THE RECOVERY OF HOPE ~ THE HOPE OF RECOVERY

# NO TOWN LIKE IT

In medieval times, when the mentally ill were caged and carted to fairs like animals, they were welcomed and cared for by families in the tiny

Belgian town of Geel.

# We offer this heartwarming account as a gift of hope to AMI members in 2015

is and Luc sat squabbling at the dinner table. Luc was going to camp for 10 days, Dis for only five. "Dis gets jealous," explained Toni Smit, their foster mother. The voices grew shriller, then after a few minutes the two men got up and cleared the dishes.

Luc, 48, suffers from OCD. He was shunted off to a psychiatric hospital and eventually he wound up in Geel, where he lives with Smit and her husband.

Dis, a much older man, came to Geel in 1938, living with one family through three

generations before being fostered by the Smits.

"Our guests are part of the family. We love them," said Toni.

When Geel's population numbered 15,000, there were 3,800 psychiatric patients living in the community and moving freely about town, attracting no more attention than any other citizen would. Today the town population has

> grown to 35,000 and some 700 families foster "boarders," as they're known.

They suffer from serious mental illnesses; about half also have what's described as "a mild mental handicap."

Geel is one of a kind. It's acknowledged as the gold standard of community care for psychiatric patients, a model that other jurisdictions have begun to adopt.

#### The legend of Dymphna

It all started, so they say, in the seventh century when an Irish princess named Dymphna refused the advances of her father and fled to Geel. The man followed and murdered her there. The town built a church in her name and Geel became a religious shrine. Dymphna was canonized as patron saint of the mentally ill.

A side door of St. Dymphna's church opens onto the sick room, where in the Middle Ages the rich brought their mad children and institutions for the poor brought cartloads of shackled men. In time the church was overwhelmed and by the fourteenth century local families began to take in the afflicted. It was understood among the townspeople that they were chosen by God to help people with mental illness.



Dis and Luc, just like family

A nineteenth-century Belgian law required "mad people" to live under lock and key in an asylum. But Geel, with its exceptional history, was exempted — for economic as much as humanitarian reasons. Patients provided cheap labor for their work on farms, in bicycle shops and houses. There was no stigma involved. The patients were also part of the Geel soccer team and the town band. In much more recent times, good triumphed over evil in a classic confrontation: the Nazis, who were quick to exterminate the mentally ill elsewhere, left Geel untouched.

#### Well organized

The family-care system today is overseen by the public psychiatric hospital. Ninety-eight percent of their patients come

continued on page 3



A Gothic church was erected in 1349 on the site of the first St. Dymphna's

# INVISIBLE AND INVALUABLE

Last Labor Day the Globe and Mail ran an op-ed piece by Sherri Torjman, vice president of the Caledon Institute of Social Policy. It examined the difficulties faced by millions of unpaid caregivers in Canada caring for parents or severely disabled individuals. Torjman proposed several changes to improve an unfair and decidedly un-pretty picture.

abour Day typically comes with a

barrage of reports on the status of work in Canada. We need this information to understand both current and future

No individual should be driven into poverty because of caregiving responsibilities.

prospects for Canadian workers. But there is another group of essential workers about whom little will have been written.

These are the 8.1 million informal caregivers who provide some form of care to elderly parents or individuals with severe or prolonged disabilities. In 2012, Statistics Canada reported, 28 percent of Canadians aged 15 and over cared for a family member or friend with a long-term health condition, disability or aging needs. Mental illness figured in seven percent of those caregiving cases, topped only by age-related conditions, cancer and cardiovascular disease.

Caregivers deliver these tasks without pay. They make up a vast but largely unrecognized and hidden work force in the country.

In fact, unpaid caregivers provide more than 80 percent of the care required by individuals with long-term conditions and contribute an estimated \$5 billion of unpaid labour a year to the healthcare system. One report pegged this figure as closer to an annual \$25 billion if all the wide-ranging tasks performed by caregivers are included in the calculation.

Either way, the sum is largely irrelevant. Both individually and collectively, caregiver contributions are incalculable and invaluable because they add profoundly to the quality of life of those being cared for.

