

一粒藥丸看世界，半生疾病說人情

「加以域」藥物事件總結

心血會代表：黃遠志

2017年6月24日



心血會是一個血癌（包括 白血病、淋巴瘤、骨髓瘤等）病人互助組織。心血會於1997年4月19日由威爾斯親王醫院的血癌患者、家屬、醫護人員等正式成立。現已將服務擴展至全港有需要的同類患者。本會在2005年6月9日由社團轉為有限公司註冊，並成為慈善團體。本會期望以全港性的朋輩互助網絡協助患者，並且提供機會讓他們助人自助。同時，本會通過提供不同類型的活動，協助病人及其家屬應付因危疾帶來的困難。

心血會

Hong Kong Adult Blood Cancer Group
血癌病人互助組織
註冊慈善團體

九龍 黃大仙下邨 龍昌樓地下 C翼2-8號
黃大仙癌協服務中心

資助團體

香港中文大學
成人血癌基金

癌症基金會
CANCERFUND

社會福利署
Social Welfare Department

www.hkabcg.org

事件背景(一)

- 我們是：
 - a. 慢性白血病患者 (CML)
 - b. 胃腸道基質腫瘤病患者 (GIST)
- 此病有何嚴重？
 - a. 傳統藥物只能暫時壓抑病情且副作用大、骨髓移植不易找到配對且風險大。若不加以適當治療，一般三至五後轉為急性，然後半年至一年內死亡。
 - b. 主要以外科手術切除，但部份病人切除後仍然復發。
- 因此我們需要：「加以域」
 - a. 能減少體內有問題的癌細胞，延長生命，且副作用少。
 - b. 未能根治疾病，但能延長生命，且副作用少

事件背景(二)

- 怎樣開始？

- 2000年瑪麗醫院試藥計劃
- 2002年註冊，自付藥費每粒\$160- (每月\$18,000 - \$28,000)
- 同年6月病人 + 癌協 + 心血會 = 『加以域』藥物關注小組

爭取目標（短期及長期）

- 政府(醫管局)

- 提供安全網予有需要的病人 / 列入常規藥物，全面資助 / 引入非轉專利藥，以合理價錢購藥

- 藥廠

- 免費供藥給試藥病人 / 提供藥物資助計劃 / 大幅減價至合理水平

- 社署

- 提供安全網予有需要的病人 / 放寬審查機制

經過

請參考「加以域事件」總結！

爭取策略

1. 洞悉各方關係

- 醫管局 vs 藥廠、醫管局 vs 議會/傳媒
- 醫管局及藥廠 vs 公眾形象
- 與醫管局及藥廠關係亦敵亦友，尋找機會，謀求福利

2. 掌握知識及資訊

- 藥物療效、全球其他地區藥費及資助情況
- 參與國際病人會議，形成聯盟，學習知識及經驗交流

3. 問題具體、目標清晰

- 短期目標 vs 長期目標
- 不抗拒小恩小惠，積少成多
- 要求合理

爭取策略

4. 積極尋找支持

- 醫生、議員、傳媒、病人組織、社工、大學講師

5. 善用事件新聞價值

- 病人個案 vs 政策失誤

6. 組織機動、成員團結

- 成立核心小組，即時回應傳媒；組員積極參與
- 整體利益先於個人利益
- 互相信任，不容分化

醫療改革團體轟政府卸膊

Breakthrough medication is our only hope, say sufferers

FIGHT FOR SURVIVAL AND DIGNITY

IS STILL GOING ON...

Our Aim

We strive for "Glivec to be categorized as a Hospital Authority standard drug" and "an affordable price from pharmaceutical company".



Our strategies and actions (2012 - 2013)

1. We attended the quarterly Patient Groups Forum to express our opinions and claims on Hospital Authority Drug Formulary and the assessment criteria for Samaritan Fund (Funding to meet expenses for new technologies which are not covered by the standard fees and charges in public hospitals and clinics).

