



Department of Dermatology
and Cutaneous Biology
Jefferson Dermatology Associates

T 215.955.6680

F 215.503.3333

Dear Patient,

We are soliciting your participation in studies on Pityriasis Rubra Pilaris (PRP). Enclosed you will find the latest version of the Pityriasis Rubra Pilaris (PRP) study packet. Please take your time to complete all questions and fill out all pages of the consent form (note: two signature pages). Answers will be analyzed as combined, anonymous data (along with those from other study patients). Your name will not be associated with any published information.

Of note, there are two Goals to this study: Goal 1 is genetic analysis to identify genes and pathways involved in PRP; Goal 2 is clinical data analysis to improve diagnosis and management of the disease. We prefer your participation in BOTH Goals; however, you may enroll in any.

Two forms must be completed for enrollment.

The first form is a consent document requesting your permission to participate in the study. The second signature page is a release of medical records document to permit a member of our research team to acquire clinical records from your physician(s). These documents will be kept confidential.

The second form is survey regarding PRP symptoms and treatments. Our research team will study these in order to describe the variety of PRP presentations, associated symptoms and treatments tried. Your protected health information will be kept confidential.

Please return ALL PAGES of EACH FORM to:

Email (PREFERRED), email subject line: "New PRP Enrollment"
PRP@jefferson.edu

Regular Mail

PRP Study, Attn: Nick Ross, MD
Department of Dermatology and Cutaneous Biology,
Thomas Jefferson University Hospital, Attn: Nick Ross,
833 Chestnut Street, Suite 740, Philadelphia, PA 19107, USA

HIPAA-compliant Fax Machine: (215) 503-3333

Do not hesitate to contact a member of the research team with any questions. Your participation is most helpful. We thank you for your time and commitment to the advancement of science and PRP diagnosis and treatment.

Sincerely,

Jouni Uitto, MD, PhD
Professor and Chair
Department of Dermatology
and Cutaneous Biology
Thomas Jefferson University
Philadelphia, PA 19107

Nicholas Ross, MD
Co-Investigator and Resident Physician
Department of Dermatology
and Cutaneous Biology
Thomas Jefferson University
Philadelphia, PA 19107

Thomas Jefferson University IRB
Approval Date 11/7/16
Expiration Date 10/5/17
Annual review due 6 weeks before expiration.



Department of Dermatology & Cutaneous Biology
Thomas Jefferson University Hospital



PITYRIASIS RUBRA PILARIS (PRP) PATIENT HISTORY

Your answers to this IRB Approved Survey will be kept strictly confidential. Data will be anonymously pooled and your name will not be associated with published findings, as outlined in the consent form.

Your DOCTOR(S)' Name (who diagnosed your PRP): _____

DOCTOR'S Telephone Number (who diagnosed your PRP): _____

PATIENT Name: _____ DATE OF BIRTH: ____/____/____ (mm/dd/yyyy)

PATIENT Mailing Address: _____

PATIENT Telephone: _____

PATIENT EMAIL: _____@_____

GENDER: Male Female

RACE/ETHNICITY: _____

Current HEIGHT: _____ (cm) or (in) Current WEIGHT: _____ (kg) or (lbs)

Age AT ONSET of Symptoms: _____ (years) Age AT DIAGNOSIS of PRP: _____ (years)

What, if any, do you/your doctor believe "TRIGGERED" your PRP? _____

Was PRP CORRECTLY DIAGNOSED at the beginning?

Yes

No; If NO, how long did it take to identify the correct diagnosis? _____ (months) _____ (years)

If NO, what was the INITIAL DIAGNOSIS? _____

CONTINUED →

*Thomas Jefferson University IRB
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SKIN FINDINGS (please *check all* that apply):

Red-Orange Plaques

Where did these start: _____

At its worst, location(s) with red-orange plaques: _____

Intervening/Normal skin "islands" in between areas of red rash

Flaking of skin (fine scales)

Waxy, red-orange thickening of palms and soles

Redness/flaking around hair follicles/openings (scalp or body hair)

