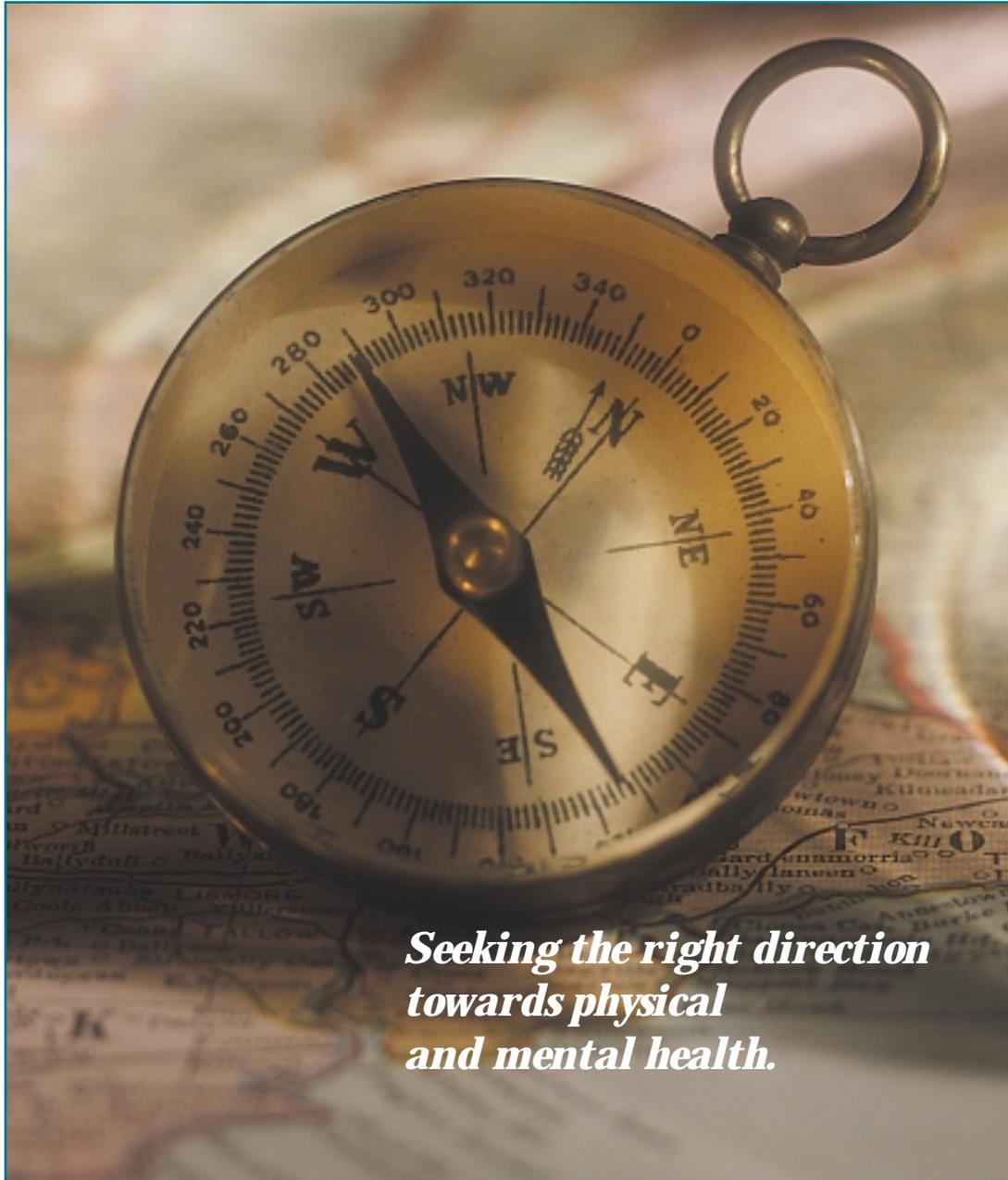


# Network

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*Seeking the right direction  
towards physical  
and mental health.*



CANADIAN MENTAL  
HEALTH ASSOCIATION  
L'ASSOCIATION CANADIENNE  
POUR LA SANTÉ MENTALE

Ontario Division/Division de l'Ontario

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#### OUR MISSION:

*To advocate with and provide programs  
and services for people with mental  
disorders, and to enhance, maintain and  
promote the mental health of all  
individuals and communities in Ontario.*

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# Meeting the Challenge

As of November 20, 2000, Dr. Barbara Everett has accepted the position of Chief Executive Officer of CMHA, Ontario Division. Barbara has a BSc and MSW from the University of Toronto and a PhD from York University. She brings to the position a wealth of clinical and academic experience. Most recently, she has been the Administrative Director of the Society, Women and Health Program at the Centre for Addiction and Mental Health. Previously, at the Ministry of Health and Long Term Care, she was the lead for the Provincial Psychiatric Hospital Governance Transfer Project and a consultant in Smart Systems for Health. Barbara also created and operated Homeward, a community mental health program serving survivors of childhood trauma with concurrent diagnoses of serious mental illness. As a writer and speaker, she has published extensively in her clinical specialty of childhood trauma and also on the role of consumers and psychiatric survivors in the mental health system.

**H**aving known and respected the CMHA throughout my career, it is with great pleasure that I take up my new duties as the CEO of the Ontario Division. I will always remember my first few weeks in this most challenging position in two specific ways: the generous and warm welcome extended to me by the Board of Directors, Division staff and the Executive Directors of the branches – and the overwhelming barrage of information, issues, projects, initiatives, committees, task forces, and meetings.

In the wake of the Board's acceptance of the Business Plan 2000 – 2005, Ontario Division staff members are planning a self-reflective review and restructuring process in order to respond effectively to the major advocacy themes in the plan: making mental health a personal issue for every Ontarian, raising awareness of the value of mental health promotion, early intervention and prevention, and ensuring the accessibility of services, supports and resources for consumers and family members. As we reflect upon our work and the changes we will need to make, we intend to take every opportunity to consult with our CMHA colleagues and other important constituents so that we can be guided by identified needs. It is an exciting and demanding time in the field of mental health and the challenge for the Division will be to remake itself in ways that are responsive and flexible within the context of an ever-changing environment. I am confident that we are up to the task.



