Understanding Personalized Care in CLL and Mantle Cell Lymphoma

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Andrew Schorr:
Greetings from Orlando, Florida. Andrew Schorr here with my sidekick...

Esther Schorr:
...Esther Schorr.

Andrew Schorr:
Thirty-four years married, 23 years a patient and a care partner...

Esther Schorr:
A lot of work.

Andrew Schorr:
...and we have a lot to talk about today in this live edition for wrap-up from right across the street from the American Society of Hematology meeting. Wow. We want to mention we’re going to talk with some leading experts here. Remember, talk to your own doctor about what’s discussed and what is right for you. Allen, let’s show them what’s going on here, if we could. There are 25,000 or more people here who study blood conditions from all over the world, a lot about cancers that affect the blood. I have had CLL since 1996, and along the way, I met some interesting people, and you’re going to meet them now.

And so, if we could see here—we’ve got Dr. Ian Flinn, who joins us from Tennessee Oncology, we’ve got Dr. Brad Kahl, who’s from the Siteman Cancer Center in St. Louis—so, Nashville, St. Louis—and joining us in a little bit is my doctor, Dr.
Tom Kipps, who is from the Moores Cancer Center at UC San Diego. All right. Just for a minute, I want to start with—you’ve been over at the convention center, and you’ve been doing interviews like crazy.

**Esther Schorr:**
I have, in a lot of different areas. I’ve spoken to some researchers and some practitioners in talking about all the new things that are developing for multiple myeloma, and for Hodgkin lymphoma, and for Waldenstrom—would you say Waldenstrom syndrome?

**Andrew Schorr:**
I can’t even say it.

**Esther Schorr:**
It’s got a really long name.

**Dr. Flinn:**
Macroglobulinemia.

**Esther Schorr:**
That’s the one! Thank you.

**Andrew Schorr:**
Good for you!

**Esther Schorr:**
But, the bottom line that I got from these discussions is that there are so many new kinds of combinations of drugs that are now being—it might be chemotherapy along with immunotherapy put together, or an old drug with a new kind of treatment, and there are also different dosages that are being looked at and balancing those, and some of these treatments are also jumping to other—they might be approved in one area, are now being tested for one of these other conditions. And so, it seems like a very big jigsaw puzzle, and there’s so much progress being made in putting those pieces together.

**Andrew Schorr:**
Do you feel positive?

**Esther Schorr:**
Oh, incredibly so. I think the only negative thing for me would be looking at it as a jigsaw puzzle, and I’m just really glad that there are 25,000 specialists and researchers figuring out how to put those pieces together.

**Andrew Schorr:**
That’s what we’re going to talk about, but there is a responsibility for you, the patient or the care partner, and that is play an active role in your care. So, these gentlemen here—and, Dr. Kipps when he comes—are from major centers. Now, you may not be there, so you need to play a role, both if you’re in a remote area or depending on where you are or get a second opinion.

**Esther Schorr:**
I heard that from every single specialist that I interviewed today, was that even if you’re not right near or being treated at a center—one of the big centers of research, you really—as a patient—need to help make the connection between your local doctor and those centers so that you can have a dialogue with them, and the two physicians can have a dialogue about what the best treatment plan is for you.

**Andrew Schorr:**
Or your loved one, because let’s—we’re going talk about CLL, where we have a big following on Patient Power. We’re also going to talk about lymphomas. So, not always, but often, people are older, so it may be your dad who has CLL, or your mom who has CLL, or grandma or grandpa, so you can help. All of you can be involved. Let’s start with Dr. Flinn. So, Ian Flinn from Tennessee Oncology in Nashville. We’ve known each other many years. Related to CLL, first of all, and there are more options than ever before. It’s really what’s the personalized approach for that patient at that time, right?
**Dr. Flinn:**
Yeah, I think that’s absolutely true. We’ve gotten—thankfully, we’re increasingly using much more targeted agents, sometimes as a single agent, in some of the more neuroclinical trials, in combination, and it’s very different than we were treating 10 to 20 years ago.

You talked about how mind-boggling it was to figure out all the different pieces and how to fit them together, and I think that’s true in CLL. There’s so many different possibilities out there about how to treat CLL. It has gotten a little bit challenging.

