**香港地中海型貧血病協會**
**The Thalassaemia Association of Hong Kong**
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Rm.201-203, Block B1, Nurses' Quarters, Queen Mary Hospital, 102 Pokfulam Rd., Hong Kong
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致 香港立法會衛生事務委員會主席及各委員

## 要求香港醫院管理局免費提供地中海貧血症新一代口服除鐵藥物 Deferasirox

香港地中海型貧血病協會（本會）一直積極向香港醫院管理局（醫管局）爭取將新一代的口服除鐵藥物 Deferasirox 納入「通用藥物」類別，免費爲香港的地中海貧血（地貧）病人提供較佳的除鐵治療，免除現有藥物引致嚴重或致命副作用的憂慮。

本會就上述訴求曾經兩度致函醫管局要求會面洽談，惜未獲回覆。及後於本年四月至五月期間，先後獲得立法會衛生事務委員會（委員會）主席及多名委員接見，以瞭解詳情，不勝感激。委員會隨即在五月十九日的會議上，決議將是項請求列入本年六月二十四日的會議議程中。

### 地中海貧血症

地貧是全球最常見的基因遺傳疾病。現時，全港約有 374 名重型地貧患者，他們因嚴重缺乏正常血紅蛋白，以致身體無法自行製造紅血球，必須終身每四星期到醫院接受輸血，以維持生命。患者同時需要經常進行除鐵治療，以防體內積聚過量鐵質，引致心臟衰竭、肝炎、肝硬化、腎衰竭等等嚴重疾病。

### 「通用藥物」— 皮下注射除鐵劑 (DFO)

目前，公立醫院爲地貧病人免費提供的除鐵藥是傳統皮下注射除鐵劑(DFO)，患者每星期要進行五至七次長達八至十二小時的皮下除鐵注射 。

經年累月的長時間皮下注射對病人的身心俱構成重大影響，常見的狀況包括骨枯、骨質疏鬆、傷疤、硬皮及注射部位長久腫脹；長期睡眠質素欠佳亦嚴重影響學習與工作能力、日常社交生活等。

### 「專用藥物」— 傳統口服除鐵藥物 Deferiprone（DFP）

現時，DFP 入於「專用藥物」類別，醫生多選用 DFP 作單一療法或配上 DFO 作混合治療，旨在減少病人注射次數及減輕傳統皮下注射劑的副作用。

但是 DFP 只適用於十歲或以上的病人，並有可能引致嗜中性白血球減少症或粒性白血球缺乏症。有關藥商早於二零零六年知會全球醫生，指藥物可能引致上述兩種嚴重情況，規定病人必須每星期抽血檢查白血球的水平，無形中加重醫療負擔。

**「自費藥物」— 新一代口服除鐵藥物 Deferasirox**

香港衛生署於二零零六年八月核准使用新一代的口服除鐵藥物 Deferasirox，新藥的副作用遠較上述兩類藥物爲少，只有短暫及程度輕微的皮疹、腸胃不適及腹痛等。新藥的服用方法亦非常簡便，每日只須服用一次，並可溶於飲品內，令病人易於遵循醫生指示，也能大大改善他們的生活素質。

醫管局現時將新藥納入藥物名冊內的「自費藥物」類別，病人必須自行負擔藥費。可是，全球有接近二十個國家由政府全數承擔 Deferasirox 藥費，包括鄰近的澳門、台灣、南韓及澳洲。

**地貧病人的訴求**

我們相信每條生命都是同樣寶貴，不論病者人數多少，均應該得到最佳效益的 治療；更加不應因爲經濟問題，而得不到合適的治療機會。其實香港自八十年代初推行產前檢查後，每年新增的地貧個案只有數個，病人數目增長有限，是以醫管局在這方面投放的資源亦不會大幅增加。

本會重申希望醫管局從速將新藥 Deferasirox 納入「通用藥物」類別，免費供給本港的地貧病人，好讓他們不用再擔心出現嚴重或致命的副作用。我們深信委員會對此事十分關注，並將會積極跟進醫管局與病人的商討進度。

現隨函附上下列文件供主席和各委員參考：

1. 澳門醫生信件
2. 地中海貧血兒童基金名譽會長楊執庸教授致醫管局的信件
3. 地中海貧血病人致醫管局的信件
4. 有關本港地中海貧血症的剪報
5. 地中海貧血國際聯合會治療指引
6. 由政府免費提供新藥 Deferasirox 的地方列表
7. 傳統皮下注射除鐵治療的相片及小冊子
8. 傳統皮下注射除鐵引致的副作用相片
9. 病人案例：傳統口服除鐵藥物 DFP 引致的副作用
10. 病人案例：傳統皮下注射除鐵治療引致的副作用

委員會對我們的訴求如有任何查詢，請與吳小姐或袁小姐聯絡（電話：2889-8399，電郵：thal@biznetvigator.com)。

祝　身體健康，工作愉快!

香港地中海型貧血病協會主席
梁家輝謹啓

二零零八年六月十八日

附件一：澳門醫生信件

June 16, 2008

Mr. Leung Ka Fai
Chairman
Thalassaemia Treatment Patient Concerned Group
c/o Children's Thalassaemia Foundation
Room 201-203, Nurses' Quarters Block B1
Queen Mary Hospital, 102 Pokfulam Road
Hong Kong
Email: ctfhk@biznetvigator.com

Dear Mr. Leung,

I am writing to you in full support of Hong Kong Thalassaemia patients' request for the reimbursement of deferasirox as first-line iron removal treatment at public hospitals, and to share with you the considerations that eventually led to the finalisation and the consolidation of this policy in Macau.

The Macau Health Authority started to evaluate the reimbursement of an oral iron chelator in January, 2008. The decision to fund deferasirox treatment was arrived at after the weighted consideration of the below factors:

**Efficiency**

At any given time only a small proportion of iron in the body is available for chelation. When comparing various treatments iron removal efficiency, deferasirox is found to be the most efficient[1] compared to deferoxamine[2] and deferiprone[3]

The goal of iron chelation is to bind the most toxic iron preventing it to cause tissue damage. In order to make this process work effectively, 24-hour non-stop chelation is required.

With this in mind it is preferable to have an iron removal therapy that offers the longest plasma half life. Among current available therapies, desferasirox has the longest half-life (9-11hrs) compared to deferiprone (1.52 hr) and deferoaxamine (0.3 hr), the last one requiring 8-12 hours subcutaneous continuous infusion.

**Better Patient Compliance**

After the introduction of deferasirox in Macau we witnessed a drastic improvement in patient well being ultimately leading to a better acceptance and compliance to this chronic treatment. The decreasing level of compliance becomes more obvious as the patients reach adolescence and adulthood where the way the drugs are administered interferes with the expectations and

way of life of an adolescent. A safe oral iron removal medication would completely side step this problem, not only enhancing compliance, but the ultimate treatment result and quality of life of Thalassaemia patients.

**Safety**

The safety profile is favorable compared to other available drugs in the market, allowing to be started early.

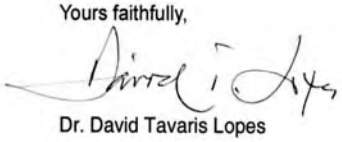
**Broad range of patients**

Iron removal is clinically preferred to start soon after a patient starts receiving blood transfusions. As most patients start to receive blood transfusions regularly during childhood, we believe deferasirox is the best choice as it allows patients as young as two to start treatment. Deferiprone, on the other hand, is only suitable for patients aged ten and above, meaning users have to suffer a painful few years using deferoxamine injection treatment until they are old enough for deferiprone.

Although deferiprone is also an oral therapy and is offered at a lower treatment cost than deferasirox, the Macau health authority chose to reimburse deferasirox as the first line iron-removal treatment for the better efficiency, safety profile of deferasirox and suitability for a broader age range of patients.

It is no small task for health authorities around the world to evaluate whether a medical treatment is cost-effective, especially with various options that all have their benefits and side-effects. The treatment outcome, patients well being and ultimately the patients productivity are the crucial factors. We hope this sharing of knowledge will assist your health authority to arrive a reimbursement decision that best fits Hong Kong Thalassaemia patients' needs.

