

Vision and Strategic Plan

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.

Scope and Sequence

Individuals with HPP face a host of extraordinary challenges, including:

- misdiagnosis and/or long, difficult path to diagnosis;
- difficulties finding physicians or clinical centers with experience treating HPP;
- feelings of isolation;
- limited treatments;
- barriers accessing available therapies;
- challenges accessing medical, social or financial services or assistance.

All of these challenges lead to increased morbidity, loss of life or poorer quality of life and increased costs to the family, the healthcare system and ultimately the Canadian economy. SBC recognizes the commitment and creativity shown by the community to date in tackling these challenges, yet the need is still great.

SBC exists to Educate, Empower and Connect those affected by HPP, be they patients, caregivers, professionals involved in healthcare or the community, with a view to directly improve quality and sustaining of life, reducing the challenges and costs to families, the healthcare system and supporting patients to be engaged as healthy, productive members of society. We support and recommend actions that will:

- Improve early detection, diagnostics and prevention across Canada;
- Improve education for patients and caregivers managing HPP;
- Advocate for evidence-informed care which is delivered in a timely and equitable manner;

- Build a strong support community to reduce the isolation and hopelessness experienced by those dealing with HPP;
- Raise awareness about gaps in programs;
- Support improving the education of healthcare practitioners and increasing the number who are aware of HPP and the related diagnostic tests;
- Advocate for equitable health care services like physiotherapy as people with common diseases;
- Support research and clinical practice guidelines and protocols;
- Explore the possibility of a patient registry to increase innovative research options, promote access to sustainable promising therapies and establish patient-centered care and voice.

Our ultimate vision may be a lofty one – to see every patient living a productive life - every caregiver with lots of support, national, established guidelines and protocols, evidence-informed care, detection at birth and equitable access to therapies. Yet, we believe our cause is a worthy one and that by working together with patients, caregivers, health care professionals, government and industry, we can bring real positive change into the lives of those affected by HPP and the families and communities that care for them.