

Patient information on use of Tamoxifen in patients with Hereditary Haemorrhagic Telangiectasia (HHT)

Who is this information for?

This information is for patients, families and carers who may commence treatment with tamoxifen for HHT.

What does the use of tamoxifen in HHT patients aim to achieve?

- Tamoxifen aims to reduce the frequency and severity of nosebleeds in HHT patients.
- There are several studies showing men and women with HHT have shorter and fewer nosebleeds when they are taking tamoxifen.
- Approximately 90% of people taking it notice improvement. Anaemia (low level of haemoglobin) may also improve.

What is the dose of tamoxifen?

- The dose of Tamoxifen is 20mg once per day for both male and female patients.



Once daily

How long does it take for tamoxifen work?

- An improvement in the frequency and severity of nose bleeds should be noticed within 1 – 2 months of starting tamoxifen.

How does tamoxifen work?

- Tamoxifen acts on the receptor for the female hormone, oestrogen. It was developed for use in patients treated for breast cancer and has been used for this for over 30 years.
- In the past, people with HHT and bad nosebleeds were sometimes given hormone treatment with progesterone and oestrogens. There are usually more side effects when these are taken at effective doses than with tamoxifen.

Who can be prescribed tamoxifen?

It is suitable for use for men and women with severe nosebleeds due to HHT as long as they are:

- over 18 years old,
- **NOT** pregnant or trying for a baby,
- **NOT** taking the contraceptive pill,
- **HAVE NOT** suffered from blood clots (*e.g. DVT or PE*)
- **DO NOT HAVE** uterine cancer
- **NOT** receiving hormone treatment for another reason (*e.g. for peri-menopausal symptoms, or for cancer*)

What are the side effects of tamoxifen?

- As with all medications there are potential side effects. The side effects are unusual and must be balanced against the annoyance and health risk of the nosebleeds.
- In women, these can be similar to the symptoms of menopause. The most common side effects are hot flushes and vaginal discharge. Some women experience irregular menstrual periods, headaches, fatigue, nausea and/or vomiting, vaginal dryness or itching, irritation of the skin around the vagina, and skin rash. As with the menopause, not all women who take tamoxifen have these symptoms.
- Men who take tamoxifen may experience headaches, nausea and/or vomiting, skin rash, impotence, or a decrease in sexual interest; again these are unusual.
- More seriously, but rarely, there is an increased risk of developing blood clots (DVT). This is about the same risk as when taking hormone replacement therapy (HRT).
- Other very rare possible side effects are strokes, cataracts and, in women, uterine cancer.

When should I seek advice from the GP when using tamoxifen?

- Women who take tamoxifen should see their GP if they experience vaginal bleeding or pelvic pain.

Concerns or questions?

You can contact your ENT Specialist at the Melbourne ENT Group (MEG):

- Phone: 1300- 952-808
- Email: admin@melbentgroup.com.au
- Website: www.melbentgroup.com.au



Your GP is also the best contact for ongoing care and concerns.

Further information

Further information about HHT can be obtained from the Australian HHT Alliance website www.hht.org.au or from the Cure HHT (previously the HHT Foundation) website www.hht.org

Further information about tamoxifen treatment can be found at:

<http://www.cancer.gov/cancertopics/factsheet/Therapy/tamoxife>



<http://clinicaltrials.gov/ct2/show/NCT00375622>



- Yaniv E, Preis M et al. Anti-estrogen therapy for hereditary hemorrhagic telangiectasia - a long-term clinical trial. *Rhinology*. 2011;49(2):214-216
- Yaniv E, Preis M et al. Antiestrogen therapy for hereditary hemorrhagic telangiectasia: A double-blind placebo-controlled clinical trial. *Laryngoscope*. 2009. Volume 119, issue 2, pages 284-288.

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