But the fact that caregivers are unpaid has meant that both their contributions and their concerns have been ignored. Their "invisibility" also results from women historically providing most of the unpaid care. Although the ratio is changing, they are still automatically expected to pick up these responsibilities as part of the caregiving role they typically assume in society.

Data from that same Statistics Canada survey show that caregiving responsibilities typically fall to those aged 45 to 64. Most informal caregivers of this age also likely participate in the paid labour market — unless they have to withdraw because of caregiving demands.

The demographics mean that employ-

ers must come to terms with caregiving realities, which will only grow with Canada's aging population. Businesses will

have to allow more time and work flexibility, particularly for the care of persons with remissions and periods of good functioning — all unpredictable.

Governments can provide more assistance with expensive health-related costs. They can modify income-security policies to allow some time off for caregiving. Employment Insurance needs a more generous approach in this regard.

Neither should workers who must take some time for caregiving be penalized in their pension vesting. Several countries have special pensions intended specifically for caregivers. Others make pension contributions on behalf of caregivers to avoid later penalty for lost employment time during working years. No individual should be driven into poverty because of caregiving responsibilities.

We need to pay attention to the informal caregivers who show up nowhere in the employment numbers, but figure so prominently in real life.  $\Box$ 

Text has been edited for length considerations.

# There are changes to T2201, the application form for a disability tax credit certificate.

### Ask us for help

ttawa recently announced modifications to form T2201. It's the one that must be filled out in order to be eligible for the disability tax credit.

The application form needs to be completed both by a qualified practitioner and the person with a disability. Once the form is approved and a disability tax credit certificate issued, the applicant will be eligible for three important federal programs.

- If he or she has revenue and files a federal or provincial tax form, a substantial amount of money may be deducted, depending on the income level.
- 2. The individual can participate in the federal government's Registered Disability Savings Plan,

- a way of securing a more comfortable future.
- 3. Testamentary trusts are often used by families as a strategy to ensure the financial future of their relative with a disability. These trusts take effect once the family is deceased.

#### AMI to your assistance

We know that filling out form T2201 may present difficulties for some families. On the other hand, there could be negative financial consequences if you don't apply.

Your best move: speak to us if you have a problem applying for the disability tax credit certificate. An experienced member of our Political Action committee will be available to help you. Call the office, 514-486-1448. 1-877-303-0264 outside Montreal. □

#### Our 21st Low-Beer Memorial Lecture

e witnessed human behavior at its worst and came away psychologically wounded himself. Afghanistan, Cambodia, Lebanon and especially the Rwandan genocide will do that to a soldier, even a seasoned lieutenant-colonel like Grenier, chalking up close to 30 years of military service.

Reluctant at first to ask a superior for any sort of professional help, Grenier suffered

in silence for six years before being diagnosed with post-traumatic stress disorder and depression in 2000. That desperate time, which included a narrowly-averted suicide, something he'd been coolly



planning for six weeks, served him in a totally unexpected way. His concern turned to other soldiers living and grieving with their own trauma. The more he read and learned. the more he questioned why the clinical help the troops were getting wasn't improving their lot by very much. What was lacking, he concluded, was the empathy and comfort that could be provided only by someone who had experienced

similar military ordeals. Grenier became a dedicated — obsessed might be more accurate — advocate for adding peer support to soldiers' mental healthcare programs.

Grenier in no way denigrates the work of healthcare professionals. To this day he continues seeing a psychiatrist and obediently takes his medication. "But that shouldn't be the sum of it," he

# THE STATUS QUO MUST GO

Stéphane Grenier makes a passionate case for adding peer support to clinical help as the next step to better mental healthcare

maintains. Calling on his own history, he asks: "What happens to a depressed person between medical appointments? Those are the dark times we need to worry about. That's when breaking the isolation through peer support could make all the difference. Nobody commits suicide in a therapist's office. It happens with a car crash, a gun, a bridge or an overdose when no one else is there."

When Grenier retired from the army in 2012, he had already devoted a decade to developing peer-support and education programs for the military. One such program now teaches peer-based mental health to over 20,000 personnel yearly.

Today this self-taught amateur, as Grenier calls himself, has his own consulting firm and delivers his peer-support message to organizations in the healthcare sector and the workplace. His efforts haven't gone unnoticed. Grenier received a Commendation for the help he provided in postwar Rwanda. He's been awarded a Meritorious Service Cross by the Governor General of Canada and a Champion of Mental Health Award by the Canadian Alliance on Mental Illness and Mental Health.

