YEAR 1 OBJECTIVES IMPLEMENTATION PLAN

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| **Date Completed: 07/13/2022** |

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| **SUBJECT:** Rare Disease Advisory Council Year 1 Objectives | **SUBCOMMITTEE RESPONSIBLE FOR IMPLEMENTATION:** Academic Research Institutions  |

| **RECOMMENDATIONS** | **OBJECTIVES** | **ACTION STEPS TO IMPLEMENT OBJECTIVE** | **ACTION STEP DUE****DATE** | **PERSON(S) RESPONSIBLE** | **COORDINATION WITH** | **STATUS/NOTES** |
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| Recommendation 1: Support research institutions in Florida. | Objective 1.1: Identify the components that constitute a best practice “rare disease research institution." | * Define a “rare disease research institution”.
* Define research as clinical and basic translational.
* Assess patient impact through patient volume, appropriately trained personnel.
* Develop framework
* Identify the necessary infrastructure to constitute a best practice institution.
* Work with national organizations to determine if this has already been done.
 | February 2023 | Academic Research Institutions Subcommittee  |  |  |
| Objective 1.2: Elicit feedback on developed components for a best practice "rare disease research institution." | * Identify stakeholders
* Identify effective process for communication and feedback
* Determine process for evaluating feedback
 | June 2023 |  |  |  |
| Recommendation 2: Promote availability of research institutions to individuals with rare diseases. | Objective 1.1: Promote expanded access to genome sequencing for all individuals with rare diseases. |  |  |  |  |  |
| Recommendation 3: Collaborate with state and national experts on complex rare disease cases. | Objective 1.1: Identify state and national rare disease experts available to consult with health care providers on complex rare disease cases. |  |  |  |  |  |