ASH Daily News: Saturday, December 5

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CLL Patient and Advocate

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Andrew Schorr:
Hello and welcome to our update from ASH in Orlando, Florida. I'm Andrew Schorr. I'm joined by Carol Preston, who is my colleague, both of us living with CLL, and me also with myelofibrosis, so we're very interested in what we're learning. And also we're joined by Dr. Jennifer Brown. She is the director of the CLL Center at Dana-Farber Cancer Institute in Boston, and also you're an associate professor at Harvard. So thank you for being with us, Jennifer.

Dr. Brown:
Sure. It's my pleasure.

Andrew Schorr:
Okay. We're going to go over some things that we've been learning and feeling from ASH. We'll be doing this for the next two days. After today, we'll also be doing some Ask the Expert live sessions, so this is us bringing you the news. Now, this is sort of the beginning of the conference.

Carol, today we've been talking to a lot of advocates, particularly myeloma advocates.

Carol Preston:
Yeah, a lot of patients, and there's a theme that kept recurring. First of all, the enthusiasm and the hope for what's going on in their lives, what they're hearing, but also some frustration because all of us patients, we're all—we're looking for the C word, which is the cure word. And everybody is, you know, happy for the bridges from one treatment to the next, but we don't know if those bridges are going to run out so a lot of hope that help is on the way.

As you know, in multiple myeloma, they're all very excited that in two weeks, three new drugs were approved by the FDA. I can't even pronounce them, but it just goes to the hope of all of this target precision therapy.

But with the positive lies the challenge with the precision therapy, because not all patients know, number one, if they can get it, how they can get it, are they going to get the right tests and on and on and on. So with every solution or every new advance, there are other challenges that come up.

Andrew Schorr:
Let's talk to Dr. Brown a little bit about that. So, Dr. Brown, so we're trying to get in this world of precision medicine. There's always a lot of buzz about that each year, more and more. So for instance, at Dana-Farber, a major academic center, you are routinely now testing people, let's say in CLL, but I know it's done in other conditions, to understand what sort of version of a disease they have, and hopefully either an approved or experimental therapy that might line up with that. But it's not done everywhere, is it?

Dr. Brown:
No, it isn't. And we actually do far more tests at Dana-Farber than we yet really know how to apply clinically. In CLL, we're actually somewhat fortunate that a lot of our new drugs work pretty broadly regardless of the set of prognostic markers. In fact, our newer drugs work even in the highest risk disease. We still like to know about the highest risk disease, because we're trying to assess the durability of the novel therapies in that setting compared to lower risk, but the therapies work across the board, which is incredible.

But at the same time, we're learning more and more about the biology, and so we're sub-grouping patients more specifically. And I think as we move forward, we'll see that we're going to start to target certain therapies, for example, for patients with mutated IGHV versus unmutated. And it may be that we'll reach the point where we have different therapies based on different underlying specific point mutations, although we're not there yet. The mutations common in CLL are not that easily targetable.

Carol Preston:
You know, I just wanted to ask, because obviously you're doing right by the patients who come to see you. So many patients don't have access to a major research center, and the oncologists or the hematologist/oncologists may not be up to speed either. So what is your advice, I'd like to know, people out there in the community at large as to what they could be doing, what they should be doing.

Dr. Brown:
The most important test to get is a FISH test in CLL, and that's still very important I think for all patients. And it is generally widely accessible in the community, although not everyone always gets it, but most physicians have access to get it. And that's the main test that potentially influences therapeutic decision-making. For example, if you do have a 17p deletion, you already have access to ibrutinib (Imbruvica) as a first-line therapy right now, even before we get further results likely to be presented at this conference.

Carol Preston:
Yeah. And I do have 17p, but it's just a small percentage of cells, so—but it's good to know.

Andrew Schorr:
Let's talk about this more broadly for a minute, because I know we have folks with us with MPNs, myeloproliferative conditions and myeloma, etc. And you're a subspecialist.

Dr. Brown:
Yes.

Andrew Schorr:
You're the director of the CLL center. In the other days, we'll be meeting with Ruben Mesa from Mayo Clinic, and he does MPNs, and Bob Orlowski from MD Anderson, he's a myeloma doctor, and there will be others we'll be bringing you. What I hear from leading advocates time and time again with the pace of change that we're hearing about here is it's really wise to at least consult with a subspecialist in your condition. Because you eat, drink and sleep this, and so it seems like good advice.

