1-877-692-SELF (7353)

www.DetroitSELF.org

Spring 2016

Dear SELF Participant,

Happy Spring and thank you for your continued participation in SELF: the Study of Environment, Lifestyle & Fibroids. We have now begun the Follow-Up 3 phase of the study and I appreciate the time and effort you dedicate to participating in SELF. We are hoping that this third and last funded Follow-Up has even higher participation than we saw for the previous Follow-Ups. Together we can do it!

As a reminder, at the conclusion of your 3rd Follow-Up, if you have completed all Follow-Up activities, you will receive an additional \$100 VISA gift card. Even if you have missed a previous Follow-Up, but complete the 3rd Follow-Up, we will be able to give you a smaller bonus gift card.

In this newsletter, we focus on the Zika virus and its effects on pregnant women. We also include study updates and reminders of important upcoming activities.

Thank you for your continued participation.

Sincerely,

Dr. Donna Baird SELF Principal Investigator

Study Update

As of April 30, 2016:

- 1435 (85%) participants have completed all Follow-Up 2 activities.
- 182 (11%) participants have completed Follow-Up 3 activities.
- 96% of all distributed Early Life Questionnaires have been returned. If you did not return one and need another sent to you, please let us know.

Reminders

- SELF will mail you a study kit containing materials you will need for the clinic visit. Please complete all included questionnaires before your scheduled clinic appointment.
- No companions (including children) are allowed at the visit. If you have children, please note that there will be no childcare available, so please make other arrangements.
- Let us know if *any* contact information changes for you or your secondary contacts.
- Visit www.DetroitSELF.org for future study updates and answers to Frequently Asked Questions (FAQS).

Any Questions?

Call us at **1-877-692-SELF** (**7353**) or send an email to *info@DetroitSELF.org*





Sister Sister

Do you have a biological sister also enrolled in SELF?

If you and your sister(s) agree to share this information with SELF, we would really like to know! Please contact us by phone at 1-877-692-SELF (7353) or send an email to info@DetroitSELF.org. We will need your name and the name of your sister(s) who are also enrolled in SELF. Sisters may have similar patterns of fibroid risk and fibroid growth if they develop fibroids. It will be good to take that into account when we try to figure out the factors that influence fibroid development.



Slow Roll Detroit

www.slowroll.bike

Now that Spring has arrived, what better way to enjoy the weather and Detroit's scenic views and neighborhoods, than to take a bicycle ride!

Slow Roll Detroit is Michigan's largest weekly group bike ride with over 3000 riders each week – of all ages, skill levels and every type of bike. The group meets every Monday night in Detroit from April 13th through October 31st, and bikes at a slow pace keeping riders safe and giving everyone the opportunity to enjoy Detroit!

For more information about Slow Roll Detroit visit their website at www.slowroll.bike.



Health in the News!

Zika Virus

According to the Centers for Disease Control, the Zika virus has been known since 1947. It had been considered a minor disease. In rare cases it could cause Guillain-Barre syndrome, an autoimmune disease in which the body attacks its own nerve cells. For those infected currently in the Western hemisphere, it is still usually without symptoms or with only mild symptoms (fever, rash, pink eye, joint pain) that can last a week. However, recently another autoimmune disease, acute disseminated encephalomyelitis (inflammation in the brain and spinal cord that damages the protective covering of nerve fibers) has also been observed in a small number of cases.

The biggest problem seen to date is that the virus can cross the placenta in pregnant women and infect the developing embryo and fetus. Microcephaly (small head usually accompanied by major brain damage) was the first problem seen. Further study showed other brain damage, eye defects, and preterm birth in babies whose mothers were infected. Problems can occur with infection during any of the three trimesters. For pregnant women with infections, there still is no good estimate of the percentage of developing babies who will have problems.

The virus is spread by mosquitoes and active transmission has been seen in 39 countries and U.S. territories (see map). So far, the only cases in the U.S. have been seen in those who have travelled to countries with active mosquito transmission. But with summer approaching, the chance for mosquitos here to pick up the virus increases. The types of mosquitos that carry the virus occur in at least parts of 32 U.S. states, including all the southern states. Luckily for SELF participants, Michigan is just outside of the mosquitos' current range. Pregnant women can also pick up the virus through sexual transmission because the virus can hang out in semen. So, men who become infected can transmit it to their pregnant partners.

For women living outside the mosquito transmission areas who want to become pregnant, the CDC recommends that if they or their partners travel to a Zika-transmission area that they wait at least 8 weeks after possible last exposure to the mosquito before trying to conceive. If the male has experienced symptoms of the virus, the recommendation is to wait at least 6 months after symptom onset. For pregnant women: CDC recommends **no travel to Zika transmission areas**, but if travel is necessary, talk to healthcare providers first, and take measures to prevent mosquito bites during the trip.

Puerto Rico, the Virgin Islands, and American Samoa are in the infected-mosquito areas and have over 350 documented cases including 37 pregnant women. If the mosquitos in the U.S. become infected, we can expect growing infection rates and newborns with Zika-related problems in the U.S.



Areas with Current or Past Zika Infection

Source: CDC, Morbidity and Mortality Weekly Report, March 25, 2016

http://www.cdc.gov/zika/index.html

Tell Us About yourSELF

We would love to hear your story! We can all learn from the experiences of others. Your personal testimony can help encourage participants to remain active with SELF in an effort to learn how to prevent fibroids. Visit the SELF website, and click on the "Share Your Story" tab to share, and for an opportunity to be featured in future newsletters!

Newsletter Suggestions

We want to hear from you! What would you like to see in future SELF newsletters? Submit your ideas and suggestions to *info@DetroitSELF.org*.



What happens after I complete my 3rd Follow-Up visit activities? Is the SELF Study over?

This is the last SELF Follow-Up planned and funded by the National Institute of Environmental Health Sciences. We hope that in the future the study can be extended so we can learn even more. At your 3rd Follow-Up, we will ask if you are interested in finding out about any study extensions that may happen in the future.



RETURN SERVICE REQUESTED

Will I receive final results after the study ends? Will SELF continue to keep in touch with me after I have completed my final clinic visit?



Receiving final results will take some time. We will need to wait until the 3rd Follow-Up phase is complete before we are able address questions about risk and factors associated with fibroid development and growth. We will continue to send newsletters after the 3rd Follow-Up.

LET'S STAY IN TOUCH!

Please call us at 1-877-692-SELF (7353) if your phone numbers, mailing address or email address changes.









What SELF Participants are saying...

- "SELF is a wonderful study for women. It has been very pleasant. Staff was wonderful and welcoming. Explained everything to me. And answered all my questions. Great staff members."
- "The experience have been exceptional."
- "Very pleased with my experience over the years with SELF. I've learned a lot of interesting information."
- "Glad for the opportunity. If my participation can help the future I'm proud to be a part of it."
- "Love being a part of something so great."
- "I appreciated the familiarity of this clinic staff, seeing the same person makes a difference."