BARBARA EVERETT, PH.D.  
Chief Executive Officer

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# Beyond the Dark Kingdom

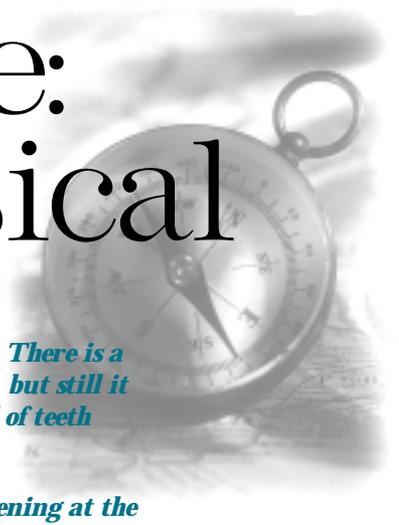
*“Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.”* (SONTAG, 1977, p.3)

**IS THE HEALTH CARE PROFESSION** providing not only physical care to people who are undergoing a serious, or life-threatening illness, or who have been the victim of some kind of physical abuse or attack, but also the support and care necessary to meet the psychological needs that have now been triggered? Do people who are going through this kind of trauma avoid mentioning the depression that they are now experiencing because they fear the stigma that may then be attached to them, not only by family members but possibly by health care workers themselves? Does our health care system truly treat the whole person? What about family members and young children, how are they affected and what is in place to help them deal with the physical and mental changes that they see taking place in a loved one? These are some of the questions that we strive to address in this issue of *Network*. Citizenship in the kingdom of the well is something we take for granted, along with all the benefits that go with it, until without warning we find ourselves in a new, dark kingdom. An unfamiliar country that we have to negotiate, not only with a traumatized body, but too often with a traumatized mind, as we try to deal with the blow that has been dealt us. Serious physical illness, or trauma associated with some kind of vicious attack or accident, doesn't limit itself to injuring our bodies. Human beings are far more complex than that, and we come with attendant feelings and emotions that must also be addressed and healed. In addition, we are surrounded by friends and family members who will also be impacted by what has occurred. What role will they have, along with our health care providers, in ensuring that we are treated as 'whole people'?

Patricia Van Tighem and Monica Wright Roberts have very different stories, very different experiences as you will discover in the following pages. But there is one common thread. They both found themselves, through no fault of their own, in the 'kingdom of the sick'. Patricia through a vicious attack by a grizzly bear that left her with permanent facial disfigurement, and Monica with the news that she had progressive breast cancer, which she was not expected to survive. Patricia was 24 and Monica 35 when they had to deal not only with the physical repercussions, but also the mental and emotional upheaval, that these events brought into their lives and into the lives of their families.

As Patricia looks back over the journey she has made over the last 17 years, she pinpoints what would have been the 'ultimate support' that could have made a difference in her desperate situation. By contrast, Monica was a fortunate recipient of that 'ultimate support' and credits it for pulling her through at her most desperate times. Support is also the key phrase that Dr. Gary Rodin, author of *Depression in the Medically Ill: An Integrated Approach*, uses as he describes what is needed to ensure that, when treating someone for a serious illness, we are not so focused on the medical aspect that we forget that there is a person involved. In his own words, "Sometimes the medical profession is a little too oriented towards thinking it's just about technical care. Of course we want the technical care. We want good surgeons and proper medication. But most people want the whole of themselves to be taken into account and treated."

# Becoming Whole: Beyond the Physical



*“For seventeen years I have had a recurring nightmare. I am locked in a cage. There is a black opening at the back, and out of the opening comes a bear. I curl up tight, but still it comes. It claws at me and bites into my face, my neck, my head, with the sound of teeth scraping on bone. There is the smell of blood and fur and fear.*

*“One night I have the dream again. I am locked in a cage. There is a black opening at the back. Out of the opening comes a bear. I am on my knees, hands clasped in front of me, and I beg the bear not to hurt me. I beseech it to leave me alone. I am too injured already. I can take no more. The bear approaches me and I cringe, preparing myself for the attack. But this time, its arms reach out to hold me close. It whispers comfort in my ear. I am held and rocked and cared for, safe in the bear’s embrace.”\**

ON A FALL DAY IN 1983, PATRICIA VAN TICHEM AND HER HUSBAND, TREVOR, SET OUT ON A WEEKEND BACKPACKING TRIP. THEIR ENCOUNTER WITH A GRIZZLY BEAR WOULD CHANGE THEIR LIVES FOREVER. IN HER BOOK, *THE BEAR’S EMBRACE*, PATRICIA SHARES HER ORDEAL, NOT ONLY OF BEING MAULED BY THE BEAR, BUT OF HER ENSUING DEPRESSION AND EVENTUAL DIAGNOSIS OF POST TRAUMATIC STRESS DISORDER. THE ATTACK LEFT HER WITH PERMANENT FACIAL DISFIGUREMENT, MAKING HER REENTRY INTO THE WORLD SOMETIMES AS PAINFUL AS THE RECONSTRUCTIVE SURGERY SHE CONTINUES TO UNDERGO. BUT FOR PATRICIA, THE EMOTIONAL AND PSYCHOLOGICAL PAIN, THE LOSS OF SELF, WAS WORSE THAN ANY PHYSICAL PAIN SHE UNDERWENT.

## ***Patricia, what was the biggest motivator to you to write this book?***

PATRICIA: I originally wrote in the couple of years after our accident back in 1983 and the motivation then was to get the strong imagery out of my head. Not just the bear attack, but the experience in the hospital – they do some pretty bizarre surgery when they do plastics and that had been traumatic as well. My husband would not talk about it, and most of my family and the world seemed frightened by my story. The response I often got was that people wanted to reassure me and not allow me my feelings, so I clammed up. I didn’t want to be reassured – I wanted to feel the

sadness and the anger and that’s where that first writing came from. And then I put it away for years and years. It was only after a particularly trying experience on a psychiatric ward when I was treated very harshly, and felt quite traumatized by it, that I realized that my getting better was up to me. One of the things I did to rejoin the world was to sign up for a writing course. I pulled out this old manuscript and the instructor said “this is great”. I immediately got a publisher, and working with them I spent two years creating the book. The motivation at that time was again for therapeutic purposes. They speak about the need with Post Traumatic Stress Disorder for re-

exposure to the traumatic event, and for me to write about not just the bear attack, but my experiences as a patient, medically and psychiatrically, was a way of facing those things again and again through the editing process. I also knew that when I read books telling of other people's experiences that really touched me that it also helped me. And I knew that many people have suffered horrific things. I really hoped that if I could be honest in writing this book and putting my story out there that it might perhaps be a comfort to them and that it also might be educational, not only to the general public, but also to medical and psychiatric health care workers.

