Form **990** 

# **Return of Organization Exempt From Income Tax**

Under section 501(c), 527, or 4947(a)(1) of the Internal Revenue Code (except black lung benefit trust or private foundation)

OMB No. 1545-0047

Department of the Treasury

▶ The organization may have to use a copy of this return to satisfy state reporting requirements.

Open to Public

	For th	ne 2004 c	alendar	vear. or ta	x year beginning /	APRIL 1	. 2004. a	nd ending MAR	RCH 31	, 20 05
			Please	C Name of o			,,			oyer identification number
		applicable	use IRS	1	-	ASSOCIATION, II	NC.	l l	13	1665552
		s change	tabel or print or	<del></del>	<del></del>	if mail is not delivered to		ess) Boom/suite		hone number
		change	type. See		T SUNRISE DRI				•	) 529-2000
$\overline{}$	nitial re		Specific		vn, state or country, a					
_	inal ret		instruc- tions.		ARIZONA 8571			1		ting method: ☐ Cash ☑ Accrual ther (specify) ►
$\overline{}$		ed return						H and I are no		le to section 527 organizations.
⊔ A	Applicat.	tion pending				d 4947(a)(1) nonexemp ledule A (Form 990 or 9				rn for affiliates? Yes No
٠,	Mahait	<b></b> W/W		AUSA.OR	•	icoano in fi cinii coc ci	JU 12,			ber of affiliates ▶
<u>u</u>	websn	(e: > ****	7 4 4 . 141	AUSA.UN	<del></del>			H(c) Are all aff		
J	Organiz	zation type	(check c	only one) <b>&gt;</b>	<b>☑</b> 501(c) ( <b>3</b> ) <b>⊲</b> (	insert no.) 🗌 4947(a)(1)	or 🔲 527			st See instructions)
_						ormally not more than \$		H(d) Is this a se	eparate retu	ım filed by an
						nization received a Form !			on covered	by a group ruling? Tes Ves No
1	n the m	nail, it shoul	d file a re	eturn without fi	inancial data Some s	tates require a complete	return.	I Group Ex	emption N	lumber ▶
				a. a. a.		220 540	440			the organization is not required
		<del></del>			o, and 10b to line 1					Form 990, 990-EZ, or 990-PF)
Pa	Til.						und Bala	ances (See pa	age 18	of the instructions.)
	1	Contrib	utions,	gifts, grant	ts, and similar an	nounts received:				
	а	Direct p	ublic st	upport .			1a	172,184,9	79.30	
	Ь	Indirect	public	support			1b	874,0	71	
	С	Govern	nent co	ontributions	s (grants) , ,		1c			4
	d	Total (ad	dd lines	1a through	1 1c) (cash \$ _1	73,059,035 noncas	h \$	O )	1d	173,059,035
	2			_		ent fees and contrac			2	
	3	-							3	
	4		•			vestments			1 .	
	5			-	om securities				5	3,762,527
	6a	Gross re					6a		*.	
	b		-				6b		merica A	1
	c			•		b from line 6a)		······································	6c	
41	7			•		LOSS ON RESTRI	CTED SE	CURITIES )	7	(82,075)
Revenue	_				of assets other	(A) Securities		(B) Other		
eVe	- Ua	than inv	entory	IIOIII Sales		123,082,059	8a		T **	
Œ	ь	BEC		Francis and	d sales expenses.	113,937,731	8b			
	<u> </u>	Seelblass.	TINEEL I	affach sak	dane) EXHIBİL V	9,114,328	8c			
		Not gain	or (los	s)./combibe	Nine 8c. columns	(A) and (B))			8d	9,144,328
	82			Z0113	fattach cohadula) l	f any amount is from g	 namina ch	ack hara	V 100 100 100 100 100 100 100 100 100 10	
	[س			-(not-includ	mariacii scriedulej. I	145,862,463 of E	yanınıy, on	CCK HOIC P	3	j
	a						9a	30,154,2	58	3
	l .			chairen ou	ner than fundrais	ing expenses	9b	30,154,2	- 20000055	
	<u> </u>					ing expenses subtract line 9b froi			9c	0
	1				•		m iine 9a)   <b>10a</b>			
	l _			-		allowances	10b			*
	b		-	goods sold				( U 40 )		1
	C					ttach schedule) (subtra		•	44	564,645
	11	Other re	evenue	(trom Part	VII, line 103)	7 9d 0o 10o and 1			11	
	12					7, 8d, 9c, 10c, and 1				186,448,460
Ś	13	_		•	ne 44, column (B	••				134,321,766
Expenses	14	_		-	-	olumn (C))			4.5	12,817,861
ğ	15				, , , , ,					28,574,306
Ð	16				tach schedule)				16	475 740 000
	17					umn (A))	· · ·	<u> </u>	17	175,713,933
ets	18					ne 17 from line 12)				10,734,527
Ass	19					of year (from line 7			19	162,764,113
Net Assets	20					nces (attach explan			20	(12,540,593)
z	21	Net ass	ets or fu	und balance	es at end of year (	(combine lines 18, 19	9, and 20)	· · · · ·	21	160,958,047

For Privacy Act and Paperwork Reduction Act Notice, see the separate instructions.

Cat No. 11282Y

Form 990 (2004)

Part II Statement of Functional Expenses

All organizations must complete column (A) Columns (B), (C), and (D) are required for section 501(c)(3) and (4) organizations and section 4947(a)(1) nonexempt charitable trusts but optional for others (See page 22 of the instructions)

		Do not include amounts reported on line 6b, 8b, 9b, 10b, or 16 of Part I.		(A) Total	(B) Program services	(C) Management and general	(D) Fundraising		
Exhibit C	22	Grants and allocations (attach schedule) (cash \$ 30,567,845 noncash \$ 0)	22	30,567,845	30,567,845				
Exhibit K	23	Specific assistance to individuals (attach schedule)	23	16,479,805	16,479,805	44 - 44 - 44 - 44 - 44 - 44 - 44 - 44			
ZAHIDIU IX	24	Benefits paid to or for members (attach schedule)	24						
	25	Compensation of officers, directors, etc	25						
	26	Other salaries and wages	26	54,557,492	46,709,064	5,333,134	2,515,294		
	27	Pension plan contributions	27	3,514,397	3,070,267				
	28	Other employee benefits	28	8,151,514	7,121,367	663,548	366,599		
	29	Payroll taxes	29	4,583,845	3,983,053	384,414			
	30	Professional fundraising fees	30		·····		•		
	31	Accounting fees	31	141,461	0	141,461	0		
	32	Legal fees	32	146,204	0	146,204			
	33	Supplies	33	2,582,749	2,034,468				
	34	Telephone	34	4,818,436					
	35	•	35	8,056,248		722,196			
		Postage and shipping	36	9,185,107	7,948,103	549,831	687,173		
	36	Occupancy	37	3,103,107	7,540,105	343,031	007,173		
	37	Equipment rental and maintenance	38	5,902,161	2,250,377	626,854	3,024,930		
	38	Printing and publications	39	6,203,559	5,278,462	412,058			
	39	Travel	40	0,203,333	3,210,402	412,030	313,039		
	40	Conferences, conventions, and meetings	<b>⊢</b>						
	41	Interest	41	1,522,756	891,978	577,801	52,977		
xhibit D		Depreciation, depletion, etc. (attach schedule)		1,322,730	091,970	377,001	32,911		
	43	Other expenses not covered above (itemize): a	43a	4 577 607	4 470 274	2 200 650	700 704		
	b	MISCELLANEOUS	43b	4,577,697	1,470,274	2,308,659	798,764		
	C	CONTRACT SERVICES &	43c	44700 057	4 000 004	405.540	40.740.044		
	d	PROFESSIONAL FEES	43d	14,722,657	1,808,064	195,549	12,719,044		
	e 44	Total functional expenses (add lines 22 through 43). Organizations completing columns (B)-(D), carry these totals to lines 13—15.	43e	175,713,933	134,321,766	12,817,861	28,574,306		
	loin	t Costs. Check ► ☑ if you are following SOF			, ,				
		ny joint costs from a combined educational campaign		ndraising solicitation	n reported in (B) Pro	ogram services?	► Ø Yes □ No		
		es," enter (i) the aggregate amount of these joint cos				to Program service			
		ne amount allocated to Management and general \$			e amount allocated		2,195,228		
		t III Statement of Program Service Acc							
							Program Service		
	All or of cli	All organizations must describe their exempt purpose achievements in a clear and concise manner. State the number of clients served, publications issued, etc. Discuss achievements that are not measurable. (Section 501(c)(3) and (4)							
		nizations and 4947(a)(1) nonexempt charitable trusts RESEARCH - EXHIBIT H, PART III a	s must a	iso enter the amou	nt of grants and allo	ocations to others.)	(4) orgs , and 4947(a)(1) trusts, but optional for others )		
	а.	ALULANOT - LATIBIT II, I AIXI III d	• • • • • • • • • • • • • • • • • • • •				•		
			· · · · · · · · · · · · · · · · · · ·			************	04 004 744		
		PATIENT & COMMUNITY SERVICES - EXHIBI		and allocations	\$	30,567,845)	34,291,741		
	D.	PATIENT & COMMONT 1 SERVICES - EXTIBI	1.115.57	N. I III D					
	-								
	•	(1	Grants	and allocations	\$	)	79,231,125		
					ΓIII c	<u> </u>	· · · · · · · ·		
	_	PROFESSIONAL & PUBLIC HEALTH EDUCA		•					
	C .	PROFESSIONAL & PUBLIC HEALTH EDUCA		·		••••••			
	<b>c</b> .	PROFESSIONAL & PUBLIC HEALTH EDUCA							
	<b>c</b> .				\$		20.798.900		
	C .			and allocations	\$	)	20,798,900		
	c .				\$	)	20,798,900		
	c .				\$	)	20,798,900		
	d .	(	Grants Grants	and allocations	\$	)	20,798,900		
	d .	(	Grants Grants Grants	and allocations and allocations and allocations	\$	)	20,798,900		

## Part IV Balance Sheets (See page 25 of the instructions.)

N	lote:	Where required, attached schedules and amounts within the description column should be for end-of-year amounts only	(A) Beginning of year		<b>(B)</b> End of year
	45	Cash—non-interest-bearing	798,889	45	5,552,040
	46	Savings and temporary cash investments	15,645,315	46	9,683,450
		1 1			
	47a	Accounts receivable	5 504 440		E 007 040
	b	Less: allowance for doubtful accounts 47b 0	5,531,419	47c	5,237,619
		Pledges receivable	40 406 760		40 240 200
		Less: allowance for doubtful accounts . 48b 0	12,486,762	<del></del>	10,319,308
	49	Grants receivable		49	
	50	Receivables from officers, directors, trustees, and key employees		50	
		(attach schedule)		V 1818	
un.	51a	Other notes and loans receivable (attach schedule) 51a		3. 12	
ssets		oriodalo)		51c	
Ass		Less. anowaried for doubtful accounts		52	
,	52	Inventories for sale or use	2,030,507		3,321,602
L 24 TS	53	Prepaid expenses and deferred charges	79,179,318		83,400,470
bit F	54	Investments—securities (attach schedule) ▶ ☐ Cost ☑ FMV	73,173,310		00,400,470
	55a	Investments—land, buildings, and equipment; basis 55a		Section.	
				Market	
	b	Less: accumulated depreciation (attach		55c	
	56	schedule)	77,403,635		87,166,757
it F		Land, buildings, and equipment: basis 57a 16,906,940	,,		
		Less: accumulated depreciation (attach		w*	
bit D	D	schedule)	10,545,733	57c	10,516,922
	58	Other assets (describe >)		58	
	59	Total assets (add lines 45 through 58) (must equal line 74)	203,621,578	59	215,198,168
	60	Accounts payable and accrued expenses	19,625,347	60	30,143,971
	61	Grants payable	21,232,118	61	24,096,150
	62	Deferred revenue		62	
es	63	Loans from officers, directors, trustees, and key employees (attach			
IIti		schedule)		63	
Liabilities	64a	Tax-exempt bond liabilities (attach schedule)		64a	
J	b	Mortgages and other notes payable (attach schedule)		64b	
	65	Other liabilities (describe >)		65	
			40.057.465	_	E4 040 404
	66	Total liabilities (add lines 60 through 65)	40,857,465		54,240,121
	Orga	inizations that follow SFAS 117, check here > 🗹 and complete lines			
S		67 through 69 and lines 73 and 74.	162,764,113		160,958,047
ဦ	67	Unrestricted	102,704,113	+	100,330,047
<u>a</u>	68	Temporarily restricted		68 69	
80	69	Permanently restricted		8.	·
Ĕ	Orga	anizations that do not follow SFAS 117, check here ▶ ☐ and			
Œ		complete lines 70 through 74.		70	
ō	70	Capital stock, trust principal, or current funds		71	
šet	71	Paid-in or capital surplus, or land, building, and equipment fund.		72	
ASS	72	Retained earnings, endowment, accumulated income, or other funds		<del>                                     </del>	
	73	Total net assets or fund balances (add lines 67 through 69 or lines		'	
et	l				
Net Assets or Fund Balances		70 through 72; column (A) must equal line 19; column (B) must equal line 21)	162,764,113	73	160,958,047

Form 990 is available for public inspection and, for some people, serves as the primary or sole source of information about a particular organization. How the public perceives an organization in such cases may be determined by the information presented on its return. Therefore, please make sure the return is complete and accurate and fully describes, in Part III, the organization's programs and accomplishments.

