



CANADIAN BLOOD SERVICES SOCIÉTÉ CANADIENNE DU SANG

SUMMARY notes of the meeting of the National Liaison Committee held at the Chateau Laurier, Tudor Room, on Monday October 22, 2001, at 9 a.m.

PRESENT:	Dr. Robin Moore-Orr	Anemia Institute
	Mr. James Davies	Arthritis Society of Canada
	Ms. Eleanor Holmgren	Canadian Association of Transplantation
	Dr. David Rush	Canadian Transplant Society
	Ms. Diane Finkle	Canadian Cancer Society
	Mr. Howard Waldner	Canadian Healthcare Association
	Mr. James Kreppner	Canadian Hemophilia Society
	Ms. Christina Morgan	Canadian Immunodeficiency Patient Organization
	Ms. Kate Gagliardi	Canadian Society for Transfusion Medicine
	Mr. Morley Reid	CLC - St. John's
	Ms. Wendy Chaulk	CLC - St. John's
	Ms. Kathie Leigh	CLC - London
	Mr. Glen Dietz	CLC - London
	Mr. Clayton Bye	CLC - Winnipeg
	Mr. Shane Wood	CLC - Winnipeg
	Ms. Lorna Stevens	Neutropenia Support Association
	Dr. Ramiro Arrellano	Physicians and Nurses for Blood Conservation Inc.
	Mr. Howard Leung	Thalassemia Foundation of Canada
OBSERVING:	Dr. Graham Sher	Canadian Blood Services
	Mr. Ian Mumford	Canadian Blood Services
	Ms. Margot Maguire	Canadian Blood Services
	Ms. Lorna Tessier	Canadian Blood Services
	Ms. Christina Van Loon	Canadian Blood Services
REGRETS:	Mr. Lothar Huebsch	Canadian Blood and Marrow Transplant Group
CO-CHAIRS:	Ms. Linda Rankin	Canadian Blood Services Board of Directors
	Ms. Adélaïde La Plante	Canadian Blood Services Board of Directors

Building Open and Transparent Partnerships

Issues raised:

- Raise awareness of need for blood donations by highlighting recipient stories
- Increase strength of relationships with donors by reducing donation time
- Partner with high schools and elementary schools to raise awareness among young people
- Hospital partnerships are viewed positively; good lines of communication between centres and hospitals that can continue to be improved
- Can learn from other organizations in terms of advocacy

Challenges of CBS Board of Directors and Impetus for NLC

Challenges faced by the CBS Board of Directors:

- Inherited fragile, outdated system
- Many things needed immediate attention
- Increased focus on public participation

The Chairs outlined the reason for the establishment of the National Liaison Committee (NLC):

- Recommended by Krever and by the Public Participation Task Force
- Need to transform the system to meet demands
- Need to ensure public contribution on matters of importance
- Need to foster openness
- Desire to engage stakeholders in active, meaningful ways
- Ensure ability to cope with future difficulties by working together

Committee members were asked to identify specific issues or concerns they might have.

Items raised by committee members included the following:

- Address need to increase blood supply
- Link need to diseases such as cancer
- Focus on need to increase volunteers
- Consider additional committee meetings
- Contemplate extending committee beyond one year term
- Discuss blood product utilization in hospitals
- Work closely with hospitals
- Address surveillance and reporting systems
- Education of patients and physicians
- Raise awareness of appropriate utilization and alternatives to blood

FOR ACTION BY: CBS/NLC

- ✓ Determine best format for additional meetings (teleconference, video conference, interactive web forum)

Overview of Current Significant Issues – Chief Executive Officer

The committee heard a presentation of significant issues facing the blood system.

- Set priorities in order to address most important issues/challenges first
- Address burden on workforce
- Focus on retaining new donors who come forward
- Streamline and re-engineer procedures in order to increase efficiency, cost-effectiveness and capacity
- Increase focus on forecasting demand rather than emphasizing supply
- Address requirements of regulators (both domestically and abroad)
- Recognize CBS has earned trust and it must be preserved
- Relationship management increasingly complex and important — clear requirement for improved communication between regulator, funders, and stakeholders (patients, professionals, donors, volunteers)
- Continue to improve customer service
- Maintain support of research and development
- Monitor emerging threats, respond quickly

Significant opportunities were also outlined:

- Ability to help set public health policy as related to the blood system
- Opportunity to increase openness and transparency
- Opportunity to increase donor base, challenge Canadians to see donation as part of duties as citizens
- Opportunity to hear opinions of public and scientific communities around specific issues (i.e. consensus conference on donor eligibility criteria related to blood-borne HIV and hepatitis C)

Response of the committee

Committee members discussed the need to balance cost, benefit and risk in order to obtain maximum benefit.

