Thank you for your interest in participating in the Research Room as an Investigative Group for the enrollment of research subjects. PHA has a proud tradition of supporting research investigators, including the continued support of the Research Room at each International PH Conference and Scientific Sessions since the initial Research Room was opened at the 1994 Conference. We anticipate that you will be thrilled with the enthusiasm and interest in the Research Room displayed by PHA 2020 attendees. It is ultimately due to their generosity of participation that progress is made to fight the challenging condition of PH.

The Research Room is dedicated to helping researchers further their studies by allowing for the collection of data, including phenotypic information and biological specimens. We anticipate that each investigative group will be provided a table and small area at which to interview and enroll potential participants. Each investigative group approved to participate may enroll subjects using their respective institutional review board (IRB) protocols on site at PHA 2020. In order to reduce the administrative burden upon research participants, we use a shared data collection form so that each participant may answer a large number of questions at one time, rather than repeatedly. Your IRB may require that you have this document approved in advanced of PHA 2020. However, you may also acquire additional data from participants as you need for your research.

The PHA and Research Room Leadership Committee will make every effort to support each proposed research project, but please be advised that not every research application request may be feasible—however, we will work with you to achieve your goals as best as possible. We anticipate the ability to provide centralized blood draw services in the Research Room as in previous years so that each research participant will only need to undergo one blood draw during their visit to the Research Room. Given the large number of anticipated research groups, and restriction of blood draw volume limitations per participant, please be advised that each investigative group may have a total blood volume limit for their studies, which may be as low as 6-8 ml per group. Please consider this issue as you plan your proposal for the Research Room. While the precise resources expected to be available in the Research Room during PHA 2020 have yet to be determined, we aim to provide, at a minimum, the capacity to keep biologic samples at 4 degrees Celsius for the duration of PHA 2020.

Please complete the below Research Room application as instructed (submission deadline: Sunday, March 8, 2020). We look forward to working with you in advance of PHA 2020, and this summer in Anaheim.

PHA 2020 Research Room hours

Thursday, June 11th (3:00pm-7:00pm/PT)

Friday, June 12th (6:30am-5:00pm/PT and closed for lunch 12-1pm)

Saturday, June 13th (7:00am-6:00pm/PT and closed for lunch 12-1pm)

Sunday, June 14th (7:00am-10:00am/PT)

**Please return this completed this form and a copy of IRB approval to:**

Olivia Onyeador, MHA, Quality Care & Research | OliviaO@phassociation.org

SUBJ: 2020 Research Room Application

***All members of the research teams must register for Conference. Go to*** <https://na.eventscloud.com/website/8605/registration/>  ***for more information.***

**1. Principal Investigator Contact Details**

|  |  |
| --- | --- |
| **First name:**       | **Last Name:**       |
| **Name of Project:**       |
| **Address:**       |
|       |
| **Zip Code:**       |
| **Phone (1):**       | **Phone (2):**       |
| **E-mail address:**       |

**2.** **Have you participated in the Research Room in the past? If so, explain your past experience.**

**3.** **Please give a brief summary of your research project, and the goal(s) and hypotheses to be tested.**

**4.** **What are the eligibility inclusion criteria for this study?**

**5.** **What are the eligibility exclusion criteria for this study?**

**6.**  **Please summarize your research project in simple, patient-friendly terms using 1 to 3 bullet points. We will use this language to highlight your research effort in participant materials, marketing videos/messages and within the Research Room to guide participant navigation.**

1.

2.

3.

**7.** **Please describe the scope of your planned activities in the Research Room. Note that phlebotomy supplies and consumables needed for your study will need to be supplied by your team.**

**8. How many team members do you anticipate working in the Research Room?**

**9.** **PHA will provide a table, two chairs and access to a refrigerator. In addition, PHA is in the process of procuring a centrifuge and -80C freezer.**

a. If you will need centrifuge, please list what size and type of tubes to be spun, speed, and duration of spin for your protocol.

b. If you need additional items, please describe them below and we will do our best to accommodate you.

c. If you will be processing onsite, please indicate how many tables you will need for processing.

*\*Please note that investigators are responsible for all processing supplies.*

**10. If a biobank is collecting blood and multiple groups need blood for the same purposes, it may be most efficient to share the sample.**

a. A biobank may be collecting blood for banking of plasma, DNA and RNA. Would you be willing to obtain aliquots of the samples in lieu of a separate blood draw?

 **[ ]** Yes

 **[ ]** No

b.Would you be willing to share an aliquot of a sample with other groups?

**[ ]** Yes

**[ ]** No

c. Will you have a blood component that you will not use and could donate to another group? (e.g., you are isolating cells and will not need the plasma)

**[ ]** Yes

**[ ]** No

Please indicate below the samples you can share or donate:

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Willing to share** | **Can donate unused fraction** | **Will be kept** |
| **Serum** | **[ ]**  | **[ ]**  | **[ ]**  |
| **Plasma** | **[ ]**  | **[ ]**  | **[ ]**  |
| **Red cells** | **[ ]**  | **[ ]**  | **[ ]**  |
| **White cells** | **[ ]**  | **[ ]**  | **[ ]**  |
| **DNA** | **[ ]**  |  |  |
| **Other (specify)** |       |  |

**11. To expedite the Research Room process for study participants, will you be able to accept patient information and demographics collected on the 2020 PHA Research Room Universal Data Collection Form?**

**[ ]** Yes

[ ]  No

**Please return this completed this form and a copy of IRB approval to:**

Olivia Onyeador, MHA, Quality Care & Research | OliviaO@phassociation.org

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