

# The Genetic Counseling Connection

The official newsletter of the University of Cincinnati and  
Cincinnati Children's Hospital Medical Center  
Genetic Counseling Program



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## **NEWS FROM NANCY**

Regards to past graduates of the Genetic Counseling Program and interested others!

It's been awhile since we've put together a newsletter, so I am particularly pleased to update you on the program and my family.

Everyone knows about the big news in our program has been undergoing a curriculum review for the ultimate goal of transformation to train genetic counseling students the best way possible to meet current, and anticipated, practice needs. Many of you participated in related discussions and review process. I would like to thank all our participants for your time and intellectual energy. While I think this process will never be "complete," we've made some great progress and I want to share what we've accomplished so far:

### **Summary**

A one year pause in program admissions was implemented in February 2007 by the University of Cincinnati administration to facilitate a comprehensive review of the genetic counseling program. The goal of the review was to determine responsiveness to the Human Genome Project and to consider how to optimally train students to assume challenging and diverse genetic counseling roles for many years to come. The admissions pause facilitated discussion of many ideas and options and re-sequencing of several courses without fear of jeopardizing progress of students in the pipeline.

Many stakeholders were involved in the review and recommendation process, including three major stakeholder groups: students, faculty, and supervisors. All meetings and subcommittees were led by educational consultants from the UC College of Education.

The following highlights noteworthy progress and changes we plan to implement in Fall 2009. All changes have been approved by the ABGC, UC and CCHMC.

- A new mission statement was developed
- All courses were reviewed, discussed and streamlined to decrease redundancy
- Content of one credit hour courses were merged to create new courses, rolled into existing courses for more cohesiveness, or deleted if deemed unnecessary
- New courses were identified as electives
- Course credits were balanced by quarter and year of training with respect to student and faculty workload
- The curriculum was determined to be responsive to the Human Genome Project by offering dynamic content in genetics, epigenetics and environmental factors
- Several courses were re-sequenced to build more gradually on the presentation of core genetics content
- Opportunities to bring additional aspects of our curriculum online continue to be explored
- A full assessment of program funding was clearly delineated and openly shared by UC and CCHMC and a five year budget was prepared

Otherwise, Melanie and I are keeping busy with our grants and I am enjoying co-teaching AGC with Betsy Peach and Angela Bedard this year. I am also working on some projects related to diversity and cultural competence, and soon, I hope to contribute some new ideas for our profession. We are surely excited to be interviewing a fine group of applicants in the next few weeks and anticipate recruiting yet another great class!

A special note to all the hard working graduates who got through the 2007 ABGC board exam. The most common comment about the exam seems to be "Thank goodness that's over!" Overall, GCP graduates had a 97% pass rate, far higher than the national pass rate! We are soooooo proud of your accomplishments!

Now for my family update. For those of you who have images of my family including babies or youngsters, you'll need to lose those images! My youngest, Jacob, graduated from high school in June 2007, and he has been attending a yeshiva in Israel this academic year. The good part is we went to visit him in December, but the bad part is that he won't be home until for another 4 months. Long time to be away, but he loves the learning and then this fall, he'll attend a yet to be finalized institution of higher learning in the US. Ariel, my "middle child" is now 20 years old and attending the University of Michigan College of Nursing. She is very much enjoying the nursing content, although it appears to be about as challenging as our GCP curriculum. Importantly for me, though, Ann Arbor is only a 4 hour drive away from Cincinnati and Ariel's been known to "show up" at our doorstep to visit for the weekend from time to time! Sarah, my firstborn, graduated from McGill University last May with a BA/BS in Biomedical Sciences, Political Science and Judaic Studies...phew! Her long term interests lie in the public health domain, but she decided to take a year off, or a few years, to work and gain additional experiences. So, (and this is the part I like most) she is back home, working for a non-profit agency, the Jewish Federation of Cincinnati. She is writing grants, working on community outreach and other interesting projects, including chaperoning a trip to Israel for teens this summer.

That's it from me for now. Please stay in touch! Thanks to the current students who helped put together this newsletter!

