

# 2019 Research Newsletter: Hereditary Haemorrhagic Telangiectasia (HHT)

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**We would like to thank all of you who have helped us with our recent research studies. Here we provide information to summarise important findings. You and your doctors will be able to find further information, and access to most of the papers, via a 2020 website under development**

## HEALTH BENEFITS FROM HHT

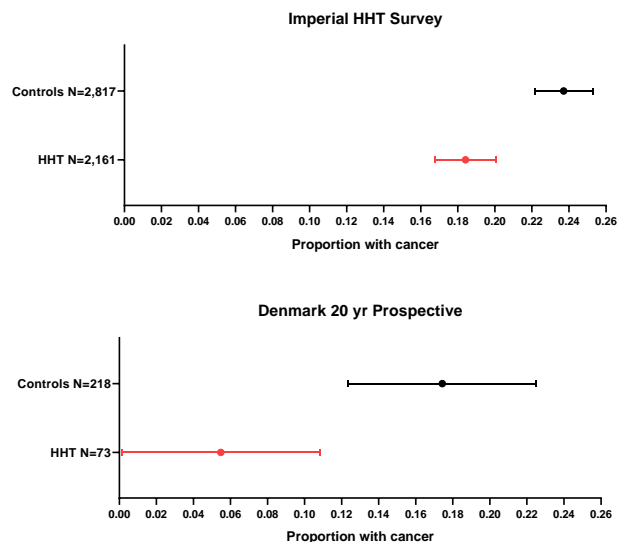
### How can life expectancy be normal in HHT, if it is managed properly?

We all know that sadly, there are deaths in HHT, and that many of these cannot be prevented, even with the most intense medical care. Yet in the superb 20 year follow up series from Denmark, life expectancy in HHT is now normal. Additionally, we can see how well many of you age- into your 80s, 90s and beyond. The European Reference Network for HHT (VASCERN HHT) chose to focus on this for their 2019 video [HHT FROM VASCERN HHT](https://www.youtube.com/watch?v=OYjWf7Agn40&feature=youtu.be) which you can find at <https://www.youtube.com/watch?v=OYjWf7Agn40&feature=youtu.be>.

We now have parts of the answer and wish to bring these to your attention:

### People with HHT have lower rates of certain cancers

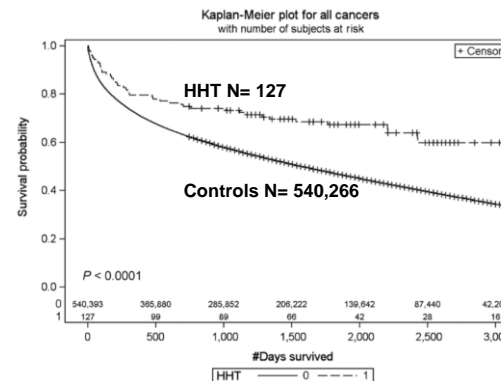
First, it seems that people with HHT have lower rates of certain cancers. This was shown by us in a survey that many of you completed, and has since been confirmed by a separate study in Denmark, and by a study in the US. The rates are replotted here so you can see the numbers and consistency of the studies. This is despite the fact that people with HHT often receive more radiation exposure than the general population due to screening tests and treatments.



HOSMAN ET AL, *ORPHANET J RARE DIS* 2013 Feb 28;368(9):876-8.  
 KJELSDEN ET AL, *ORPHANET J RARE DIS* 2016 Nov 22;11(1):157.

### People with HHT have better survival if they develop cancer:

In another large study comparing people with HHT to those without, an American group demonstrated that if people developed cancer, survival was better in people with HHT:

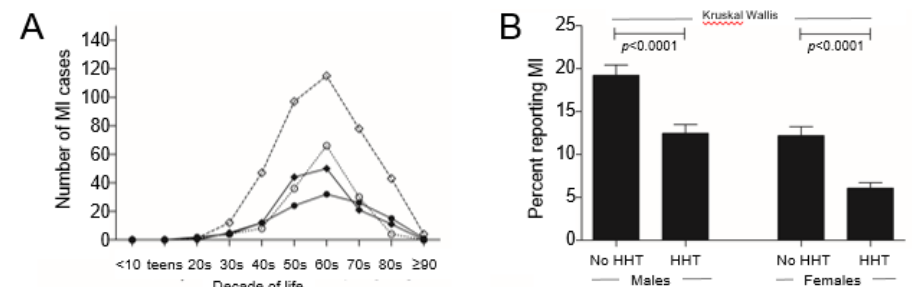


DUARTE ET AL. *CANCER EPIDEMIOL BIOMARKERS PREV.* 2014;23:117-125

These doctors looked at the health records of Americans with lung, prostate, breast or colon cancer.

**Giving cancer patients HHT to treat cancer:** Separately, drug companies report anti-cancer benefits by using injectable antibodies targeted against the proteins that are produced by the HHT genes. Their treatments also make all the cancer patients develop nosebleeds and blood spots!

**People with HHT seem to have fewer heart attacks, even though often anaemic or with other medical issues.** This has been suspected for many years. Our studies suggested people with HHT had fewer, and 2019 basic research from laboratories may explain why.



SHOVLIN ET AL, *INT J CARDIOL* 2017 Jul 15;215:179-85

## HHT TREATMENTS - STOP PRESS!

- The European Reference Network on Rare Inherited Multisystemic Vascular Diseases VASCERN HHT (<https://vascern.eu/>), and HHT International Guidelines Committee are generating new information for your doctors on how best to look after HHT for 2020,
- The UK National Health Service (NHS) is agreeing new structures for HHT for 2020.....