



# ARM UPDATE

Spring 2006

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

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### New ARM Board of Directors

It is with great pleasure that the new Board of Directors of ARM presents itself.

#### The Board of Directors of ARM:

1. Ms. Nadia Adhami
2. Dr. Babak Darvish, MD (President)
3. Mr. Shawn Gabbaie, JD
4. Dr. Bruce Kadz, MD
5. Mr. Sep Kamjoo, CPA
6. Mrs. Minoo Koutal
7. Mrs. Sunny S. Nassim, Attorney at Law
8. Mr. Hamid Soleimani, Attorney at Law
9. Mr. Rodney Yashouafar, JD

The Board of Directors of ARM is the driving force behind the fundraising efforts and the promise to find a cure for HIBM, which predominantly affects people of Middle Eastern descent. The Board of Directors is responsible for dispersing funds to research institutes and laboratories in such a way that a cure for HIBM will be realized in the most effective and fastest way.

To attend an ARM Board Meeting, please call (818) 789-1033.

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### ARM Telethon 2006

**In July 2006, ARM will have its third Telethon. This event will be broadcasted live on satellite TV.**

Besides the latest news on HIBM research and raising funds for research, there will be entertainment and enjoyment to support this wonderful cause that is so important for the Iranian community.

For more information on the Telethon and other ARM events, visit our website, [www.hibm.org](http://www.hibm.org) or call ARM at (800) ARM-2000.

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### ARM Supports Hadassah Research on HIBM

ARM has approved a grant request for 2006 from Hadassah Israel for \$ 150,000. With this grant from ARM, Hadassah will continue research on HIBM and help ARM reach its goal of finding a cure.

Besides Hadassah, ARM has awarded grants and contracts from the following institutions:

- ✓ 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 A $\beta$  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 Organization of Collaborative Research; Management of Laboratory Facilities - \$110,000.

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

<http://www.hibm.org/arm>.

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### ARM New York

**Since November 2004, ARM has a chapter based in New York. ARM New York organizes fundraising events and awareness about HIBM on the East coast. There is a Young ARM group in New York as well, organizing events for the younger generation.**

By expanding its fundraising efforts to the East coast, ARM will be able to fund more research projects, which in turn will result in finding a cure for HIBM much faster. HIBM patients lose valuable muscle tissue every day, so there is no time to waste.

## Young ARM Costume Party raises \$70,000

In October 2005, Young ARM had its Fifth Annual Costume Party. The Costume Party has become one of the best parties in town, and since the first party in 2000 has grown in size and revenue. Last year's party raised \$70,000 for HIBM research.

ARM would like to thank everybody who helped making this party an absolute success and hopes to see all of you who came to party at future Young ARM events.

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### The Mission of ARM

Finding a cure for HIBM.

**ARM (Advancement of Research for Myopathies) has been working on finding a cure for HIBM since its inception in 1997. Thanks to your generous donations, research on HIBM is progressing, and big steps have been taken towards finding a cure. ARM developed a mouse model, and soon testing on the mice to find a treatment will start. A new important phase in developing a treatment has started, and ARM needs your financial support to continue.**

### ARM

Advancement of Research for Myopathies (ARM) is a non-profit organization based in Encino, California. It was founded to accelerate research aimed at developing treatments for HIBM, Hereditary Inclusion Body Myopathy.

### HIBM

HIBM causes progressive muscle weakness and wasting. People affected with the recessive form of HIBM notice muscle weakness between the ages of 20-40. In most cases, it leads to severe disability within 10-20 years. As such, it strikes within the most productive years of its victim's lives.

Because of a "founder mutation", people of Iranian Jewish descent have a 5-10 percent chance of carrying the gene mutation responsible for HIBM but HIBM patients carrying other mutations can be found all over the world. When both parents are carriers for the gene

mutation, each of their children has a 25 percent chance of developing the disease.

ARM organizes fundraising events to be able to finance research, and hopes to reach FDA approved clinical trials with an effective treatment for HIBM in the near future. Due to the progressive and debilitating nature of this disease, it is imperative that a treatment is found as soon as possible.

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*"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."*

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### Join ARM as a Volunteer!

ARM needs volunteers of all age groups with different skills, to organize parties, gala dinners, or informative seminars, to write articles, to design and write newsletters, or produce documentaries. Various groups representing different age and skills demographics are currently active in forwarding ARM's objective.

If you would like to be involved as a volunteer, and join our great journey towards a treatment for HIBM, please contact ARM at (800) ARM-2000.. Please don't forget to leave a message in English, and we'll call you back the same or following day.

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### Testing for HIBM

HIBM Research Group in Encino, California, offers genetic testing at minimal or no cost to patients and donors of ARM. HIBM Research Group has optimized the technique to perform screening for HIBM by a simple mouth swab. This eliminates the need for a blood draw. Genetic testing is also available at GeneDx, Inc, Gaithersburg, Maryland (USA), and other centers worldwide. Contact Dr. Daniel Darvish at (818) 789-1044 for more information.