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BC Cancer Agency
CARE + RESEARCH
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Keeping the lines of communication open, what can BC learn from the HPV vaccine experience in India?

By Brittany Deeter, Vaccine Educator, BC Centre for Disease Control

In April of 2010, a major Indian newspaper bore the headline, "Indian girls not guinea pigs for HPV Vaccine". This article reported that HPV vaccine trials had been abruptly halted in India after a group of advocates publicly submitted a memo to the government asking for an immediate halt to a PATH-sponsored HPV vaccine trial until issues of "safety, efficacy and cost effectiveness of the planned interventions are re-evaluated" (Sama, 2010). Government action to halt the trials was abrupt and surprising given that they had failed to respond at all to an identical memo sent six months earlier. While the subsequent investigation failed to demonstrate any safety issues with the trial, the lingering effects of the government's response to this issue are still being felt.

The issues that sparked the sending of the memo were a complicated mixture of questions about vaccine safety, women's health and sexuality, trust in the government and the role of the pharmaceutical industry. Similar questions have surrounded the introduction of other HPV vaccination programs, and unfortunately continue to be relevant to British Columbian parents, particularly if they have been accessing information on the internet. While these issues defy easy answers, BC can certainly learn from the Indian experience – what it clearly illustrates is that the health care community must open up communication with girls and their parents on vaccine issues, on an ongoing basis.

To open communication lines, ImmunizeBC will be expanding its online education and promotion efforts in 2011. An updated website will be launched, our social media presence will be increased and a grassroots advocacy campaign called "I have immunity" will be rolled out. The focus of all of these efforts is on increasing dialogue about HPV and other vaccines, and making it easier for people to get good quality information about immunizations.

As physicians, what can you do to counteract

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On survivorship

By Dr. David Levy, Immediate Past President of the BC Cancer Agency

For many years a diagnosis of cancer was a death sentence. Despite treatment, many patients died and survival to five years was a measure of success. With better treatments available in the 21st Century many patients live for many years after cancer, living a "new normal" life. In fact, for many patients cancer can be regarded as a chronic disease – and so we have a new challenge, how do we prepare patients for survivorship – to be Back on Track?

Dr. David Levy

The BC Cancer Agency will shortly start the further development of a provincial survivorship program as part of the PHSA strategic plan. The leaders of this work will be Richard Doll and Dr. Phil White. The involvement of primary care and community care will be a critical part of the success of the program.

The intention is to identify interventions that will help patients and their care-givers maximize the opportunities for rehabilitation, after a diagnosis of cancer and treatment, to be active participants in society once again.

The likely interventions may include access to complementary treatments that have not been traditionally considered, such as exercise classes during weeks of chemotherapy (the BCCA is currently undertaking a study in Vancouver), aromatherapy, dietary advice and information on lifestyle and career choices that could positively impact on the patient and their family.

So, preparation for Survivorship is the delivery of patient-focused individualized care to promote prevention measures to reduce the risk of a new cancer, and healthy living to improve the quality of life for that patient and reduce the burden on the healthcare system.

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Late effects after treatment for childhood cancer

Contact Dr. Goddard at kgoddard@bccancer.bc.ca or visit pedsoncology education.com (Late Effects).

Dr. Karen Goddard, Radiation Oncologist, BC Cancer Agency, Vancouver Centre

Approximately 10,400 North American children (between birth and 14 years of age) develop childhood cancer each year and these numbers seemingly increase annually[1]. More than 80% of these children will be long term survivors who have been cured of their disease. This was very different 20 to 30 years ago, when many children did not survive[2]. In general, cure rates have been improved by using multiple treatment modalities (radiotherapy, chemotherapy and surgery), better supportive care and by therapy intensification (using higher total doses of chemotherapy over a shorter period of time)[3]. Though this approach has improved disease free survival, it has become obvious over the past 10 to 20 years that survivors of childhood cancer are at risk for many significant long term health risks[4] as a result of this treatment. Roughly two thirds of survivors have at least one chronic health problem related to their previous therapy and up to one third of these late effects are considered serious or life threatening[5].

Late effects are generally classified as side effects that occur more than 5 years after diagnosis. These health risks vary in severity and incidence but can affect every body system and have significant impact on the quality of survivor's lives. For example: Radiation therapy (RT) is associated with an increased risk of second cancers many years after treatment. Chemotherapy agents such as alkylating agents are associated with infertility and second cancers. Anthracyclines are associated with cardiomyopathy[6].

Early detection, prevention, and interventions to treat some of these complications provide the opportunity to reduce cancer-related morbidity and mortality[7]. The Children's Oncology Group (COG) has developed guidelines for the screening and management of late effects at: www.survivorshipguidelines.org/

These guidelines were developed using expert opinion consensus and by reviewing the current literature. The COG advocates a "risk based strategy" which involves a personalized plan for long term screening depending on what the previous cancer was, which cancer therapy was given, genetic predispositions and other co-morbidities[8]. Uncertainty regarding some of these guidelines revolves around ongoing changes in pediatric cancer therapy, the long latency period of many treatment related late effects, the multiple factors known to influence cancer-related health risks and the unknown effect of patient aging.

In general terms, the severity of long-term side effects depends on treatment intensity, the combination of cytotoxic agents (for example chemotherapy can sensitize normal tissues to RT and increase the risk of damage), the age of the child at the time of treatment and underlying patient factors such as genetics. Common problems experienced by the survivors of childhood cancer include reduced growth and development, organ damage (such as kidney, heart and lungs), endocrine problems (such as hypothyroidism), infertility and the increased risk of developing a second malignant neoplasm (SMN).

