**Data Developments**

The RDCA-DAP platform has reached over 34 different rare diseases. More data will be accessible throughout 2023 and into 2024 as outreach efforts continue. For questions or additional information about participating in RDCA-DAP, please email

**Platform Use**

- **Data Quality**
  - 26 approved workspaces for external users/researchers
  - 445 approved platform requests

**Data Developments**

- **Research and Analysis**
  - Annotations and Curation of Patient Data
  - Data Integration and Analysis across Workspaces

- **Data Sharing**
  - GCCM and OpenEHR integration
  - Support for more than 34 rare diseases

**Platform Use**

- **Platform Features**
  - Data Quality Management
  - Data Sharing and Security
  - Collaboration Tools

**NORD Corner**

- **Platform Use**
  - Engagement and Communication with Users
  - Update on Announcements and Webinars

**Announcements**

- **May 31, 2023**
  - Critical Path Institute (C-Path) announced new webinar series on regulatory considerations in rare disease research.

- **February 17, 2023**
  - The National Organization for Rare Disorders (NORD) launched a new online course for patients and caregivers.

- **February 28, 2023**
  - Accelerating Neurological Disease Research and Therapeutic Development webinar series.

- **April 21, 2023**
  - Collaboration to Accelerate Rare Disease Research.

**NORD Corner**

- **April 21, 2023**
  - NORD's IAMRARE Registry contributes two new datasets to C-Path's RDCA-DAP program.

- **May 20, 2023**
  - C-Path's RDCA-DAP program and PicnicHealth announce data development efforts.

- **June 12, 2023**
  - C-Path's RDCA-DAP program receives letter of support from EMA on Duchenne Muscular Dystrophy.

- **June 14, 2023**
  - C-Path welcomes mucopolysaccharidosis clinical trial data.

- **June 19, 2023**
  - C-Path's RDCA-DAP program receives additional modules for 2024.

- **July 19, 2023**
  - RDCA-DAP currently contains data for the following diseases:
    - Alport Syndrome
    - Amyloidosis
    - Amyotrophic Lateral Sclerosis (ALS)
    - Ataxia Telangiectasia
    - Becker Muscular Dystrophy
    - Batten Disease
    - Blau Syndrome
    - Cerebellar Ataxia Mucopolysaccharidoses (MPS)
    - Cerebral Palsy
    - Charcot-Marie-Tooth disease Myotubular or centronuclear myopathy*
    - Cystic Fibrosis
    - Duchenne Muscular Dystrophy*
    - Epidermolysis Bullosa
    - Focal Cortical Dysplasia
    - Friedreich's Ataxia
    - Glioblastoma
    - Hereditary Motor and Sensory Neuropathy (HMSN)
    - Hypertrophic Cardiomyopathy
    - Incontinentia Pigmenti
    - Lesch-Nyhan Syndrome
    - Leukodystrophy
    - Leigh Syndrome and other mitochondrial disorders
    - KAND
    - Spinocerebellar ataxias type 1, 2, 3 & 6
    - KIF1A Associated Neurological Disorder
    - Kidney Transplant Spinal Muscle Atrophy with Respiratory Failure
    - Lesch-Nyhan Syndrome
    - Liddle's Syndrome
    - Lowe Syndrome
    - Myopathy, congenital infantile hypotrophic
    - Mitochondrial Disease
    - Neurofibromatosis type 1
    - Neurofibromatosis type 2
    - Nurturing Disease(s)
    - Prader-Willi Syndrome
    - Prune-Belly Syndrome
    - Renal & Renal Tubular Acidosis
    - Rett Syndrome
    - Rett Syndrome
    - Rett Syndrome
    - Scleroderma
    - Spinocerebellar ataxias type 1, 2, 3 & 6
    - Spinal Muscular Atrophy
    - Tuberous Sclerosis
    - Usher Syndrome
    - VCP disease(s), an integrated approach to neurodegenerative disorders
    - X-linked Muscular Dystrophy

- **December 19, 2023**
  - NORDs' IAMRARE Registry contributes two new datasets to C-Path's RDCA-DAP program.

- **December 20, 2023**
  - C-Path's RDCA-DAP program receives letter of support from EMA on Duchenne Muscular Dystrophy.

- **December 21, 2023**
  - C-Path Welcomes Mucopolysaccharidosis Clinical Trial Data.

**Data Developments**

- **December 26, 2023**
  - C-Path's RDCA-DAP program receives additional modules for 2024.

**Data Developments**

- **December 26, 2023**
  - Additional modules will be released over the coming year. Each module is valuable on its own, and together they contribute to a comprehensive platform for rare disease research.

**Platform Use**

- **Platform Features**
  - Data Quality Management
  - Data Sharing and Security
  - Collaboration Tools

**NORD Corner**

- **December 26, 2023**
  - New webinar series on regulatory considerations in rare disease research.

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