

# transition

BC COALITION OF PEOPLE WITH DISABILITIES

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REPRESENTATION  
AGREEMENTS

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We're glad to see Transition material republished, with credit to "Transition, BC Coalition of People with Disabilities" and the edition date.

**Editorial Statement:** The views and opinions expressed within the pages of Transition are not necessarily those held by the total membership or Board of Directors. The material presented herein is meant to be thought-provoking and to promote dialogue. Transition is a forum to share information within the disability community, and with government and the general public. It is also an opportunity for people with disabilities to display creative talent.

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by Joanne Taylor

**C**reating a Representation Agreement (RA) is one of the wisest things you can do for yourself. If you are over the age of nineteen, you can give yourself the security and peace of mind of having an Agreement already in place if you ever need help. This Transition is devoted to RAs: what they are, what makes them so valuable, and how you and your loved ones can make one and use it.

When Representation Agreements became law in 2000, the people who knew about and supported them were little drops in a big pond. The ripples we made were often diverted by government inaction and institutional resistance to change. It took 7 years—1993-2000—of community work to put the law into force.

But thanks to the Representation Agreement Resource Centre (RARC) and community groups, like the BC Coalition of People with Disabilities, Representation Agreements are creating larger and stronger ripples—in the lives of individuals and in the community-at-large. We have stayed on course because we believe in the value of Representation Agreements—legal documents that say who you want to help you and make decisions for you if you need help because of illness or disability or injury.

We have seen the difference an RA can make for everyone involved. It empowers the individual. It eases the burden on family members and representatives by setting up a web of support with the individual. It gives

health care workers treatment directions and a chosen legal representative to ensure the person's wishes and directions are followed.

Here are some of the things people have told us about their experiences:

"Through the process of helping my son make an Agreement, I have been able to see my son as self-determined in ways I never saw before" (*parent of a 20-year-old with a developmental disability*).

"I am using the Representation Agreement to represent my mother in Small Claims Court because the assisted living residence she was in will not return her damage deposit. My mom now lives in a care facility. Since assisted living-type residences aren't covered by the residential tenancy legislation, we have to pursue justice on our own."

"Making and registering my Representation Agreement has given me such peace of mind. I have discussed everything with the people I have chosen and I know they will do a good job" (*a senior*).

"I wanted to make sure my naturopath could be involved in my health care if something happened to me. The Representation Agreement can make that happen." (*a 35-year-old adult*).

"Making and registering a Representation Agreement was very important for our blended family. When my stepmother suffered a sudden and deadly stroke, everyone pulled together. Because we all knew in

# Representation

advance who was responsible for decisions and what her wishes were, we were all able to focus on the needs of my stepmother—and my dad. Imagine—nine adult step/children, plus spouses and grandchildren and *no* arguments! It was inspiring—even though we were in shock and it was a sad loss for our family.”

“Making and registering my Representation Agreement means I will never become invisible if I can’t speak for myself.”

You will read more stories about the ripple effects of Representation Agreements throughout this Transition—for people with disabilities, seniors and their loved ones.

The Public Guardian and Trustee has said that most people will not make a Representation Agreement in advance. He is basing that statement on what is happening in other provinces—and in BC up to now. We would like to prove him wrong—and I hope you do too!

We have put together this Transition with one message in mind: *now* is the time to make and register your Representation Agreement and help spread the word to others in the community. Making your own is the best preparation for teaching others.

The RARC has developed Presentation Packages so individuals and community groups can help raise awareness among the public and among members of their groups. When people become aware of the importance of making a Representation Agreement, we have even more

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**We have put together this Transition with one message in mind: now is the time to make and register your Representation Agreement and help spread the word to others in the community.**

resources to help. Some of these resources include self-help Kits to assist people to make and register an Agreement. We also offer legal clinics in Vancouver and on the North Shore.

It’s time to take action—to ensure your wishes will be honoured when you need help with decision-making; to ease the burden on family and friends; to avoid government involvement in your personal and private affairs.

And to make sure your Representation Agreement is available when needed, register it with the Nidus eRegistry™. Read more about Nidus in this Transition.

Joanne Taylor is the Executive Director of the Representation Agreement Resource Centre and the Nidus eRegistry. ■

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**Representation Agreements**

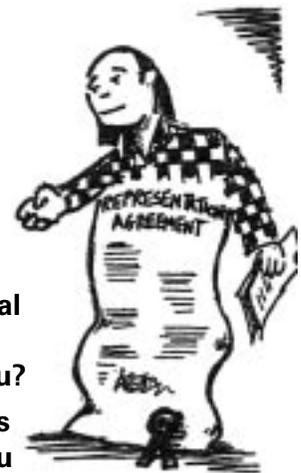
**If you become ill....  
If you are in an accident....  
If you need assistance now....**

**Who will help you:**

- > **Pay your bills?**
- > **Give or refuse consent for medical care?**
- > **Make living arrangements for you?**

**A Representation Agreement (RA) is a legal document that says who you choose to help you if you need assistance due to an illness, injury or disability. It is your legal plan if you need help now or in the future.**

**See the next page for “Representation Agreements 101.”**



# Representation Agreements 101

**Let's begin with some basics on RAs, what they can do and who can help.**



*The Sawyer family,  
members of  
Planned  
Lifetime  
Advocacy  
Network*

## **Why make a Representation Agreement?**

In British Columbia, if you are an adult (19 years or older), no one automatically has the right to manage your affairs if you need help because of illness, injury or disability. However, you can give this authority to someone you trust by making a Representation Agreement.

If you do not make a legal plan, other authorities or the court—not you—will decide who can help you.

## **What are the benefits of making and registering an Agreement?**

- Your wishes are at the centre of decisions affecting you.
- You get help from people you choose and who know you.
- People you choose will have the legal power to help you.
- You avoid the extra costs and delays that can happen if you do not have a plan.
- You avoid government involvement in your personal and private affairs.

For both health and personal care matters, making a Representation Agreement is the best protection for your wishes. It saves delay, avoids conflict and eases the burden on others.

## **What areas do I need to cover?**

You need to cover the following areas in your RA:

- Financial and legal matters
- Health and personal care

You may be able to cover all areas

in a Representation Agreement. Or, if you own real estate property, you will use the enduring Power of Attorney\* to cover financial/legal areas and the Representation Agreement for health/personal care.

A RA is a written document that must be witnessed.

### **Who can make one?**

The law says that every adult (19 years and older) in BC can make a Representation Agreement, even if they cannot manage their own affairs. This is important because someone may need help now due to a stroke, brain injury, dementia, developmental disability or other situation.

### **Where do I register my document?**

The Nidus eRegistry™ is the only centralized registry for Representation Agreements and enduring Powers of Attorney.

Nidus is an on-line, private and secure registry. It is available 24 hours a day, 7 days a week should you or those you authorize need to access your document(s). If you have authorized your hospital, for example, they will know to check Nidus to find your Agreement. Nidus is a safe place for your wishes (see “Make your voice count” on p. 11 for more on Nidus).

### **How do I make and register my Representation Agreement?**

Contact the Representation Agreement Resource Centre for more information

and for resources to help you make and register your legal plan.

See the next page for RARC contact information and description of services. ■

\*An enduring Power of Attorney is an older law and, before Representation Agreements, it was the only legal tool available for personal planning. An enduring Power of Attorney does not cover health or personal care matters—it only covers financial, legal and real estate property.

