

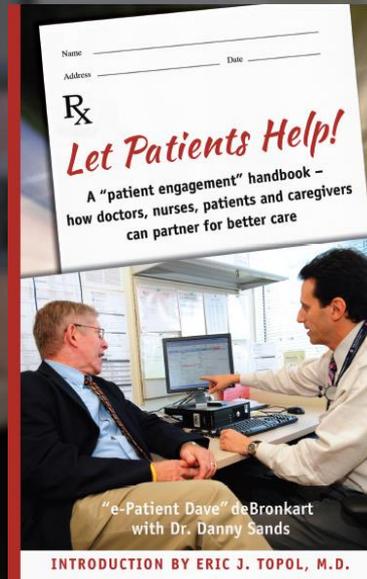
Patient Engagement: Participatory Medicine and Personal Health Data Rights

Dave deBronkart

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Bringing together e-patients and health care professionals.



How I came to be here

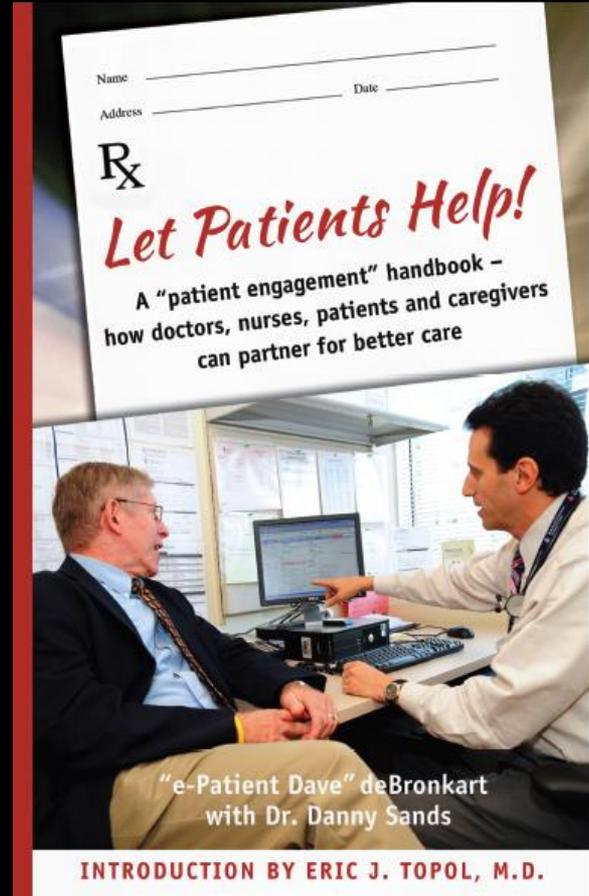
- High tech marketing: data geek; tech trends; automation
- 2007: Cancer discovery & recovery
- 2008: E-patient blogger
- 2009: Participatory Medicine, public speaking
- 2010: Full time
- 2011: international
- 2012: med schools, advisory, consult
- 650 events, 26 countries, 1400 blog posts, 13 universities, 19 articles, 2 book chapters



Fundamental Principle #1:

**Knowledge
truly is power.**

“We can perform better if we’re informed better”



INTRODUCTION BY ERIC J. TOPOL, M.D.

Fundamental Principle #2:

**When assets digitise,
things change fast.**

(Watch for it, and don't be surprised.)

Fundamental Principle #3:

**Patients are the
ultimate stakeholder.**

(They have more “at stake” than anyone)

Health tech innovation, 19th century style



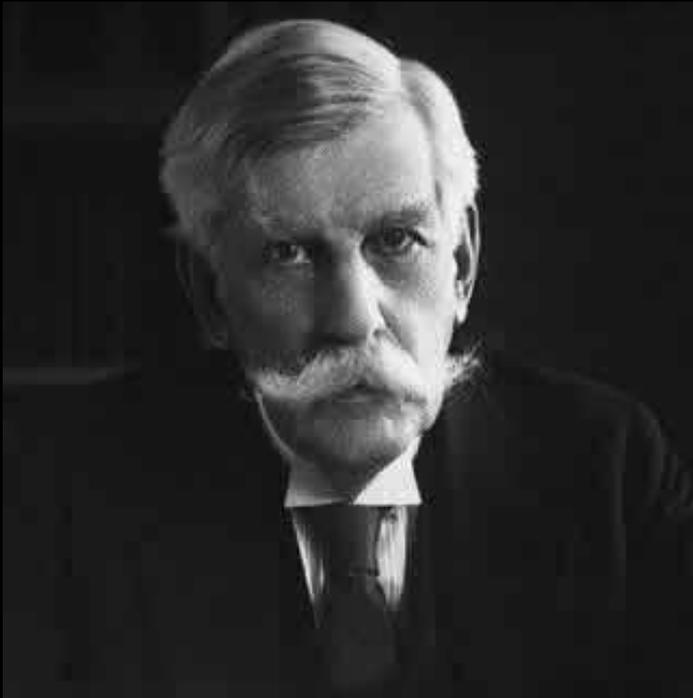
Rene Laennec (1781-1826)



