

# Introduction of MDACHINA

## **Beneficiaries: Neuro-muscular disease patients ( gradually frozen people)**

Neuro-muscular disease is one of the five most common death-threatening diseases by WHO (World Health Organization). It includes Muscular Dystrophies (DMD, life span less than 30), Amyotrophic Lateral Sclerosis (ALS, Usually progresses rapidly with 3- to 5-year average survival.) and Spinal Muscular Atrophy (SMA; Killer for two-year-old children). NMD patients will gradually lose the ability to act because of the muscle wasting and the body seems to be “frozen”, so they are cruelly called “gradually frozen men”. It will be more and more difficult for them to manage the daily activities and go out without the help of others. According to incomplete statistics, there are about 4,500,000 patients diagnosed as NMD in China and about 50,000 affected patients in Shanghai. They are the more “vulnerable” group among the “vulnerable group”. The society almost have no knowledge of the group and NMD patients could only endure the long-time sufferings silently.

## Introduction of the Organization

MDA CHINA was founded by Ms Zhu Changqing , with the help of Professor Lv Chuanzhen and Professor Ren Zhaorui. The purpose of MDACHINA is to unite the NMD patients, their families and all classes of society, to help patients build the confidence of facing the future bravely and increase the quality of their life through of acts of kindness helpful to patients’ physical and psychological health, and to promote NMD prevention, diagnostics, treatments, research, convalescence, nursing and protection, etc in China. MDACHINA is the only non-profit organization in Mainland China to join in the League of Nations of MDA, IGA and IPA.

## Mission and Vision

Comprehensively help NMD patients in China improve the quality of life and prolong their life.

Promote the academic and medical research and finally cure the NMD.

Call for more attention and help for the vulnerable group “gradually frozen men”.



**Founder: Zhu Changqing**

Ms Zhu Changqing, having ever studied abroad in Japan, is now an associate professor of Shanghai Second Polytechnic University with a Master Degree. Being a NMD patient, she founded MDACHINA and Changqing Fund with the great willpower and passion for public-spirited affairs, devoted herself to the improvement of patients’ life and calling for the attention of the society. With her tremendous efforts appreciated by the society, she has won the “National Top 10 Public Welfare Star”, “ Good Deeds of Ten Outstanding People in Shanghai Spiritual Civilization ”, “2008 Ten Great Organizers of Charitable Activities in Pudong”, “2008 Shanghai Charitable Award “and other awards. She often participates in different kinds of domestic and international exchange activities and she has some influence in the international public welfare.

Since 2003, the volunteer group of MDA has won the “Intelligence Helping the Disabled Award” every year and the second prize in the Students Challenge Cup in 2007. MDACHINA won the “ Innovation Fund Award 2008” of NIKE. “Welcome Expo, Barrier-free City” Activity won “Most Flat Charitable Activity Award” in 2008 Shanghai Youth Fashion Festival.



Zhu Changqing received an interview from Xinhua News Agency



Chen Zhu(left one), head of Health Department, Chen Saijuan, (left two), NPC member and Zhu changqing

## **Pattern of our work:**

Use the website as platform for publicity. We provide comprehensive help and service for patients in the way of policy advocating, medical research, social activities, home service, psychological counseling, etc.

## **Work and achievements**

1. Since 2002, we have held seven large gatherings of experts, in which we spread medical information and provide psychological counseling. More than 500 people, including experts, patients and their families took part in the gatherings.

(1). April 23, 2002 ,Chinese neuron-muscular disease experts had a seminar with NMD patients' families in Huashan Hospital and made reports to academician Zeng Yitao, director of Shanghai Medical Genetics Station.

(2).October 18, 2003, neuron-muscular disease experts had a second seminar with NMD patients' families in Huashan Hospital. Booklets about NMD are given out to outreach. Chairman of MDAJAPAN sent a letter and representatives to the seminar and Professor Nishino Yichizo, director of Japan NCNP Neuromuscular Research Center delivered the report.

(3). December 20, 2004, neuron-muscular disease experts had a third seminar with NMD patients' families in Huashan Hospital. Professor J . Andoni Urtizbera, MDA expert from France and chairman of the European Neuromuscular Research Center made a report. Booklets about the knowledge of 40 kinds of NMD and genetic were let out to publicize.

