

脊髓損傷在中國及香港的情況及 成立「香港大學脊髓損傷基金」 新聞發佈會

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脊髓損傷可造成不同程度的肢體及身體其他機能障礙，病人可能會出現行動不良、失去知覺、失禁和因長期缺乏運動而導致的各種併發症，大大影響病人及其照顧者的日常生活。

在中國，每年大約有數萬個脊髓損傷的新病例，而且患上慢性脊髓損傷的病人眾多。有見及此，香港大學醫學院與美國、內地及本地多位專家成立中國脊髓損傷網絡，以進行脊髓損傷的研究及臨床測試。中國脊髓損傷網絡的成員已於九月十四及十五日一連兩天於港大醫學院舉行了的交流會議，以加強雙方的合作及交流。

香港大學亦將成立**香港大學脊髓損傷基金**，希望能為香港及中國脊髓損傷網絡提供支援，以研究及發展安全、可行及有效的療法治療脊髓損傷。

此外，中國脊髓損傷網絡及香港大學醫學院計劃在二零零五年十月在香港首次舉行大型國際性有關脊髓損傷臨床測試及療法研討會，預計將有1,000名來自醫學界的代表、科學家、脊髓損傷病患者家屬、藥物及生物科技工業界代表、基金代表以及有關政府部門參與出席，一同見證研究人員在中國臨床測試的成果。

如欲支持中國脊髓損傷網絡及香港大學醫學院的工作，可以支票形式捐款，支票抬頭請註明“**HKU – SCI Fund**”或「**香港大學脊髓損傷基金**」，郵寄到香港大學鈕魯詩樓九樓，香港大學發展及校友事務部收。

希望社會大眾能多多支持中國脊髓損傷網絡及香港大學醫學院非常有意義的工作，使病人有機會恢復活動能力，享受健康的人生。

謝謝！

Speech of Professor Wise Young

*Professor II & Chair,
Department of Cell Biology & Neuroscience,
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The China SCI Network

Spinal Cord Injury (SCI) has long been considered to be irreversible. For much of human history, doctors have told patients and families with SCI that they should not hope for therapies that will restore function. In the past decade, this has changed. Many animal studies have shown that the spinal cord can regenerate. Dozens of therapies have now been reported to improve recovery in animals and some are being tried in humans. However, few of these treatments have been tested in clinical trial.

China is taking the leadership in bringing spinal cord injury therapies to clinical trial by establishing the **China Spinal Cord Injury Network (China SCI Network)**. The Network will initially have six nodes: Beijing, Guangzhou, Hong Kong, Shanghai, Xi'an, and Zhengzhou. The spinal cord centers in these six nodes have the capability of randomizing thousands of patients to the most promising experimental therapies compared with the best standard therapies. The clinical trial will be rigorously designed and executed, compatible with the highest international medical standards.

The University of Hong Kong is proud to be the coordinating center for the **China SCI Network**. I will work with Professor Kwok-Fai So from the University of Hong Kong as the co-directors of the Network. A distinguished board of advisors has been appointed to help with the fundraising. A board of investigators from each Network node will begin regular meetings to standardize care and outcome measures, to consider possible therapies to test, and to plan clinical trials with Professor Johan Karlberg who heads the Clinical Trial Centre at the University of Hong Kong.

The initial funding for the **China SCI Network** will be raised in Hong Kong by a group of dedicated families, scientists, clinicians, and other people who are committed to finding a cure for spinal cord injury. In March and October 2005, the Network will sponsor fundraising events in Hong Kong to raise the money needed to run the **China**

SCI Network. The Network plans to initiate its first randomized clinical trial by the end of 2005.

The mission of the **China SCI Network** will accelerate development and availability of therapies that improve function in people with spinal cord injury all over the world. The **China SCI Network** will work closely with other spinal cord injury clinical trial networks that are being established in North America, Europe, South America, and in other Asian countries. The **China SCI Network** will work closely with the pharmaceutical and therapeutic industry partners to help convince them to invest in spinal cord injury therapy development.

