香港地中海型貧血病協會
The Thalassaemia Association of Hong Kong
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5 June 2009

Dr Hon Joseph LEE Kok-long, JP
Chairman, Health Services Panel
Legislative Council
Legislative Council Building
8 Jackson Road
Central, Hong Kong
By email: panel_hs@legco.gov.hk

Feedback on the FHB / HA's Submission about the Latest Update on HA Drug Formulary

Dear Dr. Lee,

Reference is made to the FHB / HA's submission about the latest update on the Hospital Authority Drug Formulary (LC Paper No. CB (2) 1740/08-09 (04), we are writing to ask the Health Service Panel to review actual impact of the latest development of the Formulary.

Our 1st Request – Review the Number of Beneficiaries of "Special Drugs"

At the Health Service Panel on 24 June 2008, a motion was passed to urge the Authority to include deferasirox in the drug formulary so that doctors can prescribe the treatment when necessary and the Government would provide additional funding to the HA to support this initiative if required.

Following this motion, the Hospital Authority has enlisted deferasirox as "special drugs" earlier in 2009. A patient can receive deferasirox ONLY if he/she

1. fails to be treated with desferrioxamine (DFO) or intolerant to the serious side effects of DFO, e.g. bone deformity, hardening of skin AND
2. fails to be treated with deferiprone (DFP) or intolerant to the serious side effects of DFP, e.g., a serious reduction of white blood cells or a possibly fatal weakening of the immune system, resulting in symptoms such as serious mouth ulcers and a persistent fever AND
3. fails to be treated with the combined treatment of DFO and DFP or intolerant to the serious side effects of combined treatment

Under these stringent criteria, majority of the severe thalassaemia patients are still receiving old generation of treatments, bearing the challenges posed by almost daily DFO infusion and / or living under the risk of fatal side effects of DFP.

We would be grateful if members of Health Service Panel could look into the number of patients who can receive a better iron removal therapy as a result of this motion, and to work with the HA to broaden the access of deferasirox as early as possible.

Our 2nd Request – Recategorisation Deferasirox as "General Drugs"

Although deferasirox seems to be more expensive than traditional therapies, it saves overall medical costs and sufferings due to side effects such as treatment of neutropenia, surgery for deformed bones and heart failure due to inadequate iron removal. In addition, the new therapy helps improve productivity as it enables us to lead a normal life and continue to contribute to society.

Since the government has successfully introduced prenatal screening in the 1980s, there are only one to two new cases of severe Thalassaemia every year. The total number of severe Thalassaemia patients, which currently is 379, is now capped and will continue to decline as patients pass away.

We hope the Hospital Authority will follow the steps of the governments in the neighboring countries such as Macau, Taiwan, South Korea and Australia which have already agreed to reimburse deferasirox.

Our 3rd Request – Self-financed Patients Can Buy Deferasirox at HA's Pharmacies
Under item 6 of the submission document, it is said that only three types of self-financed item would be sold through public hospital pharmacies.

While patients are waiting for the HA to review and re-categorize deferasirox, we would be grateful if the HA could allow patients who do not fulfill the current stringent reimbursement criteria and have to self-financed their treatment, to obtain deferasirox via pharmacy at public hospitals.

Not only will it be convenient to patients, it lessens the financial burden of patients as they do not have to pay for the profit made by the commercial pharmacies.

We would be grateful if the Health Service Panel can help reflect our views to the Bureau and the HA on the 8th June meeting, so that Thalassaemia patients in Hong Kong can have access to better treatments sooner.

Please don't hesitate to contact Crystal Siu, Officer, Thalassaemia Association of Hong Kong or Jessis Ng, Coordinator, Children's Thalassaemia Foundation at 2523 5400 if you have any questions.

We are looking forward to your favourable response.

Yours sincerely,

Leung Ka Fai

Chairman
Thalassaemia Treatment Patient Concerned Group

c.c: All health services panel members.

Encl. TAHK's letter to health service panel dated 14 May 2008

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Hong Kong

14 May 2008

Hon LI Kwok-ying, MH, JP
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8 Jackson Road
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Request for Better Iron Removal Therapy from the Hospital Authority

Dear Mr. Li

We write to ask for the Health Services Panel to help liaise with the Hospital Authority for a better iron removal therapy for Thalassaemia patients in Hong Kong at the earliest convenience.

Severe Thalassaemia patients require blood transfusions every two to four weeks and as a consequence lead to excessive iron deposition in our body. Excessive iron in the body damages the heart and liver, and the consequences are fatal unless the iron is removed. Therefore, patients also need iron-removal therapy called deferoxamine (DFO), which is a subcutaneous infusion that takes as long as twelve hours or more for each session.

Currently, there are three types of iron removal therapy available in Hong Kong:

1. Traditional iron subcutaneous removal infusion deferoxamine (DFO)
2. Traditional oral iron removal therapy deferiprone (DFP)
3. New generation oral iron removal therapy deferasirox

Traditional iron subcutaneous removal infusion deferoxamine (DFO)
Currently, public hospitals are providing DFO to Thalassaemia patients for removing excessive iron from the body.

DFO is a subcutaneous infusion, taken through a needle (often at abdominal) and each session takes twelve hours or longer, five to seven sessions per week. The drug itself is free of charge provided by HA, but, patients still have to fund the treatment pump (roughly about HKD7000 each) and disposable syringes (roughly about HKD750 each month).

