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CANSW VOICE

One of the benefits of being a CANSW member is having a forum to discuss our work and learn from colleagues who share a passion for nephrology social work.

This issue is dedicated to sharing resource information, letting members know about various learning opportunities and tools of the trade.

It's not all serious as you'll see we have excerpts from a joke book about dialysis that will make you laugh!

Vancouver is hosting the Annual Conference this year and we are inviting you all to come and meet western colleagues and tour Vancouver.

Elections will be held for the new CANSW Executive at the May Conference in Vancouver. If you've been tempted to be in the leadership group or be on a CANSW committee, this is a wonderful opportunity!

CANSW EXECUTIVE:

*President - Shirley Pulkkinen, Sault Ste. Marie, On.
Vice-President - Sonya Solman, North Bay, On.
Secretary - Lise Ross-Lalande, Timmins, On.
Treasurer - Lyle Stockwell, Whitby, On.*

REGIONAL REPS:

*Eastern Ontario - Dianne Boisjoli, Ottawa, On.
Southern Ontario - Debbie Hodgins, Windsor, On.
Northern Ontario - Laura Devereaux, Thunder Bay, On.
Alberta/Sask - Natalie Innes, Red Deer, Alberta
BC/Yukon - Zhila Schofield, Penticton, BC
Eastern Atlantic - vacant*



...Words from the Editor

Like most, my mind and feelings have turned in recent weeks to the life changing events of the tsunami that hit Asia and Africa on Boxing Day. The raw emotions of so many suffering loss and grief were broadcast daily for weeks. Now the stories appear to focus on the surviving and the rebuilding needed. I am touched by the number of ordinary people who on first impression have no particular skills and yet are simply going to the area to help. What I am reminded is that so many have great compassion, energy, and resourcefulness. I wish to extend my sincere sympathy to all our members who have been affected by this tragedy.

Closer to home, you will all have your CANSW Conference packages soon and be ready for registration. The planning committee has done a wonderful job of content, location and format.

We have a few other conference dates as well. Perhaps more accessible for our westerners there is a conference in Washington State, and the first Chronic Kidney Disease Summit in Vancouver. The Professional Meetings of the U.S.Kidney Foundation will be held in Washington, D.C. this year.

We have listed some of your favourite websites and we hope helpful links. Many of the government sites and forms are now online; some region specific sites have been included for our members in those areas.

As always, we have several interesting articles about practice issues. Thank you to all our print contributors and to those who sent website links and other resource suggestions. Many thanks to our photographers, especially Michaela Leicht whose totem photos you'll find on a few pages.

Lorraine St. Martin, MSW
Vancouver General Hospital
lstmarti@vanhosp.bc.ca

PEER SUPPORT

*By Anne Brinkman, BSW, RSW
Director of Programs, Kidney Foundation
Greater Ontario Branch*

For this issue of "The Voice", focusing on resources, it seemed to be a good opportunity to highlight Peer Support, as it is a valuable resource for many patients, families and living donors.

Several of the 13 Branches of the Kidney Foundation of Canada offer Peer Support Services.

They are Northern Alberta, Southern Alberta, Saskatchewan, Central Ontario, Eastern Ontario, Greater Ontario, Nova Scotia, and Newfoundland Labrador.

As you know, the diagnosis of kidney disease can be very frightening and life altering, and for some, one of the best supports is talking with others who have had similar experiences. All peer support volunteers have personal experience living with kidney disease, have participated in training programs, and are willing to share their experiences with others.

The program is offered in various ways in conjunction with renal programs. While the way in which services are provided may differ, the goals and objectives of the program are the same for all, and that is to provide the opportunity for support from someone who truly understands living with kidney disease.

I can speak to the Ontario programs and would like to share with you our current program's direction. Presently, the three Ontario Branches are working together on piloting expansion of the Greater Ontario Branch telephone support program. Those requesting services call one toll free number and a match is initiated based on the person's expressed support needs. In turn, this expands the accessibility of services to anyone, anywhere in the province as long as they have access to a telephone, and increases the accessibility to volunteers with diverse experiences and languages. This pilot is currently underway, and is a work in progress.

If you have questions about Peer Support, I can be reached directly at (519) 971-0910, or 1-877-202-8222 or by email at peersupp@mnsi.net You can also contact your local branch of the Kidney Foundation for more information about this and other programs.



