



橋梁



亞裔奇跡骨髓配型協會
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INDUSTRY FOUNDATION™



Asians for Miracle Marrow Matches

患上威脅生命的疾病是一種挑戰。
如果您有敞開的心胸，積極的態度，和一道橋梁
就能克服許多困難。
橋梁幫助您更好的交流您的健康需要。
為了您的健康請您使用它。

橋梁

Living with a life threatening disease is a challenge.
You can overcome many problems by having an
open mind, a positive approach and **The Bridge**.
The Bridge can help you better communicate
your needs. Use it for your health!

The Bridge

Asians for Miracle Marrow Matches (A3M) helps save lives by working to improve patient access to treatment options including bone marrow transplants.

A3M's Culturally Appropriate Patient Support Services (CAPSS) program helps to improve the health and wellness of patients by empowering them to advocate for themselves.

A3M's care management services enable patients to gather information they need to make important decisions to increase their access to healthcare and improve their quality of life.

亞裔奇跡骨髓配型協會(A3M)幫助病人更有效地了解及接觸各項治療服務，包括骨髓移植。

A3M 的相應文化的病人支持服務項目是通過使用相應的文化和語言幫助病人爭取自己的權益，從而改善他們的健康和生活狀況。

A3M 的關懷管理服務幫助病人取得他們所需的資訊，使他們能有足夠的資訊做出重要的決定，提高他們對醫療服務的了解，提高他們的生活素質。

DIAGNOSIS

The diagnosis of leukemia, lymphoma, myeloma or other hematological disorders can present many challenges beginning with understanding the disease and possible treatments.

- ❑ **Aplastic Anemia:** A condition where bone marrow makes too few white and red blood cells and platelets.
- ❑ **Leukemia:** A group of cancers of the white blood cells. Leukemias can occur in two forms: acute-fast forming chronic-slow progressing. There are two main types of leukemia: **Lymphocytic and Myelogenous**. Some leukemias are **Acute Lymphocytic Leukemia (ALL)**, **Acute Myelogenous Leukemia, Chronic Myelogenous Leukemia (CML)**.
- ❑ **Lymphoma:** Cancer of the lymph tissue. There are two types: **Hodgkin's lymphoma and Non-Hodgkin's lymphoma**
- ❑ **Myeloma:** Cancer of the plasma cells in the blood. In patients with myeloma, plasma cells often exist in unusually large numbers. **Multiple Myeloma** is a type of myeloma involving multiple sites.
- ❑ **Myelodysplastic Syndrome:** Also called pre-leukemia or smoldering leukemia. It is a disease of the bone marrow in which too few platelets, red blood cells and white blood cells are made.
- ❑ **Thalassemia:** A group of chronic, inherited anemias.

診斷

被判斷出患上白血病，淋巴瘤，骨髓瘤和其它的造血異常等症狀后要面臨許多挑戰。首要挑戰，就是了解該疾病以及它的治療方式本身。

- ❑ **再生障礙貧血：**骨髓製造異常少的白細胞，紅細胞和血小板。
- ❑ **白血病：**白細胞的癌症。白血病的發展有兩種方式：急性和慢性。白血病主要有兩種形式：淋巴細胞性和骨髓增生性。所以有：急性淋巴細胞性白血病(**ALL**)，急性骨髓性白血病 (**AML**)，慢性骨髓性白血病 (**CML**)。
- ❑ **淋巴瘤：**淋巴組織癌。淋巴瘤有兩種：何傑金淋巴瘤和非何傑金淋巴瘤
- ❑ **骨髓瘤：**血液裏的血漿細胞的癌症。患者的血漿細胞出現異常多的數量。多發性骨髓瘤指的是多個位置出現骨髓瘤。
- ❑ **腦脊髓炎綜合症：**又稱為前期的或潛伏性的白血病。這種病的症狀是骨髓裏的血小板，紅血球，白血球生長得太少。
- ❑ **重型地中海貧血：**多種慢性的，遺傳性的貧血的組合。

TREATMENT

Here are some common terms your physician may use when discussing your treatment.

