# CMEology

## HAE – Hereditary Angioedema

## Interview with “08”

# June 27, 2024

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**CMEology**

## Interview with 08 – Hereditary Angioedema

[START 08 6.27.24.M4A]

[IRRELEVANT MATERIAL OMITTED]

QUESTION: What is your personal experience evaluating the HAE literature in terms of its implications for clinical practice?

08: So I keep up with the literature in general. I have found that there is a lot of literature that comes out on HAE. It's been an interesting time in terms of new medications and new developments. I think now everyone is rushing to try to get more oral options for patients. I found the literature mostly useful. I think that the issue with HAE in terms of diagnosis is always what to do with the patients who seem to have clinical symptoms but no positive lab results, and that continues to baffle a lot of us.

QUESTION: Yes. Do you have a particular approach when it comes to the literature? Are you actively searching for different papers or things, or do you find that links to papers or mentions of papers kind of come to you?

08: I have two ways that I approach the literature in general. One is I try to keep up with journals, so I get the Annals and JACI journals: I kind of leave them in a stack and every once in a while, every month or so, I'll have a day when I try to go through them. So I read, when I'm not searching for anything, any particular patient information, I'm reading mostly like those two top journals. I'm in a bunch of different allergy groups both online and then on like WhatsApp and through texts with various colleagues, and when we encounter something interesting or unique, we send it out to one another. And then, if I have a unique patient that I don't have an answer for, I'll go back and search the literature, so I usually Google or search on PubMed.

QUESTION: So you're quite actively looking for things that are out there. I'm assuming that you're also looking up other topics, not just HAE.

08: Yes, yes, of course. I try to keep up.

QUESTION: And you're an allergy-immunology practice?

08: Yes. So I joined the general pediatric practice about a year-and-a-half ago, and I'm building allergy and immunology there.

QUESTION: Oh, interesting.

08: It is, thank you. Prior to that, I was at [redacted] which is a large academic center in [redacted], [redacted] and they had more complex, very interesting cases.

QUESTION: Okay. And so, do you see patients then who are, I mean, it sounds like if you're within the pedes practice, you're seeing most pedes, adolescents?

08: So my model is, well, I'm in a pedes practice that goes up to age 24 so wide numbers [phonetic].

QUESTION: Oh my, okay. [Laughter]

08: And my model there has been kids and their parents, so when I came in, I wasn't sure if parents would want us in a pedes office, but people really just want convenience. And as both allergy and immunology tend to be genetic diseases, I have seen a lot of families all together.

QUESTION: Oh, interesting, okay. It's kind of the family practice model of [unintelligible] and immunology.

**Commented [1]:** Codes (467-733)
Literature review

**Commented [2]:** Codes (1215-1418)
Literature review

**Commented [3]:** Codes (1550-1673)
Chat room
Collegiality

**Commented [4]:** Codes (1673-1674)
Collegiality

**Commented [5]:** Codes (1760-1911)
Literature review

08: Yes, I would have fit better into the 60s in terms of what I've been [phonetic] practicing, for sure.

QUESTION: Yes, okay. So it sounds like you might have people in your practice then who have truly hereditary angioedema.

08: Yes, right now, I just have one. So the smaller practices, I think we all tend to have like one or two; a lot of my experience in getting familiar with these drugs came from [redacted] I'm actually not even sure, I think my program director there was just one of the big names in HAE, and he's [redacted] and there is a lot of HAE in [redacted].

QUESTION: Huh, did not know that.

08: At least in [redacted]. So sort of because of that connection, we ended up seeing a lot of it.

QUESTION: Huh.

08: Right now, I have one family which I think is sort of typical for a small group practice that (Overlap).

QUESTION: Okay, sure. 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 for example, formats such as abstracts; posters; live conference presentations; academic detailing; UpToDate or something similar; or journal publications.

