“Testing and Treatment Options for Ian Lewington’ (Ian Lewington) [#78]

Brad Power and Ian Lewington
November 29, 2023

“The Standard of Care offers limited options in New Zealand when you start to become hormone resistant, so I’m keen to explore all possible options.” – Ian Lewington

“I was in your shoes. How I approached it was, okay, let's do something that is within the standard of care, … and while doing that, try to identify other targets that you can go after, so you have options. And that becomes powerful because when you have a conversation with your doctor, and you talk about these various targets, and you talk about associated treatments, it can open up new doors for you.” – Brian McCloskey

Meeting Summary

Advanced prostate cancer patient Ian Lewington is facing a number of choices in his treatment strategy, testing and treatment options, and other decisions, such as:

- **Treatment options**: What treatments should he consider as his PSA (prostate specific antigen, a biomarker of prostate cancer disease activity) is rising, indicating his current androgen deprivation therapy (drugs which reduce the male hormones) is failing, and he’s becoming "castrate resistant" (not responding to androgen deprivation drugs)? Should he add a PARP inhibitor (Poly-ADP Ribose Polymerase, a protein which helps damaged cells to repair themselves. PARP inhibitors stop the PARP from doing its repair work in cancer cells and the cell dies. It is often used in ovarian and breast cancer.)
- **Treatment strategy**: When should he move to a new therapy? Is his PSA rise from 0.07 in April to 0.26 in November and 0.40 in December an indication that his androgen deprivation therapy is failing? Should he try “adaptive therapy” (flexing the amount of drugs based on PSA response) or “Bipolar Androgen Therapy” (alternating androgen deprivation drugs with testosterone) with the quantity of metastatic lesions he has? How should he sequence or combine treatment options?
- **Tests**: What tests should he get to inform his treatment strategy and treatment decisions? He got a liquid biopsy recently which showed no special mutations. He just had a second PSMA scan (Prostate-Specific Membrane Antigen, a test which lights up cancer cells) at the end of October which showed no new activity and shrinkage of all tumors vs his scan in September 2022. He has no bone pain or other health issues. His blood is good, and he has no liver or kidney issues.
- **Expert inputs**: Who should he consult? Should he travel to the Mayo Clinic or other clinic for another opinion?

We call this meeting where we focus on one patient a "hackathon", a meeting option which we offer to every patient. A diverse crowd of fellow patients, microbiologists, and medical experts join Ian to help him, his caregivers, and his medical team address the most urgent questions facing them. We will continue the conversation on our online discussion forum.

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Who is Ian Lewington and what is his medical history?

Ian lives in New Zealand. He was diagnosed in June 2021 with advanced stage 4 (metastatic) prostate cancer. His PSA was 542 (very high), with aggressive cancer (Gleason 9 – the Gleason score is based on how much the cancer looks like healthy tissue when viewed under a microscope, with scores from 1-10. Higher Gleason scores from 8 to 10 mean the cancer doesn’t look like healthy tissue.) A PSMA scan in July 2021 confirmed that he had extensive bone metastases but no organ involvement. He started goserelin/Zoladex (a hormone therapy) and had radiation to one tumor on his spine before starting six rounds of docetaxel (a chemotherapy), which finished in December 2021. He then continued with goserelin and bicalutamide/Casodex (a hormone therapy). His PSA continued to decrease through 2022 and into the first part of 2023 getting to a low of 0.07 in April 2023. Since then it has increased steadily to 0.15 in October 2023, to 0.26 in November 2023, and to 0.40 in December 2023. He had a further PSMA scan in September 2022 which showed no new activity and shrinkage of all tumors vs the scan. They don’t know why his PSA is increasing. He is also taking zoledronic acid for osteoporosis per a bone scan in October 2022.

What have been the experiences and advice of other advanced prostate cancer patients that might help Ian in his decision-making?

- Brian McCloskey had a positive response to apalutamide (effective for 15 months) and abiraterone (effective for 14 months), and recommended it as a second line hormone therapy option for Ian. Through working with various testing and matching service providers, Brian identified about 21 different treatment options, which he reviewed with his doctor. Those treatments are still on the table, and he can keep coming back to them to refine his menu of options. He recommended that Ian also build his list of treatment options from the same service providers.
- Brian also shared the cautionary stories of Bryce Olson and Rick Stanton, who responded to Bipolar Androgen Therapy with growth of their cancer.
- David Plunkett had good results from a combination of abiraterone (hormone therapy) and cabazitaxel (chemotherapy) – low PSA levels and enduring benefit after three years.
- John Sandiford shared his approach to managing his hormone-sensitive prostate cancer with a flexible, non-trial Bipolar Androgen Therapy, alternating high-dose testosterone and darolutamide, keeping track of key markers like testosterone, PSA, and estrogen. This allows him to adapt to his body's needs and maintain quality of life, while exploring further research and treatment options.
- Amit Gattani shared his successful experience with Xtandi/enzalutamide (12 months) and Zytiga/abiraterone (9 months) for his prostate cancer, suggesting these could be good options for Ian based on his low PSA. The strategy he recommended is to aim for long-term PSA stability with these established drugs before exploring targeted therapies in trials, since Ian is healthy and early in treatment. Amit decided not to pursue Bipolar Androgen Therapy due to his concerns about nerve damage. He has a lot of bone metastatic lesions very close to his spine, and their growth causes nerve damage due to

