Continuous Headache - Parent Questionn Migraine		lesize font:
Please complete the survey below.		
Thank you!		
We are asking you to take part in a research study	○ Yes	
being done by Dr. Amy Gelfand and her study team at the Pediatric Brain Center at the University of California, San Francisco. Being in this study is optional.	○ No	reset
In this study, the researchers are conducting a survey to help us learn more about "treatment outcome		
measures" used in headache research. "Outcome		
measures" are used by researchers to determine whether a headache treatment works. We are		
interested in learning which "outcome measures" are most important to teens like your child who have		
continuous daily headaches.		
If you choose to participate, you will complete a		
survey. The survey will ask you questions about your child's headaches as well as which aspects of your		
child's headache are most important to focus on		
improving with treatment and which "outcome measures" are most useful. Your contribution will		
help doctors and scientists understand the best way		
to measure the impact of headache treatment on continuous headaches. This will help to improve the		
design of future studies for headache treatment.		
We will do our best to protect the information we collect from you. The survey itself will not include		
details that directly identify you, such as your name		
or address; please do not put this information on your survey. The completed surveys will be kept secure and		
separate from information that identifies you. Only a		
small number of researchers will have direct access to completed surveys. If this study is published or		
presented at scientific meetings, names and other		
information that might identify you will not be used. The survey will take about 10-15 min to complete. You		
can skip questions that you do not want to answer or		
stop the survey at any time. You will not be paid for completing the survey.		
Questions? Please contact Dr. Gelfand at 415-860- 2202. If you have questions or concerns about your		
rights as a research participant, you can call the UCSF Institutional Review Board at 415-476-1814.		
If you want to participate in this study, click "Yes" to begin.		
* must provide value		
Please answer the following questions to help us understand mor headaces.	re about you, your child and your child	l's
How old are you? (years)		

How old is your child? (years)		
What is your relationship to your child?	○ Mother	
	Father	
	O Tutile.	reset
What sex was your child assigned at birth?	○ Male	
	○ Female	
	Other	
		reset
What gender does your child identify as?	○ Female	
	○ Male	
	Other	
		reset
What race do you identify as? (Check all that apply)	American Indian/Alaska Native	
	Asian	
	Native Hawaiian or Other Pacific Islan	nder
	Black or African American	
	☐ White	
	☐ More than one race	
	Unknown/Decline to state	
What race does your child identify as? (Check all that apply)	American Indian/Alaska Native	
~PP. J.	Asian	
	Native Hawaiian or Other Pacific Islan	nder
	Black or African American	
	☐ White	
	☐ More than one race	
	Unknown/Decline to state	
What ethnicity do you identify as?	Hispanic or Latino	
	Non-Hispanic or Latino	
	Unknown/Decline to state	
		reset
What ethnicity does your child identify as?	Hispanic or Latino	
	Non-Hispanic or Latino	
	Unknown/Decline to state	
		reset
For how many MONTHS has your child had a headache every day WITHOUT BREAKS? (Please answer in MONTHS)		

A "baseline headache" is the headache your child has all of the time. What is the AVERAGE intensity of your child's baseline headache on a scale of 0 (no pain) to 10 (most pain possible)? A "baseline headache" is the headache your child has all of the time. What is the HIGHEST intensity of your child's baseline		
headache on a scale of 0 (no pain) to 10 (most pain possible)?		
A "baseline headache" is the headache your child has all of the time. What is the LOWEST intensity of your child's baseline headache on a scale of 0 (no pain) to 10 (most pain possible)?		
Many people who have continuous headache experience days or times when they have more severe headache or "spikes". In addition to your child's background headache, does your child experience more severe headaches or "spikes"?	 NO, My child's headache intensity is always the same YES, There are times when my child's headache intensity is higher 	reset
Approximately how many times has your child had "spikes" in headache or severe headache OVER THE LAST MONTH?	 Fewer than 1 per month 1 per month 2-3 per month 1 per week 2-3 per week 4-6 per week Daily More than 1 per day 	reset
On average, do your child's "spikes" in headache or severe headaches last at least one hour?	○ Yes ○ No	reset
How many DAYS in the past MONTH has your child had a headache that he/she would rate as SEVERE?		
Acute medication use means taking a medication to treat a more intense headache. How many DAYS per WEEK, on average, does your child take ACUTE medication for headache OVER THE PAST MONTH? Please include the days your child takes over-the-counter AND/OR prescription medications for headache.		