**Commented [6]:** Codes (4353-4503)
Literature review

08: I think journal publications. Your top-of-the-line gold standard is always going to be randomized double-blinded trials, and then, you go from there. The question right now, I haven't encountered many patients that don't respond to medications. I think the issue now is quality of life, so that's obviously less reliant on randomized trials and more subjective measures. I pretty much look at everything. I try to go to conferences also, and I think I have a decent sense of what constitutes good research, and things like case reports are always interesting. I take it with a grain of salt, but I keep it in the back of my mind. For rare diseases, I don't think you can discount any research.

QUESTION: Yes, okay. Are you able to break away and get to conferences?

08: Now it's difficult. I have two small boys and two dogs [phonetic]. It's been hard. I have in the last few years, I'm going to try to go to [redacted] I usually take the days off and do the conferences remotely.

**Commented [7]:** Codes (5206-5331)
Professional Conferences

QUESTION: Okay, so you're able to just clear your—

08: It was an option during Covid, yes.

QUESTION: —yes, sure.

08: It was an option during Covid, and then this year, I just took the days off and went to a local bookstore, put in headphones, got childcare for those days.

QUESTION: Yes, it's nice to have that option, and it can be a big commitment especially, I can totally relate, my kids are now in college and beyond, but it can be really, it's a huge commitment to try to make it to in-person events.

08: Yes.

QUESTION: And that may change with you over time. You may find that you're actually able to get away and do more. But yes, it can be really difficult, and it's great that so many of the national societies now are offering an online option. Have you see HAE pop up much at conferences or any (Overlap)?

08: Yes. I haven't been to an in-person one since before Covid, but before that, yes, it was a huge, huge conference topic. That, immunoglobulin replacement, and now the biologics: they are all very heavily advertised. I remember one conference when Takhzyro came out, it was like plastered everywhere. [Laughter]

QUESTION: Yes, right. What factors are most important to you when you're interpreting the literature and trying to translate that into clinical care? I'm just wondering if things like discussions with colleagues are influential, or if there are any other factors, things that you're looking for when you're reading the literature that are important.

**Commented [8]:** Codes (6817-6946)
Collegiality

08: Discussions with colleagues are really important especially with HAE medications; there are so many of them that are so similar. So I think other people who have more experience with the diseases, their experiences are really important. In reviewing the literature, I think as things come up, I want to make sure that there is a safety and efficacy record, and then past that, I think a lot of it has to do with people's experience and what their patients like and dislike.

QUESTION: Okay, all right. Moving on here, could you describe any barriers to incorporating research findings in HAE into clinical practice that you've encountered? So I'll give you some examples of barriers that can sort of impede the translation of research into practice and those include: patient-related barriers; healthcare provider-related barriers; practice-related barriers; and institutional barriers. Anything that you've encountered regarding HAE?

**Commented [9]:** Codes (7756-7941)
No show/adherence

08: Patient-related barriers are noncompliance, so I think there is a lot of noncompliance generally with HAE, especially if people are on injectables because people don't like injectables. HAE is hard because if you're on the injectables, you know, it's one of those things that if you're diagnosed before you have severe episodes, you don't really know why you're on it. I find that my really compliant patients like from other diseases are the ones, you know, every time I have a kid with severe asthma or severe eczema getting their first injection, they're miserable, screaming and crying; and then, when they get a few injections and feel the clinical effect, it's much easier to stay compliant, keep them compliant.

So I think what distinguishes HAE is with the other diseases, we hope and we think that for the vast majority of these patients, it's really not going to be lifelong treatment. Lifelong treatment with injectables is hard, so there is a lot of noncompliance that when you get to oral medications like any chronic disease, it's just taking a medicine every day is hard and people forget to do it.

QUESTION: Sure.

08: So that's patient-related. In the office, time is always a limitation. There are so many options and explaining the disease process, going through it, going through all of the options, any sort of rare chronic disease is a really long conversation, so as you get busier, it becomes difficult. I think that's why a lot of these patients tend to end up in academic practices where you have, like my boss was [redacted] still practicing.

