YEAR 1 OBJECTIVES IMPLEMENTATION PLAN

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

|  |  |
| --- | --- |
| **SUBJECT:** Rare Disease Advisory Council Year 1 Objectives | **SUBCOMMITTEE RESPONSIBLE FOR IMPLEMENTATION:** State Agencies Subcommittee |

| **RECOMMENDATIONS** | **OBJECTIVES** | **ACTION STEPS TO IMPLEMENT OBJECTIVE** | **ACTION STEP DUE**  **DATE** | **PERSON(S) RESPONSIBLE** | **COORDINATION WITH** | **STATUS/NOTES** |
| --- | --- | --- | --- | --- | --- | --- |
| Recommendation 1: Identify data needs necessary to understand the population with rare diseases in Florida. | Objective 1.1: Define incidence of rare disease in Florida. |  |  |  |  |  |
| Objective 1.2: Develop a list of rare diseases with an overlay of distribution across the state, beginning with the top 50 most prevalent rare diseases nationally. | * Awaiting legal approval | August 1, 2022 | Jonathan Hawayek |  |  |
| Objective 1.3: Develop a list of International Classification of Diseases, Tenth Edition codes for conditions covered by the Florida Newborn Screening Program. | * Obtain final list of conditions * Complete ICD crosswalk | October 1, 2022 | DOH |  |  |
| Objective 1.4: Identify the business rules for data extraction and research questions, including legal review. | * Identify potential data sources and data stewards * Compile list of requested items * Complete process for requesting access including DOH legal review or others as required | April 1, 2023 | DOH | AHCA  Other agencies |  |
| Objective 1.5: Develop a list of resources with an illustrated network of the varying systems of care that serve individuals with rare diseases such as public services, support organizations, educational support systems, employment services, etc. | * Inventory of non-government services * Inventory of government services * Research and treatment resources * NORD resources * Develop web resources including map/resource locator | June 2023 | Jonathan – private/nonprofit including NORD  DOH | Other agencies – DCF, DOE  NORD |  |
| Recommendation 2: Identify areas of improvement for FDOH on rare diseases. | Objective 1.1: Identify FDOH programs that serve the population with rare diseases. | * Complete assessment | Jan 2023 | DOH |  |  |
| Objective 1.2: Identify the population with rare diseases FDOH serves. | * Complete assessment | Jan 2023 | DOH |  |  |
| Objective 1.3: Develop a plan to enhance public-private partnerships. | * Enhance collaboration with non-govt organizations | June 2023 | DOH | Jonathan H |  |
| Objective 1.4: Develop a plan for interagency data sharing agreements on data about the population with rare diseases. | * Identify potential data sources and data stewards * Compile list of requested items * Complete process for requesting access including DOH legal review or others as required | April 1, 2023 | DOH | AHCA  Other agencies |  |
| Recommendation 3: Identify areas of improvement for the Agency for Health Care Administration (Agency) on rare diseases. | Objective 1.1: Identify Medicaid data that can be used to determine prevalence of rare diseases in Florida. | * Complete analysis |  | AHCA |  |  |
| Objective 1.2: Identify Medicaid programs that serve the population with rare diseases. |  |  |  |  |  |
| Objective 1.3: Identify the population with rare diseases in Florida Medicaid serves and assess its needs. |  |  |  |  |  |
| Objective 1.4: Develop a plan to enhance public-private partnerships |  |  |  |  |  |
| Recommendation 4: Identify areas of improvement for the Florida Department of Education (FDOE) on rare diseases. | Objective 1.1: Identify FDOE programs that serve the population with rare diseases and identify any barriers or gaps in services. |  |  |  |  |  |
| Objective 1.2: Develop a resource guide to educate public and private school staff, students with rare diseases, and families on available resources and supports such as Individualized Educational Plans, 504 Plans, and scholarships offered. |  |  |  |  |  |
| Recommendation 5: Identify areas of improvement for the Florida Office of Insurance Regulation (OIR) on rare diseases. | Objective 1.1: OIR will determine what data on rare diseases currently exist through commercial health insurance plans. |  |  |  |  |  |
| Objective 1.2: Identify the population with rare diseases OIR serves and assess its needs. |  |  |  |  |  |
| Objective 1.3: Identify if current surveys are being utilized to collect feedback from health insurance recipients with rare diseases. |  |  |  |  |  |
| Objective 1.4: Identify OIR programs that serve the population with rare diseases. |  |  |  |  |  |
| Objective 1.5: Develop a plan to enhance public-private partnerships. |  |  |  |  |  |
| Objective 1.6: Evaluate requirements for insurance benefits not to be discriminatory against insurance recipients with rare diseases. |  |  |  |  |  |
| Recommendation 6: Identify areas of improvement for disaster preparedness and pandemic response for individuals with rare diseases in Florida | Objective 1.1: Develop partnership with the FDOH Division of Emergency Preparedness and Community Support, State Emergency Operations Center and local emergency shelter administrators on the needs of individuals with rare diseases in Florida. |  |  |  |  |  |
| Objective 1.2: Complete a needs assessment of the population with rare diseases in Florida for natural disaster preparedness and pandemic response. |  |  |  |  |  |