

SHARE & CARE

THE RECOVERY OF HOPE ~ THE HOPE OF RECOVERY

1977-2007

30
years

MISERY BECOMES MAGIC



A dazzling performance by Richard Kogan at our 30th anniversary Tchaikovsky concert

IF YOU MISSED IT, YOU REALLY MISSED SOMETHING.

Tchaikovsky was both a musical giant and a man brought low by a host of demons, including unrelenting depression, alcohol dependency and self-loathing due to his homosexuality. Fortunately for posterity, he was a compulsive diarist and wrote more than a thousand revelatory letters to his patron and confidante, Nadezhda von Meck.

Kogan unmasked the composer in all his flawed glory, while treating us to selections from the Romance, Opus 5, the Overture to Romeo & Juliet, the Fourth Symphony and the Sixth, the Pathétique. The Piano Concerto No. 1, played with a symphonic CD as accompaniment, brought the audience to its feet and his performance to a triumphant close.

Proceeds from the concert will be used to bolster and broaden AMI's growing list of activities in support of families dealing with mental illness. □



Kogan calls the last movement of the Pathétique Symphony "the most eloquent suicide note ever written"

Tchaikovsky: "Without music I would go insane."

In a return appearance for our second fundraising concert on June 6, Dr. Richard Kogan pulled out all the stops. The renowned New York-based pianist-cum-psychiatrist turned Tchaikovsky's life and *oeuvre* into an unforgettable evening of music, analytic insights, humor and juicy bits of biography.

A TIGER BY THE TAIL

How a dream was built on a mental illness nightmare

If you've been to the AMI office lately you've likely met Mike Santoro. He's been on the job as administrative assistant for over three years. What you probably don't know is that

Santoro leads another, vastly different life, one that involves website production, DVDs and documentary films.

And there's something else: Santoro has spent almost a lifetime coping with schizoaffective disorder, an illness that combines symptoms of schizophrenia and bipolar disorder. His first episode hit 25 years ago when he was 14.

Santoro has been fortunate. With the help of his medication he's now living the good life with wife Bonnie and daughter Chelsie, his own home and work he enjoys.

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Tiger ... continued from page 1

Ironically, he can thank his illness for directing him to the right place at the right time. In the late '80s his hospital referred him to *Projet ARC* (an organization, now closed, dedicated to reintegrating consumers into the community). He became the first client of Daniel Gervais, a case worker with a passion for film making.

Gervais was convinced that Santoro would be a fascinating subject for a documentary on mental illness, one that would give hope to consumers and their families. He sold *Projet ARC* on supporting the project and by 1995 the film was ready.

"This was another world for me," Santoro says, "the start of me talking about myself and my story — proving that someone with a mental illness could have a challenging but normal life." Santoro has presented the film well over 50 times to schools, hospitals and family organizations.

Today Santoro and Gervais, who has become a full-time documentary film maker, have glommed onto a much bigger idea.

The age of the Net

"I was sitting in at a presentation Mike made to AMI last November," says Gervais, "and I was overwhelmed by the audience reaction. So much had changed in Mike's life since our first film that I realized we needed to do an update." Another documentary, yes, eventually. But first, a website on the Internet, because through the Net they'd be able to deliver Mike's message to people everywhere.

www.mikesstory.com, "A story about perseverance and dedication," was given its official launch at AMI last April. Click on it and you'll find a news page of weekly articles, Santoro's blog, a movie episodes page of clips slated for inclusion in the future documentary, podcasts, a videocast page and a list of website links and partners.

For Gervais, who sometimes devotes as much as 10 hours a day to revising and editing, mikesstory.com has become a full-



Santoro preparing for a podcast

time job. Between the two of them, Santoro calculates, they've put in thousands of hours. They don't see it stopping any time soon.

The 80/20 formula

Despite his successful recovery, Santoro knows that his illness can do a nasty u-turn at any time. He's battling back with what he calls the 80/20 formula. "The 80 percent is everything I've been doing to prevent a relapse, all my work with psychiatrists, therapists and community workers, and the work I do to understand myself better and learn to deal with my symptoms. The 20 percent is my medication, which gives me the base I need to start from. I could fall sick tomorrow, but I want to reduce that likelihood any way I can."

Santoro's successful approach to his recovery will be turned into an educational DVD, which you'll be able to purchase on the website next fall.