John Forbes MD: Translator's Preface to Laennec's book:

“That it will ever come into general use, notwithstanding its value, I am extremely doubtful; because its beneficial application requires much time, and gives a good deal of trouble both to the patient and the practitioner; and because **its whole hue and character is foreign, and opposed to all our habits and associations.**”

1871: Oliver Wendell Holmes



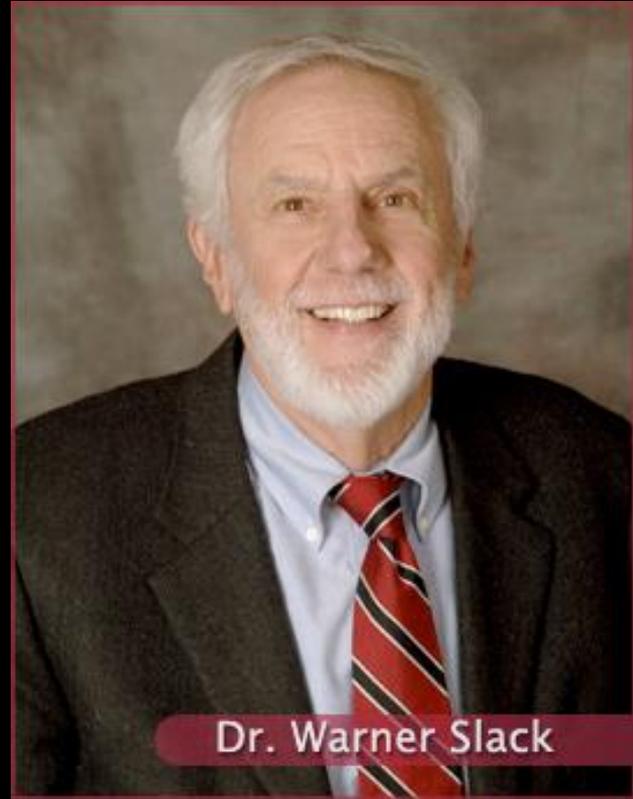
“Your patient has no more right to all the truth you know than he has to all the medicine in your saddle-bags.

He should get only just so much as is good for him.”

Bellevue graduation speech

*Informatics pioneer
Dr. Warner Slack,
since the 1970s*

**“Patients are
the most under-
used resource
in healthcare”**





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



Doc Tom said,

“e-Patients are

Equipped

Engaged

Empowered

Enabled”

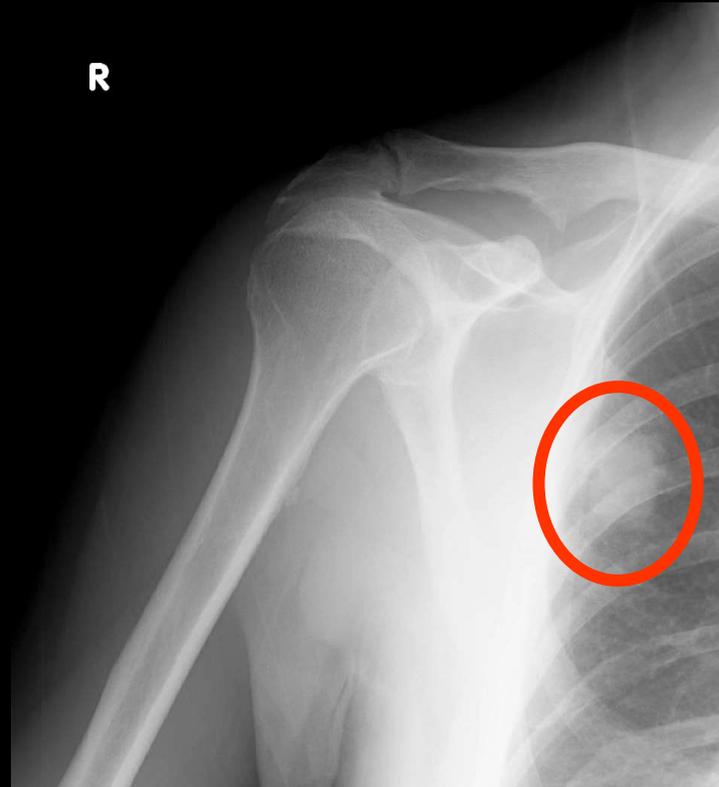


Society for
**Participatory
Medicine**

Bringing together e-patients and health care professionals.

