Request for Applications for
Registry Bootcamp

Due:
February 28th, 2021

Deliver To:
Matthew Caffet (mcaffet@geneticalliance.org)
Genetic Alliance, Inc.
Genetic Alliance Registry Bootcamp

Genetic Alliance supports organizations in their quest to improve the lives of their members and others, primarily by helping them build their capacity for research. We recognize that recruitment, retention, engagement, data collection, and community building are all activities that are often best done in advocacy organizations. Collection of real-world evidence and patient reported outcomes are more robust when done by these communities, so it is critical they have appropriate resources readily available. To support these efforts, Genetic Alliance offers many services and programs ranging from the Genetic Alliance BioBank and Genetic Alliance IRB (an established IRB with more than 125 approvals and hundreds of amendments and reviews) to the Genetic Alliance Promise for Engaging Everyone Responsibly (PEER).

Genetic Alliance established the Promise for Engaging Everyone Responsibly (PEER) to enable communities to build registries. Since its establishment in 1995, PEER has evolved steadily to meet the needs of various communities through consistent policy and technology advancements. The inherent values that guide its development – community engagement, data collection across conditions, participant control of data, and a design that asks and answers the questions most critical to those participants – remains front and center today. We enable the best and most efficacious means to generate data and research opportunities from within a community. Registry Bootcamp offers a communal, guided approach to registry building and maintenance through our previously mentioned comprehensive program, PEER. PEER is a membership-based program, developed and run by Genetic Alliance, that provides support, guidance, and the required infrastructure (e.g., IRB application writing assistance, in-house IRB review, the data platform, EHR connectivity, etc.) needed to successfully create and launch a registry.

Registry Bootcamp is a comprehensive resource providing training on a series of topics that lead to the creation of a condition- and/or community-specific registry, natural history studies, observational studies, and other clinical studies. Registry Bootcamp offers a curriculum and provides intensive hands-on training to enable a cohort of organizations to work through the various steps necessary to design and develop their own registries. Organizations engage in peer-to-peer learning and receive mentorship and lessons from Genetic Alliance staff who bring with them their 25+ years of experience in registry development. This is a three month program (See Appendix A), though some groups may graduate more quickly. Organizations are invited to apply to Bootcamp by submitting an application in response to this Request for Applications (RFA). Responses to this RFA are assessed for a few basic criteria and then reviewed holistically as described in the section below titled Evaluation Criteria.

Accepted organizations will work together as a collaborative cohort that will begin together, participate in synchronous and asynchronous trainings, and learn through hands-on activities, discussion, and interaction.

As mentioned above, this program was created to help communities/organizations plan and develop robust registries which can support their efforts and endeavors. We will measure success through completion of these steps: stakeholder engagement resulting in the development of registries/studies, development of outreach and research plans, successful IRB approval for their registry, and registry/launch.
Schedule

*Invitation for applications released:* February 10th, 2021

*Applications due date:* February 28th, 2021

*Applicants notified of decision:* March 8th, 2021

*Program start date:* March 22nd, 2021

Question Submission

All questions should be submitted via email to Matthew Caffet (mcaffet@geneticalliance.org). Please allow up to two business days for a response.

Eligibility

We are interested in enrolling organizations that will take full advantage this opportunity and will collaborate well with the other organizations in the cohort. We are interested in each cohort reflecting diversity of issues, causes, socioeconomic status, and geography.

*Eligible applicants include:*

Any organization that has participant-centric goals, is led by people with a lived experience of the condition, disease, and/or issue, and is interested in furthering their mission and goals through research.

*Eligible applicants must have:*

- A philosophy consistent with the Genetic Alliance Promise (see below).
- The ability to engage your community, consistent with the size of said community (whether that be 2 people or 2000 people), including a plan focused on recruitment, reflection, and follow-up.

*Genetic Alliance Promise*

Communities have a responsibility to support one another. Our success and failures are intrinsically linked together, we lift each other up to the benefit of us all. PEER is built by the community for the community.

- The true power within the community lies with the members.
- We empower our members to control their data, and act in accordance with their wishes.
- Every individual who provides data for research has a right to the results of that research. Built into our research processes are methods for responsibly sharing insights and research results back to the members of our communities.
- Research we support is for the benefit of individuals and communities. We will endeavor to only ask questions that have the potential to improve the lives of a group or humanity at large.

