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APPHON/ROHPPA NEWSLETTER

Atlantic Provinces Pediatric Hematology/Oncology Network
Réseau d'Oncologie et Hématologie Pédiatrique des Provinces Atlantiques
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APPHON Chair Resigns



Dr. Jack Hand presented Dr. Dorothy Barnard with flowers and a picture of a tree that was bought for her retirement home.

Dr. Dorothy Barnard stepped down as chair of APPHON at the AGM meeting in May. She initiated APPHON in 1995 as an organization to bring together all the caregivers of children with oncology/hematological disorders in order to facilitate the best care possible for them. The organization has grown even beyond her imagination. She will continue to serve on the board.

Words cannot express the gratitude and thanks that the Children and Health Care professionals of the Atlantic

Provinces owe Dorothy for her endless energy and drive. She will be missed.

Kim Chapman from Dr. Everett Chalmers Regional Hospital in Fredericton will serve as the interim chair.

Kim is the Clinical Nurse Specialist in Oncology for River Valley Health. As well, she is an honorary research associate with the Faculty of Nursing, University of New Brunswick. Kim received her Bachelor of Nursing degree from the University of New Brunswick in 1988 and her Masters of Science degree in Nursing from McGill University, Quebec in 1995.

Kim has worked as an oncology nurse for more than fifteen years in various oncology settings (in-patient, out-patient, & clinic environment), in different nursing positions (staff nurse, CNS Oncology position), and in different facilities (Jewish General Hospital, Quebec, St. Mary's Hospital, Quebec, Oshawa General Hospital, Ontario, River Valley Health, N.B.). She has served on the board of APPHON and been a dedicated member since 2004.

Another hit!

Organizers of the May AGM meeting were a bit concerned when they changed the time of the normally held fall

conference to May. With 84 registered participants on Friday and 81 for Saturday it was however a record high attendance. There were many new faces and with the break-away session there was time to rekindle and make new acquaintances.

Dr. Lynette Bowes from the Janeway Hospital graciously agreed to be moderator at this year's conference. Thanks for a job well done !



Dr. Bowes-moderator

Once again our speakers were very well received. It is a real testament to both the speakers and participants that such a wide range of professionals enjoy so many different disciplined speakers. It goes to show the commitment to multi-disciplinary care that is within the Atlantic Provinces. Thank you once again to all the speakers. Other attendees provided the comments in brackets:

- Dr. Mark Fleming for his talk on competencies and non -technical skills, "Excellent speaker. I think he should be an annual speaker because his message cannot be heard enough."
- Joanne Cumming and Nancey Roach for their presentations on the roles of Patient Navigators in Nova Scotia, "Wonderful to hear more about this role; very practical and useful information; helped to clarify communication lines/methods."
- Maartje Stroinke, Kimberley Hagan, Wanda Heading, Tracy Warren, Marc Blumberg and Monica Green-Nissen for their presentation on when to

refer to a psychosocial professional, "Very much needed information; helps with role clarification and understanding."

- Dr. Vicky Price for her presentation on Sickle Cell, "Very helpful, practical, useful information; excellent use of case examples to illustrate key points".



Dr. Magee

- Dr. Fergall Magee for his pathology presentation, "A very interesting presentation and topic. Very interested in the global aspect. Dr. Magee 'did it right'!"
- Janet Curran for her informative talk on Knowledge Translation, "There is potential to learn from her work and expand to APPHON".
- Dr. Victor Blanchette from Toronto Sick Kids for his presentation on bleeding disorders, "A complex topic explained in a very understandable and engaging way. Well done!".



Dr. LeBlanc

- Dr. Geneviève Leblanc for her presentation on Sickle Cell, "Very interesting and informative. Great use of "laymen" terms to include all professions. Very appreciated."