**Andrew Schorr:**
So, this is maybe—I want ask both of you guys this—so, I have FCR way back in 2000, two chemo agents—fludarabine (Fludara), cyclophosphamide (Cytoxan)—and then, rituximab (Rituxan) was added. I was in the Phase II trial, and I was patient number 60, so, a long time ago, and then it eventually became the standard of care worldwide. There’s a debate among you guys whether chemo in CLL is dead because you have so many oral therapies. Dr. Kahl, what’s your view in St. Louis?

**Dr. Kahl:**
I wouldn’t say it’s dead, but the number—the proportion of patients for whom FCR is appropriate has shrunk to a very small population, and even for that very small population where FCR is still appropriate, there are other very attractive options, so it’s a complicated discussion about the pros and cons of strategy A versus strategy B versus strategy C, if that makes sense.

**Esther Schorr:**
So, what drives that, then? What makes—in layman’s terms, what are the factors in there?

**Dr. Kahl:**
So, I’ll make the case for FCR, and then, a minute later, I’ll make the case against FCR.

**Esther Schorr:**
Fair enough.

**Dr. Kahl:**
This is the conversation that we have with patients. If you’re a young patient—and, “young” probably in CLL should be—to be appropriate for FCR, you should certainly be younger than 65, and probably younger than 60. It’s just very hard on the bone marrow and the bone marrow reserve, so you need to be in that age range. You need to have what’s called IGVH-mutated CLL, which is the favorable type, and that type responds better to immunochemotherapy than the unmutated type. And then, you can’t have a bad cytogenetic marker; you can’t have 17p, you can’t have 11q.

So, let’s say you meet all those criteria. You’re now in the group that could receive FCR. For FCR is long-term data with 10 years of follow-up, 15 years of follow-up, showing that if you’re in that group, you have about a 60 percent chance of still being in remission 10 years later from just that six-month exposure to treatment. So, that’s the plus side.

On the con side, still, 40 percent of patients are relapsing, and FCR has some significant risks associated with it, including infections around the time of the chemotherapy, and that risk can extend for a few years even after the chemotherapy is done. Patients can suffer from very low blood counts for a prolonged period of time after the chemotherapy, and there is probably a 5 to 10 percent risk of developing myelodysplastic syndrome or acute leukemia as a complication of the therapy, which is a terrible complication.

So, you’re taking on that risk to hope that you’re in the lucky 60 percent of people that are disease-free 10 years later. It’s like a high-risk, high-reward strategy, and that makes the decision-making difficult.

**Andrew Schorr:**
Dr. Kipps, welcome.
Dr. Kipps:
Thank you. It’s a pleasure to be here.

Andrew Schorr:
Thank you. Now, Dr. Kahl, we’ve posed a question whether in CLL, chemo is dead. So, Dr. Kahl talked about who it could be right for, but generally, what do you think now? You were going give the con. We’re just going get Dr. Kahl first. Did you give the con?

Dr. Kahl:
Yeah, the con is the short-term risk of infections and the long-term risk of bone marrow damage that could even lead to a second cancer that is disastrous.

Andrew Schorr:
And, you have a lot of other things now.

Dr. Kahl:
And, you have a lot of other choices now.

Andrew Schorr:
Okay. Do you want to weigh in, Tom?

Dr. Kipps:
Well, I think that the field is moving very quickly, but it’s a very clear thing that, like any tool, knowing how best to use it makes it most effective. It’s not that chemotherapy is bad or FCR is bad, but using it in the right circumstance for the right patient, it can be very effective. We have to consider that.

I think a lot of advances have been made by trying to understand some of the features of patients for whom you should not give chemotherapy, and that’s very clear. It’s clear that certain patients may actually be harmed by chemotherapy, and we should try to avoid treating such patients with chemotherapy. But, there are markers that can delineate a fraction of patients that do quite well, and may actually have a very successful remission that could last over a decade, and by some intents and purposes, they may be considered cured of their disease. I think this is something we have to recognize.

Now, it’s always the case that a surgeon’s scalpel can be a very important tool in surgery, but you give it to a 2-year-old, and you can have problems, so we have to be careful because these are therapies that do have a lot of toxicities, and they have to be used correctly in order to have the desired effect.

Andrew Schorr:
And, Dr. Flinn, do you just want to weigh in on chemo?

Dr. Flinn:
I think both Brad and Tom have articulated things well. There are good data, there are good trials now that show that even in the good subsets for which, potentially, FCR is appropriately applied, the outcome for those patients with drugs like ibrutinib (Imbruvica) do justice well.

