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

Name

Mailing Address (street, city, state/province, zip)

Country

Phone Number

Cell Phone

Work Phone

Fax Number

E-mail Address

How would you prefer we contact you? (Check all that are okay.)

- Phone
- Cell Phone
- Work Phone
- Fax
- E-mail
- Regular Mail

Gender

- Male
- Female

Birth Date

Place of Birth (City, State, Country)
[question("value"), id="10"] appears to be a minor (under the age of 18) or you did not enter the birth date. Please complete the following information if the questionnaire is about a minor.

2. Person filling out the questionnaire

Name

Mailing Address (street, city, state/province, zip)

Country

Phone Number

Cell Phone

Work Phone

Fax Number

E-mail Address

How would you prefer we contact you? (Check all that are okay.)

☐ Phone ☐ Cell Phone ☐ Work Phone ☐ Fax ☐ E-mail ☐ Regular Mail
3. Legal guardian of the person registering (if not the person filling out the questionnaire)

Name

Mailing Address (street, city, state/province, zip)

Country

Phone Number

Cell Phone

Work Phone

Fax Number

E-mail Address

How would you prefer we contact you? (Check all that are okay.)

☐ Phone    ☐ Cell Phone    ☐ Work Phone    ☐ Fax    ☐ E-mail    ☐ Regular Mail

List two friends or relatives who can be contacted if the IPCRR is unable to reach you
4. Contact #1

Name

Mailing Address (street, city, state/province, zip)

Country

Phone Number

Cell Phone

Work Phone

Fax Number

E-mail Address

How would you prefer we contact this person? (Check all that are okay.)

☐ Phone   ☐ Cell Phone   ☐ Work Phone   ☐ Fax   ☐ E-mail   ☐ Regular Mail
5. Contact #2

Name

Mailing Address (street, city, state/province, zip)

Country

Phone Number

Cell Phone

Work Phone

Fax Number

E-mail Address

How would you prefer we contact this person? (Check all that are okay.)

☐ Phone ☐ Cell Phone ☐ Work Phone ☐ Fax ☐ E-mail ☐ Regular Mail
6. **OPTIONAL.** Please tell us why you are participating in the IPCRR. What are your hopes and expectations? Do you have specific questions you'd like to discuss?

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

Do you give us permission to obtain the genetic test results?
   - Yes
   - No

**How should we obtain results?**
   - I will send them to you
   - I will tell you who to contact to give you results

**Name of person or laboratory**


8. 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

What were the approximate dates of the biopsy or biopsies?

1st: 
2nd: 
3rd: 

Do you give us permission to obtain the medical records/reports about the biopsy(s)?

- Yes
- No

How should we obtain results?

- I will send them to you
- I will tell you who to contact to give you results

Name of person or laboratory

Phone
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(s)?

- [ ] Yes
- [ ] No

How should we obtain the tissue blocks?

- [ ] I will send them to you
- [ ] I will tell you who to contact to give you the tissue blocks

Name of person or laboratory

[ ]

Phone

[ ]

Mailing Address (street, city, state/province, zip, country)

[ ]

9. Has a 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 cells in culture?

☐ I will send them to you
☐ I will tell you who to contact to give you the cells in culture

Name of person or laboratory


Phone


Mailing Address (street, city, state/province, zip, country)


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.
10. Contact information of Health professional interested in PC

Name

Mailing address (street, city, state/province, zip, country)

Phone

Specialty of this health professional

May we contact this person

☐ Yes  ☐ No
Contact information of Health professional interested in PC

Name

Mailing address (street, city, state/province, zip, country)

Phone

Specialty of this health professional

May we contact this person

☐ Yes  ☐ No
Contact information of Health professional interested in PC

Name

Mailing address (street, city, state/province, zip, country)

Phone

Specialty of this health professional

May we contact this person

☐ Yes  ☐ No
Please invite other family members who have PC to contact PC Project if they wish to participate.

11. Do you have any deceased relatives who had PC?

☐ Yes ☐ No

Please check all that apply

☐ Child/Grandchild  ☐ Father  ☐ Mother  ☐ Father's Father  ☐ Father's Mother  ☐ Mother's Father

☐ Mother's Mother  ☐ Brothers/Sisters  ☐ Aunts/Uncles/Cousins

☐ Other (please explain)
12. Information about deceased relative who had PC

Name

About when did this relative die?  State/Country where died

13. Information about deceased relative who had PC

Name

About when did this relative die?  State/Country where died

14. Information about deceased relative who had PC

Name

About when did this relative die?  State/Country where died

15. Information about deceased relative who had PC

Name

About when did this relative die?  State/Country where died
16. If others in your family also have PC, does PC affect all family members in the same way?

- Yes  - No

Please describe the differences you have observed.