- Biopsy:** The removal of tissue from the body to be studied under a microscope
- Bone Marrow Transplant (BMT):** Giving healthy **bone marrow** (a spongy tissue of large bones where the body's blood cells red cells, white cells, platelets are made) to patients whose marrow is damaged.
 - **Autologous-** A bone marrow/blood stem cell transplant in which the patient's own cells are used.
 - **Allogeneic-** A bone marrow/blood stem cell transplant in which the cells come from another person. The donated cells can come from a related (sibling) or unrelated donor.
- Chemotherapy:** Drugs that kill cancer cells
- HLA Typing:** A person's specific Human Leukocyte Antigens A,B,C and DR proteins
- Radiation:** Treatments that eliminate/shrink cancer cells by using high-energy radiation
- Relapse:** The return of the disease after treatment
- Remission:** When cancer cells are gone after treatment
- Transfusion:** Getting blood through infusion

治療

當醫生與您討論您的治療方式的時候，這裡的是一些常用的術語

- 活檢:** 從身體提取一些組織在顯微鏡下面 研究
- 骨髓移植(BMT):** 給骨髓受到損壞的病人輸入健康的骨髓（一種在大骨頭裏生長的海綿狀組織，用於製造紅細胞，白細胞和血小板）。
 - 自体同源移植- 採用病人自身的細胞進行的骨髓/血液干細胞的移植。
 - 異體移植- 採用別人身上的細胞進行的骨髓/血液干細胞的移植。捐贈的細胞可以來自相關的人（如兄弟姐妹）或不相關的人。
- 化療-** 用藥把癌細胞殺掉
- HLA 類型-** 人體特殊的白血球抗原的類型 A,B, C 及 DR 蛋白
- 放射治療 -** 使用高能輻射減少或縮小癌細胞的治療方法
- 復發-** 治療后疾病再次出現
- 癌症消失期-** 治療后癌細胞消失的階段
- 輸血-** 通過傳輸得到血液的方式

APPOINTMENTS

How to prepare for appointments

- Write down questions before your visit
- Bring your medicines you're taking including any alternative medicine (e.g. herbal products, Chinese medicine)
- Arrange interpretation service if needed (most hospitals have the ability to provide interpreters)

Tips for self advocacy

- Seek other opinions
- Know your health insurance coverage
- Discuss with your physician when to call him and how to communicate with him
- Consult with your physician before taking any alternative medicine
- Do not be shy about your questions. Just ask and ask.
- Talk to people who have a similar disease/treatment and situation.
- Pain can be managed. It is important to talk to your doctor.

Types of Questions to ask

- What is my disease?
- What is the standard treatment for my disease?
- How does chemotherapy work?
- What can I expect during chemotherapy?
- Are there any side effects? How would I manage the side effects?
- How many treatments will I be given?
- What about clinical trials?
- Which drugs are given?
- Is care covered by my insurance plan?
- Where would I receive my treatment?
- What about bone marrow transplantation?
- If pain becomes a problem, how would we manage it?
- How long would I usually have to wait for appointments or returning of phone calls?

約診

如何做看病前的準備

- 去看病前把問題寫下來
- 把服用的藥，包括替代藥物（如草藥，中藥等）帶上
- 必要時安排翻譯服務（大部分的醫院有能力提供翻譯）

為自己爭取權益的建議

- 尋求其他的醫療建議
- 了解您的保險計劃的覆蓋面
- 向醫生請教何時以及如何跟他聯係
- 服用替代藥物前諮詢醫生的意見
- 不要害羞，有問題要盡量問。
- 與其他同病的患者溝通病情和治療方式。
- 疼痛是可以控制的。跟您的醫生匯報非常重要。

