

Committee on ALS: Accelerating Treatments and Improving Quality of Life

August 10, 2023: Access to ALS Care

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Purpose

- Hold a public workshop to receive information and engage in discussion on navigation of the ALS care system and the underlying financing mechanisms and payment policies that impact persons with ALS, caregivers for persons with ALS, and individuals at genetic risk of developing ALS.

OPEN SESSION

12:00—12:05 **Welcome and Introduction to the Workshop**

JOSHUA M. SHARFSTEIN, *Committee Member*
Vice Dean for Public Health Practice and Community Engagement
Johns Hopkins Bloomberg School of Public Health

12:05—12:35 **Panel on Insurance Coverage for ALS Care**

What care and services for ALS are covered in the clinic and at home?
How do different payers cover ALS care? Have cost analyses been done on ALS care?
What services, interventions, treatments, and devices are covered by different payers?
Do any alternative payment models hold promise for enabling greater access to high-quality ALS care?
10 mins each

Medicare and Medicaid

TERRI POSTMA
Senior Medical Officer
Centers for Medicare & Medicaid Services

Home Health Care for Veterans Living with ALS

RENEE GOLDEN
Regional Director
Military & Federal Homecare
Maxim Healthcare Services

Private Insurance

LISA M. LATTS
Senior Medical Director, Value Based Care

Optum Health Medical Office

12:35–1:00 Discussion with Committee

- Questions/comments from webinar participants/audience as time allows.

1:00- 1:10 Break

1:10-1:50 Panel on Navigating ALS Care and Payment

How do people living with ALS navigate the care and payment system?

What barriers do people living with ALS face to accessing care? What disparities are present?

What can providers and caregivers do to help people living with ALS navigate payment?

10 mins each

Lived Experience Perspective

BRUCE ROSENBLUM

Vice President of Content and Workflow Solutions, Wiley

Person Living with ALS

Navigating ALS Care and Payment with People Living With ALS

COLLEEN HOARTY

Medical Social Worker

University of Nebraska Medical Center

MELANIE LENDNAL

Senior Vice President, Policy and Advocacy

ALS Association

JOANNE LYNN

Eldercare Consultant

1:50- 2:05 Discussion with Committee

- Questions/comments from webinar participants/audience as time allows.

2:05- 2:25 Perspectives on Needs and Opportunities in the ALS Multidisciplinary Care Model

10 mins each

ALS Multidisciplinary Care Model – ALS Association Certification

LORI BANKER-HORNER

Senior Director, Clinical Programs

ALS Association

ALS Multidisciplinary Care Model – MDA Certification

NORA CAPOCCI

Vice President, Healthcare Services

Chief Privacy Officer

Muscular Dystrophy Association

2:25—2:35

Discussion with Committee

- Questions/comments from webinar participants/audience as time allows.

2:35—2:55

ALS Multidisciplinary Care – Provider Perspectives

TERRY HEIMAN-PATTERSON
Director, MDA/ALS Center of Hope
Temple University

JOHN HANSEN-FLASCHEN
Founding Medical Director, Paul Hannon Lung Center
University of Pennsylvania

2:55—3:10

Discussion with Committee

- Questions/comments from webinar participants/audience as time allows.

3:10

Closing Remarks

END WEBINAR