

myrovlytis trust

Education Strategy
London, July 2015

1. Mission

- 1.1. To promote research into rare genetic disorders; and
- 1.2. To advance education of the public in medical and molecular genetics.

2. Why are we **advancing education in medical and molecular genetics**?

- 2.1. To offer families affected by BHD and related rare genetic kidney disorders, and the public, accurate, comprehensive and clear information on BHD Syndrome and related rare genetic kidney disorders, so that individuals may be well-informed and confident to engage with relevant information and research;
- 2.2. To engage researchers and the public together to promote an open-access model of research and to establish new models for scientific and medical collaboration and communication.
- 2.3. Our education activities are currently limited to BHD syndrome. The Myrovlytis Trust has an aspiration to replicate our efforts in BHD into related rare genetic kidney disorders, in the near future.

3. What types of projects do we fund?

Projects are organised in three areas:

- 3.1. Information: We endeavour to provide accurate and comprehensive information concerning all aspects of BHD Syndrome, and to present such information in an accessible, clear and concise way.
- 3.2. Resources: We strive to be an efficient portal for researchers and the public to pursue further any topics of interest related to BHD syndrome and provide useful resources to this aim.
- 3.3. Engagement: We aim to offer space for cross-communication amongst the BHD community, counteracting the often counterproductive separation between clinical and basic research groups, so that all participants may benefit from each other's knowledge and experiences and may actively engage in the common goals of: developing a treatment and cure for BHD; and learning about the biology of BHD to positively contribute to research in other genetic diseases.

4. How do we advance education in genetics?

4.1. Information:

- 4.1.1. Create and maintain relevant pages on BHDSyndrome.org relating to the biology of, clinical presentation of, and treatments for, BHD Syndrome as well as information concerning diagnosis and management of genetic diseases in general;

4.1.2. Organise and fund the annual [BHD Symposium](#) to provide an occasion for researchers to share ongoing research and collaborate on future projects, for patients to benefit from experts in BHD and for all attendees to interact and benefit from each other.

4.2. Resources:

4.2.1. Develop research resources for scientists on BHDSyndrome.org, such as the [BHD Literature Database](#), [BHD Article Library](#), [Laboratory Essentials](#) and [Clinical Trials](#).

4.2.2. Develop patient resources on BHDSyndrome.org, including [Clinical Trials](#) and information on obtaining [genetic counselling](#).

4.2.3. Support the [European BHD Consortium](#), a network of European researchers and clinicians collaborating to raise awareness of, improve diagnosis of, and facilitate laboratory research into, Birt-Hogg-Dubé syndrome.

4.3. Engagement: On BHDSyndrome.org: publish [video](#) interviews with researchers and [written](#) interviews with researchers and patients; maintain the public [Forum](#); maintain the [BHD Research Blog](#); maintain [BHD Worldwide map](#).

5. Who do we seek to engage?

5.1. Researchers carrying out world class research into rare genetic kidney disorders;

5.2. Individuals and family members affected by BHD and related rare genetic kidney disorders;

5.3. Members of the public who are interested in learning about genetic diseases.

6. Other useful information

6.1. Our Education Strategy is reviewed annually.