

Takeda Stride Study
IMS discussion guide

Participants

Tracy (mom)

Pierce (teen living with psoriasis)

Guidelines

- Please do not mention any brand names of drugs (you can refer to them as a class; for example “biologic”)
- Please do not mention any side effects you may have had from medication
- Please try to frame answers to include the question at hand (ie, When were you diagnosed with psoriasis? I was diagnosed with psoriasis when I was 13.)

Discussion flow

Questions	Notes to highlight from pre-interview	
	Tracy	Pierce
Introduction/Background Each participant will briefly introduce themselves		
Tell us a little about yourself and your family. What do you enjoy doing?	<ul style="list-style-type: none"> ● Licensed social worker; opened a center for young children with autism ● Has 3 boys; Pierce is the youngest at 15 years old ● The family likes to play golf together, travel 	<ul style="list-style-type: none"> ● Likes to play golf, travel, hunt, go to the gym, hang out with friends ● Has a large circle of friends
[Tracy] How would you describe Pierce?	<ul style="list-style-type: none"> ● His personality changed a lot in the last couple years as with a typical teenage boy ● He’s becoming more independent; figures out a way to make things happen ● Very social 	N/A
[Pierce] What grade are you in? What do you enjoy most about school? Least?	N/A	<ul style="list-style-type: none"> ● Currently in 10th grade ● Enjoys math and history the most ● Enjoys French the least
Family history		

<p>[Tracy]</p> <p>Do you have any family history of psoriasis or inflammatory diseases (Crohns disease, ulcerative colitis, arthritis, etc.)?</p>	To be discussed at filming	N/A
Psoriasis diagnostic journey		
<p>When did you first realize that [you/Pierce] may have a skin condition? What were the signs?</p> <p>[Tracy]</p> <p>Explain what it was like trying to find answers to help Pierce.</p>	<ul style="list-style-type: none"> Noticed thick crust on his scalp Researched on Google and thought it looked like psoriasis 	<ul style="list-style-type: none"> About 2 years ago (at 13), he first noticed white flakes in his scalp
<p>Can you describe the first doctor's appointment for psoriasis? How did the conversation go?</p> <p>When did Pierce receive a diagnosis of psoriasis?</p> <p>[Pierce]</p> <p>How did you feel after this first doctor appointment? At what point did you start to understand that you had psoriasis?</p>	<ul style="list-style-type: none"> Dermatologist first said it was dandruff – he didn't think it was psoriasis Gave Pierce different creams for dandruff but rather than getting better, it spread to other parts of his body At the next appointment, the doctor biopsied skin on his arm and finally diagnosed it as psoriasis 	<ul style="list-style-type: none"> Doctor didn't give a very good explanation [NOTE: have Pierce elaborate on how he felt at this first doctor appointment and at diagnosis]
Understanding psoriasis/educational resources		
<p>What did you know about psoriasis BEFORE diagnosis?</p> <p>What did you learn about psoriasis AT diagnosis?</p> <p>How was psoriasis explained? What kind of resources were you given?</p>	<ul style="list-style-type: none"> Weren't given any resources 	To be discussed at filming
<p>What is your understanding of psoriasis as an inflammatory condition (ie, that it's more complex than "just a skin condition")?</p>	To be discussed at filming	To be discussed at filming

What do you know now that you wish you knew at diagnosis?	<ul style="list-style-type: none"> I wish the doctor had told me about patient advocacy groups for psoriasis patients because they have wonderful resources. The National Psoriasis Foundation has been particularly helpful. 	<ul style="list-style-type: none"> That it would take such a long time to get into remission
What information/resources do you find the most helpful?	To be discussed at filming	To be discussed at filming
[Tracy] Can you expand on the importance of clear communication with the doctor as part of advocating for Pierce?	To be discussed at filming	N/A
Symptoms		
What type of psoriasis does Pierce have? Can you tell us a little about [his/your] symptoms when [he was/you were] first diagnosed/before treatment?	<ul style="list-style-type: none"> Pierce has 3 types of psoriasis [Note: confirm which types he was diagnosed with] Pierce was losing hair Plaques covered 75% of his body (under the arms, scalp, in his ears, above his eyebrows, bottoms of his feet, chest, back) 	
How long did it take for psoriasis to spread from the scalp to 75% of your body? [Pierce] What was that experience like? Explain what was going through your mind as a teen and how this affected your self image.	To be discussed at filming	To be discussed at filming

