

## 2024 Current Fiscal Year Report: Center for Inherited Disease Research Access Committee

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### 1. Department or Agency

Department of Health and Human Services

### 2. Fiscal Year

2024

### 3. Committee or Subcommittee

Center for Inherited Disease Research  
Access Committee

### 3b. GSA

### Committee No.

5167

### 4. Is this New Fiscal Year?

No

### 5. Current Charter

04/30/1997

### 6. Expected Renewal Date

### 7. Expected Term Date

### 8a. Was Terminated During Fiscal Year?

No

### 8b. Specific Termination Authority

### 8c. Actual Term Date

### 9. Agency

### Recommendation for Next Fiscal Year

Continue

### 10a. Legislation Req to Terminate?

Not Applicable

### 10b.

### Legislation Pending?

Not Applicable

### 11. Establishment Authority

Authorized by Law

### 12. Specific Establishment Authority

42 U.S.C. 282(b)(16)

### 13. Effective Date

11/20/1985

### 14. Committee Type

Continuing

### 14c. Presidential?

No

### 15. Description of Committee

Other Committee

### 16a. Total Number of Reports

No Reports for  
this Fiscal Year

### 17a. Open

0

### 17b. Closed

0

### 17c. Partially Closed

0

### Other Activities

0

### 17d. Total

0

### Meetings and Dates

No Meetings

Current Next  
FY FY

<b>18a(1). Personnel Pmts to Non-Federal Members</b>	\$0.00	\$0.00
<b>18a(2). Personnel Pmts to Federal Members</b>	\$0.00	\$0.00
<b>18a(3). Personnel Pmts to Federal Staff</b>	\$0.00	\$0.00
<b>18a(4). Personnel Pmts to Non-Member Consultants</b>	\$0.00	\$0.00
<b>18b(1). Travel and Per Diem to Non-Federal Members</b>	\$0.00	\$0.00
<b>18b(2). Travel and Per Diem to Federal Members</b>	\$0.00	\$0.00
<b>18b(3). Travel and Per Diem to Federal Staff</b>	\$0.00	\$0.00
<b>18b(4). Travel and Per Diem to Non-member Consultants</b>	\$0.00	\$0.00
<b>18c. Other(rents,user charges, graphics, printing, mail, etc.)</b>	\$0.00	\$0.00
<b>18d. Total</b>	\$0.00	\$0.00
<b>19. Federal Staff Support Years (FTE)</b>	0.00	0.00

**20a. How does the Committee accomplish its purpose?**

This committee is composed entirely of recognized biomedical and/or behavioral research authorities who represent the forefront of research and technical knowledge in the mapping of loci responsible for the genetic contribution to common disorders in humans, including, but not limited to, cardiovascular and pulmonary disease, cancer, psychiatric disorders, diabetes, and autoimmune diseases. The Center for Inherited Disease Research (CIDR) is a consortium of 10 Institutes. The National Human Genome Research Institute is the lead agency for the consortium which manages CIDR through a Board of Governors representing each of the 14 Institutes. CIDR advises the Director, NIH, and the Board of

Governors on the scientific and technical merit of applications seeking to use the genotyping and genetic analysis capabilities of CIDR. During this reporting period, the committee considered 9 applications requesting access to the CIDR facility; only 6 were approved.

**20b. How does the Committee balance its membership?**

The members of this committee are recognized authorities knowledgeable in the various disciplines and fields of human genetics, quantitative genetics, linkage and segregation analysis, and genotyping technology.

**20c. How frequent and relevant are the Committee Meetings?**

The Center for Inherited Disease Research Access Committee held six meetings during this reporting period on 11/03/2022, 01/06/2023, 03/10/2023, 05/05/2023, 07/14/2023 and 09/08/2023.

**20d. Why can't the advice or information this committee provides be obtained elsewhere?**

This committee is composed entirely of recognized biomedical and/or behavioral research authorities who represent the forefront of research and technical knowledge and who provide review of highly scientific and technical research applications requesting access to the CIDR facility. These evaluations and recommendations cannot be obtained from other sources because the specialized, complex nature of the applications requires a unique balance and breadth of expertise not available on the NIH staff or from established sources.

**20e. Why is it necessary to close and/or**

## **partially closed committee meetings?**

The meetings of the Center for Inherited Disease Research Access Committee were closed to the public for the review of applications. Sections 552b(c)(4) and 552b(c)(6) of the Government in the Sunshine Act permit the closing of meetings where discussion could reveal confidential trade secrets or commercial property such as patentable material and personal information, the disclosure of which would constitute a clearly unwarranted invasion of personal privacy.

## **21. Remarks**

Committee Function: Other - Review of requests for access to the Center for Inherited Disease Research. Reports: This committee did not produce any public reports during the fiscal year. URL: This committee does not have a website. The DFO and Decision Maker are the same person, Dr. Barbara Thomas, Scientific Review Officer, NHGRI, based on the assignment of duties in this Institute. The total number of recommendations for 2022 report should have been 385, not 384. Dr. John Belmont was reassigned as chair from 07/01/2023 until 06/30/2025. Dr. Kathryn Lunetta was reappointed from 7/1/2021 to 6/30/2022 and then reassigned as chair from 7/1/2022 to 6/30/2023; however, her FY 2022 chair record term begin date indicated 7/1/2021 instead of 7/1/2022.