Mike's dream

Santoro has been nourishing one idea for a very long time. He dreams of becoming a guest speaker and addressing large audiences about his illness and coping techniques. It's the theme that underlies both the website and the future documentary.



Gervais: in it for the long haul

The film will pull no punches. "We want to be totally realistic about mental illness," Santoro explains, "to show people the good and the bad. Without that impact we'd have just another TV show and that's not what we're after."

The camera will follow Santoro's life like a shadow. "Whatever happens

to him we'll use," adds Gervais. "And Mike's okay with that. We have a shooting plan, but we're sure to be making changes all the time. It just depends what happens along the way and what doors open for us." And, of course, the reaction from the public.

So far, so good. Hundreds of people have already connected to the website. Santoro has received a pile of e-mails from appreciative consumers and from people who have no connection with mental illness, but who say the site inspires them to follow their own dreams.

He and Gervais are thinking big, worldwide, in fact. With the Internet, they can reach people everywhere and they're convinced it will happen. Helping so many affected by mental illness — that will be the best reward of all. □



Edith Low-Beer, an honorary board of directors member, was honored by being named an Officer of the **Order of Quebec** in a ceremony in the National Assembly on June 20. Membership in the Order is considered Quebec's highest distinction

Facing the ugly facts

A two-day conference at the Douglas grapples with stigma from every angle

Members of community organizations, healthcare workers, consumers and relatives gathered at the Douglas Hospital last March 15-16 to discuss, dissect and, hopefully, to pinpoint some effective ways of combating the stigmatizing treatment of people suffering from mental illness.

Titled “**Stigma and mental illness: a vicious circle**,” the conference structured its agenda around three problem areas: stigma in the workplace, stigma in the media and stigma in mental health services. While no one expected to uncover blanket solutions to the stigma problem in two days, AMI’s managing director, Ella Amir, called the conference useful and a step in the right direction.

Amir and Loïse Forest, an AMI member who’s a tireless activist for the consumer movement, participated in the roundtable discussion on stigma in mental health services. Their addresses to the conference pulled no punches. Edited excerpts follow.

Ella Amir

The existence and prevalence of stigma in the mental health profession is so engrained that it has become the norm, especially in traditional psychiatric care.

Separate bathrooms and dining rooms are commonplace. Psychiatric wards and mental health centres group people, isolate them and set up an artificial environment. They reinforce the tendency for people to disengage, drop out and stay out.

The notion of forced treatment, forced hospitalization, forced medication and forced activities is especially stigmatizing.

Professional jargon ensures that stigma is alive and well. *Non-compliant, treatment-resistant, high or low functioning* are just some of the patronizing and



condescending terms commonly used. *Case management, placement and rehabilitation* denote passivity and the need

for someone else to do the work for you.

Stigma in the mental health profession is largely the result of the widely accepted attempt to reduce mental illness and its treatment to one single lowest common denominator. The medical model supports this attempt and has contributed to depriving consumers of their right to be equal members in society.

The recovery model acknowledges and validates the personal and subjective experience. It refers to the real experience of persons as they accept and overcome the challenges of their disability.

With our current level of knowledge we cannot cure mental illness. At best we can manage it. We will gain more

from investing efforts in strengthening the person’s abilities while hoping that it will also help in the face of a possible relapse.

Maybe we need to take a step back and look again at the education system that all professionals spend years in. Only then will we be able to take measures to correct these stigmatizing practices. I am confident that a careful, strategic application of recovery principles is likely to be followed by a reduction in both external and internal stigma.

Professional jargon ensures that stigma is alive and well.

Loïse Forest

When I was first approached to be part of this panel, I thought, WOW! Now I get to stigmatize the mental health system, which has caused endless suffering, loss of self-esteem and the snuffing out of hope. But being able to look back and forward now, I decided to try and help them change.

Most of the horror stories are created by physicians whose only concern is diagnosis and who still think the bio-medical approach is a cure-all. They might not be the majority, but this approach is deeply ingrained in the treatment of people with mental health problems.



The doctor who insults patients if they dare to disagree with him or take some unapproved-of initiative towards recovery;

the nurse who treats a 50-year old woman with a master’s degree in science as if she were five; the social worker who tries to make somebody

live in a group home with a traumatizing atmosphere — these things break the pattern of hope, of any kind of feeling that there is still hope, that we are still feeling alive despite the diagnosis.

