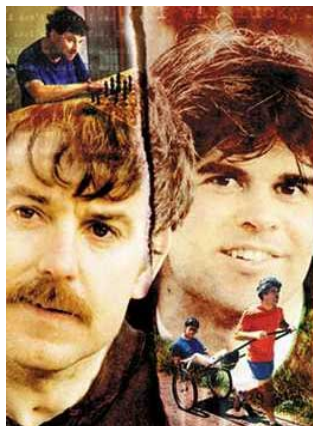


## MM email with Robert and Doug of BREAKAWAY



Bruce Saunders wrote:  
May 13/01 Hi,

I'm showing BREAKAWAY on Monday in Victoria BC and wonder if you would like to let my audience know what's going on with you now. Our venue is a lecture theatre in a psych hospital, I'm an ex-patient been dealing with manic depression but have put on a pretty cool program of films for 8 years now, every Monday. Really realize the value of inspiring people to recover. You guys certainly have done that. Congrats on the Hot Docs Award! but I already had it picked as a winner.

I'll add a piece about me but really want to know more about you.

Bruce - Movie Monday

Robert: Bruce! Thanks for the e-mail. I checked out your web page and it looks like you have a great program out there!! I think it is excellent that you are showing Breakaway, thanks. I would be interested in hearing about the discussion. Also thanks for filling me in on your own story.

As you know recovery from anything is a long, arduous process for all involved. I had been in a coma for 24 days and once I was "out" of the coma I was unable to do anything let alone walk or talk. But I had a desire to continue living and competing and thriving! I wanted to walk, I clearly remember wanting to walk. I was walking when I left the hospital for the rehab centre. I was under the impression that there would be somebody to help me get "all" better. It was during this process that I saw a gigantic need for a place, a mindset that looked upon recovery from a brain injury as positive, exciting and most importantly possible!

When I was injured I was 18 years old and I had been playing ice hockey in Southern California. I had graduated from high school and drove an old car across the continent. I believed anything was possible! So, I carried that belief with me into my recovery. My accident was in February of 1988 and later that fall I enrolled at Saint Mary's university. They had a great athletic facility where I was able to work on my "recovery". By now I understood that there was no "all" better, that I was involved in a life long process of growing, learning and one of great discovery! A process known as life.

While at Saint Mary's I was able to meet a lot of people and share experiences, it was interesting. I was still involved in a community with others who were recovering from brain injuries. I met people who had never thought they could or would improve their situations. People who had been institutionalized at a young age with no hope. I wanted to do something, I knew that I could help.

I graduated from Saint Mary's in the spring of 1992 with an arts degree in Psychology. Once again I started to travel, I was researching brain injury recovery. Interestingly, it was an experience in 1993 that I had in Cobble Hill on Vancouver Island at a facility called Skeleem Village where I decided that the time had come to do something on my own. So I came home to Nova Scotia with the thought in mind to find some land in the country and help people recover. It was in the summer of 1994 that I met Doug.

Now I will ask Doug to tell a bit about himself and his thoughts:

hi Bruce

this work on recovery is harder than I thought. it has gotten me frustrated and confused and had me depressed. until I talked to Robert the other day. since ive met Robert in 1994 ive bought a house ive learned that I can get on and off the toilet by myself, dress myself and bath myself. when I was in nursing homes they had me believing I couldn't do anything by myself always hearing everything negative. I remember sitting in my room in the nursing home waiting for the mechanical lift to be free. so I could be put on a shower chair and pushed over the toilet so I could have a bm. all the time I was waiting I was thinking. there must be a way I could get on and off the toilet without using a mechanical lift.

I quit high school when I was in grade 10 in the early nineteen seventys. so I only had my grade 9. I remember sitting in the Windsor hospital telling them id like to take my upgrading. but they never believed me they just laughed it off as a joke and nothing became of it. then I met Robert and in 1999 he helped me go to upgrading school and in

2000 I graduated. We go do talks at schools which I like doing. we are going to edmonton the 29 of may for 10 days. my biggest problem is that I get so wrapped up in walking I don't see my little improvements on my way to walking. I just have to believe other people when they tell me I'm doing good instead of getting mad. I attempted suicide once. because I thought it wasn't worth living. but was I ever wrong. I learned my lesson. life is worth living I won't try suicide again.