spinal compression. If the mets go away, the recovery of the nerves is not guaranteed, and can cause long term effects.
- Robert Gurmankin suggested that if Ian is considering traveling outside New Zealand, Australia would be a good option, as they have some excellent treatment centers and would be more convenient than traveling to the U.S.
- After the meeting, in late November, Ian spoke with Jeff Krolick, an advanced prostate cancer patient, who shared his experiences with adaptive therapy and suggested Ian contact his oncologist Dr. Dawn Lemanne. Ian had a video chat discussion with Dr. Lemanne in which they discussed adaptive therapy and Bipolar Androgen Therapy.

What are Ian’s next steps?

- In November 2023 Ian’s oncologist proposed that he start abiraterone/Zytiga (a hormone therapy) 1000mg plus 5mg of prednisone (a steroid) daily while continuing goserelin. He has recently stopped bicalutamide.
- Ian has broached the topic of doing Bipolar Androgen Therapy with his oncologist, which she is considering, but she is concerned that it could cause a worsening of the tumors. As Ian understands it, abiraterone tends to work for about 18-24 months.
- Ian’s oncologist will also be looking at adding a PARP inhibitor (olaparib) if the mutations warrant it, although that's not funded in New Zealand.
- Ian will have a video chat with his oncologist, Dr. Dawn Lemanne, and Dr. Bob Gatenby (an expert in using adaptive therapy in prostate cancer at Moffitt Cancer Center) to work out a proposed treatment plan that could include adaptive therapy and/or Bipolar Androgen Therapy.

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Meeting Notes

SUMMARY KEYWORDS

psa, treatments, options, therapy, testosterone, cancer, months, mets, bone, trials, mutations, docetaxel, identify, hormone therapy, new zealand, doctor, oncologist, drugs, talk, radiation

SPEAKERS

Brian McCloskey (47%), Ian Lewington (16%), John Sandiford (16%), Amit Gattani (12%), David Plunkett (6%), Robert Gurmankin (2%)

OUTLINE

1. Prostate cancer treatment options in New Zealand and the US. (0:00)
2. Second-line hormone therapies for prostate cancer. (6:32)
3. Prostate cancer treatment options and outcomes. (10:31)
4. Prostate cancer treatment options and side effects. (15:59)
5. Personalized cancer treatment options. (20:22)
6. Cancer treatment options and personalized medicine. (24:11)
7. Prostate cancer treatment options and monitoring. (29:24)
8. Cancer treatment options and management strategies. (35:26)
9. Cancer treatment options and side effects. (40:51)

SUMMARY

- **Prostate cancer treatment options in New Zealand and the US.** 0:00
    - Ian Lewington shares his cancer treatment journey and seeks advice from the community.
    - Ian seeks advice on potential treatment options for metastatic prostate cancer, including PARP inhibitors, despite high cost in New Zealand.
    - Ian seeks advice on treatment options for metastatic prostate cancer, including Lutetium actinium therapy and bipolar androgen therapy.
- **Second-line hormone therapies for prostate cancer.** 6:32
    - Brian McCloskey discusses his prostate cancer journey, including surgery, radiation, and hormone therapy, with a focus on apalutamide's effectiveness for 15 months.
    - Brian McCloskey found Abiraterone effective for 14 months, and recommends it as a second line hormone therapy option.
- **Prostate cancer treatment options and outcomes.** 10:31
    - David Plunkett had good results with Cabazitaxel and Abiraterone, with low PSA levels and enduring benefit after 3 years.
    - David Plunkett initially started with Lupron and docetaxel, which brought his PSA down into single digits but then rose after completion.
    - Robert Gurmankin discussed his experiences with Abiraterone for prostate cancer, with mixed results.
- **Prostate cancer treatment options and side effects.** 15:59

