

# The Family Voice

What your Family Advisory Committee is doing for you **JANUARY–APRIL 2021**  
VOLUME 3, ISSUE 1

## WHAT'S INSIDE

What do the new buildings mean for family members? More than you know .....	1
Message from the co-chairs .....	3
FAC member list.....	3
Meet the member: Gilda Martens .....	4
Spotlight organization: Families for Addiction Recovery .....	4
Self-care corner: Connecting .....	5
Where are your FAC members? .....	6
Reviews: Living Well with Schizophrenia; Being Scene exhibition .....	6
Resources .....	7
Family matters: Contact us! .....	8

## VISION

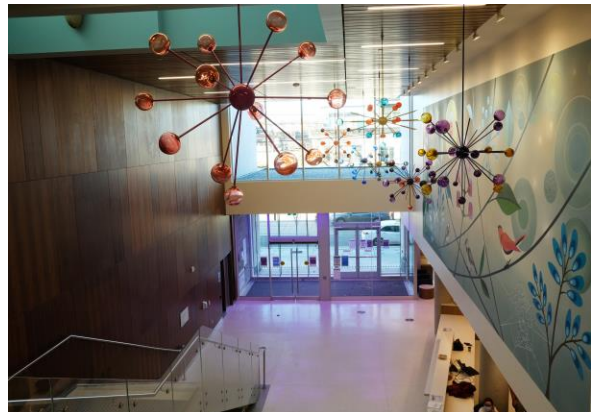
Family will be integral members of the recovery process and will be embraced by and actively engaged at all levels of the organization.

## MISSION

The Family Advisory Committee (FAC) is a partnership between CAMH staff and family members affected by a family member's mental illness and/or addiction. The CAMH FAC will engage with families, patients, community members and care providers to improve client care and enhance the experience of both patients and their families at CAMH.

## DEFINITION OF FAMILY

Any person or group of people someone identifies as belonging to their family or significant circle of support.



## What do the new buildings mean for family members? More than you know

There are two new buildings on the Queen Street West CAMH site. As families, we want to know how this will impact us, how it will improve the care that our family members receive, and how it will give families a greater sense of hope for the future. We connected with the CAMH Patient and Family Experience team and the Patient and Family Advisory Committees to learn what they think are the top benefits to patients and families in the new spaces.

### A welcoming environment

“The first thing that stands out to me about the new buildings is the feeling of light and space, especially compared to the cinder-block aesthetic of the old Queen Street units,” says Sean Patenaude, a patient engagement facilitator. “There are tall windows, high ceilings and lots of engaging and thoughtful art.”

“The new buildings have vibrant patient-centred design features like rooms with improved natural light, and enclosed green spaces for patients to get fresh air. I feel these valuable landscapes can certainly enrich patients’ therapeutic experiences

---

while making them feel safer, hopeful and more comforted in a blissful environment," says Rohan Mehta, the co-chair of the Patient Advisory Committee at CAMH.

### Central location

Kate Seifried, co-ordinator at the Family Resource Centre, says: "In the past families would call from the Emergency Department (ED) at College Street looking to access resources and navigational support, but we were here at Queen Street. Now with the ED and the Family Resource Centre on the same site, we can better support families arriving at CAMH for the first time."

### Programming for patients and families

The McCain Complex Care and Recovery Building includes many new facilities in addition to four floors of patient rooms. The ground floor state-of-the-art Tour de Bleu Therapeutic Neighbourhood includes a commercial-grade teaching kitchen and computer training room.

The Patient and Family Learning Space, the new home of the Family Resource Centre, has familiar faces, an expanded library, educational and navigational supports, and programming for family members, patients and the public. The CAMH Library, which has always been open to the public, is now just steps from Queen Street.

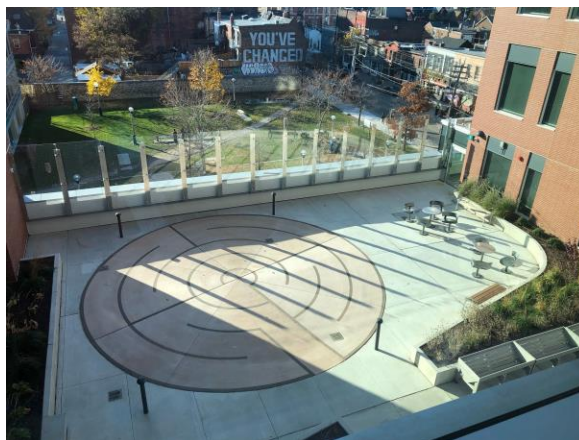
The CAMH recovery college is also based in the McCain building. The college provides nonclinical programming created, produced and facilitated by people with lived experience of mental health, addiction and/or substance use challenges, alongside program developers. Family members and supporters are welcome!

