

Douglas M. Sheeley, Sc.D.  
National Institute of General Medical Sciences  
45 Center Drive MSC 6200  
Bethesda, MD 20892-6200

June 2, 2016  
RE: NOT-GM-16-103

Dear Dr. Sheeley,

The Endocrine Society appreciates the opportunity to comment on NOT-GM-16-103 on “the need for and support of research resources for the biomedical research community”. We acknowledge the critical role of the National Institutes of Health (NIH) and the National Institute of General Medical Sciences (NIGMS) and thank you for supporting the development of and access to research resources.

Founded in 1916, the Endocrine Society is the world’s oldest, largest and most active organization devoted to research on hormones and the clinical practice of endocrinology. We have over 18,000 members, including basic and clinical researchers who develop and use new technologies to improve human health. As a member of the Federation of American Societies for Experimental Biology (FASEB), we contributed to and support their previously submitted comments<sup>1</sup>. In our comments, we make two additional recommendations for the support of shared research resources. We also identify two areas ripe for the development of new shared research resources.

#### **Endocrine Society Recommendations**

Below, we make two additional recommendations for the support of shared research resources; specifically, NIH/NIGMS should:

- implement guidelines for data providers, with clear access rules and agreed-upon standards, and
- ensure that shared instrumentation resources be maintained at a high standard to ensure sustainability.

A key concern for individual investigators and teams of researchers is the loss of control of data deposited in a shared resource. We agree that the original data-gathering investigators must be appropriately recognized for their contributions. Furthermore, it is critical that quality control mechanisms are in place to ensure that data deposited in a shared resource are appropriately and correctly utilized for research purposes. NIGMS/NIH should therefore implement guidelines that support continued oversight by investigators who contribute to the resources. This oversight could include notifications to researchers when their data is accessed for a study, or a mediation process facilitated by an expert in the resource to enable effective uses of the data and prevent future disputes. We further recommend that clear access rules and standards (e.g., standard operating procedures and rules regarding citation of the original data source) be in place and agreed to by users. These procedures will also foster collaboration between the original investigators and new users.

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<sup>1</sup>

<https://faseb.org/Portals/2/PDFs/opa/2016/FASEB%20responds%20to%20NIGMS%20RFI%20on%20research%20resources.pdf> Accessed May 26, 2016



We strongly support FASEB's statements regarding maintaining the sustainability of resources. We would add that sustainability requires that instrumentation is also maintained at a high standard, and that instruments be replaced as they become obsolete. We note that research resources such as biobanks face closure if funding concerns fail to allow resources to keep pace with rapidly evolving technology<sup>2</sup>. This not only creates issues with data and resource accessibility, but also ethical issues surrounding the transfer and management of materials. The Endocrine Society therefore recommends that sustainability be ensured through stable funding that enables regular replacement of instrumentation. The Endocrine Society does not object to the use of user fees to ensure sustainability.

### **Resource Needs**

Our members report that further development of the following shared research resources will help address institutional weaknesses and increase reproducibility among research groups.

- There is a serious need for strong computational resources and accessible user interfaces for the utilization of sequencing data. Many institutional core facilities build their own tools that can be challenging for the broader research community to use.
- There should be more resources to enable greater sharing of mouse models, especially those that involve the transplantation of human tissue into mice (patient-derived xenograft, or PDX mice). Many of these models are developed in-house and a lack of standards could result in barriers to reproducibility of research results from these models.

The Endocrine Society appreciates the role of the NIH in driving the development of shared research resources by the biomedical research community. We share your interest in exploring new approaches to maximize the efficiency and utilization of these resources and thank you for considering our comments. If we can be of any further assistance in your efforts, please do not hesitate to contact Dr. Joseph Laakso, Associate Director of Science Policy at [jlaakso@endocrine.org](mailto:jlaakso@endocrine.org).

Sincerely,

A handwritten signature in black ink that reads "Henry Kronenberg". The signature is fluid and cursive, with "Henry" on the top line and "Kronenberg" on the line below it.

Henry Kronenberg, MD  
President,  
Endocrine Society

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<sup>2</sup> <http://www.bio-itworld.com/news/09/07/2011/Quebec-Genizon-Biosciences-closes-doors.html> Accessed May 26, 2016.