

# YOUR HEALTH

REPORT

## The parent difference: from fragile newborn to healthy tot

**PLUS:** The power of the multidisciplinary team





# Bridget Hall

## NICU parent, dedicated to NICU parents

**B**ridget Hall and her husband Darcy had just started prenatal classes when, on May 1, 2001, their daughter Madeleine was born at 32 weeks gestation at Mount Sinai Hospital.

"I'd kind of touch my stomach and wonder where the baby went," she recalls. "I was in shock. I wasn't prepared to have the baby yet.

"Nobody expects to parent through the port-holes of an incubator. Nobody expects to leave the hospital without their baby, to go home to an empty nursery," says Ms. Hall. Her reality contrasted sharply with her dreams about labour and delivery, and becoming a parent.

Today, babies can survive as early as 23 weeks gestation. At 32 weeks, Madeleine was one of the healthier babies in the Neonatal Intensive Care Unit (NICU). Compared to mothers of tinier, more fragile infants, Ms. Hall seemed less in need of support. So while Madeleine was taken care of, her mother's emotional turmoil was not

understood. "I felt that nobody respected my need and my right to grieve the loss of my pregnancy," says Ms. Hall.

While in the Hospital, Ms. Hall found comfort in parent support and educational programs. She says the latter, including *Hospital to Home* and *Infant and Child CPR*, were invaluable in preparing her for motherhood in general, since she had not completed prenatal classes.

"The programs boosted my confidence," she says. "I learned that I could make parenting decisions and ensure our wishes were carried out. I felt comfortable enough to become the primary care giver for my child while she was still in the NICU: I bathed and changed her even with the IV and monitors in place, and prepared her feedings. This helped me feel like a 'real' mother."

Madeleine came home after four weeks and has continued to thrive. Ms. Hall, too, is a fighter. As she regained her equilibrium, she resolved to do what she could to lighten the emotional burden of other new mothers in her situation. She became active in Mount Sinai's Perinatal Parents Association and its hands-on subgroup, the Parent Advisory Committee, and trained as a Parent Buddy (a parent peer counsellor for others going through the NICU experience).

"Getting involved allowed me to grieve and move forward," she says. "I was able to get education and support and then to give back." She found a particular niche in the Parent Advisory Committee. There, she says, her "voice was

heard” and she found a real opportunity to be involved where her experience was relevant.

Working with Parent Resource Nurse Marianne Bracht, Social Worker Frida Ardal and another parent, Angela Jonkman, Ms. Hall took on the challenge of revising a three-ring information binder for parents of pre-term babies. The project helped satisfy her personal drive for more information: “Working on the binder was like group therapy for Angela and me,” she laughs.

They developed a user-friendly format, tabbed and indexed so that parents could access information when they needed it. They added families’ personal stories to provide more emotional support. “The binder gives parents support, information and tools to assume control and care for their infant,” she says. “It also helps them to normalize their experience and realize that others have been there too – and that they’ve made it. That’s the important thing – to show them the light at the end of the tunnel.”

Today, Ms. Hall, a chartered accountant, is taking time out from her career to be a full-time mother to Madeleine, 3 1/2, and her 18-month-old sister Allison. Much of the energy left over from that is devoted to helping parents going through the trauma of having an infant in the

NICU. Hospitals from across North America have sought out Mount Sinai’s binder as a model for their own, and she is one of its key ambassadors. She is also a Parent Buddy, a member of the Parent Advisory Committee, and one of two parent members of Mount Sinai’s Neonatal Team. She presents at conferences, events and to health care practitioners in training.

Looking at her healthy and happy older daughter, Ms. Hall says: “I once thought Madeleine’s prematurity was the worst thing that ever happened to me. Now I know better. Because of her, I have met an amazing group of people at Mount Sinai and my life has changed in a positive way. There are no words to describe my feelings of satisfaction, knowing the work we do makes a difference in peoples’ lives during a painful and trying time.”



