Celebrating 20 Years of Families Helping Families!

For twenty years, BCSS members and staff have worked hard to support families and individuals affected by schizophrenia and other serious mental illness. Because we are so involved with the issues and struggles of the present, it is easy to forget our many significant accomplishments.

Individual members of the BCSS Branches are the mainstay of our Society. The volunteer work of the thousands of BCSS members and supporters in their local communities throughout BC—in the areas of health, education, support, housing, and rehabilitation—is an invaluable contribution to the well-being of the entire province. We are greatly indebted to each and every BCSS member, past and present, for their tireless efforts. Looking over the following partial snapshot of just some of the BCSS successes, one thing is clear—we should all feel very proud!

- BCSS “Emerald Eve” Fundraising Gala. First held in 1988, this popular and successful fundraiser has raised over $100,000 for the Society.
- Partnered with Coast Foundation Society to raise more than $320,000 for a nine-unit apartment building in Vancouver in 1994
- Raised $1,000,000 to establish the Jack Bell Chair in Schizophrenia Research at the University of British Columbia, established in 1994
- Developed the Partnership Education Program—an exceptional curriculum and delivery mechanism to introduce mental illness to children in Grade 4
- Developed “Kids in Control”, an exclusive education and support program for children ages eight through thirteen whose parents have a mental illness
- Raised over $80,000 to develop “Reaching Out” Early Intervention video/manual high school curriculum resource, now being used across Canada
- Successfully lobbied for Bill 22 — Amendments to the Mental Health Act
- Successfully lobbied to have risperidone and quetiapine used as first line options for people with schizophrenia
- Successfully lobbied police and government to support the use of Taser technology for non-lethal police intervention
- Staff presentations of BCSS programs at international conferences:
  - Partnership Education at IAPSRS Conference, New Orleans 1995;
  - Reaching Out Early Psychosis program presented at International Early
Continued on page 6
An Open Letter to BCSS

Provincial and branch board members and all the other BCSS members and staff who work to advance the mission of BCSS would be less than human if they didn’t occasionally wonder, in blue moments, if their striving is worthwhile.

Recently, I had a chat with a well-respected mental health services person from the Okanagan. He spoke of the prevailing uncertainty about the future direction of general health care in British Columbia, but said he felt that the creation of the position of Secretary of State for Mental Health was a very positive event for Mental Health Services, and, that it is thanks to the efforts of groups like BCSS over two decades that mental health has its current profile in the awareness of the provincial government.

His words made me think back to what it was like in the early eighties, to the fledgling years of the BC Friends of Schizophrenics, the first incarnation of BCSS. To mention a few of my memories of those days: there was very little public understanding of mental illness, so stigma was rife; available medications tended to have heavy side-effects; knowledge of the physical basis of mental illness was limited, so parents were sometimes made to feel their child-rearing was to blame for the illness.

Since the early eighties, BCFOS which became BCSS has played a pivotal role in enlightening members, the public and various agencies about mental illness, in strongly supporting schizophrenia research at UBC and in successfully fighting for first line application of better medications. Mental illness still causes havoc, but things are better for its victims and their families than they were twenty years ago.

So if you sometimes question if your work for BCSS or the Dr. Norma Calder Schizophrenia Foundation is worthwhile, you can reply with a resounding “yes”. Progress may be imperceptible over a month or a year, but it is happening. Your dedication to continued change is so very valuable and brings you the heartfelt thanks of every thinking BCSS member.

• Rod Pringle
BCSS Member

---

We really are making progress

2002! The number still makes me feel like I’m in a science fiction movie. It seems the world has changed so much and yet so many things haven’t changed enough. We still have wars, we still have hunger and we still struggle to alleviate the suffering caused by schizophrenia. The problems seem so big and the successes always seem so small in comparison. In the following letter, long-time BCSS member and honoured volunteer Rod Pringle alludes to this tendency to be hard on ourselves, and our need to think about change over a period of years rather than days or months.

2002 is the twentieth anniversary of BCSS. Do yourself a favour and read what Rod has to say, and then have a look at some of our accomplishments on page one. Then pat yourself on the back and think about one other person you can call to thank or congratulate for a job well done in your Branch or your community. 2002 is time to celebrate our successes, big and small. Just think of what we’ll be able to do in another twenty years. Amazing!

