

Registration

Send to: K-T Support Group 1471 Greystone Lane Milford, OH 45150
Or register online at www.k-t.org

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. Donations are also accepted through PayPal at <http://k-t.org>. (All donations are tax deductible.)



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About K-T



An informational brochure

KLIPPEL-TRENAUNAY and the K-T SUPPORT GROUP

Klippel-Trenaunay Support Group
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KLIPPEL-TRENAUNAY SYNDROME

1. Symptoms

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

- a) Cutaneous capillary malformation (port wine stain or birthmark)
- b) Soft tissue and bony hypertrophy (overgrowth)
- 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

Recent studies indicate a mutation of the PIK3CA gene is involved in a group of closely related overgrowth conditions (CLOVES, M-CM, FAVA, K-T). These are referred to as PIK3CA Related Overgrowth Syndromes (PROS).

3. Treatment

There is no known “cure” for K-T Syndrome. Conservative treatment of the symptoms at a multidisciplinary clinic is recommended. Compression garments and pumps help manage the effects of lymphedema and can assist in protecting the limb from trauma. Recent drug trials with Sirolimus have proven helpful in some cases. Laser therapy may reduce or eliminate port-wine stains and help control lymphatic blebs. Surgical procedures may be necessary to debulk excessive tissue, to excise ectatic veins 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 complex combined vascular malformations.

4. Terminology

The medical community at times has used the terms Klippel-Trenaunay Syndrome and Klippel-Trenaunay-Weber Syndrome interchangeably. The consensus today is to distinguish K-T as hypertrophy and varicosity associated with capillary malformation; Parkes-Weber Syndrome is similar, but includes significant arteriovenous malformations. K-T is also referred to by an acronym describing the body systems affected—**Capillary, Lymphatic, Venous Malformation (CLVM)**.

There is often substantial crossover in presentation in the PIK3CA Related Overgrowth Syndromes (PROS), or in other conditions with similar phenotype, resulting in often inexact diagnoses.

5. Membership

The Klippel-Trenaunay Support Group welcomes patients of K-T and related conditions and their families as members.

6. Activities

K-T Support Group activities include biennial 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). Social networking via Facebook is available online. Quarterly newsletters are electronically delivered to members. Copies of archived newsletters relating shared experiences are available to members on the website. 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.

