CMEology

HAE – Hereditary Angioedema

Interview with “11”

May 9, 2024

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CMEology

Interview with 11 – Hereditary Angioedema

[START 11 5.9.24.M4A]

[IRRELEVANT MATERIAL OMITTED]

QUESTION: The first question is: what is your personal experience evaluating the HAE literature in terms of its implications for clinical practice?

11: The HAE practice parameters as they've updated, I mean, I think I've seen some of the more recent like in *New England Journal* for some of the more recent stuff, but in general, I mean, for me as a community allergist, this is kind of one topic among many, so I would say that I'm not reading everything coming out in the primary literature by any means.

Commented [1]: Codes (718-782)
Literature review

QUESTION: Okay. What are you looking for when you're looking at the literature on HAE? What kinds of questions are you bringing to your search for information?

11: Generally, it's around med selection, so stuff like on relative efficacy, relative administration mechanisms; just again not having too, too many of these patients, just mostly trying to make decisions on which agents to use.

Commented [2]: Codes (1024-1033)
Superiority of efficacy

QUESTION: Okay. And just so that I have a little bit more clearer sense of your practice setting, are you in private practice or group practice, academic practice?

11: It's a private practice in [redacted]. It really is, I like doing a little bit of everything. I mean, it is not a rhinitis practice by any means, really see a little bit of everything. I do have a couple of HAE patients on therapy among other stuff, but basically, kind of all AI topics, community-based.

QUESTION: Okay. Are you working by yourself or with a group?

11: So we're a group where we're a small group. M[redacted] We have a practice together with another c[redacted]and I'm the allergist.

QUESTION: Okay, got it. When you're considering the implications of HAE research on clinical care, is there any particular format of research results that's more influential to you? So let me give you some examples: abstracts, poster presentations, live conference presentations, academic detailing, UpToDate or similar kinds of databases, or journal pubs?

Commented [3]: Codes (2261-2286)
Expert opinion/Up To Date/Google/Medscape

11: I like UpToDate for sure. I do like stuff basically in a journal article layout, like abstracts or reading the entire article. I feel like reading is much more efficient than watching a CME or most in-person CMEs, so I generally find this stuff on the computer, either primary articles, or the practice parameter I like a lot for HAE, or UpToDate.

Commented [4]: Codes (2300-2388)
QUOTE

Commented [5]: Codes (2388-2475)
Literature review
QUOTE

QUESTION: Okay, all right. So you'd prefer to read about something if you have the chance to do that. Do you have the opportunity to attend national meetings?

11: I haven't in a little bit. Just between work and kids, it just generally is hard to find [phonetic] the time. I also feel like in this era, it's very easy to find everything on the computer and do CME that way and to keep up that way.

Commented [6]: Codes (2882-3007)
CME

QUESTION: Okay. And there are a lot more CME activities obviously that are offered online than there were even five years ago, of course. What factors are most important to you in the process of interpreting the HAE literature and applying it to clinical care? So are there particular skills or knowledge, interactions with your colleagues, time factors that impact you when it comes to interpreting the HAE literature and applying it to clinical care?

Commented [7]: Codes (3473-3507)
Clinician time constraints

11: I think, I mean, certainly the time factor, generally, it's having to answer a pretty focused question quickly. And I think for me, a lot of it is like stacking up just kind of key clinical outcomes, so like reduction in attack number, severity of duration or those types of things, and to try to compare numbers across the different products.

QUESTION: Okay. And of course, head-to-head trials are rare to nonexistent, right?

11: Right.

QUESTION: So that can obviously be [unintelligible].

11: Sure.

QUESTION: Do you have access to clinical grand rounds or anything that you might attend in your area where allergy topics are discussed?

11: Yes, I do. I trained, I'm in the same town as our program, and so, I've gone some to the allergy, these are just like their CME type of conferences that are the Fellow teaching conferences, but not a ton.

QUESTION: Not a ton, yes, okay. Do you feel like you're generally pretty well-prepared to look at the HAE literature?

11: Yes, I think so. I think for me, the challenge is not, I mean, it's not so much like reading what's out there. It's more just that I would say our area, we don't have a ton of HAE patients, so I feel like there is a lot of founder effects around this where generally, it is autosomal dominant and for whatever reason, there's just not a ton here. And so, I think that's really more the limit; it's just like I have a couple of people and typically, I'm kind of making a decision, one occasional patient at a time for HAE treatment.