The **China SCI Network** is the first clinical trial network in Asia. As such, it may well serve as a template for clinical trials of therapies for other neurological conditions, such as head injury, stroke, Parkinson's disease, amyotrophic lateral sclerosis, multiple sclerosis, and many other conditions. By adhering to the highest international medical standards, including the U.S. FDA, the network will enable China to join the international clinical trial community testing the most promising therapies of therapies.

For many families with spinal cord injury who have been told that there are no therapies that can restore function, hope is on the way. The **China SCI Network** is a partnership between the community of families with SCI, scientists and clinicians, and members of the pharmaceutical and biotechnology industry who are committed to fulfilling that hope for the millions of people who impatiently await therapies.

楊詠威教授講辭

新成立中國脊髓損傷網絡 為脊髓損傷治療帶來曙光

脊髓損傷一直都被認為是不能根治之症。長久以來，醫生都告訴脊髓損傷病人及家屬，單依靠療法並不能完全恢復病人的活動能力。但隨著近年的醫學發展，這說法已經成為歷史，現時有不少動物測試結果均證實脊髓可以再生，很多治療亦被證明有助脊髓損傷病患者康復，但當中只有小部分的療法曾進行臨床測試。

最近，中國成立了**中國脊髓損傷網絡 (China SCI Network)**，積極參與脊髓療法的臨床測試，該組織已在香港、北京、上海、廣州、西安及鄭州六個城市設立實驗中心。實驗中心設備先進，為病人進行適切的實驗性療法，而中心進行的臨床測試更可配合國際醫療標準。

很榮幸香港大學能成為**中國脊髓損傷網絡**香港的協調中心。我將與香港大學醫學院蘇國輝教授合作負責監察中心的運作，中心亦委任了本港知名人士組成顧問團，負責籌募經費工作。來自六個中心的研究員會定期進行會議，統一臨床測試的細節、程序及量度標準，以及相討其他可進行臨床測試的療法，並與香港大學醫學院臨床試驗中心的總監 Professor Johan Karlberg 計劃臨床測試。

香港將舉行為**中國脊髓損傷網絡**的籌募運作經費活動，該活動由一群致力找出徹底可醫治脊髓損傷療法的科學家及臨床研究員統籌，預計將會分別於二零零五年三月及十月舉行。他們計劃於明年年底進行首次隨機抽樣臨床測試。

研究高效性的治療及加速發展以改善全球脊髓損傷病患者的活動能力是**中國脊髓損傷網絡**的成立理念。他們將會與其他來自北美洲、歐洲、南美洲及其他亞洲國家進行有關脊髓損傷臨床測試的組織緊密合作，同時他們亦會與藥廠及業界相討開發有關治療脊髓損傷的發展。

中國脊髓損傷網絡是第一個在亞洲地區進行臨床脊髓測試研究的組織。因此，它亦可以為頭部創傷、中風、帕金森症、肌萎縮性脊髓側索硬化、多發性硬化等神經系統疾病療法的臨床測試作參照。配合最新的國際醫療技術，包括符合美國食品及藥物管理局標準，**中國脊髓損傷網絡**將帶領中國加入國際性的臨床測試組織，參與臨床治療工作。

中國脊髓損傷網絡的成立將為無數曾經對脊髓損傷而感到無望康復的患者及家人帶來新的希望，它亦將成為病人及家屬、科學家及臨床研究人員、藥物及生物科技工業的新夥伴。



一位脊髓損傷病人母親的信

很多人從不以為脊髓損傷會發生在自己或他們的摯愛身上。每天我接到的電話，都有一些令人傷感的故事—平日能活動自如的人竟瞬息間變成癱瘓。

有一天，我從電話接到一個有關我兒子的壞消息，這簡直是惡夢的開始。

我在香港居住，我的小孩子也在這裡上學。我覺得中國人都富有同情心。

中國脊髓損傷網絡為全世界的人帶來希望，為全世界每個心碎的母親帶來新的曙光。

感謝研究脊髓損傷的香港大學及內地的所有教授及醫生，他們為我們的病人及家屬送上了無盡的關懷及支持

在此我謹代表每一個母親，送上最真摯的感謝。

A letter from a mother of spinal cord injury patient

People think a spinal cord injury can never happen to them or someone they love. Everyday my phone rings with very sad stories about people who are doing ordinary things but got paralyzed.

