



Urinary Incontinence Treatment Network Newsletter Fall/Winter 2009

Congratulations! To date, there are 251 women enrolled in the ValUE Study!

Genetics and Incontinence

By Peggy Norton, MD at U. Utah Hospital

What causes urinary incontinence? And why does one woman develop the problem even though she hasn't had children, while another woman can have a large family without developing incontinence? Although we know that certain risk factors (childbirth, aging) increase the likelihood that a person will develop urinary incontinence, we still do not know the exact cause of urge and stress incontinence. The last decade has seen discoveries of how complex medical conditions can be inherited in part from our parents. Diabetes, Alzheimer's, even obesity are examples of disorders that have been found to be genetic; in other words, these disorders have been found to be due to several genes that make certain people more vulnerable to developing that condition.

Not surprisingly, urinary incontinence may be inherited. Patients may tell their clinicians that the problem "runs in our family," but researchers have believed that these families share a similar environment. An example would be that all children in a family tend to be potty-trained in the same way by their parents. New information from studies of twins suggests that urinary incontinence may be due to environment AND inherited. Researchers compared identical twins (who share all of their genes) with fraternal twins (who share half of their genes) and found that as much as 40% of urinary incontinence is inherited, and 40% is due to our environment.

Other researchers have also looked at whether incontinence runs in families. In a study in the U.S., nuns were compared with their own sisters who had had children, and vaginal birth did not seem to be associated with the development of urinary incontinence in these nuns after menopause. Instead, each nun was more likely to be incontinent if her sister was incontinent. In a large study in Norway, women were more likely to develop urinary incontinence if their mother or older sisters are incontinent.

More recent research is looking at areas on chromosomes that seem different in women who have these problems compared to those who do not. In families where two or more sisters have had surgery for pelvic organ prolapse, there is an area of chromosome 9 that is different in over half of the families studied. Since two-thirds of these women had also had surgery for stress urinary incontinence, we hope that a closer look at this area of chromosome 9 may help us understand why some women develop incontinence and prolapse, and others do not.

Based on many studies that have looked at this question from different directions, there *are* families with an increased risk for developing urinary incontinence and

other pelvic floor disorders. We don't know the mechanism yet, but we expect to find that abnormalities in genes contributing to urinary incontinence may be responsible for muscles, connective tissue, or nerves. The old saying "blame your mother, warn your daughter" may have a kernel of truth, but we need much more research to know what that risk is, and who is at risk. At some point, we may be able to use the information to help prevent urinary incontinence in future generations.

New Study! Biospecimen Repository

By Toby Chai, MD at U. Maryland

The UITN will have started a biospecimen repository to collect urine and blood biospecimens from subjects who are currently participating in either ValUE or E-TOMUS studies. These specimens will be frozen and stored in a repository for future biochemical and genetic studies. Why is this biospecimen repository important? By storing these biospecimens, in the future, investigators can explore which biochemical and/or genetic markers may be related to urinary incontinence which then might suggest a completely different treatment approach. Urinary incontinence is not a simple problem and the causes of urinary incontinence are not entirely nor precisely known. Furthermore, current treatments for urinary incontinence are limited. If we can detect new causes for urinary incontinence, this may open up an avenue for new treatments for urinary incontinence; thus there can be hope that clinicians can further improve the quality of life for those who have incontinence not effectively treated by current methods. Many large clinical trials networks have instituted biospecimen and tissue collection banks to help investigators research the possible causes of different diseases and conditions. By proceeding with the biospecimen repository, the UITN will be poised to discover new mechanisms related to the cause of urinary incontinence which can in turn suggest new treatments.

THANK YOU!

To all SISTER, E-SISTER and E-TOMUS study participants who continue to volunteer! For those who are not yet participating in E-Studies, call your nurse coordinator today to schedule an appointment for continuation of this important UITN work.

UITN Study Updates

By Judy Gruss, RN at U. Pittsburgh

The investigators are continuing to work hard to write about the results of the SISTER and BE-DRI studies, and are beginning to look at some of the data from the TOMUS study. In fact, over 30 papers have been published in scientific journals about these studies. Here are 3 more examples of the things that the investigators have learned from these studies.

The Impact of Stress Incontinence on Female Sexual Function (Am J Obstet Gynecol. 2009;200:562.)