17. How many of your fingernails are thickened at this time? *

Check the box for each fingernail that is thickened.

- Left 1  - Right 1
- Left 2  - Right 2
- Left 3  - Right 3
- Left 4  - Right 4
- Left 5  - Right 5
Check the box for each fingernail that has been surgically removed.

☐ Left 1  ☐ Right 1
☐ Left 2  ☐ Right 2
☐ Left 3  ☐ Right 3
☐ Left 4  ☐ Right 4
☐ Left 5  ☐ Right 5

18. At approximately what age did your fingernails thicken?
   ☐ Birth or less than 1 year
   ☐ 1 to 4 years
   ☐ 5 to 9 years
   ☐ 10 to 14 years
   ☐ 15 to 19 years
   ☐ 20 years and older

19. How often do you care for your fingernails?
   ☐ Daily
   ☐ 2x a week
   ☐ 1x a week (weekly)
   ☐ 2x a month
   ☐ 1x a month (monthly)
   ☐ Less than 1x a month
   ☐ Never
20. How many of your toenails are thickened at this time? *

Check the box for each toenail that is thickened.

☐ Left 1
☐ Left 2
☐ Left 3
☐ Left 4
☐ Left 5
☐ Right 1
☐ Right 2
☐ Right 3
☐ Right 4
☐ Right 5
Check the box for each toenail that has been surgically removed.

☐ Left 1  ☐ Right 1
☐ Left 2  ☐ Right 2
☐ Left 3  ☐ Right 3
☐ Left 4  ☐ Right 4
☐ Left 5  ☐ Right 5

21. At approximately what age did your toenails thicken?
   ☐ Birth or less than 1 year
   ☐ 1 to 4 years
   ☐ 5 to 9 years
   ☐ 10 to 14 years
   ☐ 15 to 19 years
   ☐ 20 years and older

22. How often do you care for your toenails?
   ☐ Daily
   ☐ 2x a week
   ☐ 1x a week (weekly)
   ☐ 2x a month
   ☐ 1x a month (monthly)
   ☐ Less than 1x a month
   ☐ Never
23. How much do thickened fingernails affect your daily life or activities?
- No impact
- Sometimes creates a problem
- Always a problem, but able to function
- Thickened fingernails make it impossible to function

24. In what way do thickened fingernails affect your daily life or activities? Please check all that apply.
- [ ] Cosmetic concerns
- [ ] Pain
- [ ] Time required for grooming
- [ ] Unable to work or attend school
- [ ] Other (please explain) [ ]

25. How often do you have fingernail infections?
- [ ] Frequently (at least every week)
- [ ] Sometimes (every month or every two months)
- [ ] Seldom (once a year or less)
- [ ] Never
- [ ] Other (please explain) [ ]

26. How much do thickened toenails affect your daily life or activities?
- [ ] No impact
- [ ] Sometimes creates a problem
- [ ] Always a problem, but able to function
- [ ] Thickened toenails make it impossible to function
27. In what way do thickened toenails affect your daily life or activities? Please check all that apply.

☐ Cosmetic concerns

☐ Pain

☐ Time required for grooming

☐ Unable to work or attend school

☐ Other (please explain)

☐ Other (please explain)

28. How often do you have toenail infections?

☐ Frequently (at least every week)

☐ Sometimes (every month or every two months)

☐ Seldom (once a year or less)

☐ Never

☐ Other (please explain)

29. Check all of the following which describe your hands

<table>
<thead>
<tr>
<th></th>
<th>Thick skin</th>
<th>Calluses</th>
<th>Blisters</th>
<th>Fissures (cracks in skin)</th>
<th>Open sores</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT THE PRESENT TIME</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AT ANY TIME IN YOUR LIFE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

30. Check all places where you have thick skin and calluses (or blisters, cracks, and open sores) on your hands.

☐ Palms and inside of fingers

☐ Knuckles or back of fingers

☐ Between fingers

☐ Back of hands

☐ Fingertips

☐ Other

☐ Other
31. At what age did the thick skin, calluses, blisters, cracks or open sores first appear on your hands?

- [ ] Birth or less than 1 year
- [ ] 1 to 4 years
- [ ] 5 to 9 years
- [ ] 10 to 14 years
- [ ] 15 to 19 years
- [ ] 20 years and older

32. How often do you have thick skin, calluses, blisters, cracks, or open sores on your hands?

- [ ] Always (never completely go away)
- [ ] Sometimes (hands clear up completely at times)
- [ ] Seldom (hands are usually clear of symptoms)
- [ ] Never

33. How often do you care for the thick skin, calluses, blisters, cracks, or open sores on your hands?

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

34. Check all of the following which describe your feet

<table>
<thead>
<tr>
<th>AT THE PRESENT TIME</th>
<th>Thick skin</th>
<th>Calluses</th>
<th>Blisters</th>
<th>Fissures (cracks in skin)</th>
<th>Open sores</th>
</tr>
</thead>
<tbody>
<tr>
<td>AT ANY TIME IN YOUR LIFE</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
35. Check all places where you have thick skin and calluses (or blisters, cracks, and open sores) on your feet

