

Inspiring others...



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While the word 'cancer' often evokes fear, it can also be a source of great inspiration – an experience that can foster a sense of dedication, perseverance and a quest for knowledge. In fact, this is the side of the journey that motivated Norah Stephen – a cancer survivor and advocate – to commit more than 30 years to improving the Nova Scotia cancer system.

Diagnosed with advanced ovarian cancer in 1974, Norah beat the odds and survived only to face a similar battle against breast cancer. She used her experience to provide one-on-one support to patients and to educate medical students about how doctors can better support their cancer patients. She was tireless in championing the development of an integrated, patient-centred system of care. Sadly, on April 30, 2008, at the age of 94, Norah passed away. Her inspiration lives on through the Norah Stephen Oncology Scholar Awards. Created by *Cancer Care Nova Scotia* in 2002 upon her retirement from its Board of Directors, the Norah Stephen Oncology Scholar Awards are intended to foster an interest in the field of cancer among undergraduate and graduate students.

Twelve awards of \$5,000 each are presented annually to students to pursue cancer-related research or clinical training and experience projects. The awards are having their desired impact. Norah would definitely be proud to know that 24 of the 80 students who have received the award, to date, have

continued on or have plans to continue on in the field of cancer, either in medical practice or research.

Stephanie Snow is one of those 24. She received a Norah Stephen Oncology Scholar Award in 2003 and has since completed three years of general internal medical training. She is about to begin a two-year medical oncology residency at Dalhousie University.

"The Norah Stephen Award is great," reflects Stephanie, "because it creates an environment of opportunity where specialists can devote time and energy to mentoring and helping students like me to determine their place in the cancer field."

Stephanie's mentors include Uro-Oncologist Dr. Ricardo Rendon and Medical Oncologist Dr. Lori Wood, both of whom Stephanie said, "Inspired my whole career." While she knew in high school that she wanted to pursue a career in oncology, she couldn't decide on which route to follow: surgical, medical or radiation.

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Her 2003 summer research studentship in prostate cancer – a follow up project from the previous year – won her the Nora Stephen Oncology Scholar Award and helped affirm her passion for research.

Looking at the information needs of early stage prostate cancer, Stephanie surveyed men who completed treatment to identify what type of information they would have liked to have known prior to deciding on treatment options.

“With early stage prostate cancer, your curative treatment boils down to a choice between surgery or radiation and each affects a patient differently with its own side effects,” said Stephanie. “From the survey we discovered a significant gap between what medical professionals think patients need to know before choosing a treatment plan and what patients say they would have liked to have known.”

Excited by the findings, Stephanie submitted her suggestions and proceeded to begin another research project that summer – a study of upper tract urothelial transitional carcinoma (UTUC), which looked at patient outcomes of this rare tumour, based on the Nova Scotia population from 1979 to present.

“The research I was able to conduct through my experience with the Nora Stephen Award was invaluable and it helped me to realize that I want to become a genitourinary (GU) specialist,” said Stephanie. “My plan is to practice in an academic centre where I can continue to pursue a research career, preferably in Halifax near family and friends.”

Like Norah Stephen, Stephanie’s dedication, perseverance and a quest for knowledge in cancer will benefit patients and hopefully inspire others along the way.

Sun Safety for Children – Where They Live, Learn and Play

Healthy lifestyles and behaviours are most successful and have greater staying power when adopted at a young age.

“This is one of the reasons that Community Services Day Care Services identified the opportunity to address the issue of sun safety within the child care sector,” said Judy Purcell, Prevention Coordinator, *Cancer Care Nova Scotia* and Coordinator of the Sun Safe Nova Scotia coalition.

While the coalition continues to promote sun safety policies in recreation settings, the childcare sector is an emerging area of focus. Through Community Services, a coalition member, influencing sun safety practices in the province’s registered daycares has become a priority.

The first step in building on sun safety efforts within daycares was to understand the current practices. Since story telling is a great way to share experiences and is especially natural for daycare workers, Sun Safe Nova Scotia asked teachers to tell their stories about how registered daycares currently address sun safety.

These stories, shared through focus groups, telephone interviews and submissions, in addition to a literature review, formed the baseline assessment. Launched in the fall of 2007 and completed in May 2008, the study invited all licensed child care centres in Nova Scotia to share their current sun safety practices. Thirty-five centres participated.

The resulting report, “*Sun Safety in Licensed Child Care Centres*,” shows that child care staff are aware of the need for and importance of sun safety, and strive to provide a sun safe environment for children under their care.

Daycares are doing good work and are taking special care to address sun safety for children. Their stories, however, identified challenges they experience while implementing sun safety recommendations. For example, some centres lack natural shade and playground shade structures don’t always exist; parents may provide their children with sun visors/baseball hats instead of the preferred bucket hats; the time required to apply sunscreen on many children means not all children are screened 20 minutes prior to playing outdoors; as well, variations exist in the SPF factor and ingredients of sunscreen, which leads to questions about what to use or recommend to parents.

“Addressing these challenges is a shared responsibility,” said Judy. “Thanks to this report we have a baseline of understanding and a foundation from which to work. By working with the province and municipalities, we will build consistent policies and develop tools for sun safe practices to support the ongoing work of parents and daycare teachers.”

“*Sun Safety in Licensed Child Care Centres*” is available on the CCNS website at www.cancercare.ns.ca





Cancer Patient Navigation – Then and Now

Without a doubt, living with cancer is one of the most arduous journeys a person will ever travel. As your body is pushed to its limit your emotions run the gamut of highs and lows. Facing the experience is daunting and facing it alone is unthinkable.

