



Compensation Guidelines for Partners with Lived and/or Living Experience (PWLE)



Research Committee
Canadian Premature Babies Foundation¹



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Introduction



These guidelines support the contributions of Partners with Lived and/or Living Experience (PWLE) in the Canadian Premature Babies Foundation's (CPBF) research, governance, and network activities. PWLE, including parents of premature babies and/or adults born pre-term, play a key role in these efforts.

Research leaders should clearly explain expectations — such as time commitments, responsibilities, financial details, and compensation — before a PWLE begins their role. To help CPBF continue coordinating and supporting the PWLE network, researchers using this network are asked to consider supporting us with an administrative fee.

Role Examples

Roles vary from low involvement (less time and interaction) to high involvement (more time and collaboration). Responsibilities may include advising, consulting, collaborating, or partnering throughout the research process, depending on project needs.

Lived-Experience Advisor/Committee Member	Offer insights from personal experience to guide research. Responsibilities may include attending meetings, reviewing materials, and providing feedback.
Study Co-Designer	Collaborate with researchers to design study elements, contribute to research questions, and ensure the study reflects relevant lived experiences.
Policy & Advocacy Contributor	Engage in policy discussions and advocacy efforts, providing perspectives to influence research-related policies, participate in events, and contribute to position statements or reports.
Workshop, Event, or Conference Speaker/Panelist	Share lived experiences and insights as a speaker or panelist. Involves preparation time and participation on event day.
Survey Developer	Provide input on survey design to ensure questions are clear, respectful, and reflective of lived experiences.
Grant/Project Reviewer	Evaluate grant applications or project proposals by reviewing materials, offering feedback, and participating in discussions.

Compensation Guidelines

To ensure fair compensation for PWLE and CPBF, it is essential that researchers include both PWLE compensation and the CPBF administrative fee in the project's budget or grant proposal, supporting the continued involvement of CPBF's network. Research leaders should also consider appropriate recognition for PWLE (e.g., naming on grants, websites, presentations, or articles) and inform them that anonymity may not be possible as part of a research team, unlike as research participants.

PWLE should be informed that compensation (e.g., money or gift cards) for participating in network activities is subject to tax laws and must be reported federally and provincially.

The CPBF Scientific Advisory and Research Committees review these guidelines annually.

Detailed compensation rates, based on the level of involvement in the research, are outlined in the tables below. A fixed **\$150** administrative fee is suggested for certain requests, supporting our database, researcher-participant connections, and essential administrative tasks.

Compensation Guidelines

TASK	DESCRIPTION	SUGGESTED COMPENSATION
Research Design, Planning & Conduct	Grant Writing and Research Application	\$40/hour
	Agenda Setting and Research Prioritization	
	Research Design	
	Assisting with application to the Ethics Committee	
	Research Advisor	
	Data Collection, Reporting, and Analysis	
	Event Speaker or Panelist	\$250 for half-day events \$500 for full-day events

Compensation Guidelines

TASK	DESCRIPTION	SUGGESTED COMPENSATION
Research Operations (CPBF)	Letter of Support (Grant Assistance)	Free
	PLWE Advisory Board Management (Set-up and coordination)	Variable (Depends on task complexity)
	PLWE Recruitment	
	Online Moderation (Meetings and group chats)	
	Findings Dissemination (Presentations, publications, infographics, posts, PREEMIE chats)	
Advocacy and Board Participation	Represent PLWE Voice in a Committee, Board or Event	\$600-\$1800/year (Depends on frequency of meetings and volume of independent work)