

Inside this Issue

1	Introduction and CANSW Executive
2	Editorial
3-5	CANSW Conference at Camp Dorset
6	Message from Shirley Pulkkinen, Cansw President
7	A Family's Transplant Story
9-11	Organ Matching & Black Market Sales
12	Winnipeg Conference Report
13	National Patient Services Committee Report
14	Jane Dicks Award
15	Brantford Hospital Research Project
16	Chicago Conference
17	Membership Form

Cansw Voice

The world of renal social work presents new challenges every day with the pressures of the health care system. This issue about transplant will report on some of the new directions in the area of transplant and living donation.

This year a number of our members have been fortunate enough to travel to various conferences around North America... highlights from their learning experiences are included in our summer edition.

We also have reminders of upcoming conferences and events you won't want to miss... the annual CANSW Conference at Camp Dorset and the 2005 Conference in Vancouver.

Cansw Executive:

*Shirley Pulkkinen, President
Gary Petingola, Past President
Lise Ross-Lalande, Vice-President
Lyle Stockwell, Treasurer
Carolyn Maingot, Secretary*

Regional Reps:

*Laura Devereaux, Northern Ontario
Nathalie Innes, Alberta, Sask. Man. & NWT
Michaela Leicht, BC & Yukon
Diane Boisjolie, Southern Ontario
Maureen Brownlow, Que. Atlantic Canada,
& Nunavut*



Words from the Editor...

It has been a challenging time in British Columbia since our January edition. The Liberal government headed by Premier Gordon Campbell has pushed forward with his goal of privatizing many hospital services such as cleaning, laundry and food services. There was a one week strike in April when social workers, physiotherapists, dieticians, nurses and other health care workers supported colleagues from the Hospital Employees Union on the picket line. HEU staff were ordered back to work but did not return. A settlement was reached hours before a general strike occurred which was to include teachers, ferry workers, community service workers and many other trade unionists. HEU workers lost approximately 15% in a wage rollback. Their union was fined for illegal job action. The Union to which social workers belong, the Health Sciences Association and the nurses' union, the British Columbia Nurses Union are still negotiating. My understanding of current negotiations is that our salaries will not be rolled back. On the table are benefits, holidays and increased hours of work.

Monday, May 3rd was the day we expected a general strike to take place. Instead, we were at work and many of our colleagues had mixed emotions. I want to report on this important event because we are faced with increasing ethical and conflictual situations in a changing social and political culture. We are still expected to work to capacity at these times.

What can we do to take care of ourselves in this environment? I would like to make a few suggestions and hope you will find helpful resources to achieve them on the following pages of this edition.

Defining our priorities and our work for ourselves:- *I was lucky enough to attend the National Kidney Foundation Conference in Chicago where I attended a workshop on Outcomes-Driven Practice. I've summarized some of these ideas in an article. I've also included some web addresses for you to check out and see for yourselves some small manageable projects being done in the US.*

Advocacy – for patients about a specific issue: *- I'm reminded of the email that Shirley Pulkkinen forwarded about advocacy for our patients. I believe that our advocacy role is the hardest to accomplish. We advocate daily for many individual patients but shifting our thinking into lobbying activities can be challenging. I always try to remember that it has only been about 3 years since due to lobbying efforts, hemodialysis patients do not have difficulty getting the Disability Tax Credit..*

Education: *– Some of our work stress comes from the constant worry about our funding being cut. I'm including a number of web-site addresses to transplant related issues, end of life websites and a variety of others so we can continue to learn and be expert in our field and speak to why we are important members of the team and what we contribute that is different from our colleagues*

Self-Care: *- This is one of the areas of focus for the Camp Dorset Conference in September. Some of us are better at accomplishing this than others...remember to share tips and try to help one another out.*

Good luck and have a wonderful summer!

Celebrating Our Strengths CANSW 2004 Conference

September 26th – 29th

Location: Camp Dorset

Located in the small hamlet community of Dorset – in the Muskoka / Haliburton region. Camp Dorset provides a vacation opportunity for renal patients and their families – on site dialysis is available and the facility has many wonderful highlights:

- Located on Kawagama Lake
- Swimming, canoeing, kayaking, paddle boats, tennis courts, fishing, baseball, hiking trails to name a few
- The facilities include large banquet hall, fireside room, indoor swimming pool, sauna and hot tub, library, and kitchen
- Accommodation: housekeeping cottages
- 14 cottages and 15 efficiency units

www.lionscampdorset.on.ca

Booking your trip

Conference will start with self care activities in the morning of Mon Sept 27th, first speaker @ 11:00 am, Check in: Sunday 26th @ 3:00 pm

REGISTRATION & COST

- Packages will be mailed to CANSW members in the near future
- Tentative costs including accommodation, full meals and entertainment \$350.00 per member
- Transportation to Dorset: from Pearson Airport = Northern Airport Service \$99.00 Round Trip