## **Designated Federal Officer**

BARBARA THOMAS SCIENTIFIC REVIEW  
OFFICER

<b>Committee Members</b>	<b>Start</b>	<b>End</b>	<b>Occupation</b>	<b>Member Designation</b>
Christensen, Brock	07/01/2023	06/30/2027	Professor, Dartmouth Medical School	Peer Review Consultant Member
Conneely, Karen	07/01/2020	06/30/2024	Associate Professor, Emory University	Peer Review Consultant Member

Crawford, Dana	07/01/2020	06/30/2024	Associate Professor, Case Western Reserve University	Peer Review Consultant Member
Li, Chun	07/01/2023	06/30/2027	Professor, University of Southern California	Peer Review Consultant Member
Li, Yun	07/01/2023	06/30/2027	Professor, University of North Carolina	Peer Review Consultant Member
Neuhausen, Susan	07/01/2020	06/30/2024	Morris and Horowitz Families Professor, City of Hope Comprehensive Cancer Center	Peer Review Consultant Member
Shaffer, John	07/01/2023	06/30/2027	Assistant Professor, University of Pittsburgh	Peer Review Consultant Member
XING, JINCHUAN	07/01/2021	06/30/2025	Assistant Professor, RUTGERS, THE STATE UNIV OF N.J.	Peer Review Consultant Member
Zoellner, Sebastian	07/01/2021	06/30/2025	Assistant Professor, UNIVERSITY OF MICHIGAN AT ANN ARBOR	Peer Review Consultant Member

### Number of Committee Members Listed: 9

### Narrative Description

NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability. NIH works toward that mission by supporting the research of non-Federal scientists in universities, medical schools, hospitals, and research institutions throughout the country and abroad. Section 492 of the PHS Act states that The Secretary...shall by regulation require appropriate technical and scientific peer review of -(A) applications...; and (B) biomedical and behavioral research and development contracts...

### What are the most significant program outcomes associated with this committee?

Checked if  
Applies

Improvements to health or safety  
Trust in government

☐  
☐

- |   |                                     |
|---|-------------------------------------|
| Major policy changes                              | <input type="checkbox"/>            |
| Advance in scientific research                    | <input checked="" type="checkbox"/> |
| Effective grant making                            | <input type="checkbox"/>            |
| Improved service delivery                         | <input type="checkbox"/>            |
| Increased customer satisfaction                   | <input type="checkbox"/>            |
| Implementation of laws or regulatory requirements | <input type="checkbox"/>            |
| Other   | <input type="checkbox"/>            |

### Outcome Comments

NA

### What are the cost savings associated with this committee?

Checked if Applies

- |                            |                                     |
|----------------------------|-------------------------------------|
| None                       | <input type="checkbox"/>            |
| Unable to Determine        | <input checked="" type="checkbox"/> |
| Under \$100,000            | <input type="checkbox"/>            |
| \$100,000 - \$500,000      | <input type="checkbox"/>            |
| \$500,001 - \$1,000,000    | <input type="checkbox"/>            |
| \$1,000,001 - \$5,000,000  | <input type="checkbox"/>            |
| \$5,000,001 - \$10,000,000 | <input type="checkbox"/>            |
| Over \$10,000,000          | <input type="checkbox"/>            |
| Cost Savings Other         | <input type="checkbox"/>            |

### Cost Savings Comments

NIH supported basic and clinical research accomplishments often take many years to unfold into new diagnostic tests and new ways to treat and prevent diseases.

### What is the approximate Number of recommendations produced by this committee for the life of the committee?

394

### Number of Recommendations Comments

There were 9 projects considered in FY2023.

### What is the approximate Percentage of these recommendations that have been or will be Fully implemented by the agency?

0%

**% of Recommendations Fully Implemented Comments**

N/A

**What is the approximate Percentage of these recommendations that have been or will be Partially implemented by the agency?**

0%

**% of Recommendations Partially Implemented Comments**

N/A

**Does the agency provide the committee with feedback regarding actions taken to implement recommendations or advice offered?**

Yes ☒ No ☐ Not Applicable ☐

**Agency Feedback Comments**

Information resulting from closed initial peer review meetings is subject to the Freedom of Information Act. The public can view information on research projects funded by NIH on the RePORT (Research Portfolio Online Reporting Tool) website located at <http://report.nih.gov>.

**What other actions has the agency taken as a result of the committee's advice or recommendation?**

Checked if Applies

Reorganized Priorities	<input type="checkbox"/>
Reallocated resources	<input type="checkbox"/>
Issued new regulation	<input type="checkbox"/>
Proposed legislation	<input type="checkbox"/>
Approved grants or other payments	<input type="checkbox"/>
Other	<input checked="" type="checkbox"/>

**Action Comments**

After considering this committee's recommendations, successful applicants were granted access to to the genotyping and genetic analysis capabilities of the Center for Inherited Disease Research facility.

**Is the Committee engaged in the review of applications for grants?**

No

### **Grant Review Comments**

Successful applicants are provided with access to the genotyping and genetic analysis capabilities of CIDR rather than funds. The access to CIDR is paid by the Institute or Center that funded the original grant application.

### **How is access provided to the information for the Committee's documentation?**

Checked if Applies

Contact DFO	<input checked="" type="checkbox"/>
Online Agency Web Site	<input checked="" type="checkbox"/>
Online Committee Web Site	<input type="checkbox"/>
Online GSA FACA Web Site	<input checked="" type="checkbox"/>
Publications	<input type="checkbox"/>
Other	<input checked="" type="checkbox"/>

### **Access Comments**

IC Committee Management Officer 240-669-5201