Pai	t IV-A	Financia	liation of Revenu I Statements with See page 27 of the	h Revenue	per	Part	F			f Expenses nents with		
<u> </u>	Total reve	nue, gains,	and other support			а	Total exp	enses	and lo	sses per	2	
	per audite	d financial	statements >	a 182,	940,829	1	audited fin	nancial s	statemen	ts ▶	а	175,713,933
þ	Amounts line 12, F		n line a but not on			b	Amounts i on line 17,			a but not		
(1)	Net unrea	lized gains nents .	\$ (3,507,631)			(1)	Donated and use of		_		,	
(2)		services of facilities	\$			(2)	Prior year ad					
(3)	Recoverie	es of prior			- Tan		Form 990		\$		designation of the second	
(4)	year gran		<u>\$</u>			(3)	Losses rep		n <u>\$</u>		2 °	\$
		•••••	¢			(4)						•
	Add amou	ınts on line:	s (1) through (4) ▶	ь (3,	507,631)			·	\$			v x .
			- (·,g (·, ·				Add amour	nts on lir	nes (1) the	rough (4)▶	b	0
C	Line a mi	nus line <b>b</b>		c 186	448,460	С	Line a min				С	175,713,933
d		included of but not of				d	Amounts II Form 990				,	
(1)		expenses				(1)	Investment					
	not includ 6b, Form 9	ed on line	\$				not include 6b, Form 99		_			
(2)	Other (sp		<del></del>			(2)	Other (spe		<del></del>		37	
• •						.,		• •	-		,	€≈‴
			\$			-			<u>\$</u>		-	÷7
_			es (1) and (2)	d	0	1_	Add amou				d	U
е			ne 12, Form 990	e 186	448,460	е	Total exper	nses pe s line <b>d</b> )	riine 17,	<b>&gt;</b>	e	175,713,933
Par	t V Lis		ers, Directors, Ti	rustees, ai	nd Key I	Emplo					sated	; see page 27 o
		(A) Nam	e and address		(B) Title a	and avera	age hours per to position	(If not p	pensation aid, enter 0)	(D) Contributions employee benefit p deferred compens	olans &	(E) Expense account and other allowances
			MPLOYEE) RIVE, TUCSON AZ	85718	Preside	ent & C	EO 100%		365,000	34,	321	0
		• • • • • • • • • • • • • • • • • • • •										
			OF OFFICERS AN		AS NEE	EDED			0		0	0
WHO	SERVE \	WITHOUT	COMPENSATION				-					
75	organizatio	on and all re	or, trustee, or key er lated organizations, edule—see page 2	of which mor	e than \$1	0,000 v	mpensation ovas provided	of more by the re	than \$100 elated org	0,000 from yo anizations?	our •	☐ Yes 🗹 No

Form	990 (2004) Muscular Dystrophy Association, Inc. #13-1665552		P	age 5
Pai	t VI Other Information (See page 28 of the instructions.)		Yes	No
76	Did the organization engage in any activity not previously reported to the IRS? If "Yes," attach a detailed description of each activity	76		~
77	Were any changes made in the organizing or governing documents but not reported to the IRS?	77		~
	If "Yes," attach a conformed copy of the changes.			
	Did the organization have unrelated business gross income of \$1,000 or more during the year covered by this return?	78a	~	
	If "Yes," has it filed a tax return on Form 990-T for this year?	78b	<b>/</b>	~
79	Was there a liquidation, dissolution, termination, or substantial contraction during the year? If "Yes," attach a statement	79		
80a	Is the organization related (other than by association with a statewide or nationwide organization) through common membership, governing bodies, trustees, officers, etc., to any other exempt or nonexempt organization?	80a		~
h	If "Yes," enter the name of the organization ►	-		
-	and check whether it is exempt or nonexempt.	<i>t</i> -		
81a	Enter direct and indirect political expenditures. See line 81 instructions .  81a   NONE	Î		
	Did the organization file Form 1120-POL for this year?	81b		~
82a	Did the organization receive donated services or the use of materials, equipment, or facilities at no charge		~	
	or at substantially less than fair rental value?	82a		
b	If "Yes," you may indicate the value of these items here. Do not include this amount	y^ w/rec	ф.	
	as revenue in Part I or as an expense in Part II. (See Instructions in Part III.)	020	~	
	Did the organization comply with the public inspection requirements for returns and exemption applications?	83a 83b	~	
	Did the organization comply with the disclosure requirements relating to quid pro quo contributions? Did the organization solicit any contributions or gifts that were not tax deductible?	84a	V	
	If "Yes," did the organization include with every solicitation an express statement that such contributions			
	or gifts were not tax deductible?	84b	~	
85	501(c)(4), (5), or (6) organizations. a Were substantially all dues nondeductible by members?	85a		
b	Did the organization make only in-house lobbying expenditures of \$2,000 or less?	85b		
	If "Yes" was answered to either 85a or 85b, do not complete 85c through 85h below unless the organization			
	received a waiver for proxy tax owed for the prior year.	en.		
	Dues, assessments, and similar amounts from members	že,		
	Section 162(e) lobbying and political expenditures	<u>v</u> . ∞.,		
_	Aggregate Herideadelible affective to seeker electricity of data fictions.	34. t		
f	Taxable amount of lobbying and political expenditures (line 85d less 85e)	85g		
-	If section 6033(e)(1)(A) dues notices were sent, does the organization agree to add the amount on line 85f to its	9		
"	reasonable estimate of dues allocable to nondeductible lobbying and political expenditures for the following tax			
	year?	85h		
86	501(c)(7) orgs. Enter: a Initiation fees and capital contributions included on line 12.			
b	Gross receipts, included on line 12, for public use of club facilities			
87	501(c)(12) orgs. Enter: a Gross income from members or shareholders	***		
b	Gross income from other sources. (Do not net amounts due or paid to other			
	sources against amounts due or received from them.)	-		
88	At any time during the year, did the organization own a 50% or greater interest in a taxable corporation or partnership, or an entity disregarded as separate from the organization under Regulations sections	er		
	301.7701-2 and 301.7701-3? If "Yes," complete Part IX	88		~
89a	501(c)(3) organizations. Enter: Amount of tax imposed on the organization during the year under:			
	section 4911 ▶ NONE ; section 4912 ▶ NONE ; section 4955 ▶ NONE			
b	501(c)(3) and 501(c)(4) orgs. Did the organization engage in any section 4958 excess benefit transaction			
	during the year or did it become aware of an excess benefit transaction from a prior year? If "Yes," attach			<b>'</b>
	a statement explaining each transaction	89b		L
C	Enter: Amount of tax imposed on the organization managers or disqualified persons during the year under			^
	sections 4912, 4955, and 4958			
	Enter: Amount of tax on line 89c, above, reimbursed by the organization ▶ List the states with which a copy of this return is filed ▶ EXHIBIT G			
	Number of employees employed in the pay period that includes March 12, 2004 (See instructions.)	1.3	35	• • • • • •
91	The books are in care of ▶ DANIEL BERECK, DIRECTOR OF FINANCE  Telephone no. ▶ ( 520 ) 52			
	Located at ► 3300 EAST SUNRISE DRIVE, TUCSON ARIZONA ZIP + 4 ► 85718	-3299		
92	Section 4947(a)(1) nonexempt charitable trusts filing Form 990 in lieu of Form 1041—Check here		. 1	▶ □
	and enter the amount of tax-exempt interest received or accrued during the tax year ▶   92			

Part	ИЩ	Analysis of Income-Producing A	activities (Se	e pa	age 33 of the I			
Note:		er gross amounts unless otherwise		ed bu	Isiness income		tion 512, 513, or 514	(E) Related or
		gram service revenue:	(A) Business c	ode	(B) Amount	(C) Exclusion code	<b>(D)</b> Amount	exempt function income
а.	100	grant service revenue.						
b .		•						
C.								
d.								
е .							'	<u> </u>
		licare/Medicaid payments	l l					
		s and contracts from government agencie						
		nbership dues and assessments	3			44	2 762 527	
		est on savings and temporary cash investmen	ts ———			14	3,762,527	
		dends and interest from securities .		. 23				
		rental income or (loss) from real estate:		80 , 140		***************************************		
		t-financed property						
		debt-financed property	v					
		er investment income	·			18	(82,075)	
		or (loss) from sales of assets other than invento			·	18	9,144,328	
		income or (loss) from special events	",					
		ss profit or (loss) from sales of inventory						
103	Othe	er revenue: a LIST RENTALS				13	144,566	
		VERTISING-PATIENT PUBLICATION	54180	0	349,651			
C.	RO'	YALTY INCOME				15	69,597	
d J	GRI	EETING CARD INCOME						831
е.							<u></u> -	
104 5	Sub	total (add columns (B), (D), and (E))	: c.		349,651	A STATE OF THE STA	13,038,943	831
105	Tota	il (add line 104, columns (B), (D), and (E	))				<b></b>	13,389,425
		105 plus line 1d, Part I, should equal th						
Part \	VIII							
Line N	ło.	Explain how each activity for which incom					portantly to the a	ccomplishment
		of the organization's exempt purposes (ot						
1030	<u>d</u>	SALES OF GREETING CARDS FEATURE						
		WITH DISABILITIES IMPOSED BY NE					<del></del>	
		IMPORTANTLY TO THE ACHIEVEME					PURPUSES BY	ENHANCING
Part	V	PUBLIC AWARENESS THAT CREATI Information Regarding Taxable Sub					24 of the instru	otions \
			(B)	ופוט		ss (See page		
	Nan F	(A) ne, address, and EIN of corporation, partnership, or disregarded entity	Percentage of ownership intere	st	(C) Nature of a	ctivities	(D) Total income	(E) End-of-year assets
				<u>% </u>				
				% %				
				<del>/</del> %				
Part	χГ	Information Regarding Transfers Ass			nal Benefit Con	tracts (See pa	age 34 of the ins	tructions.)
(b) I	Dıd	he organization, during the year, receive any funds, the organization, during the year, pay pr "Yes" to <b>(b)</b> , file Form 8870 <b>and</b> Form	emiums, direc					
	_	Under penalties of perjury, I declare that I have exar						
		and belief, it is true, correct, and complete. Declara						
Please	Ð	Man I Bons						
Sign	- 1	Signature of officer						
Here		DANIEL BERECK, ASSISTANT TRI	EASURER					
		Type or print name and title						
Paid		Preparer's						
Preparer	r's	signature Firm's name (or yours	<del></del>					
Use Only	y	f self-employed),						

## **SCHEDULE A**

(Form 990 or 990-EZ)

Department of the Treasury Internal Revenue Service

Part I

# Organization Exempt Under Section 501(c)(3)

(Except Private Foundation) and Section 501(e), 501(f), 501(k), 501(n), or Section 4947(a)(1) Nonexempt Charitable Trust

Supplementary Information—(See separate instructions.)

▶ MUST be completed by the above organizations and attached to their Form 990 or 990-EZ

OMB No. 1545-0047

**Employer identification number** 

2004

Name of the organization
MUSCULAR DYSTROPHY ASSOCIATION, INC

Compensation of the Five Highest Paid Employees Other Than Officers, Directors, and Trustees
(See page 1 of the instructions, List each one, If there are none, enter "None.")

(See page 1 of the instructions.	List each one. If there ar	e none, enter 1	vone. )		
(a) Name and address of each employee paid more than \$50,000	(b) Title and average hours per week devoted to position	(c) Compensation	(d) Contributions to employee benefit plans & deferred compensation	(e) Expense account and other allowances	
GERALD C. WEINBERG	DIRECTOR OF FIELD	200 000	00.400		
TUCSON, ARIZONA	ORGANIZATION, 100%	290,000	28,102	0	
GAIL SCHMERTZ KERNER ESQ	GENERAL COUNSEL,	400 000	04.050	0	
TUCSON, ARIZONA	100%	190,000	24,858		
DANIEL BERECK	DIRECTOR OF	450,000	24.776		
TUCSON, ARIZONA	FINANCE, 100%	150,000	21,776	0	
DAVID EPPIHIMER	VICE PRESIDENT	445.000	24.776		
TUCSON, ARIZONA	WESTERN DIV. 100%	145,000	21,776	0	
VALERIE A. CWIK, M.D.	MEDICAL DIRECTOR	445.000	40.427		
TUCSON, ARIZONA	100%	145,000	16,437	0	
Total number of other employees paid over \$50,000 ▶	253			* * * *,	

Part II Compensation of the Five Highest Paid Independent Contractors for Professional Services
(See page 2 of the instructions. List each one (whether individuals or firms). If there are none, enter "None.")

	,	
(a) Name and address of each independent contractor paid more than \$50,000	(b) Type of service	(c) Compensation
THE SEGAL COMPANY	BENEFITS CONSULTING SERVICES	
NEW YORK, NEW YORK	SERVICES	333,613
LEE MILLER PRODUCTIONS INC	TELEVISION PRODUCTION	
LOS ANGELES, CALIFORNIA		164,500
ERNST & YOUNG LLP	ACCOUNTANTS	
PHOENIX, ARIZONA		141,461
ADP SCREENING AND SELECTION SERVICES.	EMPLOYMENT SCREENING SERVICE	
CHICAGO, ILLINOIS	CERTICE	61,816
ADP, INC	PAYROLL SERVICE	
CAROL STREAM, ILLINOIS		56,667
Total number of others receiving over \$50,000 for professional services		

Sched	dule A	(Form 990 or 990-EZ) 2004 Muscular Dystrophy Association, Inc. #13-1665552		Р	age 2
Pai	t III	Statements About Activities (See page 2 of the instructions.)		Yes	No
1	atte or i	ing the year, has the organization attempted to influence national, state, or local legislation, including any empt to influence public opinion on a legislative matter or referendum? If "Yes," enter the total expenses paid neurred in connection with the lobbying activities   (Must equal amounts on line 38, t VI-A, or line i of Part VI-B.)			v
	orga	anizations that made an election under section 501(h) by filing Form 5768 must complete Part VI-A. Other anizations checking "Yes" must complete Part VI-B AND attach a statement giving a detailed description of lobbying activities.			
2	sub with owr	ring the year, has the organization, either directly or indirectly, engaged in any of the following acts with any instantial contributors, trustees, directors, officers, creators, key employees, or members of their families, or any taxable organization with which any such person is affiliated as an officer, director, trustee, majority ner, or principal beneficiary? (If the answer to any question is "Yes," attach a detailed statement explaining the isactions.)	~		
а	Sale	e, exchange, or leasing of property?	2a		~
b	Len	ding of money or other extension of credit?	2b		~
С	Furi	nishing of goods, services, or facilities?	2c		1
d	Pay	ment of compensation (or payment or reimbursement of expenses if more than \$1,000)?	2d	~	
е	Trai	nsfer of any part of its income or assets?	2е		~
3a		you make grants for scholarships, fellowships, student loans, etc.? (If "Yes," attach an explanation of how determine that recipients qualify to receive payments.). SEE EXHIBIT J	3a	•	
b	Do	you have a section 403(b) annuity plan for your employees?	3b	~	
4a	on i	you maintain any separate account for participating donors where donors have the right to provide advice the use or distribution of funds?	4a		~
<u>b</u>	Do	you provide credit counseling, debt management, credit repair, or debt negotiation services?	4b		1
Pai	rt IV	Reason for Non-Private Foundation Status (See pages 3 through 6 of the instructions	s.)		
The	orga	nization is not a private foundation because it is: (Please check only ONE applicable box.)	_		
5		A church, convention of churches, or association of churches. Section 170(b)(1)(A)(i).			
6		A school. Section 170(b)(1)(A)(ii). (Also complete Part V.)			
7	_				
8		A hospital or a cooperative hospital service organization. Section 170(b)(1)(A)(iii).  A Federal, state, or local government or governmental unit. Section 170(b)(1)(A)(v).			
9		A reducial, state, or local government of governmental unit. Section 170(b)(1)(A)(III). Enter the ho and state ▶	spital's	name	, city,
10		An organization operated for the benefit of a college or university owned or operated by a governmental unit. Set (Also complete the <b>Support Schedule</b> in Part IV-A.)	ction 17	0(b)(1)	(A)(IV).
11a		An organization that normally receives a substantial part of its support from a governmental unit or from the generation (b)(1)(A)(vi). (Also complete the <b>Support Schedule</b> in Part IV-A.)	neral pul	olic. Se	ection
11b	_	A community trust. Section 170(b)(1)(A)(vi). (Also complete the Support Schedule in Part IV-A.)			
12		An organization that normally receives: (1) more than 33%% of its support from contributions, members receipts from activities related to its charitable, etc., functions—subject to certain exceptions, and (2) no n	ore tha	n 33½	4% of
		its support from gross investment income and unrelated business taxable income (less section 511 tax) from the organization after June 30, 1975. See section 509(a)(2). (Also complete the <b>Support Schedule</b> in Particular in Par		es acc	quired
13		An organization that is not controlled by any disqualified persons (other than foundation managers) and suppose described in: (1) lines 5 through 12 above; or (2) section 501(c)(4), (5), or (6), if they meet the test of se section 509(a)(3).)	oports o otion 50	rganiz 9(a)(2) ——	ations . (See
		Provide the following information about the supported organizations. (See page 5 of the instruction	ns.)		
		(a) Name(s) of supported organization(s)	ne num om abo		
			<del>-</del>		
14		An organization organized and operated to test for public safety. Section 509(a)(4). (See page 5 of the instru	uctions \		

