Message from the President

Thankful, encouraged, enthused, and determined

"Clinical research is designed to narrow the scope of clinical uncertainty by identifying unknown risks and benefits and determining which therapy is most effective" ~Kyle L. Galbraith, Ph.D.

Dear Friends,

Worry comes with the diagnosis of lymphoma, this I don't have to tell you. My way to worry is to learn and to share what I learn. The process keeps me engaged and fulfilled, and, fortunately, what I've learned about lymphoma keeps me hopeful, encouraged and enthused.

When Joanne was diagnosed 18 years ago chemotherapy was the only option and enrolling in a trial meant participating in a trial testing different kinds of chemotherapy. But there was an exception: C2B8 (later to be named Rituxan) was also in clinical phase testing at that time, 1996.

Rituxan deserved approval because it achieved good results with modest risks … and the side effects compared to the regular treatments of the day. Because there were virtually no competing targeted agents, new ways to use Rituxan (R) were tested efficiently – such as with chemotherapy and as maintenance.

Outcome data from SEER tells us that the survival of patients with lymphoma has improved. This improvement is due, at least in part, to the addition of <u>one</u> new targeted agent, Rituxan. Despite recent progress many pressing needs remain, such as:

- To cure more patients with indolent lymphoma
- To increase the low cure rate for patients aggressive t-cell lymphomas
- To improve the good cure rate for patients with aggressive b-cell lymphoma
- To maintain and improve the high cure rate in Hodgkin's while decreasing the late adverse effects
- To more effectively treat transformed lymphoma
- To effectively treat lymphoma that's resistant to standard therapy …

Making additional progress requires good science – but it is also in our hands. The new opportunities to help patients can only be realized by the timely completion of well-designed clinical trials -- the <u>need increasing</u> in proportion to the increasing opportunities – as each new agent must compete for participants in the same small pool of patients who are eligible for the trials.

Barriers to participation in trials are many. The study must be a good fit for the patient – as a treatment decision. The patient must be eligible. The insurance company must reimburse for the parts of the study that are part of regular care. The patient, caregiver, or physician must be aware that the study exists and have the necessary background to choose a trial that is appropriate … from the many hundreds of trials that are posted on ClinicalTrials.gov.

To help address this need, PAL provides resources to help the **community** (patients, caregivers, and treating physicians) to understand and consider trials – which often compete very well against standard therapies – providing also hope that the study protocol can address the urgent needs of the participants as well.

See 7 reasons to consider trials – based on our clinical circumstances.
http://www.lymphomation.org/Trials-7-clinical-circumstances.pdf

Today we provide core trial search tools to help the community to locate lymphoma and CLL trials that are used many thousands of times:

- By type of lymphoma/CLL and treatment status http://bit.ly/fsk2W7
- PAL's trials of interest http://bit.ly/wmyD29
- By the type of treatment agent http://bit.ly/LxKoeR

Our focus for the New Year will be on doing more to help the community to become better informed about the many new classes of targeted therapies – by creating topic pages for each.

These new portals will provide concise background on the most promising investigational treatment agents, concepts, outcome reports, and the clinical trials that are recruiting patients.

With sincere appreciation to our supporters (advisors and donors alike) – making the development of PAL's resources possible,

Karl Schwartz
President, Patients Against Lymphoma