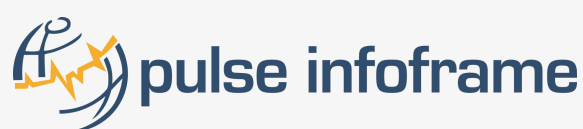


BHD Syndrome International Registry (BIRT)

A Rare Community United For Common Good



How Does BIRT Work?

- **Participants enter data** about themselves (which is updated in real time) to be used for **research**. The **more data collected**, the **greater the research possibilities**.
- **Participants are given access** to assessment instructions, previously uploaded clinical results, educational and engagement tools.
- Platform allows participants to better **understand their disease** while **contributing to research**.

How BIRT Helps Stakeholders

Prevalence

Determine how widespread BHD is.

Symptoms

Collect information on how patients manage symptoms and assess their quality of life.

Cancer

Determine which type of kidney cancer is most likely to develop in BHD.

Clinical Trials

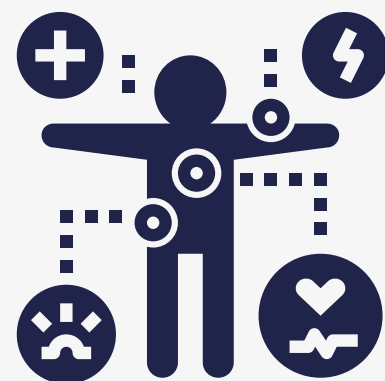
Use registry as a database to recruit for clinical trials.

Manifestations

Determine if there are any other cancers associated BHD other than what is known and understand the associated genetic variants.

Consensus

BIRT allows for consensus to be formed on diagnostic and management criteria.



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