



# Pachyonychia Congenita Project

## News Brief

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### CARING FOR PC: NEW DVD

Included with this edition of the Patient News Brief is a DVD, just released by PC Project.

The DVD illustrates various care techniques used by PC patients. There are three different sections covering (1) keratoderma care (2) nail care and (3) care for cysts, follicular hyperkeratosis and leukokeratosis.



The DVD is not intended as medical advice. However, we hope you will share the DVD with your medical care providers and discuss the information with them. Because PC is an

ultra rare disorder, we realize that many with PC (as well as their physicians) will never meet another person with this disorder and may never have a chance to share care techniques.

The DVD allows patient-to-patient demonstrations of basic daily care techniques. Developing a personal care routine is essential to managing PC and reducing pain as much as possible. Each of the patients shown in the video clips has genetically confirmed PC.

This DVD is intended as an on-going collection and we will update and add new video clips as they become available. For example, the section on caring for cysts, follicular hyperkeratosis and leukokeratosis is very incomplete. We hope to obtain additional video to make this more complete. The DVD enclosed is version 1.0. Future editions will have better quality video and, we hope, contributions from more PCers.

We have also included a preview of our next DVD which will be about how to be an informed PC patient. Being a patient with a rare disease requires you to take

more responsibility in your physician/patient relationship. The focus of that DVD will be to help PC patients develop a beneficial doctor-patient relationship as well as understand the different members of the medical care team such as primary care physician, dermatologist, physician assistants, etc.)

### DVD FEEDBACK—PLEASE HELP

We are always looking for ways to improve the lives of PC patients. Hopefully this DVD has accomplished that in some small way. In an effort to improve future media releases, we are asking for your help. We have created a short web survey at [www.pachyonychia.org](http://www.pachyonychia.org). The link is in the “Spotlight and News” section found on each page of the website. Filling out this survey will be of great value in refining and perfecting our support tools for patients. As we create future versions of this DVD and other support items, your feedback will play an important role in determining what will be the most beneficial to PC patients.

### CHANGING YOUR WORLD WITH THE RESEARCH REGISTRY

The International Pachyonychia Congenita Research Registry (IPCRR) is changing the outlook for PC. There are hundreds of people who have joined the registry. Because of these wonderful individuals, we have doctors and scientists all across the globe focusing on PC. Right now, there is more research devoted to PC than ever before. The registry gives PC patients a loud and unified voice to doctors and researchers who can help make a difference. This could not have happened without those of you who have participated. Thank you!



You may wonder how joining the registry can have any real impact. In 2004, before the IPCRR, there were no

studies or research being done for Pachyonychia Congenita, which is an ultra rare disorder. There was no medically validated data on a broad base of PCers to motivate doctors and scientists to devote any time to PC research. Five years and hundreds of registered members later, there have been 30+ studies done related to PC. As our registry numbers grow so does the interest shown by doctors and scientists worldwide. The only way to maintain that interest is to continue to increase our numbers and to include every PCer in the PC Registry.

In addition, PCers who have joined the registry receive many individual benefits. These include access to additional features on the website including treatment tips and suggestions on the PC Wiki and an active Patient Message Board where you can meet and exchange with other people who also have PC. In addition, PC Project is able to offer special services to IPCRR members. A few examples of services provided in the last weeks:

- A school teacher was assigned a permanent classroom rather than a mobile class which required lots of walking
- Disabled parking permits and disability qualifications have been processed for several patients
- An IPCRR member was connected with a caring local physician who has PC knowledge

For those of you who have yet to register, joining the IPCRR is the single most important thing you can do to help yourself and to help others. Joining takes only 30-60 minutes and there is no cost ever to you as the patient. PC Project pays an average of \$2500 per patient to complete the genetic tests and arrange for the physician consultations, IRB approvals, data entry and support. While the registry and testing is expensive, we know the value far outweighs the cost and that is why we provide this service at no cost to the patient.

You can join the IPCRR by contacting PC Project or by visiting [www.pachyonychia.org](http://www.pachyonychia.org). First register on the website. Then hover over the "Patients" tab and select IPCRR. You can print the Consent Form and Questionnaire from the website. Once we receive your information (Consent Form, Questionnaire and photos), we will set up a consultation with a physician who is familiar with PC. It is these consultations combined with the registry information that gives PC exposure on the worldwide medical scene.

Let's work together to find treatments and a cure!

## **PATIENT SUPPORT MEETING— SALT LAKE CITY 2009**

We are very excited about the upcoming Patient Support Meeting to be held September 24 to 26 in downtown Salt Lake City. This is a great opportunity for you to meet other PCers as well as doctors and scientists who are the world's leading PC experts.



