Request for Proposals: remove a basal cell carcinoma

11/29/22: This is an update on a document first published 2/11/2012 for an earlier BCC.

Client: Dave deBronkart, Nashua NH
Primary physician: Daniel Z. Sands, MD, MPH, Beth Israel Deaconess (BID), Boston

> **Summary:** I seek a care partner to remove a basal cell carcinoma (BCC) from my right nostril.
> [2012: left jawline, under the ear. For a brief introduction, see blog post and photo (low quality) at http://bit.ly/ePDaveBCC.]
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> I'm educating myself about the condition, I want to explore the available treatment options, and I'm "shopping" for a partner to do the work and follow-up with a good combination of quality, partnership, and cost.
>
> **Responses and questions to:** debronkart@gmail.com

Introduction: Partnership

The context for this exercise is responsible partnership between patient and provider, with open discussion of wants and of what works for each.

Participatory medicine:

I'm approaching this through an RFP process because I believe in "participatory medicine," in which patients play an active and responsible role in all aspects of healthcare. I believe patients should play an active role in making care more cost-effective and patient-centered, by being responsible about costs and by saying what they want.

Iterative process; dialog:

This document will express my wishes. Unlike a commercial RFP, I don't have a well defined timeline for submission of quotes, and as this proceeds and I learn more, my thoughts will probably evolve.

I eagerly welcome dialog throughout this process; I know I'm "making it up" as we go along. [comments are closed] ~~Comment on the document with the "Comments" button at top right, or send questions to the address above.~~

Social media and trust

All our conversations will be assumed private unless we both explicitly agree to go public with anything or everything.

- I am a blogger and Twitter user, but this will not be a media circus (positive or negative).
- The purpose of this public posting is to encourage discussion of the process. I'll blog about the experience, again to encourage public learning and (I assume) encourage others (patients and providers) in similar efforts.
- I'll publish the name of the partner I choose (more on this under Financial below), but this is not a contest and won't be treated as one. It's about patient engagement in fixing healthcare; it's about the learning, not about the vendor partner I select.

My Situation

Medical status

62 year old male generally in good health; somewhat overweight (BMI 31.2).

- Basal cell carcinoma diagnosed the week of 2/4/2012 at BID.
- History of a basal cell on left nostril approx 1978, removed surgically. 20 year follow-up was completed okay.
- History of stage IV renal cell carcinoma, dx 2007, treated with surgery (nephrectomy and adrenalectomy) and high dosage interleukin-2 at BID March-July 2007; 4 years of follow-up scans have found no problem. Full details and records available to you as needed.

2012: BID recommended Mohs surgery.
2022: Dartmouth-Hitchcock recommends Mohs.

Financial considerations

A key factor in my choice of treatment partner will be absolute clarity about billing.

I'm self-employed with a high deductible insurance plan ($10,000) in New Hampshire's high risk plan (NHHP, New Hampshire Health Plan), so it's a very high priority to know what the costs will be and to have a guarantee that no unexpected charges will be billed if the case proceeds as expected. Very important.

I've had (and blogged about) very bad experiences with lack of clarity about pricing and charges, and with people saying "Nobody *knows* what the actual costs are." This is ridiculous - it's incompetent management - and I will not tolerate it.

If you don't know what your costs are, don't bid: you may be personally responsible for America's out of control health costs.

Treatment options and self-education

I'm open to suggestions and comments on all of the following.

Here’s what I know so far.

- At present I know of two options: Mohs surgery and “plain old excision” (cutting it out).
    - Update 2/11 8:30 pm: radiologist @SubatomicDoc (Matthew Katz) mentioned in a comment that radiation is a third option. I asked for info on costs, risks, benefits.
- I’m learning about Mohs via its Wikipedia page, and links to other sites listed there.
- I believe in the value of good patient communities; I’ve learned of two BCC communities and two generic skin cancer groups, listed at epatientdave.com/communities. As of 2/11 I haven’t joined them yet.
- I need to understand pros and cons of all options, including (for instance)
    - Costs
    - Time required (in-patient or out-patient)
    - Recovery time
    - Scarring expected (considering the location of the lesion this isn’t a big deal for me)
    - Risk and rate of complications (see Uncertainty section below)
    - Cure rate (again see Uncertainty)

Criteria I expect to consider

I expect to consider these factors. I welcome other suggestions.

