Patient Attitude and Beliefs Regarding Cutaneous Neurofibromas and Treatment

Please complete the survey below.		
Thank you!		
Demographic Information 1. Age		
1. Age		
2. What is your biological sex?	○ Female○ Male○ Other	
2.1. Other: Please state		



3. Country of Residence	○ Afghanistan
3. Country of Residence	Alghanistan Aland Islands
	○ Albania
	○ Algeria
	Angeria American Samoa
	○ Andorra
	○ Angola
	O Anguilla
	O Antarctica
	Antigua and Barbuda
	○ Argentina
	Armenia
	○ Aruba
	○ Australia
	○ Austria
	○ Azerbaijan
	○ Bahamas
	○ Bahrain
	○ Bangladesh
	○ Barbados
	○ Belarus
	○ Belgium
	O Belize
	O Benin
	O Bermuda
	O Bhutan
	O Bolivia
	O Bonaire
	O Bosnia and Herzegovina
	O Botswana
	O Bouvet Island
	O Brazil
	British Indian Ocean Territory
	O Brunei Darussalam
	○ Bulgaria
	O Burkina Faso
	○ Burundi
	○ Cambodia
	○ Cameroon
	○ Canada
	Cape Verde
	Cayman Islands
	Central African Republic
	○ Chad
	○ Chile
	○ China
	Christmas Island
	Cocos (Keeling) Islands
	Colombia
	○ Comoros
	Congo The Demogratic Republic of the Congo
	The Democratic Republic of the Congo
	O Cook Islands
	Costa Rica
	○ Côte d'Ivoire
	○ Croatia
	○ Cuba
	○ Curaçao
	○ Cyprus
	Czech Republic
	○ Denmark
	○ Djibouti
	O Dominica
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	○ Ecuador
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	○ El Salvador
	Equatorial Guinea
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\circ	Ethiopia
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	Fiji
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	France
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	French Southern Territories
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	Gibraltar
\sim	Greece
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	Guernsey
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Ŏ	Guinea-Bissau
$\tilde{\cap}$	Guvana
\tilde{a}	Guyana Haiti
\simeq	Heard Island and McDonald Islands
\sim	Holy See (Vatican City State)
	Honduras
Ō	Hong Kong
\circ	Hungary
\circ	Iceland
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	Nicaragua
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	Norfolk Island
	Northern Mariana Islands
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	Norway
_	Oman
	Pakistan
	Palau
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	Philippines
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	Portugal
	Puerto Rico
_	Qatar
_	Réunion
_	Romania
\circ	Russian Federation
\bigcirc	Rwanda
$\tilde{\cap}$	Saint Barthélemy
	Saint Helena
	Saint Kitts and Nevis
	Saint Lucia
	Saint Martin (French part)
Ŏ	Saint Pierre and Miquelon
	Saint Vincent and the Grenadines
\circ	Samoa
\bigcirc	San Marino
	Sao Tome and Principe
	Saudi Arabia
	Senegal
	Serbia
	Seychelles
	Sierra Leone
	Singapore
Ŏ	Sint Maarten (Dutch part)
\circ	Slovakia
	Slovenia
	Solomon Islands
	Somalia
	South Africa
	South Georgia and the South Sandwich Islands
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	South Sudan
	Spain
	Sri Lanka
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Suriname Svalbard and Jan Mayen Swaziland Sweden Switzerland Syrian Arab Republic Province of China Tajikistan Tanzania Thailand Timor-Leste Togo Tokelau Tonga Trinidad and Tobago Turkey
○ Togo
○ Tokeidu ○ Tonga
○ Trinidad and Tobago
○ Tunisia○ Turkey
TurkmenistanTurks and Caicos Islands
○ Tuvalu
○ Uganda
○ United Arab Emirates
Uganda Ukraine United Arab Emirates United Kingdom United States United States United States Minor Outlying Islands Uruguay Uzbekistan
United States
United States Minor Outlying Islands
○ Uruguay ○ Uzbekistan
○ Vanuatu
○ Venezuela
○ Viet Nam
Virgin Islands BritishVirgin Islands U.S.
Wallis and Futuna
○ Western Sahara
○ Zambia
○ Zimbabwe

