

Spring 1998 - Pipeline

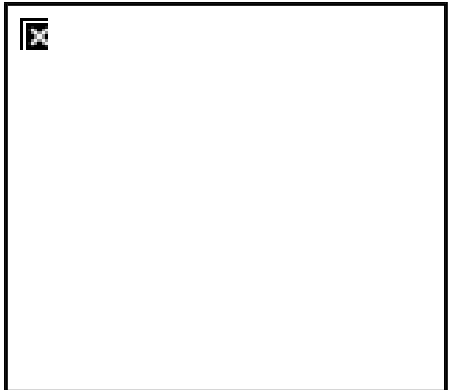
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UNC Enters the Digital Age

Ottawa - The Urology Nurses of Canada have entered the digital age with the introduction of a World Wide web site. The site was launched in December 1997.

"The site will give us a vehicle to more effectively communicate with UNC members and the general public" says Susan Madden, President of the UNC.

The site features the latest in internet technologies - such as chat groups , search engines , discussion groups. Members will be able to join the UNC or register for conferences over the Internet. A time and cost saver for the UNC.



"We have a mix of content - from UNC information , meeting minutes , research papers to publications. We even have back issues of the Pipeline".

As with all web sites - content is the most important component. "We have a mix of content - from UNC information , meeting minutes , research papers to publications. We even have back issues of the Pipeline". adds Madden

The site also contains links to important urological sites such as SUNA and the [CUA](#). So far, the feedback has been positive. Comments have ranged from "keep up the good work" to "its about time".

"You never know what to expect when you launch a site, surprisingly, about 70% of the traffic has been from the United States - mostly from educational institutions" says Charlie Massel , UNC Webmaster. "This is consistent with the use of the internet as an education and research tool" adds Massel.

Future plans include adding additional research papers and finding more ways for UNC members to interact. The regular addition of monthly chat sessions is being evaluated. Several pharmaceutical companies have expressed an interest in sponsoring the site. " We have a very powerful tool - we should become lead users" says Madden.

Journal Club: Research of Note:

New Point-of-Care Bladder Cancer Diagnosis

The single center, prospective trial was done to simultaneously evaluate two new bladder cancer diagnostics (Bard BTA and AuraTek FDP) along with two traditional ones (Hemastix and urinary cytology) in patients with a wide range of urological problems including bladder cancer. A total of 130 patients (60 with bladder cancer) provided voided or catheterized urine samples, which were divided into appropriate Aliquots for each of the above tests. Blinding was consistent with all of these test evaluators (urologist, cytopathologist, and the research associate who performed the BTA/FDP and Hemastix tests). The point of care diagnostics (BTA/FDP/Hemastix) were then read independently by a second blinded evaluator.

There was clear and significant superiority of FDP in terms of sensitivity (81%) and overall accuracy in bladder cancer detection ($p=.0001$). FDP was simple to perform and particularly striking in its ability to detect low grade tumours. Studies have indicated that cytology is poor in detecting these types of tumours. The author s concluded that FDP was a reliable test for detection of transitional cell carcinoma of the bladder and a "potential alternative to urinary cytology with important implications for clinical practice and health economics".

*Brenda Johnston, Alvaro Morlaes, Laurel Emerson and Mark Luanda
Rapid Detection of bladder cancer: A comparative study of point-of-care tests in the Journal of Urology, December 1997, Volume 158, 2098-2101*

Anecdotal Differences in DMSO Versus Heparin Used in the treatment of Interstitial Cystitis

It is difficult of compare the effects of Dimehtylsulphoxide (DMSO) with Heparin Sulphate (10,000 units), the two more commonly used bladder instillation therapies for Interstitial Cystitis. Two of the most frequently discussed drawbacks are odour and quantity. However, this does not prevent us from noting anecdotally some differences in patient tolerance and purported efficacy.