Hi, it is Robert again. Now, here we are. I have the property and am working towards developing it for the purpose of recovery. Doug still works hard and still wants to move forward even though sometimes he is frustrated. We now have another young woman, Kelly, living with us. As well a friend, Donna, is here helping us. Kelly sustained a brain aneurysm in 1988 and subsequent to that she was in a nursing home. I came by Kelly in September 1999. She moved in March, 2000 and has been thriving! Her progress is astronomical!! Kelly's arrival has been both good and frustrating for Doug.

My hope is to create an atmosphere where people can move forward in their lives everyday. I have plans to build another house. But mostly I would like people to be able to live throughout the community and not just here. I would like to help people develop their own tools and skills to help themselves to work towards their own recoveries. Whatever that means for them.

Well Bruce, there is a little information for you. If you have any more questions please ask. Once again, thanks for sharing some of your story with me and congratulations on your accomplishments. Take care, Robert.

Bruce wrote: Thanks a heap for all the update and background. I'll let you know how it goes. If I slip up give me a reminder. It's a busy life.

If you're ever to the west coast I'd love to do a Rob and Doug Night! I've got a great venue in the hospital here and know how cool and important your story is.

Bruce

May 15/01

Bruce! Hi, I hope the viewing of Breakaway went well last night. I noticed on your web page that you have shown Awakenings. When I first saw that film I was lit on fire! Incredible! There was so much possibility in Awakenings. There are people out there who are locked away, barely existing. They just need someone to find a way to unlock their chains. That really kind of thrilled me. Take care and keep in touch, Robert.

Bruce wrote: Hi Robert,

When we showed Awakenings I was particularly interested to make the point about how meds can change brain functioning in profound ways and also the ethics of using meds in trials - to experiment and withhold treatment as Oliver Sacks did. I asked the Chief of Psychiatry at the hospital to speak and do a Q&E and also added some material from the book. You've got to read the book if you haven't. The true story and actual case studies are incredibly gripping and heartbreaking, and a cool chapter on making the film too.

Unfortunately we had a balls-up with your film. The folks I was borrowing the copy from made me verify that I had the proper permission to screen it which didn't come through till Friday. I was on to them on Monday and they offered to drop it to me. The guy put it in his pack and forgot to get it to me till 2 hours too late. Just forgot... Didn't even have an address or phone number I could chase him down with.

I was very pissed off. First time I haven't delivered a film on sched in 8 years! I explained to the audience and ran a different and in its way equally inspirational film about the late, great folk singer, Stan Rogers "One Warm Line" To add to my frustration it'll be 8 weeks before I can reschedule it. That'll teach me to secure the copy at the last minute. All reasonable turns, like a Hardy novel, leading to a screw up.

My wife works in the school system with speech therapists developing augmentative communication systems for kids, fitting communication devices to they're needs and abilities. She knew your device, Doug, and said she's be looking for one that does the ticker tape but also has synthetic voice and a preview feature. So far hasn't found the combo. I thought its use in the film was excellent in the way it put your clear intelligent voice into the doc so impressively.

I'll let you know when I get it scheduled again. DAMN that was a frustration!

\*\*\* Can I pass your email along to go with Breakaway? I've managed to get a couple of copies into libraries and that background and update really enhances the film I think.

Bruce

Bruce! Too bad about the film. I did read the book by Oliver Sacks about ten years ago. You can definitely add our e-mail to your presentation, thanks. When you say that you managed to get a couple copies into libraries do you mean the film? Where did you see the film? I do not know about the legality of having proper permission, who did you borrow it from? In my opinion if it is going to help someone then the more people who see it the better. Take care, Robert.

Bruce Saunders wrote: I saw it at the Victoria Independent Film Fest last Feb. Public screenings, even if they're free, are basically using someones intellectual/financial property and permission needs to be obtained to be on the up and up, especially if you're getting a public profile and applying for funding from Canada Council and suchlike. Having made a couple of small projects, I have a great respect for the property and try to comply with that condition.

