FATHER’S DAY—JUNE 16
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“To be honest, I never really thought about becoming a doctor when I was younger,” admits Daniel Gottesman, Dr. Ron Gottesman’s middle child. Midway through finishing his undergraduate degree in electrical engineering at McGill University, Daniel became very interested in biomedical engineering. “I started thinking of ways I could combine technology and medicine,” he says. “Some of my friends suggested I do a PhD in biomedical engineering, but I was more interested in the clinical side of things. I wanted to practice medicine so I could better understand patients and therefore design technologies that would be truly beneficial for them.” And thus, Daniel’s medical journey began.

Eventually Daniel’s innate curiosity and ingenuity led him to start asking his father about the mechanics involved in his line of work as a Pediatric Critical Care specialist. “He wanted to know what I did for a living and how did all these machines work,” says Dr. Gottesman. Now in his second year of medical school at McGill, Daniel is still trying to figure out what he would eventually like to specialize in. “It definitely has to involve technology and lots of problem-solving,” he says. With plenty of time ahead for him to decide, Dr. Gottesman is certain he’ll make the right decision. “I even gave Daniel my old stethoscope from when I was in med school,” he says. “And I’m honoured that he has adopted it as his own.”

“I built a miniature boat from old motors and a battery from a camcorder,” recalls Daniel. “And, I used lots of duct tape!”

Even as a child, Daniel was curious about everything around him. He was always putting things together and taking them apart. He wanted to know how they worked and accomplished that by removing every single bit and bolt from broken appliances around the house. “We still have jars full of bolts and screws in our basement,” laughs Dr. Gottesman. “When I was younger, I would also take things apart, but I was never able to put them back together!” Before throwing out a broken toaster or dysfunctional telephone, Daniel’s grandparents would give it to him first to investigate. He would then use the scraps to build robots and other motorized devices. “When I was ten, I built a miniature boat from old motors and a battery from a camcorder,” recalls Daniel. “And, I used lots of duct tape!”

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Dr. Ron Gottesman with his son Daniel as an infant.

Daniel Gottesman proudly shows off a cartoon portrait of his dad, Dr. Ron Gottesman, that he drew when he was a child.

Following in Dad’s footsteps — By Stephanie Tsirgiotis
A new lease on life

— By Maureen McCarthy

Hélène Gaudreault is full of emotion when she talks about her daughter Karine’s early life. Karine is now 24 years old and has a full-time job, but for most of her childhood and adolescence, she suffered from several medical conditions and needed daily insulin injections for diabetes. It was a discovery at the MCH that changed everything for the better.

Within a few days of Karine’s birth in 1988, Hélène knew something was wrong. Karine wasn’t eating or drinking, so Hélène decided to return to Charles Lemoyne Hospital where she had just given birth. Within a week, Karine was transferred to the Neonatal Intensive Care Unit at the Montreal Children’s Hospital. She was investigated for many different conditions, and was eventually diagnosed with diabetes.

Karine had to be transferred to another floor for monitoring, and it was three months before the family could go home. By the time they did, Hélène had learned how to regularly test Karine’s blood sugar and give her twice-daily injections of insulin.

In the years that followed, Karine was also diagnosed with other conditions. At age two, she was put on depakene for epileptic seizures, and at age six, she was diagnosed with autism spectrum disorder.

A discovery that changes everything

When Karine reached the age of 16, she started to see Dr. Laurent Legault for her diabetes. Dr. Constantin Polychronakos was also involved in her care.

Not long after that, Hélène got a call out of the blue from Dr. Polychronakos. He told Hélène that researcher Rosemarie Grabs had identified a gene mutation in Karine, one that made her a perfect candidate to try an oral antidiabetic treatment instead of daily insulin injections.

...Continued >>
A new lease on life (cont’d)

Hélène talked to Dr. Legault, then decided to try it. They planned a two-week transition, during which Karine would be weaned off insulin injections and start taking glyburide pills three times a day.

Dr. Legault explains that Karine was the ideal candidate to try the treatment. “This medication is commonly used in patients with type 2 diabetes,” says Dr. Legault. “In certain rare patients, insulin production is dormant. Glyburide opens up the pathway which helps to restore this production and allows people to achieve normal blood sugar levels.”

