

Injections of intravenous contrast for computerized tomography scans precipitate migraines in hereditary hemorrhagic telangiectasia subjects at risk of paradoxical emboli: implications for right-to-left shunt risks.

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SUPPLEMENTARY DATA

Extracts from the questionnaire designed in SurveyMonkey¹ at https://www1.imperial.ac.uk/nhli/cardio/vascular/pulmonary_vascular/hht_pavms/hhtsurvey/

¹SurveyMonkey.com, LLC, Palo Alto, California, USA (www.surveymonkey.com)

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We invite you to help us with this research, by filling out the enclosed short questionnaire about general health issues. There are 5 sections, and it should take you about 20-30 minutes to fill in. This will allow us to see if people with HHT are more or less likely to have certain common medical conditions, than people without HHT. All questionnaires will be treated with the strictest of confidence. We will not disclose your personal results to your family doctor, or any third party.

It is up to you to decide whether to fill in the questionnaire. If you do fill it in and press the "DONE" button on the last page, we will accept your consent to use your answers in our research. We aim to publish our conclusions in a scientific journal. No study participant will be identified in any publication. Thank you very much for considering this invitation.

Dr Claire Shovlin,
Lead Clinician, HHTIC London

Note that to reduce bias, participants were provided with very general information in their information sheet, and the online survey introduction.

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47. How often do you have migraines?

- I have never had a migraine
- Less than 5 times in my life
- About once a year
- At least once a month
- At least once a week
- Most days
- Every day

48. My migraines started when I was

- younger than 5
- 5-10
- 11-15
- in late teens
- in my 20s
- in my 30s
- in my 40s
- in my 50s
- in my 60s
- in my 70s
- in my 80s
- in my 90s

49.and as I have got older, my migraines (*tick all that apply*)

- have stayed about the same
- are less frequent
- are more frequent
- seem less severe
- seem more severe

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50. What does your doctor say about your migraines?

- I have never needed to discuss them with a doctor
- My doctor says the headaches are due to something else, but I think they are migraines
- My doctor thinks my headaches are migraines, and has told me to take simple painkillers like paracetamol
- My doctor thinks my headaches are migraines, and has given me specific treatment for migraines

51. Which of these applies to your migraines. Tick all that apply. The headache is.....

- mild in intensity
- mild to moderate in intensity
- moderate to severe in intensity
- distracting but not debilitating and I can do most of my usual activities
- a steady ache
- intense, pounding, throbbing or debilitating
- on one side of the head
- on both sides of the head

*** 52. Does anything else happen before, during or after the headache?**

- Nothing really, it's just a headache
- Yes, something else sometimes or usually happens

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53. You have told us that when you get your migraine headaches, something else happens. We would like to know a little more, so please us how often you have noticed any of these before, during or after your migraine headaches.

	Never	With some	Often	With most	Always
I feel sick or vomit	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am sensitive to bright lights	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am sensitive to loud noises	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I pass lots of urine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get tummy pains	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get diarrhoea	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a nosebleed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Remember, this is something that happens at the time you have a migraine. We are not asking about other times in your life.

* 54. When you have had a migraine, have you ever had a problem with your vision, hearing, speech, sensation (how you feel things), or movement of an arm or leg ?

- Yes
- No
- I'm not sure

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55. You have told us that when you get your migraine headaches you may have a visual, sensory, speech or movement disturbance. We would like to know a little more, so please tell us how often you have noticed any of these before, during, or after your migraine headache

	Never	With some	Often	With most	Always
I see flashes of light	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Objects seem to move around in pieces	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get a temporary loss of vision	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I get a temporary loss of sensation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a speech disturbance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a problem with movement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have a problem with balance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

You have 3 lines to give a little more detail, if you want to.

Remember, we are asking about something that happens at the time you have a migraine. We are not asking about other times in your life.

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121. This is a list of simple tests in hospitals. We would like to know if you have had any of these tests, and if so, if any of them seemed to make a difference to your migraines.

	I have not had this investigation	Migraines stayed about the same	Migraines seemed to get better	Migraines seemed to get worse	This seemed to start a migraine	This seemed to stop a migraine
Getting weighed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having blood pressure measured	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Having oxygen measurements by a finger probe	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blood tests	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Giving a urine sample	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breathing tests - blowing out hard	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Breathing tests with a nose clip	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A standard x-ray of the chest, head, abdomen or another part of the body	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

You have 3 lines if you want to give us any more details.

* 122. Have you had a CT scan? This is a quiet, quick scan and you lie on a bed that goes through a doughnut-shaped ring.

- No
- Yes
- I'm not sure

If they answered "Yes" they were directed to:

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123. We would like to know if having a CT scan seemed to make a difference to your migraines.

	I have not had one	No different really	Migraines seemed a bit better	Migraines seemed a bit worse	Seemed to bring on a migraine	Seemed to stop a migraine
CT scans with no needle/injection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CT scans with an injection of contrast	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

You have 3 lines if you want to give us any more details.

* 124. Have you had an MRI scan? This is a noisy scan that usually lasts 15-20 minutes or more

- No
- Yes
- I'm not sure

If they answered "Yes" they were directed to:

125. We would like to know if having an MRI scan seemed to make a difference to your migraines.

	I have not had one	No different really	Migraines seemed a bit better	Migraines seemed a bit worse	Seemed to bring on a migraine	Seemed to stop a migraine
MRI scans with no needle/injection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
MRI scans with an injection of contrast	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

You have 3 lines if you want to give us any more details.

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* 126. Have you had an echocardiogram or ultrasound? A probe with jelly on will have been moved over your skin, pressing firmly, and the pictures are seen on a computer screen

- No
- Yes
- I'm not sure

If they answered "Yes" they were directed to:

127. We would like to know if having an echocardiogram or ultrasound seemed to make a difference to your migraines.

	I have not had one	No different really	Migraines seemed a bit better	Migraines seemed a bit worse	Seemed to bring on a migraine	Seemed to stop a migraine
Echocardiogram with no needle/injection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Ultrasound (usually of abdomen) with no needle/injection	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bubble echo (with an injection)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

You have 3 lines if you want to give us any more details.