One argument for FCR or chemotherapy in general is that it’s a relatively short-duration therapy, and then you’re done instead of having to take a chronic medication, but there’s also data on what’s called time-limited therapy with the combination of venetoclax (Venclexa) and obinutuzumab (Gazyva). So for patients who want that brief interval of therapy, which is a lot, there are also alternatives beyond chemotherapy.

Andrew Schorr:
And, aren’t you guys talking at this meeting about new kinds of combinations—ibrutinib—I don’t know what it is—IGV—a whole bunch of acronyms that are non-chemo approaches that could be fixed duration. Tom, do you want to comment on that?
Dr. Kipps:
I think some of the important trials that have looked at the combination of some of these targeted therapies—and, there have been head-to-head matchups with regimens such as FCR or bendamustine-rituximab, and it's clear that for certain categories of patients, they outperform the chemoimmunotherapy.

For some other categories that you would even consider chemoimmunotherapy for, they match up pretty well, and so, I think we're seeing the day where chemotherapy may be used less frequently as we gain more familiarity with these targeted therapies, and in particular, the combination of targeted therapies that might effect a better outcome.

I think if we have tools that have a better therapeutic index—namely, that are safe to use and are very effective—that's going to be easier for the patients and the doctors because there will be less chance for making errors of overtreatment or toxicity with treatment.

Andrew Schorr:
So, Dr. Kahl, you're in the Midwest, and you go west from there, and you've got some wide-open spaces. People may live in pretty rural areas, and yet, now, you're talking about the complexity of care in these blood cancers. So, what do you recommend to patients so that these new learnings are brought to bear for them?

Dr. Kahl:
So, one option if a patient has the means would be to just make a trip to see a CLL expert, get a second opinion. A lot of times, it's very helpful just to meet a patient. I get approached frequently from outside physicians by email or telephone, and they're describing someone to me over the phone or through an email, and I can render an opinion, but it's never as good as when I get to meet that person, and I can talk to them, and I can look them in the eye.

So, if I can have the opportunity to meet the patient, I always feel like I can give a better opinion about a strategy going forward. So, if a patient has the means, by all means, do that. If you don't have the means, then you can ask your doctor just to reach out to us. I'm sure you get this all the time, I'm sure you get this all the time, and I'm happy to try to help whenever possible.

Andrew Schorr:
Whenever we're in his waiting room, there are people from all over the place who come to see you, and in Tennessee, same thing? Would you say when you can, you like to meet people in person?

Dr. Flinn:
I absolutely agree. I think one of the issues that you—like Brad—try to help physicians around the area and elsewhere with their patients, but you don’t always get the entire picture. You don't know what—some things may not be important to them that are important to us and maybe important to the patients, so being able to meet people one on one is always the best option, realizing that’s not possible for everybody.

Andrew Schorr:
Can we change horses for a little bit to lymphoma? Do you mind if we talk about lymphoma just for a little bit? So, some of these same drugs are used in mantle cell lymphoma and have been improved. So, for instance, we have a new entry into the CLL space, Calquence, or acalabrutinib—just approved—but that was already approved for mantle cell, and we have Imbruvica that I believe has been approved for both. So, first of all, Ian, can you explain—are these illnesses similar, and this BTK inhibitor works for both?

Dr. Flinn:
Well, I’d point out there’s actually a third, Andrew, zanubrutinib, which was recently approved for mantle cell lymphoma. So, your question was are the diseases different?

Andrew Schorr:
Why does the drug work for these two different diseases?
Dr. Flinn:
I think they have some—they do share some common signaling pathways—some of the pathways that drive some of these different malignancies are similar—so, CLL and lymphoma, and then we’re extorting those processes that are disrupted with these new medications, and so, it allows us to use...

Esther Schorr:
...is it that they have the same markers?

Dr. Flinn:
It’s not necessarily they have the same markers, and the biology isn’t exactly the same, but it’s the same—if you can imagine a staircase that—different steps to get up to next floor. In a lot of cancers there, these different steps that occur that drive the cancer forward, and so, being able to block that staircase—or, the ladder, you might call it—both CLL and mantle cell lymphoma share some of these same staircases.

Andrew Schorr:
Even if you’re going to a different floor, you start on the same staircase, and if you can block it at the right place, you can eliminate...

Dr. Flinn:
...exactly. So, a lot of times, what we learn in one malignancy is very helpful for treating another, and they’re different, so, not always are they equal, but it helps to know and be able to use this information from one cancer to the next.