	rt IV-A Support Schedule (Complete onle: You may use the worksheet in the instructions					accounting.
	ndar year (or fiscal year beginning in)	(a) 2003	(b) 2002	(c) 2001	(d) 2000	(e) Total
15	Gifts, grants, and contributions received. (Do	(4) 2000	(2) 2002	(6) 200 .	(4) 2000	(6) 1014
	not include unusual grants. See line 28.).	176,254,772	167,334,500	152,734,601	144,842,611	641,166,484
16	Membership fees received					
17	Gross receipts from admissions, merchandise sold or services performed, or furnishing of facilities in any activity that is related to the organization's charitable, etc., purpose					
18	Gross income from interest, dividends, amounts received from payments on securities loans (section 512(a)(5)), rents, royalties, and unrelated business taxable income (less section 511 taxes) from businesses acquired by the organization after June 30, 1975	16,883,930	(4,778,299)	8,724,173	7,606,160	28,435,964
19	Net income from unrelated business activities not included in line 18					
20	Tax revenues levied for the organization's benefit and either paid to it or expended on its behalf					
21	The value of services or facilities furnished to the organization by a governmental unit without charge. Do not include the value of services or facilities generally furnished to the public without charge					
22	Other income. Attach a schedule. Do not					
	include gain or (loss) from sale of capital assets					
23	Total of lines 15 through 22	193,138,702	162,556,201	161,458,774	152,448,771	669,602,448
<u>24</u>	Line 23 minus line 17	193,138,702	162,556,201	161,458,774	152,448,771	669,602,448
<u>25</u>	Enter 1% of line 23	1,931,387	1,625,562	1,614,588	1,524,488	
26	Organizations described on lines 10 or 11:	a Enter 2% of	amount in colum	n (e), line 24	▶ <u>26a</u>	13,392,049
b	governmental unit or publicly supported organiz	zation) whose tota	ll gifts for 2000 th	rough 2003 exce	eded the	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,
_	amount shown in line 26a. <b>Do not file this list w</b> ith Total support for section 509(a)(1) test: Enter li	-		tnese excess am	501710 F	669,602,448
c d	Add: Amounts from column (e) for lines: 18	28,435,964	19			
u	Add. Amounts from column (e) for lines.		26b		▶ 26d	28,435,964
е	D.11					641,166,484
_	Public support percentage (line 26e (numera					96 %
27	Organizations described on line 12: a For person," prepare a list for your records to show Do not file this list with your return. Enter the	or amounts includ the name of, and e sum of such am	led in lines 15, 1 total amounts rec nounts for each y	6, and 17 that we served in each yeare	vere received fro ar from, each "dis	m a "disqualified qualified person.
	(2003) (2002)		•			
b	For any amount included in line 17 that was received show the name of, and amount received for each (Include in the list organizations described in lines the difference between the amount received and amounts) for each year.	year, that was more 5 through 11, as we the larger amount	re than the larger vell as individuals.) described in (1)	of (1) the amount <b>Do not file this li</b> e or (2), enter the s	on line 25 for the st with your retur um of these differ	year or (2) \$5,000 n. After computin rences (the exces
	(2003) (2002)		. (2001)		. (2000)	
С	Add: Amounts from column (e) for lines: 15		16 21			1
d		and line 27b tota			1	<u> </u>
е	Public support (line 27c total minus line 27d to	otal) ,			▶ <u>27e</u>	
f	Total support for section 509(a)(2) test: Enter a				í -	
g	Public support percentage (line 27e (numera					
<u>h</u>	Investment income percentage (line 18, colu	<del></del>				<del></del>
28	Unusual Grants: For an organization describe prepare a list for your records to show, for ea description of the nature of the grant. Do not	ch year, the name	e of the contribu	tor, the date and	amount of the	grant, and a brie

Part V

Pai	Private School Questionnaire (See page 7 of the instructions.)  (To be completed ONLY by schools that checked the box on line 6 in Part IV)			
29	Does the organization have a racially nondiscriminatory policy toward students by statement in its charter, bylaws,		Yes	No
	other governing instrument, or in a resolution of its governing body?	29	-	
30	Does the organization include a statement of its racially nondiscriminatory policy toward students in all its brochures, catalogues, and other written communications with the public dealing with student admissions,	,	·	
	programs, and scholarships?	30		ļ
31	Has the organization publicized its racially nondiscriminatory policy through newspaper or broadcast media during			
	the period of solicitation for students, or during the registration period if it has no solicitation program, in a way that makes the policy known to all parts of the general community it serves?	31		
	If "Yes," please describe; if "No," please explain (If you need more space, attach a separate statement.)			
		\*\*		
		- our	ş .	
32	Does the organization maintain the following:	<u> </u>		
a	Records indicating the racial composition of the student body, faculty, and administrative staff?	32a		
b	Records documenting that scholarships and other financial assistance are awarded on a racially nondiscriminatory basis?	32b		
c	Copies of all catalogues, brochures, announcements, and other written communications to the public dealing	00-		
4	with student admissions, programs, and scholarships?	32c		
a	Copies of all material used by the organization of on its behalf to solicit contributions?			
	If you answered "No" to any of the above, please explain. (If you need more space, attach a separate statement.)	- ,		
		١.		
33	Does the organization discriminate by race in any way with respect to:	, ,		
				ļ
а	Students' rights or privileges?	33a		
b	Admissions policies?	33ь		
	Final control of Contr	33c		
С	Employment of faculty or administrative staff?	000		
d	Scholarships or other financial assistance?	33d		
_	Educational policies?	33e		
•	Educational policies?	-		
f	Use of facilities?	33f		
g	Athletic programs?	33g		
9				
h	Other extracurricular activities?	33h		
	If you answered "Yes" to any of the above, please explain. (If you need more space, attach a separate statement.)			
		· · · · · · · · · · · · · · · · · · ·		
34a	Does the organization receive any financial aid or assistance from a governmental agency?	34a		<b></b> -
b	Has the organization's right to such aid ever been revoked or suspended?	34b		
-	If you answered "Yes" to either 34a or b, please explain using an attached statement.	-		
3F	Does the organization cortify that it has complied with the applicable requirements of sections 4.01 through 4.05	, ,		
35	Does the organization certify that it has complied with the applicable requirements of sections 4.01 through 4.05 of Rev. Proc. 75-50, 1975-2 C.B. 587, covering racial nondiscrimination? If "No," attach an explanation	35		<b> </b>

	rt VI-A Lobbying Expenditures by E (To be completed ONLY by an				instructions.)	rage O
Che	ck ▶ a ☐ If the organization belongs to an affil	ated group. Ch	eck ▶ b 📋 if	you checked "a" a	nd "limited control"	provisions apply.
	Limits on Lobby				(a) Affiliated group	(b) To be completed for ALL electing
	(The term "expenditures" mea		<del></del>		10.00	organizations
36	Total lobbying expenditures to influence public	, , , , , ,		36		<del> </del>
37	Total lobbying expenditures to influence a legi		• •	37		<del> </del>
38	Total lobbying expenditures (add lines 36 and			· · ·		
39	Other exempt purpose expenditures			• • • •		<del> </del>
40	Total exempt purpose expenditures (add lines	•				
41	Lobbying nontaxable amount. Enter the amou		-	, , , , , , , , , , , , , , , , , , ,	Sheff -	*
			able amount is-	. I%		·*
	Not over \$500,000			1 1 200 1		
		-	the excess over \$5	,00,000	**************************************	* ·
		•	ne excess over \$1,0	300,000	America de a de Caraco	
		•	e excess over \$1,5	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		· ·
42	Over \$17,000,000 \$1,000 Grassroots nontaxable amount (enter 25% of			1 -	Sidd Sealth a Santa	
43	Subtract line 42 from line 36. Enter -0- if line		. 00	43		
44	Subtract line 42 from line 38. Enter -0- if line 4	· · · · · · · · · · · · · · · · · · ·		44		
~	Cubitact line 41 from line 30. Litter -0- it line	+1 IS INDIO CILATI II	ne 30			*
	Caution: If there is an amount on either line 4	3 or line 44, you	must file Form 47	20.		
	4-Year Av	eraging Perio	d Under Section	on 501(h)		
	(Some organizations that made a section See the instructions	on 501(h) election	do not have to o	complete all of the	e five columns b ns.)	elow.
		Lot	obying Expenditu	ires During 4-Ye	ar Averaging Po	eriod
	Calendar year (or	(a)	(b)	(c)	(d)	(e) Tetal
	fiscal year beginning in) ▶	2004	2003	2002	2001	l Total
		<del>                                     </del>	<u> </u>			1
45_	Lobbying nontaxable amount					, , , , , ,
45 46	Lobbying nontaxable amount				of the second	
					92	
46	Lobbying ceiling amount (150% of line 45(e))				92	
46 47	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures				92	
46 47 48	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures				and the second s	
46 47 48 49 50	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures				and the second s	
46 47 48 49 50	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public C	harities	Part VI-A) (See	all and a second a	
46 47 48 49 50 Pa	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that did	harities not complete F tate or local legis	lation, including	page 11 of th	
46 47 48 49 50 Pa	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that did	harities not complete F tate or local legis	lation, including	page 11 of th	e instructions.)
46 47 48 49 50 Pa	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that diduence national, smatter or reference	charities not complete feate or local legis stum, through the	lation, including a	page 11 of thany Yes No	e instructions.) Amount
46 47 48 49 50 Pa Duri atter a b	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that diduence national, smatter or reference	charities not complete for tate or local legis dum, through the comported on lines	lation, including a	page 11 of thany Yes No	e instructions.)
46 47 48 49 50 Pa Duri atter a b	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that diduence national, smatter or reference	harities not complete fetate or local legis dum, through the	lation, including a	page 11 of thany Yes No	e instructions.) Amount
46 47 48 49 50 Pa Duri attei a b c	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that did uence national, s matter or reference	harities not complete F tate or local legis dum, through the	lation, including a	page 11 of the any Yes No	e instructions.) Amount
46 47 48 49 50 Pa Duri atter a b c d e	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that diduence national, smatter or reference in the control of the control	harities not complete fetate or local legis dum, through the	lation, including a	page 11 of thany Yes No	e instructions.) Amount
46 47 48 49 50 Pa Duri atter a b c d e f	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that diduence national, smatter or reference communities in the communities of the comm	harities not complete fetate or local legis dum, through the	lation, including ause of:  c through h.)	page 11 of the any Yes No	e instructions.) Amount
46 47 48 49 50 Pa Duri atter a b c d e f g	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that did uence national, smatter or reference communities in the communities of the com	harities not complete is tate or local legis dum, through the eported on lines in the complete is the complete	lation, including ause of:  c through h.)  c through continued the conti	page 11 of the any Yes No	e instructions.) Amount
46 47 48 49 50 Pa Duri atter a b c d e f	Lobbying ceiling amount (150% of line 45(e))  Total lobbying expenditures	cting Public Cations that did uence national, smatter or reference communities in the communities of the com	harities not complete is tate or local legis dum, through the eported on lines in the complete is the complete	lation, including ause of:  c through h.)  cody.	page 11 of the any Yes No	e instructions.) Amount

chedule A (Form 990 or 990-FZ) 2004	Muscular	Dystronhy	Association	Inc	#13_1665552

Page 6

Pal	T VII			Insters to and transaction 1 of the instructions.)	s and Helationships With Noncharitabl	e Exe	mpt
51					following with any other organization describe on 527, relating to political organizations?	d in se	ection
а	Trans	sfers from the repo	ortıng organization	to a noncharitable exempt orga	nization of:	Yes	No
		Cash			51a(i)		~
	• • •	Other assets			a(ii)		V
		-					
D		r transactions:			h(i)	1	~
		_		noncharitable exempt organizat			~
	(ii)	Purchases of asse	ets from a nonchar	itable exempt organization .		-	
	(iii)	Rental of facilities	, equipment, or oth	ner assets	b(iii)		7
	(iv)	Reimbursement ar	rrangements		b(iv)	<u> </u>	~
	(v)	Loans or loan gua	rantees		<u>b(v)</u>		~
	(vi)	Performance of se	ervices or members	ship or fundraising solicitations	b(vi)		7
c				sts, other assets, or paid employ	vees		~
					Column (b) should always show the fair market	value	of the
ŭ	good	s, other assets, or	r services given by	the reporting organization. If the	ne organization received less than fair market s, other assets, or services received:		
(a	a)	(b)		(c)	(d)		
Line		Amount involved	Name of none	charitable exempt organization	Description of transfers, transactions, and sharing an	angeme	ents
	$\overline{}$						
	-+		<u> </u>	·			
			· · · · · · · · · · · · · · · · · · ·				
	desc	ribed in section 50		other than section 501(c)(3)) or i	e or more tax-exempt organizations n section 527? ▶ ☐ Yes	s <b>Z</b>	No
		(a)		(b)	(c)		
Name of organization		Type of organization	Description of relationship				
			<del></del>				
			···				
			<del></del> -				
				1	Ī		

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 FOR THE FISCAL YEAR ENDED MARCH 31, 2005

The net capital gain realized was solely from the sales of publicly traded stocks and bonds through brokers. The total sales price was \$123,082,059 with a cost basis of \$113,937,731, resulting in a net gain of \$9,114,328.