問題的類型

- 我的病是什麼？
- 這種病的常規治療方式是什麼？
- 化療是怎樣的？
- 在化療過程中我將要面對的是什麼？
- 有沒有副作用？我怎麼處理這些副作用？
- 我要經歷多少療程？
- 臨床試驗怎麼樣？
- 會給我吃什麼藥？
- 我的保險計劃覆蓋這些治療嗎？
- 我要在哪裏接受治療？
- 骨髓移植是怎麼回事？
- 如果疼痛成了一個問題，我應該怎麼處理？
- 我一般的約診或打電話要等多久才能等到回音？

INSURANCE

Cancer imposes a heavy financial strain on both patients and their families. For many, some medical expenses are covered by health insurance. For those who may need financial assistance, resources are available. Patients and their families should discuss concerns and questions about health care costs with their physician and social worker.

Understanding your financial situation:

1. Organize your records
2. Understand the type of plan that you have to know your benefits.
 - Types of plans include:
 - Group plans offered by your employer
 - Individual policy
 - Medicare-Federal health insurance program for those who receive Social Security benefits (65 and older).
 - Medicaid (Medical Assistance) –Federal/state health care program which provides health insurance for low-income individuals.
 - Disability Programs
 - High-Risk Insurance
3. Develop a financial plan
4. Look for resources
5. Fundraising

RESOURCES:

National Marrow Donor Program

Office of Patient Advocacy
www.marrows.org
 888-999-6743

CancerCare

www.cancercare.org
 800-813-4673

Social Security Administration

www.ssa.gov
 800-772-1213

Medicare

www.medicare.gov
 800-633-4227

Medicaid

www.cms.hhs.gov/madicaid
 877-267-2323

The Bone Marrow Foundation

www.bonemarrow.org
 800-365-1336

保險和經濟資訊

癌症對病人及家人都造成重大的經濟壓力。對於許多病人，他們的治療費用是由他們的醫療保險來承擔的。但對於需要經濟輔助的人，這裡是一些資源可供參考。病人及家人應該向他們的醫生和社工提出他們的問題和表達他們的憂慮。

了解您的經濟情況

1. 整理您的醫療紀錄
2. 了解您的醫療計劃和您的福利。保險計劃的類型包括：
 - 僱主提供的團體保險
 - 個人保險計劃
 - 聯邦政府給享受社會安全福利（65 歲及以上）的人士提供的醫療保險計劃
 - 聯邦政府或州政府給低收入人士提供的醫療保險計劃
 - 殘疾人計劃
 - 高風險保險計劃
3. 制定出一個經濟計劃
4. 尋找可以利用的資源
5. 籌款

資源：

全國骨髓捐贈計劃

病人支持辦公室
www.marrows.org
 888-999-6743

癌症關懷

www.cancercare.org
 800-813-4673

社會安全管理局

www.ssa.gov
 800-772-1213

聯邦給老人的醫療保險計劃

www.medicare.gov
 800-633-4227

聯邦或州政府給低收入人士的醫療保險計劃

www.cms.hhs.gov/madicaid
 877-267-2323

骨髓基金會

www.bonemarrow.org
 800-365-1336

HOSPITAL STAY

While hospitalized, a patient may need to have a caregiver present.

WHO'S WHO

It is important for the patient and the family to get familiar with the hospital medical team.

- Primary oncologist/hematologist
- Attending Physician
- Discharge Nurse
- Social Worker
- Bone Marrow Transplant Coordinator
- Nutritionist
- Nurse

ASKING QUESTIONS

Ask all the questions that you can. Do not wait until your doctor's next visit. Report everything. It is important to report any and all pains, discomforts, and changes in your body.

COMMON QUESTIONS THAT YOUR DOCTOR MAY ASK

- How do you feel?
- Do you have diarrhea?
- Do you have a rash?
- Did you have a bowel movement?
- Do you have a fever?

