

## Working with Pharmaceutical and Research Companies

### Definitions

**CGD:** Chronic Granulomatous Disorder

**CGDS:** Reference to CGDS includes all the functions, staff, medical panels, patient panels, volunteers, sub-contractors and any other resources used from time to time by the Chronic Granulomatous Disorder Society.

**Pharma:** Pharmaceutical and research companies including any enterprise that researches into or offers patients directly or indirectly a therapy or medical intervention for treating the effects of CGD.

**Medical Advisory Panel:** An independent group of clinicians with knowledge and expertise in CGD across a range of disciplines that advises CGDS on clinical matters and reviews all CGDS publications.

### Background

The CGD Society's mission is to support, represent and improve the care and quality of life of people affected by CGD, working with healthcare professionals and other relevant organisations in the UK and across the globe.

Pharmas are significant parties in the search for better treatments and cures for CGD. Working with Pharmas that manufacture and market drugs and treatments gives CGDS important background knowledge and can provide positive networking opportunities.

CGDS relies on the generosity of its members and donors and on the proceeds from fundraising events to fund its activities. CGDS also seeks grants from commercial organisations, government and philanthropic funds and is committed to developing a variety of long-term dependable income sources to fund its work. Pharmas may be willing to sponsor and fund certain activities that CGDS may want to undertake.

CGDS recognises that Pharmas may have different interests from CGDS's including a direct commercial interest in CGD. CGDS acknowledges that in many cases the partnership is not equal and that Pharmas have many more resources at their disposal than itself. For these reasons, CGDS takes particular care in how it works with Pharmas and other for-profit healthcare providers.

The purpose of this policy is to provide clear principles and guidance about how CGDS works with Pharmas to achieve its objectives, without compromising its integrity and ability to support its members. These principles and guidance will ensure that CGDS's activities are not in any way influenced by the commercial interests of the for-profit companies it works with.

## CGDS Aims

- To be the provider of best practice information on all aspects of CGD, its management and treatment options.
- To promote awareness and understanding of CGD
- To provide direct support to individuals and families affected by CGD
- To be an advocate and campaigner for the needs and rights of people affected by CGD.

## Policy review

CGDS will review this policy at least every two years.

## Principles

- CGDS will independently set its own priorities, policies and plans.
- CGDS is committed to total transparency in all dealings with Pharmas.
- CGDS will not endorse individual Pharma's products or suppliers of healthcare services.
- CGDS will seek to develop relationships with multiple Pharmas, so as not to develop a special relationship with any single company.
- CGDS will engage in dialogue with Pharmas about CGD treatments for the benefit of its members and community.

## Practice

1. Openness and transparency
  - a. This policy will be published on the CGDS website.
  - b. Details of donations and grants received from Pharmas will be published in the annual reports of CGDS.
  - c. CGDS will acknowledge financial support for projects on its website at [www.cgdsociety.org](http://www.cgdsociety.org)
  - d. CGDS Trustees, members of the Medical Advisory Panel, staff and other relevant groups or individuals representing CGDS will submit a disclosure of interests form annually.
2. Funding of projects
  - a. CGDS will encourage funding for projects that have been identified as priorities in the CGDS planning process. These will be projects that align with CGDS's mission and objectives. Projects that are initiated by a Pharma will be approved by the trustee board of CGDS, in discussion with its Medical Advisory Panel and other relevant advisors, before they proceed.
3. Promotion
  - a. CGDS will not endorse any specific drug or treatment. Where possible, when discussing treatments, CGDS will refer to a class of treatment rather than a specific drug or brand name.
  - b. CGDS will not accept or distribute promotional products provided by a Pharma and will not allow distribution of such products at CGDS events.

4. Education

- a. CGDS will keep its key staff and volunteers informed on CGD research, the drug development process and the way in which the Pharma operates.
- b. CGDS will work with members of IPOPI, other charities and organisations and learn from their experiences of working with Pharmas.
- c. CGDS will seek to ensure that all medical information it publishes is reviewed by CGDS's Medical Advisory Panel.

5. Surveys and Member Information

- a. CGDS will work with Pharmas on sponsored surveys on the understanding that CGDS has approval over the content and manner of approach to patients, that such surveys are labelled as commercial, that responses are anonymous and that the information gained is shared with CGDS and its members. Any use of such information must be attributed to CGDS.
- b. CGDS may facilitate the collection of information from its members from which the identity of a member may be inferred (e.g. photographs, stories etc.). In such cases, written permission must be obtained from the member via CGDS for the restricted use of such information. Members may withdraw their permission at any time without reason after which the information must not be used and all copies of the information deleted or otherwise destroyed.

6. Other

- a. CGDS will not offer direct third-party access to its database of members.
- b. CGDS will review and declare any offer of hospitality, including travel and accommodation that is provided or funded by a Pharma to any member or representative of CGDS.
- c. The CGDS logo and other trademarks owned by CGDS can be used only with the permission and prior written agreement from CGDS.
- d. The CGDS logo and name cannot be used by any Pharma to promote any product.
- e. When members or representatives of CGDS are asked by Pharmas to give an expert patient perspective, it is with the implicit and explicit understanding that in doing so they are not endorsing any company or any product the company offers to patients. To ensure transparency, such presentations will include a disclaimer similar to: 'In accepting [company name's] invitation to present, I am not endorsing [company name] or the products it offers to patients.'
- f. CGDS will not accept sponsorship that:
  - Promotes alcohol, tobacco products, firearms, other weapons or gambling activities
  - Promotes unlicensed pharmaceutical products
  - Promotes any activity deemed to be illegal

Dated February 2019

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