Yours faithfully,



Dr. David Tavaris Lopes

Head of Haematology

**Conde de São Januário Hospital (CHCSJ)**

仁伯爵综合醫院
Centro Hospitalar C.S. Januário
综 合 科
Unidade Associada
血液腫瘤科/耳鼻喉及頭面外科
Hemato - Oncologia
ORL e Cir. Cérvico-Facial
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1 Thalassaemia International Federation, Guidelines for the Clinical Management of Thalassaemia, 2nd Edition, December 2007, p.55

2 Thalassaemia International Federation, Guidelines for the Clinical Management of Thalassaemia, 2nd Edition, December 2007, p.39

3 Thalassaemia International Federation, Guidelines for the Clinical Management of Thalassaemia, 2nd Edition, December 2007, p.48

附件二：地中海貧血兒童基金名譽會長楊執庸教授致醫管局的信件

# CHILDREN'S THALASSAEMIA FOUNDATION
## 地 中 海 貧 血 兒 童 基 金
(Incorporated with Limited Liability)

November 27, 2006



Mr. Shane Solomon
Chief Executive
Hospital Authority
147B Argyle Street
Kowloon

Dear Mr. Solomon,

Re: ICL 670 (Exjade) – An Oral Chelator

I write to indicate my strong support of the request of a group of thalassaemia patients, asking for ICL670 (Exjade) chelator to be provided in HA hospitals for use. I am sure you are aware that thalassaemia patients require daily chelating therapy because of the repeated blood transfusions which are needed to sustain life.

Currently, HA hospitals are providing desferal which is required to be infused by needles over 8 to 10 hours each day. The pains and anguish generated are therefore understandable. An alternative chelator (L1) was introduced a few years ago. Unfortunately, this drug has frequently provoked significant arthritis and bone pain beside other complications. Its acceptance by patients has therefore not been overwhelming.

I am glad to note that there is a new oral chelator which holds great promises, not only in alleviating the painful needle everyday but also in not generating arthritis and bone pain like L1.

I therefore strongly urge you to consider purchasing this new medication as another option for the doctors and patients to choose within HA hospital system accordingly.

Thanking you in advance.

Yours sincerely,

Professor C. Y. Yeung
Chairman
Children's Thalassaemia Foundation


Rm. 201-203 Nurses' Quarters Block B1, Queen Mary Hospital, 102 Pokfulam Road, Hong Kong Tel: 2523 5400 Fax: 2818 0636 E-mail: ctfhk@biznetvigator.com
香港薄扶林道102號瑪麗醫院護士宿舍B1座201-203室　電話：2523 5400　傳真：2818-0636　電郵：ctfhk@biznetvigator.com

附件三: 地中海貧血病人致醫管局的信件

c/o Thalassaemia Association of Hong Kong
Room 201-203, Nurses' Quarters Block B1
Queen Mary Hospital
102 Pokfulam Road
Hong Kong

April 21, 2008

Mr. Shane Solomon
Chief Executive
Hospital Authority
147B Argyle Street
Kowloon

**Request for Better Treatment for Thalassaemia Patients**

Dear Mr. Solomon,

We write to ask for your time to kindly review the current treatment options for thalassaemia patients at public hospitals, and to consider the feasibility of implementing a Treatment Funding Shared Contribution Model (TFSCM) for Exjade in order to ease the financial strain on patients.

Almost all of us thalassaemia patients receive a daily, twelve-hour long iron removal infusion treatment, deferoxamine (DFO). Without adequate iron removal, we would die prematurely due to the damage excessive iron would cause to our hearts and livers.

This time-consuming regimen poses for us several challenges:

- **Scarring, Swelling and Hardening of the Skin:** Over the years, the painful infusion treatment causes irreversible scarring and hardening of the skin, as well as persistent swelling at the injection site. Due to this side effect, many of us have to intermittently skip infusion and this adversely impacts the outcome of the treatment.

- **An Inability in Staying Productive:** The infusion requires binding a treatment pump, which is like a box (sized 5 cm x 16 cm), that not only limits us from resting fully, but also limits our productivity at work or school in the daytime. A once daily oral chelator can give us an equal opportunity to have normal and productive lives.

- **A Limitation on our Social Lives:** The daily twelve-hour long infusion means that we can never participate in night time activities and absolutely must leave work by 6pm, a feat that is difficult to achieve in view of the prolonged working hours in this city.

The Hospital Authority does provide an oral medication, L1 (deferiprone) DFP, which has a plethora of side effects. Many of us who used DFP experienced a drastic reduction of white

blood cells and a weakening of immune systems, resulting in symptoms such as serious mouth ulcers and persistent fever. Some of us even required hospitalization in the isolation ward for two weeks.

The Department of Health approved a new oral iron chelation therapy called Exjade in 2006. Currently it is regarded as a "Self-financed Item" in the drug formulary, and public hospital pharmacies are not stocking this medicine. This means patients are forced to purchase Exjade from a commercial pharmacy. Not only does this pose inconvenience, but also adds to each patient's medical financial burden.

Although Exjade is more expensive than L1 and DFO infusion, it can save treatment costs due to its lack of side effects, unlike infusion treatment and L1, and also because patients can better comply with their iron chelation treatment, which results in fewer complications from iron toxicity leading to reduced medical costs for related health problems, and also to healthier patients.

We noted that Hong Kong has been facing the challenge of an increasing financial burden in the healthcare sector. As responsible citizens, we feel obliged to work with the HA in overcoming this challenge together.

Providing a seamless healthcare environment, which maximizes healthcare benefits and meets community expectations, has always been a vision of the Hospital Authority. We, the thalassaemia patients of Hong Kong, appreciate the challenges that the HA is facing and are prepared to work hand-in-hand with you to overcome them.

We would be grateful if you could meet with us to discuss our proposition further. Please don't hesitate to contact Jessis Ng, Coordinator, Children's Thalassaemia Foundation or Mandy Yuen, Officer, The Thalassaemia Association of Hong Kong at 2523 5400.

We are looking forward to your feedback and to meeting with you.

Yours sincerely,

Leung Ka Fai

Representative

Thalassaemia Treatment Patient Concerned Group

附件四：有關本港地中海貧血症的剪報

**AM730　30/4/2008**

# 60萬人擁有地貧基因

**地中海貧血症屬全世界最普遍的基因變異遺傳疾病，本港亦約有60萬人帶有地貧基因。重型地貧患者更需要終身接受輸血，以維持生命，又要注射除鐵劑避免體內積聚過量鐵質損害其他器官。有兒科醫生指出，由於地貧是基因遺傳疾病，因此建議夫婦接受婚前檢查或產前檢測，若證實帶有地貧基因，可與醫生商討不同的治療方法。**

地中海貧血兒童基金名譽主席及兒科專科醫生楊執庸表示，本港每11人便有1人帶有地貧基因，由於大部分人沒有病徵，亦毋須治療，故唯有抽血檢查才會知道自己是否地貧基因攜帶者，萬一夫婦雙方均是基因攜帶者，他們所誕下的嬰兒，亦有四分一機會患有重型地貧。

本港約有400名重型患者，該基金董事夏修賢(上圖)指出，重型地貧患者不能製造足夠的血紅蛋白，因而不能有效地製造正常的紅血球，導致長期嚴重貧血，須終身接受輸血。他續稱，除輸血之外，患者必須每隔4星期到醫院接受輸血，又必須每星期5至7晚進行8至12小時的皮下除鐵注射，以防止鐵質在體內積聚，損害心臟、肝臟等器官。目前患者主要以皮下注射除鐵劑，但對患者造成皮膚敏感、注射位置潰瘍、社交生活受限制等副作用。因此，醫學界近年亦採用新的口服除鐵劑Deferasirox，患者只須每天服用一次，藥效便可持續24小時，但因新藥屬自費藥物，故期望政府可資助患者，使用更好治療。

現年25歲的子軒(圓圖)，自幼便證實患有地貧，目前仍然需要每兩星期到醫院接受輸血，每次均用上6小時輸兩包血，「每次都要請假去輸血，對工作都有影響。」此外，他每晚都需要注射除鐵劑，手臂、肚皮都已佈滿針孔，有時他也會感到社交生活受影響。