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### **What about capability?**

The traditional test of capability—deciding if someone is legally “capable” to make decisions—is that you must “understand the nature and effect” of what you are doing. This is necessary for making an enduring Power of Attorney and for a Representation Agreement that includes broader powers, such as refusing life support.



However, Representation Agreements with standard powers [covering routine financial matters, minor and major health care, and personal care] do not have an up-front test of capability. The law says that all BC adults may make this Agreement, even if they cannot manage their own affairs.

The *Representation Agreement Act* says that the way a person communicates cannot be used as a factor in determining their capability. It recognizes that people communicate their choices and wishes in many ways including by using symbols, gestures or behaviour.

# Make the RARC your first stop

*Everyone should make a Representation Agreement—before a crisis happens.*

*information  
materials*

- ▶ *Who should make a Representation Agreement?*
- ▶ *Who can be my representative?*
- ▶ *Do they have to live in BC?*
- ▶ *Can I name more than one person?*
- ▶ *Does it have to be a family member?*
- ▶ *Do I have to go to a notary or a lawyer?*
- ▶ *Where do I register my Agreement?*

*self-help  
kits*

For the answers to these and other questions, contact the Representation Agreement Resource Centre (RARC). Volunteers and staff of the RARC have practical experience helping people to make Agreements, including things to consider for different life situations.

*legal clinics*

The RARC is a provincial, non-profit, charitable organization. It was established in 1995 and provides information, education and assistance to the public.

*individual  
assistance*

## **We're here to help**

The RARC produces and distributes information materials, provides speakers to groups, conducts training workshops for organizations and professionals and assists individuals to make a Representation Agreement and register it with the Nidus eRegistry.

*speakers*

## **Self-help Kits**

The RARC sells self-help Kits for people who want to make and register their Agreement. Kits sell for \$50 and include legal forms, step-by-step instructions, details on the rights and responsibilities of representatives, and how to register your completed form with Nidus.

*training*

## **Legal Clinics**

Legal Clinics are available in Vancouver and on the North Shore for people who are making Representation Agreements that require consultation with a lawyer. A lawyer is needed if you want to give your trusted representative the authority to refuse or withdraw life support on your behalf, according to your wishes.

*Nidus  
eRegistry*



*From left to right: Pat Fulton, RARC President; Joanne Taylor, Executive Director and Program Director, Susanne Gray*

## **Nidus eRegistry**

The RARC operates the Nidus eRegistry, a centralized registry for Representation Agreements, so your Agreement and wishes are available to authorized parties when needed.

## **The RARC thanks...**

the BC Retired Teachers' Association, Legal Services Society of BC, The Law Foundation of BC, VanCity Credit Union, VanCity Community Foundation and Lexmark for grants to support our current projects. We also rely on donations from individuals. Tax receipts are provided.

### **Contact the RARC at:**

**Phone: 604-408-7414**

**Fax: 604-801-5506**

**E-mail: [info@rarc.ca](mailto:info@rarc.ca)**

**2nd floor, 411 Dunsmuir Street  
at Homer, Vancouver, BC**

**[www.rarc.ca](http://www.rarc.ca). ■**

## **BCCPD UPDATE**

### **Nutrition/Food Project for People with Disabilities**

#### **Be part of a research project on disability and nutrition.**

There is a lack of research information on how people with disabilities access food.

The BCCPD Wellness and Disability Initiative (WDI) and a graduate student from the Department of Human Nutrition at UBC are starting a project to explore how people with disabilities access food including any barriers and challenges they experience. The data collection will begin in spring 2005 and will include brief interviews of people with disabilities who are on disability benefits (PWD).

If you would like more information about this worthwhile project, please contact Julieta Flores at [Julieta@interchange.ubc.ca](mailto:Julieta@interchange.ubc.ca) or 604-822-9214. ■

“Patients are encouraged to speak to their physician about writing a Representation Agreement...It eases the burden on family members who might otherwise have to make decisions for someone else, and provides health care workers with treatment guidelines and a chosen legal representative. ... a Representation Agreement is the only legally binding future care consent plan.”

*BC Medical Association, November 17, 2003.*

## handyDART users change TransLink agenda

The Coalition of handyDART Users applauded a recent decision by the TransLink board to take handyDART service off their agenda. TransLink had made the decision to find a new handyDART service provider, instead of Pacific Transit Cooperative.

At a November meeting, TransLink Chair and Surrey Mayor Doug McCallum said the TransLink board had voted to deal with the handyDART issue over the next year and that Pacific Transit would continue to deliver the service.

"This is a tremendous victory for the users of the service, who had urged the board to re-examine the entire handyDART organization in the GVRD," said Paul Tubbe, of the Coalition. "We are delighted that the TransLink board has listened to the users of the service who are the people who have the clearest perspective on its strengths and weaknesses."

The Coalition used the opportunity to bring forward other key recommendations which were accepted by TransLink:

1. immediately cease the tendering process for Vancouver handyDART,
2. set up a planning table which includes consumers,
3. design a GVRD-wide handyDART plan that coordinates rides and removes jurisdictional boundaries,
4. maintain a status quo for all handyDART contracts during planning. ■

## hiv/aids education booklets

BCCPD's Wellness and Disability Initiative/AIDS and Disability Action Program has produced several booklets on HIV prevention. The booklets are plain language, in a reader-friendly layout.

Booklets so far in the series are:

*Know About....HIV and AIDS*

*Know About....Condoms*

*Know About....Safer Sex*

*Know About....Seniors and HIV*

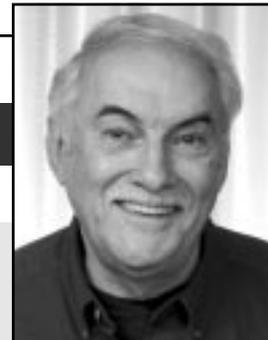
Small quantities are available free of charge in Canada. For more information, please contact Shelley Hourston at [wdi@bccpd.bc.ca](mailto:wdi@bccpd.bc.ca) or 604-875-0188.

*The Wellness & Disability Initiative (WDI) includes the AIDS & Disability Action Program (ADAP) and the Health Literacy Network (HLN). WDI, ADAP and HLN provide health and wellness information in plain language and alternative formats. We serve people with disabilities, family members, caregivers, healthcare workers and educators.*

*These HIV education booklets are funded by the BC Ministry of Health and the BC Ministry of Public Safety and BC Solicitor General.*



## “Where do I start?”



This worksheet, produced by the RARC, is not a legal form. The Centre offers it as a place to start. Fill in your information and/or contact the Centre for help to make and register your plan. Phone 604-408-7414 or email [info@rarc.ca](mailto:info@rarc.ca).

1. Your name (person who the plan is for): \_\_\_\_\_

2. Do you own real estate property (house, apartment, condo, mobile home pad)? Yes  No

3. Do you already have an enduring Power of Attorney? Yes  No

If you are not sure that you have an 'enduring' Power of Attorney, check to see if the following wording (or something similar) is included in the document:

*In accordance with the Power of Attorney Act I declare that this Power of Attorney may be exercised during any subsequent mental infirmity on my part.*

**Note:** A Power of Attorney made with your Bank or Credit Union is useful but is not sufficient to cover all necessary financial and legal matters if you become incapable.

A Will and joint ownership of property are plans that only apply after death, not if you are incapable.