Maybe not everybody can get to Boston, but maybe they can go to Stanford on the West Coast or wherever they may be, MD Anderson or somewhere else even in another country. But it seems like it's hard for the general doctor to keep you up, not that they wouldn't want to execute a plan that you might come up with and be part of the team, right?

Dr. Brown:
I absolutely agree with that because the centers do have this wide molecular profiling, can give you a much better idea what your disease looks like. It's not perfect at any given point in time, but it provides information, and information is power especially as we move forward with these novel agents. So I absolutely agree that seeing a subspecialist at some point in your disease is worthwhile. And it may be that you don't need to keep going there, that you can return to your local physician.

Andrew Schorr:
Right. And you work in partnership with local physicians all the time.

Dr. Brown:
Absolutely. All the time, right.

Andrew Schorr:
Okay. Carol, let's talk a little bit about clinical trials because there are advocates. We met people who clearly say they would not be alive—and I will say that too, about me and CLL had I not been in a trial.

Carol Preston:
Absolutely. And although I was not in a trial, you and the people in your trial paved the way for me with FCR, which in 2010, knock on wood, is holding in you since, what, 2000?

Andrew Schorr:
I got it in 2000.

Carol Preston:
Yeah. So whether you've been in a clinical trial or the beneficiary actually after the fact of a clinical trial it's—you know, that dominos, those dominos keep falling in a good way.

Andrew Schorr:
And that leads to two things, Jennifer. So you have new pills in many cases, monoclonal antibodies, infused therapies that are being approved or being developed, and you're trying to see can one plus one equal three, right? Let's talk about combination therapy. You can use CLL as an example. I understand you have more agents than you've ever had before, either approved or investigational, but we're trying to get to that place that Carol said, the C word, being cure.

Dr. Brown:
Right. So I think with the drugs that we have now we really need to focus on the C word in CLL and that we really have an opportunity to do that. And actually it's interesting you both mention FCR, which has become a little less interesting to many people. But at the same time we have long-term follow-up data showing that particularly people with mutated IGH have a very high chance of still being in remission 12 years later after FCR.

Andrew Schorr:
Fifteen years.

Carol Preston:
Exactly. And so one thing we're doing at Dana-Farber, for example, is for that group we're building on FCR, adding novel agents to FCR to see if we can improve that even further. But then for people for whom FCR has not as good an average outcome, we're trying to perhaps add or move to novel agents entirely and in combination to see if we can beat FCR.

And, in fact, we have ongoing national randomized trials to see if novel agent therapy versus FCR in the higher risk group which one will win, because we don't know. And the only way we find out is through the randomized trials.

Andrew Schorr:
So you're a researcher. What do you tell people—and you're a hematologist, and you're hearing in these other areas, too, a lot's happening. Questions to be answered, but maybe the promise of tomorrow's medicine today or greater effectiveness combining medicines. What do you tell patients who come see you about at least considering a trial?

Dr. Brown:
Right. So the first thing I say is that until we have a cure for everyone with this disease we need to put everyone on trials, because that's the only way that we really learn anything. And then the other thing I say is that you get a lot of attention. You get much more attention…

Andrew Schorr:
I love attention.

Dr. Brown:
…than you would get on standard—well, everybody loves attention, right? It's a new thing. You haven't been through it before. You want support. You need support. You get a whole extra team of research nurses and people who are looking after you if you're on a trial, and so that is very appealing I think for many people and provides a lot of extra support in thinking about sort of potentially taking on the unknown, but recognizing that—and the way we do trials now everyone gets a good therapy, a reasonable therapy, at least the standard of care therapy.

Carol Preston:
It's not the old…

Dr. Brown:
It's not the old idea…

Carol Preston:
…double-blind, random, placebo.

Dr. Brown:
…a lot of people have misconceptions that we put cancer patients on placebo, which, you know, we don't do. We have therapies for everyone, and we use them. And then we try to build on them and make them better.

Carol Preston:
I do want…

Dr. Brown:
And so that's really what we're doing.

Carol Preston:
I'm sorry. I do want to ask, with all of these therapies, as I said the floodgates have opened. It doesn't matter which blood cancer you're talking about, and they're so targeted, and they're so precise. Does that mitigate the issue of resistance, because you're really going after those, say, leukemic cells?