The pain suffered diminished quality of life and well documented and bladder capacities are reduced form the patients perspective .Other diagnostic indicators will not be discussed in this article. Frequency as often as every five minutes and extreme urgency are experienced, therefore the quality of the solutions used for treatment could be seen as very importunt. DMSO is prepared as a 50ml instillation and Heparin as 10ml. A majority of patients seem to be able tolerate the reduced volume, in fact, they hardly seem to notice 10ml. and rarely expel this amount, whereas more patients seem to involuntarily expel 50 ml of DMSO. More patients reported a "burning" or "stinging" effect with DMSO, whereas heparin appears to have no ill effects and the patients are able to withhold the solution for a longer period of time. This may well have an effect on the success of the treatment, at the very least form the patients perspective. There does not seem to be an improvement in their quality of life with Heparin bladder installations more than DMSO. If you have noticed this, please comment

*Adrienne Caldwell RN
Ottawa Civic Hospital*

Anatomy of a Support Group Ready, Set Go!

At past UNC conferences, I occasionally overheard some centers express difficulty in initiating a prostate cancer support group. On three separate occasions, I heard the comment: "I wish we could get a support group going in our hometown. But how do we get started? We can't seem to get anything off the ground."

In my hometown, we have a successful prostate cancer support group. It is young. Yet this commendable group fulfils a great need in our community. I felt that it would perhaps be helpful to write about the early beginnings of our local support group. Our group is not unique. There are many successful support groups throughout Canada. In highlighting one group, it is hoped that it can serve as inspiration to a UNC colleague who has a vision for his/her own community.

In Ottawa, the prostate cancer support group has been in existence for 5 years now and gradually evolved to the point where it is self-sustaining. As with any organization, it started with a vision. The success of the prostate cancer support group lay with its "people". First of all, a small group of people believed that men and their partners, if given the opportunity, would come together to talk about their disease. As an adjunct to the existing good care by the medical community, it was believed that personal awareness of this disease and the quality of the education received could influence a well-informed patient's chance of survival. Central to the support group's inception was a belief that the group should be patient-driven rather than doctor driven. But they needed help to get started.

The people who had this vision were from both professional and patient populations. The chief of Urology at the local university hospital was instrumental in providing the initial incentive for the group's formation and was the protagonist in its inception. One very dedicated social worker became the volunteer advocate dealing with those universal yet concrete hurdles that sprang up at every turn. An interested pharmaceutical company provided financial support to get the project off the ground with printing and rental costs. They also willingly volunteered much needed clerical support in those early days.

From the onset, the question was asked: "How will the group develop?". Five years later, this question is still being asked even as the support group evolves.

Two very competent leaders emerged from the ranks of that early support group. In turn, these two volunteers were given titles of "Chairman" and "Vice-chairman" respectively.... Fancy titles that scarcely reflected the many hours of dedicated commitment to the early formation of the group.

The inaugural meeting of the prostate cancer support group took place in a public library in December 1992. By the second meeting mid-January 1993, the group showed signs of early growth. New volunteers came forward. Another four men accepted organizational challenges. In one 1993 newsletter, the following was recorded: "We are playing this all by ear and simply trying to make the meetings as meaningful and effective to everyone as we possibly can". To this end, a priority list was developed covering future topics of interest.

By 1994 a solid core of individuals formed a steering committee in determining the group's needs. The social worker continued to act as a liaison and facilitator for their goals.

On the third meeting of the group, the membership adopted a mission statement. This was subsequently revised and updated when younger men were being diagnosed and research was indicating a need for early detection. By January 1996 the mission statement read:

1. To provide support and enhance communication opportunities between patients/families;
2. To serve as an information source on prostate cancer;
3. To interact with the health community;
4. To cooperate with other groups having mutual interests;
5. To promote awareness of prostate cancer.

By spring 1995 a permanent chairman was elected, along with a council that could oversee the programme. At this point in time, the social worker was able to gradually ease out of the facilitator role and eventually cut the group loose. They were stable. The chairman worked tirelessly in his pursuit of excellence in prostate cancer support. He helped found the Canadian Prostate Cancer Network (CPCN), an umbrella organization for all the prostate support groups in Canada, and also the Hormonal Cancer Research Network which included the breast cancer support groups.

A support group dealing with prostate cancer has its share of tragedies, and the chairman died of prostate cancer early February 1997. This was not the first death in the ranks of the group. Dealing with death and sharing adversities amongst members also coping with these same dreadful disease bonds the members in a special way.