4. What areas does your plan need to cover? Financial & legal  Health & personal

5. Who are the people you choose to help you? Who are they in relation to you – spouse, sister, friend?

Representative(s): \_\_\_\_\_ who is my: \_\_\_\_\_

Alternate(s): \_\_\_\_\_ who is my: \_\_\_\_\_

Monitor?: \_\_\_\_\_ who is my: \_\_\_\_\_

6. What other documents do you have?

Nomination of Committee

Living Will / health care directive / do not resuscitate order

7. What other areas might need to be covered?

I own a business

I receive funds through the CSIL program (Min. Health)

I have responsibility for minor children

8. Is someone managing your money now as "Trustee of Pension" (applies to OAS, CPP)? Yes  No

9. Does someone have legal authority over you now?

a) Public Guardian & Trustee (by Certificate or court order)? Yes  No

If you checked Yes, indicate areas of authority: Financial and legal  Health and personal

b) A family or friend as court-appointed Committee? Yes  No

If you checked Yes, indicate areas of authority: Financial and legal  Health and personal

# What people are saying about Representation Agreements

by David Chalmers

Imagine the following scenario. You are by yourself out on the town, when suddenly you suffer a heart attack. You are rushed unconscious to the hospital. A quick decision has to be made on whether to perform emergency surgery...

At this point, the hospital will act in accordance with the Health Care Consent Law. Hospital staff will try to contact family members in a pre-determined order so that someone may consent to the surgery. So, the

Now let's go back to our hospital scene. You are lying unconscious in the emergency ward. Let's assume that you have entered into a Representation Agreement and have appointed your daughter who is a physician as your Representative.

The problem is that the hospital staff does not know that you have entered into this agreement. They don't know who to call.

This is where the Nidus eRegistry comes in.

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## You are rushed unconscious to the hospital. A quick decision has to be made on whether to perform emergency surgery...

person who ultimately makes a life and death decision on your behalf may not have been your first choice.

While you may have granted a Power of Attorney that empowers a trusted relative to deal with your finances during your incapacity, this has not granted anyone the power to make health care decisions on your behalf.

The solution to this problem may be to enter into a Representation Agreement (RA). This is a legal document that empowers your chosen Representative(s) to make health care and personal care decisions on your behalf.

There is a wonderful organization called the Representation Agreement Resource Centre (RARC) that provides very helpful and complimentary information about RAs.

The RARC provides a way for you to register the details of your Representation Agreement on a secure website registry for a very modest cost.

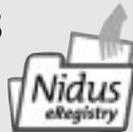
The hospital is one of a very few entities that has access to the eRegistry information. Upon your arrival, hospital staff check to see if there is a record for you. They find important details of your Representation Agreement, including the emergency pager number of your daughter.

Congratulations. The combination of a Representation Agreement and the Nidus eRegistry may have just saved your life.

From David Chalmers' article in "The Financialist", Rogers Group Financial, October 2004. ■

# Make your voice count Register with Nidus

by **Ron Usher CEO Juricert Inc.,  
Law Society of British Columbia**



The Nidus eRegistry™ helps manage information about legal documents, such as Representation Agreements and enduring Powers of Attorney, so these important plans are available when needed. Nidus is Latin for “nest.”

Registering with Nidus is a protection for you and your wishes.

Nidus is operated by the Representation Agreement Resource Centre and the Law Society of BC's Juricert Program and Gateway File Systems, a private company based in Victoria.

The Law Society of BC is pleased to be part of this first-in-Canada on-line registry for personal planning tools. One of the recent goals of the Law Society, through Juricert Inc.™, is to help lawyers use current technology to enhance service to their clients. Nidus is one of the products we encourage lawyers to use.

Juricert is a unique initiative of the Law Society of British Columbia. Juricert was created to confirm the identity of people using the Internet for important professional communications, such as court filings, government filings and registration services.

For more information on Nidus, contact the Nidus eRegistry™ at 604-408-7414 or e-mail [info@nidus.ca](mailto:info@nidus.ca). ■



**STEP 1 ▶**  
*Make your  
Representation  
Agreement*

**STEP 2 ▶**  
*Register it with the  
Nidus eRegistry™*

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## Thank you to our contributors

Joanne Taylor  
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Chamberlayne  
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carol weaver  
Fiona Gamiet

And the sponsor for  
this edition

**The Society of  
Notaries Public  
of BC**

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# Remembering Drew Dickey



Drew Dickey  
1955 - 2004



Drew's mother Jo

**D**rew Dickey was inspired by music. He was an Elvis Impersonator—if only for a brief inspired moment! Drew loved all kinds of music, especially playing the drums.

Drew was also inspired by his family: his big brother Rod, his dad, Rod senior, and his mom, Jo. Drew had a caring, loving family who never abandoned their right to be part of Drew's life, despite the urging of experts who claimed they knew better than the family.

Drew was inspired by his experiences—especially those at Woodlands—many so painful they could never be forgotten.

Drew was inspired to be a pioneer and a leader. He, along with others, inspired:

- the closing of institutions for people with developmental disabilities in BC;
- the inclusion of people with disabilities in the Canadian Charter of Rights and Freedoms;
- the idea of Individualized Funding, and
- the creation of Representation Agreements.

For Drew, Representation Agreements were an alternative to guardianship. When Drew Dickey signed his Representation Agreement his mother Jo hosted a "signing party" complete with champagne and chocolate cake.

The signing of Drew's Representation Agreement was also a celebration of the community effort to create

alternatives to guardianship. For Jo Dickey, involved in the reform of guardianship law for over 10 years, it was about Drew's right to have help from those he knew and trusted. "My son couldn't talk, but he was still able to make decisions about his life, like signing the Representation Agreement."

While working on the new law, Drew's family discovered that the Public Trustee was legal guardian of his finances through a procedure called "Certification of Incapability."

Living in Woodlands had automatically made Drew a "ward" of the government. When the institution closed, no letter of discharge was issued. With the help of his family and the cooperation of the Public Trustee and the Ministry for Children and Families, Drew was able to locate and have the Certificate of Incapability discharged. Now the long forgotten and once effective Certificate sitting in the files of the Office of the Public Guardian and Trustee, could not conflict with the Representation Agreement which ensured Drew would have assistance to make his own decisions.

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*The signing of Drew's Representation Agreement was also a celebration of the community effort to create alternatives to guardianship.*

Certificates of Incapability are still issued today by authorized health professionals. These mean that the Public Trustee automatically takes over the person's affairs. They may also cancel an existing Power of Attorney. This may affect people with a mental illness or dementia (such as Alzheimer Disease) who are admitted to a hospital psychiatric unit or to a mental health facility. Sometimes it also affects those living in the community

when they have been assessed through a mental health unit.

The good news is that Representation Agreements are an alternative for people who need some assistance and who wish to get this assistance from people they trust. Because a Certificate is difficult to discharge, it is important that people have the option to make Agreements as a first resort!

