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Name _____

IPCRR # _____



INTERNATIONAL PACHYONYCHIA CONGENITA RESEARCH REGISTRY (IPCRR)

IPCRR - PC Project
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QUESTIONNAIRE

Thank you for being part of the IPCRR and for completing this questionnaire. Through the registry, information will be gathered so that physicians and other scientists can more effectively study PC and actively seek a cure for this disease.

We believe it will take about one hour to complete the questionnaire. You may finish it all at once, or start and stop as you wish. **You may skip any question which you do not wish to answer or which is unclear to you.** You will have an opportunity to discuss your responses with a physician in your telephone consultation.

There are six sections in the Questionnaire.

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Consultation. After receiving the Questionnaire, PC Project will schedule a telephone consultation for you with a dermatologist (a physician who specializes in skin). Please keep a copy of your completed Questionnaire and photos, so you can refer to the copies during the consultation with the physician. Also, it will be most helpful if you have information on medications (type, dosage, etc.) available while speaking with the physician. Thank you.

Submitting the completed Consent Form, Questionnaire and Photos. When you have completed the Consent Form, Questionnaire and have your photos ready, please send them to IPCRR - PC Project at the above address.

If you have any questions, please do not hesitate to contact PC Project by phone or email.

THANK YOU for your valuable contribution to PC research.

SECTION 1. IDENTIFYING INFORMATION

The purpose of these questions is to provide the IPCRR with contact information so we may keep in touch with the person registering.

Name of person registering			
Mailing Address (street, city, state/province, zip, country)			
Phone ()	Cell Phone ()	Work Phone ()	
Fax ()	E-mail		
How would you prefer we contact you? (Check all that are okay.) <input type="checkbox"/> Phone <input type="checkbox"/> Cell Phone <input type="checkbox"/> Work Phone <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Regular Mail			
Gender <input type="checkbox"/> Male <input type="checkbox"/> Female		Birth date	
Place of birth (City, State, Country)			
Are you willing to be contacted by the IPCRR to update your information? (about once a year)			Yes <input type="checkbox"/>
			No <input type="checkbox"/>
If the person above is a minor (under the age of 18) please complete the following.			
Name of person filling out this questionnaire			
Mailing Address (street, city, state/province, zip, country)			
Phone ()	Cell Phone ()	Work Phone ()	
Fax ()	E-mail		
How would you prefer we contact you? (Check all that are okay.) <input type="checkbox"/> Phone <input type="checkbox"/> Cell Phone <input type="checkbox"/> Work Phone <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Regular Mail			
Name of legal guardian of the person registering if not the person filling out the questionnaire			
Mailing Address (street, city, state/province, zip, country)			
Phone ()	Cell Phone ()	Work Phone ()	
Fax ()	E-mail		
How would you prefer we contact you? (Check all that are okay.) <input type="checkbox"/> Phone <input type="checkbox"/> Cell Phone <input type="checkbox"/> Work Phone <input type="checkbox"/> Fax <input type="checkbox"/> E-mail <input type="checkbox"/> Regular Mail			

SECTION 2. DIAGNOSIS

1. Have you ever had **genetic testing?** (A test that looks at your genes.) Yes No

If yes, do you give us permission to obtain the **genetic test results?** Yes No

How should we obtain results?

I will send them to you Contact the following person/institution for genetic testing results

Name of person or laboratory	Phone
Mailing Address (street, city, state/province, zip, country)	

2. Have you ever had a **skin biopsy?** (A skin biopsy is when a piece of skin is removed and sent to a doctor or scientist for examination under a microscope.) Yes No

If yes, what were the approximate dates of the biopsy or biopsies?

2a. Do you give us permission to obtain **medical records/reports** about the biopsy(sies)? Yes No

How should we obtain results?

I will send them to you Contact the following person/institution for genetic testing results

Name of person or laboratory	Phone
Mailing Address (street, city, state/province, zip, country)	

2b. Do you give us permission to request the **tissue blocks** (skin tissue that is left in storage) and **glass slides** (prepared pieces of tissue on a microscope slide) of your biopsy(sies)? Yes No

How should we obtain these tissue blocks?

I will send them to you Contact the following person/institution for genetic testing results

Name of person or laboratory	Phone
Mailing Address (street, city, state/province, zip, country)	

3. Has any researcher put your **cells into a culture** to grow them? Yes No

Do you give us permission to request the **cells in culture?** Yes No

How should we obtain these tissue blocks, glass slides or cells in culture?

I will send them to you Contact the following person/institution for genetic testing results

Name of person or laboratory	Phone
Mailing Address (street, city, state/province, zip, country)	

SECTION 2. DIAGNOSIS

PC Project is creating a worldwide network of physicians and scientists interested in treating and researching PC. Please list those health professionals you know who you feel may be of help in this project.

