

## New Treatments for Rare Bone Diseases

New Mexico Clinical Research & Osteoporosis Center is a well-recognized leader in the development of new treatments to improve bone health and reduce fracture risk in patients with osteoporosis. As knowledge of the molecular regulators of bone metabolism has advanced, so has our insight into potential treatments for bone diseases other than osteoporosis.

Take, for example, a rare metabolic bone disease called hypophosphatasia (HPP) that prevents bone from becoming fully mineralized. This has an incredibly diverse range of expression, from babies born with no recognizable skeleton followed by rapid death, to adults with mild forms of disease who are mistakenly diagnosed with osteoporosis. For adults under our care, the distinction between these two diseases is critical, since the treatments are quite different, and choosing the wrong medication may be harmful. Although the diagnosis of HPP is usually easy, many adults with it are not recognized due to a general lack of awareness. We consider the possibility of HPP when a common blood test called alkaline phosphatase is unusually low. The diagnosis is confirmed by the finding of a high level of vitamin B6, which is normally broken down by alkaline phosphatase. When the diagnosis remains uncertain, genetic testing may be helpful. The treatment of HPP involves avoidance of medications that might be harmful.

For adults with childhood onset HPP who have recurrent fractures and poor bone healing, there is a newly approved medication called asfotase alfa (brand name: Strensiq) that replaces the missing enzyme. This is given as an injection several times each week.

Another rare disease with a new treatment is hypoparathyroidism, which most often occurs as a complication of surgery for primary hyperparathyroidism or thyroid cancer. This disease causes low blood calcium levels, which is usually treated with high doses of calcium and active forms of vitamin D. The problem with this conventional treatment is poor control of calcium in some patients; for other patients, their treatment may be complicated by kidney stones, kidney failure, or soft tissue calcification. The new treatment, for patients who are not doing well with calcium and vitamin D alone, is a daily injection of parathyroid hormone (brand name: Natpara). This reduces the need for taking high doses of calcium and vitamin D and may provide better control of blood calcium levels for some patients.

Tumor induced osteomalacia (TIO) is a rare bone disease, usually caused by a small benign tumor, that can be first suspected when a low serum phosphorus is detected. This can cause bone pain, muscle weakness, and fractures that may be mistaken for osteoporosis or even bone cancer. Patients can be cured by removing the responsible tumor.

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# Clinical Research

By participating in a clinical research study you play a more active role in your healthcare. Please call today to see what studies we have available **505-923-3232**.

## Current Available Studies May Include

Cardiovascular	GERD	Hypertension	Migraine	Osteoporosis
Constipation	Gout	IBS	Neuropathy	Overactive bladder
Diabetes	High Cholesterol	Insomnia	Obesity	Pain Syndrome
Fibromyalgia	Hot Flashes	Low Testosterone	Osteoarthritis	Vaginal Dryness

## Chronic Low Back Pain

This is a trial for patients who have had chronic low back pain for at least 3 months. If you have back pain below your ribs, you may be eligible to participate if you:

- Are 18 years or older
- Have a history of inadequate treatment response to medication

*Pfizer A4091059*

## Complex Regional Pain Syndrome

This is a study for patients that have a diagnosis of Complex Regional Pain Syndrome in an upper or lower limb. You may be eligible to participate in this study if you:

- Are 18 years or older
- Have a history of a traumatic event inciting CRPS symptoms

*Axsome AXS02-301*

## Diabetic Kidney Disease

This is a study for patients with diabetic kidney disease. If you have high diabetic urine proteins or have an eye condition due to diabetes, you may be eligible to participate if you:

- Are 18 years or older
- Have a history of Type 2 Diabetes

*Bayer 17530-T2D-DKD*

## Fibromyalgia

This is a clinical trial for patients who have pain associated with Fibromyalgia. This study is to evaluate the safety and efficacy of the study drug. You may be eligible to participate if you:

- Are 18 years or older
- Have experienced similar pain symptoms for at least 3 months

*DS-E310 FM*

## Are you interested in participating in a research study?

Our clinical research program is recruiting patients to participate in studies to test new medications and evaluate new uses for currently available drugs. By participating in a study you will have the opportunity to use one of these medications, have free examinations and tests, and receive reimbursement for your time and travel. If this interests you, please take a few minutes to read the major criteria for participation.

*If you think you may qualify for a study or are interested in participating in a research study, call a study specialist at (505) 923-3232.*

Feel free to pass this newsletter to a friend or relative who may be interested. The drug study information is updated often, since we are continually starting new studies and closing existing studies. Call and give your information to a study specialist for consideration for future studies. If there is nothing for you now, there may be one soon.

# ☀️ Summertime ☀️

Summer is here and with it comes the heat and the dryness and possibility of over heating and dehydration. These are some of the things that we can do to stay healthy.

