



PC Project Patient Newsletter

Dear Friends:

I wanted to write to you to let you know about the progress at PC Project. It has been just one year since our website was launched on the internet, only 7 months since the first scientific symposium on PC was held in February 2004, and our research grant awardees have just reported their first quarter (3 months) progress. So much is happening in PC Project and I want you to feel and know what I get to experience each day.

WEBSITE at www.pachyonychia.org, On my 'to do' list are a number of improvements for the website including better information on the genetics of PC. How does the website work for you? Do you have any special requests? I try to always post for you what is new on the site or updated and there is a link to that information at the top of the For Patients page.

As you must know, I am a 'webmaster novice!' for sure...and I appreciate the help that many PCers are providing in giving me feedback when something doesn't work or sending ideas of things to do. It helps me so very, very much when I hear from you. I want all of our funds to go towards research -- so be patient as I learn each day how to better provide a useful website for PC.

PC PATIENT MESSAGE BOARD (PMB). Your postings on the PC PMB help people so much. I often get messages telling how much it meant to people just to see others postings -- even though many don't post anything themselves. Thank you for sharing on the PC PMB!

We purchased software for a new 'improved' PMB and it has been up since July. It is 'double-protected' so that only PC patients or their family members can view the board or post to the board. Here's a link to [How To Join the PC PMB](#)

If you forget your password, just send me an email and tell me the password you'd like to have (CAPITALS and lower case matter) and I'll get you cleared again. [I no longer have to assign, but I need to know what password you want if you forget yours, so I can get you back on the PMB quickly].

PATIENT SUPPORT MEETINGS

We have had two patient support meetings during this first year! We had none even thought about or planned a year ago and these meetings have been amazing. Jan wrote some comments in Jan's Corner .I asked several of those

who were at the Dundee, Scotland meeting to write a sentence about their feelings and I'd like to share those with you.

"I thought my family were the only ones in the world, but now I have met other all over the world with PC. Absolutely fantastic experience. Hope we all will meet again"

We cannot find in English the words to thank you for the wonderful meeting at Dundee. To see many patients with PC, the wonderful job done by the researchers, the kindness of everybody with PC Project and all laboratory staff, and the Doctors -- it was wonderful. We are very happy to see others with the same mutation and we promise you we'll make progress in English to have a better participation.

"This is almost too good to be true. After decades of hiding and pretending, one could meet people, who speak the 'same (PC) language' and don't need to hear any excuses. It was hilarious to hear comments that could have been coming from my own mouth. I believe we were witnessing something historical: PC-specialists are working seriously. I strongly believe, that the medicine will be found and even I can one day walk at least some years without thinking of my feet .

There is not a day, that I don't visit our web-site, not an evening that I don't think of our meeting and all the beautiful people I met there. Many wonderful things have happened in my life, but all this conquers them all. I only wish I shall live long enough to see the miracle happen!

There are no words to describe the feeling of finally meeting people that know exactly what living with PC means. It was hilarious to notice that someone else walks the same way, wears the same colored nail polish, the same kind of shoes... None of us will ever be alone with this again, and that is the greatest feeling ever! And to know that there are people really doing something to help us - I am so grateful!

"The patient meeting in Dundee Scotland made me understand for the first time how PC works and the possibilities of a cure in the near future. I'm glad I got to meet other patients with PC and share valuable information that helps when living with PC"

NEXT PC PATIENT SUPPORT MEETINGS

SEPTEMBER 2005 - Niagara Falls, NY. The exact dates and details will be available on the website on the "Events" page.

SEPTEMBER 2006 - Dundee, Scotland

SEPTEMBER 2007 - Salt Lake City, UT

GOALS AND GRANTS

I have posted a [GOALS](#) graph to show our focus and our progress during this year 2004. I've grouped our goals these into three areas - Research, Support, and Patient Advocacy...although there is clearly overlap across all our goals. The 'Clinical Trials' goal will become a major emphasis once the initial phase of research is completed.