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 SPECIAL FUND RAISING EVENTS AND ACTIVITIES FOR THE FISCAL YEAR ENDED MARCH 31, 2005

Approximate No. of Events	Type of Event	Gross Revenue	Direct Benefit Expenses	Net Income
1	Telethon	\$53,814,337	\$15,359,679	\$38,454,658
1,780	Sports Programs	21,064,976	3,798,041	17,266,935
300	Social Events	12,920,013	2,927,963	9,992,050
39,489	Special Events - Other	88,217,395	8,068,575	80,148,820
		\$176,016,721	\$30,154,258	\$145,862,463 <u></u> *

<sup>\*</sup>Included in Direct Public Support Part I Line 1(a)

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 MDA RESEARCH GRANTS FOR THE YEAR ENDED MARCH 31, 2005

# **FUNDING PROGRAM LEGEND**

(EMG)	Earmarked Gift
(RF)	Research Fellowship
(RG)	Research Grant
(SG)	Special Grant
(NIDA)	New Investigator Development Award
(DG)	Research Development Grant
(TCL)	Tall Cedars of Lebanon
(TRAC)	Translational Research

## **ALABAMA**

## Birmingham - University of Alabama

#### David Curiel, M.D., Ph.D.

(RG) Exploiting transcytosis to facilitate adenovirus-mediated muscle cell transduction \$ 90,000

## **ARIZONA**

## Phoenix - St. Joseph's Hospital & Medical Center

## Fu-Dong Shi, M.D., Ph.D.

Immune therapy with Atorvastatin in murine models for clinical application to mvasthenia gravis \$ 80,000

## Tucson - University of Arizona

## Ronald E. Allen, Ph.D.

(RG) Regulation of skeletal muscle satellite cell activity \$ 100.000

#### Vince Guerriero, Ph.D.

Neuromuscular diseases and (RG) misfolded proteins 56,195

#### David Labiner, M.D.

Neurology in the 21st Century: A Tribute to Dr. William A Sibley \$ 3,150

## F. John Meaney, Ph.D.

(RG) Promoting health and wellbeing in boys with muscular dystrophy \$ 98,560

#### Lawrence Z. Stern, M.D.

(EMG) Research at the Uniiversity of Arizona Foundation \$ 163,068

# **CALIFORNIA**

#### Davis - University of California

#### Ricardo Maselli, M.D.

(RG) Congenital myasthenic syndromes: Pathogenesis and treatment \$ 100.000

(RG) Microarray analysis of congenital myasthenic syndromes \$ 100,000

## Emeryville - University of California

#### Hongkyun Kim, Ph.D.

(DG) A genetic study of muscular dystrophy in c. elegans \$ 45.000

## Irvine - University of California

## John H. Weiss, M.D., Ph.D.

Motor neuron ROS, glutamate (RG) transport disruption and amyotrophic lateral sclerosis (ALS) \$ 100,000

#### Sara Winokur, Ph.D.

(RG) Therapeutic approaches to aberrant myoblast differentiation in facioscapulohumeral dystrophy (FSHD) \$ 85,634

(RG) Investigation of FSHD as a nuclear envelope disease \$ 90,000

# La Jolla - Salk Institute for Biological **Studies**

#### Kuo-Fen Lee, Ph.D.

The potential role of neuregulin (RG) in muscular dystrophy therapy \$ 80,000

## La Jolla - Scripps Research Institute

#### Joel M. Gottesfeld, Ph.D.

(EMG) Restricted funds for FA research

\$ 19.413

## La Jolla - University of California

#### John Ross, JR. M.D.

(RG) Cardiac gene therapy in muscular dystrophies \$ 264,000

#### G. Diane Shelton, DVM, Ph.D.

(RG) Canine inflammatory myopathy:
An animal model for human inflammatory myopathy
\$ 66,712

## Koji Yamanaka, M.D., Ph.D.

(DG) The role of ALS2 in the postnatal survival of human motor neurons

\$ 45.000

## <u>Loma Linda - Musculoskeletal Disease</u> <u>Center</u>

#### Ashok Kumar, Ph.D.

(RG) Myogenic signaling and Duchenne muscular dystrophy (DMD)

\$ 75,000

#### Los Angeles - University of California

## Giovanni Coppola, M.D.

(EMG) Restricted funds for support of Friedreich's ataxia research \$ 12,750

#### Michael Graves, M.D.

(EMG) For ALS research and care at UCLA

\$ 7,500

## <u>Los Angeles - University of Southern</u> <u>California</u>

#### Valerie Askanas, M.D., Ph.D.

(RG) Unfolded proteins in the pathogenesis of s-IBM \$ 100,000

(SG) Neurology Supplement - IBM Meeting \$ 20,000

#### Dr. Michel Baudry

(EMG) Restricted funds for support of Friedreich's ataxia \$ 29.930

## W. King Engel, M.D.

(EMG) Restricted funds for neuromuscular disease research \$ 265,995

#### Sita Reddy, Ph.D.

(RG) Role of the muscleblind proteins in myotonic dystrophy (DM) \$ 110.000

(RG) Dissecting CNS dysfunction in myotonic dystrophy (DM) \$ 95.000

## Zuo-Zhong Wang, Ph.D.

(RG) Role of agrin in muscle development and regeneration \$ 100,000

# <u>Pasadena - California Institute of Technology</u>

#### David C. Chan, M.D., Ph.D.

(RG) Role of mitochondrial fusion in mitochondrial myopathies \$ 75,000

#### San Diego - San Diego State University

#### Sanford I. Bernstein, Ph.D.

(RG) Analysis and amelioration of defective protein folding in skeletal muscle
\$ 96,084

# San Francisco - California Pacific Medical Center

#### Robert G. Miller, M.D.

(EMG) Restricted funds for support of the MDA Clinic – Zimmerman Fund

\$ 40,230

- (EMG) Restricted funds for Forbes Norris MDA/ALS Center \$ 435,344
- (RG) Minocycline in amyotrophic lateral sclerosis (ALS) \$ 74,457
- (TRAC) MDA/ALS Web-based Database \$ 158,515

## San Francisco - University of California

#### Marc Diamond, M.D.

- (RG) Molecular and genetic modifiers of AR protein toxicity in spinal bulbar muscular atrophy (SBMA)
  \$ 100,000
- (RG) Evaluation of Y-27632 in mouse models of SBMA \$ 100,000

#### Sachiko Hoshino, M.D., Ph.D.

(DG) CHC22 clathrin in normal and regenerating muscle \$ 45,000

#### Mei Li, M.D., Ph.D

(DG) Analysis of the effects of ROCK inhibitor Y-27632 in an SBMA mouse model \$ 45,000

## Charles Ordahi, Ph.D.

(RG) Myogenic progenitor cells: A new muscle stem cell class \$80,068

#### Santa Cruz - University of California

#### Brian Ackley, Ph.D.

(DG) Nidogen and LAR phosphatase function during the formation of C. elegans neuromuscular junctions
\$ 45,000

## Stanford - Stanford University

#### Carmen Bertoni, Ph.D.

(DG) Oligonucleotide mediated gene repair for Duchenne muscular dystrophy (DMD)
\$ 45,000

#### Guowei Fang, Ph.D.

(RG) Role of ubiquitin-mediated proteolysis in muscular dystrophies \$ 104,513

## Thomas A. Rando, M.D., Ph.D.

(RG) Integrase-mediated gene therapy for muscular dystrophy \$ 120,000

# Ching H. Wang, M.D., Ph.D.

(RG) A pilot therapeutic trial of hydroxyurea on type 1 spinal muscular atrophy (SMA) \$ 100,000

#### Hai Wu, Ph.D.

(DG) Calcineurin/NFAT signaling and the generation of V1 interneurons \$ 45.000

#### Yanmin Yang, M.D., Ph.D.

(RG) Functional characterization of gigaxonin \$ 103,668

#### **COLORADO**

## **Boulder - University of Colorado**

## Dawn Cornelison, Ph.D.

(DG) Signaling in satellite cells of mdx and other dystrophic muscle \$ 45,000

#### Hugo Olguin, Ph.D.

(DG) Pax-7 role in satellite cell selfrenewal \$ 45,000

## Bradley Olwin, Ph.D.

(RG) A molecular switch for satellite cells

\$ 80.091

## **Denver - University of Colorado**

#### William Betz, Ph.D.

(RG) Synaptic vesicle recycling in motor nerve terminals \$ 66,000

## CONNECTICUT

## New Haven - Yale University

## Anton M. Bennett, Ph.D.

(RG) Muscle cell survival by protein tyrosine phosphatases in muscular dystrophy (MD) \$ 100,000

#### **DISTRICT OF COLUMBIA**

## <u>Washington - Children's National</u> <u>Medical Center</u>

#### Marina Bakay, Ph.D.

(DG) Downstream consequences of biochemical defects in muscular dystrophies \$ 45,000

#### Diana Escolar, M.D.

(RG) High-dose prednisone in Duchenne muscular dystrophy (DMD) \$ 115,220

## Eric Hoffman, Ph.D.

(EMG) Restricted funds for support of Duchenne muscular dystrophy research \$ 246,800

(RG) Transcriptional cascades in muscle regeneration \$ 90,000

#### **FLORIDA**

## Gainesville - University of Florida

#### Lucia Notterpek, Ph.D.

(RG) Protein aggregation and degradation in Charcot-Marie-Tooth (CMT) disease \$ 114,634

#### Patana Teng-umnuay, M.D., Ph.D.

(DG) The role of phosphorylation in muscleblind function \$ 45,000

## Jacksonville - Mayo Clinic Jacksonville

## Terrone Rosenberry, Ph.D.

(RG) Interactions in the active site of acetylcholinesterase \$ 55,000

## Miami - University of Miami

#### Antoni Barrientos, Ph.D.

(RG) Role of evolutionary conserved cytochrome c oxidase assembly factors \$ 75,000

#### Lisa L. Baumbach, Ph.D.

(RG) Final steps in discovery of the X-linked SMA gene \$ 101,742

## Walter Bradley, M.D.

(EMG) Restricted funds for support of the Kessenich Family MDA/ALS Center \$ 155,739

#### Francisca Diaz. Ph.D.

(DG) A mouse model of cytochrome oxidase deficiency \$ 45,000

#### Alison Grossman, Ph.D.

(DG) Impact of psychosocial factors on ALS onset and disease progression \$ 45,000

5

#### Karl Magleby, Ph.D.

Modulation of BK channels by (RG) beta subunits \$ 71,053

#### Carlos Moraes, Ph.D.

Mitochondrial dysfunction in (RG) amyotrophic lateral sclerosis (ALS)

97.824

## Richard Rotundo, Ph.D.

Assembly of (RG) acetylcholinesterase and the synaptic basal lamina \$ 55,939

#### St. Augustine - University of Florida

#### Fumilito Ono, M.D., Ph.D.

Molecular basis of myasthenialike syndromes in mutant synapses 99.000

#### **GEORGIA**

## Atlanta - Emory University

#### Tamara Caspary, Ph.D.

hennin: a novel mechanism of motor neuron specification \$ 45,000

#### Peter Hedera, M.D.

Molecular characterization of distal myopathy linked to chromosome 14q (MPD1) 53,117

## Jeffrey Myers, Ph.D.

Folding of myelin proteins implicated in peripheral neuropathy \$ 45,000

## Grace Pavlath, Ph.D.

Regulation of myoblast migration and fusion by class III semaphorins \$ 80,000

## Augusta - Medical College of Georgia

#### Lin Mei, M.D., Ph.D.

Erbin regulation of AChR expression \$ 90,000

#### Mark Becher, M.D.

Pathology of oculopharyngeal muscular dystrophy 65,149

## **ILLINOIS**

## Chicago - Children's Memorial Institute for Ed. & Research

#### Christine DiDonato, Ph.D.

Gene therapy for animal models of spinal muscular atrophy (SMA) \$ 92,360

## Chicago - Northwestern University

#### Robert Goldman, Ph.D.

Functional aspects of nuclear (RG) lamins in muscular dystrophy \$ 113,744

## Teepu Siddique, M.D.

High throughput screening (RG) 54,865

(SG) Primary lateral sclerosis diagnostic criteria conference 5.000 \$

#### Jianhua Yan, M.D.

A molecular target for amyotrophic lateral sclerosis (ALS) therapy: A gene for ALS/FTD \$ 45,000

#### Chicago - University of Chicago

#### James R. Brorson, M.D.

(RG) Glutamate receptors on corticospinal motor neurons and amyotrophic lateral sclerosis (ALS)

\$ 38,125

# Elizabeth McNally, M.D., Ph.D.

(RG) Stem cell transplantation in limb-girdle muscular dystrophy \$ 86,372

#### Raymond Roos, M.D.

(EMG) In memory of Barbara Anderson for ALS research \$ 5,965

## Kamal Sharma, Ph.D.

(RG) SMN regulates motor neuron subtype identity \$ 100,000

# Chicago - University of Illinois

#### David Featherstone, Ph.D.

(RG) Molecular mechanisms regulating extracellular glutamate \$ 74,179

#### Maria Krasilnikova

(EMG) Restricted funds for Friedreich's ataxia \$ 18.300

## Maywood - Loyola University

#### Julio A. Copello, Ph.D.

(RG) Coordinated gating of ryanodine receptor channels \$ 80,000

## **Urbana - University of Illinois**

#### Suzanne Berry, Ph.D.

(DG) Integrin enhancement of mesoangioblast cell therapy \$ 45,000

#### Stephen Kaufman, Ph.D.

(RG) Integrin alleviation of muscular dystrophy \$ 90,000

#### Derek Milner, Ph.D.

(DG) Alpha-7 beta-1 integrin mediated alleviation of muscular dystrophy \$ 45.000

## **INDIANA**

## Indianapolis - Indiana University

#### William J. Groh, M.D.

(RG) Predictors of sudden cardiac death in myotonic dystrophy \$ 46,285

## Muncie - Ball State University

## Derron Bishop, Ph.D.

(RG) Axon loss in a mouse model of amytrophic lateral sclerosis (ALS) \$82,289

## **IOWA**

# Iowa City - University of Iowa

# Kevin P. Campbell, Ph.D.

(EMG) Restricted funds for limb-girdle research \$ 102.339

(RG) Development of treatment strategies for LGMD2I \$ 100,000

## Shawn W. Flanagan, Ph.D.

(RG) The effect of mitochondrial antioxidant manipulation on mutant SOD1 cytotoxicity \$ 79,884

#### Lori Wallrath, Ph.D.

(RG) Drosophila as a model for Emery-Dreifuss muscular dystrophy \$ 79,398

## Robert Weiss, M.D.

(RG) Stress-induced cardiac dysfunction in dystrophinopathy \$80,000

#### **MAINE**

## Bar Harbor - Jackson Laboratory

#### Roger Sher, Ph.D.

(DG) Role of choline kinase beta in a murine muscular dystrophy \$ 45.000

## Leonard Shultz, Ph.D.

(RG) SCID mouse models for stem cell therapy of muscular dystrophy
\$ 60.000

## **MARYLAND**

## Baltimore - Johns Hopkins University

#### Daniel B. Drachman, M.D.

(EMG) Restricted funds for specific immunotherapy \$ 2,875

(RG) Specific immunotherapy of myasthenia gravis by gene transfer \$ 130,032

## Douglas A. Kerr, M.D., Ph.D.

(RG) Utilization of embryonic stem cells in motor neuron diseases \$ 73,356

#### Vassilis Koliatsos, M.D.

(RG) Neural stem cells as experimental therapies for motor neuron disease \$ 167,071

