



Summit Agenda



— Alnylam —
PHARMACEUTICALS
GLOBAL RARE DISEASE
PATIENT ADVOCACY
COLLABORATIVE
— **SUMMIT 2019** —



Global Advocacy Leadership Summit

Day 1: November 9, 2019 - Building Alliances & Capabilities

Morning Agenda	
8:30 – 9:30	Welcome and Introductions, including introduction to Alnylam, attendees and leadership
9:30 – 10:45	Panel: The importance of the patient voice in drug development. Objective: Understand and identify opportunities for PAGs and patients to become more involved in the drug development process.
10:45 – 11:00	Break

*Notes:

- Welcome reception to be hosted evening prior to program start
- Resource table at back of room for sharing of educational resources



Breakouts

11:00 – 12:30

Concurrent Breakouts: *Participants will be divided into three groups. Participants will rotate through the sessions across the course of the two days.*

A: Funding Strategies for Growing and Emerging Patient Organizations

B: Building physician networks, working with professional associations, and developing and maximizing the value of your scientific committees

C: Expanding your reach - Growing membership, reaching diverse populations, and maximizing volunteers



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Day 1: November 9, 2019 - Building Alliances & Capabilities

Afternoon Agenda	
12:30 – 1:30	Lunch and networking
1:30 - 3:00	Keynote: Working with the media – using storytelling to raise disease awareness and address issues Objective: Gain greater understanding on ways to work with the media to advance disease awareness and address issues of concern to the community.
3:15 – 3:30	Break
3:30 – 5:00	Concurrent Breakouts (repeated)
6:00	Networking reception and group dinner



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Day 2: November 10, 2019 – Enhancing Access

Agenda	
8:00-8:30	Welcome RNAi from Bench to Bedside: Communicating about RNAi
8:30- 10:15	Panel Discussion: Access to cutting edge therapies and diagnostic technology Objective: Discuss strategies for collaborating to navigate patient access to novel therapies
10:15-10:30	Break
10:30-12:00	Concurrent Breakouts (repeated)
12:00-1:00	Meeting summary, call to action, and close of formal program