

Here is an excerpt from my journal on Jan. 13 1999

Christopher has Ewing Sarcoma (ES) and a peripheral neuroectodermal tumor (PNET) in the bone. The tumor is located in the right hipbone. It was approx. 10+ lbs and the size of a watermelon. Besides the primary tumor, there are other parts of his body that involved by tumor spread, such as the bone marrow and the base of his spine and the 11th left rib. This is a cancer that has spread and requires chemotherapy (drugs) and radiation.

The best treatments for patients with ES/PNET that has spread have had poor success. Most of the patients respond to treatment at first, but then the disease comes back. When the disease comes back it is very hard to treat, and is almost always fatal. Chris has a 10 - 30 % survival rate. OK, what did you say??? We can't possibly be talking about my son. Ah, you must be wrong. I've got the wrong doctor. All right regroup, Joan.

Our Oncology team continued to inform us that there was a case study Plan B (Treatment Plan for CCG-7951), going on for ES and Chris is eligible to participate in it. The purpose of this study to find out if the use of very high doses of drugs and radiation after the usual treatment will improve the chances that the tumor will not come back. Patients on this study will be treated with drugs for a minimum of 15 weeks. During this time, they will have tests to see if the tumor is getting better. If the tumor gets better, they will have some of the blood removed and stored for later use. They will then receive radiation treatments to the parts of the body where tumor was seen before treatment began. Afterwards, radiation will be given to the whole body. Then high doses of drugs will be given, followed by return of the blood cells that had been stored.

While participating in this study, Chris cannot take part in any other research project without approval from all of the investigators. This is to protect Chris from possible injury arising from such things as extra blood drawings, extra x-rays, interaction of research drugs, or similar hazards.

Alternative therapy for this tumor might include chemotherapy or radiation or some combination of these two treatments. The chemotherapy drugs might be the same drugs in different doses or order, or additional drugs might be administered.

The recommended treatment will consist of induction (initial drug therapy to control the disease), stem cell harvesting (collection of bone marrow stem cells by machine), radiation treatments to limited areas of the body, then total body irradiation, high dose chemotherapy, and stem cell rescue (repopulation of the bone marrow with harvested stem cells). Induction will last approximately 15 weeks. (Providing of course on Christopher's health). Stem cell harvesting will be done during the induction period. Limited radiation treatments will be given on the isolated areas where the cancer was found. The treatment will last approximately three weeks. Total body irradiation will then be given twice a day for three days. High dose chemotherapy will be given for the next three days after that. Two days later, stem cells will be returned to the body. Following this, the patient will be in the hospital until recovery. This will take a minimum of several weeks. The time in the hospital may be much longer. (You just know I have already mentally checked out, not only did I NOT understand what was being said, I didn't want to know. Tape recorder, heck I needed an interrupter.)

The doctor continued . . . the first stage of treatment is called the induction period. Chris will receive chemotherapy drugs for five cycles of treatment. Each cycle is supposed to begin 3 weeks from the start of the previous cycle. He will receive the following drugs.

Cyclophosphamide, Mesna, Doxorubicin, Vincristine, Ifosfamide and Etoposide. The side effects we will discuss.

Between treatments Chris will have blood tests checked. After at least two cycles of treatment, more tests will be done to check to see if the tumor has shrunk. If the tumor is smaller, the patient will have blood removed and frozen for storage. After five cycles of treatment, more tests will be performed to check on the tumor again. If the tumor is still shrinking, Chris will begin radiation treatment.

Radiation therapy: will be given after Chris recovers the five cycles of chemotherapy. The first parts of the body to be treated will be the areas of spread, which were seen at the beginning of the treatment. The radiation therapy doctor at Stanford, in Palo Alto Calif, will decide the areas to be treated and the doses of radiation.

After the areas of spread have been treated, Chris will begin total body irradiation. This means that the entire body will receive radiation. These treatments will be given twice each day for three days (six treatments in all).

Cytoreduction: is the next period of treatment. This is a period of intense drug treatment aimed at killing tumor cells. It begins as soon as the radiation is finished. Two drugs are given, Melphan and Etoposide, each day for three days. This is also known as the Conditioning Treatment.

Blood cell infusion: After Melphalan and Etoposide, there will be a two-day rest period. Then Chris will get back the blood cells that were removed earlier. The blood cells are thawed and are given intravenously. They run in over several minutes to a half hour.

After that Chris will be going through a recovery program and Stanford will go over that with you.

The staff gave us this disclaimer to sign. WE CANNOT AND DO NOT GUARANTEE OR PROMISE THAT CHRIS WILL RECEIVE ANY BENEFITS FROM THIS STUDY. We hope that this study will benefit him and others. Other possible treatment for him could include other drugs used alone or in combination. These could be either experimental or conventional drugs. Although we hope that this research study will be of benefit to him, we cannot say it will help him directly. We hope that the first chemotherapy will shrink the tumor in his body. We hope that the radiation and high dose chemotherapy will kill remaining tumor cells in his body. We hope that the combined treatments will increase Chris's chance to remain well. We hope that the treatment will decrease the risk that the tumor will return or relapse.

Participation in this study is voluntary. Chris does not have to take part in this study. If you do not want to take part, you could get the standard treatment and still be looked after by the same doctors here. Hey, wait a minute. Didn't you say that the other treatment wasn't successful? Duh...

The Team continued to talk very frankly to us. They informed us that Chris is now or will be sterile soon and that if we wanted to do any sperm donation the next few days is the time to do it. After that it will be too late. The Oncology Team felt it was already too late because of the location of the tumor and cancer. What did they say? Are they still talking about Chris? You know this isn't a groin pull.

They asked if there were any questions before we proceed to consider the case study. Dr. Leung did show us a "road map" of the procedure and discussed all the side effects. Chris, Paul and myself were numb!

We accepted The Case Study Plan B.