***In your book you talk about the deep need you had to be respected by your doctors. Do you think that health care providers see patients differently once they have admitted to accompanying mental health problems?***

PATRICIA: Most people certainly do lose credibility. The stigma of mental illness isn't just in the perception of the public, it's also within the health system itself. I think when I was as scared or angry as I was it made people uncomfortable. They didn't want to acknowledge those feelings in themselves. As North Americans we spend most of our time struggling to be in control, to feel empowered, and coming close to strong feelings of sadness and anger is very frightening. I feel that the doctors often had to reject me, or deny the intensity of what I was going through, simply because if they acknowledged it they would have to acknowledge the depth of those feelings, their reality, and then acknowledge and see them in themselves. They would have to recognize the fact that they were human too and could feel those things. The denial and trivialization of my problems was an attempt for them to stay in control and feel powerful. It couldn't be their fault what I was going through so somehow it had to be my fault. I certainly found that when I started to have psychiatric difficulties and had a record of being on psych wards and on medication there was less validity given to my complaints. The feeling [from them] was that maybe I was just weak. On the psych ward itself I was absolutely amazed at

the response I would get compared to being a surgical patient. When I would step up to the desk on a psych ward and say I need to talk to a nurse for such and such, at different times I was yelled at. One time one nurse said 'I'm sick of seeing your face, go sit on that chair'. On a surgery ward a nurse would never get away with it! But on the psych ward it was almost standard. This isn't true of every psych ward of course, but it was typical of some of the experiences I had. The other thing I found on the psych wards was that the feelings that I had of sadness, anger and grief were tremendously pathologized. It took years before I found a psychiatrist who said that what I was having was a normal reaction to an abnormal amount of stress.

***It seemed to be a long while before you were actually diagnosed as suffering from Post Traumatic Stress Disorder. Was it not as clearly understood when you went through this?***

PATRICIA: I think initially when we first had our accident PTSD was just being named. It certainly wasn't brought up at that time. It was seen as something that the Vietnam war vets went through but it hadn't been applied to other situations. When I started to ask about it my psychiatric care givers never seemed to take it seriously. I did have one assessment and was told I had PTSD, these are the treatment plans and so forth, and it was put at the back of my chart. But it wasn't until much later when I once again changed psychiatrists that he recognized what was wrong and said let's just knock all these other labels off the list and put PTSD at the top. It was unreal how it fit exactly – the disconnection from people, the visual stuff, the feeling of constant vigilance which was so exhausting. To have that explained to me, to see it, was just such a gift, I felt normalized. I don't like that word but it was such a comfort. Everywhere

***"I think of suicide for the first time. My despair is unfathomable, terrifying, and it feels as if there is no way out, no one who can reach me. I have alienated my doctors by developing a chronic pain and infection pattern, with recurrent episodes of facial cellulitis. I mourn for the loss of their positive regard, their friendship, their powers."\****

# Becoming Whole: Beyond the Physical

else I had felt so pathologized, that the way I was reacting was somehow wrong and bad and I needed to change before I could be acceptable or respectable. But this psychiatrist said that he was so honoured to work with me. He told me too what incredible strength I had and what a good person I was – all those kinds of things. Something lit inside of me – that positivity was crucial. People see me now and I'm articulate, well dressed, my hair is combed, but they don't realize that at that time I was enormously obese on the Lithium and Epival. I often didn't bother to wash my hair. I was dressed slovenly, I walked slumped, I had a flat low voice, so it was easy for people to look at me and push the reject button. So for this doctor to see me like that, to see me acting in the scattered and agitated way I used to do, and uphold for me a vision of who I was, who I really could be, was a tremendous gift. I had felt that my difficulties were forever, and many of my psychiatric experiences had validated that – this is who you are – and I felt written off. His explanation of the normalcy of my response to an incredibly high amount of stress, changed that for me. So many things had happened to us. On top of the bear attack we had had a stillbirth, one child born with Down Syndrome, five family deaths in a short period, over 25 surgeries and constant infection and pain. When I look back on it now, with the perspective I have, I want to take that woman and embrace her and say 'you did what you could'. And that's what the psychiatrist did for me. He said, what you are coping with is unusually stressful. You're doing better than lots of people could and you will get out of this. And that was the first time I had felt that. My husband kept that for me as well, that vision of who I was and who I could be, as did my mother.

***One of the phrases that jumped out at me from your book was where your psychiatrist said to you 'what you need is an experience of hope'.***

PATRICIA: The psychiatrist who said that was actually not the doctor who ended up helping me. I was just starving for their approval, their respect. I was so afraid that my doctors were going to get sick of me. And this psychiatrist kept reassuring me

he wouldn't, but very sadly with my suicide attempt he afterward told me he felt angry and betrayed and that he couldn't care for me anymore. He shunned me, and that hurt me to the quick. And it was he who sent me off to the city saying he couldn't see me on his ward any more because I had betrayed them. That hurt so much because that suicide attempt to me is the most painful and traumatic thing in my life. The bear attack comes second. I felt I didn't deserve to live; I was in such pain physically and mentally. I had admitted myself to the ward and pleaded with them not to leave me alone. I felt betrayed by them and he was telling me I had betrayed them.

***What kinds of support do people need when they have undergone a traumatic life event, like yourself, that will offer them an experience of hope?***

PATRICIA: You know the ultimate support, if I am talking about a dream world, would be some kind of a group or a person that could be proactive for a person. When I was in that state, for a long time I was completely unable to search out anything on my own or make things happen. Everything took

such a tremendous effort that to make the phone calls required to get things going were totally beyond me.

Trevor was so incredibly taxed with taking care of the kids and me and going to work, he was at the end of his

rope too. We were barely surviving, just coping. I realized when I met this last psychiatrist, who was very proactive, what a gift it was. There were four things that he was able to do that I think if someone had been able to do sooner might have helped. He had the knowledge about what was going on. He was totally able to accept my feelings and handle them without turning me off. Many times he sat with me for an hour or two while I shook and cried and saw things but he let me go

***"Most mornings I don't want to leave my room. I don't get dressed until the nurse hassles me, and then it takes forever. I'm long past caring whether or not my hair is brushed or my teeth are clean. The psychiatrist comes to see me in my room. His woolly jacket and tie are crisp and clean, his face neatly shaved. I crave his approval. The smile in his eyes when he says hello means more to me than he will ever know."\****

through to the end of it and then it would go away. He was also enormously respectful of both of us and our story. He also, and this is an important thing because this is often segregated, encouraged care of our basic physical needs. Getting someone to help at home, getting a nanny in, that was a huge thing for us. It could have been done much much sooner but we didn't think of it and it took someone to say do it. So some of those really practical things that just needed a little kick. Someone else to have the perspective to say do this. When I think back all the things were so commonsense, but we were drowning and didn't see them ourselves. Even initially after our accident when we were in the hospital for two months, there was absolutely nothing in place, even when we left. We were desperate for someone to talk to; certainly as a couple we needed something.