• Michelle Colussi
Research Update

Brain Scan to Diagnose Schizophrenia

The New Scientist, a leading British science magazine, recently reported on the accomplishments of Dr. Peter Liddle. Emphasizing the fact that diagnosing schizophrenia could be revolutionized by computer analysis of brain scans, the article points out that the controversial computer test developed by Dr. Liddle at the University of British Columbia has been surprisingly accurate in early trials identifying patients with schizophrenia. The test is based on a learning system called a neural network, and may be able to diagnose the illness before patients show any symptoms.

Dr. Liddle developed the system with his colleagues at UBC using computer software to analyze fMRI (functional magnetic resonance imaging) brain scans. This technique—which in early tests has been 100% successful in distinguishing people with schizophrenia from healthy volunteers—could theoretically detect the illness before symptoms even develop.

The computer program looks for certain characteristics in the cerebral blood flow that might indicate the presence of schizophrenia. This method has the ability to identify relatively complex patterns that the naked eye cannot see.

Although ongoing studies are needed to verify the system, the implications for the diagnosis and treatment of schizophrenia, the most severe form of mental illness, are considerable. Because schizophrenia can be hard to diagnose, sometimes it takes several years before it is made clear. “Being able to make a reliable diagnosis early in the illness can help optimize the outcome,” said Dr. Liddle.

The ability to detect and treat schizophrenia before symptoms develop would significantly reduce the impact of the disorder and improve the quality of life for patients and their families.

Hope for Safer Delivery of Drugs

A recent article in The New Scientist magazine featured a promising new technique for the safer delivery of drugs to some parts of the brain. The technique, using Ultrasound, makes a tiny hole in the blood brain barrier, the membrane that usually stops large molecules from crossing from the bloodstream into the brain.

This barrier prevents researchers from using big molecules to treat a range of brain disorders, including schizophrenia. Because different parts of the brain have different functions, small molecules meant for one area can cause unwanted side-effects in another.

The researchers at Brigham and Women's Hospital, Boston attempted to breach the blood brain barrier by focusing ultrasound to a discrete point. They found that a low power ultrasound beam could vibrate and pop any bubble it was focused on, leaving a tiny hole in the blood brain barrier. The hole repaired within a couple of days and there was no damage.

The researchers say that the bubbles could be filled with any drug. This would then be released into the brain through the hole made when the bubble pops. This could deliver a discrete dose that wouldn’t spread to other parts of the brain.

This is particularly exciting because there’s currently no way to deliver drugs to a small volume of the brain without an invasive injection.

• Based on an article in The New Scientist 5th December 2001

Using Smells to Explore Schizophrenia

A recent report in The Journal of the American Medical Association suggests that studying the sense of smell might help shed light on schizophrenia symptoms.

Researchers at the University of Iowa exposed people with schizophrenia and healthy volunteers to an unpleasant smell and a pleasant smell. All subjects were asked to rate each smell, and an imaging device was used to track the cerebral blood flow to different areas of the brain.

The brain images showed marked differences in mental processing. The limbic system, an area linked to smells and basic emotions like fear, was highly active in healthy subjects as they smelled the unpleasant odours. However, the limbic system was largely unused in people with schizophrenia, who relied instead on the frontal cortical areas, usually reserved for higher level functions like decision-making.

Researchers hypothesized that deficits in the limbic systems of people with schizophrenia might prompt their brains to "hijack" cortical areas to process unpleasant stimuli, which could then indicate a threat. This misuse of brain circuits could play a role in a common symptom such as paranoia by creating habitual association with danger for all kinds of stimuli.

The limbic system was also not available to respond when people with schizophrenia sniffed a pleasant lemon odour. This suggests a direct link between difficulties with the limbic system and another common schizophrenia symptom, “anhedonia”—the loss of the capacity to experience pleasurable emotions.
expanding the horizons of hope

The Planned Giving Program of the B.C.S.S. and the Dr. Norma Calder Schizophrenia Foundation

The Basics of Discretionary Trusts

A trust is a relationship established where one person (the settlor) gives property to another person (the trustee) for the use or benefit of another or others (the beneficiary or beneficiaries). A beneficiary can be a beneficiary of the income of the trust property or the capital of the trust property, or both.