*Accepted applicants will be expected to:*

1. Attend all webinars
2. Complete the homework assignments throughout the program, which will result in:
   a. Engagement and Outreach Plan
   b. PEER Membership Application
   c. Registry IRB Application
d. Practice data type selection and survey creation

3. Collaborate with other members of the cohort

If you have questions about your eligibility, please contact Matthew Caffet (mcaffet@geneticalliance.org)

**Cost: $0**
Typically, the costs are:
Application: $500
IRB: $500
Consortium membership: $5000 to $30,000 (depending on your budget)
Thus, this has a >$6,000 value.

**Acceptances**
The Genetic Alliance team will notify the organizations that are accepted on or before March 8th, 2021 for a March 22nd orientation date.
How to Apply
Complete proposals should demonstrate the organization’s commitment and capacity to participate in Registry Bootcamp. Proposals must include the following:

- Identification of the primary contacts for the organization and project, including email and mailing address.
- Personal statement and CV/Biographical Sketch of the registry/project lead(s) (See Appendix B).
- Proposal narrative (Times New Roman/Calibri, 12-point-font, one-inch margins, single-spaced).

Proposal Narrative – 4 pages maximum; must include the following information:

- A brief description of the organization’s mission
- A brief description of the topic of interest, disease, condition, quality of life, or study on which you wish to focus your registry and/or study
- Brief description of why you need a registry and/or study
- Description of your community
- Number of staff and volunteers that will participate in RegistryBootcamp
- Whether you have had a registry and/or study in the past, and if yes, a short description

Evaluation Criteria
Genetic Alliance reserves the right to conduct discussions with applicants. Genetic Alliance will not disclose any information regarding proposal submittals. Submit proposals to Matthew Caffet.

<table>
<thead>
<tr>
<th>Scoring Criteria</th>
<th>Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proposal Clarity</td>
<td></td>
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<tr>
<td>Does the applicant clearly describe why they should be awarded a place in the Registry Bootcamp?</td>
<td>35</td>
</tr>
<tr>
<td>Capacity</td>
<td></td>
</tr>
<tr>
<td>Does the applicant clearly demonstrate adequate capacity to successfully complete the Registry Bootcamp?</td>
<td>25</td>
</tr>
<tr>
<td>Need</td>
<td></td>
</tr>
<tr>
<td>Does the applicant demonstrate their need for a registry and/or study?</td>
<td>25</td>
</tr>
<tr>
<td>Impact</td>
<td></td>
</tr>
<tr>
<td>Does the applicant clearly describe the outcomes they believe this opportunity will afford them?</td>
<td>15</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

The deadline for receipt of full proposals is February 28th, 2021.

For other Inquiries or Additional Information, please email Matthew Caffet.
# Appendix A
Draft Course Syllabus

## Genetic Alliance Registry Bootcamp Syllabus - Draft

*All times are listed in ET and are subject to change.*

<table>
<thead>
<tr>
<th>Date</th>
<th>Session Goal</th>
<th>Session Workshop</th>
<th>Deliverables</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mar 22, 2021</td>
<td>• Orient Groups to the process • Self-presentations • Provide an overarching view of what the next three months will look like (process, takeaways, final deliverables)</td>
<td>• High-level Bootcamp Walkthrough • Self-Assessment Tool • Walk through SMART Objectives worksheet • Write down preliminary goals</td>
<td>• Goals activity • <em>Top Tasks</em> sort activity</td>
</tr>
<tr>
<td>Mar 26, 2021 – 10:00</td>
<td>Office Hours</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apr 2, 2021 – 12:00</td>
<td>Office Hours</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apr 5, 2021</td>
<td>• Explain Inclusive Design versus Accessible Product Design • Practice focusing on SMART goals • Begin Stakeholder Engagement, Selection, and Assessment</td>
<td>• Iterate on the “wrong ways” to go about this • Refine SMART goals • Walk through <em>Stakeholder</em> Worksheets – refine via short-listing</td>
<td>• Review Registry Business Case resource and come up with one question to post • Reach out to a potential advisory board member • Refine goals and stakeholder lists with worksheets • Begin <em>PROMISE</em> first draft</td>
</tr>
<tr>
<td>Apr 9, 2021 – 12:00</td>
<td>Office Hours</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apr 16, 2021 – 19:00</td>
<td>Office Hours</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apr 19, 2021</td>
<td>• Finish Stakeholders and complete Engagement Intro • Discuss resources required to succeed</td>
<td>• Expected or previous challenges writing activity • Revisit self-assessment and update • <em>How are you reaching them</em> worksheet and</td>
<td>• Begin Membership Application • Begin IRB Application • Identify study and survey designers • Complete registry handbook intro readings • &quot;Understanding data types available&quot; quiz</td>
</tr>
<tr>
<td>Date</td>
<td>Time</td>
<td>Office Hours</td>
<td>Action</td>
</tr>
<tr>
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<tr>
<td>Apr 23, 2021</td>
<td>19:00</td>
<td></td>
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<tr>
<td>Apr 28, 2021</td>
<td>10:00</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>May 3, 2021</td>
<td></td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>May 8, 2021</td>
<td>10:00</td>
<td></td>
<td>-</td>
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<tr>
<td>May 13, 2021</td>
<td>12:00</td>
<td></td>
<td>-</td>
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<tr>
<td>May 17, 2021</td>
<td></td>
<td></td>
<td>-</td>
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<tr>
<td>Apr 21, 2021</td>
<td>10:00 and 19:00</td>
<td></td>
<td>-</td>
</tr>
<tr>
<td>Apr 26, 2021</td>
<td>12:00 and 19:00</td>
<td></td>
<td>-</td>
</tr>
</tbody>
</table>