  - Amit Gattani discusses his experience with various treatments for prostate cancer, including docetaxel, Lupron, and Zytiga.
  - Amit Gattani suggests maintaining low PSA for a year and a half to increase chances of success in clinical trials.
- **Personalized cancer treatment options.** 20:22
  - Brian McCloskey shares his experience with bipolar androgen therapy and treatment options for cancer patients.
  - Brian McCloskey discusses using combinatorial approaches to identify potential cancer treatments with US-based firms, with quick turnaround times for recommendations.
- **Cancer treatment options and personalized medicine.** 24:11
  - John Sandiford discusses his experience with cancer and how he approached treatment by identifying a bridge strategy, such as standard of care option, while also exploring new targets and treatments through genomic information.
  - John Sandiford highlights the importance of having a conversation with one's doctor about various targets and treatments, and how this can open up new doors for cancer patients.
  - Brian McCloskey and John Sandiford discuss bipolar androgen therapy for prostate cancer, with Brian mentioning a third of patients responding well, a third experiencing little progression, and a third seeing their cancer take off.
  - John Sandiford is using Russ Hollyer's protocol and mentions Paul Van Camp as a good source for BAT therapy, with Paul having bought a J591 radio ligand therapy in Australia.
- **Prostate cancer treatment options and monitoring.** 29:24
  - John Sandiford is hormone sensitive and wants to delay the progression of his cancer while maintaining a better quality of life.
  - Sandiford is using a non-trial approach involving testosterone propionate and darolutamide, with flexible dosing and monitoring to manage side effects and PSA levels.
  - John Sandiford discusses his experience with prostate cancer, including his decision to delay hormone therapy to focus on other treatments.
  - Sandiford mentions consulting with a radiologist and undergoing radiation therapy, but notes that Ian is still experiencing pain and is considering other options.
- **Cancer treatment options and management strategies.** 35:26
  - Brian McCloskey discusses adaptive therapy with Bob Gattenby, using Abiraterone as a treatment agent, and monitoring PSA levels to determine when to switch.
  - Ian Lewington shares his oncologist's receptiveness to the idea and provides information from the group, hoping to extend quality of life with new treatments on the horizon.
  - Ian Lewington shares their experience with using cypionate and propionate for prostate cancer treatment, with mixed results.
  - Ian Lewington suggests that propionate may be a better option than cypionate due to its shorter half-life and easier management.
- **Cancer treatment options and side effects.** 40:51
  - Amit Gattani shares his experience with radiation treatment for brain metastases, highlighting the potential risks of nerve compression and the importance of careful consultation with doctors.
  - Brian McCloskey warns of potential cancer flare-ups from testosterone therapy, citing personal experience with liver mets.

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- Brian McCloskey and John Sandiford discuss the potential benefits of Abiraterone for bone metastases, with Brian suggesting it may be a safer option than traditional treatments.
- John Sandiford mentions purchasing drugs from a steroid.click , and Brian provides a link for further information.
- Brian McCloskey provides a treatment spreadsheet to help the speaker identify different options for their cancer treatment.
- Ian Lewington is waiting for genomic testing results to further evaluate treatment options.

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TRANSCRIPT

Brian McCloskey
Welcome to the Cancer Patient Lab. Today we have a special guest, Ian Lewington, who has been a member of the Cancer Patient Lab for quite a while and has helped us out with managing our finances. We're thankful for that. But Ian is here today to talk a little bit about his journey, his treatment options, and tests he's had, and really to get advice.

This is what we would consider a “hackathon”, where we're using the crowd, the community in this case, to help Ian find options that may not have been on the table prior to this call.

Ian Lewington 1:42
The overall rationale for this is that I've learned a lot from the group and being in New Zealand, the only approved metastatic prostate cancer drugs are Goserelin and Abiraterone. We don't have any access to the likes of the newer drugs without being self-funded. I'm keen to get a view on potentially whether I should seek some further expert advice in the States.

I've had a recent meeting with my oncologist so I'll just recap on all of that. Really quickly online my history. I was diagnosed at Novo stage for advanced metastatic prostate cancer in June of 2021, psa of 542, extensive bone Mets. No organ involvement, Gleason nine, so aggressive. Started Goserelin and then six rounds of docetaxel, which got the PSA down and then added by bicalutamide in December of 2021. And my PSA kept coming down until about March this year. And at that point, it started to rise, albeit slowly initially up to 0.15 in October and then it pretty much doubled and November went to 0.26. The oncologist's view is that I am developing hormone resistance and her recommendation is I move to Abiraterone and prednisone as a next stage treatment and potentially with a PARP inhibitor Olaparib, but the only issue with that is that it's not funded in New Zealand. So that will cost me about $60,000 US a year, which is pretty horrendous.

I've just had a liquid biopsy done which has gone up to Cigna, Singapore, to test for new mutations to decide whether or not it's worth adding in that PARP inhibitor. My initial biopsy showed that I had p10 p53 mutations and a couple of other mutations as a lot of people do. There are options here I have also consulted about having lutetium actinium treatment. I'm quite keen on looking at bipolar androgen therapy given that my last PSA scan, which was about a month ago showed that bone mets were quite small with low SUV expression, around two, with nothing significant showing up, and they've all shrunk from the year before. So the PSA rise is separate from the existing mets it would appear, and perhaps is just an indication that there's some circulating tumor cells or something that's starting to trigger a PSA rise.

It's the oncologist's desire to introduce abiraterone and prednisone into the mix.

