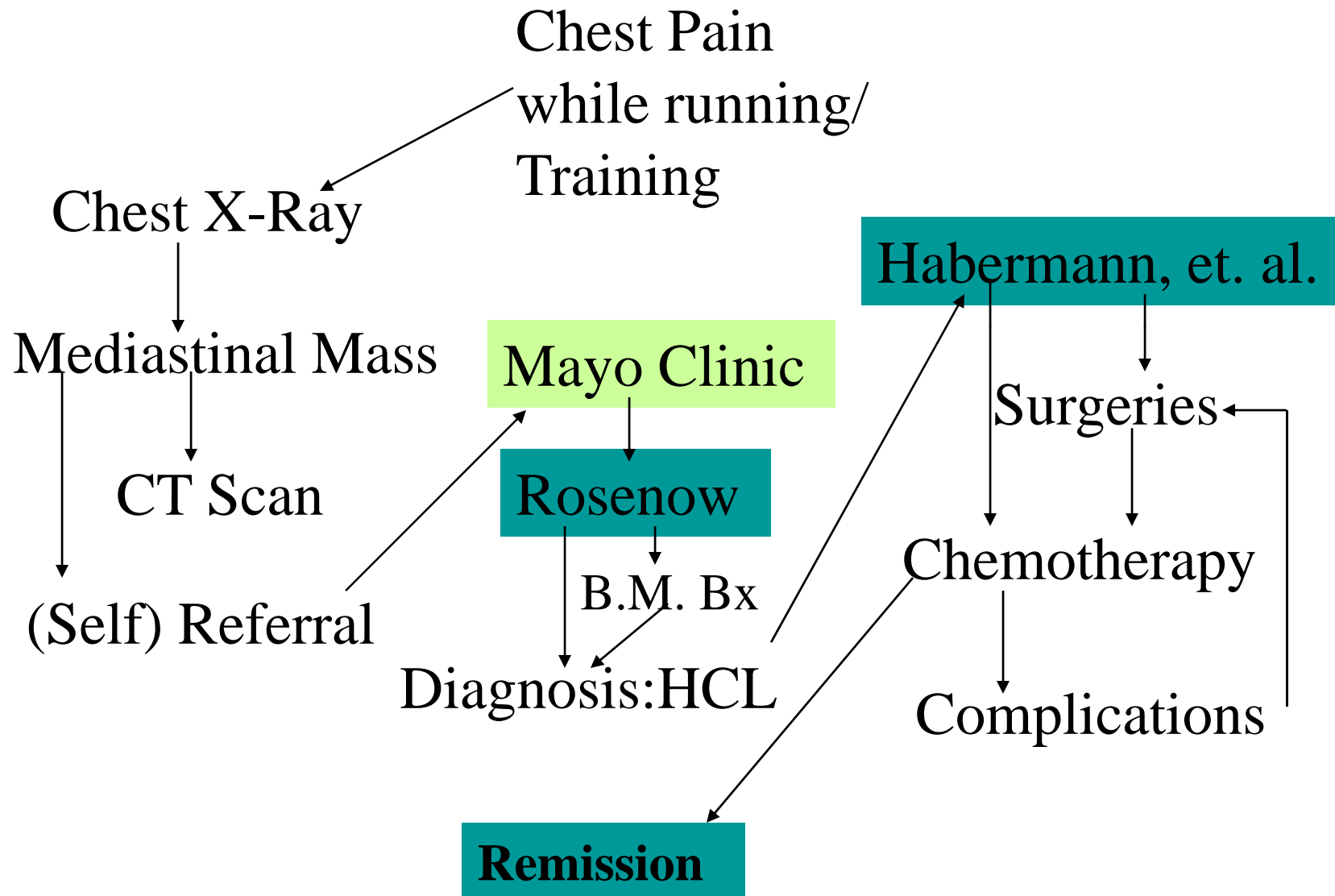
Susan Sontag

"Illness as Metaphor"

"While there are several chronic diseases more destructive to life than cancer, none is more feared."

Charles H. Mayo, M.D. *Ann. Surg.* 83:  
357-363, 1926

# A "SIMPLE" STORY



Simple Stories Aren't  
Necessarily Simple...