Hair loss/thinning

Eczema-like skin changes (dry, red, cracked); where: _____

Nail Changes: thickened; yellow; deformed; buildup under nails; other: _____

ONLY Elbows/Knees with thick, yellow-red-orange plaques/flaking of skin

Lower legs (around shins) with larger, rectangular/rhomboidal scales of dry skin/cracking

SKIN BIOPSY (a sample of your skin taken/removed by a healthcare provider to examine further):

NOT DONE

DONE

If YES, BIOPSY DATE(S): ___/___/___; ___/___/___; ___/___/___

If YES, was Pityriasis Rubra Pilaris (PRP) CONFIRMED BY SKIN BIOPSY?

Yes

No

PLEASE SUBMIT A COPY OF THE(SE) SKIN BIOPSY REPORT

Do you STILL HAVE SKIN FINDINGS/SYMPTOMS?

Yes; If YES: TOTAL TIME, since onset, with skin FINDINGS/SYMPTOMS? _____ (years)

No; If NO: TOTAL TIME with skin FINDINGS/SYMPTOMS? _____ (years)

What TYPE OF PRP Did Your Doctor Diagnose?

Don't Know

Classic Adult, Type I: Red-orange plaques with islands of normal skin, rough bumps around hair follicles and waxy, red-orange thickened skin on palms and soles.

Atypical Adult, Type II: Areas of eczema-like skin irritation, irregular, thick brown scales on lower legs, thickened skin on palms and soles, hair thinning.

Circumscribed Juvenile, Type III: Pre-pubertal onset involving only elbows and knees with skin thickening, scaling and redness.

Classic Juvenile, Type IV: Onset within first 2 years of life, same appearance as Type I (red-orange plaques with islands of normal skin, rough bumps around hair follicles and waxy, red-orange thickened skin on palms and soles).

Atypical Juvenile, Type VI: onset within the first few years of life, red bumps around hair follicles, tightened skin of the hands and feet, genetic link (often others in the family with PRP).

Is there a FAMILY HISTORY of PRP or Psoriasis?

Yes; If YES, WHO has it? _____ AND is it PRP or PSORIASIS? _____

No

TREATMENTS TRIED for PRP

NONE

CONTINUED→

TOPICAL TREATMENT (please *check all* treatments tried) || **Was it helpful?**

Moisturizers: type: _____; start ___/___/___ stop ___/___/___||... **Yes** **No**

If yes, what symptoms improved/over how many months? _____

Topical Steroids: name/strength: _____; start ___/___/___ stop ___/___/___||... **Yes** **No**

If yes, what symptoms improved/over how many months? _____

Urea Cream: name/strength: _____; start ___/___/___ stop ___/___/___||... **Yes** **No**

If yes, what symptoms improved/over how many months? _____

Salicylic Acid: name/strength: _____; start ___/___/___ stop ___/___/___||... **Yes** **No**

If yes, what symptoms improved/over how many months? _____

Retinoids (Topical): name/strength: _____; start ___/___/___ stop ___/___/___||.. **Yes** **No**

If yes, what symptoms improved/over how many months? _____

Calcipotriene/Calcipotriol: start ___/___/___ stop ___/___/___||.. **Yes** **No**

If yes, what symptoms improved/over how many months? _____

Pimecrolimus/Tacrolimus: start ___/___/___ stop ___/___/___||.. **Yes** **No**

Other: name/strength: _____ start ___/___/___ stop ___/___/___||.. **Yes** **No**

If yes, what symptoms improved/over how many months? _____

Other: name/strength: _____ start ___/___/___ stop ___/___/___||.. **Yes** **No**

If yes, what symptoms improved/over how many months? _____

SYSTEMIC TREATMENT (please *check all* treatment tried) || **Was it helpful?**

Retinoid (oral): name/dose/schedule: _____ start ___/___/___ stop ___/___/___|| **Yes** **No**

Retinoid examples: acitretin, etretinate, isotretinoin, others

If yes, what symptoms improved/over how many months? _____

Methotrexate: name/dose/schedule: _____; start ___/___/___ stop ___/___/___||.. **Yes** **No**

