JORDAN'S GUARDIAN ANGELS

Jordan's Syndrome (PPP2R5D) EL-PFDD Draft Agenda
January 12, 2027
10:00 AM – 3:00 PM EST

Welcome
Opening Remarks
Overview of Discussion Format
FDA Speaker Remarks
Clinical Overview and Background

Topic 1: Health Effects and Daily Impacts

Topic 1 Panel

Topic 1: Large Group Facilitated Discussion

Q1: Of all the symptoms that you experience because of your condition, which 1-3 symptoms have the most significant impact on your life?

Q2: Are there specific activities that are important to you but that you cannot do at all or as fully as you would like because of your condition?

Q3: As it relates to your condition, what does a good day look like? What does a bad day look like?

Q4: How have your condition and its symptoms changed over time?

Would you define your condition today as being well managed?

Q5: What worries you most about your condition?

Open Discussion

Break

Topic 2: Current Approaches to Treatment

Topic 2 Panel

Topic 2: Large Group Facilitated Discussion

Q6: What are you currently doing to help treat your condition or its symptoms?

Q7: How has your treatment regimen changed over time, and why?

Q8: How well does your current treatment regimen treat the most significant symptoms of your disease? For example, how well do your treatments improve your ability to do specific activities?

How well have these treatments worked for you as your condition has changed over time?

Q9: What are the most significant downsides to your current treatments, and how do they affect your daily life?

Q10: Short of a complete cure, what specific things would you look for in an ideal treatment for your condition?

What would you consider to be a meaningful improvement (for example symptom improvements or functional improvements) in your condition that a treatment could provide?

Open Discussion

Documentary Viewing

Closing Remarks

Wrap Up

End