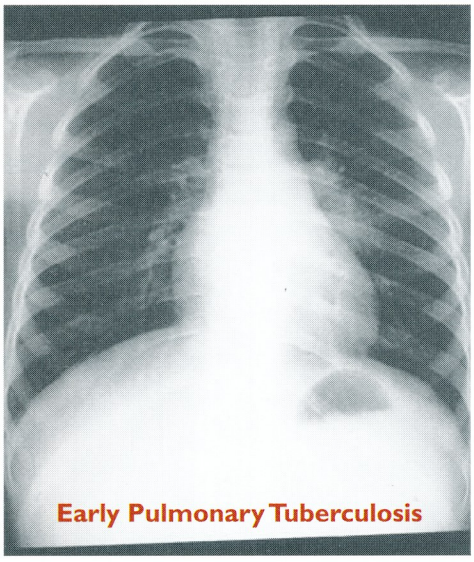
THE
Arthritis Research
NEWSLETTER
JULY 2001

SOME RESEARCH NOTES FROM THE DIRECTOR

For people with arthritis, having arthritis is more than just having joint problems. It alters many aspects of life in ways that are hard to understand for people who don't have arthritis. Some of the research that we will be reporting at the 2001 meeting of the American College of Rheumatology (ACR) annual meeting this November addresses these hidden differences. Here are some of the results of the 20 research presentations we have submitted to the ACR meeting.

Work limitation and income.

We have used your answers to several questions about your work ability and income to show that people with arthritis who work are still different from persons without arthritis. Employed persons with arthritis or fibromyalgia who are limited in half the usual work activities earn, on average, $12,500 less than persons without arthritis. By the way, the average cost of arthritis medications last year was $3,400.



Early Pulmonary Tuberculosis

Tuberculosis anyone?

Over the last year many of you have received calls from us regarding whether you had ever had tuberculosis (TB). Although this may seem a strange interest, it turns out to be important, here's why. With the release of the newer arthritis drugs, reports of TB cases have been filtering in. There has been some concern as to whether drugs that alter the body's immunity might also alter its response to infection. But there is no information available at all about TB, arthritis and arthritis drugs. Shouldn't we expect that people with illnesses like rheumatoid arthritis (disturbed immunity and steroid use) might be at increased risk for TB and similar illnesses? After analyzing your questionnaires and speaking to many of you to get additional details, we found that there is no increased risk of tuberculosis at all. For every 100,000 persons with RA, 6.3 will develop TB each year compared to 6.8 without RA. With this information, we can now see if the newer anti-TNF drugs are associated with an increased risk of TB. Stand by, we should be able to answer that question in the next year or two, and that's an important question for everyone.

Diagnosing fibromyalgia.

We have found an additional way to improve the diagnosis of fibromyalgia by understanding just which regions people have pain in. We will be presenting those data at the ACR meeting, as well.

And...

Among the other presentations we will be making are some about the value of x-rays, living longer with arthritis, the lifetime costs of having arthritis, which drugs lead to a longer and which to a shorter lifespan, how insurance companies should not judge response to arthritis treatment, whether the newer nonsteroidal anti-inflammatory agents (NSAIDS) cause side effects, and what questions doctors should ask to best predict arthritis outcome.

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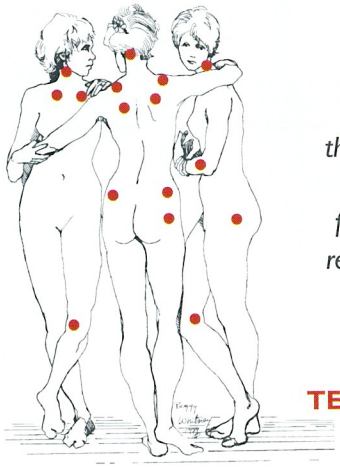

The original figure of the American College of Rheumatology Criteria for Fibromyalgia. It was redrawn from a painting hanging in the Louvre Museum in Paris.

TENDER POINTS

About this questionnaire.