**Commented [10]:** Codes (8917-8961)
Clinician time constraints

QUESTION: Oh, my goodness, wow.

08: Yes. So he sees the patients and he talks to the patients, and he doesn't write a single note because he's got Fellows doing it. So it's a very different style of practice, and I think that's how a lot of them end

up there where he has the time to sit there and schmooze and explain everything, and everyone else is doing the documentation. For me, that's definitely a barrier. I don't even have a nurse right now, so I'm giving my own allergy shots, my own food challenges, so it's a barrier. But I tend to, I can also template myself, so when I know a patient is going to require, obviously not for the first encounter but later on if I know a patient is going to require more time, I'm able to sort of make space for that.

Commented [11]: Codes (9708-9861)
Clinician time constraints

QUESTION: Okay. So you do have a little bit of flexibility that can help you adapt to that. Are there any other resources that you found to be helpful that can reduce the amount of time pressure that you (Overlap)?

08: Yes, I hate to say this, but reps are useful.

QUESTION: Sure, it's okay.

08: They're very nice and you get along with them really well. So the Orladeyo rep, I know him by name and I only met him a few times; he's very nice, very personable, and has been really helpful for helping me get patients on Orladeyo.

QUESTION: Any literature, handouts, anything else of that sort that you have used with patients? I know HAE is not very common, right?

08: I like to have, no, but I can extrapolate for you. I mean, the handouts that like the biologics give, when there are handouts that they target for doctors, I honestly find those useless; I find that my knowledge highly exceeds what they are giving me. And so, I don't really understand why they are giving me like one sheet of paper when we've all read piles of documents on these medications. I do find the handouts for patients explaining the medications in a really digestible way for them, I find that to be helpful.

QUESTION: Okay. Yes, and certainly, the treatment landscape in your area has become a lot more complex and I guess the biggest example of that would be biologics for asthma. I mean, I would imagine many people who have severe asthma now are getting used to the idea of being on a biologic but, of course, there was a day when that was an enormously novel thing [phonetic].

08: Yes, I mean, biologics were for everything [unintelligible] most all the diseases we treat.

QUESTION: Yes, right. So that's interesting because there are other fields in medicine where the concept of using a biologic is still just completely novel—

08: Oh, yes.

QUESTION: —and the idea of then testing people and giving them infusions and all of these things is just sort of, you know—

08: I get a lot of referrals from dermatologists and pulmonologists which angers me because (Overlap).

QUESTION: Oh, really? Because they don't want to deal with?

08: They just don't do it. I don't know, like I'll get a lot of eczema patients who are sent to me for allergy testing for eczema, and aren't put on a biologic.

QUESTION: Huh, interesting.

08: They'll end up staying with me because I put them on a biologic—

(Overlapping Voices)

QUESTION: Yes, exactly, okay.

08: So yes, there is a huge gap; there is a huge gap. I think the biggest frontier now is oral immunotherapy and Xolair for food allergy. That just got approved, but before [redacted] gave us handouts for Xolair for food allergies, someone in one of my groups ended up creating their own question spreadsheet [phonetic] essentially for patients, which is really nice because you could just mention the concept to them. I always try to keep in mind that patients will remember one to two things that you said in the entire visit, and I'll usually introduce the concept, give them literature, tell them to research at home and come back in two weeks and talk about it more; or set up, like now, we have video visits which also really helps because the types of things that maybe patients wouldn't want to come in for, like let's have this conversation, it's just really easy, you could give them time to digest the information, look it up themselves, and then circle back and discuss with you what they want to do for their next steps. I really try to involve patients in decision-making; they're just not going to do it. You can't make decisions for people; they need to be onboard.

QUESTION: Of course. Why do you think that there are delays when it comes to introducing evidence-based practice into clinical practice for HAE?