#### In a nutshell

During a visit to Halifax for a mental health conference a while back, Grenier found himself unavoidably privy to an elevator conversation. "Nancy was away for six months and only one person reached out to ask, 'How's it going?'" a woman mentioned.

Grenier recalls thinking that the support of peer understanding may well have shortened Nancy's recovery time. "There must be hundreds like her," he told his audience. "It's another example of how we've abdicated our responsibility to others."

Grenier has written: At a time when society is arguably more fragmented than ever before, when technology and social media have overtaken face-to-face communication, the power of human interaction has never been greater.

And the most powerful way for a peer to reach out? "It's simple," says Grenier. "You just start with two little words. 'Me, too.'" □

Geel ... continued from page 1

from other institutions; most have had no contact with their birth families for years. The hospital also provides therapy through sport, work, cooking and gardening, but it's their foster-family program that has put them on the map.

Those living in the community remain officially wards of the hospital and placements are carefully monitored. To begin the fostering process, an evaluation is

done. (Violent patients are not considered for family care.) Next, patients live for a while in one of the smaller houses on the hospital grounds to see how they cope with a more homelike environment. They're given basic chores to do and are taken on brief excursions. Can they ride a bike, the most popular means of transportation? Do they understand traffic lights and how to handle cash?

Patients who prove comfortable with their new freedoms are placed with foster families. The motivation certainly isn't money: hosts receive the equivalent of \$13 a day to offset expenses. In return, they provide individual rooms for their boarders and a normal family life.

The hospital maintains a hands-off policy. A treatment team makes unannounced visits every couple of weeks for a chat and to drop off any medication. The rest is left to the families, who are told to

continued on page 8

#### **Book Review**

Suspicious Minds: How culture shapes madness, Ian Gold and Joel Gold, (Simon & Schuster)

# Ever had the suspicion you're being watched?

aybe you've taken to checking for cameras watching you when you're out and about. With the growing use of surveillance devices and grim accounts of governments spying on their own citizens, a number of us have begun feeling paranoid.

For those already prone to psychosis, the ever-watchful eye of our digital age has become a hook on which to hang their belief that external forces are influencing their thoughts and manipulating reality.

Remember the hit movie of 1998 called *The Truman Show*? Jim Carrey played Truman Burbank, a man whose life was being staged by paid players and filmed for TV without his knowledge or consent.

Now, in *Suspicious Minds*, the Gold brothers Ian (McGill research chair in philosophy and psychiatry) and Joel (a psychiatrist at New York University) have referenced the movie title to examine a concept they call the Truman Show delusion. Their provocative premise is that our culture may be affecting our mental health.

In the years following 9/11, a number

of Joel's patients began insisting that the terrorist attacks and other events in their lives were actually staged to boost their reactions and attain higher TV ratings levels. Other psychiatrists reported hearing similar delusional complaints. The two brothers were intrigued with the thought that culture might be contributing to mental illness. Their collaboration ultimately led to *Suspicious Minds*. In it they define the Truman Show delusion as the belief that one is the unwilling star of his own reality show, his every action televised to millions of viewers.

The book opens with a recounting of how psychosis has been explained and treated throughout history, from Galen to Freud to the dawn of the psychopharmacological era in the '70s. The writers determined that today's accepted purely-biological theory—neurons in the brain misfiring—is far from flawless. They provide well-established evidence of the ways the cultural environment is influencing mental illness and illustrate the psychological harm it can be doing.

One of the book's central tenets is the



theory that long ago the human brain developed what the authors call a "suspicion system," a survival mechanism that looks for signs of danger and various kinds of threats posed by those around us. A healthy suspicion system makes our lives safer through "heightened responses to ambiguous signs of social danger." To the extent that our social world becomes more threatening, more pressure will inevitably be put on our mental life. As a result, our suspicion system can begin to malfunction, sounding the alarm without good reason. The Golds hypothesize that our era, with its information overload and swift technological and social changes, provides precisely the kind of environment that could overwhelm the suspicion system in some of us. As they

> note, "People predisposed to certain mental illnesses, such as schizophrenia and bipolar disorder, are very sensitive to fears of being watched and manipulated by others. Our culture could be pushing them over the edge."