3.1. State of Residence	Alabama Alaska Arizona Arkansas California Colorado Connecticut Delaware District Of Columbia Florida Georgia Hawaii Idaho Illinois Indiana Iowa Kansas Kentucky Louisiana Maine Maryland Massachusetts Michigan Minnesota Mississippi Missouri Montana Nebraska Nevada New Hampshire New Jersey New Mexico New York North Carolina North Dakota Ohio Oklahoma Oregon Pennsylvania Rhode Island South Dakota Tennessee Texas Utah Vermont Virginia Wasconsin Wyoming
4. What is your race?	 American Indian or Alaska Native Asian Black of African American Native Hawaiian or Other Pacific Islander White Other
4.1. Other: please state	

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5. What is your ethnicity?	Hispanic or LatinoNot Hispanic or LatinoOther	
5.1. Other: please state		
6. What is the highest level of education you have completed?	 ○ Did not complete high school ○ High school degree or equivalent (e.g. GED) ○ Some college but no degree ○ Associate degree (2 year college degree) ○ Bachelor degree (4 year college degree) ○ Graduate degree 	
7. Do you currently work outside of the home?	○ Yes ○ No	
8. Are you the first person in your family diagnosed with NF1?	○ Yes ○ No	

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What are cutaneous neurofibromas?

Cutaneous neurofibromas are benign (not cancerous), flesh-colored flat or raised bumps on or in the skin that are commonly seen in people with Neurofibromatosis type 1 (NF1). You may have also heard people call them tumors, dermal neurofibromas, or even moles. Here are some pictures of cutaneous neurofibromas:









Please tell us about your cutaneous neurofibromas:

An example of someone with 100-500 cutaneous neurofibromas



An example of someone with more than 500 cutaneous neurofibromas



How many cutaneous neurofibromas do you estimate you currently have across your whole body? (Please refer to image above for a visual example of number of cutaneous neurofibromas)	 ○ 0 ○ 1-19 over entire body ○ 20-99 over entire body ○ 100-500 over entire body ○ > 500 over entire body
2. What age did you first notice cutaneous neurofibromas?	Less than 10 years old10-19 years old20-29 years old30-39 years old40 years or older
3. Where are your cutaneous neurofibromas? (select all that apply)	□ Scalp □ Face □ Neck □ Trunk (chest, belly, back) □ Arms □ Hands □ Legs □ Feet □ Genitals □ Nipple/Areola □ Other
3.1. Other: please state	
4. Do you have flat (not raised above the skin) cutaneous neurofibromas?	YesNoI don't know

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Please tell us what you think about cutaneous neurofibromas and treatment: 5. How much does each FEATURE of your raised cutaneous neurofibromas bother you? (physically, cosmetically, or emotionally) Not at all N/A (1) Not so much (2) Very much (4) Somewhat (3) Extremely (5) 5.a. The NUMBER of cutaneous \bigcirc \bigcirc \bigcirc \bigcirc neurofibromas bother me 5.b. The SIZE of cutaneous \bigcirc \bigcirc \bigcirc \bigcirc \bigcirc neurofibromas bother me \bigcirc \bigcirc \bigcirc \bigcirc 5.c. The COLOR of cutaneous neurofibromas bother me 5.d. The APPEARANCE of \bigcirc \bigcirc \bigcirc \bigcirc \bigcirc cutaneous neurofibromas bother me 5.e. The FIRMNESS of the \bigcirc \bigcirc \bigcirc \bigcirc \bigcirc cutaneous neurofibromas bothers me 5.f. The ITCH associated with \bigcirc \bigcirc \bigcirc \bigcirc cutaneous neurofibromas bother me 5.g. The PAIN associated with \bigcirc \bigcirc \bigcirc \bigcirc \bigcirc cutaneous neurofibromas bother \bigcirc \bigcirc \bigcirc \bigcirc \bigcirc 5.h. The LOCATION of the cutaneous neurofibromas bother me

