

BRONJ... what to expect?



Zhyravlik•

2 days ago•[20 Replies](#)

Hi again! So my second post is about worse side effect: BRONJ
- **bisphosphonate-related osteonecrosis of the jaw.**

My father was diagnosed (PSA 944) in April 17, 2017. With uncountable mets in bones and Gleason 9 (4+5). Immediately he started Casodex + Zometa 1 in 28 day.

A year later, the implants began to wobble. And only then my sister and I found out that he was doing them at all. He did not tell his dentist about the diagnosis at all, and even less did he tell about bisphosphonates !!! He felt that this information was not so important for the dentist.

Long story short ...

In April 2020, at the beginning of the pandemic, a part of the bone augmentation with 2 implants fell out. The father went to the maxillofacial surgeon and he said that the process should be kept under control. But in June 2020, my father started having pains in his back and knees. The dog began to grow strongly and in August 2020 he started chemotherapy + Denosumab. A few hours after the first injection of Xgeva, he clearly felt better. Improved mood, appetite and at night he slept.

But after 3 days, his cheek swelled and a toothache began. The most interesting thing is that it was a completely different place. The implants fell out of the upper jaw. And the pain was in the lower jaw, where there were no teeth. A small piece of bone was exposed. The doctor prescribed antibiotics and no change in Xgeva shots. The antibiotic helped and the pain was gone. He had 4 cycle of

Docetaxsel and 5 shots of Xgeva. After that there was change in treatment. Almost 2 month he waited for new treatment. And with Zytiga he had Xgeva shoot again in beginning of December 2019. Pain in bones has gone, but just after New Year pain in jaw returned...

The jaw on the inside was even more exposed, but a new hole appeared on the outside in same place. There was no suppuration. The maxillofacial surgeon canceled Denosumab and told to have a CT scan of the jaws in a month.

And now when my father was about to do a CT scan, his jaw began to swell again and pain returned.

I understand that there is no cure, you have to wait for the necrotic bone to separate itself (but there is little chance of that) or wait for the right time for bone resection.

But if someone experience BRONJ how did it go? What time it took to heal? Did 't heal at all? What about Xgeva? Did you add some supplements something like "Bone restore" to make all this process go faster? Maybe hyperbaric oxygenation of the jaw?

So many post how to prevent this BRONJ but not so many how did it go after you have it...

p.s. sorry for long post



Tall Allen 2 days ago

Yikes! I can't see why some oncologists start Zometa routinely. Knowing that BRONJ increases with time on it, they should wait until there is evidence of osteoporosis on a DEXA scan. Xgeva is no better than Zometa for osteonecrosis. He might consider an estrogen patch to help maintain bone mineral density.



[Zhyravlik](#) in reply to [Tall Allen](#) 1 day ago

Actualy i first learned about estrogen patches on this site. And father didn`t get any DEXA scan. But he made osteoscintigraphy in July and it was pretty bad - superscan.



[Tall Allen](#) in reply to [Zhyravlik](#) 1 day ago

DEXA scans tell you about loss of bone mineral density, not metastases.



[Zhyravlik](#) in reply to [Tall Allen](#) 1 day ago

Thank you. I will try to learn how to get those patches here in Russia. And DEXA scan also.



[LearnAll](#) 2 days ago

Once ONJ occurs..its a serious tragedy. Prevention is absolutely better when it comes to using such dangerous Infusions . Resistance exercises and small dose of estrogen patches can be enough in most men. I believe if really needed one should use these bone infusions (Zometa, Xgeva)intermittently to minimize the risk of ONJ. But, most Oncs will not do it. You got to convince him/her.



[CalBear74](#) in reply to [LearnAll1](#) day ago

IP6 treats osteoporosis. A classic Harvard study in the 1950s found Phytate (the older term for IP6) to be effective in inhibiting osteoporosis. My PCP had me do a dexta scan when I passed my 75th birthday. I had been on IP6 3 years. He laughed at my scores and said "you'll never have trouble with your bones". That was six years after I was diagnosed G8, metastatic. See Dr AKM Shamsuddin's text (2011) for a discussion of osteoporosis and the Harvard study.



[Zhyravlik](#) in reply to [CalBear74](#)1 day ago

Actually he is taking IP6 for last 6 month. But probably not enough.. twice a day 800 mg. It's Nature's Way, Cell Forté, IP-6 & inositol. It did reduce his blood sugar.



[CalBear74](#) in reply to [Zhyravlik](#)21 hours ago

Not enough. He should buy the powder and put 3 scoops in cold water, shake vigorously and drink first thing in AM on an empty stomach.