A preventive medication is a medication that your child takes every day to decrease frequency of headaches.		
How many preventive medications has your child tried for at least 6 weeks?		
Please enter a number in the box. Enter 0 if your child has not tried any.		
A preventive medication is a medication that your child takes every day to decrease frequency of headaches.		
How many preventive medications has your child had to stop taking after less than 6 weeks due to side effects?		
Please enter a number in the box. Enter 0 if your child has not tried any.		
Has your child ever had a nerve block for treatment of headaches?	○ Yes ○ No	reset
Has your child ever had Botox for treatment of headaches?	○ Yes ○ No	reset
Has your child ever been admitted to the hospital for treatment of headaches?	○ Yes ○ No	reset
What percent of the headache preventive treatments that your child has tried have been at least somewhat helpful?		
Please enter a number between 0 and 100.		
How many full days of school has your child missed in the past MONTH due to headache?		
A partial day of school means that your child went to some, but not all of the school day.		
How many partial days of school has your child missed in the past MONTH due to headache?		
How many days in the past MONTH was your child not able to participate in other activities (play, go out, sports, etc.) due to headache?		
Do you have a history of headaches yourself?	○ Yes	
	○ No	reset

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In research studies, a "treatment outcome" is a way of measuring whether or not a treatment works. For example, in a study of whether "treatment" with water helps plants grow, the "treatment outcome" might be the number of inches the plant grew from the beginning of the study to the end of the study OR how many new leaves the plant grew.

The goal of this study is to determine the best headache treatment outcomes for teens like your child who have headache every day.

Please answer the following questions to help us understand which aspects of your child's headaches are most important to YOU to help measure improvement from treatment.

Headache "FREQUENCY" means how often your child gets headaches.

Which of these would be the BETTER way to measure how headache treatment affects your child's headache FREQUENCY?

Please rank your TOP choice.

 Decrease in frequency of background headache (in other words, decrease in total number of days of headache per month)

O Decrease in frequency of severe headaches or headache spikes

reset

Headache "SEVERITY" means how bad or how intense your child's headaches get.

Which of these would be the BETTER way to measure how headache treatment affects your child's headache SEVERITY?

Please rank your TOP choice.

O Decrease in severity of background headache

O Decrease in severity of headache during severe headache days or "spikes"

reset

These are some of the ways that researchers measure your child's level of "functioning", or ability to participate in day-to-day activities.

Which of these would be the BEST way to measure how headache treatment affects your child's FUNCTIONING?

Please rank your TOP THREE choices.

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0	0	re
	0	

For some people, the symptoms that go along w than the headache pain itself.	rith headache are	just as bothersome or ev	en more bothersom	ne
Which of these would be the BEST way to measu child experiences during headaches?	ıre how headache	treatment affects the ot	her symptoms your	٢
Please rank your TOP THREE choices.				
(One selection allowed per column)	1st choice	2nd choice	3rd choice	
Decrease in nausea and/or vomiting	0	0	0	
			re	eset
Decrease in light sensitivity	O	O	C	eset
Decrease in noise sensitivity	0	0	0	eset
Decrease in dizziness/vertigo (the room or self spinning/moving) and/or light-headedness (feeling faint)	0	0	0	eset
Decrease in difficulty with concentration and/or "brain fog"	0	0	0	
Decrease in difficulty with sleep	0	0	\circ	eset
Decrease in change in vision such as blurry vision	0	0	0	eset
Acute medication use means how ofte to take a medication to treat a more in headache.	-	O Decrease in how ofte take acute medication	en your child needs to	
Which of these is the BETTER way to meadache treatment improves the way uses acute medications?		 Improvement in how acute medications w needs to use them 	-	set
When headaches are more troubleson sometimes need extra help from their medical team.		O Decrease in how ofte go to the emergency because your heada	room for help	0
Which of these is the BETTER way to m treatment affects how often your child from the medical team?		Decrease in how often need to call the clinic line for help because headache is so sever	c, nurses or advice your child's	set
Overall, which category of headache impact is the	he BEST way to m	easure how treatment af	fects your headach	e?
Please rank your TOP THREE choices.				
(One selection allowed per column)	1st choice	2nd choice	3rd choice	
Number of headache days (frequency)	O	O	()	ocot
How bad headaches get (severity)	0	0	\circ	eset
The impact of headache on your child's life and ability to do things he/she enjoys (functional impact)	0	0	0	eset
Other symptoms that happen with headaches, like light or noise sensitivity, nausea, difficulty with concentration (associated symptoms)	0	0	0	
			re	eset

ant category o	of			re
dache would b	e the BEST wa	y to measure l	now treatmen	t affects
1st choice	2nd choice	3rd choice	4th choice	5th choi
0	0	0	0	0
0	0	0	0	r
0	0	0	0	r
0	0	0	0	r
0	0	0	0	r
et 🔾	0	0	0	r
et 🔾	0	0	0	r
et 🔾	0	0	0	r
0	0	0	0	r
0	0	0	0	0
0	0	0	0	
0	0	0	0	r
O t-	0	0	0	r
0	0	0	0	r
0	0	0	0	r
0	0	0	0	r
	alache would b	1st choice 2nd choice	dache would be the BEST way to measure I	Asche would be the BEST way to measure how treatment 1st choice 2nd choice 3rd choice 4th choice