**Oriental Daily News 30/4/2008**

# 新口服劑治地貧省時方便

【本報訊】地中海貧血病是最常見的基因遺傳病，目前本港有每十一人便有一人是地貧基因攜帶者，即約有六十萬人，而嚴重地貧患者有近三百八十人。地中海貧血兒童基金董事夏修賢（圖）表示，地貧患者需接受輸血及除鐵治療，傳統除鐵治療需作十至十二小時的皮下注射，傳統口服劑亦有機會引致白血球缺乏症，嚴重或會致命。本港近年引進新一代口服除鐵劑，每天只需服一次便可達注射相同效果，亦可減少病人不便。

夏修賢表示，地貧患者因不能製造足夠血紅蛋白，令氧氣不能運送到器官，引致貧血及影響器官運作。乙型地貧患者約在六個月大時開始出現貧血症狀，如不接受治療可引致肝脾腫大及骨骼變形，嚴重更會死亡。雙親若屬地貧基因攜帶者，子女有四分之一機會患上重型地貧病，呼籲市民婚前做身體檢查。

他指，地貧患者需接受每四至八星期一次的輸血及每日的除鐵治療，傳統治療法較為不便。新的口服除鐵劑適合兩歲以上患者，副作用為較輕微的腸胃不適等，但長期療效仍有待監察。心臟有問題的病人不建議服用；傳統療法每月約需二、三千元，新藥費四至五倍。

廿五歲的地貧病患者子軒亦患有糖尿病，每月打一百支針，肚皮及雙臂滿布針孔的經歷最痛苦，若果換新藥每月需花三萬元。十五歲的桐桐兩年前轉服新藥，相比以往每晚七時前必須回家注射十多小時除鐵針，現在方便許多。

## 下月國際地貧日籌款

為支援嚴重地貧患者及籌募經費，地中海貧血兒童基金將於下月八日國際地貧日，發起「基因實練日」籌款活動，呼籲市民穿牛仔褲上班及捐款。

有關活動的詳情可以致電熱線29863311查詢。



（左起）桐桐及子軒曾患地中海貧血，受過打針之苦。（王嘉昌攝）

**The Sun 30/4/2008**

# 新除鐵劑治地中海貧血

## 日服一次 效同打針

◀本報訊 本港醫學界近年引入新藥醫治地中海貧血症，地中海貧血兒童基金董事夏修賢表示，地貧患者需接受輸血及除鐵治療，傳統除鐵治療需作十至十二小時的皮下注射，傳統口服劑亦有機會引致白血球缺乏症，嚴重或會致命。本港近年引進新一代口服除鐵劑，每天只需服一次便可達注射相同效果，亦可減少病人不便。

地中海貧血症是本港常見的基因遺傳病，現時每十一名港人中便有一人是地貧基因攜帶者，即約有六十萬人，嚴重地貧患者亦有近三百八十人。

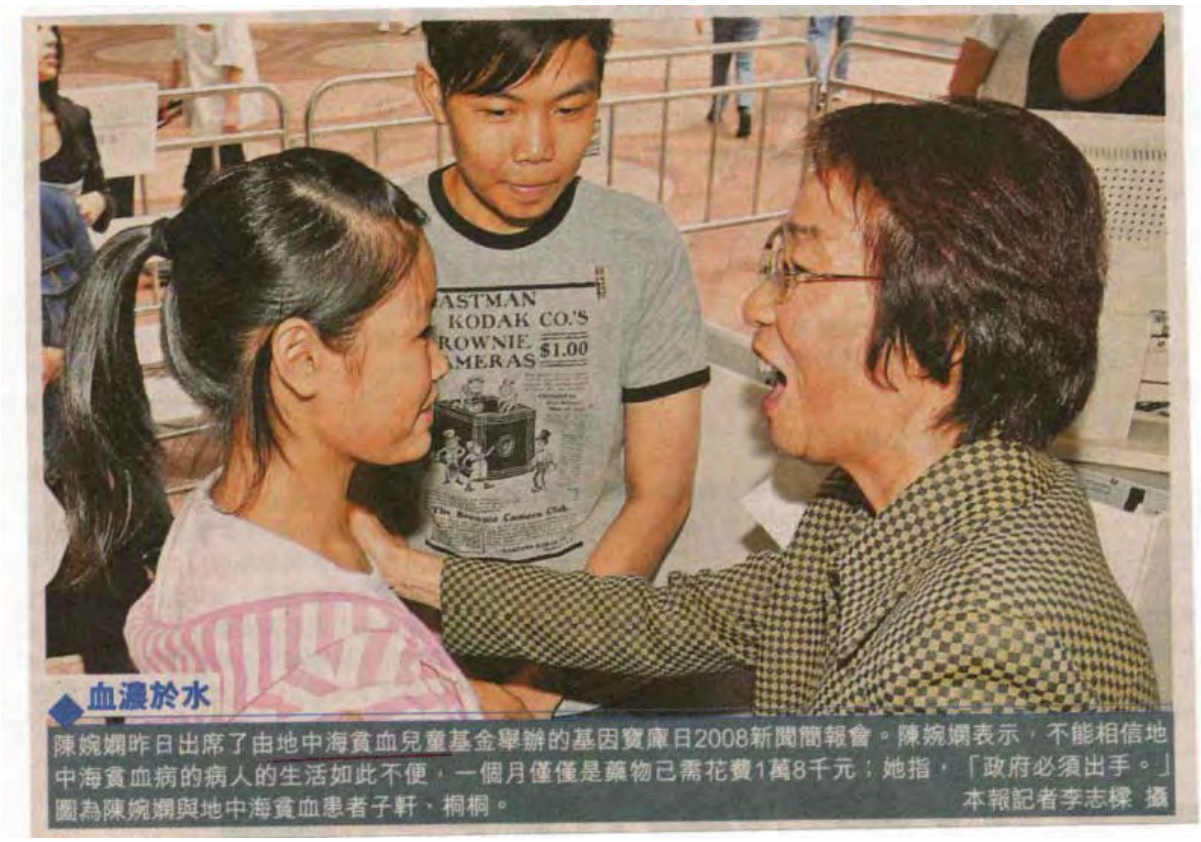
夏修賢指，地貧患者需接受每四星期一次的輸血及每日的除鐵治療，傳統治療法較為不便，新的口服除鐵劑適合兩歲以上患者，副作用為較輕微的腸胃不適等，但長期療效仍有待監察，心臟有問題的病人不建議服用；傳統療法每月約需二、三千元，新藥貴四至五倍。

二十五歲的地貧病患者子軒亦患有糖尿病，每月打一百支針，肚皮及雙臂滿布針孔的經歷最痛苦，若換新藥每月需花三萬元。十五歲的桐桐兩年前轉服新藥，相比以往每晚七時前必須回家注射十多小時除鐵針，現在方便許多。

為支援嚴重地貧患者及籌募經費，地中海貧血兒童基金於下月八日國際地貧日，發起「基因寶褲日」籌款活動，籲市民穿牛仔褲上班及捐款，詳情可致電熱線29863311查詢。


◆（左起）桐桐及子軒同於七個月大時患上地中海貧血病，均受過打針之苦。子軒手持協助打除鐵針的用具。

**Wen Wei Po 30/4/2008**

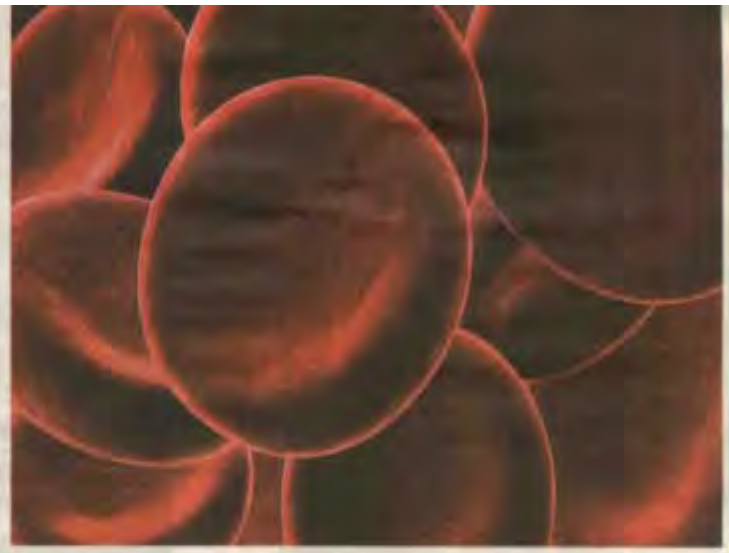



◆血濃於水

陳婉嫻昨日出席了由地中海貧血兒童基金舉辦的基因寶庫日2008新聞簡報會。陳婉嫻表示，不能相信地中海貧血病的病人的生活如此不便，一個月僅僅是藥物已需花費1萬8千元；她指，「政府必須出手。」圖為陳婉嫻與地中海貧血患者子軒、桐桐。 本報記者李志樑 攝

## Hong Kong Magazine 8/5/2008

# In Your Blood



With International Thalassemia Day falling in May, **Sarah Fung** discovers more about the genetic blood disease carried by one in 11 Hong Kong Chinese.

