



ARM UPDATE

Vol. 2006-07
Donor Newsletter

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

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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 the Iranian communities worldwide in our fight against HIBM. Together, we can and we will 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
- Shawn Gabbai, JD
- Bruce Kadz, MD
- Sep Kamjoo, CPA
- Minoo Koutal
- Sunny S. Nassim, Esq.
- 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 are 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 realized as soon as possible.

Volunteers Needed

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. Currently, skilled volunteers are needed for website maintenance (webmaster), special events management, newsletters, executive actions committee, scientific advisors committee, and internal audit committee. Please send your resume by email to arm@hibm.org.

Job Opportunity

ARM is looking for a motivated administrative assistant who is able to work independently and meet reasonable deadlines. The wage is negotiable at \$8-15 per hour. The duties include working with the ARM Board of Directors and ensuring deadlines are met. For further information, please visit the ARM website.

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.

If you would like us to include other specific information regarding HIBM or ARM in the next newsletter, please email us.

Calendar of Events

The following events are planned for the remainder of 2006:

- Jul 20: Young ARM Hollywood Party
- Jul: ARM Fundraising Luncheon
- Aug: ARM Televised Telethon
- Oct 26: Young ARM Costume Party

To receive detailed information, please leave a voice message at 1-800-ARM-2000. Your message will be forwarded to the person in charge of each planned event.

July Mail Out

Quarterly broadcast email and postal mailings to over 5,500 Iranian homes are planned. We have been working diligently to organize the July mail out, which includes this newsletter.

Currently, ARM needs more funds to be able to support new research projects vital for finding a cure for HIBM. If every household makes a donation, regardless of the amount, we will be able to fund more research towards developing an effective treatment.

Please take a moment and donate as much as you can afford. Time is of the essence as research grant funds are at an all time low. Your donations are crucial for developing a treatment.

ARM Supported Research

ARM is currently supporting the following projects:

- Hadassah Israel (Stella Mitrani-Rosenbaum, PhD): "In vitro and in vivo models for HIBM" – \$150,000.
- University of Quebec in Canada (Jacques P. Tremblay, PhD): "Genetic Correction of Myoblasts" \$92,100.
- University of California, Irvine (Masashi Kitazawa, PhD): "Impact of Aβ on GNE transgenic mice" – \$45,000.
- HIBM Research Group, Encino, CA (Daniel Darvish, MD): Genetic Testing & Consultation; Research Grant Program Administration; Preservation and Distribution of IBM2 Biological Research Samples; Development and

For more detailed information about the approved grants and research please visit ARM's website.

New Grants Awarded

ARM received two research proposal applications for the Spring 2006 peer-review process. Both applications received high review scores, and the board of directors has voted to award the following research grants.

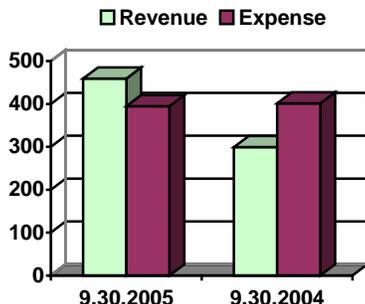
Dr. Jon Wolff, of the University of Wisconsin, is awarded \$100,000 for a one-year project to develop gene therapy for treatment of HIBM. Dr. Wolff is a renowned scientist in the field of muscle gene therapy.

Dr. Ajit Varki, of UCSD, is awarded \$81,201 for a one-year project to develop a unique mouse model that may resemble the human muscle biochemistry better than currently available mouse models. Dr. Varki is a leader in the field of sialic acid biology.

The award recipients are top-notch scientists in their respective fields. Their contributions will be a boost to HIBM research.

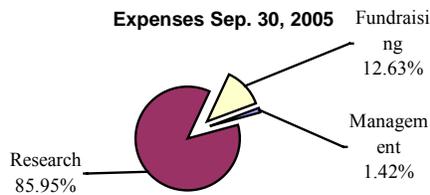
Financial Report

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 of the years that ended on Sep. 30, 2005 and 2004.



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.



For the year that ended on Sep. 30, 2004, the total revenue was \$299,544.85, which included 31.44% funds raised from special events, and 68.56% direct donations. The total expenses were \$401,419.22, which included 87.93% grants awarded, 10.61% fundraising costs, and 1.46% management costs.



Detailed financial report is available for review at the ARM website.

Young ARM New York

Over the past year, the Young ARM Committee of New York 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.

- David Amirian
- Michael Azizi
- Ben Haghani
- Misha Haghani
- Melody Kohandarvish

If you live in New York, and you come across one of these young angels, please give them your gratitude and appreciation for carrying the torch for HIBM families.

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 are 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.

The amount of funds currently raised by ARM each year is not adequate for clinical trials. Therefore, we have tried successfully to raise 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.

The first clinical therapeutic trial for HIBM was started at the NIH late last year using a medication known as IVIg (Intravenous Immune Globulins). This was an important first step toward developing an effective prevention.

Other scientists have also expressed interest in developing a therapy for HIBM. They recognize that it may be possible to develop an effective treatment in a short time.

The more funds that are available for research on HIBM, the more scientists will become interested in developing a therapy. If our annual budget were in the multi-millions, it may take as little as 1-5 years to develop an effective treatment. With current limited budget, it will take much longer.

To raise the funds needed for finding a cure as soon as possible, we must unite our community.

In summary, every dollar brings us closer to a cure. The pace at which we can get there is in your hands.

“Hope is the companion of power and the mother of success, for those of us who hope strongest have within us the gift of miracles.” - Sydney Bremer