Throughout the main floor are numerous lounge spaces and many installations and pieces from the CAMH Therapeutic Art Project's 34 works. These spaces make this ground floor a community hub for patients and families.

### Private, public and outdoor spaces

The new buildings include a number of public and private spaces. Inpatient rooms are now private with private washrooms. On the ground floor of both new buildings there are spaces to sit and enjoy a coffee with your family member. Inpatients can also enjoy improved access to the outdoors with terrace spaces and greenery.

"One of the most important things my son learned during the early stages of his psychotic illness was that there was no need for shame or embarrassment," says Susan Conway, co-chair of the FAC. "However, he continued to feel embarrassed by his environment while hospitalized and wouldn't let friends and family visit, despite having shared with them the mental health challenges he was experiencing. He felt the environment would distress them and there was nowhere to go that was conducive to visiting. This has changed—the new site feels part of the larger community, has a noninstitutional vibe and is more respectful of a patient's need for privacy and personal time."



People can stroll and get fresh air at the TD Commons at Queen and Shaw streets and the outdoor space just south of the ED, which features a meditative labyrinth [pictured above] that everyone is welcome to use.

### How far mental health care has come

The new buildings are part of a hopeful vision for the future of mental health care—one that prioritizes dignity, respect and collaboration. Steve Lincoln, a patient engagement facilitator, shared an interaction he had with an older adult patient during a COVID-19 screening. The gentleman talked about psychiatric treatment in the '60s and Steve recounts: "We had a brief but pleasant conversation during which he remarked how he was struck by the welcoming and comfortable feel of the new building. As he was reflecting on the surroundings, he turned to me and said he felt things were so 'different' and 'so much better.'"

*The Family Voice* will introduce you to more new spaces and their benefits in future issues.

## Message from the co-chairs

In the fall of 2020 the Family Advisory Committee (FAC) held our first full-day retreat to consider the work plan. This was an opportunity to reflect on and celebrate the accomplishments of the past three years, review and evaluate our goals, and define our work plan for the next three years. Highlights of what we've done include having FAC members on all program quality councils at CAMH, establishing *The Family Voice* newsletter, and hosting our monthly Café Connection, which gives families the space to learn and connect with other family members.

Looking at the next three years, we were very aware of the ongoing challenges families face as a result of the COVID-19 pandemic and the heightened awareness of existing inequities in our society. When setting our goals we made sure to first understand the broad perspective of families. We reflected on the results from the Ontario Perception of Care Survey and reviewed data from visits to the Family Resource Centre to better understand the current needs of families. While the FAC was happy to celebrate our

accomplishments so far, we have important work yet to do. Here is a snapshot of a few goals we identified for the next three years:

- Improve information sharing and communication with families.
- Continue to collaborate with the Family Resource Centre (and its move to the Patient and Family Learning Space) to expand support and resource options for families.
- Further integrate the family perspective across CAMH by partnering on new projects and committees.

The Family Advisory Committee would love to hear your thoughts and feedback about families at CAMH by phone, email, and—once restrictions lift—in person. Please see page 8 for phone numbers and email address!

—Susan Conway, mother, CAMH FAC co-chair

—Ashley Bowe, sister, CAMH FAC co-chair



FAC member list, 2020–21

*Top row, from left:* Ashley Bowe, Thanisa Sundaralingam, Gilda Martens, John Im.

*Middle row, from left:* Mary Beth Odell, Miriam McCann, Vivien Cappe, Morgan Bush.

*Front row, from left:* Nicole Waldron, Pauline Lefebvre-Hinton, Susan Conway and Robert Burns.

*Absent from photo:* Mara Jayenthiran





## Meet the member: Gilda Martens

### What drew you to the FAC?

My 30-year-old daughter is an outpatient at CAMH and I've been in the mental health and addiction field as a housing support worker for over 10 years—that's what drew me to the FAC. I needed to know more about CAMH and what it had to offer in the way of family support groups to help me understand my daughter's emotional distress a.k.a. mental illness.

The FAC was where I could help bring about changes in how families are viewed and let everyone know the important advocacy role that family members have in their loved one's recovery.

### What's been the most rewarding thing you've done on the FAC?

Being an integral part of the important work that FAC is doing and having a united voice in bringing about much needed changes.