Cost - total and my out-of-pocket

- I especially need to know what my actual out-of-pocket will be, but I also have a strong interest in cost to the insurance company, even though I hope I won’t come near to my $10,000 deductible.
    - I understand that there’s a big messy shell game of what money actually changes hands (and what prices are negotiated) between providers and insurers. I won’t try to solve that here; I just insist on knowing my costs.
- **No special favors:** Although I’m something of a “celebrity blogger” my purpose here isn’t to get a special deal, it’s to improve healthcare for all. I *will* publish the provider I choose and the price, so don’t offer me anything you don’t want the public asking for.:-)

“Gimme My Data”

I have two strong biases for engaging in my case as knowledgeably as I can:

- **Engagement with medical records:** I’m known in social media for the slogan “Gimme my damn data,” which I used (in frustration) as the title of a keynote speech in 2009. I also testified in Washington on meaningful use regulations, advocating for patient and family access to records.
- **Engagement with my case:** I have a very strong preference for learning as much as I can about my case. I will select a provider who’s happy to give me high res images of my tissue and treatment, and any other clinical information I ask for.

Patient portal with secure messaging
A good online patient portal will be a strong plus (nearly mandatory), especially since I travel a lot and my ability to make calls during office hours is limited. (If you don't yet offer secure online messaging, what are you thinking??)

Location of treatment and follow-up: Closer to home (Nashua NH) is better.

Outcomes: I'll want your data on success rate (whatever that is), infections, etc.

Retail / customer service issues:

All other things being equal, convenience factors (e.g. office hours, ease of getting there, parking, etc.) may influence the decision.

List to be continued.

About Uncertainty, Errors, Infections and Partnership

I do not expect perfection in medicine; I expect honest and open partnership.

I've read a few books about the difficulties of diagnosis (*How Doctors Think*), practice variation and shared decision making (*Tracking Medicine*), the difficulties of understanding cancer (*Emperor of All Maladies*), etc. I understand that there's uncertainty in medicine, and I believe we must work together to do what we can within the limitations of what we know today.

Added 8:30pm 2/11: Also recently read Groopman's *Your Medical Mind*.

Having said that, I absolutely require that a partner accept how common medical errors and hospital acquired infections are. I'm familiar with *To Err is Human* and the HHS Inspector General's Nov. 2010 report on accidental deaths among Medicare patients. I don't believe in "shame and blame"; to the contrary, I'm a hobby student of Lean, with all stakeholders working together in an open atmosphere of acknowledging that medicine is risky and mistakes happen so we need to partner - and *welcome* each other as partners - in avoiding problems.

Indeed, the patient is the ultimate stakeholder. Nobody's needs and interests are greater.

So I will choose a provider who *welcomes* questions, suggestions, reminders to wash hands, etc.

I believe modern medicine is complex so we should help each other. But I also know that much of what we need to do is *not* complex, it simply requires reminders to do what works. And that applies to both of us - provider and patient.

Alternative treatments

In principle I’m open to unconventional ideas, but I have a very strong bias for evidence and the scientific method. If you don’t, that’s fine with me, but I’m unlikely to be interested. In particular, I reject these statements I’ve been told in the past:

- “Chemo is a fraud. All you need is ionized water.”
- “The cancer treatment industry is a giant scam.”
- “Cannabis cures cancer.”
- “Wherever big money is being spent on medicine, there’s sure to be dirty work.”

If you think that way, it’s fine with me, but don’t waste your breath talking to me.

Conclusion 9 a.m. EST 2/11

This is the beginning of a process. Let’s talk.