PROTOCOL ID: VISIT ID:	date of t			S	
Questionnaire for Children and	d Teenage	rs	Kids' long \	Version	age: 13-16
Hello there! We would like to find out how you have been feeling during the past weeks, so we have worked out a few questions that we would like you to answer. This questionnaire was designed for teenagers with hemophilia. ⇒ Please read each question carefully. ⇒ Think about how things have been for you over the past weeks.					
\Rightarrow Choose the answer that	fits you b	est and pu	ut an "X" i	n the appr	ropriate box.
There are no right or wrong an	swers. It	's what <u>y</u> a	<u>ou</u> think t	hat matte	ers.
For example:	never	rarely	some- times	often	all the time
During the past 7 days, I felt like eating ice cream				X	

TMF Document Identifier and Annotation Missing study number and document date for paper questionnaires Program Code: B784 Study Number: B7841005 Site Identifier: N/A. These are blank diaries for all sites/subjects to complete Document Date: 04-Jun -2019

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We would like to find out about your physical health ...

	During the past 7 days	never	rarely	some- times	often	all the time
1.	I felt ill					
2.	I was in pain					
3.	I was tired and worn-out					
4.	I felt strong and full of energy					
5.	I was afraid that my illness might get worse					

... then about how you've been feeling in general...

	During the past 7 days	never	rarely	some- times	often	all the time
1.	I had fun and laughed a lot					
2.	I was bored					
3.	I felt alone					
4.	I felt scared or unsure of myself					
5.	I was sad because of my illness					

... and how you have been feeling about yourself.

	During the past 7 days	never	rarely	some- times	often	all the time
1.	I took pride in myself					
2.	I felt on top of the world					
3.	I felt content with myself					
4.	I had lots of good ideas					
5.	I was able to cope well with my illness					

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The next questions are about your family...

	During the past 7 days	never	rarely	some- times	often	all the time
1.	I got along well with my parents					
2.	I felt fine at home					
3.	we argued at home					
4.	I felt restricted by my parents					
5.	my parents treated me like a baby because of my illness					

... and then about your friends.

	During the past 7 days	never	rarely	some- times	often	all the time
1.	I did things together with my friends					
2.	I was popular with my friends					
3.	I got along well with my friends					
4.	I felt different from other people					
5.	I did not want others to notice my illness					

Now, we would like to find out about school.

	During the past 7 days	never	rarely	some- times	often	all the time
1.	doing my schoolwork was easy					
2.	I found school interesting					
3.	I worried about my future					
4.	I worried about getting bad marks or grades					
5.	I missed something at school because of my illness					

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	NOW WE WC	OULD LIKE TO A	SK YOU SEVERAL HEMOPHILIA	QUESTIONS	ABOUT YOUR
	Here we wo	ould like to find	out about your B	LEEDS (JOIN	T BLEEDS)
1.	How frequent w	vere your bleeds in	the past month?		
	□ no bleeds	□ 1	□ 2	□ more than 2	
	The follo	owing questions sl	nould only be answ	vered if you had	bleeds.
2.	How much were	e you troubled by b	leeds during the pa	st month?	
	□ not at all	□ a little	□ moderately	□ a lot	
3.		5	ing the past month? answer for the mos		
	□ slight	moderate	□ severe	□ very severe	
4.	Did you feel a s	strange sensation i	n your joints before	you had a bleed?	
	□ never	□ rarely	□ sometimes	□ often	□ always
5.	Did you have to	o stay quiet (e.g., li	e in bed) when you	had bleeds?	
	□ never	□ rarely	□ sometimes	□ often	□ always
6.	When you had	bleeds, did you inf	orm your parents im	mediately?	
	□ never	□ rarely	sometimes	□ often	□ always

We would like to find out who gave you your INJECTIONS

	In the past month	never	rarely	some- times	often	all the time
1.	I injected myself					
2.	my mother injected me					
3.	my father injected me					
4.	a nurse injected me					
5.	a doctor injected me					

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Here we would like to find out about hemophilia and your **PHYSICAL HEALTH**