***Your children were born after this event took place but during a time when you were still dealing with the physical and mental repercussions. What was in place for them to understand and deal with what you were going through?***

PATRICIA: Absolutely nothing. Many times I would say to my social workers, to the psychiatrist, to my nurses, 'What can I do for my kids, I am so worried? I'm a terrible role model.' During one twelve month period I spent six months of it in the hospital. My kids had a tremendous amount to cope with. They saw me shut down at home in the bedroom, with the lights out and the door shut. They had a non-functioning mother. And I was terribly afraid of them internalizing it, blaming themselves, thinking 'if only I was a better kid'. One social worker suggested that I go to the provincial social services, but I had a huge fear that the children might be taken away, so I didn't do it. I didn't have the strength to make connections either and people didn't realize that. That's where I wish someone could have come alongside and said there's art therapy, or there's this group of children whose parents have mental disorders, and let me choose. Now that I'm doing better one of my sons is in art therapy and I am aware of a local group where kids are getting together, but I've discovered these things through my own initiative.

***Where are you now Patricia in your life?***

PATRICIA: Well in a tremendously better space than I was two or three years ago. I couldn't be reading and speaking and even writing this book if I'd stayed where I was at. People ask me, 'did you work?', and I think, you don't get it. Half to three-quarters of every day I spent in bed or being reclusive. Some days I didn't get up at all. I couldn't speak to my family, and I felt a terrible disconnection from the world. Where I am now is somewhat a result of the anger I felt after that final psych experience. It made

***"My reputation as a difficult patient precedes me. Along with chronic pain and recurrent infection, I now have a psychiatric history. In many doctors' eyes, I have no credibility."\****

me realize that it was up to me really, that the responsibility of deciding to stay alive was mine. The book has really bolstered my sense of self, my validity in the world. And the response from the public is also doing that. It's so gratifying. When I was in that space many people did push the reject button and yet now that my story is in print they are hungry for it and I am getting a lot of respect. The other thing that I've come to is a much stronger sense of my right to be here, to exist. I didn't feel before that I deserved to be alive. Now I feel I have a place in the world and it's just as valid as anyone else's. Not better or worse, just that I have this place and that fills me with a strength that I never felt before. Many people say you haven't changed at all, and I think you don't know, inside I feel so different. It's not all fixed. I still have the infections, I still get low, but there's a much much stronger sense of acceptance and of love. I'm not fighting myself anymore thinking I have to be different. And with that acceptance and love I've been able to heal and am in a much more peaceful place.

*\*Excerpts from The Bear's Embrace, published by GreyStone Books.*

# The Team Approach



**A** SINGLE MOTHER WITH A SUCCESSFUL CAREER, THE LAST THING MONICA WRIGHT ROBERTS HAD PLANNED WAS A BATTLE WITH CANCER. BUT AT THE AGE OF 35 THE LINES WERE DRAWN, AND THE DEADLY DUEL BEGAN. AS SHE TOOK THOSE FIRST, UNPLANNED STEPS ALONG A ROUTE WHICH CARRIED A ROADSIGN LABELLED 'CANCER', SHE HAD NO IDEA OF THE MANY FRIENDS AND BUSINESS ASSOCIATES WHO WOULD ULTIMATELY CHOOSE TO TAKE PARTS OF THAT JOURNEY WITH HER. HER LIFE TOOK ON A PATTERN OF ITS OWN THAT HAD VERY LITTLE TO DO WITH HOW SUCCESSFUL SHE WAS IN BUSINESS; TOOK NO ACCOUNT OF EDUCATION, BACKGROUND, OR MONEY. SHE BECAME A STATISTIC: A HOSPITAL GOWNED FIGURE WHO LOOKED IDENTICAL TO ALL THE OTHER PATIENTS WHO WERE ATTEMPTING TO COPE NOT ONLY WITH SURGERY, CHEMOTHERAPY AND RADIATION TREATMENTS, BUT ALSO TRYING TO COME TO TERMS WITH THE FACT THAT THEIR LIVES HAD CHANGED, PROBABLY FOR EVER.

***As a single parent with two young children, what kind of support was offered to you beyond the physical care when you were diagnosed with cancer?***

MONICA: I was very fortunate in that a business associate of mine, who was well aware of what I was going to have to face in the weeks and months after surgery, took the time to put together a team for me. He challenged people who knew me to commit to doing something on a regular basis – things like helping out with my children, delivering meals, one was even in charge of putting some humour back in my life! This helped me to devote my energy to fighting the cancer itself, and to letting my body heal. In Arthur Frank's book, *At the Will of the Body*, he makes the comment that anybody who wants to be a caregiver must not only have real support to offer but must also learn to convince the ill person that this support is there. The support I received through this person, whom I called my 'coach' and the team he put together for me was

overwhelming. It gave me encouragement at my lowest points; it enabled me to still treasure my uniqueness as a human being while coping with the indignities of a body which was suffering from the aftermath of surgery, chemotherapy and radiation. Most importantly it didn't fail.

I think a key thing to emphasize when you are going through a physically traumatic experience, whether it's cancer, MS, heart attack, or any other kind of assault on your body, is that typically family members, or people that you are emotionally tied to, try to immediately turn the bad into the good. They say things like 'well, at least you didn't die', or 'things could have been so much worse'. So you find yourself trying to ignore your true emotions in order to make

everything okay for the people around you. You need to have someone who is somewhat emotionally detached from you, so that you can be absolutely frank about what is going on without being given advice as to how to handle it. I was fortunate in having a business acquaintance who took on that role for me, but I do also strongly believe that psychiatrists can, and do, fill that role. Unfortunately there still is stigma attached to that for some people. My family physician, Dr. Connie Townsend who works out of Sunnybrook, was also extremely supportive. She clearly kept the emotional state of myself and my children together, and has continued to be there for me for much more than just my physical care.

