The Importance of Long Term Follow-up
Powerful Patient Event

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**Andrew Schorr:**
So he flew across the country today, right Chappie? Come on up here. He came in from New York I think it was, Dr. Ernest Chappie Conrad who has also been on our Patient Power program. He is the Vice-Chairman of Orthopedics at UW Medicine. He makes his office most of the time over at Children’s Hospital, but both with adults and with children he deals with in particular very, well all cancers are serious, but one that is a really rough one called sarcoma, and so it can be in your bone or it can be in soft tissue, and Chappie has really been one of the leaders in the country in advancing the treatment of sarcoma. So he deals with adults, and he deals with parents and kids with this condition. Tips in that setting Chappie? Thank you for being here.

**Dr. Conrad:**
It’s my pleasure. I’m a big fan of Andrew’s and Patient Power. Like most of the people talking today we’re big believers in championing your own healthcare and getting good treatment.

I’m a tumor surgeon. I’m an orthopedist, but I’m a tumor surgeon. I do adults and kids. My advice to you is to make sure you’re seeing somebody who; I think it’s a team sport. When I see somebody in the room by themselves my antennas go up about why they’re by themselves. I think you need to take your loved ones, your best friends, and your family with you to; I’m going to talk about oncology now because that’s my world; you need to take your family and your loved ones with you, at least a few, to help you with that visit. I would tape record every visit especially in the beginning, especially the first couple of visits. So it’s your team versus their team. They need to have a team that works. They need to have a team that meets and discusses all the cases specific to that disease so that they’re having some sort of chemistry in their own group, and I think no matter how good they are the communications need to work.

Like Dr. Kiss said you need to understand how the communications work in any one office. I don’t know if primary care doctors are getting just as challenged as surgeons. Surgeons are sort of famous for being hard to get a hold of, but you need to know who’s on their team and be comfortable seeing people in that team with very short notice.

In the tumor world if you get treatment that’s not optimal treatment the first time around it’s hard to recover your losses. I take care of unusual tumors, the tumors of the tissues that hold you together; they’re called sarcomas. In the tumor world if you have a poor result early on it’s very hard to recover from that, so I think you need to make sure that
you have some trust in your treating physician, that the communications are working, and that they have some level of expertise, and that would be my best advice for you.

Somebody talked about the Lance Armstrong Foundation and all the money that they’ve appropriately put into long-term follow-up, ironically enough when you get through with your tumor treatment, tumor oncologists, medical oncologists, and surgeons now don’t follow a lot of patients for a long period of time, and they’ll have special groups that provide long-term follow-up. Ironically enough the long-term follow-up is the best summary note you will usually have of your oncology care, and it’s really a good reason to go to long-term follow-up because that’s their main first purpose is to write a very concise summary of your entire oncology care, and it will probably be the only time you’ll get a very concise summary, ironically enough, of your oncology care. So it’s a really good reason to go to a long-term follow-up person at least for a few times.

Don’t be afraid of clinical trials. They’re really, really important for oncology care, and make sure the communications are working for you and your treating physicians.

Andrew Schorr:
I just want to underscore one thing, and I think this was embedded in what you said. I’ve heard it said in cancer care your first shot is your best shot. I heard you really say that in a different way, but it really is true. If somebody, let’s say for sarcoma but it could be with other cancer, they kind of went down the wrong road first for whatever reason; maybe they didn’t fully grasp or weren’t told of all the various options or maybe the most appropriate options; that makes it harder to recover from.

Dr. Conrad:
It does. I think it’s a little troubling to me that you can get in to get your ACL repaired in a week but if you have a breast cancer you can’t get in to see them very quickly, and that’s a problem. That’s a huge problem emotionally and sometimes clinically. We have a one-week rule where if you have a sarcoma diagnosis you get in within the week to see us or at least to see somebody connected to us, and in the world of oncology your follow-up happens at three-to-six month cycles, and follow-up is very important, and that needs to work. Those are the timelines that we work with in my tumor world. You get in to see us within a week, at the most within two weeks, but typically within a week, and we follow people with high-grade tumors at three-month intervals for at least the first year if not the first two years.

As somebody just said a few minutes ago and I like to say somewhat crudely, the best questions are the most basic, dumbest questions. Do not be embarrassed to ask a “dumb” question. If you are belittled about asking basic questions I think that’s a big red flag.

So congratulations on being interested enough to come today to support this incredible, Andrew’s a pioneer, and championing your own care. Patient advocacy next to establishing clinical programs with a research basis and academic institutions, which has been most of our desires in the world, I think patient advocacy is the greatest
phenomenon occurring in this country. It’s now happening in the European international spheres as a sort of a second consequence, but in North America patient advocacy is an enormously important phenomenon today, and you should embrace it with all your energy and passion. Thank you very much.

Andrew Schorr:
Thank you Dr. “Chappie” Conrad.

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