



Campaigning  
For Equality

# Women's Equality Women's Health – Thalassaemia



An advice leaflet  
for Usdaw Members



# What is Thalassaemia Major?

**Thalassaemia Major is a serious form of anaemia which is inherited from both parents.**

Our blood carries oxygen from the lungs to every part of our bodies. Oxygen is carried in the haemoglobin which is part of the red blood cells.

**People with Thalassaemia Major cannot produce enough haemoglobin within their blood cells.**

**When there is not enough oxygen in the blood we become anaemic.**

**Thalassaemia Major is not contagious or infectious. It is inherited.**

## Who does it affect?

It is most common amongst people of Mediterranean descent, including people from Cyprus, Italy, Spain, Portugal, as well as North Africa, India, Pakistan, Bangladesh, the Middle East and the Far East.

## How do you know whether you have Thalassaemia Trait?

If you are concerned that you may have Thalassaemia Trait, you can ask your doctor to refer you to the local hospital for a test. A simple blood test tells you whether you have inherited Thalassaemia Trait.

**Thalassaemia Major is not contagious or infectious. It is inherited. Thalassaemia Trait, which is also called Thalassaemia Minor, is not the same as Thalassaemia Major – this is also not contagious or infectious and it cannot turn into Thalassaemia Major.**

## Thalassaemia is an important issue for Usdaw

- As workers, people with Thalassaemia Major will have special health concerns which need to be understood and shared by workmates and employers.
- Women and men with Thalassaemia Major or Trait will face difficult decisions about having children and extending families. The stress and pressure this may create can affect lives inside the workplace as well as outside.
- Women will usually be the people who deal with the day-to-day caring needs of children, partners and relatives, as well as their own needs, in the absence of adequate back-up and support services from the Government.
- During pregnancy, women may need extra support to deal with day-to-day concerns.

## What can Usdaw do?

- Make sure our members and employers know about Thalassaemia and its effects.
- Campaign for Government funding of research, especially into an eventual cure, alternative forms of treatment and administering treatment, and for support services.
- Take up workplace issues such as:
  - Procedures to ensure recognition of Thalassaemia to avoid discrimination in hiring, in employment and in promotion.
  - Paid time-off for treatment.
  - The provision of a suitable working environment which takes the special needs of workers with Thalassaemia into account.
  - Paid time off for screening.
  - The provision of confidential counselling and support services.

## Further information

The Thalassaemia Society provides information, support and counselling.

UK Thalassaemia Society  
19 The Broadway  
Southgate Circus  
London N14 6PH

Tel: 020 8882 0011  
email: [office@ukts.org](mailto:office@ukts.org)  
web: [www.ukts.org](http://www.ukts.org)

The ATR-X Support Group provides information, support and contact with other families living with the condition.

ATR-X Support Group  
82 The Crescent  
Northwich  
Cheshire CW9 8AD

Tel: 01606 44943

## How does Thalassaemia Major affect you?

- Thalassaemia Major causes severe anaemia.
- Babies born with Thalassaemia Major may show no signs of the disorder until they are three to six months old, when they may become anaemic. This may cause eating and sleeping difficulties resulting in tiredness and irritability.
- People with Thalassaemia Major are treated with regular blood transfusions. This can prevent or reduce complications.
- Treatment by drug is also necessary to reduce the dangerous levels of iron which can build up, which can affect the liver and the heart.
- The combined use of blood transfusions and an iron-removing drug enables many people with Thalassaemia Major to live a fully active life.

### What is Thalassaemia Trait?

- Thalassaemia Trait, which is also called Thalassaemia Minor, is not the same as Thalassaemia Major.
- People with Thalassaemia Trait are perfectly healthy and do not require special medical treatment.
- Thalassaemia Trait cannot turn into Thalassaemia Major.
- Thalassaemia Trait is not contagious or infectious.
- An important point is that if two people with Thalassaemia Trait have children then there is a one in four chance that the child could inherit Thalassaemia Major, a one in two chance that the child could inherit Thalassaemia Trait and a one in four chance that the baby would have normal haemoglobin.

# Usdaw contacts

To find out more about the work of the Divisional Equalities Forums and Usdaw's equality work or about joining Usdaw contact:

## South Wales and Western Division

Cardiff Office  
Tel: 029 2073 1131  
email: cardiff@usdaw.org.uk

## Eastern Division

Waltham Cross Office  
Tel: 01992 709280  
email: walthamx@usdaw.org.uk

## Midlands Division

Redditch Office  
Tel: 01527 406290  
email: redditch@usdaw.org.uk

## North Eastern Division

Leeds Office  
Tel: 0113 232 1320  
email: leeds@usdaw.org.uk

## Scottish Division

Glasgow Office  
Tel: 0141 427 6561  
email: glasgow@usdaw.org.uk

## Southern Division

Morden Office  
Tel: 020 8687 5950  
email: morden@usdaw.org.uk

## North West Division

Warrington Office  
Tel: 01925 578050  
email: warrington@usdaw.org.uk

## Equalities Section

Usdaw  
188 Wilmslow Road  
Manchester M14 6LJ  
Tel: 0161 224 2804  
email: equalitymatters@usdaw.org.uk



Improving workers' lives –  
Winning for members  
[www.usdaw.org.uk/equalities](http://www.usdaw.org.uk/equalities)

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