

英國註冊慈善團體號碼 1160496

網頁 www.cacaca.org.uk 聯絡 07508 039775 (岑偉鵬總監) 07874 326572 07514 850596 (CACACA16)

電郵 info@cacaca.org.uk

臉書 Chinese Association for Cancer Care



## 2023 年 6 月 協會財政報告:

# 蘇豪關懷癌症月會(MCSG Soho)

£ 32,842.59 5月結存 6月收入 £ 5,211.26 6月支出 £ 44.44

38,009.41 6月結存

每月第二週六 • 上午 11:00 至下午 1:00 • 倫敦中華基督教會蘇豪福音堂地庫 Soho Outreach Centre (SOC), 166A Shaftesbury Avenue, London, WC2H 8JB

## 癌友園地

# 十災不是災

近幾年冬天我都咳,飲了自行購買的咳藥和鼻水藥,個多月 便好轉,家人和我都習以為常。2022年在香港,我起床後 咳有白痰,鼻水有血。3月我退休前不斷咳嗽,四個衣袋都 裝滿摺好的厠紙,預備來接收白痰。因為疫情,乘客必須戴 口罩,我無法除口罩來咳痰是最辛苦。GP 只檢驗新冠肺 炎,我每次都是陰性。政府醫院預約非常困難,也只會檢查 病毒、處方感冒藥和止咳水。當日黃昏我太辛苦了,用手機 找正開診的 GP。我隨即求診,獲處方抗生素治療氣管炎。 我有好轉但再惡化,求診中醫,服了六劑中藥也無效。後再 求診那位 GP, 在4月初的肺 X光顯示右肺頂葉有陰影, GP 建議我求診 A&E。P 醫院的急症室醫生認為長者的肺片有 陰影是非常普遍,但因 GP 的要求便轉介胸肺科。輪候時間 頗長,我自費在21/4照CT顯示有腫瘤,令全家不知所措。 醫生提議自費於 27/4 做 PET,確診肺癌已擴散左右肺、鎖 骨、胸縱膈淋巴結及腦部,再做 MRI 大腦,發現一大四小 的腫瘤。太太在網上以 CT 報告登記 W 醫院胸肺科,獲快 症在 4/5 見專科醫生, 10/5 在右頸近鎖骨處摸到的淋巴結取 活組織檢驗,確診「四期非小細胞肺線癌」。原本是支氣管 窺探取活組織,但腫瘤緊接氣管,我也怕打針而拒絕此檢 杳。

教會弟兄協助我在 18/5 求診 Q 醫院的腫瘤科,醫生說: 「治療肺癌的化療無法治療大腦的腫瘤, 因此要放射腦 部。」想較好的還有免疫療法,但每月8萬港元,我不能負 擔。Q醫院安排5月底開始全腦的電療共十次,做了四次令 我嚴重嘔吐、全身痛、意識模糊、蓋被會令胸口痛、胃口 減、無法下床。妻子上網得知有義診的腫瘤科,獲藥廠基金 提供的免費基因檢查,可取用公立醫院的活組織來檢查十種 基因,而Q醫院只可以自費檢查六種基因。檢測確認我有 ALK 基因突變, 而 ACT 監測發現基因 P53 有突變。私家的 腫瘤科處方第二代的標靶 L 藥,可同時抑制腦部腫瘤。我 自費買藥並停止電療,服藥翌日我便恢復正常下床,服用一 個月後左頸的淋巴結和肺的陰影也縮小。我不能負擔L藥 費,醫生處方另一標靶A藥。雖然療效較遜色都要服用, 因 A 藥可申請藥物基金。可惜我也無法通過經濟評估,8月 我唯有重新自費服食 L藥。

我從事低密度屋苑的保安 19 年,每日工作 12 小時,交通來 回 4 小時,日間工作量是夜間的十倍。退休前 4 年我做夜 班,只有每週放假才見妻子。除了鼻敏感,我的健康一向良 好。2018年小兒子懷疑患肺癆,全家須照肺 X 光, 當時我