Does Canadian Blood Services intend to charge hospitals for blood products or make them aware of the cost? The decision to charge for blood products would not be made by Canadian Blood Services but rather by the Provincial and Territorial Ministers of Health. CBS is examining the cost of a unit of blood and will provide this information as it becomes available.

Is Canadian Blood Services Research and Development partnered with the Canadian Institutes of Health Research? CBS is partnered with CIHR in a number of endeavours, which enables more research than would be possible in-house and the leveraging of more funding. CIHR is also used by CBS as a peer review mechanism for research funding.

Is the education of transfusion safety officers a priority? Canadian Blood Services has appointed a director of transfusion medicine whose mandate includes education. CBS will continue to consult stakeholders on the issue of transfusion safety officers.

Community ownership is an important principle for the blood system recognizing that clinics, donors, volunteers, partners and sponsors are members of specific communities. This must be balanced with regulatory requirements.

Remarks from Community Liaison Committee Representatives

Community Liaison Committees have been established in three pilot sites as part of CBS's goal to ensure public participation at the community level. Committees currently have two structures. Winnipeg is hosting an electronic forum, while St. John's and London are hosting face-to-face meetings. The committees are intended to provide a locally based consultation process.

St. John's:

- There are approximately 14 people on the committee, representing all aspects of health care.
- Currently determining its goals
- Has appointed a co-chair from membership outside CBS
- In the process of prioritizing the issues it examines
- Challenge is to accomplish as much as desired in four meetings per year.
- Examining possibility of sub-committees

Winnipeg:

- The virtual forum has an open structure - participants encouraged to put forward topics of interest, comments posted
- Start up has been slow-moving
- NLC meeting will be used to help fuel activity
- Forum allows for access on a broader level
- Strength is that there is time for consideration of comments and very honest responses
- Suggestions for improvement are being examined (such as initial face-to-face meeting)

London:

- Issues and concerns examined are similar to others
- Focusing on youth and ethnic groups
- Committee determining whether it is an advisory committee or to be used as volunteers to bring CBS news and information to the community and to galvanize action

After the presentation, there was discussion about combining the two meeting structures in order to take advantage of the strengths of each -- the impetus to act that comes from meeting face-to-face, together with the convenience and flexibility of the electronic forum. This would allow more progress to be made between meetings.

Regardless of whether committee suggestions are adopted or not, feedback is important to demonstrate that comments are heard and considered and that the committees are valued. Committees will most likely be implemented in other areas in the future.

Nomination of Spokesperson to present to CBS Board of Directors

This was deferred until later in the afternoon, at which time three potential spokespeople were nominated and two agreed to act jointly.

Dialogue to establish committee forum (transparency, expectations, committee procedures, links, and evaluation)

The committee will arrive at a common understanding and determine committee procedures. In view of these, five major topics were discussed: transparency (how to achieve it, what is it), function and procedures, evaluation (how to determine effectiveness), linkages (how to support each other) and member expectations.

Transparency

Main component defined as communication — CBS receiving information from the public and the public receiving information from CBS. Community organizations require access to all relevant information. Organizations prefer to receive the information directly from CBS and not from other sources.

A cross-purpose exists between the needs of donors (example, less time taken in donation process) and the needs of recipients (example, increased safety by more rigorous screening). There is a need to ensure openness to make sure both needs are met.

There is a need for increased communication among all players in the blood system -- between CBS and physicians, physicians and patients, and CBS and the general public. CBS should maximize use of regular donors as ambassadors. Time spent in clinics could be used to educate people on issues that need to be brought to the public.

Recipients of blood and blood products are excellent ambassadors of the blood system and need to be utilized.

The committee commended the CBS Board for its advances in transparency, noting an increase in trust. Specific examples of transparency were noted, including weekly teleconferences regarding inventory levels of Factor VIII, and the consultation of stakeholders on a new fractionation contract.

The committee looks forward to the Board considering their advice and providing feedback on decisions related to that advice.