Speakers

Keynotes

Dr. Hugh Walker – Director of Spiritual Care, St. Joseph's Hospital / Thunder Bay. "Spiritual aspects of our work"

Dr. Beverley Antle – University of Toronto Faculty of Social Work. "Difficult Decision Making - Pt and Team"

CANSW Members

Joan Spittal – "Approaching Dialysis: Patient Stressors, Responses, & the Role of the Multidisciplinary Team"

Joyti Kapur – "Impact of Patient Transfer from a Regional Hemodialysis Centre to a Satellite Hemodialysis Clinic on Quality of Life"

Laura Devereaux – "Compassion Fatigue: Identifying the Impact of Our Work & Affirming a Commitment to Taking Care of Ourselves"

Cathy Mosher & Dave Nicholas – "Research Development"

Shirley Pulkkinen & Doug Parsons – "Dialysis Withdrawal / End of Life Pamphlet"

Something New!!!!

On the first morning (Monday) members will be able to receive self-care therapy.

- Massage
- Cranial Sacral Treatment
- Reflexology Treatment

Please email Sonya if interested solmas@nbgh.on.ca

- **Sylvia Jurgitis** – CANSW member has volunteered to offer Yoga class(es) as well for FREE!

Individual cost for the therapy sessions will be confirmed in the near future.



CELEBRATING OUR STRENGTHS
Camp Dorset - by Sonya Solman, North Bay

So very often I feel a sense of isolation in doing the work I do. It differs from my fellow hospital social workers in that they often do not know their clients and families as intimately as we do in renal. I find that it is easy to get lost in our work - we listen, we counsel, we advocate, we teach, and we are always there for someone else. We then go on to think that it has not had an impact on our day to day lives and can be without eventual consequences. So how do we “refuel”? We have all been close at one time in our professional career to being “lost”, forgetting why we do what we do, and if we haven’t, we need to be prepared for the possibility.

I believe that we as renal social workers have the ultimate privilege: we are there at all stages of the disease, and at all of the stages of life, often all in the same day, for people of every race, religion, culture, and gender living with kidney disease. It is a merciless disease and there is no refuge from it. It can be so emotionally draining and at times you can’t help but have a heavy heart, even when you are the optimist. Yet, I find strength from having this privilege and with that am able to be the best I can be in the lives of the people I work with every day and go home to every night.

Recently, my program manager retired and in looking back on some very important lives in our unit we realized just how much it is like a bowl of vegetable soup. At any given moment you don’t know what you will come across, how it will really taste and how it will impact on you and everyone around you. The emotions run high and they run low. We walk into the unexpected and the devastating and sometimes we even get a glimpse into the happiest moments in the lives of our patients. (Isn’t this the typical Monday?) Self care, at best, seems so far off on any given day yet it is the core of what keeps us going. It keeps us strong, not only for our families, and our patients but for ourselves. It is a struggle to ensure that it can be incorporated into daily life. And, it is essential that we acknowledge and embrace the “struggle” to find and achieve that balance, and ensure that we do take care of each other and ourselves. We must commit ourselves to practicing what we preach!!!

We have reason to celebrate...we are part of a group that recognizes this as a professional need. We acknowledge it and it will be the central focus of our conference this year! The serence and celebrated location will help us embark on our three day journey of self care, reflection on our professional experiences. We have reason to celebrate the strength in our differences and in the differences we make.

LIONS CAMP DORSET

By Bryn Milner, Huntsville - Ontario

All of us agree that vacation and travel is a good idea. However, the reality, for our dialysis patients is that it is often not possible for a variety of reasons. The cost of out of country dialysis treatments are often prohibitive; treatment centres are, all too often, full and therefore unable to accommodate transient treatments; and, patients are often leery of dialyzing with staff that they are not familiar with.

We, in Ontario, are very lucky to have Lions Camp Dorset! Camp Dorset (CD) is in the heart of Muskoka (a rather beautiful area). Each summer they provide dialysis for approximately 400 people (give or take) in a safe, friendly and warm environment. There is regular staff at Camp Dorset as well as staff from various renal units throughout Ontario. Patients will likely know at least one nurse from their unit and (if they are returning to Camp) they will see familiar faces. CD is open from the 3rd week in June until the first week of September. The first two weeks of September and thanksgiving CD is set aside for CAPD, CCPD and Transplant patients. Hemo patients attend CD throughout the summer as each unit in Ontario is assigned a week and a certain number of spots. Unfortunately, there is limited space at CD. There are 14 three-bedroom cottages, 9 efficiencies and 6 trailer sites available for patients. The cost per patient ranges from \$125.00-\$275.00/week with an extra charge for those who are not immediate family.

As I think most of you know, this year we will be enjoying Muskoka's fall splendor for our CANSW conference. If you are driving, CD is approximately 3 to 3 ½ hours North East of Toronto with the last ½ hour or so on back roads. If you think that you are lost... don't worry, you probably aren't. I've been to CD a few times as I live in the area and I still wonder (for a moment) if I've missed it just before the sign comes into view. A brief cautionary note if you are driving: Beware of creatures (bears, moose, deer) that don't understand road signs.