Drs. Legault and Polychronakos called Hélène every day to check Karine’s blood sugar tests until she completed the transition. Hélène says it was much easier than she had anticipated and in the end, Karine’s dose was stabilized at two pills, two times a day.

Beyond expectations
To be free of the responsibility that comes with daily injections was a tremendous relief for Hélène. But what else happened was far greater than anything she ever expected. Up until the age of 16, Karine was not a very social or expressive child. “You could say that the new treatment was a sort of liberation for Karine. Her behaviour and demeanour completely changed for the better.”

Karine now works five days a week at L’école Aérotechnique de St-Hubert on a project sponsored by the Centre de réadaptation en déficience intellectuelle (CRDI). She has also developed her hobbies and interests: Hélène says she’s a whiz at jigsaw puzzles, and knows virtually every song on the radio—artist, title and lyrics.

Once a month, Karine participates in a weekend retreat with a program called Aux Quatres Poches, where she gets to socialize with other young adults with handicaps. Hélène, who is on the board of directors for the program, says it has given her family the opportunity to get a bit of respite and has also allowed Karine to feel independent and to socialize with others.

According to her mother, Karine has evolved significantly. And she is still evolving, which is exciting for the family. “My life was pretty difficult before Karine started her new treatment. I was the one who had to inject her with insulin every day for 17 years. It was very stressful at times. But once she started her new treatment, I had more time to spend with my other daughter, Stéphanie, and with my partner. Honestly, it changed all our lives for the better.” •

Note: Karine is taking part in an exhibition of 30 photographs entitled Porter un regard différent sur la déficience intellectuelle, which asks us to see intellectually challenged people in a new light. Its organizers hope to offer a different point of view, a fresh perspective on their sensitivity, intelligence, creativity, passions, strengths, pleasures, friendships and love. The subjects depicted in the photographs are continually encouraged with support from their families, friends, and communities. They are generous and participate actively in society. Valued by those who know them, they also provide us with wonderful life lessons. They are not just men, women, and children to whom something is owed—they are active agents in their own lives, in a position to give back. And it is no coincidence that the term intellectually challenged reflects the daily challenges they face, obstacles they have to meet and surmount, and they do so with grace. The 30 photographs and the stories behind each portrait have been compiled in a soon-to-be-published book. You can follow the project at www.chutregardez.com
Few lab technicians or coordinators ever see their names on “red hot papers” published in the top scientific journals. Fewer still ever encounter, on a personal level, the results of tests and experiments they run. The path that brought Rosemarie Grabs face to face with Karine and her mother, Hélène, is exceptional.

Working in a research lab wasn’t Rosemarie’s first career choice. Yet by good fortune, the career that more or less chose her is with a Montreal Children’s Hospital laboratory that has earned worldwide recognition for breakthroughs in diabetes research.

Rosemarie has shared in the growth of Dr. Constantin Polychronakos’s endocrine genetics lab from its outset, when she was the sole employee. She has seen the lab work shift from looking at proteins to DNA analysis and immunological testing. She now sees research opening the prospects for individualized medicine that twenty-first century technology brings.

An opening for a research technician brought Rosemarie to the Montreal Children’s Hospital in 1980, but she didn’t expect to work at the institution for long. She had just finished her Bachelor of Science and hoped to get a feel for research in Dr. Eleanor Colle’s endocrinology lab before re-applying for veterinary medicine.

Rosemarie had little idea how a day in the lab would unwind, or whether she had any affinity for research. Yet instead of a pathway into veterinary medicine, Rosemarie found another niche. “The dynamism – the fun – of trying to do research and solve a problem got hold of me,” she explains. “And here I am, still!” When Dr. Colle retired, Rosemarie brought 12 years of experience in diabetes research to Dr. Polychronakos’s lab.

The next best thing to curing diabetes

Among the experiments that Rosemarie has run is one that identified a rare genetic mutation as the cause of Karine’s diabetes, permitting her to switch from insulin injections to oral medication. A strong proponent of individualized medicine, Dr. Polychronakos was concerned with the 1% or 1,000 diabetic children in Canada who might be able to take a pill rather than injections, allowing them to produce their own insulin – “the next best thing to curing their diabetes,” as he has stated.