- Ball of foot
- Heel of foot
- Arch of foot
- Outside of foot
- Between toes
- Other

36. At what age did the thick skin, calluses, blisters, cracks or open sores first appear on your feet?

- Birth or less than 1 year
- 1 to 4 years
- 5 to 9 years
- 10 to 14 years
- 15 to 19 years
- 20 years and older

37. How often do you have thick skin, calluses, blisters, cracks, or open sores on your feet?

- Always (never completely go away)
- Sometimes (feet clear up completely at times)
- Seldom (feet are usually clear of symptoms)
- Never

38. How often do you care for the thick skin, calluses, blisters, cracks, or open sores on your feet?

- Daily
- 2x a week
- 1x a week (weekly)
- 2x a month
- 1x a month (monthly)
- Less than 1x a month
- Never
39. Are you able to walk with PC?

☐ Yes ☐ No

40. Please indicate how PC affects your ability to walk

☐ Walking is not affected
☐ Walk with pain
☐ Cannot walk without assistance or walking aids
☐ Cannot walk at all

Please choose the distance you are able to walk

☐ 1 city block ☐ Less than 1 city block

How long can you walk before the pain is unbearable?

[Blank space]

41. Do you use any walking aids (such as crawling, crutches, walker, cane, or wheelchair?)

☐ Yes ☐ No

Check all walking aids that you currently use.

☐ Crawl (on knees) ☐ Crutches ☐ Walker ☐ Cane(s) ☐ Wheelchair

42. Do you use any special shoes, socks or insoles?

☐ Yes ☐ No
43. How much do thick skin, calluses, blisters, cracks, lesions or open sores affect your daily life or activities?

<table>
<thead>
<tr>
<th>ON YOUR HANDS</th>
<th>ON YOUR FEET</th>
</tr>
</thead>
<tbody>
<tr>
<td>No impact</td>
<td>No impact</td>
</tr>
<tr>
<td>Sometimes creates a problem</td>
<td>Sometimes creates a problem</td>
</tr>
<tr>
<td>Always a problem, but able to function</td>
<td>Always a problem, but able to function</td>
</tr>
<tr>
<td>Condition makes it impossible to function</td>
<td>Condition makes it impossible to function</td>
</tr>
</tbody>
</table>

44. In what way do thick skin, calluses, blisters, cracks, or open sores ON YOUR HANDS affect your daily life or activities? Please check all that apply.

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

45. How painful are the thick skin, calluses, blisters, cracks, or open sores ON YOUR HANDS?

- Not painful
- Somewhat painful
- Very painful, but do not use medication
- Often require medication to handle the pain
46. How often do thick skin, calluses, blisters, cracks, or open sores ON YOUR HANDS affect or impede your daily life or activities?

- Frequently (at least every week)
- Sometimes (every month or every two months)
- Seldom (once a year or less)
- Never
- Other (please explain)

47. In what way do thick skin, calluses, blisters, cracks, or open sores ON YOUR FEET affect your daily life or activities? Please check all that apply.

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

48. How painful are the thick skin, calluses, blisters, cracks, or open sores ON YOUR FEET?

- Not painful
- Somewhat painful
- Very painful, but do not use medication
- Often require medication to handle the pain

49. How often do thick skin, calluses, blisters, cracks, or open sores ON YOUR FEET affect or impede your daily life or activities?

- Frequently (at least every week)
- Sometimes (every month or every two months)
- Seldom (once a year or less)
- Never
- Other (please explain)
50. Explain the ways you measure your pain or limitations. For example, do you know the distance you can walk (i.e. 3 blocks)? or the number of steps you can take (i.e. 100 steps)? or the length of time you can stay on your feet (i.e. 10 minutes or 4 hours)? or tasks you can finish or have to do a portion at a time (i.e. mow 1/2 the lawn)?

51. How would you measure improvement after using a medicine? (Not just describe the improvement, but quantify and measure it for yourself?)

52. Do you have or have you had thickened white skin (leukokeratosis) in your mouth?

- Yes
- No

Where is the thickened, white skin?

- Cheeks
- Roof of mouth
- Other (please explain)
- Tongue
- Inside of lips
- Gums
- Under tongue

At approximately what age did the leukokeratosis begin?

- Birth or less than 1 year
- 1 to 4 years
- 5 to 9 years
- 10 to 14 years
- 15 to 19 years
- 20 years and older
53. As an infant did you have any trouble nursing/sucking?
   - Yes
   - No
   - Don't know

54. 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

55. How do you care for the thickened white skin (leukokeratosis) in your mouth?
   - Brush vigorously
   - Scrape
   - Use mouthwash
   - Other

What type of mouthwash do you use?

