

## HIBM Testing: Simple & Painless

HIBM is the most common muscle wasting disease in young adults of Iranian Jewish (IJ) heritage. About 1 in 500-1000 in the IJ community will become affected with HIBM, and about 1 in 15-20 carry the defective gene. This is even more common than Tay-Sachs disease. By a simple test you can find out if you or your kids are at risk for HIBM. This test may significantly reduce your anxiety regarding becoming affected with HIBM.

You may give the HIBM testing postcard, which was mailed with this newsletter, to your physician. If your doctor is unaware of HIBM, you or your doctor may contact HIBM Research Group (HRG) for further information. HRG contact information is on the postcard.

If you don't already have a preferred doctor, you may contact **Dr. Michael Eshaghian** at (310) 247-9988 or (818) 784-4100. Dr. Eshaghian is knowledgeable about HIBM, and he can help you in genetic screening for HIBM and other serious genetic disorders. If you are planning to get married and have children, or if you are already pregnant, you could contact Dr. Eshaghian or another ObGyn doctor of your choice for advice.

The HIBM test is simple, painless, and may be covered by your insurance. The test does not require blood draw and is performed by just gently rubbing a Q-Tip inside the mouth (buccal swab). Additionally, the test is **100% confidential** and may be performed **anonymously**.

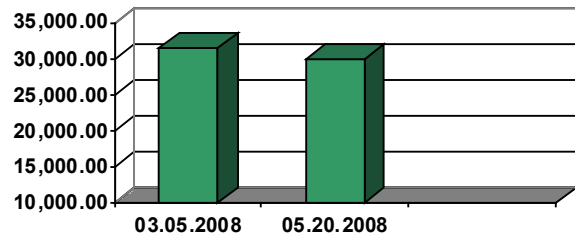
## ARM Mission and Vision

The purpose of ARM is to accelerate biomedical research aimed at developing treatments for IBM2 (recessive HIBM - Hereditary Inclusion Body Myopathy), and skeletal muscle regeneration. ARM's mission is to accomplish this goal in the most efficient manner possible.

The vision of ARM is to unite communities worldwide in our fight against HIBM. Confidential genetic testing for HIBM is available at the HRG lab in Encino.

Together, we can significantly shorten the path to development of an effective treatment.

**Donor Newsletter Response**



## Calendar of Events

The following events are planned for 2008-2009:

- October 30<sup>th</sup> - Young ARM Costume Party (Los Angeles)
- December 7<sup>th</sup> - ARM Telethon 2008 (Los Angeles)
- March 2009 - ARM Benefit Gala 2009 (Los Angeles)

To receive detailed information, call 1-800-ARM-2000.

## ARM Costume Party (October 30th, 2008)

The Annual Young ARM Costume Party is scheduled for Thursday October 30<sup>th</sup>, 2008 at Club Vanguard (Hollywood).

We look forward to see as many of you as possible. The Costume Party promises to be a wonderful evening filled with food, music and entertainment!

For more information and tickets, please contact the ARM office or visit the ARM website. All revenue of the Costume Party goes directly towards research on HIBM.

## Board of Directors

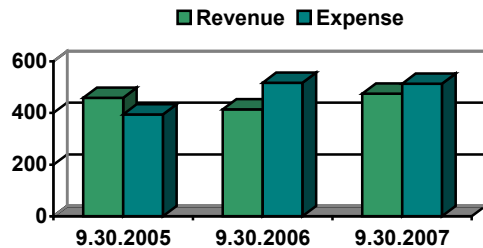
The Board of Directors of ARM includes the following dedicated and hardworking individuals:

- Nadia Adhami
- Babak Darvish, MD
- Mahrokh Eshaghian (NY)
- Mino Koutal
- Hamid Soleimani, Esq.
- Rodney Yashouafar, JD
- Kam Redlawsk

The board members serve a term of one year, and elections are held in November of each year. The Board of Directors of ARM is the driving force behind the fundraising efforts and the promise to find a cure for HIBM. They are responsible for awarding funds to research institutes and laboratories in such a way that a treatment for HIBM will be achieved in the most timely and efficient manner.

### Financial Report

For the year that ended Sep. 30, 2007, the total revenue was \$474,751, which included 47.16% funds raised from special events, 52.64% direct donations and 0.2% from bank interest. The total expenses were \$513,039, which included 87.26% research grants awarded, 12.62% fundraising and administrative costs.



The total revenue of the year 2008 will be available at the end of the year.

### Telethon 2008

Currently, ARM is working on organizing the upcoming Telethon. ARM depends on volunteer participation for its upcoming Telethon on December 7th, 2008. Volunteers can help us reach our fund-raising goals in several ways, such as:

- If your relatives and close friends own businesses and corporations and are willing to benefit from tax-exemption opportunities, please don't hesitate to contact the Corporate Funding Department and coordinate your efforts with our professional team. ARM will promote the names of business donors and individual donors in many ways.
- If you are a professional musician, artist or poet and you are willing to perform for the Telethon as a volunteer.

- If you would like to donate your time for helping us during the Telethon.
- If you have access to patients, who are still not aware of our activities, please introduce them to us base on their consents. Patients' family members with a special talent can be introduced during the Telethon, if they wish to be part of the program.
- If you are running an advertisement or public relations firm and you are willing to donate some services to ARM and promote our Telethon, please contact our office.
- Editors, journalists and editor-in-chiefs of newspapers and magazines who are interested in ARM and the Telethon, will be provided with materials and press releases.
- College and university students, who are willing to create a volunteer background and are welcome to work in a highly professional environment and get credits for their sincere volunteer services.



### A Family Affair: Giving to ARM

This year Dr. Bobby Soleiman, who is a successful periodontist, and his 7-year-old daughter Kiana urged their family and friends to make a donation to ARM as a present to them on their birthdays. ARM Board Members extend their warmest gratitude to the Soleiman family for their generous and thoughtful gesture. It is with the help of active members of our community that we are able to continue funding the cure for HIBM.

### When Will We Have A Cure?

A cure for HIBM may mean either stopping the muscle wasting (prevention), or returning the lost muscles (muscle regeneration). We believe therapies for "prevention" will be developed years before therapies for "muscle regeneration." Each proposed therapy must be tested in people through clinical trials, before we can be certain the treatment is effective for patients. Scientifically, it might be easier to stop the muscle damage caused by HIBM than by other more common muscle diseases. There are several promising proposed therapies for HIBM. Testing these therapies on people are very expensive.

Unfortunately, the amount of funds currently raised by ARM each year is not adequate for clinical trials. Therefore, we have tried and succeeded in raising the interest of well-funded scientists to work towards developing a treatment for HIBM. These scientific investigators, including those at the National Institutes of Health (NIH), have realized the potential for developing an effective treatment for HIBM. *To raise the funds needed for finding a cure as soon as possible, we must unite our community. Every dollar brings us closer to a cure. The pace at which we can get there is in YOUR hands.*