PATIENT INFORMATION FOR TROPHOBLASTIC DISEASE

The information given here is not meant to be comprehensive, particularly not for non-hydatidiform trophoblastic disease.
If you have questions these may be addressed to your doctor or your nearest trophoblastic disease center.

WHAT IS A HYDATIDIFORM MOLE?

A hydatidiform mole is an abnormality of fertilization. There are two types of hydatidiform mole, complete and partial. With complete mole the chromosomal genetic material from the ovum (egg) is lost, by a process that is yet not understood. Fertilization then occurs with one or two sperm and an androgenic (from the male only) conceptus (fertilized egg) is formed. With this conceptus the embryo (fetus, baby) does not develop at all but the placenta does grow but it is abnormal and forms lots of cysts and has no blood vessels. These cysts look like a cluster of grapes and that is why it is called a hydatidiform mole (grape like). A hydatidiform mole miscarries by about 16 to 18 weeks gestational age. Since the diagnosis can be made by ultrasound before that time, it is better for you to have an evacuation of the uterus (D & C) so that there is no undue bleeding and no infection. human chorionic gonadotropin (hCG) will assist in making the diagnosis.

The other type of hydatidiform mole is called a partial mole and this is also a genetically abnormal pregnancy. In this case there are three sets of chromosomes instead of the usual two and this is called triploidy. With such a pregnancy the chromosomal (genetic) material from the ovum (egg) is retained and the egg is fertilized by one or two sperm. Since with partial mole there are maternal chromosomes there is a fetus but because of the three sets of chromosomes this fetus is always grossly abnormal and will not survive.

WHAT KIND OF SYMPTOMS WOULD SOMEONE WHO HAS A HYDATIDIFORM MOLE HAVE?

Symptoms usually appear in the second or third month of pregnancy. There may be abnormal bleeding or cramps or the passage of some tissue. There may be severe vomiting, more than in normal pregnancy.

HOW DOES THE DOCTOR MAKE THE DIAGNOSIS OF HYDATIDIFORM MOLE?

By examination the doctor may find that the
uterus is larger than normal for the duration (age) of the pregnancy. An ultrasound examination will make the diagnosis and will help distinguish mole from other early pregnancy abnormalities. A blood test, that is a special pregnancy test of human chorionic gonadotropin (hCG) will assist in making the diagnosis.

HOW IS A HYDATIDIFORM MOLE TREATED?

The treatment for a hydatidiform mole is to remove the tissue from the uterus by a procedure called a Suction Curettage or “D & C”. In this procedure the mouth of the uterus is opened or “dilated” in order to allow a suction curette to enter and suction out the abnormal tissue. If you are sure you do not want any more children, a hysterectomy (the removal of the uterus) may be performed.

WHAT KIND OF SYMPTOMS SHOULD I WATCH OUT FOR AND REPORT TO MY DOCTOR AFTER THE D & C?

You should report any new bleeding, any fever, or if you pass any tissue from your vagina. You should also report anything that seems to be out of the ordinary, *EVEN IF YOU THINK IT MAY BE UNIMPORTANT!*

WHAT IS THE CAUSE OF HYDATIDIFORM MOLE?

Although some studies have linked hydatidiform mole with dietary or genetic factors, and it has been found to have a higher incidence in the Far East, the real cause of hydatidiform mole is still unknown. It is of interest that persons born in the Philippines who immigrate to Hawaii or California lose their higher propensity for hydatidiform mole by the next generation. If you wish to have more detailed information about the difference between a complete or a partial mole, your doctor will talk to you about this and he will certainly tell you which type of mole you have.

IS IT RARE FOR A PERSON TO HAVE A HYDATIDIFORM MOLE?

Hydatidiform mole occurs approximately in 1 out of 1500 pregnancies in the eastern United States. It is three times more common in some countries of Eastern Asia and Northern Brazil.

WHAT IS MY CHANCE OF HAVING ANOTHER HYDATIDIFORM MOLE?

The chance for a hydatidiform mole occurring in a subsequent pregnancy is 1%.

I HAVE HEARD THAT IF SOMEONE HAS A HYDATIDIFORM MOLE IT MIGHT LEAD TO CANCER. DO I HAVE CANCER?

If you have had a hydatidiform mole, it does not mean you have cancer. One in five or 20% of patients who have had a hydatidiform mole have tissue not completely removed by the D & C. This happens because the molar tissue can grow into the wall of the uterus and from there may spread to other parts of the body through the bloodstream. If this occurs it is called “trophoblastic neoplasia” or "persistent trophoblastic tumor". Trophoblastic disease may be a form of cancer but is very treatable with chemotherapy. When treated early with chemotherapy trophoblastic disease has a 99.9% cure rate.

HOW WILL MY DOCTOR AND I KNOW IF THERE IS STILL MOLAR TISSUE REMAINING?

The tissue of the hydatidiform mole or trophoblastic tissue produces a chemical substance called Human Chorionic Gonadotropin (hCG) which is found in both the blood and urine. The amount of hCG hormone acts as a measure of the amount of tissue left after the D & C.