08: Probably because people are used to what they're used to, and there are already medications that treat the condition. And two, insurance: as new medications come out, insurance is a huge barrier, like a huge barrier. I just got two denials for Xolair for food allergy because, quote, I'm applying for a condition that's not approved.

QUESTION: Oh, boy.

08: Yes. So when new medications come around, I mean, that's like just a huge time-suck. And I'm very good at kind of finding workarounds, so I find local pharmacies that will do prior auths for me, which is a thing in [redacted] it's interesting, so I found one and that really helps me because they end up doing the letters and I can kind of battle it.

But even so, I have the same medication that will be, it was approved in one day for one patient, and now I've been waiting like six weeks for another patient and I'm giving samples. If I was doing that entirely on my own, what if I was doing that entirely on my own, I don't see myself just having the time to do it. Two, I am not young as an allergist, but I'm in the younger generation and you have to kind of have the ability to navigate; I think that's something that's really important.

So one of my colleagues who's not an allergist is gen pedes; she is [redacted] is like baffled at the concept that if I don't know something, I immediately will take pictures of a case and go to my colleagues and ask for advice. So I think you're always going to have generational gaps; the way that younger allergists practice is very different from how older allergists practice. They usually do what they do; they're not onboard with uptake of new meds, new ideas as quickly. Obviously, some exceptions to the rule, but generally speaking, we trained in a time with many more developments, so if you don't read constantly, you're going to fall behind basically.

QUESTION: Yes. And of course, that really is something that I think the effects of that are cumulative over the years, right? So it's hard to make up for ten years of not keeping up or not reading.

08: Right, right.

QUESTION: And there's just an enormous amount of information that's always coming at us now, too, so that does make it difficult even if you're trying hard to stay current with everything that's going on. What's been your experience identifying patients with HAE who would benefit from long-term prophylaxis?

**Commented [12]:** Codes (16243-16640)
Severity/frequency of attack

08: The easiest is patients, I had one girl in, I don't remember if it was at [redacted] or in my Fellowship, who came in and ended up getting, you know, they put her on an epi drip because she had such severe swelling that everyone thought it was anaphylaxis, and it ended up being HAE in the long-term; those patients, it's pretty easy to convince, the ones that end up in the ICU with severe swelling. There are certain symptoms, I think, that are more like gut issues, they're extremely painful and quite dangerous for patients. Those patients have been, as long as they come back positive on labs, they're easier to identify for prophylaxis.

I think what's harder is genetics, like if you have a child born to a parent with HAE and you identify it pretty early on, there is so much polymorphism in how you see the trait expressed in people, it's tough to know when to put someone who, in your like backwards way of diagnosing someone who may have the disease but hasn't expressed symptoms, tough to know when to pull the trigger and start giving them a daily prophylaxis.

QUESTION: Yes. So someone who might have a genetic or family predisposition but maybe has not had the defining, big, severe event.

08: Yes. If patients are suffering, they will go on treatment; that is not hard to do. That's the easiest to identify.

QUESTION: Okay. How do you gather information about the impact of HAE on a patient's work, school, social, family life?

**Commented [13]:** Codes (17686-17799)
HRQOL self assessment instruments

08: I don't know that there are any validated measures for that. I certainly haven't heard of any and don't use any. I think I just ask. But I tend to ask about quality of life issues for a lot of different diseases, maybe more so than I've seen my colleagues do[redacted], it's a fairly new development. My little [redacted]d it's given me a lot of insight into how much quality of life, you know, coming from an angle of I treat food allergy for years, and then I [redacted] with it, it makes you kind of, I think, relate to the patient experience a bit more.

Allergic diseases like ANI diseases in general, I think we tend to gloss over because they're maybe not, you know, the spectrum of things we treat is so diverse and when you go from like severe combined immunodeficiency which can kill someone pretty immediately, to things like allergic rhinitis, it might be easier to gloss over the quality of life stuff.