The investigators were interested in finding out 2 main things about the sexual function of the women in the study. (1) How does having incontinence affect a women's sexual function? (2) Does having surgery for incontinence improve a women's sexual function? Women in the SISTER study answered a series of questions about sexual function both before and after their surgery.

About two thirds of the women in the SISTER study were sexually active before they had surgery. It appeared that those women who had worse incontinence (as indicated by their pad test and other measures of incontinence severity) were more likely not to be sexually active before surgery. Other studies have also found that having incontinence can have a negative affect on sexual function.

Women who had a successful surgery and who were no longer incontinent after their surgery had better improvement in sexual function. It did not matter which surgery the women had – both the women who had a Burch and those who had a sling had significant improvements. This tells us that women who are undergoing surgery for stress incontinence can expect their sexual function to improve after the surgery.

Quality of Life after Surgery for Stress Incontinence

(Int Urogynecol J (2008) 19:1631-1638)

Similar to the effect that successful urinary incontinence surgery has on sexual function, the investigators wanted to confirm that a women's quality of life improves after surgery.

In general, quality of life is the way you perceive your physical and mental health over time. Investigators look at how illnesses interfere with your day-to-day life. In the SISTER study, the questionnaires that the women completed were done before and after receiving surgical treatment for incontinence, and the two time periods were compared.

The investigators found results very similar to those with sexual function. Women who did not leak after surgery (and thus had a successful surgical outcome) had more improvement in quality of life. In this study, the improvement in quality of life occurred right after the

surgery and continued through 2 years. Also, as we reported in an earlier article, the women who had the Burch procedure had more improvement in their quality of life, than women who had the sling procedure.

Complications in Women Undergoing Burch Colposuspension Versus Autologous Rectus Fascia Sling for the Treatment of Stress Urinary Incontinence

(J Urol. 2009 May;181(5):2192-7. Epub 2009 Mar 17)

When we reported the results of the SISTER study, we told you that the women who had a sling surgery had a complication of surgery more often than women who had a Burch procedure. The investigators were interested in trying to figure out why this was so. This paper goes into more detail about the complications that the women had.

The investigators carefully looked at all of the complications that were reported in the study. They also looked at characteristics of the women in the study (like age, height and weight, and smoking and medical history) to see whether these had any impact on whether they had a complication. Also, some women in the study had the incontinence procedure and other surgical procedures at the same time, and the investigators wondered whether that had any effect on complications.

The investigators learned that those women who had longer surgeries and who had more blood loss during the surgery were more likely to have a complication. None of the characteristics (like age, height and weight, or history) seemed to cause a higher risk of a complication. In all, women who had additional surgery done at the time of the incontinence procedure had more complications. Women who had the sling were more likely than women who had the Burch procedure to be treated for a bladder infection within the first 6 weeks after their surgery.

The investigators plan to compare this information about surgical complications to the information that we obtain from the women who are in the TOMUS study to see whether there are similarities even though the surgical procedures are different.

REMINDER:

We would love to hear from you!!

Anonymous newsletter comments and stories can be sent via the UITN Public Website: www.uitn.net

In order to protect your privacy as a research participant, please do not include your name or address on the comments submission.

To all of our UITN Research Participants

By Barb Leemon, RN at Beaumont Hospital

Many holidays revolve around a religious tradition. Others are more secular by nature or have become non-religious in our present culture. However you choose to view them, they are a part of our lives and they provide events for which we gather together and share our beliefs or just celebrate and enjoy! Memories are made of such things as these. The best memories are those shared.

I have found some ideas for sharing our best wishes with friends and family that are both easy and an exercise for our communication abilities. Whether you are sending e-mail greetings or postal greetings, having small family gatherings or larger holiday parties, you could try some of these ideas.

Print up some small sheets of paper with the following themes: *My Holiday Wish for You....*, *What I Love About You....*, *Thank You For....*, and complete one of each for your guests or mail buddies. You could even make sheets up for each person at the gatherings and have everyone complete them for everyone else there also! The messages could be given to each person they were intended for to read whenever they wish, or you could all share the contents right at the gathering. Some examples are:

- ★ *What I love about you is your excitement about life.*
- ★ *What I love about you is your giving spirit.*
- ★ *What I love about you is your gorgeous hair.*
- ★ *Thank you for showing me how to live a more love filled life.*
- ★ *Thank you for all the times you reminded me to pick up my clothes.*
- ★ *My wish for you is that you experience a loving marriage.*
- ★ *My wish for you is to have a fabulous vacation.*

And so on.

