



ARM UPDATE

Vol. Sept/Oct. 2007
Donor Newsletter

Advancement of Research
for Myopathies (A.R.M.)
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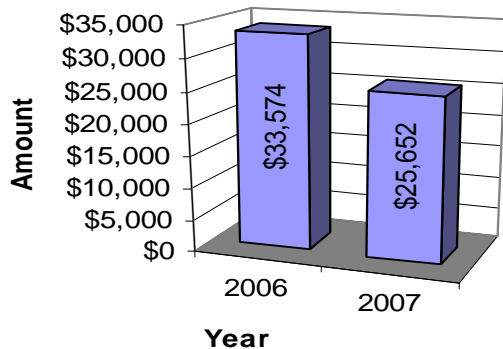
Recent Development

On June 1, exciting news was released by National Institutes of Health (NIH) regarding *possible therapy* for HIBM. Please refer to the following website for more information (<http://www.jci.org/cgi/content/full/117/6/1585>).

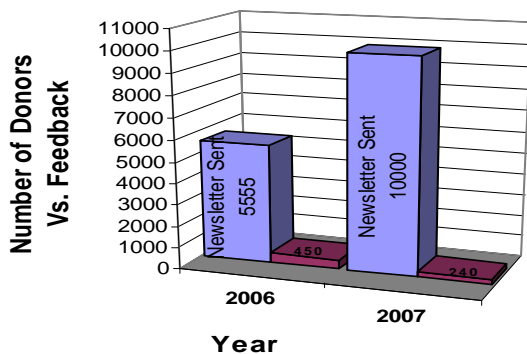
We are currently in the process of completing a *Media Kit* which will help increase awareness of our efforts. It will be completed by November and will be available on the net as well as through a mailer. The media kit will be an important part of our outreach and awareness efforts. ARM is going through exciting changes and we could not have done it without your help.

We truly appreciate all your efforts in helping us succeed. As of this month we will update these numbers quarterly as a part of our newsletter. We could not be more pleased, since 2006 our donor list has increased to 10,000 members; unfortunately our donation funding has decreased. This data is available upon request in our office; please call us for more information.

Donations Raised



Donor Newsletter List



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 Iranian 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.

Calendar of Events

The following events are planned for the remainder of 2007:

The *Young ARM Costume Party* is scheduled for October 25th. We look forward to see many of you as possible. Further news will be announced shortly. We encourage all of our young leaders to attend and have a great time.

End of October: Young ARM Costume Party

November: Completion of Media Kit

December: Newsletter Mail out
ARM Televised Telethon

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

Board of Directors

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

Nadia Adhami
Babak Darvish, MD
Shawn Gabbaie, JD
Mahrokh Eshaghian (NY)
Minoos 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.

Research Opportunity

ARM is in need of genetic scientists who have experience in pharmaceutical research. Any scientist who has experience in such field is encouraged to reach us as soon as possible.

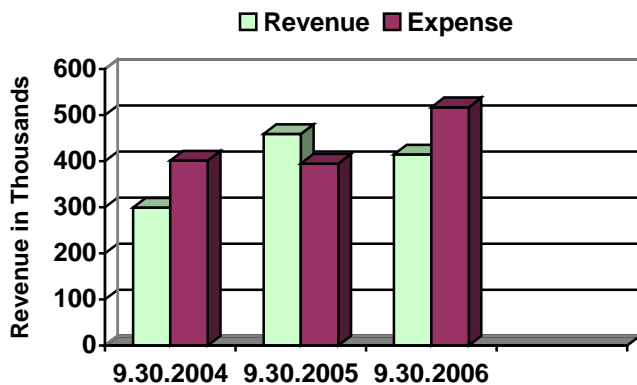
ARM relies heavily on a strong volunteer group. Currently, the management team is undergoing a few significant changes and we are in desperate need of skilled volunteers. If you are bright, motivated, hardworking, and have specific office and management skills, we want to hear from you today. Please send your resume by email to arm@hibm.org.

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.

Financial Report

ARM accounting is based on the fiscal year beginning on October 1, and ending on September 30. The following chart shows the revenue and expenses for the years that ended on Sep. 2004, 2005, 2006. These were recently audited in 2006.



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.

A Cure Maybe Closer Than You Think !!

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 in people requires millions of dollars 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.*

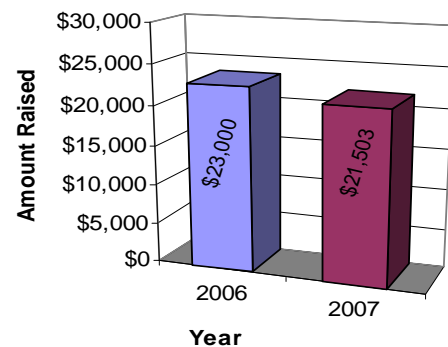
The total expenses were \$516,805, which included 87.26% research grants awarded, 12.62% fundraising and administrative costs.

For the year that ended Sep. 30, 2005, the total revenue was \$459,154.28, which included 47.16% funds raised from special events, 52.64% direct donations, and 0.2% from bank interest. The total expenses were \$394,711.50, which included 85.91% research grants awarded, 12.62% fundraising costs, and 1.42% management costs.

Young ARM New York

Young ARM of New York has successfully raised over \$20,000 for ARM through their efforts in the past few months. We truly appreciate their efforts and hard work. The total specific amounts raised are available in our offices and available upon request.

Donations Raised by Young ARM NY



Over the past year, the Young ARM of New York Committee has done an amazing job in both spreading awareness, and raising funds for HIBM research. We applaud the members for their organization skills and hard work. For more information you can contact ARM by email.

Newsletter Programs

ARM has begun two periodic newsletter programs: 1) **Update**, the newsletter for donors and 2) **Review**, the newsletter for healthcare professionals and scientists. These newsletters will include important information regarding scientific updates, ARM funded research, activities and ARM's financial position. If you or someone you know would like to receive one or both of the newsletters, please email a request to arm@hibm.org.