 \bigcirc

 \bigcirc

 \bigcirc

5.i.1. Other: please state		

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 \bigcirc

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5.i. An OTHER feature of

me (please state):

cutaneous neurofibromas bother

6. How much does each FEATURE of your flat cutaneous neurofibromas bother you?					
(physically, cosmetically, o	r emotionally)				
	Not at all N/A (1)	Not so much (2)	Somewhat (3)	Very much (4)	Extremely (5)
6.a. The NUMBER of cutaneous neurofibromas bother me	0	0	0	0	0
6.b. The SIZE of cutaneous neurofibromas bother me	0	0	0	\circ	0
6.c. The COLOR of cutaneous neurofibromas bother me	0	0	0	0	0
6.d. The APPEARANCE of cutaneous neurofibromas bother me	0	0	0	0	0
6.e. The FIRMNESS of the cutaneous neurofibromas bothers me	0	0	0	0	0
6.f. The ITCH associated with cutaneous neurofibromas bother me	0	0	0	0	0
6.g. The PAIN associated with cutaneous neurofibromas bother me	0	0	0	0	0
6.h. The LOCATION of the cutaneous neurofibromas bother me	0	0	0	0	0
6.i. An OTHER feature of cutaneous neurofibromas bother me (please state):	0	0	0	0	0
6.i.1. Other: please state					

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7. What FEATURE of your cutaneous neurofibromas bothers you the MOST? (select top three)	□ Number □ Size □ Color □ Appearance □ Firmness □ Itch □ Pain □ Location □ Other
7.1. Other: please state	Uther Other

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Please rank the three features selected in Question #7. that bother you the MOST, where 1 is				
the most bothersome				
	1	2	3	
Number	\circ	\bigcirc	\circ	
Size	\circ	\circ	0	
Color	\circ	\bigcirc	0	
Appearance	\circ	\circ	\circ	
Firmness	\circ	\circ	0	
Itch	\circ	\bigcirc	\bigcirc	
Pain	\circ	\bigcirc	\circ	
Location	\circ	\bigcirc	\bigcirc	
Other: [fibro_bothr_most_state]	0	0	0	
8. For the features you selected in quabove, what is it about those feature you?				

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9. How much do your cutaneous neurofibromas bother you on each AREA of your body? (physically, cosmetically, or emotionally)						
9.a. The cutaneous neurofibromas on my SCALP bother me		Not so much (2)	Somewhat (3)	Very much (4)	Extremely (5)	
9.b. The cutaneous neurofibromas on my FACE bother me	0	0	0	0	0	
9.c. The cutaneous neurofibromas on my NECK bother me	0	0	0	0	0	
9.d. The cutaneous neurofibromas on my TRUNK bother me	0	0	0	0	0	
9.e. The cutaneous neurofibromas on my ARMS bother me	0	0	0	0	0	
9.f. The cutaneous neurofibromas on my HANDS bother me	0	0	0	0	0	
9.g. The cutaneous neurofibromas on my LEGS bother me	0	0	0	0	0	
9.h. The cutaneous neurofibromas on my FEET bother me	0	0	0	0	0	
9.i. The cutaneous neurofibromas on my GENITALS bother me	0	0	0	0	0	
9.j. The cutaneous neurofibromas on my NIPPLES/AREOLAS bother me	0	0	0	0	0	
9.k. The cutaneous neurofibromas on an OTHER body site bother me	0	0	0	0	0	

9.k.1. Other: please state

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10. Which AREA of your body do your cutaneous neurofibromas bother you the MOST? (select the top three)	☐ Scalp ☐ Face ☐ Neck ☐ Trunk (chest, belly, back) ☐ Arms ☐ Hands ☐ Legs ☐ Feet ☐ Genitals ☐ Nipple/Areola ☐ Other
10.1. Other: Please state	