Thirty-year-old Fai has lived with thalassemia for as long as he can remember. "My little sister and I are both sufferers. I was diagnosed at a few months old and can't imagine life without the illness. I've had monthly day-long blood transfusions and nightly iron removal therapy for as long as I can remember," he says.

Fai is one of around 400 sufferers in Hong Kong who has to undergo painful, lengthy treatments to combat the effects of the disease. With one in 11 Hong Kong Chinese, or 8.4 percent of the population, carrying the gene that causes the illness, awareness of the condition—and how to prevent it—is vital in our city, which is why May 8 is "Jeans for Genes" day, an event that aims to raise awareness and funding for thalassemia research and treatment.

### What is Thalassemia?

It's not pretty. Thalassemia is a blood disorder that manifests as chronic anemia, and can lead to painful and costly daily blood therapy and monthly transfusions. Dr. Ha Shau-yin, pediatric consultant at Queen Mary Hospital and representative of the Children's Thalassaemia Foundation, explains. "Thalassemia is a genetic condition that affects globin synthesis—globin chains are the molecules that form parts of hemoglobin, which affects the part of red blood cells that carry oxygen from your lungs to your tissue and organs. When your globin chains are reduced, it means that you have insufficient hemoglobin to carry oxygen around your body. Severe symptoms include liver and spleen enlargement, bone deformities from excessive bone marrow growth because the body is trying to compensate for the lack of oxygen carried by the blood, a predisposition to infection as a result of a weakened immune system and eventually heart failure."

### It's in the Genes

How does one contract the disease? Like many genetic disorders, it is transmitted in an autosomal recessive style, meaning that the problem occurs when both parents are carriers of the thalassemia trait. The bad news is that an abnormally large number of Hong Kong Chinese carry the trait. "These carriers are generally in good health, though some may be slightly anemic. In fact, most don't even know they are carriers until a routine blood test shows that their MCV (mean cell volume) is low, meaning that their blood cells are slightly smaller. Further tests then establish whether the individual is a thalassemia carrier," says Dr. Ha. The problem arises when two people who both carry the thalassemia trait have a child. "There is a 25 percent chance that the infant will contract thalassemia major, the severest form of the disease," he warns.

### Treatment

Thalassemia is a trying disease to live with. "Unless the patient can undergo a bone marrow or cord blood transplant from a sibling donor—and even then there's only a 25 percent chance of finding a match—the patient will need to go to hospital around every four weeks for blood transfusions for the rest of his or her life in order to maintain hemoglobin and red cell count," says Dr. Ha. But the treatment can be almost as damaging to the body as the disease itself. "One of the side effects is that once the red blood cells degrade, an excess of iron remains in the body. This iron can damage the organs, leading to heart failure, liver fibrosis, diabetes and endocrine gland complications, and if it affects the pituitary gland, stunted growth."

Removal of the iron is carried out by a process called iron chelation, a difficult procedure that in itself also causes health problems for the patient. "The most common method of iron chelation is a nightly, 10-hour-long injection, where the drug desferoxamine is released into the arms, legs or stomach," says Dr. Ha. This treatment is painful and can cause skin hardening, inches and rashes. It also compromises the patient's quality of life due to the dependency on lengthy vaccinations. Fai agrees. "It's as painful as one would imagine," he says. "It causes scars and skin hardening, and once the skin is scarred, I can't inject into it and I have to find new places for the injections. Having done this for over 30 years, my stomach is full of scars and hardening skin. However, I'm lucky." Fai adds. "My work schedule is flexible so I can take days off for my day-long blood transfusions quite easily, though I still have to have iron removal therapy every night."

### Hope on the Horizon?

Recently, a breakthrough iron chelation drug has entered the market. Exjade is an oral medication that has far fewer severe side effects than traditional treatments and can be taken by children as young as 2. The problem is it's far too expensive. "At present, the Hospital Authority does not supply Exjade for free and it can cost $15,000-$20,000 per month to treat a child with the drug, and $30,000 to treat an adult," says Dr. Ha. Most sufferers and their families do not have that kind of money available. "Exjade is expensive and I can't afford it at the moment," says Fai. "I hope that the government will one day be able to provide Exjade to myself and my fellow patients for free." As of this moment, the government has no plans to subsidize the drug.

### Get Tested

The only way to avoid passing thalassemia major to your children is to undergo prenatal and pre-marital blood tests. "I recommend that all couples take a blood test at the Family Planning Clinic or at their family doctor before starting a family. That way, a thalassemia-carrying couple can make an informed decision whether to have a child, and get all the information they need from charities such as the Children's Thalassemia Foundation," says Dr. Ha. "These are not mandatory, though it's certainly easier and less traumatic than having to find out further into the pregnancy that the child is carrying the disease."

**International Thalassemia Day falls on May 8. This year, the Children's Thalassaemia Foundation is running a "Jeans for Genes" day, which aims to raise awareness and funds for thalassemia research. If you missed the dress casual day at work, you can make a donation by filling out a crossed check, payable to the Children's Thalassaemia Foundation. Or you can deposit the donations directly into the foundation's bank account (HSBC: 511-024341-002), faxing the deposit slip to the foundation at 2818-0636.**

For more information and support contact the Children's Thalassaemia Foundation, 2980-3311; www.thalassaemia.org.hk (website in Chinese only).

**South China Morning Post 8/5/2008**

Sufferers of a genetic blood disorder are finding the strength to pursue their dreams, writes **Charmaine Carvalho**

# Alive and kicking

Under the stage lights, Chen See-kwan from hip-hop group Fama is pumping it up, raising the excitement level at a concert in Wan Chai. It's hard to imagine but the 24-year-old has had to have a blood transfusion every four weeks since he was a baby. C Kwan, as he is better known, suffers from thalassaemia, a genetic blood disorder that inhibits haemoglobin production.

Kwan remains upbeat as he raps about the ups and downs of life in Hong Kong. Diagnosed when he was four months old, he is used to the treatment and says he grew up like any other child – he was even on his school table tennis team.

"It didn't affect my extracurricular activities at all," he says. "Once a month I had to take a day off to go to the hospital, and I quite liked having the holiday."

Despite Kwan's matchadatria, it couldn't have been easy to cope with the treatment. Repeated transfusions cause iron to be accumulated in the body and the excess must be removed regularly through an injection of drugs in the stomach that lasts up to 12 hours.

"This kind of prolonged injection through the night causes a lot of pain and discomfort," says Li Chi-keung, a doctor who helps run the Children's Thalassaemia Foundation. "When they hit adolescence, especially, patients can be less co-operative but if they do not receive the treatment regularly, problems start. They may develop heart disease, liver problems, diabetes and other complications."

The incidence of thalassaemia is relatively high in Hong Kong. One in 11 people, or 6.5 per cent of the population, carries the gene and can pass the illness to their children. That's more than three times the rate of 2.56 per cent of people in neighbouring Guangdong province. The incidence in Shenzhen is even lower at 1.99 per cent, which some researchers attribute to a large influx of people from northern China, who are less likely to have the gene.

Thalassaemia is the most common genetic disorder in the world, Li says, and affects people living within a belt stretching from the Mediterranean to southern China. Although it isn't clear why they are more prone to thalassaemia, one theory is the blood composition makes them more resistant to malaria, which is common in those regions.

In its severe form, the inability to produce sufficient haemoglobin causes long-term anaemia that may lead to an enlarged liver and spleen, bone deformities and inhibited growth.

Carriers are asymptomatic and do not require treatment. But since there is a 25 per cent chance of passing the severe form of the disease to their children, pregnant women in Hong Kong are tested to prevent new cases developing.

The foundation, which seeks to raise awareness about the illness, is marking International Thalassaemia Day today by organising a Jeans for Genes campaign. Office workers and students get the chance to wear jeans for the day by making a small donation to aid research and treatment for poorer sufferers.