If yes, what symptoms improved/over how many months? _____

TNF- α Inhib: name/dose/schedule _____ start ___/___/___ stop ___/___/___|| **Yes** **No**

TNF- α Inhib Examples: adalimumab (Humira), etanercept (Enbrel), infliximab (Remicade), golimumab (Simponi), certolizumab pegol (Cimzia)

If yes, what symptoms improved/over how many months? _____

IL12/23 Inhib: name/dose/schedule _____ start ___/___/___ stop ___/___/___ ..||.. **Yes** **No**

IL12/23 Inhib Example: ustekinumab (Stelara)

If yes, what symptoms improved/over how many months? _____

Light Therapy: type/strength/schedule _____ start ___/___/___ stop ___/___/___|| **Yes** **No**

If yes, what symptoms improved/over how many months? _____

Other: name/strength _____ start ___/___/___ stop ___/___/___||.. **Yes** **No**

If yes, what symptoms improved/over how many months? _____

CONTINUED→

MEDICAL HISTORY: (please *check all* that apply)

- Skin Disease: If so, what disease(s): _____
- Myasthenia Gravis
- Celiac Sprue (“celiac disease”)
- Myositis (“inflammation” of muscles)
- HYPOthyroidism (“low” thyroid function)
- Cancer/Malignancy; Type: _____ YEAR DIAGNOSED: _____
- HIV Infection
- Diabetes
- Dyslipidemia (e.g. “high cholesterol,” “high triglycerides,” etc.)
- Heart Disease

OTHER SYMPTOMS related to PRP:

Regarding your MOOD, how often do you FEEL DOWN or DEPRESSED?

- Don't Know
- ALWAYS OFTEN SOMETIMES RARELY NEVER

In your opinion what percent of your DEPRESSION IS RELATED to PRP?

- Don't Know
- 0% (Not at all related) 1-25% 26-50% 51-75% 76-100% (Extremely related)

List WHAT ABOUT YOUR PRP makes you feel DEPRESSED/IS HARD TO DEAL with:

- Don't Know

<i>-example: people stare at me in public</i>
<i>-example: I am not allowed in the public pool because of my rash</i>

END OF PATIENT SURVEY

PLEASE RETURN all pages of **this form** and the **research consent form** via:

1. **Email** (preferred): PRP@jefferson.edu

OR

2. **Mail**

Department of Dermatology & Cutaneous Biology, Attn: Nick Ross, MD, 833 Chestnut St., Ste. 740, Philadelphia PA 19107. (If you require a stamped envelope, please contact (215) 503-3787).

OR

3. **Fax:**

(215) 503-3333, attention PRP Study, Nick Ross, MD

Thank you for taking the time to complete this form. Your information is very helpful and will be used to advance dermatology's understanding of Pityriasis Rubra Pilaris (PRP).

As you identify Counsel - Inpatient
10/5/17

Thomas Jefferson University
Informed Consent Document for Human Subjects Research – OHR-8

Department: Dermatology & Cutaneous Biology

Principal Investigator: Jouni Uitto, MD, PhD **Telephone:** 215-503-5785

Co-Investigator(s): Nicholas A Ross, MD; Qiaoli Li, Ph.D., Matthew Keller, MD

Key Personnel: Ashley Gochocco; Joshua Kingman, MS

Medical Study Title: Investigation of Potential Genetic Causes of Pityriasis Rubra Pilaris (PRP) by Mutational Analysis of Patient Tissues

Lay Study Title: A research study to enroll patients in a PRP registry, collect information about the presentation, diagnosis and management of the disease and identify genetic causes and pathways triggered by the disease

Is email a good method for study communication?