2007: My “Incidental Finding”

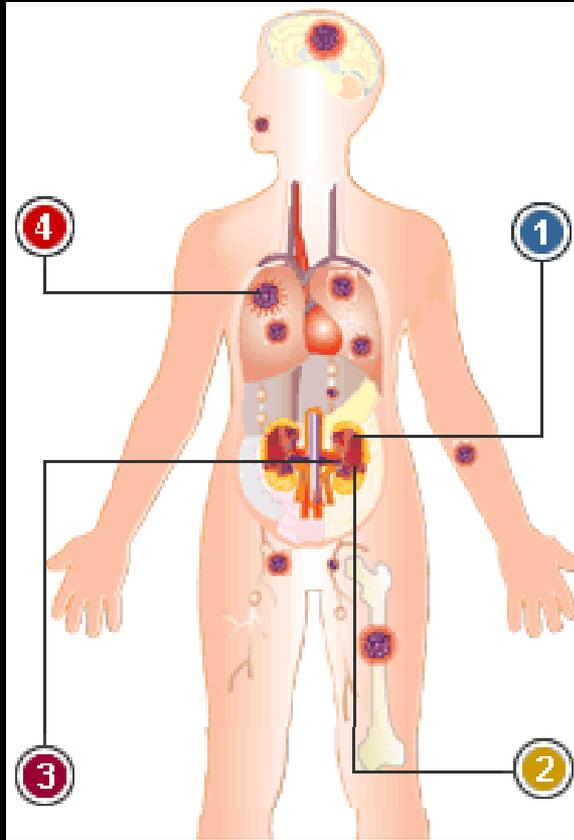
Routine shoulder x-ray, Jan. 2, 2007



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

Classic Stage IV, Grade 4 Renal Cell Carcinoma

Illustration on
the drug company's
web site



**Median Survival:
24 weeks**

Facing death

My mother

My daughter

“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
- TYPES OF CANCER
 - AN A-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 ...

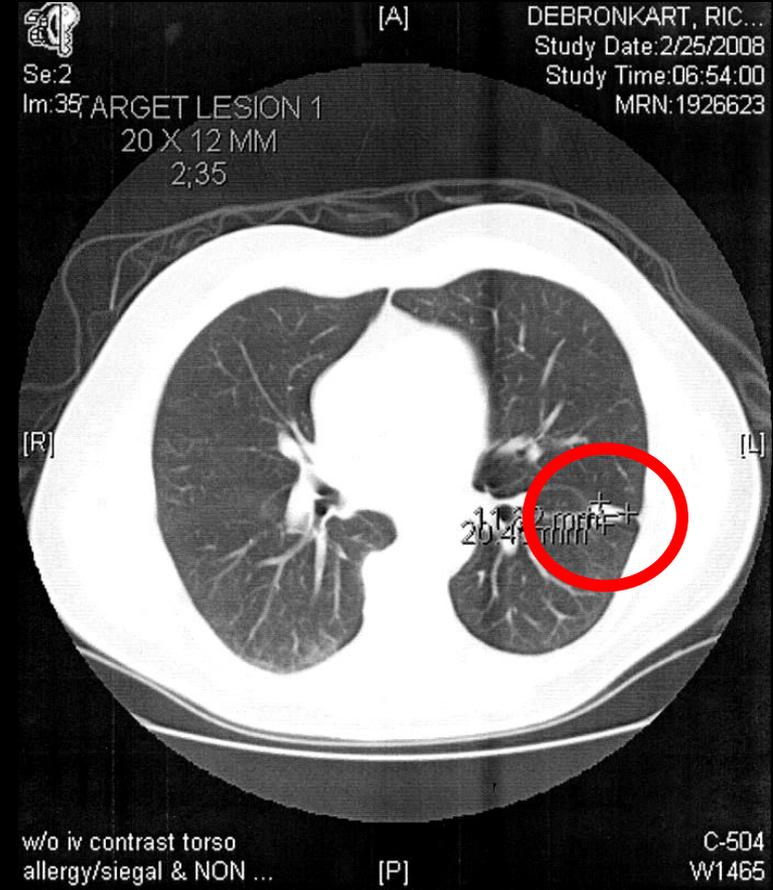
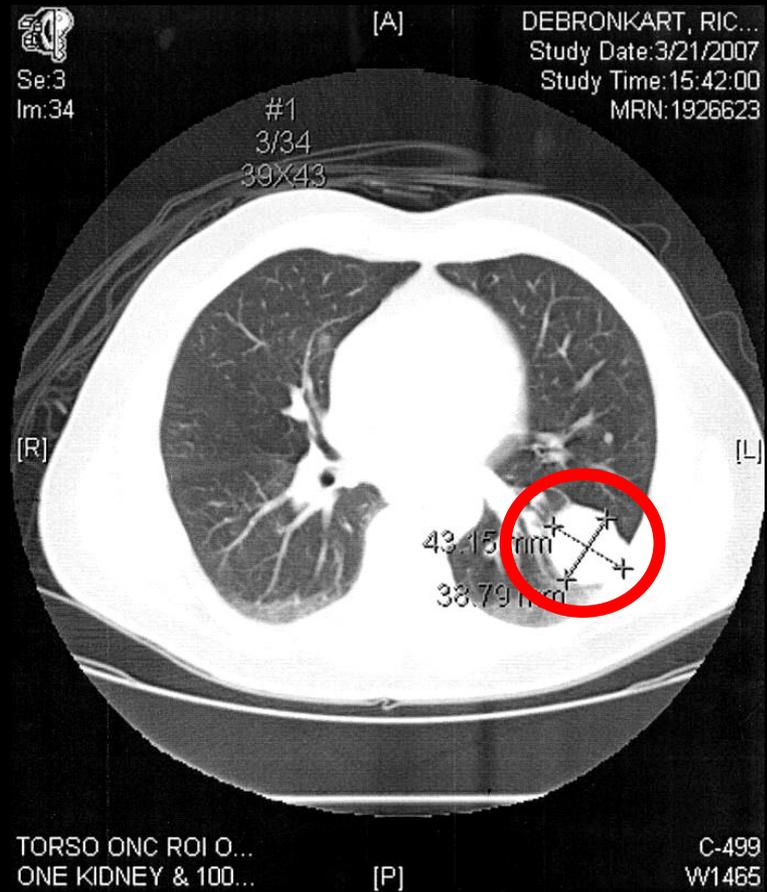
Apr 29, 2007