With a Jeans for Genes Day grant from the Canadian Gene Cure Foundation in 2005, the lab set out to review the DNA samples that it had collected over the years from children diagnosed with type 1 diabetes, to see if any had a genetic mutation that would permit the switch. It took a year to pinpoint Karine’s case, along with two others.

In a research hospital, Rosemarie explains, patients like Karine benefit from diagnostic tests that would not be cost-effective to run routinely in clinic. “In an ideal world we could run 20 tests on each patient to determine what the cause of diabetes is,” she says. The clinical norm is three tests, which do not always detect type 2 diabetes in young patients, or rare variants of type 1.

An unprecedented connection

How does it feel to learn of Karine’s long-term improvement? “It feels very, very good,” says Rosemarie. The level of connection that research technicians generally have with the subjects of tests is, she notes, “in theory, nothing... Samples get shipped to me with a number, and that’s it.” For those who work with the numbers that ensure subject anonymity, it is a rare gift for a patient’s family to come forward, as Karine’s family has done, with news of how the work of a lab has touched lives positively.
One morning in 2011, Michael Kolenko woke up crying. “He said his side was hurting,” says his mother Margaret Kolenko. “I thought that perhaps he may be constipated so I gave him a children’s laxative.”

But when Mikey was still complaining 15 minutes later, Margaret knew something was very wrong. “Call it mother’s intuition,” she says, “But I know my son. He is a boy who is never sick and has a high threshold for pain. I knew I needed to take him to the hospital.”

Fearing it was his appendix, Margaret rushed Mikey to the Children’s, where he was admitted right away. “They kept doing more and more tests,” she says. “X-rays, blood tests, urine tests. I knew they could see that something wasn’t right. The doctors kept asking me ‘Did he have blood in his urine? Fever? Vomiting?’ But he didn’t have any of those. He had no symptoms. All I could tell them was that he had a pain in his right side and that my intuition told me to take him to the Children’s.”

Mikey spent the night on the 7th floor at the MCH, while Margaret worried and paced. The following morning – Mother’s Day – a Computerized Tomography (CT scan) scan revealed a 5 x 5 x 5 centimeter mass on Mikey’s right kidney. He was diagnosed with a Wilms’ tumor, a rare type of kidney cancer that occurs in about 1 in every 250,000 children, and generally manifests itself when the child is between three and four years old. Wilms’ generally affects one kidney, and the exact cause is unknown.

Realizing they had to move quickly, Dr. Pramod Puligandla and his team set to work. After five hours of surgery, they successfully removed Mikey’s right kidney, and surgically placed a portacath – an implanted device that connects to a vein – in his upper chest to administer chemotherapy directly into his bloodstream.

“I couldn’t believe my baby boy had cancer. I kept asking myself, how did we get here? He is a healthy boy. Yesterday he had a pain in his side, and now he is in the operating room,” Margaret says. “In the blink of an eye our lives were changed forever.”

The family spoke to oncologist Dr. Catherine Vezina, who took them through each step, explaining how chemotherapy treatment would work to destroy any other potential cancer cells, and why it was important as a precautionary measure.

Mikey spent a total of five days at the MCH. He was monitored for an additional six weeks to ensure that the tumor hadn’t spread, and he underwent 19 weeks of chemotherapy treatment at the MCH Oncology Day Centre.

Mikey had his portacath removed by Dr. Puligandla on September 24, 2012, and May 7, 2013 marked the two-year anniversary of Mikey’s surgery. He will continue to have regular check-ups, scans and blood tests with Dr. Aida Daoud, but today he is active, cancer-free, and in good health. He knows how lucky he is, says his mother, so he prays for the friends he met while he was at the Children’s. “He’s so brave, and he has made me brave,” Margaret says. “He is my hero. Cancer took his right kidney, but he fought back, and he won.”

After many months of treatment, Mikey made a trip to the Mount Royal lookout on September 24 last year, the day his portacath was removed at the Montreal Children’s Hospital.
The University of California in San Francisco (UCSF) was the first institution in the world to perform open fetal surgery in 1981. Repairing birth defects in the womb was no longer science fiction—the unborn child had become a patient.

This tectonic shift in medicine had a direct impact on The Montreal Children’s Hospital (MCH) and the future of fetal medicine in Canada. At the MCH, the Fetal Diagnosis and Treatment Group (FDTG) was born. It is now one of the few specialty centres in the world that provides prenatal diagnosis, care for mothers who carry babies with congenital abnormalities, and medical and surgical intervention for the fetus.