1. Use sunscreen
2. Wear long sleeves and hat when out in the sun.
3. Drink plenty of fluids, especially water.
4. Due to recent wildfires, stay indoors if you have asthma or other lung problems.
5. Avoid sitting in a hot car unless the air conditioner is on.
6. If you are travelling, remember to take your medications with you.
7. Stay cool and out of the hot sun as much as possible.
8. Eat your fruits and vegetables now that they are fresh and inexpensive.

## **Osteoporosis Foundation of New Mexico (OFNM)**

### **Educational Presentations (NEW LOCATION)**

OFNM Office and Meeting Room  
Courtyard @ Monroe  
4600 B Montgomery Blvd NE  
Suite B-200  
Albuquerque, NM 87109

(This is on Monroe, 1 block south  
of Montgomery, in the last  
building on the right)

RSVP to 505.854.3956

#### **2016 Meetings**

(All are 1:30-3:00 PM)

**August 11, 2016**

**E. Michael Lewiecki, MD**

*“New Concepts for Treating Osteoporosis”*

**November 10, 2016**

**George Fraser, PT**

*“Exercise Smart with Osteoporosis”*

These meetings are open to the public. It is a great opportunity to talk to osteoporosis experts for as long as you want. There is limited space, so please sign up by calling 275-8731 in order to attend. A \$1 contribution is requested in order to cover the cost of educational material. You may donate more if you wish.



If you enjoyed this newsletter and would like to be placed on an electronic mailing list, email [ybrusuelas@nmbonecare.com](mailto:ybrusuelas@nmbonecare.com).

[www.ofnm.org](http://www.ofnm.org)

**Ask Dr. Mike Lewiecki about . . . OSTEOPOROSIS**

**Dear Dr. Lewiecki – I have been taking medication for osteoporosis for the past 2 years. My most recent bone density test showed a large loss of bone. I am very worried that I am now worse than when I started. Have I wasted 2 years of treatment? What should I do?**

**Rosalie P., Los Alamos, NM.**

Dear Rosalie – One of the most common reasons for referrals to us is bone loss on treatment, as may be the case with you. There is process for checking this out.

The first step is to verify that your bone loss is real and not just a measurement error or a mistaken interpretation of the results. Unfortunately, this is a common occurrence. We see many patients who turn out not to be “bone losers” when this is investigated. How can you recognize when you have had a good quality bone density test that is likely to be correct? One way is to check whether the facility follows “DXA Best Practices.” This is a recent publication with guidance from the International Society for Clinical Densitometry. You can download and print this for no

cost by going to [www.iscd.org](http://www.iscd.org). This includes recommendations for training, certification, and facility accreditation. The intention is to help DXA facilities achieve high quality in their measurements, and you can use the same information to better inform yourself on the quality of the staff and the facility.

In your case, you want to be sure that the bones that were compared are truly comparable, that the measurements were reliable, and that the “least significant change” is known, allowing a high level of confidence in distinguishing a trivial change from one that is clinically meaningful. If it is decided that you have really lost bone despite treatment, then you need a thorough evaluation to find out if you are on the right medication, taking it correctly, absorbing it well, and do not have any other disease or conditions that might be interfering with the expected benefits of treatment. Depending on the results, your plan of treatment may need to be revised to better treat your osteoporosis.

**Mike Lewiecki**

*From the editor: If you have a question for Dr. Lewiecki, please send it by mail to the address on the front page of this newsletter or by email to [mlewiecki@nmbonecare.com](mailto:mlewiecki@nmbonecare.com). It is not possible to respond to all questions submitted, but those that are of general interest will be considered for publication.*

**OSTEOPOROSIS MYTHBUSTERS**

**Myth:** Don’t bend or twist or lift anything heavy if you have osteoporosis.

**Background:** Some patients with osteoporosis are told to avoid bending, twisting, or lifting heavy objects for fear of causing a fracture. This is well-meaning advice that is given with the very best intentions, but is difficult or impossible in real life.

**Fact:** Physical inactivity is exactly the wrong approach for managing osteoporosis. Regular weight-bearing and muscle strengthening exercise is highly recommended by the National Osteoporosis Foundation (NOF). Walking is terrific exercise for most of us, and lifting light weights is good as well. Avoid extreme flexion of the spine (bending forward) and emphasize spine extensions (arching your back) to strengthen your back muscles. Yoga and Tai-Chi are good ways to improve your core strength and balance, but take care to find a teacher who is knowledgeable about osteoporosis; if you take a class, try to find one with people a lot like you.

**To learn more:** The NOF website at [www.nof.org](http://www.nof.org) is an excellent source of reliable information. For detailed testing of your exercise potential and physical limitations with exercise, see a good physical therapist.



**Support osteoporosis education in New Mexico. Help to reduce the burden of osteoporotic fractures. Osteoporosis Foundation of New Mexico is a local non-profit 501(c)(3) foundation. Consider a tax-deductible donation or bequest. Donations may be mailed to Osteoporosis Foundation of New Mexico at 300 Oak St. NE, Albuquerque, NM 87106. [www.ofnm.org](http://www.ofnm.org) For more information, call Yvonne Brusuelas at 505-855-5627.**