YES NO

EMAIL: _____@_____

Please check BOXES (page 8) of the study sections in which you wish to participate

RISKS: E-mail correspondence is not always secure and there is a risk of loss of confidentiality. To help protect against loss of confidentiality, all e-mail that originates from Jefferson University or Jefferson Hospital employees using Jefferson University or Jefferson Hospital e-mail addresses is encrypted. That means, unless you have allowed others to have access to your e-mail, only you will see the e-mail. **YOU SHOULD NEVER USE E-MAIL TO REPORT A SUSPECTED ADVERSE EVENT OR ANY OTHER MEDICAL PROBLEM. THESE SHOULD BE REPORTED BY TELEPHONE**

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37 **What Is Informed Consent?**

38 You are being asked to take part in a medical research study. As required by federal regulations,
39 this research study has been reviewed and approved by an Institutional Review Board (IRB), a
40 University committee that reviews, approves and monitors research involving humans. Before a
41 knowledgeable decision about whether to participate in a research study can be made, the
42 possible risks and benefits related to the study should be understood. This process of learning and
43 thinking about a study before deciding to participate is known as *informed consent* and includes:

- 44 • Receiving detailed information about this research study;
- 45 • Being asked to read, sign and date this consent form once the nature of the study is
46 understood and a decision is made to participate. If there is anything about the study you
47 don't understand or if there are questions, you should ask for explanations before signing
48 this form;
- 49 • Being given a copy of the signed and dated consent form to keep.

50
51 **Can I enroll in the study?**

52 Any patient with a diagnosis of PRP, WHETHER ACTIVE OR IN REMISSION, is permitted to
53 enroll in this study. The study is divided into "goals" (see below) to improve data analysis and
54 outcomes. You are allowed to enroll into both CURRENT and PAST goals at any time.

55
56 **What is the purpose of this study and what will happen during this study?**

57 This study has two Goal: Goal I includes genetic data analysis. Goal II includes clinical data
58 analysis.

59
60 During Goal I, our research team seeks to identify genetic link and pathways involved in PRP.
61 Analysis will involve patient saliva (spit)/buccal smear (cheek swab), blood and skin samples.
62 This portion of the study is always open for sample enrollment.

63 Three steps of Goal I:

- 64 1. You will receive information and this consent form allowing study personnel to request a
65 biological specimen from you (either blood, saliva, cheek swab or skin biopsy).
- 66 2. If interested in participating, you will complete the consent form, which you may review at your
67 own pace, returning all completed forms and biologic specimens to our Clinical Research Office.
- 68 3. Our study team will use specimens provided to perform genetic mutational analysis and compare
69 your specimen with all other specimens collected. When we have achieved a sufficient number of
70 specimens and analysis is complete, the data will be published and you will be informed of our
71 findings.

72

73
74 During Goal II, there are no tests. Our aim is to gather clinical information from patients
75 regarding their experience, symptoms, and treatment of PRP. We request your permission to
76 allow study team members (listed above) to contact your diagnosing/treating physician(s) to
77 acquire medical records (clinical and/or pathologic) and/or skin biopsy slides. Specifically, we
78 seek your permission to contact your physician in order to confirm your diagnosis of PRP. We
79 also request permission for study personnel to contact you, solely for the purpose of obtaining
80 these documents and information related to the PRP study. Through this research, we hope to
81 establish a possible genetic link of the disease that can enable further research that may improve
82 diagnosis and treatment options.

83 The three steps of Phase II are:

- 84 1. You will receive information regarding the study (Patient Study Packet), which you may review
85 at your own pace.
- 86 2. If interested in participating, you will complete the (i) Consent Form, (ii) Release of Medical
87 Records form and (iii) Patient Questionnaire and return all documents (all pages included) to our
88 Clinical Research Office.
- 89 3. Our study team will use information provided in the study packet to contact your physician(s) and
90 gather your clinical and/or biopsy records in order to review and confirm your diagnosis of PRP.
91 We seek medical records containing clinical (doctor's notes) and/or pathologic (biopsy) reports
92 and/or biopsy slides that will allow us to definitively establish your diagnosis of PRP through pre-
93 defined study criteria. The goal is to collect this information and allow the physicians associated
94 with this study at Thomas Jefferson University's Department of Dermatology and Cutaneous
95 Biology to review the diagnosis for study purposes.

