I recently lost my father to Lung Cancer. We spent over 5 years on the roller coaster with Dad thru all his medical needs relating to his lung cancer treatments including appointments, lab works, infusions, scanning, medications, surgeries, and doctor’s visits and consultations. Treatments appointments and related visits could be as short as 2 hours to as long as several days during hospitalizations. Because my dad was blessed with 8 children, and some very resourceful spouses, we were able to collaborate and navigated thru all the jungle of paperwork and medical terminologies to meet Dad’s needs a priority in our lives. We rotated as administrators, interpreter, chauffeurs, and manager of his treatment plans, his medications, his documentations, and myriads of study drugs and their and related needs. We successfully managed in large due to the contribution of our experienced family members that worked as nurses and patient care case manager for hospitals and health care professionals. I could imagine the burden of a patient who does not have the same support network that my father received.

In hindsight, I feel my personal walk with my dad during his treatments in the last 5 years were valuable insights into how to replicate it to provide similar support for other patients. This available personal support will encourage families to continue in their participation in treatments and available clinical trials. If you could commit at minimal an initial period to your new patient as guidance to help them and their family navigate the new, confusing and stressful journey to treat their disease, it will make all the difference the longevity of their participation in your clinical studies and treatments.

To begin, I would invest the duration of one initial year to pair a staff professional with the new patient to assist in the understanding of their new disease. The staff must be well trained and knowledgeable to support patients with understanding of the disease in their own languages if English is not their first language. The professional staff will help patient navigate the treatment plan, the effect of the treatments, pros and cons of the medications, assistance with paperwork, managing patients schedule and appointments, and possibly providing ride services and emotional support. I believe if these resources are available in the initial year, as a training wheel for patients, it will remove most barriers that are hindering patients from pursuing and exhausting all their options to the end.

I envision such support could be considered a total care or a VIP service to the patient. The assigned staff would work closely to manage the patient and all his needs administratively. The staff would be available to personally manage the patients and answer any and all questions and concerns to the patient, as if the staff “adopted” the patient as family member.

You can begin by investing in one staff with an assigned base of patients that is manageable for the staff. Let the pilot program begin with a handful of patients during the course of the patients’ first year to train the patient and set them on the course to continue in their treatments.

During the pilot, process will continue to be reviewed, enhanced and refined so that it would be cost effective and at the same time raise the participation level. Once refined, it could be modeled in its approach to grow in patient participation to a larger scale.

The service will in time alleviate confusions and stress for the families of the affected patients. This will encourage participation and the sharing of its success by the patients themselves to fellow afflicted populations of such VIP resources.

Our family would be so lost had we not have each other, but because our sister who was a nurse and case manager was available to guide our family in the understanding of the system, the process, the terminologies, and the medical languages that is required on this journey. Honestly I am not sure I would have had been blessed with the additional 5 years with my Dad had we been clueless and stressed over the medical documents and bills and coverage. We would not have pursued the available clinical studies or trials medicines had it not been for our sister. It’s sad to think there are many families out there could miss out on available resources because of the aforementioned barriers.

This solution should be quick and easy to implement. Our family had no training, no manual, no experience. We managed because we made ourselves available to understand and to figure it all out for Dad. We have a few nurses and case managers who understand the system as our navigators. If you could provide the medical staff to the patients, they too could be successful with a partner who can function as a navigator thru the jungle of available treatments and study drugs and their processes.