# Ultra Rare Strategies

These aren’t inpatient/outpatient/pharmacy issues . . .

*These are ultra rare issues – & we are the voice.*

Weekly Conference Call

September 7, 2017

**Agenda**

1. Ultra Rare Strategies Dinner – **Oct 16 @ 6:30pm** – NEED RSVPs PLEASE
	1. NORD Annual Meeting – October 16-17 -- Marriott Wardman Park, 2660 Woodley Rd.
	2. Speaker: CMS, ex-CMS, Hill….
2. Website – **ultrarare.org**
	1. Add logos, and put up press releases, etc. as you send them or links to your website.
	2. Facebook next
3. 340B Update – **PLEASE SIGN ON BY TOMORROW**
4. ICER Ultra Orphan Proposal response – draft #1 shortly
5. Patient Assistance Programs next…
6. Hill meetings
	1. September 11 Hill meetings – DRG/NTAP and OPPS/340b; ICER if ready;
	2. Hill staff ready for patient group meetings/emails…

**These aren’t inpatient/outpatient/pharmacy issues…**

***These are Ultra Rare issues!***