

Public Engagement Goals

Soft Bones Canada™ (herein “SBC”) was originally referred to as the Canadian Hypophosphatasia Contact, prior to being incorporated under the Canada Not-for-profit Corporations Act.

SBC is a source of education, information, encouragement, and support for Canadian individuals and their families affected by hypophosphatasia (herein “HPP”), including interested individuals in the medical community.

The purposes of SBC as set out in the articles of incorporation are:

- (a) To advance education by providing courses, seminars, workshops, and educational materials about Hypophosphatasia to the public, patients and medical professionals;
- (b) To promote health by providing Hypophosphatasia patients and their caregivers with access to health counselling, information, and group support programs;
- (c) To advance education by supporting and conducting research into the causes and possible treatments of Hypophosphatasia and making the results publicly available; and
- (d) To undertake activities ancillary and incidental to the attainment of the aforementioned purposes.

ACTIVITIES TO ADVANCE VISION AND STRATEGY

The specific activities and means by which SBC’S purposes are to be accomplished as follows:

EDUCATE

Educational programs for persons with HPP, as well as their caregivers and family, are intended to educate them about the causes and treatment of HPP, as well as various aspects of living with HPP. Examples of the types of programs in this regard include:

- Holding webinars with expert speakers on topics related to HPP, such as the causes and cure of HPP;
- Conduct patient education sessions and conferences, with expert guest speakers;
- Create and publish pamphlets and factsheets to explain what HPP is, its causes and treatments;
- Disseminate information on SBC’s website and through social media about HPP, new diagnoses, treatments, important updates, etc.;
- Disseminate information to HPP health care professionals across Canada to provide them with information to give to their HPP patients.

SBC provides patient education sessions to provide health information to patients, their families, friends and caregivers concerning HPP, support and treatments related to HPP. These sessions will be offered for no charge. All education programs of SBC are overseen by its Board of Directors to ensure that the programs will provide the public and attendees with accurate information about HPP, together with our Scientific Advisory Board (“SAB”).

Dr. Cheryl Rockman Greenberg will be assisting SBC in conducting patient education seminars and as Chair of the SAB. Input on educational programs will also be sought from persons with HPP, and from representatives in relation to the latest treatments and access to those treatments.

EMPOWER

SBC strives to empower HPP patients and caregivers to confidently engage in topics and public policies/programs that significantly impact them and provide researchers and health care professionals with patient insights that result in improved diagnostics, primary care and therapies.

Opportunities abound through:

- Sharing patient journeys and relevant information that shorten time to diagnosis, provide evidence for access to therapies and improved diagnostics;
- Networking and collaborating with medical and research industries through conferences, events and working groups to get the latest updates in science and medicine related to HPP, cause, research and therapies, and make the results publicly available;
- Raising awareness, and disseminating info to multi-stakeholders about our organization and activities;
- Educating in regards to the process/roles of various agencies and organizations whose policies and decisions affect the HPP community;
- Developing understanding to dialogue effectively with the public, participate and provide opportunities to engage in discussions surrounding access to healthcare and share the HPP community voice informing policy and decision makers.

CONNECT

Connecting patients, caregivers with each other and resources to build a stronger HPP community, effective in overcoming challenges through corroboration with the aim to improve quality of life.

This is achieved in part through:

- Establishing regional support groups to bring together a local HPP community to support patients and caregivers where they live and address the unique needs for each area;
- Provide opportunities through social media, email, telecommunications, newsletters and MailChimp to keep up-to-date with happenings, newsworthy items, patient journeys and other events;
- Offer ways to identify as a community through t-shirts, novelties, and other materials;
- Share resources to improve quality of life and overcome challenges.
- Provide health care professional references for local areas to access HPP aware care and services.