I did get the Mental Health Library of B C to get a copy including public performance license and also the hospital chaplain is purchasing a copy from my enthusiasm about its usefulness in his 'pastoral' work. Neither of those copies came in time so I attempted to use the copy from the Fest's archive.

I pay \$588 and \$570 a year to two companies to show any 'theatrical' films available on video - as many as I want a year. Usually works out to \$25 or so a night. I did it without ppl for a couple of years when I started out as a kind of guerrilla outfit and before I figured out how to afford to do it right. But you can get clobbered with law suits, especially if they see an institution like a hospital or school to squeeze. Now I even have a SOCAN ppl for the right to play music without fear of the music police down our backs. Sometimes we get \$15, sometimes \$60-80 in donations but part of the reason I'm doing it is to allow folks who are impoverished to come out to a movie night and not feel guilty for not "paying up"

Nice to be in touch. I feel very close the what you're doing, being on an exploration of recovery for me and many people I know challenged with mental illness. Many just slip off the edge. Seems to me the biggest element needed and usually missed in peoples' "care plan" is hope. It's a most valuable commodity and a volatile one to hold on to. An interesting thing to try to model.

Bruce

Bruce! Breakaway is going to be aired nationally on CTV on June 17th. I do not know if that coincides with your movie night or if it will affect you at all. But I thought I would send you that bit of information.

So true about hope, everything seems to begin right there. Take care, Robert.

Bruce wrote: Thanks for the info. I'll get to showing it in August or Sept. You guys are STARS now. Are you overwhelmed with mail and speaking requests? Something about getting ones story told that's satisfying and threatening both. I've had local newspapers run a triumphant article about me when I was crapping out mood-wise and felt like a complete hoax. And also when something totally brilliant is going on, to be completely ignored by the folks that are apparently encouraging positive media to beat the stigma of mental illness. It's crazy-making in itself! Even the friendly board I've gathered doesn't quite get the model of recovery concept that I'm attempting. Still it seems a positive and constructive to do this public experiment, risking to be a high profile ex-mental patient. I find it a fascinating process and have gone about it very consciously from the start. It strikes me you're doing the same. Happy to hear from you any time. Again, let me know if you're ever out this way. Bruce

May 23/01 Bruce! Well, Doug and I are speaking in Edmonton next week at a conference and we will be spending a week there visiting and speaking at hospitals and rehab facilities. That will be fun. When I was injured it was a big media event so I was high profile like it or not. But it has been good for me and hopefully for people going through recovery. Take care, Robert.

Bruce Saunders wrote: Sept 4/01 Robert, Just thinking about directions our discussion might go. I'd be interested to know the economics of your model of care/living. How's it compare, now that you're three, with institutional care?, aside from the other positives. There ought to be more options for folks with mental illness disabilities than the ones we have now. Thinking about a live tele-conference with you guys and the audience. We did it once during our fest last year with a director, to talk with the audience about his film. Worked splendidly. But there is a 3 hour time zone delay which would get us into 10 pm or so. Got to decide how far I want to stretch myself too. Would you be game? Send me your address and I'll send you the poster. Or look on the net - [www.islandnet/mm](http://www.islandnet/mm) Bruce

Sept 7/01 Bruce! Hi, been meaning to send you something for a while. I received the cheque for the copy of Breakaway, thanks.

For economics it is pretty simple: Doug is a recipient of home care which pays him for his attendant care (that is me) plus he has a small Canadian pension plan cheque each month. The total is roughly three thousand dollars a month. If Doug lived in a nursing home the government would pay about a thousand dollars more than that for his care.

Kelly came from a nursing home where the per diem was \$121.50 per month. She has been living with us for roughly 18 months and is the recipient of a family benefit cheque of \$421.00 a month, about 10 per cent of what the nursing home was being paid to warehouse her. When she first came here we began the process of applying to social services for Kelly to receive an amount similar to Doug. That process continues still.

Basically when Doug and I moved here we were able to get a mortgage. Doug had an amount in his budget for rent each month and with my salary (from Doug) we were able to do it. Also, I had a little bit of money saved and I paid extra on the mortgage every chance I could. I am pretty good with my money, I do not need a whole lot. So after a little under 4 years Doug and I owned the house outright.