We have negotiated special room rates for anyone attending the meeting. The meeting will be held at the Red Lion Hotel. Rates for single or double occupancy are \$98 per night. Triple or quad occupancy rates are \$109 per night. You can make your reservation by calling 1-800-RED-LION. In order to receive the special rate, you need to tell them that you are with the PC Project Conference. If you wish to make reservations online you can use the special promo code PACH0926 to receive the discounted rate. You must register before September 4th to receive the special rate.

Scholarships are available to those in need of financial assistance to attend the conference. The scholarship can cover up to \$500 for travel and meeting fees. If you are interested in scholarship funds please (1) register online or with the form attached and (2) fill out the scholarship application either online or attached to this newsletter. For paper applications, mail the form to:

PC Project  
2386 E Heritage Way Suite B  
SLC UT 84109

**Meeting registration and scholarship applications must be submitted by August 1, 2009.**

## **WWW.PACHYONYCHIA.ORG**

We are constantly trying to improve our website. For those of you that have never been to the website, it has a wealth of information regarding PC. We offer the most information on Pachyonychia Congenita in the world! If you aren't familiar with the PC website, we encourage you to take the time to visit [www.pachyonychia.org](http://www.pachyonychia.org) and complete the brief website registration as a patient. We are confident you will find the most comprehensive and up-to-date information about PC.

If you have any tips or suggestions for the website, please email us at [info@pachyonychia.org](mailto:info@pachyonychia.org).

# Salt Lake City, Utah—PC Patient Support Meeting Registration Form

September 24, 25, & 26, 2009

**Red Lion Hotel Salt Lake Downtown**

161 West 600 South, Salt Lake City, UT 84101

You may complete and mail this form or register on-line at [www.pachyonychia.org/Events](http://www.pachyonychia.org/Events).

If you cannot access the meeting registration, please first complete the website registration.

**REGISTRATION and SCHOLARSHIP APPLICATION DEADLINE is 1 Aug 2009.**

MEETING FEE of \$125 (\$200 for two and \$250 for three or more family members is due 15 Sep 2009.)

Last Name	First Name
Mailing Address	
Telephone	Email

Please answer the following questions for yourself and for each person who will be attending the meeting with you. If you are registering more than three people, please use additional copies as needed.

<b>First Person</b> Your name as you would like it on your name tag: _____ Adult:        ___ YES        ___ NO Type of Attendee:    ___ Has PC        ___ Family Member has PC        ___ Other: _____ Special Food Needs:    ___ NO        ___ YES (Please indicate) _____
<b>Second Person</b> Your name as you would like it on your name tag: _____ Adult:        ___ YES        ___ NO Type of Attendee:    ___ Has PC        ___ Family Member has PC        ___ Other: _____ Special Food Needs:    ___ NO        ___ YES (Please indicate) _____
<b>Third Person</b> Your name as you would like it on your name tag: _____ Adult:        ___ YES        ___ NO Type of Attendee:    ___ Has PC        ___ Family Member has PC        ___ Other: _____ Special Food Needs:    ___ NO        ___ YES (Please indicate) _____
<b>Additional Comments:</b>          

# Salt Lake City, Utah—PC Patient Support Meeting 2009 Scholarship Application Form

**PC Patient Support Meetings will be held each year and will alternate between USA-Utah (odd years) and UK-Europe (even years). We encourage you to apply for scholarship funding for the meeting closest to your home.**

Last Name	First Name
Mailing Address	
Telephone	Email

Those answering YES to the following questions will be given special consideration in deciding (a) whether any scholarship funds should be awarded and (b) the amount of the award.

1. This will be my first PC Patient Support Meeting. YES \_\_\_ NO \_\_\_
2. I have joined the IPCRR. I have already submitted the Questionnaire and Consent Forms to PC Project and I have scheduled or completed the consultation. YES \_\_\_ NO \_\_\_
3. Statement of Need. I will not be able to attend the Patient Support Meeting unless I receive scholarship funds. YES \_\_\_ NO \_\_\_

So that as many as possible can use the available funds, we ask that you make your request the minimum amount that you need in order to attend the meeting. Travel stipends will be limited to \$500 per PC patient.

I am applying for funding for :

PC Patient Support Meeting Fee in the amount of \_\_\_\_\_

Travel Funds in the amount of \_\_\_\_\_

TOTAL SCHOLARSHIP FUNDS REQUESTED \_\_\_\_\_

Please list any others that will be attending the meeting with you, whether or not they have PC and what their relationship is to you:

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You must submit a formal typed essay of 300 to 500 words answering "Why I hope to receive scholarship funds to attend the PC Patient Support Meeting ." You may submit the essay in English or in your own language. The essays will be judged by members of the PAB, MSAB, and Board of Trustees who will determine the award amounts. You may submit this form and your essay by mail, or you may scan this form and your essay and send via email. The deadline for meeting registration and scholarship applications is August 1, 2009.