***THE
PRESIDENT'S
KEYBOARD***

***President of
CANSW, Shirley
Pulkkinen works in
Sault Ste. Marie,
Ontario.***



Some days, it is hard to look at the big renal picture in Canada when my own desk is overflowing with chart notes not yet done and statistics not yet “inputted”. The red light on my phone is perpetually blinking indicating yet another voice message. The dreaded email demon reminds me that yet again, my mailbox is full and would I please do something about it. It's a constant challenge to carve out the time to attend to the multiple demands of work, school council, family life, health and sanity and of CANSW. Yet, I find the time. I get immense pleasure and gratitude from every aspect of my life. I have the blessing (or curse) to see the positive in the negative and am always amazed by the miracles of everyday life. Lucky for me I have a cast of supportive individuals surrounding and encouraging me. And in CANSW's case, I have the Executive to thank as they are always a phone call away with ideas, enthusiasm and wisdom. I only wish we lived closer to one another so that we could see each other more often than just at the Annual Meeting.

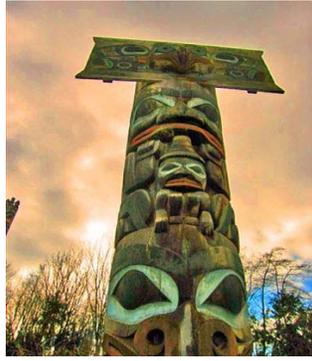
All has seemed quiet on the CANSW front, at least appearing so on the listserver. But the organization has a mounting energy reverberating across the country. Final edits are being completed on the Choosing To Stop Dialysis Brochure draft that was presented at the Annual Conference in Dorset. The Vancouver Conference committee spearheaded by Vancouver's Michaela Leicht is anxiously awaiting it's first time hosting our conference on the West Coast. The subcommittees made up of members across the country

have had initial discussions regarding some core initiatives and continue to inch forward. Amy Canter, our colleague at Sunnybrook in Toronto, has put together a wonderful calendar collection of photos using part of a presentation that I did in Dorset last fall. There are a few calendars left if interested. If the membership is interested, we may do another calendar for 2006. And in approximately two month's time, we will be unveiling our new website. But of course I must leave some mystery and drama about the new website, so, I won't tell you anything else other than WOW! You are going to like it.

We will be doing a new search of our own in the months to come. The term of office for both the President and the Treasurer are up this fall (elections will occur in Vancouver in May). The Nominating Committee will be welcoming any nominations and following up on any recommendations from the membership. Please consider stepping forward for an Executive position. I was kept motivated and challenged and would highly recommend the experience.

And to sum up my article today, I want to leave you with a motivational saying I've kept around since my teenage years, which, I think, sums up our role as social workers: "Any good that I can do, let me do it now, for, I shall not pass this way again".

Still an honour and a privilege. See you in Vancouver.



WHISPERS FROM THE TOTEM: Challenges of Nephrology Social Work

**27th Annual CANSW Conference
May 1 – 3, 2005, Vancouver, BC**

Seeking inspiration from the ancestral people of the Northwest Coast, the title of our conference is intended to honour heritage, history and stories and to seek truth and understanding in renal patients and their families. The theme also reflects the haunting and mesmerizing presence of majestic Totem Poles behind the Museum of Anthropology, located just a few steps from our conference venue, historic Cecil Green Park House.

For the first time in the history of our national organization, this year's conference will take place in Vancouver, BC, Canada's gateway to the Pacific Rim. At a conference a few years ago, somebody planted the seed of having a future conference take place on the West Coast. With the synergy of a dedicated group of people this vision has indeed sprouted into reality. All it takes now to transform the vision into a truly successful conference is a great turnout of delegates from across the country and beyond.

Why should you come to Vancouver, you ask? First of all, the conference takes place in the magnificent setting of the University of British Columbia. Only 30 minutes away from the heart of downtown, the campus of UBC is located on a peninsula surrounded by spectacular natural scenery. West Coast Suites, the designated apartment hotel, is a short walk from the conference venue.

Even if you do not have the time to combine the conference with a vacation, you might want to spend a few days before or after the conference to explore Vancouver and its surroundings. You might enjoy taking a ferry over to Vancouver Island and visit BC's charming capital Victoria – city of gardens, or perhaps Salt Spring Island, if you are in the mood to savour relaxed island living. If exercising is your thing, you could rent a bike and explore Vancouver's Seawall or get your heart-rate up by doing the Grouse Grind, our famous "outdoor Stairmaster".