96
97 Once you provide your medical records and/or samples, the following will occur:

98 Documents will be reviewed for pertinent information that may identify triggers
99 (medications, illnesses, other conditions at the time of PRP onset), information useful for
100 diagnosis and treatment of the disease as well as long term outcomes. Samples will be
101 kept in a locked -80C freezer at Dr. Uitto's research laboratory. Tissue samples will be
102 used to study the genetics and pathways involved in the disease. DNA will be extracted
103 from the sample you provide; we will analyze it to identify mutations, specifically in the
104 CARD14 gene that is associated with the disease. Skin biops(ies) will be examined for
105 target gene (*CARD14*) involvement, immuno-histochemical staining and upregulation of
106 inflammatory pathways. This may allow for a better understanding of the pathways
107 involved in the disease and better, targeted treatment options.

108
109 **How many individuals will participate in the study and how long will the study last?**

110 The goal is to enroll as many participants as possible in the PRP registry to expand the quality
111 and quantity of research and improve patient access to PRP research. To date, more than one
112 hundred PRP patients, just like you, are participating in this research study.

113
114 You can enroll if you have ACTIVE OR RESOLVED PRP. Your participation in any Goal of
115 the study will last only as long as it takes you to complete the documents followed by the time it
116 takes our study team to obtain clinical records from your diagnosing/treating physician(s)
117 (approximately six months to one year). Once information has been gathered, you will have
118 "completed" your enrollment in the study; we will maintain your information, however, to

119 continue to reach out to you about progress and subsequent Goals of the study. Your
120 participation, of course, is voluntary and can be terminated at any time at your request or at the
121 discretion of the principal investigator.
122

123 **What are the side effects and other risks or discomforts involved?**

124 **Saliva (spit)/Buccal Swab (Cheek Swab) Sample**

125 Providing a saliva (spit)/buccal smear (cheek swab) sample involves spitting into a sterile
126 specimen container or using a specimen cotton tip collector and stroking the inside of the cheek
127 to collect skin cells.

128 **What are the Risks of Saliva (spit)/Buccal Swab (Cheek Swab) Sample?**

129 There are no risks associated with this specimen collection.
130

131 **What Are the Risks of Drawing Blood?**

132 If you choose a blood draw method: The amount of blood drawn will be about 10 milliliters (2
133 teaspoons); only one sample is required at this time. The risks of blood sampling are the same as
134 any routine blood draw including discomfort as the needle is inserted, bleeding, bruising and
135 discoloration around the site of the blood draw, infection and, rarely, fainting. Risks will be
136 minimized by having the blood drawn by an individual who is trained to perform this procedure.
137

138 **What Are the Risks of Skin Biopsy?**

139 If you choose a biopsy (skin sample) method: You may have a skin biopsy performed on both
140 affected (eg. rash) and non-affected (eg. normal) skin. The risks of skin biopsy are discomfort
141 during anesthetic administration, bleeding, bruising at the site, infection at the site, scar and,
142 rarely, fainting. Risks will be minimized by having the biopsy performed by a trained
143 professional.
144

145 **What is the risk of releasing my medical record?**

146 By releasing your medical records, there is always a risk of a breach in confidentiality. By
147 following preventative privacy measures outlined in the study protocol, we hope to minimize this
148 risk. All information we obtain will be kept confidential and protected in a secure, on-campus
149 office within a locked file cabinet. Your name will not be linked to any published data.
150

151 **Are there benefits from being in this study?**

152 There may be no personal benefit from being in this research, but we hope that what we learn
153 may be helpful to future patients or society, in general.
154

155 **Are there alternatives to being in the study?**

156 Participation in this study is entirely voluntary. The alternative is not enrolling in the study. You
157 do not have to complete the study survey nor do you have to provide permission for our study
158 team to contact your treating/diagnosing physician. If, however, you are interested in
159 participating, please complete all study forms.
160

161 **How will privacy and confidentiality (identity) be protected?**

162 Federal regulations require that certain information about individuals be kept confidential. This
163 information is called "protected health information" (PHI). PHI includes information that

164 identifies an individual personally such as name, address and social security number, or any
165 medical or mental health record, or test result, that may have this sort of information on it. The
166 laws state that people may see and review their medical records at any time. However, in a
167 research study, people may not see the study results or other data about the study until after the
168 research is completed unless the study doctor decides otherwise.

