



BBS UK Research Statement & Pharma Policy

Research definition

The systematic investigation into and study of materials and sources in order to establish facts and reach new conclusions.

Our Vision and Purpose

Research is an integral part of the history and future of Bardet-Biedl Syndrome UK and enables the Charity to improve the lives of those with the Syndrome through better management and treatments and in understanding the underlying causes of the Syndrome.

As a Charity, we have been primarily patient support focused and are only just starting to consider our role with regards to research and collaboration with the scientific and medical professionals across the globe. Our aim is to engage with rare disease research, to share experience and knowledge of our genetic condition with others and network with similar organisations. Most importantly, we wish to share and publish updates regarding research to our members and patients.

In 2017 BBS UK set up the 'Bardet-Biedl Syndrome UK Scientific Advisory Board' with Professor Philip Beales, Dr Elizabeth Forsythe and Dr Helen May-Simera becoming the founding members. BBS UK looks forward to providing greater support into the research of BBS and hopes that the Scientific Advisory Board will provide a useful mechanism to assist collaboration with others in the national and international community.

BBS UK's involvement with research will allow the Charity to learn more about this complex condition in the hope that it can improve the quality of life for patients and seek further treatments. BBS UK believes the research objectives of the Charity and the Scientific Advisory Board and its collaboration in research will directly further the aims of the Charity.

BBS UK's aims are:

- To preserve and protect the health and promote the welfare of persons diagnosed with Bardet-Biedl Syndrome and their families;
- To advance the education of the medical and educational professions and the general public on the subject of Bardet-Biedl Syndrome and its implications for the family and to promote research for the public benefit in all aspects of that subject and to publish the useful results.

In furtherance of these aims, specific to research, the Charity's objectives are:

- To support persons diagnosed with Bardet-Biedl Syndrome, their parents and carers in their right to be kept informed about the likely progression of Bardet-Biedl Syndrome and more importantly of the outcomes of treatments offered at various stages;

- To increase the understanding of the relationship between the physical condition of Bardet-Biedl Syndrome and learning development and to aid the development of beneficial therapies and learning programmes;
- To promote and carry out or assist in or support, organisations promoting and carrying out research into, surveys and investigations on and the management of Bardet- Biedl Syndrome and publish the useful results thereof.

Strategic Area of Focus and Priorities

BBS UK and the BBS UK Scientific Advisory Board priorities are:

- To identify future collaborators in the scientific community who may also wish to join the Scientific Advisory Board (patient groups, researchers, students, pharmaceutical representatives and stakeholders).
- To work collaboratively with other organisations to support development of treatments, understanding and knowledge of BBS.
- To discuss what areas should be researched through a patient led alliance.
- To work towards providing a comprehensive review of research papers.
- To publish verified research articles to BBS UK members through the website, newsletters and annual conference.
- To promote opportunities for members to take part in research.

Pharma Policy

Purpose

This policy document provides a framework by which the BBS UK will work with industry partners in a transparent manner, ensuring the integrity and independence of BBS UK is maintained at all times.

BBS UK exists to improve the lives of people with Bardet-Biedl Syndrome (BBS) by providing accessible, evidence-based information to people affected by the condition and by working with BBS specialists to ensure people with BBS get the best care possible. In order to meet its objectives, BBS UK believes it is important to maintain cooperative relationships with all industry partners and stakeholders in BBS, including the pharmaceutical, medical equipment and biotechnology companies and contract research organisations.

The best interests of people with BBS are a priority of BBS UK and it should be noted from the outset that BBS UK will not:

- Endorse any specific product or service (and the BBS UK name/logo must not be used to imply such endorsement).
- Take part in any project designed to give one company competitive advantage over another.
- Be influenced by commercial pressure to meet a particular marketing agenda or objective.
- Accept any attempts to influence its policy in any way.
- Allow any one company to dominate an activity through sponsorship.
- Allow its independent voice or objectivity to be constrained.

This policy governs the relationship between all members of the BBS UK staff, including volunteers and trustees and representatives of industry partners, including consultants and agencies.

Funding

As a Charity, BBS UK must source income to fund its work. Industry partner funding will be considered so long as:

- The outcome of the project will benefit people affected by BBS.
- The project fits within the strategic objectives of BBS UK.
- A contract or grant agreement is in place outlining the arrangement and agreed objectives between the parties.
- The name and/or logo of BBS UK is not used to imply approval or endorsement of any of the donor's products or policies without prior explicit permission.
- BBS UK will not accept funding for specific publications to be delivered directly to people affected by BBS.
- All funding will be acknowledged on the BBS UK website.

Interaction with the Government, Medical Profession and other Stakeholders

BBS UK and industry partners share certain objectives, such as the allocation of increased appropriate resources to the management of BBS. There will be occasions when the Charity wishes to work with the Industry to influence the Government, the medical profession, or other groups and cooperation will rely on objectives being agreed at the outset, the independence of the Charity not being compromised in any way, and total transparency in the relationship.

Signed Off/Reviewed By:	Date:	Comments:
Board DH, RF, LD, SC, JA	03/06/19	New Policy
Next Review:		