Let’s look at a different approach: For years consumers of mental health services have been talking about recovery and empowerment. Recovery is a concept where the system accompanies us on a journey of hope by helping us find the

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MEMBERS ENDORSE AMI NAME CHANGE AT ANNUAL GENERAL MEETING

Action on Mental Illness

We've been this way before. Our very first name, Association of Relatives & Friends of the Mentally Ill (ARAFMI), became AMI-Québec Alliance pour les malades mentaux/Alliance for the Mentally Ill in 1984. Now it's time for another change. At our annual general meeting, members

approved a new name that, among other benefits, better reflects our evolution into the dynamic and proactive AMI of today.

Upon the completion of necessary legalities, AMI will be officially known as **AMI-Québec Agir contre la maladie mentale/Action on Mental Illness**.

Also at the meeting, our new board of directors was elected and awards of recognition were presented. There was a tribute to our founder, the late May Gruman, and to Monty Berger, in whose memory the AMI library has been dedicated. Jean Berger and Monty's daughter Joy unveiled the commemorative plaque.

Business concluded, everyone headed for the sweet table and viewed a showing of Mike's Story (see p. 1). The evening wound down with the buzz of friendly chitchat. Fortunately, some things at AMI never change. □



The Exemplary Psychiatrist Award to Suzanne Lamarre, psychiatrist-in-chief at St. Mary's Hospital, described by Warren Steiner as "an integral part of the psychiatric scene in Montreal."



To Bryna Feingold (l), marking 10 years of commitment to Share&Care, the Monty Berger Award for Exemplary Service, presented by Ella Amir

Board of Directors 2007-2008



EXECUTIVE COMMITTEE: (l-r) Joseph Lalla, secretary; Lorna Moscovitch, president; Claudia Ikeman, treasurer; Paul Rubin, immediate past president; Renée Griffiths, vice president; Annie Young, vice president

MEMBERS: Jean-Claude Benitah, Alison Clark, Elva Crawford, Moira Edwards, Sherry Ellen, Danielle Gonzalez, Judy Phillipson, Judy Ross, Lynn Ross, Norman Segalowitz, Joanne Smith, Sylvia Smith, Al Winslow

DIRECTORS EMERITUS: Marilyn Block, Queenie Grosz, Sylvia Klein, Dorothy McCullogh, Anita Miller, Evelyn Ortenberg, Monica Reznick, Sylvia Silver, Kay Simpson, Elizabeth Tremain



Volunteers of the Year, Connie Di Nardo and David Moscovitch. "The sort of volunteers whose legs AMI stands on," noted presenter Kimberley Jackson (centre)



"She not only walks the walk, she walks the extra mile," said Chana Werzberger (r) in presenting the Extra Mile Award to Sylvie Albert



Jean Berger (r) and Joy Berger display the plaque that will identify our newly named Monty Berger Library



Eleanor Beattie (r), cited for her "commitment to the ideal of community," accepts the AMI-Québec Award for Exemplary Service from Nancy Grayson

Photos of annual general meeting and Kogan concert by Mark Griffiths

SUMMER 2007

SUPPORT GROUPS

Mondays 7:30pm 4333 Côte Ste-Catherine Road
unless otherwise indicated

FAMILY for relatives

July 9, 23; August 6, 20; September 10, 17, 24

SOUTH SHORE for relatives

Wednesdays 6:30pm
2499 rue St-Georges, room 200, Le Moyne
July 4, 18; August 1, 15, 29; September 12, 26

PAC Parents of Adult Children

No meetings July or August
Resume at AMI September 11

SIBLINGS AND ADULT CHILDREN

July 23; August 20; September 17

DEPRESSION for consumers and relatives

July 23; August 20; September 24

DEPRESSION/BIPOLAR DISORDER for consumers and relatives

July 9; August 6; September 10

OBSESSIVE COMPULSIVE DISORDER for consumers and relatives

July 23; August 20; September 24

KALEIDOSCOPE for consumers

July 9; August 6; September 17

LIFELINE for consumers

Thursdays, 1pm
Alternative Centregens, 5770 Auteuil, Brossard

BOARD MEETINGS

Tuesdays 7:00pm at AMI
No meeting in July; August 7; September 4

Battle in the BEDROOM

**Millions of us wrestle
with sleep problems.
You're extra-vulnerable if
you have a mental illness**

Why is something so essential to our lives so apt to cause trouble? It's an unwelcome tie that binds us all — adults, children and the elderly, the healthy and the ill.