的肺片無異常。2019年底,全家計劃移民,毫無心理準 備患肺癌。兩個兒子在澳洲工作假期三年,他們3月已獲 得簽證,約定2022年6月在英團聚。得悉我患癌後,全 家擔心我未必成功申請 BNO 簽證。我自幼參加的教會, 某姊妹鼓勵我們繼續申請,順服耶穌的帶領。2022年5 月,小兒子先到倫敦找居住地方,大兒子回香港照顧 我。我們照 X 光肺和留痰化驗, 獲得無肺癆的證明便上 網申請。想不到十日收到電郵回覆, 我倆獲批 BNO 5+1, 真是耶穌帶領。9月檢查 CT 大腦/胸/腹/骨盆,確認 所有腫瘤均縮小或消失。10月底,我們抵達倫敦。12月 我獲 GP 轉介到 S 醫院呼吸科,再轉介腫瘤專科 R 醫院。 我從香港帶來的標靶 L 藥在平安夜那日便吃完, 很擔心 治療中斷。香港教會的女傳道介紹我認識癌症協會的義 工,她幫我打電話和傳電郵給R醫院的專科護士。我終於 接到電話,在19/12首次覆診腫瘤科。豈料火車罷工,義 工用了個半小時還未到一半路程。她只能在電話翻譯,我 們才了解 NHS 的治療原則:病人必須服食第一線標靶藥 並確認無效,才可以免費使用第二線的L藥,因為L藥的 副作用多。在香港我只服食 A 藥兩週, 未能確認 A 藥對 我無效, 所以腫瘤科無法給我處方免費的 L 藥, 建議我 將餘下的六日藥隔日服食,已向 NHS 上訴等待回覆。

港英兩地的醫療用語,例如藥物的名稱、第幾代和第幾 線,真的令我們很混亂,但我們願意學習適應。得義工的 提醒, 我們向 GP 申請了藥物免費卡,並且傳電郵給專科 護士,希望在聖誕節假前確認上訴的進展。後來太太發 現,我自作聰明將L藥片切開為二,存放在雪櫃內。義 工上網查看, 原來 L 藥只可放在室溫的密封容器內,遠 離熱量、濕氣和直射光線,更不可以切開,否則藥效便大 受影響。我白白浪費了幾粒寶貴的L藥!在一月初,我拿 到小姨由香港帶來的一個月L藥,我衷心說「阿們」。稍 後,專科護士來電話:「藥廠提供恩恤藥物,提早一週 覆診以便取藥。」全家再次感謝耶穌!我每次覆診都要求 翻譯,但每次都無譯員出現, 唯有靠兒子傳譯。義工終 於可以前來翻譯,腫瘤科解釋L藥的治療和副作用後,我 簽紙同意。隨後,藥劑師用半小時解釋藥物的種類、服食 和儲存方法等。獲得如此專業服務,我的心以耶穌為樂。 我們仍然等候 NHS 的上訴結果,但每月取到免費的 L 藥,我們都滿心感激。參加了鄰近的華人教會,弟兄姊妹 均樂於協助。我們雖然小信,但耶穌總有帶領,先後派遣 不同的天使來幫助。

於 2023 年 7 月 5 日 NHS 的 75 歲生日前提升 GP 服務計劃:

- ❖ 為了結束上午8時的預約高峰時段,藥房可以為常見病症直接處方藥物,包括耳痛、喉嚨痛和尿道感染。
- ❖ 無須先求診 GP,病人可以自行轉介物理治療、聽力測 試和足病治療。
- ❖ 在短信/電子郵件發送病假紙,避免病人再回去 GP 領取。
- ❖ 在未來一年,90%的人在 NHS 的應用程序,可查閱自己在 GP 的記錄、檢驗報告,和向醫生傳遞信息。

https://www.england.nhs.uk/2023/05/patients-to-benefit-from-faster-more-convenient-care-under-major-new-gp-access-recovery-plan/