Thanks Drew, for your many legacies and inspiration. ■

**transition**   
 s u b s c r i p t i o n   f o r m

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Organization \_\_\_\_\_ Phone \_\_\_\_\_ email \_\_\_\_\_

Address \_\_\_\_\_ Please send Transition in the following format:

- Paper  Text only disc  
 Audio Tape  email

\_\_\_\_\_

*I would also like to include a donation of \$ \_\_\_\_\_. Donations over \$10 are tax deductible.*

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# Family, friends and a secure future

by Jo Dunaway

*How are RAs used in the "real world"? Transition spoke with some people who have made Agreements and used them.*

## The Cucek Family

"Our Representation Agreement has given our family peace of mind," says Linda Cucek. Her 19-year-old son Jamie recently made a Representation Agreement (RA) with his parents Linda and Stan as his representatives, and his brother Brian as his alternate representative.

Jamie has high-functioning autism. He graduated from high school and is a talented pianist. But there are times when the side effects of his various medications cause him to act in an irrational manner.

"It can be the roller coaster from hell," says Linda. "His medications can

make him very paranoid and angry. He will sometimes just take off if no one is watching."

In the past, Jamie was placed briefly in a group home against his wishes and those of his parents. When Jamie was admitted to hospital to have his medications adjusted, he was kept in the psychiatric ward or in isolation, a situation that frightens and frustrates Jamie and his entire family.

Not long ago, side effects of his medications caused Jamie to hallucinate and become paranoid, and he fled to his neighbours for protection from his family. Fortunately, a knowledgeable policeman was able to help resolve that situation.

To Linda, this latest episode was a signal that something had to be done to protect Jamie who was now an adult and legally beyond his parents' control.

"We knew that once Jamie had turned 19, we would no longer have parental control," says Linda. "It really frightened us—and it frightened Jamie too—that if he were having an episode, decisions could be made for him that he wouldn't want."

Linda and her family were referred to the Representation Agreement Resource Centre by advocates at the BCCPD and found, Linda says, "peace of mind and security."

With the Representation Agreement that he helped draft, Jamie



From left to right: James, Linda and Brian Cucek

knows that the wishes he has expressed when he is calm will be honoured when he is suffering from the side effects of medications. And his family feels empowered because they have the legal standing to speak up for Jamie and carry out his wishes. With older brother Brian a party to the RA as alternate representative, the family feels more comfortable about Jamie's future.

The Cuceks have registered their Representation Agreement with Nidus so a copy will be available, 24 hours a day, if it is needed.

"Our Representation Agreement has made such a huge difference. We're like a different family now, not always dreading what is going to happen next," says Linda.

### Fay Sherlock

Fay lives with her two dogs, Polo and Skippy, in a co-op in Burnaby. She used to live in Woodlands, a facility for

continued on next page

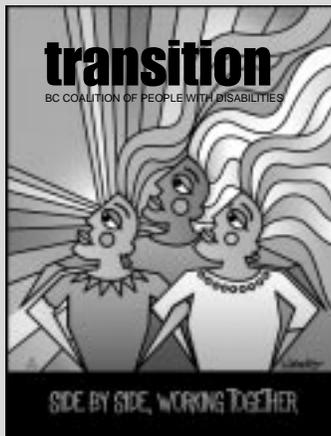
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*"Our Representation Agreement has made such a huge difference. We're like a different family now, not always dreading what is going to happen next."*

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### Do I have to go to a lawyer or notary public?

For certain powers to be effective, such as dealing with real estate matters, your document must be signed by a legal professional. The RARC can refer you to legal help.



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See the inside back cover for our non-profit rates.

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*Fay had a bad experience at a hospital that dismissed her claims that she had a RA.*

people with developmental disabilities. She is a member of the Woodlands Action Group and it was at one of the group's meetings that she found out about Representation Agreements.

"Joanne and Susanne from the RARC came and told us about what a Representation Agreement is for," says Fay. "I liked the idea that it could protect you and no one could take advantage of you."

Fay is determined and persistent. She didn't like the first RA she made and she decided she did not want the people she had chosen as representatives involved in her decision-making. So, she revoked it and made a new Agreement. She now has two representatives that she trusts.

Fay takes medication for a mental illness and has several health problems that require constant medical care and result in frequent encounters with health care facilities. She makes her own medical decisions, but she wants to make sure that her decisions would be listened to and that she will have people who she trusts to help her if she is unable to make her own decisions.

She has learned that it is not enough to have a legal document—you have to make sure that people know you have it and that they understand and respect it. Fay had a bad experience at a hospital that dismissed her

claims that she had a RA. The hospital staff also decided that her agitated behaviour meant she was not capable of making her own decisions. After that, Fay took steps to make sure it didn't happen again. She has given that particular hospital a photocopy of her Agreement to keep on file and she carries a card in her wallet from the Nidus eRegistry with the names of her representatives and their phone numbers. She has also made all her doctors aware that she has an Agreement in place and who her representatives are.

Having a Representation Agreement makes Fay feel that she can take more control over her future. She is trying to set up a living arrangement that will keep her safer and is looking for a subsidized suite in a building where there will be someone she could call on if she needed help. "I have a condition where I get sick very suddenly and there's no one where I am now to check on me." Ideally, the place will have a fenced yard for Polo and Skippy to play in.

### **Lori Holmes and her grandmother**

When Lori Holmes' grandmother, a very independent 80-year-old, ended up in hospital and could not go back to living alone, Lori stepped in. She soon realized that, while being named a "committee" (court appointed guardian) could help with things like sorting out where her grandmother's private pension would be redirected, it wasn't going to help with a lot of other practical and personal issues—and it is expensive to go to court.

The Public Trustee Office suggested that Lori contact the RARC to

see how she could help her grandmother make decisions about her needs. She learned about RAs, and she and her grandmother created one naming Lori as the representative and another relative as the monitor. It helped with many practical issues such as having her grandmother's mail redirected, clearing out her apartment and deciding how to deal with her possessions. And some personal issues were made more manageable because Lori was able to express what she knew her grandmother wished, like going to her favourite hairdresser, even if in some instances it was impossible to give her exactly what she wanted.

"My grandmother has always been independent and taken care of herself," Lori says. "She didn't want to be in a facility. If she had to leave her own home, she wanted to go and live with a friend. This was impossible. The level of care she needed was too great." But, along with making that difficult decision, Lori made sure that her grandmother's friend remained involved in her grandmother's life.

"It has been so good to be able to participate in health care decisions. I really feel that I am helping my grandmother take care of herself. The Representation Agreement is there to protect her."

When most of the practical items were taken care of, Lori set her sights on having her grandmother moved to a facility in Victoria where she would be closer to Lori and her family. The frequent trips to the Lower Mainland were taking a toll on Lori's family and on her own health.

"I'd worry until I could go over to see her and I'd worry all the time that I

wasn't there," Lori remembers. "Sometimes I'd make a trip over in the morning and come back that night. I was exhausted," says Lori. "I knew it would be better if she was here in Victoria. Now she has family and some old friends near by."

Finally, in mid-November, with the help of her RA and a lot of persistence, Lori was able to set her grandmother up with a new doctor and move her into an Extended Care facility in Victoria. She still feels the heavy responsibility of being the sole representative on her grandmother's RA—the only person that her grandmother feels comfortable enough with. But she feels that she understands her grandmother's wishes and can see that with the RA they are honoured. And, having her grandmother close by has made things easier for Lori and her family.

"Christmas is a special time for my grandmother. We're already planning outings, like going to see the lights," says Lori. "I'm glad she's going to be able to do family things together with her granddaughter and her great-grandchildren. She was always there for me. So now I'm able to be there for her." ■



### **What if I have a living will?**

The Representation Agreement Act is BC's "living will" legislation. If you want your living will or advance directive to be legally binding, make a Representation Agreement.