Recognized as a Canadian leader in the emergent field of fetal therapy, the FDTG is the brainchild of Dr. Jean-Martin Laberge, who conducted fetal surgery research at the UCSF in 1984. “I wanted a front row seat to learn from the pioneer in fetal surgery,” he says. “The awe of intervening before birth, to save the unborn child, or to prevent or minimize severe consequences of malformations, attracted me to this nascent field.”

When he returned to Montreal, Dr. Laberge set up a multi-disciplinary fetal team at The Montreal Children’s Hospital, which attracted experts from other medical institutions. The Royal Victoria Hospital (RVH) was the first to partner with the MCH and the Jewish General Hospital and St. Mary’s Hospital came aboard a few years later.

“We were probably the first centre to have an integrated ‘fetal interest’ team in Canada, but we did not make the FDTG official until 15 years later at a press conference in 2000,” explains Dr. Laberge. Fetal interventionists on the team include pediatric surgeons, neurosurgeons, pediatric cardiologists, perinatologists, neonatologists and genetic counsellors.

But another event would soon thrust the FDTG into the limelight.

In December 2000, Dr. Laberge and his surgical team made international headlines when they performed the first EXIT procedure (Ex-utero Intrapartum Treatment) in Quebec. They operated on a 32-week gestation fetus with a massive teratoma attached to her neck while she was still in her mother’s womb. The benign, but life-threatening growth was larger than the baby’s head and weighed 1.4 kg, almost as much as she did once the tumour was removed (1.6 kg).

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(l. to r.) Lola Cartier, Genetic Counsellor, Dr. Jean-Martin Laberge, Pediatric Surgeon, and Andrea Secord, Genetic Counsellor are part of an experienced team that provides prenatal diagnosis and treatment of fetal abnormalities.
A total of 42 specialists participated in the risky childbirth and corrective surgery.

A modified caesarean section was performed while the mother was under deep maternal anesthesia to allow the uterus to relax and expose parts of the baby. The upper body and the teratoma were cautiously lifted from the womb and both were held for almost 40 minutes as Dr. Laberge and pediatric anesthesiologist Dr. Karen Brown inserted a breathing tube into the baby girl and checked its position by bronchoscopy. When her breathing was assured, the umbilical cord was clamped and little Liora was born.

Three hours after her birth, Dr. Laberge removed the teratoma in a complicated and delicate operation that lasted almost four hours. Liora was then admitted to the MCH’s neonatal intensive care unit where she stayed for the next three months. She is now a vibrant and happy 12 year old.

Today, the FDTG is recognized for its excellence and compassionate care. The highly accomplished multidisciplinary team of specialists and subspecialists provide different types of procedures, including prenatal intervention that can correct a number of birth defects, such as lung cysts, urinary blockages, certain types of tumours and cardiac defects. Open fetal surgery, during which the fetus is partially lifted out of the womb, is used to repair potentially devastating conditions such as spina bifida, a malformation of the spinal cord or its coverings; and fetoscopic surgery, which is one of the less invasive methods, is commonly used to treat twin-twin transfusion syndrome, a condition where a twin absorbs most of the blood supply at the expense of the other.

And the future of the FDTG continues to look bright. Dr. Laberge says services will be enhanced when the MCH and RVH move to the Glen site in 2015. “Working together under one roof will allow us to treat more babies before they take their first breath.”

Treating babies before they take their first breath (cont’d)
The MCH is holding its ANNUAL BBQ/GARAGE SALE!
Don't miss out on your chance to indulge in some summer fun on Thursday, June 20th! There will be lots of food, a garage and toy sale, as well as other entertainment outside the hospital, facing Lambert Close St. Tickets for the event are $3 and include 2 hotdogs, a snack, a drink and a dessert. See Security, TinyTim, Cafeteria or Les Tourelles T-105 to buy your tickets.