But what I'm keen to discuss with the group is how that might be approached in the US. What are the options that I might consider? I can travel. I'm still quite fit, I don't have any bone pain. There's a lot of discussion about the Mayo or Moffitt centers and other centers of excellence and just how I might pursue treatment options given that I'm still at the initial start of what could be quite an accelerated period given the Gleason score I have.

Brian McCloskey 6:32
I can maybe start us off here. I was diagnosed in 2016. And I also had a Gleason nine, so aggressive cancer. My mets are, well, they started out being primarily our own tissue based, now there are bone mets, but they're localized. But in any event, my first treatments were surgery, radiation. Then I went to apalutamide, which is a second line hormone therapy. So, that would put that in the same category as out a rat around apalutamide. By the way, it also goes by the name of Erleada. I believe apalutamide was very effective for me for a while. Maybe I got at least 15 months or so of benefit from that where my PSA remained pretty low. So when I say low, like below three, and then I went on a holiday. When I talked about a second line hormone therapy. I've been on Lupron for selling hormone therapy pretty much since January or today, March 2017. So very early. And so that's like that's just like a given, in my situation, which is interesting. But so I got about 15 months of benefit from apalutamide. I went on a holiday and I came off of that. It came off the holiday and my cancer just came roaring back. My PSA just went through the roof. Then I had another surgery. I did a few things. But I ended up doing Abiraterone. I got about 14 months of benefit from that as well. And I can share with you my journey. I don't want to detract too much from this, but I'll share with you my whole PSA chart and the overlay of my treatments to see you have that. And in that you might find some treatments that can be used as options. It also has what my genomic mutations are by proteomic signatures, etc. So I'll share that with you as we wrap this up. But, I would say that , a second line hormone therapy like Abiraterone or apalutamide for that matter, or , some people get a lot of benefit from Enzalutamide. I'm sure there's folks here that are going to chime in regarding some darolutamide as well. Regarding those four second line hormone therapies that can be very, very helpful. But I would just say if Abiraterone is on the menu, it's a good drug. It was very effective for me. I didn't have tremendous side effects from it. It seems to me like that's an easy option, at least a second line hormone therapy, whether it's Abiraterone, Enzalutamide, darolutamide, or Abiraterone, those four all fit within that category. It seems like that could be like a very effective next step for you.

David Plunkett 10:31
I'll add to what Brian was saying. When I became castrate resistant, my next therapy was abiraterone. I got excellent results from it. So I hope that's encouraging. It's a little less clear in my case, because I was eligible for and encouraged to enroll in a clinical trial that in addition to abiraterone put me down for six cycles of cabazitaxel. The excellent benefit that I've had since then could be attributed to one or the other or both. There's no way to know. But I've had enduring benefits. It's been two and a half years…almost…no, it's been a full three years since I started abiraterone. My PSA is still very, very low. So I hope that's a little bit encouraging, that it's worked well for me.

Ian Lewington 11:43
Yeah, I did read some of the studies about cabazitaxel and the benefits of it and whilst I'm not keen on further chemo, it is a potential option, even though I'd have to fund it myself.

David Plunkett 12:07
As I said, I've had very good results. I found the side effects from cabazitaxel to be harder to deal with. I was very glad not to have more cycles than I did. So it's worked out well. For me, it may well be that abiraterone alone would have been enough for the same benefit. But I'm in the camp of “hit it hard and hit it as early as you can,” while you still have the greatest strength and stamina and resilience.

Ian Lewington 12:41
Did you have docetaxel initially as well? Was that your first chemo?

David Plunkett 12:46
Yes, I started out with Lupron and docetaxel. I got very good results from that. It brought my PSA down into single digits. I hit a nadir of one and a half about two months after I finished the docetaxel and then I had a slow rise. So when it doubled from nadir I was at three, and that's when we started plans for the next set of therapies. And by the time I started, abiraterone and cabazitaxel had climbed up to four and a half. So I'm not…I don't even remember what that calculates out to as a doubling time, it was several months still. But it was accelerating. I got very quick results. I reached a nadir of 0.01 perhaps ten to twelve months later. It was a steady drop. And it has stayed down at that level ever since. Again, I don't know if it was one or the other or the combination. But abiraterone is a very good next step to pursue.

Robert Gurmankin 14:10
I would agree that abiraterone is a good next step. Unfortunately for me, it didn't do much. I failed abiraterone within a matter of like four months.

In terms of seeking treatment, outside of New Zealand, it might be a lot easier to go to Australia. I know they have a lot of things available there that maybe you don't have in New Zealand. Certainly with your SUV values you're not at this point a good candidate for lutetium. They want you to be in the teens or higher.

Is Radium 123 available to you In New Zealand? Because that goes for bone mets.

Ian Lewington 15:16
I talked to a Dr. Nat Lenzo in Australia, who some of you might have heard of, who does pluvicto/actinium combination treatment, but he was of the same view with you that I needed my SUV over 10 to be a candidate, so probably not wanting to pursue that at this stage.