For over 20 years Monica Wright Roberts has been the principal of Roberts Advertising Consultants Limited in Toronto, specializing in public and media relations, sales promotion, events strategy management and special event sponsorship. Monica was co-chairman on the marketing committee for the sponsors and suppliers of the 1988 Calgary Winter Olympics.

Her business took a dramatic turn when in 1988, at the height of her professional career, she was diagnosed with progressive breast cancer. This experience, including her battle with chemotherapy, radiation and surgery and coping as an independent mother, shaped her current role as business owner, philanthropist and outspoken advocate inspiring groups of television and in-person audiences across the country. She is president and founder of the National Breast Cancer Fund, a grassroots organization dedicated to raising and distributing funds to cancer centres in communities across Canada.

Monica is also involved with the Terry Fox Foundation and Ronald McDonald House. Past affiliations include the Canadian Breast Cancer Foundation and the Foundation for Canadians Facing Cancer. Through her numerous affiliations Monica has been responsible for developing educational materials including videos, primetime television documentaries and print resources for people with serious illnesses. Included in this is a guidebook entitled *Side by Side* which details the 'Coach' and team approach to dealing with illness – an approach which she pioneered.

One of her more recent educational projects included a cooperative research initiative with Princess Margaret Hospital and the Hospital for Sick Children where talking books are used to assist children dealing with the emotional aspect of serious illness. An upcoming project will include a primetime documentary for men dealing with prostate cancer.

In May 2000, AstraZeneca Canada Inc. announced their partnership with the National Breast Cancer Fund in support of an innovative educational program called *The Dolphin Project* which is designed to assist children facing life-threatening illness or the illness of a loved one. Resources include a children's picture book, an animated video and a book for teenagers. The stories and animated program focus on the growing friendship between an ill child and a dolphin, and the secret they share about his incredible ability to speak as he provides support during her illness.

For more information on *Side by Side* or *The Dolphin Project*, call the National Breast Cancer Fund at 1-877-788-NBCF.

# The Team Approach

***Do you believe that the support you got made the difference not only to your mental and emotional state but also your physical condition?***

MONICA: Oh yes. Absolutely. I think too it made a difference in that the illness allowed me to admit the weaknesses. I had always done everything on my own. I couldn't let on to anyone that I was in a bad marriage. I had to cover on every corner. I had to be successful in business, in bringing up my children and I never turned to anybody. But the illness suddenly allowed me the opportunity to admit weakness and it was acceptable to turn and get help. That's one of the privileges of the illness. Definitely the support I received from the team of people that my business associate put together for me, and from both my family doctor and psychiatrist, emotionally got me through. At my very lowest point I had a team of people who cared about me and who were sensitive enough to pick up on how I was feeling and intervened at a desperate point in my life. A lot of that feeling of course was drug induced, so there's that fear of ever having to go through the drugs, chemo, whatever again, when you lose touch with reality. You lose yourself. But I had one of the best experiences in the health care profession, surrounded by the best and given enough good advice both from my family doctor, and a great psychiatrist. When I share my story with others I say, your story is unique but we have similarities and as I tell my story it's a piece of your story too. We all have stories and some are just more traumatic than others.

***You had to go through this as a single parent with two young children. What was this like for them?***

MONICA: From the standpoint of my children, they also needed that person at arms length, and again it was my family physician who stepped in to fulfil that role. She scheduled regular checkups for them so that she was able to build a relationship with them and give them a chance to feel comfortable with her and talk with her. And she kept that going for them the whole time I went through cancer treatment. She knew what was

going on with me and she knew when I was having particularly bad times, and she would make sure she had the kids in at those times. I asked her if I should be getting a psychiatrist for the children and she felt that because my children were spending so much time with my really close friend Liz, who is ten years younger than me and more like a big sister to them, they would do fine because they were allowed to talk and be who they wanted to be.

***“Definitely the support I received from the team of people that my business associate put together for me, and from both my family doctor and psychiatrist, emotionally got me through. At my very lowest point I had a team of people who cared about me and who were sensitive enough to pick up on how I was feeling and intervened at a desperate point in my life.”***

***So it's a time when children still really need to feel that they are children?***

MONICA: Yes, and I think one of the typical reactions is that you turn to them and expect them to do more. And the reality was my kids ended up having to do meals and things like that but the actual physical acts of doing things are not really the point – it's being allowed to be kids. And to me there is a difference. Kids can get meals when they are young, but they don't have to feel like they are parenting, being adults. They have to be allowed their fun times and their play times. You can't use your kids as an emotional crutch.

***Let's lead into what you are doing now, because obviously what you have gone through has had a huge impact on what you have chosen to do with your life from that point on.***

MONICA: I can get pretty emotional thinking about the fact that my kids have lived most of their lives in an incredibly stressful situation. It was a vow to them as much as to myself that I decided I would do whatever I could to make a difference to other families going through this kind of situation. Physically in our country we are given good medical care, but emotionally, the psycho-social is always lacking. The other thing that hit me was that the kids feelings kept being discounted because I didn't die. I think everyone was prepared

for me to die, preparing the kids for me to die, and when I didn't it was as if it negated their emotions, my emotions, and my children's emotions. It was like, well how can you be sad, your mum is still here. It would have been easier for a lot of people had I died, because people know how to handle that, but most people don't understand that the emotional and mental struggles that we as a family, and me as a person, struggle with is because I didn't die and because in most people's minds I am doing well. They forget the fact that we need to focus on those who are living with the disease and their families. I saw funding going constantly to finding the cure, finding the answer to this disease, but little or nothing towards the psychological and emotional consequences. There weren't support groups available to my children when I went through this. There weren't materials available for my children. So I was determined to make them. The first thing published was *Side by Side*, the first psycho-social material ever done in this country. That book explained how to put together a team approach to help a friend who is going through a life-threatening illness – specific guidelines on how to practically meet the needs they will experience. After that I started to look at the best way to speak to children and became convinced that it should be done through a fantasy story where you just lead them down a path and let them talk about their feelings rather than saying this is what cancer is about. Because that is usually the issue. The kids and I can talk a lot about the cancer, but what needs to be talked about is what's going on inside you. *The Dolphin Project* has grown out of that concern and is now supporting activities that keep the focus on dealing with the emotional needs of children. Backtracking a little in all of that was having heard in the last few years that it is more emotionally and mentally difficult for a child to live long term with a parent who is ill, than for a child to have a parent die.