OPPOSITE: Bridget Hall gets some help on the NICU parent binder from daughters Madeleine (left) and Allison.

ABOVE: Madeleine Hall, age two weeks, in the NICU at Mount Sinai.

## Q+A

### What is a Parent Buddy?

As a parent of a pre-term baby, Bridget Hall’s emotional experience was not unusual. Parents often feel helplessness, anxiety and grief as they come to grips with the risks inherent in their situation. Through Mount Sinai’s Parent Buddy Program, parents who have had babies in the NICU reach out to those going through the experience. Initiated by members of the Perinatal Parents Association and coordinated by Social Worker Frida Ardal and Nurse Marianne Bracht, the support program has been in place since 1990. There are 60 beds in the NICU. More than 60 trained Parent Buddies, representing over 20 languages, are involved in the program at any one time. At least 20 parents are trained each year, replacing others who leave as their children get older. Ms. Ardal and Ms. Bracht answered the following questions for *Your Health Report*.

#### Why is the Parent Buddy Program important?

Parents who experience a pre-term birth are in crisis. It’s amazing how powerful it is to tell your story to someone who’ll understand because they’ve been there.

**What is the role of the Parent Buddies?** Mostly they offer phone support. They go through a day-long training session but we tell them their experience is the main qualification, and listening is the main skill.

**How is a particular Buddy selected for a new parent?** Parents are matched by language and culture, specific diagnosis, or number of weeks pre-term.

**What pleases you most about this program?** It’s gratifying to see how Parent Buddies can use an experience that was so traumatic to be helpful to others and derive personal satisfaction in doing so.

Part III of a continuing series highlights the multidisciplinary team

# People Power

**T**o deliver the best health care, it is important to have the right science, the right technology and the right infrastructure. But most of all, it is important to have the right people.

The People Power series has already introduced you to some of the talented doctors and nurses at Mount Sinai. But no hospital could provide quality care with only doctors and nurses. In this third installment of the series, you will meet four members of the multidisciplinary health care team. They are among the highly-trained professionals of various stripes who help patients meet very specific needs. Through these profiles, you will see why teamwork is one of the core values of Mount Sinai Hospital. If you are a patient at Mount Sinai, you will be cared for by the very best, and the entire team will work together to ensure you get exactly the care you need.

Following this issue, individual People Power profiles will become a regular feature of the magazine.



## The right prescription

### Lisa Burry

Pharmacist, Intensive Care Unit  
At Mount Sinai since 2000

“She’s brilliant in terms of her knowledge,” says Bill Wilson, Director, Pharmacy. “Lisa’s very energetic, she’s the consummate team player who works with the ICU team to help ensure that the ICU patients not only get the best medicine, but the safest.”

“Working in the Intensive Care Unit suits my personality,” says Lisa Burry with a laugh. “I get bored easily. I flourish with the adrenaline rush, the speed, the acuity. In the ICU, when physicians and nurses ask a drug-related question, they need the answer right away. There’s no ‘Can I get back to you tomorrow?’ You have to be ready and you have to be right because they take action.”

Dr. Burry says she is passionate about being the advocate for unconscious or severely ill patients – who may not be able to advocate for themselves – and working with the team to ensure appropriate drug therapy.

As part of the ICU team, Dr. Burry has the opportunity to research improvements in patient care. One of her upcoming studies will focus on reducing medication errors in the ICU. One of her recent studies looked at reducing the time that patients experience high blood sugar in the ICU.

“Our patients teach us a lot about humanity,” says Dr. Burry, “about the fragility of life. I’m very grateful for this. It gives you a different perspective on life.”



### Prime occupation

## Susan Chmelnitsky

Occupational Therapy Professional Practice Leader  
At Mount Sinai since 1991

You may not think of newborns needing occupational therapy, but some need a lot of help with primary occupations like eating and sleeping. “For example, some premature babies who have been fed passively through a feeding tube learn that they can sleep through feedings,” says Susan Chmelnitsky. “Before they can go home, I help them transition to bottle feeding, if breastfeeding is not an option. I help them learn that they need to work to get their belly full.”