[Full Story]

What's New

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

Surgery & Interleukin worked – in six months



ACOR's practical information may have saved my life

As a responsible engaged patient, knowing that IL-2's side effects might kill me, I sought to prepare myself. First I sought authoritative sources; there I found dry facts: "Side effects are often severe and rarely fatal, and include . . ." I thought, "What am I supposed to do with that?" and turned to my peers on ACOR. I asked, "You who've done this—what was it like? What do I need to know?" From them I received 17 firsthand stories—a wide range of experiences. I felt prepared—and today Dr McDermott says, "You were really sick. I don't know if you could have tolerated enough medicine if you hadn't been so well prepared." In this case

**How can it be
that the most useful
and relevant and
up-to-the-minute information
can exist outside of
traditional channels?**

Answer:

**Knowledge is power,
and access has changed forever**

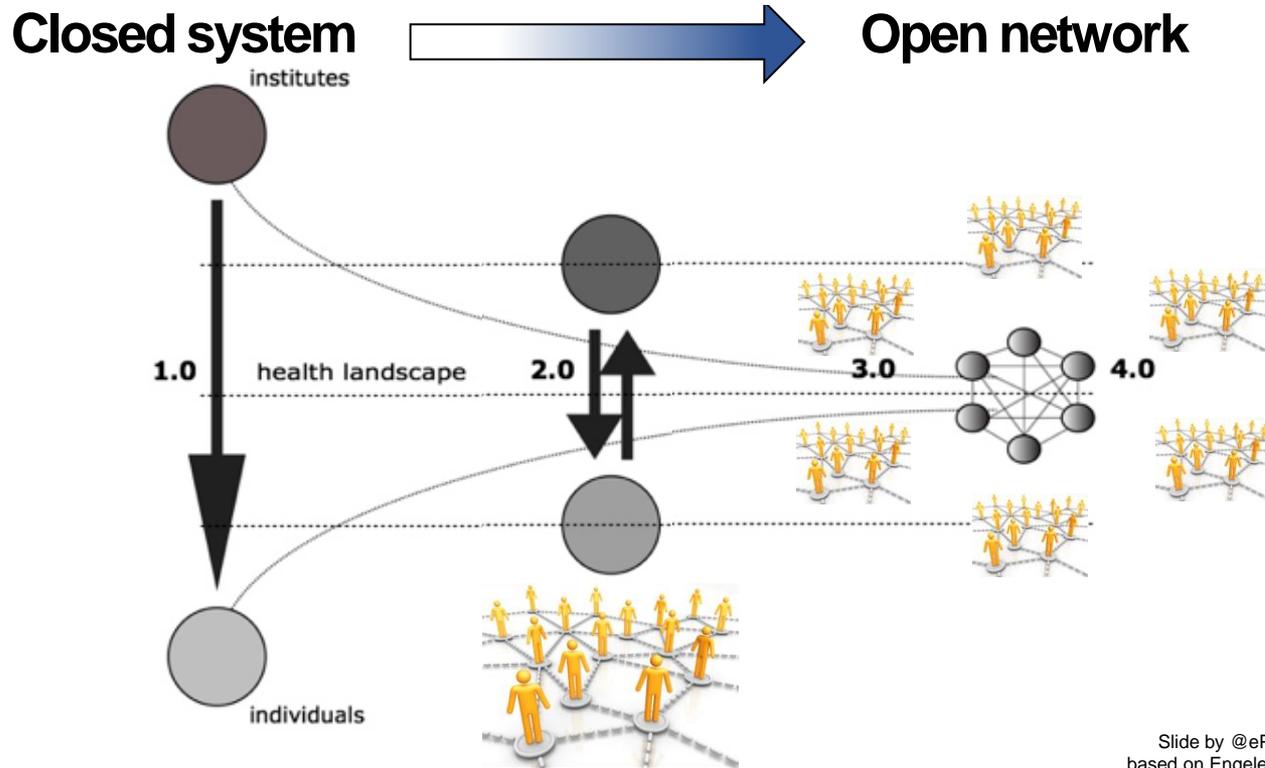
Because of the Web, patients can connect to information and each other



