

## Notes from the Director

Frederick Wolfe, MD

### The Weight Problem

Most people have at least a little concern about their weight. According to some pretty big national surveys about 65% of us are overweight or obese, of which 30% are obese and 5% are extremely obese, and 2% are underweight. Stated differently, only about 33% of the US population has a normal weight. From your answers to NDB questionnaires it appears that 33% of NDB participants have a normal weight.

How do researchers know what normal weight is? A simple measure that is very widely used is called the body mass index, or BMI. The idea is simple: There is a constant relationship between your height and weight — taller people are heavier, shorter people are lighter. The normal range for BMI is between 18.5 and 25. Set by a US committee of experts, it has been confirmed and used by the World Health Organization (WHO). No matter your height, if you have a normal BMI then you have a normal weight. If you want to calculate your own BMI, go to the Web and find [www.nhlbisupport.com/bmi/bminojs.htm](http://www.nhlbisupport.com/bmi/bminojs.htm). This is the website of the National Institutes of Health.

BMI isn't really the best way to measure weight. The same weight can mean different things depending upon whether the pounds come from muscle or fat. But BMI works well enough: It's easy to measure height and weight, and really difficult to determine the amount of fat and muscle. Another problem with BMI is that height decreases as we age. This happens because the discs in our spine shrink, and sometimes we lose bone in our vertebrae (we become little old men and little old ladies). Your BMI will increase with age even if you maintain the same weight you had when you were 30

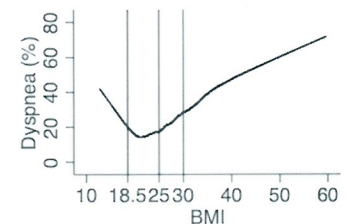
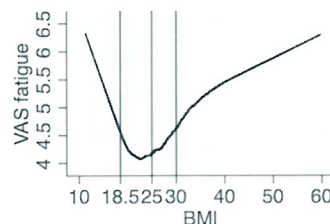
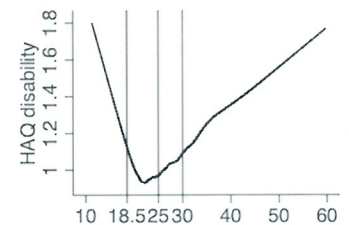
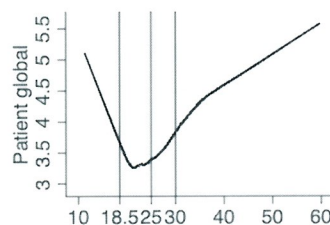
years old. It seems a little crazy, but you can become "overweight" even if your weight doesn't change.

When we ask people on questionnaires what their height and weight is, heavier people tend to under-report their true weight and thinner people to over-report. No surprise, just a little wishful thinking that we all do. And we all tend to over-report our height because most of our height measurements were obtained when we were young, before we started shrinking. All of these "errors" cause problems for NDB statisticians and statisticians everywhere, so methods have been developed to "correct" for these reporting errors.

***"NDB participants with a normal BMI are healthier and feel better overall."***

It might be fair to ask here, "How does this apply to arthritis?" What do we need BMI for? Well, people with the best BMI feel best, and this is true of NDB participants also. In the graphs below, the left part of

each graph shows what we are measuring: overall disease severity ("Patient global"), functional problems ("HAQ disability"), fatigue ("VAS fatigue") and trouble breathing ("dyspnea"). The scale under each graph is the BMI. BMIs



## Notes from the Director — continued

below 18.5 indicate underweight, between 18.5 and 25 indicate normal weight, between 25 and 30 overweight, and over 30 means obese.

As you can see, global severity increases when it leaves the normal BMI range, as do functional problems, sleep problems, and the percent of people with significant breathing problems. From the global graph you can see that NDB participants with a normal BMI feel better overall than those in the outside of the normal BMI range. Another important aspect of BMI comes from NDB data on diabetes and high blood pressure. The higher your BMI, the more likely you are to develop diabetes, high blood pressure, or both.



While it's good to have a normal BMI, you should remember that differences in the levels of symptoms, such as global or fatigue, aren't really much different for BMIs between 18.5 and 30. It's good if you have a "normal" BMI. But it isn't the end of the world if you can't.

## Upcoming research

In research that will be presented at the American College of Rheumatology annual meeting this fall, we used your data to investigate the relationship between a rheumatic disease treatment and reducing the risk of heart attacks. We have to wait until November when the research will be presented to tell you the names of the treatments, but it looks like we may be on to something important here. We also will be presenting data on BMI.