Trusts can be established during the life of the settlor (in which case, they are called inter-vivos or living trusts) or upon the death of the settlor (in which case, they are called a testamentary trust). Trusts can also be revocable (where the settlor retains the right to terminate the trust) or irrevocable.

Trusts can also be non-discretionary, where the terms of the trust specifically direct the trustee as to what each beneficiary is to receive, and when. Our readers are, however, generally more interested in discretionary trusts, since such trusts can often provide long-term financial security for a vulnerable family member (the beneficiary).

Basically, a discretionary trust provides the trustee with complete discretion as to what monies, if any, will be spent by the trust, when and upon what. Typically, the trustee is given absolute discretion as to what will be spent from the income and/or capital of the trust for the benefit of a vulnerable family member, and is directed to transfer what is left in the trust, if anything, upon the death of the vulnerable family member to the ultimate beneficiary (e.g. another family member or a charity of the settlor’s choosing).

Another advantage of discretionary trusts is that, because the only interest the vulnerable family member has in the trust is a right to call upon the trustee to exercise the trustee’s discretion, the trust property and income is not considered an asset or income of the family member, and therefore doesn’t affect their entitlement to disability benefits. This is a significant consideration for most settlors, unless the trust property is so substantial that the family member will have no need for disability benefits.

As you may be aware, in order to receive disability benefits, a recipient must have assets of no more than $3,000 (certain assets, such as an interest in your own home or a car are presently exempted), receive no unearned income whatsoever, and receive earned income of not more than $200 per month. Accordingly, direct receipt of an outright inheritance, or income and/or capital from a trust, may result in the termination of disability benefits until the inheritance or funds have been spent. Present legislation provides, however, that expenditures from a trust for the following items on behalf of a beneficiary, will not affect the beneficiary’s entitlement to disability benefits:

- medical aids and supplies
- necessary renovations to a home to accommodate a beneficiary’s needs that relate to the disability
- necessary repairs to the beneficiary’s home
- education or training
- caregivers or home support services

In addition, up to $5,484 per year may be spent on any other item or service necessary to promote the independence of the person with the disability, without it affecting the beneficiary’s disability benefits.

Any other type of expenditure will affect entitlement to disability benefits. Other options that can be considered by a trustee to preserve disability benefits include:

- the purchase of assets for a beneficiary that are exempted from consideration (such as a home or car),
- limiting payments to one or two particular months, so that a beneficiary will only be cut off their benefits for a limited time.

Please note, however, that preservation of disability benefits should not be the only consideration for the trustee. The vulnerable family member’s best interests should be the overriding concern. Choosing an appropriate trustee is therefore critical.

In certain circumstances, it may also be possible for the vulnerable family member to place a lifetime total of up to $100,000 in their own trust, without it affecting their disability benefits, if the only expenditures from the trust are on account of the health/medical and disability related costs referred to above.

Please note that this article is for general information purposes only. Trusts are complicated and you should seek legal and professional advice and assistance in determining whether a trust would be appropriate for your particular needs. For further information, or for a copy of our Discretionary Trust Kit, please contact the Director of Planned Giving at (604) 270-1303 or email: plannedgiving@bcss.org.
BRIDGES Teacher Training
Well Received

Comments from the training held during November in the Lower Mainland

Debbie Sesula and Doug Shea just finished facilitating a successful BRIDGES Teacher Training with 13 teachers graduating. Here’s what some of the graduates had to say:

"It was very informative. Made me realize that it will be easy to follow the book, it is written in a clear and precise manner."

"The best parts of the training were the fun, relaxed atmosphere, the instructors open and honest easy-to-approach attitude, role playing and practice teaching assignments."

"I have learned a lot from the training, it was very well organized, informative being taught teaching skills. The humour and laughing was cool. Debbie and Doug are very well presented, they’re good public speakers and mentors, the training as a whole was a very positive experience."

"The best parts of the training were getting the material and information across to us in a fun manner and a lot of support and positive talk that we are all very capable. Debbie and Doug both complimented each other and worked very well as a team. They know their material well and have done their homework. Thank you, I really appreciate being given the opportunity to 'shine'."

"The training built my self-confidence, made me feel I can do anything I set my mind to. I am going to be a 'shining light' to others."