MCH Auxiliary
UPCOMING SALES ON 2B
Wednesday, June 19 – books
Wednesday, June 26 – videos, books and miscellaneous
Wednesday, July 3 – miscellaneous
Wednesday, July 10 – books

An Enchanted Journey raises $1,127,000!
This year’s Ball for The Children’s was held on May 23 at Windsor Station. Under the leadership of co-patrons of honour Isabelle Marcoux, Chair of the Board, TC Transcontinental Inc., François Olivier, President and Chief Executive Officer, TC Transcontinental Inc., Roland Lescure, Executive Vice-President and Chief Investment Officer, Caisse de dépôt et placement du Québec, and Susie O’Reilly, the event hit an all-time high, raising $1,127,000. Funds raised this year will support research, bursaries and ambulatory care.

COUREZ LA CHANCE DE GAGNER DES BILLETS DE SAISON POUR LES CANADIENS DE MONTRÉAL!
WIN SEASON TICKETS TO THE MONTREAL CANADIENS!

1 chance sur 1 000 de gagner!”
1 chance in 1,000 to win!”

Achetez vos billets dès maintenant sur fondationduchildren.com / Tickets on sale now at childrenfoundation.com ou appelez / call: 514-934-4846

Ce tirage est offert par le comité organisateur du Tournoi de golf de La Fondation de l’Hôpital de Montréal pour enfants. This raffle is offered by the organizing committee of The Montreal Children’s Hospital Foundation Golf Tournament.

* détails et règlements sur fondationduchildren.com / details and rules at childrenfoundation.com
The *Caring for Kids* Radiothon raised $1,460,000!
The 10th edition of the *Caring for Kids* Radiothon was an amazing day. Not only did more than 30 families from across Quebec gather in one place to share stories of hope, courage and care, but we collectively raised **$1,460,000 for the MCH Foundation**. Thank you to the incredible people at Virgin Radio 96, CHOM 97.7 and CJAD 800 Montreal for dedicating this day to the kids at the MCH, and to each and every person who listened, called, donated or volunteered at the event!

**MCH Public Relations and Communications Coffee Hour**
The Public Relations and Communications office will be in the MCH cafeteria on **June 19** with coffee and muffins—and our annual survey! Stop by on your break to get a copy of the survey—those who complete it will have a chance to win a $100 gift certificate for Place Alexis Nihon (accepted at almost all retailers and restaurants).

_WEDNESDAY, JUNE 19, MCH CAFETERIA_
9:30 to 10:30 a.m. / 2:15 to 3:15 p.m.

Our survey will also be available online at surveymonkey.com/s/ChezNousSurvey

**REMINDER TO ALL MCH EMPLOYEES**
If you have not received the gift (a USB bracelet) that was given out to MCH employees at the Awards of Excellence on May 8, 2013 – please stop by the MCH Public Relations office (F-372) between Monday and Thursday to pick it up.
HELP US CELEBRATE THE HISTORY OF THE CHILDREN’S THROUGH ART AND ARTIFACTS

As we transition to the new MUHC, departments, programs and teams are consolidating and merging in an effort to be ready for their new physical surroundings and in many instances, ways of working.

But another part of this transition includes not forgetting our past—who we were and how this has contributed to defining who we are today. This historical thread can be depicted through existing art and artifacts. In forging our path to the new MUHC, we would like to create a visual storyline—perhaps a museum of sorts—to remember where we came from, and how far we have come. To do this, we are in the process of building an inventory of all the art and artefacts in our hospitals today.

We ask that anyone who has historical artwork or artifacts in offices, clinics, departments or in storage that belong to the hospitals, please call Karine Raynor at ext. 71478. With your help, the journey from past to present will not be forgotten. Please note we will not take these items from you—we are simply building an inventory.

THE MCH FAMILY ADVISORY FORUM

The Family Advisory Forum (FAF) at the Montreal Children’s Hospital is a group of parents, family members and caregivers of children who have been patients or are currently patients at the hospital. The role of the FAF is to represent and protect the interests of patients and their families. The FAF executive includes Chairperson Joe Caprera, Vice Chairperson Wendy Longlade, Treasurer Alfie Randisi, Secretary Linda Jurick and Information Officer Claudette Woodgate. There are presently 24 members on the forum which is the largest number since the FAF’s inception. The members come from a variety of backgrounds and bring to the table a richness of experience, variety of ideas and valuable voluntary time. They all share the same goal: to ensure the best care possible for the children we treat. For more information on the FAF, contact Joe Caprera at jcaprera@yahoo.ca.