Dr. Kahl:
Yeah. Mantle cell has been lagging a bit behind CLL in terms of the rapidity of the progress, and one of the reasons is these oral agents that work so beautifully in CLL work well in mantle cell lymphoma, but not as well as they do in CLL—not even close, actually—and so, while these have been great additions in mantle cell lymphoma, they haven’t had the same impact as they’ve had in CLL.

Andrew Schorr:
So, Dr. Kahl, the progress that we’ve been hearing in CLL—the whole range of treatments—oral, oncolytics, pills we can take—that’s really been a revolution in mantle cell too, hasn’t it?

Dr. Kahl:
So, Dr. Kipps, you’re kind of the chairman of the board here. When you look at these oral pills—and, I alluded to about combinations now—is that where we’re headed? Where does this whole idea of immunotherapy come into play? Like CAR T—you’ve been investigating CAR T, chimeric antigen receptor T-cell therapy—activating the immune system. How does all this fit together? It makes our head spin, doesn’t it, Esther?

Esther Schorr:
Too many letters.

Dr. Kipps:
Everyone’s heads spin, and I think at this meeting at the ASH, there’s been a lot of discussion about some of the newer agents that Dr. Flinn alluded to. The newer "brutinibs", as I call them—all of them have that suffix, and there’s quite a few of them, and they come in a couple of flavors: One that binds to the enzyme BTK and makes a covalent bond, which is irreversible, and the other one that’s reversible.

They have different pharmacologies, they have different spectrums of activity, and you have other types of inhibitors of other kinases, such as PI-3 kinase. And then, we have the drug venetoclax, and we have also the monoclonal antibodies, the anti-CD20 antibodies, particularly the new kid on the block, obinutuzumab, which is quite effective.

And so, the question becomes, then, what combinations are you going to use? I think some of the combinations I see, it’s hard to understand what the rationale is other than using drugs that have different toxicities. I don’t really feel comfortable with that strategy. I like combinations where you can try to define things that might be additive or what we call synergistic, where they work together very well. I think we’re struggling to try and figure out those combinations.
Also, the sequencing of what drug to use first and what drug to use second. It’s oftentimes said that sometimes, there’s a reservation that oncologists have that boy, if they use this drug too quickly, they’re going to actually exhaust their potential to use it later on, and we have to address these with clinical trials to gain experiences to what is actually going to happen.

We do know this: The therapy itself does effect changes in the tumor population, and we have to be aware of what’s happening with the tumor, and it’s like the beast that keeps biting back. We have to understand it so that we can stay one step ahead, and when we do get recurrence or relapse, that we have something to deal with it.

Andrew Schorr:
Well, that’s what I want to probe a little bit about CAR T. So, supposedly, you can make a drug for the patient in the lab from their cells, put it back, and it helps activate their own immune system to fight the cancer they have.

Dr. Kipps:
CAR-T cells has come a long way, and it's still got a long way to go. I think it's very seductive, because for some patients, it could be home run, and the problem is either you have a home run or you fail to get onto first base, and I think that there are some dangers involved in the treatment strategy, too, that we have to be aware of. But, as the time goes on, we're understanding more the toxicities and strategies to mitigate those toxicities, so you can improve upon the safety of the approach, and I think also, with improvements in the type of CAR-T cells that we're using and how to administer them.

In chronic lymphocytic leukemia has not been as stellar a performance as we've seen in childhood leukemias and acute lymphocytic leukemia, and there are reasons for that that have been explained, but newer technologies, including paying attention to the types of cells that you're transducing to make the CAR-T cells and how you administer them to the patient is improving the batting average, and that's very exciting.

Andrew Schorr:
Ian, you’re nodding your head. This whole what you guys call patient selection—so, somebody who gets to CAR T may have run through a lot of treatments, and we know patients like that in myeloma, in CLL, in lymphoma, and a number of areas. So, you as a specialist recommending that, you want to have some confidence that it's right for them.

Dr. Flinn:
Absolutely, and that’s coming from studies as we get more and more experienced with them. I think Tom talked about the different diseases and using CAR-T cells, and the outcome is different, the side effects are different—the rate of adverse effects are different, I should say; side effects are different—and so, one size does not fit all.