Lack of public awareness can create difficulties for many sufferers. "People stare at me on the street but my parents tell me it's because they think I know better," says 19-year-old Angel Yeung Sheung-yu, whose physique was stunted by the illness.

That also makes getting a job tougher. "Some employers thought I had a mental illness; others worried that I would take too much leave," she says. Now working as a receptionist, Yeung says she enjoys the job but can get very tired just before she is due for a transfusion because her haemoglobin count is low.

Angela Chang Hei-tung, a 15-year-old student, is helping to educate people about her illness. Discouraged by her mother, Susanna Chang Ip Pik-sun, she has appeared on TV since she was four to talk about living with thalassaemia.

As a toddler, Angela found it hard to explain to friends that the illness wasn't contagious but her appearance helped. "My principal saw me on TV and explained to the school at [illness] at assembly the ne[xt] After that people understo[od]

"I can't do very physic[al] like volleyball, which I enj[oy] watching, but I have my b[ig] and teachers and parents [are] so I don't think I've m[iss] much," she says.

Sufferers must also [eat] certain iron-rich foods [like] beef, apples and choco[late] although Angela admi[ts] snacks the odd sweet [as] her mother isn't lookin[g]

Chang is proud of h[is] daughter. "There are m[any] parents who hide that t[heir] has thalassaemia, even [from] own relatives," she says. [But] this is harmful for the ch[ild] needs to accept her illne[ss]

Angela thinks it's imp[ortant] let more people know ab[out] disorder and coping wit[h] iron-removal treatment[s] voices at the thought. "Th[e] is quite thick, so it hurts," s[he] Yeung says she has become the all-night drug regimen[s] it restricts her activities. "I[t] out longer than 9pm so I c[an't] experience Halloween," sh[e] "Going camping means I m[ust] up for skipping the treatm[ent] undergoing a whole day [of] which is not healthy."

Oral medications were introduced in 2000 as an a[lternative] to painful injections. How[ever] patients don't always emp[loy] to the drugs, which can ca[use] joint pain and a dangerous reduction in the white cell[s]. Another oral medicine, wh[ich] patients better, has just ar[rived] 2006, but the high cost – [up] HK$350,000 a year for an a[dult] puts it out of reach of many sufferers.

Fortunately, Angela is [not] among them. Thanks to [the] medications, which is taken once a day, she can includ[e] passion for acting. "Previo[usly] to rush home from school [to] ready to take the injection. I couldn't stay on for the di[sco] the student, who has won [a] for outstanding actress in [a] drama festival for the past[.]

The new drugs have al[so] Kwan to lead a relatively n[ormal] life, including the many h[ours] performances that are par[t] pursuing a pop career.

"Most people in the in[dustry] know about [the illness] a[nd] been a problem at all," he[re] have a busy schedule with [the] recording, performing and[/or] attending events, so I feel t[ired] sometimes. But I can't say [it's] that's because I have thala[ssaemia]

"There are those who [are] throwdown as unfortunate [and] are lucky in many ways be[cause] we can get advanced treat[ment] in Hong Kong," he says. "I achieve our dreams despite [the] illness if we're optimistic."

> We can achieve our dream despite this illness if we're optimistic
>
> Chen See-kwan (above)

Angela Chang and Aslam Ho suffer from thalassaemia, a blood disorder that causes fatigue and can lead to complications if not treated correctly

For more information, visit thalassaemia.org.hk or ca[ll]

## Summary of Iron Overload and its treatment:

- 1.08 mg of iron in 1ml of pure red cells (HCT = 100%);
- Rate of iron loading: volume of RBC x 1.08 (annual transfusion requirements x donor Hct = volume of RBC). On average 200mg iron/donor unit;
- Recommended transfusion 100-200 ml/kg/year is equivalent to 116-232 mg iron/kg/year or 0.32-0.64 mg/kg/day;
- Serum ferritin broadly related to body iron. When high, the following should be considered:
  (i) iron overload;
  (ii) inflammation;
  (iii) hepatitis; and/or
  (iv) liver damage.
  When serum ferritin is low, the following should be considered:
  (i) low body iron;
  (ii) vitamin C deficiency.
  In thalassaemia intermedia, ferritin underestimates the degree of iron overload. Ferritin levels related to low risk are below 2,500 mg/l, preferably below 1,000 mg/l;
- Ranges of LIC reflecting levels of RISK:-
  Very low risk = <1.8 mg/g dry weight
  Low to moderate risk = 1.8 - 7 mg/g dry weight;
  Moderately high to high risk = 7 - 15 mg/g dry weight;
  Very high risk = > 15 mg/g dry weight;
  Total body iron stores = 10.6 x LIC (mg/g dry weight);
  LIC is measured by:
  a) Liver biopsy – indicated if ferritin levels deviate from expected trends, if co-existent hepatitis and if uncertain response to chelation;
  b) SQUID – not universally available;
  c) MRI – R2.
- Cardiac iron reflected by heart function tests and measured by MRI T2*;
- Urinary iron – used to monitor desferrioxamine or deferiprone dose effects. Variability in daily excretion, and
- NTBI and LPI – not yet routinely used.

## Desferrioxamine:

- Initiate treatment after first 10-20 transfusions or ferritin level above 1,000 µg/l;
- If before 3 years of age monitoring of growth and bone development is recommended;
- Therapeutic index = mean daily dose (mg/kg) (Mean daily dose = actual dose of each infusion x doses/7 days) /ferritin (mg/l). Keep index < 0.025 at all times;
- Standard treatment: a) Slow subcutaneous infusion over 8-12 hours, b) 10% desferrioxamine solution (5 ml water for each 500 mg vial), and c) infusion pump (several types available);
- Standard dose: a) children 20-40 mg/kg (not exceeding 40 mg/kg, until growth has ceased), and b) adults 50-60 mg/kg. Infuse 8-12 hours 6 nights minimum per week;
- Alternative route: subcutaneous bolus – two S.C. boluses/day to a total daily dose of 45 mg/kg;
- Vitamin C-dose limited to 2-3 mg/kg/day given orally at the time of infusion;
- Pregnancy – desferrioxamine can be used in pregnancy. It should be interrupted during the first trimester and can be used in the second and third trimesters, in selected cases;
- Intensive chelation with desferrioxamine – continuous 24-hourly infusions IV or SC. Indications:
  a) Persistently high serum ferritin;
  b) LIC > 15 mg/g dry weight;
  c) Significant heart disease, and;
  d) Prior to pregnancy or bone marrow transplantation
  Dose: 50 mg/kg/day (up to 60 mg/kg/day)
- In-dwelling catheters: danger of infection and thrombosis.