In fact all trophoblastic tissue, like a normal placenta, produces hCG. With trophoblastic disease, hCG is measured weekly by an assay that identifies all portions of the hCG molecule. If hCG gradually disappears over 6 to 8 weeks you will know that your body is destroying any residual tissue left after the D & C. If the hCG persists or actually rises this means that trophoblastic tissue persists in the uterus and may be invading the uterine wall. It is then that chemotherapy will be needed.

hCG FOLLOW UP

Every week after molar evacuation you must come to your Doctor to have a blood specimen taken for hCG. The result is usually available the next day. Some clinics follow the level of hCG by a urine test for some time and then do blood samples to ensure the hCG is in fact negative.

WHEN WILL I KNOW WHETHER OR NOT I WILL NEED CHEMOTHERAPY?

You must have blood drawn weekly (WITHOUT FAIL!) to measure your hCG hormone. You need to be carefully followed to make sure each week that the blood level of hCG progresses downward. Your body has the capacity on its own to break down and rid itself of a certain amount of the tissue. If, however, your hCG level stays the same for several weeks or starts to go upward, this means that the molar tissue is growing at a faster rate than your body can destroy it. Chemotherapy will then be necessary.

WHAT IS THE CHANCE I WILL REQUIRE TREATMENT WITH CHEMOTHERAPY?

About 80% of patients with hydatidiform mole have no further problems after the D & C or hysterectomy. Only 20% of patients who have had hydatidiform mole require treatment with chemotherapy as part of their follow-up course.

MALIGNANCY (CANCER) AND HYDATIDIFORM MOLE.

With complete hydatidiform mole the molar tissue remaining in the uterus may not be destroyed by your body's immune mechanism and may begin to grow into the wall of the uterus. This is called an invasive mole. From there the molar tissue may spread to the lung and then to other organs like a cancer. This cancer is called choriocarcinoma. Very, very rarely choriocarcinoma may occur after a normal full term pregnancy or after an apparently uneventful miscarriage. Invasive mole and choriocarcinoma are treated with chemotherapy with virtually 100% effectiveness.

WHAT IS CHEMOTHERAPY?

Chemotherapy is a treatment, which uses medication to kill the trophoblastic cells that continue to grow. The amount of chemotherapy you need will depend upon your hCG hormone level. Your treatment will continue until the hCG hormone disappears from your blood. The hCG "zero" level means all trophoblastic tissue is gone from your body.

IF I DO NEED CHEMOTHERAPY, HOW IS IT GIVEN AND WHAT KIND OF SIDE EFFECTS CAN I EXPECT?

The chemotherapy or medication(s) used to treat trophoblastic disease is given through a small needle in a vein in your hand or arm. You can usually receive the chemotherapy as an outpatient. Each treatment course consists of either 2 weekly or weekly injections or a course of daily injection for five days. If necessary, courses are repeated until the hCG "zero" level is reached.

Some of the side effects you might experience are nausea and vomiting but this is nowadays nearly completely prevented by medication. You may have TEMPORARY hair loss (the amount of hair loss will depend on the number of courses of chemotherapy given), some mouth soreness and a skin rash. All side effects will be explained to you in much greater detail if it becomes necessary to give you chemotherapy. To remind you again, this disease is 99.9% curable with chemotherapy if followed properly.

HOW LONG WILL IT BE NECESSARY TO HAVE BLOOD TESTS?

Once your blood level comes down to "zero" you will need to return to have blood drawn each week for two more "zeros", then every month for twelve months. If your hCG level falls very quickly indeed, you may need to be followed for only six months before you undertake another pregnancy. If you have received chemotherapy, you will continue to have hCG drawn once a year.

ONCE MY BLOOD LEVEL REACHES "ZERO" IS THERE A CHANCE OF IT GOING UP AGAIN?

The chance of your hCG blood level going up again after reaching "zero" is very low.

WHY IS IT SO IMPORTANT THAT I DON'T GET PREGNANT IN THE NEXT YEAR?

The hCG hormone that measures molar or trophoblastic tissue is the same hormone that is secreted during pregnancy. If you should become pregnant, we would not be able to determine whether this hormone is being secreted by your pregnancy or by remaining molar tissue. Therefore, it is essential that you use reliable birth control.

COULD HAVING A HYDATIDIFORM MOLE CAUSE ME TO HAVE PROBLEMS WITH FUTURE PREGNANCIES?

The pregnancies in women who have had a hydatidiform mole are normal and the incidence of complication with pregnancy is no greater than in the normal population. If you required many courses of chemotherapy, you may have a SLIGHTLY higher chance of miscarriage.

WILL MY BABY BE NORMAL?

The chance of your baby having any abnormalities is NO GREATER than in the normal population EVEN IF CHEMOTHERAPY WAS ADMINISTERED.

OTHER FORMS OF TROPHOBLASTIC TUMOR.

Very rarely trophoblastic disease may occur after full term pregnancy. If so the patient will have bleeding and sometimes the baby, which is quite normal, may be anemic. Your gynecologist would then refer you to your nearest Trophoblastic Disease Center for treatment. Even more rarely trophoblastic disease may have already spread outside the uterus when it is diagnosed. Even then it is very treatable and nearly all patients are still cured.