

CASEY HOUSE NEWSLETTER
SPRING 2011: TEXT-ONLY VERSION
March 2011

STORY 1:

EVERYTHING CHANGES:

REBUILDING A LIFE WITH HIV-ASSOCIATED BRAIN DISEASE

For many long-term survivors, life with HIV/AIDS can be filled with hope and well-being. Unfortunately, for many of our clients long-term survival with HIV/AIDS also brings elevated risk for sudden and dangerous associated illnesses, including brain disease.

“I’ll tell you all about my life, but you’re going to have to be patient,” chuckles John. In his mid-40’s, John* contends with severely impaired short-term memory. He keeps dozens of notebooks stacked on shelves in his apartment, to fill in the gaps in his memory.

HIV-positive since the mid-80’s, John ran a successful business in the arts. He lost friends to AIDS through the years, and visited one friend often at Casey House, where he witnessed the care and compassion of our staff first-hand. He never expected to need Casey House himself: he thought he’d made it through the bad years already.

Then two years ago he got a throat infection that he just couldn’t seem to beat. “I couldn’t swallow food, I was losing a lot of weight and got really thin,” he recounts. He ended up in hospital. “One thing turned into another, first it was pneumonia and then meningitis and then encephalitis. It was clear to everyone then that I was going to die. Of course, to me, it was all a blur.”

Weeks later, John’s severe brain damage caused him to be declared incompetent by the province. His business was lost, property seized, home gone. He felt angry, terrified, desperate.

Then, despite his anxiety, John agreed to be transferred to Casey House. With the help of our interprofessional care team, in collaboration with specialists at St. Michael’s and Sunnybrook Hospital, he threw himself into an aggressive rehab regimen, desperate to regain control over his life. He stayed at Casey House for 10 months, though he remembers little of that time. “I couldn’t tell you the colour of the walls or drapes at Casey House,” he says now. “But what I do remember are the people. I made some really good friendships, and the nurses, they’ve always been so incredibly kind.”

Today John lives independently, with regular visits from his Casey House community nurse and social worker. Despite ongoing memory and mobility problems, he manages his own day-to-day needs. His medications arrive in blister packs, already counted out so he doesn’t have to remember by himself. He continues to keep careful notes to support his memory, and he’s on a waiting list for supportive housing. He’s even planning to rebuild his business one day.

“I was so scared when I went into Casey House,” says John. “I thought of it as a place where you only go to die. But as it turns out, Casey House saved my life.”

STORY 2:

KREMBIL FOUNDATION SUPPORTS RESEARCH AT CASEY HOUSE

Through 23 years of excellence in care, Casey House has developed expertise in some of the most challenging aspects of HIV/AIDS treatment and support. Recognizing this opportunity to enrich the wider field of HIV/AIDS knowledge, our Board of Directors identified “Research, Knowledge Transfer and Exchange” as a strategic goal.

Thanks to a generous grant from the Krembil Foundation, Casey House will soon hire a dedicated Research Coordinator, the first role of its kind at Casey House.

“We’re excited to be part of this unique and innovative research project,” says Michelle Tricarico of the Krembil Foundation. “With so many individuals living decades longer, AIDS organizations such as Casey House are finding themselves in uncharted territory. We feel Casey House has the experience and knowledge to undergo a project of this degree, but more importantly they have the compassion and heart for the individual to strive for solutions to improve the quality of life for people suffering with HIV/AIDS.”

STORY 3:

ANNOUNCING THE CASEY AWARDS

Created in tribute to June Callwood, The Casey Awards annually celebrate individuals and organizations across Canada that demonstrate leadership in the fields of HIV/AIDS & social justice.

JAY MACGILLIVRAY

For 30 years, Jay MacGillivray has been an outstanding advocate for people and communities who are marginalized because of HIV/AIDS, disability, poverty, immigration, orientation or other systemic barriers to access. One of Ontario’s first registered midwives, MacGillivray’s work with women who were pregnant and HIV-positive led her to partner with Dr. Mark Yudin in creating The Positive Pregnancy Program at St. Michael’s, providing comprehensive pregnancy, birth, and postpartum care to HIV-positive mothers and their babies. This is the first time in Ontario that a midwife and physician have worked shoulder-to-shoulder in an interdisciplinary maternal HIV care team. Since its launch five years ago, not one baby born through the program has been HIV-positive.

FIFE HOUSE FOUNDATION

Driven by the fundamental need for safe housing as a requirement for health and well-being, for over 20 years Fife House Foundation has provided innovative and client-centred supportive housing programs, transitional housing, homeless outreach and community programs for thousands of people affected by HIV/AIDS in Toronto. Today Fife House provides 80 per cent of the supportive residential programs and housing services to people living with HIV/AIDS in Toronto. Additionally, Fife House is the host agency for the AIDS Bereavement and Resiliency Project of Ontario and the Ontario HIV & Substance Use Training Program, and partners with the Ontario HIV Treatment

Network to offer HealthyHousing.ca, a national HIV and housing portal through which people living with HIV/AIDS, service providers and researchers can learn more about issues related to HIV/AIDS and housing. www.fifehouse.org

STORY 4:

MONOGRAM DINNER BY DESIGN AT INTERIOR DESIGN SHOW 2011

On January 27, hundreds of people from Toronto's design community converged at the Interior Design Show 2011 Opening Night Party for an auction benefitting Casey House. Organized by Shauna Levy, Director of IDS 2011, the auction featured 20 Vitra Panton chairs, retooled by some of Toronto's most celebrated designers and architects. Crystallized, upholstered and laser lit, the proceeds from the auction of these one-of-a-kind works of functional art will directly support care at Casey House.