QUESTION: And how do you, just curious, what kinds of questions are you asking patients to sort of dig into the quality of life impact?

08: For kids, I ask about missed school days and complaints of symptoms. For adults, missed workdays. I think I'm just direct about it: how often are you having symptoms, are you suffering, is this keeping you from sleeping, is this keeping you from having a normal social life?

QUESTION: Okay. So sleep, social interactions, which I have learned—

08: (Overlap).

QUESTION: —yes, can be an area of HAE that maybe people don't really think about so much, but people who are kind of afraid to go and do things like travel or go to an event because they don't know what they'll do if they suddenly would get ill—

08: Right.

QUESTION: —yes, could see how that would certainly impact people's quality of life.

08: For advanced medications and advanced medical care, it's really hard for people to leave the U.S. So this is a topic for many, many different diseases because we have really good care here, and what if you end up in a place with not-so-good care?

QUESTION: Well, I'm empathizing with you because my, I guess [redacted] was diagnosed with[redacted] at about the same age, about two, so yes, I think I can relate to what you're saying. It certainly gives you a completely different view of things, even different from having a disease or disorder yourself, when you have to think about your child having to deal with something like a food allergy, a food allergy issue. And when he was diagnosed, I happened to be working at a [redacted] so I kind of just shuffled, I was like, oh my God, I know exactly what this is, right? So I kind of shuffled him in, we did all the testing and all that other stuff. But it is, I think, quality of life issues are important and it sounds like with food allergy now, with Xolair being approved, it's getting more complicated to think about how to manage that.

08: Yes, so my kid reacted and a week later, he was on oral immunotherapy, so I guess in that way, I'm lucky.

QUESTION: Right.

08: While my colleague sat here fitting him in, I got labs in my own office. Yes, I mean, the quality of life especially when it's your kid, you know?

(Overlapping Voices)

QUESTION: Yes. And everybody always says, well, you know, and food allergies, they impact the entire family, right, which honestly, it's true. Siblings, everybody, right, kind of ends up becoming (Overlap).

08: Oh, yes, my [redacted], [redacted] hat perspective. I also come from a family, like my parents and siblings where we've unfortunately encountered a lot of healthcare needs, so I do think I ask about the quality of life stuff; things affect people way more than it seems.

QUESTION: Yes, okay. How do you engage patients in treatment decision-making when it comes to prevention and long-term prophylaxis for HAE?

08: Oh, I try to be really nonjudgmental and give people options, and then, I have them think about it, talk to their family, and then I schedule like the video follow-ups to discuss what they want to do for next steps. I usually do tell them what I would do in their scenario like if it was for [phonetic] my kid.

QUESTION: Okay. Any challenges that you've encountered with trying to get people engaged in discussions about long-term prophylaxis?

08: Well, at [redacted] it was the ultra[redacted]s just not easily engageable. So long-term prophylaxis, I think anytime you're talking about something that's forever, it's going to be a difficult discussion for people. So as I mentioned, it's easier when they've encountered some suffering from the condition.

QUESTION: Okay.

08: Certainly having an oral option has made things easier. Even people who are very happily comfortable on injectables wanted to switch over. And I guess why, I don't want to inject myself, either.

QUESTION: Yes, yes. No, I completely understand that. And then, do you have patients who are getting long-term prophylaxis and then they are also given an on-demand therapy as well?

08: Yes. I tend to, and from what I've seen, if someone is getting long-term prophylaxis, they will have an on-demand therapy available to them. I have also seen patients who really only have one or two breakouts every few years, who just have an on-demand and not a daily therapy. But everyone on daily gets on-demand (Overlap).

QUESTION: Okay. Have you had patients who are in that group where they only have an on-demand and don't want to consider adding a long-term agent onto that?

08: Yes, when they don't have many breakthroughs.

QUESTION: Yes. So if they're infrequent or perhaps not as severe in terms of symptoms?

