

Internet Social Support

Plus questions and answers about POA, Osteoporosis, and the importance of calcium, and other questions brought up on websites

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**Internet has
reshaped today's
role in work,
leisure, lifestyles,
social relationships,
and expanded our
world**



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**Most Internet
activities are linked
to social support**



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**A Social Support
Network**
Is a common group of people who share a common set of experiences or expertise, this allows an individual to feel tied to a larger community



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Advantages

- Finding others with the same disorder that share your experiences.
- Finding friends you can talk to about things only another person with galactosemia can understand.
- Networking to find new information on the galactosemia.
- Finding people in and around the area you live with the galactosemia so that you might meet.
- Talking or asking about different findings or experiences with the galactosemia.



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Advantages continued

- New people discovering the site to become enlightened and to learn about galactosemia
- Feeling part of a group, you are not alone in this.
- Sharing ideas and recipes'
- Talking about your children and asking questions to others who have been through an experience already.
- Talking with peers about subjects only galactosemic's go through.



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Disadvantages

- Giving the wrong medical advice.
- Hurting someone else's feelings.
- Not everyone is at the same cognitive level, so this needs to be taken into account before you post something.
- Not everyone's doctor agrees on the same diets or treatments.
- Everyone is affected differently by galactosemia.



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Disadvantages continued

- Some people come more for companionship, some more for information
- Some people get very upset with what other doctors are telling their patients and lash out at the persons affected with the disorder and then they take great offense.



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Disadvantages continued

- People leaving the group if offended by another's comment.
- Everyone has the right to participate or not, but if someone see's incorrect information posted instead of telling them they or "their doctor is full of beans". Please do some research on the topic, and give back a medically correct reason.



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Premature Ovarian Failure (POF)

The definition of POF is menopause before 40 years of age.

This has been a big topic on the websites. Some young women telling others to forget what their doctors say because the doctors do not know anything, and then some of these young women taking the advice at the risk of their bone health.



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POF

- A majority of girls/women who have classic galactosemia experience Primary Ovarian Insufficiency.
- However, there are women with classic galactosemia who have successfully conceived and given birth.
- There are some tests (hormone level testing) which may be performed to check the condition of the ovaries.



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POF continued

- Some adolescents and women have some hormones even if minimal, and therefore are able to conceive a child. So far it does not seem to matter what genotype the woman is.
- This however is not the norm. You need to stay on your hormone supplementation unless said otherwise by your physician. This is for the prevention of osteoporosis.



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Osteoporosis Defined

A disorder characterized by abnormal loss of bone density and deterioration of bone tissue, with an increased risk of fractures.



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What is Bone

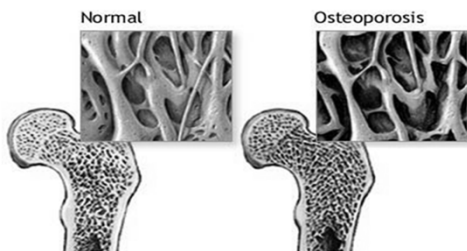
- Bone is living, growing tissue.
- Bone consists of compact bone that surrounds spongy bone; bone marrow is located in the center and supplies the blood to bone



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The look of Bone



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Controllable risks

- Inactivity-A decrease in exercise especially weight bearing can lead to bone loss.
- Low calcium intake-Calcium is important for the formation of bone. Galactosemics need calcium supplementation.
- Lack of sun exposure-Vitamin D aids in the absorption of calcium, a major source of Vitamin D is sunlight. Many Galactosemics need extra vitamin D supplementation.



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More Controllable Risks

- Smoking can cause lower bone density.
- Alcohol-Regular consumption of 2-3 ounces of alcohol a day can be damaging to the skeleton.
- Drinking beverages high in caffeine and phosphorus can lead to lower bone mass.



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Smoking

- Most studies on the effects of smoking suggest that smoking increases the risk of having a fracture.
- Smokers who have a bone fracture may take longer to heal than nonsmokers and may experience more complications during the healing process.
- Significant bone loss has been found in older women and men who smoke.
- At least one study suggests that exposure to *secondhand smoke* during youth and early adulthood may increase the risk of developing low bone mass.



