RESEARCH PARTICIPANT AND PARENT INFORMATION SHEET
(for adolescents age 12-17 and their parents / guardians)

Alopecia & US: A Global Disease Impact Study

Invitation

You and your parent / guardian are being asked to take part in our research project, 'Alopecia & US'. The study will be looking at the psychological of alopecia areata on adolescents (people aged 12-17) and their family.

Before you make you and your guardian make your decision, we would like to explain why this is being done and what it would involve. If you require further information, you can message our team and they can clarify any questions you or your guardian may have. Please take the time for you and your guardian to read this and discuss it with anyone else you feel you would like to before making the decision to participate in this study. The study is entirely voluntary and you are under no obligation to participate.

1. What's involved?

We are interested in alopecia areata, a hair condition which is characterised by inappropriate immune response to the hair follicle. This leads to autoimmune hair loss which may be patchy or widespread, affecting the entire scalp or the whole body. The exact mechanism of alopecia areata is still unknown.

It is known that there is a strong link between alopecia areata and psychological and emotional stress, however this has not been studied in depth and neither has the impact of the illness on adolescents and family life.

To do this we would like to collect information about your health. The anonymised data collected will help us to better understand how to manage this hair condition holistically.

2. Why have we been chosen?

You and your parent have been invited to take part in this study because **you have been diagnosed with alopecia areata** by a dermatologist or by a GP who has a special interest in skin conditions. This study does not include any clinical consultations and we rely on the diagnosis of alopecia areata that your clinician has already made for you.

3. Do we have to take part?

No. It is up to you and your parent to decide whether to take part. You are free to withdraw from this research project at any point, and there is no obligation for you to provide a reason. This will not affect any treatment that you receive.

4. What would taking part involve?

If you and your guardian decide to take part in the study, you both will be asked to complete online questionnaires which are available via our online platform together. The questionnaires will assess the impact that alopecia areata has on your quality of life, your family's quality of life, your disease perception, stigma and mood. Completing the questionnaires should take approximately 10-15 minutes. Please complete the online questionnaires only once. All information that you will provide us with will be anonymised.

5. What will we have to do if we agree to take part?

If you both are happy to take part, and you are satisfied with the explanation from this participant information. You must confirm you parent / guardian is present to proceed.

If this is completed, you will be allowed to have access to the online questionnaires. The study is only available online and no paper versions have been used. You will have access without the need to provide your personal email address. However, if you want to save your unfinished document and revisit it later then a parental email address will be requested. An automated identification code can be provided to your parent which will allow you both to revisit and complete the online questionnaire. If you want to keep a record of your completed form, a parental email should also be provided. Upon completion of the form an automated identification code will be assigned to you. It is advisable to make a note of this and to keep it safe in case you wish to withdraw from the study in future – please see below for further information.

6. How can we get support to complete the Alopecia& Us survey?

If you are unclear about how to answer any questions, please contact the research team at the contact us page

7. What if I decide to withdraw my information?

You have the right to have your information removed from our survey at any time. Please contact us to let us know that you do not wish your information to be excluded. You will need to provide your Alopecia&Us identification number so that we can find your information in the database and we will then ensure that your information is removed. You also have the right to raise concerns or make a complaint by contacting us.

8. Can I participate in any other research study or clinical trial?

Yes, you can participate in other research studies or clinical trials whilst this research study is ongoing.

9. What if I do not wish to take part in the study?

If you or your parent do not wish to take part in the study, you will continue to be treated by the medical and nursing staff with the same level of commitment and expertise.

10. What are the possible benefits of taking part?

We cannot promise that the study will help you personally, but by joining in you will be helping us to understand more about alopecia areata. We hope this research will help people and families affected by this condition in the future. If it is of interest, the research results will be accessible to you and your parent when completed. This will either be through relevant patient support group websites or social media.

11. What are the possible disadvantages and risks of taking part?

There are no risks involved in taking part in this study.

12. What happens to my information and how is it protected?

We will be collecting your information through a secure website. We do not collect any personally identifiable information. The information that we do collect from you is stored safely and protected so that you remain anonymous in accordance with General Data Protection Regulation (GDPR). The information is stored in secure servers that are built and hosted by UKCloud, in compliance with best practice. The UKCloud will be managed by the King's College London Division of Health and Social Care Research.

The study team will analyse the information and it will only be used for the purposes of scientific and medical research in the public interest. Sharing information with researchers will always be under relevant data protection and information governance regulations. Your information will not be used for commercial purposes. Alopecia&Us is a not-for-profit initiative.

13. What happens when the research study ends?

You will carry on with your normal care at the hospital, as required and your data will be stored for 5 years after the completion of the study.

14. How will the results of the study be disseminated?

The results gathered from the study will be published in scientific journals and presented at national and international scientific/medical meetings. All data will be anonymised before publication.

15. Where can you find out more about how your information is used?

You can find out more about how we use your information

- At www.hra.nhs.uk/information-about-patients/
- Our leaflet available from: www.guysandstthomas.nhs.uk/research/patients/use-of-data.aspx (For GSTT)
- By asking one of the research team (contact us)
- By contacting the Data Protection Officer: Nick Murphy-O'Kane DPO@gstt.nhs.uk

16. What if there is a problem?

If you or your parent have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (contact us). If you remain unhappy and wish to complain formally, you can do this through the Guy's and St Thomas' Patients Advice and Liaison Service (PALS) on 02071888801, pals@gstt.nhs.uk. The PALS team are based in the main entrance on the ground floor at St Thomas' Hospital and on the ground floor at Guy's Hospital in the Tower Wing.

In the event that something does go wrong, and you are harmed during the research and this is due to someone 's negligence then you may have grounds for legal action for compensation against

[Guy's and St Thomas' NHS Foundation Trust] but you may have to pay
your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

17. Will I be paid for taking part in this study?

You will not be paid for taking part in this study.

18. Who is organising and funding the study?

The study is funded by a non-commercial, academic grant by the National Alopecia Areata Foundation (NAAF) & Pediatric Dermatology Research Alliance (PEDRA).

19. Who has reviewed the study?

This study was reviewed by Guy's and St Thomas' NHS Foundation Trust Research and Development (R&D) in 2023.

20. Are other languages available?

Yes, multiple translations are available upon request. Please contact the study organizer who will arrange this for you.

Further Information and Contact Details:

Principle Investigator(s) at Guy's and St Thomas NHS Foundation Trust

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Thank you for reading this.

If you have any questions, please ask us.