



Why Keep Records?

Reasons and Tips for Keeping Records for Neuroblastoma Treatment

If you multiply many patients by many hundreds of pages of records, you can quickly see the medical professionals deal with a vast amount of information about their patients. Electronic records allow quick recall of information from your child's chart, but there are times when it is handy for you to have important information at your finger tips. You can ask good questions about trends, check for accuracy in drug dosages, and quickly access pertinent information about your child. You have only one patient, and one disease. You can do it!

Ask for copies of everything

Ask for copies of everything, including scans on CD. Persistence is occasionally required to get everything after each series of tests. Organize the records in a way that makes sense to you, so you can find what you need while at the hospital or clinic. It is helpful to keep a chronological log of counts, tests, results, chemo, and all drugs including dosage. Cumulative drug dose is important for several of the chemos.

Most oncologists and nurse practitioners will respect your desire to be a part of the team and appreciate your efforts to make his/her job easier. Keeping your child's chart up to date is important, so add to it as you go.

Tailor the charts to your child

This chapter includes example charts for you to use or modify. (The web version of this handbook has downloadable charts in Microsoft Word and Excel). Be sure to eliminate items that do not apply, and add in items of importance that concern your child. For example, if your child has asthma, you may want to make a column on your chart for pulmonary function tests. You can consider keeping a separate food diary (noting what foods stay down!) If weight is a non-issue, take it off the chart. By contrast, for infants you may have to keep careful track of fluids (in and out) or total calories, in addition to weight. Skin issues, infections, magnesium levels, cardiac function, seizures, moods, and a host of other possibilities may be very important in tracking the care and making decisions for your child.

Keeping track of anti-emetics (anti-nausea) drugs is very important, because each child is unique in how well certain combinations work, and some of these drugs have powerful and unpleasant side effects. The nurses and doctors will not remember the combination that works for your child, nor will they catch every unacceptable reaction to the drugs. Always record infections, reactions to drugs, and complications of any kind.

Color code any items you want to highlight, such as reactions to blood products or drugs, or inpatient versus outpatient days. Make a legend of what the color codes indicate, and a list of abbreviations are helpful if you give copies of your chart to medical professionals.

Terminology

Drugs and tests often have more than one name, and you should make a list of all the drugs and tests and all their names and abbreviations, including common side effects of the drugs. Note that various abbreviations are used in the medical literature. For example, anthracyclines are a class of chemotherapy drug in the antibiotic family. One drug in this class is doxorubicin, which is sometimes referred to by the brand name Adriamycin (brand names are capitalized). You will need to know total dose of anthracyclines your child received because of potential long term heart damage from this class of drug.

EXAMPLE definition from:

<http://www.medterms.com/script/main/art.asp?articlekey=20134>

Anthracycline: A member of a family of chemotherapy drugs that are also antibiotics. The anthracyclines act to prevent cell division by disrupting the structure of the DNA and terminate its function. They do so in two ways: (1) they intercalate into the base pairs in the DNA minor grooves; and (2) they cause free radical damage of the ribose in the DNA. The anthracyclines are frequently used in leukemia therapy. The anthracyclines include daunorubicin (Cerubidine), doxorubicin (Adriamycin, Rubex), epirubicin (Ellence, Pharmorubicin), and idarubicin (Idamycin).

Common Misspellings: anthracyclin

Thou shalt know the side effects

Every drug administered to your child has potential side effects. You must know what they are. As wonderful as the nurses and doctors are, they simply will not be able to pin it down every time your child has an unpleasant side effect to something. Here is the really difficult part, and why you should have an honorary MD by the time you are done: many of the side effects overlap from drug to drug, so if your child is on 10 different meds, and is having blistering headaches, and five of the drugs can cause headaches, which one is it, Sherlock? Parents are often the most apt to figure this out, because they know their child and can keep careful track of responses.

An excellent resource for thorough information about many chemotherapy drugs can be found at <http://www.bccancer.bc.ca/HPI/DrugDatabase/DrugIndexPro/default.htm>

Units and reference ranges

Lab tests for blood and urine are reported by each institution with test name, units, and reference range. Be sure to record your results with units so that the results can be understood by different institutions, and also record what was tested (i.e. blood/serum, or urine). Reference ranges are established for each lab, and some are based on age and gender. You will become accustomed to interpreting the results of white cell counts, hemoglobin, and platelets. Other tests will be done less frequently, but will be important to determine organ function and possible tumor activity. Always ask why a particular test is done, so you understand the significance of the test and the result.

