

Policy Governing Relationships with Pharmaceutical Companies

Industry-developed treatments are important strategies in managing CLL/SLL. However, *conflict of interest concerns* (COI)¹ whether real or perceived can jeopardize the aims of CLL Canada and may reduce the confidence of the public in CLL Canada as an autonomous patient advocacy group. The goal of this document is to provide a clear policy to support essential ethical future relationships between CLL Canada and pharmaceutical companies.

To allow appropriate activities of mutual benefit while protecting our ethical and advocacy integrity, the following are required:

1. CLL Canada's financial relationships with pharmaceutical companies must be transparent to the public. CLL Canada will post on its web site: and the names of companies that provided financial support to CLL Canada projects in the previous calendar year.
2. CLL Canada Board of Directors must disclose, on candidacy and annually while in their Board position, any direct financial or other relationships with pharmaceutical companies with an existing or potential COI. This includes relationships of immediate family members who work with the pharmaceutical industry.
3. CLL Canada will maintain an arms-length relationship with pharmaceutical companies, providing the perspective of people with CLL, while protecting individual patient privacy.
4. CLL Canada accepts pharmaceutical funding in support of its activities on a project-by-project basis, including the CLL LIVE conference. Financial support must be an unrestricted grant and not conditional on any real or implied quid pro quo, other than the commitments related to the execution of the project made by CLL Canada in its application for funding.

"Unrestricted funding" means that pharmaceutical companies do not have any control of content or provide direction to these activities. Meeting programmes must be free of commercial influence, including selection and content of speakers, and be based on the best scientific evidence. Speakers must disclose any COI. Whenever feasible, project funding will come from more than one funding source and public events sponsorship must come from more than one source.

5. CLL Canada will not:
 - i. Distribute branded information on behalf of any company;
 - ii. Provide personal information about subscribers including for panels or research;
 - iii. Endorse or promote any product or brand in any CLL Canada activities, including the website, eBulletin, and conferences.
6. All requests for participation in pharmaceutical company activities made to CLL Canada or to individual board members representing CLL Canada will flow through the Chair, with actions pertaining to the request requiring Executive approval. Participating board members will inform the board chair of any additions or modifications to previously agreed to activities.

Board members will report on their activities with pharmaceutical companies at board meetings.

7. CLL Canada will participate in activities and meetings organized by pharmaceutical companies, or by a third party working for them, when doing so will benefit people with CLL. This includes the following criteria:

- Helping a company improve its understanding of patient needs, unmet needs and the patient experience.
- Helping a company improve its support services for patients.

CLL Canada will not participate in activities organized by pharmaceutical that are not of benefit to people with CLL.

8. The criteria in point 7 also apply whenever the participation of members of CLL Canada is requested by pharmaceutical companies. These requests will be reviewed for relevancy and COI issues, and if appropriate, circulated to the membership who will be invited to communicate directly with the project sponsor should they wish to participate in the project.

The policies governing requests for board or membership involvement in academic/scientific research are dealt in CLL Canada's Research Policy.

9. Board members who are representing CLL Canada in conferences, panels, and/or meetings organized by pharmaceutical companies or third party working for them can accept reimbursement of expenses related to their own travel and accommodation as well as fees for the time involved in preparing for and attending meetings.

Whenever possible the fees for the time involved in preparing for and attending meetings will be paid directly to CLL Canada. The board must approve any exceptions to this rule to permit these fees to be paid directly to the individuals representing CLL Canada.

CLL Canada representatives must not accept personal gifts.

¹**Conflict of interest (COI):** Conflict of interest is defined as situations in which financial or other personal considerations may compromise, have the potential for compromising, or have the appearance of compromising a Director's objectivity in meeting CLL Canada duties or responsibilities. COI includes any relationships of the Board member or family/relation with commercial interests and/or contracts involving CLL Canada, its Board of Directors that could potentially influence its advocacy work, whether real or presumed. A Director must declare to the Board any known or perceived conflicts of interest. However, mere evidence of a COI does not imply wrongdoing, only that this needs to be disclosed to the Board and properly managed according to the Board's decision.