> Suspicious Minds toggles between theoretical discussions of mental illness and anecdotes about some of the many delusional patients Joel has treated. It's both entertaining and alarming. And at the end we're left with an unsettling question:

Could our culture be making us crazy?  $\Box$ 

Suspicious Minds: How culture shapes madness is available in our library.

Edited from publications.mcgill.ca/ mcgillnews and bostonglobe.com/ arts/books.

#### **Inspired by Geel?**

Sweden also believes there's no place like home. Through its program called Healing Homes, the Family Care Foundation places people suffering from severe mental illnesses, includ-



ing schizophrenia, with host families. These are usually families farming in the countryside and the people they welcome have previously failed to benefit from traditional psychiatry.

Their new life together includes help for the families and, for their new members, intensive therapy and support

as they strive to live free of medication. Diagnosis has little relevance. What counts is that everybody participates in building a pleasant life of mutual respect.

For a free video about Healing Homes, visit http://wildtruth.net/dvd/healinghomes

## "THANKS A MILLION."

# Nominate someone whose work you admire for an AMI award or recognition

ood deeds deserve applause. If you know someone whose exceptional efforts are helping us achieve our goals, a nomination for an AMI award or recognition is a fine way to show your appreciation.

Mail or email us (**info@amiquebec.org**) your choice or choices with a brief rationale for each. Deadline for submissions is March 1, so hop to it. Call us if you need more information or help. Presentations will be made in June at our annual general meeting. The current board of directors makes the final decision.

#### **Monty Berger Award for Exemplary Service**

Presented to a volunteer, usually an AMI member, who has made a significant contribution to our organization over an extended period of time.

#### **AMI-Québec Award for Exemplary Service**

For someone working in the field of mental health. Selection criteria include extraordinary care to those with mental illness, guidance and support to families and active support of our goals.

#### **Exemplary Psychiatrist Award**

Presented to psychiatrists who endorse our agenda by guiding and supporting families, sensitizing health professionals to the difficulties families face, promoting the inclusion of family members in treatment teams and increasing public awareness of mental illness.

#### Volunteer of the Year

Awarded for service to AMI during the previous 12 months that far exceeded the norm along with outstanding and inspiring dedication to our objectives.

#### The Extra Mile Award

Presented to an individual or organization for special efforts to further the understanding of mental illness.  $\Box$ 

#### WANTED: A TOP-NOTCH BOARD OF DIRECTORS

#### You can help make it happen

every year at this time we call for nominations for our next board of directors. How important is this? Very. Because the better our board, the more effective AMI will be as an organization.

Our members hold the key to making it happen. If you know an enthusiastic person dedicated to seeing us reach our goals, submit your nomination, mail or email (**info@amiquebec.org**), along with a brief rationale for your choice. Multiple nominations are welcome.

Deadline for submissions is March 1. Board elections are held at our annual general meeting in June.  $\Box$ 

# **WINTER 2015**

#### **SUPPORT GROUPS**

For details visit amiquebec.org/programs-support

Mondays 7:00pm 4333 Côte Ste-Catherine Road unless otherwise indicated. No registration necessary

**FAMILY** for relatives and friends only

January 5, 12, 19; February 2, 9, 16; March 2, 16, 30

**SIBLINGS AND ADULT CHILDREN for relatives only** *January 12; February 9; March 16* 

**BIPOLAR DISORDER** for family, friends and people with mental illness

January 19; February 16; March 30

**DEPRESSION** for family, friends and people with mental illness

January 5; February 2; March 2

**OBSESSIVE COMPULSIVE DISORDER** 

for family, friends and people with mental illness January 12; February 9; March 16

HOARDING GROUP (in collaboration with Quebec OCD Foundation) for family, friends and people with mental illness

January 19; February 16; March 30

KALEIDOSCOPE for people with mental illness only

January 12; February 9; March 16

**ANXIETY** for family, friends and people with mental illness

January 5; February 2; March 2

**SOUTH SHORE** for relatives

Wednesdays 6:30pm Greenfield Park Baptist Church, 598 Bellevue North, Greenfield Park