Robert Gurmankin 15:47
Is Radium 123 available?

Ian Lewington 15:50
I don’t know. I'd have to pay for it.

Amit Gattani 16:05
I have a few comments similar to what Bob said, given your SUV has reduced it doesn't look like Pluvicto will be the primary option. I don’t know much about New Zealand, but it seems like Australia tends to be more cutting edge, and ahead of the curve and offering treatments that are not available even in the US. So before exploring the US options, getting to Australia might be simpler and easier.

Have you been on Enzalutamide?

Ian Lewington 17:02
No, I've had nothing other than goserelin and with docetaxel and a period on bicalutamide.

Amit Gattani 17:13
I have had a tough journey, as you probably know. After my initial docetaxel and Lupron, we got started on enzalutamide/Xtandi which is really similar to Zytiga/abiraterone. I was given enzalutamide first, and that gave me 12 months of stability. I wouldn't say that it brought down my PSA. But it kept it flat in the single digits. That's as low as I've ever gone in anything. I'm looking at my PSA chart, and probably the longest response I got from any drug was Xtandi/enzalutamide, and that was 12 months. Then I switched to Zytiga/abiraterone, and I probably got about nine months of response on that. So typically the data is that if you follow one ADT with another, there is a 30% chance that you will get a good response.

My suggestion would be since your PSA is relatively low, it’s not an NED situation, but if you can maintain it for a year, year and a half at that, and it seems like some people get a pretty long response on these things, that would be the way to go. I don't recall – for me this was back in 2019 and 2020 – I did not have any meaningful side effects from either of those things at that point in time. I would say these are easier to take. These are just old drugs. We're into IV infusions and stuff like that.

Given your P10 mutation – I missed some of the other mutations you have – looking at any of the trials or any very targeted therapies around that – I don't have P10 or the other mutation you mentioned, so I'm not knowledgeable as specifically on those -- But my suggestion would be if you can maintain this low PSA that you have for some period of time, and then look for a targeted trial option to try and hit it because trials and other things are just better in the early phase. Like somebody else said, when you're pretty healthy, you can afford more risks and stuff like that. Then you can go through a trial and see if that helps. A radioligand doesn't seem to be the path right now at least based on my experience of where you are.

Brian McCloskey 20:22
Thanks, there's a few additional thoughts I have, then I'd love to pull John into this conversation too, and his experience with bipolar androgen therapy. But I'm gonna put in the chat here, this could be useful. I'm not going to pull it up right now. But it's something , these are just, these are resources for you to think about. Everything is in the Google Drive, which you have access to. If you don't have access to it, let me know. But I'm pretty sure you do.

What I just put in there is basically how I thought about various treatment options. This was back in 2022. What I did was I worked through our partners here at the Cancer Patient Lab, to take my electronic medical record information, and all of my genomic reports at the time. Then I worked with, at the time, three different groups.

One was Massive Bio, which is in New York. They specialize in clinical trials around the United States. They may be international. Now, I'm not 100% sure on that. But again, they're using your EMR and your genomic profile, as well as other criteria to look for clinical trials that can be useful.

I also worked with Cancer Commons/xCures. They have a very simple way to upload information. Then they will come up with treatment options that can include clinical trials, standard of care treatment options, as well as targeted therapies.

The other group that I worked with was CureMatch, which specializes in combinatorial approaches.

Again, these are US-based firms, but the process is pretty painless. And it could help you to identify treatments. So you can just look at the spreadsheet that I just dropped in the chat. And you can see how I approached it. One component is okay, what is the target that I'm going after? So I've got for example, I've got a pDRm alteration, I got TP53. I've got another one which escapes me right now.

John Sandiford 23:05
You have HER2.

Brian McCloskey 23:09
Yeah, you're right, I have a HER2 to relatively high RNA expression. It is not an alteration, but a high RNA expression.

So in any event, maybe the way to think about this is there is sort of like maybe a bridge strategy for you to take something now that can keep your cancer in check, or minimize it, while you're looking for other targeted therapies that might take a little bit longer for you to identify. The identification process is actually pretty quick. All three of these vendors that I just mentioned, came back with recommendations within two weeks. So it was pretty quick.

John Sandiford 24:11
But were they actionable?

Brian McCloskey 24:13
They were. Some of them were not. CureMatch is a little bit more of a challenge just because getting a physician to prescribe combinatorial drugs can be a little bit challenging, like what's the dosing strategy, for example. B7-H3, for example, and the B7-H3 antibody drug conjugate was

identified. There's also trastuzumab for HER2. And there were some others that came about as a result of that. Working with Cancer Commons was really helpful for me. And Massive Bio as well. As we have evolved, if you can get RNA expression, then we have partnerships with Shepherd Therapeutics, and Genomic Expression. That can help, and they will help to identify targeted therapies for you.