Back to the real purpose of why you should attend this conference, our keynote speaker is Dr. David Kuhl (MD and PhD), internationally known for his book "What Dying People Want". Indeed, he now feels the book would have been more appropriately entitled "What Living People Want". He is a riveting and thought-provoking presenter who will no doubt get us out of our comfort zone. Using case examples from a nephrology setting, his presentation will integrate the Ethical Grid, challenge us to self-reflection, and explore ways to sustain ourselves as compassionate caregivers throughout our careers.

In addition to exciting presentations by renal social work colleagues from across Canada, two Vancouver based social workers will present about their fields of expertise: Kathleen Mackay will speak about domestic violence

and Bob Martel will impart his knowledge about addiction as well as gay men, all in the context of chronic illness.

Stay tuned. The conference pamphlet will be in your hands before long.

Michaela Leicht is a renal social worker at St. Paul's Hospital in Vancouver and is Chair of the Planning Committee.

CANSW 2005

CALL FOR POSTER PRESENTATIONS

We are inviting CANSW members to submit abstracts for presentation at the Annual Conference in **Vancouver, British Columbia on May 1-3, 2005**. Our CANSW membership has voiced the wish to have more expertise presented from our professional group. A small honorarium of \$25 is given for original poster presentations.

If you are performing research or are involved in the development or enhancement of any aspect of Renal Social Work and would like to share your findings/progress with your peers, please submit the following information:

POSTER PRESENTATION

Title:

Synopsis of the Presentation:

Handouts:

Size of Table Required:

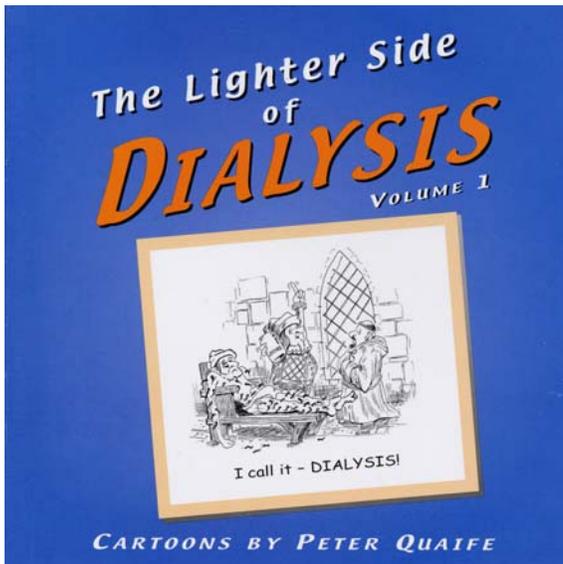
Presenter:

Hospital:

Address:

Deadline: April 1st, 2005

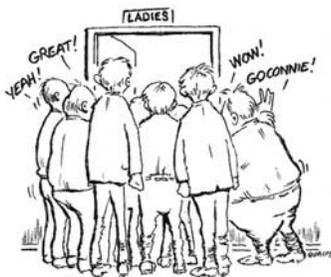
Submit to: Shirley Pulkkinen, MSW, RSW
Renal Social Worker
Sault Area Hospitals
969 Queen Street East
Sault Ste. Marie, Ontario
P6A 2C4
Phone: (705) 759-3434 ext. 4168
Fax: (705) 759-3860
Email: pulkkinens@sah.on.ca



BOOK REVIEW

“The Lighter Side of Dialysis – Volume 1” Cartoons by Peter Quaipe

Jazz Communications



Connie was so proud of her new kidney that she invited everybody to watch her newfound function.



I don't care what day it is. Four hours is four hours.

They say that “good things come in small packages” and if you haven’t already received a copy of this small booklet, you just may have to wait for Volume 2.....

Jazz Communications, the publishers of this collection of dialysis cartoons printed a limited number of books in December of last year and gave them free of charge to any dialysis unit across Canada who was interested in handing them out to patients.

Peter Quaipe is the creative mind and artist behind all of the cartoons. He has been a dialysis patient for over six years. During his treatments in Belleville, Ontario, he sketched vignettes of the psyche of a dialysis patient as a way to get through the standard four hours three times a week. His subjective perspective at times is hilarious, at times sarcastic, at times painful and morbid, but is always presented with an element of truth and reality, from the eyes of one who copes with CKD and treatment with a sense of humour. His

cartoons are best appreciated by seasoned dialysis patients and staff who have travelled the rocky dialysis journey for some time. Peter is also a founding member of the rock group The Kinks who you might remember had a hit with “You Really Got Me” in the 1960s.