### Deferiprone:

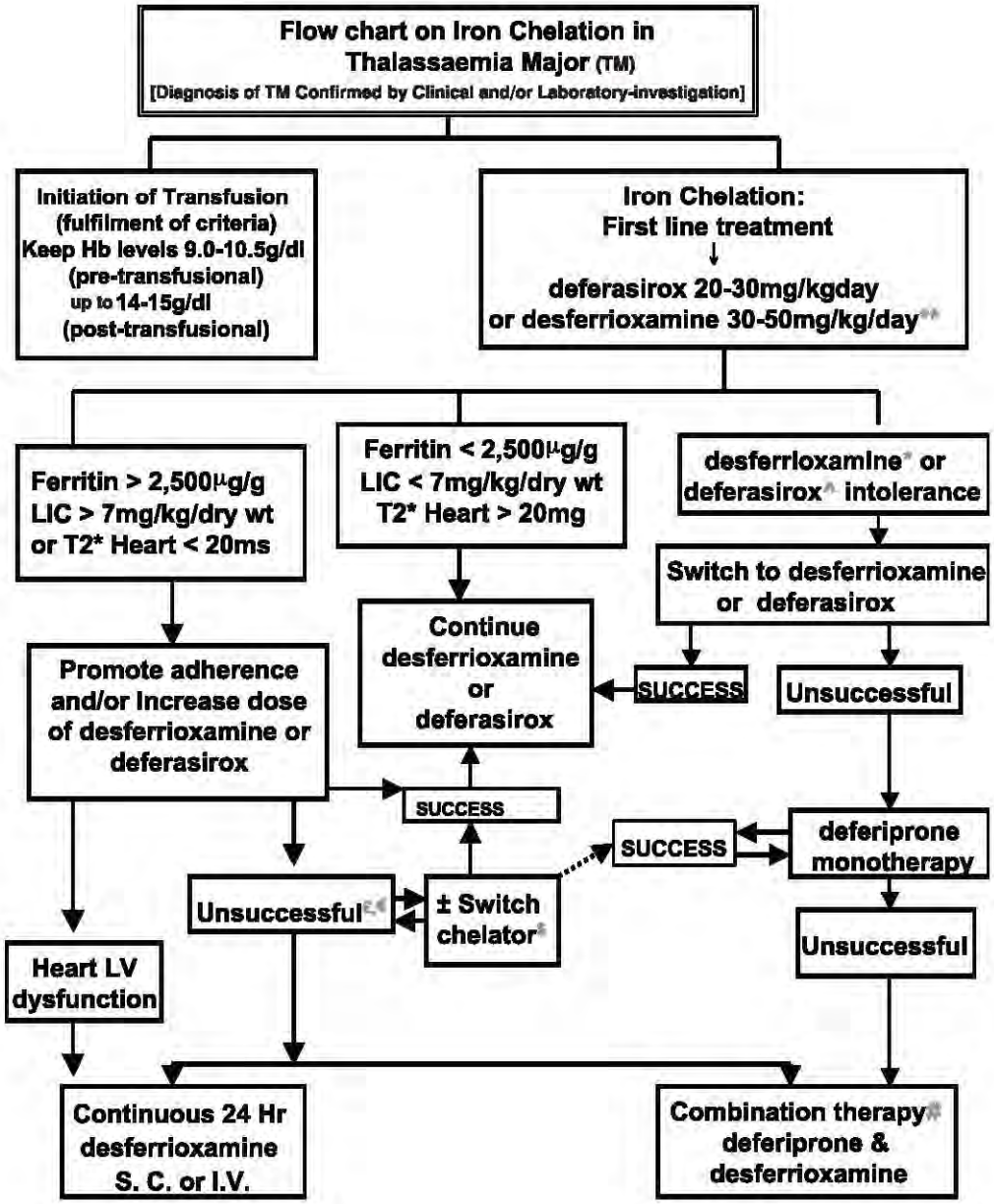
- Standard dose: 75 mg/kg/day in 3 divided dose (up to 100 mg/kg/day, but as yet not enough information);
- Children above 10 years of age;
- Vitamin C concomitant treatment not recommended;
- Weekly blood counts (more frequently if signs of infection);
- Pregnancy – stop treatment. It is recommended that sexually active patients should use contraception;

**COMBINATION THERAPY.** In patients for whom monotherapy with desferrioxamine or deferiprone is not controlling body levels of iron or myocardial iron, some combined regimes offer an alternative that can reduce iron levels in both the liver and heart. No recommendations as to which is the more effective combination can be made at present.

**CAUTION:** agranulocytosis may be more frequent in combination therapy, especially in simultaneous use.

### Deferasirox:

- Recommended dose:
  Starting dose 20 mg/kg/day. After 10-20 transfusions (iron intake (0.3-0.5 mg/kg/day);
  If pre-existing iron overload (or iron intake > 0.5 mg/kg/day), the dose of 30 mg/kg/day is recommended. For patients with low rate of iron loading (<0.3 mg/kg/day), 10-15 mg/kg/day may be sufficient to control iron loading;
- Administration: Tablet dissolved in water (or apple juice), using a non-metallic stirrer. Taken once a day before a meal.
- Continuous Monitoring
- Use in children > 2 (FDA) and >6 (EMEA) years of age
- Contraindicated in renal failure or significant renal dysfunction;
- Can not be given during pregnancy


Flow chart on Iron Chelation in Thalassaemia Major (TM)
[Diagnosis of TM Confirmed by Clinical and/or Laboratory-investigation]
Initiation of Transfusion (fulfilment of criteria) Keep Hb levels 9.0-10.5g/dl (pre-transfusional) up to 14-15g/dl (post-transfusional)
Iron Chelation: First line treatment
deferasirox 20-30mg/kgday or desferrioxamine 30-50mg/kg/day**
Ferritin > 2,500µg/g LIC > 7mg/kg/dry wt or T2* Heart < 20ms
Ferritin < 2,500µg/g LIC < 7mg/kg/dry wt T2* Heart > 20mg
desferrioxamine* or deferasirox^ intolerance
Switch to desferrioxamine or deferasirox
Promote adherence and/or Increase dose of desferrioxamine or deferasirox
Continue desferrioxamine or deferasirox
SUCCESS
Unsuccessful
SUCCESS
SUCCESS
deferiprone monotherapy
Unsuccessful
± Switch chelator#
Heart LV dysfunction
Unsuccessful
Continuous 24 Hr desferrioxamine S. C. or I.V.
Combination therapy## deferiprone & desferrioxamine

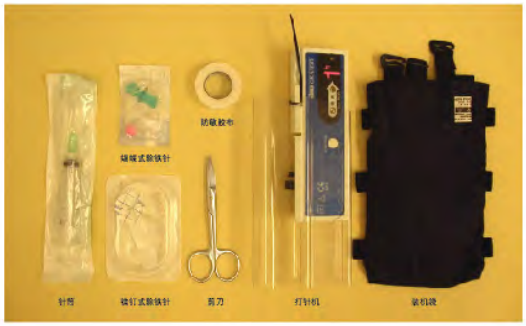
附件六：由政府免費提供新藥 Deferasirox 的地方列表

| | 地區 | 國家 | |
|---|---|---|---|
| 1. | 歐洲 | Austria | 奧地利 |
| 2. | 歐洲 | Belgium | 比利時 |
| 3. | 歐洲 | Denmark | 丹麥 |
| 4. | 歐洲 | Finland | 芬蘭 |
| 5. | 歐洲 | France | 法國 |
| 6. | 歐洲 | Germany | 德國 |
| 7. | 歐洲 | Greece | 希臘 |
| 8. | 歐洲 | Iceland | 冰島 |
| 9. | 歐洲 | Ireland | 愛爾蘭 |
| 10. | 歐洲 | Italy | 意大利 |
| 11. | 歐洲 | Netherlands | 荷蘭 |
| 12. | 歐洲 | Norway | 挪威 |
| 13. | 歐洲 | Spain | 西班牙 |
| 14. | 歐洲 | Sweden | 瑞典 |
| 15. | 歐洲 | Switzerland | 瑞士 |
| 16. | 歐洲 | UK | 英國 |
| 17. | 亞洲 | Australia | 澳大利亞 |
| 18. | 亞洲 | Japan | 日本 |
| 19. | 亞洲 | Macau | 澳門 |
| 20. | 亞洲 | Malaysia | 馬來西亞 |
| 21. | 亞洲 | South Korea | 南韓 |
| 22. | 亞洲 | Taiwan | 台灣 |
| 23. | 亞洲 | Turkey | 土耳其 |
| 24. | 美洲 | Canada | 加拿大 |
| 25. | 美洲 | USA | 美國 |
| 26. | 美洲 | Brazil | 巴西 |
| 27. | 中東 | Israel | 以色列 |
| 28. | 中東 | Saudi Arabia | 沙烏地阿拉伯 |

附件七：傳統皮下注射除鐵治療的相片及小冊子

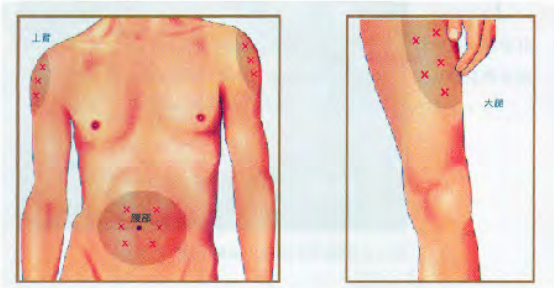
## 如何注射除铁药

### 所需药物及仪器




### 注射部位



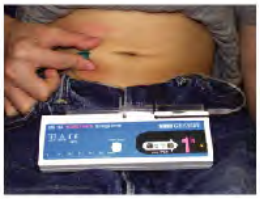

- 图中有X符号的地方是一般适当的注射位置，尤以腹部注射为最容易和稳妥。
- 幼童及纤瘦小孩子不宜在上臂注射。
- 每天要更换注射位置（例如 选择腹部范围内的不同位置作注射），以助药物吸收。