But, it is—if we could take large cell lymphoma, where these drugs have recently been approved, there is a lot of success there, to the point that the current generation of clinical trials are looking at if someone has a relapse, they initially get treated with R-CHOP for their large cell lymphoma. If they’re in that unfortunate group of people—a minority, thankfully—that it comes back in, the standard treatment approach is to give another chemotherapy and then do a stem cell transplant.

Well, the current generation of trials are saying that outcomes aren’t that great with that approach. Maybe we should just be replacing stem cell transplant completely and going directly to CAR-T cells. Well, we have no idea whether that’s the right thing to do or not, but those trials will read out in the not-too-distant future, and I think it’s really an encouraging approach.

Esther Schorr:
So, I have a question, then. I keep hearing “clinical trials, try this, try that.” So, from a patient perspective or care partner perspective, what are the questions that you have to ask about a clinical trial as an option when we’re hearing that there are 10 trials now for somebody with CLL. What should a patient be asking or talking about with their specialist?

Dr. Kipps:
It gets very confusing, and it’s intimidating. I must say, there are people who are participants in clinical trials, and I think they’re the true heroes of modern medicine. They’re like the astronauts who are going places where we have not gone, and
they're risking their lives so that we can learn more about these therapies, and from that information, benefit people that come after them.

So, you have to be of the right stuff to be a clinical trialist, and if you're not and would like to stay grounded on Earth and watch the TV as the astronauts go into outer space, then that possibly—it may not be the right thing for you, but I do think patients who participate on clinical trials are really tremendous, and the willingness to try and learn more.

And, I believe it also involves some degree of self-education and discussion with your physician, and I think that usually, what happens with the clinical trial is you get just a complete barrage of information about the hazards and the potential benefits, and it can be intimidating. You sometimes get a book to read, which can be quite intimidating.

But, I think it's important when you participate in a clinical trial to be fully informed, to know what the potential hazards are so you can report them back. You're the only one that is with yourself 24/7, so you have to be aware so that you can help your physician guide you through the protocol and be a participant in this thing that we call a clinical trial.

Andrew Schorr: I have a question for you, Brad. So, you're at a research center too. A lot of patients have been frustrated, as we've had previous treatments. Would we be excluded from—let's say you're doing something cool, like the next mission to the moon, and I've had this drug or that drug, and then I'm excluded. That's kind of frustrating. I want to beat my cancer now, but I don't want to shoot myself in the foot for the next big thing.

Dr. Kahl: I don't blame patients for being frustrated when they would like to participate in a clinical trial, and they find out they can't, because they don't meet some eligibility criterion. It is frustrating for the physicians too, and we—when we have the opportunity to develop the eligibility criteria, we try to be very generous and inclusive. Some of the trials are overly restrictive, to be perfectly honest, and we as investigators will often push back on the sponsors of trials to make them more inclusive.

Andrew Schorr: So, Esther, you have been talking to many other experts at the convention center across the way. Is what we've been hearing—what we've heard from Dr. Flinn, what we've heard from Dr. Kipps, Dr. Kahl—a lot of common themes here.

Esther Schorr: Absolutely. A lot of this is resonating across—I was talking to researchers around Waldenstrom's, mantle cell lymphoma, which I know we're going to talk a little bit more about, and multiple myeloma, and the through-line for me that I picked up today was this whole idea of combining older drugs, newer drugs, combining immunotherapy—new immunotherapies. CAR T has come up. What's really interesting to me is how these things are being combined across conditions. So, yeah, it seems to cover the whole gamut.

Andrew Schorr: Let's bring up one word that's come up here: BiTE. If I understand it right—and I'm not sure I do—so, CAR T, you take someone's cells, you make a drug personalized for them, you give it back, and hopefully, it helps activate the immune system and fight the cancer.

Esther Schorr: I got that was the one in the petri dish that then gets put back. The BiTE is different.

Andrew Schorr: I've also heard with this BiTE approach that maybe you could inject something in the body—I'm not quite sure—and the immune system is activated...it happens within you. So, could you describe it a little, and could that affect these lymphomas and CLLs, Dr. Kahl?
Dr. Kahl:
So, BiTE is a name for a bispecific monoclonal antibody. I’m sure a lot of patients are familiar with certain monoclonal antibodies like rituximab and obinutuzumab, and basically, those antibodies just stick on the surface of the cancer cell, and you hope that it sends a signal to the immune cells to come in and kill the cell.