### 十週年紀念聚餐

9/6 40 人進餐細數祝福









**美倫月會(普通語)** 20/7(週四) 11am-1pm **Zoom** 15/6 Zoom 3 人參加,互相支持。



# 十周年 潘麗娟

我已經參加癌症協會的活動十年了,當時我的家人也患上癌症。每次「蘇豪月會」的內容豐富,有健康講座、運動和聚餐,病人和家屬都踴躍出席,我也獲益不少。此後,我成為義工,出席每次月會。我認識的親友中也有十多位曾患癌症,正如 NHS 統計,目前英國一半的人口,一生中會患上癌症。

封城期間,我用電話和視頻關心癌友,也參加網上月會和 訓練班。如今,我不單自己出席「美景月會」,也鼓勵朋 友參加。雖然健康資訊發達,但一般華人較為保守,不願 公開自己的癌症。醫治身體的癌症不容易,醫治心靈的創 傷更需要時間。我可以貢獻的很有限,但總能以母親的心

# 誠邀出席《關懷癌症月會》MCSG

您,並不孤單!

我們是您抗癌路上的同行者。 歡迎癌症病友、家屬、照顧者和朋友, 大家分享近況,互相關懷,祝禱支持。 感謝義工齊心侍奉,出席者預備愛心美食, 一同分享分擔,為抗癌勇士打氣!



**蘇豪月會(週六)**8/7 11am-1pm SOC, 166A Shaftsbury Ave, SOC WC2H 8JB 24/6 十週年紀念 36 人參加慶祝





美景月會(粵語) 25/7 (週二) 2pm-4pm

Maggie Centre, Charing Cross Hospital, Fulham Palace Road, W6 8RF

27/6 16 人參加,互相支持。





腸預備我認為健康的食物。在兩個小時的自由氣氛下,與 癌友們同行是我所享受的。我聆聽他們的爭扎和喜與怒, 也私下為他們祈禱和祝福。看見他們重拾健康,再次展現 笑容和盼望,是最有意義的時刻。

「癌症並不岐視」,無人例外免於癌症。我希望癌症協會的服務能持續,更多在英國的華人參與義工行例,多方面推廣癌症知識。事實上,海外華人不必忌諱「癌症」二字,因為癌症不會傳染,患上癌症也不必感到羞恥。癌友獲得親友的接納和支持,是邁向健康的起步。我快七十歲了,每日如常生活是耶穌給我的禮物,能付出多少就量力而為。總言之,施比受更為有福。



UK Registered Charity Number: 1160496

Website www.cacaca.org.uk

**Contact** 07508 039775 (CE Mr. Sham)

07874 326572

07514 850596 (CACACA16)

Email info@cacaca.org.uk

Facebook Chinese Association for Cancer Care



#### **CACACA June 2023 Finance Report**

32,842.59 May Balance £ 5,211.26 June Income June Expenses £ 44.44 June Balance 38,009.41

