

# where to find further support

## trps support group uk

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## trpsa (trichorhinophalangeal syndrome association)

This is an American based support group with international membership that offers support, compassion and information to those with TRPS.  
<http://health.groups.yahoo.com/group/TRPSA/>

## facebook profile

[www.facebook.com](http://www.facebook.com)

# where to find further support

## the london clinic

### CONTACT:

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*Supporting those with  
Tricho-Rhino-Phalangeal Syndrome*

# what is trps?

TRPS represents the genetic condition of TrichoRhinoPhalangeal Syndrome.

## cause

- ✎ A change in the genetic make up of a developing embryo.

## types

- There are three known types
  - ✎ TRPS 1
  - ✎ TRPS 11
  - ✎ TRPS 111

## common features

- ✎ Short stature
- ✎ Sparse and slow growing hair
- ✎ Bulbous tip of the nose
- ✎ Protruding ears
- ✎ Fingers and toes may be short and crooked

## features of type 11

- (Previously known as Langer-Giedion Syndrome)
  - ✎ Presence of exostoses - outgrowths of (bony lumps) of cartilage. These are benign, but, can cause pain.
  - ✎ Often accompanied by learning difficulties.

## features of type 111

- (This is very rare)
  - ✎ Short fingers and toes
  - ✎ Limited stature

## general

Many people with TRPS comment on their similarity in looks. This requires a multidisciplinary approach to care. Appearance can be mild through to severe. Making precise diagnosis difficult without a genetic screening.

# what is the trps support group uk?

A patient-led group of individuals

## aim

To provide kindly and sympathetic support to those affected by TRPS, their families and loved ones.

## about the group

- ✎ TRPS is a not-for-profit organisation, our members are all volunteers.
- ✎ We are a small group, all members live daily with the affects of TRPS.
- ✎ All have a desire to help others who may be without support and/or information about the condition.
- ✎ We seek to give reassurance from our own experience, passing on our knowledge and enabling others to gain self assurance and respect about living with TRPS after diagnosis.

## support

Support is offered in a variety of ways

- ✎ A forum for exchanging knowledge, as well as seeking further information.
- ✎ Supply contact details to source clinical help and management.
- ✎ We are willing to speak by phone to those requiring a listening ear.
- ✎ Exchanged emails
- ✎ Arrange introductions (after permissions are obtained).
- ✎ We have a profile established on the social networking site of 'facebook'

## our hope

We hope that by building a wider network of membership across the UK, awareness of this very rare condition will be improved amongst the broader community and a wider understanding amongst the professionals, such as Doctors, health professionals and teachers.

## future plans

- ✎ Work on building our website will soon begin, making communication easier and more beneficial.
- ✎ As membership grows it is hoped that Charity Status can be sought. Giving us greater recognition and help with fund raising to discover further treatment regimes and extend diagnostic services.

## in the mean time

A London Clinic has been established for those who have never been diagnosed or for whom further guidance and advice is required after diagnosis at another regional genetic centre closer to home.

A fuller idea of the life time impact of the disorder is being recorded and monitored by the Professor of Genetics and Clinical Lecturer and Consultant in Clinical genetics leading the work here.

Contacts are already made with regional centres and slowly European alliances will become established.

## our main aim

To assure you that we are lay people, who understand that you may have many doubts, anxieties and questions, still unresolved.

Most of all we seek to befriend and assist you, and would like to invite you to come and join us.

Your contribution really matters!

**Care, Concern, Compassion.**