Within the support group, there emerged those "special" individuals that aided in the group's development and progression. It was decided very early in the life of the group to give what they call "The Dried Prostate Award". This rather odd yet unique "trophy" is given annually to a person who has made an outstanding contribution to the life and work of the group. Like the Stanley Cup, the recipient cares for it for only one year and must pass it on the following year. This award was initiated in 1993, with the first honor going to the founding urologist. In the following years, recipients included such people as a CBC reporter that did a much appreciated presentation of the group on local television, the social worker that helped in the founding of the group, and one of the corporate sponsors that so willingly continued to help in financial ways to the group's longevity.

The growing size of the group began to present a real challenge. The meetings had to be moved. This has been done three times, each time to facilities better suited to the growing group.

While the group continues to be administered by a steering committee, there are now positions within the organization, which are formally acknowledged, such as the Chairman, and the Newsletter Editor.

Appeals to "participate" and "get involved" continue to be made on a regular basis by both the Chairman of the day and the still active veteran members of the group. You should expect this to be always necessary to ensure the survival of the support group.

Support groups have expenses and the Ottawa group is no exception. However, they have been minimal, as meeting space has been provided free-of-charge, speakers have not charged for their appearances, and those who have traveled on support group business

have done so without reimbursement. But publishing and mailing newsletters and making copies of articles for the membership and printing pamphlets and business cards, assembling Information Kits and refreshments for the monthly meetings, all cost money. The group developed the "looney bin" which accepts donations from those participating in the group. An income also comes from corporate sponsors, and a local service club has seen fit to help the group by donating funding.

March of 1997, just 5 years after the inception of the group, "Charitable Status" was obtained. About the same time, the City of Ottawa approved a "Nevada License" for fund-raising. These efforts combine with the original backers and the "loonie bin" to provide the dollars for major expenses. The current mailing list consists of 250 names!

With the granting of Charitable Status, the names of the group officially changed from The Ottawa Prostate Cancer Support Group to the Prostate Cancer Association (Ottawa-Carleton). The Prostate Cancer Association (Ottawa-Carleton) was proud to be a founding member of the national umbrella organization of support groups named the Canadian Prostate Cancer Network (CPCN) established in November 1996.

Over forty speakers have appeared at the monthly meetings during the past five years. Suffice to say, one would be hard pressed to think of a subject, even remotely related to prostate cancer, which has not been presented by an expert in the field. Each presentation is followed by a question period. An informal social exchange concludes each meeting.

The group mandate has always included informing the public about prostate cancer, the benefits of a support group in becoming educated about the ramifications of this disease, and improving communications with one's doctor. To this end, they permitted the CBC to come to their second meeting in January 1993 at which many of our members spoke although they were all very "new to the game".

Other avenues used to inform the medical community and/or the public were:

1. Calling cards
2. establishment of a "Friendly Visitor" program at the local hospital
3. dedicated phone-line with answering machine to field queries
4. Development of "Information Kits". The Information Kits consists of a school bag containing 2 books, 2 videos, articles about prostate cancer and information about the support group.

One "service" that did not work for this group as initially visualized, related to the matter of bereavement. Sympathy cards were sent to widows and children of members who died. However, it was soon learned that while the intentions were good, it was disconcerting to some newly diagnosed person attending their first or second meeting, so this practice was abandoned.

Words of appreciation have been received from several urologists in our medical community. The medical community appreciates the role the group plays in managing this disease. Kudos comes from both the participants and their families.

The group plays a unique role in our community. And it works! Perhaps you can be that conduit that starts the "ball rolling" in your community. If you see the need, act. It may prove to be one of the most rewarding accomplishments in your career.

Peg Graham
UNC member

From data, facts, and material authored by Martin Collier and the Steering Committee of the Prostate Cancer Association (Ottawa-Carleton).

UNC Executive Board 1998

The Urology Nurses of Canada is managed by an executive board composed of: President, Past President, Vice-President (west, central, east), Membership, Sponsorship, Treasurer, and Secretary. Descriptions of each positions are available in the UNC Constitution.