### How long have you been supporting your family member?

I have been supporting my daughter since she was born. Only in the last 10 years has she been unwell to the point of having to take medication.

### The best advice from another caregiver?

Accept any offer of support that you can. Tell your story to someone who can relate to what you are experiencing. Practice self-care, breathe often, take one day at a time. The journey of recovery

will play out the way it needs to play out. Focus on what you can control.

### Your favourite pearls of wisdom?

Our loved one doesn't want us to worry all the time. • Give your family member dignity and respect: that's at the core of recovery-oriented practice. • Know that this experience can be a traumatic one filled with pain and grief but you will survive!



## Spotlight organization: Families for Addiction Recovery

Addiction is not an easy subject to talk about, and caring for someone struggling with addiction is not easy to do. Families of people with addiction benefit from supporting each other, and a peer support group can help in a way that a general addiction support group may not. No matter what you've been through, what you say or how you say it, your peers have likely been through it, seen it before, or heard it from someone else. There is no need to fear the judgment of peers.

Parents and caregivers can find helpful peer supports through Families for Addiction Recovery (FAR), a Canadian charity founded by parents of children who have struggled with addiction from their teens. FAR supports parents/caregivers of children struggling with addiction (regardless of age) through their free peer support programs:

- **Parent-to-Parent ("P2P") one-on-one support by phone:** Trained parent supporters will listen with understanding and speak with you about resources and coping skills to help you and your family member.
- **Parent support groups** (currently online due to COVID): These groups offer a safe virtual space where supporters can discuss practical strategies, find support and share resources

---

and information that worked for them. They are facilitated by a parent with lived experience, who also holds a B.A. in psychology and an Addiction Care Worker diploma.

- **Phone Support Line:** connect to a trained volunteer who understands those who care for a child of any age struggling with addiction and who are looking for support. The line is free of charge from anywhere in Canada, Monday to Friday from 1:00 to 3:00 p.m.

With FAR you will meet people who have been where you are, seen what you have seen—and moved forward to a place of recovery. This provides you with a regular reminder that healing and hope are real. And even if your child doesn't want help, helping yourself can help your child.

For more information, please visit:  
[www.farcanada.org/](http://www.farcanada.org/)

—Mara Jayenthiran, sibling, FAC member



## Self-care corner: Connecting

As I write this I feel it's important to say it's been 10 months since this pandemic began. When it started, I hunkered down, I think like many of us did, watching too much news and scrolling endlessly on social media in an attempt to gain some control. When that strategy didn't work, and it looked like we were in this for the long haul, I re-examined what I did when my daughter got her diagnosis and we started that journey together.

What I learned from being a supportive family member for 10 years is that connecting with others is essential to my self-care. Reaching out and joining support groups (now of course on Zoom) were an important part of my self-care. Sharing your stories is therapeutic and talking to peers makes you realize you're not alone. You can learn other ways people have faced what you are facing, and learn from their success and misses. You can exchange ideas on how to stay calm and create an environment conducive to recovery. We are in this together.

Volunteering is a way to connect on two levels—with the people who are also volunteering, and the people or furry friends you're helping. And you can do it while respecting COVID-19 restrictions (see Resources, *below*).

When I would have a particularly tough day, I learned early on it was better for me to reach out to a friend or relative for some support. These days, calling friends that you haven't spoken to in a long time is really helpful. I stay in touch through social media, especially Facebook and email. You can also call The Ontario Caregiver Organization, with a line just for caregivers so you can connect with someone who is judgment free and helpful too (see listing on page 8).

In our roles as caregiver and supporter, made harder by the restrictions of COVID-19, we can feel isolated and alone, and miss our old way of life. When I look at my self-care plan, in addition to trying to eat right, take time to breathe, get out and walk in nature, and give myself the same kindness and compassion that I would give my loved one, I find keeping connected to others is a must-do, no matter how big or small. Staying connected has given me a better perspective on how to best support my loved one. We are both on a journey of recovery.

—Gilda Martens, mother, CAMH FAC member

### Resources

- To find people with interests similar to yours, try [Meetup.com](https://www.meetup.com/). With this app you can find a group near you or create a group yourself.
- To connect with your neighbours without leaving your home, check out [Nextdoor.com](https://www.nextdoor.com/), a social

## WHERE ARE YOUR FAC MEMBERS?

### Highlight: Clinical Quality Committee

The Clinical Quality Committee (CQC) oversees the quality program across CAMH's main programs: Complex Care and Recovery; Acute Care; and Child, Youth and Emerging Adult.