Name of Health professional interested in PC	
Mailing Address (street, city, state/province, zip, country)	
Phone ()	Specialty of this health professional
May we contact this person? <input type="checkbox"/> Yes <input type="checkbox"/> No	

Name of Health professional interested in PC	
Mailing Address (street, city, state/province, zip, country)	
Phone ()	Specialty of this health professional
May we contact this person? <input type="checkbox"/> Yes <input type="checkbox"/> No	

Name of Health professional interested in PC	
Mailing Address (street, city, state/province, zip, country)	
Phone ()	Specialty of this health professional
May we contact this person? <input type="checkbox"/> Yes <input type="checkbox"/> No	

Name of Health professional interested in PC	
Mailing Address (street, city, state/province, zip, country)	
Phone ()	Specialty of this health professional
May we contact this person? <input type="checkbox"/> Yes <input type="checkbox"/> No	

Section 3. FAMILY HISTORY

Please invite other family members who have PC to contact PC Project if they wish to participate.

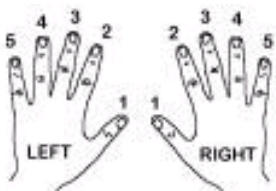
<p>Do you have any deceased relatives who had PC? If yes, please check all that apply</p> <p><input type="checkbox"/> Child, grandchild</p> <p><input type="checkbox"/> Father <input type="checkbox"/> Mother</p> <p><input type="checkbox"/> Father's father <input type="checkbox"/> Father's mother</p> <p><input type="checkbox"/> Mother's father <input type="checkbox"/> Mother's mother</p> <p><input type="checkbox"/> Brothers, sisters</p> <p><input type="checkbox"/> Aunts, uncles, cousins</p> <p><input type="checkbox"/> Other (please explain) _____</p>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<p>Name of deceased relative who had PC _____ About when did this relative die? _____ State/Country where died _____</p> <p>Name of deceased relative who had PC _____ About when did this relative die? _____ State/Country where died _____</p> <p>Name of deceased relative who had PC _____ About when did this relative die? _____ State/Country where died _____</p> <p>Name of deceased relative who had PC _____ About when did this relative die? _____ State/Country where died _____</p>		
If others in your family also have PC, does PC affect all family members in the same way?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If not, please describe the differences you have observed _____ _____ _____ _____ _____ _____		

Section 4. PHYSICAL FINDINGS

NAILS

1. How many of your fingernails are thickened at this time? _____

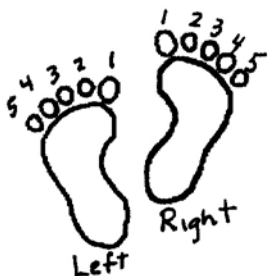
2. Put an **x** on each nail that is thickened
Put an **R** for any nail that has been surgically removed



Left	Right
1 _____	1 _____
2 _____	2 _____
3 _____	3 _____
4 _____	4 _____
5 _____	5 _____

3. How many of your toenails are thickened at this time? _____

4. Put an **x** on each nail that is thickened
Put an **R** for each nail that has been surgically removed



Left	Right
1 _____	1 _____
2 _____	2 _____
3 _____	3 _____
4 _____	4 _____
5 _____	5 _____

5. At approximately what age did your nails thicken?

FINGERNAILS

TOENAILS

CARE FOR THICKENED NAILS

6. How often do you care for your nails?

FINGERNAILS

- Daily
- 2x a week
- 1x a week (weekly)
- 2x a month
- 1x a month (monthly)
- Less than 1x a month
- Never

TOENAILS

- Daily
- 2x a week
- 1x a week (weekly)
- 2x a month
- 1x a month (monthly)
- Less than 1x a month
- Never

Section 4. PHYSICAL FINDINGS

EFFECT OF THICKENED NAILS	
7. <u>How much</u> do thickened nails affect your daily life or activities?	
FINGERNAILS <input type="checkbox"/> No impact <input type="checkbox"/> Sometimes creates a problem <input type="checkbox"/> Always a problem, but able to function <input type="checkbox"/> Thickened nails makes it impossible to function	TOENAILS <input type="checkbox"/> No impact <input type="checkbox"/> Sometimes creates a problem <input type="checkbox"/> Always a problem, but able to function <input type="checkbox"/> Thickened nails makes it impossible to function
8. In <u>what way</u> do thickened nails affect your daily life or activities? Please check all that apply.	
FINGERNAILS <input type="checkbox"/> Cosmetic concerns <input type="checkbox"/> Pain <input type="checkbox"/> Time required for grooming <input type="checkbox"/> Unable to work or attend school <input type="checkbox"/> Other (please explain) <hr/>	TOENAILS <input type="checkbox"/> Cosmetic concerns <input type="checkbox"/> Pain <input type="checkbox"/> Time required for grooming <input type="checkbox"/> Unable to work or attend school <input type="checkbox"/> Other (please explain) <hr/>
9. <u>How often</u> do you have nail infections?	
FINGERNAILS <input type="checkbox"/> Frequently (at least every week) <input type="checkbox"/> Sometimes (every month or every two months) <input type="checkbox"/> Seldom (once a year or less) <input type="checkbox"/> Never <input type="checkbox"/> Other (please explain) <hr/>	TOENAILS <input type="checkbox"/> Frequently (at least every week) <input type="checkbox"/> Sometimes (every month or every two months) <input type="checkbox"/> Seldom (once a year or less) <input type="checkbox"/> Never <input type="checkbox"/> Other (please explain) <hr/>