- Common registry funding sources
- Dissemination Plan work
- Social Media review and examples
- Planning the Technical Aspects – Data types and data collection
- Participants’ specific-characteristics worksheet
- Study design – data collection worksheet
- Physical samples: why versus why not?
- Progress on IRB Application
- Draft with study and survey writers
- Refine Study design – data collection worksheet with stakeholders
- Watch PRO Video Series Intro
- Physical Samples worksheet and Biobanking worksheet
- Scope of Data Collection worksheet
- Review and refine Scope of Data Collection worksheet
- Review LunaDNA Collection model
- Refine data types selection: timing and other considerations
- PROS and VI – when and when not to create your own
- Complete PRO Video Series
- Complete initial IRB Application
- Complete and submit Membership Application
- Progress with survey writers
- Complete Progress and Tracking worksheet – identify own pain points
<table>
<thead>
<tr>
<th>Date</th>
<th>Time</th>
<th>Event Description</th>
</tr>
</thead>
</table>
| May 31, 2021  |               | • Registry goals, successes, and unexpected uses  
• Address pain points  
• Presentations from mature groups  
• Highlight session goal topics and re-review SMART goals  
• Open working session on pain points  
• Bring survey writers to a stopping point  
• Submit completed IRB Application  
• Short-list questions and to-do’s for final session |
| Jun 3, 2021   | 10:00 and 19:00 | Office Hours                                                                       |
| Jun 8, 2021   | 12:00 and 19:00 | Office Hours                                                                       |
| Jun 14, 2021  |               | • Review next steps  
• Open problem solving and networking session  
• “All-hands” session: Final questions and completion of remaining items  
• Networking, feedback, and sharing of work from the cohort  
• All remaining outstanding deliverables necessary for Graduation |
| By Appointment|               | Additional Office Hours                                                             |

By Appointment
Appendix B
Biographical Sketches

Personal Statement

“Briefly describe why your experience and qualifications make you particularly well-suited for your role in the project that is the subject of the application.”

We suggest limiting this section to between one third and one half of a page, dependent on space available (if you have fewer publications and/or grants). The goal of this section is to clearly and concisely describe the qualities that make you best suited to fulfilling your role in the proposed project. Write this in the first person (“I am...”).

Suggested points to address:
1. Brief (1-3) sentence outline of the proposed project.
2. Describe your outreach, advocacy, community and/or scientific experience, highlighting specific skills that are applicable to your leadership in this project. Why is this project feasible because of you?
3. How is your expertise complementary to the expertise of the other members of the team? How does your role integrate into the team structure?
4. Describe any background that you feel would be useful to both the training, and the launch of a registry or study.
5. State what role, if any, you had in working with the community you represent to envision this registry or study.
6. End with a summary (one sentence) that generalizes why your experience has prepared you for this training and launching of your registry or study.

CVs/Resumes (feel free to use whatever you usually use)

Do not include personal information such as home address. Provide information in the following sections:
1. Education: Institution, Location, Major/Concentration, Degree, and Year.
2. Relevant Experience: Include technical and/or commercial experience. List in reverse chronological order beginning with the current position.
3. Any publications you have authored (choose the top 5 with relevance to this application if more than 5.
4. Other awards or funding.