

BHD Syndrome International Registry

Everything You Need to Know

- BIRT is the patient registry for Birt-Hogg-Dubé syndrome (BHD) managed by the **Myrovlytis Trust** and **BHD Foundation** and is powered by **Pulse Infoframe**.
- BIRT will help **researchers** and **health care professionals** better **characterize the disease**, it's **prevalence** and **trajectory**.
- This registry will seek to **improve quality of life** for the BHD community, to **facilitate faster diagnoses** and **development of treatments** for BHD.



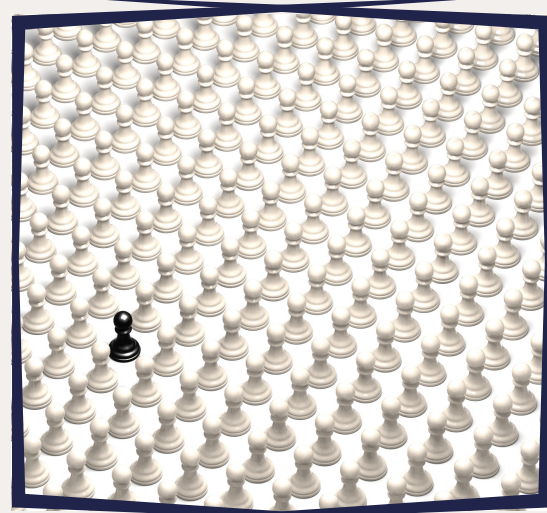
What Is BHD?

- BHD syndrome is a **rare, inherited condition**.
- BHD is characterized by the development of benign skin tumors, pulmonary cysts, collapsed lung and a predisposition to kidney cancers.
- **Currently, there is no cure for BHD**, so patients must have individual symptoms treated as they appear.



How Rare is BHD?

- Only **600 families** are known to be affected by BHD. However, it is **believed** to be far **more prevalent** and is **underdiagnosed**.
- This scarcity is why the **Myrovlytis Trust**, **BHD Foundation** and **Pulse Infoframe** have initiated the BHD International Registry.
- This registry will aid **vital research** for new BHD treatments.



Patient Privacy

- **Security processes** and **technologies** are integrated across the BHD International Registry to ensure only **authorized people** can **access the data** they are allowed to see.
- All personal identifying information about patients is **removed** (name, age, sex).
- **Patients** must give **consent** for their data to be seen and can pick when it is most appropriate.



Learn More Or Sign Up For The
BHD International Registry
Through The QR Code or visit
birt.healthie.net