Because I was in your shoes, that's how I approached it, which was, okay, let's do something that is within standard of care, at least in the United States. And while doing that, try to identify other targets that you can go after, so you have options. And that becomes powerful, because, when you have a conversation with your doctor, and you talk about these various targets, and you talk about associated treatments, it can open up new doors for you. And I'm not the only one who has actually gone through that process. There are other folks within the Cancer Patient Lab who have also done that. They've identified treatments that were previously not on the table. And I can talk to you offline, if you want to have any of that stuff.

But that is one approach. So that approach, again, is to have a bridge strategy, maybe it's a standard of care option. Second line, hormone therapy can be very helpful while you're using all of your genomic information and getting new genomic information to identify new targets and new treatments. So that's one one path. Another path, which is why I call John into this is Bipolar Androgen Therapy, something that you might respond to.

John Sandiford 27:07
1/3 of people respond.

Brian McCloskey 27:11
We had a session on bipolar androgen therapy from Dr. Antonarakis. That's one of our recorded sessions. A third of their patients see, like, tremendous response, a third see, sort of like stasis where their PSA just like remains flat, and there's no progression, which is great. And then a third see their cancer take off. I don't know if there's a test right now, that will help us determine which bucket you would fit into. But that would be a very interesting approach. And that fits into the whole lane of adaptive therapy. And again, we've had several sessions on adaptive therapy. There's actually one that's a clinical trial out of Florida that is using abiraterone on an adaptive therapy approach.

John, do you want to talk a little bit about your experience, because your experience is even different than what Dr. Antonarakis talked about? Because you're using Russell's protocol.

John Sandiford 28:30
Right. I am. And another thing, Ian, is that Paul van Camp is a good source for you for BAT. And I'm sure you've already communicated, but Paul van Camp is an awesome resource. He has a different BAT protocol, but he's also done J591 in Australia, and I thought he had a couple of bone mets, but I'm not sure. He went there. And it was about $11,000 to get it done. But he did it for just two sessions. you were familiar with that. I read some of your bio, you're thinking about taking J591?

Ian Lewington 29:14
Yes.

John Sandiford 29:17
What I'm doing for BAT as I'm hormone sensitive. So I'm not castrate resistant yet. So that's why when we say 1/3 of the people respond to it. That's a castrate resistant group. For hormone sensitive people, we're breaking ground. Our goal is really just two goals: to delay resistance and to have a better quality of life, instead of staying on constant ADT. We cycle it, and you're familiar with all that, but being hormone sensitive, there's no trials, there's nothing for me to get into. Except, I mean, you could go into a BAT trial. You do the long, testosterone cypionate but when you get into the trials like that you're stuck in a cookie cutter situation, where it doesn't matter what your PSA is doing. You just take high T for this month, or three months, and then you go into low testosterone, meaning, you do ADT for another month, and then you go back and forth with the same set of goals, same set of timeframe. That's not for me. I have to be flexible. I had to talk to my doctor at Mass General, and he was receptive. So that was really great. But I have to get the drugs myself. So I buy testosterone propionate. And like with Russ, we inject every other day. And we do that for two weeks. Then we do about two weeks of darolutamide. That's the stage I'm at now. And it's flexible, because like for example, I went on a vacation, it was going to be kayaking and hiking and all that stuff. So I stayed on testosterone for another week. And it did bring my PSA up quite a bit, well, quite a bit being 0.17 is from a 0.07. So it did go up. But you can't worry about that too much. So I just stayed on darolutamide for another week on my ADT session, and I brought it back down. So it's a flexible, non-trial, but it's so far, I mean, I've been on it for, I guess, 20 weeks now. And it's working. I definitely feel better. It takes a little bit of tweaking to get things going, like we have to take a drug called letrozole to stop the estrogens from climbing too high, because when you're taking high testosterone, you're gonna get a lot of estrogens going down, what they call the aromatase pathways and into estrogens. High estrogen is dangerous. So we have to keep track of that. And we just do a lot of testing. Now, I don't know how your testing is done over there. But in the US we have labs you can do on your own. And that's what I do. I do quarterly with my regular oncology labs, but pretty much every other week I'm buying labs through Quest Diagnostics. In going, that's how we keep track of where we are with testosterone, our PSA, and E2. Those are the three markers we really have to watch. So, I mean, it's an option. I like the idea of what everybody's saying is staying on that Abiraterone as a bridge, and that will give you time to relax a little bit and focus, like get those Cancer Common tests to do more research yourself. It gives you focus on those things instead of just worrying about everything, so it's good to have a direct focus on where your cancer is – like you have the TP53 gene. Yeah, so there's plenty of information on that to focus on and trials and stuff like that. I'm not. I know that's a pretty serious gene and you have a quantity of bone mets.

Ian Lewington 33:51
They are extensive up my spine through my ribs, pelvis.

John Sandiford 33:58

So there's just too many to zap, I guess.

Ian Lewington 34:02
Correct. I've had various consultations with the radiologist and only had one round of radiation, because I had a large met pushing on my spinal column. And I Had that before I started docetaxel.

