

Myrovlytis Trust, Education Strategy

London, May 2011

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 BHD family members and the public accurate, comprehensive and clear information about genetic diseases in general and BHD syndrome in particular, 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 so as promote an open-access model of research and to establish new models for scientific and medical communication.

3. What types of projects do we develop?

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 genetics education?

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 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 interviews with researchers (video and written) and patients; maintain the public Forum; maintain the BHD Research Blog; create and maintain BHD Worldwide map.

5. Who do we seek to engage?

- 5.1. Researchers carrying out world class research into BHD syndrome;
- 5.2. BHD patients and family members
- 5.3. Members of the public who are interested in learning about genetic diseases.

6. When did we begin and when do we review the strategy?

- 6.1. The MT was founded in late 2007. Our strategy is reviewed annually.