Patient Experience

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My Health Journey

- Diagnosed with uterine fibroids in early 20s
  - Positive family history for uterine fibroids & leiomyomas; no genetic testing done
- Began developing leiomyomas on back and arms in late 20s
- Anemic, severe fatigue, and hypertension
- Two years after raising concerns with doctors, diagnosed in May 2016 with 13-cm tumor and stage IV papillary renal cell carcinoma
  - Now classified as FH-deficient papillary renal cell carcinoma from HLRCC (hereditary leiomyomatosis and renal cell cancer)

Diagnosis

- June 2016: radical right nephrectomy at University of California, Los Angeles (UCLA)
  - right adrenal gland
  - most of inferior vena cava (IVC)
- August 2016: Post-op scans showed metastasis to liver, lungs, and chest
- Enrolled in SWOG S1500/PAPMET clinical trial in September 2016 and randomly assigned cabozantinib

- First scan on treatment in December 2016 showed 80% reduction in my tumor burden
- Declared NED in August 2017
- Discontinued cabozantinib in April 2020
- NED as of July 2024 with 6-month surveillance scan regimen

Caregiver Experience

- Mother was diagnosed August 2018 with B-cell lymphoma and kidney cancer
- Received R-CHOP for lymphoma, and SBRT, nivolumab and cabozantinib
- Contracted the flu in January 2019 and passed from sepsis.

Side Effects and Their Impact on Patients

- Today's cancer patient is not yesterday's – targeted therapy & immunotherapy are yielding different patient responses in many cases than chemo & radiation
  - Patients may not always "look" like a cancer patient, requiring education for not only themselves, but caregivers too
- Be honest with patients on the severity they may experience with side effects. "Fatigue," "diarrhea," and "mouth sores" don't always adequately prepare the patient for what to expect.
  - It's better to be honest and transparent than to cause unnecessary concern and panic when side effects hit (usually after hours)
- For patients on targeted therapy and/or immunotherapy, provide them with easily transportable information on their treatments in case they need treatment from other providers, especially in emergency settings.

Discussing QoL and Side Effect Management

- Involve palliative care early on, and determine what is most important to patients when dealing with side effects from treatment. How risk tolerant or averse are they?
- Discover barriers to successful treatment and help patients develop a game plan on how to address
  - Is home health needed?
  - Do they need ADA/work accommodations?
  - Do they need supportive services from social worker or therapist?
- Encourage patients to have a caregiver present at all appointments. If not possible due to COVID or other factors, encourage patients to voice record appointments to refer back to later (less stressful and more comprehensive than writing notes)
- Create an environment of trust with your patient. You, your staff, the patient and the caregiver(s) are one team fighting the same enemy. The more a patient trusts you, the more open they will be with their side effects and other quality of life concerns.

Patient Perspective on Precision Oncology

- **Earlier Diagnosis**
  - Encouraging genetic testing for high-risk patients
  - Educating providers outside of oncology about genetic disorders that may have oncologic implications
- **Biomarkers & Therapies**
  - Specialized treatment plans
  - Improving quality of life
- **Socioeconomic Impacts**
  - Reducing economic burden
  - Instilling confidence in patients & shared-decision making
- **Patient Samples**
  - Encouraging patients' enrollment in clinical trials when appropriate
  - Other ways for patients to contribute their tissue and biofluid samples
- **Education on Genetic Testing**
  - Family & Friends' Buy In
  - Language and socioeconomic appropriate resources

Impact of the Patient Voice

No Decisions About Us Without Us

Our experiences as patients are valuable and irreplaceable. Invite patients to the table: when scientists and patients work together in research, it helps advance the field.

Patient advocates change research and can improve clinical trial accrual! I have helped make trials more accessible by suggesting changes to scan schedules, reimbursements for travel and parking, and encouraging "dealer's choice" when clinically appropriate.

Most patients want to give back and contribute – help us give purpose to our lived experiences!