As you drive into CD, the first thing you will see are the tennis courts to your right, the clinic straight ahead and, what appears to be a small village of cottages just past the tennis court. The efficiency units are to your left and back. The community center, with the kitchen, the pool and heated Jacuzzi is located next to the clinic. It also has a lounge with a VCR and a library. Each of the cottages has three bedrooms with either twin or double beds. There is a full three piece bathroom with a shower and a fully equipped kitchen (cutlery, dishes, pots/pans). Each cottage has a large deck with a picnic table or Muskoka chairs on it. The efficiencies are quite like bachelor apartments and also have a three piece bathroom and fully equipped kitchenette. All units are furnished by donations and there is a "cottage" flavor to them.

Camp Dorset is situated on Deer Lake, which is connected to Raven Lake. There are some aluminum fishing boats, a few canoes, paddleboats and kayaks with a limited number of paddles, oars and life jackets. There is a small beach area with a volleyball pit; a baseball diamond with some equipment; horseshoe pits; a walking trail, and as previously mentioned, a double set of tennis courts where basketball can also be played. So much to do!!!

In terms of comfort items and necessities, we will need to bring our own bedding and linens (flat sheets, tea towels, bath towels etc...) Every place has a comforter but you may want to bring your favorite blanket and/or sleeping bag. There is no corner store nearby so bring anything you might want or need to get you through a few days. The town of Dorset is approximately 7 kms away and they have a general store and a liquor store. There is a bank that is only open on Mondays...closes for lunch. However, there is an ATM in the general store. It gets really, really, really, dark at night therefore people may wish to bring their own flashlights.

It is rustic and beautiful. The Fall colours are spectacular!



Shirley Pulkkinen is President of CANSW and works in Sault Ste Marie, Ontario. She attended the National Kidney Foundation of Canada's Annual General Meeting in Montreal (Picture) in June of this year.



Here I am 8 months into this Presidency and as I scratch the surface of issues facing CANSW, I must admit I often feel inadequate and as though I'm floundering in limbo. But limbo is where we all in Renal Social Work should be accustomed to functioning. In limbo, alongside a patient who is faced with the cruel reality of an amputation versus the uneasy allure of discontinuing dialysis. In limbo, with the patient who has an access that is holding on, just barely, full well knowing that by the next run, the fistula may clot forever. And, in limbo, with the family who is anxiously waiting for that life saving transplant that beckons with the tentative but sweet promise of rejuvenated health and a return to a life no longer in limbo.

At this moment, I'm in the Montreal airport at 0810 hours on June 13th feeling excited and rejuvenated, feeling like I'm not in limbo. I've spent the last 2 ½ days at the National Kidney Foundation of Canada's Annual General Meeting (NAGM). I have had the privilege of being enlightened with the work and ongoing vision of KFOC and celebrated with them their 40 years of existence.

I heard the story of 26 year old Morty Tarder who tragically passed away in 1963 and whose father approached Dr. John Dossetor as to what could be done to prevent another dad suffering the same misfortune. Dr. Dossetor's answer was RESEARCH and a group to FUND research, and thus the Kidney Foundation Of Canada was born.

Patient services, advocacy and education are important to KFOC, but what drives the life force of this organization is the incredible commitment to research – research into kidney diseases and treatments. Their commitment to research has translated into **\$67 MILLION, YES, \$67 MILLION** since 1964 – and a lot of that has gone into transplant research.

And as I'm sitting at the NAGM, I see energy, commitment and vision in the faces of everyone at this meeting. Then I get to hear the stories – of one participant who has had a kidney transplant for 30 YEARS and who existed on a very restrictive diet for more than 10 years before going on hemo because dialysis was not available in his province (I actually talked to this remarkable fellow!) And the story of another person who has had her transplant of 29 years and is still on Imuran, a word I thought was only in renal archives. And of another volunteer whose transplanted husband was

the catalyst in convincing his community nephrologists to actively promote their local golf tournament, thus making it a success. And yet several other volunteers who also devote their time to the KFOC with a healthy functioning kidney transplant. And my favourite, a social worker who is a President of a KFOC Branch who sits on many committees – I bonded and found so many similarities between her life and mine. It wasn't until a later workshop that she stated "Oh yeah – I keep forgetting to tell people that I got a transplanted kidney two years ago".

All of these people with their health rejuvenated, their hearts bursting with hope and commitment, give back so others can firmly hold what they have today – health. All of these folk willingly, gladly, repeatedly give of their time and energy to volunteer as Presidents, VPs, Executive and Other Committee Members. They all work together to find out more about kidney disease. What a life force. What a commitment.

Finally stepping out of my comfort zone and looking to do more for CANSW as your President has given me the opportunity to safely say that "I finally GET IT" when it comes to the Kidney Foundation. I think I truly understand and appreciate the depth of their vision and commitment to renal patients and families. And I know that this life force will only continue to flourish with the continued partnering and collaboration with other groups such as CANSW.