2. We met with pharmaceutical company regularly to ask for price reduction and subsidy to self-financed patients.



and the members of Legislative Council to support Glivec to be categorized as a Hospital Authority standard drug.

4. We allied with other patient support groups, namely Patients' Alliance on Healthcare Reform, to petition the Government for subsidy of extremely expensive but curative treatment and reform of Health Care Policy.



Our Achievements

1. The funding for Samaritan Fund is increased and the means test is relaxed, eventually it favors a part of self-financed patients.

2. Novartis implements a "Glivec patient loyalty program" for self-financed patients to buy 11 get 1 free.



3. The members of Legislative Council support us. They condemn Hospital Authority and Food and Health Bureau during their meetings and request Glivec to be categorized as a Hospital Authority standard drug.

4. The Hospital Authority promises to discuss with Novartis about the price reduction of Glivec and will hold a "Three-Party Meeting" (Patient Support Group - Government - Pharmaceutical Company) in the near future.



Our aim is not yet fulfilled and our fight will go on...

Hong Kong Adult Blood Cancer Group Limited
Glivec Concern Group (A CML and GIST patients support group in Hong Kong)

Room C, Ground Floor, No.2-8, Lung Cheong House, Lower Wong Tai Sin Estate, Kowloon, Hong Kong
Tel: (852) 2603 6869

www.hkabcg.org



Building alliances on drug access, Hong Kong

What's the Problem?

Unaffordable price of Glivec + Restricted access to standard drug = Risky of Life, heavy financial burden and family problem.



Our aim and fight

- The patients of CML and GIST team up to fight for survival and dignity.
- Alliance with social workers, doctors, nurses, professors, legislators, media, NGO and patient groups.
- We strive for "Glivec can be categorized as a Hospital Authority standard drug" and "Price reduction from Pharmaceutical Co." in past ten years.



Our gain

Government (Hospital Authority)

1. Established Glivec as the first-line drugs and set a funding (Samaritan Fund) to subsidy the lower-income patients and middle class patient (subject to a mean test)
2. Continuously review the assessment criteria of Samaritan Fund subject to patient group and other patient groups' opinions.
3. To become a regular group to give opinions to government regarding the Health Care Reform.



Pharmaceutical Company

1. Small amount of patients could obtain the medicine below the market price.
2. Patients in trial or after trial can use the medicine free of charge.
3. To offer some trial and patient assistant program to help the middle class patient who couldn't fulfill the requirement of the funding.

Our aim is not yet fulfilled and our fight will go on...

Conference

public aware:
no longer fatal with
TKI therapy
close monitoring.

public understand
patients' difficulty and
when prescribed
TKI. Also fight for
reasonable
from government and
a co.

1ST IN HONG KONG CML DAY

Last year, our achievements...

Doctor Medical and Patient Sharing Sessions



treatment—
and Present,
by HKU School of
Medicine Blood
Oncologist
Prof. YL Kwong



Close monitoring
first step in CML
therapy.
by Blood Oncologist
Doctor Sif Yip.



Comprehensive view
of CML treatment,
by CUHK Dept of Medicine
Prof. Raymond Wong.

Cancers and Emotions, sharing by CMLer Anthony



Food, Drug and Nutrients, sharing by CMLer Ken



a milestone for HK CML patients. **THANKS** to all parties
2013 HK CML Day a success: doctors, patients, pharma co.,
CML Advocates Network. Wish our joint effort will continue in future!

Other achievements

Reached agreement with Novartis HK to provide
discount to patients who have been paying full price for glivec therapy for
3 years or longer, up to 50%. Government agreed to provide subsidy through
charity donation to patients who have been paying full price for glivec therapy
for under 3 years.

Conference
Sponsor
CANCERFUND

Hong Kong Adult Blood Cancer Group Limited - CML & GIST Group

Wing C, Ground Floor, No.2-8, Lung Cheong House, Lower Wong Tai Sin Estate, Kowloon, Hong Kong
Tel: (852) 2603 6869 www.hkabccg.org

(7) 曉報

新聞



HK's
Healthcare budget
compressed by 100%.