Become familiar with how drug dosages are written, so you can quickly copy chemo and other drugs onto your chart or drug list. See the list of dosage abbreviations below. Always indicate how the drug is administered (IV, oral, injection, etc) along with the dose. Ask a nurse if you don't understand the units. Drug dose is determined based on weight (kg or kilograms) or surface area (m² or "meters squared"). Surface area is calculated from height and weight, and an average five year old has roughly one meter squared of surface area. It is a good idea to record both the dose (amount of drug per kg or m²) and the actual amount given. This way you can keep track of dose errors. You should

keep track of both weight in kg and surface area, as these will change and affect the amount of drug given on a particular day.

Example: Doxorubicin 25 mg/m²/day IV x 3 days

This means 25 milligrams per meter squared of body surface area of doxorubicin is to be administered intravenously per day for 3 days. This is a continuous infusion, because there is no additional information on how long the infusion is—such as over 30 minutes. Total dose for this course would be 75 mg/m².

Prescription abbreviations are handy to know, so you can check to be sure that administration of drugs prescribed is correct. See chart for abbreviations used for prescribing drugs below, with the Latin origin.

Drug Prescription Abbreviations

<u>Term</u>	<u>Abbreviation</u>	<u>Meaning</u>
ante cibum	ac	before meals
bis in die	bid	twice a day
gutta	gt	drop
hora somni	hs	at bedtime
oculus dexter	od	right eye
oculus sinister	os	left eye
per os	po	by mouth
post cibum	pc	after meals
pro re nata	prn	as needed
quaque 3 hora	q3h	every 3 hours
quaque die	qd	every day
quater in die	qid	4 times a day
ter in die	tid	3 times a day

Test limitations

Even more tricky than keeping track of terminology, units, and results of all these tests, is understanding the limitations of each test. For example, your child may have a bone marrow biopsy that is reported as simply “positive for neuroblastoma” or “negative for neuroblastoma.” What can you know from that result? In the case of “negative,” it means that in the sample that was examined, no neuroblastoma cells could be found. These biopsies are usually bilateral, meaning two sites were checked at the same time. Those two sites are clear of tumor, but unfortunately, it does not mean the child’s entire bone marrow is clear, because NB cells could be clumped in other locations (referred to as “sampling error”). How do you interpret the “positive for neuroblastoma” result? There is little chance of “false positive” in this case, unless there is very small amount of tumor, and it may be well-differentiated (matured) into harmless ganglioneuroma cells. These are items to discuss with your doctor and possibly the pathologist who reads the slides. Some pathologists will report the amount of neuroblastoma in a bone marrow biopsy as a percentage, but keep in mind this is visually estimated. In other words, there is no significant difference between 40% and 50% because this is difficult to estimate to a high degree of precision, especially since neuroblastoma often appears in clumps. The oncologist will be more interested in obvious trends in a series of biopsies over the course of several weeks or months, such as 100%, then 40%, then 5%.

Another example of understanding results with respect to limitations, is urine catecholamine metabolites (HVA and VMA). HVA and VMA indicate tumor activity in 82% of children with stage 1-3

neuroblastoma, and in 96% of children with stage 4 (Cheung 67), but in certain circumstances levels can be highly inaccurate. The spot test for HVA and VMA is much less accurate than the 24 hour urine test, unless done simultaneously with urinary creatinine (Cheung 68). Many food items will affect the results (such as apple juice), so you will want to know what foods your child should avoid so the test will be as accurate as possible. Finally, VMA/HVA are often tested during follow up visits after treatment is completed, but only 54% of patients in one study had elevated values at the time of recurrence (Cheung 68).

Long term effects

Keeping a treatment summary for long term follow up is very important. A concise but thorough history of treatment, with all follow up tests should be kept up to date. Many children who are long term survivors of neuroblastoma know very little about their treatment when they become adults and become responsible for their own medical care. Recent studies have been published indicating the lack of knowledge about the disease and treatment can jeopardize the child's future health care: <http://annalsfm.highwire.org/cgi/reprint/2/1/61>.

Overwhelming?

Do not be discouraged! This may appear to be an overwhelming task at first, but becomes easier as time passes. You will learn as you go, and develop your own strategies for keeping track of things as you see fit. The medical world respects your important role as advocate for your child. Your understanding of the disease and treatment can only benefit your child. Eventually you will want to pass this on to your child, so that as a survivor, your child will know how to become his or her own advocate.

Source:

Cheung, Nai-Kong V., and Susan L. Cohn, eds. *Neuroblastoma*. Berlin: Springer; 2005

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