

## Guidelines for Patient-Partner Compensation

The purpose of these guidelines is to support the contribution of patients in research, governance and other activities as a member of CHILD-BRIGHT. ‘Patient-partners’ include both patients (youth and young adults with disabilities) and caregivers who are involved in such activities.

Patient-partners involved in CHILD-BRIGHT network activities will be offered honoraria in recognition of their contribution. There are 4 forms of compensation:

1. Annual honoraria for commitments to a committee or research project
2. Annual honoraria for CHILD-BRIGHT Network participation
3. Additional honoraria for extra activities on behalf of the CHILD-BRIGHT Network
4. Honoraria for training activities

For each fiscal year, honoraria are paid twice yearly, mid-way through (October) and at the end of each fiscal year (March). The fiscal year for the RI-MUHC is April 1– March 31.

Patient-partners may refuse to accept an honorarium or choose to offer it for donation without their decision impacting their ability to participate in network activities.

Project coordinators and committee chairs are requested to submit annual compensation expectations, including a list of patient-partners, by May 1 of each fiscal year. For example, for fiscal year 2019 (April 1, 2019 – March 31, 2020) requests should be submitted by May 1, 2019.

\*Should any patient-partners or activities (for which patient-partners will be compensated) be added to a project or committee plan after May 1, please advise CHILD-BRIGHT immediately.

All requests can be sent to Citizen Engagement program coordinator at [citizen.engagement@child-bright.ca](mailto:citizen.engagement@child-bright.ca) if there are any questions or concerns.

## 1. Annual commitments to a committee or project

Suggested honoraria are described in Table 1. The amounts reflect the estimated level of engagement required for these different activities.

Table 1

Commitment	Level of Engagement		Example of Network Activity	Suggested Honorarium
	Responsibility	Scope		
Availability by email; willing and able to participate in a few meetings by phone or in person	Contributes advice and feedback for decision making by research team	Assigned to a specific research project	Representative on a research project	\$500.00 per year
Commitment to a committee (includes meetings, follow-up actions, etc.)	Participates in decision making by providing options and recommendations	Activity has a network wide mandate	Member of CHILD-BRIGHT Training or KT committee, Citizen Engagement Council or National Youth Advisory Panel	\$1,000.00 per year
Contributing member in a governing committee (includes meetings, follow-up actions, etc.)	Has joint responsibility for decision making and mobilizing; Initiates and leads activities	Activity has a governing mandate for the network	Member of CHILD-BRIGHT Network Steering Committee and or Executive Committee	\$1,000.00 per year (NSC) 1,500.00 per year (Executive Committee)

In order for patient-partners to make an informed choice to participate, research leaders and committee chairs should provide a best estimate of time and effort required specific to the project or committee. Expectations of attendance and contribution, as well as financial considerations and designated honorarium should also be communicated in advance of the patient partner’s activity with the project or committee.

In cases where a patient-partner in a research project contributes substantially more over the course of a year than is described under “Commitment” and “Responsibility” in Table 1, the patient-partner may be compensated up to \$1,000 for that year from the Network’s Citizen Engagement funds. If the project and the patient-partner agree that the patient-partner’s role and contribution should be compensated at an amount greater than \$1,000, the amount over \$1,000 should be paid from the project’s budget.

## 2. Annual honoraria for CHILD-BRIGHT Network participation

Patient-partners (whether youths, parents, or other family members) are members not only of research teams or committees but of the network. Indeed, for CHILD-BRIGHT to succeed as a patient-oriented network, patient-partners need both to inform the network and be informed about it, whether by keeping abreast of what’s happening and changing in the network through reading the newsletter, by identifying through interviews or survey responses what’s working well and what should be changed, or by participating in network meetings or training sessions. Of course, patient-partners who require some accommodation to participate in such activities will receive the accommodation they need.

In recognition of the contributions patient-partners make to the network, to encourage them to continue making such contributions, and to make it a little easier to do so, patient-partners will receive compensation of \$100 per year in addition to the compensation they receive for their contributions as members of research teams or network committees.

If they choose, as they may, not to participate in these activities, they should email [citizen.engagement@child-bright.ca](mailto:citizen.engagement@child-bright.ca) to inform our coordinator of their choice, in which case the additional compensation will not be paid.

## 3. Additional activities on behalf of the network

Table 2 reflects the suggested honoraria for activities additional to those included in Table 1 that are undertaken by patient-partners on behalf of the CHILD-BRIGHT Network, as requested by the network’s central office.

Table 2

Level of Engagement		Example of Network Activity	Suggested Honorarium
Commitment	Responsibility		
Preparation and delivery of formal presentation after working with network organizers to ensure alignment with meeting’s objectives	Preparing presentation and materials (e.g., slides) and delivering presentation	Making formal presentation at CHILD-BRIGHT Annual Meeting	\$100.00 per event
Participation in informal panel or facilitation of small group	Preparing for and performing the particular role as a patient representative	Participating in informal panel or facilitating small group at CHILD-BRIGHT Annual Meeting	\$50.00 per event

Level of Engagement		Example of Network Activity	Suggested Honorarium
Commitment	Responsibility		
Active participation at external event as a patient partner	Attending event and reporting on it to a member of the Network Executive appropriate person within CHILD-BRIGHT	Representing CHILD-BRIGHT at SPOR Summit or another event	\$75.00 per ½ day
			\$150.00 per day

**4. Training**

Patient-partners will be compensated for participating in training activities organized by CHILD-BRIGHT, other SPOR networks, or SPOR support units.

Patient-partners should discuss their training needs and interests with their project coordinator or committee chair and obtain written approval for any training activities for which they wish to be compensated.

Table 3

Level of Engagement	Example of Training Activity	Suggested Honorarium
Attendance	CHILD-BRIGHT Webinar	\$75.00 per ½ day
		\$150.00 per day
Attendance and Completion	CHILD-BRIGHT Online Module	\$75.00 per ½ day
		\$150.00 per day
Attendance and Completion	In-Person Training	\$75.00 per ½ day
		\$150.00 per day
	Other SPOR Training (i.e. PORCCH module)	\$75.00 per ½ day
		\$150.00 per day

## **Travel and childcare expenses**

Travel expenses (e.g. airfare, ground transportation, hotel, food) that are reasonable and necessary for participation in CHILD-BRIGHT network-wide activities (e.g. annual meeting, face-to-face committee meeting) will be covered in line with the reimbursement policies of the host institution for the project or program administering the patient-partner's activities. Included in these expenses are those incurred by parents to provide childcare, including care for children with special needs.

CHILD-BRIGHT will reimburse patient-partners up to a maximum of \$500 per event for childcare costs. Patient-partners must submit a request for reimbursement for childcare costs in advance of the event and receipts (or other appropriate documentation) after the event.

Compensation for all these activities will be covered by the CHILD-BRIGHT central office.

Note: Patient-partners should be advised that many forms of compensation received through their participation in a Network research project or related activity are subject to relevant tax laws and regulations issued by the Canada Revenue Agency and the patient-partner's home province. While research leads should inform patients when a compensation option has the potential to impact a patient's financial situation, it is the responsibility of the patient to determine whether that option is the right fit for them.

\*\*These guidelines are reviewed and updated by the CHILD-BRIGHT Network Steering Committee at least annually.