56. 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
57. 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)

58. **How painful is the leukokeratosis?**

- [ ] Not painful
- [ ] Somewhat painful
- [ ] Very painful, but do not use medication
- [ ] Often require medication to handle the pain

59. **How often is the leukokeratosis painful?**

- [ ] Always (pain never stops)
- [ ] Sometimes (pain stops at times)
- [ ] Seldom (mouth and tongue are usually pain free)

60. **Were you born with any teeth?**

- [ ] Yes
- [ ] No

61. **Have you had any premature tooth loss (not due to injury)?**

- [ ] Yes
- [ ] No

Please explain
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, grown or other part of the body.

62. Do you have cysts or other growths?

☐ Yes  ☐ No

63. Check all of the following which apply

☐ 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)

☐ Cysts on your scalp, armpits, groin or back. They may often drain a cheesy, sometimes foul smelling or pus-like material. These often become painful and inflamed. (Called PILOSEBACEOUS)

☐ Groups of bumps that form around hair follicles usually on the outer arms, thighs, waist or buttocks. (Called FOLLICULAR HYPERKERATOSIS)

☐ Other (please describe)

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

<table>
<thead>
<tr>
<th></th>
<th>Daily</th>
<th>2x a week</th>
<th>1x a week (weekly)</th>
<th>2x a month</th>
<th>1x a month (monthly)</th>
<th>Less than 1x a month</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>STEATOCYSTOMA</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>PILOSEBACEOUS</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>FOLLICULAR HYPERKERATOSIS</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

65. 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
66. 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)

67. How painful are the growths on your skin?

- [ ] Not painful
- [ ] Somewhat painful
- [ ] Very painful, but do not use medication
- [ ] Often require medication to handle the pain

68. How often are the growths on your skin painful?

- [ ] Always (pain never stops)
- [ ] Sometimes (pain stops at times)
- [ ] Seldom (growths are usually pain free)

Explain when pain stops

69. Do you feel your hair is unusual or abnormal at all?

- [ ] Yes  
- [ ] No
70. Please select all that apply

- Brittle
- Excessively thick
- Thin
- Unruly (hard to comb)
- Wooly
- Other (specify)

71. Do you have hair loss (alopecia)?

- Yes
- No

72. Do you feel you have excessive ear wax?

- Yes
- No

Please select the color of the wax.

- Whitish
- Brown
- Yellow/orange
- Other (please explain)

73. Do you have sharp pain in your ears unrelated to any other ear problem?

- Yes
- No

Please indicate what causes the pain (such as chewing, cold air, etc.)
How long does the pain last?

- 10-20 seconds
- Less than one minute
- Several minutes
- Other (please explain) [ ]

74. Do you have hearing loss?

- Yes [ ]
- No [ ]

Please select all that apply

- Partial hearing loss [ ]
- Loss of hearing for certain frequencies [ ]
- Tinnitus [ ]
- Deafness [ ]
- Other (please explain) [ ]

75. Do you now or did you at one time have emotional or psychiatric problems?

- Yes [ ]
- No [ ]

Please select all that apply

- Depression [ ]
- Suicidal feelings [ ]
- Anger management problems [ ]
- Other (please explain) [ ]

Please note where and how they were/are treated

[ ]
76. Do you now or have you ever had any learning problems?
- Yes
- No

Please describe

77. Have you ever been tested as 'gifted' or with an above-average IQ?
- Yes
- No

78. Do you have corneal lesions (a tear in the eye) or degeneration?
- Yes
- No

79. Do you feel you have persistent hoarseness of voice?
- Yes
- No

Please check all factors you feel affect your hoarseness
- Work environment
- Allergies
- Season of year or weather
- Lack of rest
- Other (please explain)

80. Do you sweat? Please choose the best answer
- Not at all
- Less than most people
- About average
- More than most people
81. Do you have any other physical conditions which you feel are associated with PC which have not been described in this questionnaire?