The committee members include the CEO, VPs and board members. This provides FAC members on the committee a wonderful opportunity to present the family perspective on enhancing patient- and family-centred care.

Some feedback the FAC has provided includes reviewing data analysis of safety risks, including common fall hazards; better synchronization of quality programs; and a consistent perspective on client and family needs beyond clinical needs.

—John Im, CAMH FAC member

FAC members are also representing family interests through:

### Internal committees and work groups

- Digital Health Steering Committee & the Digital Health Patient and Family Engagement Working Group
- Horizontal Violence, Anti-Racism, Anti-Oppression Working Group
- Virtual Café Connection Planning Committee FAC Subcommittee
- BrainHealth Databank, Research and Care Co-ordination Portal (RCCP) Virtual Workshops
- The HOPE Suicide Safety App Project Phase 2

### External committees and projects

- OFCAN (Ontario Family and Caregiver Advisory Network)

networking site that requires your real name, street and verification that you live there to join.

- To volunteer, there are many organizations such as [Sparkontario.ca](http://Sparkontario.ca), with tasks that can be done from your own home.
- To connect with other CAMH carers, join a Virtual Café Connection (see page 7).

## Reviews: Books and more



*Living Well with Schizophrenia* (YouTube)

[www.youtube.com/c/LivingWellWithSchizophrenia](http://www.youtube.com/c/LivingWellWithSchizophrenia)

**The Gist:** *Living Well with Schizophrenia* is a YouTube channel produced by young Canadians Lauren Kennedy and her partner Rob Lim. They provide a first-person look at having schizophrenia or schizoaffective disorder and what it's like to live with someone who experiences these illnesses. Their videos cover topics ranging from what a psychotic episode feels like to experiences with medication, hospitalization and recovery.

**The Good:** Lauren and Rob are refreshingly open about their relationship and how Lauren's schizoaffective disorder affects their lives and family. While most of the videos are Lauren relating her experiences—with her partner as camera operator and editor—there are some topics they address together, such as what happens when Lauren stops taking her medications or has an episode that requires intervention. I was impressed and moved by the couple's frankness and honesty about what they've experienced and how they were affected, particularly in the video "How to Support a Loved One Through Hospitalization." Rob and Lauren talk about a particularly difficult

psychotic episode, explaining what helped, what made things worse, and how they got through it together. I found it deeply moving to hear about these experiences from the people going through them, and I respect the way Lauren's tone remains positive and encouraging while being forthcoming about times when her illness makes life difficult to manage.

**The Bad:** The only bad I can think of is something that Lauren and Rob are very open about: they enjoy many privileges due to race, education, status and other social determinants that can mean that their experiences and options may not be shared by everyone living with psychosis.

—Sean Patenaude, son,  
patient engagement facilitator



Being Scene 2019  
Photograph by Julie Riemersma

## Being Scene

Being Scene, Workman Arts' juried exhibit of artwork by artists with lived experience, will be held digitally March 2021. For up-to-date information, and an archive of past Being Scene exhibitions, please go to:

<https://workmanarts.com/being-scene/>

## Resources

**ACCESS CAMH** provides centralized information, intake and scheduling for most CAMH services, Access CAMH makes it easy to find the help and

services you need with a single call. Access CAMH Family Line is 416 535-8501, press 2, listen to the choices to the end, and you'll be connected.

For community resources on a wide range of topics, see: [www.camh.ca/en/health-info/guides-and-publications/community-resource-sheets](http://www.camh.ca/en/health-info/guides-and-publications/community-resource-sheets)

**CAMH FAMILY INFORMATION AND SUPPORT CENTRE** phone line is an information and support resource for CAMH families during COVID-19. It includes a recorded message on current CAMH policies and where to find more information on a variety of topics. Callers can also leave a message with questions about services and supports: 416-535-8501 ext. 33472.

**FAMILY RESOURCE CENTRE (FRC) at CAMH** has materials on mental health and addiction, a lending library and information on community supports and family-focused events. It is now in the RBC Patient and Family Learning Space, McCain Complex Care and Recovery building. Until COVID-19 restrictions lift, the FRC is open virtually 9:00 a.m. to 4:45 p.m., Monday to Friday. 416 535-8501 ext. 33202  
Email: [family.engagement@camh.ca](mailto:family.engagement@camh.ca)

**CAMH VIRTUAL CAFÉ CONNECTION** is an informal gathering of CAMH friends and family members held the last Thursday of the month, 6:00–7:30 p.m.; call for details to join virtually. 416 535-8501 ext. 33202  
Email: [family.engagement@camh.ca](mailto:family.engagement@camh.ca)  
[www.camh.ca/families](http://www.camh.ca/families)

**SUBSTANCE ABUSE PROGRAM FOR AFRICAN CANADIAN AND CARIBBEAN YOUTH (SAPACCY)** provides support and counselling to Black youth (ages 13–24) and their families who are dealing with substance use and/or mental health problems. Family members can self-refer for an assessment.