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*"I really feel that I am helping my grandmother take care of herself. The Representation Agreement is there to protect her."*

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**Immediately I think, how could my body do this to me? Enough of these frustrations, I want control.**

## **Transforming anger**

**by Nancy Chamberlayne**

Anger explodes in me. Curses spew from my mouth. I have just had a painful, shocking fall. I am wrestling with anger....again.

Since my 1987 diagnosis of Multiple Sclerosis (MS), my body has been fatigued, had poor balance, loss of leg strength and coordination, numbness, tingling sensations and bladder and bowel problems. I often feel I have no control over my body, my anger or what comes out of my mouth.

When I hurt myself or get foiled because my body does not do what I

think it "should" due to my physical disabilities, anger erupts. Immediately I think, how could my body do this to me? Enough of these frustrations, I want control. How could my body be so stupid? I'm scared!

The power of my anger shocks me, yet I allow it to surface. These angry thoughts are self-destructive. They cause terrible tension in my mind and body, to the point of sometimes irritating my MS symptoms. It is also unpleasant for my husband to hear. The consequences of my anger are lousy. I realize I need to change my behaviour, but how?

With personal counselling and by participating in Adlerian psychology courses, I have learned that I can, and need, to take responsibility for my anger. I have a choice about which emotion I choose to use and how I choose to use it.

Adlerian Psychology taught me that I am not the victim of my emotions. Choice gives me great freedom. I can either choose to be angry or not. I am in a power struggle with my MS and I need to bow out. Intellectually, I know this, but in the heat of the moment it is not easy to put into practice. Right now, I am "catching myself in the act" of being angry which enables me to make a choice. I may not be able to control the MS, but I can control my thoughts. I am learning that I can either choose to be angry, use a different emotion or find a different way to express my anger.

Alfred Adler, the founder of Adlerian Psychology, believed that



emotions always serve a purpose. My anger is there so I don't pity myself, burst into tears and/or succumb to fear. My anger is like lightning. It is over in a flash. I don't carry the anger or take it out on others.

Adlerians believe emotions are like the gas in a car, the driving force behind our movements. I am converting my anger into useful energy. My anger becomes action, supporting my determination to keep going, providing the incentive to reach my goals. With perseverance and the use of my cane, I stand up on my wobbly legs. This is the positive side of anger.

Recently, I had the revelation that my body is my friend. My body is doing the best it can with what it has. My body is working very hard for me. Now I get angry at the disease not my body.

When I choose to be angry, I am now aware of how I am using the energy generated by my anger. My behaviours are changing. I am slowly learning not to get wrestled to the mat by my anger. I am using it constructively, except for the swearing...that has got to go! ■

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**I am converting my anger into useful energy. My anger becomes action, supporting my determination to keep going, providing the incentive to reach my goals.**

CPPD	Disability Benefits	Advocacy Access
<b>About CPP Disability benefits</b>		
<ul style="list-style-type: none"> <li>✓ <b>Are you a Ministry of Human Resources client?</b></li> <li>✓ <b>Have you recently been denied CPP Disability?</b></li> <li>✓ <b>If so we can help you to appeal.</b></li> </ul>		
<p>Unlike provincial disability benefits, CPPD benefits is not asset tested: there is no limit to the personal assets you can have. Receiving income from other sources (with the possible exception of employment income) will not disqualify you from receiving CPPD.</p> <p>Unlike provincial disability benefits, you will keep your CPPD if you become involved in a dependent relationship, e.g. if you get married.</p> <p>Most people receiving provincial disability benefits will still get a top-up from the Ministry. This means you will not lose your medical coverage and annual bus pass when you qualify for CPPD.</p> <p>You do not have to apply for CPP early retirement benefits at age 60 if you are already receiving CPPD.</p> <p>You can attend school or do volunteer work without jeopardizing your CPPD.</p> <p>If you move to another province your CPPD will go with you.</p> <p>CPPD is taxable, but recipients can apply for the Disability Tax Credit.</p> <p><b>Phone Advocacy Access for one-on-one assistance with CPPD appeals, tribunals and Pension Appeals Board cases.</b></p>		
<p>Local calls: 872-1278 Toll-free: 1-800-663-1278 TTY: 875-8835</p>		
<p><b>Thank you to the funders of our CPPD program: the BC Ministry of Human Resources</b></p>		

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This Transition on  
Representation Agreements  
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### **What services can a BC Notary provide?**

- Affidavits for All Documents required at a Public Registry within BC
- Authorization of Minor Child Travel
- Business Purchase/Sale
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- Commercial Leases and Assignment of Leases
- Contracts and Agreements
- Easements and Rights of Way
- Estate Planning
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- Health Care Declarations
- Insurance Loss Declarations
- Letters of Invitation for Foreign Travel
- Manufactured Home Transfers
- Marine Bills of Sale and Mortgages
- Marine Protestations
- Mortgage Refinancing Documentation
- Notarization/Attestation of Signatures
- Passport Application Documentation
- Personal Property Security Agreements
- Powers of Attorney
- Proof of Identity for Travel Purposes
- Purchaser's Side of Foreclosures
- Representation Agreements
- Residential and Commercial Real Estate Transfers
- Restrictive Covenants and Builder's Liens
- Statutory Declarations
- Subdivisions and Statutory Building Schemes
- Wills Preparation
- Wills Searches
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### **Some BC Notaries provide these services:**

- Marriage Licences
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**For the BC Notary office nearest you, please call  
1-800-663-0340 or visit [www.notaries.bc.ca](http://www.notaries.bc.ca).**



## Laurie Salvador

NOTARY PUBLIC

Notaries public tend to reflect the communities they serve, says Laurie Salvador of Salvador Davis & Co. Laurie lives in Sidney on Vancouver Island where she has been a notary since 1986.

“Our area is dominated by people who are elderly and retired. Representation Agreements are a natural fit with the wills and estate planning and related services that make up about 50 percent of our practice,” says Laurie.

“In the first two years after the Representation Agreement Act was proclaimed in 2000, we did around 400 RAs in this office.”

“People come to us when they want to make decisions about their future health care and about their end-of-life wishes, and who they want to be involved in that. We help them set up a Representation Agreement with a health directive so they can say who they want involved and what they want to happen in their future.”

Some people are able to craft their own Representation Agreement with the help of information from the Representation Agreement Resource Centre or People’s Law School, says Laurie. But “sometimes they just can’t make it all the way through on their own and come to a notary for assistance in making sure that they have a legally binding agreement.” If her client needs to create a Representation Agreement with the broader powers, a lawyer must be brought into the process.

Although not every notary deals with as many RAs as Laurie, it is part of their training.

“Notaries working in communities with a younger population will do a much bigger portion of their work in areas such as mortgages and

*“Representation Agreements are a natural fit with the wills and estate planning and related services that make up about 50 percent of our practice.”*

conveyances,” says Laurie. “But all new grads are trained in Representation Agreements and our society continually upgrades those notaries already in practice. We have a very high attendance at our continuing education seminars.

“Language skills are also important in our work—we deal with international documentation for business and property in estate planning and wills. At least 65 percent of our members speak two or more languages.”

All 12 Canadian provinces have notaries public. In BC, the governing body is the Society of Notaries Public of British Columbia which administers an 18-month course in cooperation with the Faculty of Commerce and Business Administration at the University of BC.