Social media: “information capillaries”



Transformation of Knowledge Access



Slide by @ePatientDave 2015
based on Engelen & Derksen 2010 at

Healthcare's "Copernican Shift"



Copernican Shift

Microsoft

Meet the Superpatients

Patients who
extend science
when all other
options are gone

SUPERPATIENTS
Patients who extended science
when all other options were gone
by cancer survivor Dave deBronkart

KIM GOODSELL
Found the genetic cause
for her two rare diseases

SHARON F. TERRY
Religion major identified the gene
of her children's rare disease

HURO CAMPOS
Graphic Designer. Got deeply
involved in his heart data.

JILL VILES
Figured out the unknown cause
of her muscle disease

JACK ANDRAKA
Teen who created a radically improved
pancreatic cancer test

YOU?

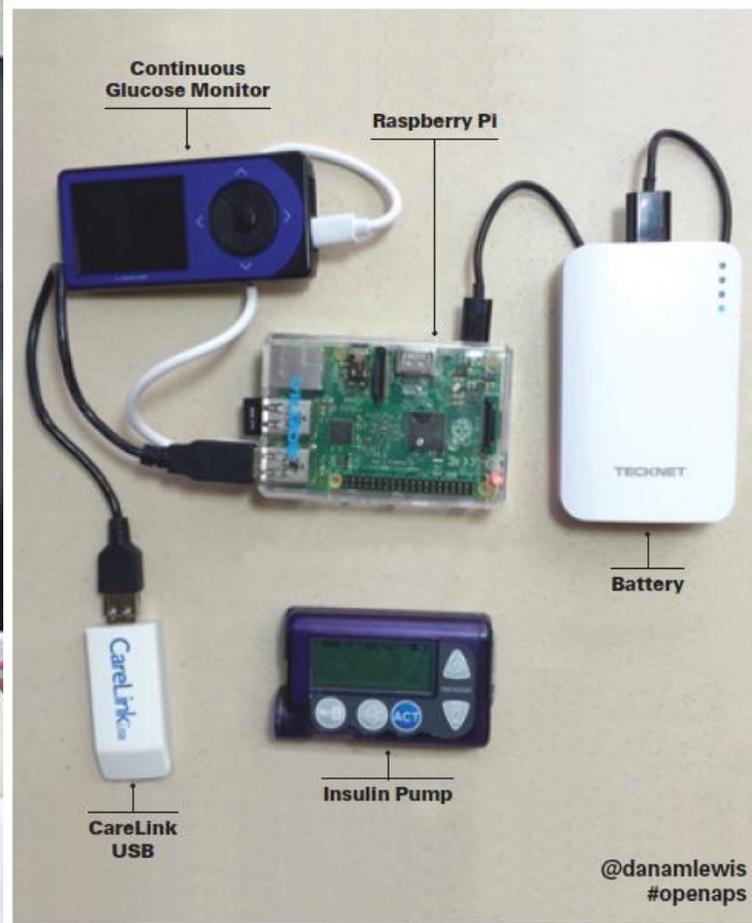
Superpatient: @DanaMLewis

with @ScottLeibrand
and the whole
#OpenAPS #DIYPS
#NightScout crowd



A DIY ARTIFICIAL PANCREAS

The artificial pancreas that type 1 diabetes patient Dana Lewis and her co-innovators developed for themselves used an off-the-shelf microcomputer to connect commercially available continuous glucose monitors with commercially available insulin pumps.