John Sandiford 34:19
Yeah, so BAT is your other option, but like it's 1⁄3 are responders. If you're not getting any pain from the bone that you can do, you can try that. But as soon as you start getting pain from bone that you got to get off of it because it will cause your cancer to grow. I mean, your testosterone will go up and your cancer will grow. But that's the whole idea of it, keeping it hormone sensitive, and then we're just hitting it again, keeping it hormone sensitive and androgen dependent, I should say. And then we hit it with darolutamide. So it's that extinction level stuff that Dr. Siegfried at Boston College talks a lot about. Hitting it with whatever makes the cancer happy, then hit hard with extinction level events. That's what we're doing with the cancer. I'm not really in your shoes. I mean, I'm not castrate resistant yet. I know it's gonna go there, but I just tried to delay it as all I'm doing is quality of life.

Brian McCloskey 35:26
On the adaptive therapy component, and , because our rad room is, , our is in your sights, Jeff Krolick. He is doing adaptive therapy with Bob Gatenby. He is using Abiraterone as his treatment agent. He's doing a lot with Oregon ethics. So he's cycling between those two? Well, yeah, he's not, he's not even using testosterone. So it's like, it's just watching his PSA. When his PSA increases to a certain threshold, which is based upon a model that Bob and I believe it's customized for him, just confirm that with Jeff. As it rises, then he starts Orgovyx and abi, I believe, and then his PSA comes down. And then he takes a break, and watches his PSA go up. And so it's just like watching your PSA like, move. I put it in the chat. A couple of links regarding Bob's discussions with us. One of them is really around just the whole theory that Bob approaches cancer with. You'll find that interesting, if you haven't heard it. His basic idea is that we should be trying to manage cancer as opposed to going to an event, which is like what our general approach is. So it's really fascinating. And something that maybe you could talk to your doctor about, or other doctors as appropriate. If you're going to be going after Abiraterone.

Ian Lewington 37:33
My oncologist is receptive to the idea, and she's done a bit of research. There's only one other person in New Zealand that's done BAT. So that's a little bit out there from a New Zealand perspective. So I have been firing off some of this information from the group. Russ's information. Yeah, because like a lot of people here I'm not keen on the slow slide if I can get a better of quality of life and extend things while some of these new treatments come on board, because there's clearly no right answer at the moment.

Brian McCloskey 38:14

right. Yeah. Well, I will tell you that. So I tried that. And you'll see this in my journey. Sorry, I'm probably inundating you with a whole bunch of links and whatnot. But I did, I did do that for about three months. Now. Again, this was just in June of this year. And I ended up doing cypionate as opposed to propionate. And that that was a mistake. But you'll see it like you'll see in my chart. My PSA went from about a 3.5 up to an 11 After the first round. And then it started to come down. And it hovered at about eight and a half or nine for a few months. And the way that I did it was I had scans before. And then I had scans three months after to see what was going on. And I thought that I was going to fit in sort of that middle third tranche, where, , it was just going to maintain stasis. And unfortunately, I saw radiographic progression after the three months, and so I ended up hitting the brakes on it, and with apalutamide and so I wouldn't say that it didn't work for me, um, , I would consider doing it again. I just don't think I would use cypionate because the half life of it is longer and then propionate. And so it's just harder to to manage that way, propionate is the way to go.

John Sandiford 40:07
It's good because you can find out in a couple of weeks, wereas T-cypionate lasts a whole month, right? So T-propionate only lasts a day, so basically every other day you have to inject it. So you're hitting it hard, with a high T then you're dropping it right off when you're done. Cypionate gradually goes down and if you plan it near the certain level/time of your cypionate, like maybe the last couple of weeks. Paul's actually starting to do what they've been doing recently. Yeah, Paul VanCamp,

Amit Gattani 40:51
I considered BAT, and I decided not to do it. There may be some similarities here that you have to be watchful of. I have a lot of bone mets very close to my spine, and I've had multiple growths in those mets where spinal compression has happened. While radiation takes care of those, in the past 15 months, I've gone through four or five radiation treatments. The other issue is that if you get nerve compression, the recovery of the nerves is not guaranteed, and can cause long term effects. I'm dealing with some of those. I have a lot of mets very close to my spine. I've gone through skull base radiation, I've gone through cervical, thoracic, radiation, thoracic, spine, radiation, lumbar spine radiation. I would say the pain goes away with radiation because the tumor is gone. But the nerve compression issues that happened, I have maybe 75% recovery on those and they become long term issues. So I would be very careful in clearing up any mets which are close to a spine, and you might get an effect that you may not be able to recover from. So I would consult. I would really look very closely at the scans. The doctors you can solve. That's my viewpoint. I consulted with five doctors about that. I was basically given a “No” because of that. My personal experience is that this is something you can get yourself in more trouble with.