Although Representation Agreements continue to play a major role in the services she provides in her community, Laurie has seen a drop in requests.

“There was a lot of interest when the Act was proclaimed and the media was highlighting it,” she says. “I think the awareness about Representation Agreements has dropped somewhat. It’s just not in front of people as a news item like it was before.

“So, it is very important now to make sure that doctors and social workers are telling their clients about RAs.” ■

# The Flickering Flame Becomes a Warm Glow

## Securing the Future of the *Representation Agreement Act*

by Christine Gordon

**O**n June 24, 2004 the Board and staff of the Representation Agreement Resource Centre (RARC) invited the community to celebrate the Attorney General's decision to maintain the *Representation Agreement Act*.

The celebration heralded the beginning of summer, but it also marked another step in the community's odyssey to preserve the vision of the Representation Agreement. It seemed a good time to count our blessings. The campaign to convince Attorney General Geoff Plant and his caucus colleagues that the *Representation Agreement Act* embod-

ies the best thinking on self-determination, capability and decision-making that British Columbia can offer to the world had been successful. It had also served to remind us how much we value the legislation and the process that created it. It had renewed old alliances and taught us again that the journey is as important as the outcome.

So we had

every reason to celebrate and people were welcomed at the entrance by dozens of floating origami birds handcrafted by the Representation Agreement Resource Centre's (RARC) summer student and symbolizing the Nidus eRegistry whose name is the Latin word for "nest." Amid the crowd were old friends, people who had marked 15 years of commitment to the Representation Agreement, and new friends who had signed on during the recent campaign.

There were many wonderful moments during the afternoon. The BCCPD's Kids on the Block puppet troupe delighted the audience with a surprise performance.

Ron Usher, the CEO of the Law Society's Juricert, a partner in the Nidus eRegistry, presented a travel slide show, *Slinky's Excellent Adventures*, about a trip that he and his Slinky (last year's present to him from the RARC) took to Toronto. The audience was in stitches of laughter as they followed Slinky's escapade in the big city. Afterward, there was a lot of buzz about a possible sequel, *Slinky Goes Hawaiian*.

Joanne Taylor spoke about the future for RARC and Nidus, and recognized the commitment of our partners, Gateway Filing Systems and Juricert, in creating and promoting this unique registry. Nidus realizes the community's vision for a simple and

*Some of the long-time supporters of Representation Agreements*





*"The new city hall is cool."  
From Slinky's Excellent Adventures.*

accessible way to register Representation Agreements and to communicate their existence to those who need to know.

We all raised a glass to toast the fact that the *Representation Agreement Act* has withstood many years of uncertainty and, thanks to the community that has never failed to rally behind it, a flickering flame has turned into a warm glow.

British Columbians will now be able to use the warmth and light that the Representation Agreement Resource Centre offers to ensure that self-determination within the nest of trusted personal relationships is the legal anchor for decision-making. Something to celebrate indeed!

**Christine Gordon is Treasurer of the RARC. ■**

“we...heard...from a wide variety of citizens that the existing instruments [Representation Agreements] are being used and relied upon and that any reform would not be helpful or necessary. Government has sat down, done its homework and listened to what we've heard, and we have decided to maintain the status quo. Accordingly, we will not be pursuing any further reforms in this area.”

*BC Attorney General Geoff Plant (Hansard, May 13, 2004)*

BCCPD UPDATE

# DO YOU NEED HELP TO APPLY FOR PWD ?



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*Our experienced advocates help people to complete the PWD application form.*

**T**he BC Coalition of People with Disabilities provides free one-on-one assistance to people who want to apply for the Persons with Disabilities (PWD) benefit.

Our experienced advocates help people to complete the PWD application form. The advocates will also review completed application forms to make sure that all the required information from doctors and other health care professionals (assessors) has been included.

We can also arrange for a qualified assessor to come to our office to complete Section 3, the assessor's portion of the PWD application form.

## **About the PWD benefit**

PWD is a disability benefit under BC's income assistance system. People who qualify for PWD:

- receive the highest monthly income assistance rate. For example, single people with no dependents may receive up to \$856.42 a month
- can purchase an annual bus pass for \$45 per year
- are eligible for better health benefits
- are among those not affected by the 2 out of 5 year time limit rule
- can earn up to \$400 a month and keep their full monthly benefit

For help applying for PWD, contact Advocacy Access at tel: (604) 872-1278, Hearing Impaired Only: (604) 875-8835.

*Thank you to the funders of our PWD application program: Human Resources Development Canada National Homelessness Initiative. ■*

*Mary Williams  
Memorial Core  
Volunteer Fund*



The BCCPD has established the Mary Williams Memorial Core Volunteer Fund to support and expand our core volunteer program. BCCPD's core volunteers provide crucial support to our many programs and Transition magazine.

We gratefully accept donations to the Fund; a tax receipt will be issued for all donations of \$10 or more.

"There is life after disability. I'm not my spinal cord injury and I'm not my wheelchair. I'm still Mary. I have a great quality of life; not just a good one, but a great one."

Mary, April 2001

Please accept my tax-deductible donation of \$ \_\_\_\_\_ to the Mary Williams Memorial Core Volunteer Fund.

Please call me for a credit card donation.  
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*Thank you for supporting the Fund.*

## Be aware of Camera Phones

Keep alert for people with cell phones in hand standing near you in the checkout line at stores, restaurants, grocery stores, etc.

With new camera cell phones, a person can take a picture of your credit card with your name, number and expiration date. Identification theft is one of the fastest growing crimes today and this is just another example of how technology can be used against you. So, be aware of your surroundings. ■

Transition would like to thank our super hard-working mailout team. Florence Corbett, Jim Corbett, Audrey Spry, Brian Rafferty, Cady Williams and Marie Lands. We can't thank you all enough.



Any resemblance to actual volunteers is completely accidental!

# One Lawyer's Perspective on RAs

by Hugh McLellan

Representation Agreements were created and proclaimed to much skepticism by lawyers. How have lawyers adapted to Representation Agreements since then?

A number of British Columbia lawyers were actively involved with the community efforts to reform the Adult Guardianship laws in the late 1980s and early 1990s. They worked with the community on its response to the government regarding new legislation.

When the *Representation Agreement Act* passed Third Reading in the Legislature in 1993, most of us expected the Act would be proclaimed into force. However, this was delayed by a number of concerns raised by lawyers and others.

Lawyers are very busy with their own practice so most do not take the time to learn about new laws until the law will affect their work. When there was such a long delay from the new Act being created, in 1993, and when it was proclaimed in force in 2000, many lawyers lost interest.

However, some lawyers did stay involved and worked with others to identify much needed amendments to enable the legislation to work more smoothly. But the government did not

make these amendments until a year after the law came into force in 2000. Because of these factors, many lawyers were reluctant to draft Representation Agreements even when they became law. However, this is now changing.

Thanks to Continuing Legal Education (a non-profit organization that organizes seminars for lawyers), some amendments to the Act and market forces, most lawyers are now able to draft Representation Agreements. While I have heard of some situations where lawyers advised their clients against making Representation Agreements because they were "no good"; in reality, those lawyers probably still had not taken the time to learn about them. Such instances are much rarer today.

