

# Registration

Send to: K-T Support Group • 5404 Dundee Road • Edina, MN 55436  
or email information to: ktnewmembers@gmail.com

Name \_\_\_\_\_

Parents' name (if applicable) \_\_\_\_\_

Street address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_

Birthdate \_\_\_\_\_

Email address \_\_\_\_\_

*I understand that there is no charge for registration; however I am enclosing a donation of \$ \_\_\_\_\_ for further support and informational services.  
(All donations are tax deductible.)*



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## KLIPPEL-TRENAUNAY

And the

## K-T SUPPORT GROUP



## INFORMATIONAL BROCHURE

Klippel-Trenaunay Support Group  
5404 Dundee Road  
Edina, MN 55436  
(952) 925-2596  
www.k-t.org  
ktnewmembers@gmail.com

# THE KLIPPEL-TRENAUNAY SYNDROME

## 1. Symptoms

The K-T Syndrome is a rare congenital malformation that may include the following:

- a) Port-wine stain or birthmark” (cutaneous capillary malformations)
- b) Soft tissue and bony hypertrophy (excessive growth of the soft tissue and/or bones)
- c) Venous malformations & lymphatic abnormalities

Complications may include bleeding, cellulitis, venous thrombosis, or pulmonary embolism. Associated abnormalities in other systems, such as gigantism of toes, hand and feet anomalies, lymphedema, or involvement of the abdominal and pelvic organs may also occur.

K-T usually is limited to one limb, but may occur in multiple limbs and/or head or trunk area. Internal organs may be involved. Each case of K-T is unique and may exhibit the above characteristics to differing degrees.

## 2. Etiology

The etiology of Klippel-Trenaunay Syndrome is unknown. One theory is that K-T may be caused by mesodermal abnormalities during fetal development. Another medical opinion suggests the cause may be the result of mutation of a gene.

## 3. Treatment

There is no known “cure” for the K-T Syndrome. Conservative treatment of the symptoms seems to be

the most effective, without significant side effects. For example, elastic garments and pumps often relieve the effects of lymphedema. The elastic garment is also helpful in protecting the limb from trauma and decreasing the chances of bleeding from the hemangioma. Laser therapy may reduce or eliminate port-wine stains. Surgical procedures may be necessary: to debulk excessive tissue, to excise veins or hemangiomatous tissue or to correct uneven growth in limbs (epiphyseal arrest), for example.

Computed Axial Tomography (CAT) and Magnetic Resonance Imaging (MRI) scans, and color doppler studies are useful in determining the scope of the syndrome and how best to manage it. Interventional radiologists may, in some cases, perform minimally invasive alternative treatment of vascular and lymphatic malformations, but this type of therapy is best performed by interventional radiologists with extensive experience and training in the field of vascular anomalies, and with specialized knowledge of K-T syndrome.

## 4. Terminology

The medical community at times has used the terms Klippel-Trenaunay Syndrome and Klippel-Trenaunay-Weber Syndrome inter-changeably. The consensus today is to distinguish K-T as hypertrophy and varicosity associated with port-wine staining; Parkes-Weber Syndrome is similar, but includes significant arteriovenous malformations.

## 5. Membership

The Klippel-Trenaunay Support Group welcomes patients and their families as members.

## 6. Activities

K-T Support Group activities include bi-annual meetings of patients and their families with speakers and a panel of medical experts. The Group maintains an informative web page and a confidential group roster (distributed only to group members). A periodic

newsletter of shared experiences is available online to members. A file of medical literature pertaining to K-T is maintained. Phone support among members is available. Membership privacy always is respected.

## 7. Affiliations and Tax Status

The K-T Support Group is an Associate member of the National Organization of Rare Disorders (NORD). The K-T Support Group encourages contributions from members and others interested in Klippel-Trenaunay Syndrome. All activities are funded by and dependent upon these contributions which are the Group’s sole means of financial support. Donations are greatly appreciated and put to maximum use in furthering support and informational services. No one is refused admission to the Group for financial reasons, however.

The K-T Support Group is a 501 (c)(3) non-profit organization, and all donations are tax-deductible.

## 8. Objectives

The Group’s mission is to provide support for K-T Syndrome patients and their families. Our objectives in accomplishing this mission are:

- To act as a support group for sharing experiences and information,
- To provide a clearinghouse for correspondence among members,
- To maintain a list of current medical literature pertaining to K-T Syndrome and to make it available to members and professionals.