The mechanisms CBS currently has in place, such as Open Board Meetings, provide access to stakeholders, but are not practical for the general public. Multiple approaches to openness and transparency are necessary to be as inclusive as possible.

Expectations

Committee members listed their expectations of the committee:

- Input to be considered
- Feedback to be provided on input
- Make constructive suggestions on improving the quality of the blood system
- Learn more about the system and share information with own organizations
- Help to expand into community and increase trust and ownership
- Be given the opportunity to express the opinions of the organization/group/public the member represents and to inform them in turn
- Work together in providing product information to patients
- Learn about the needs and concerns of others
- Glean successful strategies from each other
- Improve informed consent for patients
- Use stories of recipients to enrich communication and recruitment
- Engage in proactive and responsive communication and education of donors
- Improve hospital involvement
- Work towards greater openness
- Advocating together for the common good
- Provide input in order to help provide a safer system
- Balance the needs of all stakeholders
- Ensure both current and future safety of blood
- Discuss strategies to increase the donor base and improve donor retention
- Provide guidelines to physicians on the use of blood products and their alternatives
- Sharing information on systemic issues related to the health care system as a whole (i.e. aging population)
- Some benefit to oneself or one's organization
- Help the Board to set policy, allocate resources, manage delivery system
- Help shape priorities through feedback
- To focus on policy issues before the Board and not day-to-day management issues

Procedures/linkages

(These topics were joined, as they were considered highly related.)

Suggestions included:

- A summary of the meeting be provided to all committee members to be shared with their respective organizations within two weeks of each meeting
- A package of information related to meeting agendas be prepared and provided well in advance of each meeting
- Agenda to be issue driven and structured to ensure efficient operation of the meetings
- The committee should prioritize the issues it addresses in order to ensure maximum effectiveness
- The main areas of focus should be transparency/communications and supply/recruitment
- The priorities and list of issues before the Board should be provided to guide the committee
- The committee will bring forward issues to the Board

- CBS Board minutes are available on the web site at www.bloodservices.ca
- NLC summary notes will also be made available on the web site
- NLC notes will summarize the meeting rather than simply reflect decisions made. Names should not be attributed
- The committee meet more than twice per year. It was suggested that there could be two face-to-face meetings per year and additional meetings (teleconference, video conference or other) twice per year and as required

Evaluation

Major areas to look at include participation, effectiveness, feedback and outcomes. A couple of key successes could be identified to evaluate the effectiveness of the committee.

It was agreed that the value of the committee should be apparent after one year.

The purpose of the evaluation would be both to determine whether the committee should continue and to provide information about ways to improve it.

The mechanism of evaluation should be determined later, once issues to be addressed are determined and the committee has a sense of its purpose.

Key evaluation measures should be usefulness, communication, shared understanding of what success looks like, meaningful activity, and increased awareness, knowledge, trust and satisfaction.

It was agreed that key outcomes should be defined at the next meeting.

FOR ACTION BY: CBS/NLC

- ✓ Include open board meetings on next agenda: how to make them a productive exercise for all concerned.
- ✓ Prepare notes for approval within two weeks, post to Internet once approved.
- Key evaluation outcomes to be defined at next NLC meeting.

Key Topics for Future Discussion

Committee members were asked what key issues they would like to discuss at future meetings. Suggestions included the following:

- Promoting ownership of the blood collection process in the communities
- Plasma self-sufficiency
- Alternatives and choices
- Informed consent and education of physicians, patients and the public

- Reporting and surveillance
- Universal access
- Recruitment and retention of specific groups
- Blood safety and perceptions
- Appropriate use of products and minimizing wastage at hospital level
- Vein-to-vein accountability and seamless structure to allow common systems and standards
- Comprehensive strategy for communication for the blood system
- Easing the process for the donor
- Availability of plasma products
- Heeding the precautionary principle/how risk analysis works
- Role of CBS in advocating for access and informed consent
- How to improve stakeholder relationships
- Continuous improvement of communications between suppliers and users
- Improve understanding of true blood needs of the healthcare system, patterns over time

Preparation of presentation to the Board

Committee members discussed the key topics listed above and developed a presentation to be given to the Board of Directors on day two.

Feedback from Participants

Voluntary feedback forms are available in the information package.

FOR ACTION BY: CBS

- ✓ Collect and analyze feedback

Schedule next meeting

There was no discussion of this agenda item.

Adjournment

The meeting was adjourned at approximately 5 p.m.