HANDS AND FEET

10. Check all of the following which describe your <u>hands</u> :	
AT THE PRESENT TIME <input type="checkbox"/> Thick skin <input type="checkbox"/> Calluses <input type="checkbox"/> Blisters <input type="checkbox"/> Fissures (cracks in skin) <input type="checkbox"/> Open sores	AT ANY TIME IN YOUR LIFE <input type="checkbox"/> Thick skin <input type="checkbox"/> Calluses <input type="checkbox"/> Blisters <input type="checkbox"/> Fissures (cracks in skin) <input type="checkbox"/> Open sores
11. Check all of the following which describe your <u>feet</u> :	
AT THE PRESENT TIME <input type="checkbox"/> Thick skin <input type="checkbox"/> Calluses <input type="checkbox"/> Blisters <input type="checkbox"/> Fissures (cracks in skin) <input type="checkbox"/> Open sores	AT ANY TIME IN YOUR LIFE <input type="checkbox"/> Thick skin <input type="checkbox"/> Calluses <input type="checkbox"/> Blisters <input type="checkbox"/> Fissures (cracks in skin) <input type="checkbox"/> Open sores

Section 4. PHYSICAL FINDINGS

12. Check <u>all places</u> where you have thick skin and calluses (or blisters, cracks, and open sores)	
HANDS <input type="checkbox"/> Palms and inside of fingers <input type="checkbox"/> Knuckles or back of fingers <input type="checkbox"/> Between fingers <input type="checkbox"/> Back of Hands <input type="checkbox"/> Fingertips <input type="checkbox"/> Other _____	FEET <input type="checkbox"/> Ball of foot <input type="checkbox"/> Heel of foot <input type="checkbox"/> Arch of foot <input type="checkbox"/> Outside of foot <input type="checkbox"/> Between toes <input type="checkbox"/> Other _____
13. At approximately what age did the thick skin, calluses, blisters, cracks, or open sores first appear? ON YOUR HANDS _____ ON YOUR FEET _____	
14. <u>How often</u> do you <u>have</u> thick skin, calluses, blisters, cracks, or open sores?	
ON YOUR HANDS <input type="checkbox"/> Always (never completely go away) <input type="checkbox"/> Sometimes (hands clear up completely at times) <input type="checkbox"/> Seldom (hands are usually clear of symptoms) <input type="checkbox"/> Never	ON YOUR FEET <input type="checkbox"/> Always (never completely go away) <input type="checkbox"/> Sometimes (feet clear up completely at times) <input type="checkbox"/> Seldom (feet are usually clear of symptoms) <input type="checkbox"/> Never

CARE FOR THICK SKIN, CALLUSES, BLISTERS, CRACKS AND OPEN SORES

15. <u>How often</u> do you <u>care</u> for the thick skin, calluses, blisters, cracks, or open sores	
ON YOUR HANDS <input type="checkbox"/> Daily <input type="checkbox"/> 2x a week <input type="checkbox"/> 1x a week (weekly) <input type="checkbox"/> 2x a month <input type="checkbox"/> 1x a month (monthly) <input type="checkbox"/> Less than 1x a month <input type="checkbox"/> Never	ON YOUR FEET <input type="checkbox"/> Daily <input type="checkbox"/> 2x a week <input type="checkbox"/> 1x a week (weekly) <input type="checkbox"/> 2x a month <input type="checkbox"/> 1x a month (monthly) <input type="checkbox"/> Less than 1x a month <input type="checkbox"/> Never

EFFECT OF THICK SKIN, CALLUSES, BLISTERS, CRACKS OR SORES

16. Are you able to walk with PC? <input type="checkbox"/> Walking is not affected <input type="checkbox"/> Walk with pain Please list distance you are able to walk ____ 1 city block ____ less than 1 city block Please list how long you can walk before the pain is unbearable _____ <input type="checkbox"/> Cannot walk without assistance or walking aids <input type="checkbox"/> Cannot walk at all	Yes <input type="checkbox"/>	No <input type="checkbox"/>
17. Do you use any walking aids? If yes, check all that you currently use <input type="checkbox"/> Crutches <input type="checkbox"/> Walker <input type="checkbox"/> Cane(s) <input type="checkbox"/> Wheelchair <input type="checkbox"/> Crawl (on knees)	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Section 4. PHYSICAL FINDINGS