Ms. Chmelnitsky works with adults too, rehabilitating clients with musculoskeletal problems, often as they recover from surgery. She assists in determining how people, including Mount Sinai employees, can safely get back to work during recovery. “If an employee is injured, he or she may not be able to put in an IV, suction, or transfer a client.”

“Susan has helped make our Occupational Health and Safety program much more proactive,” says Sharon Currie, Director of Rehabilitation. For example, Ms. Chmelnitsky assesses the physical requirements of different jobs and workstation furniture for its ergonomic design in order to prevent repetitive strain injuries. She advises on the purchase of some new chairs and desks.

“I’m such a nag,” she says, laughing. “I try to plant a seed in peoples’ heads that they need to be healthy and fit to do their work and that includes home and recreational activities too.”



### Socially smart

## Jodi Goldstein

Social Worker, General and Geriatric Medicine  
At Mount Sinai since 2000

Jodi Goldstein started her career as a teacher, but turned to social work to focus on helping the vulnerable. She discovered her passion was working with the elderly. “People who have had strokes, who struggle with cancer or who are no longer thriving at home due to multiple medical issues are overwhelmed with the loss associated with their illness,” she says.

“Sometimes the needs of the elderly can be overlooked when we are dealing with very complex medical cases,” says Diane Savage, Director of Social Work. “Jodi is just tenacious at getting people the services they deserve. She’s a champion for the elderly.”

“I think a big part of my role is to allow families to vent,” says Ms. Goldstein. “I listen to their stories. It’s really important to get the patients’ perspective before jumping in with an agenda.”

A growing issue is where to get personal care. “We face real challenges finding adequate resources in the community. There are fewer rehabilitative services available. Retirement homes are expensive and many nursing homes have long wait lists. Working closely with a multidisciplinary team is an incredibly supportive and effective way to assist patients in overcoming these barriers.”

Ms. Goldstein plans to research interventions that assist geriatric patients and families with complex needs. “We’re just scratching the surface of helping this population,” she says. “It makes me want to do even more.”

# People Power



## Physio focus

### Leanna Graham

Physiotherapy Professional Practice Leader  
At Mount Sinai since 1991

“The pleasure I get from my work is related to the people I interact with,” says Leanna Graham. “I learn something from everyone: patients, the public, students, or my fantastic colleagues. That helps me to reflect on my practice and improve.”

“Leanna is very self-directed,” says Sharon Currie, Director of Rehabilitation. “She approaches everything with a high level of thoughtfulness, confidence and drive.”

An example of this is a program focussed on care for lymphoedema patients that Ms. Graham helped start three years ago. After surgery and/or radiation treatment, some patients may develop swelling in a limb due to damaged lymphatics. Through this program, patients access valuable education and custom-fitted garments. Ms. Graham explains that the physiotherapy program is designed to work in harmony with other programs at the Hospital. “Since oncology care such as breast and orthopaedic oncology are major program focusses at Mount Sinai, our department strives to provide specialized services for these patients,” she says.

“I’m not for a recipe approach to patient care. Patients should receive a specific treatment program based on their individual needs,” she says. “It’s something I try to instill when teaching physiotherapy students at the University of Toronto.” The students appreciate her take on it: in 2003, she won a “Rising Star” teaching award.

# notes

## PSF factor

### Lunenfeld team brings us closer to preventing pre-term births

The discovery by scientists at Mount Sinai’s Samuel Lunenfeld Research Institute of a mechanism that starts labour may be the key to preventing pre-term birth, the biggest health problem in obstetrics.

“Pre-term births have been difficult to prevent because physicians and scientists did not fully understand the mechanisms involved in labour and delivery,” says Dr. Xuesen Dong of the Lunenfeld. The team knew, however, that the answer would be found in understanding the role of progesterone in human labour.

