

PCers Form an Immediate Bond

The story of Kansas City is best written by the PCers who attended...Jan, Bob, Ted, Tim, Roseann, Cameron, Alexis, David, Russell, Ronald. Their comments are on the PMB at <http://www.pachyonychia.org/ForPatients.org/html#MessageBoardc>.

There was a tangible bond among those at Kansas City that will not end quickly. There is a power in joining together with a dedicated purpose.

DOCTOR'S COMMENT

Dr. Leonard Milstone wrote "The face to face meeting in KC was an important start to our collaborative effort to improve our understanding of PC and to begin formulating new approaches to evaluation and treatment. As an investigator and as a physician treating PC patients, nothing replaces seeing many examples and hearing comments first hand. .."



REPORT ON KANSAS CITY PATIENT SUPPORT MEETING July 2-4, 2004

After KC, I felt strongly that PC Project must find a way to host meetings that result not only in 'good feelings' but in actual research advances based on the information gleaned at the meeting. After several discussions, we have some exciting decisions which have come as a result of the KC experience.

(1) Over the next year, PC Project will increase funding for Dr. Leachman so that she can coordinate these projects.

(2) PC Project will host small regional meetings for those in the PC Registry (not large national meetings). These will be coordinated by Dr. Leachman who will assist in establishing regional specialty groups. This approach will bring a power and consistency to the observations and physician exchange which has never before been possible.

(2) Based on information gathered, PC Project will then conduct real 'clinical

trials' on the various care/cure ideas developed from these meetings. The local experts will be trained to coordinate local participation. A few of the ideas gained in KC and through the Registry that we may wish to pursue include

[A] Vitamins providing relief from some PC symptoms. (Dr. Leachman is formulating the scientific hypothesis in connection with antioxidant reactions to set up a clinical trial on this).

[B] Special mouthwash to reduce leukoplakia on tongue

(3) A goal to provide special tools to PCers such as the double-hinged clippers, ear syringes, special insoles, etc. We are making contact with manufacturers to see what can be arranged.

We do not ever want to hand PCers a sack of samples and say 'try these.' We

want our 'try these' options to be measured and evaluated so that real progress can result.

The mission of PC Project is to find a cure and we do not want to divert from this goal. At the same time, we want to gather information from PC patients as in this information may be the clue which activates research which is successful. Further, while PCers are sharing their information, they should be benefited as well.

"Good feelings' after a meeting is a great accomplishment. We certainly want that to happen — but we don't want that to be all that happens.

I hope you agree, PC Project has some very exciting goals as a result of KC. We are adding a significant component to our patient support goals. We need patient participation...in the Registry and in the meetings. See you in Dundee for our next patient meeting. Mary



Characteristics, Caring, Coping

The discussion topics included 'Characteristics, Caring and Coping' as we move forward toward a cure.

The **characteristics** of PC were dramatic in the differences from one person to the next — is it the genetic difference that causes that? the differences in care? other factors for individuals? Why are PC nails so different from person to person? Why are PC blisters and callouses so remarkably different from

person to person. Having a group of PCers together provided remarkable 'empirical' information and observation. The **care** aspect also showed that most PCers have found their own methods and means of care over years of trial and error — finding what works for them and what does not. Most are not eager to immediately try someone else's methods, but are willing to share what they have learned.

Coping techniques included special insoles and shoes, avoiding walking when possible, taking aspirin or other drugs to deaden the pain a little (including alcohol use for this purpose). Most PCers have never shown their feet to anyone other than close family members or at specific doctor visits.

Family support is a very major part of coping with PC and the support group

there (Deborah, Linda, Marcia, Mike) were the best! They demonstrate the fact that PC people know who their friends really are.

The 'glow in the dark' light sticks waved by PCers Friday night (above) symbolize the contribution each one of us is making as we participate in the PC Registry and join together to move forward towards a cure. KC was a step forward!



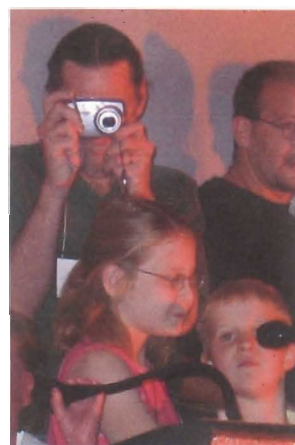
Left & Center—Bus Tour & Train Station
Above—'the docs!' l to r Drs. Milstone,
Dr. Dyer and Dr. Fleckman

Below 'it's hard to say goodbye!'



It's about time...!

Kansas City Patient Support Meeting July 2004



PCers together breakfast, lunch and dinner!



Taking 1st
Place
(above)

Lighting up
the dance
floor (right)