### ***Is that because there is no closure?***

MONICA: Yes, and also because in the community nobody supports you. I can't tell you how many times I've heard the children being told, yes but your mum's okay, your mum has done

wonderfully, and thinking, yes, but you know what, they are still really sad. I'm not the mum I was 12 years ago. My daughter Jody has no memory of me being a well person. Every moment I'm not feeling well clearly panics them.

### ***Where are you now, what are your goals, your fears?***

MONICA: My fear is not of dying itself, it's the fear of what my death is going to be like for my children. Because the reality is I'll be so sick that it's not going to be a big issue for me. But I'm not sure that I even want to think about the fact of what it will be like for my children. I think after I'm gone, they will be so well established that it is not going to be an issue, but it's that moment of death.

***“I can get pretty emotional thinking about the fact that my kids have lived most of their lives in an incredibly stressful situation. It was a vow to them as much as to myself that I decided I would do whatever I could to make a difference to other families going through this kind of situation. Physically in our country we are given good medical care, but emotionally, the psycho-social is always lacking.”***

And then all the other things they are going to have to deal with with people. So if there is a fear that is what the fear is. As an aside to that I'm doing all kinds of reading and checking on the palliative care aspect but that's another whole realm. As to what my goals are, it will be to continue what I am doing. To get my children happy and well established in life and content with who they are. In the larger community I will continue to seek out the areas that most need support, and to develop a way of getting the word out there saying let's not forget the family and the whole picture here. The reality is it will never be accomplished but we will continue to work on it. We have to continue to think about the families of the living.

# An Integrated Approach



**T**HAT DEPRESSION IS ASSOCIATED WITH MEDICAL ILLNESS IS CONSISTENT WITH THE GENERAL LITERATURE ON LIFE EVENTS AND DEPRESSION... WE HAVE VENTURED INTO THE AREA OF DEPRESSION IN THE MEDICALLY ILL FOR A VARIETY OF REASONS. WE WERE CERTAINLY IMPELLED BY A WISH TO UNDERSTAND AND BETTER TREAT PATIENTS IN THE MEDICAL SETTING WHO PRESENTED WITH VAGUE, PUZZLING, DEPRESSION-LIKE SYMPTOMS... WE ALSO HOPED TO GENERATE INTEREST IN THIS SUBJECT AMONG HEALTH PROFESSIONALS BECAUSE WE BECAME AWARE THAT MANY DO NOT IDENTIFY, TREAT, OR REFER DEPRESSED MEDICAL PATIENTS FOR PSYCHIATRIC ASSESSMENT AND INTERVENTION. FURTHER, MENTAL HEALTH PROFESSIONALS ACCUSTOMED TO TREATING THE PHYSICALLY WELL ARE OFTEN UNNECESSARILY RELUCTANT TO ACCEPT INTO THEIR CLINICAL PRACTISE, PATIENTS WITH SERIOUS MEDICAL ILLNESS.

**DEPRESSION IN THE MEDICALLY ILL: AN INTEGRATED APPROACH,** written by Gary Rodin, M.D., John Craven, M.D., Christine Littlefield, Ph.D., published by Brunner/Mazel, New York.

*Dr. Gary Rodin is Head of the Psychosocial Oncology Program at Princess Margaret Hospital, and of the Mental Health Program at the University Health Network. He is a Professor of Psychiatry at the University of Toronto and a psychoanalyst who has conducted research on psychological disturbances in patients with cancer and other medical conditions. He has written about the psychology and psychotherapeutic treatment of patients with cancer and chronic illness and is the author of Depression in the Medically Ill: An Integrated Approach.*

***Dr. Rodin, what are some of the things you are discovering about people who are experiencing depression because of a medical condition?***

DR. RODIN: A lot of the work I have done has been focused on the longer term response to serious trauma and medical illness. We've particularly been looking at depression in medical populations, and that's interesting for a number of reasons. For one thing, treatable depression is often overlooked in medical populations. Many physicians will say, well of course they are depressed, anyone who had that would be depressed, and so they take that to be a reason not to treat it. There is one study of suicides that showed that a number of people who committed suicide had actually seen their doctor a month or two previously, but when the doctor was able to find a reason for their depression it was incorrectly assumed that it wasn't treatable. The other thing is that in medical populations, many of the symptoms of depression are similar to the symptoms of the illness. The person experiences fatigue, low energy, they can't sleep, have low sexual drive, and generally do not feel too hopeful about the future. It's sometimes difficult to know just how much is due to the medical illness and how much is due to the associated depression. In fact, in medical populations, serious treatable depressive illness is present in about 5-10 percent of medical patients. Another 25 percent have significant depressive symptoms. They do not necessarily have a depressive illness, but their depressive symptoms are a sign of distress and many of those people will respond or benefit from intervention.

***As a single mother of two young children, Monica was given the news that she had breast cancer at the age of 35. Patricia was 24 years old when she and her husband were attacked by a grizzly bear. What do you believe should be in place in the health care system when people undergo physical traumas such as these to meet not only their immediate physical needs, but the mental trauma it entails?***

DR. RODIN: Well we know that in those kinds of traumatic situations there is an immediate stress response syndrome that occurs. There is an

oscillation between having overwhelming intrusive thoughts and feelings related to the trauma – in Patricia's case the attack by the grizzly bear and in Monica's the memory of the diagnosis being delivered – and that of avoidance, there is the need to ward off these feelings altogether. People can be in a quite agitated state with a lot of physiological symptoms – hyper arousal, difficulty sleeping, not being able to concentrate, etc. – and some of those people will go on to develop a

***“In medical populations, serious treatable depressive illness is present in about 5-10 percent of medical patients. Another 25 percent have significant depressive symptoms. They do not necessarily have a depressive illness, but their depressive symptoms are a sign of distress and many of those people will respond or benefit from intervention.”***

formal acute stress disorder. In some cases that becomes chronic and they develop Post Traumatic Stress Disorder. We know that people without support, and people who have had prior trauma in their life, are at a higher risk to develop symptoms when they go through one of these events. By support, I don't just mean support in terms of family and friends, but it appears that support in the medical context is also extremely important. And that support has a lot to do with the way in which the news is first communicated and then the support which is provided afterwards.