“Progesterone is a hormone that helps maintain pregnancy; it actually suppresses the genes that trigger labour,” says Dr. Stephen Lye, Senior Investigator at the Lunenfeld. In almost all animal species, progesterone levels fall at the onset of labour. But in humans, progesterone levels do not change with labour.

Dr. Dong, Dr. Lye and their colleagues at the Lunenfeld and the University of Toronto found a previously unknown protein in the uterus, called PTB-Associated Splicing Factor (PSF), that blocks the function of progesterone. During pregnancy, the PSF level is typically low but at the onset of labour the level rises, blocking progesterone and causing contractions to start.

“If we can develop therapies to block this PSF protein, we can let progesterone do its job of preventing pre-term labour,” says Dr. Lye. “That would allow the pregnancy to continue until the baby is ready to be born at full term.”

The positive effects of this would be far-reaching. About one in 10 births is pre-term, sometimes resulting in disabilities or infant death. The annual cost to the health care system in Canada and the United States is about \$15-billion. That doesn’t include the cost of dealing with the lifetime of disabilities for the most seriously affected.

There could also be a flipside benefit to this discovery. Dr. Lye thinks using PSF to actually induce labour may be much more effective than current methods. “It might be the first therapy we develop out of this discovery because it’s easier to turn something on than turn off a normal process,” he says. “The goal of all this research is not to regulate labour itself, but at the end of the day to get healthy babies.”



## Breakthroughs in genetics

### Genetic link to colon cancer

Dr. Steven Gallinger and his team at Mount Sinai's Samuel Lunenfeld Research Institute have found that a genetic mutation puts people at increased risk of developing colon cancer.

As many as 20 per cent of colorectal cancer patients have a family history of the disease. The population-based study revealed that what could be behind some hereditary colorectal cancers is a combination of one parent having the MutY human homologue (MYH) gene and having a family history of acquiring the disease.

### RESEARCH FOCUS

This research builds on previous studies that suggest that when both parents are MYH gene carriers, their child has a one in four chance of developing a severe form of colon cancer. Dr. Gallinger and his team found that someone who has one parent who is a MYH gene carrier has a 50 per cent risk of carrying the mutation, meaning increased risk of developing the disease.

"This is going to contribute to new knowledge of colon cancer and it may impact who goes for testing," said Dr. Gallinger.

### Hope for hearts

Researchers at Mount Sinai's Samuel Lunenfeld Research Institute and the Hospital for Sick Children have discovered a genetic mechanism behind congenital heart defects that may lead to genetic tests for some defects.

It was previously believed that all developing cells contained the same set of proteins to unwind DNA, a process that is important for genes to be 'turned on'. However, the team found that in mouse models, a protein called Baf60c is expressed specifically for the developing heart. If the protein is completely suppressed, it leads to dramatic heart defects; if half the protein is suppressed, the result is defects similar to those seen in infants.

"This new protein may provide insights into how to treat cardiovascular problems," said Dr. Janet Rossant, Senior Investigator at the Lunenfeld and the study's co-principal investigator, with Dr. Benoit Bruneau of Sick Kids.

Congenital heart defects are among the most prevalent and serious conditions affecting children, occurring in approximately one out of 100 live births in Canada. Future research will determine if patients with heart defects have the modified protein found in the models.



## Holiday eating? Relax!

"Let's stop worrying about what we're eating over the holidays," says Fran Berkoff, Mount Sinai's outpatient dietician. "You shouldn't deny yourself the traditional foods you really like. There are some things that we look forward to eating and we should. Instead of saying, 'well I can't eat that because it's too rich', a better strategy is to take a small serving and really enjoy it."

Ms. Berkoff suggests that people find a balance to their eating. "If you know you're going out for a big dinner, eat a little lighter throughout the day. Or if you've had a really big meal the night before, then get a little bit of exercise, go out for a walk, a run or a cross-country ski."