You will not receive another UITN Newsletter until after the fall and winter holidays take place. We don't want to miss out on the opportunity to send our best wishes to you for each of the holidays during the coming season so we will express them to you right now!

We wish you health, happiness and peace.

What we love about you is that you are each so unique and special to know.

We thank you for giving your time and effort to the study so that others may benefit from this information one day. Until next year, Happy Holidays!

From Your UITN Staff

Meet a UITN Team Member

Name: Jennifer Tablado, LMT, NCTMB

Title: Administrative Assistant II, Data Manager, E-SISTER Coordinator

Institution: UCSD

Tell us about your time with the UITN - Jenn has been part of the UCSD UITN team for over 6 years. She began as part-time data entry assistant and soon became the full-time Data Manager for both the UCSD and Kaiser sites. In the past year, Jenn was certified as an E-SISTER interviewer and data collector and finds that she very much enjoys talking with patients and keeping up with them over the long term. She finds the patient interaction a nice compliment to data entry and report tracking and hopes to become a full-time coordinator in the future.

What are some things that people may not know about you? As some of you *may* know from her recent contribution to the newsletter, Jenn is a licensed and nationally certified massage therapist and body worker. She works at Health and Vision Acupuncture Massage Center, while building her list of private clients that, not surprisingly, includes several co-workers. She is also a good Mah Jong player.

Tell us about your family life – Jenn enjoys spending time with her long time boyfriend Archie and their large extended families. Jenn is especially fond of her 4 year old nephew Nathan and 1 year old niece, Leyla.

Describe a perfect day – Starting with a massage and pedicure, Jenn would enjoy some time reading, spending time with family and maybe catching a movie.

As a co-worker relatively new to the UITN, I found Jenn to be a great resource and we all very much enjoyed working with her.



Mini Tomato and Mozzarella Appetizer 'Kabobs'

Submitted by JoAnn Columbo at UCSD

Ingredients:

- 1 16 oz tub of baby mozzarella balls
 - 1 pint of pearl tomatoes
 - 1 bag of 'rocket' arugula
- Add the following to taste
- balsamic vinegar
 - Olive oil
 - cracked pepper and salt

Directions

Using toothpicks, alternate skewering the mozzarella and tomatoes (skewer tomatoes length-wise through the stem point) leaving just enough room to pick them up (about 3 pieces).

Arrange on a bed of arugula and chill covered until ready to serve. Drizzle with oil and vinegar; add pepper and tiny bit of salt just before serving.

The "M" Word

The Journey Toward Menopause

By Kimberly Woodson, MPH, RN at Loyola University

Menopause is the permanent end of menstrual cycles. It officially occurs when you have not had a menstrual period for at least 12 consecutive months. There is no way to predict when it will occur in a specific woman. However, the average age of menopause is 51. Most women begin having irregular periods anytime between 45-55 years old. The transition from regular menstrual periods to no menstrual periods (a.k.a. peri-menopause) usually takes 4-5 years.

Every woman will experience the eventual end of menstrual periods and the accompanying decrease in hormone production by the ovaries. This decrease in hormone production may cause a number of symptoms that mark the transition toward menopause such as: unpredictable menstrual periods, sleeplessness, night sweats, vaginal dryness, mood changes, fatigue, weight gain, hair loss or thinning, memory lapses and the infamous "hot flashes". It's hard to say which, if any of these symptoms you will experience. Most peri-menopausal women report at least one of these symptoms.

If the symptoms become bothersome, there are several options for seeking relief. You and your doctor can explore the benefits of lifestyle modifications (i.e. exercise and nutrition), over-the-counter aids (i.e. lubricants for vaginal dryness), and prescribed hormone replacement treatments. Some women find relief from complementary or alternative treatments such as herbal supplements. Research continues in this area.

Be assured. Just as you survived the awkward stage of puberty, the discomforts of menstrual cramps, perhaps the pains of labor and the cracked nipples of breastfeeding...this too shall pass.

For more information about the UITN studies, please call the office nearest to you.

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