AGENDA

Meeting Date: Tuesday, September 11, 2018

**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
* Website

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

11:45a - 12:45p The Many Roles of a Cystic Fibrosis Caregiver

Andrea L. Mattie, MSW

Children’s Hospital of Philadelphia

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 - 3:00p Efficacy of Sebelipase Alfa

Maria Barr, Pharm.D.

Alexion Pharmaceuticals, Inc.

3:00p-4:00p Spinal Muscular Atrophy:  Today and Tomorrow

John Brandsema, MD

Attending Physician, Neuromuscular/General Neurology & Electromyography

Children's Hospital of Philadelphia

**4:00p Adjournment**