- Dr. Lynette Bowes who presented on Tumor Lysis: “An excellent overview of this topic. Concepts were presented in a comprehensive manner. Very well done!”
- Dr. Marie-Claude Grégoire for her presentation on pain, “Excellent! Loved the slide show.”
- Dr. Bruce Crooks for his presentation on delivering bad news “Would come to APPHON just to listen to this great speaker.”

Break away Reports

This year’s conference saw more time devoted to break away meetings. As well as having discipline specific meetings we had provincial meetings. From the feedback we received on our conference evaluations, these were very well received and will need to be duplicated next year. Here is a brief synopsis of key points:

New Brunswick Provincial Meeting:

This APPHON meeting afforded the dedicated pediatric oncology health care providers in New Brunswick a great opportunity to meet one another and establish a provincial networking group.

Our discussion identified issues of concern that relate directly to APPHON and it’s role such as the need for levels of care to be implemented in New Brunswick, yet the question of who and how the monitoring would be defined; the issue of limited pediatric resources and how important it is to be aware of each professional’s strengths and skills so that they could be accessed when needed within each of the pediatric health disciplines and the need to address the importance of language. Other issues discussed were the need for accurate and timely access to surveillance information; the burden to families for travel and medication costs; the role of the patient navigator and application to New Brunswick.

The New Brunswick Cancer Network hopes to establish a pediatric oncology

committee that will provide the forum necessary to bring issues such as those discussed back for consideration. *Deanna*

Stewart-McGarry

Nova Scotia & Newfoundland Provincial Meeting:

Representatives of Nova Scotia and Newfoundland met together for the Provincial Breakaway group. Several concerns were discussed including: communication, care plans/discharge planning and education. In terms of communication, it was agreed that the tertiary care centers will attempt to have a telehealth conference when discharging patients to their home communities whenever possible. It was also agreed that the family care coordinators would try to help ensure that there are regular updates to home communities. The Patient Navigators, where available, were also seen as primary coordinators within the home sites. It is hoped that families will be referred to their regional Patient Navigator when newly diagnosed so that communication will start early in the process. This and a detailed Care Plan that is sent to the community hospital should help with the discharge planning.

In addition, formalized skills labs are being looked at to help provide specific training in hematology/oncology. There was much discussion about what education is needed on site and what can take place at the tertiary care centers. For example, educational support for chemo nurses is best done on site so that it matches the reality of their clinic, where as a didactic teaching or a training session with psychosocial members might be better done at the tertiary centers. The discussions were helpful, informative and supportive to all. *Wendy Digout*

Psychosocial Group Meeting:

The Psychosocial Group met on the Thursday before the AGM as well as during the breakaway sessions. Major concerns within the group were how to make the lines of communication from

the Tertiary Centers back to home communities more effective and the scope of psychosocial information shared between centers: legal and ethical concerns. Very often patients return to their home communities and the caregivers will not be aware that they were seeing a psychologist or social worker and what the concerns were.

The group will look at "Shared Care" and the information that is currently included in charts when care is transferred. One recurring theme (throughout the AGM as well) was the usefulness of a video/teleconference when a patient is being transferred back to their home community. *Carol Digout*

Physicians Group:

The physicians had a very productive meeting at this year's AGM which covered many areas .

One of the first discussed was education. It was felt that the website was not being used to its full potential as an educational tool. The AGM is appreciated and it was felt that it has a good educational format. Participants felt that the review and sharing of pertinent articles would be beneficial. Grand rounds are felt to be a great educational tool.

The second major area under discussion was communication. Videoconferencing is seen as a great facilitator of communication between sites. Physicians would like the opportunity to participate each time a patient is discussed at tumor board. A videoconference on diagnosis would also be helpful and strongly encouraged. They would like to see audio improvements in videoconferencing. Better communication between sites and with family physicians is seen as a continual challenge.

Levels of Care were also discussed and how to safely give chemotherapy in rural areas is a major concern. Keeping up knowledge and experience in the smaller communities is a problem that needs to be addressed. How to implement Levels

of Care and education is important but decisions need to be made regarding the responsibilities of up-dates and the responsibilities of credentialing.