For more information, contact Access CAMH at 416 535-8501, press 2 or 1 800 463-6273

**ACROSS BOUNDARIES** provides community mental health and addiction supports and services, and in-house programs that include individual and family supports, as well as a peer support group, men's group, women's group, community kitchen and more. Services are available in Caribbean dialects, Shona, Amharic,



Harare, Xhosa, Afrikaans, Urdu, Tsonga, Swahili, Somali, Twi, Dari, Pashto, Farsi (Persian), Punjabi, Hindi, Bengali, Tamil and Mandarin.

51 Clarkson Ave., York

416 787-3007

[www.acrossboundaries.ca/](http://www.acrossboundaries.ca/)

**FAME (FAMILY ASSOCIATION FOR MENTAL HEALTH EVERYWHERE) RECONNECT** offers families ongoing monthly support groups across the GTA. The groups are drop-in format and are facilitated by FAME staff. One-on-one support is also offered.

416 248-2050

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

**FAMILY OUTREACH AND RESPONSE PROGRAM, CMHA** offers educational information, programs, support services and referrals for friends and family of people recovering from serious mental illness.

416 539-9449

[toronto.cmha.ca/programsservices/family-support](http://toronto.cmha.ca/programsservices/family-support)

**MOOD DISORDERS ASSOCIATION OF ONTARIO (MDAO)** provides information, resources and support groups for people with depression, anxiety and bipolar disorder, and for their families and friends. Services include WRAP for Families; drop-in groups and short-term professional counselling for families.

1 888 486-8236 or 416 486-8046

416 486-8046 ext. 300 (line for family members of youth ages 14–35)

[www.mooodisorders.ca](http://www.mooodisorders.ca) or [www.mdao.ca](http://www.mdao.ca)

**NATIVE CHILD AND FAMILY SERVICES OF TORONTO** offers children's mental health assessments and treatment (0–6 years and 6+ years), transitional support for women in domestic violence situations, women's and men's healing, family work, group programs (including Strengthening Families). 9:00 a.m.–5:00 p.m. Ninosche program provides home support for ages 0–6.

30 College St., Toronto

416 969-8510

<http://www.nativechild.org/>

**THE ONTARIO CAREGIVER ORGANIZATION** is an independent nonprofit dedicated to caregivers.

1 833 416-2273 for 24/7 helpline

Online chat 7:00 a.m. to 9:00 p.m., Mon. to Fri.

[www.ontariocaregiver.ca](http://www.ontariocaregiver.ca)

**THE SASHBEAR FOUNDATION** offers Family Connections, an evidence-based 12-week group that meets weekly for education, skills training and support for people in a relationship with someone who has emotion dysregulation (e.g., borderline personality disorder). Groups are available across Canada.

[info@sashbear.org](mailto:info@sashbear.org)

[www.sashbear.org](http://www.sashbear.org)

**TROPICANA** provides culturally appropriate programs to youth, newcomers, people of Black and Caribbean heritage and others in need. Family supports include individual and group counselling and training for parents whose kids are in SNAP.

1385 Huntingwood Dr., Scarborough

416 439-9009

[www.tropicanacommunity.org](http://www.tropicanacommunity.org)

## Family matters We want to hear from you!

Family members—including relatives, partners, friends and co-workers—play an essential role in supporting the care and recovery of people living with mental illness and/or addiction.

Do you have an experience or story to share?

Do you have feedback about your experience at CAMH?

Your voice matters and we want to hear from you!

How to share feedback with CAMH's Family Advisory Committee (FAC):

- Phone: 416 535-8501 ext. 33202
- Email: [family.engagement@camh.ca](mailto:family.engagement@camh.ca)
- In person when COVID-19 restrictions lift: Family Resource Centre, now in the RBC Patient and Family Learning Space, McCain Complex Care and Recovery building. Hours will be 9:00 a.m. to 4:45 p.m., Monday to Friday.

The logo for CAMH (Centre for Addiction and Mental Health) features the lowercase letters "camh" in a bold, purple, sans-serif font.