

**RARE DISEASE ADVISORY COMMITTEE MEETING**  
**May 14, 2019**  
**MoHealthNet Howerton Building, 615 Howerton Ct.**  
**Conference Room 202,**  
**Jefferson City, MO**

**Committee Members Present**

Patricia Dickson, MD chairperson  
Susan Abdel-Rahman, Pharm D  
Sherry Graf, RN  
Rosemary Britts  
Michael Burke  
Jonathon Cooper, PhD  
Claire Elson, Pharm D  
Jonathan Wagner, DO  
Matthew McLaughlin, MD  
Eric Rush, MD  
Gerald Wyckoff, Ph.D.

**MO HealthNet Staff Present:**

Mark Roaseau, R.Ph, Clinical Pharmacist  
Elizabeth Sissom, RN, Clinical  
Management  
Angela Wilson, Pharmacy Operations  
Manager  
Beth Mitchell, Administrative Office  
Support Assistant  
Dr. Timothy Kling, MD, Assistant Medical  
Director  
Dr. John Dane, State Dental Director  
Lisa E. Smith, Program Development  
Specialist  
Kerri Ballew, Drug Rebate  
Jackie Hickman, Drug Rebate  
Elizabeth Short, Finance  
Mitch Ruth, Finance

**Contractors in Attendance:**

Luke Boehmer, Pharm D, Conduent  
Jennifer Colozza, Pharm D, Conduent  
Olivia Rush, Pharm D, Conduent  
Jennifer Colozza, Pharm D, Conduent

**Others Attending:**

Brittany Slossbery, Novo Nordisk  
Benjamin Filas, Sobi  
Melissa Duvall, Sobi

<b>Welcome, Introductions and Opening Remarks</b>	Patricia Dickson, Chair, called the meeting to order. Mark Roaseau introduced himself and started the introductions and opening remarks.
<b>New Business</b>	
<b>Gamifant-- Hemophagocytic Lymphohistiocytosis (HLH)</b>	Mr. Roaseau introduced the product for discussion to the Board. The Board had much discussion of recommended criteria.
<b>Firdapse – Lambert-Eaton Myasthenic Syndrome (LEMS)</b>	Mr. Roaseau introduced the product for discussion to the Board. The Board had much discussion of recommended criteria.
<b>Oxervate – Neurotrophic Keratitis</b>	Mr. Roaseau introduced the product for discussion to the Board. The Board had much discussion of recommended criteria.
<b>Adjourn</b>	
	The meeting was adjourned(See attached roll call) The next meeting of the Rare Disease Advisory Board will be held on a Tuesday in August 13, 2019 at the 615 Howerton, conference room 202, Jefferson City, MO.

<b><u>Roll Call for August 13, 2019</u></b>					
<b><u>Member</u></b>	<b>March Minutes</b>	<b>Gamifant</b>	<b>Firdapse</b>	<b>Oxervate</b>	<b>Adjourn</b>
Susan Abdel-Rahman, Pharm D					
Patricia Dickson	Y	Y			
Sherry Graf	MY	Y	Y	Y	Y
Michael Burke	Y	Y	Y	Y	Y
Jonathan Cooper	Y	Y	Y	Y	MY
Gerald Wychoff	abstain	Y	Y	Y	Y
Francis Cole	A	A	A	A	A
Claire Elson	SY	Y	MY	Y	Y
Christopher Oermann	A	A	A	A	A
Daniel Rosenbluth	A	A	A	A	A
Johathan Wagner	Y	Y	Y	Y	Y
Matthew McLaughlin	Y	SY	Y	MY	SY
Eric Rush	Y	MY	SY	SY	Y
Rosemary Britt	Y	Y	Y	Y	Y

**Roll Call Abbreviations:**

**A-Absent**

**AL-Alternate**

**R-Ratify**

**M-Motion**

**S-Second**