

A Special Appeal from the UFS Study Manager

To current, former, and future fibroid sufferers and also to those of you who see your friends and relatives suffer from fibroids:

During the years we were conducting the baseline Uterine Fibroid Study, I was coping with the pain and bleeding from fibroids that were growing inside my own body. I searched for causes and answers from physicians and researchers but there were no answers. Though the therapy I chose helped, I still had questions. As the data from the study interviews came in, I was encouraged that somewhere in our collective wisdom and experience we may find out what causes fibroids.



Many women are seeking advice from their physicians but there is very little information available until studies like this one are complete. Our best answers to chronic health problems come from studies that follow the health of participants for several years.

In this follow-up we are learning about women who have had surgery to treat their fibroids and the symptoms they had to cope with before their surgeries. Just as importantly, we are learning about women who have no symptoms even though they have fibroids, and women who haven't yet developed fibroids. We need to figure out what protects some women.

We would really like to know what we could do to encourage your participation in the follow-up interview. We have a wonderful staff of professional interviewers and supervisors that have been trying hard to contact you. I am personally looking forward to hearing from you.

Please call us at the toll free number 1-800-948-7552, extension 327. We really want to hear your comments and questions about fibroids and participating in the follow-up studies.

Thanks so much.

Sincerely,

Glenn Heartwell, MPH

WHAT'S GOING ON WITH THE UTERINE FIBROID STUDY?

We are currently interviewing for **Follow-Up 2001**. We are following those of you who were premenopausal when you participated in the baseline Uterine Fibroid Study (UFS) between 1995 and 1999. We want to know who has stayed free of fibroids, and see what has happened to those with fibroids.

- 935 of the 1229 premenopausal women have already completed the 25 to 30 minute telephone interview.
- This is the chance to have your health experiences affect information used by physicians and other scientists to make decisions about women's health.

Thanks to all of you who have participated so far!

Why do we need to follow-up everyone?

- We need to reach all of the 1229 targeted participants to get an accurate picture of the effect of fibroids on women and their health. You are considered a participant if you completed a baseline telephone interview and were found to be premenopausal at that time.
- We do not want to bias our results by only including the health effects of some women and not others. This is important regardless of whether or not you have fibroids.

If you received a letter about follow-up 2001 and we haven't been able to reach you, please help us. Maybe we have the wrong phone number for you. Maybe you didn't know who we were when we called. Maybe you received our phone messages and have been too busy to call us back. If for some reason we have missed you, please call **us** as soon as possible. The toll-free number is: 1-800-948-7552, extension 327. Give us your contact information and the best time to reach you and we'll get back to you right away.



- Glenn and several other interviewers have been successfully treated for fibroids and are doing very well.

HATS OFF to all the staff who continue to make the study successful!



REFERENCES FOR PUBLICATIONS BASED ON UTERINE FIBROID STUDY DATA

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- ◆ Dunson, D.B. and Baird, D.D. (2001). A Flexible Parametric Model for Combining Current Status and Age at First Diagnosis Data. *Biometrics* 57, 396-403.
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- ◆ Dunson, D.B. and Baird, D.D. (2002). Bayesian Modeling of Incidence and Progression of Disease from Cross-Section Data. *Biometrics*, revision submitted.
- ◆ Newbold, RR, DiAugustine, RP, Risinger, JI, Everitt, JI, Walmer, DK, Parrott, E, and Dixon, D. Advances in Uterine Leiomyoma Research: Conference Overview, Summary, and Future Research Recommendations. *Environ Health Perspec*, 2000: 108:769-773.
- ◆ Vines, A.I., McNeilly, M.D., Stevens, S., Hertz-Picciotto, I., Bohlig, M., Baird, D.D. Development and Reliability of a Telephone-Administered Perceived Racism Scale (TPRS): a Tool for Epidemiological Use. *Ethnicity and Disease*, 2001; 11: 251-262.
- ◆ Vines, A.I., Baird, D.D., Hertz-Picciotto, I. (2002). Perceptions and Responses to Racism among Black Women: The Results of the Telephone-Administered Perceived Racism Scale. *American Journal of Public Health*, submitted.

NEW FINDINGS FROM THE UTERINE FIBROID STUDY

Fibroids and Menstruation:

Ganesa Wegienka, a pre-doctoral fellow at NIEHS, is examining menstrual bleeding characteristics and uterine fibroids. Ganesa can't wait to finalize her analysis and let you know her results. They will be part of her doctoral dissertation in epidemiology at the University of North Carolina at Chapel Hill (UNC-CH). Some follow-up 2001 participants may know Ganesa because she also interviewed during the past year.