住院治療

住院治療的時候，病人可能需要陪同照顧的人。

了解誰是誰

病人和家屬了解和熟悉醫院的醫療人員非常重要。他們包括：

- 主診的腫瘤學醫生和化療醫生
- 主診醫生
- 主理護士
- 社工
- 骨髓移植的協調人
- 營養學家
- 護士

提問

要盡量提問。不要等待下一次看病的機會。向醫生及時匯報一切症狀，如疼痛，不適和任何身體的變化。

醫生常問的問題

- 您覺得怎樣？
- 您有腹瀉嗎？
- 您有皮疹嗎？
- 您有腸動嗎？
- 您有發燒嗎？

住院治療 (HOSPITAL STAY)

常用的問題和句子- 講的時候應指向物體

- 1. I need an interpreter.**
我需要翻譯。
- 2. I need some water.**
我需要喝水。
- 3. I need to go to the bathroom.**
我需要去洗手間。
- 4. What medication is that? What is it for?**
那是什麼藥? 這種藥是治什麼的?
- 5. I want to see the doctor.**
我要去看醫生。
- 6. Where are you taking me and for what?**
您帶我去哪? 去干什麼?
- 7. I have pain.**
我有點痛。
- 8. I have a headache.**
我頭疼。
- 9. It is hard to breathe.**
我覺得難以呼吸。
- 10. I have a rash.**
我有皮疹。
- 11. I have trouble swallowing.**
我感到吞食有困難。
- 12. I have diarrhea.**
我有腹瀉。
- 13. I have constipation.**
我有便秘。

住院治療 (HOSPITAL STAY)

- 14. I have cramps.**
我有腹絞痛。
- 15. I have swelling.**
我腫了。
- 16. I feel cold/hot.**
我感到冷/熱。
- 17. I feel nauseous.**
我想吐。
- 18. I feel numb.**
我覺得四肢麻木。
- 19. I feel tired/I have no energy.**
我覺得累/沒有精力。
- 20. What is going on with me?**
我怎麼了?
- 21. Am I alright?**
我還好嗎?
- 22. Is the chemotherapy working?**
這次化療有效嗎?
- 23. Can I bring food from home and eat?**
我能從家裏帶東西來吃嗎?
- 24. What is the next step?**
下一步是什麼?
- 25. When can I go home?**
我什麼時候能回家?
- 26. When I go home, what should I be careful with: diet, visitors, pets, environment, work, sex?**
我回家后要在飲食, 訪客, 寵物, 環境, 工作和性生活方面注意點什麼?

GET HELP

You could play a role in your healthcare.

Most patients are benefited by:

1. Asking Questions
2. Gathering more information (knowing more about your disease)
3. Attending support groups (groups in language may be available)
4. Speaking with other patients with the same disease/treatments
5. Eating Healthy (Consult your physician and/or nutritionist regarding your ethnic foods)
6. Seeking other medical opinions

Resource Directory:

American Cancer Society

www.cancer.org - 800-227-2345

Leukemia and Lymphoma Society

www.leukemia-lymphoma.org - 800-955-4572

National Marrow Donor Program

Office of Patient Advocacy

www.marrows.org - 888-999-6743

National Cancer Institute

www.cancer.gov - 800-422-6237

Culturally Appropriate Patient Support Services (CAPSS)

Asians for Miracle Marrow Matches

www.AsianMarrow.org - 888-236-4673

尋求幫助

您可以在您的醫療過程中起到重要的作用。

大多數的病人都能得益於：

1. 提問
2. 了解更多的關於您的病情的資訊
3. 參與一些支持組織的活動（有些組織是講同一語言的）
4. 與患有同種疾病的病友溝通病情和治療的信息
5. 注意飲食健康（向您的醫生和營養師查詢關於您的家鄉食物）
6. 尋求其他的醫療建議

有關的資訊

美國癌症學會

www.cancer.org – 800-227-2345

白血病和淋巴瘤學會

www.leukemia-lymphoma.org – 800-955-4572

國家骨髓捐贈計劃

病人支持辦公室

www.marrows.org – 888-999-6743

國家癌症研究院

www.cancer.gov – 800-422-6237

相應文化的病人支持服務 (CAPSS)

亞裔奇跡骨髓配型協會

www.AsianMarrow.org – 888-236-4673