<p>18. Do you use any special shoes, socks or insoles? If yes, please describe in detail (If you have information on where/how to order, that will be appreciated.)</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p>Yes <input type="checkbox"/></p>	<p>No <input type="checkbox"/></p>
<p>19. <u>How much</u> do thick skin, calluses, blisters, cracks, lesions or open sores affect your daily life or activities?</p>		
<p>ON YOUR HANDS</p> <p><input type="checkbox"/> No impact</p> <p><input type="checkbox"/> Sometimes creates a problem</p> <p><input type="checkbox"/> Always a problem, but able to function</p> <p><input type="checkbox"/> Condition makes it impossible to function</p>	<p>ON YOUR FEET</p> <p><input type="checkbox"/> No impact</p> <p><input type="checkbox"/> Sometimes creates a problem</p> <p><input type="checkbox"/> Always a problem, but able to function</p> <p><input type="checkbox"/> Condition makes it impossible to function</p>	
<p>20. In <u>what way</u> do thick skin, calluses, blisters, cracks, or open sores affect your daily life or activities? Please check all that apply.</p>		
<p>ON YOUR HANDS</p> <p><input type="checkbox"/> Cosmetic concerns</p> <p><input type="checkbox"/> Pain</p> <p><input type="checkbox"/> Time required for grooming</p> <p><input type="checkbox"/> Unable to work or attend school</p> <p><input type="checkbox"/> Other (please explain)</p> <p>_____</p> <p>_____</p>	<p>ON YOUR FEET</p> <p><input type="checkbox"/> Cosmetic concerns</p> <p><input type="checkbox"/> Pain</p> <p><input type="checkbox"/> Time required for grooming</p> <p><input type="checkbox"/> Unable to walk</p> <p><input type="checkbox"/> Unable to work or attend school</p> <p><input type="checkbox"/> Other (please explain)</p> <p>_____</p> <p>_____</p>	
<p>21. <u>How painful</u> are the thick skin, calluses, blisters, cracks, or open sores?</p>		
<p>ON YOUR HANDS</p> <p><input type="checkbox"/> Not painful</p> <p><input type="checkbox"/> Somewhat painful</p> <p><input type="checkbox"/> Very painful, but do not use medication</p> <p><input type="checkbox"/> Often require medication to handle the pain</p>	<p>ON YOUR FEET</p> <p><input type="checkbox"/> Not painful</p> <p><input type="checkbox"/> Somewhat painful</p> <p><input type="checkbox"/> Very painful, but do not use medication</p> <p><input type="checkbox"/> Often require medication to handle the pain</p>	
<p>22. <u>How often</u> do thick skin, calluses, blisters, cracks, or open sores affect or impede your daily life or activities?</p>		
<p>ON YOUR HANDS</p> <p><input type="checkbox"/> Frequently (at least every week)</p> <p><input type="checkbox"/> Sometimes (every month or every two months)</p> <p><input type="checkbox"/> Seldom (once a year or less)</p> <p><input type="checkbox"/> Never</p> <p><input type="checkbox"/> Other (please explain) _____</p> <p>_____</p>	<p>ON YOUR FEET</p> <p><input type="checkbox"/> Frequently (at least every week)</p> <p><input type="checkbox"/> Sometimes (every month or every two months)</p> <p><input type="checkbox"/> Seldom (once a year or less)</p> <p><input type="checkbox"/> Never</p> <p><input type="checkbox"/> Other (please explain) _____</p> <p>_____</p>	

Section 4. PHYSICAL FINDINGS

28. How often do you manage the thickened white skin (leukokeratosis) in your mouth?
 Daily
 2x a week
 1x a week (weekly)
 2x a month
 1x a month (monthly)
 Less than 1x a month
 Never

29. How do you care for the thickened white skin (leukokeratosis) in your mouth?
 Brush vigorously
 Scrape
 Use mouthwash. What type _____
 Other _____

EFFECT OF LEUKOKERATOSIS (WHITE TONGUE OR MOUTH)

30. How much does leukokeratosis affect your daily life?
 No impact
 Sometimes creates a problem
 Always a problem, but able to function
 Condition makes it impossible to function

31. In what way does leukokeratosis affect your daily life or activities? Please check all that apply.
 Concerns about appearance
 Pain
 Time required for grooming
 Unable to use mouth or tongue comfortably
 Unable to work or attend school
 Other (please explain) _____

32. How painful is the leukokeratosis?
 Not painful
 Somewhat painful
 Very painful, but do not use medication
 Often require medication to handle the pain

33. How often is the leukokeratosis painful?
 Always (pain never stops)
 Sometimes (pain stops at times)
 Seldom (mouth and tongue are usually pain free)

34. Were you born with any teeth?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
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35. Have you had any premature tooth loss (not due to injury)?	Yes <input type="checkbox"/>	No <input type="checkbox"/>
-----------------------------------------------------------------------	---------------------------------	--------------------------------

If yes, please explain _____

Section 4. PHYSICAL FINDINGS

SKIN (CYSTS OR OTHER GROWTHS)

In this section, please describe any growth on your skin, such as a cyst, boil, large puss-filled bump, bump filled with a greasy fluid, bump filled with a cheesy material. This bump may be on the scalp, chest, underarms, groin or other part of the body.

<p>36. Do you have cysts or other growths? If yes, check all of the following which apply</p> <p><input type="checkbox"/> Cysts that are usually pea-sized or smaller that are flesh or yellow color. They are usually on the chest, neck, or face and may drain a clear yellow oily fluid. They are not usually painful. (Called STEATOCYSTOMA)</p> <p><input type="checkbox"/> Cysts on your scalp, armpits, groin or back. They may often drain a cheesy, sometimes foul smelling or pussy-looking material. These often become painful and inflamed. (Called PILOSEBACEOUS)</p> <p><input type="checkbox"/> Groups of bumps that form around hair follicles usually on the outer arms, thighs, waist or buttocks. (Called FOLLICULAR HYPERKERATOSIS)</p> <p><input type="checkbox"/> Other (please describe) _____ _____ _____</p>	<p>Yes <input type="checkbox"/></p>	<p>No <input type="checkbox"/></p>
-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------	----------------------------------------

CARE FOR SKIN (CYSTS OR OTHER GROWTHS)