As you receive this Transplant Edition of the VOICE, contemplate how you too can be a bigger part of the KFOC's life force and influence change. Keep up your commitment to the renal patients and families. You too make a difference and are vital to the life force of all renal patients. See some of you in September at Camp Dorset, or perhaps in Vancouver in May 2005. Have a safe and happy summer!

PS. The KFOC's Medal for Research Excellence Award has been renamed the "Dr. John Dossetor Medal for Research Excellence Award" in recognition of the founding member of KFOC, a very humble elderly gentleman with a single idea. I got to meet him. I actually got to meet history. An honour and privilege indeed.

"The Kidney News", Volume & Issue I, Spring 2004, a publication of The Kidney Foundation of Canada, BC Branch featured an article by Dr. Toni Henderson. Entitled "Living Anonymous Donor (LAD) Study discovers highly altruistic humanitarians."

The article summarizes Dr. Henderson's study about this type of donation, which is still fairly new in Canada. In 1997, the British Columbia Transplant Society (BCTS) conducted a survey asking British Columbians their thoughts on organ donation. In that study, 33% of participants indicated they would be willing to donate an organ to someone they didn't know.

Dr. Henderson set out in 2000 and 2001 to tease out more detail and to 1) find out what the public thinks (Landolt, et al., 2001), 2) judge behavior about living anonymous kidney donation (Landolt et al., 2003) and 3) study motivation "The living anonymous donor: lunatic or saint?" (Henderson et al. 2003) Quite interesting read with the results of the 1997 study being fairly representative of her current work and she states "consistent with other survey research indicating anywhere from 19% to 54% of individuals surveyed reported a willingness to stranger donations".

Dr. Henderson's summary, "let me add that as a psychologist I am trained to look for pathology. And yet, try as I might, the individuals I met in this project did not fit the model of psychologically disturbed individuals. What I did find, and what I did not expect, were individuals at the other end of the continuum of psychological health – individuals who were purely and solely motivated to do a good thing to make the world a better place to live, without any expectation of anything in return".

A FAMILY GIFT OF LIFE

By Lise Ross-Lalande,
Timmins, Ontario

I have the privilege of telling the special story of a family's gift of life, shared by Claire, a hemodialysis patient, loving wife and mother of four.

Claire was diagnosed with Polycystic Kidney disease at age 36. With medical follow-up she was able to delay dialysis until the age of 53.

Claire had always worried how this genetic disease might affect her children. As soon as they were old enough, each of her children were tested. Three of the four children were subsequently diagnosed with polycystic kidney disease. Her eldest son Brad, started showing symptoms at age 16 with a sudden onset of back pain. Recognizing the importance of his brother's well being, Chris, the only child without the polycystic gene, began offering his kidney to his brother at the early age of 11.

A few years later when Brad started dialysis, both Claire's husband Ed and Chris were tested. Although a match, Ed was unable to donate because of other health problems. Fortunately, Chris was also a match and preparations began for Chris to donate one of his kidneys to his brother Brad.

After some lobbying from the family to Chris's university, he was granted a leave of absence from his program to allow him to give his brother the gift of life. On July 22 1998, in London, many family members gathered to support the boys through the transplant. Ironically, Claire was receiving her dialysis on one floor while two of her sons were having surgery on other floors. Everyone recovered well. In appreciation Brad offered Chris a watch that was engraved "**thank you for buying me some time**". Chris humbly accepted it stating it was "No big deal" and he would do it again if he could.

Unfortunately tragedy struck this family once again. On September 8, 2002, Claire's youngest son Derek was diagnosed with Acute Lymphocitic Leukemia. Within a month, without any hesitation all three siblings were tested for possible organ donation. As fate would have it, only Brad, who had received the gift of life only five years earlier, was a perfect match. Throughout the next seven grueling months of chemo,

family members encouraged Derek to keep fighting, knowing his brother would soon give him a new lease on life.

On June 26, 2003, the stem cell transplant took place in Toronto. Brad was hooked up for four hours as Derek sat by his side that morning. Brad smiled as his fistula, which had once been used to treat his kidney disease, was now being used to transport his healthy cells to his brother. The doctor's checked the blood and then in the evening with Brad sitting by his side, Derek received the stem cells that would save his life. This procedure took around 45 minutes. At Claire's dismay, she was not able to be present as a precaution to her own health within the SARS crisis. Knowing his family's angst, Derek dutifully sent them a video the next day, stating this was the "first day of his new life". Derek went through some hardships at this time for approximately 4 weeks as his chemo was taking hold- Derek's family took turns staying by his side every day until the worst had past. Today, Derek continues on his road to recovery and everyone is quite encouraged with the follow-ups thus far.