## Meet the Participants — Cheryl Kuykendall

When we can, we like to introduce participants to others like themselves who participate in NDB research. If you would like to share a bit about yourself, please contact the NDB.

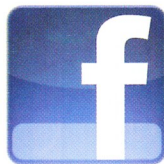
Cheryl Kuykendall is a long-time NDB participant from Amite, LA. Her story with RA starts at age 17, but other medical problems, namely polio, dominated her life up to that point. Polio kept her paralyzed from the neck down and in an iron lung so she could breathe. In fact, it wasn't until she was 17 that she learned to walk.

Cheryl found that she was naturally interested in science, which she attributes to a long line of academics on her grandmother's side of the family. Her grandmother graduated from Stanford University in mathematics at a time when women did not go to college. Also remarkably, her great grandmother was a

professor of physics and her great grandfather a professor of chemistry, both emigrated from Germany.

Cheryl, herself, became a chemist working first for industry and later for the Environmental Protection Agency as an educator teaching industry how to safely use and dispose of chemicals. To work in that men's world, she first had to go through school as the only woman in her science classes, and then prove herself on the job. As she put it, back then in the field, "You'd have to be fifty times better [than a man] to be thought of as half as good."

All her years of physical struggle have left Cheryl with few RA treatments that help. She's limited in what she can take by chemical allergies. Additionally, she is unable now to work. Although she would rather be employed and using her mind, Cheryl spends her time working around the yard and going to church. A deeply religious person, she credits faith and prayer with helping her endure. That, and a get tough attitude with herself: "Stop sitting on your can. Do what you can!"



### Join Us On Facebook

You can find us on Facebook as "National Data Bank for Rheumatic Diseases." We will try to keep you up to date with any news items that occur between questionnaires. You can also connect with other participants and NDB staff who have joined our group.

# LATEST RESEARCH

Last year we reported that people with RA lose functional ability at a slower rate over time. The slowing is most likely because RA treatments are getting better. Now we've followed up on that with a new report on how RA progresses.

We looked at 18,485 people with RA who participated in the NDB for up to 11 years (3.7 average) from our ongoing research. The study divided RA patients into two main groups: moderate/severe RA and less severe RA. We then looked at how their functional level changed over time. We monitor this with a series of questions that asks about what physical things you are able to do, and if you have any difficulty doing them.

We also tried to account for other conditions that may affect function, such as other diseases, age and type of treatment.

The results show that age and other concurrent diseases you may have affect function the most. We found little difference in the effects of various biologic treatments. Taking biologics has a big role in preserving function, but the differences between the effectiveness of particular medications don't show up in the study group as a whole. (However, individuals often notice that some biologics work for them and some don't.)

## *New fibromyalgia criteria confirmed*

A new study by Prof. Kusuki Nishioka, MD & PhD (Professor of Medicine, Director & Chairman Institute of Medical Science, Tokyo Medical University) concluded that the Japanese version of the new American College of Rheumatology fibromyalgia criteria "have high reliability and validity, and are useful for assessing fibromyalgia among Japanese chronic pain populations." You can read more about the criteria on our website at [www.arthritis-research.org/research/fibromyalgia-criteria](http://www.arthritis-research.org/research/fibromyalgia-criteria).

## *More on the Hawthorne Effect*

In the last issue we reported on the Hawthorne Effect. The Hawthorne Effect was originally noticed in an industrial setting when workers who were singled out and made to feel important increased their productivity. The definition has been expanded to treatment response in medical settings. In a clinical trial, the Hawthorne effect may be defined as extra improvement caused by increased attention to participants during the clinical trial.

Visit our website to see NDB researcher Kaleb Michaud discuss the effect in a short video. <http://www.arthritis-research.org/news/kaleb-michaud-discusses-hawthorne-effect>. You can find the link in the news section on the home page of the NDB website.

## *View your NDB results online*

Many of the questions we ask every six months give researchers and doctors scores that show how you're doing. We have heard from many of you that you want to see your results. You can now get these scores any time you need them on our website. If you don't already have an account on our website, start on this page: [www.arthritis-research.org/user/register](http://www.arthritis-research.org/user/register). Having an account helps protect your privacy and lets you access your scores.

