Canterbury
District Health Board
Te Poari Hauora ō Waitaha

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RE Official Information Act request CDHB 10132

I refer to your email dated 29 June 2019 and received on 1 July 2019 requesting the following information under the Official Information Act from Canterbury DHB.

1. **What is the criteria to run the test for Leiden Factor V?**

The criteria to run the test for Leiden Factor V is available to Clinicians on the Canterbury Community HealthPathways website. (Please refer to **Appendix 1** attached).

HealthPathways is designed and written for use during a consultation. Each pathway provides clear and concise guidance for assessing and managing a patient with a particular symptom or condition. Pathways also include information about making requests to services in the local health system.

Content is developed collaboratively by general practitioners, hospital clinicians, and a wide range of other health professionals. Each pathway is evidence-informed, but also reflects local reality, and aims to preserve clinical autonomy and patient choice. HealthPathways serves to reduce unwarranted variation and accelerate evidence into practice.

There is also information provided which is publicly available on the HealthInfo website. www.healthinfo.org.nz;

2. **When and why did the Leiden Factor V test criteria change?**

The Leiden Factor V criteria has not changed. The guidelines within HealthPathways (referred to above) were last reviewed in March 2015.

3. **How much money does it cost to run the test for Leiden Factor V?**

The list price is $193.16 + GST. This includes testing for the Factor V Leiden mutation and Prothrombin c.20210G>A variants.

4. **In the past five years, how many of your patients have had blood samples taken for the Leiden Factor V test?**

A total of 1477 patients from Canterbury DHB have had a Factor V Leiden gene mutation test in the last five years.

5. **Out of those samples taken (as per the above question) how many have tested positive, how many have tested negative, and how many have not been processed?**

Of the total 1477 patients tested in the last five years, it is not possible to break these down into 'tested positive or tested negative' as this information is not held in an easily retrievable data system. It would necessitate us going through individual patient records and this would require a substantial amount of time and resource. We are therefore declining to do this under section 18(f) of the Official Information Act.

The Factor V Leiden gene mutation test reports as not detected, heterozygous or homozygous. All samples received have been processed unless the patient has previously been tested. Previously tested patients are not retested as an individual's genetics do not change, hence the result will not change.

I trust that this satisfies your interest in this matter.

If you disagree with our decision to withhold information you may, under section 28(3) of the Official Information Act, seek a review of our decision from the Ombudsman. Information about how to make a complaint is available at www.ombudsman.parliament.nz; or Freephone 0800 802 602.

Please note that this response, or an edited version of this response, may be published on the Canterbury DHB website after your receipt of this response.

Yours sincerely

Carolyn Gullery
Executive Director
Planning, Funding & Decision Support

Thrombotic Disorders

See also:

- Deep Vein Thrombosis
- Pulmonary Embolism

Background

About thrombotic disorders

Assessment

Practice point

The decision as to whether to test for thrombotic disorders is complex and testing may not help with clinical management. Thrombophilia testing is expensive. There are criteria to help determine who should be tested.[1]

1. Obtain a careful personal and family history of venous thromboembolism (VTE).
    - Look for a provoking cause e.g., immobility, surgery, oestrogens, if there is a personal history of VTE. If there is a provoking cause, no further testing is required.

      Provoking cause

      The American College of Chest Physicians (ACCP) 2008 guideline on DVT and PE places a strong focus on assessing whether or not there was a provoking cause for the VTE episode.[2]

    - If there is a family history of VTE, determine the abnormality.
2. Based on British guidelines, locally, thrombophilia screening tests will now **only be performed** in patients with:[3]

   Thrombophilia screening tests include

   Antithrombin III, activated protein C resistance, and protein C and S.

    - VTE or stroke, age younger than 45 years without a precipitating cause.
    - Unprovoked thrombus plus a thrombosis prone family with more than 1 symptomatic family member.
    - First degree relative with a confirmed, inherited thrombophilia.
    - VTE in an unusual site without an obvious cause, e.g. cerebral or mesenteric, but excluding retinal vein thrombosis.
    - Skin necrosis associated with oral vitamin K antagonists and no longer receiving anticoagulants.
    - Recurrent pregnancy-related complications, e.g. recurrent miscarriage, with no alternative obstetric or cytogenetic cause.
    - Other indications as discussed with a haematologist on a case-by-case basis.
3. Thrombophilia testing is **not recommended** in these patients.

Thrombophilia testing is not recommended in patients:

- currently receiving anticoagulation treatment with warfarin, low molecular weight heparin, or unfractionated heparin.
- at the time of an acute venous thrombus or within 3 months of a thrombotic event.
- where a decision has been made to treat with lifelong warfarin.
- with superficial venous thrombosis (formerly superficial thrombophlebitis) without other risk factors.
- who are asymptomatic children unable to give informed consent to testing even with a positive family history of inherited thrombophilia.
- with:
  - arterial thrombosis.
  - retinal vein thrombosis.
  - a venous thrombus with an obvious precipitating cause.
  - central venous catheter-related thrombus.
- unselected with a first-degree relative with an unprovoked thrombus in whom the oral contraceptive pill or hormone replacement therapy are being considered.

4. Arrange all thrombophilia blood tests using the Thrombophilia Testing Request Form.

Management

1. Provide education on how to recognise symptoms of a VTE and minimise risk.

   Risk factors for DVT

   - Recent surgery or trauma
   - Malignancy – either known or occult
   - Previous thrombosis or family history of thrombosis
   - Pregnancy, postpartum, or current oestrogen therapy, e.g., combined oral contraceptive, hormone replacement therapy
   - Immobilisation
   - Travel – airline flight > 6 hours
   - Thrombocytosis
   - Obesity
   - Stroke
   - Varicosities

   Note: These risk factors are cumulative.

