Canadian HPP Clinical Expert Committee

TERMS OF REFERENCE

1. PURPOSE

The Canadian HPP Clinical Expert Committee (Also known as the HPP Advisory Committee) has been established to provide expert advice on the treatment and management of Hypophosphatasia and the use of Strensiq® as a treatment option.

2. FUNCTIONS

The functions of the Canadian HPP Clinical Expert Committee are:

a) To provide advice on the current and emerging treatment options to health professionals with regards to HPP and to articulate the goals of treatment;
b) To advise on best practice (including timing of implementation and monitoring) for quality use of Strensiq®;
c) Manage the requests for Strensiq® review to the HPP Committee in a timely manner including
    i. Review the appropriateness and accuracy of diagnostic information
    ii Review applications for new patient starts
    iii Review requests for renewals of patients on Strensiq at 24 weeks, then at 48 weeks, then 1 year intervals to ensure that the patient is continuing to meet criteria for treatment
    iv. Develop guidelines for the initiation and discontinuation of Strensiq in patients with Perinatal HPP
d) Report to Provincial Health Authorities the recommendations of the committee;
e) Apprise the Provincial Health Authorities of issues arising from benefit reviews;

3. MEMBERSHIP

a) Chair:
The Committee will be chaired by 1 person, preferably a person with particular expertise in metabolic bone disease

The Chair is responsible for:
- Guiding the meetings according to the agenda and time available
- Ensuring all discussion items end with a decision, action or definite outcome
- Reviewing and approving the draft minutes before distribution
- Authoring correspondence external to the HPP Committee when a request for advice has been sought

NOTE: If an immediate decision is needed on urgent treatment of an unexpected severely affected neonate the Chair of the Committee or his/her replacement will be authorized to approve treatment for 1 month to allow time for full review by the Committee.

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b) Secretariat:
The secretariat for this committee will be Erika Bloomfield

The secretariat is responsible for:
- Scheduling meetings and notifying committee members
- Inviting specialists/subject experts to attend meetings when required by the committee
- Preparing agendas and issuing notices for meeting, and ensuring all necessary documents requiring discussion or comment are attached to the agenda
- Distributing the agenda and meeting materials
- Taking notes of proceedings and preparing minutes of meeting
- Distribute the minutes to all committee members. The minutes should be checked by the Chair and accepted by committee members as true and accurate record at the commencement of the next meeting.

c) Membership:
Membership of this Advisory Committee will be multi-disciplinary and include one member with special expertise in each of the core positions below:
- Genetics and Metabolism
- Neonatologist
- Endocrinologists (peds and adult)
- Pain Specialist
- Rheumatologist (peds and adult)

Committee members will cease to be a member of the HPP Advisory Committee if they:
- Resign from the committee
- Fail to attend 3 consecutive meetings
- Breach confidentiality

4. MEETING OPERATING PROCEDURES

a) Accountability:
The Committee is accountable to TBD (Provincial Drug Plans)

b) Quorum:
A quorum of the Advisory Committee shall be 50% of the Committee membership inclusive of the Chair and Secretary. Decisions will be made by

consensus. Where no consensus can be achieved, decisions will be made by voting.

c) Meetings:

There shall be a minimum of 4 meetings scheduled (quarterly) for a period of one (1) hour each calendar year. Additional meetings can be held at the call of the Chair through the secretary.

The agenda and accompanying materials shall be circulated within a minimum of seven (7) days prior to a meeting.

The business of the Committee may continue in its entirety with or without a full membership complement appointed.

Meetings will be held via Teleconference unless otherwise stated.

d) Attendance:

Attendance by the member at a minimum 60% of the meetings in a 12-month period is required. If a particular member's attendance is below the minimum, the Member's membership on the Committee may be reviewed at the discretion of the Chair, in consultation with the other members of the Committee.

e) Term:

Each member's participation on the Committee will be reviewed every 2 yrs.

f) Voting:

All decisions of the Committee will be by a majority vote, or in a manner as designated by the Committee. Each Committee member is allocated one vote irrespective of membership representation.

g) Minutes:

A master copy of the minutes will be located at the Children's Hospital Research Institute of Manitoba 5th floor (715 McDermot Ave Winnipeg, MB R3E 3P4). All members will be sent a copy of the minutes. An annual report will be prepared and distributed to all Committee members and Provincial Drug plans.