@danamlewis
#openaps

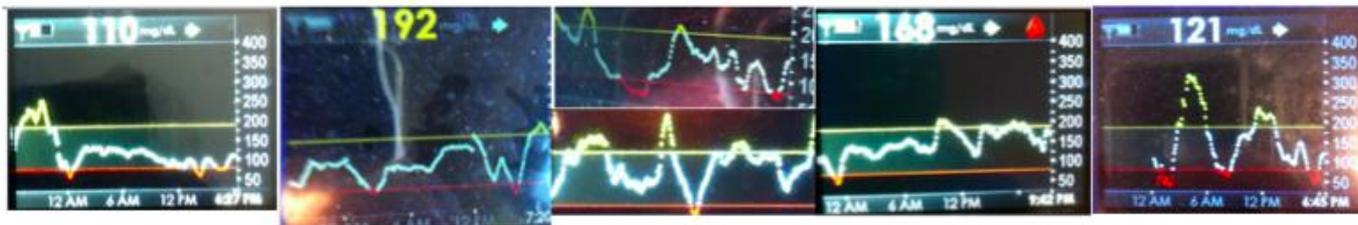
#WeAreNotWaiting

(to change the way we **research** and **innovate** in **healthcare**)

@DanaMLewis

#OpenAPS (open source): Better control than a working pancreas

Before:



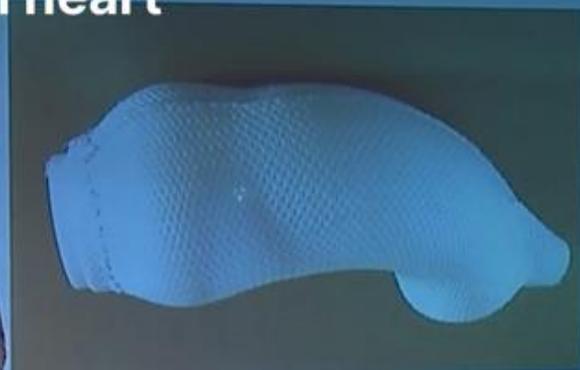
After:



Tal Golesworthy | TEDxKrakow

How I repaired my own heart

Making the Exovasc



TEDxKraków



Share



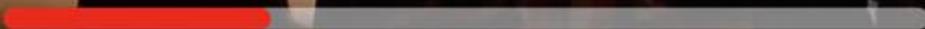
Add to list



Like



Recommend



9:13

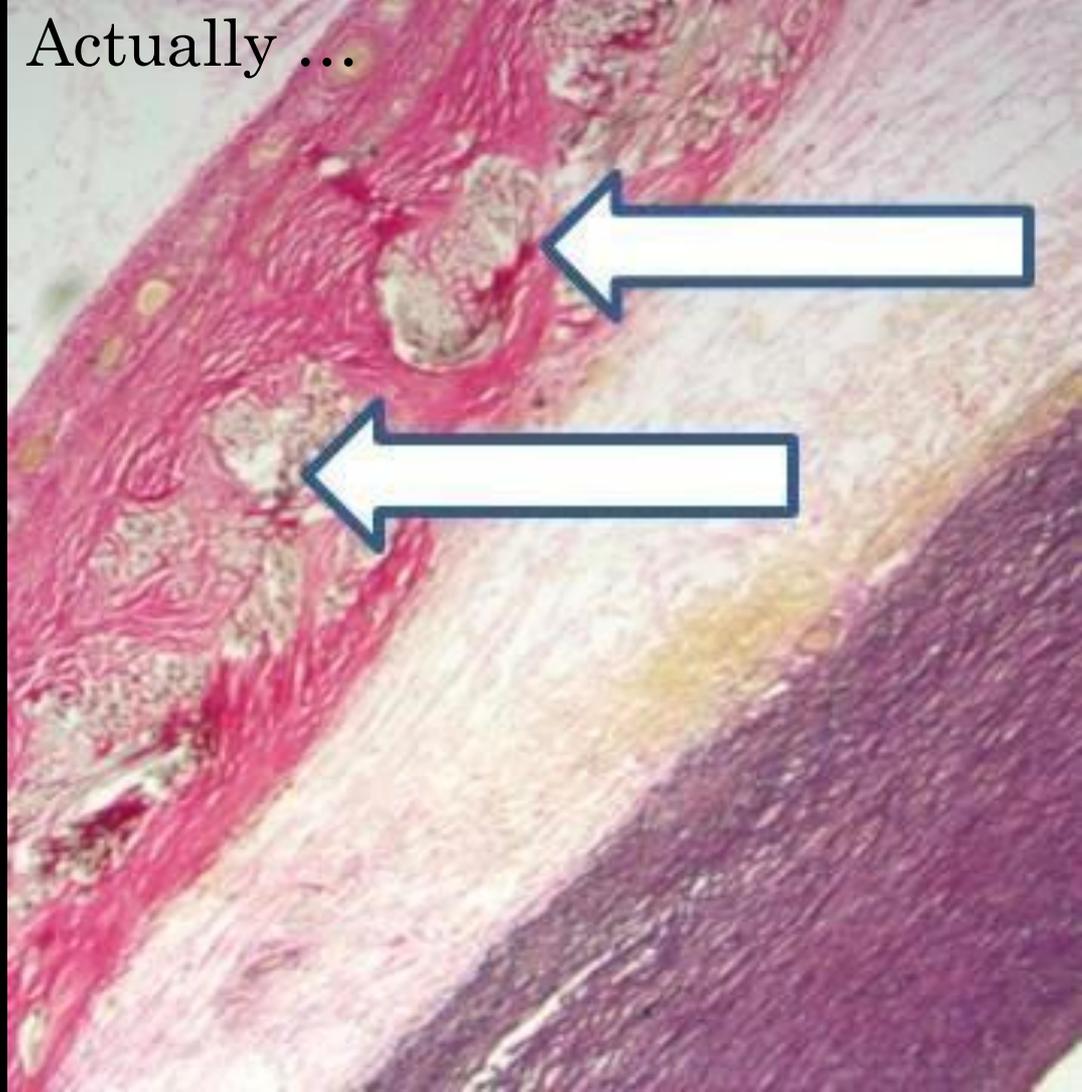


The establishment is always skeptical:

“Oh, you mean that wrap invented by that plumber?

Oh no, you don't want that: lots of patients have died and the surgeons are either retired or have lost their license.”

Actually ...



Fundamental Principle #4:

**“Patient” is not
a third person word.**

Your time will come.