- Yes
- No

**Please explain**

82. Do certain things affect your PC symptoms?

- Yes
- No

83. Please check all areas affected by the things in the next question.

- [ ] Nails
- [ ] Hands
- [ ] Feet
- [ ] Skin
- [ ] Mouth
- [ ] Hair
84. Please check all that apply that cause your symptoms to improve

- Standing
- Walking
- Sitting
- Sleeping/resting
- Hot weather
- Cold weather
- Wet weather
- Dry weather
- Sweaty feet
- Swimming
- Overly dry feet
- Hot feet
- Cold feet
- Wool socks
- Nylon socks
- Cotton socks
- Morning
- Afternoon
- Evening
- Night
- Winter
- Spring
- Summer
- Fall
- Drinking lots of water
- Eating lots of chocolate
- Eating lots of sugar
- Puberty
- Menopause
- Oral contraceptives
- Hormone therapy
- Pregnancy
- Other food/drink

Other (please list)
85. Please check all that apply that cause your symptoms to become worse

- Standing
- Walking
- Sitting
- Sleeping/resting
- Hot weather
- Cold weather
- Wet weather
- Dry weather
- Sweaty feet
- Swimming
- Overly dry feet
- Hot feet
- Cold feet
- Wool socks
- Nylon socks
- Cotton socks
- Morning
- Afternoon
- Evening
- Night
- Winter
- Spring
- Summer
- Fall
- Drinking lots of water
- Eating lots of chocolate
- Eating lots of sugar
- Puberty
- Menopause
- Oral contraceptives
- Hormone therapy
- Pregnancy
- Other food/drink
- Other (please list)
86. Please check all that apply that cause your *pain to decrease (less pain)*

- [ ] Standing
- [ ] Walking
- [ ] Sitting
- [ ] Sleeping/resting
- [ ] Hot weather
- [ ] Cold weather

- [ ] Wet weather
- [ ] Dry weather
- [ ] Sweaty feet
- [ ] Swimming
- [ ] Overly dry feet
- [ ] Hot feet

- [ ] Cold feet
- [ ] Wool socks
- [ ] Nylon socks
- [ ] Cotton socks
- [ ] Morning
- [ ] Afternoon
- [ ] Evening

- [ ] Night
- [ ] Winter
- [ ] Spring
- [ ] Summer
- [ ] Fall
- [ ] Drinking lots of water
- [ ] Eating lots of chocolate

- [ ] Eating lots of sugar
- [ ] Puberty
- [ ] Menopause
- [ ] Oral contraceptives
- [ ] Hormone therapy

- [ ] Pregnancy

- [ ] Other food/drink

- [ ] Other (please list)
87. Please check all that apply that cause your pain to increase (more pain)

☐ Standing  ☐ Walking  ☐ Sitting  ☐ Sleeping/resting  ☐ Hot weather  ☐ Cold weather

☐ Wet weather  ☐ Dry weather  ☐ Sweaty feet  ☐ Swimming  ☐ Overly dry feet  ☐ Hot feet

☐ Cold feet  ☐ Wool socks  ☐ Nylon socks  ☐ Cotton socks  ☐ Morning  ☐ Afternoon  ☐ Evening

☐ Night  ☐ Winter  ☐ Spring  ☐ Summer  ☐ Fall  ☐ Drinking lots of water  ☐ Eating lots of chocolate

☐ Eating lots of sugar  ☐ Puberty  ☐ Menopause  ☐ Oral contraceptives  ☐ Hormone therapy

☐ Pregnancy

☐ Other food/drink

☐ Other (please list)
88. Please check all that apply that have no affect or are not applicable

- [ ] Standing
- [ ] Walking
- [ ] Sitting
- [ ] Sleeping/resting
- [ ] Hot weather
- [ ] Cold weather
- [ ] Wet weather
- [ ] Dry weather
- [ ] Sweaty feet
- [ ] Swimming
- [ ] Overly dry feet
- [ ] Hot feet
- [ ] Cold feet
- [ ] Wool socks
- [ ] Nylon socks
- [ ] Cotton socks
- [ ] Morning
- [ ] Afternoon
- [ ] Evening
- [ ] Night
- [ ] Winter
- [ ] Spring
- [ ] Summer
- [ ] Fall
- [ ] Drinking lots of water
- [ ] Eating lots of chocolate
- [ ] Eating lots of sugar
- [ ] Puberty
- [ ] Menopause
- [ ] Oral contraceptives
- [ ] Hormone therapy
- [ ] Pregnancy
- [ ] Other food/drink

89. 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)
90. Do you use any mechanical means or tools to care for your PC? Please check all that apply.

- [ ] Razor blades
- [ ] Scalpel
- [ ] Pumice Stone
- [ ] Sanders
- [ ] Clippers
- [ ] Other (specify)

Please describe the sanders that you use.

91. Have you ever been prescribed Isotretinoin (a retinoid) for your PC?

Brand names are: Accure, Accutane, Accutane Roche, Acnal SC, Acnetrex, Acnotin, Akinol, Aknenormin, Amnesteem, Claravis, Curacne Gel, Curatane, Isotane, Isotren, Isotret-Hexal, Isotrext, Isotrext Gel, Newtinon SC Nimegen, Oratane, Pimple, Procuta Gel, Roaccutan, Roaccutane, Roaccutattan, Roactan, Roacttan, Rortet, Tretin

- [ ] Yes  
- [ ] No

92. Have you ever been prescribed Acitretin (a retinoid) for your PC?

Brand names are: Neotigason, Neo-Tigason, Soriatane

- [ ] Yes  
- [ ] No

93. Have you ever been prescribed Etretinate (a retinoid known as Tigason) for your PC?

- [ ] Yes  
- [ ] No
94. Have you ever been prescribed Tretinoin (a retinoid) for your PC?