PROJECT SUNSHINE

Sunshine is always welcome after a long winter, especially when it comes from Project Sunshine, a non-profit organization based in Toronto. For the last two years, Giuseppe D’Asti and Sunita Kheterpal have been volunteering with Project Sunshine’s Quebec chapter, coordinating monthly volunteer programs at the Montreal Children’s Hospital. Volunteers transform hospital conference rooms and playrooms into a relaxing environment where caregivers receive massages from professional therapist, Jenni Lee, while Giuseppe and Sunita organize activities for patients and siblings.

“We like to play educational games with the kids,” says Giuseppe, a university student who plans to pursue a career in health care. “The patients range in age, so we have a good variety of board games, plus arts and crafts. Through this experience I’ve noticed that when a parent feels good, their child starts to feel better too.”

For more information about Project Sunshine please visit www.projectsunshine.org or contact Marie-France Haineault from Child Life at 22570.
MCH researchers and colleagues join in a program planning retreat
A retreat held on April 19 drew 38 participants from genetics and reproductive and maternal medicine to decide on the nature and leadership of a program proposal to the Research Institute of the MUHC (RI-MUHC). On the table was reorganization into one or more maternal and child health and development programs, with a single program leader or composite leadership.

“I was very impressed and surprised at the unanimity and enthusiasm for creating a single program incorporating the entire spectrum of research on human development and child health,” said Dr. Michael Kramer, a member of the program steering committee. “Very collaborative, constructive, and promising—augurs well for the future!”

Dr. Jacquetta Trasler, Director of Child Health Research at the RI-MUHC, said that this consensus works with the aim of the new programs. “We want to create an environment of interdisciplinary collaboration,” she explained. “We also want to set the stage for original, innovative research that allows translation of basic discoveries into health care and policies. By including our colleagues in basic, clinical and health outcomes research, we can build on—yet go beyond—the Prenatal and Childhood Origins of Disease theme in our submission for the $100 million Canada Foundation for Innovation grant awarded in 2008.”

AWARDS AND ACKNOWLEDGEMENTS
On May 7, the “MUHC 2012 Code Orange Simulation project” was awarded the 2013 Recognition Prize for Partnership and Support by the Quebec Minister of Health and Social Services during a Symposium on Civil Security. The MCH would like to thank Dr. Elene Khalil, Dr. Ilana Bank and Margaret Ruddy for all their hard work and dedication towards this project.

Dr. Sam Daniel was recently inducted into The American Laryngological, Rhinological and Otological Society, the most prestigious society in otolaryngology.

Patricia Wade, a Nursing Practice Development Educator in the MCH Operating Room, won three prizes at this year’s Operating Room Nurses Association of Canada (ORNAC) conference.

Dr. Jean-Martin Laberge and his wife, Dr. Louise Caouette-Laberge, pediatric plastic surgeon at Sainte-Justine, recently received the 2013 Humanitarian Award from the Collège des Médecins du Québec for their work in developing countries. The couple created Mission Sourires d’Afrique to help African children born with cleft lip and palate.

The MCH Audiology department deserves a big round of applause for the very successful training session they held in April. Almost 160 professionals participated in a discussion about how to best support families of newly diagnosed newborns with hearing loss by looking at Québec’s Universal Newborn Hearing Screening Program. Telehealth sites were also set up in different regions so that professionals could weigh in from across the province.

The MCH would like to thank our Food Services department for their exceptional work during this year’s Awards of Excellence tea on May 8. You helped make it a memorable experience for staff and award recipients!

MCH volunteers recently celebrated Volunteer Week with a special dinner – making it the first time all volunteers have reunited under the same roof! Volunteers from the Foundation, Auxiliary, Patient Services, plus the Youth Advisory Forum (YAF) and the Family Advisory Forum (FAF) joined in on the festivities. Volunteer coordinator Ann Hébert also said a few words in honour of Mr. Georges Martineau, a dedicated MCH volunteer who passed away recently at the age of 82. He volunteered for 28 years at the MCH and will forever be remembered for the detailed portraits and landscapes he drew for patients during his visits. Special thanks to Lucette Bennett (Auxiliary), Phyllis Djoboulian (Foundation), Imma Gidaro (FAF), Wendy Reis and Bertrand Dupuis (YAF), Rose Giunti (MCH Volunteer Services) and all the students from Miss Edgar’s and Miss Cramp’s who helped make the night such a success.