

TTD

Trichothiodystrophy

Trichothiodystrophy is a rare condition that causes a critical reaction when exposed to light. This condition is so painful that Trichothiodystrophy sufferers must not be exposed to UV RAYS must be covered up whenever going outside, must wear UV protective clothing , sunscreen at all times and spend as little time outside as possible, it is important that the quality of life of these individuals is maintain , so the hours which a person can venture outside is between the times of 4am to 7am and then from 6pm to 7am, in the winter months , in the summer months the person must measure the level of UV before venturing outside as levels need to be as low as 1 for the UV not to damage , although some people with TTD have been known to be affected after being exposed for less than ten minutes on this level of UV.



Trichothiodystrophy is a rare Genetic DNA repair disorder. Many symptoms can arise and early diagnoses is essential it can help to manage some of the symptoms of the disorder early.

One of the most common features of TTD is hair loss, lack of speech, failure to thrive, stunted growth, photosensitivity to light and sunlight, UV especially, loss of language skills, some times the children may be known to be quite small at birth and have continued failure to thrive.

Trichothiodystrophy is a rare genetic dna repair disorder, it has a group of symptoms and signs can also be characterised by the number of different skin problems , blistering , hair loss whenever exposed to any form of light.

To recognise this illness includes DNA tests, Genetic testing, observations and history taking, thorough medical examination and a hair strand test also needs to be done .

If you feel your child may have TTD or a similar illness please contact Maria Liistro, a support group has been set up and the contact person is Maria has also set up a webpage to describe in detail her perception of her sons illness, as TTD is extremely rare, there are many different variants of the illness, Maria s son Sammy-Joe has the photo sensitive kind, but there are also five different variants in the illness, most sufferers blister, experience extreme pain when being exposed to light, and also chronic hair loss.

Trichothiodystrophy is a DNA repair disorder, which means the cells are constantly breaking down due to UV exposure and cannot be repaired, the result is they die off and mutate causing all sorts of problems to health and tremendous pain for sufferers.

Bright lights, sunlight, glare, and fluorescent lights bombard the central nervous system and result in fatigue, anxiety, dizziness, headaches, and other physical problems. Natural sunlight and glare make it hard for sufferers to sustain visual focus. Fluorescent light, and the sun in particular, are the most problematic to their everyday living.

Some people may also have other characteristics such as poor weight gain, failure to thrive , Autistic characteristics , insufficient immunity and also experience allergies and skin disorders. We can all help provide care and enhance their survival to give these children a better quality of life. There are certain measures that can be put into place, things such as Tinted windows, solar protective clothing , roller shutters and the right sunscreen can be applied and used. A diagnoses needs to be established and this can happen if your family doctor refers you to the nearest Genetic Department in your area.

If you think you also need help with this please contact:

Maria Liistro (Support Group spokesperson) on
PH:03 9305 61 82 Mobile 0407 558 151 or email sammyjo2@bigpond.com.au

We are here to guide you in the right direction.

For more information please visit Sammy-Joes website:
www.vp-it.com.au/sammyjoe and www.caringbridge.org/ok/sammyjoe