



**Right Care Alliance (RCA) Patient Council
Meeting Agenda & Minutes
May 21st, 2020
7:00 to 8:00 pm EDT**

Participation Instructions:

- Zoom in Link: <https://us02web.zoom.us/j/4138836986>
OR
- Phone in by your location:
1- 646 558 8656 US (New York)
1- 669 900 6833 US (San Jose)

Patient Council Introductions & Communications—5 mins

- Members Attending: (Poppy will join at 7:30) **Tamera Stewart, Bill Adams, Casey Quinlan, Julie Martinez, Steph Aines, Helen Haskell, Ken Zaiken, Poppy Arford**
- Scribe: **Casey Q**
- **Mission Statement:** The Right Care Alliance Patient Council brings together patients and their families to radically transform our health care system into one that places the health and well-being of patients first and delivers Right Care to all people.
- **Right Care Definition:** Right Care is a human right. It places the health and well-being of patients first. Right Care is affordable and effective. It is compassionate, honest, and safe. Right Care brings healing and comfort to patients, and satisfaction to clinicians. Achieving Right Care will require radically transforming how care is delivered and financed.
- Review [4.3.20 Patient Council Meeting Minutes](#)

Patient Council (PC) Activities—5 mins

- **Member News Brief:** Need Brief for May/June ([see Guidelines](#)). Check out our most recent Patient Council webpage [“What Worries You Most About American Healthcare? We asked. People answered.”](#) by Casey Quinlan. FMI contact [Casey Quinlan](#), Exec Editor. **TAMERA STEWART IS INTERESTED IN WRITING A POST ABOUT HER EXPERIENCE GETTING LEGISLATION PASSED TO PROTECT CHRONIC PAIN PATIENTS FROM BEING THROWN UNDER THE BUS BY OPIOID-CRISIS FEAR MONGERING.**
- **Right Care Alliance (RCA) Political Action Study Group:** The Political Education Study Groups are RCA Members sharing an intellectual and comfortable conversation while they teach and learn from each other. Please come with an open mind, curiosity, and excitement to teach and learn in community. FMI [Contact Stephanie Aines.](#) **KEN ZAIKEN ATTENDED LONG-TERM CARE MEETING, NOT SURE IF IT WAS PART OF POLITICAL ACTION STUDY GROUPS OR NOT. None of us are participating, could be conflated with Coffee Hours?**

Patient Council (PC) Action Reports—10 mins

- **Covid 19 Community Conversation (Bil)** **ONGOING, CHALLENGE IS TO GET CLINICAL PROFESSIONAL(S) UP TO SPEED, READY TO PARTICIPATE IN DELIVERING CONTENT RE COVID19 CURRENT ISSUES, STATUS, SCIENCE, POLICY**

- **WWYM Survey Costs Blog & Infographic: Financial Worries of Patients (Casey)** **IN THCB MAY 15:** <https://thehealthcareblog.com/blog/2020/05/15/americans-are-worried-about-the-cost-of-their-healthcare-and-they-have-good-reason/>
- **RCA Steering Committee Meetings & Town Hall (Bill)**
- **JULIE M: BAY AREA CHAPTER HAS BEEN ON FULL-STOP; SURPRISE MEDICAL BILLS ZOOM SESSION ONLINE MID-MARCH, RECORDED, WILL WORK ON FINDING LINK.**
- **BILL A: RAISES QUESTION ON HOW RCA WILL RESPOND TO LETTERS TO RCA ON SUGGESTION(S) FOR WHAT ISSUES WE'LL TACKLE/JOIN/SUPPORT AS AN ALLIANCE. SUMMER MEETING OF RCA IS BEING PLANNED, WILL BE VIRTUAL, WITH OPTION TO ATTEND IN PERSON IN BOSTON. "MEETING OF RIGHT CARE ALLIANCE" NOT TOWN HALL.**
- **AFP Advisors:** American Family Physician (AFP) Editorial Advisory Board Link to the current Editorial Board. **(John & Helen) HAVE WORKED ON TWO PIECES, PREPPING A THIRD. LOWN IS DOING A SERIES ON OVERUSE, CAME TO PATIENT COUNCIL TO GET PATIENT COMMUNITY INPUT. WILL BE A COUPLE OF GRAFS IN EACH PIECE, PATIENT PERSPECTIVE ON HOW ISSUE IN ARTICLE COULD BE IMPROVED W/PATIENT INPUT**