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How soda robs calcium from your bones

- The carbonation irritates the stomach.
- The stomach "counteracts" the irritation the only way it knows how. It adds the only antacid at its disposal: calcium. It gets this from the blood.
- The blood, now low on calcium, replenishes its supply from the bones. If it did not do this, muscular and brain function would be severely impaired



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Phosphorus is a mineral your body requires to add structure to your bones.

Another problem with most soft drinks is they also contain phosphoric acid (not the same as the carbonation, which is carbon dioxide mixed with the water). This substance also causes a reduction of the store of calcium.

- Soft drinks soften your bones (actually, they make them weak and brittle) in three ways:



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Phosphorus continued

- 1 - Phosphoric acid reduces the calcium in the bones.
- 2 - Phosphoric acid is also known to neutralize the hydrochloric acid in our stomachs. This is unfortunate, for we need hydrochloric acid to help us digest our food and utilize its nutrients. It is especially required for calcium utilization. Not only does the phosphoric acid leach calcium from our bones, it also prohibits hydrochloric acid from helping to restore it. Bones and teeth just can't win with this stuff in our diet.



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Phosphorus Continued

3 - One of these chemical additives, *phosphoric acid*, is added to many kinds of soda pop to help keep the carbonated bubbles from going flat. Because good health depends upon our bodies being able to maintain a one-to-one balance between calcium and phosphorus in our systems, calcium is released from our teeth and bones into our bloodstreams to help balance the phosphoric acid in the pop we drink. Eventually the phosphoric acid is excreted, taking with it the released calcium.



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Caffeine also robs bones of calcium

- Another possible culprit is caffeine, which experts have long known can interfere with calcium absorption.



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Sugar also robs Calcium from bones

- Sugar can cause calcium loss from the body leading to bone decay. Eating sugar changes the calcium/phosphorus ratio in the blood, with the calcium usually going up and phosphorus going down and therefore upsets the balance of the body.
- This calcium/phosphorus ratio remains disturbed for as long as 48 hours after the ingestion of sugar and therefore people remain out of homeostasis for a long time after eating sugar. Because of disturbance of this ratio, calcium is not fully absorbed by the body.



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Sugar Continued

- In fact, sugar for its own metabolism and burning also requires calcium and since it is devoid of any minerals, this calcium is taken out of bones. This loss of calcium from the body will cause weakening of bones and teeth leading sometimes to osteoporosis.



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Diet pills and energy drinks, continued

- Energy drinks do not contain as much phosphorus, but contain large amounts of caffeine.
- 5 hour energy drink has B vitamins, and if you drink too much you can an overdose of vitamin B3 and can even cause your body to turn red and to tingle. Nerve spasms are a common side effect of taking too much vitamin B6



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Uncontrollable Risks

- Gender-Women are 4 times more likely to be diagnosed with osteoporosis.
- Heredity-A family history puts you at risk for osteoporosis.
- Body structure-People who are thin-boned or have a smaller frame are at increase risk of osteoporosis.
- Race- Caucasian and Asian Americans are at greater risk than African Americans of developing osteoporosis.
- Galactosemia



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Uncontrollable Risks continued

- Estrogen deficiency-Bone loss begins to exceed bone formation in the post-menopausal woman because of a decrease in estrogen.
- Age-The older you are the greater your risk of osteoporosis.
- Existing medical or genetic conditions



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Risks of diet pills and energy drinks

- This problem may be more prevalent among young people, according to a team of researchers from Northwestern University in Chicago. When they tracked calls to the Illinois Poison Center in Chicago for three years, they found that more than 250 cases of medical complications occurred from ingesting caffeine supplements and that 12% of the callers had to be hospitalized. The average age of the callers was 21.