37. How often do you care for the cysts or other growths on your skin?

STEATOCYSTOMA	PILOSEBACEOUS	FOLLICULAR HYPERKERATOSIS
<input type="checkbox"/> Daily	<input type="checkbox"/> Daily	<input type="checkbox"/> Daily
<input type="checkbox"/> 2x a week	<input type="checkbox"/> 2x a week	<input type="checkbox"/> 2x a week
<input type="checkbox"/> 1x a week (weekly)	<input type="checkbox"/> 1x a week (weekly)	<input type="checkbox"/> 1x a week (weekly)
<input type="checkbox"/> 2x a month	<input type="checkbox"/> 2x a month	<input type="checkbox"/> 2x a month
<input type="checkbox"/> 1x a month (monthly)	<input type="checkbox"/> 1x a month (monthly)	<input type="checkbox"/> 1x a month (monthly)
<input type="checkbox"/> Less than 1x a month	<input type="checkbox"/> Less than 1x a month	<input type="checkbox"/> Less than 1x a month
<input type="checkbox"/> Never	<input type="checkbox"/> Never	<input type="checkbox"/> Never

EFFECT OF CYSTS OR OTHER GROWTHS ON SKIN

38. How much do the cysts or other growths on your skin affect your daily life or activities?

- No impact
- Sometimes creates a problem
- Always a problem, but able to function
- Condition makes it impossible to function

39. In what way do the conditions on your skin affect your daily life or activities?

Please check all that apply

- Cosmetic concerns
- Pain
- Time required for grooming
- Unable to walk
- Unable to work or attend school
- Other (please explain) _____

Section 4. PHYSICAL FINDINGS

<p>40. <u>How painful</u> are the growths on your skin?</p> <input type="checkbox"/> Not painful <input type="checkbox"/> Somewhat painful <input type="checkbox"/> Very painful, but do not use medication <input type="checkbox"/> Often require medication to handle the pain
<p>41. <u>How often</u> are the growths on your skin <u>painful</u>?</p> <input type="checkbox"/> Always (pain never stops) <input type="checkbox"/> Sometimes (pain stops at times) Explain when pain stops _____ <input type="checkbox"/> Seldom (feet are usually pain free)

OTHER

<p>42. Do you feel your hair is unusual or abnormal at all? If Yes, please select all that apply <input type="checkbox"/> Brittle <input type="checkbox"/> Excessively thick <input type="checkbox"/> Thin <input type="checkbox"/> Unruly (hard to comb) <input type="checkbox"/> Woolly <input type="checkbox"/> Other (specify) _____</p>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<p>43. Do you have hair loss (alopecia)?</p>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<p>44. Do you feel you have excessive ear wax? If yes, please select the color of wax <input type="checkbox"/> Whitish <input type="checkbox"/> Brown <input type="checkbox"/> Yellow/orange <input type="checkbox"/> Other (please explain) _____</p>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<p>45. Do you have sharp pain in your ears unrelated to any other ear problem? If yes, please indicate what causes the pain (such as chewing, cold air, etc.) _____</p>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<p>46. If yes, how long does the pain last? <input type="checkbox"/> 10-20 seconds <input type="checkbox"/> Less than one minute <input type="checkbox"/> Several minutes <input type="checkbox"/> Other (please explain) _____</p>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<p>47. Do you have hearing loss? If yes, please select all that apply <input type="checkbox"/> Partial hearing loss <input type="checkbox"/> Loss of hearing for certain frequencies <input type="checkbox"/> Tinnitus <input type="checkbox"/> Deafness <input type="checkbox"/> Other (please explain) _____</p>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<p>48. Do you now or did you at one time have emotional or psychiatric problems? If yes, please select all that apply <input type="checkbox"/> Depression <input type="checkbox"/> Suicidal feelings <input type="checkbox"/> Anger management problems <input type="checkbox"/> Other (please explain) _____ Please note where and how they were/are treated _____ _____</p>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
<p>49. Do you now or have you ever had any learning problems? If yes, please describe _____ _____</p>	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Section 5. TREATMENT AND CARE EVALUATION

55. Do certain things affect your PC symptoms? If yes, please check all that apply.

Please check all areas affected by the things listed Nails Hands Feet Skin Mouth Hair

