AGENDA

Meeting Date: Tuesday, January 14, 2020

**Meeting Location:** St. Peter’s University Hospital

254 Easton Avenue

MOB #1, Ground Floor

New Brunswick, NJ 08903-0591

9:30a-10:00a **Executive Committee Meeting**

(Sharp) Everyone is welcome to attend.

10:00a-11:10a **Concurrent Committee** **Meetings**

Everyone is encouraged to participate in a committee.

* Education
* Legislative
* Clinical Practice

11:00 a - 11:45a Break/Networking – Lunch

11:45a - 12:45p Congenital Vertebral Malformations

Philip Giampietro, MD, PhD

Rutgers- RWJMS

12:45p - 1:30p **General Membership Meeting**

* Agenda
* Secretary’s Report
* Treasurer’s Report
* Introduction of Members and Member Announcements
* Committee Reports
* New Business

1:30p – 2:15 PKU Update and New Treatments

Darius Adams, MD

Morristown Medical Center

2:15p-3:00p Duchenne Muscular Dystrophy Update

Erin O’Rourke, MS, CGC

Sarepta Therapeutics

**3:00p-4:00p Rare and Undiagnosed Conditions**

**Kimberly LeBlanc, MS, CGC**

**Undiagnosed Disease Network, Harvard Medical School**

**4:00p Adjournment**