Common Late Effects

Only a few of the commoner long term health problems that may affect childhood cancer survivors are outlined below. Suggested screening recommendations are based on COG guidelines:

Increased risk of Surgical Complications

After moderately high dose RT, fibrosis and damage to small blood vessels can result in significant wound healing problems. Hyperbaric oxygen prior to surgery in these circumstances may improve the surgical outcome[9].

Thyroid problems

Survivors of childhood cancer who had RT to the neck (or any adjacent area such as the head) are at increased risk for hypothyroidism[10], the development of benign thyroid nodules and papillary carcinoma of the thyroid. Hypothyroidism is most commonly seen in patients who have received doses exceeding 2000 cGy, but any patient who has received scattered RT to the neck is at risk. Papillary carcinoma of the thyroid is the commonest tumor[11] to occur in these circumstances and is especially prevalent in survivors of Hodgkin lymphoma[12].

Advice for patients is outlined at: www.survivorshipguidelines.org/pdf/ThyroidProblems.pdf

Screening for thyroid problems in patients with a history of head and neck RT

Problem	Screening/Investigation	Frequency
Hypothyroidism	Blood work (T_4, TSH)	Annually
Thyroid neoplasm	Palpation of neck and thyroid	Annually
	Ultrasound scan of thyroid	Every 3 years

Renal Damage

The risk of chronic renal failure is especially high in survivors of Wilms tumor and neuroblastoma. Even low dose RT can affect renal function. Any survivor of neuroblastoma is likely to have received nephrotoxic chemotherapy (such as Cisplatin), RT to renal tissue and may also have had a nephrectomy. These survivors are at increased risk for renal dysfunction and hypertension.

Advice for patients is outlined at: www.survivorshipguidelines.org/pdf/KidneyHealth.pdf

Screening for Hypertension/Renal Damage in patients with a history of abdominal RT and or nephrectomy

Problem	Screening/Investigation	Frequency
Hypertension	Check blood pressure	annual
Renal failure	Blood work (electrolytes, creatinine and BUN)	annual

Second Cancers

This is one of the most serious long-term consequences of therapy for childhood cancer. Childhood cancer survivors have at least a 6 fold risk of developing second cancers. Some tumors may be benign and not life threatening. For example, low dose cranial RT is associated with an increased risk of meningiomas and it is prudent to screen with intermittent MR scans of the brain more than 10 years after therapy.

However, survivors are also at risk for development of a second malignant tumor (SMN). There is a significantly increased risk of breast cancer in female survivors after thoracic RT. This is especially a problem for girls who had mantle RT for Hodgkin lymphoma during adolescence[13]. Their risk of developing a breast cancer is significantly elevated.

Advice for patients is outlined at: www.survivorshipguidelines.org/pdf/BreastCancer.pdf

Screening for Increased Risk of Breast cancer (if thoracic RT given of 2000 cGy or more in childhood, adolescence or early adulthood)

Problem	Screening/Investigation	Frequency
Increased Breast cancer risk	Breast self examination	monthly
	Breast examination by HCP	Annually until aged 25 and then 6 monthly thereafter
	Breast MR	Annually starting at age 25 or 8 years after the RT was given
	Mammograms	Annually starting at age 25 or 8 years after the RT was given

RT induced SMNs include bone and soft tissue sarcomas[14] and it is difficult to recommend firm follow up guidelines. The first warning a patient may have is a rapidly increasing swelling which may occur between annual assessments. Patients should be aware of this complication and know to seek help immediately in these circumstances. There is an increasing emphasis on a healthy life style[6] (not smoking for instance) to help reduce the risk of SMNs in long term survivors of childhood cancer.

Conclusion

Long term follow up of these patients is critical. Knowledge of late effects informs our current clinical practice and drives innovative treatment approaches in children with cancer which are less likely to be associated with late effects. Also progress in the field of genomics may help us in the future to identify those patients who are especially at risk of these serious long term health problems.

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On survivorship
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So what do primary care physicians need to do? At present, simply be aware that this initiative is being developed and that the BCCA will update you in further issues. Those who have a particular interest may wish to contact Richard Doll at rdoll@bccancer.bc.ca or Phil White at drwhitemd@shaw.ca.

Undoubtedly the Ministry of Health will take an interest and may wish to see cancer rehabilitation as a mainstay of a sustainable Cancer Control program that is, in turn, part of a sustainable healthcare system in British Columbia.

Surveillance and counseling survivors of childhood, adolescent and young adult cancers

By Drs. Chris Fryer and Sheila Pritchard, BC Provincial Pediatric Oncology Hematology Network

Much has been written regarding late health problems relating to survivors of childhood cancer and the need for long term follow up. While the problem also affects adolescents and young adults, children are the most commonly and severely affected. Currently there is no systematic program in BC for such survivors and an article addressing this issue by Lauren MacDonald entitled "The Need for Long Term Follow-up of Childhood Cancer Survivors in British Columbia" was published in the December 2010 *British Columbia Medical Journal*. General Practitioners in Oncology (GPOs) are in a unique position to fill this void. This is especially true in the current situation of fiscal restraint with essentially no funding for new programs.

	Distribution	Projected 5Yr DFS
Overall		80%
Leukemia	30%	AML60%-ALL85%
Brain	19%	74%
Lymphoma	13%	75%
NBL	8%	75+% stg3-4 ‹20%
Rhabdo/STS	7%	70%
Wilms	6%	90%
Ewings/OS	5%	70%
Retinoblastoma	3%	98%
Hepatoblastoma	1%	60%
Other	8%	

In BC there are approximately 3,000 adult survivors (5+ years cancer free) of childhood cancer (age 0-17 years) and each year this number increases by about 120. If one includes age up to 24 years this figure doubles. Some survivors, especially children with prior brain tumours or bone cancer, may have residual health problems related to their cancer[1]. Subgroups of patients, based on the therapy received, may be at an increased risk for significant late effects[2]. It is important to identify patients at risk and provide them with appropriate counseling and surveillance. The corollary is to identify those patients who are likely to enjoy a healthy outcome for who such surveillance is superfluous.