The team at Jazz Communications is already getting very excited about Volume Two, scheduled for release in spring 2005. According to Jonathan Zweig, Jazz Communications’ Vice President of Operations, the key factor that makes the book possible is sponsorship and advertising from corporations across Canada and the U.S. “We are always looking for new advertisers”, he says. “Any assistance we can get from CANSW members in this regard would be greatly appreciated.”

If you haven’t already received a copy of the book (or if you would like to share any ideas or contacts for potential advertisers for volume two) please contact info@jazz-communications.com. Copies of Volume One will be available for CANSW members at the Annual Conference in Vancouver.

Oh No! Lorraine’s Leaving!

Comment [I1]: Title to add some context

We’re sorry to see that Lorraine is moving onwards and away from the creative ingeniousness she has provided to CANSW in her role as Editor for the “VOICE”. Lorraine has been instrumental in taking the development and distribution of the CANSW “VOICE” to a higher level. She will be done in her role as editor following the publication of the Spring Edition of the VOICE. Lorraine, your work and commitment to the CANSW Voice is very much appreciated...but we are not bidding farewell just yet...to be continued...

In the meantime, the Executive is putting a bug in the ears of CANSW members...

WANTED... for a 2 ½ year term (mid 2005 to 2007)...CANSW “Voice” Editor. Are you a current member of CANSW with a passion and familiarity of advancing the mission of CANSW? Do you have experience with publication, editing or the like? Are you experienced in desktop publishing and/or digital imaging?

If you’ve answered yes to these questions, you may be the person we’re looking for to fill this part time position. As the editor for The VOICE, you would be responsible for the concept, content, design, production and mailing of the three editions of “The Voice” within expected time frames and budget. Duties include: writing, assigning and inviting article submissions, commissioning photography and other art, editing text and graphics and recruiting additional volunteer assistance as required. Remuneration is provided in the form of an honorarium of \$250.00 per edition plus expenses.

Comment [I2]: Took out the word “developing” because I think Lorraine did this pretty well already

Interested applicants can apply to the CANSW Executive, care of:

**Shirley Pulkkinen, Presiden
Renal Program#149, Sault Area
Sault Area Hospital
969 Queen Street East
Sault Ste. Marie, ON P6A 2C4
Fax 705-759-3860 or at pulkkinens@sah.on.ca**

WINNER OF THE JANE DICKS AWARD



Mary Mariano is the 2004 Winner of the Jane Dicks Award.

Pat Reed (on the right) presented Mary with the award at the Regional CANSW meeting

Photo taken by Rachel Carson, Ontario

The following letter was written by Mary Mariano.

To My wonderful Cansw Colleagues:

Over the past several months, it has been particularly difficult for me due to changes in the organization in which I am working, it has taken me some time to regroup. Those of you who know me well, were probably wondering what has happened to me. I am still here and it is these times that remind me of the strength of our association (CANSW) and the support and understanding we share with one another.

The Jane Dicks Award! Well, I cannot tell you how honoured and privileged I am to receive this award. I am especially honoured, as I had the opportunity many years ago to work with Jane. I respected her values, her dedication to patients, to CANSW and to our profession. Jane was the very first nephrology social worker I met at a CANSW conference in Toronto, September 1991.

She welcomed me with a huge warm smile and home baked muffins. (CANSW has come a long way from home baked muffins). Over the years and particularly during my 5 year term as treasurer, I had the opportunity to speak and get to know many of our members across Canada. Serving on the CANSW Executive were five of my most fulfilling years. I encourage all members to become actively involved. Keep our spirit alive.....

A very special heartfelt thank you to Pat, Cathy, and Anita for my nomination; to Janet Bick for the letter of support; to Shirley and Lise for the videotape (my family and I thoroughly enjoyed it- sideways and all); to Robert for being the first to congratulate me and inform me of the award. You have all been unknowingly my mentors in those early days and today. I had and continue to have the privilege to learn from dedicated professionals across the country.

Thank you to all of you...Mary Mariano

Meeting the Challenges of Renal Patients: Creating a Legacy

Mari O Brien, MSW, RSW is a Renal Social Worker at St. Joseph's Healthcare in Hamilton, Ontario

(This article was written by Mari O Brien for the Ontario Association of Social Workers for Social Work Week and is reprinted with permission of the author.)