One day I got a very terrible phone call. It was about my own son. It was the beginning of a nightmare.

I lived in Hong Kong. My Children went to school here. I found the Chinese to be very caring people.

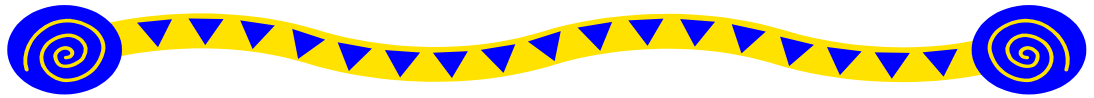
This China Spinal Cord Injury Network is a very caring deed. It will bring hope to people all over the world. It will bring hope to heartbroken mothers all over the world.

I want to thank the University of Hong Kong and all of these Professors and Doctors in China for being so caring, and so courageous.

For mothers everywhere, thank you from the bottom of my heart.



*From: Dr Patricia Morton
Director, Planning and Development
The Spinal Cord Injury Project
Rutgers University, USA*



斌仔的來信—好消息

一次意外，我折斷了頸椎的第一、二節，致使全身癱瘓及不能自我呼吸。在不得動彈的日子裡，大部份的時間都是在等。等日夜的交替；等別人的幫忙；等親人朋友的探望；等死亡一刻的來臨。等的滋味是如何？相信我就算用上千百詞語亦難道出真正的感受來。但其實傷害我更深的是求。求別的手為我餵食；求為我清潔；求為我搔癢；求為我做東做西。開口乞求本是一個降低自尊的行為，每事都要求人，難堪得叫我就此算吧。當遇上拒絕或臉色的時候，仰人鼻息的感覺沖走一切的意欲，我所擁有的尊嚴幾乎蕩然無存，生命的價值亦會質疑起來。

像寄生蟲般的生活，我已過了足足的十三年，那份無力感所帶給我的苦痛，早已磨滅盼望能夠再起身走路的心。怎樣去浪費時間就是我現在最重要的工作，人生意義已不在我的腦袋裡。在谷底裡徘徊，可以說是甚麼也沒有了。

突然，一線曙光照射過來，香港大學醫學院將會與美國及內地專家成立脊髓損傷專家網絡，共同研究治療脊髓受創的新方法，無疑是我們殘障病人的強心針。雖然可能終我一生亦未必讓我等到有效的成果，但有一個開始已經能重燃內心深處的希望。若果有一天我可以重新命令雙手，恢復自由意志，毋須再等待，既擺脫完全依賴別人而繼續生存，又重拾失去的尊嚴，這樣一定會帶給我新的生命。

Letter from Ah Pun — A Good News

I suffered from my first and second cervical spinal cord injury in an accident which led to paralysis and breathing difficulty by myself. During the days that I cannot exercise and move freely, I get used to waiting – waiting for the assistance of the others, waiting for the days and night to pass by, waiting for the visit of my friends and my beloved family members and waiting for the moment of death. Do you understand the feeling of “waiting”? I believe even using thousands of words could not describe my feelings completely. However, what indeed hurting me is “never-ending asking”: asking someone to feed me, clean me, scratch for me and to do this and that for me. Asking for help always devalued my self-esteem. When everything has to be asked for help, I rather give up. When being rejected, I choose to give up my requests. All my esteem barely retained, I started questioning the meaning of life.