- Illness is experienced within a personal context, a personal set of needs, and a personal view of the world.
- Remembrance of any event such as an illness is just that: A highly *personal* reminiscence.

"It is quite true what  
Philosophy says: that Life  
must be understood  
backwards. But that  
makes one forget the  
other saying: that it must  
be lived - forwards..."

S. Kierkegaard, journal entry 1843

# Facts About my Treatment (1)

- When I was diagnosed, the long-term survival with HCL was about 40-50%.
- My physicians had to decide how to approach my disease: I had a chest mass and newly diagnosed leukemia. Were they related? What was the safest and best approach?

# Facts About my Treatment (2)

- I participated in a clinical trial of a new chemotherapeutic agent (Pentostatin) after a course of Interferon
- I developed FUO during Interferon...my physicians had to decide if I could continue treatment.
- They also tried to find the cause of the fever, which involved invasive procedures.

# Lessons I Learned

## (About Me...)

- Some parts of me are strong...others aren't
- Post-op pain is a real phenomenon
- "Learn about procedures by having them done to you" sounds a lot better than it actually is... (Informed consent???)
- A sense of humor doesn't hurt
- Mom's chicken soup almost always helps

"Pain is inevitable;  
suffering is optional."

Anonymous Ultrarunner

# Lessons I Learned

## (About Me...)

- Signs/Symptoms are easy to miss, especially if you're the one experiencing them.
- Sir William Osler was right: The physician who treats himself has a fool for a patient.
- Receiving a diagnosis may lead to temporary "brain paralysis".

“Don't know what happens when people die.  
Can't seem to grasp it as hard as I try.  
It's like a song I can hear  
Playing right in my ear.  
I can't sing it;  
I can't help listening.”

Jackson Browne “To a Dancer”,  
Album “Late for the Sky” 1974



# Lessons I Learned (About Me...)

- Recovery requires patience.
- Illness can be simultaneously isolating, painful, and demoralizing, while still being focusing, uplifting, and enlightening.
- The appearance of strength is sometimes more important than the weakness that is real.

# Lessons I Learned

(About Patients and Their Physicians...)

- Physicians don't always know the answers...but they can always look for them and adjust the treatment.
- Honesty and Full Disclosure are good policy for patients as well as physicians.

# Lessons I Learned

(About Patients and Their Physicians...)

- The patient-physician relationship is, like any relationship, fluid and built upon compatibility and communication.
- The ability to listen enhances one's ability to communicate...this goes for patients as well as physicians.

Yours

POLS

54ct

When it comes

to communication

# Lessons I Learned

## (Societal...)

- There are different coping strategies for dealing with sickness (and with friends who are ill).
- A plethora of books on "Non-Traditional Medicine" or related topics (e.g. psychology of disease) are out there...and many were sent to me...
- I read none of them...

Walking through the fire  
always changes the person  
doing the walking.

It may also change the people  
watching and supporting the  
person doing the walking...

"Theories that diseases are caused by mental states and can be cured by will power are always an index of how much is not understood about the physical terrain of a disease."

Susan Sontag  
Illness as Metaphor

“Modern biology has now proven the physical reality of the mind-body connection and uncovered some of the mechanisms...But there are limits. We can't cure cancer with good thoughts, but good thoughts can make us feel better and allow us to function more effectively.”

Bernd Heinrich *Why We Run*





"Prayer indeed is good, but while calling on the gods a man should himself lend a hand."

*Hippocrates; Regimen, book IV, 87*

To a large extent I found that the lessons I learned were already in place:

My experience reinforced many of the tenets that shaped my life as a physician...and a runner

# Lessons I Learned

(About Patients and Their Physicians...)

- "Listen carefully, the patient is telling you the diagnosis."
- Honesty is accepted and appreciated.
- Take advantage of the medical team.
- Recognize that improvements in medical care, knowledge, and understanding are constant and should be expected.

# Lessons I Learned

(About Patients and Their Physicians...)

- Physicians can (and should) listen and talk to their patients about their diagnosis, treatment, prognosis...
- Patients can (and should) listen and talk to their physicians about their illness, their treatment, their fears, their needs, and their goals...