UNC Executive

Pictured from left to right: Membership; Sandra Rowan, Treasurer; Adrienne Caldwell, Sponsorship; Carol Lancaster, Vice President Central; Brenda Johnston, Secretary; Frankie Bates, Past President; Laurel Emerson, Vice President East; Lee McLeod, Vice President West; Katherine Moore, President; Susan Madden

UNC Provincial Representatives

British Columbia - Bridget Ittah
 Alberta - Liz Smits
 Saskatchewan - Judy Pare
 Manitoba/Northern Ontario - Phyllis Wearing
 Ontario - Jan Pelletier
 Quebec West - Rachael DeLeon
 Quebec East - Martine Laviolette
 New Brunswick - Gina Porter
 Nova Scotia - Kim McGill
 Newfoundland/Labrador - Sue Hammond

Contact your UNC Executive Member or Provincial Rep by calling Sandra Rowan 604-381-3747

Feature on UNC Members

Focus on....

Katherine Moore

In January, Katherine Moore of the University of Alberta started a 12-month postdoctoral fellowship at King's College London. Part of the responsibilities includes research. Two projects are underway. The first is an evaluation study testing hydrophilic catheters used for intermittent catheterization. This study is being undertaken at the Continence Products Evaluation Network headed by Mandy Fader and Allen Cottenden of University College London. The other study is investigating the relationship between stress urinary incontinence

and pyuria. Five hundred women are being screened for pyuria and are answering a brief questionnaire about the presence/absence of stress incontinence. The principal investigator in this project is Professor James Malone Lee.

Incontinence care in England is progressive and collaborative between physiotherapy and nursing. Katherine was part of a small working group of physiotherapists and nurses who discussed the roles of the respective professions in the care of the patient with incontinence.-- The debate, "were physios acting as nurses and nurses acting as physios" was informative and cooperative. The bottom line is that the Chartered Society of Physiotherapists and the Royal College of Nursing will issue a statement about the collaborative nature of incontinence therapy.

Health care in every country has its challenges and certainly England is no different. Health care trusts pose boundary problems that exist to a lesser degree in Canada. In Alberta, for example, a service available in one Health Care Region may not be available in another. For people with incontinence, specialized services may only be available in large centres, in much the same way that it is in Canada, a source of frustration for the health care professionals.

David Smith

David Smith graduated in 1979 with a diploma in Nursing and proceeded to work in general medicine and general surgery for five years while also working on a Bachelor in Nursing (BN) from Dalhousie University. David describes his introduction to ambulatory care and urology as follows. "I looked after the urology clinic, male dysfunction clinic, urodynamics and relieved in cystoscopy. That accounted for three of my five working days per week. After my first year, I started looking for other nurses in these areas. I attended the American Urological Meetings in New York, where I met Debbie Steele and discussed the value and importance of nurse's network this way. The UNC was born that day!"

David is a strong advocate of networking and feels it is important that we network and encourages every one to take advantage of the many opportunities UNC provides. "Conferences, local and national meetings, the Pipeline and the UNC Web site are all excellent vehicles for keeping connected."

Over time, David's practice has developed into full time work in Male Sexual Dysfunction. David recently completed a Master of Nursing. He is a strong advocate of advanced practice and envisions a role of Clinical Nurse Specialist with a focus on Male Sexual Health in ambulatory care.

Award of Merit ...Don't Miss It!

We can often name that someone special...you know the one that puts out that "extra" for our UNC organization. This could be the individual that "keeps our local chapter going", or is "our inspiration". Well, now the UNC has adopted a way to publicly acknowledge those very special people! It's called the [Award of Merit](#). ! UNC is looking for that "someone special". He/she may or may not be in the spotlight. She may be the quiet one that "gets things done" or he may be the central figure in your organization! He/she may be busy only at the local level, or well known at the national level. What we are looking for is a UNC member who has

made a significant contribution either in education, research, or clinical practice. Distinction may be through excellence in UNC promotion, UNC mentoring, or other enhancement of the UNC Mission. Someone come to mind? Well, don't be shy! All it takes is your nomination, (along with a second nominator that believes as strongly as you do), to get the ball rolling toward national UNC recognition of that exceptional person.

Our second UNC ***Award of Merit*** will be announced during the Annual General Business meeting at the Urological Excellence Conference in Toronto. So let's hear from your neck of the woods! [Get those nominations in!](#) The deadline is August 15 th, 1998. A form outlining the purpose of the award and nomination form will be sent to you soon or visit the [UNC web site](#) at unc.org for more information.