Access Issues and Acromegaly

October 2014

What You Know

- Acromegaly is a rare, slowly progressive, acquired disorder that affects individuals when the pituitary gland produces too much growth hormone.
- In most cases, acromegaly is caused by the growth of a benign tumor (adenoma), affecting the pituitary gland.
- Untreated, acromegaly can potentially cause serious illness and painful complications that affect one's life.

What You Know

Treatment Interventions for Acromegaly:

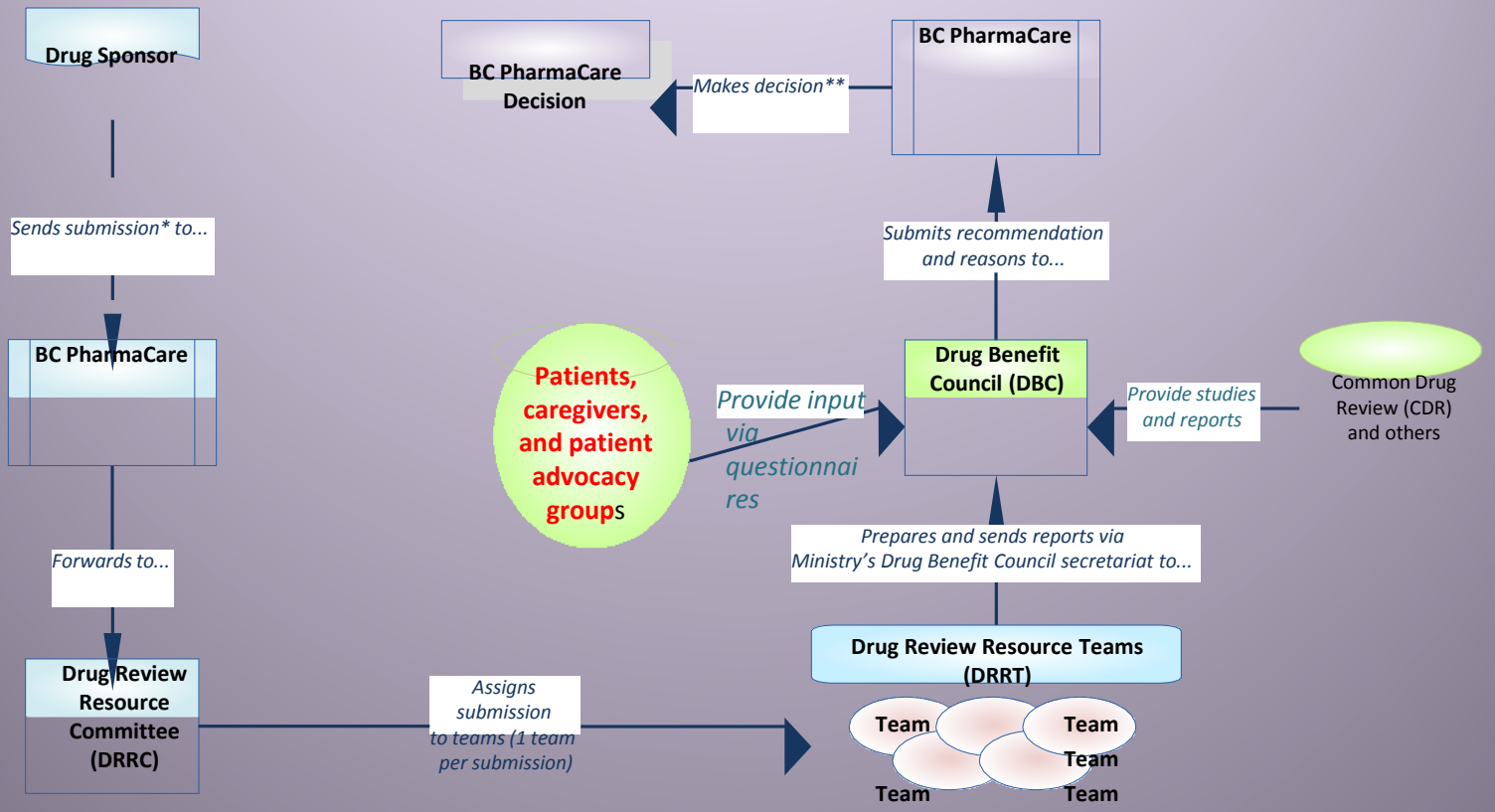
- Surgery
- Radiation Therapy
- Medical Therapies
  - Somatostatin analogues (eg. Sandostatin)
  - Dopamine agonists (eg. Dostinex, Bromocroptine)
  - pegvisomant (Somavert)

What You May Not Know

- Medical therapies to treat acromegaly are approved for safety and efficacy by Health Canada
- The price for these therapies are regulated by the federal government (PMPRB)Patented Medicines Pricing Review Board
- The Common Drug Review is a national organization that reviews drugs on behalf of provincial drug plans (Pharmacare)
  - Makes recommendations to cover /not cover
- British Columbia decides which therapies to cover as an eligible benefit on it Pharmacare plan

Medical Benefits Pharmaceutical Services Divsion

Drug Review Process in British Columbia — Details



** Drug must have Health Canada Notice of Compliance (NOC) and Common Drug Review recommendation, if applicable. A drug may not need to go through the CDR if the manufacturer asks for a change in coverage criteria (e.g., switching from Limited Coverage to Regular Benefit status).*

*** PharmaCare's decision is based in part on the Drug Benefit Council recommendations and in part on other factors such as whether it already covers drugs used to treat similar medical conditions and the overall cost of covering the drug.*

BC PharmaCare *"Your Voice."*

- Through the Pharmacare website, patients, caregivers, and patient groups can add their voice to the BC PharmaCare drug review process by filling out an online questionnaire for consideration by the Drug Benefit Council as part of their review.

  http://www.health.gov.bc.ca/pharmacare/yourvoice/

- Process is confidential & responses will be separated from your identifying information before being provided to the Drug Benefit Council.
- **For patient groups that are providing input:** Only the name of your organization will be forwarded to the Drug Benefit Council.

- **Who can give input?**
- If you **are a B.C. resident** and any of the questions below applies to you for a drug listed on the website that is up for review:
- Do you have the medical condition for which the drug would be used?
- Are you a caregiver to someone who has that medical condition?
- Does your patient group represent patients who have that medical condition AND have you registered with PharmaCare to give input? **CORD; Vancouver Acromegaly Support Group;**

- Pharmacare will send you an e-mail when drugs are being reviewed if you sign up for the subscription service.

- **How do I find out about PharmaCare's coverage decision for a specific drug?**
- After the Drug Benefit Council provides its formal recommendation to the Ministry of Health, the Ministry reviews the recommendation and makes a coverage decision in the context of existing policies, programs, priorities and resources.
- To find out when a decision will be made about PharmaCare coverage for a specific drug, visit the Drug Review Results section.

BC Reimbursement

Drug name	Pharmacare Status
• Octreotide acetate Sandostatin LAR	• Non-benefit
• Octreotide acetate Sandostatin SC	• Covered on Palliative Care
• Cabergoline Dostinex	• Non- benefit
• Bromocroptine • Dopamine agonist	• Covered as a regular benefit
• Pegvisomant • Somavert	• Non-benefit

What You Can Do

- For New Medications
  - Participate in the public review process
- Communicate with your physician
  - Doctors are the best advocates for patients with Acromegaly
- Communicate with your MLA
  - Share your story with your elected representative; MLAs often don't receive the whole picture of an issue and welcome insights from constituents
- Communicate with other patient groups
  - Learn from the experiences of other patients associations