

THE PROBLEM WITH TESTIMONIALS

Comparing patient stories with testimonials

Patient stories can be an excellent resource. They can tell us something about the range of what's possible for a disease, and may therefore provide encouragement and sometimes important lessons.

See *Patient Stories* page:
<http://www.lymphomation.org/stories.htm>

Testimonials, on the other hand, are stories put forth as evidence that an action led to an outcome.

The intent is to persuade and promote a medical practice, often one that is not yet proven:

"I did this, and I benefited. If you do this you can benefit too."

The presumption is that the patient knows that his or her outcome was influenced by the chosen action, and that it predicts what your experience will be too.

A testimonial can be a form of practicing medicine.

Testimonials cannot
inform about:

- The **number** of persons who used an intervention and did not benefit, or were harmed

Compare with peer-review clinical trial where the number of patients receiving the treatment are known and the positive and negative outcomes are measured uniformly – and, prior to marketing are reviewed independently by FDA.

- The **authenticity** of the report, and it's accuracy

Can we know if the person reporting the benefit really has the condition?

- The **biases** of the individual reporting his case as evidence

Do they have a financial conflict of interest? Do they also sell the product or charge a fee for dispensing the information?

Is the testimonial a way of validating their personal decision process and theories?

- The **natural course of the disease**

What is the natural course of the disease? Does it sometimes wax and wane without intervention?

Did the intervention cause the outcome, or was it coincidental?

... Even for cancers with a very poor prognosis there are case reports in the literature of spontaneous remissions, independent of any intervention.

People sometimes win the lottery, but this does not mean that playing the lottery is a good bet – particularly when betting your life.

- How the **outcomes** were measured?

Was it an objectively measured response, or a patient reported outcome? Was it subjective: that the patient felt better?

Did the response lead to a lasting clinical benefit?

- What **other medical treatments** were given shortly before or after?

A CT scan will often show lesions after standard treatment that is necrotic scar tissue. Credit might be given to an alternative practice used after this treatment, when it was merely the resolution of a scar tissue, a normal bodily process.

- The **accuracy of the diagnosis**

Was it a false diagnosis of a cancer?

RED FLAGS

Here are some **red flags** that can alert you that a web site or unknown person is trying to sell a bogus unproven cancer treatment:

- The treatment is for **ALL** cancers
- The treatment is said to **CURE** cancer.
- The treatment has **no side effects**.
- The words **secret** or **conspiracy** is used to explain why the product is not mainstream.
- Online purchasing of the cancer product is permitted - it does not require a doctor's prescription.
- The promotion relies entirely on **patient testimonials**.
- There is **no independent review** from FDA, or a similar independent regulatory agency
- The clinical data is **not published in respected scientific journals** (no peer review).
- There is **only one group** promoting the product or service – the group that is selling it.
- The scientific evidence in support of the product is preclinical - does not involve human subjects.

CONSPIRACY THEORY?

Saying that secret cures are hidden from the public because of a conspiracy is just not credible.

"Scientists, regulators, politicians, medical doctors, and their loved ones also get cancer. "

Are we to believe that all professionals around the globe are involved in a conspiracy?

And would not the diagnosis of cancer in the child of a "conspirator" not force the parent to relent and to go public? Would this not happen often?

LIMITATIONS OF PRECLINICAL SCIENTIFIC EVIDENCE

When you hear about the anti-cancer properties of natural supplements based on scientific research ...

ASK: Was the anti-cancer activity detected in a test tube (in-vitro) experiment?

The human body is infinitely more complex than a test tube. The tumor cells change when removed from the body; oftentimes they die spontaneously. Nevertheless, indications of activity in a test tube often become the basis for product claims. Be aware that this can only be a starting point for additional experiments.

Furthermore, you might ask if the dose used to produce the in-vitro effect is possible to achieve in the body, or if can it be achieved safely? Does the active compound reach the blood, or is it merely excreted?

PATIENTS AGAINST LYMPHOMA

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~ Education ~ Support ~ Advocacy ~

Providing evidence-based resources on lymphoma and its treatments – and informed perspectives on clinical research and clinical trial design – independent of health industry funding

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Lymphomation.org 

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