☐ Yes ☐ No

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. 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.**

For each photo type, click the Browse button to find the picture, then click Upload.

95. Photo of the sole (bottom) of the foot.

[Image of the sole of a foot]
96. Photo of the top of foot showing toenails

97. Photo of the arch side of the foot.

98. Photo of the ankle side of the foot.

99. Photo of the palms of your hands
100. Photo of the top of your hands showing fingernails

101. Photo of one nail from the top

102. Photo of one nail from the side
103. Photo of one nail from the front

104. Photo of tongue from the front

105. Photo of tongue from the side
106. Photo of follicular hyperkeratosis (often on knees, elbows, shoulders, waist or other areas where there is friction). Take photos of those areas affected.

![Photo of follicular hyperkeratosis](image1)

107. Photo of 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.

![Photo of cysts](image2)

---

**RESEARCH SUBJECT INFORMATION AND CONSENT FORM**

You may sign online at the end. If completing for a person ages 12-17, they also sign at the end. The Consent Form provides patient information protection under the Health Information Privacy Protection Act (USA).

**TITLE:** International Pachyonychia Congenita Research Registry (IPCRR)

**PROTOCOL NO.:** WIRB® Protocol #20040468

**SPONSOR:** PC Project
Salt Lake City, Utah
United States

**INVESTIGATOR:** C. David Hansen
Pachyonychia Congenita Project (PC Project)
2180 East 4500 South, Suite 166
PO Box 17850
Salt Lake City, Utah 84117
In this consent form, "you" always refers to the subject. If you are a legally authorized representative, please remember that "you" refers to the study subject.

STATEMENT

We are asking you to participate in the International Pachyonychia Congenita Research Registry (IPCRR). The purpose of the IPCRR is to gather information about PC patients in a useable research registry, which may be used to assist researchers in understanding PC in order to find treatments and a cure for PC. So that qualified doctors, scientists and researchers are able to use information in the registry, PC Project must follow specific laws of the U.S. government regarding medical registries and the IPCRR must be approved by an Institutional Review Board (IRB).

The purpose of this consent form is to give you the information you will need to help you decide whether or not to be in the IPCRR. You may ask questions about the purpose of the IPCRR, what you will be asked to do, any possible risks or benefits, your rights as a volunteer participant, and anything else about the IPCRR or this consent form that is not clear. This is called informed consent. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

Please keep one signed copy of this consent form for your records. Please return one signed copy to the principal investigator listed above. The consent form may be completed online or sent by email, fax or mail.

Who is being asked to participate in the IPCRR?

All persons with PC in all countries are being invited to register. It is not known how many persons have PC although it is known it is a very rare disease.

For how long will the IPCRR maintain your information?

The information contained in the IPCRR will be maintained for an indefinite period of time unless you withdraw your permission for participation in the registry.

What will your participation in the IPCRR involve?

If you agree to participate in the IPCRR you are asked:

- to complete a questionnaire providing detailed information about you, your family history, your PC condition and how PC affects your life
- to have a consultation (in person or by telephone) with a Board Certified Dermatologist to review and validate your responses to the Questionnaire. There will be no cost to you or your insurance carrier for this consultation.
- to ask other family members who also have PC to contact the investigator
- to give permission for PC Project to contact you about once a year to update your information
- to give permission for PC Project to contact you if you are eligible for participation in a future research study concerning PC. If you qualify for any future research studies, you will be asked to sign a separate consent form that outlines that study in detail. There is no obligation to participate in future studies.
- to indicate whether or not you wish genetic tests, if the Dermatologist recommends this option. There is no cost to you or your insurance carrier for the genetic tests. There is no obligation to participate in genetic tests.
What are the possible risks of my participation in the IPCRR?

Participation in the IPCRR does involve the possible risk that information about you might become known to individuals outside of PC Project. We will assign a research code number to your information stored in the IPCRR, and we will separate personal identifiers (for example, your name, social security number, address). Access to personal identifiers will be password protected. Further, information linking the research code number to your name and other personal identifiers will be stored in a separate secure location.

If you request genetic testing, a small saliva sample or a small blood sample will be needed. Drawing blood from your arm may cause pain, bruising, lightheadedness, and, or rare occasions, infection.

What are the possible benefits of my participation in the IPCRR?

You will receive no direct benefit from participation in this study. However, information contained in the IPCRR will be available for research studies directed at improving knowledge, treatment and cure for PC.