Lastly the pre-transplant consultation between Toronto and Newfoundland was discussed and seems to be working very well, limiting unnecessary travel for the patients. The teleoncology system in Newfoundland needs to be looked into further to see how it can be used to better serve pediatrics. *Dr. Nicole Leblanc*

Nursing Group:

This year's Nursing Breakaway session was attended by our largest number yet (40) with several attending their first APPHON AGM. Yahoo! Word is finally getting out there. Most of our discussion revolved around housekeeping items that affect us all.

Carol Digout updated everyone on the APPHON website, talking briefly about some of the information it houses as well as handing out an information sheet on how to access the site. We are hoping to establish a nursing directory on the website soon that will list nurses, their role and the hospital in which they work, so keep a look out for that in the future.

Review of the Transfer of Care Guideline revealed positive feedback from both tertiary and community care staff. Everyone felt they were getting the information they needed and in a timely fashion.

Gloria Gallant, Clinical Leader from the 6th North Clinic at the IWK Health Centre, explained the recent changes in staffing in the clinic and distributed a handout with the names and new phone numbers for the different Care Coordinators and 6th North clerical support staff.

Mickie Al-Molky, our fearless Levels of Care Coordinator, updated everyone on the sites that have been visited giving valuable suggestions to centers they would be visiting soon on how to be well prepared.

Kim Chapman spoke about the work that has been done over the past year on the Nursing Competencies and plans for where we hope to go over the next year. She encouraged everyone to review the competencies on the website and welcomed any comments.

Discussion was also held around potential educational topics that could be presented at next year's nursing session. Several suggestions were brought forward, i.e. Presentation(s) of an interesting case(s), practical information on a new protocol, family centered care, troubleshooting central line problems, etc. We'll be putting together ideas and checking with everyone to see what they think would be most beneficial. *Judy Clarke*

Please note: The PEI Group meeting summary was unavailable at time of printing and will be included in the next newsletter.

Levels of Care

To help establish Levels of Care, Mickie Al-Molky, Dr. Barnard and Carol Digout have been touring some of the hospitals in Nova Scotia with Jill Petrella from Cancer Care Nova Scotia [CCNS], and an IWK Family Care Coordinator [FCC]. Bridgewater, Kentville, Truro, Amherst, Antigonish and Yarmouth have been visited in April, May and June. Thank you to all for your hospitality and time spent in preparation and with us. Thanks also to Sue Ann Hawes, Annette Penney and Erin Little of the IWK who accompanied us on our visit.

The Levels of Care go forward plan is to work on a database for the information that has been collected; to look at education and competencies; to continue visits in New Brunswick and to hopefully re-visit some sites.

Thank You

A very special thank you to Lorne MacPhail from St. Peters, Nova Scotia. He has donated a beautiful hand made dollhouse with furniture to APPHON that will be used to raise money towards

education. The dollhouse, pictured below, took over 100 hours to complete.



Lorne MacPhail, crafter of donated dollhouse with Dr. Dorothy Barnard

It measures about four feet by three feet. Tickets will be on sale for July and August with a draw held in September. Perfect for any little girl. Thank you Lorne!

Important Tidbits

- French translated guidelines have been placed on the web site; more will be coming soon!
- Conference presentations are on our web site.
- Thank you to all our wonderful guides at the AGM: Virginia Fox, Joanne Verge and their Manager Fran O'Brien (Lab); Annette Avery, Renette Amirault and their manager, Debbie Weatherhead (Emergency); Mickie Al-Molky and 6N manager, Lois Laroche.
- Thank you to Melanie McInnis for coming for her AV support.
- Any health professional who does not have access to the APPHON website please contact Carol Digout at: email carol.digout@iwk.nshealth.ca: phone no. 902-470-7429

Our Vision:

To facilitate access for Atlantic province children and youth to comprehensive, current, effective, evidence-based hematologic/oncologic treatment delivered as close to home as safely feasible