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neurofibromas bother you the MOST, where 1 is the most bothersome 1 2 3 Scalp Comparison Compariso	Please rank the three AREA selected in Question #10. of your body where cutaneous						
Face O O O O O O O O O O O O O O O O O O O	neurofibromas bother you the MOST, where 1 is the most bothersome						
Face O O O O O O O O O O O O O O O O O O O		1	2	3			
Neck Trunk (chest, belly, back) Arms O Hands Legs O Feet O Genitals O O O O O O O O O O O O O O O O O O O	Scalp	\circ	0	\circ			
Trunk (chest, belly, back) Arms O Hands C Legs O Genitals O Nipple/Areola	Face	\bigcirc	\circ	\circ			
Arms O O O O O O O O O O O O O O O O O O O	Neck	\circ	\bigcirc	\circ			
Hands O O O O Legs O O O Feet O O O O Genitals O O O O Nipple/Areola	Trunk (chest, belly, back)	\circ	\bigcirc	\circ			
LegsOOOFeetOOOGenitalsOOONipple/AreolaOOO	Arms	\bigcirc	\bigcirc	\circ			
Feet O O O O O O O O O O O O O O O O O O	Hands	\bigcirc	\bigcirc	\circ			
Genitals O O O Nipple/Areola O O	Legs	\bigcirc	\bigcirc	\circ			
Nipple/Areola O O	Feet	\bigcirc	\bigcirc	\circ			
	Genitals	\bigcirc	\bigcirc	\circ			
Other: [fibro_area_bothr_othr]	Nipple/Areola	\bigcirc	\bigcirc	\circ			
	Other: [fibro_area_bothr_othr]	\circ	0	\circ			

Raised cutaneous neurofibromas change in number

a. 0% decrease/No change in number





c. 66% decrease in number





b. 33% decrease in number





d. 100% decrease in number





11. When thinking about the raised cutaneous neurofibromas that bother you the most, what is the minimum decrease in cutaneous neurofibroma NUMBER that would be acceptable to you if a new treatment was available? (Please refer to image above for a visual example of % change in number)

- 0% decrease/No change in number
- 33% decrease in number66% decrease in number
- 100% decrease in number

Raised cutaneous neurofibromas change in size

a. 0% decrease/No change in size





c. 66% decrease in size





b. 33% decrease in size





d. 100% decrease in size







12. When thinking about the raised cutaneous
neurofibromas that bother you the most, what is the
minimum decrease in cutaneous neurofibroma SIZE that
would be acceptable to you after participating in a
treatment trial? (Please refer to image above for a
visual example of % change in size)

0% decrease/No change in size
33% decrease in size
66% decrease in size
100% decrease in size

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13. Surgical removal is a treatment option that is currently used to remove individual raised					
cutaneous neurofibromas by cutting them out.					
13.a. Have you heard of this treatment before?		t know			
13.b. Have you tried this treatment before?	○ Yes ○ No				
13.c. Would you be willing to try this treatment if you have never had it before or again if you have tried it before?		е			



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14. Laser removal is a light based treatment option that is currently used to remove many					
raised cutaneous neurofibromas at a time.					
14.a. Have you heard of this treatment before?					
14.b. Have you tried this treatment before?	○ Yes ○ No				
14.c. Would you be willing to try this treatment if you have never had it before or again if you have tried it before?					



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15. Heat-based removal (called radiofrequency ablation) is a treatment option that is currently					
used to remove many raised cutaneous neurofibre	omas at a time.				
15.a. Have you heard of this treatment before?	○ Yes ○ No	○ I don't know			
15.b. Have you tried this treatment before?	○ Yes ○ No				
15.c. Would you be willing to try this treatment if you have never had it before or again if you have tried it before?	○ Yes ○ No	○ Maybe			



16. Removal by an electrical current (called electrodessication) is a treatment option that is					
currently used to remove many raised cutaneous neurofibromas at a time.					
16.a. Have you heard of this treatment before?	○ Yes ○ No	○ I don't know			
16.b. Have you tried this treatment before?	○ Yes ○ No				
16.c. Would you be willing to try this treatment if you have never had it before or again if you have tried it before?	○ Yes ○ No	○ Maybe			



