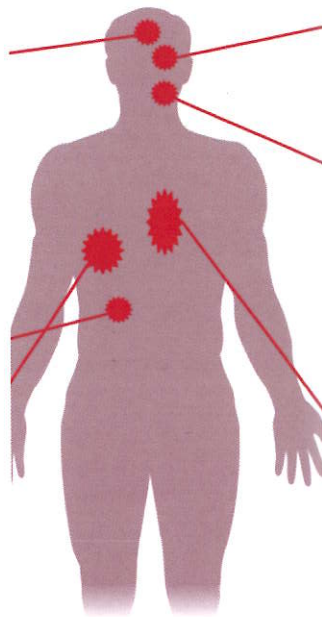


## 甚麼是結節性硬化症？

結節性硬化症——Tuberous Sclerosis Complex (TSC)，是罕有的先天性或遺傳性基因突變疾病。

患者體內細胞失控地增生，導致重要器官長出大量腫瘤，影響器官功能，引發嚴重的健康問題。

患者體內不同器官會出現大量的良性腫瘤，不單影響該器官功能，大部分患者更有癲癇症、智力障礙、情緒問題等等。若得不到適當藥物治療，腫瘤生長不受控制，甚至會破裂和出血，甚至威脅患者生命。



### 現時治療方法：

- 目前尚未有任何根治的治療方法
- 藥物治療：mTOR抑制劑（需長期服用，抑制腫瘤生長，否則腫瘤會復發）
- 若體內腫瘤過大，嚴重影響身體運作，可考慮採用切除手術

研究發現，每7000人就有1個人患上此病。截至2018年，全港有284名患者。

## 關於香港結節性硬化症協會

我們是一群患者及患者家屬成立的組織。



通過建立此平台，我們希望：

- 讓結節性硬化症患者和家屬交流互助
- 加強患者、家屬及醫護人員的溝通
- 支援患者和家屬，讓患者得到適當的治療
- 提升本地結節性硬化症的醫療及護理水平
- 為結節性硬化症患者爭取合理的醫療服務
- 增加公眾對此病症的認識



香港結節性硬化症協會  
Tuberous Sclerosis Complex  
Association of Hong Kong





## 過往的工作

### 連結兩岸三地

- 定期舉辦學術研討會和活動

### 連結國際

- 協會委派委員及贊助醫科生參加TSC國際會議
- 邀請海外TSC專家來香港與本地醫生及病人舉行座談會

### 連結社區

- 接受傳媒訪問
- 舉辦大型籌款、義賣活動
- 組成醫院義工團隊
- 拜訪學校，舉辦分享會
- 參與院校組織的「真人圖書館」

## 未來工作及發展

### 醫患同行

- 資助醫科學生參與國際性會議
- 舉辦不同的活動和醫生講座
- 舉行罕有不罕見「3CM」放映會

### 醫療輔助

- 爭取跨專科綜合治療
- 遙距診症支援
- 促進公私營醫療機構合作計劃
- 引進腦癲癇監測手錶
- 引進瑞士皮膚塗敷藥物

### 罕病資料庫

- 建立兩岸三地結節性硬化症華人數據庫

### 結伴作樂

- 為患者提供為期兩年的管弦樂培訓及表演機會
- 為協會10周年慶典作準備

我覺得這是基本的醫療權利。我能負擔，不代表其他家庭能夠負擔。所以我認為這是一個原則性的問題、一個社會公義的問題。

——TSCAHK創辦人、患者家屬 Rebecca

只要肯努力堅持，無論是站在那裡起步，都一樣可以發光發熱！

## 捐款或聯絡我們



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香港浸會大學翻譯工作室

特別鳴謝：香港浸會大學翻譯工作室



TSCAHK is an organisation founded by a group of patients and their families.



## Mission & Objective:

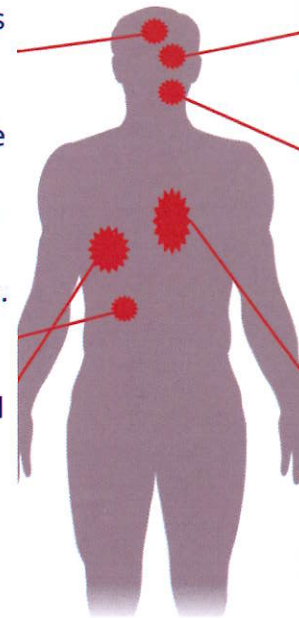
- Provide a platform for TSC patients and their families to communicate and support each other
- Improve communication between patients, their families, and medical personnel
- Support TSC patients and their families and let patients to receive suitable treatments
- Improve local medical and healthcare level for TSC
- Strive for reasonable medical services for TSC patients
- Raise public awareness of TSC

## What is Tuberos Sclerosis Complex?

Tuberos Sclerosis Complex (TSC) is a rare congenital or hereditary disease from genetic mutations.

Cells will grow in the patient's body exponentially and uncontrollably, which will lead to multiple tumours growing in vital organs. It will affect the function of the organs and cause critical health problems.

Multiple benign tumours will appear in patients' organs. They not only affect the function of the organs, most patients also have epilepsy, intellectual disability, emotional problems, etc. If they don't receive appropriate medical treatments, tumours will grow uncontrollably, even burst, bleed, and finally threaten their lives.



## Current treatment:

- No radical cure for TSC currently
- Medical treatment: mTOR inhibitors (require long-term usage to prevent the growth of tumours or they might recur)
- Surgical resection may be considered if the tumour is too big and severely influence the operation of the body

Studies have found that 1 out of 7,000 people suffer from this disease. As of 2018, there are 284 patients in Hong Kong.



香港結節性硬化症協會  
Tuberos Sclerosis Complex  
Association of Hong Kong





## Past Work

### Connect with China, Taiwan, Hong Kong and Macau

- Organised academic seminars and events regularly

### Connect with the World

- Appointed committee members to take part in international conferences on TSC by Association and sponsored medical students to join as well
- Invited overseas TSC experts to come to Hong Kong to hold symposiums with local doctors and patients

### Connect with the Community

- Accepted media interviews
- Held large-scale fundraising events and charity sale
- Formed a hospital volunteer team
- Shared in schools
- Took part in "Human Library" organised by institutions



## Future Work and Development

### PATIENTS & DOCTORS HAND-IN-HAND

- Subsidise medical students to participate in international conferences
- Organise different activities and medical talks
- Hold the screening of a documentary : 3CM

### MEDICAL ASSISTANCE

- Strive for integrated multidisciplinary treatments
- Support tele-consultation
- Facilitate public-private clinical institutions partnership programme
- Introduce brain epilepsy monitoring watch
- Introduce skin applying medication from Switzerland

### DATABASE FOR RARE DISEASES

- Develop a database of TSC Chinese patients from China, Taiwan, Hong Kong and Macau

### HAVING FUN TOGETHER

- Provide patients with a two-year orchestral training and performance opportunities
- Prepare for Association's 10th anniversary



I think this is a basic medical right. Although I can afford the medical expenses, it doesn't mean other families can afford the expenses either. Therefore, I think this is a matter of principle and social justice.

—Founder of TSCAHK,  
Mother of a patient, Rebecca

As long as you are willing to persevere, you can shine regardless of where you start.

## Donate or Contact Us



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