## 注射方法

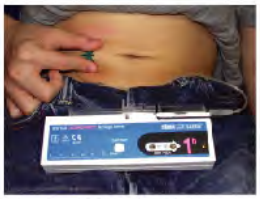
把除铁针刺入皮下前先启动打针机，确保钢针内没留有空气，或可减少滴注进行时的痛楚。

### (一)蝴蝶式除铁针

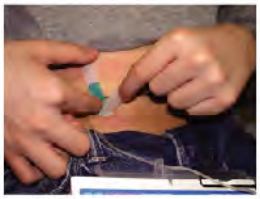
1. • 除去美肤贴，用火酒棉花消毒注射部位
   • 将肚皮拉起，并以45度角把飞机仔刺入皮下



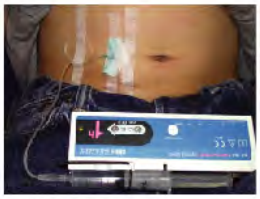
2. 如图所示，把除铁针完全刺入皮下



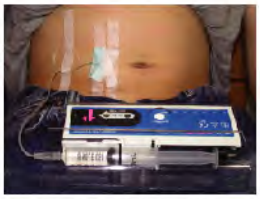
3. 如图所示，把除铁针完全刺入皮下



4. 以防敏胶布固定除铁针



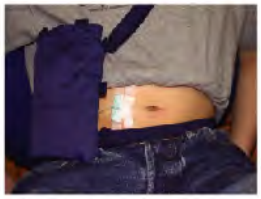
5. 以防敏胶布固定除铁针



6. 把针筒及打针机一起放进保护胶盒内



7. 将推动器放进布袋内



8. 病人可以随身携带打针机，行动自如

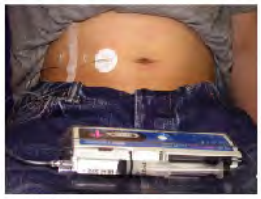
### (二)襟钉式除铁针

除以下步骤外，注射方法与蝴蝶式除铁针相同

1. 在刺入除铁针前先除去保护胶贴和针套

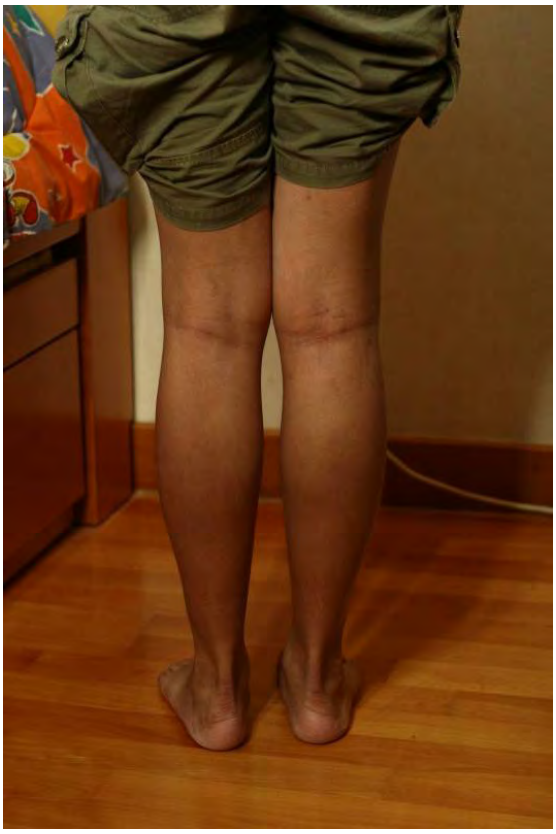
2. 在刺入除铁针前先除去保护胶贴和针套

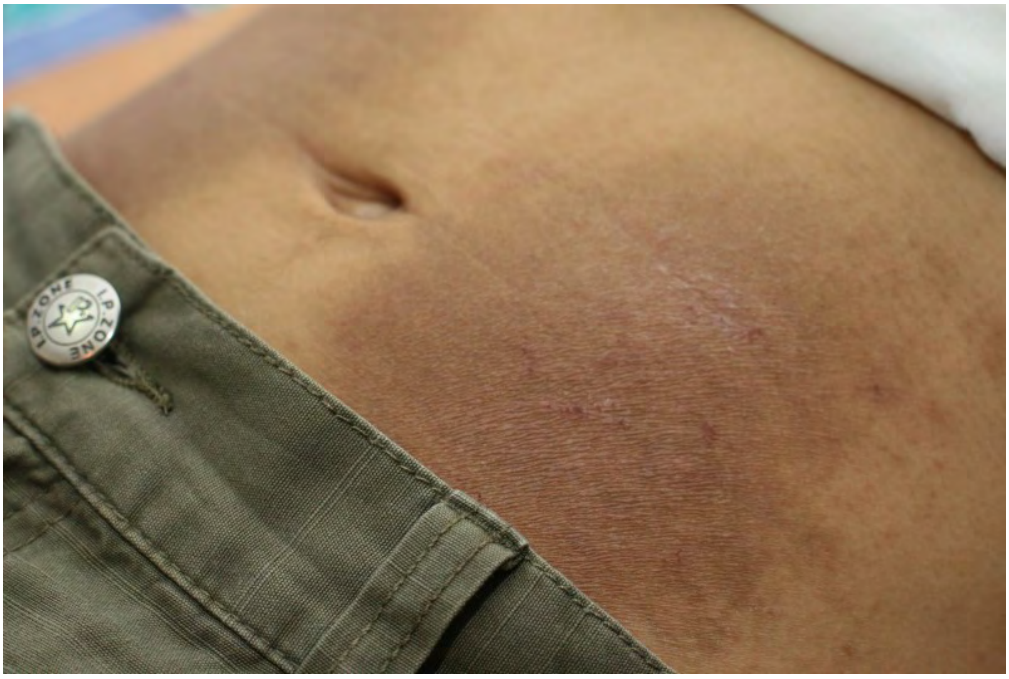
3. 在已消毒部位以90度角把除铁针完全直刺入皮下



4. 以防敏胶布固定除铁针

附件八：傳統皮下注射除鐵引致的副作用相片





**香港地中海型貧血病協會**
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附件九：病人案例：傳統口服除鐵藥物 DFP 引致的副作用

## Anna

我是 Anna，一位地中海貧血重型病患者，在我出生數個月後，已被驗出這個會陪伴着我終身的病。因爲身體未能製造出正常的紅血球，所以要依靠每個月到醫院進行輸血來維持生命。這個療程由我只有半歲便開始。媽媽告訴我當時我年紀很小，血管很幼，很難將針打進血管內，常常要打 10 至 20 針才能成功。我更試過因打針而導致面腫，頭腫及腳腫，但也未能成功把針打進血管內。媽媽不忍看見我痛苦，決定把我抱回家，改天再回醫院打針。由那時開始，針已成爲我這生一位很重要的朋友了。

到了大約五歲，媽媽告訴我長期輸血會帶來很多問題，包括過多的鐵質儲存在身體內，所以一定要接受除鐵注射以避免造成心臟和肝臟衰竭。媽媽爲了讓我可以在晚上睡得好一點，所以選擇在中午的時候幫我打除鐵注射針，因此令我放棄了不少課外活動及同學生日會的機會，影響了我的社交生活。長期打針會令肌肉變硬，甚至失去知覺，連針藥亦無法打進體內。除鐵注射還會令我身上佈滿針孔，導致皮膚敏感。我常因此感到很失望，但每次想放棄的時候，媽媽都會鼓勵我。現在我已是一位在職人士，由於每天晚上都要在家裏接受除鐵注射，以至不能留在公司晚一點，阻礙了我在工作上的發揮，表現未能如其他同事一樣。這也令我錯失了很多可以爭取工作表現及聯誼的機會。

直至 2007 年，我開始服用口服藥 L1，不再需要打針。在服用前，醫生告訴我這藥物有一定程度的風險，可能會導致中性白血球驟降而出現併發症，甚至有生命危險，所以每星期都必須到醫院抽驗白血球。有口服藥的消息令我感到很高興，因爲我再也不用忍受每晚打針所帶來的痛苦。