It's hard to thank you enough for all of your help with the questionnaires. So, we have been listening hard to your comments, and have tried to make the questionnaires easier and better. Here's what we have done this time: 1) Eliminated all of the "lifetime" questions, and 2) Eliminated separate supplements unless we are missing data. As long as you don't miss a questionnaire, you won't see those dated questions again. If you do, we may have to catch up some. Overall, the new questionnaire should be completed in about 40% less time.

We have also been working to develop an e-mail or Web-based version of the questionnaire. We are not quite there yet. Some of the important problems not yet solved include protecting your privacy at the same time that we speed up the whole electronic process of getting your replies. We'll try again in January.

By the way, privacy … I think we can never state it enough times. Everything you tell us is confidential. We will NEVER share any information that can identify you with anyone.

We appreciate your feedback too. If you have any comments on the newsletter or the questionnaire please do not hesitate to contact us. Our contact information is on the back page of this newsletter.

WIN $1000

Return your research questionnaire within two weeks of receiving it and be eligible for one of three $1,000 awards. The research data bank can best contribute to research when the mailed questions are complete and returned as soon as possible. All persons who complete the questionnaire within two weeks of receiving it will be eligible for the drawing for the award - given as a token of our gratitude in help with arthritis research. **The winners from the last questionnaire were Elizabeth Hedge, Newton, KS; Ann Ingram, Flower Mound, TX; and Margaret Ward, Natchez, MS. Our congratulations to these winners!**

A PROMISING NEW OSTEOPOROSIS DRUG MAY HELP BONE GROWTH

Osteoporosis is a serious health problem. It affects more than 12 million Americans, causing bones (osteo) to lose mass and become porous (porosis). The result: fractures and falls that can incapacitate. People with arthritis and related conditions can be at special risk, from the disease itself, or from drugs taken over many years.

Up to now, there have only been treatments to slow bone loss. Now an experimental drug promises to be the first to actually grow new bone. It's most likely to help women with severe osteoporosis – and it's a "natural" remedy. To be called Forteo, it's a whole new class of drug – a synthetic substance identical to the parathyroid hormone made by our bodies to contribute to bone formation.

A study published in the New England Journal of Medicine in May looked at more than 1,600 postmenopausal women who had already had one or more spine fractures related to osteoporosis. The women who had daily injections of parathyroid hormone had significant new bone growth – and reduced their risk of fractures by between 53 and 90 percent.

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Women in the two-year trial averaged age 69, and were from 17 countries. Divided into three groups, one third got an inactive substance, one-third a 20 microgram dose of parathyroid hormone and one-third a 40 microgram dose. All got daily calcium and vitamin D supplements.

Those getting parathyroid hormone had increases in bone mineral density of between 3 and 9 percent –

and 65 percent less risk of any new spine fracture, 90 percent less risk of moderate to severe spine fractures, and 53 percent less risk of fractures elsewhere in the body such as the wrist, hip or ribs. They also reported less new or worsening back pain than those taking placebo. Eli Lilly, which makes the drug, has applied for FDA approvals, and wants to have it on the market within the year.

NEW HELP FOR MANY WITH ARTHRITIS

It used to be that osteoporosis was regarded as a disease of frail little old ladies. Now we know it's an equal-opportunity disease, attacking men and women at young ages as well – and that arthritis and related conditions are among the many factors contributing to bone loss.

In people with an inflammatory kind of arthritis – such as rheumatoid arthritis, juvenile RA, lupus or ankylosing spondylitis – the inflammation itself produces substances than can cause bone loss. And, ironically, the cortisone-type drugs used to treat the inflammation can accelerate bone loss over time. The pain of fibromyalgia and arthritis can interfere with exercising or eating well, which undermines bone health.

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Other contributors to bone loss: smoking; heavy alcohol use; early menopause; being underweight; and a family history of osteoporosis.

The current treatment is a combination of drugs and lifestyle changes. Drugs that help slow or prevent bone breakdown include estrogen replacements; alendronate (Fosamax); calcitonin in a nasal spray (Miacalcin) or injection (Calcimar, Miacalcin); and raloxifene hydrochloride (Evista). Risedronate sodium (Actonel) is used especially for cortisone-caused osteoporosis.