Symptoms improve	Symptoms become worse	Pain is less (decreases)	Pain is more (increases)	No Affect or not applicable
Activity <input type="checkbox"/> Standing <input type="checkbox"/> Walking <input type="checkbox"/> Sitting <input type="checkbox"/> Sleeping/resting Climate <input type="checkbox"/> Hot weather <input type="checkbox"/> Cold weather <input type="checkbox"/> Wet weather <input type="checkbox"/> Dry weather Wet/Dry <input type="checkbox"/> Sweaty feet <input type="checkbox"/> Swimming <input type="checkbox"/> Overly dry feet Foot temperature <input type="checkbox"/> Hot feet <input type="checkbox"/> Cold feet Type of sock <input type="checkbox"/> wool <input type="checkbox"/> nylon <input type="checkbox"/> cotton Time of day <input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Night Time of year <input type="checkbox"/> Winter <input type="checkbox"/> Spring <input type="checkbox"/> Summer <input type="checkbox"/> Fall What you eat/drink <input type="checkbox"/> Lots of water <input type="checkbox"/> Lot of chocolate <input type="checkbox"/> Lot of sugar <input type="checkbox"/> Other food/drink <hr/> <input type="checkbox"/> Puberty <input type="checkbox"/> Menopause <input type="checkbox"/> Oral contraceptives <input type="checkbox"/> Hormone therapy <input type="checkbox"/> Pregnancy Other please list <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____	Activity <input type="checkbox"/> Standing <input type="checkbox"/> Walking <input type="checkbox"/> Sitting <input type="checkbox"/> Sleeping/resting Climate <input type="checkbox"/> Hot weather <input type="checkbox"/> Cold weather <input type="checkbox"/> Wet weather <input type="checkbox"/> Dry weather Wet/Dry <input type="checkbox"/> Sweaty feet <input type="checkbox"/> Swimming <input type="checkbox"/> Overly dry feet Foot temperature <input type="checkbox"/> Hot feet <input type="checkbox"/> Cold feet Type of sock <input type="checkbox"/> wool <input type="checkbox"/> nylon <input type="checkbox"/> cotton Time of day <input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Night Time of year <input type="checkbox"/> Winter <input type="checkbox"/> Spring <input type="checkbox"/> Summer <input type="checkbox"/> Fall What you eat/drink <input type="checkbox"/> Lots of water <input type="checkbox"/> Lot of chocolate <input type="checkbox"/> Lot of sugar <input type="checkbox"/> Other food/drink <hr/> <input type="checkbox"/> Puberty <input type="checkbox"/> Menopause <input type="checkbox"/> Oral contraceptives <input type="checkbox"/> Hormone therapy <input type="checkbox"/> Pregnancy Other please list <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____	Activity <input type="checkbox"/> Standing <input type="checkbox"/> Walking <input type="checkbox"/> Sitting <input type="checkbox"/> Sleeping/resting Climate <input type="checkbox"/> Hot weather <input type="checkbox"/> Cold weather <input type="checkbox"/> Wet weather <input type="checkbox"/> Dry weather Wet/Dry <input type="checkbox"/> Sweaty feet <input type="checkbox"/> Swimming <input type="checkbox"/> Overly dry feet Foot temperature <input type="checkbox"/> Hot feet <input type="checkbox"/> Cold feet Type of sock <input type="checkbox"/> wool <input type="checkbox"/> nylon <input type="checkbox"/> cotton Time of day <input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Night Time of year <input type="checkbox"/> Winter <input type="checkbox"/> Spring <input type="checkbox"/> Summer <input type="checkbox"/> Fall What you eat/drink <input type="checkbox"/> Lots of water <input type="checkbox"/> Lot of chocolate <input type="checkbox"/> Lot of sugar <input type="checkbox"/> Other food/drink <hr/> <input type="checkbox"/> Puberty <input type="checkbox"/> Menopause <input type="checkbox"/> Oral contraceptives <input type="checkbox"/> Hormone therapy <input type="checkbox"/> Pregnancy Other please list <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____	Activity <input type="checkbox"/> Standing <input type="checkbox"/> Walking <input type="checkbox"/> Sitting <input type="checkbox"/> Sleeping/resting Climate <input type="checkbox"/> Hot weather <input type="checkbox"/> Cold weather <input type="checkbox"/> Wet weather <input type="checkbox"/> Dry weather Wet/Dry <input type="checkbox"/> Sweaty feet <input type="checkbox"/> Swimming <input type="checkbox"/> Overly dry feet Foot temperature <input type="checkbox"/> Hot feet <input type="checkbox"/> Cold feet Type of sock <input type="checkbox"/> wool <input type="checkbox"/> nylon <input type="checkbox"/> cotton Time of day <input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Night Time of year <input type="checkbox"/> Winter <input type="checkbox"/> Spring <input type="checkbox"/> Summer <input type="checkbox"/> Fall What you eat/drink <input type="checkbox"/> Lots of water <input type="checkbox"/> Lot of chocolate <input type="checkbox"/> Lot of sugar <input type="checkbox"/> Other food/drink <hr/> <input type="checkbox"/> Puberty <input type="checkbox"/> Menopause <input type="checkbox"/> Oral contraceptive <input type="checkbox"/> Hormone therapy <input type="checkbox"/> Pregnancy Other please list <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____	Activity <input type="checkbox"/> Standing <input type="checkbox"/> Walking <input type="checkbox"/> Sitting <input type="checkbox"/> Sleeping/resting Climate <input type="checkbox"/> Hot weather <input type="checkbox"/> Cold weather <input type="checkbox"/> Wet weather <input type="checkbox"/> Dry weather Wet/Dry <input type="checkbox"/> Sweaty feet <input type="checkbox"/> Swimming <input type="checkbox"/> Overly dry feet Foot temperature <input type="checkbox"/> Hot feet <input type="checkbox"/> Cold feet Type of sock <input type="checkbox"/> wool <input type="checkbox"/> nylon <input type="checkbox"/> cotton Time of day <input type="checkbox"/> Morning <input type="checkbox"/> Afternoon <input type="checkbox"/> Evening <input type="checkbox"/> Night Time of year <input type="checkbox"/> Winter <input type="checkbox"/> Spring <input type="checkbox"/> Summer <input type="checkbox"/> Fall What you eat/drink <input type="checkbox"/> Lots of water <input type="checkbox"/> Lot of chocolate <input type="checkbox"/> Lot of sugar <input type="checkbox"/> Other food/drink <hr/> <input type="checkbox"/> Puberty <input type="checkbox"/> Menopause <input type="checkbox"/> Oral contraceptives <input type="checkbox"/> Hormone therapy <input type="checkbox"/> Pregnancy Other please list <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____ <input type="checkbox"/> _____