Nancy

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## Current Student Updates

### Where we were last summer and what we're doing for thesis projects

**Christine Spaeth:** I spent three weeks at the Center for Maternal-Fetal Medicine, Ultrasound and Genetics at Miami Valley Hospital in Dayton, Ohio. This busy practice is a referral center for the Dayton area. They employ three full-time and one part-time genetic counselor. During my rotation, I was able to gain experience with routine prenatal counseling, such as AMA, abnormal serum screens and first trimester screens. I was able to participate in pre-conception counseling, and learned a tremendous amount about ultrasound detection of fetal anomalies. For the second part of my summer rotation, I spent two weeks working under Carrie Atzinger and Dr. Brad Tinkle. I was able to see patients in the Marfan/EDS clinic as well as in the Skeletal Dysplasia clinic.

For my thesis project, I am conducting interviews with key members of divisions within CCHMC. I am interested in learning how specialists use genetic services in patient care, as well as additional services that may be needed. I hope to learn more about potential roles for genetic counselors within specialty areas.

**Brian Strike:** I did my summer internship at Vanderbilt University Medical Center in Nashville, Tennessee. I spent three weeks working with Martha Dudek (UC GC alum) in the prenatal clinic and the Center for Advanced Maternal-Fetal Care. For the second half of my rotation I worked with the Division of Human Genetics at Vanderbilt, seeing mostly pediatric genetics patients at Vanderbilt Children's Hospital. Additionally, I also researched heritable colon cancer syndromes and gave a brief presentation on this subject to the doctors and genetic counselors at a Division of Genetics meeting.

For my thesis research project, I am working with Dr. John Greinwald, an otolaryngologist at Cincinnati Children's Hospital. I am working on a project that will analyze the clinical utility of microarray designed to screen for autosomal recessive causes of hearing loss. Patient samples have been screened for mutations in five genes known to cause hearing loss using the microarray platform and also traditional sequencing. My project will be comparing the accuracy of the microarray in identifying mutations to that of sequencing. Also, I will be comparing the cost effectiveness of screening for hearing loss using a microarray platform compared to the current diagnostic paradigm. The utility of the microarray will be based upon its ability to accurately identify a genetic cause for a patient's hearing loss in addition to its cost-effectiveness. My thesis will discuss the difficulty of interpreting the results of a complex genetic test. Also, I will discuss the implications that complex genetic test results will have on the field of genetic counseling.

**Kim Edge:** I kicked off my second year in the Genetic Counseling Program with my summer internship at The Ohio State University center of Maternal Fetal Medicine. This was a wonderful experience through which I saw many interesting cases involving prenatal genetic risks, and I enjoyed working with OSU's excellent genetic counselors, doctors, and staff. Toward the end of the summer I turned my attention toward my thesis

project: a survey investigating pediatricians' knowledge of genetic risks posed to the offspring of older men. I now look forward to completing this research and I anticipate graduating this spring. I can't wait to use my Cincinnati background as a "real" genetic counselor!

**Melissa Fuller:** My research study will be assessing primary care providers' use and perceived value of a patient's family history in routine patient care, as well as perceived value of a provider generated family history versus a patient generated family history. Recently, the U.S. Surgeon General launched a national public health campaign, called the U.S. Surgeon General's Family History Initiative, to encourage all American families to learn more about their family health history. While studies are currently being done to assess the patients' perspectives of this initiative, the perspectives of primary care providers, the intended recipients and utilizers of the information, have not been explored. Primary care providers, including internists, family practitioners, pediatricians, and advanced practice nurses in the Cincinnati area are being asked to participate in the study by completing a short survey which addresses these issues.

**Margaret Au:** I spent my summer in Nashville, Tennessee, doing both prenatal and pediatric genetic counseling at Vanderbilt University Medical Center. This experience was facilitated by great supervisors, including two UC alums (Martha Dudek and Misti Williams). I was also able to share the experience at Vandy with my classmate Brian. In addition to seeing patients for genetic counseling, I was able to interact with the clinical ethicist who works with the Center for Advanced Maternal Fetal Care at Vanderbilt and discuss the foundations and practice of clinical ethics. Overall, I had a wonderful time in Nashville.

For my thesis project, I will be conducting interviews with women in the urban Appalachian population in Cincinnati. I will be interviewing women who participated in the Family History Demonstration Project (Melanie's project) and women who did not participate to assess decisions to seek medical care based on family health history.