QUESTION: Yes, not treating a whole big clinic full of people with the disorder.

11: Mm-hmm.

QUESTION: Okay. Can you describe any barriers to incorporating research findings in HAE into clinical practice that you've experienced? So barriers that might impede translation of the literature into practice might include patient-related barriers, healthcare provider-related barriers, practice-related issues, or maybe institutional barriers.

11: I think mainly it'd be institutional barriers. I mean, I enjoy reading about the different newer options and mechanisms and stuff, but I think in practice, we really run into that payers really will, you know, this is rare enough that they'll push one or two things, and it's hard enough to get those. So a lot of it is sort of what we do, I think, is limited by somebody's insurance.

QUESTION: Okay. So getting approval from insurance to use something that's relatively new in the field is the main barrier?

11: Yes.

QUESTION: Okay, all right. Any patient-related issues that you've encountered that are barriers?

11: Yes, I think there's always sort of this cultural thing that everybody feels like every time they have something that sounds like an allergic reaction, it has to be a food. I had one patient that, not argued with,

Commented [8]: Codes (3576-3808)
Improve skills

Commented [9]: Codes (4173-4311)
Collegiality

Commented [10]: Codes (5564-5793)
Insurance/Prior authorization

Commented [11]: Codes (6032-6519)
Patient education

but clearly has no C1 inhibitor that's convinced that she has alpha-gal, which is the really common red meat allergy in the [redacted] where we are, and no amount of convincing, so anyway, sorry, but let's do this medicine and we'll have you avoid that, and let's go from there.

QUESTION: Okay. I didn't realize that alpha-gal was more prevalent in the [redacted]

11: Oh my goodness, yes, it's epidemic.

QUESTION: Why is that?

11: I think it probably tracks with bite frequency, but it's sort of through the [redacted], it's just really, really heavy. It's got to be the most common adult [redacted] even setting aside all the imaginary alpha-gal of which there is lots.

QUESTION: Okay. Imagined.

(Overlapping Voices)

11: Or emerging, start emerging with chronic Lyme in the popular imagination.

QUESTION: Hmm, interesting. Well, that's quite fascinating. Well, I'm based here [redacted] here we, knock on wood, have fortunately very few mosquitoes, partly because it's just such an incredibly dry climate; I don't think it has to do with [redacted] much. But we're relatively fortunate in that regard that we don't, you know, we'll get the occasional bites and a few things, but we don't really have a huge problem with that. I had forgotten that mosquitoes are so prevalent in the [redacted] Thank you for reminding me of that for my next trip down there. Okay, all right. So what do you think delays the introduction of evidence-based practices in HAE into clinical care?

Commented [12]: Codes (7757-8060)
Insurance/Prior authorization

11: I really think most of it is payer preferences and acceptance. It's just, I mean, these have been some of our hardest PA's and that's even when we're trying to go in with the one that theoretically they're saying is their preferred, and trying to branch out from that just gets really, really difficult. And so, if there were something that new evidence is saying it's better but that insurer hasn't updated it, still, it's very hard to make that happen given the price point.

QUESTION: Okay. So hard to get prior auths for some of the newer treatments partially because of price point, maybe also because payers have not really updated their own, and I understand that happens late, right?

11: Yes.

QUESTION: But they update their standards and practices relatively slowly compared to the rate at which things come onto the market. Anything that you do in your office to overcome barriers related to payer and insurance issues?

11: Yes. I think generally the manufacturer reps are helpful that they'll, if we really get stuck getting someone onto foundation, it's really nice and really helpful. But I think most of it is just sort of working these PA's and going through this process, and again, for whatever reason, the HAE ones have just been really challenging. I mean, I guess certainly the price point is a little higher than an asthma biologic or something, but those seem to be going through pretty routinely at this point and really not so for the HAE meds.

QUESTION: Okay. Yes, maybe we've reached a point where people have become accustomed to the fact that there are going to be multiple asthma biologics out there, and obviously, asthma is a much more common condition, too, right?

11: Yes.

