

2019

## Medical update as of the end of 2018

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# NOW WITHOUT HESITATION

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## Medical update as of the end of 2018

So as you may already know I'm back in the hospital at Sloan Kettering again; Teresa and I have been here since late in the evening on Thursday, December 27. It wasn't a perfect time to be admitted to the hospital: we'd missed an important consultation with our oncologist because she was ill, and now a lot of people seemed to be on their way to vacation. But it was the time we needed to come in. We have two big issues to deal with, plus the complication that it's unclear whether these two issues are actually related, and, if so, how. None of these add up to a crisis, but they do require attention. Some of what we've learned may be confusing to you, and it certainly still confuses me, so in an effort to be as clear as possible here's an end-of-the-year medical update.

The first issues deal with the recurrence of the cancer, which I discussed at length in my previous post. These are mainly in the liver; there is a possible spot on my iliac (pelvic) bone too, but a senior physician from the National Institutes of Health (long-time friend of the organizer of my "dads' dinner" group in Montclair!) said that if I didn't feel any symptoms from this – and I don't – I shouldn't worry about it.

The question, in any event, is what to do about these spots of cancer. One possibility is more radiation, since many or all of these spots were not irradiated in the summer (because there was no activity there to be attacked). Another possibility is more chemotherapy, on the basis that even though my entire liver, and in fact my entire body, has received chemotherapy over the past three years, in many spots no tumors ever did appear, so in those spots – which may include the current instances of new growth – chemotherapy may actually have been successful up till now. The fact that the tumors have started growing does not disprove this idea, because I haven't had any chemo treatment since the spring, and at that point these spots didn't appear to be cancerous; the new growth may simply be the result of non-use of treatment over the past half a year.

Or there are two further alternatives. One is to do nothing, as the NIH physician suggested for my iliac bone spot. If the likely symptoms are slow-moving and low-intensity, this may actually make more sense than more dramatic interventions. It's always possible that the side-effects will be more severe than the cancer effects themselves, and this is another reason for caution. I think my oncologist may lean in this direction.

But the other is roughly the opposite: to try to become part of an experimental clinical trial. The fact is that in my case this would not be a tremendously radical step, at least in the eyes of the NIH physician we talked to today; he felt that my radiation treatment this summer was a pretty radical step itself. To be sure, as a surgeon, he may start from a certain skepticism towards radiation as an alternative approach. But he concurred with our MSK doctor in being interested in a broadly-targeted immunotherapy drug called Keytruda, and he also described a dramatic treatment NIH has had some success with, in which the patient's immune system is completely broken down and then completely re-constructed, with a view to creating a set of immune cells that would take on and take down my particular, individual cancer.

All of that deals with the "first issues." The second issue has to do with the various ways my liver functioning has been impaired. It turns out that virtually anything the body does, the liver may be involved with, not necessarily as a whole cause but as a contributing factor. So, for example, my ability to do multi-figure subtraction, which seems to have lessened, could be an effect of liver malfunction leading to ammonia in the brain; for that there is a medication I am taking vigorously every day. I've felt myself growing more impatient than I (hope I) usually am: liver again. And the retention of water in my feet – really quite a lot of water, and probably affecting my balance and if unchecked then generating bruising of the feet, which was the symptom that probably tipped the balance in favor of our coming in to the hospital: liver too.

But since my hospitalization at MSK began a few days ago, we've encountered other theories about the water retention. One theory was that I had congestive heart failure, in which the heart and/or the lungs are unable to do the work involved in pushing water through the

circulatory system and out. But they've done fresh testing of both my heart and lungs and I don't have congestive heart failure. Another theory is that there is some sort of a block to the flow of liquid, conceivably a tumor that they haven't yet been able to find on a scan, conceivably a clot. They did a scan looking for clots in my abdomen early in my stay here; it didn't show anything but that they thought might be attributable to difficulties in the ultrasound process making these hypothetical clots hard to see. But then this afternoon one of the doctors said that a blockage of the flow of liquid would require a really big clot, that they hadn't found such a clot in my previous CT scan with contrast, done on December 11 2018 or just under three weeks ago, and that the chance that a clot of the necessary size had developed since then that would account for my worsening water retention was small – and so, in short, that the cause of the water retention probably is not a clot (logic that I think applies to the possibility of a new tumor too).

So it seems possible that the water retention – though in some unspecified sense due to the liver's damage in the course of the radiation and other treatment it has had – is not related to any physical structure created in the process. I evidently have renewed cancerous activity (see “the first issues” above), but that doesn't seem to be the direct cause of my fluid retention. Meanwhile they're contemplating at least two further scans to try to get to the bottom of my various symptoms, and still trying to treat the fluid retention as a symptom of its own, which can be alleviated better at the hospital than at home because the hospital can give me intravenous Lasix, (a diuretic, or in other words an anti-fluid-retention drug). And of course the hospital can play close attention – good-willed but sometimes maddeningly close attention – to my overall condition.

The personal tale of my hospital saga may deserve a separate post. Fortunately, Teresa knows better than I do what's going on for me medically, and keeps a careful monitoring eye on my day-to-day experience here. So besides a lot of medical thought and effort, there's a lot of monitoring of the monitors under way. Speaking as the patient (and I know Teresa feels the same way as the caregiver), I do find it rather exhausting! With luck, though, we'll be home, with a plan, soon.

Holiday wishes to all of you!

