

Q. Have you ever heard of a patient who went on hormone therapy after stereotactic radiation and had the tumor grow or stop? My daughter is biochemically hyperthyroid but not clinically. The doctors say it was just a coincidence that the tumor started growing when she was on the thyroid hormone and then stopped growing when she went off it.

What type of tumor did she have?

Pilocytic astrocytoma and it was an optic glioma before that.

A. We would think that a pilocytic astrocytoma tumor does not grow or stop growing when a patient is on or off the thyroid hormone. However, thinking and knowing are two different things. The take away lesson for the general audience is, as you already mentioned, a very uncommon cancer that had an uncommon outcome. We read in the newspaper the Women Health Initiative study that looked at low fat diets and calcium supplementation to prevent osteoporosis. If you look at the numbers they were talking about studies with 40,000, 50,000, 60,000 women. But we don't have 40,000 to 60,000 of your daughters that we are able to study. A lot of times we have to have fairly detailed studies but we also take information from our biology that we understand or from other populations.

When we replace the thyroid hormone with levothyroxin or synthroid, what we are doing putting a synthetic preparation of what our thyroid gland is already putting out. What we typically see is we are restoring it back to physiologic or physical levels. It should not effect tumor growth at all. There are so many things that effect tumor growth that we do not understand. It's easy to say that it may be related to this because that's one definable thing we noted. But from a biological mechanism that we be very unusual.

Q. My son had ALL high risk t-cell and is two and a half years post treatment. My hospital does not have a late effects clinic, but I have had the neuropsych testing done from the very beginning. Since my hospital does not have a late effects clinic, should I consider changing hospitals? I am in New York and you are too.

A. Wonderful question. To people who are listening, if we look at long term follow-up programs there are 240 institutions within the children's oncology group but less than 100 have a long term follow-up, only about 25 to 30 of those are comprehensive and only about 8 to 10 follow people after age 25. So the vast majority of people listening in on this call may be in the same shoes. In the book Childhood Cancer Survivors that Nancy Keene published a year ago it lists the comprehensive late effects program. These clinics are also listed on the Beyond the Cure website (www.beyondthecure.org).

Talk with your provider, if it is not a service that they offer they can get you referred. I strongly, strongly, strongly recommend that all survivors are involved in some type of follow-up program. It is very important. The T-cell leukemia population definitely does have some risks that we address and a lot of those are endocrine, so I strongly recommend that.

The program here for our children, our childhood cancer part of it, is run by Dr. Charles Sklar who is a pediatric endocrinologist who is world renowned for his work with endocrine related problems as well as general late effects in the pediatric cancer survivors.

It is important for you to be an advocate for your child or yourself. Sometimes there is nobody else who can do it but you. Don't worry about being persistent. You have to push the system sometimes because our medical system is not well set-up for cancer survivors. It is even worse for survivors of adult cancer, but it can be very difficult for pediatric cancer survivors. I encourage you to be an advocate for yourself or your child.

Q. My son was diagnosed with neuroblastoma at 16 months and has been off treatment for a year. In July, they did hearing tests on him, the behavior ones, and he failed. They did a BAER (Brainstem Auditory Evoked Response) test on him and he failed that also. So he now has hearing aides. Since July he passed two behavior tests so they are going to repeat the BAER test again next week. Is it common for someone to have hearing loss from chemotherapy and then for it to reverse itself?

A. No, it is not and it is wonderful when it does. Hearing losses tend to be very static. The good news for people who have a hearing loss, it tends not to be progressive after the first year or two. Some of the other things that we see like lung function problems is once they are there they stay at that level unless there is something that adds to it. So with hearing some of the other medications later on may affect it. We usually do not get improvement, but we are thrilled if we do.

So it is possible that it could have reversed.

It is definitely possible that it could have reversed. The body is amazing in ways we don't understand. In medicine we never deal with nevers and always. We deal with percents and hopes.

He has also developed sensory integration dysfunction since chemotherapy. This makes a lot of things difficult.

Neuroblastoma, especially the advanced stage, is still an incredibly difficult cancer to treat. The therapy used is still quite toxic, similar to what we would look at with some of our other cancers from the 1980's.

Back to looking at which side of the coin we are talking about. The exciting part is that we are at a cure. The tough part is we have to figure out where the problems are and then get you what you need so you are able to take care of him and so his development period is as normal as it can be.

This questions was received via email after the conference

Q. I think I might have misheard something you said and am asking for clarification.

I think I heard: you are most likely to get leukemia as a secondary cancer during the first four years off treatment. My son is a little over three years off treatment, and I always thought the leukemia was something we would have to worry about his entire life.

If the chances greatly decrease after four years that would be something off our "high worry" list.

A. The risk is not lifetime. Also, the risk, while very real, is also very small. By ten years after therapy, about 2-3 children in 100 will develop leukemia from the treatment. That means that 97-98 will not.

There are two major types of leukemia following cancer therapy. The first type arises after treatment with alkylating agent therapy. Most cases occur between 4-8 years after the cancer therapy. In this group, there are often preleukemic changes that can be seen on a standard blood count. This is one of the reasons that we have a blood count drawn at each annual visit.

The second type of leukemia follows treatment with either etoposide or teniposide. This usually occurs within 2-3 years after the cancer therapy. This type of leukemia often does not show changes on our screening blood counts. It just suddenly occurs.

At 10-12 years following the cancer therapy, the risk of cancer-related leukemia is very small. In fact, it is quite rare to have a cancer-related leukemia after 12 yrs off of therapy.

So, again, risk depends upon what chemo was used and what doses. As always, we encourage our patients and families to discuss this with their oncologists to clarify any questions.