In reviewing the published results one can make the following general statements regarding 5 year survivors of childhood cancer. Recurrence of the initial cancer remains the most likely cause of death even up to 20 years post diagnosis[3-7]. The next most common and serious life-threatening events are second malignancies primarily related to prior radiation, and cardiovascular disease related to radiation to the heart or total anthracycline doses › 250mg/m2. Females who received radiation to the breast in adolescence are at an especially high accumulated risk of developing breast cancer and therefore should be offered appropriate screening[8,9]. Children who received cranial radiation are at an increased risk of developing brain tumours both benign (meningiomas) and malignant, as well as thyroid cancer[10,11]. While infertility related to gonadal irradiation is usually irreversible, the same may not be true of alkylator therapy. There is an increasing awareness of premature menopause associated with chemotherapy and female survivors should be advised of this risk[12].

Since essentially all childhood cancer patients are seen and treated at BC's Children's Hospital we now counsel, 5 year survivors age 17 years and older regarding their risk for late health problems, and make individualized recommendations regarding future surveillance. We provide them and their family physician with a medical summary of their cancer, its treatment and complications as well as recommendations for surveillance. We ask them to consent to annual contact via letter to themselves and their family physician. Feedback is essential in order to ascertain if any health problems have developed that might be attributable to newer therapies[13,14].

We instigated a pilot recall program for survivors of childhood cancer who were never provided with a medical summary or information regarding potential future health problems. We are currently ascertaining whether this counseling is best undertaken by a patient visit or by telephone.

Utilizing GPOs for assistance in counseling adult survivors of childhood, adolescent and young adult cancers who have treatment related health problems and those at high risk for future problems seems most appropriate. The Provincial Pediatric Oncology/ Hematology Network (PPOHN) provides GPOs with some additional knowledge through the Family Practice Oncology Network's Preceptor Program and is in the process of updating risk based guidelines. Providing GPOs with the necessary information would enable them to provide a comprehensive follow up program to those at risk for late health problems. Discussions should take place with GPOs regarding their possible role in a late effects surveillance program, ascertaining their interest, willingness and availability.

Contact Drs. Chris Fryer or Sheila Pritchard at cfryer@cw.bc.ca and spritchard@cw.bc.ca respectively.

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Long term risks and care for survivors of childhood and adolescent cancer

By Mary L. McBride and Miranda Tsonis, Cancer Control Research Childhood/ Adolescent/Young Adult Cancer Survivors (CAYACS) Research Program, BC Cancer Agency

Mary McBride, Distinguished Scientist, Cancer Control Research, BC Cancer Agency

Advances in treatment have improved survival for children and adolescents diagnosed with cancer, with over 80% surviving five or more years[1]. There are about 6,000 five-year survivors diagnosed under age 25 in BC, and this number increases by over 3% each year. Many survivors face long-term or late-occurring problems, mainly treatment-related[2]. The Childhood/Adolescent/Young Adult Cancer Survivors (CAYACS) Research Program at BCCA, funded by the Canadian Cancer Society, is a BC-based resource for survivorship research that aims to identify risks faced by survivors, examine patterns and quality of healthcare, and to inform healthcare policy and practice, in order to optimize patient and healthcare outcomes[3].

Hospital-related morbidity

By 25 years after diagnosis, 41% of survivors diagnosed under age 20, compared with 17% of the general population, had at least one type of morbidity leading to hospitalization. Risks of all types of morbidity were elevated, except pregnancy and birth-related hospitalizations. Survivors were at highest excess risk for cancers, blood disorders, nervous system diseases, endocrine, and other metabolic disorders. Late effects other than cancers predominated 10 years and more post-diagnosis.

Health Care Utilization

In a three year period, 97% of survivors visited a physician, compared to 61% of their peers. Survivors were significantly more likely to visit a GP, have at least 10 GP visits, or consult a specialist (other than oncologists)[6]. Survivors were also more likely to receive prescriptions and to have higher numbers of prescriptions[7]. Additionally, survivors had four times the odds of hospitalization, as well as more admissions per person and more days in hospital per admission[8].

Educational Outcomes

For survivors enrolled in Grades K-12, many (33%) received special education, usually due to a physical disability (19% of survivors). Survivors of brain tumours, and those receiving cranial irradiation, were found to have severe educational deficits; brain tumour survivors performed at only 20% to 60% of the level of their peers in Foundation Skills Assessment tests.

Conclusions

These survivors face many long-term health risks that persist over time. Family physicians are the primary care providers for this group. Unfortunately, although there are published guidelines for follow-up care[9], awareness of these guidelines among family physicians is low. Furthermore, preliminary analysis shows that only 13% of at-risk survivors received the recommended follow-up care; and while 50% received some, 37% received none at all7. Additional research is needed to further examine risks of late effects, to create awareness of risks, and to encourage evidence-based uptake of risk-based care.

