

CureSHANK Grant Policies

Open Science Policy

As a nonprofit funded through contributions from the Phelan-McDermid syndrome community and the public at large, we are committed to being responsible stewards of these funds. We support projects that will rapidly advance our understanding of PMS and the development of therapies for the disease.

CureSHANK seeks to stimulate discovery and innovation by improving access to scientific data and outputs including data, code, software, protocols, materials, and assays. Improved dissemination will lead to more opportunities for investigators to collaborate and build upon the latest developments in research. CureSHANK has adopted an Open Science Policy to ensure transparency of and broad access to CureSHANK-funded research.

A primary output of this research is new ideas and knowledge, which we expect our researchers to publish as high-quality, peer-reviewed research articles and book chapters.

We believe that maximizing the distribution of publications – by providing free, online access – is the most effective way of ensuring that the research we fund can be accessed, read, and built upon. In turn, this will foster a richer research culture. Specifically, we:

- require electronic copies of any research papers, that have been accepted for publication in a peer-reviewed journal, and are supported in whole or in part by CureSHANK, to be made available through PubMed Central or the publisher's website as soon as possible, and
- require authors and publishers to license research publications using the Creative Commons Attribution license so they may be freely copied and re-used (for example, for text-and data-mining purposing or creating a translation).

As a funder, CureSHANK, works to ensure that the results of the research we fund are applied for the public good. This includes creating an environment that enables and incentivizes researchers to maximize the value of their research outputs, including data, code, software, and protocols and materials.

Specifically, we:

- expect our funded researchers to maximize the availability of research data, code, software and materials, and protocols with as few restrictions as possible. As a minimum, the data underpinning research papers should be made freely and publicly available in an established, open repository at the time of publication, as well as any original code and software that is required to view datasets or to replicate analyses;
- require anyone applying for CureSHANK funding to consider their approach to managing and sharing anticipated outputs at the research proposal stage. In cases where these outputs are significant – generating data, code, software, materials or protocols that will hold clear value as a resource for others in academia or industry – applicants will need to include an outputs management plan explaining their planned approach;
- expect researchers to make sure their shared outputs are discoverable, use recognized community repositories for data and other outputs where these exist and use persistent identifiers for these outputs wherever possible;
- recognize and value a range of research outputs – including inventions, code, datasets, software, protocols, and materials, as well as publications – in assessing the track record of researchers. Guidance to our reviewers emphasizes that our funding decisions should take account of the full and diverse types of outputs that result from research and efforts made by researchers to use outputs to deliver health benefits or assist further research;
- CureSHANK will also consider whether researchers have managed and shared their research outputs in line with our requirements, as a critical part of the end of grant reporting process.

CureSHANK recognizes that there are costs associated with making research outputs open access. As such CureSHANK will allow researchers to include these costs in their research grants.

CureSHANK Review Process

The first stage of providing fair and expert review for research funding applications submitted to CureSHANK consists of scientific peer review by a committee of highly esteemed basic and clinical scientists and clinicians that

form our Strategic & Scientific Advisory Boards and additional experts as necessary. Reviewers score applications on innovation, scientific rigor, and relevance to the mission of CureSHANK. Applications will also be reviewed based on the experimental design, methods, rationale, budget, feasibility, and outputs management plans. Applicants should concisely and adequately detail how the hypotheses will be tested, demonstrating adequate power for testing the hypothesis, and clearly define all variables and aims.

Reviewer's conflicts of interest must be disclosed prior to the review. Reviewers with conflicts will be recused from the review process.

The review committee's recommendations for funding are made to the CureSHANK Board of Directors (BOD). Funding recommendations are based on scientific merit, as determined by the review committee, budgetary considerations and discussion of relevancy and priority to the mission of CureSHANK. Final approval is required by the CureSHANK BOD before funding may occur.

Amendment of Policies

CureSHANK reserves the right to modify its policies governing research awards at any time. The recipient agrees to abide by any changes or to terminate the grant at the time when such changes become effective. Failure to abide by the policies governing awards shall be considered sufficient grounds for cancellation of an award or refusal to consider any pending application by the grantee.