Unfortunately, far too often, for a whole variety of reasons, including how busy medical staff are with case volumes etc., people are frequently delivered bad news in a very brief interaction. Often, in fact, when they hear the initial diagnosis they can't hear anything else, they are in a state of shock. So what we are now looking at is paying more attention to the context in which the news is communicated, the way it is communicated and then the support that is provided afterwards. The ability, in a supportive environment, to talk about the feelings related to a traumatic event and also having access to information may be therapeutic. Often, in the cancer situation, people have a lot of unrealistic fears – for example that it is automatically fatal. In the case of the grizzly bear attack there is a need for victims to be able to process their feelings about what has happened in an environment where those feelings are held in a mid-range. Support can help individuals so that they don't have to block

# An Integrated Approach

their feelings out altogether, nor be completely overwhelmed by them. That usually requires a supportive environment, sometimes a therapist who is able to help them process the feelings and keep them in that tolerable window, otherwise they are at risk to continue getting those intrusive overwhelming thoughts and feelings.

***When I spoke to Monica she brought up the fact that sometimes family are not necessarily the best people to surround yourself with. They want to believe the best and want you to believe the best to the extent that they prevent you from being able to voice the way you really feel.***

DR. RODIN: I agree with that. I think family are important in their own right, but what you are describing is a reason why, in addition to family, it could be useful to have support coming from outside. One of the things that could be hard about the aftermath of a grizzly bear attack is that there is no peer group. It's a very unusual occurrence so there is no frame of reference for that, no one to relate to. Where are you going to find someone else who has been through that experience? I also don't think we have enough support services for individuals who have suffered physical trauma, in general, in Canada. In the case of cancer, MS, heart attack etc., we are now trying to develop more coordinated services. We are on a mission really, and we are having some success in convincing the medical groups about the importance of this: the importance of approaching the whole person. In the past we have had people with serious diseases such as brain tumours who weren't even receiving a routine assessment of their emotional or social state. There's no such thing as a minor brain tumour, especially a malignant brain tumour. It's a tragedy for everybody involved. But people are now coming around to the idea that, in a routine way, we should be providing support and counselling and family assistance. Peer support groups, individuals who have experienced or are experiencing what you are going through, can often be extremely helpful in processing feelings and also help you feel less isolated.

***Patricia made me realize how extremely vulnerable people are when they are going through physical trauma. She spoke about the need for approval from her doctors. She wanted to be a 'good' patient and felt that because of everything she was going through she was viewed as a 'bad' patient because of the amount of care she required. In our health care system, where there often doesn't seem to be enough time to spend with patients, does that sense of vulnerability increase because people feel they are demanding time and comfort that just isn't available?***

DR. RODIN: A serious illness, whether it follows an attack or a medical illness like cancer, does disrupt all of your ways of coping and does make most people feel extremely vulnerable. Dealing with a large, complex health system only increases that feeling of vulnerability. It is also common for people who have been victims of attack, including physical attack and sexual abuse, to blame themselves for what has happened, or blame themselves for not getting better quickly enough, although of course it is through no fault of their own. What we are trying to do, in addition to ensuring all of the high tech care, is to provide human support. To have in place case managers, support groups, social workers, nurses and other staff who are able to spend some time with the person and also allow them to achieve a sense of mastery. People's usual active coping skills are often taken away when there's been an illness or injury, and it's important to help them develop strategies that will give them back some control. They need to feel that they can do things to help themselves. Someone may blame themselves for not getting better quicker, but we may not have provided enough tools for them to help themselves. For example, people with advanced diseases who suffer a lot of pain can now use pumps that allow them to deliver pain medication themselves, so they don't have to wait helplessly for the next dosage. And sometimes they

***"I think medicine has sometimes been so focused on treating the disease that we have forgotten that there is a person attached to that disease, and a family attached to them. We have to treat the whole person."***

use less pain medication that way, because they are not so worried about when they are going to get the next dose.

***For Patricia there was a very real sense in which she felt stigmatized by her health care providers once she sought psychiatric help for the depression she was experiencing due to the attack. She felt she lost credibility and her physical complaints were not taken as seriously. Could you comment on that?***

DR. RODIN: Well, there is some truth to that. We are trying to diminish that stigma and one of the ways we are trying to do that is by normalizing mental health services. For instance if you experienced a heart attack then you would routinely be given physiotherapy, exercise therapy etc. We are trying to introduce strategies for support and help with coping with the emotional and psychological consequences as part of the routine management you would receive.

***Making it a whole person approach?***

DR. RODIN: Exactly. Cancer for instance is a traumatic event for everybody. You don't have to be especially vulnerable, and that kind of normalizing makes it a lot easier for people to receive the help and support they need. Going back to your question about stigma, a big target of our education is the doctors, because sometimes the public is further ahead with this. People who have had cancer, for instance, know all about the emotional impact. They know how important support is. Sometimes the medical profession is a little too oriented towards thinking that it's just about technical care. We want good surgeons and the proper medication, but most people also want the whole of themselves to be taken into account and treated.

***Monica was not expected to survive her treatment and she realized afterwards that it would have been easier for many people if she had died. They knew how to deal with that and how to comfort her children – there was some kind of closure. But dealing with an ongoing serious illness that holds out the spectre of death at some undefined point is a lot harder for***

***people to cope with. She also raised the point that it's emotionally and mentally more difficult for a child to have to live long term with a parent who has a serious illness***

DR. RODIN: In reality I am not sure whether it is easier for a child to deal with the death of a parent, but I know what she is talking about. For example, medical training is very much orientated around active treatment. It is more focused on surgery and active treatment, giving chemotherapy etc., and the harder part for the medical profession is dealing with what Monica is talking about,

***“We know that people without support, and people who have had prior trauma in their life, are at a higher risk to develop symptoms when they go through one of these events. By support I don't just mean support in terms of family and friends, but it appears that support in the medical context is also extremely important. And that support has a lot to do with the way in which the news is first communicated and then the support which is provided afterwards.”***

which is just living with something that you can't take away. Physicians who treat such patients must deal with their own feelings of helplessness, of frustration, and also with their own mortality. Being around illness continually makes people get in touch with their own feelings, and with the fear of dying. We are all susceptible to that, and many people are uncomfortable with those kinds of thoughts. We see that in the hospitals as well. However the outcome depends on how it is addressed. If it is addressed openly and a child is given help with it, then in the end they can often manage extremely well.

***But are children being given this help, or do they typically get overlooked?***

DR. RODIN: Unfortunately this is an area that I believe is often overlooked. In many settings we are only just now beginning to develop family services and programs for the children. Medicine has sometimes been so focused on treating the disease that we have forgotten that there is a person attached to that disease, and a family attached to them. We have to treat the whole person.

