Appendix S1

Questionnaire about pruritus in neurofibromatosis 1

1. Chronology

When did pruritus begin?

weeks □ months □ years □

Is pruritus :

continuous □ episodic □

Do you feel pruritus :

Every day…..……... □
Almost every day…..……... □
Every week…….…….. □
Every month..……... □
Seldom…….. □

Please indicate the frequency of appearence of pruritus for each part of the day : (put a cross on each line)

	Never	Occasionnal	Often	Always present
Morning	□	□	□	□
Afternoon	□	□	□	□
Evening	□	□	□	□
Night	□	□	□	□

2. Location

Is pruritus localized on neurofibromas?

yes □ no □

3. Characteristics of pruritus

Does these sensations accompanying your itch?

	Yes	No
Sweating	□	□
Headache	□	□
Pain	□	□
Heat sensation	□	□
Cold sensation	□	□

Do you also feel these sensations?

	Yes	No
Stinging	□	□
Tickling	□	□
Crawling	□	□
Stabbing	□	□
Pinching	□	□
Burning	□	□
Biting	□	□
Stroking	□	□

4. Intensity

What is the intensity of pruritus on a scale from 0 to 10 ?
(0 : no pruritus ; 10 : the worst pruritus imaginable)
Put a cross on each line

No pruritus → Worst pruritus

	0	1	2	3	4	5	6	7	8	9	10
Now											
In worst moment											
In best moment											
In mean											

5. Treatment

Please indicate treatment (medication, cream…) you take for your pruritus and if no effect, short effect, long effect.

Treatment	No effect	Short effect (less than 24hours)	Long effect (more than 24hours)

6. Disruption of daily activities

Please indicate how each item affects your pruritus :
Put a cross on each line.

	Increases	Does not affect	Relieves
Sleep			
Rest			
Activity			
Stress			
Fatigue			
Physical effort			
Skin dryness			
Hot water			
Cold water			
Sweat			
Cold			
Heat			
Clothes			

7. Characteristics of scratching

Do you scratch ?

No…….... □
Rarely…..…….. □
Often…….…..... □
Very often…….…..... □

If yes, is scratching :

Higlhly pleasurable……..……. □
Moderatly pleasurable……... □
Neutral……...……..... □
Moderatly unpleasurable……... □
Higlhly unpleasurable...…… □