Is it safe for women with Down syndrome to take the birth control pill (oral contraceptives)?

We have a number of female patients who successfully take oral contraceptive pills (OCP’s) for a variety of reasons including birth control, managing dysmenorrhea (discomfort during menses), reduction of mood changes associated with the menstrual cycle and others. However, we have seen some complications from taking OCP’s. Of particular note is the issue of blood clots.

It is interesting to note that we see very little atherosclerotic disease in people with DS. Heart attacks (myocardial infarctions), strokes due to narrowing of arteries and peripheral vascular disease (narrowing of the arteries in the legs and/or arms) are very uncommon in people with DS. These are diseases of the arteries, the vessels that carry blood from the heart to the body.

However, we have seen some patients develop blood clots in their veins (the vessels that carry blood back from the body to the heart).

Some general information on blood clotting can be found at this website: http://www.nhlbi.nih.gov/health/dci/Diseases/ebc/ebc_causes.html

Are people with DS more susceptible to blood clotting in their veins? I have not been able to find studies that indicate that is the case. However, there are some things to consider especially before considering taking OCP’s because OCP’s also increase the risk of blood clots in the veins.

People with DS are thought to have more auto-immune diseases. An auto-immune disease is one in which the body attacks part of itself as if that part of the body were a foreign invader. Our immune system helps us fight off infections by killing or suppressing bacteria, viruses, fungi, etc. Unfortunately, in auto-immune conditions, our immune system also attacks part(s) of our body.

There are several auto-immune conditions that are thought to be more common in people with DS. Some examples include:

- Auto-immune thyroid disorders (about 40% of our patients have hypothyroidism- an underactive thyroid- and the most common cause of hypothyroidism in people with DS is on the basis of auto-immunity.
- Type 1 Diabetes mellitus (the type that most commonly starts in childhood and requires insulin)
- Celiac disease (the sensitivity to gluten)
- Rheumatoid arthritis
A condition that increases blood clotting is called a “hypercoagulable state” (increased coagulation/clotting). There are some auto-immune conditions that cause hypercoagulability/increased clotting. Anti-phospholipid syndrome (increased anti-phospholipid antibodies) is associated with increased blood clotting. An increase in antithrombin antibodies seen in lupus erythematosis and other auto-immune conditions is also a risk factor for abnormal clotting. We have found these conditions in some patients.

Other conditions that are associated with hypercoagulability (some of which we have found in people with DS) include:

- activated protein C resistance
- Protein C deficiency
- Protein S deficiency

We have not found studies that indicate that these conditions are more common in people with DS. However, we have seen some women with DS develop blood clots in their veins while taking OCP’s and some have had the blood clots travel to their lungs which can be a very dangerous situation. Some of these women had one of these hypercoagulable conditions. Due to our experience, we recommend that a woman with DS who is considering taking OCP’s have blood testing to assess for hypercoagulable states before starting on the OCP.

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There is one other consideration. Moyamoya disease is more common in people with DS. Moyamoya is associated with both increased bleeding and clotting in the brain. However, in both our experience and in my review of the studies I could find, the strokes associated with Moyamoya in people with DS more commonly occur in childhood. Therefore, there is a greater chance that the existence of the condition will be known before OCP’s are being considered. If a woman has Moyamoya, OCP’s would be contraindicated.