## Se-Jin Lee, M.D., Ph.D.

(RG) Regulation of myostatin latency \$ 139,102

#### Jeffrey D. Rothstein, M.D., Ph.D.

(RG) Excitatory amino acid transporters: Development of a therapy \$ 45,000

(EMG) Restricted funds for ALS research \$ 169,827

#### Shanthini Sockanathan, Ph.D.

(RG) The specification of spinal motor neurons \$80,000

## Kathryn Wagner, M.D., Ph.D.

(DG) Effect of myostatin on satellite cells and muscle regeneration \$ 45,000

## Baltimore - University of Maryland

#### Robert J. Bloch, Ph.D.

(RG) Intermediate filaments that organize the sarcolemma \$ 94,659

(RG) Signaling by the RhoGEF domain of obscurin \$ 83,642

## Aikaterini Kontrogianni-Konstantopoulos, Ph.D.

(DG) Proteins organizing the sarcomere and the SR of skeletal muscle \$ 45,000

## <u>Bethesda - American College of Medical</u> Genetics

#### Michael S. Watson, Ph.D.

(SG) ACMG 2005 Annual Clinical Genetics Meeting \$ 10,000

#### **MASSACHUSETTS**

## Allston - Brigham and Women's Hospital

Ronan Walsh, MC, BCh, FRCPC

(TRAC) Clinical Research Training \$ 90,000

## **Boston - Boston University**

#### William Lehman, Ph.D.

(RG) An atomic structure of dystrophin bound on F-actin \$ 74,291

#### Boston - Brigham and Women's Hospital

## Steven Greenberg, M.D.

- (RG) Single cell molecular methods in the inflammatory myopathies \$ 67,123
- (RG) Blood gene expression profiles in autoimmune and inherited neuromuscular diseases \$ 26.283

## Yaming Wang, M.D.

(RG) Study of Msx1-dedifferentiated cells for cell therapy of muscular dystrophies \$ 98,204

#### Karen Westerman, Ph.D.

(RG) Treatment of LGMD by homing therapeutic cells to muscle \$ 85,000

## Boston - Children's Hospital

# Alan H. Beggs, Ph.D.

(RG) Molecular genetics of congenital myopathies \$ 99,852

#### Emanuela Gussoni, Ph.D.

(RG) Myogenic potential and systemic delivery of human muscle SP cells \$ 45,000

#### Jeffrey Guyon, Ph.D.

(DG) Isolation of zebrafish with mutations causing muscular dystrophy \$ 45,000

## Peter Kang, M.D.

(DG) Molecular basis of selective weakness in muscular dystrophy
\$ 45,000

# Giles Watts, Ph.D.

(DG) Molecular basis of h-IBM, Paget disease of bone and dementia

\$ 45,000

#### Boston - Dana-Farber Cancer Institute

#### Christoph Handschin, Ph.D.

(DG) The role of PGC-1 in neuromuscular junction formation \$ 45,000

## Boston - Harvard Medical School

## Alfred L. Goldberg, Ph.D.

(RG) Protein breakdown in muscle in normal and disease states \$ 95.676

## Boston - Harvard University

#### Andrew B. Lassar, Ph.D.

(RG) Cell cycle control of skeletal muscle differentiation \$80.000

#### Tiffany Reiter, Ph.D.

(DG) Heme oxygenase in motor neuron resistance to NO toxicity \$ 45,000

## <u>Cambridge - Whitehead Institute for</u> Biomedical Research

#### Prakash Rao. Ph.D.

(DG) The role of microRNAs in myogenesis \$ 45,000

## <u>Charlestown - Massachusetts General</u> Hospital

#### Susanna Benn, Ph.D.

(DG) Studies of the therapeutic effect of Hsp27 in amyotrophic lateral sclerosis (ALS) mice \$ 45.000

#### Robert Brown, Jr., D.Phil, M.D.

(RG) High throughput drug screening in SOD1-mediated amyotrophic lateral sclerosis \$ 88,110

#### Merit Cudkowicz, M.D., M.Sc.

- (RG) Clinical trial of coenzyme Q10 in patients with amyotrophic lateral sclerosis (ALS)
  \$ 93.577
- (RG) Safety and dose escalating study of oral sodium phenylbutyrate in subjects with ALS \$ 113,769

## Jonathan Francis, Ph.D.

(RG) Tetanus toxin fragment C for delivery of GDNF to the CNS \$ 71,972

## Kimi Kong, Ph.D.

(DG) Investigation of stem cell therapy in Mıyoshı myopathy and LGMD-2B \$ 45,000

## Piera Pasinelli, Ph.D.

(DG) Proteomic analysis of apoptosis in GFP-labeled motor neurons of amyotrophic lateral sclerosis (ALS) mice
\$ 45,000

#### Bryan J. Traynor, M.D.

(DG) The role of a start codon mutation of the SOD1 gene in amyotrophic lateral sclerosis (ALS) pathogenesis

\$ 45,000

#### Clifford Woolf, M.D., Ph.D.

(RG) Hsp27 and motor neuron survival \$ 87,977

# Waltham - Brandeis University

#### Carolyn Cohen, Ph.D.

(RG) Atomic structures of the muscle motor \$ 68,712

## <u>Watertown - Boston Biomedical</u> Research Institute

## Jeffrey B. Miller, Ph.D.

(RG) Dysferlinopathy model studies \$ 35,000

## Worcester - University of Massachusetts

#### Davide Gabellini, Ph.D.

(DG) Definition of the molecular basis of facioscapulohumeral muscular dystrophy (FSHD) \$ 45,000

## Laxman D. Gangwani, Ph.D.

(RG) To define the function of the Zinc Finger Protein ZPR1 in spinal muscular atrophy (SMA) \$ 110,575

#### Lawrence Hayward, M.D., Ph.D.

(RG) Autophagic stress and neuroprotection in SOD1-mediated amyotrophic lateral sclerosis (ALS)

\$ 70,141

#### Jeanne Lawrence, Ph.D.

(RG) The role of nuclear structure in myotonic dystrophy (DM) and facioscapulohumeral dystrophy (FSHD)

\$ 72,177

#### Rossella Tupler, M.D., Ph.D.

(EMG) Restricted funds for support of FSHD research \$ 1.177

#### **MICHIGAN**

## Ann Arbor - University of Michigan

## Denise A. Figlewicz, Ph.D.

(RG) New models of familial amyotrophic lateral sclerosis (FALS): Unmasking modifier genes

84,713

## Andrew Lieberman, M.D., Ph.D.

- (RG) Altered androgen receptor function in Kennedy's disease \$ 74.297
- (RG) A knock-in mouse model of Kennedy's disease \$ 100,000

#### Mark Russell, M.D.

(RG) Obscurin's role in myofibril assembly and structural support \$ 87,600

## **Detroit - Wayne State University**

## Gyula Acsadi, M.D., Ph.D.

(RG) Gene therapy for amyotrophic lateral sclerosis (ALS) by AAV mediated gene transfer \$ 93,696

#### John Kamholz, M.D., Ph.D.

(RG) Structural analysis of the extracellular domain of MPZ from patients with Charcot-Marie-Tooth type 1B (CMT1B) \$ 100.000

#### Jun Li, M.D., Ph.D.

(DG) The pathophysiology of conduction block in HNPP \$ 45,000

## Michael E. Shy, M.D.

(RG) GDNF gene therapy in Charcot-Marie-Tooth type 1 (CMT1) \$ 100,000

(TRAC) CMT North American Database \$ 85.000

## **MINNESOTA**

## <u>Minneapolis - Fairview University</u> Medical Center

John Day, M.D., Ph.D.

(EMG) Restricted funds for research \$ 5,000

#### Minneapolis - University of Minnesota

#### Atsushi Asakura, Ph.D.

(RG) Transplantation of myogenicendothelial progenitors for muscular dystrophies \$ 166,338

#### Christopher M. Gomez, M.D.Ph.D.

(RG) Cysteine proteases in the slowchannel myasthenic syndrome \$ 104,052

#### David Thomas, Ph.D.

(RG) Spectroscopic probes of muscle degeneration \$ 90,000

## Wei Wang, M.D.

(DG) AChR epitopes restricted by DR and DQ molecules relevant to myasthenia gravis (MG) \$ 45,000

#### Rochester - Mayo Clinic

## Andrew Engel, M.D.

(RG) Congenital myasthenic syndromes \$ 113,353

(EMG) Research at the Mayo Clinic \$ 10,000

## Grazia Isaya, M.D., Ph.D.

(RG) Function and regulation of human frataxin \$ 86,400

(EMG) Restricted funds for FA research \$ 24.755

#### Ann M. Reed, M.D.

(RG) HLA genetics and chimerism in juvenile dermatomyositis \$78,933

#### Xiaolei Xu, Ph.D.

(RG) Genetic studies of titin in myofibrillogenesis and muscular dystrophy \$ 109,322

#### **MISSISSIPPI**

## Jackson - University of Mississippi

#### Michael Hebert, Ph.D.

(RG) Regulation of coilin and SMN interaction by coilin associated proteins

\$ 80,000

(EMG) Research for Friedrich's Ataxia \$ 17,800

#### **MISSOURI**

#### Columbia - University of Missouri

## Dongsheng Duan, Ph.D.

(RG) AAV-mediated micro-dystrophin gene therapy of the mdx heart disease

\$ 140,000

## Christian Lorson, Ph.D.

(RG) Analysis of SMN exon 7 function

\$ 117,312

## Sinead O'Connell, M.D.

(RG) Motor axon pathway selection to muscle targets

\$ 7.500

## <u>Kansas City - Stowers Institute for</u> Medical Research

#### Olivier Pourquie, Ph.D.

(RG) Role of atrophins in patterning/differentiating early muscle precursers
\$ 111,378

## St. Louis - Washington University

## Anne Connolly, M.D.

(RG) Role of complement 3 and Bcells in muscular dystrophy \$ 89,605

## Paul Golumbek, M.D., Ph.D.

(DG) Non-immune effects of steroid treatment on Mdx/SCID mice \$ 45,000

#### Didier Hodzic, Ph.D.

(DG) Sun2-lamin B1: The end of [another] affair for muscular dystrophy?

\$ 45.000

## **MONTANA**

## Great Falls - McLaughlin Research Institute

## John Bermingham, Ph.D.

(RG) Positional cloning of the mouse hypomyelination mutation claw paw

\$ 65,107

## **NEW JERSEY**

## <u>Newark - University of Medicine and</u> <u>Dentistry of NewJersey</u>

#### Langdon Miller, M.D.

(TRAC) PTC124 treatment for Duchenne muscular dystrophy \$ 1,023,460

#### Martha C. Nowycky, Ph.D.

(RG) TRPC channels and calcium in Duchenne muscular dystrophy \$ 100,887

#### Natalia Shirokova, Ph.D.

(RG) Metabolic control of calcium signaling in skeletal muscle \$84,784

#### **NEW MEXICO**

#### Albuquerque - University of New Mexico

## Richard Cripps, D.Phil.

(RG) Transcriptional control of muscle remodeling in Drosophila \$ 78.377

#### **NEW YORK**

#### Albany - Albany Research Institute, Inc.

#### Arnulf H. Koeppen, M.D.

(EMG) Restricted funds for support of Friedreich's ataxia research \$ 22,000

#### Albany - State University of New York

#### Gang Li, Ph.D.

(DG) Inhibition of GluR2 AMPA receptors: A microsecond time resolution study
\$ 45,000

#### Li Niu, Ph.D.

(RG) Discovery of aptamers to prevent excitotoxicity in amyotrophic lateral sclerosis (ALS)

\$ 77,064

## <u>Bronx - Albert Einstein College of</u> <u>Medicine</u>

#### Gary J. Bassell, Ph.D.

(RG) Axonal function of the survival of motor neuron protein \$ 75,000

#### Hanh Nguyen, Ph.D.

(RG) Analysis of skeletrophin, a novel essential component of muscle differentiation \$ 77,440

#### Buffalo - State University of New York

#### Luc Gosselin, Ph.D.

(RG) Mechanisms of failed regeneration in dystrophic muscle \$ 107,195

(SG) 5th Annual Dr. S. Mouchly Small Muscle Symposium \$ 2,000

#### Georgirene D. Vladutiu, Ph.D.

(RG) Improved diagnosis of metabolic diseases among the statin myopathies
\$ 87,723

## Ithaca - Cornell University

#### Jun Liu, Ph.D.

(TCL) Functional studies of nuclear membrane proteins emerin and MAN1 in C. elegans \$ 100,000

## New York - Columbia University

#### Salvatore DiMauro, M.D.

(RG) Pathogenesis of the human glycogenoses \$ 95,000

(RG) Studies of human mitochondrial myopathies \$ 100,000

#### Robert Gilkerson, Ph.D.

(TCL) Mitochondrial DNA nucleoids:
Organization and dynamic
\$45,000

#### Veronica Hinton, Ph.D.

(RG) Cognitive phenotype associated with Duchenne muscular dystrophy (DMD) \$ 42,949

#### Michio Hirano, M.D.

(RG) Molecular pathogenesis and treatment of MNGIE \$ 60,407

(RG) Pathogenesis of mitochondrial myopathy due to thymidine kinase 2 deficiency \$ 100,942

#### Edward Laufer, Ph.D.

(RG) Control of limb motor axon dorsal-ventral projection \$ 68,222

## Chung-Ming Lin, Ph.D.

(DG) Studies of muscular dystrophy in dystonia musculorum mice \$ 45,000

#### Hiroshi Mitsumoto, M.D.

- (RG) Genetic-environmental epidemiology in amyotrophic lateral sclerosis (ALS) \$ 137.628
- (SG) ALS Research Group Annual
  Meeting
  \$ 4.496

#### Makiko Nagai, M.D., Ph.D.

(RF) Stem cell research for ALS \$ 45,000

#### Cecilia Ostlund, Ph.D.

(DG) The role of A-type laminins in Emery-Dreifuss muscular dystrophy (EDMD) \$ 45,000

## Howard J. Worman, M.D.

(RG) Abnormal Smad2/3-mediated signal transduction in nuclear envelopathies \$ 109,646

#### New York - Cornell University

## M. Flint Beal, M.D.

(RG) Testing novel therapeutics in a transgenic mouse model of amyotrophic lateral sclerosis (ALS)

\$ 73,058

## Giovanni Manfredi, M.D., Ph.D.

(RG) Bcl-2 and adenine nucleotide translocator in mitochondrial disorders \$ 81,364

# <u>New York - Mount Sinai School of</u> <u>Medicine</u>

#### Dale Lange, M.D.

(EMG) Restricted for ALS research \$ 50,000

#### Giulio Pasinetti, M.D., Ph.D.

(RG) The role of cyclooxygenase-2 inhibitors in a model of ALS neurodegeneration \$ 87.698

#### David A. Sassoon, Ph.D.

(RG) Functional analysis of a potential regulator of muscle stem cells \$ 90,000

## Rochester - University of Rochester

## Emma Ciafaloni, M.D.

(RG) The pathophysiology of hypersomnolence in myotonic dystrophy
\$ 48.886

## Robert Griggs, MD

- (SG) Pathogenesis and treatment of the periodic paralyses \$ 11,860
- (SG) Deflazacort vs. Prednisone Date Publication \$ 25,464
- (SG) Optimizing Medical Treatment for Duchenne Muscular Dystrophy \$ 10,000