[Zhyravlik](#) in reply to [CalBear74](#)14 hours ago

Thank you! What else are you taking with ip6?



[CalBear74](#) in reply to [Zhyravlik](#) 9 hours ago

Start his day (following his IP6) thirty minutes later with some berberine, turmeric/curcumin, and some decaf green tea capsules. Wash them down with a bottle of Pure Leaf's Mango & Hibiscus herbal tea recently shown to inhibit prostate cancer.



[Zhyravlik](#) in reply to [LearnAll1](#) 1 day ago

Thanks. I think it will be quite tricky, but maybe we will find some good doctor. 😊



[GARunner12](#) 2 days ago

I am confused. Are Prolia, Zometa and denosumab the same drug? Does Prolia have BRONJ as a side effect?



[Zhyravlik](#) in reply to [GARunner11](#) 1 day ago

Denosumab (trade names Prolia and Xgeva) is a human monoclonal antibody. And Zoledronic acid (Zometa) is a supportive care drug in the category of bisphosphonates. Both of them have BRONJ as side effect. And worse case scenario of BRONJ actually happening after switch from Zometa to Prolia. As I recently learned.



VHRguy in reply to GARunner11 1 day ago

I went from normal bone density to osteopenic (just a couple tenths of a point from osteoporosis) after less than 2 years on Lupron. We started Prolia, but first I had to get a letter from my dentist that no significant dental problems existed or were expected. Jaw necrosis is a serious risk of these treatments.

I stopped it a year after we stopped Lupron. As my testosterone recovered we felt the Prolia wasn't needed anymore. It seems to be best not to stay on such drugs too long, due to a risk of "atypical femur fractures". Here's a link mentioning this:

americanbonehealth.org/medi...

Anyway, today I am again on testosterone suppression, supported by estradiol patches to protect bone density and prevent hot flashes. I have a DEXA bone scan every two years, and my bones have regained density almost back to normal, barely osteopenic now.



Jbooml 1 day ago

So I was diagnosed with multiple bone Mets accompanying high psa. I was never offered or inquired (until now) about bone recovery. I've been on both Eligard and zytiga for 2+ years. Here's my question. My wife has recently diagnosed with multiple bone Mets arising from breast cancer. She's been scheduled for zometa infusions after recently starting EDT. Her bone scans indicate osteoblastic Mets....she's flaring high ALP numbers two weeks into treatment but appears to have very little joint or other boney related issues that I did initially suffer. Given

these 'biphosphonate' disasters should she stay the treatments until scans show serious degradation.

I've had multiple falls, slips and twisting recoveries with no breaks or sprains in my recovery history and am becoming somewhat unconvinced of zometa's risk benefit.

Thanks to anyone advising or commenting on her options.



[dentaltwin](#) in reply to [Jboom](#) 1 day ago

Both bisphosphonates and denosumab are given not only to prevent fractures due to drug-induced osteoporosis, but as well to prevent fractures due to the metastases themselves. I am not aware of how different the incidence of MRONJ is for one over the other; but the half-life in bone of denosumab is much shorter than zoledronate or other bisphosphonates, which should mean that drug holidays may make more sense with denosumab. This meta-analysis claims an advantage for denosumab over zoledronate in preventing pathologic fracture, but the advantage for MPC was not significant:

pubmed.ncbi.nlm.nih.gov/327...



[bubbles48](#) 1 day ago

I was given prolia since I am now metastatic. I had two six month shots. I had BRONJ with the extraction of a tooth. It was extremely bad pain. A few months down the road I had some bone to separate. Again I had to have oral surgery. I thought this would never heal either, but it finally seems to be healing. I was taken off Prolia because my DEXA scan was excellent. My mouth is full of crowns and possibilities of more extractions. I will not take Prolia again unless it

is absolutely necessary. I have found that using mouthwash daily has apparently helped to eliminate some of the pain I have had.



[Zhyravlik](#) in reply to [bubbles48](#) 1 day ago

Thank you for reply. How long did it take before it is started to heal? And was is big part of bone?



[bubbles48](#) in reply to [Zhyravlik](#) 1 day ago

It took at least a couple of months. The bone that came out was very small thankfully.



[Break60](#) 1 day ago

I never had any problems with Prolia or Xgeva . I started the latter when a bone met was found but switched from monthly to quarterly after bone scans came out ok, then I stopped after no more bone mets were found. So sorry to hear of your problems!! I also switched to estradiol two years ago since they are not known to cause osteoporosis as are LHRH agonists like lupron.