

Public Engagement

Soft Bones Canada™ (herein “SBC”) conducts a broad range of public engagement activities on a variety of issues related to hypophosphatasia (herein “HPP”). Although “public engagement” and “consultation” are sometimes used interchangeably, “public engagement” has a broader meaning and reflects a wider variety of interactions and outcomes, such as:

- Engage multi-stakeholder discussion to deepen a shared understanding of impacts and solutions and deliberate, debate, and shape decisions;
- Exchange information with each interested group to clarify, understand and influence the issues, considerations, alternatives and solutions;
- Consider feedback on proposed programs, policies, and initiatives;
- Provide balanced and objective information to help the community understand the issues, alternatives, and/or solutions.

Public engagement activities can include, for example:

- Patients, caregivers and their families;
- Stakeholders, professionals, academia, business and industry, international organizations, non-governmental organizations, health care professionals, government health agencies, professional associations, licensing bodies, federal government, provinces, territories and municipalities.

Public engagement is an important part of the democratic process and allows SBC to fulfill key responsibilities. It enables us to:

- Foster information exchange and knowledge sharing to improve the understanding of health issues and build relationships among interested and affected parties;
- Facilitate discussions to provide opportunities to shape policies, best practices and decisions;
- Consider the feedback and perspectives of various stakeholders in the development or assessment of SBC policies, programs, services and initiatives in order to inform decisions;
- Enable informed decision-making that ultimately fulfills the mandate of SBC and improves the health and safety of our patients.

The input obtained during public engagement guides our discussions and informs our decision-making on policy and program development, service delivery, and initiatives. This guidance also supports the kind of organization we strive to be as we advance our mandate and evolve in response to the needs of the HPP community. It is our aim to strengthen public engagement that promotes effectiveness and best practices, and allows for flexibility to address varying needs for conducting engagement.

Public engagement activities vary in how they are conducted, but most will include planned two-way discussions with those external to SBC, promoted to ensure the involvement and consider the views and perspectives of a wide variety of participants who are interested in or affected by SBC initiatives. These activities are designed to gather input, clarify information and foster understanding among those interested and affected by an issue, decision or action and to better inform SBC’s decision-making.