It is anticipated that the IPCRR will assist study doctors in two ways:

(a) allow researchers to review and study information on many individuals with PC
(b) help researchers identify and recruit patients who may be eligible for participation in future research studies. There is no obligation to participate in any future study. There are no current research studies for PC.

Will I be paid for my participation in the IPCRR?

No. You will not receive any payment for participating in the IPCRR.

Will I or my insurance provider be charged for my participation in the IPCRR?

There will be no costs to you or your insurance provider to participate in the IPCRR. Any costs will be paid by PC Project (which is funded by PC Fund, a 501(c)3 charity.)

Is there any alternate registry for PC patients?

PC Project is aware of no other registry specifically for PC patients. Your alternative is not to participate in this study.

Who will have access to my identifiable information in the IPCRR?

Access to your identifiable information contained within the IPCRR will be limited to the PC Project principal investigator, PC Project staff and those serving on the Medical Advisory Board of PC Project. A current, complete listing of these individuals is posted on the PC Project website (www.pachyonychia.org) and will be provided to you upon your written request.

AUTHORIZATION TO USE AND DISCLOSE INFORMATION FOR RESEARCH PURPOSES

Federal regulations give you certain rights related to your health information. These include the right to know who will be able to get the information and why they may be able to get it. The study doctor must get your authorization (permission) to use or give out any health information that might identify you.

What information may be used and given to others?

If you choose to be in this study, the study doctor will get personal information about you. This may include information that might identify you. The study doctor may also get information about your health including:

- Past and present medical records
- Research records
- Records about phone calls made as part of this research
Records about your study visits
Information obtained during this research about
   Physical exams
   Laboratory, x-ray, and other test results
   Questionnaires

Who may use and give out information about you?

Information about your health may be used and given to others by the study doctor and staff. They might see the research information during and after the study.

Who might get this information?

Your information may be given to the sponsor of this research. "Sponsor" includes any persons or companies that are working for or with the sponsor, or are owned by the sponsor.

Information about you and your health, which might identify you, may be given to:

   - The U.S. Food and Drug Administration (FDA)
   - Department of Health and Human Services (DHHS) agencies
   - Governmental agencies in other countries
   - The Western Institutional Review Board® (WIRB®)

Why will this information be used and/or given to others?

Information about you and your health that might identify you may be given to others to carry out the research study. The sponsor will analyze and evaluate the results of the study. In addition, people from the sponsor and its consultants will be visiting the research site. They will follow how the study is done, and they will be reviewing your information for this purpose.

The information may be given to the FDA. It may also be given to governmental agencies in other countries. This is done so the sponsor can receive marketing approval for new products resulting from this research. The information may also be used to meet the reporting requirements of governmental agencies.

The results of this research may be published in scientific journals or presented at medical meetings, but your identity will not be disclosed.

The information may be reviewed by WIRB®. WIRB is a group of people who perform independent review of research as required by regulations.

What if I decide not to give permission to use and give out my health information?

By signing this consent form, you are giving permission to use and give out the health information listed above for the purposes described above. If you refuse to give permission, you will not be able to be in this research.

May I review or copy the information obtained from me or created about me?

You have the right to review and copy your health information. However, if you decide to be in this study and sign this permission form, you will not be allowed to look at or copy your information until after the research is completed.

May I withdraw or revoke (cancel) my permission?

Yes, but this permission will not stop automatically.

You may withdraw or take away your permission to use and disclose your health information at any time. You do this by sending written notice to the study doctor. If you withdraw your permission, you will not be able to continue being in this study.

When you withdraw your permission, no new health information, which might identify you, will be gathered after that date. Information that has already been gathered may still be used and given to others. This would be done if it were necessary for the health of study participants or others.
research to be reliable.

Is my health information protected after it has been given to others?

If you give permission to give your identifiable health information to a person or business, the information may no longer be protected. There is a risk that your information will be released to others without your permission.

Who should I contact if I have questions about the IPCRR or about my rights?

If you have questions about the IPCRR, you may contact the principal investigator or study staff:

801-987-8758 (24 Hours).

If you have questions about the IPCRR, which you feel you cannot discuss with the principal investigator or questions about your rights as a participant, you may contact:

Western Institutional Review Board® (WIRB®)
1019 39th Avenue SE Suite 120
Puyallup, Washington 98374-2115
Telephone: 1-800-562-4789

WIRB is a group of people who perform independent review of research.

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Is my participation in the IPCRR voluntary?

Your participation in the IPCRR for the purposes described above is completely voluntary. You may choose to participate or refuse to participate. Whether or not you participate in the IPCRR will have no affect on your association with PC Project.

May I withdraw, at a future date, my consent for participation in the IPCRR?

You may withdraw, at any time, your consent for participation in the IPCRR and no further information will be gathered or distributed from your submission. However, any research use of your information before the date that you formally withdraw your permission will not be destroyed.

