Participant newsletter December 2022



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Welcome to our ATHENA study December newsletter





Seasons Greetings from the ATHENA Study Team

Hello,

We have written this newsletter to update you on the study and to thank you for your continuing support.

Whether it's completing questionnaires or speaking to research staff, all your contributions are vital to the outcome of the study.

THANK YOU for choosing to be part of this research.

Best wishes from the ATHENA Study Team!



Study Recap and Update

Some people can have nerve pain in the area of the shingles rash, months after the rash has gone. This is called "post-herpetic neuralgia".

We currently do not have any treatments that prevent this. We want to find out if taking a low dose of a tablet called Amitriptyline may help prevent it.

Since the start of the study we have so far recruited 150 participants.

We are delighted that we now have sites recruiting within seven UK regions and plan to open more sites in 2023.

Regions where practices are currently recruiting are:

- · West of England
- Wessex
- Thames Valley/South Midlands
- South West Peninsula
- North West London
- North West Coast
- Greater Manchester

We plan to open more sites in 2023 in:

- Kent, Surrey and Sussex
- West Midlands
- Yorkshire and Humber
- East Midlands



Questionnaires

Thank you to everyone for continuing to complete your questionnaires.

To be able to find out whether low dose Amitriptyline is effective in preventing post-herpetic neuralgia we need you to continue to complete your questionnaires.

They are sent to you 30, 60, 90, 120, 180 and 360 days after your rash appeared. Please try and complete them as soon as you can.

The 90 and 360 day questionnaires are slightly longer. The 90 day questionnaire asks a few additional questions to check how you are

at an important timepoint: 20 days after you have stopped taking your medication.

You can contact us by email at any point if you have any queries or questions. You can find our email address at the bottom of this newsletter.

Remember....

- ...to continue to complete the questionnaires <u>even if you stop</u> <u>taking the medication</u> so we can find out how you have been getting on and answer the research question properly.
- ...to look out for the emailed questionnaires (check your "spam" folder) if you are completing them online, or in the post, if you are completing them on paper.
- ...to help us to answer the research question by completing as many questions as you can.
- ... you will receive an email (or phone call) after 70 days, to remind you that it is time to stop taking your study medication. You may wish to dispose of any unused study medication at your local pharmacy.

THANK YOU!



Webinar: "Shingles - what's all the fuss?"

On November 29th, Dr Bob Johnson and Professor Matthew Ridd hosted a Webinar (a live online video presentation) explaining what you need to know about shingles and the prevention and treatment of the most common complication, post-herpetic neuralgia.

Dr Johnson is Emeritus Consultant in Pain Management and an international expert on shingles vaccination and the prevention and treatment of post-herpetic neuralgia. Professor Ridd is a GP and Chief Investigator on the ATHENA Study.

You can view a recording of the Webinar here.

"Anyone can get long-term pain from shingles" By Lorelei Hunt, Patient and Public Involvement Representative on the ATHENA Study



Lorelei is the patient representative on our Trial Management Group and she has recently written a couple of blogs about her experience of shingles. You can read about her experience here.





Gill is a Research Nurse for ATHENA, based in Southampton.

Gill says: "I qualified as a nurse with the University of Southampton in 1994. I've been working in Primary Care since 2004 and been involved with research since 2014. I find research really fascinating and have recruited for a variety of different research studies.

In my spare time, I enjoy walking with family in the New Forest and along the coast!"

Who oversees the ATHENA study?

The study is overseen by an independent Trial Steering Committee and a Data Monitoring and Safety Committee.

The Trial Steering Committee comprises a number of experts from across the UK; this committee meets regularly to review the progress and conduct of the study.

The Data Monitoring and Safety Committee is responsible for reviewing issues related to the safety and ethics of the study.



Keeping in touch

Remember to update us if your email address changes as this is how we will continue to contact you over the coming months.

To let us know if your details have changed you can email us at athena-study@bristol.ac.uk.

You can also stay up to date with us on Twitter: @AthenaStudy or keep yourself informed about study updates on our website: www.athena-study.bristol.ac.uk.



Who we are

Trial Manager: Siân Wells
Administrator: Zoë Wilkins

Qualitative Researcher: Dr Sophie Rees

Research Nurses:

Lyn Liddiard, Anna Gilbertson, Gill Kirkup, Erin Shearn

A happy festive season to our participants.

The hard work goes on - but it is only a result of your support!



For further information or help:

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