Contact Mary McBride at mmcbride@bccrc.ca

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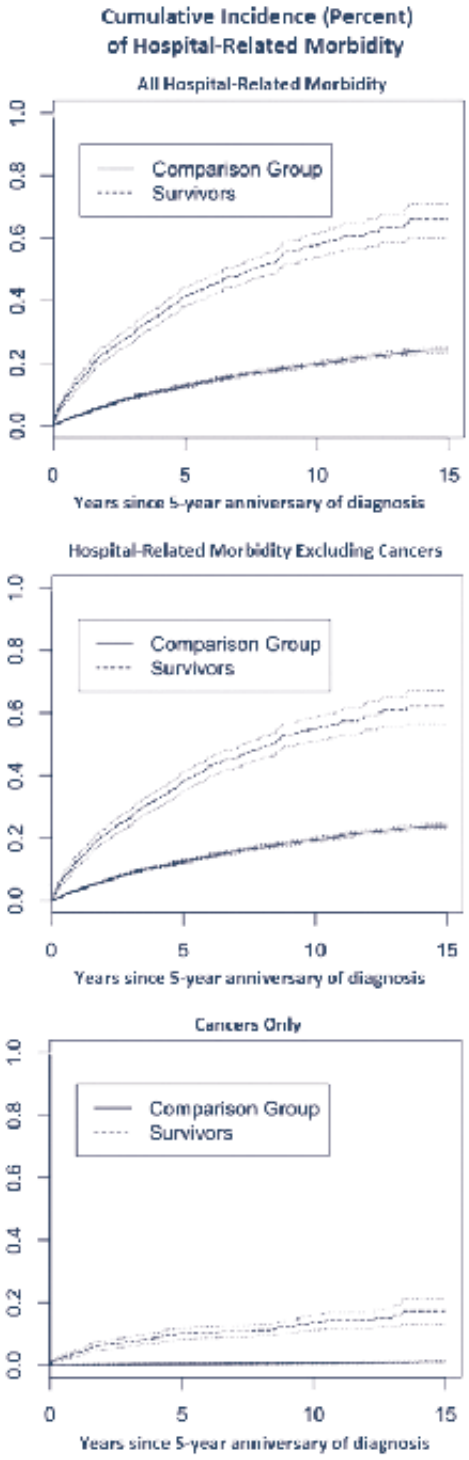

The CAYACS publication on risk of hospitalizations among these survivors was selected as one of the Canadian Cancer Society's Top 10 Research Stories of 2010.

HPV vaccine experience continued from page 1

public misinformation and improve the uptake of this vaccine? The answer is decidedly low tech – recommend it! Research suggests that one of the strongest influencers of parental intention to vaccinate against HPV is the recommendation of their GP (Ogilvie et al., 2009). As much as possible, all health care providers can advocate the benefits of vaccines and engage the public in positive interpretations of vaccine effectiveness!

Take the time to open up a conversation about HPV diseases and vaccine with girls and their parents – **all girls born after 1994 are eligible for publicly funded HPV vaccine, even if they missed it in grade 6 or 9.** While this may seem to be an add-on to an already packed health visit, your recommendation is invaluable in helping them sort through all of the information in the media and online about this vaccine. If they need more information, direct them to our site www.ImmunizeBC.ca – there they will find answers to common parental questions, videos explaining HPV disease and vaccine, and an email address to direct any further questions to.

Contact Brittany Deeter at brittany.deeter@bccdc.ca

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Enhanced cancer care in Grand Forks

For 20 years, Dr. Geoff Coleshill was a busy family physician in Grand Forks looking after his patients, performing anaesthesia at the local hospital and handling obstetrics. That changed when the latter two services were withdrawn from the community and Geoff decided to pursue the Family Practice Oncology Network's eight-week Preceptor Program gaining the designation General Practitioner in Oncology or GPO.

Dr. Geoff Coleshill is a graduate of the Network's Preceptor Program and part of Grand Forks' dedicated cancer care team.

"At our community hospital, we now offer different services than before and chemotherapy is an increasingly important one," notes Dr. Coleshill. "Previously patients had to drive 2.5 hours to Kelowna or 1.5 hours to Trail for treatment. Now they are looked after in Grand Forks which is a huge convenience that is much appreciated. My colleague, Dr. Mary Wall, first took the Preceptor Program in 2006 and established the chemo program for her patients. She then moved to work as a GPO at the BC Cancer Agency's Centre for the Southern Interior in Kelowna and I decided to fill the gap locally."

"I enjoyed the Preceptor Program. The two-week introductory module in Vancouver was pretty intense, but everyone was really friendly, helpful and accommodating. The following six weeks of clinical modules included more time at the Vancouver Centre, two weeks at the Centre in Kelowna and another shared between the hospital in Trail and the pharmacy in Nelson which prepares all of our chemo drugs. Establishing this network of contacts and expertise made a huge difference to the level of care we provide and is a resource that I didn't have before. The program opened up a new world for me in chemo treatment which was always a mystery before. Now I have a solid understanding of what it's all about and can even pronounce the names of the drugs."

"We have since developed a dedicated cancer care team here including myself, four oncology nurses, a social worker, dietician, rehabilitation therapist, and home and community nurses who all work closely together. The work environment is much richer. There is a lot going on and a great deal of support required beyond my contribution. I enjoy this work immensely and feel lucky to be in Grand Forks and involved in oncology care beyond general practice."

Contact Dr. Geoff Coleshill at geoffgecol@hotmail.com

Next preceptor course begins September 26, 2011

If you are a family physician keen to provide enhanced cancer care for your patients and their families, please consider the Family Practice Oncology Network's Preceptor Program. This program provides opportunity, especially for rural family physicians with the support of their community, to strengthen their oncology skills and become a GPO – General Practitioner in Oncology. A two-week introductory module is offered every spring and fall at the Agency's Vancouver Centre followed by six weeks of clinic experience at the Cancer Centre where your patients are referred. The latter can be scheduled over one year to best meet your schedule and tailored to particular needs of your community. Nurse practitioners are also welcome to participate.

