We are pleased to announce the formal establishment of a provincial network aimed at providing support for health professionals, patients, and families throughout BC. In September 2002, the BC's Children's Hospital (BCCH) and the BC Cancer Agency (BCCA) began developing the Provincial Network by forming a task force and holding a workshop with key individuals from several communities in BC. Since the workshop, a comprehensive proposal was prepared, a Steering Committee was established, and several initiatives are now underway.

History

In British Columbia, the history of Pediatric Oncology/Hematology spans 50 years. During this time, the BC's Children's Hospital has developed a sophisticated oncology/hematology program of diagnosis, treatment, and follow-up care. Since the early 1990's, BCCH has extended its program into communities across the province and strengthened linkages with other organizations such as the BC Cancer Agency.

In late 2001, the BC government reorganized health care into five regional health authorities and one Provincial Health Services Authority (PHSA). The PHSA is responsible for both the BC's Children's Hospital and the BC Cancer Agency. The PHSA has also established a Provincial Child Health Network to strengthen consistency and continuity of care for children across the province. The Provincial Pediatric Oncology/Hematology Network is a working group of the Provincial Child Health Network and is co-led by both the Children's Hospital and the Cancer Agency. It includes active participation of partners with primary and secondary organizations in all health authorities.

Goals of the Network

- To ensure all children and adolescents in British Columbia have access to “state-of-the-art” comprehensive, interdisciplinary clinical care and to enhance the quality of life for patients and their families.
- To support community hospitals and practitioners and develop a partnership with other health facilities to enable integrated care to patients and their families throughout the province.
- To further develop and enhance the research programs of basic, translational and clinical research that are world class and make a significant contribution to the global care of children with oncology and hematology disorders.
- To provide an outstanding educational program for clinical and research trainees at all levels of their careers.
- To develop and implement a comprehensive cancer control strategy for children and adolescents.

Vision

The Network enhances community care of children and families by an integrated and multidisciplinary approach to ensure appropriate diagnosis, management and follow-up and end-of-life care for pediatric patients with malignancies and blood disorders.
Dr. Simon Sutcliffe

– President, BC Cancer Agency

The BC Cancer Agency has a mandate for provincial cancer control which includes prevention, screening, treatment, follow-up, palliation and research. The Agency is pleased to work with Children’s Hospital to share its resources in the communities throughout the province. The four cancer centres in Victoria, Vancouver, Surrey and Kelowna can play a vital role in the long term success of the Network.

Dr. Paul Rogers

– BC’s Children’s Hospital, Principal Investigator within the Children’s Oncology Group, specific interest in the conduct of clinical trials, long-term surveillance and nutrition.

BC’s Children’s Hospital is the centralized facility in the province for initial treatment planning for pediatric cancer patients. There is a huge need for a formal provincial network to provide acute and long-term care. While the initial management should be centralized, there are many components that can, and should be delivered in the community. This approach is very beneficial to the patient and family. If resources are made available in the communities, long term follow-up care can be done closer to home. Additionally, there are needs for psychosocial and palliative support. Partnering with BC Cancer Agency will allow for more efficient utilization of resources and enhancement of services. I am happy to be working with the newly appointed Steering Committee to establish the network and plan activities.

Dr. Simon Sutcliffe

– Acting Co-Chair, BC Cancer Agency

Dr. Chris Fryer

– Medical Advisor
DMRT(T), FRCP(C)
Pediatric Oncologist/Hematologist,
BC’s Children’s Hospital
Former Chairman of the Radiation Oncology Committee of the Children’s Oncology Group
Former Head of the Pediatric Oncology/Hematology Program at BC’s Children’s Hospital

As the Medical Advisor to the Network my role is to ensure that more acute and long term care for children with cancer and allied hematological disorders is given in the patient’s own community. I have been working with other professionals to develop appropriate guidelines and resources to ensure that the care provided in the home community is at the highest standard.

Sharon Toohy

– President, BC’s Children’s Hospital & Sunny Hill Health Centre

BC’s Children’s Hospital is pleased to partner with BC Cancer Agency in establishing the Provincial Pediatric Oncology/Hematology Network. The Network will also be part of the Provincial Child Health Network, with the goal to improve the access, affordability and accountability, and quality of health of children and youth in British Columbia. The Children’s Hospital is committed to continuous and effective dialogue and collaboration with communities and health professionals throughout British Columbia. The Networks are the key to generating coordination and standardization of care across the province. I am happy to support the many initiatives of the Network, some of which are already underway.

Grace Chan

– Network Manager
RN, BSN

I am excited and honoured to be the Network Manager for the Provincial Pediatric Oncology/Hematology Network. I have had the privilege to be involved in the care of a group of very brave children and their families for more than 20 years as a pediatric oncology/hematology nurse and more recently, as the coordinator of the apheresis and stem cell harvest program at BC’s Children’s Hospital. I see the Provincial Pediatric Oncology/Hematology Network as a key organization to promote a high standard of care in all communities for children with cancer and their families. Continuing education for those involved in the care of children with cancer is essential to maintaining this high standard of care. My goal will be to work closely with health care professionals in various communities to continually identify needs, plan, implement, and evaluate projects and initiatives to improve and uphold the level of care we offer our patients. I look forward to meeting and working with many of the care providers in all the communities.
Development of Professional Practice Guidelines

Dr. Chris Fryer, Dr. Sheila Pritchard, Roberta Esau, Patti Byron and Pia DeZorzi are working to establish professional practice guidelines that will lead to updated “levels of care” for communities. These guidelines include: diagnosis, treatment, supportive care and long term follow-up. The “levels of care” provide different complexities of therapy from simple short stay outpatient treatment to complex in-patient management.