Decrease in how often your child needs to take acute medication	0	0	0	0	rese
Improvement in how well your child's acute medications work when he/she needs to use them	0	0	0	0	0
Decrease in how often your child need to go to the emergency room for help because your child's headache is so severe	0	0	0	0	rese
Decrease in how often you or your child need to call your doctor or nursing advise line for help	0	0	0	0	rese
Is it more helpful to think about the in headache days over a one week, two month, or three month p	week, one	0 1	One week Two weeks One month Two months Three months Six months		reset
What is the MINIMUM decrease in yo background headache intensity that make a difference to your child? (Nur a 0-10 scale; for example, decreasing would be a 3 point decrease)	you feel wo	nts on	~		
What is the MINIMUM decrease in yo or severe headache intensity that yo make a difference to your child? (Nur a 0-10 scale; for example, decreasing would be a 3 point decrease)	u feel would mber of poir	l nts on	•		
If a preventive treatment makes you headaches better, what level of side of feel your child would be willing to tol	effects do yo	ou		V	
We know that many preventive treat to work. How long would you be willing child to participate in a research stud preventive treatment for before seeing	ng to allow y dy for a new	your			
In other words, if a preventive treatm cause side effects, how long would yo wait to see if it works for your child? Please answer in MONTHS.					
	Submi	it			

Continuous Headache - Teen Questionnaire - Chronic Migraine	Resize font:
Please complete the survey below.	
Thank you!	
We are asking you to take part in a research study being done by Dr. Amy Gelfand and her study team at the Pediatric Brain Center at the University of California, San Francisco. Being in this study is optional.	reset
In this study, the researchers are conducting a survey to help us learn more about "treatment outcome measures" used in headache research. "Outcome measures" are used by researchers to determine whether a headache treatment works. We are interested in learning which "outcome measures" are most important to teens like you who have continuous daily headaches.	
If you choose to participate, you will complete a survey. The survey will ask you questions about your headaches as well as which aspects of your headache are most important to focus on improving with treatment and which "outcome measures" are most useful. Your contribution will help doctors and scientists understand the best way to measure the impact of headache treatment on continuous headaches. This will help to improve the design of future studies for headache treatment. We will do our best to protect the information we collect from you. The survey itself will not include details that directly identify you, such as your name or address; please do not put this information on your survey. The completed surveys will be kept secure and separate from information that identifies you. Only a small number of researchers will have direct access to completed surveys. If this study is published or presented at scientific meetings, names and other information that might identify you will not be used. The survey will take about 10-15 min to complete. You can skip questions that you do not want to answer or stop the survey at any time. You will not be paid for completing the survey. Questions? Please contact Dr. Gelfand at 415-860-2202. If you have questions or concerns about your	
rights as a research participant, you can call the UCSF Institutional Review Board at 415-476-1814. If you want to participate in this study, click "Yes" to begin.	
* must provide value	
Please answer the following questions to help us understand more about you and your headaches.	
How old are you? (years)	

What sex were you assigned at birth?	FemaleMaleOther
What gender do you identify as?	FemaleMaleOtherreset
What race do you identify as? (Check all that apply)	American Indian/Alaska Native Asian Native Hawaiian or Other Pacific Islander Black or African American White More than one race Unknown/Decline to state
What ethnicity do you identify as?	Hispanic or LatinoNon-Hispanic or LatinoUnknown/Decline to state
For how many MONTHS have you had a headache every day WITHOUT BREAKS? (Please answer in MONTHS)	
A "baseline headache" is the headache you have all of the time. What is the AVERAGE intensity of your baseline headache on a scale of 0 (no pain) to 10 (most pain possible)?	
A "baseline headache" is the headache you have all of the time. What is the HIGHEST intensity of your baseline headache on a scale of 0 (no pain) to 10 (most pain possible)?	
A "baseline headache" is the headache you have all of the time. What is the LOWEST intensity of your baseline headache on a scale of 0 (no pain) to 10 (most pain possible)?	
Many people who have continuous headache experience days or times when they have more severe headache or "spikes". In addition to your background headache, do you experience more severe times or "spikes"?	 NO, My headache intensity is always the same YES, There are times when my headache intensity is higher