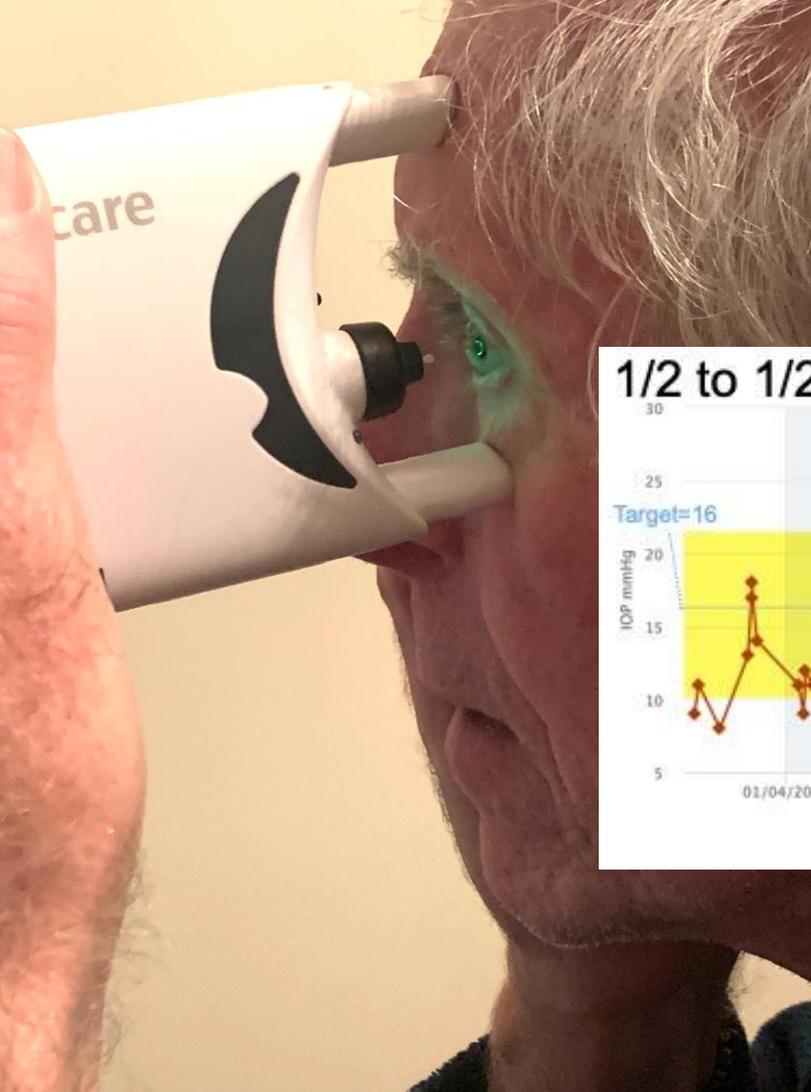


iCare HOME

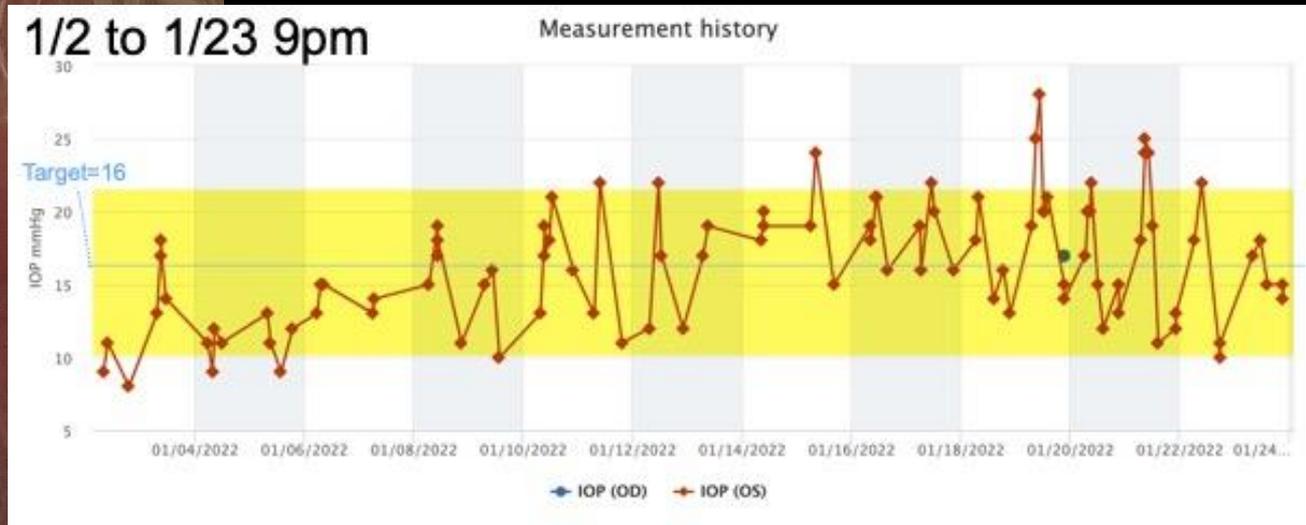
iCare HOME tonometer for diurnal IOP
Self-Monitoring

Key features

- Ease of use
- Reliability and accuracy
- Automatic eye recognition
- Intelligent positioning assistant
- Gentle measurement technique
- Instant data transfer to the clinic



Better data – at home, by myself.





2.8 e-Patient Years in Pictures...

December 2006



October 2007



May 2009





Please: let patients help. Welcome data sharing.

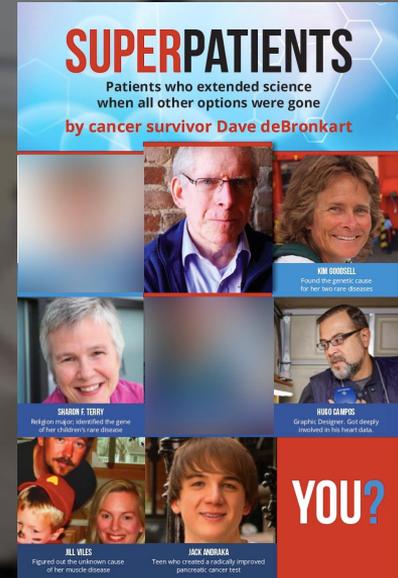
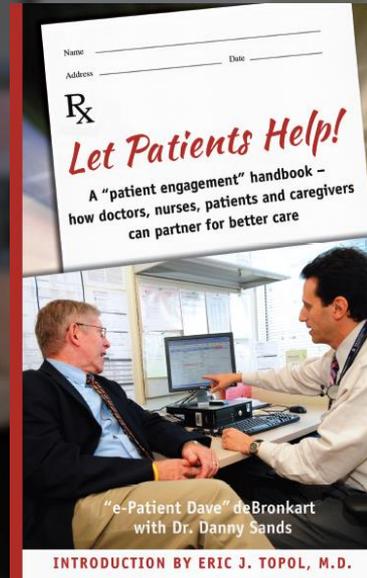
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Please: let patients help. What do you see differently now? How can best care be achieved?

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