(4). June24, 2005, “love fuses freezing----MDA cross-strait exchanging meeting” was held in Shanghai. The executive director of Gradually Frozen Men Association, Yu Shuhua, shared with us their experience. Shen Xinci, chairman of Gradually Frozen Men Association sent a message. Professor Ren, on behalf of MDA went to congratulate and Professor Jiang Yuping introduced the development of the treatment of ALS. After the meeting, they visited the ALS patients.

(5). August 10, 2005, MDA experts and ALS patients' families had a seminar in Shuguang Hospital. Professor Zhi Huiping gave an introduction of the integrated treatment on motor neuron myopathy. Volunteers from SSPU, SHUTCM, SHSMU, School of Public Health, Fudan University, etc came to demonstrate how to massage, how to carry out psychological adjustment and interacting with the patients.

(6). September 8, 2005, Poortman, vice president of the Prevention of birth defects and

disability of the International Association and the secretary-general of International Genetic Union, came to Shanghai to visit . MDA convened a meeting in Medical Genetics Station and invited Mr. Prootman to make a report.

(7). September 11-14, 2005, Zhu Changqing was invited to Beijing to attend the second international conference of prevent birth defects and disability of developing countries held in Great Hall of the People and made a speech at the meeting. She also made a collective report to Jiang Zuojun, vice-minister of Health Department, and Wang Bin, director of Maternal and child Health Care and Community Health Division.

2. We set up a website at 2002 to provide NMD patients with medical information on convalescence, prophylaxis and nursing, etc. The website has got more than 340,000 hits and registered patients cover 29 provinces except Tibet and Qinghai province.

3. From 2003, MDACHINA organizes volunteers from Shanghai Second Polytechnic University, Shanghai International Studies University, Shanghai Fudan University and Shanghai University of Chinese Traditional Medicine and other seven universities to provide home teaching, recovery and nursing. It adds up to more than 20520 persons and 61560 hours.

4. From 2005, we organize patients to go outside and display their talent in order to enhance patients' confidence and attract public attention. There have been held 22 large public welfare activities, 255 patients and 320 family members have been benefited:

(1). November 12, 2005, MDACHINA ,cooperated with U.S. Chamber of Commerce, organized 15 patients to visit the Shanghai Urban planning Exhibition Center and the central greenbelts in Pudong. They also showed their talents and played games together.

(2). December 3, 2005, MDACHINA hosted the "Same Wishes" event for NMD patients with the program "major medical consultations" and Johnson &Johnson. Fifteen patients visited the Shanghai Urban planning Exhibition Center and JinMao Building.

(3). May 14, 2006, cooperated with the Shanghai Botanical Garden ,the Shanghai Armed Police Force, East China University of Science and Technology and the Shanghai Institute of Environmental, MDACHINA organized 20 patients to visit the Shanghai Botanical Garden and to be close to nature.

(4). June 5, 2006, on the program "Lightning-moving", model Hu Bing and our patient Rongrong held a concert which six other patients and over 200 volunteers attended.

(5). May 20, 2007, over ten patients and more volunteers participate in the large-scale theme of

youth public-spirited activities “caring Shanghai 2007” held in Jing’an Park.

(6). June 27, 2007, 30 NMD patients watched the wonderful performance by the Cirque du Soleil in the Sun Castle.

(7). November 17, 2007 , during Shanghai Youth Fashion Festival, patients, their families and volunteers publicize “caring for gradually frozen men” activities and we also held a charity bazaar on works of patients and donated clothes.

(8) January 13, 2008, we cooperated with the League Party Committee to host “If I can walk for one day”--- large public-spirited action of Shanghai Youth’s caring gradually frozen men. 30 NMD patients visited the Madame Tussauds, the Shanghai Urban planning Museum, the Shanghai Science and Technology Museum and other famous scenic spots.