## Richard T. Moxley, M.D.

(TRAC) MD Cooperative Center Supplement - Rochester \$ 499,999

#### Charles A. Thornton, M.D.

(RG) Molecular pathogenesis of oculopharyngeal muscular dystrophy (OPMD)
\$ 100,000

#### **NORTH CAROLINA**

## <u>Chapel Hill - Asklepios</u> <u>Biopharmaceutical Inc.</u>

#### R. Jude Samulski, Ph.D.

(TRAC) Phase I/II Study of Mini-Dystrophin Gene in AAV Vector \$ 640,261

## Chapel Hill - University of North Carolina

#### Nikolay V. Dokholyan, Ph.D.

(RG) Uncovering the origins of mutant SOD1 toxicity in familial ALS \$ 107,735

## Da-Zhi Wang, Ph.D.

(RG) Control of skeletal muscle differentiation and function by SRF and myocardin family of transcription factors
\$ 80,000

# Charlotte - Carolinas Medical Center

#### Qi Long Lu, Ph.D.

(RG) Systemic delivery of antisense oligonucleotides for the treatment of DMD \$ 120,000

## **Durham - Duke University**

#### John R. Gilbert, Ph.D.

(RG) Genetic and expression studies of non-chromosome 4 facioscapulohumeral muscular dystrophy (non-4q FSHD) \$ 103,416

## Dwight Koeberl, M.D., Ph.D.

(RG) Preclinical studies with AAV vectors in acid maltase deficiency (AMD)
\$ 92,118

#### OHIO

#### Cincinnati - University of Cincinnati

#### John Quinlan, M.D.

(RG) Prevention and treatment of cardiomyopathy in mdx mice \$ 100,000

## <u>Cleveland - Case Western Reserve</u> University

#### M. Edward Medof, M.D., Ph.D.

(RG) An active model of myasthenia gravis (MG) with targeted treatment \$ 108,313

# <u>Cleveland - University of Kentucky</u> Research Foundation

#### Stephen Testa, Ph.D.

(RG) The development and assessment of a therapeutic strategy for myotonic dystrophy (DM)

\$ 62.192

# <u>Columbus - Children's Research</u> <u>Institute</u>

## Paul Martin, Ph.D.

(RG) UDP-Ga1NAc as a therapeutic in mdx mice \$ 72,721

#### Jerry Mendell, M.D.

(TRAC) Transfer of alpha-sarcoglycan gene to LGMD2D patients \$ 60,000

(RG) S. Mouchly Small Scientific Award \$ 10,000

## Columbus - Ohio State University

#### Jerry R. Mendell, M.D.

(EMG) Restricted funds for gene therapy research \$ 47,843

## Thomas Prior, Ph.D.

(PPG) WAVE-based mutation analysis for MD

\$ 77,600

#### **OREGON**

## Eugene - University of Oregon

## J. Andrew Berglund, Ph.D.

(RG) Understanding the RNA structure responsible for myotonic dystrophy \$ 97,951

#### Janis Weeks, Ph.D.

(RG) A novel screen for muscle and motoneuron death and protection genes \$ 62.800

#### **PENNSYLVANIA**

## **Danville - Geisinger Clinic**

#### Yiumo Chan, Ph.D.

(TCL) The assembly of the sarcolygcans and their role in muscular dystrophies \$ 94,571

#### Hershey - Pennsylvania State University

## James R. Connor, Ph.D.

(RG) Genotyping analysis for Hfe mutations in amyotrophic lateral sclerosis

\$ 80,032

## <u>Philadelphia - Children's Hospital of</u> Philadelphia

#### Carsten Bonnemann, M.D.

(TCL) Molecular mechanisms of dominant negative congenital muscular dystrophy type Ullrich (UCMD)

\$ 75,000

#### David R. Lynch, M.D., Ph.D.

(PPG) Clinical measures in Friedreich's ataxia (FA) \$ 160,658

#### David Pleasure, M.D.

(RG) Neuropılın-2 facilitates axonal regeneration in PNS \$ 95,064

#### Weidong Xiao, Ph.D.

(RG) Optimization of AAV vector for gene therapy of neuromuscular diseases
\$ 102,090

## Philadelphia - Drexel University

#### Terry Heiman-Patterson, M.D.

(EMG) Restricted funds for support of the MDA/ALS Center of Hope \$ 170,288

## <u>Philadelphia - Thomas Jefferson</u> <u>University</u>

#### Michael P. King, Ph.D.

(RG) Correction of mtDNA mutations resulting in myopathies \$ 89.329

#### Diane E. Merry, Ph.D.

(RG) Pathogenesis and treatment of a mouse model of spinal and bulbar muscular atrophy (SBMA)

\$ 75,000

# <u>Philadelphia - University of</u> <u>Pennsylvania</u>

## Sasha Bogdanovich, M.D.

(DG) Myostatin blockade for improvement of limb-girdle muscular dystrophy phenotype \$ 45,000

## Thomas Kadesch, Ph.D.

(RG) The control of myoblast proliferation and differentiation by Notch \$ 154,636

#### Stephen Kolb, M.D., Ph.D.

(DG) Quantitative measurement of SMN complex proteins in SMA patients

\$ 45,000

## Hong Lin, Ph.D.

(DG) Role of NF-L RNA-binding protein in protein aggregation and neurodegeneration in amyotrophic lateral sclerosis (ALS)

\$ 44,550

# Christiane Massicotte, DVM, MS, Ph.D.

(RG) Alterations in mutant protein Cx32 trafficking which cause Charcot-Marie-Tooth (CMT) disease

\$ 79,702

## Joseph W. Sanger, Ph.D.

(RG) Titin and myosin in myofibril assembly: Insights into muscle diseases

\$ 96,184

#### H. Lee Sweeney, Ph.D.

(TRAC) Preclinical studies to support clinical trials for muscular dystrophy
\$ 224,796

J. Paul Taylor, M.D., Ph.D.

(RG) Characterizing a Drosophila model of spinal bulbar muscular atrophy (SBMA) \$ 96,925

## <u>Pittsburgh - Children's Hospital of</u> <u>Pittsburgh</u>

#### Johnny Huard, Ph.D.

(RG) Improving skeletal and cardiac muscle function via stem cell transplantation \$ 100,000

#### Pittsburgh - University of Pittsburgh

#### Paula R. Clemens, M.D.

(RG) Adenoviral vector targeting for muscle gene transfer \$ 85,000

## Joseph C. Glorioso, Ph.D.

(TRAC) MD Cooperative Center Supplement - Pittsburgh \$ 500,000

#### Chunping Qiao, M.D., Ph.D.

(DG) Congenital muscular dystrophy (CMD) gene therapy with novel AAV-miniagrın vectors

\$ 45,000

#### Xiao Xiao, Ph.D.

(RG) AAV vectors for stem cellmediated Duchenne muscular dystrophy gene therapy \$ 100,000

## **TENNESSEE**

## Memphis - University of Tennessee

#### Harry Jarrett, Ph.D.

(RG) Muscular dystrophy and cell signaling \$ 90,000

#### **TEXAS**

## **Austin - University of Texas**

## Ruth A. Hagerman, Ph.D.

(RG) Effect of mutations in complex III on ubiquinone stability \$ 66.355

## College Station - Texas A&M University

## Emily Wilson, Ph.D.

(RG) Arterial remodeling in mouse models of muscular dystrophy \$ 93,005

#### Dallas - FASEB

#### Daniel Garry, MD, PhD

(SG) Skeletal muscle satellite and stem cell population \$ 10,000

#### Dallas - Texas Scottish Rite Hospital

#### Susan T. lannaccone, M.D.

(EMG) Restricted funds for SMA research

\$ 40,000

#### Dallas - UT Southwestern Medical Center

## George N. DeMartino, Ph.D.

(RG) Regulation of muscle protein degradation by the proteasome \$ 88.810

#### Jeffrey Elliott, M.D.

(EMG) Restricted funds for ALS research \$ 73.032

## Ronald G. Haller, M.D.

(RG) Exercise therapy for mitochondrial myopathies \$ 125,997

#### Osamu Nakagawa, M.D., Ph.D.

(RG) Roles of MEF2-regulated kinase Stk23 in muscular dystrophy \$ 65,000

#### Eric N. Olson, Ph.D.

(RG) Control of muscle growth by a novel small molecular \$ 60,000

#### Galveston - University of Texas

#### Tetsuo Ashizawa, M.D.

(RG) Accelerated cellular senescence in myotonic dystrophy type 1 \$ 79,590

#### Premkumar Christadoss, M.D.

(RG) New model of ocular myasthenia gravis in HLA transgenic mice \$ 119,323

#### Henry F. Epstein, M.D.

(RG) Regulation of myotonic dystrophy protein kinase (DMPK) in brain \$ 82,371

#### Erdem Tuzun, M.D.

(DG) Effector roles of C1q, IL-6 and TNF-alpha in murine myasthenia gravis (MG) \$ 45,000

#### Houston - Baylor College of Medicine

#### Stanley H Appel, M.D.

(EMG) Restricted funds for ALS research

\$ 7,568

(RG) Immune mechanisms in amyotrophic lateral sclerosis (ALS)
\$ 110.000

# Michael A. Barry, Ph.D.

(RG) Development of metabolically biotinylated gene therapy vectors \$ 141.658

#### Aladin M. Boriek, Ph.D.

(RG) Signal transduction in genetically altered dystrophic mice

\$ 75,000

## Thomas A. Cooper, M.D.

(RG) Splicing mis-regulation in the central nervous system in myotonic dystrophy \$ 104,987

#### Gabriella D'Arcangelo, Ph.D.

(RG) Reelin signaling in Schwann cell development and function \$ 100,000

#### William J. Durham, Ph.D.

(DG) Oxidative metabolism and contractile function in dystrophic skeletal muscle \$ 45,000

## Margaret Goodell, Ph.D.

(RG) Stem cell transplantation for therapy of neuromuscular disease \$ 95,000

#### Yasuo Hamamori, M.D., Ph.D.

(RG) Regulation of muscle differentiation by notch effectors

\$ 95,294

#### Susan L. Hamilton, Ph.D.

(RG) Mouse models of central core disease

\$ 92.248

## Kathyjo Jackson, Ph.D.

(DG) Improvement of bone marrow incorporation into skeletal muscle

\$ 45,000

#### Andrea Ladd, Ph.D.

(DG) Developmental alternative splicing programs in normal and DM muscle

\$ 45,000

## Irina Serysheva, Ph.D.

(RG) Structure-function correlation's within skeletal muscle L-type Ca2+ channel

\$ 78,366

#### G. Jackson Snipes, M.D., Ph.D.

(RG) Protein degradation in Charcot-Marie-Tooth disease \$ 100.000

#### Houston - Methodist Hospital

## Jenny Henkel, Ph.D.

(DG) The role of dendritic cells in ALS pathogenesis \$ 45.000

#### Stanley Appel, M.D.

(EMG) Restricted funds for ALS Research

\$ 15,405

# Houston - University of Houston

#### Werner Hoch, Ph.D.

(RG) Generation of an animal model for a new form of myasthenia gravis (MG)

\$ 75,000

## Houston - University of Texas

## Vasanthi Jayaraman, Ph.D.

(RG) High throughput screening for AMPA receptor antagonists for ALS

\$ 100,000

#### William Klein, Ph.D.

(RG) Using myogenin to manipulate muscle stem cells \$ 74.353

#### Robert A. Schulz, Ph.D.

(RG) Calcineurın function in muscle development \$ 90.000

## San Antonio - University of Texas

#### Eileen Lafer, Ph.D.

(RG) Basic mechanisms underlying neurotransmission \$ 92.422

## Holly Van Remmen, Ph.D.

(RG) Alterations in mitochondrial function in the initiation and progression of ALS \$ 100,000

#### **UTAH**

#### Logan - Utah State University

#### Brett A. Adams, Ph.D.

(RG) Novel signaling proteins in motoneurons \$ 70,000

#### Katarina Stroffekova, Ph.D.

(RG) CaM as a calcium sensor of skeletal muscle DHPR and its implication in EC coupling \$ 85,000

## Salt Lake City - University of Utah

#### Mark Bromberg, M.D., Ph.D.

(EMG) Restricted for the support of the MDA clinic at the University of Utah School of Medicine \$ 27.871

#### Kathleen Clark, Ph.D.

A potential role for muscle LIM (DG) protein in limb girdle muscular dystrophy (LGMD) \$ 45,000

## Michael T. Howard, Ph.D.

Restorative decoding of premature stop codon and frameshift mutations 45,000

#### Kathryn J. Swoboda, M.D.

Refinement of outcome (RG) parameters for clinical trials in **SMA** 

\$ 44.963

(EMG) SMA Research at the University of Utah School of Medicine 50,000 \$

#### **VIRGINIA**

#### Charlottesville - University of Virginia

#### Mani Mahadevan, M.D.

(TCL) Inducible transgenic mouse model of myotonic dystrophy type 1 (DM1) \$ 169.026

## Norfolk - Eastern Virginia Medical School

## Earl Godfrey, Ph.D.

Role of nitric oxide synthase (RG) pathway in neuromuscular development \$ 90,450

#### **WASHINGTON**

#### Seattle - University of Washington

#### William Catterall, Ph.D.

Regulation of Ca2+ channel (RG) by protein phosphorylation 88.238

#### Jeffrey S. Chamberlain, Ph.D.

(TRAC) MD Cooperative Center Supplement - Seattle \$ 499,968

## Ying-Zhang Chen, M.D., Ph.D.

Genetic analysis in (DG) amyotrophic lateral sclerosis 4 (ALS4) 45.000 \$

#### Stanley C. Froehner, Ph.D.

Identifying the genetic basis of (RG) a novel form of congenital muscular dystrophy \$ 100,000

(SG) 2nd Seattle Muscular **Dystrophy Conference** 7,690

#### Paul Gregorevic, Ph.D.

Techniques for therapeutic gene delivery to cardiac and skeletal muscles 45,000

#### Stephen D. Hauschka, Ph.D.

Regulatory cassettes for expressing therapeutic proteins in diseased muscle \$ 112.500

#### Albert La Spada, M.D., Ph.D.

(RG) Modeling motor neuron degeneration in spinal bulbar muscular atrophy (SBMA) \$ 101,208

## Sheng Li, M.D., Ph.D.

(DG) Developing bone marrow stem cell based ex vivo gene therapy for Duchenne muscular dystrophy (DMD)

\$ 45,000

#### **WISCONSIN**

# Madison - University of Wisconsin

#### James M. Ervasti, Ph.D.

(RG) Role of costameric actin in dystrophinopathies \$ 94,593

#### Jon A. Wolff, M.D.

(RG) Intravascular injection of naked plasmid DNA into the mdx mouse model for Duchenne muscular dystrophy (DMD)
\$ 90,000