Having spent my life in paralysis for 13 years, I live like a parasite. The helpless endlessly brings me great pain and I would never have a hope to stand and walk again. I can do

nothing but to kill time.

New hope is brought to me when the University of Hong Kong collaborates with experts from US and Mainland for setting up the China Spinal Cord Injury Network. The Network hopes to develop effective therapies for Spinal Cord Injury patients. The news strengthens the faith of patients like me. Though I may not be able to wait for the new therapy before I die, this great news relights my heart. If someday I can regain the ability of free body movement, I can then lead a happy life, without depending on the others.

I am looking forward to this brand new start of my life.



香港大學 - 脊髓損傷基金 HKU - SCI Fund

目標

由香港大學成立的香港大學脊髓損傷基金，志於為香港及中國脊髓損傷網絡提供支援，以研究及發展安全、可行及有效的療法治療脊髓損傷。

醫學界一直都認為脊髓損傷是不能根治之症，但科學家在近十年的研究中已推翻脊髓不能再生的理論。現時有不少動物測試結果均證實脊髓曾受損傷的動物可以恢復活動能力，但當中只有很小部分的療法曾進行臨床測試。由於在中國每年大約有數萬個脊髓損傷的新病例，而且患上慢性脊髓損傷的病人眾多，所以在中國建立臨床中心網絡，進行大規模脊髓損傷臨床測試以協助研究脊髓損傷療法，將得到比在其他地區更有效及更迅速的成果。

中國脊髓損傷網絡在北京、鄭州、廣州、香港、上海及西安六個城市設立實驗中心，將負責臨床測試脊髓損傷的療法。

香港大學及中國脊髓損傷網絡計劃在二零零五年十月在中國舉行首次國際性有關脊髓損傷臨床測試及療法研討會，屆時醫學界代表、科學家、脊髓損傷病患者家屬、藥物及生物科技工業界代表、基金代表以及有關政府部門將獲邀出席，一同見證研究人員在中國臨床測試的成果。

支持方法

可以支票形式捐款，支票抬頭請註明“HKU - SCI Fund”或
「香港大學脊髓損傷基金」。

郵寄地址：香港大學基金秘書處或 HKU Foundation Secretariat

查詢：852-2857-8584

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HKU - SCI Fund 香港大學 - 脊髓損傷基金

Objective

The “HKU – SCI Fund” is set up by the University of Hong Kong (HKU) to find ways of support for the Spinal Cord Injury (SCI) Network in Hong Kong and China to assess the safety, feasibility, and efficiency of promising therapies for human SCI.

Clinicians have long considered spinal cord injury to be an irreversible condition. In the past decade, scientists have overturned the dogma that the spinal cord cannot regenerate. Many therapies have now been reported to restore function in spinal-injured animals. However, few of these therapies have gone to clinical trial. As China presents a unique opportunity to carry out large-scale clinical trials of promising SCI therapies and regional medical centres in China see over a few ten thousands new cases a year and care for many people with chronic spinal cord injury, a network of clinical centres in China can test spinal cord injury therapies more efficiently and rapidly than any other country.

The **China SCI Network** is a network of spinal cord injury centers in Beijing, Chengzhou, Guangzhou, Hong Kong, Shanghai, and Xi’an that will carry out clinic trials of promising therapies. All the centers have investigators committed to developing spinal cord injury therapies.

The University of Hong Kong and the China SCI Network plans to host the first **Annual International Symposium on Spinal Cord Injury Clinical Trials and Therapies** in China, tentatively scheduled in October 2005. This symposium will showcase achievements of clinical trials in China. Clinicians, scientists, and families with spinal cord injury will be invited to participate, as well as representatives of the pharmaceutical and therapeutic industry, foundations, and government agencies.

Way of Support

Cheques can be made out to “HKU – SCI Fund”.

Mailing Address: HKU Foundation Secretariat

Enquiries: 852-2857-8584

Tax-deductible receipts will be issued by HKU.