169
170 The following individuals or entities may have access to your/your child's (if enrolled) PHI and
171 by law must protect it. These include investigators listed on this consent form and other
172 personnel of Thomas Jefferson University, Jefferson University Physicians, and Thomas
173 Jefferson University Hospitals, Inc. (add the Rothman Institute if applicable) involved in this
174 specific study, the University's Office of Human Research and the Institutional Review Board
175 (IRB), and your/your child's (if enrolled) health insurance company (if necessary for billing for
176 standard medical care).

177
178 PHI collected during this study may also be shared with the following entities that, while not
179 obligated by law to protect PHI, will protect it to the best of their ability:

- 180 • The National Institute of Health (NIH) if supplying grants in the future
- 181 • With any person or agency required by law

182 If you develop an illness or injury during the course of participation in this study, other PHI
183 about treating and following the condition may be generated and disclosed as it relates to this
184 study.

185
186 PHI collected as part of this research may be used/disclosed indefinitely.

187
188 You may quit the study and revoke permission to use and share PHI at any time by contacting the
189 principal investigator, in writing, at: **Jouni Uitto, MD, PhD, Professor and Chair, Department of**
190 **Dermatology & Cutaneous Biology, Thomas Jefferson University, 233 South 10th Street Bluemle**
191 **Life Sciences Building, Room 450, Philadelphia, PA 19107.** Further collection of PHI will be
192 stopped on those who quit the study, but PHI that has already been collected may still be used.

193
194 The results of clinical tests and procedures performed as part of this research may be included in
195 your medical records. The information from this study may be published in scientific journals or
196 presented at scientific meetings but no one will be personally identified in these publications and
197 presentations.

198
199 A description of this clinical trial will be available on <http://www.ClinicalTrials.gov>, as required
200 by U.S. Law. This Web site will not include information that can identify you. At most, the Web
201 site will include a summary of the results. You can search this Web site at any time.

202
203 **What happens in case of injury as a result of being in this study?**

204 In the event of a research-related injury, necessary and available medical care (including
205 hospitalization) will be provided. A research-related injury is a physical injury or illness that is
206 directly caused by any procedure or treatment used in this study that is different from the
207 treatment you would receive if not participating in a research study. If physical injury occurs due
208 to any drug/substance or procedure properly given under the plan for this study, medical

209 expenses for treating the injury will be billed to your insurance carrier. You should be aware that
210 some costs may not be covered by insurance and may become your responsibility.

211
212 If a bill related to a research-related injury is received that seems wrong, please discuss it with
213 the study doctor or research coordinator.

214
215 **Is there payment for being in this study?**

216 There is no payment for participating in this study.

217
218 **Are there costs related to being in this study?**

219 The only cost to you with participating in this study is for postage to mail the forms. If you are
220 unable to afford this cost, please contact our study team (information below) to request
221 assistance. the clinical research fellow (information in the patient study packet) who can assist
222 you in finding alternative means of supplying the study team with your documents.

223 **What if the research results in new findings?**

224 Anything learned during the study, beneficial or not, that may affect your health or willingness to
225 continue in the study, will be explained.

226
227 **Can I be removed from the study or quit the study?**

228 Your decision to participate in this research study is entirely voluntary. You have been told what
229 being in this study will involve, including the possible risks and benefits.

230
231 Your participation in this research project may be terminated by the study doctor without your
232 consent for any reason that he/she feels is appropriate.

233
234 You may refuse to participate in this investigation or withdraw consent and quit this study
235 without penalty and without affecting the ability to receive medical care at Thomas Jefferson
236 University/the Rothman Institute.

237
238 If you withdraw from this study, you may continue treatment with your Jefferson doctor, or you
239 may seek treatment from another doctor of your choice. Should you decide to withdraw from the
240 study, please be sure to inform the study doctor.