Research Grants. Dr. Sancy Leachman gave an excellent presentation at the Dundee patient meeting on the Worldwide Research Efforts for Pachyonychia Congenita. She explained the 7 Research Grants we have funded and what each one is for. We have now added an 8th research grant.

We have chosen this first year to pursue several different approaches as we don't know which one may work most quickly -- DNA research, cell lines we can use for testing, a PC mouse we can use in testing, a 'small molecule' drug screen, RNA approaches -- we have chosen a broad spectrum of proposals in distinct areas and we have asked the scientists to collaborate and exchange information with each other. The PC research is happening and is exciting.

IPCRR (International PC Research Registry)

Thank you! Thank you! Thank you! for participating in the IPCRR. We received on IRB (Institutional Review Board) approval on May 12 and your response to the Registry and the response has been wonderful. The information submitted has been utilized by our research group in many ways and is definitely having an impact on our strategic planning.

For those of you who want to participate, but who have contacted us after September 1 when the Questionnaire was closed for a short time - don't worry. You are definitely a part of the "PC Family." We are in the process of simplifying and re-writing the Questionnaire so that it will be shorter and still accomplish the information-gathering we need.

We have learned so much from those who have already submitted -- facts about PC that were never recognized previously. It is because of the great response we've had that we are able now to revise the Questionnaire.

Once we have the 'new' Questionnaire (maybe mid-November?), we have to then submit it again to the WIRB (Western Institutional Review Board) for approval. Then, we'll get the new version out to all of you who are waiting. We are trying to work carefully so that no one has to fill out another Questionnaire -- but if we do have to ask everyone to try the 'new' one...we plead with you to take time to help us. It is so very important.

We have seen over and over in important meetings, that if we say something about PC, even if it is true, it may not have much weight with those in the meeting. However, if we say, 'based on the 34 Questionnaires we have reviewed,

we find that 'pain' is the most important thing that PCers would like to have improved...we have EVERYONE's attention. I really cannot explain how important turning in the Questionnaire is and will be in the research process.

To see how the IPCRR is growing and where the PC patients live who have contacted us, check out the statistics (posted at least quarterly) on the website.

[Statistics](#) [Who Lives Where](#)

IPCC (International PC Consortium). The growth of this consortium has been amazing. Those of you who have met Dr. Leachman in person or by phone can understand what an incredible asset she is to PC Project. Through her ability to build trust and collaboration among scientists, physicians and other health care providers, our IPCC membership has grown each month.

Those who are a part of the IPCC are absolutely the leaders in their fields of work -- they are people who care about PC, who want to treat and help PC patients, who want to do the research to make a difference for PC. A major undertaking right now is the publication of a special "Pachyonychia Congenita" edition of the Journal of Investigative Dermatology (JID). This is going to be a major, major tool in helping physicians obtain accurate information on PC (many of the published papers are out-of-date and incorrect), as well as in interesting additional scientists who may wish to collaborate on PC. The IPCC is very important to the success of PC Project.

IRS and Fund Raising. We have been designated a 'public charity' under the 501 (c) (3) charity status. The IRS expects us to conduct fund raising efforts. We have one project underway which is a 2005 Calendar which will feature photography of Dr. Irwin McLean (the scientist who discovered the PC gene). I hope you will help us with this endeavor. I hope we can also find many other ways to introduce effective fund raising programs to that we maintain our public charity status. If we have only one donor, the IRS is not pleased with that.

Please stay in touch! You can't know how delighted I am to hear from each of you. I think about you...I wonder how you are doing...I want PC Project to be successful and helpful to you. Please don't let us lose track of you and don't lose track of us ----because we need each other. If you move or change email addresses etc. be sure and tell us because we'd hate to have something wonderful happen and not be able to tell you about it!

A loving goodbye with a special thanks for being part of the PC Project team.

Mary Schwartz

PC Project Grandma (and Director)