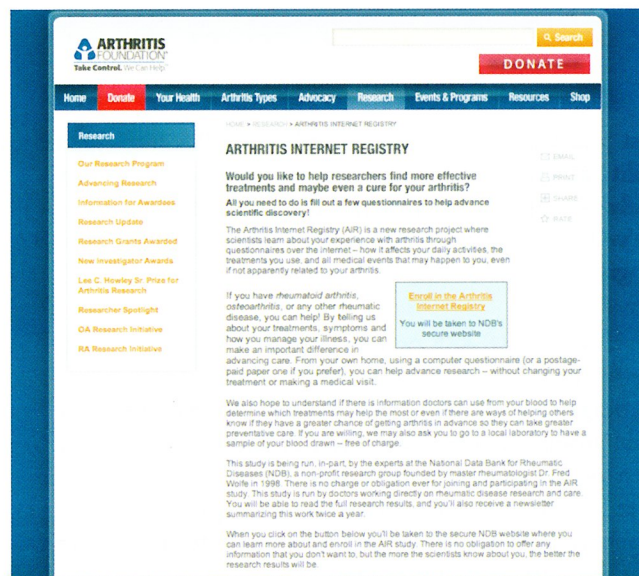
You will be able to see scores for every questionnaire you've ever completed for the NDB, and print them for your own information or to show to your doctor. Please email us at [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org) if you have any questions about the website or your scores.



# AIR turns 1 year old

One year ago with the help of the Arthritis Foundation we began to recruit patients with rheumatic diseases into the Arthritis Internet Registry (AIR). After one year we're about to enroll our 1000th participant! We are also updating and modifying our online questionnaires to be smarter and shorter. We will soon begin testing ideas to both improve the quality of our research and help you better manage your health. This will include creating an online medication diary, use of very short questionnaires (1 to 5 questions) that can be answered online or with your phone during flares or important medical events, and an online login system where you can see how your health changes over time.

The other important and completely optional aspect of AIR is the collection of a blood sample from a local Quest Diagnostics laboratory site. Combining blood tests with results from our questionnaires, we hope to discover biological reasons for why some treatments work better and some are more toxic to an individual.



So far this has only been offered to participants in AIR, but now we'd like to open this up to all NDB participants. If you are interested in donating a blood sample, please contact Kimberly Harp by email at [kim@arthritis-research.org](mailto:kim@arthritis-research.org) or by phone at 1-800-323-5871 ext. 143.



## Our website for rheumatology questions, [RheumMD.org](http://RheumMD.org)

On RheumMD.org we've brought together more than 20 volunteer experts to answer your questions about any rheumatic condition. You can also search existing questions and engage the doctors in discussions about the answers.

Here are some questions we've had on the site lately:

- How safe is prednisone if you have a history of glaucoma and cataracts?
- How does a TENS unit help fibromyalgia?
- What effects do RA medications have on healing fractures?

There are many more questions, and we invite you to ask your own at <http://RheumMD.org>.

## Support rheumatic disease research with a financial donation

As a non-profit project conducting ongoing research to improve conditions for people with arthritis, fibromyalgia, lupus and other conditions, the NDB is an organization with ongoing financial needs.

If you would like to make a tax-deductible monetary donation to the NDB to help support this research, we would be very appreciative of your support.

If you would like to make your donation in memory of or in honor of someone please let us know. We will send a card to the person of your choice to acknowledge your gift.

Donations should be payable to:

The Arthritis Research Center Foundation Inc.  
and sent to:

The Arthritis Research Center Foundation Inc.  
1035 N Emporia Ste 288  
Wichita, KS 67214

For more information please contact Rebecca Schumacher at 1-800-323-5871, ext. 119.

Thank you very much for considering a donation to support this important research.

## Welcome New Participants!

Everyone who works for the NDB and all of the doctors and researchers who benefit from our research are extremely grateful for the dedication of you, the participants, to helping this project. Many of you have been with us for several years or more. But every 6 months we are also glad to see many new people join us. Here is a quick primer on the NDB for the new and a refresher for the old timers.

The NDB is a non-profit organization that performs research in rheumatoid arthritis, osteoarthritis, fibromyalgia, lupus and other rheumatic diseases. The research is designed to improve the treatment and outcomes of these conditions.

The NDB is an independent organization that conducts its own research without influence from pharmaceutical, insurance, financial or other outside interests. Our research is so well respected that we are often hired to provide independent drug safety verification to the government.

Your personal information will always remain private. We do not sell or share any identifying information about NDB participants. Before we work with researchers or collaborate with other research groups

we remove any of your answers that could be used to identify you.

