

## Regional Support Groups – Vision and Mandate

Regional Support Connections are in the process of being implemented with an initial connection starting in Alberta with expansions planned for Manitoba and Ontario. The Connections' host roundtable discussions, coffee get-togethers and guest speakers with the potential to add an annual conference. These conferences could be webcast to an online community with a library of previous webcasts. There is potential to have a forum and shared resources for each connection on our website for the various locations. These connections enable patients and families to find support and develop a stronger voice as a local community thus mobilizing to improve access to resources where they live.

### Vision

EDUCATE • EMPOWER • CONNECT

### Mandate

When peers directly impacted by HPP are able to share diagnosis, experiences, resources, tips and their journey at a local, compassionate and receptive get-together, extraordinary things begin to happen. No longer isolated, their identification with and understanding of all things HPP, achieves a unique sense of community not found anywhere else, as needs differ from location to location. Members of regional groups or “connections” come together and evaluate relevant information and regional resources. They raise awareness and educate in their local area providing non-professional, non-material support. They are empowered to host roundtable discussions and guest speakers. As they educate, discuss and understand, their confidence increases to solve problems and suggest solutions, share coping strategies, relate personal experiences and establish needed social networks. Most importantly these local networks enable patients, families and peers to discover connection, find support and develop a stronger voice as a local community encouraging real change that results in improved access to resources where they live.

### Goals

- Establish program under Education and Events (as a meeting/event) which will then move to come under Connect with facilitators consecutively set up in each new location;
- Facilitate a regional connection event in each province;
- Train facilitators for each local connection to take over after initial meeting.

### Facilitators

- Comfortable with speaking;
- Set tone, help members to listen to each other, explains ground rules, facilitates introductions;
- Supports and encourages sharing;
- Addresses problems that arise;
- Maintains the list of members, mailing list, telephone chain (individual signs confidentiality agreement);
- Provides website updates to the Office Manager.

### Delegate:

**Advertising:** (poster, flyer, announcement, local radio) – clergy, HCP's, Administrators, city/county/community resources, hotlines, Hospital/clinic/pharmacy, library, agencies, bulletin boards;

**Refreshments:** (can be as simple as meet at local Tim's);

**Meeting Space:** needs to be easily accessible, parking, wheelchair (see above – local hospitals, pharmacies, community centers will provide free space – do not recommend person's home;)

May oversee a chat forum; Newsletter/MailChimp.

### **Ground Rules:**

- Open or Closed – join in anytime, join in beginning of the year, only HPP patients/caregivers, or can there be interested peers (needs to retain HPP focus);
- Refreshments;
- Meet - how often;
- How long;
- Focus – can be as simple as a couple of people/families meeting at a local coffee shop or park all the way up to a more established group;
- Budget options, fundraiser (if a larger gathering);
- Each region could have an annual meeting – maybe coffee meetings every other month and one bigger meeting.

*Please contact us if you are interested in starting a connection in your area.*

### References

<https://ctb.ku.edu/en/table-of-contents/implement/enhancing-support/peer-support-groups/main>

<https://ctb.ku.edu/en/table-of-contents/structure/strategic-planning/vision-mission-statements/main>