As Renal Social Workers working with a chronically ill patient population, we are frequently challenged to respond to the catastrophic financial circumstances of our patients, resulting from their renal disease. Social Workers are skilled patient advocates and are remarkably adept at identifying services and resources to support our patients. Our ability to do so is frequently constrained by a contraction of available formal financial supports and a restriction in eligibility criteria in informal programs.

Financial support provided through the Kidney Foundation is very helpful to patients but often patients present with needs for resources or financial assistance which are outside the scope of conventional support programs. Typically, these needs are urgent and often have very significant consequences, sometimes even catastrophic for the patient. Finding creative ways to respond to these patient needs prompted one social worker, Mari O Brien to create a dedicated fund for financial assistance for nephrology patients at her hospital.

Initially the Social Worker experienced some systemic resistance and reluctance to acknowledge the need for such a Fund. Subsequent additional concerns developed around how such a Fund might be managed within the hospital and the obvious pitfalls of conflict of interest and breaches of confidentiality. The situation of the "M" family provided the initial impetus for setting up the fund and its success created the legacy for renal patients in need at the hospital.

In June 2000, Mr. M. was diagnosed with renal cancer. The M family comprised Mr. M., his wife and two children, ages 19 and 12. The family had come to Canada to escape war-torn Eastern Europe. Neither Mr. nor Mrs. M. could speak English. When Mr. M's employer learned of his illness, he attempted to fire Mr. M. and cancel his life insurance. Mrs. M's employer terminated her employment, because of her need to take time off to care for her husband. The stress on this family became intolerable. The family's financial situation deteriorated rapidly when Mr. M. was forced to stop working due to ill health. Soon bills began to pile up, and the family attempted to cope by obtaining cash advances on their credit cards to pay for their mortgage and essential bills. However, this situation quickly spiraled downward into financial catastrophe. The M family was facing mortgage foreclosure and disconnection of essential services. When the social worker, Mari O Brien, at St. Joseph's Healthcare, Hamilton, became aware of this family's situation she undertook some fundraising to help this family cope. The goal was to help pay their mortgage and utility bills until Mr. M.'s death, at which time Mortgage Life Insurance would be activated. The social worker raised close to \$10,000.00 This financial assistance allowed the M family to stay together

and maintain as normal a life as possible during Mr. M's illness. The fund helped pay for funeral expenses. The family continues to live in their home and are in the process of rebuilding their lives.

The experience of the M family acted as an impetus to the Social Worker to create a fund that could respond to similar situations of financial need of patients with ESRD. Consequently, a fund was set up as a charitable trust – the Catastrophic Relief Fund in Nephrology. This fund, which continues to grow, is able to respond to the catastrophic financial needs of patients as a result of their kidney disease. This unique Fund, in a short period of time, has helped a variety of patients and their families. It has a high level of credibility and regularly receives donation. It is currently celebrating its third anniversary, and is a wonderful example of the power of Social Work to influence change and reach out to vulnerable clients and patients in a profound way.

Social Workers play a major role in identifying resources, providing advocacy and promoting client/patient needs. They are uniquely suited to challenging the status quo and bringing about changes in practice and services that have a direct benefit for patients and their families.



CONFERENCES

Northwest Renal Update – Council of Nephrology Social Workers and Northwest Renal Network.
TLC: TEAMWORK/LEADERSHIP/COMMITMENT - March 10 & 11, 2005 Seattle, Washington

National Kidney Foundation which holds Professional Meetings for Council of Nephrology Social Workers and other medical and allied health staff will be held in Washington, D.C. from May 4-8

Chronic Kidney Disease Summit – the first summit organized in Canada and the purpose is to focus on an integrative approach to patient care in BC and Canada. Vancouver, June 23-24, 2005. More info:
www.bckidneysummit.com

GRANT APPLICATIONS

The Kidney Foundation of Canada's Allied Health Fellowship and Scholarship Forms and Guidelines are now available on the website. The deadline for this competition is March 15, 2005. For information about the Foundation's Research Program, check the website at www.kidney.ca For questions contact Christine Marquis at chris.marquis@kidney.ca or (514) 369-4806, ext. 232.

