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Kidney

This pamphlet tells you about the kidney 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.

Kidney cysts and tumours

- People with BHD can get kidney cysts and/or tumours.
- Kidney cysts are fluid filled sacs in the kidney.
- Kidney cysts and tumours should be checked regularly in case they become cancerous.

Kidney cancer - symptoms

The symptoms of kidney cancer are:

1. Blood in your urine
2. Constant pain below your ribs
3. A lump in your stomach
4. Weight loss, even if you're not on a diet

If you have any of these symptoms, you should see your doctor as soon as possible.

- Up to 1 in 3 people with BHD will get kidney cancer.
- This type of kidney cancer is called renal cell carcinoma.
- This normally develops after the age of 30.

Kidney cancer - Screening

- People with BHD should have a kidney scan every year from the age of 20.
- If possible, you should get an MRI scan as this will show up smaller tumours.

Treatment

- BHD kidney cancers grow slowly and are **not** aggressive.
- Tumours should be checked regularly by a doctor, and removed when they are 3 cm or bigger.
- For most people with BHD, 1 kidney operation is all they will need in their lifetime.

Things to think about

- Normal kidney cancer can be very aggressive, so doctors often remove the whole kidney.
- If possible, people with BHD should **not** have a whole kidney removed because tumours might grow in the other kidney later.
- It is very important that your doctor knows you have BHD, and that you might get more tumours.
- If you do get more tumours, these should be treated in the same way.
- If found early and watched closely, kidney cancer is **not** life threatening for most people with BHD.

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http://www.bhdsyndrome.org/wp-content/uploads/2013/11/BHD-information-pamphlets-references_v2.pdf