One person with answers is Roger Godbout. He's a professor of psychiatry at *Université de Montréal* and director of the sleep laboratory and clinic at *Hôpital Rivière-des-Prairies*, a psychiatric centre affiliated with the university.

The best-known sleep problem is insomnia, but there's also hypersomnia and parasomnia. "Insomnia tells you there's something wrong," Godbout says, "It could be psychological — stress, anxiety, apprehension — or something physical, such as arthritis, heartburn or headaches. It could also be aging, diet [think wine or coffee] or a mental health condition. You have trouble falling asleep or staying asleep. You wake up too early. The next day you're tired and irritable, slow to react and remember. It's hard to concentrate."

Hypersomnia is having too much sleep. "It's normal to feel drowsy around two or three o'clock after lunch," says Godbout. "But with hypersomnia people are sometimes so sleepy throughout the day that they can't work. Others sleep 14, 15, 16 hours at night." Narcolepsy, one form of hypersomnia, has neurological roots. Narcoleptics often sleep poorly at night, but get uncontrollable sleep attacks during the day. Anywhere from half to one percent

of the population suffers from narcolepsy. Parasomnia involves abnormal nighttime behaviors: sleepwalking, sleep-talking, teeth-grinding. Your brain is asleep but your body is wide-awake. Completely oblivious, you can stroll into your closet, curl up in the cold outside or fall from an open window. Parasomnia is not unusual in children and increases with

Not a panacea

We tend to think of sleep as a healer. Not always, Godbout notes. "REM-type sleep puts a lot of pressure on the autonomic nervous system, so it quickens your heartbeat and breathing. If REM derails at any point it can trigger symptoms. Some pre-existing medical conditions [think cardiac] can recur or worsen. In fact, some conditions, including epilepsy, headaches and asthma, might appear only during sleep."



Godbout with Elyse Chevrier, biomedical technician and coordinator of lab activities

disturbances can also result from post-traumatic stress disorder. With bipolar disorder, sleep starts to deteriorate one or two nights before the mood shifts from depressive to manic. Once it swings back, sleep improves.

of the population suffers from narcolepsy.

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Godbout found the lure of sleep irresistible

You might expect schizophrenia would present a special set of sleep disorders, but that's not the case. In fact, schizophrenia, depression and a majority of psychiatric disorders share the same problems of too much light sleep and not enough deep slow-wave sleep. But whereas 25 percent is the number Godbout cites among mentally healthy populations who complain about poor sleep, questionnaire responses show that figure rises to 50 percent and more among people suffering from depression or schizophrenia.

Medication is a mixed blessing. Every pill will affect sleep somehow, either helping or worsening the problem. Physicians need to balance that reality with the patient's personality and sleep requirements. Taking medication earlier or later in the day is one strategy. People on meds soon realize, however, that if their daily life is improved,

they may have to accept the tradeoff that their sleep is being compromised.

Not for adults only

Children also suffer from sleep problems. Godbout hears a familiar litany of complaints about anxiety, stress, poor concentration, exhaustion and depressed moods.

Rivière-des-Prairies Hospital treats mostly children and adolescents. Godbout's lab has two mandates: research and clinical work. "We're interested in learning how poor sleep impacts daytime functioning," he says, "and how a medical, psychological or psychiatric condition might impact sleep organization. It's a vicious circle."

The clinical work involves recording patients, mostly young adolescents, with anxiety disorders, depression, ADHD, psychosis or bipolar disorder. They're looking for disturbances such as sleep apnea that might interfere with the patients' general medical state. They're also digging deeper for what Godbout calls micro-signs, tiny elements of sleep that can provide a clearer picture of the patients' condition.

The adult equivalent of the *Rivière-des-Prairies* Hospital is *Louis-H.-Lafontaine* and Godbout directs an identical operation there.

His first career choice wasn't sleep, but clinical psychology and basic neuroscience. He switched studies when he grew fascinated with sleep as being "the perfect interface between mind and body." His attraction has become an all-consuming passion, particularly when the discussion turns to the importance of sleep and how mindlessly we all abuse it.

One worry: few of us sleep enough. "Children lack concentration at school because they're playing video games and turning in way too late," he says. "But the school bus still shows up at 7:30 next morning. Adolescents chronically miss an hour and more of sleep each night because they're just not tired until later. I've seen figures showing that

with only 45 minutes more sleep each night a teenager's marks will go from B to B+ and from B+ to A. I'm trying to sell school boards on considering a later start."