Claire smiles as she shares her story. She still can't believe that each child could give to the other. She feels so fortunate to have had four children, three boys who shared life with one another and a daughter who stood by their side through it all. She thanks God that through prayers and support it all came together. Claire's message to others is "Don't be afraid, face your fears, get information and soon people will realize it is not as intimidating as it seems to share your organs and the gift of life".

As for Claire, she waits patiently on the cadaveric waiting list for a kidney transplant. In the meantime she basks in the joy of seeing her sons alive and enjoying themselves, thanks to the gift of life they have shared with one another.

There is a saying that holds so true – **PLEASE DON'T TAKE YOUR ORGANS TO HEAVEN, HEAVEN KNOWS WE NEED THEM HERE!**

NEW LAW IN WISCONSIN WILL GIVE ANY LIVING DONOR A \$10,000 TAX BREAK THAT YEAR.

An article in the Whittier Daily in February, 2004 featured the story of one of 83,000 transplant patients waiting for an organ in the United States. Sherry Buescher who lives in La Habra has a working pancreas transplant but lost her kidney transplant. Back on dialysis, she is waiting for another kidney.

As in Canada, organ recipients are not allowed to solicit or to pay for a donor. In Canada, donors are eligible to apply for medical benefits under the Employment Insurance Act.

Exciting news according to Bryan Stewart, the spokesman for OneLegacy, southern California's donor transplant network is a new Wisconsin Law. Any Living Donor would get a \$10,000 tax break the year they donate!

MATCHING DONORS.COM !

By Shelly Serhyenko

Vancouver General Hospital Transplant Social Worker

For some time now, those of us working in the field of transplant have been hearing stories and talking with patients who have or want to buy an organ. We have frequently had these discussions with patients who have connections or family members in other countries and who may be offering money for compensation for temporary loss of work or to support their family. We have not encouraged patients to buy organs outright and talk with them about the ethical issues of organ procurement outside of Canada. We also talk with patients about the medical matching and care they may receive through these pursuits. The goal of our discussions is clear. It is not legal in Canada to pay for an organ and we do not encourage patients we follow to procure an organ for money elsewhere. We occasionally have patients who do so regardless.

In British Columbia, we are starting a pilot research program through the British Columbia Transplant Society for Living Anonymous Donors (LAD)s. This will involve donors who do not know the recipient but wish for altruistic reasons to donate. **There will be no money given to donors.**

On Saturday, April 10th the National Post had an article about a new Internet company called www.matchingdonors.com. According to the article the site acts like a dating service – people who need organs pay a \$295 monthly listing fee to describe their situation. The donors are able to browse for free.

The arguments for and against this site are somewhat the same as the arguments transplant centers have been making about buying organs in other countries.

The arguments for this site are that 83,000 Americans wait on the transplant (70%) kidneys and of these 16 people die every day. What is wrong with encouraging potential donors to come forward? Paul Dooley, from Massachusetts is the businessman running the site. He thinks they are doing a good thing. He states that 85% of potential donors using the site had not considered donating previously and that they are therefore finding new donors which will ease the resource problem. About 50 people are currently signed up.



The arguments against this site and its practice is that the site offers hope for a price to those that are sick and vulnerable. People who have money to pay will also be bypassing waiting lists and jumping the queue, thus a two-tiered medical system.

Most in the transplant medical community is opposed. Their reasons are that it commercializes dealing with human tissue. They reject the practice on legal and moral grounds, although understanding patients' desperation due to the shortage of organs. In addition to the argument of two-tiered care, one for those that can pay and another for those that cannot, there is concern that recipients with a poor chance of survival may be able to afford an organ whereas others that may need an organ more urgently may not.

Mr. Hickey, 58 is expected to receive an organ through a match on the site with Rob Smitty, 32. Rob Smitty was surfing on the Internet trying to find a site to sign up as an organ donor after he died but liked the idea of having some control about who received his organ once he found this site. Rob Smitty was one of 41 potential donors that wanted to contact Mr. Hickey. The only fee sited in the article is the \$295.00 listing fee for patients to sign up.

Wherever you stand on this issue, I have a feeling that this Internet site is just one of many that we may see in the future.

ORGAN DONOR REGISTRY - ARE YOU REGISTERED?

Did you know that having a decal on your drivers' license in BC is no longer a valid way of registering to be an organ donor?

Did you know that in 1997, BC changed the way donors register and that you must register with the province to be a donor at www.transplant.bc.ca.

In BC, 85% of the population support organ donation but only 15% are registered to be donors after they die.

Spain, Belgium and France have an "opt-out" system for organ donation, ie. Presumed consent for organ donation which means they are considered donors unless they state they do not want to be.

Austria places people who refuse to be donors at the bottom of the waiting list if they ever need a transplant themselves.

Do you know what system is in place in your own province?

Taken from Gail Johnson's article in the Georgia Strait

This might convince you if you're not sure about donating an organ! Mitzi Nichols says she believes that if you do good things for people, good things will happen to you. In 2001, Mitzi who is from Hampton, Virginia anonymously donated a kidney. June 14th, 2004 she won \$500,000 in a Virginia Lottery scratch game! She plans to buy a house, pay her daughter's student loans and repair the kidney recipient's car.