Nearly all of our research is available for you to read on our website.

We are glad to answer your general questions about rheumatic diseases and treatments, but we are not able to give personal medical advice.

NDB research is different in an important way: Participants report on themselves; data is not collected by doctors or medical staff. With patient-reported data, researchers get a perspective that short, small clinical trials cannot provide. Our long-term study offers a much broader view of treatment and results. Clinical trials are good at identifying common side effects, but rare or subtle problems, or problems that take longer to develop, are better detected by studies like the NDB. The same is true of long-term effectiveness of a treatment.

So, welcome to the NDB, or thanks again for your continuing participation! If you ever have any questions or need help with your questionnaire, feel free to contact us.

### FOR MORE INFORMATION OR TO PARTICIPATE

Arthritis Research  
Center Foundation, Inc.

1035 N. Emporia  
Suite 288  
Wichita, KS 67214

Director:  
Frederick Wolfe, MD

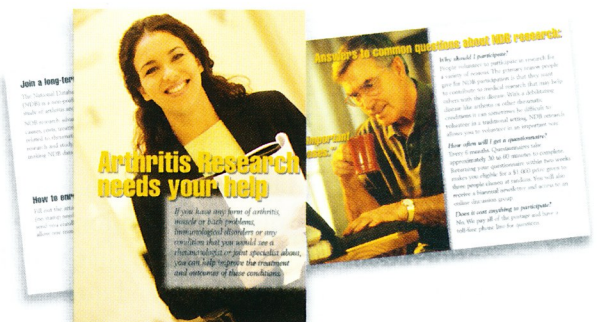
Executive Director:  
Rebecca Schumacher

Please call 1-800-323-5871  
ext. 140 or email  
info@arthritis-research.org

## Helping the NDB in other ways

Achieving the NDB's goals of telling the rheumatology community about patient experience depends on a large group of participants. Here are a couple of ways you can help.

Now available for your support group or arthritis, fibromyalgia or lupus meetings: Our pamphlets explain what we do and how you can help. Each one has a postage-paid postcard to request more information or an enrollment form to join the project. The pamphlets and a small table-top stand are available free from the NDB. Just contact us at info@arthritis-research.org or 800-323-5871 ext. 133 or 140. Thank you!





## *Refer a Friend*

Here's a really easy way to let a friend know about the NDB. Just give us your friend's email address and we'll send out an email invitation to join the study. Go to <http://www.arthritis-research.org/participate/tell-friend>.

## *Lottery Winners!*

The research data bank can best contribute to research when the questionnaires are completed and returned as soon as possible. We conduct the lottery as a token of our gratitude in help with rheumatology research.

The \$1,000 winners from the last questionnaire were Laura Isaacs, Decatur IL and Debby Fuller, Richmond VA. Winning smaller amounts were Diana Stanley, Parachute CO; Suzanne Guzman, Lakewood CA; Patricia Maniaci, Chesterfield MI; Hermalinda Hernandez, Mesquite TX; Aileen Schroffner, Honolulu HI; Kathleen Conway, Tamaqua PA. Congratulations to all!

## *WebQuest*

WebQuest is the online version of our questionnaire. The questions are the same as what you get on the paper questionnaire. People who are comfortable using computers should find it easier than the paper version. If you would like to try it, follow the links from our home page, [www.arthritis-research.org](http://www.arthritis-research.org) and make the request, or send us an email at [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org).



## *Reminders*

While working on your questionnaire, if you have ANY questions about the questionnaire, please contact us right away by email or phone. These might be about technical difficulties or how to interpret a question. If you put your immediate questions in the comments section we probably won't see it in time to answer.

Please use the comments section for any information you think we should have that isn't covered in the questionnaire. This could be about a change in medication that needs explanation or information about other considerations of your condition that you think we need to know. You may also ask general questions that don't require an immediate answer.



## *Important Information about Email*

For patients using WebQuest, email is our primary method of getting in touch with you. Even if you're not using WebQuest, we'd like to be able to send you important information by email.

We cannot emphasize enough how important it is for you to let us know whenever you change your email address. To update your email address go to our website and look in the participant's links, or call us.

Here's a VERY IMPORTANT step you can take to make sure our email gets to you: Add us to your email address book. Our address is [webquest@arthritis-research.org](mailto:webquest@arthritis-research.org). This will ensure that our mail makes it through the spam blockers. You will need to do this every time you change your email address. Thank you!