QUESTION: I'd imagine that probably plays a role in that as well. Okay. What's been your experience identifying patients with HAE who would benefit from long-term prophylaxis?

11: So once we diagnose them and then trying to assess what their attack frequency is and their feelings around it, if they feel like, if it's kind of a lesser number per year or if they're okay with rescue only, so I think a lot of patient preference there. But I think it's just kind of feeling out what's happening, how severe, and how the patient feels about it.

QUESTION: Okay. So essentially, trying to get a sense from patients whether they feel like being on a regular prophylactic medication is, the benefit of that outweighs some of the practical concerns that could come along with that?

11: Right.

QUESTION: Right? Obviously either having to take a medication orally once a day, or have to take a sub-Q therapy periodically, most people, I would imagine, you don't have anyone on an IV preparation at this point, do you?

11: No.

QUESTION: Okay. Any other challenges that come up when it comes to identifying patients who should be on prophylaxis, or getting pushback from patients even?

11: I think that the patients are happy with the outcomes with the therapy, I mean, I think once we can get them to try it and see that it really helps a lot. I think from the patient perspective, it really is just like can we get it approved and at a reasonable cost.

QUESTION: Okay. So approvals and cost, obvious, it sounds like also impact of patients' considerations when it comes to this as well?

11: Yes.

QUESTION: Okay. Moving along, how do you gather and assess information about the impact of HAE on work, school, social life, family life?

11: I think really just sort of that informal discussion with the patients as they're having their follow-up visits, not necessarily using an instrument or anything written or formal, really just asking them, how's it going, how many attacks, when, what was the situation, how bad were they, did you use rescue, are you using a rescue only and how did that work, and just kind of the normal HPI of a visit but nothing special beyond that.

QUESTION: Are you aware that there are validated tools and questionnaires for looking at health-related quality of life issues in HAE?

11: I didn't know there were specifically for HAE now.

Commented [13]: Codes (9641-9850)
Few episodes/pref episodic tx

Commented [14]: Codes (11192-11340)
HRQOL self assessment instruments

Commented [15]: Codes (11764-11815)
HRQOL self assessment instruments

QUESTION: Okay. I think the perception, what I'm hearing is that most people see those as being something that might be used in a research-related setting but not necessarily routinely in clinical practice.

11: Yes.

QUESTION: There is some recommendation, there are recent recommendations that quality of life be kind of one of the main things that people think about when it comes to prophylaxis, and naturally, as soon as that cup [phonetic] rises to the top, then everyone wants to make a validated instrument for it, right? So there actually are validated instruments now, yes; they have actually only been used so far pretty much in a research setting but they do exist for use in that. But it sounds like you're relying more on your clinical intuition and then just a frank discussion with the patient in the exam room about how they've been doing and what their thoughts are.

11: Yes.

QUESTION: Okay. How do you engage patients in treatment decision-making regarding long-term prevention or reduction of HAE attacks?

11: So generally, I will say it may be presenting them with a few options, but it's maybe not presenting them with the whole world of options. So the last one that we put onto therapy, honestly, before we'd sent her blood work and everything and in preparation for her follow-up visit, we had one of our specialty pharmacies that we work with just kind of run it and help us to figure out what were going to be the preferred ones, so again, just that we've had such a hard time on some of these PA's that typically, I'm sort of limiting it to what I think we can simply get.

Commented [16]: Codes (13125-13414)
Specialty pharmacist

QUESTION: Sure, okay. So it has to be very patient- and insurance-specific then?

11: Yes.

QUESTION: You wouldn't want to discuss every single option out there if you know already that those are—

11: Right, because I could have—

(Overlapping Voices)

QUESTION: Okay.

11: —a 20-minute conversation about Haegarda and then not be able to get Haegarda, or what have you, you know?

QUESTION: Okay, sure. So that sounds like one way that you have kind of made that conversation a little bit easier, maybe shorter, is just to find out based on that person's coverage what might be available.

11: Yes.

QUESTION: And then, what are you seeing or hearing as far as patient preferences about long-term prophylaxis? Assuming that the patient [phonetic] has choices, what sense are you getting?