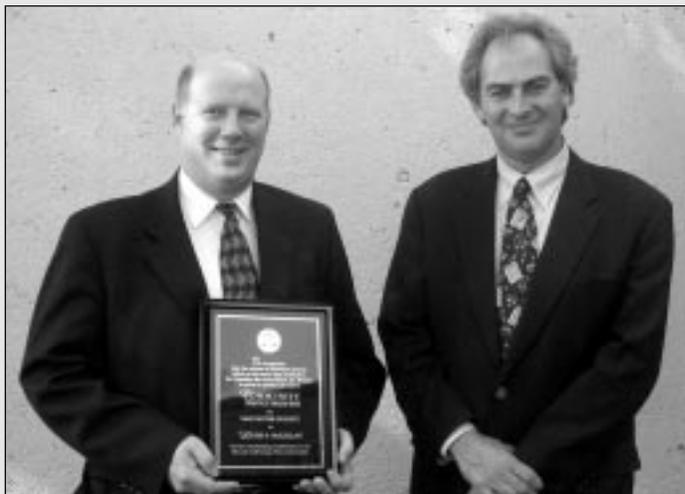
The Nidus eRegistry for Powers of Attorney and Representation Agreements, operated by the Representation Agreement Resource Centre, has been welcomed by many clients. However, many lawyers still do not know it exists. In addition to registering an RA with Nidus, I usually recommend that clients give copies of the Agreement for health care to their representatives and doctor.

We have come a long way since the *Representation Agreement Act* was introduced in 1993. RARC and others are continuing to educate lawyers and the public about this important tool.

Hugh McLellan is a lawyer with the firm of McLellan Herbert in Vancouver. For over 15 years, Hugh has volunteered his time to the reform of adult guardianship legislation and the new Representation Agreement Act (see opposite page). ■

**“ We hope the government will take into consideration the requirements and well-being of those citizens who rely on Representation Agreements to ensure their needs are met, as well as the recommendations of the community support groups who work with these individuals every day.”**

*Trial Lawyers Association of BC, May 4, 2004*



*Hugh McLellan (left) with Canadian Bar Association BC Branch President, Michael Woodward*

## **Friend of the community wins award**

On October 2, 2004, Hugh McLellan, a lawyer with the firm of McLellan Herbert in Vancouver, was awarded the Community Service Award by the Canadian Bar Association, BC Branch. This is a significant award that honours lawyers who give exceptional volunteer service to their community. Hugh was nominated by the Representation Agreement Resource Centre (RARC) and supported by eight other community groups, including the BCCPD.

Hugh volunteered his time and expertise during the reform of adult guardianship legislation (1989 to 1999) and continues to provide support as a volunteer to the RARC and other community groups. Hugh and his wife Kathy have three children. Hugh has also volunteered as a soccer coach, with Scouts Canada and on the board of the Community Living Society.

Congratulations Hugh—you really deserve this award!

## **Artist's statement**



I've chosen the blue as a base colour for the Representation Agreements image for several reasons.

Blue is calming, a natural colour, from the blue of the sky. In many diverse cultures, blue is significant spiritually—it brings peace and embraces protection. Blue also conveys importance and confidence, intelligence and stability.

The "rays" of energy (the work of the Representation Agreement Resource Centre) extend into the distance, "reaching out to the community." I hoped to illustrate capable interdependence, relationship and support. The rays can also give a sense of "stitchery" or a "web" depicting the weaving of community.

*carol weaver – [www.carolweaver.com](http://www.carolweaver.com)*

# Happy 2005

*To all our funders,  
donors, supporters  
and subscribers -  
best wishes for 2005*

*From everyone at  
BCCPD and Transition*

# Environmental Illness and Allergies

You may think that today's fragrances are made from flowers. However, they contain toxic chemicals you inhale and absorb through your skin. Fragrance chemicals in fabric softeners, laundry detergents, perfumes, personal care products, air fresheners and many other products may contribute to health problems and environmental damage.

By working together, communities, institutions, businesses and governments are improving air quality by eliminating and controlling exposure to toxic fragrance chemicals. Businesses also benefit with increased productivity from healthier employees.

Once these chemicals are absorbed by your skin and inhaled as vapours, they go directly into your blood and can affect the entire body. Some fragrance chemicals can alter the skin's surface tension which makes it easier for other chemicals to be absorbed into the skin.

For a full brochure on this topic, contact: Redemske Design, 833 Colrain

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Road, Greenfield, MA 01301 , 413-773-5375 - [sandyr@shaysnet.com](mailto:sandyr@shaysnet.com).

## **What is Environmental Illness?**

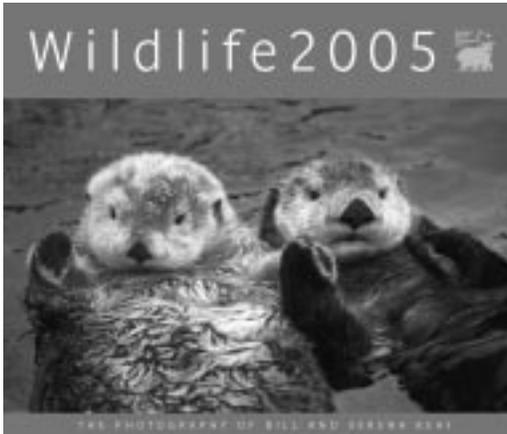
EI, also called Multiple Chemical Sensitivity (MCS), is a condition that is becoming more common where people experience problems with their health after even small exposures to environmental factors such as foods, chemicals and electro-magnetic fields.

Symptoms may occur in any body system, including the skin, lungs, muscles and joints, gastro-intestinal system, nervous system and brain.

For more information, contact: EHA/AEHA BC Branch, Ecological Health Alliance, Box 30033 Saanich Centre PO, Victoria, BC V8X 5E1, Telephone: 250-658-2027, [www.ehabc.org](http://www.ehabc.org).

## **Other resources**

[www.fpinva.org](http://www.fpinva.org)  
Fragranced Products Information Network  
[www.nottoopretty.org](http://www.nottoopretty.org)  
Poisoned Cosmetics, Not Too Pretty  
[www.noharm.org](http://www.noharm.org)  
Health Care Without Harm ■



## BCCPD 2005 Calendar Fundraising Campaign

We are honoured to participate with world-renowned photographer Bill Keay and his daughter Serena Keay on a 2005 Wildlife Calendar.

Treasure this beautiful calendar and show your support for BCCPD. The calendars are high-quality, full-colour and are available for \$20 each. Consider making a bulk order for your business or organization, to use the calendars as thank you's for employees or clients, or as gifts.

For details, contact Val Stapleton at 604-875-0188 email: [feedback@bccpd.bc.ca](mailto:feedback@bccpd.bc.ca).

Details are also available on our website at [www.bccpd.bc.ca](http://www.bccpd.bc.ca).

### BCCPD UPDATE

## February HLN Online Discussion on Sexual Health

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*BCCPD's Health Literacy Network is very pleased to join a national organization in highlighting the importance of sexual health information for people too often marginalized on many fronts.*

The BCCPD's Health Literacy Network (HLN) online community discussion on February 10-11, 2005, will be on the topic of accessible sexual health. Our guest will be Gail McVicar, sexual health educator with Planned Parenthood Federation of Canada (PPFC).