## Monthly Cancer Support Group (MCSG Soho)

Second Saturday of each month • 11:00 am − 1:00 pm

Soho Outreach Centre (SOC), 166A Shaftsbury Avenue, London, WC2H 8JB

### Patient's Story

### Not a disaster

In recent years, I coughed in the winter & recovered after taking cough syrups for month. In 2022, in HK, I coughed with white phlegm & bloody nasal discharge. In March, before my retirement, my cough worsened. My 4 pockets were full of tissues to catch the white phlegm. Due to the pandemic, I found it very difficult to cough up the phlegm on public transport without removing the mask. Most GPs only tested for C-19, & I always tested -ve. Booking appointments at government hospitals was hard & they only tested for C-19 & prescribed cough syrups. That evening, I coughed badly so I searched online for an available GP. I went immediately & was prescribed antibiotics for bronchitis. I initially felt better but then my cough worsened. I consulted a TCM & took 6 doses of Chinese medicine but in vain. I turned to the same GP; a chest X-ray in April revealed shadows in my Rt upper lobe. Following the advice, I directly attended P Hospital A&E. The doctor commented shadows was quite common for the elderly, but upon the GP's request, I was referred to the Chest Clinic. The waiting time was long, so I paid for a CT scan on 21/4 which showed a tumour, leaving my whole family at a loss. Another paid PET scan on 27/4 confirmed the lung cancer had spread to both lungs, collarbones, mediastinal lymph nodes & the brain. Then a brain MRI revealed 1 large & 4 small tumours. My wife registered me online at W Hospital's Urgent Chest Clinic on 4/5. On 10/5, the LNs near my Rt collarbone were biopsied, confirming "Stage IV nonsmall cell lung adenocarcinoma." Originally, a bronchoscopy was offered for biopsy, but the tumour was located close to the trachea. I also refused it due to my fear of needles.

A church member booked me an appointment at Q Hospital on 18/5. The oncologist said, "Chemo for lung cancer can't treat brain tumours, so R/T is necessary." Immunotherapy was a better option, but it cost HK\$80,000/month, which I couldn't afford. I started 12 fractions of whole brain R/T at the end of May. After 4 fractions, I had severe vomiting, whole body pain, confusion, chest pain when under a blanket, no appetite & inability to get out of bed. My wife found a charitable oncology clinic online, which offered free testing of 10 types of genes while Q Hospital could only test 6 types of genes at an additional cost. The test confirmed my ALK gene mutation & ACT monitoring revealed the P53 gene mutation. The private oncologist prescribed a 2nd-generation target therapy, called L, which also inhibits brain tumours. I paid for it & stopped the R/T. The day after taking L, I felt better & could get out of bed. After 1 month, the LN in my left neck & the shadows in my lungs had shrunk. However, I couldn't afford the cost, so the doctor prescribed a less effective drug called A. I hoped it could be covered by medication funds but I was not eligible after assessment in August, so I paid for L once again.

I had worked as security in low-density residential estates for 19 years, 12 hours a day & a 4-hour commute. The workload in daytime was 10 times more than the night shift. In the final 4 years, I exclusively worked the night shift, which meant I only saw my wife on my days off. Apart from a runny nose, my health was good. In 2018, my younger son was suspected of having TB, so the entire family underwent chest X-rays. My X-ray was NAD. At the end

of 2019, my family planned to immigrate & lung cancer never crossed our minds. My sons had a working holiday in Australia for 3 years & received their UK visas in March 2022. Our plan was to reunite in England 3 months later. My family was worried about my BNO application being rejected due to my cancer. A church sister encouraged us to apply & trust in Jesus' guidance. In May, my younger son arrived in London to find accommodation & my older son returned home to care for me. We underwent chest X-rays & sputum tests, which were -ve for TB, & then we submitted them online. To our surprise, we received an email after 10 days approving our BNO 5+1 visa. It was truly a testament to Jesus guiding us. In Sept, a whole-body CT scan confirmed that all my tumours had either shrunk or disappeared. At the end of Oct, we arrived in London. In Dec, my GP referred me to the Chest Clinic at S Hospital, & then I was referred to a tumour specialist at R Hospital. I was worried that the drug L I bought from HK would run out on Christmas Eve. An HK church worker introduced a CACACA's volunteer who called & emailed the CNS at R Hospital. Finally, I received a phone call that my 1st appointment was on 19 Dec. There was a train strike & the volunteer was only halfway through her journey after half an hour. She could only interpret over the phone & then we came to understand the NHS principles: patients must undergo 1st-line target therapy, proving its ineffectiveness before using the 2ndline free medicine L which has more side effects. In HK, I had only taken drug A for 2 weeks whose effectiveness couldn't be confirmed. Therefore, the oncologist couldn't prescribe L for free & said, 'Take the remaining 6 days of L every other day while awaiting the NHS appeal.'

