

Moderator: Welcome to Managing Hodgkin Lymphoma With Antibody–Drug Conjugates, a three-part podcast series presented by the publishers of the *Journal of the Advanced Practitioner in Oncology* and Harborside Medical Education. This certified educational podcast is supported by an unrestricted educational grant from Seattle Genetics Inc. Please visit advancedpractitioner.com to view faculty disclosure information.

Ms. Goodrich: I'm Amy Goodrich, a nurse practitioner and research associate at The Johns Hopkins University School of Medicine and the Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins. I'm joined today by Kevin Nguyen, a patient of mine who was treated for classical Hodgkin lymphoma. Today, Kevin and I will be discussing shared decision-making, how to discuss therapeutic options with your patients considering treatment for classical Hodgkin lymphoma, including risk-adaptive management strategies that incorporate prognostic factors, patient age, performance status, and comorbidities. Kevin, welcome.

Mr. Nguyen: Hello.

Ms. Goodrich: Shared decision-making is key to driving patient-centered care. Shared decision-making occurs when clinicians and patients work together to select tests and treatments and care plans. Together, we make these decisions using clinical evidence that balances risks and expected outcomes, as well as patient preferences and values. Shared decision-making is critically important in situations where there is more than one reasonable treatment option, where no treatment option has a clear advantage, and the possible benefits and harms of each of those options may affect the patient differently.

Ms. Goodrich: Shared decision-making teaches patients about their health condition and their options, and that includes the pros and cons of each and the information and tools that they need to evaluate them. Shared decision-making better prepares patients to talk about and collaborate with their healthcare provider. It increases the likelihood that patients will follow through with their treatment plans, and it truly makes patients feel included and valued, which they definitely are. Shared decision-making can also build lasting and trusting relationships between patients and clinicians, and it ensures that both parties are satisfied with the outcomes. Successful shared decision-making results in the patient's understanding.

Ms. Goodrich: Steps to shared decision-making success are the acronym SHARE. S is seek. You seek your patient's participation. They may not otherwise know they have options, and it allows you to create an environment where patients can express their thoughts and their feelings openly.

Ms. Goodrich: The H in SHARE is help. Help your patient explore and compare treatment options by presenting all of their options, providing information on risks and benefits, and recognize that patients want to know. Being clear and open with information about prognosis is another important factor here. Studies have shown that oncologist devote less than 10% of their time talking to patients

about prognosis. Check their understanding by patient teach back, so that's how we can help them. After you speak to them about a treatment, or a buffet of treatment options, make sure that you're asking them questions that allow you to assess their understanding. You can use decision aids, they can provide a comprehensive review of their condition. Medical centers have used lots of different specialized resource units and specialized research to help with shared decision-making.

Ms. Goodrich: The A in SHARE is to assess your patient's values and preferences. This takes into consideration their cultural influences, motivating factors such as things like fear and expectations and past experiences. The R in SHARE is Reach. Reach a decision with your patient, work with the patients through deliberation and decision-making. Give them time to think things over, give them time to answer questions. You absolutely can provide your recommendation and opinion, but as long as they know that they're part of reaching that decision together, that's great.

Ms. Goodrich: E is evaluate. You evaluate your patient's decision along with the patient, so you assist them to follow through. You explain the steps, you make sure they understand the steps and discuss any possible challenges with the plan that were agreed upon. It's also important to engage family and caregivers as well. Their involvement is key to providing support and positive decision-making experiences for your patients.

Ms. Goodrich: Let's start by talking about your initial diagnosis. You were diagnosed in August of 2012. You were 22 at the time.

Mr. Nguyen: Yes, ma'am.

Ms. Goodrich: You started having a cough and some itching and fatigue and night sweats. Do you want to talk about what was going on in your life and how you came to your diagnosis and just sort of what was going on at that point in time?

Mr. Nguyen: Okay. At first I didn't think much of my symptoms. I just thought that, oh, it's getting over a cold or something like that. With the cough and the night sweats, I just thought – I didn't think much of it actually. My friend was actually giving me a massage one time and actually made me promise to get this lump checked out, and it was on my right trapezoid muscle. I guess when I got it checked out through a, I believe it was a CT, they did more testing, and then ended up to be cancerous. No one likes to hear that type of news. I guess during that time I recently graduated undergrad, and I was looking into taking MCAT and testing into or applying into medical programs.