This discussion is scheduled to commemorate Planned Parenthood's Sexual and Reproductive Health (SRH) Day held each year on February 12th, two days before Valentine's Day. The theme this year is *Every Body Needs and Every Body Deserves Sexual Health Information*. PPFC has prepared a Resource Kit (available at <http://www.ppfc.ca/ppfc/content.asp?articleid=338>) to help Canadians raise awareness of the importance of information about sexual health.

PPFC notes, "Many Canadians feel invisible and ignored because of their orientation, ethnicity, age, disability or gender identity. National Sexual and Reproductive Health Day is an excellent time to look through the eyes of another person and consider how they feel about their body, their relationships and their ability to have access to services that are culturally appropriate, comfortable and which ensure the dignity of the individual."

BCCPD's Health Literacy Network is very pleased to join a national organization in highlighting the importance of sexual health information for people too often marginalized on many fronts. People with disabilities have long been seen as non-sexual and therefore not needing information about sexual health. Join us on February 10-11, 2005 for an HLN online discussion about making sexual and reproductive health available for everyone.

Contact Shelley at 604-875-0188 or email [wdi@bccpd.bc.ca](mailto:wdi@bccpd.bc.ca). ■

# Make the magic happen!

## Become a Kids on the Block sponsor



**D**oes your organization or business want to be part of a unique educational program? Read on to see how you can support a program that aims to educate and entertain children about “being different.”

Kids on the Block is a troupe of near life-size puppets who look and act like real kids. These likeable and imaginative characters—some with disabilities, some without—play-act together to discover their differences and similarities.

In the classroom, the Kids help initiate discussions that increase awareness and understanding that benefit all the children. The program can also be used for Special Education programs, schools that train nurses, daycare centres, community groups, children’s festivals and summer camps.

The Kids on the Block program is currently funded, in part, by our Founding Partner, the Kinsmen Foundation of BC and Yukon. It also receives contributions from BC Rehab Foundation, BC Gaming Policy and Enforcement Branch, the CKNW Orphans’ Fund, BC Nurses’ Union and the Spina Bifida and Hydrocephalus Association of BC. Variety—the Children’s Charity of BC has just contributed a generous donation to purchase eight new puppets. Thank you to all our funders.

But we need additional support if we are to meet the challenge of expanding our Kids on the Block program. Your organization or business can help make the magic happen by becoming a sponsor. There are four levels of sponsorship: Sustaining Partner (\$10,000 or more), Performance Partner (\$7,500), Program Partner (\$5,000) or Friend of KOB (\$1,000).

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For more information on the benefits of being a KOB sponsor, please contact:

Margaret Birrell at  
tel: 604-875-0188,  
fax: 604-875-9227,  
email: [kob@bccpd.bc.ca](mailto:kob@bccpd.bc.ca).

## Help Bring the Kids to your Block!

## Placing relatives with dementia in care

A recent study in the US shows that caregivers of people with dementia who must make the difficult decision to place their relatives into institutionalized care get no relief from the depression and anxiety of caregiving. In fact, they suffer additional emotional trauma following their decision. The study, funded by the National Institute of Nursing Research and the National Institute on Aging, part of the National Institutes of Health, appeared in the August 25, 2004 issue of the *Journal of the American Medical Association (JAMA)*.

The four-year investigation, which was coordinated by the University of Pittsburgh School of Medicine and led by Richard Schulz, Ph.D., found that clinical intervention may help caregivers to prepare for the placement of their relatives and by treating their depression and anxiety during the placement process.

According to Dr. Schulz, this is the first study to provide a real analysis of the emotional turmoil caregivers experience during the transition of their loved one from home to a long-term care facility. The investigators looked at a number of factors, including the conditions that led to placement, the nature of contact between the caregivers and relatives after institutionalization, and the impact of these factors on health outcomes among caregivers following the placement.

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**According to Dr. Schulz, this is the first study to provide a real analysis of the emotional turmoil caregivers experience during the transition of their loved one from home to a long-term care facility.**

Caregivers who were married to the patient and those who visited most frequently had the most difficult transition. Spouses reported higher levels of depression both before and after placement, and more anxiety after placement than their non-spouse counterparts.

The study recommends that spouses, caregivers who remain actively involved with the care recipient, caregivers who have high levels of depression, and those who lack adequate support from others should receive assistance.

"We need to help caregivers who place their relatives," said Dr. Schulz. "We need to treat their emotional distress, educate them about long-term care facilities and their impact on patient functioning, engage them in end-of-life planning and prepare them for the eventual death of their loved one," he added. ■



news  
from  
around  
the  
world

**T**he 2004 Paralympic Games in Athens have been declared to be the most successful yet.

However, some people with disabilities weren't invited. People with learning disabilities are currently banned from all Paralympic competition. The decision to ban these athletes came after the discovery during the Sydney Games in 2000 that a small number of athletes had falsely claimed to have a learning difficulty. The International Paralympic Committee continues to defend its decision saying the classification process cannot identify potential cheats.

**Bio-Ethics:** Do medical advances hold as much bad news as good news for people with disabilities? Some may say the news is more bad.

People with disabilities need to be concerned about rationing health care, judgements about people's quality of life, genetic testing and screening, euthanasia, gene therapy and similar medical issues.

Historically, people with disabilities have faced enforced sterilization, pre-natal termination, infanticide and euthanasia. According to Disability Awareness in Action (DAA), many of the attitudes and approaches that made these practices possible still exist today. DAA has prepared a Briefing paper on Disabled People and Bioethics. For a copy, contact DAA at DAA, 11 Belgrave Road, London SW1V 1RB, United Kingdom or see their website at <http://www.daa.org.uk>.

Courtesy of Disability Tribune, October/November 2004. ■

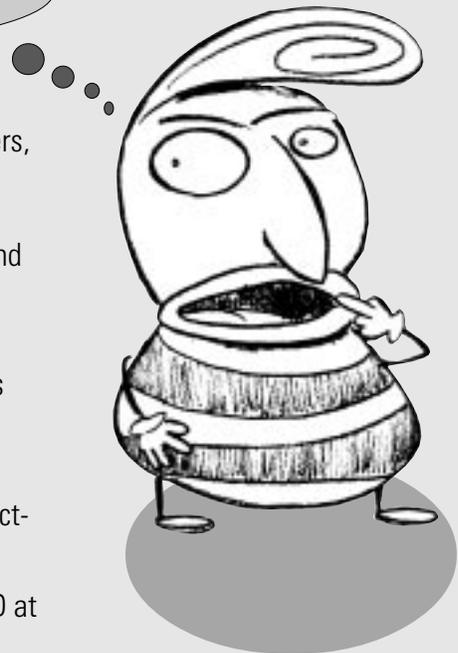
**Question: How does Transition stay on the presses?  
Answer: Through the support of readers like you!**

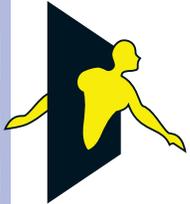
The truth is: Transition depends not on the kindness of strangers, but of friends, supporters and like-minded people like you. We need your financial support to keep us going—it's that simple. Funding from our traditional sources is far from guaranteed—and every year, we see more funding disappear.

Transition is an independent voice on disability issues and we believe people with disabilities in BC need independent voices today more than ever. We hope you believe this too.

**Please make your donation today.** Any donation, small or large, will make a difference—donations over \$10 are tax deductible.

Please make cheques payable to Transition and send to BCCPD at 204-456 W. Broadway, Vancouver, BC V5Y 1R3.





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