**Erin Acra:** I spent the summer interning at Riley Hospital for Children and Indiana University in Indianapolis. I participated in the Genetic Counseling Clinic, Medical Genetics Clinic, and Neurogenetics Clinic. I spent the majority of my time in pediatrics, which I loved. At the beginning of my internship I wasn't sure if I would enjoy being at an institution that had a genetic counseling training program; however, it didn't take me long to realize what an excellent opportunity it was for me. My supervisors were used to teaching and working with students, and they were wonderful. I also really enjoyed working with the genetic counseling students from IU. I made some good friends, and we had a lot of fun. It was a great experience.

My research thesis project involves determining the recurrence risk of two types of anorectal malformations: rectovestibular fistula and rectoperineal fistula. The exact etiology of anorectal malformations is unknown, and although, many families have reported numerous individuals with an anorectal malformation, there are very few published studies that have looked at the genetic component of these malformations. We

hope to determine an accurate recurrence risk to quote to families. For my study, we will be concentrating on two specific types of malformation: rectoperineal fistula and rectovestibular fistula. We are taking detailed family histories of patients treated for one of these two malformations to determine the recurrence risk as well as the most likely mode of inheritance. We hope to provide more information to families as well as gain information to help with future genetic linkage studies.

**Courtney Doughty:** I spent my summer clinical rotation as The Ohio State University Hereditary Cancer Program in Columbus, Ohio. While at OSU, I had the opportunity to provide hereditary cancer counseling for a variety of indications. I also was involved in enrolling participants in research studies including research on the incidence of Cowden syndrome and understanding risks for BRCA1/2 variants. I also spent a day at The OSU Ross Heart Hospital observing a genetic counselor who was recently incorporated into a multidisciplinary high-risk heart disease evaluation team.

My thesis project, entitled "Communicating BRCA1/2 Test Results: Impact of telephone versus in-person disclosure of results", received funding from the National Society of Genetic Counselors in the Spring of 2007. The project received dual IRB approval from CCHMC and UC in January of 2008. Shortly following, surveys were mailed to participants and data analysis will begin in February.

**Thea Owens:** This summer I was able to go home to Wisconsin for my summer internship. I was able to set up a split rotation between Children's Hospital of Wisconsin and Froedtert Hospital. Mondays, Wednesdays, and Friday mornings I participated in a variety of prenatal and preconceptional cases in the Fetal Care Center. Tuesdays, Thursdays, and Friday afternoons I counseled patients in Children's Metabolic Clinic. My summer internship was a wonderful educational opportunity and I thank all of my summer supervisors for their time and dedication.

My research project is titled "Teachers' Roles in Presenting Genetic Counseling as a Career Option to High School Students." This project has a special place in my heart, because I was introduced to the genetic counseling profession during my ninth grade biology class in high school. I will be surveying 500 high school biology teachers that are member of the National Association of Biology Teachers. The results of this survey will hopefully provide insight into how genetic counseling programs can more effectively recruit high school students of all backgrounds.

**Jessica Hoffman:** I did a two week laboratory genetic counseling rotation at the Mayo Clinic in Rochester, MN. The rotation gave me a chance to observe molecular, cytogenetics, and biochemical laboratory genetic counselors in action. I was able to gain an understanding of the role of a genetic counselor in a laboratory setting, as well as learn more about the ins and outs of the laboratories themselves. By the end of the rotation, I was even able to call out abnormal results to a couple of physicians. It was a great learning experience, and the dormitory style housing provided allowed me to become friends with other genetic counseling students from around the country.

I spent my 6 week internship in New Orleans, LA. At this time, there is only one genetic counselor in the entire state of Louisiana, so I was able to see a wide variety of cases and traveled to several satellite clinic locations. Everyone at the Hayward Genetic Center of Tulane Medical School was extremely welcoming and took a real interest in my getting the most out of my time there. The rotation allowed me a great deal of independence while still feeling supported. By the time I left, I felt like a real part of the genetics team. I would definitely recommend the site to future genetic counseling students.

The title of my research thesis is: Prevalence of Sleep Disturbance and Pain and the Association with Quality of Life in Ehlers-Danlos Syndrome. Sleep disturbance is a common complaint among Ehlers-Danlos patients in clinic but has not been well described in the literature. We hope to assess whether sleep disturbance is, indeed, a common finding in EDS and whether it is always associated with the chronic pain often experienced by these patients or is an independent finding. The study will be conducted via postal surveys, and has received IRB approval by both CCHMC and UC. The first mailing has been sent out, and a second chance mailing will be sent at the end of the month. Data analysis will begin in March.