## **AUSTRALIA**

## Brisbane Old - University of Queensland

#### **Louise Cahill**

(EMG) Restricted funds for Friedreich's ataxia research \$ 21,660

# Concord - University of Sydney

## Garth Nicholson, Ph.D.

(RG) Construction and characterization of hereditary sensory neuropathy type I transgenic mouse \$ 47,065

## Fitzroy - St Vincent's Hospital Melbourne

#### Robert Kapsa, Ph.D.

(RG) Improved delivery of wt dystrophin locus in the mdx mouse \$ 66.545

## <u>Melbourne - Murdoch Children's</u> Research Institute

#### Panos Ioannou, Ph.D.

(EMG) Restricted for Friedreich's ataxia research \$ 20,000

(RG) Novel approaches to the therapy of Friedreich's ataxia \$ 100,000

#### Martin Delatycki, M.D.

(EMG) Restricted for Friedreich's ataxia research \$ 25.500

## Melbourne - University of Melbourne

## Gordon Lynch, Ph.D.

(RG) Growth factor therapy for improving muscle function in muscular dystrophy \$ 83.264

## David Thorburn, Ph.D.

(RG) Finding the pathogenic mechanisms by which different genes cause mitochondrial complex I deficiency \$ 97,179

## Murdoch - Murdoch University

#### John McC. Howell, DVSc, Ph.D.

(RG) Gene transfer to mature muscle in myophosphorylase deficiency \$ 82.080

#### Perth - University of Western Australia

## Stephen D. Wilton, Ph.D.

(RG) Reducing the severity of DMD by redirecting pre-mRNA splicing \$ 108.864

# <u>Randwick - University of New South</u> Wales

# Des Richardson, B.Sc., M.Sc., Ph.D., D.Sc.

(RG) The role of iron in Friedreich's ataxia and the use of iron chelation therapy
\$ 128,793

# Sydney - Children's Hospital at Westmead

## Sandra Cooper, Ph.D.

(DG) The role of dysferlin in the pathogenesis of limb gırdle muscular dystrophy
\$ 44.832

## <u>Sydney - Victor Chang Cardiac Research</u> Inst.

## Peter Currie, Ph.D.

(RG) Characterization of zebrafish dystrophin mutants \$ 70,000

# <u>Toowoomba - University of Southern</u> <u>Queensland</u>

#### Andrew Hoey, Ph.D.

(RG) Cardiac dysfunction in Duchenne muscular dystrophy (DMD) \$ 69,152

#### **AUSTRIA**

## Vienna - Medical University of Vienna

# Dr. Barbara Scheiber-Mojdehkar

(EMG) Restricted funds for FA research \$ 20,255

#### **BELGIUM**

#### Leuven - VIB

## Peter Carmeliet, Ph.D., M.D.

(RG) Therapeutic potential of VEGF for amyotrophic lateral sclerosis (ALS) \$ 124,482

#### Mons - University of Mons-Hainaut

#### Frederique Coppee, Ph.D.

(DG) Characterization of DUX4c and its role in facioscapulohumeral dystrophy (FSHD)

\$ 44,712

#### **CANADA**

## **London - University of Western Ontario**

#### Christen Shoesmith, BSc, M.D.

(TRAC) Clinical Research Training \$ 74,200

## Michael Strong, M.D, FRCPC

(RG) The regulation of microglial activation in amyotrophic lateral sclerosis (ALS) \$ 81,846

#### Montreal - McGill University

#### Jeffrey N. Agar, Ph.D.

(DG) Mechanisms and consequences of altered protein solubility in amyotrophic lateral sclerosis (ALS)

\$ 44.820

# Brendan J. Battersby, Ph.D.

(DG) New animal model for mitochondrial diseases \$ 44,990

## Salvatore Carbonetto, Ph.D.

(RG) Dystroglycan associated proteins in synaptic vesicle recycling \$ 90,000

#### Heather Durham, Ph.D.

(RG) Mechanisms of motor neuron vulnerability to disease \$ 89,419

#### George Karpati, M.D.

(RG) Molecular therapies for dystrophin deficiency \$ 80,000

#### Basil Petrof, M.D.

(RG) Plasmid-mediated delivery of therapeutic genes in muscular dystrophy \$ 88.588

## Eric Shoubridge, Ph.D.

(RG) Assembly of cytochrome c oxidase in mitochondrial myopathy \$82,393

## Montreal - Montreal General Hospital

## Guy Rouleau, M.D., Ph.D.

- (RG) Investigation of the pathogenesis of oculopharyngeal muscular dystrophy (OPMD)
  \$ 100.000
- (RG) Identification and characterization of the ALS3 gene \$ 100,000

## Ottawa - Children's Hospital of Eastern Ontario

## Robert G. Korneluk, Ph.D.

(RG) Therapeutic potential of apoptosis suppression for myotonic dystrophy (DM)
\$ 99,440

## Alex MacKenzie, M.D., Ph.D.

(RG) Compound testing in organotypic cultures of spinal muscular atrophy (SMA) mouse model spinal cords
\$ 77,000

# Ottawa - Ottawa Health Research Institute

#### Rashmi Kothary, Ph.D.

(RG) The role of sodium channel 8a in skeletal and cardiac muscle function \$ 100,000

## Lynn A. Megeney, Ph.D.

(RG) Characterizing the role of the TC10/JNK1 atrophic pathway in dystrophic muscle \$ 100,000

#### Michael Rudnicki, Ph.D.

(RG) Molecular regulation of satellite cell function \$ 130,000

#### Ottawa - University of Ottawa

#### Stephen H. Gee, Ph.D.

(RG) The role of diacylglycerol kinase-zeta and syntrophins in myoblast fusion \$ 81,930

#### Bernard Jasmin, Ph.D.

(RG) Role of calcineurin signalling in the regulation of utrophin in skeletal muscle
\$ 124,700

#### Luc Sabourin, Ph.D.

(RG) Role of SLK in myoblast migration \$ 98,709

## **Quebec - Laval University**

#### Francois Berthod, Ph.D.

(RG) Development of a tissueengineered model of spinal cord to study amyotrophic lateral sclerosis (ALS) \$ 71,569

#### Jack Puymirat, M.D., Ph.D.

(RG) Stratagems in vitro for a gene therapy for myotonic dystrophy \$ 33,594

### Toronto - Hospital For Sick Children

#### Christopher Pearson, Ph.D.

(RG) DNA replication, DNA repair and drug-induced CTG repeat instability in DM1 patient cells \$ 75,000

## **Toronto - University of Toronto**

#### Anthony Gramolini, Ph.D.

(DG) Generation and characterization of transgenic mouse models of central core disease (CCD)
\$ 44.550

## <u>Vancouver – University of British</u> <u>Columbia</u>

## Fabio Rossi, M.D., Ph.D.

(RG) Identification and engineering of circulating myogenic progenitors \$ 90,000

#### **CHILE**

## Santiago - Catholic University of Chile

## Enrique Brandan, Ph.D.

(RG) DMD fibrosis: Role of CTGF, LRP and proteoglycans \$ 63,982

## **CYPRUS**

## <u>Nicosia – Cyprus Institute of Neurology</u> and Genetics

## Kyproula Christodoulou, Ph.D.

(RG) Neuromuscular diseases in Eastern Mediterranean countries \$ 65,930

## **FRANCE**

## Gif sur Yvette - CNRS

#### Sabine De La Porte, Ph.D.

(RG) Finding the best NO-related compound for treating Duchenne and Becker dystrophies \$ 28,350

## Illkirch cu de Strasbourg - INSERM

## Helene Puccio, Ph.D.

(EMG) Restricted funds for Friedreich's ataxia research \$ 11,500

## <u>Montpellier - Centre National de la</u> <u>Recherche Scientifique</u>

#### Anne Fernandez, Ph.D.

(RG) A comparative proteomic analysis of muscle degeneration in FSHD \$ 60.000

## **GERMANY**

## Aachen - RWTH Aachen

## Christoph M. Fahlke, M.D.

(RG) Modification of CIC-1 function by cytoplasmic domains in normal and myotonic muscle \$ 95,349

## Essen - University Hospital of Essen

## Helge Amthor, M.D.

(DG) Evaluating the adverse effects of myostatin loss on normal and dystrophic skeletal muscle \$ 44,965

#### **GREECE**

#### Athens - Hellenic Pasteur Institute

#### Socrates Tzartos, Ph.D.

(RG) Autoantibody depletion and down-regulation in myasthenia gravis (MG) \$ 97,900

#### **ISRAEL**

### Jerusalem - Hebrew University

#### Millet Treinin, Ph.D.

(RG) Identification and characterization of genes needed for nAChR mutation \$ 63,074

## <u>Rehovot – Weizmann Institute of</u> Science

## David Yaffe, Ph.D.

(RG) The DMD gene products in mammals and drosophila:
Functional implications
\$ 92.061

## Tel-Aviv - Open University of Israel

## Miriam Souroujon, Ph.D.

(RG) Immunotherapies for experimental myasthenia \$82,720

## **ITALY**

## Milan - Istituto Scientifico San Raffaele

#### Giulio Cossu, M.D.

(RG) Isolation, in vitro expansion and characterization of human mesoangioblasts for the cell \$89,000

## <u>Monterotondo Scalo - Dulbecco Telethon</u> Institute

## Livio Pellizzoni, Ph.D.

(RG) Characterization of SMN interactions in the mouse spinal cord \$ 49,600

#### Napoli - TIGEM

#### Elena I. Rugarli, M.D.

(RG) Towards a therapy for hereditary spastic paraplegia due to paraplegin deficiency \$ 65,560

#### Rome - Dulbecco Telethon Institute

#### Pier Lorenzo Puri, M.D., Ph.D.

(RG) Deacetylase inhibitors as a pharmacological tool for muscular dystrophies \$ 90.000

#### **MEXICO**

## Mexico City - CINVESTAV-IPN

#### Bulmaro Cisneros, Ph.D.

(RG) Molecular mechanism of the inhibition of neuronal differentiation induced by the DM expanded CTG repeats \$ 32.950

## **NETHERLANDS**

## **Leiden - Leiden University**

# Silvere van der Maarel, Ph.D.

(SG) International FSHD Workshop \$ 4,750

(EMG) Restricted funds for facioscapulohumeral muscular dystrophy research \$ 53,000

(RG) Epigenetic studies of facioscapulohumeral muscular dystrophy (FSHD) \$ 119.590

#### Silvere van der Maarel, Ph.D.

(RG) Comparative analysis of 4qlinked FSHD, non-4q-linked FSHD, and ICF syndrome \$ 88,961

#### Judith C. T. van Deutekom, Ph.D.

(RG) Antisense therapy in different Duchenne muscular dystrophy (DMD) mouse models \$ 100,000

#### Nijmegen - University of Nijmegen

## Berend Wieringa, Ph.D.

(RG) Treatment of somatic (CTG)n repeat instability in myotonic dystrophy (DM)
\$ 103,475

## **PORTUGAL**

## Lisboa - University of Lisboa

# Mario do Carmo-Fonseca, M.D., Ph.D.

(RG) Profili

Profiling alternative splicing in muscular dystrophies \$ 100,000

## **SINGAPORE**

## <u>Singapore – National Cancer Centre</u>

## Mac Mengfatt Ho, D.Phil

(RG) Functional proteomic analysis of dysferlinopathy and dysferlin-mediated membrane repair

\$ 70,152

#### SPAIN

## <u>Barcelona – Center for Genomic</u> <u>Regulation</u>

#### Pura Munoz Canoves, Ph.D.

(RG) Role of the plasminogen activation system in mdx dystrophinopathy \$ 100,000

#### Lleida -University of Lleida

#### Jordi Tamarit, M.D.

(EMG) Restricted for Friedreich's ataxia research \$ 12,500

#### **SWEDEN**

## Huddinge - Karolinska Institute

#### Nils-Goran Larsson, M.D., Ph.D.

(RG) Mechanisms of pathology in a mouse model for mitochondrial myopathy \$ 79,970

### **SWITZERLAND**

#### Basel - University of Basel

## Markus A. Ruegg, Ph.D.

(RG) Treatment of congenital muscular dystrophy (CMD) by an agrın mınigene \$ 92,716

## **UNITED KINGDOM**

#### **Dundee - University of Dundee**

## Miguel Maroto, Ph.D.

(DG) Role of notch signaling in patterning/differentiation of early muscle precursors \$ 45,000

## <u>London - Imperial College School of</u> <u>Medicine</u>

# Richard Festenstein, MB, MRCP, PhD

(RG) Epigenetic modifiers as disease modifying agents in myotonic dystrophy? \$ 80,000

## London - King's College Hospital

#### Michael Rose, M.D.

(RG) US Validation of a neuromuscular disease quality of life measure \$ 53,946

### London - University College London

## Linda Greensmith, Ph.D.

(RG) Treatment of ALS with
Arimoclomol, a novel inducer
of heat shock proteins
\$ 107,140

## Nottingham - University of Nottingham

#### J. David Brook, Ph.D.

(RG) The role and interactions of muscleblind proteins in myotonic dystrophy \$ 150,000

## Oswestry - RJAH Hospital

## Glenn Morris, D.Phil.

(TRAC) A monoclonal antibody resource for genetic neuromuscular diseases \$ 117,437

## Oxford - University of Oxford

## Kay E. Davies, MA, D.Phil.

(RG) Analysis of the role of syncoilin in muscle disease \$ 86,047

(RG) Increased utrophin expression in therapy of DMD \$ 99,260

Total Grants and Awards
Return of Unexpended Funds
Cancellations of Prior Year Awards

\$ 32,171,171
(991,937)
(611,389)

\$ 30,567,845

Total Grants and Awards
Outstanding at 8/31/05

\$ 18,551,565

27

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 SCHEDULE OF FIXED ASSETS, DEPRECIATION AND AMORTIZATION FOR THE FISCAL YEAR ENDED MARCH 31, 2005

	3/31/2004 Balance	Removal of Fully Depreciated Assets	Acquisitions & Disposals	Depreciation, Amortization & Other Expenses	3/31/2005 Balance
Land and Improvements	\$2,183,300				\$2,183,300
Building Furniture & Equipment Accumulated Depreciation-	7,904,956 6,475,956	(\$1,151,219)	\$1,493,944		7,904,956 6,818,681
Building and Furniture & Equipment	(6,018,479)	1,151,219		(\$1,522,755)	(6,390,015)
	\$10,545,733	\$0	\$1,493,944	(\$1,522,755)	\$10,516,922

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 SCHEDULE OF INVESTMENTS - SECURITIES