Calcium and Vitamin D supplements are essential to bone health. Recommended daily doses are about 1,200 mg of calcium, and 200-600 international units of Vitamin D. Weight-bearing exercise – including lifting weights – have also been shown to keep bones strong, and some forms of exercise such as Tai Chi also improve balance and help prevent falls.

Who is at special risk for Osteoporosis?

- ✓ People with inflammatory arthritis
- ✓ Those taking certain drugs including glucocorticoids, anti-convulsants and heparin (warfarin)
- ✓ Post-menopausal women, especially those of Asian or Caucasian heritage
- ✓ Men with lower levels of testosterone
- ✓ Smokers and those who have more than two alcoholic drinks a day
- ✓ People who don't exercise regularly
- ✓ People whose diets are low in calcium

News from the NDB Staff

Welcome to Summer 2001! We appreciate all the time and effort you put into making our work successful. Since we spend so much time getting to know you, we thought you would enjoy getting to know *us* for a change.

Am I Just Talking to Another Machine? This is a question frequently asked by study participants. The answer is ***NO***. As a matter of fact, behind all those recorded messages and pages of questionnaires there are *real* people who work hard to process your

information. Let's introduce you to two of our real people who are likely to call you or to reply to your phone messages:

Linda is the lead person in our communications department. She is married and has two grown children and three grandchildren. At home, she enjoys gardening, bowling, and caring for her German Shepherd and one cat. Linda has a special connection with some of the people who call because both of her parents suffer from Rheumatoid Arthritis.

Linda enjoys her work at the NDB because she feels she is helping people and wants to hear how each person is doing. She says "I enjoy talking to people on the phone. They are funny, they are interesting, and they have a lot of good information." Frequently we can tell when Linda is working with a participant on the phone. Her laughter and smile brighten the whole office.

Beverly is another real person in our communications department. She balances college with caring for a husband and two small children. Bev plans to graduate in December with a degree in psychology. She enjoys camping, fishing, and going to movies with her family. In her spare time, she enjoys reading and writing stories.

Bev says "I enjoy talking to the people in the study every day because they are so courageous and friendly." She would like everyone to know that taking time to fill out a questionnaire is important and that it really does make a difference in our efforts to improve treatment for arthritis and fibromyalgia.

So, why are phone calls necessary anyway? There are 5 main reasons we call people.

1) Telephone Questionnaires (Telequests): Some people have problems with their eyesight, holding onto a pen, or some other problem that makes filling out a questionnaire difficult. In these circumstances, we set up an appointment, and then ask the questions over the telephone. If time is short, or someone tires easily, we divide the questionnaire into two parts, and call a 2nd time a few days later. This past six months we completed over 250 questionnaires by telephone !

2) Data Clarification: Sometimes we need additional information on certain items. For example, in the past few months, we have called many of you to clarify whether you had TB or had a positive skin test for TB, but did not have the disease. Results from this additional information are expected to be included in research articles published this year.

3) Missing information: When critical information is missing we need to call. For example, if someone tells us she was in the hospital for a side effect to a medication, but does not include the name of the hospital, we will call to find out. We need the name of the hospital to track down additional details.

4) Validation: Occasionally, boxes are checked in error. During each 6 month period we select certain questions to review. We call people who have answered those questions to determine that their answers are correct. If we find a high rate of error, we consider changing the questionnaire to make it easier to understand.

5) Participant information: Particular questions and special mailing requests are easier to handle over the telephone. Sometimes there are complaints or an issue that is brought to our attention. We always try to take the time to personally call to make sure there is no misunderstanding and find out what we can do to help.

Each of these phone calls is important to insure the quality of our data. We always enjoy talking to you, but before we call we work very hard to make sure we cannot find the information another way. It is our commitment to protect and respect the privacy of our participants.

FOR MORE INFORMATION OR TO PARTICIPATE

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