Ms. Goodrich: When you were initially talking about treatment with your original oncologist, what were those discussions like?

Mr. Nguyen: The discussion actually was pretty – it alleviated a lot of my anxiety. During that time, it seemed pretty promising, the physician was telling me I had about 90% cure rate. My friends and family and my sort of core group was pretty – I guess they felt pretty positive about that.

Ms. Goodrich: Because you're young, you were young, you're still young, you had relatively early-stage disease, you had stage II disease that you were having symptoms, and so yes, that on paper, that is good risk status.

Mr. Nguyen: Exactly.

Ms. Goodrich: You talk about your family and your friends. Did you feel like you had a lot of support at that time?

Mr. Nguyen: I think so, yes. I think that it would be extremely difficult for anyone to go through a cancer diagnosis without any support. I was pretty lucky to have a strong friend basis, and my family values are very strong as well. We're all very close, sometimes a little bit too close, but you know, it worked out.

Ms. Goodrich: Had you just finished college? Is that where you were and you were studying for MCATs, is that right?

Mr. Nguyen: Yes. I actually graduated that spring 2012. I studied at Virginia Commonwealth University and graduated with a biology degree. That was also a blessing in disguise that I was able to graduate before I got diagnosed with lymphoma.

Ms. Goodrich: Got it. So then you went on to get six cycles of ABVD. Do you remember any conversation about other treatment options?

Mr. Nguyen: I did not. I am sure the physician did go over multiple courses of, I guess healthcare, but that was the standard of care and that helped many patients in the past, so that was highly encouraged to me and it seemed like a no brainer.

Ms. Goodrich: Right. You said you knew your prognosis, and you had a very good prognosis at that point in time. How the treatment go and how did you get back to life after you were treated?

Mr. Nguyen: Treatment went pretty well. I think it helps to be young. Currently right now with the new treatment that is out there, I don't really encourage people to take this treatment. I guess it seemed a little bit like, comparative to the newer treatments that I've received later, the ABVD did not feel too great. There was a little bit of nausea. I still had a cough because I think the bleomycin causes lung scarring.

Ms. Goodrich: Yes.

Mr. Nguyen: That was something that I was susceptible because I also had asthma, and that agitated my asthma.

Ms. Goodrich: If I remember correctly, you had your bleomycin eliminated for the last few cycles because –

Mr. Nguyen: Exactly, yes.

Ms. Goodrich: Did you have any long-term symptoms from that or any limitations from that?

Mr. Nguyen: I can't tell. I'm not sure if it's solely because of that or it is an extension of everything that my body has went through.

Ms. Goodrich: You finished your ABVD and you were in a complete remission. What did you do at that point to get back to life?

Mr. Nguyen: I was worried about paying off debts, honestly. I was worried about paying off healthcare debts and my financials actually, so I started working at a restaurant. I started bartending at this restaurant called Chasin' Tails. As funny as it is, bartending is kind of lucrative especially when you are trying to pay bills. The time that I spent at Chasin' Tails really did help accumulate, and I did pay off a majority of my debt, so that was really awesome.

Ms. Goodrich: Did you not have health insurance at that time?

Mr. Nguyen: My health insurance got dropped, so from the year, from 2012 to 2013, I didn't qualify for some reason, and there was an issue, so I did not get covered for, I guess, until the later end of my treatment.

Ms. Goodrich: Understood. But you were young and healthy otherwise, and were able to work hard and get that paid down.

Mr. Nguyen: Yes. Getting cancer really changes your perspective on things. Even with a positive prognosis, I was able to view it as a blessing and was grateful for my prognosis, getting a 90% success rate is pretty nice. It's weird to say but it is one of the luckier cancers that you can get, which is, I guess, a strange thing to say. If you look at it that way, there's positives in it too.

Ms. Goodrich: Silver lining, it sounds like.

Mr. Nguyen: Yes.

Ms. Goodrich: What happened with MCATs? What did you do after that, assuming at that point you were cured?

Mr. Nguyen: I took about a year just to pay off debts and kind of recenter myself, focused on health rather than academics, and I started studying again. The sucky thing was it did relapse right before I was going to take my test again.