WWYM Survey - 2020 Annual. Late Summer / Fall send out. Compile results. Report out w/ Blogs. Leads: Bill & Helen - 5 mins

WORKGROUP: CASEY, HELEN, JOHN J. [VOLUNTOLD]

- **ON DECK: FORMAT, QUESTIONS, DATA CAPTURE METHODS, DATA ANALYSIS AVAIL IN FORMATS/METHODS UNDER ASSESSMENT**

Member Talk Time: Patient need to make noise (write blogs, LTE, etc) in response to Covid-19—30 mins

- Critical need for patient advocacy and engagement in the Covid conversation. **PATIENT VOICES ARE GETTING SHUT DOWN, SIDELINED, SILENCED IN COVID CRISIS.**
- Critical need for quality transparency & patient safety protections.
 - **HELEN REPORTS, FROM PSAN CALL, THAT NURSING HOMES SHARE STAFF, MOVING THEM AROUND TO MEET CMS RATIOS; THIS IS HOW COVID IS SPREADING IN THAT LONG-TERM CARE LANDSCAPE.**
 - **JULIE REPORTS THAT COFFEE HOUR GROUP ON LTC IS TALKING ABOUT FLAUTING OF INFECTION CONTROL, PATIENT SAFETY RULES THAT'S ONLY GETTING WORSE IN COVID. HELEN SAYS THAT HOSPITALS AREN'T PAYING ENOUGH ATTENTION TO INFECTION CONTROL, EITHER. LACK OF WITNESSES (IE FAMILIES ARE CUT OUT DUE TO COVID) IS WORKING TO LTC AND HOSPITAL ADVANTAGE. EXAMPLE: PRIOR TO COVID, IF PATIENT WAS IN INFECTION CONTROL ISOLATION (IE MRSA), FAMILY WAS ALLOWED IF FAMILY WAS IN PPE. DURING COVID, THAT'S GONE BY THE BOARDS.**
 - **TAMERA REPORTS THAT HER UNCLE JUST EMERGED FROM A COMA, HER MOM (SISTER OF PATIENT) WAS NOT ABLE TO VISIT BROTHER DESPITE BEING A NURSE LICENSED IN THAT HOSPITAL; HE WAS HOSPITALIZED DUE TO ACCIDENT, HOSPITAL SAID "HE CAN'T TELL US HE WANTS YOU TO SPEAK FOR HIM"**
- Critical need to understand cost of care reality (i.e. are payers waiving OOP cost associated w/Covid-19, how many patients are falling through insured population cracks due to loss of employment, etc)
- Critical need for patient interests being represented in Tele-health movement
 - **BILL AND HELEN ARE GOING TO WORK UP A FRAMEWORK/TEMPLATE FOR WRITING TO MEDIA OUTLETS ABOUT THIS BURNING ISSUE**

Wrap Up—5 mins

- Rotating meeting Schedule for 2020: Monthly meetings will take place on the 3rd Thursday of each month from 7:00 to 8:00 pm EDT (July, Sept., Nov.) and from 12:00 to 1:00 pm EDT (June, Aug., Oct., Dec.)
- Next Monthly Meeting: June 18th from 12 to 1 pm EST

“Sharing a heartfelt thank you to everyone who participated in the meeting. Together we are building the Patient Council and working to put patients first, one meeting, one member and one action at a time.”