Brian McCloskey 42:57
I'll just add some context to that. There is another session that we had with Bryce Olson along with Bob Gatenby. Bryce was a patient. He had been battling prostate cancer for about eight years, when he tried that in 2022. We don't know for sure, but shortly after, maybe like, five, six months after, he discovered that he had mets in his liver. The theory was that those cancer cells

were dormant. And potentially the testosterone just made them bloom. He ended up finally succumbing to his cancer, and it was due to the liver mets.

Also, Rick Stanton, who is the co-founder of the Cancer Patient Lab tried that too. He thinks that he had a flare of cancer in his bone marrow, again, probably sleeper cells that may have been fueled by testosterone. So we know for these two patients, for sure that they have or it looks like a fit into that group of a third where their cancer takes off. Both of those patients used cypionate. That's why I would say, I would think long and hard about which drugs you would use. I don't think that probably cypionate is the way to go. Propionate is the way to go. But I would also just heed ominous warnings, and definitely some of the experiences that we've had in the past. And the reason that I did it.

I should also mention that my mets were really localized to my pelvis, so I don't have distant mets. But I did see bone mets, which I never had before. They appeared after bipolar antigen therapy.

These are just words of caution. But again, Bipolar androgen therapy is just a version of adaptive therapy. It's just using testosterone as the agent to create the cycles. Jeff Krolick is not using testosterone. He's using Orgovyx and abiraterone. Talk to him. Because I do think the Bob Gatenby adaptive therapy approach intuitively makes a lot of sense to me.

John Sandiford 46:15
It's a lot safer when you have bone mets in the spine.

If you do propionate, KiwiDrugs are in New Zealand, believe it or not. You can get it from them. I buy it from Steroids.click That's what Russ had turned me on to. It takes about a month to get it. But that's where I buy my propionate. I have to buy it myself. I didn't even ask my doctor to prescribe that. I don't even think they would, though. But mets in the spine, the bone, that’s a tough thing to think about.

Brian McCloskey 47:25
We've given you some food for thought. The challenge here is how you access some of these things that we're talking about, so I put in the link there. I do think it's good advice to maybe go to Australia, it's a little bit closer. Peter Mac has done pioneering work with Lutetium. I'd give that some serious consideration. I’m not an expert in what they do. But I do know that they've done a lot in that area.

Ian Lewington 48:01
I have heard of that Institute.

Thank you, everyone. I will pursue that and talk to my oncologist a bit further. She is actually really good. She's receptive to these alternative conversations, and some of the things that aren't trials and standard of care, which I know a lot of my previous oncologist wouldn't look at anything that hadn't been through the whole trial process, which is you're saying at the start isn't ideal for us on a shortened timeline.

Brian McCloskey 49:54
We can help you by providing a means to get a menu of options. I walked you through that process. Perfect. Now, once you have a menu of options, again, to have that you have to have your basic electronic medical record, and you need to have genomics. And so I'm assuming that you can get access to some sort of testing.

Ian Lewington 50:23
I got all that. I'm just waiting to get a liquid biopsy genomic testing back.

Brian McCloskey 50:29
Do you have any tissue-based?

Ian Lewington 50:33
Yeah, I do the initial, that's where I got the results around the PTM and p 53. And there's a couple of other mutations.

Brian McCloskey 50:42
Those are like the building blocks to be able to get some options. The treatment spreadsheet that I sent you, which I'll send you again, so you have it, is using that as the foundation to identify different options. I had about 21 different treatment options across those three service providers. Then I took that to my doctor, and we talked about them, and we said, okay, hey, which ones make sense, so that you're covering all of your bases. It's an iterative process. So even though I haven't really refreshed that since last year, those options are still on the table, and so I can keep coming back to them, to develop that menu of options. It's going to be figuring out the access component, and hopefully she can help you with that.

Ian Lewington 51:44
That would be excellent. Thank you very much, everyone.

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Chat

00:24:39 Brian McCloskey: My PSA/Treatment chart: https://drive.google.com/file/d/1K7gZO4abcVvBt290reBXeEiDb-oekWSk/view?usp=drive_link
00:26:34 Brian McCloskey: Well known cancer center in Australia. Pioneering work with Lutetium: https://www.petermac.org/
00:29:29 Brian McCloskey: https://docs.google.com/spreadsheets/d/1p54bOMLSI5BWXN6jZOJyBCGSMZVC0loz/edit?usp=drive_link&ouid=115425783146269748601&rtpof=true&sd=true

“Testing and Treatment Options for Ian Lewington’ (Ian Lewington) [#78]

00:40:59 Brian McCloskey: Bob Gatenby session: https://community.cancerpatientlab.org/c/learning-sessions/cancer-patient-lab-meeting-10-adaptive-therapy
00:42:11 Brian McCloskey: Another with Bob: https://community.cancerpatientlab.org/c/learning-sessions/prostate-cancer-lab-meeting-9-an-evolutionary-treatment-strategy-bob-gatenby