Ms. Goodrich: That was in April of 2015, so it's about 2 years and 4 months after you've completed the ABVD, and that's when I met you was back in 2015. What was that like for you? How did that impact you? How was that different from your initial diagnosis?

Mr. Nguyen: One of the hardest things to do and one of the hardest things in this situation would be having to tell your family and friends that you have cancer again. Seeing the pain, I guess, that the ones closest to you go through I think is one of the hardest things. When that happened, it was during that snow storm, the "Snowmageddon," I think that the term was called. How I found out was I was shoveling my car out of the – I live in DC, so I was shoveling my car out of the street parking, and my back started hurting, and then after my back started hurting, night sweats came back, I was coughing an immense amount. I just knew the cancer was back, like it was too familiar. It was really difficult. I probably shouldn't have tried to hide it from people, but I did. I guess you just don't want to deliver that news.

Ms. Goodrich: When you came to us and started talking about next steps, I'm sure you were given a multitude of options, how did you make decisions about more treatment and ultimately next going on to an autologous stem cell transplant? What was that like making those decisions, and what did you want to know, and how did you work through that?

Mr. Nguyen: The main pathways to take were either an allogeneic or autologous. We believe that, as a family, and myself, we believed that going the autologous way would be the best course of action for us because if that didn't work, we could go the allogeneic. With the autologous transplant, it wouldn't be too difficult on the body was what I was told, I guess in a more layman terms. It was difficult to tell my family and kind of like get out of an emotional mindset to think logically of the situation. Imagine, a loved one you would never want to think that, "Oh, this is the better of the worst," or something like that just to weigh out a difficult decision like that. At the end of it all, we decided to go with the autologous stem cell transplant.

Ms. Goodrich: Clearly, your family was a big part of that decision-making. Do you feel like you had enough information in hindsight? Do you feel like you asked enough questions or were given enough information to comfortably make those decisions?

Mr. Nguyen: Yes, I did. It does help being in the healthcare field with a biology major going into all of this; you do have a finer understanding of these things. That was a little encouraging and actually very interesting as well.

Ms. Goodrich: In a convoluted sort of way, right?

Mr. Nguyen: Yes.

Ms. Goodrich: That was April of 2015, so you ended up getting ICE, which is a salvage chemotherapy regimen, and then you had your autologous transplant in September of 2015. We all went into that with curative intent. How did that go for you?

Mr. Nguyen: The ICE was indeed more intense than ABVD. I think this also ties in with being young. I was able to handle it pretty well. I didn't know if other patients in the same mentality or in the same care plan that did not fare as well, and that did make me sad. It's very difficult to see the same people that are kind of comrades in the same situation that you were going through that aren't doing as well. Being young does help a lot.

Ms. Goodrich: Were these people that you met during your ICE or during the transplant?

Mr. Nguyen: During the ICE.

Ms. Goodrich: I think that's something that we as healthcare providers don't really think about are the patients and the relationships that you form with one another, and the difficulty when other folks around you are not doing as well as you are.

Mr. Nguyen: The comradery is there and sometimes you feel a little bit guilty that a person who started at the same time as you, another patient who started at the same time as you is still stuck at their first phase and they still haven't moved on to the transplant phase for example.

Ms. Goodrich: How did that transplant go for you?

Mr. Nguyen: I thought the transplant went great.

Ms. Goodrich: You got through that pretty well for sure. Unfortunately, by 6 or 7 months later, March, February/March of 2016, the lymphoma came back again – the Hodgkin came back again.

Mr. Nguyen: Yes.

Ms. Goodrich: Tell me what was going through your mind at this point. What were your priorities? What were your challenges and stressors?

Mr. Nguyen: At this time, after this happens and it relapses multiple times, I guess you start losing faith and you start to think about how your loved ones would do if you, say, passed away. That would be my primary concern. One of the things that I guess would scare me—Amy, we spoke about this before—the things that would scare me would be like being unresponsive but still kind of on life

support. We did get into a big argument with my family, with me trying to get a Do Not Resuscitate or an Advanced Directive, because as you can imagine being a spectator or a supporter of someone who is sick, you don't want them to think like that. The emotion kind of clouds your vision about how the patient may think and try to take that weight off of your shoulders in the future if, say, the worst happens.