"Encouraged me to believe further that I can be a teacher and make a difference, I have so much more confidence about that … Thank you for all the effort put in for the success of this program, I know the effects will be far reaching."

Contribute to a New Resource

The Provincial Office is developing a resource to help families who have relatives in the forensic psychiatric system. Families who would like to help us identify information that should be included in this resource are asked to call Nicole Chovil at (604) 270-7841 or email nchovil@telus.net.

Volunteers Needed!

The Provincial Office is creating a volunteer pool to assist us with the various fundraising activities we have planned for this year and we need you! If you have an interest in fundraising, like working on fun creative projects, enjoy dealing with the general public and would love to volunteer some of your time, please contact Nancy Panchuk at 604-270-7841 or email npanchuk@telus.net. We’d love to hear from you!

New BCSS Regional Staff

Bulkley Valley Regional Coordinator

I am the new Coordinator in the Bulkley Valley. I have lived in the Smithers area for the past 11 years. During this time I have been involved with various community groups working toward healthier communities. In my previous position as Coordinator with the BC Federation of Foster Parent Associations I provided family support and education opportunities to Foster Parents. I am very excited about my new position with the BCSS and look forward to working with families in this region. I can be reached at tel/fax (250) 847-9779.

• Cindy Savage

South Fraser Regional Coordinator

Greetings to all of you from the new part-time South Fraser Regional Coordinator. My name is Judy Gabriel, I have replaced Mary Rennie as the Coordinator for the South Fraser region. I have a background of seven years as a front line worker in mental health, as a health care worker in psychiatric residential care group homes and then as a Community Living Support worker with the Richmond CMHA Housing Program. I am enjoying my new position and have had an opportunity to meet many wonderful people. I welcome you to contact me at (604) 273-6504 or I can be emailed at judygabriel@telus.net.

• Judy Gabriel
How to Deal with the Denial of Illness

Avoid an overzealous attack on the consumer's denial. When the denial of illness is chronic and seems unrelated to relapse, the first step is to determine whether the denial should be addressed at all. Denial of illness may not be harmful as long as the consumer is doing well and is compliant with treatment. Indeed, several studies have shown that the consumers who deny their illness see themselves as having more purpose in life, are more optimistic and have few active symptoms. This is a difficult concept for families to accept. But denial of illness often only needs to be addressed if it is causing problems with accepting proper medical treatment.

If denial has to be addressed, it should be addressed indirectly. Enlarge the consumer's perspective by helping him or her to acknowledge the existence (or at least the possibility of) different points of view. There are four steps to accomplish this:

1. Recognize the consumer's point of view. Assume the consumer's point of view is to be believed, even cherished, highly learned or over-determined. For example, if the consumer says, “I'm not sick, it's others who are sick and making up these stories about me,” hold off disagreeing. Instead you should think (but not say); “Let me assume that this statement is true. Now, in what way can this be true?” In this context you can acknowledge the consumer’s beliefs as being one point of view—even if it is delusional, without having to agree with that point of view.

2. Establish that the consumer's view is only one point of view. After you have comprehended the consumer’s rationalization of the denial, the goal here is to establish with the consumer that people can have legitimate differences in viewpoint and that they can agree to disagree without taking offense. Discuss non-threatening issues (for example political events, sports, music etc.) and come to an understanding that different opinions are acceptable and a part of life. Then you can bring it up that it is acceptable to hold different points of view about the consumer’s own situation or need for treatment.

3. Supply an alternative. This step marks the first time that the denial is directly addressed. You have to suggest alternative explanations in a way that leaves the consumer a way to disagree without getting into a power struggle with you. Be respectful. Try to see why it is necessary for the consumer to take the position of denying the symptoms. For example, you may broach a new topic with some-

“Denial of illness may not be harmful as long as the consumer is doing well and is compliant with treatment.”

thing like, “Other people have found that … it is possible that this is true for you?”

4. Anticipate setbacks after successfully addressing denial. When denial of illness abates be prepared for trouble ahead. Demoralization, sense of failure or despair often follow. The most striking example is the development of suicidal despair during the period when the recently psychotic consumer is regaining insight. This is often triggered by setbacks with the recovery process. The denial may have been proactive, shielding the consumer from attributing setbacks to his or her symptoms. When consumers become aware of their real-life defeats, show how apparent defeat sometimes represents real progress.