January 7, 21; February 4, 18; March 4, 18

LIFELINE for people with mental illness

Alternative Centregers, 3820 Montée St-Hubert in St-Hubert. Call 450-651-0651 for dates and times

Registration required for programs below. Call 514-486-1448 for details or to register

**COPING WORKSHOPS** for caregivers only

January 27; March 24

**EDUCATION** families living with mental illness

4-session program begins March 25

**ROUNDTABLE DISCUSSIONS** 

February 18; March 18

**TELE-WORKSHOPS** 

January 14; February 11; March 11

#### **BOARD MEETINGS**

Tuesdays 7:00pm at AMI February 3; March 3

# OUT OF THE CONVERSATION LOOP ONCE AGAIN

## Schizophrenia can keep you sidelined by robbing you of your communication skills. Here's how you can regain the upper hand

All the others are talking around you, but you're ill at ease, awkward, unable to join the conversation. It's called social exclusion and it's a problem for many people with schizophrenia.

Believe it or not, Hollywood could be coming to the rescue.

Motion capture is a process that digitally records movement in unprecedented detail. It's the magic behind the amazing animation in the science fiction movie *Avatar*. Now that same technology has been used to study patterns of communication among clinical populations to learn more about how people relate to each other and the barriers that can deter easy communication.

#### More important than words

A research study using motion capture technology revealed some surprising facts. First, rapport between people is established in less than 30 seconds. Second, for anyone with schizophrenia the biggest stumbling block in those 30 seconds isn't words, but body language, everything from facial expressions, gestures and eye contact to sitting, standing and walking posture. This nonverbal behavior can rep-

#### **STAY INFORMED**

Our website is updated regularly with the latest news about our programs, services and upcoming events. Get the good habit of checking our homepage often. There's always something happening. www.amiquebec.org.

resent up to 70 percent of actual communication. When it's missing or inappropriate, it can derail a conversation. When it happens repeatedly, a person feels more and more excluded and a sense of isolation begins to set in.

# How schizophrenia isolates

The researchers found that when participants with schizophrenia spoke, they displayed fewer speaking gestures than other people; as listeners, they nodded less. They were more withdrawn and found it harder to engage in conversation. Even during the critical first 30 seconds they appeared marginalized or sidelined and participated less actively in the interaction. Although their involvement increased with time,

the first impression that was made lingered on.

As is well known, those who have good interpersonal relationships tend to enjoy better health outcomes. So it's encouraging that motion capture technology may ultimately point the way to new approaches of treating those who feel hindered by their poor nonverbal behavior.

Meanwhile, a simpler — and fun — way of looking at the quirks and kinks that pepper just about everyone's con-

# Six ways to better rapport

- 1. Straighten your posture. Convey confidence and competence by holding your head up, standing tall and sitting up straight.
- **2. Smile.** It's a universal sign of welcome.
- **3. Make eye contact.** Looking directly at another person in conversation indicates interest and openness. It's an important nonverbal skill you need to master.
- **4. Lean in slightly.** Leaning forward (without invading another's space) shows you're interested and engaged.
- **5. Raise your eyebrows.** Raised eyebrows signal recognition and acknowledgement. Opening your eyes wider will raise your eyebrows just enough to show interest.
- **6. Shake hands.** During a first introduction shaking hands is the quickest, most effective way to establish rapport. Research shows it takes on average three hours of continuous interaction to develop the same level of rapport you can establish with a single handshake.

versations is to videotape yourself or others engaged in casual discussion and take a close look at the messages being conveyed.  $\Box$ 

Condensed and adapted from *Case Study of Motion Capture Technology* and *From Screening Room to Hospital Room* by Karen S. White, *SZ Magazine*, summer 2014.

## Finding needles in a haystack

# Researchers strike it rich, discover a major new group of schizophrenia triggers

worldwide consortium of scientists, Canadians included, have now identified more than 100 locations in the human genome associated with the risk of developing schizophrenia. Their most recent study uncovered 83 locations of genetic variations in the DNA of people with the illness. That brings the total of known locations to 108. The discovery makes a compelling case for schizophrenia's genetic underpinnings.

"We now have a whole new avenue of research to pursue," says Jo Knight, a senior scientist with the Centre for Addiction and Mental Health in Toronto, who was part of the research group. "It's like being handed a huge haystack with a large number of needles hidden inside. We know we have the right haystack and we know the needles are in there. Now we just have to find them."