08: Yes.

QUESTION: Okay. How do you choose, you said, well, you'll make a recommendation for a patient about long-term prophylaxis and then discuss the options with them, of course, and let them decide, but when you're thinking about what am I going to recommend, how do you make that choice when it comes to long-term prophylaxis for HAE?

08: I think truthfully now, I go to the oral option if I can. That's just what most people are going to want. I think it works and patients are happy on it. I actually wonder why not everyone is on that, but you're always going to have people who are on something forever and don't want to switch.

QUESTION: Sure, of course. Anything else that you're looking at aside from patient satisfaction when it comes to looking at particularly the new agents for long-term prophylaxis? What are the differentiating points that you are looking at there?

08: Repeat that? I'm sorry.

QUESTION: So obviously, route of administration, patient satisfaction might be one thing that distinguishes a long-term agent from another agent. Are there other factors that you're considering when you're thinking about what to recommend?

08: Safety and efficacy. But I tend to, you know, by the time something is getting prescribed by my colleagues, for something like this, I would never prescribe something first; I just don't have enough

**Commented [14]:** Codes (22375-22516)
Patient anxiety/concerns
Barriers to prophylaxis

**Commented [15]:** Codes (22516-22517)
Patient anxiety/concerns

experience with it. I would go with really the world experts and see what they're doing, and then try to gather the experience from people who see more of this with like rare diseases. So I'm an early adopter, but I'm not going to be the first adopter. For newer medications, I do tend to review the safety pretty closely, just always myself to make sure that I know what to look for and that I'm not missing anything.

QUESTION: Okay. And you did not participate in a CME activity on HAE, is that correct?

08: No.

QUESTION: Okay. Some of our interviewees have done that, some have not, so I just wanted to make sure about that. We have two more questions.

**Commented [16]:** Codes (25642-25731)
CME

08: No, I think the last time I did CME activities was when I was at conferences in person.

QUESTION: Okay.

08: Most [phonetic] CME is always in the evening.

QUESTION: Yes, right, that's right.

08: Very annoying.

QUESTION: Do you have a requirement that you have to meet for CME credits?

08: Oh, I don't even know because I always more than meet it. I don't pay attention to it. I don't think so.

QUESTION: Yes, okay.

08: I tend to do more than I'm required because I make sure that I always do a conference a year (Overlap).

QUESTION: I see, yes, and it's pretty easy to get a bunch of credits that way, okay. Clinical guidelines are one way that research gets translated into clinical practice, and what effect might HAE clinical guidelines have on your practice?

**Commented [17]:** Codes (26413-26754)
Guidelines

08: Oh, I think in, I guess, the community, broadly speaking, of how I practice and people who practice like I practice, like everyone I trained with and people I engage with, we tend to go to clinical guidelines first if they exist. As soon as new ones come out like the practice parameters, whenever there is something new, we tend to read those. For immunology, there is some stuff that's more reliable, so I think clinical guidelines go a long way. It's nice to have. You know, the people who are always reviewing those guidelines are like the most involved in that field. And it's a small field, we all know the same names: once you've been in the field for a few years, you know who is the best at whichever subset you're looking at in the field. So if you have guidelines that are reviewed by those top people, they're influential. Who doesn't love guidelines?

QUESTION: Yes, okay. 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?

08: No.

QUESTION: Okay, all right. Well, I do very much appreciate your time and your insights today. Wish you the best with getting your practice going; it sounds like a really interesting—

08: Thank you.

QUESTION: —really interesting practice and practice style that you've developed. How long have you been with this group now?

08: A little over a year.

QUESTION: Little over a year, okay. And are you located in the [redacted]?

08: I live [redacted] a ways.

QUESTION: I see. Okay, so you're a little ways out, all right.

08: Yes.

[IRRELEVANT MATERIAL OMITTED]

[END 08 6.27.24.M4A]