但數月後，我發現牙肉腫脹，喉嚨痛和發燒，以爲是因爲工作壓力大而導致生病。但之後情況愈來愈嚴重，後來發現中性白血球下降至很低的水平，如有病毒入侵，便會導致死亡。我需要入住隔籬病房，打入了大量激素和抗生素，與癌症病人所使用的劑量一樣。血管亦因注入了大量的藥物而嚴重勞損。這次住院，我向公司請了 10 天病假，而我深信這次一定會影響我將來的晉升機會。

因爲L1與我的身體產生嚴重抗衡，我只可接受除鐵注射。數月前，醫生告訴我另一種口服藥Exjade已在香港註冊，但因並未列入藥物名冊而要用者自負。這藥物的副作用很少，比每晚打針方便得多，但藥費十分昂貴，以我的情況每週藥費要5000元，這是我們很多地中海貧血病患者都不能負擔的藥。在此，我們希望政府能資助我們這藥物，讓我們能過不用打針的新生活。

附件十：病人案例：傳統皮下注射除鐵治療引致的副作用

## 子軒

我叫子軒、今年二十五歲，出世不久便證實患上地中海貧血病。由七個月大開始便需要接受輸血，每隔四個星期便要到醫院接受輸血治療。由於血液中含有豐富的鐵質，因此在輸血過程中會吸收了很多的鐵質，而過量的鐵質會爲身體帶來很多併發症。隨著自己長大，身體已積聚了過多的鐵質，所以從六歲開始便需要配合除鐵注射針的治療。除鐵針是要病人在晚上於家中注射的，而除鐵藥需以打針機用長達八至十二小時慢慢注射入體內。

因爲每晚都需要接受除鐵注射，所以爲生活帶來了很多的不便。像我前一份須輪班的工作，有時會很晚才下班回家，若是第二天需要早起，根本沒有足夠時間注射除鐵針。有時寧願少打一晚，亦希望不影響我的工作時間。

但由於未能依時接受除鐵注射，所以我三年前得了糖尿病，是因爲多餘的鐵質在胰臟積聚，令身體不能正常地製造胰島素。糖尿病亦需要依靠藥物注射及改變飲食習慣來改善，又是不能根治的疾病。同年我的心臟亦因爲積聚了太多的鐵質導致心衰竭，那一次更住進了深切治療病房，情況令家人十分擔心，那次之後，我間中也會因心臟問題而進出醫院好幾次。爲了可以維持心臟正常運作，我每天都需要吃六種、多達二十多粒的藥丸，幸好這些藥的副作用不大。

除了併發症外，長期而密集的除鐵注射在我手臂、肚皮及大腿上留下了無數的針疤。我自小就喜歡游泳，是因爲自己體能可以應付，亦是希望藉著游泳時讓自己的身體曬黑一點來遮掩那些討厭的針疤。但是三年前身體變差後便不能再游泳了，皮膚亦變白，針疤亦蓋不住了。到了炎炎的夏天，就算多熱我也不會穿著沒袖子的衣服，因爲害怕針疤暴露於人前。就算和朋友到沙灘遊玩，也不敢換上泳褲，害怕不知情的陌生人向自己投下奇異的眼光。另外，因爲長期在同一位置注射除鐵針，很多時針口會出現紅腫和微燙的情況，嚴重的更會導致發炎和受細菌感染。

除了身體和精神上的負擔外，治療用的藥物價錢一點也不便宜，令到經濟上負擔變得重了。若果用新的口服除鐵藥物，平均每個月需要支付多達三萬元的醫療費用，而我的收入根本負擔不到這麼龐大的費用。就算家人幫忙，也只可能短時間用到新的口服藥，而且亦會令家人的負擔也一起變得沉重。患上地中海貧血病的我已常常需要家人照顧，亦經常要他們憂心，在我感到最無助想放棄的時候，家人都會支持和鼓勵我。曾經在病危的一刻，家人不眠不休的在床邊陪伴著我，令我感受到愛和親情。

我真的很希望政府能提供援助，資助地中海貧血病患者的醫療費用，讓我們能使用更好的藥物來治療，從而減輕我們經濟上的負擔，讓我們每一個地中海貧血患者及我們的家人，能夠擁有更美好的生活、更燦爛的人生。

## 湘渝

我是一個重型地貧患者，今年１９歲。

出世後不久，醫生便證實我患上了重型地貧。自 1 歲開始，我便要每月到瑪嘉烈醫院接受輸血來維持生命。另外，我亦要每星期五晚注射除鐵針，以排除過剩的鐵質，免它們積聚在身體內導致心衰竭。

可是，這些除鐵針影響了我骨骼的生長，使骨骼變型，身高比常人矮，亦有一個比其他人闊大的骨架。身高和身型常常令我變得很受注目，使我感到很不自在。這也使我在找工作時遇上很多困難，常常受到歧視，令我自尊心受創。在當電話接線生前（現時的工作），我曾應徵超過二十多份工作，當中包括售貨員，而每個接見者都因我奇異的外觀，拒絕聘用我。有些接見者更會用奇異的目光注視着我，令氣氛變得很尷尬，亦讓我感到很沮喪而想放棄找工作。

除了在找工作時遇上困難，我在街上也會受到言語的傷害。有一次，有一群小孩嘲笑我说他們長得比我高，令我感到很自卑和難堪。有時甚至連街上的人都會用奇異的目光望着我，令我感到很尷尬。

另外，除鐵針亦令我的腳骨變型，出現「Ｏ」型腳的問題，使我在步行時腳骨會互相碰撞，令我經常跌倒。在小學四年級時，醫生曾替我進行矯正手術，但手術只能改善了少許彎曲情況，手術後亦常常感到疼痛。

地中海貧血病令我的身高與他人有別，而身高和身型的局限令我在找工時遇到不少困難，即使我有工作能力，亦未必能受到公平的對待。加上除鐵針要在晚上注射八至十二小時，故必須定時回家，故下班後又不能跟同事們聯誼，嚴重影響我的社交生活。

我很希望政府能改善重型地貧患者的治療，令我們不用打除鐵針。雖然，我的身型是無法改變的事實，但我亦希望再沒有病友被長期注射的除鐵針而影響骨骼生長。

# 李太的女兒(露璐)

露璐今年已經二十三歲，是一位教師。由於她在三個月大的時候發現患上地中海貧血病，需要接受很好的照顧，作爲一個母親，在考慮辭去工作的時候我並沒有掙扎很久，因爲我希望能在辭職後全心全意把女兒照顧好。

露璐是一個依從醫生吩咐的病人，我從她小時候就讓她知道她需要接受輸血，病才會好，所以她並沒有抗拒打除鐵針去清除過多的鐵質。她自己亦很想接受除鐵注射以避免過多的鐵質在身體內積聚，但除鐵副作用導致她骨質疏鬆，一打針就感到腳痛，令注射也只能由每星期五次縮減至兩次。醫生更說過若她繼續接受除鐵注射就有坐輪椅的可能，更提議她暫停上學。露璐的膝蓋亦因骨質疏鬆而導致骨碎，需要接受手術才可慢慢康復。

露璐曾嘗試服用口服藥 L1，但治療效果並不理想。儘管她已服用最高的份量，L1 並未能有效地發揮作用，降低超標的含鐵量。服用 L1 亦會令白血球數量驟降，令免疫系統出現問題，抵抗力減弱，令病人很容易受病毒感染，後果可能會很嚴重。所以服用 L1，便須每星期向公司請病假到醫院抽檢白血球的度數。但露璐因工作關係，不能經常向學校請假到醫院驗血。而且露璐的身體並不能接受 L1 這種口服藥，所以只能選擇接受除鐵注射的治療方法。

但露璐接受除鐵注射最令我擔心的是她心臟的情況，因爲她現在已不能接受太多的除鐵注射，因而令她身體內儲存太多的鐵質，怕她心臟負荷不了而衰竭。看見她從小就受地中海貧血病的困擾多年了，作爲一個母親，我真的感到很痛心。我已常常觀察露璐的情況向醫生報告，不希望有任何遺漏的地方，令她的健康受影響。

新藥 Exjade對露璐的情況是最好的，因爲副作用不大，不會對她的身體造成太大的負荷或影響，亦比每晚打針方便得多，所以我希望政府能幫助地中海貧血病患者，接受更好的治療，減輕我們在經濟上的負擔。讓露璐等地中海貧血病患者能免除打針之苦，過正常生活。