The guidelines are now in draft form and are under review by the Steering Committee as well as by nurses and pediatricians in the communities. Completion is anticipated by December 2003. They will be available on the Web and in paper format.

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Education and Communication Working Group

Members

Pia DeZorzi (Clinical Nurse Educator, BCCH, Vancouver)
Eleanor Shambrook (Pediatric Ambulatory Nurse, Royal Jubilee Hospital, Victoria)
Patti Byron (Program Manager, BCCH, Vancouver)
Lael Cole (Clinical Instructor, Prince George Regional Hospital)
Karen Janes (Nurse Educator, BCCA, Vancouver)
Dan Mornar (Patient/Parent Advocate, BCCH, Vancouver)
Beverly Sieker (Nurse Manager, Kelowna General Hospital)
Dr. Paul Rogers (Pediatric Oncologist, BCCH, Vancouver)

In order for the Network to be successful, effective communication methods for patient care are being developed. Effective communication needs to be comprehensive, easy to access, and two-way between the patient’s home community and the Children’s Hospital/ Cancer Agency. Some of the initiatives the Education & Communication Working Group are developing include:

- An electronic patient record
- A web site for patients, families and professional use
- A newsletter
- Video conferencing through telehealth

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BCCA Annual Conference
November 27-29, 2003
at the Vancouver Hotel

Every year the BC Cancer Agency organizes a three day conference. On the third day professional groups meet with their own program. This year the Pediatric Oncology/Hematology Network will hold its own session. The session will be of interest to pediatricians, nurses, social workers, palliative care professionals and others involved in pediatric cancer care. Here is the agenda …

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BCCA Annual Conference,
Pediatric Oncology Day
Saturday, November 29th, 8:45 am – 3:15 pm

08:45 – 09:00 Welcome: Dr. Victor Ling BC Ballroom
09:00 – 09:30 Cancer in Adolescents and Young Adults: The Great Divide
Keynote Speaker: Dr. Archie Bleyer

Theme: The Management of Childhood Cancer – The Community Perspective
Moderator: Cathy Massey Moresby Room
09:45 – 10:00 Overview of the Problems & Solutions: Provincial Pediatric Oncology/Hematology Network
Speakers: Dr. Paul Rogers/Dr. Chris Fryer

10:00 – 10:15 Childhood Cancer: Incidence & Prevalence in British Columbia
Speaker: Mary McBride
10:15 – 10:45 What a Family Doctor and Pediatrician Should do at Diagnosis
Speaker: Dr. Mason Bond
11:00 – 11:30 Oncologc Emergencies
Speaker: Dr. Jeff Davis
11:30 – 12:00 Chemotherapy: Toxicities & How to Prevent Them
Speaker: Dr. Caron Strahlendorf
12:00 – 12:30 The Cancer Survivor: Age Transition & Follow up Evaluation
Speaker: Angela Pretula/Dr. Sheila Pritchard
12:30 – 13:30 Lunch: Open or Participation in Working Lunch
Working Lunch: Community Discussion – Organizational Problems and Solutions
Moderator: Eleanor Shambrook
13:30 – 14:00 Supportive Care
Speaker: Pia DeZorzi
14:00 – 14:30 Expert Panel: Management Problems – Questions & Answers
Moderator: Cathy Massey
14:30 – 15:00 Discussion: Report from Working Lunch – Community Organization Problems & Solutions
Moderator: Eleanor Shambrook
15:00 – 15:15 Wrap-Up

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Development of Professional Practice Guidelines

Dr. Chris Fryer, Dr. Sheila Pritchard, Roberta Esau, Patti Byron and Pia DeZorzi are working to establish professional practice guidelines that will lead to updated “levels of care” for communities. These guidelines include: diagnosis, treatment, supportive care and long term follow-up. The “levels of care” provide different complexities of therapy from simple short stay outpatient treatment to complex in-patient management.

The guidelines are now in draft form and are under review by the Steering Committee as well as by nurses and pediatricians in the communities. Completion is anticipated by December 2003. They will be available on the Web and in paper format.
At the present time, there are more than 7,000 survivors of childhood cancer in the province. It is estimated that by 2010, 1 in 500 young adults in BC will be survivors of cancer. Long term care for children who have survived cancer is complex and continues throughout their lives. The Long Term Follow-up Working Group is developing several initiatives to address the needs and improve the quality of care for this group of patients. Some of the projects that are underway are:

- A pilot survey of the needs of young adults who are cancer survivors
- An assessment of the available medical and psychosocial support for long term survivors as well as present gaps in service
- Development of a Long Term Follow-up framework with a smooth transition from pediatric to adult care

Co-chairs: Sheila Pritchard and Karen Goddard