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Current Genetic Counseling Program students.

## **DR. HUETHER'S RETIREMENT**

### **Genetic Counseling Program founder announces his retirement**

After 41 years of service at the University of Cincinnati, Dr. Carl Huether retired in January 2008. Dr. Huether contributed to UC's genetic counseling program from the beginning. In fact, he worked very hard for many years to get the program started and was its first director. Although he no longer holds a formal role in the program, he still contributes much to the program by serving on both faculty and student committees. Dr. Huether has also done important research that is relevant to the field of genetic counseling from his work in the epidemiology of Down syndrome to his most recent studies in human genetics education. Dr. Huether will be missed at UC, but there is no doubt he will continue dedicate his time to the things he feels are most necessary and important.

### **A Note of Thanks from Professor Emeritus Huether**

How thoughtful of Nancy to ask Program graduates to send comments regarding my retirement January 2, and how nice of so many of you to respond! Nancy assembled all of them into a wonderful packet, which Melanie presented at my retirement party. A total of 40 of you responded, along with comments from Carol Christianson, Melanie, and Nancy. Collectively, they tell me things I don't think I ever knew, things I knew but clearly forgot, what a high regard each of you shares for the Program, and how many of you have become good B.Sers since your graduation days (but OK, I still appreciated the mush)! The salutations included Dr. Huether, Bert, Carl, and Huether, but none of what I'm sure you really called me when you were here!

To give you a flavor of the comments, I'll share some thoughts from those who were part of the Program while I was Director, even though all of you from later years shared many wonderful comments as well.

- Betsy Schmalz ('85) reminds me of our taste-testing different varieties of Cincinnati vanilla ice-cream, and the winner wasn't Graeters as expected, but Sara Lee!
- Connie Motter ('87) reminds me of being allowed to bring her shaggy mutt Angie to the office every night so she would feel safer walking home at 1:00 AM!
- Eric Krivchenia ('88) tells me it is all my fault that he is today an "old burnt out, jaded, cynical genetic counselor", although he was jaded and cynical even 20 years ago!
- Jay Moskovitz ('88) reminds me of my futile fight not to be "kicked" up to the 16<sup>th</sup> floor office of Crosley Tower, where I remain today; of our sleeping up to five to a room on our Down syndrome data collection trips around the State; and of my challenging students in the human genetics course to draw the pedigree for the song "I'm My Own Grandpa"! (I still have the song for those interested, and Jay correctly drew the pedigree!)

- Faith Callif-Daley ('89) reminds me of our canoeing expeditions she endured in the spring.
- Martha Walker ('90) thinks I should grow a “ponytail”!
- Jen Ivanovich ('92) thinks I actually showed her how “hard work, dedication, and genuine concern for others can build a community”
- Alison Elliott ('92) tells me I should learn how to drink REAL martinis (vodka instead of gin)!
- Andrea Shugar ('92) actually thinks I was “friendly, enthusiastic and warm” when she interviewed (but perhaps not once she got here!)
- Diane Barker ('94) reminds me that SOME students in her class got an A in human genetics by “rounding up”!
- Denise Needham ('94) reminds me one of the first comments I made to her during the interview was “didn't do so well in chemistry, did you”. Her daughter is now taking that same Organic Chem class at NC State (where I also graduated with my MS).
- Karen Huelsman ('94) reminds me she entered the Program during the “tumultuous year of 1992” when the Program continued its transfer to the Dept of Environmental Health (I'm glad she stayed none-the-less!)
- Susan Manley ('95) reminds me her parents were very nervous when leaving their “little girl” so far from their WI home, but that after a cocktail at our home, their fears vanished!
- Ann Salvino Martin, Tammy Stumbaugh, and Jennifer Beeman Stroop (all '95 as well) represented the last entering class while I was Director, and thanked me for my “imprint”.

Many of you also told me about family and current activities, which I very much appreciated and enjoyed reading.

So if this is what retirement is about, I am a happy camper, although Carol refuses to fix my lunch on days when I stay home!

