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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

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

Kidney cancer

- Roughly 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.
- 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.

Kidney cancer - Screening

- People with BHD should have a regular kidney scan from the age of 20.
- If no tumours are seen on the first scan, you should get a scan every 3 years.
- If a tumour is found, then you must get a scan at least once a year.
- 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 is 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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