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Skin

This pamphlet tells you about the skin symptoms of Birt-Hogg-Dubé syndrome.

Birt-Hogg-Dubé Syndrome

Birt-Hogg-Dubé (BHD) Syndrome is a rare disease caused by changes in the Folliculin gene.

People with BHD can get:

1. Skin bumps (fibrofolliculomas)
2. Lung cysts
3. Collapsed lungs (pneumothorax)
4. Kidney cancer (renal cell carcinoma)

BHD affects people differently. If you have BHD, you may get none, some or all of these symptoms.

Fibrofolliculomas

- Most people with BHD get small pale skin bumps on their face, neck, ears and upper body.
- These skin bumps are called fibrofolliculomas.
- People with BHD can develop a few or hundreds of skin bumps.
- Skin bumps usually grow after the age of 20 and can get worse over time.
- These bumps are benign tumours of the hair follicle.
- They are **not** cancerous or dangerous to your health, but some people do feel self-conscious about them.
- There are a number of skin conditions that look like BHD but are not. You **must** see a dermatologist who will be able to tell you what type of skin bumps you have. Your doctor should be able to arrange this for you.



Photos courtesy of Derek Lim, University of Birmingham, UK

Treatment - things to think about

- There are several treatments for fibrofolliculomas (listed on the next page).
- All of these treatments are temporary and will not stop new fibrofolliculomas from growing. They might cause scarring, or have other side effects. **You should talk to your doctor about this.**
- When choosing a treatment, make sure your doctor knows you have BHD.
- You may also want to talk to a counsellor if you feel self-conscious about your skin condition.

Treatment

1. Laser treatment - uses a laser to remove fibrofolliculomas.
2. Surgery - fibrofolliculomas are cut off.
3. Cauterisation - use of very high or low temperature to remove fibrofolliculomas.
4. Radiofrequency ablation - uses radio waves to remove fibrofolliculomas.
5. Hyfrecation - uses electricity to remove fibrofolliculomas.

Which country you live in and your health insurance plan will affect which treatments you can get.

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Information sources are available at:
http://www.bhdsyndrome.org/wp-content/uploads/2013/11/BHD-information-pamphlets-references_v2.pdf