The journey of illness is one almost never taken willingly. Its hoped for destination is a good outcome, but with severe disease that outcome may not be attainable.

A lot of "surviving" an illness is about maintaining a good "quality of life."

Just What Is "Quality of  
Life"?

"I can't define it, but I  
know it when I see it."

Paraphrasing Justice Potter Stewart in *Jacobellis v. Ohio*  
(1964)

**"Quality of Life" is  
not just a catch  
phrase to get  
Government funding  
for research grants.**



As a physician, I had  
some control over my own  
life... and the lives of my  
patients.

As a patient, I found myself at the mercy of my illness, its treatment, its complications, and its course.

My own illness sought to control my life, insinuating itself into every fiber, thought, and action.

My Personal "QOL" Meant Taking  
Back Some of that "Control"...

- Work
- Relationships
- Running









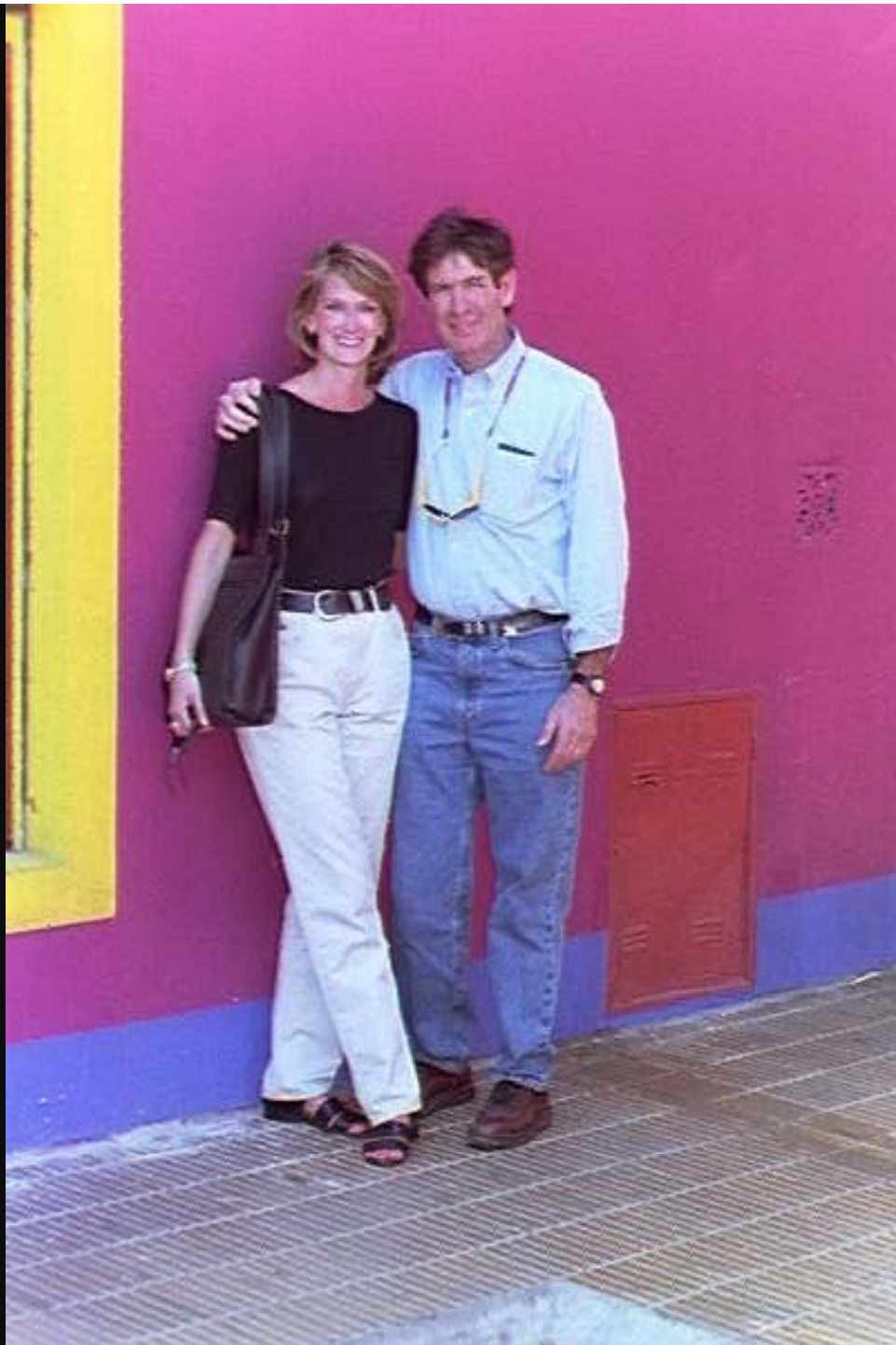


**UC Davis Medical Center**

"I desire no other epitaph...than the statement that I taught medical students in the wards, as I regard this as by far the most useful and important work I have been called on to do."