241

242

243

244 **THIS SPACE IS INTENTIONALLY LEFT BLANK**

245

CONTACT INFORMATION

If you are having a medical emergency, call 911 or go directly to an emergency room. You should let emergency personnel or providers know that you are participating in this study.

PRP Study Group Contact Information

Email (preferred)	<u>PRP@jefferson.edu</u>	Note: this mailbox is checked periodically.
Mail	833 Chestnut Street, Suite 740, Philadelphia PA 19107, USA	Mark attention: PRP Study Nicholas Ross, MD
Fax	215-503-3333	Mark attention: PRP Study Nicholas Ross, MD

Other Useful Contact Information

Telephone number for questions about your rights as a research participant	The Jefferson Institutional Review Board	215-503-8966
For questions, concerns or complaints about the research, or if you suspect a research-related injury	The Principal Investigator, Dr. Jouni Uitto, MD, PhD or any co-investigator listed at the beginning of this form	215-503-5785
If you have difficulty contacting the study staff	Call the Jefferson Office of Human Research	215-503-0203

If you want more information about the Jefferson Institutional Review Board or Jefferson's Human Research Protection Program, please visit our website at http://www.jefferson.edu/human_research/irb/index.cfm.

270 **Non-Waiver of Legal Rights Statement**

- 271 • By your agreement to participate in this study, and by signing this consent form, you are not
272 waiving any of your legal rights.
273 • In order to be in this research study, you must sign this consent form.
274 • You affirm that you have read all pages of this consent form. You have been told that you
275 will receive a copy.
276
277

278 Please **ENROLL ME IN** the following (*check all parts you wish to join*):

279 **1. Clinical Survey / PRP Registry**

280 Yes No

281 **2. Genetic Analysis** (*check all methods you allow*)

282 Yes No.....a. **Saliva (spit)/buccal smear (cheek swab) Sample**

283 Yes No.....b. **Blood Sample**

284 Yes No.....c. **Skin Biopsy**

285 _____
286 Your Name

287 _____
288 Your Signature

289 _____
290 Date

291 _____
292 Name of **Person Conducting**
293 **Consent Interview**

294 _____
295 Signature of **Person Conducting**
296 **Consent Interview**

297 _____
298 Date

299 _____
300 Name of **Investigator**
301 **or Co-Investigator**

302 _____
303 Signature of **Investigator**
304 **or Co-Investigator**

305 _____
306 Date

307 **Copy of Signed and Dated Consent Form Given to the Subject/Parent/LAR**

308 _____
309 Your Name (**if Minor**)

310 _____
Your Signature (**if Minor**)

_____ Date

(*If subject is a minor and this document is being used both as consent and assent form.*)

_____ Name of **Witness**

_____ Signature of **Witness**

_____ Date

(*Witness only required if subject speaks and understands is English, but the subject cannot read English, the subject is blind or cannot physically sign the consent form*)

10/5/17

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By signing, you give permission to your diagnosing/treating physician to release your medical record(s), biopsies/slides to the Thomas Jefferson University PRP Research Team for the purposes of scientific study.

*****Instructions*****

Please enter **diagnosing physician information** (e.g. dermatologist).
If you saw multiple physicians/dermatologists for the diagnosis please attach additional pages as necessary.

322
323
324
325
326
327
328

1. **PHYSICIAN Name:** _____
2. **PHYSICIAN Telephone:** _____
3. **PHYSICIAN Fax:** _____
4. **PHYSICIAN Address:** _____

City State/Province
Postal Code Country

329 **I hereby authorize the physician(s) listed above to release my medical records to the**
330 **research personnel listed above at Thomas Jefferson University Hospital for the purposes**
331 **of scientific study.**

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_____	____/____/____	_____
Print YOUR Name	YOUR Date of Birth	YOUR Telephone Number
_____	____/____/____	
Signature	Date	
_____	____/____/____	
Witness Signature	Date	

343 *(Witness required if the only language the subject speaks and understands is English, but*
344 *the subject cannot read English, or if the subject is blind or cannot physically sign the*
345 *consent form.)*

10/5/17