

*The National Academies of*  
**SCIENCES • ENGINEERING • MEDICINE**

*Health and Medicine Division, Board on Health Care Services*

**Committee on Selected Heritable Connective Tissue Disorders and Disability**

**\*\*DRAFT\*\***

**Public Meeting Agenda**

May 11, 2021

Zoom

Please contact Torrie Brown ([vbrown@nas.edu](mailto:vbrown@nas.edu)) for meeting connection details.

**Public Session I**

**10:05—11:15 a.m. Eastern Daylight Time**

- 10:05 a.m. **Welcome and Introductions**  
*Paul Volberding, Committee Chair*  
*SSA representative/s—TBD*
- 10:10 a.m. **Social Security Administration Presentations Relevant to the Committee's Task**  
*SSA Presenter/s—TBD*
- 10:30 a.m. **Questions and Discussion**
- 11:15 a.m. **Adjourn Public Session I**

**Public Session II**

**12:15—2:00 p.m. Eastern Daylight Time**

- 12:15 p.m. **Gastrointestinal Conditions in Heritable Disorders of Connective Tissue**  
*Laura A. Pace, M.D., Ph.D.*  
*Center for Genomic Medicine*  
*University of Utah*
- 12:30 p.m. **Questions and Discussion**
- 12:50 p.m. **Orthostatic Intolerance in Heritable Disorders of Connective Tissue**  
*Peter C. Rowe, M.D.*  
*Director, Children's Center Chronic Fatigue Clinic*  
*Sunshine Natural Wellbeing Foundation Professor and Professor of Pediatrics*  
*Johns Hopkins Children's Center*
- 1:05 p.m. **Questions and Discussion**
- 1:25 p.m. **Mental Health Conditions Associated with Heritable Disorders of Connective Tissue**  
*Antonio Bulbena-Vilarrasa, M.D., Ph.D., M.Sc. (Cantab)*  
*Distinguished Professor of Psychiatry*  
*Chair, Department of Psychiatry and Forensic Medicine*  
*Universitat Autònoma de Barcelona*
- 1:40 p.m. **Questions and Discussion**
- 2:00 p.m. **Adjourn Public Session II**