



**Assembly Select Committee on Biotechnology  
Legislative Rare Disease Caucus  
Roundtable  
Wednesday, October 18, 2023**

**Roundtable Discussion  
The Alexandria at Torrey Pines  
10996 Torreyana Road  
San Diego, CA  
11:00 a.m. – 1:00 p.m.**

Members Attending:

Assemblymember Chris Ward, Chair, Biotechnology Select Committee  
Senator Catherine Blakespear  
Assemblymember Liz Ortega  
Assemblymember Kate Sanchez  
Assemblymember Akilah Weber

Roundtable Attendees:

Julie Boyd, Ultragenyx  
Joy Burkhard, Policy Center for Maternal Mental Health  
Sam Chung, California Life Sciences  
Claire Conlon, Biocom CA  
Flo Kahn, PhRMA  
Lynne Kinst, Hemophilia Council  
Dean Marcoccia, Horizon Therapeutics  
Russell Nofsinger, Rady Genomics Institute  
Alisa Reinhardt, Bayer  
Ken Sprague, BioMarin  
Craig Swaim, Rostrum  
Ryan Taft, PhD, Illumina  
Sara Koffman, Biogen  
Sarica Klein, PhD - Biogen  
Steven Shultz, Sage Therapeutics

## AGENDA

1. Opening Comments - Assemblymember Ward
2. Introduction of Attendees
3. Rare Disease Panel – Barriers to Access

### Questions for Discussion:

- ❖ What are the barriers to access facing rare disease patients?
  - ❖ What role does California play in innovating treatments and cures for rare disease patients—what are we doing well, what do we need to improve? What does the future of medicine in the rare disease space look like?
  - ❖ What can the state do to prepare for innovative new therapies that will become available in the coming years?
  - ❖ Within the health care system, what are the structural barriers that most impact patients and their ability to get the care they need?
4. Women’s Health Panel – Disparity in Coverage for Women’s Treatments

### Questions for Discussion:

- ❖ What are today’s emerging frontiers in the women’s health space?
  - ❖ What separates women’s health from the rest of the healthcare system? What disparities and barriers to access exist within women’s health?
  - ❖ Can you talk about how current policies impact women’s health overall and what are some best practices you can recommend in this space?
  - ❖ What are some ways the legislature can address the disparity in coverage for women’s health treatments?
5. Closing Thoughts