

NIH Wellstone Center for FSHD officially launched

October 10, 2008, members of the FSH Society and friends of the Boston Biomedical Research Institute (BBRI) gathered to recognize the establishment of the first Wellstone Center in New England and first research center in the world to focus exclusively on FSHD.



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Charles Emerson, Ph.D., director of the new center and president of BBRI, "We have recruited the best minds in basic and clinical research and have an extraordinarily committed patient advocacy group to help us focus on this problem." Emerson invites William R. Lewis, Sr., M.D., chairman of the board of directors of the FSH Society, to cut the ribbon and launch the new center. Louis Kunkel, Ph.D., co-director of the new center, and Daniel Paul Perez, president of the FSH Society, also pictured.

FSH Society Annual Donor Report 2008

The Challenge for the Wellstone Center for FSHD reaches its goal!

From the Chairman, Board of Directors, FSH Society

February 2009

Dear Friends,



William R. Lewis,
Sr., M.D.

In November, I wrote to ask you to participate in the Challenge for the Wellstone Center for FSHD Muscular Dystrophy, a collaboration of the Boston Biomedical Research Institute, the FSH Society and others important to this work. Board members joined together to offer to match your gift and the gifts of others, up

to a total of \$117,200 on a dollar-for-dollar basis if you made your gift by December 31, 2008.

I am pleased to report that 280 individuals, foundations and businesses in the FSHD community contributed \$123,856 to the Challenge. Board members have made our matching gifts in recognition of all of you who have made gifts large and small. Together, we have all contributed \$241,056.

Notwithstanding the extraordinary economic environment in which we find ourselves, the FSH Society has concluded one of our most successful fundraising years ever, raising \$750,000 from

generous friends like you.

You helped the Society make important progress. Thank you for supporting advances in research, education, outreach and advocacy.

The list that follows includes all donors to the FSH Society in 2008. We hope you will continue to support this work by joining the Society again in 2009.

Sincerely,

William R. Lewis, M.D.

William R. Lewis, Sr., M.D.

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Gifts received January 1, 2008 through December 31, 2008

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 Helen Zimmer and Karen Prill

In Memory

Family and friends of these individuals have made gifts in their memory in 2008.

Elizabeth A. "Betty" Black
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 Roger Brown
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 Francis Cameron
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 Henry E. Smith
 Dr. Russell E. Smith
 Jean E. Soldan
 Jean E. Soldan on Father's Day
 George Stangas
 Charlyne Deeg Stasiuk
 Benjamin L. "Ben" Stout
 Adelyn Tyll
 Joseph Vengelar

In Honor

Family and friends of these individuals have made gifts in their honor in 2008.

Joseph Daniel Albunio, Jr.
 The Jeffrey Bache Family
 Carol and Horace Barsh on
 their marriage
 Sandy Batkin on Father's Day
 Sanford Batkin on his 85th birthday
 Ann Biggs-Williams
 Barbara Birnbaum
 Steven Blier
 John Bowden
 Marge S. Brchan
 Corinne Bronfman
 Mimi Brown
 Don Burke
 Brian Cavanaugh
 Howard Chabner
 Howard Chabner on his 50th birthday
 Justin Cohen
 Justin Cohen on starting
 Tufts University
 Gary Cohen on his 50th birthday
 Haley Cohen
 Betsy Conron
 Betsy Conron on her 50th birthday
 Grace Corradino
 Pauline Cuoco
 Rosalind Devon on her birthday
 Charles Emerson, Ph.D.
 Richard T. Fields and family
 Frank Fitzmaurice

Sixto Garcia
 Catherine Gibson
 Omi Thea Giesen
 Alan Gordon
 Joseph Donald Hawkins
 Ruth Hereford
 Bill and Judy Herzberg
 Harry Herzberg
 Monica and Peter Herzberg on their
 new home
 Dr. William Herzberg
 William Herzberg on his birthday
 The Herzberg Family
 Andrew Hoffman on his 21st birthday
 David E. Housman, Ph.D.
 Lauren Jacobs
 Shelley Jacobsen
 Jeff Johnston
 Beth and Jeff Johnston and their Family
 Picnic for FSHD Fundraiser
 The Katz Family
 Julie Kelly
 Maureen Kelly
 Pauline Kelly
 The Kelly Family
 Lewis M. Kunkel, Ph.D.
 Berni Kuntzelmann
 C. Larry Laurello
 Aubrie Lee
 Mary and Man So Lee on
 their 50th anniversary
 Richard Lefebvre on his birthday
 Andrew Levinson on his making
 Phi Beta Kappa
 Duncan and Wm R. Lewis, Sr., M.D.
 and family
 Kathy Lucero
 Myra Marantz on her birthday
 Lin McClay
 Marilyn Meisel
 William Michael
 John Milne
 Michael Moffat
 Nathan Morin
 Camry Murdoch
 Kyle Pablo
 Pachx2
 Linda Passon
 Allison Patapa
 Denise Patapa
 Ron Paynter
 Carol Perez on her birthday
 Carol and Charles Perez
 Dan Perez for his great work
 Sue Perez on her birthday
 Hilda Perez-Shafer
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 Nicolas Pogany
 Edward J. Reed
 Valerie Renosto
 Jennifer Rhatigan
 Joanna Roberts
 Zeke Ross
 Jane Rowlett
 Jessica Ryley
 Edward Schechter
 Eli Schindelheim
 Deborah Schwartz
 Rod Shuster
 Gina, Dana and Lora Simone
 Saul Smolar on his 80th birthday
 Linda Stapleton
 Monti Staton

Chris Stenmon and his "Tenth Annual
 End of Tax Season Celebration"
 Jayne Turner-Hughes
 Nancy Van Zant
 John Weintraut
 Jack and Debra Wilt
 Dr. and Mrs. Glenn Wing
 Matthew Worley
 Dr. David Younger
 Helen Younger on her birthday
 Helen and David Younger

Gathering of Members and Fundraising Events, 2008

- Northport, NY, Tennis Fashion Show, March
 Laura and Paul Kampa, Hosts
- Quincy, MA, 10th Annual After Tax Season Celebration, April
 Ellen and Chris Stenmon, Chairs
- New York, NY, Gathering of FSH Society Members, April
 New York Botanical Garden
- Pebble Beach, CA,
 50th Birthday Party. April
 Betsy Conron, Honoree
- Fire Island, NY, Yard Sale, July
 Grace Corradino and
 Brian Kerr, Chairs
- Coralville, IA, FSH Society International Patient and Researcher Network Meeting
 July
- Staten Island, NY,
 50th Anniversary Party, August
 Mary and Man So Lee, Honorees
- Mamaroneck, NY,
 Family Picnic for FSHD, Sept.
 Beth Johnston, Chair;
 Judy and Ken Seslowe, Hosts
- Spring Lake, NJ, Luncheon
 December

Family Fundraising, 2008

- Biggs-Williams Family
- Chabner Family
- Gillespie and Gibson Families
- Herzberg Family
- Jacobs Family
- Kelly Family
- Perez Family

FSHD Future Fund

Members of the FSHD Future Fund are individuals who have remembered the FSH Society through a bequest or other estate planning instrument.

- Amy Bekier
- Greg and Tanya Bergstein
- Michele DeSha
 and Howard Chabner
- Barbara and James A. Chin, Sr.
- JoAnn Forance
- Judy Marantz and
 William Herzberg, M.D.
- Jeff and Chris Jacobs
- Donald and Judy Lokerson
- William and Virginia Michael
- Jennifer Moore
- Deborah Schwartz
- Robert Smith
- Helen and Marc Younger