(9). June 21, 2008, “World Gradually Frozen Men Day”. There held an event called “2008 AXA-Minmetals Assurance • MDACHINA Love Movement” while the first power wheelchair soccer team in China was established –MDA power soccer team. 29 NMD patients, leaders in Pudong district and Shanghai, the guests from cooperative units, medical experts and altogether more than 100 guests attended it. Some young patients demonstrated their talents, sitting in the powered wheelchair to play football and works of the patients were on a jumble sale.

(10) July 12, 2008, held “Heart by heart, hand in hand” activity with SSPU, 11 patients and their families and volunteers, altogether more than 60 people took part in the activity. They visited the Oriental Pearl TV Tower in the morning and joined in a party in the afternoon. At the same time the 2<sup>nd</sup> activity of MDA football team was held.

(11) Nov. 16, 2008, as part of Shanghai Youth Fashion Festival, we held “Welcome the Expo, building up a barrier-free city “activity outside the Yaohan Plaza. The 3<sup>rd</sup> MDA football team activity was held.

(12) Dec. 3<sup>rd</sup>, 2008, “Visit space and play football” was held in Shanghai Science and Technology Museum. 12 patients, their families and volunteers took part in the activity. They visited “Shenzhou VII” exposition. The fourth activity of MDA Powered-chair football team was held.

(13) Feb. 2<sup>nd</sup>, 2009, a big commonweal ceremony named “Commonweal Circle and NGO” was held at the Pudong Citizen’s Centre. MDACHINA participated in it and 6 patients accompanied by their families were there in charge of the sale of work. Dou Yupei, Vice Minister of the Ministry of Civil Affairs, accompanied by Ma Yili, Minister of the Ministry of Civil Affairs Of Shanghai was shown around the MDA exhibiting area and was introduced to

## MDA by Zhu Changqing.

(14) On March 1<sup>st</sup>, 2009, MDA invited Liu Renzhou, from Taiwan to give our patients a lecture on the meaning of life at EAP` s office. 20 patients attended the lecture.

(15) On March 26<sup>th</sup>, 2009, the singing game of freezing people was held at Holiday. With the help of 9 volunteers, 7 patients and their relatives sang their favorite songs at Holiday, enjoying the entertainment of common people. On the mean time, the fifth game of power-wheelchair football by MDA was held at the People` s Square.

(16) On April 6<sup>th</sup>, with the help of 7 volunteers, the sixth football game was held. There were 8 patients who participated. Afterwards, the first official group work of MDA happened at EAP` s office. 20 patients and relatives in all attended and shared their storied of life.

(17) On April 21<sup>st</sup>, the activity named as “life on wheelchairs” was held in Fudan University. 20 students from Fudan and 9 volunteers took part in the activity.

(18) On the evening of April 23<sup>rd</sup>, Zhu Changqing addressed the lecture named as “Emblazing by passion, Defrosting by love — the growing path of MDACHINA as a NGO of China” in Fudan University. 18 students and 5 volunteers attended. This lecture served as a good opportunity to advocate the ideas of MDA and commonweal.

(19) On April 28<sup>th</sup>, 2009, the 7<sup>th</sup> football game of MDA was held at Xianghe Park. The Youth Daily covered the activity. Then, 35 patients and relatives went to visit the Future` s Home for free. Xinmin Daily and ICS covered the activity.

(20) On May 3<sup>rd</sup>, 2009, the third episode of the group work by MDA and EAP was held with help of Wang Jinnan and Luo Qiong. Volunteers from Fudan and Huashida University attended. The eighth football game of MDACHINA was held.

(21) On May 12<sup>th</sup>, 2009, our patients visited Fudan University. With the guidance of the student, we patients were shown around the beautiful campus and communicated with those cordial volunteers on dreams. The ninth football game of MDA was held. MDACHINA conferred a banner on the S.S.D.P of Fudan University. ICS covered the acitivity. The Love-Driving team leaded by Wu Xiaoxiong offered the service of delivery.

