Obtaining support

The New Zealand Porphyria Support Group has access to a number of documents, personal stories and case studies.

Because Porphyria is rare, our community support is spread across the world. The internet allows us access to the Australasian Support Group and the American Porphyria Foundation (APF) and many other organisations and resources.

Also, by communicating with others who have the disease you will start to understand its impact and how other people cope.

Useful internet sites

http://www.nzord.org.nz/

http://www.porphyriafoundation.com/

http://www.uq.edu.au/porphyria/

http://www.cpf-inc.ca/links.htm

http://www.electiveservices.govt.nz/guidelines/porphyria-cutanea-tarda.html

http://www.nzhis.govt.nz/

http://www.nzma.org.nz/journal/118-1222/1658/

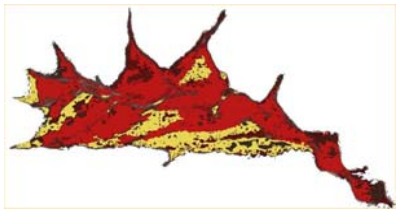
The PSG (NZ) wishes to acknowledge the New Zealand Medical Journal (NZMJ) for allowing use of its article.

ACUTE PORPHYRIA	ACUTE INTERMITTENT PORPHYRIA (Swedish Porphyria) VARIEGATE PORPHYRIA (South African Genetic Porphyria) HEREDITARY COPROPORPHYRIA (Coproporphyria) ALAD PORPHYRIA (ALA Dehydratase deficiency)
NON-ACUTE PORPHYRIA	PORPHYRIA CUTANEA TARDA (Cutaneous Hepatic Porphyria: Symptomatic Porphyria) HEPATOERYTHROPOIETIC PORPHYRIA ERYTHROPOIETIC PROTOPORPHYRIA (Erythrohepatic Porphyria) CONGENITAL PORPHYRIA (Gunther's disease: Erythropoietic Porphyria)

Porphyria Support Group New Zealand

Porphyria

Supporting Porphyria sufferers within New Zealand



Porphyria Support Group (NZ)

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Christchurch
New Zealand

Statement

The Porphyria Support Group (PSG NZ) is a non funded, non medical group, offering support to New Zealanders suffering from Porphyria. No claim is made to any medical information printed or stated. We encourage contact with health professionals in all cases.

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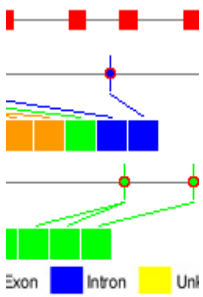
Living with Porphyria



Part of the PPOX gene sequencing affected by Variegated Porphyria

You are reading this information probably because you have or think you have Porphyria.

Our aim is to support you in discovering and learning about Porphyria, its impact and effect on our lives. We also provide a bridge between sufferers, with a New Zealand focus.

Because Porphyria in all it's forms, is relatively rare, (approx 1:50,000 have the disease in New Zealand), it is difficult to communicate the issues and problems experienced by those with the disease.

The term "Porphyria" is derived from the Greek word for "purple" and originally referred to the red to purple colour of the urine of affected patients.

There are eight variations of Porphyria; all caused by the accumulation in the body of substances called porphyrins. This accumulation is generally the result of an enzymatic defect and blocks in certain chemical processes.

The various types of Porphyria are:

- ALAD Porphyria (ADP) or Plumboporphyria (PP)
- Acute Intermittent Porphyria (AIP)
- Congenital Porphyria (CEP)
- Porphyria Cutanea Tarda (PCT)
- Hepatoerythropoietic Porphyria (HEP)
- Hereditary Coproporphyria (HCP)
- Variegate Porphyria (VP)
- Erythropoietic Protoporphyria (EPP)

It is a difficult disease to diagnose as the symptoms vary according to the type, degree of genetic defect and other aspects specific to each individual person. People with AIP, HCP, ALAD or VP are always at risk of an acute attack of porphyria. Those with PCT, EPP and CEP are not at risk. In either case the major issues involve reactions to sunlight and chemicals.

You can do simple tests yourself to determine increased levels of Porphyrins; standing urine in natural sunlight during the day, may turn it red, or if it is exposed to ultra violet light, it produces florescence. Note that neither test, positive or negative, indicates you have or don't have the disease. However positive tests should be followed up with a health professional.

The Skin

People with VP, HCP, CEP and PCT may have a sensitive skin. Even the slightest knock can cause the skin to break. Often these damaged areas can take a long time to heal.

Sunlight is a contributing factor in causing the skin to become fragile and people with porphyria find that the parts of their bodies that are affected are those that are exposed to light, particularly their hands, faces, necks, legs and feet. Blisters and open sores can develop.

EPP and CEP are somewhat different to the other variations. Firstly, the skin may already be affected as a very young child or even in infancy, whereas the other variations usually only become obvious later in life. Secondly, such people often find that they react to sunlight rapidly, developing a sensation of burning or stinging shortly after going into the sun. This is unlike VP, HCP and PCT, where the damage takes much longer to develop. Affected people learn to avoid excessive sunlight because of this discomfort.

Chemicals and Medicines

There are many medicines that can aggravate porphyria, possibly resulting in an acute attack. Therefore never take any medicine or remedy without checking that it is safe for porphyrics. This includes drugs given by a doctor, pharmacist or dentist, as well as those that can purchased without prescription.

In the worse case scenario, taking the wrong chemicals may result in seizures, severe abdominal pain, vomiting and constipation. Liver damage may also occur.

Genetics

If you have AIP, HCP, VP or EPP, your children have a 50:50 chance of being affected.

Is there a cure?

Unfortunately, there is no current cure for porphyria, but there is a lot that you and your doctor can do to make it less severe. With a little care, your symptoms probably will be mild and you can live a normal life.

First, you must obtain an accurate diagnosis so that you can be absolutely certain you have porphyria and if so, the type. Speak to your doctor in this regard. Patients with Porphyria can help themselves by avoiding alcohol or any other known trigger for the condition. Smoking is considered another contributing factor.

Consider your work environment in regards to the chemicals you may come in contact with.

Diet is important. Eat regularly and avoid fad diets which may reduce carbohydrate intake below the recommended required level.

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