Taken from Associated Press, June 16th, 2004

“Tracking the Sale of a Kidney on a Path of Poverty and Hope”

– an Excerpt by Lorraine St-Martin

On April 23rd, 2004 there was an article in the New York Times written by Larry Rohter which tracked some of the illegal organ trade from Brazil, New York, Israel to South Africa. We have seen previous documentaries about illegal organ selling in Turkey and the Philippines. This article talks about the reasons that motivate the buyer, primarily severely ill-health and the fear of death and what motivates the seller, primarily abject poverty and survival. It also talks about the dealer who is primarily in it for the money.

These stories are sadly becoming all too common with our knowledge of people who are living in extreme poverty, who sell an organ and do not live happily ever after. Stories of shame, ill-health, arrest and theft of their money is now becoming the norm for these donors who thought selling their organs would change their lives.

What is also interesting about the article, is the information that many in the United States and other economically world-leading countries turning a blind eye to this situation where the organs are most sought after. Alexander M. Capron, the director of the ethics department of the World Health Organization are “transplant surgeons who believe that a good way to remedy the shortage of organs would be to offer payments” and bioethicists and philosophers who see organ trade as an extension of the principle of autonomy.

Dr. Scheper-Hughes of the Organs Watch, a human rights group in Berkeley, California says that it is common practice of many larger clinics in the US to advertise on the Internet for transplant tourists. She says that some transplant doctors have developed a “don’t ask, don’t tell policy”.

Other opposing groups make the argument that as in sex trafficking, the marketplace is one in which coercion and exploitation may be unavoidable.

Whether we are aware of it or not, we are embroiled in many ways in the black market organ trade.

Other websites related to the transplant issue and sale of organs taken from the Council of Nephrology Social Work listserv (CNSW), our American counterpart and for the complete article summarized above:

- <http://query.nytimes.com/gst/abstract/html>
- <http://www.kidneypatientguide.org.uk/site/messages>
- <http://news.scotsman.com>
- <http://news.bbc.co.uk>

Article references for Living Altruistic Donation and the Organ Trade:

- **Nephrology Nursing Journal (Vol 29, #3) June 2002**
- **“Renal Transplantation, Leo RJ, Smith BA, Mori DL; Psychosomatic.2003 Nov-Dec;44(6):452-60” Article Abstract INTERNATL6/9/2004 Donald Prebus**



**The Other Side of the Bed
Conference in Winnipeg, Manitoba
April 25 – 26th, 2004**

By Sylvia Boudreau from Winnipeg

A journey through chronic kidney disease was the first conference of its kind in Manitoba designed specifically for professionals involved in the care of renal patients. The conference was set to bring together all health care professionals to allow learning amongst each other. Presentations were provided by dietitians, social workers, Peritoneal nurses, pharmacists, and doctors.

The keynote speaker was Lori Hartwell from Southern California, a renal patient who has endured a life of renal ups and downs since the age of 2 years. Lori had used the Wizard of Oz as a metaphor to address the conference members. Using the characters to describe her journey with kidney disease since childhood. Other notable mentions were strategies to help patients and their families adjust to chronic kidney disease, dialysis as a palliative issue, how Aboriginal people view chronic kidney disease and planning for end of life care.

The walls were filled with demonstrations and displays courtesy of various sponsors from Amgem, Ortho-Biotech, Fresenius, Genzyme, Hoffman La Roche, Baxter, Gambro and Bard Canada.

Hemodialysis is offered at several sites in Manitoba including the Health Sciences Centre, St. Boniface General Hospital and Seven Oaks General Hospital in Winnipeg and local center units in Ashern, Dauphin, Flin Flon, Kenora, Morden, Norway House, The Pas, Portage La Prairie, Pine Falls Selkirk and Thompson.

Report from the National Patient Services Committee – Kidney Foundation of Canada

by Doug Parsons

I am currently the Ontario rep on this committee and have been a member since 2003. Our committee's mandate is to review and develop national policies and programmes in regards to Patient Services. We want to ensure the core programmes continue to be given priority and adequate funding.

As a result of my participation on this committee, I've had the opportunity to

learn about new, unique and innovative programmes throughout the country. This gives me the perspective about which regional programmes may be beneficial if implemented on a national basis. We currently have a sub-committee looking at the feasibility of a national peer support programme. Some of the considerations for implementing the programmes nationally are financial issues and

regional diversity. Models of programmes are also being reviewed and one currently being considered is the phone peer support programme from the Greater Ontario branch.

The other project currently under way, is the collaboration with CANSW on a brochure on withdrawing from dialysis. We anticipate presenting a draft copy for discussion at the Camp Dorset Conference. Cansw's recommendations would then be presented to the NPSC at our next meeting in October in Winnipeg.