Mr. Nguyen: Ultimately, I guess that decision-making, I decided not to pursue it just to appease my family and friends. But that is something that would be more of an issue after the third relapse where you're thinking about mortality rates more so and your effect on the family.

Ms. Goodrich: Your prognosis, the mortality rates, those are definitely, at this point, something that we're talking about as healthcare providers, but were you asking as well?

Mr. Nguyen: Yes.

Ms. Goodrich: At this point, things like you're saying you were losing hope and there's not – when patients are initially diagnosed with particularly classical Hodgkin lymphoma, ABVD is pretty much the standard initial therapy. But when you get to the point where you were, you're outside the cookie cutter now, you're making your own path. What options were discussed with you at this time? And you ended up going on a clinical trial. How did you decide to do that?

Mr. Nguyen: The option that was discussed with me – there was cord blood discussion. There were numerous of ways to get different types of transplant. The main pathway I think that was described that would lead to the most success would be a transplant, but it would be like different types of transplant if we should access the database of donors, I think the donor database, but unfortunately they are, I believe, eastern Caucasian, eastern European, Caucasian people. I am an Asian/Vietnamese American, so that would be highly unlikely to find at least a 50% match. We went over cord blood options, but we decided ultimately not to pursue that.

Ms. Goodrich: In order to get to the transplant you needed to get back into a remission, and that's the point at which you joined a clinical trial?

Mr. Nguyen: Yes.

Ms. Goodrich: You received nivolumab and brentuximab vedotin. How did you make that decision to go on a trial at this point?

Mr. Nguyen: I guess in a weird way, it didn't feel like I had a choice. It feels like this would be my only shining light it seemed like, for myself and my family as well.

Ms. Goodrich: I'm sure we talked to you at that point about those drugs separately versus getting them together on a trial. Do you feel you had enough information to make that decision?

Mr. Nguyen: Yes, I did. I think that the care team that I had at John Hopkins were amazing. They were informative, they were empathetic, that care was compassionate, it was wonderful. I would encourage those drugs for anyone actually. The side effects that I had with that combination, it wasn't as bad as ICE or ABVD, and I would encourage that. I know that brentuximab is meant for patients who have relapse, but I support it 100%.

Ms. Goodrich: Understood. Fortunately, you had a complete response to that clinical trial therapy and you had an allogeneic transplant from your brother in July of 2016. How hard was it for you to make this decision to do this allogeneic transplant knowing, you know, that, certainly, you had been through all standard approaches at that time?

Mr. Nguyen: I think it was the best decision because I would be fighting. Having the choice to continue to have this despite the losing options is very human I guess. Yes, it shows great human spirit, and it made it easier that I had such a strong support group. My little brother, his name is Brian, he is the sweetest little man ever. For him to be ready and willing and excited to do a transplant with me, it's actually great. I thought it was extremely cute.

Ms. Goodrich: What impact did that have on him? What impact do you think that experience had on him?

Mr. Nguyen: He is a little bit less mature. I think he understands it, but I don't think he understands or gets a grasp like I do. I am eternally grateful that he was able to do that, and because of him I have a second, third chance. As much as I tell him, he has difficulty accepting compliments, so he doesn't truly understand I guess the weight of how much you helped me. That is something that I guess sometimes other people don't understand the gratitude that you feel towards another person as much as you try to explain that to them.

Ms. Goodrich: You're currently in your longest remission?

Mr. Nguyen: Yes.

Ms. Goodrich: You're going on 3 years now that you have been in remission after the allogeneic transplant. Do you think about recurrence at this point?

Mr. Nguyen: I think about it all the time. Generally because, and especially at this time too, during this period was when I had two relapses. It's hard because it happened so many times, and it was such a big part of my life that it was basically my only focus on that. It really trains you to always prepare for the worst. Currently right

now, my biggest difficulty is realizing that I do have a future, that I can create plans that will last for more than a couple of years.

Ms. Goodrich: What have you done in your life since that to get back to some type of normalcy?

Mr. Nguyen: I have pursued a job in the healthcare sector. I work as a medical administrator at a wonderful place. We provide compassionate care to all of our patients, which I think is great. Currently right now, I just took a GRE prep class. I decided to go for a master's program because I was afraid that I wouldn't be healthy enough to complete a medical school program.

Ms. Goodrich: You mean in terms of relapse?