A colleague told me what Emeritus really means—““E” means you're out, and “meritus” means you deserve to be out”!

Carol and I have much to be thankful for, but particularly that all of you have been such a wonderful part of our lives over the past 25 years. So warm wishes and our own thanks to each of you.

Bert/Carl and Carol

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## *Alumni News*

Sidra Shapiro is getting married on March 30<sup>th</sup>, 2008, and has moved to Las Vegas, Nevada.

Ann Reinhard is now working at Children's Hospital Boston dividing her duties 50/50 between clinic and the DNA Diagnostic Lab.

Kami Wolfe was married on May 27, 2007 to David Schneider, who she met in Cincinnati. Her name is now Kami Schneider.

Jill Yelland (1998) and husband Andre are pleased to announce the birth of their son. Scott William Yelland was born July 2, 2007, weighing 7 lbs 13 oz and measuring 20 1/2" long.

Please continue to update us regarding your newsworthy events! Send information to [gcprog@cchmc.org](mailto:gcprog@cchmc.org).

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## **Coming soon...The Class of 2010!**

### **The interview process, open houses, and "Meet a Grad"**

Interviews for the Genetic Counseling Program Class of 2010 are underway! UC's Graduate Recruitment Weekend—the first round of interviews for the Genetic Counseling Program—will occur February 29-March 2. Feb 29 (Graduate Recruitment Weekend). Interviews will also occur on April 7, 14, and 28.

We've been taking some additional steps to recruit phenomenal students and share information about the program this year. Applicants to the UC Genetic Counseling Program had a new opportunity to learn about the impact of the graduate training from the important perspective of program graduates. Applicants were encouraged to schedule an informational meeting with a UC graduate working in a nearby location. Graduates working in 35 locations throughout the United States and Canada volunteered to meet with applicants to discuss how their experience at UC prepared them for real world genetic counseling, the board exam and for continued professional development. "Meet a Graduate" was an optional aspect of the Fall 2008 application process. Many thanks to the alumni who participated in the "Meet a Grad" program. More information about meeting a UC Genetic Counseling Program graduate can be found at <http://www.cahs.uc.edu/gc/MAG.htm>.

Additionally, the Genetic Counseling Program held two Open Houses this fall for prospective students. Individuals interested in the career of genetic counseling were invited to learn more about the UC program, first-hand, from Nancy, Melanie and current students. At these evening sessions, attendees heard about the program's curriculum, clinical and research opportunities, job placement successes, and were then invited to ask

questions of the program directors and students, and take a tour of the facility. Interested individuals from Greater Cincinnati, Dayton, Columbus and other locations in the region were in attendance.

The “Meet a Grad” and Open Houses offered opportunities for potential applicants to become more familiar with the field of genetic counseling and the special characteristics and strengths of our program. We hope to attract motivated and informed candidates who will ultimately become an asset to the field.

If you are giving community outreach presentations to junior/high school students, college classes, or career fairs where you'll be interfacing with future prospective students, think about taking along our recruitment materials. We have LOTS of recruitment posters and single fold program brochures on hand. Just tell us how many you want and where to send them, and they are yours for the asking. This helps us get the word out about our program, and gives you some "props"!



Students taking a break at their cubicles

## Family History Project

Since September 2006, Melanie has been busy working on her NHGRI-funded family history project. This project involved education about the collection and use of family health history using the Surgeon General's Family History tool—My Family Health Portrait—to urban Appalachian women with less than a college education in Cincinnati, Dayton, and northern Kentucky. These areas were targeted as there are large populations of individuals who migrated or whose parents or grandparents migrated out of the Appalachian mountain region. Collectively, this community faces large high-school drop out rates and high rates of chronic diseases. Approximately 100 women of urban Appalachian descent participated in initial and follow-up education sessions. In these sessions, they learned about the importance of family health history in relation to common chronic diseases, how to collect and document family health history using My Family Health Portrait, and how to talk to healthcare providers about their family history. Analysis of the gathered family health histories and evaluations is ongoing and the final touches are being placed on the materials and fact sheets developed through this program. You can find a link from our website at [www.cahs.uc.edu/gc/FamilyHistoryProject.htm](http://www.cahs.uc.edu/gc/FamilyHistoryProject.htm)

This project brought together investigators from the University of Cincinnati, Cincinnati Children's Hospital Medical Center, the Ohio State University, Sinclair Community College, and community organizations including the Urban Appalachian Council, Lower Price Hill Community School, Brighton Center, Sunrise Center, Voices of America, and Life Enrichment Center.