The program meets the accreditation criteria of the College of Family Physicians of Canada and has been accredited for 25 Mainpro-C and 50 Mainpro-M1 credits. Physicians from rural communities (REAP eligible) will receive a stipend and have their travel and accommodation expenses covered. First year membership in the Canadian Association of General Practitioners in Oncology is also included. For more information please visit www.fpon.ca.

Richard Gallagher awarded O. Harold Warwick prize

Earlier this year, Richard Gallagher, distinguished scientist with the BC Cancer Agency, was awarded the Canadian Cancer Society O. Harold Warwick Prize for 2010.

The O. Harold Warwick Prize is given to a scientist whose research has had a major impact on cancer control in Canada. The prize is named after Dr. Warwick, a pioneering researcher in cancer control and treatment, who became the first executive director of both the former National Cancer Institute of Canada and the Canadian Cancer Society.

Richard was selected for making a major impact on cancer control in Canada and for his collaborative work on identifying the causes of melanoma and other skin cancers, which has received international acclaim. The Canadian Cancer Society is celebrating Richard's work, which is focused primarily on the environmental causes of malignant melanoma, non-melanocytic skin cancers and other malignancies. In collaboration with other investigators in Canada and Australia, he identified intermittent sun exposure as a significant cause of both melanoma and cutaneous basal cell carcinoma, and occupational sun exposure as a cause of squamous cell skin cancer.

Update on cervical cancer screening changes

The BC Cancer Agency's Cervical Cancer Screening Program introduced two key changes late last year. The first is the adoption by the Provincial Health Services Authority's Cervical Cancer Screening Laboratory of the internationally standardized Bethesda nomenclature to report Pap test results, and the second is the recommendation that cervical cancer screening begin at age 21 or three years after first sexual contact – whichever comes first.

Dr. Dirk van Niekerk

"The Bethesda nomenclature is the most commonly used classification system throughout North America," states Cervical Cancer Screening Program Medical Director, Dr. Dirk van Niekerk. "Switching to this system improves and simplifies ongoing clinical management for women who move out of province and enables comparisons of our outcomes against those of others."

The new recommendation indicating age 21 as the year to begin screening is part of an updated Cervical Cancer Screening Guideline for BC. Previously, screening was recommended to commence soon after a woman's first sexual activity. Specifying age 21 (or three years after first sexual contact) recognizes that while cervical cancer is extremely rare in younger women, temporary mild cervical cell changes caused by transient Human Papilloma Virus infections are not. Delaying the onset of screening as such reduces detection of these temporary cervical changes without increasing the risk of invasive cervical carcinoma and prevents unnecessary investigations and anxiety for the patient.

"Women under age 21 still need to visit their healthcare provider regularly to learn how to protect themselves from HPV and other sexually transmitted diseases," cautions Dr. van Niekerk. "And we recommend HPV vaccination for females between 9 and 26 years of age."

Women who have never had any sexual contact do not need to be screened.

The new Cervical Cancer Screening Guideline, published in February of this year, is available on the Agency's Website at www.bccancer.bc.ca/cervicalscreening along with the updated *Screening for Cancer of the Cervix: An Office Manual for Health Professionals*.

Please send any questions or comments to ccsp@bccancer.bc.ca.

Facts about Screening and Cervical Cancer

- Since BC's Cervical Cancer Screening program was established in the 1950s, it has successfully reduced cervical cancer rates in BC by 70%.
- Despite the success of the program there are age groups and areas of the province where participation rates remain a challenge, especially in the 20-29 year olds in the Lower Mainland and older age groups in some Northern Communities.
- The HPV vaccine protects against two of the high risk strains of HPV which cause cervical cancer. Pap tests are still necessary to identify changes to the cervix caused by other high risk strains of HPV.

Newsflash: update on BIONJ!

By Dr. Lina Jung, General Consultant, Dept. of Oral Oncology/Dentistry at BCCA-CCSI

Shortly after my last article, new data was shared at a presentation given by the UBC Dean of Dentistry, Charles Shuler, regarding the incidence of osteonecrosis of the jaw related to bisphosphonates. The true incidence will probably be never known. In early trials, no oral exams were done and BIONJ was not listed as a side effect on the report forms, contributing to the previously reported low rates of 0.007-0.01% (1in 10,000 to 14,300) associated with the oral version, which were generally accepted until 2009. Until 2009 Stage 3 BIONJ (exposed, necrotic bone in patients with pain, infection and pathologic fracture, extraoral fisula, or osteolysis extending to the inferior border of the mandible) was the focus. More recent presentations and publications have refocused on the more common Stages 1 and 2 BIONJ (sequestra without or with pain and infection respectively). Preliminary findings in recent studies suggest that the frequency of ONJ secondary to oral BPN therapy with alendronate sodium (Fosamax) was more common than previously suggested; the numbers showed **1 in 23 patients taking Fosamax developed ONJ!** Imagine the implications considering it is estimated that 30 million individuals worldwide have received or are receiving BPNs, while 13 million women in the USA alone are currently receiving it! Developing a strategy for our patients is critical — prevention is the only known way to address this complication and hence the key is multi-professional, inter-disciplinary care! Referral to the patient's dentist is the first step in management, either to prevent or treat BIONJ.

For more information, view the recorded Network/UBC-CME webinar Bisphosphonates and *Osteonecrosis of the Jaw* given on Jan. 20, 2011 at www.fpon.ca under CME Initiatives.

Contact Dr. Lina Jung at ljung@bccancer.bc.ca

Following a referral to the hereditary cancer program

The BC Cancer Agency's Hereditary Cancer Program (HCP) strives to identify individuals at risk for hereditary cancer before a malignancy develops and to provide a comprehensive program for cancer prevention and/or early detection. The following case study demonstrates what patients and their physicians can expect from a referral to the HCP.

