EMPOWERING PROVIDERS TO EMPOWER PATIENTS (EPEP)

CLL Healthcare Provider Resource Guide

HOW TO ENCOURAGE YOUR CLL PATIENTS TO BE MORE ACTIVE IN THEIR CARE

- Tell patients you welcome questions and honest, detailed conversation.
 - They can even have a list of questions/topics they'd like to address during the appointment.
 - They can also reach out via the patient portal or call your office after the appointment for any follow-up questions.
- Remind them they can bring family members or friends to appointments, so they feel supported.
- Allow patients to take notes or record, if appropriate.
- Be open to talking about financial assistance options they may be eligible for.

"Understanding the mutation profile of patients will allow you to describe how their disease is going to behave over the whole long marathon of CLL...when they're on treatment, when they're not on treatment, and it will just help us help you understand what to expect and help assist with treatment choice. It's important that you as a provider add in that type of evaluation." - Jennifer Brown, MD, PhD

CLL MUTATION PROFILES | KEY TAKEAWAYS

- Most common mutations at baseline are TP53 gene, NOTCH1, SF3B1, and ATM. These occur in 10-20% of patients.
- It is important to do next-generation sequencing test for the TP53 mutation.
 - This is because this particular mutation is not well evaluated by any other test and is often missed, because it's often thought that checking for the 17p deletion is sufficient (which it is not).
 - If a newly diagnosed patient has the TP53 gene, that moves them into a higher risk category and could be eligible for early intervention clinical trials like the SWOG EVOLVE trial. TP53 patients should not receive chemotherapy either.
- Patients can also acquire a mutation in TP53 or in NOTCH after their second or third line of therapy, so it is important to re-test after each line of therapy.
- BTK mutations are mutations that occur as resistance to therapy; Covalent BTK inhibitors have transformed CLL therapy by binding to the cysteine 481 residue of BTK and inhibiting the activity of BTK.
 - Mutation testing should always be done in a well-monitored setting, as some tests may be practical in research settings rather than in the clinic.
- Don't forget to test for IGHV mutation.
 - In some large facilities, this is an in-house test, but Mayo Clinic and other vendors can also run this test.

BEST PRACTICES FOR MANAGING CLL SIDE EFFECTS

- Utilize other practitioners on the team such as nurse practitioners, oncology nurses and pharmacists.
- Recognize what common toxicities are and how to mitigate those.
 - For example, venetoclax (Venclexta) can cause neutropenia which can be mitigated through administering growth factor.
 - Side effects from BTK inhibitors may warrant working with a cardio oncologist.
- Warn patients ahead of time on what side effects they can expect and how to manage them.
 - This can help them worry less and feel more involved in their care.
 - Specific examples include:
 - headaches often occur when acalabrutinib (Calquence) is initiated but typically go away quickly. You can
 advise patients of this and then talk about using caffeine or acetaminophen to manage the headache.
 - venetoclax may cause diarrhea or nausea, so you may suggest to patients to move the drug to the evening or try an antiemetic.

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"CLL is a chronic disease that affects our primarily elderly patients, and so it's a marathon, not a sprint. However, with all of the advances that we've had in excellent drug therapies, despite these resistance mutations, patients can attain many years of high quality of life. But it's incumbent upon us as their providers to help ensure quality of life through effective management of side effects that may be encountered over the course of their time on therapy for the patients that do need therapy." - Callie Coombs, MD

CLL EPEP PORTAL

The Empowering Providers to Empower Patients Portal uses PEN's robust resource library and that of numerous trusted advocacy partners to collate a vetted list of patient education resources, all in one place. Select resources within the form and receive an emailed PDF within minutes to share with your patients – try it today.