CML Patients' plight
Killed
by economic
stress
before the
pharma.

Pharma's private of medicine
Check the life-saving drug
raised out of
standard territory.



TKI Therapy: A BLESSING OR CURSE

May 2015 | Hong Kong Max 100C, min 0C

Some real events from **HONG KONG**.
If you are one of us, what would you think?



Patients reflections

Government fails
to maintain a healthy
environment for citizens
to thrive; and pharma unaware of
their social and ethical responsibilities,
patients alone have to pay the price.



Opportunities

1. TKIs, the most effective
CML therapy, transform fatal
blood cancer to chronic disease,
offer patients second life.
2. Government's sound finance
should allow stronger commitment
to public healthcare.



THREATS
PUBLIC FINANCE HIJACKED
BY SCROOGE BUREAUCRATS. LIFESAVING
TKIs RULED OUT OF STANDARD DRUG
REGISTRY FOR 14 YEARS AND COUNTING.
PHARMA COS TREAT TKIs AS CASH COWS.
DISMISS ANY PATIENTS ASSISTANCE PROGRAM.
PATIENTS ARE BEING RIPPED OFF A
MILLION DOLLARS EVERY 4 TO 5 YEARS.

Project: TKI Access Campaign achievements and setbacks

1. Hospital Authority **agreed**
to approve TKIs as first line
treatments for CML.



2. Pharma denied GIPAP, M
Foundation **skipped** HK
3. Government introduced
means-tested subsidy
to milk patients of life-long
savings.
4. Pharma offers customer
loyalty program
(not patient assistance)
to silence the patients.
5. H.A. agrees to **import**
generic TKIs. But legal
threats from pharma immi

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CML病人組織 國際會議





“Knowledge is no value unless you put it into
PRACTICE.” – Anton Chekhov



爭取結果 . . .

十五年後的今天

- 政府(醫管局) + 社署

- 確立加以域為第一線藥物→提供撒瑪利亞基金資助有需要的病人 (需經濟審查)
- 引入非專利藥物，以\$10 -價格提供藥物

- 藥廠

- 免費提供藥物予試藥的病人→曾減價至每粒\$122-，但其後又恢復回舊價，但已給予舊價的病人不受影響
- 設立藥物優惠計劃，提供折扣由20%至72%

一粒藥丸看世界

1. 病態社會

- 社會富庶，但疾病致窮
- 妻離子散，臨老唔過得世才得資助
- 短視及怕事的政府（要”有壓力”才會關注及照顧需要）

2. 扭曲的社會價值觀

- 公平 VS 公義（少數病人吃了大部份市民的醫療資源？生病 = 個人問題？）
- 社會成本（無視因病及沉重經濟困境引起的家庭及社會問題）
- 生命價值 VS 資源效益 VS 企業利益

一粒藥丸看世界

3. 病人充權的意識及力量

- 病人權益的缺失
- 為自己的權益，積極爭取
- 病人需要→發出聲音→組織→推動及集結力量→政策倡議→服務監察（循環不息）

4. 病人組織的功能

- 發掘需要及聲音，組織及推動病者爭取權利，達至政策倡議及服務監察的目的

半生疾病說人情

1. 眾人小故事，有血有淚

- 散盡大部份養老金買藥
- 為求資助，辭去工作、忍痛離婚及離開家人
- 寧願停藥留錢給家人，以致失救

2. 點解手牽手：憂戚與共，患難真情

- 全體利益先於個人利益
- 互相贈醫施藥、情緒支援

革命尚未成功，同志仍須努力

- 「胃腸道基質腫瘤」病人仍繼續以昂貴價錢購藥
- 其他病類病人仍面對貴價及有療效藥物的經濟沉重壓力
- 撒瑪利亞基金的審查機制仍然苛刻



The best way to survive is to keep
smiling and sleeping!

謝謝各位用心聆聽!