Approximately how many times have you had "spikes" in headache or severe headache OVER THE LAST MONTH?	Fewer than 1 per month 1 per month 2-3 per month 1 per week 2-3 per week 4-6 per week Daily More than 1 per day	reset
On average, do your "spikes" in headache or severe headaches last at least one hour?	○ Yes ○ No	reset
How many DAYS in the past MONTH have you had a headache that you would rate as SEVERE?		
Acute medication use means taking a medication to treat a more intense headache.		
How many DAYS per WEEK, on average, do you take ACUTE medication for your headache OVER THE PAST MONTH? Please include the days you take over-the-counter		
AND/OR prescription medications for headache. A preventive medication is a medication that you take		
every day to decrease frequency of headaches. How many preventive medications have you tried for at least 6 weeks?		
Please enter a number in the box. Enter 0 if you have not tried any.		
A preventive medication is a medication that you take every day to decrease frequency of headaches.		
How many preventive medications have you had to stop taking after less than 6 weeks due to side effects?		
Please enter a number in the box. Enter 0 if you have not tried any.		
Have you ever had a nerve block for treatment of headaches?	○ Yes ○ No	reset
Have you ever had Botox for treatment of headaches?	○ Yes ○ No	reset
Have you ever been admitted to the hospital for treatment of headaches?	○ Yes ○ No	reset

What percent of the headache prevent that you have tried have been at least helpful?			
Please enter a number between 0 and	100.		
How many full days of school have you past MONTH due to headache?	ı missed in the		
A partial day of school means that you but not all of the school day.	went to some,		
How many partial days of school have the past MONTH due to headache?	you missed in		
How many days in the past MONTH we to participate in other activities (play, etc.) due to headache?	-		
PLEASE READ: Information About Treatment Out	comes		
In research studies, a "treatment outcome" is a vexample, in a study of whether "treatment" with the number of inches the plant grew from the belieaves the plant grew.	n water helps pla	nts grow, the "treatment o	outcome" might be
The goal of this study is to determine the best he headache every day.	eadache treatme	ent outcomes for teens like	you who have
Please answer the following questions to help us are most important to YOU to help measure imp			hes
Headache "FREQUENCY" means how of	ften you get	O Decrease in frequenc	v of background
headaches.		headache (in other w total number of days	ords, decrease in
Which of these would be the BETTER w how headache treatment affects your		month)	or ricadactic per
FREQUENCY?	ricadaciic	 Decrease in frequence headaches or headaches 	•
Please rank your TOP choice.			reset
Headache "SEVERITY" means how bad your headaches get.	or how intense	Decrease in severity of headache	of background
Which of these would be the BETTER w how headache treatment affects your SEVERITY?	-	O Decrease in severity of severe headache day	-
Please rank your TOP choice.			
These are some of the ways that researchers me your day-to-day activities.	asure your level	of "functioning", or ability	to participate in
Which of these would be the BEST way to measu	re how headach	e treatment affects FUNCT	IONING?
Please rank your TOP THREE choices.			
(One selection allowed per column)	1st choice	2nd choice	3rd choice
Decrease in number of missed school days due to headache	0	0	0
adys due to fieddactie			reset

Decrease in how much headaches get in the way of your relationships with friends or family	0	0	reset
Decrease in how much headaches get in the way of falling asleep and/or staying asleep	0	0	0
Decrease in how much headaches get in the way of physical activities (activities that require moving around)	0	0	reset
Decrease in how much headaches get in the way of mental activities (activities that require thinking, concentrating)	0	0	reset
Decrease in how much headaches effect your emotions (mood, stress)	0	0	reset
For some people, the symptoms that go along withan the headache pain itself. Which of these would be the BEST way to measurexperience during headaches? Please rank your TOP THREE choices.			
(One selection allowed per column)	1st choice	2nd choice	3rd choice
Decrease in nausea and/or vomiting	0	0	0
Decrease in light sensitivity	0	0	reset
Decrease in noise sensitivity	0	0	reset
Decrease in dizziness/vertigo (the room or yourself spinning/moving) and/or light-headedness (feeling faint)	0	0	0
Decrease in difficulty with concentration and/or "brain fog"	0	0	reset
Decrease in difficulty with sleep	0	0	0
Decrease in change in vision such as blurry vision	0	0	reset
Acute medication use means how often take a medication to treat a more interwhich of these is the BETTER way to medications?	nse headache. easure whether	 Decrease in how ofter your acute medication Improvement in how with medications work who them 	n well your acute
When headaches are more troublesom sometimes need extra help from their medical team.	•	O Decrease in how ofter the emergency room your headache is so s	for help because
Which of these is the BETTER way to m treatment affects how often you need medical team?		O Decrease in how ofter clinic, nurses or advice because your headach	e line for help