Andrew Schorr:
Yeah, you get these new pills. Are they going to work forever?

Dr. Brown:
Yeah, so that probably depends on the specific disease, the specific situation. But in general if you're just using one drug, the wily cancer cells many times will eventually find a way around it. And so the model historically has been to use multiple drugs that work together by different mechanisms to try and suppress the ability of the wily cancer cell to escape.

And so what I'm looking to do in CLL, particularly for the more aggressive-behaving CLLs, is to combine these and that way hopefully suppress any development of resistance. For people with much more indolent CLL, it may be that one drug will last for a very long time and maybe long enough that it doesn't matter if it's technically a cure or not, but if it lasts long enough…

Carol Preston:
They'll die from something else. Live with the disease…

Dr. Brown:
If they die of something else, then that…

Carol Preston:
…die from something else.

Dr. Brown:
…right. That's perhaps a functional cure.

Andrew Schorr:
Let's just mention about people we've been meeting, Carol, and you interviewed some today. People who by old therapies would have been dead a long time ago, and they know it. And one fellow we've been following in myeloma, and we love the guy, is Pat Killingsworth. He just went through a double transplant for myeloma. He's had successive therapy, but he's walking the halls, right?

Carol Preston:
He is walking the halls. He's 59 years old. I interviewed Pat last year, and in all honesty, and he agreed, I didn't know if we were going to see him this year. And so here he is, lost all of his hair, lost a lot of weight, smiling. Never saw him smile before. Very, very hopeful, and I said, Is it a cure? He said, I don't think so, but he said, I think it's going to work, and I'm going to get some mileage out of this.

So, you know, here's a guy who probably should have not been with us several years ago, so that is the hope. But you know, for guys like Pat who really is my myeloma hero, and—we raised our arms in victory as a champion, I'm just—I'm hoping in his lifetime that he'll see the cure. Maybe not, but I hope it's coming soon.

Andrew Schorr:
I hope so.

Dr. Brown:
With the pace of change…

Andrew Schorr:
A couple headlines—go ahead.

Dr. Brown:
With the pace of change, there's hopefully always a new therapy by the time you need a new one.

Andrew Schorr:
Yeah.

Dr. Brown:
I have a whole cadre of patients sort of going from one trial to another with the next therapy down the line…

Carol Preston:
That's the bridge.

Dr. Brown:
…and they're like, well, what do you have for me now? And I have something.

Andrew Schorr:
Well, that's good news. Now, let's just look ahead and talk about that, then we'll talk about that again in other days. So there has been tremendous buzz among the solid tumors about so-called checkpoint inhibitors or using the immune system to fight the cancer. Certainly transplant does that, but now these other medicines. You all have been involved in studying that seeing does it apply to blood cancers. And I know there's some thought that that might be something, and

even there's a lot of work going on in these sort of CAR-T cells we've talked about sometimes and can that be done even beyond the expense of a custom medicine. So this whole immunotherapy is sort of maybe the next wave?

Dr. Brown:
It is definitely coming into its own as a new mechanism really to add to kinase inhibition, so add to antibodies, and so that's very exciting. Certainly for Hodgkin's disease and for lymphomas it's looking extremely promising. We haven't tested it yet in CLL, but there are some trials initiating that people are very excited about.

Andrew Schorr:
Okay. So we'll be talking about all that in the coming days. You and I will be doing updates.

Carol Preston:
Lot of experts that we're going to speak with over the next couple of days.

Andrew Schorr:
Right. And I just want to tell you, we'll be looking for your questions as well. Just send them to info, I guess, at patientpower.info or questions@patientpower.info. We'll have other guests, eminent specialists like Dr. Jennifer Brown from Dana-Farber and Harvard, who will be with us as well. So be sure to send us your questions, what you're hearing, what you're thinking about.

But I think the bottom line so far is, it's underscored by everybody we talk about, is lots of stuff happening, connect with a specialist, consider clinical trials, and have hope, and I think hope is a big story, right?

Carol Preston:
Absolutely.

Dr. Brown:
Absolutely.

Andrew Schorr:
Okay. Well, with Dr. Jennifer Brown, Carol, thank you, okay. And Andrew Schorr on location in Orlando, Florida at the ASH meeting. Look for us at the same time tomorrow and the next day for another live update.

Remember, knowledge can be the best medicine of all.