	In the past month	never	rarely	some- times	often	all the time
1.	my swellings hurt					
2.	I had pain in my joints					
3.	it was painful for me to move					
4.	my joints felt stiff					
5.	it was difficult for me to move my arms or legs					
6.	I had difficulty walking as far as I wanted to					
7.	I was afraid of hurting myself					

and now about how you have been FEELING because of your hemophilia

	In the past month	never	rarely	some- times	often	all the time
1.	I was in a bad mood because of my hemophilia					
2.	I was sad because of my hemophilia					
3.	my hemophilia was a burden (real problem) for me					
4.	my hemophilia made me angry					
5.	I was worried because of my hemophilia					
6.	I felt lonely because of my hemophilia					
7.	I was afraid of bleeds					
8.	I felt excluded by my friends					
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	How does hemophilia affect your VIEW OF YOURSELF?						
	In the past month	never	rarely	some- times	often	all the time	
1.	I envied healthy boys my age						
2.	I felt physically weaker than other boys						
3.	I felt as well as other boys my age						
4.	I felt comfortable with my body						
5.	hemophilia made my life more difficult						
6.	I was happy even with my hemophilia						
7.	I felt embarrassed about my hemophilia						
8.	I had difficulty doing things with other kids my age						
9.	I was unable to do as much with my friends because of my hemophilia						
10.	I felt healthy even with my hemophilia						

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The next questions are about hemophilia and your FAMILY
--

	In the past month	never	rarely	some- times	often	all the time
1.	I was treated differently by my family because of my hemophilia					
2.	my mother protected me too much					
3.	my father protected me too much					
4.	my parents criticized me when I hurt myself					
5.	my parents didn't allow me to do certain things because of my hemophilia					
6.	there were problems at home because of my hemophilia					
7.	I felt I was causing my family trouble because of my hemophilia					
8.	my parents had less free time or had to miss work because they had to look after me					

and then about hemophilia and your FRIENDS

	In the past month	never	rarely	some- times	often	all the time
1.	I was able to talk to my friends about my hemophilia					
2.	my best friend cared about how I was feeling					
3.	there was a best friend that I felt very close to					
4.	my friends took care of me when I felt bad					

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and then about hemophilia and the SUPPORT YOU FELT YOU WERE RECEIVING

	In the past month	never	rarely	some- times	often	all the time
1.	others showed special consideration for me because of my hemophilia					
2.	others showed understanding for my hemophilia					
3.	I was able to talk to others about problems with my hemophilia					
4.	others stood by me					

	These questions are about your hemophilia and OTHER PEOPLE					
	In the past month	never	rarely	some- times	often	all the time
1.	I felt different from others because of my hemophilia					
2.	I was bothered by others knowing about my hemophilia					
3.	others kids teased me because of my hemophilia					
4.	people behaved differently towards me because of my hemophilia					
5.	I felt left out when others did things together					
6.	others made dumb comments about my hemophilia					

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	These questions are about SPORTS AND SCHOOL						
	In the past month	never	rarely	some- times	often	all the time	
1.	I had to avoid sports that I like because of my hemophilia						
2.	I had to do indoor activities more than other kids because of my hemophilia						
3.	I had to avoid sports like football or skateboarding						
4.	I played sports just as much as any other kid						
5.	I was treated differently by teachers because of my hemophilia						
6.	I participated in gym class/PE at school even with my hemophilia						
7.	I was able to participate at school even with my hemophilia						
8.	I had to avoid special school events (e.g., field trips) because of my hemophilia						
9.	I found it difficult to pay attention at school because I was in pain						

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The next questions are about **DEALING WITH HEMOPHILIA**

	In the past month	never	rarely	some- times	often	all the time
1.	I tried to recognize early on when a bleed developed					
2.	I was careful with my body					
3.	I was able to tell whether or not I was bleeding					
4.	I felt that my hemophilia symptoms were under control					
5.	I felt well informed about hemophilia					
6.	hemophilia was a normal part of my life					
7.	I accepted having hemophilia					

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	and what about your TREATMENT?						
	In the past month	never	rarely	some- times	often	all the time	
1.	I was satisfied with the hemophilia center						
2.	the treatment I got was okay						
3.	I trusted my doctors and nurses						
4.	I disliked visiting the hemophilia center						
5.	I felt dependent on others because of my hemophilia						
6.	the injections annoyed me						
7.	I was annoyed about the amount of time spent having the injections						
8.	I felt the injections interrupted my activities						

What do you think about the FUTURE?

	Recently	never	rarely	some- times	often	all the time
1.	I have been thinking that it will be difficult for me to lead a normal life					
2.	I have been expecting that things will get better as I grow older					
3.	I have been worrying about my health					
4.	I have been sure about having a family later on					

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relationships with girls because of

my hemophilia

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What about RELATIONSHIPS ?						
	Recently	never	rarely	some- times	often	all the time
1.	I have been finding it difficult to date because of my hemophilia					
2.	I have been insecure in my					

And your OVERALL HEALTH?						
In general,	excellent	very good	good	fair	poor	
1 would you say your health is						

Great job - congratulations!

THANK YOU FOR YOUR ASSISTANCE

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