ank your TOP THREE choices.					
(One selection allowed per column)	1st choi	ce	2nd choice	3r	d choice
Number of headache days (frequency)	0		0		0
(irequency)					re
How bad headaches get (severity)	0		\circ		re
The impact of headache on your life and ability to do things you enjoy (functional impact)	0		0		0
Other symptoms that happen with headaches, like light or noise sensitivity, nausea, difficulty with concentration (associated symptoms)	0		0		re
Other	0		0		O
If there is an "Other" most importa headache improvement, what is it?		f			r
, which of these aspects of your heada adache? rank your TOP FIVE choices.	che would be	e the BEST wa	y to measure ł	now treatmen	t affects
(One selection allowed per column)	1st choice	2nd choice	3rd choice	4th choice	5th choi
(one selection unorrea per column)	13t Choice	ZIIU CIIOICE	Ji a choice	4th thoite	Juli Cilon
Decrease in frequency of baseline headache	0	0	0	0	0
	0	0	0	0	
headache Decrease in frequency of severe	0	0	0	0	0 r
Decrease in frequency of severe headaches or headache "spikes" Decrease in severity of baseline			0	0	r
headache Decrease in frequency of severe headaches or headache "spikes" Decrease in severity of baseline headache Decrease in severity of severe			0 0	0 0	
headache Decrease in frequency of severe headaches or headache "spikes" Decrease in severity of baseline headache Decrease in severity of severe headache (or headache "spike") Decrease in how much school you		0	0 0 0	0 0	o r
headache Decrease in frequency of severe headaches or headache "spikes" Decrease in severity of baseline headache Decrease in severity of severe headache (or headache "spike") Decrease in how much school you miss (due to headache) Decrease in how much headaches get in the way of your relationships with	0	0			o r
headache Decrease in frequency of severe headaches or headache "spikes" Decrease in severity of baseline headache Decrease in severity of severe headache (or headache "spike") Decrease in how much school you miss (due to headache) Decrease in how much headaches get in the way of your relationships with friends or family Decrease in how much headaches get in the way of physical activities (activities that require moving	0	0 0			0
Decrease in frequency of severe headaches or headache "spikes" Decrease in severity of baseline headache Decrease in severity of severe headache (or headache "spike") Decrease in how much school you miss (due to headache) Decrease in how much headaches get in the way of your relationships with friends or family Decrease in how much headaches get in the way of physical activities (activities that require moving around) Decrease in how much headaches get in the way of mental activities (activities that require thinking,	0 0 0	0 0	0		

Decrease in light sensitivity	\cap	\cap	\sim		
· ·	O	0	O	O	0
Decrease in noise sensitivity	0	0	0	0	0
Decrease in dizziness/vertigo (the room or yourself spinning/moving) and/or light-headedness (feeling faint)	0	0	0	0	0
Decrease in difficulty with concentration and/or "brain fog"	0	0	0	0	0
Decrease in difficulty with sleep	0	0	0	0	0
Decrease in change in vision such as blurry vision	0	0	0	0	0
Decrease in how often you need to take your acute medication	0	0	0	0	0
mprovement in how well your acute medications work when you need to use them	0	0	0	0	0
Decrease in how often you need to go to the emergency room for help because your headache is so severe	0	0	0	0	0
Decrease in how often you need to call your doctor or nursing advise line for help	0	0	0	0	0
e it mara halaful ta think shaut the m	umbor of	woro o			
is it more helpful to think about the nu headache days over a one week, two w month, two month, or three month pe	veek, one	О Т О С О Т	one week wo weeks one month wo months hree months ix months		r
neadache days over a one week, two w	veek, one riod? r backgrour n difference r; for examp	○ T ○ C ○ T ○ S	wo weeks one month wo months hree months		ı
neadache days over a one week, two wenth, two month, or three month pe What is the MINIMUM decrease in you neadache intensity that would make a you? (Number of points on a 0-10 scale decreasing from a 10 to a 7 would be a	r backgrour difference for examp point r spike or make a on a 0-10 sca	TO CO TO Some Source of the control	wo weeks one month wo months hree months ix months		

to work. How long would yo in a research study for a ne	w preventive treatment	
for before seeing improven	ent?	
In other words, if a prevent	ive treatment did not	
cause side effects, how long	g would you be willing to	
wait to see if it works?		
Please answer in MONTHS		
Please answer in MONTHS.		
Please answer in MONTHS.		