# 2001 – The International Year of Volunteers

IN NOVEMBER 1997 THE UNITED NATIONS GENERAL ASSEMBLY PROCLAIMED 2001 AS THE INTERNATIONAL YEAR OF VOLUNTEERS. TO PREPARE FOR THE YEAR, THE UNITED NATIONS VOLUNTEERS PROGRAMME (UNV) HAS BEEN DESIGNATED AN INTERNATIONAL FOCAL POINT. WITH ITS MAIN OBJECTIVES OF INCREASED RECOGNITION, FACILITATION, NETWORKING AND PROMOTION OF VOLUNTEERING, THE INTERNATIONAL YEAR OF VOLUNTEERS 2001 PROVIDES A UNIQUE OPPORTUNITY TO HIGHLIGHT THE ACHIEVEMENTS OF THE MILLIONS OF VOLUNTEERS WORLDWIDE AND TO ENCOURAGE MORE PEOPLE GLOBALLY TO ENGAGE IN VOLUNTEER ACTIVITY.

AS CANADIANS WE HAVE A LONG TRADITION OF VOLUNTEERING TO ACHIEVE OUR SOCIAL GOALS, MOBILIZING ENORMOUS ENERGY FOR THE COMMON GOOD. VOLUNTEERS SUPPLY THE HUMAN ENERGY THAT DRIVES MANY THOUSANDS OF ORGANIZATIONS AND GROUPS ACROSS CANADA. VOLUNTEERING IS THE MOST FUNDAMENTAL ACT OF CITIZENSHIP AND PHILANTHROPY IN OUR SOCIETY.

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***In the next three issues of Network we will be profiling individuals who represent what is being done by CMHA volunteers in the mental health field.***

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## ***What is Volunteering?***

Volunteering is the most fundamental act of citizenship and philanthropy in our society. It is offering time, energy and skills of one's own free will. It is an extension of being a good neighbour, transforming a collection of houses into a community as people choose to help others. By caring and contributing to change, volunteers decrease suffering and disparity, while they gain skills and self esteem.

## ***What is the difference between volunteer work and unpaid work?***

Volunteer service is offered by choice – it is not mandated or coerced. It contributes to the well-being of an individual or the community, and is usually coordinated by a nonprofit or public sector organization, and pays no salary or wages.

## ***What is the importance of voluntary activity in Canada?***

Voluntary activity plays such a unique role in Canadian society that it has sometimes been described as the glue that holds all spheres of society together. And while volunteerism provides volunteers themselves with a great feeling of satisfaction, it can also articulate unmet needs in the community and the organization of services to meet them.

Volunteers come from all walks of life and represent a wide cross-section of the Canadian population. Volunteering fosters community integration and cohesion by encouraging friends, colleagues and neighbours to work together through the sharing of a common concern. As people search for ways to enrich their lives, many are giving their personal time and skills to the community. Others are looking for new routes to personal and professional development. Individuals with special needs are becoming empowered to take charge of their lives as they contribute their energies to helping others. In short, more and more people are considering volunteering.

***According to the latest Statistics Canada survey of voluntary activity and giving, over five million volunteers filled more than 9 million different positions in one year.***

*For more information on what is taking place across Canada and around the world during this special year, visit [www.iyv2001.org](http://www.iyv2001.org).*

**APRIL 17-18, 2001**

Hannah International Conference on the History of Mental Illness. Sponsored by University of Toronto and McMaster University. For more information: Tel: (905) 525-9140 ext. 22752, Fax: (905) 522-9509, Email: dwright@fhs.mcmaster.ca

**APRIL 19, 20 & 21ST, 2001**

Founding Conference of the International Association of Mental Health Services. Vancouver, BC. For more information: Tel. (604) 669-7055, Fax: (604) 669-7054, Email: info@iafmhs.org, Website: www.iafmhs.org

**JUNE 10-12, 2001**

Ontario Association of Community Care Access Centres 2001 Conference. Community Care...Partnerships at Work. International Plaza Hotel, Toronto. For more information call Meeting Management Services at 905-335-7993.

**OCTOBER 22-23, 2001**

Annual Canadian Mental Health Association / Centre for Addiction and Mental Health Conference, keynote speaker Roy Bonisteel. Toronto Airport Marriott Hotel, 901 Dixon Road, Toronto. Info: Tel. (416) 977 5580 ext. 4121, Fax. (416) 977-2264

EVENTS

**2001 WFMH World Congress**

The World Assembly for Mental Health will take place in Vancouver, July 22 - 27, 2001. One of the innovations at this assembly will be a track on behavioural medicine. A new WFMH Collaborating Center, the Applied Behavioral Medicine Research Institute at the State University of New York, Stonybrook, is participating for the first time and has set up a task force to prepare for Vancouver. Behavioral medicine does not address mental illness itself, but focuses on the interplay between psychosocial factors and medical illness. Colloquially known as "Mind-Body Medicine", it considers the linkage between one's mental state and physical illness. Research has documented that level of disability, impact on well-being and in some cases morbidity are influenced by psychological factors as well as the degree of disease severity. The behavioral medicine task force will include experts in the field, representatives from health organizations, and regional WFMH members. Its aim is to summarize the knowledge base in behavioral medicine, and to outline the implications for international health policy. For more information, contact: Joan E. Broderick, Ph.D. Email: Joan.Broderick@sunysb.edu.

**THE 4TH ANNUAL ALL-STAR GAME PARTY!!**

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*(all proceeds to benefit Canadian Mental Health Association)*

Sponsored by the Toronto Sun and TALK 640.

For more information contact

**Karen Wilkinson at 416-977-5580 ext. 4138 or kwilkinson@ontario.cmha.ca. Visit the website: www.ontario.cmha.ca/act/hockey.html.**

# Sweet Support for CMHA's Stride Candy Dispensing Program

Dear proprietors, patrons and route operators, The Staff and volunteers of the Canadian Mental Health Association, Ontario Division, thank you for supporting their Stride Candy Dispensing Program over the last year. This program, which has raised over 2.5 million dollars since it was established in 1978, is a vital source of revenue for our 35 Branches across Ontario who deliver essential services and programs across Ontario for children and adults. Our goal is to provide you, your staff and customers with quality service and product, and your continued support is very much appreciated.



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# Network

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