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17. Assuming equal effectiveness and safety, what is your willingness to try these					
EXPERIMENTAL treatments	for cutaneou	s neurofibroma	as?		
	Not at all (1)	Not so much (2)	Somewhat (3)	Very much (4)	Extremely (5)
17.a. Taking a medication by mouth (pill/liquid) at home at least once a day	0	0	0	0	0
17.b. Receiving infusions by vein once a week at a doctor's office	0	0	0	0	0
17.c. Applying a cream or ointment to skin at least once a day at home	0	0	0	0	0
17.d. Drug injection into individual cutaneous neurofibromas ~2 times at a doctor's office	0	0	0	0	0
17.e. Light therapy (similar to an intense sunburn) of a subset of cutaneous neurofibromas every 6 months at a doctor's office	0	0	0	0	0



18. As briefly described in question #17. above, which EXPERIMENTAL cutaneous neurofibroma treatment would you most prefer?	 Medication by mouth Infusions by vein Topical skin cream/ ointment Drug injection into individual cutaneous neurofibromas Light therapy
19. How long would you be willing to be treated for cutaneous neurofibromas? (select all that apply)	 □ One day treatment only □ Once a week □ Once a month □ Once a year □ Once every couple years □ Every day for a week □ Every day for a month □ Every day for a year □ Every day for a couple years □ Every day for the rest of your life

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20. What side effects are you willing to risk for treatment of your cutaneous neurofibromas							
even if they may grow back later?							
	Not at all N/A (1)	Not so much (2)	Somewhat (3)	Very much (4)	Extremely (5)		
20.a. Scarring	\circ	\circ	\circ	\circ	\circ		
20.b. Nausea/vomiting	\circ	\bigcirc	\bigcirc	\bigcirc	\bigcirc		
20.c. Tiredness	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc		
20.d. Rash	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc		
20.e. Itching	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc		
20.f. Skin color change (lighter or darker)	0	0	0	0	0		
20.g. Pain	\circ	\circ	\circ	\circ	\circ		
20.h. Time off work	\bigcirc	\bigcirc	\circ	\circ	\bigcirc		



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21. How do you agree with	the following	statements?			
	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
21.a. I would prefer a scar instead of a cutaneous neurofibroma	0	0	0	0	0
21.b. I would prefer skin color changes (lighter or darker) instead of a cutaneous neurofibroma	0	0	0	0	0
21.c. If my raised cutaneous neurofibromas looked more flat I would be okay with my cutaneous neurofibromas	0	0	0	0	0
21.d. If the itching went away I would be okay with the way my cutaneous neurofibromas currently are	0	0	0	0	0
21.e. If the pain went away I would be okay with the way my cutaneous neurofibromas currently are	0	0	0	0	0

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22. If you were participating in a clinical trial for cutaneous neurofibromas, how would you be									
willing to provide answers to questionnaires that are part of the study?									
	Not at all (1)	Not so much (2)	Somewhat (3)	Very much (4)	Extremely (5)				
22.a. Completing questionnaires on paper and pencil in your doctor's office or clinic	0	0	0	0	0				
22.b. Completing questionnaires on an iPad from your doctor's office or clinic	0	0	0	0	0				
22.c. Completing questionnaires on your home computer using a link in an email	0	0	0	0	0				
22.d. Completing questionnaires on your home computer or mobile device using an application (app)	0	0	0	0	0				



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23. How much do your cutaneous neurofibromas affect the following?									
	Not at all (1)	Not so much (2)	Somewhat (3)	Very much (4)	Extremely (5)				
23.a. General quality of life	\bigcirc	\circ	\circ	\circ	\circ				
23.b. Physical (pain)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc				
23.c. Physical (itching)	\bigcirc	\bigcirc	\bigcirc	\bigcirc	\bigcirc				
23.d. Appearance	\circ	\bigcirc	\bigcirc	\bigcirc	\bigcirc				
23.e. Emotions	\circ	\bigcirc	\bigcirc	\bigcirc	\bigcirc				
23.f. Day-to-day functioning	\circ	\bigcirc	\bigcirc	\bigcirc	\circ				

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24. How do cutaneous neurofibromas affect you? (optional)	
25. What would prevent you from participating in a clinical trial that this survey did not previously address? (optional)	
26. If you would like to explain a previous answer in more detail or feel like there is something the survey hasn't addressed, feel free to comment here: (optional)	