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Diet pills and energy drinks, continued

- One of these chemical additives, phosphoric acid, is added to many kinds of soda pop to help give the brown colored sodas a tangy taste. Because good health depends upon our bodies being able to maintain a one-to-one balance between calcium and phosphorus in our systems, calcium is released from our teeth and bones into our bloodstreams to help balance the phosphoric acid in the pop we drink. Eventually the phosphoric acid is excreted, taking with it the released calcium.




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Diet pills and energy drinks, continued

- Diet pills can contain phosphorus, caffeine, or a chemical called a diuretic.




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Prevention

- Activity-weight bearing exercises
- Diet-increase calcium and vitamin D
- Avoid drinking and smoking
- Maintain an ideal body weight
- Limit caffeine, and or soda intake
- Avoid energy drinks and diet pills




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Prevention

- Weight bearing such as walking or running for 20 minutes 3 times a week
- Weight lifting 3 times a week
- Eating healthy




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Recommended Calcium Intake

- Calcium
 - Children and adults up to age 50 need 1300mg/day
 - Adults over the age of 50 should have 1500 mg/day
 - Consult your doctor




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Recommendations for Vitamin D

- Main source other than food is the SUN
 - 10-15 minutes between the hours of 10-3 during the summer months is sufficient
- Is needed for calcium absorption
- Dietary recommendations
 - Children need 400 IU/day
 - Adults between the age of 20-50 need 400-800 IU/day
 - Adults over the age of 50 need 700-800 IU/day
 Also consult your doctor




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Additional Comments addressed on Web sites

- Coordination- fine and gross motor
- Speech
- Trouble with bowel movements
- Lack of sensation around face and lips
- Difficulty making friends
- Difficulties in math



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Constipation

- A patient that has a certain degree of constipation that is not adequately treated only partially empties the colon throughout life, leaving larger and larger amounts of stool inside the rectosigmoid, which results in greater degrees of megasigmoid. Most doctors believe that the dilatation of the bowel produces poor peristalsis or movement. This explains why there is fecal retention, which produces megacolon (an enlarged colon) that exacerbates the constipation.



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Constipation Continued

- In addition, the passage of large, hard pieces of stool may produce painful anal lacerations (fissures), which result in a reluctance by the patient to have bowel movements. The constipation worsens and becomes an increasingly serious problem.
- Children with certain genetic disorders are known to have this as a problem.



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Questions & Comments

- Any comments on the material discussed or questions that you have, nothing is off limits.



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References

- archpedi.ama-assn.org/cgi/content/full/153/4/380 -
- Anderson, D.M., Keith, J., and Novak, P.D. (2002). *Mosby's Medical, Nursing and Allied Health Dictionary*. (6th edition). St. Louis: Mosby, Inc.
- Carne, K. (2009). Osteoporosis: Maintaining bone health and preventing fractures. *Journal of Community Nursing*, 23(1), 11-13.
- Chiodo, B. (2007). Preventing osteoporosis: Healthy bones for life. *Journal of Community Nursing*, 21(5), 22-27.
- Hetzell, C.B. (2005). New help for old bones. *Nursing* 2005, 35(5), 20-21.



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References

- Holcomb, S.S. (2005). Boning up on Osteoporosis. <http://life.familyeducation.com/nutrition-and-diet/healthy-lifestyle/36000.html#ixzz1wkTbKcL7>
- <http://www.livestrong.com/article/502939-phosphorus-in-sodas/#ixzz1wIwaCrCi>
- *Nursing made Incredibly Easy*, 6-17.
- Schrader, S., Blue, R., and Horner, A. (2005). Better bone buddies: An osteoporosis prevention program. *The Journal of School of Nursing*, 21(2), 106-114.
- Seabolt, J. (2007). Bone up on osteoporosis. *LPN* 2007, 3(6), 30-38.
- Williams, S.D. (2001). *Basic Nutrition and Diet Therapy*. (11th edition). St. Louis: Mosby, Inc.



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References

- www.vanguardngr.com/2012/01/sugar-the-good-the-bad-and-the-u-38k
archpedi.ama-assn.org/cgi/content/full/153/4/380 -



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