This time-consuming regimen poses several challenges:

- **Bone Deformity:** Many patients are suffering from bone deformity, including short height, broad shoulders, U-shape legs and protruding breast bones due to the side effects of DFO. Some of us have to undergo surgery to rectify these medical conditions. In addition, the deformity causes us an odd appearance making it difficult to find work.

- **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, adversely impacting the outcome of the treatment, leading to further health issues and higher health care costs.

- **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 Limitation on our Social Lives:** The daily twelve-hour long infusion means that we can never participate in nighttime 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 negative impact on the ability to engage in social interaction often has a corresponding negative impact on the mental and psychological well being of the patients. This affects all aspects of life for the thalassaemia patients, including self-confidence, productivity, and even the will to live. Worldwide, many thalassaemia patients have chosen death rather than comply with the painful subcutaneous nightly injection, which in the eyes of many patients, makes life not worth living. Patients in Hong Kong are no exception and non-compliance is the single most important factor leading to the premature deaths of patients. This is the saddest fact about treatment with DFO. Access to an oral, easy to use, iron removal drug, is essential for patients to lead normal lives.

Traditional oral iron removal therapy deferiprone (DFP)

The Hospital Authority does provide a thrice-daily oral medication, L1 (deferiprone) DFP, as an alternative to DFO. However, only some patients with medical indications are given L1 free of charge. Moreover, DFP has a plethora of side effects, rendering it unsuitable for many patients.

Some DFP patients experienced a drastic reduction of white blood cells and a weakening of the immune system, resulting in symptoms such as serious mouth ulcers and a persistent fever, and even death in some cases. Many patients also experience severe joint pain, resulting in discontinuation of the drug. Some have required hospitalization in the isolation ward for two weeks, due to a risk of severe life threatening infections, which adds significant medical cost. These side effects are not isolated incidents and we widely recognized in the medical community. In 2006, the National Health Service in the United Kingdom published a letter to doctors worldwide to ask for weekly monitoring of the white blood cell level for patients treated with DFP. Not only does the weekly monitoring pose extra medical cost, but many of us are also struggling with the weekly monitoring schedule and normal work and school life. While DFP is effective in some patients, its side effects prohibit its use in far too many patients, thereby eliminating it as an option for the majority of Hong Kong thalassaemia patients.

New generation oral iron removal therapy

A new generation oral iron removal therapy, deferasirox (also known as “Exjade), is approved by the Hong Kong Department of Health in 2006 for treating patients aged 2 and above who have iron overload as a result of blood transfusion.

This new generation oral iron removal therapy is a once-daily therapy and can be dissolved in drinks. As such, it overcomes challenges posed by traditional subcutaneous infusion and helps patients comply with doctors’ instruction. The side effects of this deferasirox are transient with mild skin rashes, stomach upsets and stomach aches. These side effects are normally not serious enough to cause any reduction in use of the drug, and typically vanish after some weeks of use.

In 2007, the Hospital Authority enlisted this treatment as a “self-financed item” under the drug formulary, meaning patients have to pay the full cost of treatment. The average treatment cost per patient per month is roughly around HKD 18,000. Because no one iron removal drug can meet the needs of all patients, thalassaemia experts recommend that all three drugs be made available, so that patients can choose the drug that best suits them. Every attempt needs to be made to guarantee that all patients have access to the medicines that can give them equal access to normal lives. We are asking that our lives not be weighed against the cost of treatment.

Our Request – Reimbursement of New Generation Oral Iron Removal Therapy

We hope the Hospital Authority can reimburse the new generation oral iron removal therapy, deferasirox.

Although deferasirox seems to be more expensive than traditional therapies, it saves overall medical costs and sufferings due to side effects such as treatment of neutropenia, surgery for deformed bones and heart failure due to iron removal. In addition, the new therapy adds productivity as it enables us to lead a normal life and continue to contribute to society. Attached please find the recent SCMP's interview about patients who are receiving new therapies and are leading a much more productive life.

Since the government has successfully introduced prenatal screening in the 1980s, there are only one to two new cases of Thalassaemia Major. The total number of Thalassaemia Major patients, which currently is 379, is now capped and will continue to decline as patients pass away.

We wish the Hospital Authority to follow the steps of governments of neighboring countries such as Macau, Taiwan, South Korea and Australia, which have already agreed to reimburse deferasirox. We hope that you will see that a positive response from your panel will help give us an equal opportunity to both life itself and also the quality of life that we are allowed to lead. As citizens, we should have every expectation that we will be given the same opportunity to live and fulfill our potentials as every other citizen.

We, the thalassaemia patients of Hong Kong, appreciate the challenges that the HA is facing and are prepared to work hand-in-hand with the Authority to overcome challenges. We had sent a written request to Mr. Shane Solomon, CEO of Hospital Authority for a discussion on 23 April 2008 but until now, we have not received any response.

We would be grateful if this issue could be discussed at the health service panel as soon as possible so that Thalassaemia patients in Hong Kong can have access to better treatments sooner.

Please don't hesitate to contact Jessis Ng, Coordinator, Children's Thalassaemia Foundation or Mandy Yuen, Officer, Thalassaemia Association of Hong Kong at 2523 5400 if you have any questions.

We are looking forward to your favourable feedback.

Yours sincerely,

Leung Ka Fai
Chairman
Thalassaemia Treatment Patient Concerned Group

c.c: All health services panel members.