There are many unique and exciting programmes in place throughout the

country which may be looked at on a national basis in the coming months. Manitoba has developed a wonderful programme in collaboration with public school system educating students on healthy eating and exercise in an effort to help prevent obesity, diabetes and kidney disease. As well, in BC there is a province wide education programme for family doctors to facilitate early detection of kidney disease.

It has been both rewarding and educational to be involved at the national level of the Kidney Foundation and if given the opportunity, I would encourage you to do so.

ADVOCATING FOR HEALTH AS A BASIC HUMAN RIGHT!

After listening to Stephen Lewis, the UN's Secretary General's Special Envoy on HIV/AIDS in Africa, a number of attendees at the 4th International Conference on Social Work in Health & Mental Health in Quebec drafted the following statement:

ShirleyPulkkinen, Cansw President forwarded the complete statement to us all on the listserv on June 14, 2004. You can access this statement again on the conference web page at <http://www.swh2004.com/> You can also get more information from Stephen Lewis's website at: <http://www.stephenlewisfoundation.org>

New Hemodialysis Unit

On October 22, 2002, Northumberland Hills Hospital in Cobourg opened the doors to its new facility. A few days later, a new 12 station hemodialysis unit was opened in this hospital as a satellite of the Peterborough Regional Dialysis Program. With current funding, we are able to accommodate up to 48 level one patients, and have morning and afternoon runs, six days per week. As a level one program we would like to extend our services to those patients who until now have been unable to relocate because of a lack of services, or who are travelling to the Greater Toronto area yet living in the Northumberland region. Please note we are unable to provide services to those wishing transient or "traveler" treatments.

Contact Kathleen Fair, R.N., CnepH(C) at kfair@nhh.ca or (905) 372-6811, ext.3016



Please take the time to consider nominating a CANSW member for the Jane Dicks Award for 2004!

This award was initiated in 1995 to commemorate the contributions made to Nephrology Social Work in Canada by Jane Dicks. Previous recipients of the Jane Dicks Award include:

- 1995 Mary Catherine McDonnell
- 1996 Mary Lou Karley
- 1997 Phillipa Prescott
- 1998 Douglas Parsons
- 1999 Betty Ann McKenzie
- 2000 Robert Fraser
- 2001 Gail Picone
- 2002 Cathy Mosher
- 2003 Pat Reed

The award will be presented as an acknowledgement of significant achievement within the profession of Nephrology social work in Canada. It is a recognition, by the community of Nephrology social workers, of outstanding contribution made by a Nephrology social worker in many (not necessarily all) of the following areas:

1. Community work (such as Kidney Foundation participation)
2. Outstanding clinical work within the individual's renal unit
3. To the Canadian Association of Nephrology Social Workers
4. Education
5. Research/ publication

The award recipient will:

1. Be a member in good standing of CANSW
2. Be a member in good standing of the provincial college / association/ regulating body
3. Have a minimum of 3 years Nephrology social work practice
4. Have recognized educational achievement in the field of social work

The CANSW executive will make the decision regarding the presentation of the award. The award may be presented annually, but will not be awarded in a given year if the nominated candidates do not, in the opinion of the Executive, meet the level of achievement outlined in these guidelines.

Any members in good standing of the CANSW may present a nomination to the Executive for consideration. A nomination shall include a description of the Nominee's achievements in the 3 areas described by the Nomination Guidelines, and the reason(s) why, in the opinion of the nominating individual(s), the Jane Dicks Award should be presented to this Nominee.

*An individual may receive the Jane Dicks Award no more than one time. **Nominations for the award should be sent to Shirley Pulkkinen President CANSW, Renal Program #149, Sault Area Hospital, 969 Queen Street East, Sault Ste. Marie, Ontario P6A 2C4 by mail OR by Fax (705) 759-3860 OR by Email Pulkkinens@sah.on.ca by August 1, 2004.** Please include the reason this individual deserves this coveted award.*

Research at Brantford General Hospital by Ruth Locis, Renal Social Worker

In March 1998, the S C Johnson Dialysis Clinic opened at the Brantford General Hospital. This was an opportunity for residents of Brantford and the surrounding rural area, to avoid the long drive to St. Joseph's Healthcare in Hamilton and most importantly, receive dialysis closer to home.

Initially, 20 patients received hemodialysis in the clinic. In 1999, the clinic expanded to 32 patients and by 2000, was able to accommodate 40 patients. Staff working in the dialysis unit began to notice that our clients began to "blossom" over time. On the whole, they were more relaxed, their bloodwork improved. The clients and their families got to know the dialysis staff and felt confident to bring up "little things" they noticed. This allowed the clinic staff to be proactive and problem-solve issues before things got to a crisis point.

Due to the increasing numbers of Brantford-area clients needing hemodialysis, plans were made to expand the clinic once again. Clinic staff also felt that this was a prime opportunity to see if their anecdotal observations about client improvement could be scientifically verified.

