



Tallaght
University
Hospital

Ospidéal
Ollscoile
Thamhlachta

An Academic Partner of Trinity College Dublin



Vasculitis Ireland Network

PATIENT
INFORMATION
BOOKLET

What is Vasculitis?

Vasculitis means ‘inflammation of the blood vessels’ in the body. Inflammation is the body’s normal way of dealing with an injury or infection. Inflammation can help the body deal with invading germs, but for some unknown reason, in patients with Vasculitis, the immune system attacks healthy blood vessels.

This causes blood vessels to swell and narrow. The impact this has on the body differs for each person. It can affect the skin, causing minor problems, or cause more serious illnesses that impact organs like the kidneys or lungs. It is usually treatable with medications that work on the immune system. These include prednisolone, cyclophosphamide and rituximab. As these reduce your ability to fight infection, your medical team will monitor you closely, especially in the first six months after treatment. The condition may recur so medication to prevent this is usually required for several years.

The Vasculitis Ireland Network (VINE)

Tallaght University Hospital is a member of the Vasculitis Ireland Network. This is a virtual centre of expertise Health Care Provider in the European Reference Network for rare immune disorders (ERN-RITA).

Adult and childhood centres across the country have developed a network of specialist units with **Vasculitis Ireland Awareness**, the national vasculitis patient organisation. This “VINE” network is comprised of dedicated centres that provide a care pathway from diagnosis, managing relapse and complications and on to long term remission. The network enables access to clinical trials of new therapies for patients with vasculitis regardless of where they live on the island of Ireland. The centres maintain close ties and difficult cases are often discussed in a cross-centre forum.

Participating Units

Coordinating unit:

Tallaght University Hospital

Vasculitis & Allergy Group

Lead clinician: Prof. Mark Little

St. James's Hospital

Dept of Immunology

Lead clinician: Dr. Niall Conlon

St. Vincent's University Hospital

Dept of Rheumatology & Nephrology

Lead clinicians: Dr. Eamonn Molloy & Dr. John Holian

Children's Health Ireland at Crumlin

Department of Rheumatology

Lead clinician: Dr. Orla Killeen

Cork University Hospital

Department of Nephrology

Lead clinician: Dr. Michael Clarkson

University Hospital Galway

Department of Nephrology

Lead clinician: Prof Matthew Griffin

Southern Health & Social Care Trust

Dept of Nephrology & Rheumatology.

Lead clinicians: Dr. Neal Morgan, Dr. John Harty & Dr. Nicola Maiden

Vasculitis Ireland Awareness

Vasculitis Patient Organisation

Patient Contact & Policy Officer:

Ms. Julie Power

VINE coordinator: Ms. Pamela O'Neill

Further information:

1

Vasculitis Ireland Awareness (VIA) – VIA is an all-Ireland support group for patients with vasculitis. **Contact:** vasculitisireland10@gmail.com

2

Vasculitis UK is a UK based charity whose goal is to support those suffering from vasculitic diseases and their families by providing information and advice. Excellent disease specific information written for patients.

Contact: www.vasculitis.org.uk

3

The Vasculitis Foundation - (formerly the Wegener's Granulomatosis Association) a non-profit US organisation dedicated to providing emotional and informational support to patients with vasculitis. Helping patients and their families in understanding the disease and supporting research into the cause and cure of these diseases.

Contact:

www.vasculitisfoundation.org

A microscopic view of several cells, likely endothelial cells, with a prominent nucleus and cytoplasm. The cells are rendered in shades of blue and red. A central orange circle with a white border contains the text "VINE Registry and Biobank".

VINE Registry and Biobank

To provide a foundation for developing the vasculitis service in Ireland and to support translational Vasculitis research, the VINE network has established the **VINE Registry**.

Website:

<https://www.tcd.ie/medicine/thkc/research/rare.php>

As a vasculitis patient, you may be asked if you would like to take part in this. This is linked to one of the most complete vasculitis biobanks in the world based in Trinity College Dublin. The network is closely aligned with the **UKIVAS Vasculitis Rare Disease Group of the UK and Ireland** (<https://rarerenal.org/rare-disease-groups/vasculitis-rdg/>) and to the **European Vasculitis Society** (<http://vasculitis.org/>).

Tallaght University Hospital

Wards and Units

Tallaght Vasculitis and Allergy Group

Includes a range of specialists (including kidney, lung, rheumatology, ear/nose/throat, immunology, radiology, pathology and dermatology) to provide multi-disciplinary care for patients with vasculitis.

Website: www.tuh.ie/Departments/Tallaght-Vasculitis-Allergy-Group/Tallaght-Vasculitis-Allergy-Group.html

Inpatient care

If your kidneys are affected, you may need admission to Osborne Ward, located on Level 3 in the main Hospital.

You may phone Osborne Ward directly on:

01 414 4002

Outpatient Services

Vasculitis Outpatient Clinics are held in Suite 3 of the outpatient department on the Hospital's ground floor each Friday.

Blood tests

Should you require blood tests these will be carried out in our phlebotomy department.

Renal Day Ward

If you need to have treatment for your condition as an outpatient this will take place in the Renal Day Unit under the supervision of your consultant.

The Renal Day Unit is situated on Level 3 beside the Osborne Ward. The Unit is open from:

Monday to Thursday	7.30am-5pm
Friday	7.30am-3pm

To contact the Renal Day Unit, ring direct to:

01 414 4044

Clinical Nutrition and Dietetics

Patients may be seen as inpatients, at our outpatient clinics or in the Haemodialysis unit. After initial face-to-face contact, consultations and advice can be given over the phone. If you wish to see the Dietitian ask your doctor or nurse to refer you to the service.

Out of hours

Emergency service is supplied by the Nephrology and Medical on call teams. These are accessed through the Emergency Department.

Website: www.thkc.ie

Twitter: @thkc1

Vasculitis support smartphone app

The VINE network has designed a support app for patients with vasculitis, developed by PatientMpower. The app, which is downloadable on iPhone, Android and iPad, keeps a portable record of the medicines you will use, medical wellbeing (blood pressure, weight, symptoms etc), appointments, daily activity. It is also a portal to support research into the environmental triggers of vasculitis.

Search for “patientMpower” in App store or Google Play

← My Profile CANCEL LOG OUT

About me

Firstname

Surname

Gender:

Date of birth: Jan 01 2015

Hospital: St Vincent's Private

About my Condition

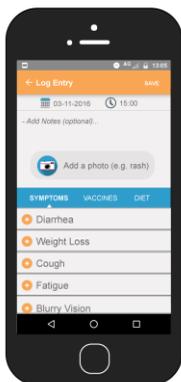
Type of Vasculitis: ANCA vasculitis - MPA

Date of Diagnosis: Jan 01 2015

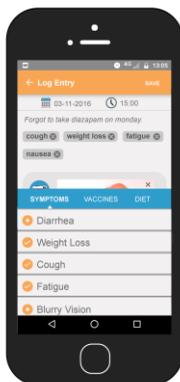
Has your diagnosis been confirmed by a Clinical Expert?
 Yes No

Treatment Start Date: Jan 01 2015

Journal Entry



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We would like to hear your feedback

Did you find this leaflet helpful?

How can we improve?