2. If testing is done:
   - Negative thrombophillic testing in a patient with a strong family history of VTE does not mean that they are at low risk of VTE.
   - Provide information about individual risk.[4]

     Information about individual risk

     - If antithrombin, protein C, or protein S deficiency, the annual risk of a first DVT is 1.5% (15 to 19 times increased risk relative to community controls).
     - If factor V Leiden or prothrombin 20210A deficiency, the annual risk of a first DVT is 0.34% (3 to 5 times increased risk relative to community controls).
3. Discuss the duration of anti-coagulation treatment:
   - unprovoked VTE, consider long-term anti-coagulation.
   - provoked VTE, 3 to 6 months treatment may be adequate, provided the provoking cause has resolved.[4]

Provoking cause

The American College of Chest Physicians (ACCP) 2008 guideline on DVT and PE places a strong focus on assessing whether or not there was a provoking cause for the VTE episode.[2]

4. Consider thromboprophylaxis during periods of increased risk:
    - For major surgery, all should receive prophylaxis with low molecular weight heparin (LMWH).
    - See also Christchurch Hospital Haematology Department Protocols and Guidelines:
        - HRT/COCP and Thrombosis
        - Pregnancy – consider thromboprophylaxis and seek advice.[5]
        - Air Travel and Venous Thrombosis

Request

1. Request non-acute haematologist assessment if:
    - advice for pregnancy thromboprophylaxis is needed.
    - management after a VTE is needed.
2. For thrombophilia screening, give the patient the Thrombophilia Testing Request Form.
3. Where appropriate, written advice may be available.

Information

For health professionals

- CDHB Haematology Department Protocols and Guidelines – Thrombotic Disorders
- Patient:
    - Deep Vein Thrombosis
    - Thrombophilia

For patients

On HealthInfo

- Give your patient a HealthInfo card and encourage them to search using the keywords "DVT" or "PE".
- HealthInfo:
    - Deep Vein Thrombosis (DVT) of the Lower Limbs
    - Pulmonary Embolism (PE)
    - Warfarin Monitoring

Printable Resources

- Patient:
    - Deep Vein Thrombosis
    - Pulmonary Embolism
    - Thrombophilia

Preventing DVT When You Travel

Patient Medication Information

- My Medicines:
  Dabigatran
  Warfarin

Search My Medicines for patient information leaflets for any medications not listed in this section.

Contact the HealthInfo team at info@healthinfo.org.nz if you have any resources that you would like us to consider for this section.

Factor V Leiden (FVL) in Pregnancy

See also Thrombotic Disorders.

Background

About Factor V Leiden (FVL) in Pregnancy

About Factor V Leiden (FVL) in pregnancy

- Factor V Leiden (FVL) is a relatively common gene mutation in the general population:
  - A 2008 Australian study found a prevalence of heterozygous FVL of 5.3% in 2,031 women with no personal or family history of thrombosis.[1]
  - The significance of being heterozygous for FVL depends on the circumstances that lead to the test being done originally.
- Possible risks associated with FVL:
  - No apparent increase in the risk of early fetal loss.
  - Possible increase in the risk of late fetal loss and stillbirth. Some studies support this, and others do not, so any effect is likely to be very small.[2]

Management

Practice point

50% of venous thromboembolism (VTE) episodes related to pregnancy occur during the pregnancy and 50% in the 6 weeks postpartum.

1. Women who are homozygous for FVL or are heterozygous for FVL and have a family history of VTE:

   Family history

   First-degree relative aged < 50 years with venous thromboembolism (VTE).

   - Arrange assessment as below.
   - Low molecular weight heparin (LMWH) may be advised during the pregnancy and postpartum or only postpartum depending on the risk.
2. Women who are heterozygous for FVL but have no personal or family history of VTE:

   Family history

First-degree relative aged < 50 years with venous thromboembolism (VTE).

- Provide reassurance that the risk of pregnancy-related VTE is < 0.3%.
- After caesarean delivery, or during a lengthy postpartum recovery period, consider cover with LMWH.
- After vaginal delivery if there are risk factors, consider cover with LMWH.

  Additional risk factors

  - Obesity
  - Aged > 35 years
  - Smoking
  - Surgery
  - Immobilisation
  - Parity ≥ 3
- See Christchurch Women's Hospital guidelines – Postpartum Thrombophylaxis Assessment.

Request

Refer women to the Antenatal Clinic, for obstetric physician and obstetrician review, who:

- are homozygous for FVL, for consideration of prophylactic LMWH.
- are heterozygous for FVL and have a family history of VTE, for consideration of prophylactic LMWH.

  Family history

  First-degree relative aged < 50 years with venous thromboembolism (VTE).

- have previous VTEs regardless of FVL result - their risk of VTE during pregnancy is 10%.
- have a previous history of a late fetal loss irrespective of their FVL status.

Information

For health professionals

- Canterbury DHB Red Book – Pregnancy and Thrombosis
- Christchurch Women's Hospital guidelines – Postpartum Thrombophylaxis Assessment
- Royal College of Obstetricians and Gynaecologists (RCOG) – Thrombosis and Embolism during Pregnancy and the Puerperium, Reducing the Risk

For patients

On HealthInfo

- Give your patient a HealthInfo card and encourage them to search using the keywords "Deep Vein Thrombosis (DVT) in pregnancy" and "Blood clotting disorders"

- HealthInfo
  - Blood Clotting Disorders
  - Deep Vein Thrombosis (DVT) in pregnancy

Printable Resources

- HealthInfo – Deep Vein Thrombosis (DVT) in pregnancy

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