A bispecific antibody actually will stick on the cancer cell, but has another end that’s sticking out in space that will specifically bind to T cells—other cells of your immune system—so it brings the T cells of your body physically close to the cancer to make it easier for those T cells to kill the cancer cells. It's just another way to try to trick your own immune system to fight the cancer.

Esther Schorr:
And, that’s all happening inside as opposed to pulling your T cells out.

Dr. Kahl:
Correct. You just take the drug off the shelf, and you infuse it in the vein, and the magic happens.

Andrew Schorr:
Will this be magic? What do you think?

Dr. Kahl:
The data looks very promising. There was data presented at our plenary session today, where they pick the most impactful scientific presentations of the whole meeting, and so, there was a whole presentation on one particular BiTE or bispecific antibody today, and they detailed the results in diffuse large B-cell lymphoma and in follicular lymphoma, and some of these patients had already relapsed after prior CAR T-cell therapy, so they were very difficult patients. There were very high response rates from the BiTE therapy in both diffuse large B cell and in follicular lymphoma, so I think it’s a very promising strategy.

Andrew Schorr:
Okay. So, Dr. Kipps, you’re nodding your head, and you’ve been a scientist for so many years. What are you thinking about—it’s all about harnessing the immune system, right?

Dr. Kipps:
It is, and I think one advantage of the BiTEs, as Brad was mentioning, is that you can give it as you would a monoclonal antibody, namely by infusion, and so, in some ways, there’s some hope that it might do what we expect CA-T cells to do, which is namely to put a receptor on a T cell that allows it to find the tumor cell. This way, we passively administer a means to be a matchmaker and bring the T-cells together with the tumor cell and activate the T cell at the same time.

Andrew Schorr:
Okay. So, do we—we talked about...a long time ago, many minutes ago, we were talking about chemo, so let’s say that’s going to fade largely into the background for most people. Then, you have these oral pills, combinations of them, maybe with a monoclonal antibody, perhaps, and then maybe some people would move on to CAR T cell, maybe, in some conditions—or not, it sounds like. I wonder if what you just described—could the BiTE approach supersede CAR T? And certainly, stem cell transplant we talked about—that seems way in the background.

Dr. Kipps:
And, there’s another approach, too, which is...

Andrew Schorr:
There’s more?

Esther Schorr:
"Wait, there’s more."
Dr. Kipps:  
...called an antibody-drug conjugate. Namely, the antibody can be—like Amazon delivers your package to your door, the antibody is the address label, which provides the ability to take a drug, you attach it to the antibody, and it’s a special delivery –

Andrew Schorr:  
As a payload.

Dr. Kipps:  
As a payload—and, that may have potential as well.

Andrew Schorr:  
So, how do you guys keep this straight?

Dr. Kahl:  
It’s getting harder. That’s a good problem to have, though. I do lots of presentations in lymphoma, and sometimes, you might go a whole year before you talk about one particular kind of lymphoma, and a really interesting way for me to measure progress is when I look at a talk I gave a year ago, how much updating do I need to do from what I said a year ago? And, in CLL, for example, I have to update my slides constantly. That’s how much progress there has been.

You asked a very good question about the appropriate sequencing of treatments—what should come first, what should come later. It’s all about risk/benefit ratio. What is the potential benefit? What’s the potential risk? We don’t know yet for the sequences of some of these things because they’re too new. We don’t know how good BiTEs are going to be in some of these diseases yet because we’re really interested in long-term outcomes—how are patients doing at three years, five years, seven years, and nine years, same as CAR T.

So, we need a little bit more time for some of this to sort itself out, and the picture will become clearer as to how good CAR T is, how good BiTEs are, but by the time that happens, we’ll have other new things that we’ll have to integrate into our decision-making. So…

Esther Schorr:  
Well, it sounds like patients are going to have to be a little patient, which is difficult when you’re in a situation where you need to be treated.

Dr. Kipps:  
I think it’s more complicated because there could be a good drug that, used in the wrong way, could kill the drug, and so, some of these drugs are almost like the patients themselves, and you have to shepherd them into a clinical trial that allows you first to examine and to come to a full appreciation of the safety and the safest way to administer the drug, but also the way to give it most effectively, and I’ve seen a lot of drugs that are very good go by the wayside, because they were developed not in the correct way. So, I think it’s a sad thing to see because if the drug has potential usefulness and it’s not developed correctly, then it’s not going to be helping anybody.