I hope that answers your question about economics. I believe there are many ways that people could make it work living in the community if they are committed to it. I do not think that our relationship here would work if this was not my life. Do you understand? Also I have a friend, Donna, and she stays here with us and volunteers her time to help Kelly and thus all of us. In a sense this is our family.

Doug's balance continues to improve each day, he had a really good summer. We put a lot of thought into building a new house on our property or onto this house. I would like to have two more people with brain injuries come live with us. People who are presently living in nursing homes. We visit people in these nursing homes and there is so much human potential going to waste it is sickening. I hope that when people see the success that we have had in the community they will start asking questions to better their own lives and that of their family members. The new house is still a thought but not a priority.

I wanted to tell you a little bit about Kelly's progress. Kelly is the young woman that you see at the end of the film with Doug and I. Kelly moved in with us in March 2000. I "found" her in a nursing home in Arichat on Cape Breton Island. She had been living there following a brain aneurysm in 1988 when she was 18 years old. When Kelly moved in with us she was in a wheelchair, she weighed 272 pounds, she was incontinent and she had what is called polycystic ovarian syndrome, and she hardly smiled. Now Kelly exercises everyday she walks upstairs to bed every night, she bathes and dresses herself everyday. She still uses a wheelchair but is walking everyday on the deck and in the yard. Kelly has control of her bladder now and she has been cured of polycystic ovarian syndrome. Kelly smiles and laughs much more often and feels much better about herself, she now weighs 143 pounds!!! Kelly's goal is to walk and she is closer and closer with each new day.

Doug and Kelly are both doing extremely well while living without the constraints of an institution.

Bruce the idea of a phone call is a good one, however ten o'clock in Victoria is two in the morning here. But let us know, I am sure we can work something out. Please let me know if you would like any more information. Do you still have the last update that I sent you? Take care, love Robert.



**"Doug & Robert in their MM leisure wear at their NS home. Awesome!"**

**Postscript: November 2002**

We did show the film at MM to a big audience we did the telephone conference for about a half hour, till midnight Atlantic time.

The question I forgot to ask Robert: What your hair style now?

He's now got a beard!

From Robert 31 Aug 2004  
Bruce!

The venue for the film sounds pretty cool, I hope it goes well. As far as an update goes, Doug and I are still here and working every day. Doug continues to make progress on a daily basis. His balance is improving as is his endurance. He is on his feet more and more all the time. Doug had experienced a lot of difficulty while eating but as his posture improves all else improves as well. Also recently we were to see a prosthodontist, which is a dentist who puts prosthesis in the mouth. Doug was fitted for and is now utilizing a palative augmentation. Doug's tongue was very weak and it did not reach the roof of his mouth and therefore was of no use during chewing and swallowing. Well, this augmentation lowers the roof of his mouth and what a difference. Doug said after the first day that he was tasting his food again!! Plus he is no longer choking and gagging while eating. Perhaps most interesting is that Doug's tongue has grown!! I suppose that the tongue being a muscle it only makes sense! His device slips in and out like a retainer, it is kind of neat. So, we continue to ask questions and try to find solutions. Last April (2003) Doug and I were in Iqaluit on Baffin Island visiting my sister, Shannon and her friend, John. We had a great trip, went dogsledding and had a fantastic time!

Kelly-Ann has moved into her own home in her home town in Cape Breton. Her family is helping her there as opposed to her living in a nursing home. They are in a constant struggle to secure funding for outside help.

From Robert Sept 30/04  
Bruce!

Hi there. My own health is perfect, I eat well and exercise and life is good. My "conviction" to Doug's recovery only gets greater with time. As time moves on and Doug continues to work at recovery and progress naturally occurs Doug is able to see and feel his own success and he becomes motivated and works harder. Doug's recovery continues to move forward and that is very exciting.

I would tell anybody who is working to help other people recover from Brain Injury or from anything that no matter what the situation or who you are that life can always get better. It is important to focus and to put in the time in order to be able to see and work with changes.

If anyone is interested in contacting Doug and I you could give them our contact information - rafuse.hessian-14@ns.sympatico.ca. Take care, love Robert.