Section 5. TREATMENT AND CARE EVALUATION

56. What types of creams or lotions have you used on your PC? Please check all that apply.

Aquaphor Carmol Retin-A Epilyt Eucerin LacHydrin Lacticare

Retin-A Vaseline Other (Please list) _____

Include all ingredients and percentages _____

Or, if available photocopy the medication label and return with this Questionnaire

57. Do you use any mechanical means or tools to care for your PC?

Razor blades

Scalpel

Pumice Stone

Sanders (describe) _____

Clippers

Other (specify) _____

58. Have you ever been prescribed any of the following medications (retinoids) for your PC?

Please circle all that apply.

Generic Name	Trade Name	Yes	No
Isotretinoin	Accure; Accutane; Accutane Roche; Acnal SC; Acnetrex; Acnotin; Akinol; Aknenormin; Amnesteem; Claravis; Curacne Gel; Curatane; Isotane; Isotren; Isotret-Hexal; Isotrex; Isotrex Gel; Newtinson SC Nimegen; Oratane; Pimple; Procuta Gel; Roaccutan; Roaccutane; Roaccuttan; Roacnetan; Roacutan; Roacuttan; Sotret; Tretin	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Acitretin	Neotigason; Neo-Tigason; Soriatane	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Etretinate	Tigason	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Tretinoin	A-Acido; Aberel; Aberela; Acid A Vit; Acne Free; Acta; Airo; Alquingel; Alten; Altinac; Avita; Avitcid; Betarretin; Derm A; Dermairol; Dermik A; Effederm; Eudyna; Facenol; Ilotycin-A; Locacid; Optimal; Prosome A Cream; Reacel-A; Renova; Retacnyl; Retavit; Retiderma; Retin A; Retin-A; Retin A Micro Gel; Retinova; Retrieve Cream; Stieva A; Stieva-A; Stieva-A forte; Tracne; Trentin; Vesanoid; Vitamin A Acid	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Adapalene	Adaferin; Adaferin Gel; Differin; Differine; Differin Gel	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Bexarotene	Targretin; Targretin Topical	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Tazarotene	Avage; Tazorac; Zorac	Yes <input type="checkbox"/>	No <input type="checkbox"/>
Vitamin A	A313; Acon; Aquasol A; A; Arovit; Avibon; Avipur; Avitan; Avitina; Avitol; Davitamon A; Ido A 50; Ro-A-Vit; Vitamin A	Yes <input type="checkbox"/>	No <input type="checkbox"/>

If any of the above medications (retinoids) have been prescribed for your PC please complete the information on the next page. Please make a copy of the next page for each different medication you have used.

Section 5. TREATMENT AND CARE EVALUATION

59. If more than one medication (retinoid) has been prescribed for you, please make a copy of this page for each one and complete the following for each different medication (retinoid).

Please list the name of the retinoid _____

Check whether it was a ____Pill or ____ Lotion/Cream

Approximately how long did you take or use this medication? _____

How often did you take or use the retinoid medication? _____

If you remember, what dose or strength of the medication did you use? _____

If available, please photocopy the medication label and return with this Questionnaire.

Was this medication effective? Yes No

If yes, what kind of improvement did you notice? (thinning of calluses? reduced pain? other?)

Please rate the improvement on a scale of 1-10 _____

(1 being no improvement and 10 being a complete improvement of the symptoms.)

Are you still using this medication? Yes No

If no longer taking the medication, please state why you stopped using it.

Did you experience any side effects related to taking this medication? Yes No

If yes, please describe

Would you recommend this medication to other members of your family? Yes No

Why or why not?

On a scale of 1-10 what was your overall satisfaction with this medication? _____

(1 being completely dissatisfied and 10 being totally satisfied.) Why?

Section 5. TREATMENT AND CARE EVALUATION

60. We want to know about any medications or products **that have been of help to you**. Please list as much information as you have available including the brand name, generic name and all ingredients. Make copies and use a separate page for each medication.

A list of some possible medications is on the next page. If your medication or product isn't on the list, we do still want to have information on it.