Osler W. Valedictory Address at Johns Hopkins. JAMA  
44: 705-710, 1905

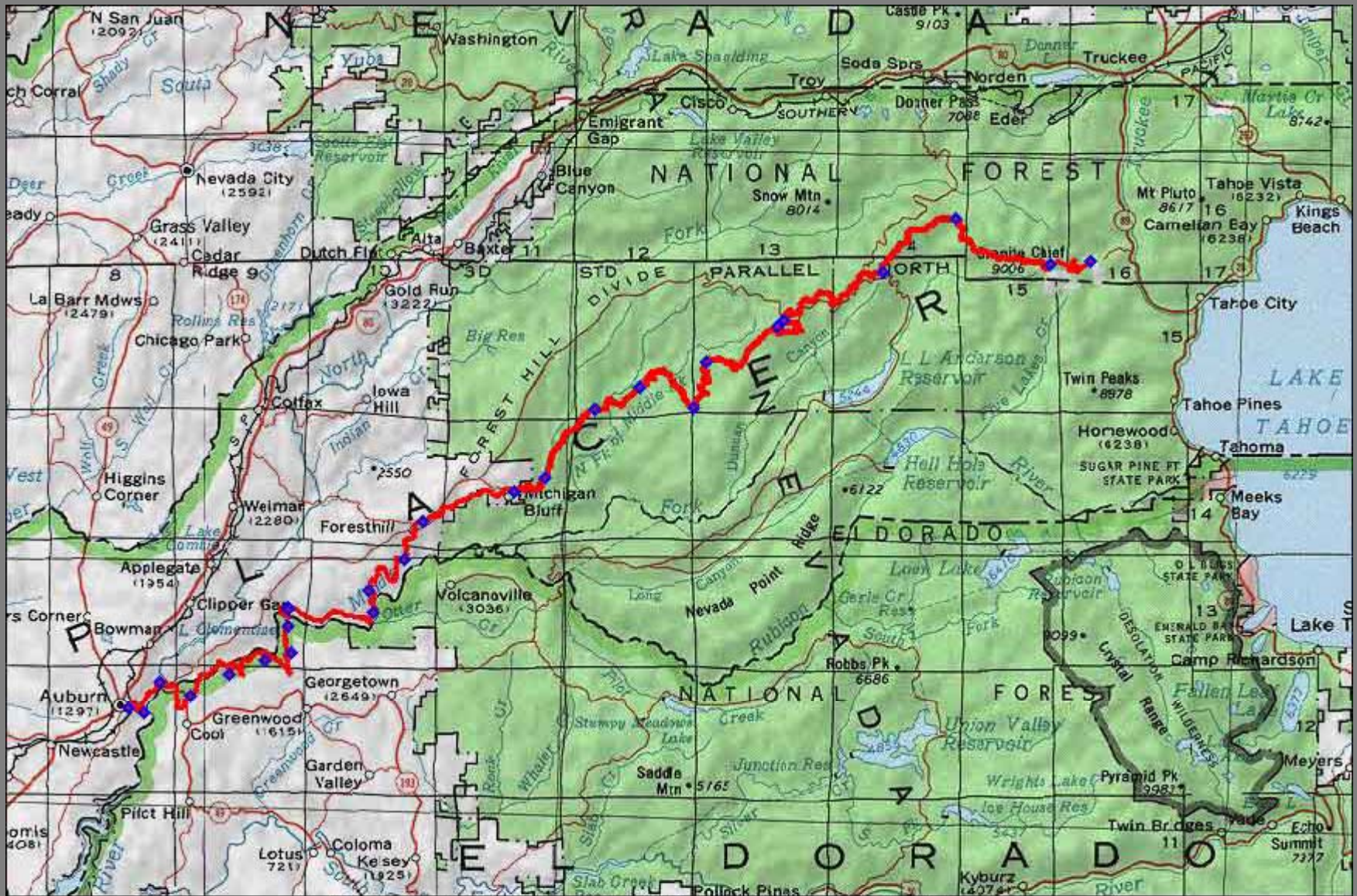




# Running and my Illness

- Did running cause my illness?
- Did running make me strong enough to withstand my illness?
- Did running allow me some level of "control" to get through my illness?
- I had a definite "goal": WS100.





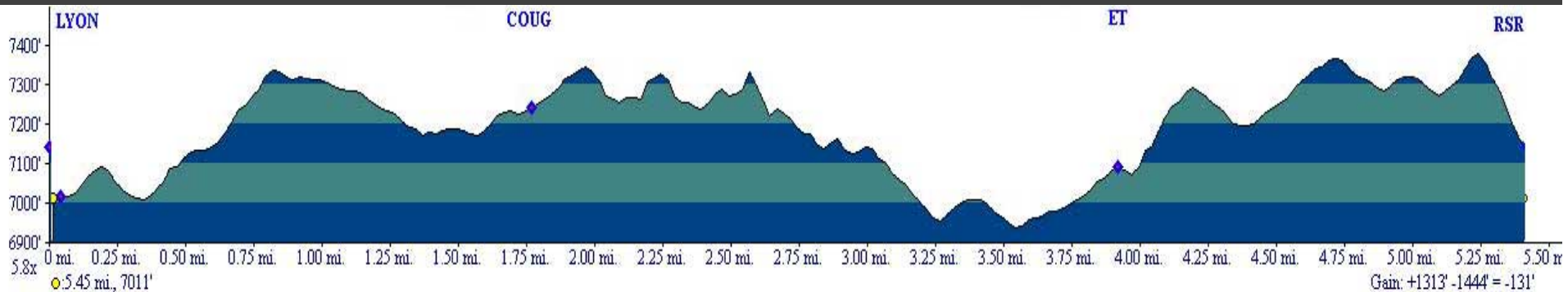
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**Anything someone is stupid  
enough to do once is  
probably worth doing a  
second time...**







**WESTERN STATES 100-MILE  
ENDURANCE RUN  
SQUAW VALLEY TO AUBURN, CA**

29:39:10



# Ethics and Ironies

- Informed consent is nice...but communication counts for a lot more on a personal level.
- Is Informed Consent possible in all situations?
  - Lung transplantation
  - Diagnosis without known cure
  - Sometimes informed consent is difficult...and sometimes it is also difficult to prove the effectiveness of therapy...
- Should every treatment be proven with RCTs??

# **Parachute use to prevent death and major trauma related to gravitational challenge: systematic review of randomised controlled trials**

Gordon C S Smith and Jill P Pell

*BMJ* 2003;327:1459-1461

doi:10.1136/bmj.327.7429.1459

**Conclusions** As with many interventions intended to prevent ill health, the effectiveness of parachutes has not been subjected to rigorous evaluation by using randomised controlled trials. Advocates of evidence based medicine have criticised the adoption of interventions evaluated by using only observational data. We think that everyone might benefit if the most radical protagonists of evidence based medicine organised and participated in a double blind, randomised, placebo controlled, crossover trial of the parachute.

Smith GCS and Pell JP. Br Med J 2003; 327: 1459-1461

THE ROAD TO ENLIGHTENMENT IS LONG AND DIFFICULT, WHICH IS WHY I ASKED YOU TO BRING SANDWICHES AND A CHANGE OF CLOTHING.





"The True Mystery of the World is the Visible, not the Invisible."

Oscar Wilde

Thank You!

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