To help alleviate the burden, *Cancer Care Nova Scotia (CCNS)* collaborated with three health districts in 2002 to launch Cancer Patient Navigation – placing patient navigators (oncology certified nurses) into the community to work closely with family doctors, cancer specialists, patients and families to improve access to and coordination of cancer services.

Patient navigators play an integral role on their community cancer team. They are an important resource for family physicians and community-based surgeons, providing a formal link to cancer specialists. They also work closely with cancer patients and families to:

- educate them about their cancer;
- discuss treatment options;
- prepare them for appointments with specialists;
- provide psycho-social support; and
- address questions and concerns.

Today, Cancer Patient Navigation is available in five health districts – South West Health, Pictou County Health Authority, Guysborough Antigonish Strait Health Authority, Annapolis Valley Health and South Shore Health. Although the navigators are employees of the district where they work, the Patient Navigation Program is supported and coordinated by *Cancer Care Nova Scotia*.

“The cancer journey is complex,” said Sandra Cook, *CCNS* Patient Navigation Project Manager. “Because of the nature of the disease and the number of potential treatment options, a cancer patient could expect to see at least 11 doctors during their cancer treatment and care. The Patient Navigators act as a liaison, providing guidance and support across the continuum of treatment and care. Above all, the Navigators educate patients about their type of cancer so they can make informed treatment decisions and access the supportive care they need.”

CCNS recognized the need for patient navigation early in its mandate when gaps in the cancer system were identified through focus groups held across the province. Through a process called ‘journey mapping’, it was clear that patients didn’t always have enough information to make informed decisions and that communication with family physicians should be strengthened. Needing a leader to champion the development of Patient Navigation, *CCNS* Board Member Judith Fuller was quick to volunteer to lead concept development.

Already a leader in the field of palliative and hospice care, Judith chaired the planning committee that developed the province’s Patient Navigation Model. After extensive stakeholder consultation – including a needs assessment with African Nova Scotians – and endorsement from the Nova Scotia Department of Health, three health districts were chosen as early adopter sites. In 2001, Sandra was hired to implement the committee’s action plan. A year later, Donna Smith joined *CCNS* as Patient Navigation Community Liaison. She works with diverse communities to improve their access and education. Sadly, Judith recently passed away. However, her legacy continues to make a difference in the lives of countless Nova Scotians.

To date, the program has helped between 5,000 and 6,000 individuals. The Patient Navigation network continues to grow with the addition of two cancer site-specific navigators / breast educators at the IWK Health Centre’s surgical breast cancer clinic. As a result, the number of patients benefiting from the service will continue to rise. *CCNS* is hopeful that patients in all health districts will have access to a Patient Navigator as district health authorities can make funding available.

As the program grows, the role of Patient Navigators continues to mature. “Since its inception, we have seen greater consistency in the quality of care, increased support at the community level and patients and families who are better equipped to make informed decisions about their treatment options,” said Sandra.

Moreover, with continued support of Navigation from *CCNS* in all areas from education to research, the program is gaining recognition throughout the country and in the United States. *CCNS* is routinely contacted to provide advice on how to establish similar programs. Cancer Patient Navigation is cited as the standard of care in the United States Medicare with the Nova Scotia model being identified as the gold standard.

While the program has received kudos from patients and health professionals alike, Sandra is always looking for ways to improve it. Currently, her focus is on standardizing education care plans and identifying learning resources to better meet patient needs.

“Cancer Patient Navigation has made a huge difference in the lives of those living with cancer and those working to care for them,” said Dr. Mark Dorreen, Head, Medical Oncology, Capital Health Cancer Care Program. “The community feedback has been excellent. Listening to patients and families to respond to their needs is critical to the success of a navigation program.”





celebrate life

The Pearl

Just as the pearl is made from irritants inside of the shell
If we choose, cancer can make us more beautiful as well

I call my experience with cancer a brush with life
It's made me a better mother, daughter, friend, and wife

The journey is lonely and like a deep dark hole
Sometimes hard to climb out of but so good for the soul

My way has been brightened by faith, courage, and friends
My strength has been challenged as my body mends

I am a survivor. I won't live in fear.
No worries for tomorrow for today is too dear

On the days I remember what cancer has taken
I think of the oyster. We're all just pearls in the making

I spend every day full of peace, quite content
There's no guarantee in life, our days are just lent

Through the soul searching, I've been challenged to be
The person God created, not what others expect. You see

Life is a challenge, every struggle a test
Defining moments presented, we must all do our best

Help others to see when the fighting is done
The battle with cancer is what we have won

Some have given their lives so others can live
We can't let them down we have so much to give

The day we lose hope is the day all dreams die
We must never give up we all have to try

To fight this disease with hope, courage, and love
Till it's a thing of the past and no longer heard of

Written by Paula Jones



Above: Derek Caine, cancer survivor and blues musician entertains the audience during Celebrate Life 2008.

Below: Gary Beals, East Coast Music Award winner and former Canadian Idol contestant, performs during Celebrate Life 2008.



The event, held on June 1st at Pier 21 in Halifax included performances by Terry Kelly, Derek Caine, Gary Beals, Hallelujah Choir and the Amethyst Scottish Dancers of Nova Scotia.

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We welcome and encourage everyone's input to this newsletter. Please submit your stories or story ideas to: *Cancer Care Nova Scotia* Newsletter
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The deadline for articles and story ideas for Volume IX, Issue Four is August 5, 2008.

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