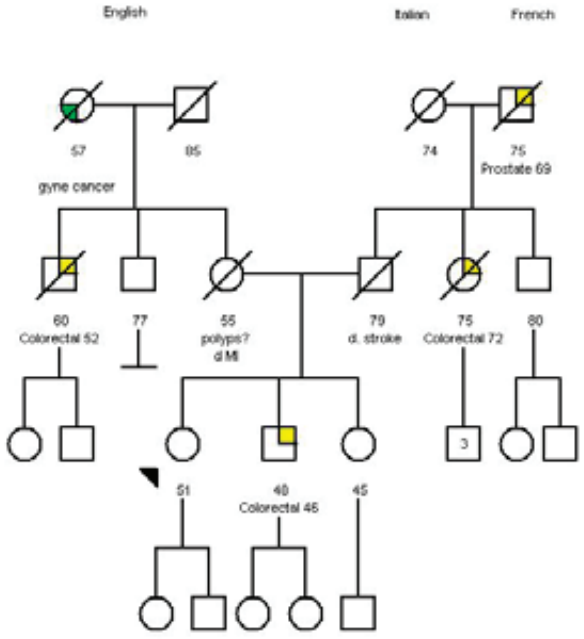
Julie is a 51 year old woman living in Vanderhoof who visits her family doctor to inquire whether she should have a colonoscopy due to her family history of cancer. Her physician documents Julie's family tree and notes that, through her mother's family, she has 3 relatives over 3 generations who have had a cancer related to Lynch syndrome, one of whom was diagnosed before age 50. This fits criteria listed on the second page of the HCP Referral Form (printed from the BCCA Website: www.bccancer.bc.ca/hereditarycancer — see Information for Health Professionals). They decide to submit the referral.

Referral and Booking Process

- Upon receipt of the referral, HCP staff send Julie a detailed Family History Form. As soon as that form is returned, the referral will move forward. *(If the completed form is not returned within 4 months, Julie will receive a letter to advise that her referral has been closed but can be re-opened on request.)*
- HCP clinical staff review Julie's completed form and confirm that she is eligible for a genetic counselling appointment. A clerk contacts Julie to book an appointment 2-3 months hence, to take place by video-conference between the HCP office in Vancouver and her local hospital. She is encouraged to invite any interested adult relatives and/or a support person to join her.
- Julie receives a confirmation letter along with an "FAQ" page, and Release of Information Forms to authorize request of medical records to confirm reported cancer diagnoses in the family.

At Julie's appointment:

- The genetic counsellor (GC) interprets her family and medical history to evaluate her personal risk for cancer and the chances of Lynch syndrome.
- Julie has an opportunity to learn about genes and cancer and inheritance. She also gains an understanding of differences between sporadic, familial and hereditary cancers.
- Review of her family's medical records confirms eligibility for Lynch syndrome genetic testing. Julie and the GC discuss some of the potential benefits, risks and limitations of genetic testing, including the need to start the process with an affected "index" case.
- The GC suggests that Julie invite her brother, diagnosed with colorectal cancer at age 46, to self-refer for genetic counselling and genetic testing through the HCP office in Vancouver. Depending on his results, carrier testing for a specific gene mutation may then become available to Julie and other family members.
- They also review current recommendations for early cancer detection and prevention related to Lynch syndrome. Julie is advised to undergo a baseline screening colonoscopy with further advice to follow pending her brother's test results.
- Julie receives a copy of *Understanding Lynch Syndrome*, a booklet that covers the information addressed in the appointment. She is encouraged to re-contact her GC with any related questions or new information.



Appointment Outcomes

Julie's family physician will receive a letter detailing the genetic counsellor's assessment, including recommendations for her cancer risk management and the suggested approach to genetic testing in the family. A copy of that letter is also sent to Julie. A follow-up appointment will be booked for Julie when her brother's genetic test results are available.

If you have a patient who you think may benefit from assessment by the HCP, but are unsure whether they meet referral criteria, please call us at 604.877.6000 local 2325. All inquiries are welcome.

In the next newsletter we will share information on the genetic testing process and possible results. Your suggestions for hereditary cancer topics to be addressed in future issues are most welcome.

Contact Mary McCullum,
HCP Nurse Educator:
mmccullum@bccancer.bc.ca

The Genetic Counselling Appointment

The purpose of this one-hour appointment is to help people with a significant personal and/or family history of cancer to learn more about hereditary cancer and to make informed decisions moving forward. The appointment is with a genetic counsellor unless it is related to a rarer hereditary cancer syndrome and/or requires a physical exam, when a medical geneticist will see the patient. Genetic counselling offices are located in Abbotsford, Victoria and Vancouver, with appointments also available via outreach clinics or video-conference to most BC/Yukon communities.

PanCanadian Lung Cancer Screening Program

By Dr. Annette McWilliams, Respiratory Physician, BC Cancer Agency, Vancouver Centre

Lung cancer is the most common cause of cancer death worldwide. Former heavy smokers remain at an elevated risk even years after they stop smoking and 50% of newly diagnosed lung cancers occur in former smokers. Screening has been shown to be effective in reducing the mortality of cancer of the cervix, breast and colon. Previous efforts to use sputum and chest x-ray to detect early lung cancer in the 1980s failed to demonstrate a reduction in lung cancer mortality. This was probably due to the insensitivity of conventional sputum cytology and chest x-ray.