Mr. Nguyen: Yes, in terms of relapse.

Ms. Goodrich: Okay.

Mr. Nguyen: I was afraid that say if I did go into a medical program that lasts for 4-plus another 4 years, I would not be healthy during the whole thing and then I would have to drop out.

Ms. Goodrich: I see. Physically, have you rebounded from all of this? What physical issues do you continue to have as a result of this very long cancer journey that you've had?

Mr. Nguyen: One of the side effects that I had, I think it came from the brentuximab, was neuropathy in my hands. One of the things that it would, it would lock up my fingers, and I am a pianist, I love playing piano, it was one of my stress relievers. My finger function has almost returned to normal, which is great. I can play the piano, and I'm happy because I thought that I was going to lose that ability, and that was one of my escapes from reality.

Mr. Nguyen: Healthwise, I have gained about 20 pounds back. I lost a lot of weight during the whole treatment, and I've gained about maybe 20 pounds just being active, going to the gym, eating a lot more. My first year of the most current remission, I focused on health and weight gain and to try to get back my stamina when I run, my strength when I lift weights. I do have vein scarring so my circulation is a little bit not as good as it was before. I guess those were the main things.

Ms. Goodrich: Today, I heard you saying your biggest concern related to the Hodgkin is that it's going to come back. Do you have any concerns about the long-term effects of the treatments that you have received? Is there anything that you are concerned about?

Mr. Nguyen: Yes. I understand that with the treatment that I have had, it would most likely decrease my life expectancy. I think that is something that I just have to

understand, that that is how it is. But I am more grateful to have a longer life rather than a shorter life. The effect that it has on my family is astounding, it's great, everyone is very optimistic about me and my future. I think that that's wonderful to see after you let them down for a good while.

Ms. Goodrich: It's actually very sad to hear that you felt like you were letting people down, but I can see how that is somewhere your mind would go. I think this has been really helpful, very helpful. This has been a great conversation, but if you could wrap this up for patients or caregivers or healthcare providers—mainly healthcare providers who are embarking on this cancer journey with their Hodgkin patients—what would you recommend that healthcare providers think about, and talk about, and educate patients about with Hodgkin lymphoma specifically?

Mr. Nguyen: They would like an emotional approach to this, and I felt like I received a lot of that. I think that having multiple perspectives on the situation and the patient would be the best bet. Thinking about how you would feel in their shoes and delivering that information accordingly would be really nice. I love my doctors, and, Amy, you were great too during the whole process, so I didn't feel like you guys needed to change anything. I would encourage you to do the same thing to other patients.

Ms. Goodrich: Do you have any advice for us as healthcare providers for approaching patients who aren't quite as articulate and open and educated, and asking? You always asked a lot of questions and really paid very close attention to answers, and then layered your questions after that. Do you have any advice for us when patients are not so forthcoming and organized with their thoughts and their questions?

Mr. Nguyen: I think that it would be the feeling that you create in that situation. Sometimes it takes some patients longer to open up and to be transparent, creating that comfortable, accepting, open atmosphere is extremely important in connecting with anyone. I was lucky in a weird way to have met Amy for 3, 4 years now. I feel like we're close.

Ms. Goodrich: Yes, Kevin. Kevin, you're here. You know, I love you, Kevin.

Mr. Nguyen: I love you too, Amy.

Ms. Goodrich: This has been very helpful. I thank you for your time.

Mr. Nguyen: It was my pleasure.

Ms. Goodrich: I thank everyone for listening and joining us today.

Ms. Goodrich: Our PEARLS, or our takeaways, today are that shared decision-making is critical, particularly when new therapy is being considered. Empathy and compassion,

foster trust and open communication. Classical Hodgkin lymphoma, as we heard with our patient, can be a life trajectory–changing diagnosis for young adults. We learned that families play a critical role in decision-making.

Ms. Goodrich:

For us as healthcare providers, it's critical for us to stay current on new therapies, the expected success and side effects, the administration details, monitoring requirements, and all of those details that we need to assure that patients are educated and able to make informed decisions. Lastly, survivorship issues: they are common, there are physical issues, financial, psychosocial, with our classical Hodgkin lymphoma patients, and that requires assessment and appropriate referrals for intervention. Again, thank you for joining me.