WEBSITES

**Although many of these websites contain useful information, please be aware that the accuracy of the information received online cannot be guaranteed* (Thanks to everyone who sent website info and special thanks to Mary Lou Karley and Dianne Boisjoli for this information)*

Medical and Renal Sites:

www.aakp.org (American Association of Kidney Patients) Email: AAKPnat@sol.com

www.niddk.nih.gov (National Institute of Diabetic, Digestive and Kidney Diseases) E-mail:
nkudic@info.niddk.nih.gov

www.rarediseases.org (National Organization for Rare Disorders Inc.)

www.RenalAdvances.com (web site for nephrology professionals - Amgen Inc.)

www.baxter.com

www.lifeoptions.org (Rehabilitation Resource Center - Madison, Wisconsin) E-mail:
lifeoptions@medmed.com

www.kidneydirections.com (Baxter-support/resources for people with Kidney Disease and families)

www.iKidney.com (R&D Laboratories - Renal Community discussions on nutrition and lifestyle)

www.Nephron.com

www.ajkd.org (official journal of National Kidney Foundation)

www.Kidney.org (National Kidney Foundation) has a link to the Council of Nephrology Social Workers (the American equivalent of CANSW)

www.Renal.com.ar (Spanish Language)

www.kidney.ca<<http://www.kidney.ca>> Kidney Foundation of Canada – National Branch

www.kidney.ca<<http://eob.kidney.ca>> (Kidney Foundation of Canada – Eastern Ontario Branch)

www.Kidney.org.uk

www.he.net/~brumley/renal/patientboard.html (Access discussions on topics related to kidney disease)

www.transweb.org (Information on organ donation and transplant/resources for patients and families)

Government of Canada:

www.cra-adrc.gc.ca (Revenue Canada)

British Columbia Sites:

www.seniorshousing.bc.ca

www.gov.bc.ca/healthservices.gov.bc.ca

www.gov.bc.ca/mhr

www.bchousing.org

Province of Ontario Sites:

Family Service Ontario

<<http://www.familyserviceontario.org>>

Government of Ontario

<<http://www.gov.on.ca>>

Ombudsman Ontario

<<http://www.ombudsman.on.ca>>

Ontario Association of Children's Aid Societies <<http://www.oacas.org>>

Ontario Social Development Council <<http://www.web.net/~osdc>>

Children's Mental Health Ontario

<<http://www.cmho.org>>

www.cleo.on.ca has legal information specific to Ontario and some general Can. info

Journals/Print Materials:

Canadian on-line journal

<http://www.uofcpres.com/journals/currents/>

Other Journals:

<http://ejournals.ebsco.com>

Professional Teaching Tool:

The Mid-Atlantic Renal Coalition (MARC) have a free teaching tool containing a set of 5 teaching modules on: Professionalism in the Dialysis Unit, Patient Centered Care, When Patients Have Concerns, Fistula First and Caring Through the End. www.esrdnet5.org/in-service.asp.

American Nephrology Social Work Practice Guidelines which are being discussed on the CNSW listserve (US listserve) www.cms.hhs.gov/cop3818pdf

Resources for Social Workers:

World Wide Web Resources for Social Workers

<<http://www.nyu.edu/socialwork/wwwrsw/>>

<<http://gwbweb.wustl.edu/websites.html>>

Social Work Access Network

<<http://www.sc.edu/swan>>

Social Work Cafe

<http://www.geocities.com/heartland/4862/swcafe.html>

Social Work education

<http://www.educationindex.com>

Global Issues

<http://www.globalexchange.org>

Social Work education lists - <http://www.rit.edu>

Social Services:

Campaign 2000

<<http://www.campaign2000.ca>>

Canadian Council on social Development

<<http://www.ccsd.ca>>

Centre for Social Justice

<<http://www.socialjustice.org>>

Community Information Centres <<http://www.informontario.on.ca/meminfo.htm>>

Canadian Association of Schools of Social Work

<http://www.cassw-access.ca>

Canadian Association of Social Workers <<http://www.casw-acts.ca>>

International Federation of Social Workers

(including links to associations around the world)

<<http://www.ifsw.org>>

National Association of Social Workers (US) <<http://www.naswdc.org>>

Travel Sites:

www.globaldialysis.com/ (Hemodialysis and travel destinations around the world)

The Patient Travel Service (no web site) - locates clinics near patient's destination and answers questions re: dialysis and travel - Email:pts@fmc-na.com

www.hditravel.com

www.dialysisfinder.com

www.medicaltravel.org

www.dialysisatsea.com

www.dtv.tierranet.com