

## LSOCA Data Access Request (DA)

## SOCA

**Purpose:** To make available the following LSOCA resources to LSOCA investigators:

- Electronic data sets with documentation.
- Frozen specimens: plasma and leukocyte aliquots obtained at the baseline visit and at all study visits thereafter (every 6 months).
- Fundus photographs:
  - obtained from patients with an Ocular Opportunistic Infections (OOI) at the baseline visit and at all study visits thereafter (every 3 months until 2008, then every 6 months);
  - obtained from patients without an Ocular Complication Infection (No OOI) at baseline visit and every 5 years thereafter.

**Instructions:** Send a completed *LSOCA Data Access Request form*, along with any supporting materials, to the SOCA Chairman's Office located at:

Douglas Jabs, MD MBA  
SOCA Chairman's Office  
Department of Ophthalmology, Mount Sinai School of Medicine  
Box 1183, One Gustave L. Levy Place  
New York, New York 10029-6574  
Email: [jill.slutsky@mssm.edu](mailto:jill.slutsky@mssm.edu) Attention: Jill Slutsky

*After review by the LSOCA Study officers, the Chairman's Office will notify the investigator of the decision made and any changes necessary.*

*SOCA Chairman's Office use only:*

Date reviewed by Study Officers:

Recommendation: Approve (  ) Reject (  ) Approved with revisions (  )

Date investigator notified by LSOCA Chairman's Office: \_\_\_\_\_

Date approved LSOCA Data Access Request form sent to the CC: \_\_\_\_\_

*SOCA Coordinating Center use only:*

Date approved LSOCA Data Access Request form: \_\_\_\_\_

Date received copy of submission to investigator's local IRB (if applicable): \_\_\_\_\_

Date received IRB letter of approval from investigator (if applicable): \_\_\_\_\_

Queries may be made to the Director of the SOCA Data Coordinating Center:

Mark L. Van Natta  
The Johns Hopkins Bloomberg School of Public Health  
Department of Epidemiology  
615 North Wolfe St., Room W5025  
Baltimore MD 21205  
Email: [mvnatta@jhu.edu](mailto:mvnatta@jhu.edu)

*The SOCA Coordinating Center will maintain this form in the official LSOCA file.*

**Information Access Policy**

- SOCA General Handbook, Protocol, Data Collection forms and other associated documents are considered to be in the public domain
- LSOCA data provided are divorced of personal identifiers other than a 4-digit study ID number
- Data analyses will be the responsibility of the proposing investigator(s)

**A. Administrative information**

1. Name and contact information of investigator requesting LSOCA resources:

Print Name: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

2. Other collaborating investigators: ( ) Yes ( ) No

If yes, list name(s) and contact information:

Print Name: \_\_\_\_\_

Telephone: \_\_\_\_\_

Email: \_\_\_\_\_

B. The agreement is for the analyses of data from The Study to evaluate: *(Provide brief description of proposed project):*

I understand that any presentations or publications using LSOCA resources (data, specimens, fundus photographs) are requested to credit the SOCA Research Group.

The LSOCA Data Coordinating Center will prepare a dataset with requested data elements for the Recipient. The data set will be extracted from the final version of the Study database(s). The Effective Date of this agreement is: \_\_\_\_\_

Recipient Signature: \_\_\_\_\_

Print signature: \_\_\_\_\_

Date of signature: \_\_\_\_\_

Attachments to this form:

( ) \_\_\_\_\_

( ) \_\_\_\_\_

( ) \_\_\_\_\_

Date this request submitted to SOCA Chairman's Office: \_\_\_\_\_

**C. Request for LSOCA resources**

3. Does investigator request LSOCA data:

( ) Yes ( ) No

*If yes, specify number of patients and selected time points:*

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

4. Does investigator request frozen plasma and or leukocytes:

Yes  No

*If yes, specify the type of aliquots requested:*

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a. Plasma

Yes  No

*If yes, specify number of plasma aliquots and selected time points:*

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b. Leukocytes

Yes  No

*If yes, specify number of leukocyte aliquots and selected time points:*

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5. Does investigator request fundus photographs:

Yes  No

*If yes, specify number of fundus photographs and selected time points:*

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### Data Use Agreement

Please review and, if willing to agree to the following terms, sign and date below.

Recipient agrees to:

- Use or disclose the data only as permitted by this Agreement or as required by law, including but not limited to the Privacy Rule provisions of the Health Information Portability and Affordability Act (45 CFR 164, Subpart E).
- Use appropriate safeguards to prevent use or disclosure of the data other than as permitted by this Agreement or required by law.
- Data will not be copied or reproduced for use or distribution to any person or organization other than the requesting investigator(s) and his or her organization without the express approval of SOCA Study Officers.
- Individual patients will not be identified in tables or listings.
- Analyses and interpretation of data contained in presentations or publications are those of the requesting investigator(s) and not the LSOCA Research Group.
- Requested to credit the SOCA Research Group in publications/presentations.
- Corresponding authorship and reprints are the responsibility of the requesting investigator(s).

This agreement is between the SOCA Data Coordinating Center (Provider) and \_\_\_\_\_ (Recipient) for use of data from the Longitudinal Studies of the Ocular Complications of AIDS (LSOCA) study. The purpose of this agreement is to give the Recipient access to data from the Study to use for health research-related analysis.