Here are a few points Ganesa has noted from the baseline interview:

- Fibroids were often diagnosed incidentally. About half the women found out they had fibroids through a routine exam, not because of some problem that was being investigated.
- Fibroids were often asymptomatic. Between 25% and 30% of women who had been previously diagnosed with fibroids had no symptoms.
- The most commonly reported symptoms were pain, cramps, and abdominal heaviness (reported by over 50% of women who had been diagnosed with fibroids).

The Perceptions of Racism Among African American Participants:

In 1999, some of you participated in the Racism Study, a sub-study of African American participants. Results from this study show the following:

- Personal experiences of racism were common: 68% reported being followed while shopping; 38% reported discrimination when applying for a loan; and 41% reported being called insulting names, though for most this happened rarely.
- Current income and education were not associated with perceived racism.
- Higher levels of perceived racism were associated with more daily stress, an increased level of race-consciousness, and the view that racism was an obstacle to achieving professional goals.

- Most participants reported high concern for their children because of racism. The highest concerns were in regard to institutionalized forms of racism such as police harassment (over 70% expressed being very concerned about this). Respondents were less concerned about their children being considered less attractive than their white counterparts or being excluded from social activities because they were black.
- The most common behavioral responses to racism were praying (84%) and working harder to prove others wrong (68%).

With so many experiences of racism and so much concern, it seems like this could really add to women's stress. We want to look at this further in relation to health problems like uterine fibroids, hypertension, obesity, and diabetes.

Anissa Vines, who conducted the racism sub-study, successfully defended her doctoral dissertation in December of 2001 in the Department of Epidemiology at UNC-CH. In April of this year, Dr. Vines will become Associate Director of the UNC-CH Program on Ethnicity, Culture, and Health Outcomes (ECHO), but will also continue to analyze the UFS data regarding racism and health. Congratulations Anissa, and a big thank you to all of you who gave their time and shared their experiences for the racism study!



STUDY STAFF NOTES

In addition to UFS Study Participants, without whom we would have absolutely no study, many other hands are necessary to pull off the daily work that a large field study involves. Most of you are familiar with our Study Manager, Glenn Heartwell, MPH; Senior Study Supervisor and Programmer, Deborah S. Cousins, MSPH; and Study Supervisors, Lynda Tatum; and Susie Covington. Our staff of nine interviewers is exceptional, and we rely on several other gifted staff members to "keep it together."

Incidentally,

- Deborah will be on maternity leave during late spring and early summer. She and her husband are expecting their first child, a boy, in late April.

WHAT'S NEW ON THE NATIONAL FIBROID SCENE?

- The Agency for Healthcare Research and Quality recently put out a report entitled *Management of Uterine Fibroids*. The web site address for this report is: <http://www.ahrq.gov/clinic/utersumm.htm>. The report summarizes the risks and benefits of common medical treatments for fibroids. It states that 7% of white women and as high as 20% of black women have hysterectomies for fibroids by the time they reach age 45. The primary finding of the report was that not enough is known. Here are some quotes from the report:

“Data are insufficient to allow conclusions about the most appropriate therapy for a given symptomatic patient.”

“The current state of the literature does not permit definitive conclusions about benefit or harm.”

- Legislation to address the need may eventually help discover more about fibroids. Congresswoman Stephanie Tubbs Jones (D-OH) introduced legislation several months ago entitled the Uterine Fibroid Research Education Act of 2001. Ms. Jones stated:

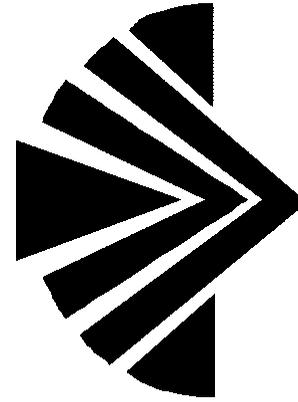
“My bill will increase the spending in fiscal year 2002 to help further existing research into the origins of this condition.”

- A weekly publication that summarizes new scientific findings reported on a study of a rare heritable condition that involves both uterine fibroids and skin tumors (*Science News*, March 9, 2002; 161(10): 149). Researchers found that a particular enzyme, active in the breakdown of food to produce energy, was needed to prevent the fibroids from developing. This may give some hints about the biology that goes amiss in the common form of uterine fibroids. As background, the article talks a little about the NIEHS Uterine Fibroid Study in which you participated.



KEEP IN TOUCH WITH US

We want to keep all UFS study participants informed about the findings from the UFS, but we need your help. If you have moved or changed your telephone number, please call us at our toll-free number, 1-800-948-7552 extension 327, and give us your new contact information.



UTERINE FIBROID STUDY

NEWS

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