11: I have felt like, I mean, I think Orladeyo sounds great in terms of an oral. The couple that we've had where it basically was sub-Q versus oral, there's really not been a pushback. I think starting at IV is a nightmare and it's not realistic to expect patients to do either routinely or under duress even less. But I really haven't had much strong preference like oral versus an injectable, like a home injectable, a sub-Q injectable. And so, generally there, I'm probably pushing the sub-Q based on a little better efficacy.

QUESTION: So you're looking more at efficacy and thinking that the sub-Q may offer some advantage there?

11: Yes.

QUESTION: Okay, all right. That kind of leads right into the next question: how do you choose medications for long-term prevention or reduction of HAE attacks? Are you kind of prioritizing different factors and thinking about those issues?

11: Yes. I think, I mean, certainly not an IV, for one, but actually, the last two that I've had have both been prophylaxis and I did Haegarda for both of them, and the reasoning was they were ones we could get, number one, but the sub-Q and then also like a really effective sub-Q, but then also something that could reasonably be used as a prophylaxis. So I'll typically have them try to order right at 28 days or whatever and kind of stock a little extra, and then use it essentially for both if there are already attacks, again with the thought that one PA is better than two.

QUESTION: Sure, yes, can certainly understand that, especially if it sounds like being so much of a problem to go through the process for just one medicine, why do it twice, right?

11: Mm-hmm.

QUESTION: Okay. Anything related to mechanism of action with medications, does that influence the way you think about using one over the other?

11: To me, I like the idea of a C1 inhibitor product: just if that's what you're missing, replacing that seems very straightforward. But I think they all work pretty well, everything in the pathway, whether a C1 inhibitor or kallikrein inhibition. I feel like Firazyr, I've used a couple of times for rescue. I think that's worked well; that certainly makes sense being kind of at the end of the line. But I think all of the different points in the pathway are all pretty reasonable.

QUESTION: Okay. All right. Did you by any chance participate in the CME activity on HAE?

11: No.

QUESTION: Okay, I didn't think so. I think one of your colleagues did, and then, they may have referred you to us to do this particular interview, okay.

11: I think that's right, yes.

QUESTION: Yes.

11: That was a friend, yes.

QUESTION: Okay, perfect. So clinical guidelines can be one way that research gets translated into clinical practice. What effect might HAE clinical guidelines have on your practice?

Commented [17]: Codes (14380-14634)
IV route

Commented [18]: Codes (16994-17386)
Guidelines

11: So I've always really liked the practice parameters. I feel like they're a really nice kind of distillation and reasonable recommendations. And so, I think those are really useful, and having updated guidelines and parameters I think is nice to reference back. They're also nice to be able to, we've occasionally pulled pages and sent them with PA's as well, so having some backup is also nice.

QUESTION: Okay. Yes, that can certainly provide the, quote, "evidence" that you might need to be able to get someone onto a treatment, especially perhaps one of the newer ones. This is the last question: is there anything else that comes to mind while we're talking that you think it would be good for me to know about HAE or HAE treatment?

11: I just think that maybe it's just our area or not a huge sample number of patients, but it just seems very, very hard to get these meds, unusually so. I feel like that's also a little bit true of immunoglobulin; that also has been a lot of pushback in our area where some of these other things that are more common, it seems like, are more and more routine. I think that from the manufacturer standpoint, if there is ability to sort of lobby and interact with the insurers and say like, this is the thing, these need to be reasonable approvals when they can meet these criteria, like this is reasonable.

QUESTION: Okay. All right. Well, I absolutely appreciate your taking time out of your busy day to chat with me. It was very valuable being able to speak with you. And you will be receiving [redacted]. She is the person that emailed you about this interview—

11: Okay.

QUESTION: —and set it up for us. But again, appreciate your help very much, also appreciate your educating me a little bit about alpha-gal. By background, I'm a pulmonary critical care physician, but I trained at [redacted], and so, I was around allergy people all the time and honestly learned so much about allergy and immunology that I had never been exposed to when I was a house officer [phonetic]. And of course, as pulmonary and critical care folks, we are so involved in taking care of acutely decompensating people that we don't get much time to think about allergy issues. So at any rate, it's always fun for me to learn new things about allergy, and I will definitely keep that in mind as I look at the literature going forward. At any rate, thank you again for your help today, appreciate it [phonetic].

[IRRELEVANT MATERIAL OMITTED]

[END 11 5.9.24.M4A]