As adults, we work longer hours and sacrifice sleep to spend more quality time with our family and friends. That compromises our immune system and hurts our physical and psychological health. A few years ago, Statistics Canada figures revealed that 20 percent of workers and civil servants were responsible for bad decisions due to lack of sleep. The cost of their mistakes: likely billions of dollars.

Later this year a dream will be realized when Godbout's *Rivière-des-Prairies* lab expands into a major sleep-disorder clinic. They'll be doing both evaluations and diagnoses and suggesting treatment plans. "It'll be the first clinic of its kind in Quebec," he says, "and it's badly needed. We'll start with patients referred by physicians here or from our partner hospitals. Eventually, I hope, we'll service the entire province." □

Poor sleep is so identified with depression it's part of the diagnosis.

TRIBUTES & MEMORIALS

In honor of Lee Pik

Irene and Rubin Dacks
Ted Silverman

In honor of Mrs. M. Perlman

Marylin Block

In honor of Annie Young

Vera Wiener

In honor of Claire Socransky

Marylin Block

In honor of Lina Rappaport

Freda Siegal
Eva, Herbie and family

In honor of Sherry Ellen

Jo-Jo and Brahm Gelfand

In honor of The Rev. Shirley Smith

Judy and Lynn Ross

In honor of Alice Cheifetz

Patti and Simon Elster

In memory of Mary Zavergiu

Vivianne Hebert

In memory of Tova Sochaczewski Marder

Claudia and Jerry Ikeman

In memory of Steve Young

Kay Simpson
Sylvia Klein

In memory of Sybil Kert

Fran and Howard Brenhouse

In memory of Helen Steinberg

Pat and Paul Rubin

In memory of Joseph Moses

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In memory of Joan Anna-Maria Di Chiaro

Monette and Jean-Guy Choquette

In memory of May Gruman

Barbie and Lenny Cohen
Marilyn and Al Fraiberg
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Sylvia and Max Silver

Riva and Carl Gelber

Sylvia and Bill Klein

Pat and Paul Rubin

Joanne Smith

Ella Amir

In memory of Daniel Rosenberg

Kimberley, Hugo and family

Marian Gruman

Patti Elster Gruman

Thelma and Dave Wolfe

Kay Simpson

Connie Di Nardo

Marylin, Jeffrey and Jonathan Block

Sherry Ellen

Lorna and David Moscovitch

Claudia and Jerry Ikeman

Sylvia and Bill Klein

Tammy, Jamie, Ben and Rebecca Tepper

Sue and Nat Tepper

Sylvia and Max Silver

Joanne Smith

Ella Amir

In memory of Monty Berger

Joanne Smith

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5253 Décarie, Suite 200, Montréal, Québec H3W 3C3

Stigma ... continued from page 3

tools, the will, the responsibility and strength necessary to learn to live with our problems and learn from them rather than hide them with the help of numbing medication. It informs us about our problems, helps us try to find ways to take them in stride, encourages and supports us while we learn.

To look at us only as mentally ill people, patients, is to stigmatize us and discriminate against us. It is putting us in boxes that only you know how to open. By doing so, you deny the expertise we have developed that could open new paths to recovery. You spread the stigma and discrimination to those who love us and to the media. Marginalization of the worst kind becomes a constant in our lives.

Accept our differences, help us live with and through them. See us, really look at us, even in our worst moments, our hardest suffering. Educate us about our problems, educate the public and last, but not least, educate the media.

Believe in us. We are citizens of your world and an integral part of your future. ☐



This issue of *Share&Care* has been made possible by an educational grant from Janssen-Ortho.

amiquebec

Alliance pour les malades mentaux Inc.
Alliance for the Mentally Ill

AMI-Québec, a grassroots organization, is committed to helping families manage the effects of mental illness through support, education, guidance and advocacy. By promoting understanding, we work to dispel the stigma still surrounding mental illness, thereby helping to create communities that offer new hope for meaningful lives.

Mental illnesses, known to be biologically-based brain disorders, can profoundly disrupt a person's ability to think, feel and relate to others. Mental illness affects not only individuals, but also their families, friends and everyone around them.

Lorna Moscovitch, *President*
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SHARE&CARE

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Ella Amir, *Managing Editor*
Bryna Feingold, *Associate Editor*
Liane Keightley, *Designer*

Articles and comments are invited. Anonymity will be respected if requested. Guest articles reflect the opinions of the authors and do not necessarily reflect the views of AMI-Québec.
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