Success and progress frequently go unnoticed. Even the most striking success can be viewed (by the consumer or you) as a failure. Often, the hidden success is the willingness and courage to make an attempt.

* This information first appeared in In Focus the newsletter of the Schizophrenia Society of Saskatchewan. It was edited from an article by Dr. Peter Weiden and Dr. Leston Havens.

Celebrating 20 Years of Families Helping Families continued


• Creation of the Dr. Norma Calder Schizophrenia Foundation, grants from which now total $536,000—entirely the result of donations from individuals and fund raising efforts by BCSS branches.

• Since 1995, the Calder Foundation has funded twelve graduate students, five of whom now have their doctorates and are working in the field. In addition, we have been able to fund lead researchers to investigate new ideas, and are particularly proud that two of their pilot projects have attracted major government support.

• These efforts have attracted national attention. In 2002, we begin a matching grant program with the NeuroScience Canada Foundation and the Canadian Institute for Health Research (CIHR).
Reflections of Caring

2002 marks the 20th Anniversary of the British Columbia Schizophrenia Society. Watch for details of our celebration event scheduled for September 20th, 2002 as we reflect upon our triumphs, successes and accomplishments of the past 20 years.
2001-2002 Executive Committee
Board of Directors & Standing Committee Chairpersons

EXECUTIVE
President Michelle Colussi (Port Alberni)
1st Vice President Charlotte Sinclair (Kelowna)
2nd Vice President Rajpal Singh (Burnaby)
Secretary Bev McNee (Courtenay)
Treasurer Herschel Hardin (North Shore)

BOARD OF DIRECTORS
Paul Bhushan Surrey
Catherine Burkmar Parksville
Richard Dolman White Rock
Marilyn Duncan Victoria
Bejay Kenny Nanaimo
Benito Montagliani Kamloops
Deborah Nyberg Victoria (resigned)
Evelyn O’Sullivan Prince George
Larry Richardson New Westminster
Matt Sinclair Kelowna

HONOURARY DIRECTORS
Dr. Fred Adrian Frank Deck
Ida Hilton Nancy Kirk
Betty Vaughan

HONOURARY PATRON
TBA

MEDICAL ADVISORY COMMITTEE
Dr. Bill MacEwan, FRCPC
Dr. April Sanders, CCFP, Dip. Sports Med.

STANDING COMMITTEES
Advocacy • Charlotte Sinclair
Education • Joan Nazif
Executive • Michelle Colussi
Family Support/Membership • Benito Montagliani
Fund Development • Michelle Colussi
Nominations/AGM • Fred Dawe
UBC Schizophrenia Chair Liaison • Gary Glacken
UBC President’s Circle Liaison • Dr. Otto Forgacs

BCSS STAFF MEMBERS
Gary Glacken • Executive Director
Nicole Chovil • Staff, Branch and Community Support
Jane Duval • Policy Development and Communications
Nancy Pandhuk • Fund Development and Administration
Carole Pauley • Financial Administrator
Jill Watkins • Administrative Assistant

REGIONAL COORDINATORS
see inside back cover (page seven)

NEWSLETTER EDITOR
Siobhan Rowe

BC Schizophrenia Society
#201 – 6011 Westminster Hwy.
Richmond, B.C. V7C 4V4
Tel. 270-7841 • Fax. 270-9861
e-mail: bcss.prov@telus.net
http://www.bcss.org
BN: 11880 1141 RR 0001

British Columbia Schizophrenia Society is celebrating

Mardi Gras!
It’s carnival time!

Don your masks for Emerald Eve 2002
Join master of ceremonies, Global B.C.’s Deborra Hope for an
evening of frivolity, enchantment and excitement.

Friday May 3rd, 2002
The Westin Bayshore Hotel
For ticket information or sponsorship opportunities call Nancy at 604-270-7841
or email emeraldeve@bcss.org
Avoid disappointment!
Book your tickets/tables now
1/3 already sold!

Members receive the BCSS newsletter, Friends and the Schizophrenia Society of Canada (SSC) Bulletin. Please make cheques payable to:
BCSS, 201-6011 Westminster Highway, Richmond, B.C. V7C 4V4

Easiest way to make a donation? Call (604) 270-7841 and use your Visa or Mastercard!