To formally withdraw your permission for participation in the IPCRR, you should provide a written and dated notice of this decision to the PC Project principal investigator at the address listed on the first page of this consent form.

Can the IPCRR refuse my participation?

Your participation in the IPCRR may be ended by the PC Project principal investigator or by the sponsor, PC Project, for any reason, without your consent. However, if this situation arises, PC Project will advise you of this decision.

Who will provide the source of funding?

Funding for this research study will be provided by PC Project.

How will I know about significant new findings or future research studies?

The PC Project website (www.pachyonychia.org) will describe progress of the IPCRR and will list any future research studies that are developed using the IPCRR information.

If you participate in the IPCRR, you will be contacted if you qualify for participation in any future study. You will then be able to request information on that study. Once you have received information, you will decide whether or not you wish to participate in that study. There is no obligation to participate in future studies and your decision will not change your participation in IPCRR.
May PC Project contact you?

If you agree to participate in the IPCRR, you will receive a copy of this signed and dated consent form.

In addition to listing with the IPCRR for research purposes, do you give PC Project permission to use your contact information to provide you with information on PC Patient Retreats, news about PC, or other activities of PC Project which may be of interest?

Please mark your choice

- Yes
- No

Consent and Assent Instructions:
Consent: Subjects 18 years and older must sign on the subject line below
For subjects under 18, consent is provided by the Parent or Legal Guardian. For Adult subjects who cannot consent for themselves, consent is provided by the Legally Authorized Representative.
Assent: Is not required for subjects 11 years and younger
Is required for subjects ages 12 through 17 years or adult subjects for whom consent is provided by a legal authorized representative using the Assent Section below.

Optional Participation in Genetic Tests

PC Project is providing genetic testing at no cost to registry enrollees. The results of these tests will be given to each patient in a confidential communication with a physician and/or genetic counselor. The results will be kept for review in the research studies conducted on PC. After my questionnaire is submitted and if recommended by the dermatologist:

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I request genetic testing to verify my specific genetic mutation.</td>
<td></td>
</tr>
<tr>
<td>I agree the results of the tests can be released to PC Project for the IPCRR.</td>
<td></td>
</tr>
<tr>
<td>I agree the DNA can be stored by the laboratory for possible further tests or study. If DNA is to be used for any tests other than genetic studies, PC Project will contact me to obtain consent before using my DNA in that future study.</td>
<td></td>
</tr>
<tr>
<td>I agree that if the laboratory cannot store the DNA, PC Project can arrange for storage at another fully-qualified facility.</td>
<td></td>
</tr>
</tbody>
</table>

Consent

I have read this consent form (or it has been read to me). I have had the opportunity to ask questions. All of my current questions have been answered to my satisfaction. I voluntarily consent to participate (to allow my child to participate) in the IPCRR.

I authorize the use and disclosure of my (my child's) health information to the parties listed in the authorization section of this consent for the purposes described above.

By signing this consent form, I have not waived any of the legal rights, which I (or my child) otherwise would have as a subject in a research study.
CERTIFICATION OF INFORMED CONSENT

I certify that I have explained the nature and purpose of the IPCRR to the above-named individual. I have discussed the possible risks and potential benefits of participation in this research registry. Any questions the individual has about the IPCRR have been answered, and I (or a member of PC Project Advisory Council) will be available to address future questions as they arise.

Principle Investigator or Study Staff
Printed Name of Person Conducting Informed Consent Discussion

Signature of Person Conducting Informed Consent Discussion

Date

ASSENT SIGNATURES, For Subjects Ages 12 through 17 years and adults lacking capacity:

Assent:

This research study has been explained to me and I agree to be in this study.
**Subject’s Signature for Assent**

<table>
<thead>
<tr>
<th>Typing your name in this box serves as your signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
</tbody>
</table>

I confirm that I have explained the study to the extend compatible with the subject’s understanding and that the subject has agreed to be in the study.

**Signature of Person Conducting Assent Discussion**

<table>
<thead>
<tr>
<th>Typing your name in this box serves as your signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
</tr>
</tbody>
</table>

-----------------------------------------------Use the following only if applicable-----------------------------------------------

*If this consent form is read to the subject because the subject is unable to read the form, an impartial witness not affiliated with the research or investigator must be present for the consent and sign the following statement:*

I confirm that the information in the consent form and any other written information was accurately explained to, and apparently understood by, the subject. The subject freely consented to participate in the research study.

**Signature of Impartial Witness (only for subjects who cannot read).**

<table>
<thead>
<tr>
<th>Typing your name in this box serves as your signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
</tr>
</tbody>
</table>

Note: This signature block cannot be used for translations into another language. A translated consent form is necessary for enrolling subjects who do not speak English.

Thank you for joining the IPCRR!