Esther Schorr:  
But there are examples of a drug that was tested in a clinical trial, and it sort of didn’t look so good, and then it got brought back to be combined with something else—that happens.

Dr. Kipps:  
Oh, yes. There’s a whole process there of getting drugs that have been left off to the wayside, and they get dusted off and tested in new clinical trials.

Andrew Schorr:  
Or classes of drugs.
Dr. Kipps:
Yes, classic drugs that have been around for some time, but I think it does take a little bit of intelligence and guidance to make sure that you don’t do anything stupid.

Andrew Schorr:
Let me just tick some things off as we’re in our last few minutes here. So, first of all, what I get out of this—what Esther said from being over at the convention center, from you being in various sessions and doing the work yourself—is that for those of us living with chronic cancer, that you have more to offer us, more research going on, and if we can have an active dialogue with knowledgeable providers, we hopefully can live well for a long time. Would you agree with that, Dr. Kahl?

Dr. Kahl:
I would agree with that. There are lots of tools in the toolbox, which is fantastic, and yet there’s still room for improvement. You mentioned clinical trials earlier and how do patients decide, and it can be a difficult decision. It all depends on what are your standard treatment options versus what are your clinical trial options, but one thing I will explain to patients at times is everything I know about how to treat your cancer right now today we’ve learned from patients before you who participated in clinical trials.

So, in a way, the clinical trial that you are now considering—the clinical trial isn’t so much for you. That is for somebody else who’s going to be sitting in that chair three years from now or five years from now. Now, the treatment that’s in the trial is for you, but what we’re trying to learn from the trial is for somebody else, and that’s how we keep the progress moving in cancer.

Andrew Schorr:
Now, you may get—obviously, your hope on your journey is you will get tomorrow’s medicine today. I got that with FCR in 2000. Tom has known me since then, and I had a ’17 remission, and he talked about long remissions from a chemo-based approach, and so, some people—as I was young, fit—mutated in CLL.

Esther Schorr:
I guess you qualified as an astronaut.

Andrew Schorr:
Yeah, so I’m glad. However, as Tom knows, I did develop a second cancer—whether it was related, we don’t know—many years later, myelofibrosis, but I think when we meet with you, Dr. Kipps, we’ve had a long relationship, I hope we have a really long relationship, and I think it’s the dialogue we have as these new options come up, including a discussion about trials.

Dr. Kipps:
And, you bring up an important point because I think everyone’s different, and you have to consider the entire patient. I know that for discussions, it’s—sometimes, you can reach for these newer therapies or protocols, but then, in the context of what else is going on, you have to sometimes rely on agents that you had used in the past in this setting. I think it’s a challenge because not one size fits all. That’s why it’s great to have all these different choices, so that we can try to make the right call with the right patient.

Andrew Schorr:
Right. That’s been the very discussion we’ve had, and we will mention one thing—this was a discussion we had—these drugs, as they’re approved—particularly the oral ones—are expensive, so there’s sometimes going to be a financial decision about infused therapies that might be covered at the hospital in one way in your insurance versus insurance and how they’d be covered as oral therapy, and there’s a whole discussion in legislatures and Congress about “oral parity,” they call it, and hopefully we’ll solve that. So, stay tuned.

I will mention just Esther—we’re covering the finance issues and access issues for people, so look for that on Patient Power so that whatever therapy is right, it’s affordable and accessible. These guys spend time fighting with insurance companies—they’re nodding their heads—so that we can make sure that you get what’s right for you. Okay, hopeful time. Next year, we’ll talk again, maybe, and you’ll have whole new things to talk about.
Esther Schorr:
We need the other part of the alphabet next year.

Dr. Flinn:
We look forward to it.

Andrew Schorr:
And, we’ll be back in sunny Southern California—although it’s sunny Florida right now—with Dr. Kipps. Dr. Brad Kahl from the Siteman Cancer Center in St. Louis, thank you for what you do.

Dr. Kahl:
My pleasure.

Andrew Schorr:
And, thank you for being with us today. Dr. Tom Kipps, old friend, my doctor—Esther, we love him.

Esther Schorr:
Yes, absolutely.

Andrew Schorr:
We love you. Thank you for being with us, Dr. Tom Kipps, and your leadership in these illnesses.

Dr. Kipps:
My privilege.

Andrew Schorr:
All right. What do we like to say, Esther?

Esther Schorr:
Knowledge can be the best medicine of all.

Andrew Schorr:
Thanks for joining us.

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