



Impact of Rare Endocrine Diseases on Young People (ages 12 to 17)

Introduction

AMEND is a patient group charity that helps families with your rare disease. We want to understand how your disease affects you, and what kinds of fun things you'd like to do and learn with others who have rare diseases like you. This survey is aimed at young people aged 12 to 17. Please answer all the questions yourself as this will help us plan events for you and other young people with your rare disease.

1. Are you happy to take part in this survey?

Yes

No



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About You

Please tell us a little about yourself

2. How old are you?

3. What is your gender?

- Female
- Male
- Prefer not to say
- Other (please specify)

4. Which rare endocrine disease do you have?

- MEN1
- MEN2A
- MEN2B
- Phaeo Para Syndrome (PPGL/SDH)
- Not Sure

5. How long ago did you find out that you have your disease? (Write years/months, not sure, or not yet diagnosed)



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Emotions and Feelings

Tell us a bit about how you feel about having your rare disease

6. How do you feel about having a rare disease? (Choose the one that fits the best)

- It doesn't really bother me
- Sometimes I feel sad or worried
- I feel really upset and frustrated about it
- I feel alone
- Other (please specify)

7. Do you ever feel different from other people your age because of your rare disease?
(Choose the one that fits best)

- Yes I do feel different
- No, I feel the same as others my age
- Sometimes I do, but not always

8. Have you ever felt left out or left behind because of your rare disease?

- Yes I have
- No I haven't
- Sometimes but not often



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Support and Friendship

9. Do you have friends who understand your rare disease and are supportive?

- Yes, I have supportive friends
- No, my friends don't really understand
- I'm not sure



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10. If you do have supportive friends, how do they help you feel better? (You can choose more than one)

- They listen when I need to talk
- They make me laugh and have fun
- They don't treat me differently
- Something else (tell us what they do):



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11. Do you feel comfortable talking to your family or guardian about how your rare disease makes you feel? (Choose the one that fits best)

- Yes, I can talk to them
- No, I find it hard to talk about
- Sometimes I can, but not always

12. Do you talk to a doctor or therapist about how your rare disease affects your emotions? (Choose the one that fits best)

- Yes, I talk to someone
- No, I haven't talked to anyone, but I would like to
- No, I haven't talked to anyone, and I don't one to
- I'm not sure

13. Is there anything else you want to share about how having a rare disease makes you feel or any ideas for what would make you feel better? [Write anything you want]



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Fun Stuff and Learning

We really want to hear from you about the types of activities you would like to do. Feel free to think up any other activities that aren't listed and write them in the boxes below too.

14. Would you like the chance to meet with other young adults who have your diseases?
(Pick one)

- Yes please!
 No, no really

15. What kind of activities or events would you like to do with friends who also have similar rare diseases? (You can choose more than one)

- Going on outdoor adventures
 Learning interesting stuff in workshops
 Doing art and creative things
 Talking with others in a support group
 Having fun at parties and gatherings
 Learning about how to stay healthy
 Fundraising activities
 Something else (tell us what you would like to do or that interests you most)

16. What things would make you more likely to join these events? (You can choose more than one)

- Being able to go if you have special needs
 Meeting and making friends who understand you
 Learning from experts about important things
 Being able to pick a good time to go (like weekends or evenings)
 Raising money for charity
 Letting your family and caregivers join in too
 Getting help with the cost of taking part
 Something else (tell us what would make you most likely to come along to an event. Perhaps you need a lift there and back, etc.)

17. When do you think would be the best time of the year for these events? (You can choose more than one)

- January to March
- April to June
- July to September
- October to December
- Any time is fine
- I'm not sure

18. Is there anything else you can think of that you'd like to say about what you want to do with others who have rare diseases? We'd love to hear from you!

[Write anything you want]



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Thank you!

Thanks for answering our questions! What you've said will help us plan events for you and other young people with your rare disease. We appreciate your help!