

UNIVERSITY STUDENT HEALTH SERVICES • Fact Sheet

GILBERT SYNDROME**WHAT IS IT?**

Gilbert syndrome is a benign inherited disorder of the liver that leads to an elevated level of bilirubin in the blood.

- Bilirubin is a natural waste product that results when old red blood cells break down. Small amounts of bilirubin are normally present in the blood.
- The liver uses an enzyme to convert bilirubin into a form that can be eliminated through the stool. People with Gilbert syndrome have less of this enzyme available, leading to an elevation of a form of bilirubin known as unconjugated (or indirect) bilirubin.
- Elevated bilirubin levels can cause the skin to appear yellow or jaundiced. Though this finding may be alarming, Gilbert syndrome is not dangerous and does not cause long-term health problems.

WHAT CAUSES IT?

In order to have Gilbert syndrome, you must have inherited an “abnormal” gene from both of your parents.

- About half of the general population has at least one “abnormal” gene, so inheriting this gene from both parents is not unusual.
- Some people with only one “abnormal” gene have slightly higher levels of unconjugated (or indirect) bilirubin but do not have the syndrome.
- Due to unclear reasons, some people who have two “abnormal” genes do not develop the syndrome.

Triggers that can increase bilirubin production and lead to jaundice include:

- Fever, infection.
- Menstruation.
- Fasting or dehydration.
- Lack of sleep.
- Physical exertion.
- Stress.

Medications that are metabolized by the same enzyme affected in Gilbert syndrome can also trigger symptoms.

HOW COMMON IS IT?

Gilbert syndrome affects people of all races. Its prevalence has been reported to be 4-16% in different populations.

- The syndrome is more often diagnosed in men because they produce higher levels of bilirubin.
- It is usually detected after puberty since bilirubin production increases at this developmental stage in life.

WHAT ARE THE SYMPTOMS?

Most people with Gilbert syndrome do not have any symptoms. It is often diagnosed entirely by chance, when blood work is obtained for other reasons.

Mild episodic jaundice (yellowing of the eyes and skin) may be seen in Gilbert syndrome when bilirubin levels rise above a certain level. Initially, the bilirubin pigment will cause the whites of the eyes to appear yellow. At higher bilirubin levels, the skin will also become jaundiced.

Some patients may report associated fatigue or abdominal discomfort.

HOW IS IT DIAGNOSED?

As mentioned previously, Gilbert syndrome is usually a diagnosis of coincidence.

- Blood work will show isolated mild elevations in unconjugated (or indirect) bilirubin and total bilirubin. The total bilirubin level is typically less than 3mg/dL.
- Other blood tests will show normal liver function tests and a normal complete blood count.
- No further work-up is needed unless symptoms and exam findings suggest another cause of an elevated bilirubin level.
- Genetic testing for Gilbert syndrome is available at some laboratories but is rarely required.

WHAT IS THE TREATMENT?

Because Gilbert syndrome is essentially a harmless condition, no treatment is necessary. However, if you notice persistent jaundice or other concerning symptoms (abdominal pain, nausea, vomiting, dark tea-colored urine, etc.), consult your medical provider to rule out serious causes of jaundice.

WHAT PRECAUTIONS NEED TO BE TAKEN?

Patients may be at greater risk for side effects from medications that are cleared from the body using the bilirubin-processing enzyme affected by Gilbert syndrome.

- For example, Gilbert syndrome is known to increase the risk of toxicity from irinotecan (Camptosar), a medication used to treat colon cancer, and some HIV medications known as protease inhibitors.
- Acetaminophen (Tylenol) is also metabolized by the same enzyme. However, it is safe for use in patients with Gilbert syndrome when taken at the usual recommended doses.

Therefore, basic precautions for Gilbert syndrome include:

- Checking with your doctor before taking new medications.
- Taking only the recommended dose of over-the-counter medications, like acetaminophen (Tylenol).
- Seeking medical attention if you have drug side effects that are concerning or that last for a prolonged period of time.

ARE THERE OTHER COMPLICATIONS?

No. Individuals with Gilbert syndrome experience no long-term negative effects. Interestingly, some researchers believe that an increase in bilirubin levels over time produces an antioxidant effect, which may result in lower rates of cancer and atherosclerotic heart disease.