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HITS (Worldwide) Family Support Network

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AN INTRODUCTION TO HI



We're Hitting Back!

The Hypomelanosis of Ito Syndrome

HITS (Worldwide)

Family Support Network

INTRODUCTION

Many families when first given the distressing news that their child has HI are devastated and distraught because they are also told that the syndrome is extremely rare and that they may never come across another family with HI so they feel isolated and alone. And, for some, this has been true.

However, this is no longer the case because HITS (Worldwide) was established by families already affected by HI to support other families during this distressing time.

WHAT IS HI

The definition of HI is: A neurocutaneous syndrome of streaky, patchy, whorl-like, or linear macular hypopigmentation of the skin, often associated with seizures, developmental and intellectual retardation and other anomalies.

The symptoms of HI include: Asymmetry of the body, patchy pigmentation which can occur on any part of the body, but not normally the palms, scalp or soles of the feet. Gross motor and psychomotor retardation, epilepsy, scoliosis, dental and bone anomalies, unusual ophthalmic features and kidney problems, amongst others.

Diagnosis of HI

HI is a manifestation of an etiologically heterogeneous group of disorders, some of which are associated with genetically distinct cell lines.

WHAT IS HITS (Worldwide)

HITS (Worldwide) is a family support network which was specifically set up by families to support other families with this syndrome because no other support group existed anywhere else in the world.

HITS (Worldwide) aims to support families by e-mail, telephone, Yahoo Group and Facebook” and by bringing families together at events to reduce the sense of isolation often felt.

The Family Support Network’s aim is: To enrich the lives of families and children affected by Hypomelanosis of Ito by facilitating and encouraging communication and linking families together, and by being a focal point offering verbal and written support :

- To put families who have a common situation or difficulty in touch with each other to enable them to gain mutual support and friendship.
- To reduce the sense of isolation families and children with disabilities or special needs often feel.
- To liaise with the medical profession to communicate the group’s existence and to share medical information available to us.
- To produce an annual Newsletter.

- To organise an Annual or Bi-Annual Family Event.
- To promote the importance of the group and the need for communication.

Terri Grant, Chair.

MEMBERSHIP

Membership is open to all families in the UK and throughout the world affected by HI.

Please contact Sandra Field at the address at the back of this leaflet or Terri Grant at

Indy5258@hotmail.com

for further information relating to HI or HITS (Worldwide).

We currently support families in the UK and Ireland, Argentina, Australia, Belgium, Brazil, Canada, Chile, Cyprus, Denmark, Ecuador, France, Germany, Holland, India, Italy, Japan, Malta, Mexico, New Zealand, Singapore, South Africa, Spain, Sweden, Turkey, United Arab Emirates (Dubai) and the USA (including Hawaii).

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