[NOTE: Make this a big focus of discussion]		
<p>What symptoms bother [you/Pierce] the most?</p> <p>Which symptoms were/are the most challenging to manage?</p>	<ul style="list-style-type: none"> Pain, itching 	<ul style="list-style-type: none"> The constant shedding of dead skin Expressed "Mom, I feel like I'm an amphibian" [Note: be sure to capture this quote] Most challenging thing is to not scratch or pick at the dead skin
How have these symptoms changed since diagnosis?	To be discussed at filming	To be discussed at filming
Are there any specific triggers that make symptoms worse?	To be discussed at filming	To be discussed at filming
Effects on daily life/social life/self-confidence		
<p>How does [your/Pierce's] symptoms affect everyday life?</p> <p>[Pierce] How did having psoriasis impact your self-confidence? Describe your self-confidence at diagnosis compared to now.</p>	<ul style="list-style-type: none"> Affected his sleep in the beginning [Note: will have to remove any mention of muscle pains from final cut] 	<ul style="list-style-type: none"> Initially had to wear a hat to cover his bald spot; would sometimes swim with his shirt on [Note: probe more into the effects on Pierce's self-confidence]
<p>[Tracy] What struggles have you felt as a parent as it relates to psoriasis?</p> <p>[Pierce] What struggles have you had in school related to psoriasis? How did your classmates react? [Note: probe into how the incident with the teachers affected Pierce.]</p>	<ul style="list-style-type: none"> Advocating to get treatments that help Navigating situations at school: Situation with a teacher who was discussing Pierce's hair with another teacher in a negative way; Tracy had to send an email explaining his health issues 	To be discussed at filming
<p>[Pierce] What are the most frustrating aspects of having psoriasis?</p>	N/A	<ul style="list-style-type: none"> Itching, constant shedding of dead skin

<p>[Pierce] How does psoriasis affect your social life, if at all? How have your friends reacted to your diagnosis?</p> <p>[see if Tracy has anything to add]</p>	<ul style="list-style-type: none"> Pierce was very self-conscious in the beginning 	<ul style="list-style-type: none"> Friends have been very supportive
<p>[Pierce] Have you made any friends or met others with psoriasis? If so, what's that experience like?</p>	N/A	To be discussed at filming
Treatment and management		
<p>[Tracy] What kinds of treatment options have been presented to you and how have you navigated those choices as a caregiver?</p> <p>[NOTE: Don't focus on biologics, but rather on Tracy advocating for Pierce through researching different treatments and going through hoops to find one that works.]</p>	<ul style="list-style-type: none"> Initially given cortisone creams; talked about a biologic as a possible last resort Nothing they tried was helping Tracy researched different treatments and pushed the doctors and navigated the insurance companies to prescribe a treatment that worked for him 	N/A
<p>How did you feel about the different types of treatments you tried (specifically how they're taken; eg, injection, cream, oral)?</p>	To be discussed at filming	To be discussed at filming
<p>What types of treatments and/or lifestyle changes helped the most?</p>	<ul style="list-style-type: none"> Tried and failed several therapies until they finally found a treatment that worked 	To be discussed at filming
<p>[Tracy] As Pierce becomes more independent, how has the ownership of care shifted, if at all?</p> <p>[Pierce]</p>	To be discussed at filming	To be discussed at filming

In what ways do you take ownership of your psoriasis treatment?		
Clinical studies		
How aware are you of clinical studies for psoriasis?	To be discussed at filming	To be discussed at filming
Would you ever consider taking part in a clinical study? Why or why not?	To be discussed at filming	To be discussed at filming
Where would you go to learn more about a clinical study? What sources and/or people do you trust for information?	To be discussed at filming	To be discussed at filming
Conclusion		
What advice would you give to other teens/parents of teens living with psoriasis?	Go with your gut; if you know something is wrong or a treatment isn't working, be your child's advocate and keep pushing for better treatment options.	It'll get better eventually, but it'll take time and effort to find the right medicine that works for you.
What is your hope for the future of psoriasis treatment and for kids and teens living with this skin condition?	To be discussed at filming	To be discussed at filming