Genetic Counseling students in Advanced Genetic Counseling Issues (AGC)

## Online Courses

The Genetic Counseling Graduate Program now offers three online courses that professional genetic counselors can take for continuing education credits (CEUs). These online courses are accessible from anywhere at any time. Course enrollment is continuous and can be completed at the user's own pace and convenience. Each lecture is presented using a combined audio/video format and detailed PowerPoint slides.

Clinical Embryology Online (CEO) can be taken for 2.5 Category 1 Genetic Counseling CEUs. This extensive course is divided into basic developmental lectures and clinical application presentations. Course objectives for CEO include: to understand normal human development, to provide a basis for explaining the process of developmental anomalies, and to provide an introduction to the treatment of patients with congenital anomalies as well as counseling options for families of affected individuals.

Online Teratology Course (OTC) can be taken for 2.3 Category 1 Genetic Counseling CEUs. Course objectives for OTC include: understanding the major principles of teratology, use this knowledge to explain the effects on patients who have been exposed to specific teratogens, introduce the treatment of patients who have been exposed to teratogens, and discuss the reproductive implications and counseling options for the family of affected individuals.

Topics in Personalized Medicine (TPM) can be taken for .7 Category 1 Genetic Counseling CEUs. TPM provides an overview of personalized medicine, and places particular emphasis on the current and potential applications of personalized medicine in the field of genetic counseling. The course also features an "*Introduction to Personalized Medicine*" annotated PowerPoint Tutorial and a bibliography with PDFs of several dozen articles on personalized medicine to further challenge the learner.

Your registration fees help us financially, as well as enhance our national reputation for providing first rate educational opportunities, while providing a flexible and challenging venue for acquiring CEU's. For more information about these exciting online courses including costs and registration materials, please visit our online courses website at:

[www.cahs.uc.edu/gc/online.htm](http://www.cahs.uc.edu/gc/online.htm)

Course Name	Number of GC CEU's	Cost
Clinical Embryology Online (CEO)	2.5	\$350
Online Teratology Course (OTC)	2.3	\$350
Topics in Personalized Medicine (TPM)	0.7	\$100

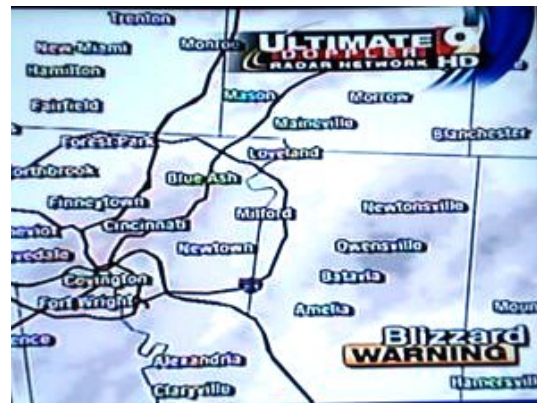
## Blizzard Hits Cincinnati

Snow started falling Friday morning, March 8<sup>th</sup>, and didn't stop for 2 days! A blizzard warning was issued for the entire tri-state area. The only difference between this and 1978 (the last blizzard warning) was that the river didn't freeze.



(looking out the 4<sup>th</sup> floor window of Tangeman University Center Friday March 8<sup>th</sup>)

Brian had taken a shuttle to Tangeman University Center to display posters at the UC Showcase for the GC program when the storm hit. He said that as fast as the posters went up they started coming back down and everyone headed for home. He did the same but decided to walk back to CCHMC after watching the shuttle he was waiting for slide sideways in front of him.



News of the blizzard was non-stop with what started with predictions of 8 inches Saturday ended with an additional 8 inches by the middle of Sunday for a total of 12-15 inches of snow.

Traffic slowed to a crawl as interstates were covered in snow.  
(looks like Canada eh!)



(175N at 74)



It was fun while it lasted

## The New "S" Building Opens... (research building)



**...and the new parking garage nears completion**



(view from Nancy's office looking toward Burnet Ave.)



HAPPY SPRING EVERYONE!!!