



PIRC

PROTECTING INNOVATION IN RARE CANCER

REBALANCE THE IRA

PIRC Meeting

November 13, 2023

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PIRC Purpose

- Speak loudly with one voice
- Speak from a rare cancer perspective
 - **Educate** ourselves (& our communities)
 - **Applaud** what we can
 - **Prepare** for what is coming
 - **Fight** against what must change
 - NOW AND NEXT YEAR
 - PREPARATION



Agenda

1. “Facilitator” Sign On Letter
2. Imbruvica Listening Session

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Listening Session



Speakers

- Consider downstream impact/how plans respond to MFP will impact plans and patients
 - ACSCAN: Negotiated prices could have plans steering patients to specific drugs.
- Took about 2.5 years from initial approval in related blood cancer. Hairy cell leukemia phase 2 study
- Concerns are unique to cancer - patients cannot switch from one treatment to another or step through one BTK to another.
- Cms taking a passive approach to monitoring plans will be dangerous to patients
 - ACSCAN: Urge cms to continue to reach out to patients. Were real savings achieved? Did patients retain to drugs they needed?
- Ask the experts
- Most patients are unaware treatment driven by coverage policies, formularies, utilization management
- Having an oral option was a game changer for patients
- Significant number of patients remain on Imbruvica, but significant number also have reduced dose or discontinued altogether due to unmanageable side effects.
- There is potential for real savings if savings directly reach patients. Patients won't benefit from negotiation unless they pay less out of pocket for their treatment

Listening Session: Price/Cost Confusion



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Price/Cost to Medicare vs. Cost to Patient

- Speakers confused the two
- 73 yr old Medicare patient on Imbruvica: Imbruvica is not affordable. Hopes future negotiations will make meds more affordable to more seniors. Believes negotiation pricing will not impede research or innovation since “this” is funded by taxpayers. Asked CMS to continue vigorous negotiations to make all cancer treatments affordable to all seniors. (Does not understand out of pocket cap or smoothing.)
- Patient: Did well on Imbruvica, only minor side effect. Happy there are additional treatments since she had to stop taking it. Pleased imbruvica was included in negotiations b/c she hopes it helps patients concerned with cost of drugs.
- ACSCAN: There is potential for real savings if savings directly reach patients. Patients won't benefit from negotiation unless they pay less out of pocket for their treatment

Other Speakers/Additional Points:

- Enormous unmet need for new cancer treatments. Innovation is hugely important. Work with fda to monitor impact of IRA on research and development.
- Waldenstrom's patient: Confusing – Said Dana Farber developed imbruvica, noted concern for effect of negotiations on other BKTs; Cited expense of drugs/need to take for the rest of your life, but said he was now off all treatments but would likely need treatment again at some point.
- Researcher: Also confusing – Spoke of research funded by government, NIH database lists manufacturers as sponsoring 25% of research, but then spoke of costs for a manufacturer study as being ‘massive’



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Remember

“Facilitator” Sign On Letter

PIRC Standing Calls:

1. 11/27 (likely cancelled for Thanksgiving holiday)
- 2. 12/11**
3. 12/25 (cancelled for holiday)

We will cancel calls if:

1. No CMS actions
2. No requests for deep dives on particular topics (good time for learning)