People on diets are often anxious at this time of year because they're afraid they're going to blow it. Ms. Berkoff's advice: "Just decide that your goal will be to maintain your weight over the holidays by balancing overeating with healthy meals and exercise." Stress also triggers many people to eat, and holidays are filled with stress. "Go for a walk instead or do something nice," says Ms. Berkoff. "Take some personal time for yourself."

Watch for Fran Berkoff's columns in *Canadian Living* and in *the Toronto Sun*.

### Nutrition Web sites

- ◆ Dietitians of Canada [www.dietitians.ca](http://www.dietitians.ca)
- ◆ American Dietetic Association [www.eatright.org/Public](http://www.eatright.org/Public)
- ◆ The Heart and Stroke Foundation of Canada [www.heartandstroke.ca](http://www.heartandstroke.ca)
- ◆ Centre for Science in the Public Interest [www.cspinet.org/](http://www.cspinet.org/)

### HEALTH TODAY

#### Holiday nutrition tips

- ◆ Balance large heavy meals with light meals and exercise
- ◆ Eat small portions of your favourite holiday foods
- ◆ Eat a light snack before going to a party
- ◆ Don't stand near the food table at parties
- ◆ Watch how much alcohol you drink
- ◆ De-stress with walks, exercise and downtime
- ◆ Put your diet on hold
- ◆ Pick your favourites out of gift boxes of chocolates and cookies, then pass them on to friends, family and colleagues

# ANNOUNCING

## MOUNT SINAI HOSPITAL

is dedicated to discovering and delivering the best patient care with the heart and values true to our heritage. In other words – *The Best Medicine.*

ON THE COVER: Madeleine and Allison Hall playing in Madeleine's bedroom. Madeleine was born pre-term at Mount Sinai Hospital.

### Carol Wilding to lead Mount Sinai Hospital Foundation

Carol Wilding will join Mount Sinai Hospital Foundation of Toronto as President on February 1, 2005. She takes over from Nicholas Offord, who is stepping down after 10 years as President to establish his own consulting practice.

Carol has served as President and CEO of Foster Parents Plan of Canada (FPP) since 1996, where she oversaw a period of strong growth and success. She has extensive experience in both the not-for-profit and private sectors and is a skilled leader in fundraising, strategic planning, corporate partnering and financial management. A Chartered Accountant, she also held the positions of Deputy National Director and Controller at FPP, and prior to that was with PriceWaterhouse for several years.

A member of Young President's Organization, Carol was awarded the Queen's Golden Jubilee Medal in 2002 and the Public Sector Excellence Award in 2000. She received her Honours Bachelor of Business degree from York University, which recognized her with the Outstanding Public Contribution Alumni Award in 1998. She is also a member of the International Development Executives Association, the Association of Fundraising Professionals and the Canadian Institute of Chartered Accountants.

Carol will take the helm from Nicholas Offord, who



came to Mount Sinai in 1995 and since then, raised close to \$250 million for the Hospital and the Samuel Lunenfeld Research Institute. He implemented a donor-focused approach to fundraising, sought out the next generation of community and corporate leadership, and

instilled a belief in the critical importance of good donor stewardship. Nicholas worked closely with his volunteer leadership and Foundation team to establish the ambitious and unprecedented *The Best Medicine* campaign, one of the most successful hospital fundraising campaigns in Canadian history.

Funds raised through *The Best Medicine* provide Mount Sinai Hospital with the flexibility and opportunity to innovate, upgrade, and adapt to the changing face of health care delivery. *The Best Medicine*, now in Phase II, continues under Carol's leadership with a goal of \$400 million and beyond.

"Nicholas has provided great leadership for the Foundation over the past 10 years, and we wish him well in his new career," says Michael Bregman, Chair of the Foundation Board of Directors. "Carol is an outstanding successor and we are delighted to welcome her to our team. We look forward to working with Carol, confident that she will help Mount Sinai reach new, even greater levels of success."

[www.mtsinai.on.ca](http://www.mtsinai.on.ca)

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**THE BEST MEDICINE**