Those needles that raise the potential for someone developing schizophrenia are genetic mutations. The new findings implicate genes expressed in brain tissue, particularly the ones related to the functioning of neurons and the pathways that enable intercellular chemical and electrical signaling.

There's more than one theory, Knight noted, as to why someone might be susceptible to developing schizophrenia. One prevalent belief holds that it's caused by a combination of many different genes as well as environmental triggers.

Another, intriguing hypothesis is that genes active in immune system functioning may also be involved. If so, this suggests that the devastating illness could be an autoimmune disease, at least in part.

Schizophrenia affects one in every 100 people worldwide. In Canada alone the price tag of healthcare, social costs and lost productivity from this single illness runs to an estimated 6.85 billion yearly.  $\Box$ 

From a report by Sheryl Ubelacker, Canadian Press.

#### TRIBUTES & MEMORIALS

In honor of Daniel Drudi Leonard Drudi

In honor of Paul Rubin Edward Schachter

In honor of Dr. Daniel Frank Fran, Michael and Howard Brenhouse

In honor of Barbara and Abe Weiss Fran, Michael and Howard Brenhouse

In honor of Faigie Stark

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Lynn and Andy Nulman
Susan Sofer
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Eileen Waxman

Bernice and Harold Yancovich

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In honor of Norma Nutkevitch Lynn and Andy Nulman

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In honor of Carole Spector Claudia Ikeman

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In honor of Barbara and Jerry Sheiner Rickie Heft

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In honor of Lillian Mauer Barbara and Jerry Sheiner

In honor of Brenda Cormier's Walk for Mental Health

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Dino Forgione Enzo Gabrielli Alana Geller Audrey Hadida

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In honor of Kay Simpson Janis North

In honor of Kay and Don Simpson Sylvia Klein

In memory of Robin Williams Derek Seguin

In memory of Deborah Kopelman Faigie Stark

In memory of Pieter Boudens Beppie Boudens-Alexander

In memory of Jeffrey Zemel

Judy Gardos Robin Schiller

In loving memory of Liz Kane Sally McNamara

In memory of David Tencer Lynn and Andy Nulman

In memory of Hilary Griffiths Elizabeth Mayor

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In memory of Geoffrey Sachs

Lynn Harris Nulman Pam Litman

In memory of Mary Elizabeth Quinlan Katherine Stern

In memory of Dennis Vossos Eleanor Beattie

AMI-Québec extends sympathy to the bereaved and appreciation to all donors for their generosity. If you wish to honor someone with a donation, please phone 514-486-1448 or visit amiquebec.org/donate/.

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Geel ... continued from page 3

simply carry on as they normally would.

At any point, the family or boarder can end the relationship, yet that seldom happens. Should the original foster parents die, one of their children usually takes over.

And the rate of recovery? Says a hospital spokesperson: "They always get better. When a patient is placed with a family, motor function improves, medication levels go down. More important, there's healing after a lifetime of rejection."

Visiting skeptics can't believe a town can live so comfortably with so many mentally ill people. One such visitor asked about police interventions. In 10 years, the hospital replied, there have been three, none of them violence-related.

Many foster-family programs based on the Geel model have sprung up in other countries, often after considerable community resistance. That never happened in Geel. "No one here," maintains Toni Smit, "has ever said they don't want mentally ill people around. They're just people. They need caring for, too."

Watch a Geel video at Youtube.com/watch?v=wQR1LF8T5zM



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

# <u>ami</u>québec

Agir contre la maladie mentale Action on mental illness

AMI-Québec, a grassroots organization, is committed to helping family caregivers\* 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.

\* Family caregivers are those in the circle of care, including family members and other significant people, who provide unpaid support to a person living with mental illness.

Jean Claude Benitah, President Anna Beth Doyle, Vice President Joanne Smith, Secretary Norman Segalowitz, Treasurer Annie Young, Immediate Past President Ella Amir, Executive Director



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Ella Amir, Executive Editor Bryna Feingold, 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.

Legal deposit: Bibliothèque Nationale du Québec, National Library of Canada.

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Member of La Fédération des familles et amis de la personne atteinte de maladie mentale (Québec)