

Dear ------

I have just registered for the BHD Syndrome International Registry (BIRT) and am inviting you to take part.

The BHD Syndrome International Registry (BIRT) is funded and managed by the Myrovlytis Trust and BHD Foundation. We envision a future in which we can cure or prevent the symptoms of BHD and believe that a BHD-specific registry will help us achieve that goal.

The data collected within this registry will facilitate research to further our understanding of BHD, enable the development of therapies or a cure, and put patients at the centre of research.

Broadly, the BHD Syndrome International Registry aims to:

* Determine the prevalence of BHD.
* Determine if there are other manifestations associated with BHD (aside from those existing known in the skin, lung and kidney).
* Collect information on the type of kidney cancer most likely to develop in BHD.
* Collect information on the ongoing management of your symptoms (e.g. kidney scan type and frequency).
* Include information on genetic sequencing to determine if any particular variants are associated with particular manifestations.
* Collect lifestyle information to understand if environmental factors influence the treatment or management of BHD.
* Assess the quality of life of those living with BHD
* Use the registry as a database for clinical trials recruitment.

It is vital that as many people participate in the registry as possible. The more people in the registry, the more data there is for researchers to study. More data means there increased confidence in the results of any research. In turn, this will support the aims of the registry and will ultimately lead to an improvement in the quality of life for those living with BHD.

To participate in the BHD Syndrome International Registry (BIRT) please register here: birt.healthie.net

If you would like to talk to me about the above, please do contact me on ------ or email me at ------. You can also contact the team at the Myrovlytis Trust with any questions via email: contact@myrovlytistrust.org

Best wishes

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