(22) On May 22<sup>nd</sup>, 2009, MDA members visited the SWFC and enjoyed the beautiful sightseeing of the evening Shanghai from the cruise ship over Huangpu River. With the assistance of SWFC, the Oriented Pearl Cruise Company and Jinsheng, the activity

was successfully ended. 32 patients and relatives and 40 volunteers participated. The tenth power-wheelchair football game was held. SMG, ICS, Jiefang Daily, Xin Min Night Newspaper, Youth Daily, Pudong Times covered the activity. Also, the news named as “Freezing People Stepping on the Highest Building in Shanghai” was covered at the Evening News on SMG.

5. From 2006, develop the necessary auxiliary equipment, including breathing machine, ramp, lifting chairs, lifting bed, powered wheelchair and all kinds of lifting equipment, etc. The Assisting the Disabled Robot developed by Zhu and her students got the second prize of the Challenge Cup 2007.
6. Establish Changqing Fund and receive donations from society. Build platform for social group and individuals who care about the charity.
7. Go to USA, Japan and other 10 countries to attend MDA exchanging meeting to develop the medical research and the treatment.
8. Publicize the vulnerable group “gradually frozen men” to call on the attention of the society. Our activities are reported by the Xinhua News Agency, China news agency, Dragon TV, Shanghai TV, Shanghai Radio, Radio Pudong, China Youth Daily, "Liberation Daily", "Oriental Morning Post", "Morning News", "New People's Daily", Sina and more than 50 media networks and over 300 reports, which have a lot of social repercussions.
9. May 10,2008, Ding Ming, a NMD patient, recommended by Lenovo as an Olympic torch bearer, joined in the torch relay in Huangshan. Sep. 1, 2008, Zhu Changqing, recommended by China Olympic Committee as a Special Olympic Games torch bearer, joined in the torch relay in Shanghai.
10. Submit the motion to the CPCC and NPC deputies concerning the enhancement of gradually-frozen men’s education, employment, medical and social security system.
11. June 21<sup>st</sup>, 2008, the first power-wheelchair football team was founded. Since then, ten activities have been held, involving 100 patients, 130 relatives and 200 volunteers.
12. MDACHINA has cooperated with EAP to organize a group work named as “Warm Your Freezing Heart” since March, 2009. Till now, it has been held three times.



MDA held a forum in Huashan Hospital, Prof. Jin Li delivered a speech.



Volunteers went to give a massage to patients.



In 2004 at 3rd MDA conference, Foreign experts had a warm chat with Little patient, Rongrong



In Jan 13 2008 "If I could walk for one day" activities Little patients watched the wax of Yao Ming in Madame Tussauds.



June 21, 2008, MDA Powered Chair Football Team was established.



Dec.3, 2008, the football team held the fourth activity in Science and Technology Museum



Sep 1<sup>st</sup>, 2008, Zhu Changqing joined in the Special Olympic Games torch relay



Jan.6,2009, Zhu Changqing won “Shanghai Charitable Award “

### What we need:

**Organizational survival and development:** Need space / funds / office supplies / professionals

**Services and activities:** Need more volunteers to join us , especially people who can offer medical treatment, nursing, public relations, publicizing and other professional assistance.

**Building rehabilitation centers:** Need space, equipment, staff and operating funds

**Patients’ housing recovery and nursing:** Need rehabilitation, volunteer services, poverty relief of the patients, etc.

**Policy support:** Need people to make good use of their own advantages to win the government policy support for NMD patients into the special medical insurance, pension protection of life and medical assistance system.

Strict monitoring mechanism to ensure that every donation is implemented.

**Are you willing to offer your help?**

### Contact us:

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## **Account for Charitable donations**

### **Changqing Fund (RMB Currency Account):**

**Account name:** Shanghai YanBaohang Foundation

(Please add “Changqing Fund” for neuro-muscular disease research and help”, and inform us by sending message, e-mail or Fax)

**Bank:** Shanghai Huaihai Road (M) No.2 Branch Office, Industrial and Commercial Bank of China (ICBC)

**Account number:** 1001221009014454290 **Swift code:** ICBK CNBJSJI

### **USD Currency Account:**

**Name:** YAN BAOHANG PUBLIC FOUNDATION SHANGHAI

**BANK:** The Industrial And Commercial Bank of China Sub-Branch of Xu-Hui district, Shanghai , International Department

**Account number:** 1001221009141600424