



ARM UPDATE

Vol. February 2008
Donor Newsletter

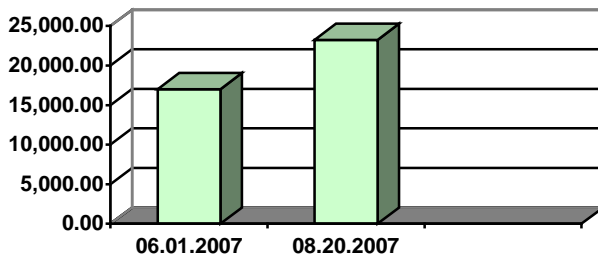
Advancement of Research
for Myopathies (A.R.M.)
PO Box 261926
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Phone (800) ARM-2000
<http://www.hibm.org/arm>

Recent Development

You may be aware of the exciting news released by National Institutes of Health (NIH) regarding possible therapy for HIBM using a sugar-like molecule N-Acetylmannosamine (<http://www.jci.org/cgi/content/full/117/6/1585>). Before we are able to proceed to clinical trials on patients, the Food and Drug Administration (FDA) has requested more thorough "toxicology" testing in both rodent and non-rodent models. This toxicology study will provide further evidence that N-Acetylmannosamine will be safe for human consumption. With your support, we will be able complete the needed toxicology studies and proceed to clinical trials in the near future.

Additionally, ARM is currently supporting transnational research for both gene and stem cell based therapies for HIBM. For further information please contact us or visit ARM website.

Donor Newsletter Response



Current Research

We are at a very promising stage in research. Our immediate goals include two clinical development translational research plans that will lead to *Phase I Therapeutic Trials* on human patients; one is for gene therapy and the other for stem cell therapy using a patient's own muscle stem cells. Unfortunately, the costs of moving forward with these plans are higher than ARM has been able to raise over the past few years. We estimate that roughly \$2-5 million will be needed for these trials. If adequate funding is available, we are hopeful that both trials could begin within the next two years. With your help we know that we can succeed and we are closer than ever in reaching our goals.

Calendar of Events

The following events are planned for 2008:

The *ARM Gala Event* is scheduled for Sunday, March 16th at Marriott Hotel (Los Angeles Airport).

February: Newsletter mail out

March: Gala event (Los Angeles)

TBA: Party (Los Angeles)

TBA: Comedy Show (Los Angeles)

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

ARM Benefit Gala (March 16th, 2008)

On Sunday, March 16, 2008, ARM will host a formal Benefit Gala to introduce the new look of ARM. We are at an unprecedented moment in the search for a cure for HIBM. The foundational research has been laid and a cure for HIBM is in sight. ARM is currently supporting projects that are preparing for clinical trials in the coming years. This is a great accomplishment and represents a pivotal moment in the research.

In keeping with the importance of this great moment, ARM has been working hard on strengthening our outreach materials. A new logo, brochures, website, and documentary show what has been accomplished so far and reflect the future of ARM. ARM will introduce each of these at the Gala. The Gala promises to be a wonderful evening filled with food, live music and entertainment! For more information and tickets, please contact the ARM office or the ARM website.

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 (using saliva) for a nominal fee. Together, we can significantly shorten the path to development of an effective treatment.

Board of Directors

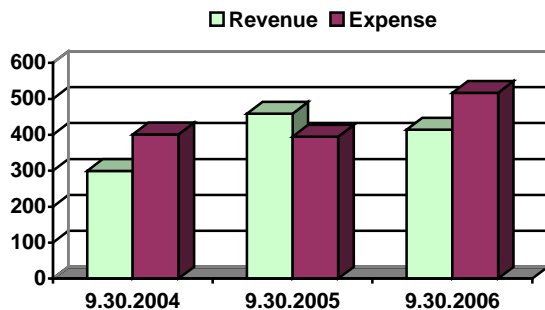
The Board of Directors of ARM includes the following dedicated and hardworking individuals:

Nadia Adhami
Babak Darvish, MD
Mahrokh Eshaghian (NY)
Minoo Koutal
Hamid Soleimani, Esq.
Rodney Yashouafar, JD

The board members serve a term of one year, and elections are held November of every 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 cure for HIBM will be achieved as soon as possible.

Financial Report

For the year that ended Sep. 30, 2006, the total revenue was \$414,214, which included 47.16% funds raised from special events, 52.64% direct donations and 0.2% from bank interest. The total expenses were \$516,805, which included 87.26% research grants awarded, 12.62% fundraising and administrative costs.



The total revenue of the year 2007 will be available at the end of the year 2008.

When Will We Have A Cure?

A cure 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 and a team of specialized scientists.

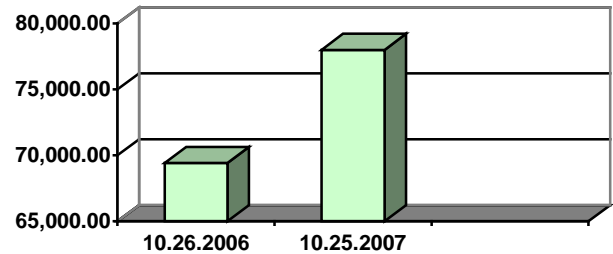
Unfortunately, the amount of funds currently raised by ARM each year is not adequate for clinical trials. Therefore, we have tried and succeeded in raising the interest of well-funded scientists to work towards developing a treatment for HIBM. These scientific investigators, including those at the National 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.*

Young ARM Party (Vanguard)

The annual Young ARM Costume Party was a great success. More than 1400 people attended the event on October 25th, 2007 at Vanguard in Hollywood. The revenue of the party was more than \$70,000, which will all go to HIBM research.

ARM would like to thank the Young ARM group for organizing the party, and for doing a great job once again! And ARM would also like to thank everyone who attended the event; we hope to see you again next year.

Donations Raised by Young ARM



All revenue of the Costume Party goes directly towards research on HIBM.

Telethon 2007

Currently ARM is gathering all the donations pledged on Sunday December 2nd 2007 Telethon. If you have not yet send in your pledged donation please do so. Remember every dollar brings us closer to a cure. ARM would like to thank all of you for your continued support. This years Telethon revenues will be available in the next newsletter.

Major Contributor

Mr. Reuben Yeroushalmi who is a successful attorney <http://www.yeroushalmi.com/> has been responsible for over \$90,000 in contributions to ARM over the past two years. ARM board members extend their warmest gratitude to Mr. Yeroushalmi. It is with the help of young active members of our community that we are able to continue our plight against HIBM.