<p>MEDICATION or PRODUCT Brand name _____</p> <p>Generic name _____</p> <p>Ingredients (if you know) _____</p> <p>_____</p>
<p>What was the main <u>reason</u> for using the medication?</p> <p><input type="checkbox"/> Grooming <input type="checkbox"/> Infection <input type="checkbox"/> Pain <input type="checkbox"/> Improve appearance</p> <p><input type="checkbox"/> Other (please explain) _____</p>
<p>How was the medication administered?</p> <p><input type="checkbox"/> Applied directly to affected area</p> <p><input type="checkbox"/> Took it by mouth</p> <p><input type="checkbox"/> Received an injection into your nailbed or in the affected area</p> <p><input type="checkbox"/> Received an injection into your muscle or into your vein</p>
<p>How often did you use the medication?</p> <p><input type="checkbox"/> One or more times daily <input type="checkbox"/> Once or twice weekly <input type="checkbox"/> Once a month <input type="checkbox"/> Several times a year</p> <p><input type="checkbox"/> Once a year <input type="checkbox"/> When needed</p>
<p>Are you currently using this medication? Yes <input type="checkbox"/> No <input type="checkbox"/></p> <p>If yes, how long have you used the treatment?</p> <p><input type="checkbox"/> Days _____ <input type="checkbox"/> Weeks _____ <input type="checkbox"/> Months _____ <input type="checkbox"/> Years _____</p> <p><input type="checkbox"/> Other (please explain) _____</p> <p>If no, why did you stop using? (check all that apply)</p> <p><input type="checkbox"/> Caused side effect(s) (please describe side effects) _____</p> <p><input type="checkbox"/> Was ineffective</p> <p><input type="checkbox"/> Better treatments available</p> <p><input type="checkbox"/> Expense</p> <p><input type="checkbox"/> Too difficult or too much time</p> <p><input type="checkbox"/> Other (please explain) _____</p>
<p>How many times has this treatment been repeated?</p> <p><input type="checkbox"/> Used only once <input type="checkbox"/> Two courses <input type="checkbox"/> Three or more than three courses <input type="checkbox"/> Constantly repeated</p>
<p>How effective was the treatment?</p> <p><input type="checkbox"/> Had no effect <input type="checkbox"/> Somewhat effective <input type="checkbox"/> Completely eliminated the problem</p>
<p>How long did the effect last?</p> <p><input type="checkbox"/> Days _____ Weeks _____ Months _____ Years _____</p> <p><input type="checkbox"/> Other (please explain) _____</p>
<p>How satisfied were you with the result on a scale from 1 to 3? (with 1 being completely dissatisfied and 3 being completely satisfied) 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/></p>

Section 5. TREATMENT AND CARE EVALUATION

The purpose of this list of medications is for your reference to help you remember medications which may have been prescribed in the past. If we can learn what has been effective and what has not been effective (or been damaging) it will be a great benefit to researchers, physicians and PC patients.

Antibiotics

- Aminoglycosides – *Generic names
 - Amikacin
 - Gentamicin
 - Netilmicin
 - Streptomycin
 - Tobramycin
- Cephalosporin – Generic names
 - Cefazolin
 - Cefepime
 - Cefotaxime
 - Cefotetan
 - Cefpodoxime
 - Ceftazidime
 - Ceftizoxime
 - Ceftriaxone
 - Cefuroxime
 - Cephalexin
- Chloramphenicol
- Chlotrimazole
- Clindamycin (antiprotozoal)
- Dapsone
- Imipenem/Cilastatin
- Isoniazid
- Macrolides – Common names
 - Azithromycin
 - Clarithromycin
 - Erythromycin
- Metronidazole
- Nitrofurantoin
- Penicillin or derivative - Common names
 - Amoxicillin
 - Amoxicillin/Clavulanate
 - Ampicillin
 - Ampicillin/sulbactam
 - Dicloxacillin
 - Nafcillin
 - Penicillin
 - Piperacillin
 - Ticaracillin
- Pentamidine (antiprotozoal)
- Quinupristin-Dalfopristin
- Quinolones – Common names
 - Ciprofloxacin
 - Gatifloxacin
 - Levaquin
 - Ofloxacin
- Rifampin

- Tetracyclines – Common names
 - Doxycycline
 - Minocycline
 - Tetracycline
- Trimethoprim-Sulfamethoxazole
- Vancomycin

Other (please describe in detail other antibiotics you have used in the treatment of PC)

Antifungals

- Amphotericin
- Fluconazole
- Itraconazole
- Ketoconazole
- Nystatin

Antivirals

- Acyclovir
- Foscarnet
- Gancyclovir
- Valacyclovir

Antineoplastics

- Fluorouracil-5% - Brand names
 - Adrucil
 - Carac
 - Efudex
 - Fluoroplex

Keratolytics

- Salicylic Acid-20%
- Urea-40%
- Salicylic Acid-20%, Urea-40% and hydrophilic ointment compound
- Urea-20%, Salicylic Acid-10% in emulsifying ointment with occlusion

Retinoids

SEE SEPARATE QUESTION

Steroids

- Hydrocortisone
- Triamcinolone
- Clobetasol

Phenytoin (Dilantin)

Over the counter

such as Vaseline®

Photographs. Photographs are one of the main tools used by dermatologists and researchers to most clearly show the PC signs. To complete your Questionnaire, please take photographs of your PC signs/symptoms. Photographs can be sent in digital or print format. Please do not worry about getting a close-up. If your photos are in focus we can enlarge or crop the print as needed for the physician. The most important thing is to be sure the photos are in focus. Additional sample photographs are also available on-line at <http://www.pachyonychia.org/Images.html>.

FEET – (1) sole (bottom), (2) top showing toenails, (3) arch side and (4) ankle side



HANDS – (1) palms, (2) top showing fingernails



(3) one nail from top and (4) from side and (5) from the end.



TONGUE – (1) from front (2) from side



FOLLICULAR HYPERKERATOSIS – often on knees, elbows, shoulders, waist or other areas where there is friction. Take photos of those areas affected



CYSTS – may be found on many different places on your body such as face, neck, chest, back, groin, arms or legs. Take photos of those areas affected