The IDS event falls under the umbrella of a new interior design-focused fundraising initiative at Casey House, Monogram Dinner by Design, a series of by-invitation-only dinners and cocktail parties hosted by well known interior designers and members of the design community in support of Casey House.

GE Monogram is the lead sponsor for Dinner by Design. "Casey House has provided exemplary treatment, support and compassionate care for people living with and affected by HIV/AIDS for more than two decades," says Philippe Meyersohn, GM of marketing for GE Monogram Canada and a Casey House board member. "We are truly proud and excited to support Toronto's talented design community as they, in turn, support Casey House."

For more information about how you can host or join a Monogram Dinner by Design event, please contact Michael Cress at 416-962-4040 x236.

STORY 5:

HOW FUNDRAISING EVENTS MAKE A DIFFERENCE

Casey House services such as home nursing care, homemaking support, nutrition, recreation therapy and street nursing are funded almost entirely by donors and fundraising events.

By making a gift to Casey House or by attending or organizing a fundraising event, you can bring health and hope into the lives of people living with HIV/AIDS in Toronto. To discuss your fundraising idea for Casey House, please contact Michael Cress at 416-962-4040 x236.

STORY 6:

VOICES OF HOPE CONCERT FOR WORLD AIDS DAY 2010

Once again, Voices of Hope for World AIDS Day was a beautiful evening of remembrance and song, celebrating the lives of those we have lost to HIV/AIDS, and demonstrating support for the millions of people around the world and here in Canada who continue to struggle with the disease.

Created through a collaboration by Casey House, La Maison du Parc (Montreal) and Dr. Peter AIDS Foundation (Vancouver), Voices of Hope / Voix D'Espoir is the only nationally-coordinated concert for World AIDS Day in Canada.

Toronto's landmark Metropolitan United Church, under the guidance of Event Chair Rev. Dr. John Joseph Mastandrea, was brimming with the hope and love shared by the Casey House community of support. Performers included The Nylons, Jean Stilwell and Dr. Draw, with CBC's Tom Allen serving as host. Casey House clients also took part, sharing their stories produced in the donor-funded Writer's Workshop, as well as exhibiting their photography.

Our deep thanks to all the performers, attendees and evening sponsors, including M.A.C AIDS Fund which not only led the national event sponsorship, but also sent a team of volunteers. Thank you for joining us!

STORY 7:

A NEED YOU CAN'T IGNORE

MARK JOHNSTON, CASEY HOUSE DONOR & VOLUNTEER

Mark Johnston is CEO of Fusion Television, producing such hits as "Divine Design," "Fearless in the Kitchen" and "Colour Confidential." For the past four years, Mark has also been an active donor and volunteer at Casey House, volunteering with special events and fundraising committees.

Why do you donate to Casey House?

Because I can. Because there is so much more to do. Because whatever we do in life there is nothing more important THAN life. My cousin Bobby, an incredibly talented musician and beautiful human being, passed away a few years ago at Casey House. To see the love, the dedication and the compassion the staff and volunteers at Casey House provide every single day and night is incredibly moving. You can't ignore that. You can't.

You've played a volunteer role at Casey House, in various capacities. What has that been like?

My first volunteer position was on the SnowBall Committee in 2008. To help plan such an incredible event was a privilege. Glitter and giving, what a perfect combination! I've been a volunteer member of the Foundation Committee since 2009, collaborating with other members and staff to carry out existing initiatives and create brand new ones. Supporting the work Casey House does has been so rewarding. Life is precious – I think it's really important to make a difference.

You've been helping to organize the Casey House fundraising program Dinner By Design. How is that going?

It's such an exciting venture! I've had the pleasure of working with the designers and television personalities Jane Lockhart and Candice Olson for some time. More than two decades after June Callwood called on the design community to help create Casey House, some of Canada's top design talent is coming together once again to support the new capital campaign and build the new home for Casey House. The way I see it, it's the design community coming full circle, and it's so exciting to be a part of that.

What do you see as the current impact of HIV/AIDS on our community? Is the issue “done”?

Absolutely not! We’ve made so much progress, and yet infection rates are similar today to what they were when the disease first appeared. This battle has evolved, and so has our community. The evolution, the work and the hope continue every day, and I see it all the time at Casey House. There is a brightness in the future, and we can all be a part of it. We need to be.

STORY 8:

**THE CASEY HOUSE FRIENDS INDEED LEGACY SOCIETY:
PLAN TODAY TO SUPPORT CASEY HOUSE TOMORROW**

By making a planned gift today through Casey House’s Friends InDeed Legacy Society, your wish to leave a lasting legacy of support will help to ensure that people living with HIV/AIDS will receive exemplary treatment, support and palliative care for generations to come.

In addition, your estate will receive tax advantages.

Ensure that you are leaving the legacy you desire. To learn more about the Friends InDeed Legacy Society, please contact Tracy Hatten at 416-962-4040 ext. 233.

STORY 9:

UPCOMING EVENTS:

Casey House All-Day Symposium on HIV & Mental Health – March 11, 2011

Board of Directors Applicants Open House – March 29, 2011

Volunteer Information Session – April 25, 2011

Casey House Seminar of HIV & Mental Health – April 29, 2011

Nursing Week – May 9-15, 2011

Annual General Meeting – June 14, 2011

Pride Week – June 24, July 3, 2011

Art with Heart at The Carlu - October 18, 2011

CASEY HOUSE

9 Huntley St.

Toronto, ON M4Y 2K8

416-962-7600

www.caseyhouse.com

To make a donation, volunteer, or for more information, please contact us at

heart@caseyhouse.on.ca

Charitable Registration #10687 8374 RR0001

END OF NEWSLETTER