After researching various instruments, we decided to use the American Kidney Foundation SF36, Quality of Life research tool. This survey instrument asks a series of questions that covers a client's physical and emotional health. Various markers in the client's monthly bloodwork are also evaluated. In our research design, we decided to administer the SF36 over a year, at 3 time intervals to the dialysis patient who were just starting.

The first time the survey was given was approximately one week before clients began dialyzing at our clinic. They were invited for a tour to see the unit, meet some of the staff and have any questions answered. Clients were asked if they would like to participate in our research project. If they agreed, the questionnaire was administered by the unit's social worker, to ensure survey completion, as many were elderly or had decreased vision. We achieved 100% participation in phase one on the research.

The second phase of the research project involves repeating the SF36 after clients have been receiving dialysis in our clinic for 6 months. The client's answers and blood work markers will be compared to the initial results. The third phase involves repeating the process after clients have been dialyzing "at home" for a year.

As more and more satellite centers for dialysis open up to meet the demand, we hope that our research will show that dialyzing closer to home, in a smaller unit is good for the client and their family. The research should be completed by the fall of 2005, and we hope to publish our results in 2006.



Council of Nephrology Social Workers
National Kidney Foundation Conference
Chicago, April 2004

by Lorraine St-Martin, Vancouver Renal
Social Worker

I found it extremely rejuvenating to attend the conference in Chicago. It was a wonderful opportunity to learn about so many issues related to our renal patients and the intricacies of practice in a different country. I learned a lot from our American colleagues and the many patient groups represented.

The highlight of the 4 days was the first when I attended a workshop by two CNSW members (our CANSW equivalent). Beth Whitten from Texas and Stephanie Johnstone from San Diego gave a workshop on **Outcomes Driven Practice**. I can't begin to impart all their knowledge and ease of practice about this issue as they have been focusing their practice this way and teaching this course for 6 years. What I hope to do is to summarize some of their ideas and encourage you to find out more about the possibility of applying these principles to your work.

Stephanie & Beth emphasized over and over again to start small! To try and state very simplistically what they taught in a day, social workers need to look at some of the indicators in our patients and focus our practice to address these issues. One example they discussed was depression. Chronic renal failure and depression is linked. In some studies, they estimate about 25% of renal patients are depressed. Based on this information, they use the Quality of Life tool that can be used to indicate depression in patients. Coupled with these results would be their interview where they would discuss this finding with the patient and perhaps suggest another tool such as the Beck Depression Inventory or another type of treatment. They also educate the patients by giving them written handouts about depression and resources. Thus the social work intervention is directly related to some of the specific disease-related issues in our practice.

Stephanie & Beth say a project can mean 3 people who you ask 3 questions. **Start small!** If you want to find out about some of these outcome driven projects, CNSW members are trying, you can check out the "Project Solidarity" Bulletin board which is new and specifically set up to encourage social workers to try new projects or repeat one that was successful somewhere else. Check out their web site at: <http://www.kidney.org/professionals/CNSW/messageboard.cfm>

I look forward to seeing some Canadian projects listed there soon!

CANSW

Canadian Association of Nephrology Social Workers
Membership Application/Renewal
January 1, 2004 - December 31, 2004

Name: _____

Business Address: _____

_____ Postal Code _____

Business Tel# (____) _____ Fax#(____) _____

E-Mail Address _____

Education: MSW _____ BSW _____ Other _____

Members of Professional Social Work Association /College: Yes _____ No _____

Name of Association / College: _____

Areas in which you work: Pre-dialysis _____ Hemodialysis _____ Peritoneal _____

Transplant _____ Adults _____ Children _____

Years in Nephrology: _____ Other Experience: _____

Committee Work (eg. working committee on renal services, Kidney Foundation, etc...)

How can CANSW assist you to meet your professional goals and objectives?

Activities you are willing to assist CANSW with:

- ___ Mentorship for new Renal Social Workers
- ___ Renal Social Work Standards/Guidelines
- ___ Advocacy for renal patients
- ___ Submissions for the Voice newsletter
- ___ Developing a resource library for the website
- ___ Assist in redeveloping CANSW website
- ___ Any other activity _____



Active Membership Fee \$60.00 due by March 1, 2004, \$75.00 thereafter. *Any Social Worker currently working in a dialysis/transplant program in Canada. Active members may vote and hold office and act as a chairperson of a committee. The immediate Past President will be considered an active member.

Associate Membership Fee \$65.00 due by March 1, 2004, \$75.00 thereafter. *Those eligible for Associate Membership include the following: Social Workers practicing Nephrology Social Work in any area outside Canada; professionals practicing in a related field of Nephrology; laypersons from related organizations; previously Active Members. Associate Members may attend meetings, conferences, participate on committees, receive significant mailings. Associate Members may not vote or hold office in the Canadian Association of Nephrology Social Workers.

Please make cheques payable to CANSW and return to:

Lyle Stockwell MSW, RSW
c/o Lakeridge Health Whitby, Room M073
300 Gordon Street,
Whitby ON
L1N 5T2
(905) 686-6411 ext. 4156