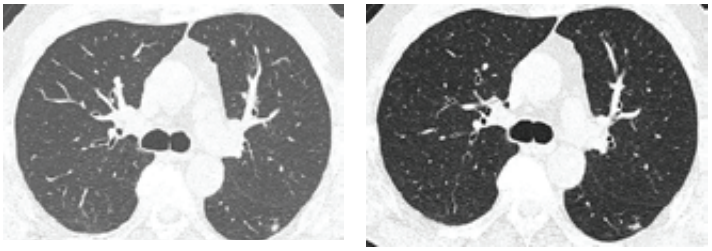
Over the last decade there have been rapid technological advances in helical CT scanners. The development of multidetector row scanners has allowed a decrease in slice width, improved spatial resolution and radiation dose management, providing excellent image quality with reduced radiation dose. As a result there has been renewed international interest in using thoracic CT scans for lung cancer screening.

At the BCCA, we incorporated CT scan into our early lung cancer detection program in 2000. Our results confirmed that CT scans can detect lung cancers at a small size and early stage and it is feasible to perform in a screening setting. One of the problems is that 85% of current or former smokers will have small noncalcified pulmonary nodules that will require follow-up. In addition, CT scan alone cannot detect small central lung cancers that are best detected with autofluorescence bronchoscopy. Mortality outcome studies using CT scan are ongoing in the United States (NLST) and Europe (NELSON), but initial results from the NLST study are very encouraging showing a 20% reduction in lung cancer mortality with CT screening. However, with millions of current/former smokers in Canada that would be eligible for CT scan screening, a cost-effective strategy that targets those at highest risk of lung cancer is required.

The PanCanadian Early Lung Cancer Detection program is a multicentre study funded by the Terry Fox Research Institute in eight centres across Canada. It is led by Dr. Stephen Lam at the BCCA. The aim is to evaluate the role of a risk prediction model and the additional incorporation of a number of biomarkers as a "first step" screening strategy. Those subjects at high risk then received low dose chest CT scan and half of the subjects also underwent autofluorescence bronchoscopy. The target of a total of 2500 subjects was reached in December 2010 and these subjects are presently being followed. Direct and indirect costs and quality of life data is also being collected to evaluate the impact of this screening strategy on the community. When the final results of the large scale mortality outcome studies become available, Canada will be poised to implement a cost-effective lung cancer screening program across the country.

Contact Dr. Annette McWilliams at amcwilli@bccancer.bc.ca

April 2010 August 2010



These CT scans, taken 3 months apart, show a Stage IA adenocarcinoma detected through the program. The lesion was resected and was only 9mm in size at time of surgery.

Cameo research program update

The CAMEO Program, a collaborative University of British Columbia/BC Cancer Agency research program continues to explore how to best meet the complementary medicine (CAM) information and decision support needs of people and their families living with cancer. A variety of new and existing projects, within a research framework, are underway and available for patients, family members, and health professionals:

CAM and Cancer in BC Booklet: CAMEO's newest information resource is now available online. The Booklet provides an overview of credible CAM resources available in BC and tips on many issues: Selecting a credible CAM practitioner, talking with conventional health professionals about CAM, reimbursement for CAM therapies, accessing credible CAM websites, making CAM decisions, and monitoring and evaluating CAM use. Available under "Documents" at www.bccancer.bc.ca/cameo.

CAM Decision Support Coaching for Patients and Families: This telephone-based and/or in-person program involves decision support counseling with a CAMEO research nurse to help patients and families make CAM decisions. Health professionals may also utilize this program to gain practice-ready CAM information to better support their patients' safe CAM use. Contact aporcino@bccancer.bc.ca or 604.707.5960

CAM Workshops for Patients and Families: A half-day patient and family CAM education workshop will be held May 28, 2011 in Vancouver. Contact aporcino@bccancer.bc.ca or 604.707.5960 to register.

On-line CAM and Cancer Learning Modules for Health Professionals: Three short, interactive CAM learning modules will be ready for release shortly. Content covers CAM basics to prepare health professionals to offer CAM decision support to their patients and family members to ensure safe and evidence-informed CAM use. Anticipated release date is Fall 2011.

continued on page 11

Advice on early diagnosis of multiple myeloma

By Dr. Kevin Song, Member of the Leukemia/BMT Program of BC, BC Cancer Agency

Dr. Kevin Song provides insight on diagnosing "very treatable" multiple myeloma.

Multiple myeloma is a cancer of blood cells. It is an uncommon cancer with 150-200 people being diagnosed with this condition every year in British Columbia. Although it is not considered curable, it is VERY TREATABLE with the majority of patients surviving more than 5 years from diagnosis and many surviving greater than 10 years with appropriate treatment. For this reason, it is extremely important to consider this diagnosis when a patients presents with complaints.

Common symptoms include back pain, fatigue, anorexia and recurrent infections. Multiple myeloma results in bone destruction which leads to the boney pains and fractures. Vertebral body fracture is one of the most common presentations, but other possible bone fracture can include the ribs, and the bones in the limb. Myeloma cells typically reside in the bone marrow. This in combination with anemia of chronic disease can result in patients having low hemoglobin. Because myeloma cells are abnormal plasma cells, this can result in the suppression of the normal plasma cells which ultimately results in an increased susceptibility to infections. These abnormal plasma cells produce immunoglobulins which can lead to many problems and can also facilitate the diagnosis.

The initial tests to diagnose myeloma are quite simple and readily available:

- Complete Blood Count (to look for anemia)
- Creatinine (to look for renal dysfunction)
- Serum protein electrophoresis (to look for a monocolonal protein)
- Urine protein electrophoresis (to look for monoclonal proteins in the urine which sometimes are not found in the blood)
- A skeletal survey or an X-ray of the area of boney pain can also give radiological clues to the diagnosis of myeloma.