We are indeed confused by the medical terms used in HK & the UK, e.g. drug name, generations, & lines. Yet, we are willing to learn & adapt. Following the volunteer's reminder, we applied for the medication exemption card through our GP & emailed the CNS to confirm our appeal before Christmas. Later, my wife discovered that I had cut the L in half & stored it in the refrigerator. The volunteer confirmed online that drug L should only be kept in a sealed container at room temperature, away from heat, moisture & direct sunlight, & it should not be divided. I had wasted several precious L tablets for no reason! In early Jan 2023, I sincerely said "Amen" when my cousin brought me a one-month supply of the L from HK. Later, the CNS called, "The medicine company provides L for free. Come 1 week earlier to collect it." Once again, my whole family thanked Jesus! I always requested an interpreter, but none turned up, so my son assisted me. Finally, the volunteer interpreted onsite for the oncologist to explain L & its side effects before I signed the consent form. The pharmacist further explained in detail for half an hour. I appreciated such professional service. We are still waiting for the outcome of the NHS appeal & grateful to receive the free monthly drug L. We have joined a nearby Chinese church with helpful members. Though our faith may be small, Jesus always guides us & sends different angels to help us.

In the run-up to the NHS' 75th milestone birthday on 5 July 2023, the major new GP access recovery plan:

- To end the 8 am rush hour of booking, pharmacies can directly prescribe medicine for common conditions including earache, sore throat & UTI.
- Patients can self-refer to physiotherapy, hearing tests & podiatry without seeing their GP first.
- Sick leave notes will be sent via text/email, avoiding patients' return trips.
- 90% of people can access their GP records & test results & message their doctor on the NHS App within the following

https://www.england.nhs.uk/2023/05/patients-to-benefit-from-fastermore-convenient-care-under-major-new-gp-access-recovery-plan/



### **10th Anniversary meal**

9/6 40 people joined to count the blessing









MCSG Macmillan 20/7 (Thurs)11am-1pm Zoom 15/6 Zoom 3 people supported each other



## **Monthly Cancer Support Group**

MCSG is open to individuals touched by cancers, patients, survivors, family, friends & carers. We move forward together. None of us is alone! Big "thank you" to participations' dedication & wholesome food.

Let us stand together to fight cancer!



MCSG Soho 8/7 (Sat) 11am-1pm SOC, 166A Shaftsbury Ave, WC2H 8JB 24/6 10th Anniversary 36 people joined the celebration





MCSG Maggie 25/7 (Tue) 2pm-4pm

Maggie Centre, Charing Cross Hospital, Fulham Palace Road, W6 8RF

27/6 16 people joined





### 10th Anniversary

Laisar Poon

I have joined CACACA's activities for 10 years, as my family battled cancer. Each MCSG Soho was well-organized with talks, exercises & meals. Patients & families actively attend, & I benefited greatly. Since then, I've been a volunteer with over 10 friends & relatives having cancer. Per NHS stats, half the population will be diagnosed with cancer in their lives.

During the lockdown, I supported my cancer friends via phone & video, joining online MCSGs & training. Now, I attend MCSG Maggie & invite friends too. Though health info is available, the Chinese community is still hesitant to discuss cancer openly. Treating cancer isn't easy & healing the soul takes time. My contributions are limited, but I prepare healthy food with a

mother's heart. Walking alongside my cancer friends for 2 hours, listening to their struggles, joys & anger, & privately praying for them is what I truly enjoy. Seeing them regain their health, smiles & hopes is most meaningful to me.

"Cancer doesn't discriminate," no one is exempt. May more Chinese volunteers support cancer & raise awareness. Cancer isn't contagious; avoiding the term or feeling ashamed for having cancer is unnecessary. Acceptance & support from family & friends are the first steps towards health. At nearly 70, living a normal life is Jesus' gift to me. I can only do what I can. It is more blessed to give than to receive.