Confirmation of the diagnosis of MM requires a bone marrow biopsy. This can be requested through the laboratory or a referral to a hematologist or oncologist should be made so that they may arrange the bone marrow biopsy.

Once a diagnosis is confirmed, treatment will include chemotherapy, radiation and possible high-dose chemotherapy followed by stem cell rescue (known as an autologous stem cell transplant). Supportive therapies will also be required including bisphosphonates (such as pamidronate) and medications for pain control.

With timely diagnosis and treatment patients suffering from MM can live long and fruitful lives. For this reason, it is important to remember to consider this diagnosis in patient who may present to the office of a General Practitioner.

Contact Dr. Kevin Song at ksong@bccancer.bc.ca

Cameo research program update continued from page 10

Natural Health Product Decision Aid: A three-phased decision aid research project is in progress to help women post breast cancer treatment to make informed decisions about natural health products for hot flashes. This online decision aid is nearing completion of its first phase and is anticipated to be available for pilot testing in the fall of 2011. Contact lynda.balneaves@nursing.ubc.ca if you would like to learn more about this research project.

Chinese Canadians with Cancer and CAM: Recruitment is complete for a study to address the unique CAM needs of Chinese Canadians living with cancer. Future CAMEO plans include developing educational programs for this population. Contact mwong9@bccancer.bc.ca for more information.

Additional information on the CAMEO research program is available at www.bccancer.bc.ca/cameo.

Patient support for multiple myeloma

By Lillian Barton, Multiple Myeloma Vancouver Island Support Group

You've told your patient they have myeloma, and despite giving the information in simple plain language, you know they absorbed little of what you said. They feel afraid, lost, helpless, sad, or angry. Now what? Across BC, five local groups supporting people with multiple myeloma meet regularly, ready to help patients at every stage in their healing process.

Fear and the need to know more bring people to groups initially. Peer support, continuing education, and mentoring help new patients understand the complexities of myeloma, chemotherapy regimes, and stem-cell transplant. The social aspect of learning, sharing concerns and questions, and knowing that others with the same condition understand, are the ties that bind group members.

For those people who lack computer skills or a viable social support network, we reach out with patient handbooks from a number of agencies at meetings (arranging for home delivery through the mail if needed), as well as any resources and services that will help them attend.

If one-to-one counselling or information is needed anywhere in the province, patients can call Lillian Barton at 1. 250.743.2693 to leave a message and she will return their call.

Meetings are held monthly or bi-monthly in Vancouver and on Vancouver Island depending on location. Visit www.myeloma vancouverisland.ca for more information.

Message from the chair

By Dr. Phil White, Chair and Medical Director of the Family Practice Oncology Network and family physician in Kelowna

The value of partnerships and effective relationships is very much apparent to the Family Practice Oncology Network as we grow and fine-tune our initiatives to better meet the oncology learning and resource needs of family physicians and General Practitioners in Oncology in BC.

One of our most significant partnerships is with the Guidelines and Protocols Advisory Committee (GPAC). The Network and GPAC worked together earlier to develop and publish a set of three guidelines on palliative care customized to meet the specific needs of family physicians. The first of these guidelines – the Palliative Approach – was published last fall and the second two – Pain and Symptom Management and Grief and Bereavement – will be published this summer and are already being to put to use by the General Practice Services Committee in its Practice Support Program on end-of-life care. Now we are moving forward with another GPAC guideline – this time on breast cancer screening, diagnosis and follow-up care.

Further, as part of the BC Cancer Agency, the Network strives to serve as the liaison between primary care and the organization overall. To this end, we work in close partnership with the Agency executive team and with Fiona Walks, newly appointed Vice President, Safety, Quality and Supportive Care, in particular. Fiona just recently took on the leadership of our portfolio and we welcome her insight and expertise while expressing our appreciation to Dr. Mark Elwood, Vice President, Family and Community Oncology, for his many contributions.

One of Fiona's first initiatives was to move forward with the Agency's commitment to addressing survivorship issues. She recently established an Interdisciplinary Survivorship Steering Committee to lead this direction of which I was appointed Deputy Chair.

Another key relationship for the Network is that with UBC Continuing Professional Development. We have partnered informally for more than a year to develop our CME Webcast program and are now moving forward with a major community workshop initiative called Cancer Care Outreach Program on Education which will include locally led events in 40 BC communities focussing initially on the management of breast and colorectal cancer. Our CME efforts are truly flourishing thanks to UBC CPD's drive and commitment.

Finally, as we review our upcoming priorities, partnerships extending beyond the borders of BC will become a stronger focus. We will continue to work closely with the Canadian Association of General Practitioners in Oncology and build stronger relationships with like-minded provincial organizations which will benefit and enhance our initiatives at home.

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Mark your calendars: upcoming oncology CME events

Here are a few you won't want to miss:

- Oncology CME Webcasts presented by the Family Practice Oncology Network and the University of British Columbia's Division of Continuing Professional Development – **June 16**: *Management of Thrombosis in Cancer* featuring Dr. Agnes Lee, Medical Director of the VGH Thrombosis Clinic **September 15**: *Late Effects after Treatment for Childhood Cancer* featuring Dr. Karen Goddard of the BC Cancer Agency, Vancouver Centre. Register at www.ubccpd.ca/Events/Webinar_Program.htm.
- CAGPO 2011 – the annual conference of the Canadian Association of General Practitioners in Oncology set for October 27-30 in Quebec City. Register at www.agora-event.com/cagpo2011.
- BC Cancer Agency Annual Conference, December 1-3 at the Westin Bayshore. Family Practice Oncology CME Day will be held December 3. Registration to open in June.