STOCKS	3/31/2004	3/31/2005
Abbott Laboratories	\$4,114,233	\$0
Ace Ltd	0	4,127,000
American International Group Inc	2,140,500	3,326,706
American Vantage Companies	9,840	5,700
Applied Materials Inc	0	2,843,750
Autonation, Inc.	2,557,500	0
Barretville Bank & Trust 100,000th	UNPRICED	UNPRICED
Cisco Sys Inc	0	4,472,500
Citigroup Inc	2,585,000	4,497,550
Comcast	4,177,500	0
Walt Disney Co	, , 0	4,309,500
EMC Corp-Mass	0	3,696,000
General Electric	3,819,334	4,507,500
Goldman Sachs	339,159	354,360
Goodrich Pete Corp New	2,047,595	4,226,000
Hewlett Packard Co	4,572,568	0
Intel Corp	2,720,000	4,065,250
Intl Business Machines Corp	3,680,029	4,121,238
Johnson & Johnson	2,028,800	0
JP Morgan Chase	0	4,325,000
Jetblue Airways Corp	0	3,332,000
Lucent Technologies	0	3,300,000
WTS Lucent Technologies	0	4,439
Max Re Capital Ltd	2,260,000	0
Merk & Co	3,096,614	0
Microsoft Corp	3,116,250	3,625,500
Nasdaq 100 Trust Ser 1	3,584,000	0
Natural Gas Company VA Inc Class A	UNPRICED	UNPRICED
Networks Associates Inc.	3,600,000	0
Old Repbulic International Corp	4,912,000	0
Oracle Corp	3,000,000	2,496,000
Pfizer Inc	2,641,087	3,950,272
SBC Communications Inc	0	3,553,500
Sırus Satellite Radio Inc	3,060,000	1,124,000
Southern Un Co	4,194,147	0
State Street Bank	57,708	0
Texas Instruments Inc	0	4,460,750
Time Warner Inc	3,793,500	0
Total Management Inc	UNPRICED	UNPRICED
Travelers Prop Casualty	3,430,000	0
UBS PaineWebber Inc Access Account	140,495	0

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 SCHEDULE OF INVESTMENTS - SECURITIES

STOCKS US Bancorp Del New Valley Cmnty Bancshares Inc Wal-Mart Stores Inc	3/31/2004 3,456,250 3,520 0	3/31/2005 0 0 3,758,250
TOTAL STOCKS	79,137,629	78,482,765
CLOSED END FUNDS Nasdaq 100 Trust Ser 1 TOTAL	0 0	4,571,250 4,571,250
BONDS AND OTHER Mission Management Mission Management UBS Paine Webber State of Israel AT&T Money Market	0 0 20,800 16,840 0 4,049	165,144 55,608 0 15,641 105,750 4,312
TOTAL BONDS AND OTHER	41,689	346,455
GRAND TOTAL	\$79,179,318	\$83,400,470

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 SCHEDULE OF INVESTMENTS - OTHER

	3/31/2004	3/31/2005
U.S. Treasury Notes	\$77,403,635	\$87,166,757

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 STATES WHICH WILL RECEIVE COPY OF THIS RETURN FOR THE FISCAL YEAR ENDED MARCH 31, 2005

Alabama

Arkansas

Arizona

California

Connecticut

Florida

Georgia

Illinois

Indiana

Kansas

Kentucky

Maryland

Massachusetts

Michigan

Minnesota

Mississippi

New Hampshire

**New Jersey** 

**New Mexico** 

New York

North Carolina

Ohio

Oklahoma

Oregon

Pennsylvania

South Carolina

Tennessee

Utah

Washington

West Virginia

Wisconsin

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 RESEARCH FOR THE FISCAL YEAR ENDED MARCH 31, 2005

## General

The Muscular Dystrophy Association, Inc., (MDA) is a not-for-profit corporation incorporated on June 6, 1950, under the laws of the State of New York. MDA supports worldwide research to find the causes of and cures for muscular dystrophy and related neuromuscular disorders. The programs of MDA are supported almost entirely by individual private contributions from the general public. MDA neither receives fees from those it serves nor applies any means test for services, and by choice is not a United Way-supported agency.

The diseases supported by MDA are the muscular dystrophies (among which are Duchenne and Becker); motor neuron diseases (including amyotrophic lateral sclerosis (Lou Gehrig's disease) and spinal muscular atrophy); the peripheral nerve disorders Charcot-Marie-Tooth disease and Friedreich's ataxia; inflammatory myopathies; disorders of the neuromuscular junction; metabolic diseases of muscle as well as other myopathies. Some of the over 40 neuromuscular diseases covered by MDA are fatal, while others result in chronic mobility impairment.

As reported by the U.S. Department of Health and Human Services, National Institutes of Health (NIH), in the United States alone, muscular dystrophy and other neuromuscular disorders are estimated to affect some 1 million people.

#### Research

MDA sponsors research grants in the United States and 19 foreign countries. Association's research program accounted for some \$34.3 million of its expenditures for the fiscal year. MDA's Scientific and Medical Advisory Committees, whose members are among the nation's foremost scientists and physicians in the field of neuromuscular disease, carefully review all research supported by the Association. MDA maintains a diverse program of basic research which advances investigations of possible treatments for neuromuscular diseases, muscle function, regulation and regeneration; biochemical changes involved in muscle disease; the genetics of neuromuscular disease; and the interaction of nerve and muscle. This work is necessary in order to provide a sound scientific foundation from which practical advances against disease can arise. Additionally, the Association's recently established Translational Research Advisory Committee (TRAC) is focused on milestone driven contracts with the biotech industry, pharmaceutical companies and academic investigators for research that is directly relevant to bringing new therapies to market. Members of TRAC include a number of top neuromuscular disease researchers, as well as representatives of NIH and industry. Among the first assignments of TRAC was to develop a strategic plan for research priorities.

## Searching for the Causes of Neuromuscular Disease

The majority of the neuromuscular diseases, including all of the muscular dystrophies, covered by MDA programs are genetic disorders. In 1986, MDA researchers ushered in a new era in neuromuscular disease research with the identification of the gene that when defective causes Duchenne and Becker muscular dystrophies. This gene, identified as the largest human gene ever discovered was the first major human disease gene isolated without prior knowledge of its protein product. MDA has been in the forefront of research on inherited diseases with an ever-expanding list of new genetic research projects and an extensive list of genes that have been found defective in inherited neuromuscular disorders.

MDA-funded scientists continue to investigate the causes of muscle disease. Other Association-supported researchers are focusing on the body's immune system. Several neuromuscular diseases, such as myasthenia gravis, polymyositis and dermatomyositis are known to involve an abnormal immune system attack on muscle or nerve. In addition, amyotrophic lateral sclerosis may result from excitotoxic or oxidative injury to motor neurons and MDA scientists are studying these disease mechanisms in the hope of finding possible modes of treatment. Findings from early research supported by MDA served as the scientific basis for approval by the FDA of the first drug available for prescription use for ALS. This drug, called riluzole, works by partially blocking the natural substance glutamate. MDA researchers worked on the glutamate theory that led to riluzole's development. Based on this theory MDA-supported scientists have been testing other drugs that block glutamate.

## Search for Treatment

A number of measures have been adopted to treat neuromuscular diseases including, nutrition, bracing, physical therapy and drugs such as prednisone. Several measures are used to successfully manage these disorders. Plasma exchange is a life saving measure for myasthenia gravis, prednisone slows the progression of muscle weakness in Duchenne muscular dystrophy (DMD) and L-carnitine is used in the treatment of carnitine deficiency.

A flaw within the cells of the body—the genes—causes the majority of the diseases MDA is striving to combat. MDA has advanced research directed at developing effective ways to treat muscular dystrophy by correcting the basic gene disturbance causing muscle weakness. This can be done through cell-based therapies. MDA researchers are using a variety of strategies to achieve this.

One potential treatment is to replace the missing or defective muscle proteins. This is the technique known as gene therapy. By inserting healthy genes into muscle cells, MDA-supported researchers have demonstrated in the laboratory that these genes can begin to produce the essential protein needed to develop healthy muscles. It is known with certainty that gene therapy can at least slow muscle destruction.

Another cutting-edge technology being applied to neuromuscular diseases is stem cell therapy. Stem cells are undeveloped cells that give rise to and assemble tissues and organs. Within the body millions of these cells are waiting to be called into action. MDA scientists have been able to encourage these undeveloped cells to form muscle and other tissue. The next step will be to insert stem cells into muscles weakened by muscular dystrophy and have them replace the damaged cells.

Another measure being developed to repair muscle cells is through gene correction. In the laboratory, scientists have been able to correct an improper message in the gene code that blocks the gene's ability to make a protein. A clinical trial in one method of gene correction is now underway and researchers are developing other methods with the hopes of applying the procedure to those affected by certain neuromuscular disorders.

MDA continues to strengthen its partnerships with industry and the NIH to advance therapies for neuromuscular disease. For example, MDA is partnering with Wyeth Pharmaceuticals (Collegeville, PA) through providing supplemental funding for a clinical trial of MYO-029, a compound that blocks myostatin, a natural protein that ordinarily inhibits the growth of muscles. Both MDA-funded investigations and Wyeth-conducted research have suggested that blocking myostatin's activities might improve muscle growth and survival and at least partially offset the muscle degeneration associated with certain disorders. MDA continues to fund research on the biological mechanisms underlying myostatin's effects. MDA continues its support of the clinical trial of a potential treatment of Pompe's disease sponsored by Genzyme Corporation. For example, Pompe's, a severe disease that is usually fatal in infants, is now being treated with great success in clinical trials. Research supported by MDA provided the scientific basis for a potential The expanded trials will include a larger population of those treatment for Pompe's. affected by Pompe's. Additionally, a study designed to observe the course of the disease in adults is underway. Some of the participants in that study will later have the opportunity to enroll in a late-onset treatment study in which they will receive the enzyme.

The Muscular Dystrophy Association will supplement funding from the NIH, a component of the Federal Department of Health and Human Services, for up to three muscular dystrophy cooperative research centers. This partnership between NIH and MDA is a critical step toward improving quality of life for those affected by muscular dystrophy. MDA's supplemental funding of the cooperative centers will provide the additional support essential to advancing highly focused muscular dystrophy research and training in medical management MDA is providing grant funding up to a maximum of \$500,000 per center per year for three years.

MDA continues its support of the North Carolina biotechnology company Asklepios to develop gene therapy for DMD. Researchers at the Gene Therapy Center of the University of North Carolina at Chapel Hill and the Department of Molecular Genetics & Biochemistry at the University of Pittsburgh make up the research team. The company plans to develop and test a virus-based system designed to deliver a miniaturized

dystrophin gene to the muscles of boys with DMD. Dystrophin is the muscle protein missing in the disease.

## Recent Research Accomplishments

MDA-funded research in 2004-2005 steadily built on earlier advances against a wide variety of muscle-wasting diseases. Progress was made at both the molecular level -- in decoding disease mechanisms -- and at the practical level, in identifying and testing promising treatments.

MDA continued its strategy of collaborating with researchers, physicians, government and businesses to fast-track promising research into lifesaving practical therapies. MDA grantees studying amyotrophic lateral sclerosis (ALS) identified potential drug treatments and uncovered new triggers and risk factors. Although the cause of the disease remains unknown in most cases, an MDA-supported research group concluded there is "biologic plausibility" that activation of dormant retroviruses in DNA could be a contributing factor. Possible ALS risk factors also were identified in variants in the genes for Hfe and peripherin.

MDA-supported researchers also identified the senataxin gene as one that, when flawed, causes a juvenile-onset form of ALS.

To gain further insight into the causes of ALS, MDA grantees launched a study of disease patterns and genetics, using interviews, questionnaires and blood samples. ALS mouse and human trials of various compounds yielded encouraging results. After finding that the compound sodium phenybutyrate prolonged the life of mice with ALS, a trial in humans was begun in conjunction with the Veterans Administration.

A clinical trial of the breast cancer drug tamoxifen showed it may prolong survival in people with ALS when given at certain dosages. A human trial is under consideration for the drug ceftriaxone after finding it extends life and prolongs strength in mice with ALS. MDA researchers followed up on their finding that a lack of vascular endothelial growth factor (VEGF) may contribute to ALS by demonstrating that delivering VEGF as a gene or protein benefits mice with ALS.

In DMD, the Recombinant DNA Advisory Committee of the NIH gave the green light to MDA-supported gene therapy researchers hoping to do human trials of a gene therapy compound for DMD. This approval was critical to the work of the biotechnology firm Asklepios, which is receiving funding from MDA to develop gene therapy strategies for DMD.

Also in the area of gene therapy, MDA awarded a \$1.5 million grant to PTC Therapeutics, which is developing a drug (PTC124) that causes cells to "read through" a specific type of genetic error that affects approximately 15 percent of children with DMD. A phase 1 study showed the compound is safe and reached adequate blood levels in healthy volunteers. The next step is testing the drug in boys with DMD with the specific genetic flaw.

A subcommittee of the American Academy of Neurology (AAN), composed primarily of MDA clinic directors and research grantees, released a practice guideline for physicians treating children with DMD, outlining the most effective way to use the steroid prednisone to prolong muscle strength.

In researching treatments for spinal muscular atrophy (SMA), an MDA-backed researcher found that drugs known as aminoglycosides help cells produce more of the protein which is necessary for nerve cells to survive and function.

People with facioscapulohumeral, Becker and limb-girdle muscular dystrophies were enrolled in a trial of the drug MYO-029 developed by Wyeth Parmaceuticals.

MDA continues to build upon and expand research programs in a number of fronts and seeks to create new and innovative research opportunities.

## MUSCULAR DYSTROPHY ASSOCIATION #13-1665552 PATIENT AND COMMUNITY SERVICES FOR THE FISCAL YEAR ENDED MARCH 31, 2005

Throughout the United States and Puerto Rico, the Muscular Dystrophy Association, Inc. (MDA) provides a wide variety of services to those affected by any of the disorders in its program, irrespective of age, race, creed, color or sex. MDA's services program is designed to assist those affected by muscular dystrophy and related diseases of the neuromuscular system, which affect children as well as adults. A complete list of diseases covered by MDA is contained in the Association's services brochure, copies of which are available upon request through MDA's National Headquarters at 3300 East Sunrise Drive, Tucson, Arizona 85718, from any of its 230 field offices in the United States and Puerto Rico, or its Web site at www.mdausa.org.

MDA maintains the most comprehensive services program of any voluntary health agency in the country, helping individuals and their families meet the problems imposed by chronic, progressive neuromuscular diseases. This aspect of the Association's program accounted for over \$79.2 million of its expenditures for fiscal 2005. The Association makes available a broad program of services ranging from a nationwide network of clinics providing access to top health professionals skilled in the diagnosis and medical management of neuromuscular diseases to assistance with essential support services. In this connection, MDA offers the following to benefit individuals affected by neuromuscular diseases:

- Diagnostic consultations and follow-up examinations by neuromuscular specialists through a nationwide network of over 235 MDA clinics (see Exhibit L attached)
- > Genetic counseling services through MDA clinics
- Assistance with the purchase and repair of wheelchairs to maintain independence and mobility
- Assistance with the purchase and repair of leg braces
- > Assistance with the purchase of communication devices
- Durable medical equipment loan programs through which individuals can receive walkers, hospital beds, bath aids or other items to enhance independence
- 90 week-long camp programs for young people affected by neuromuscular disease

- Assistance with transportation for MDA clinic appointments and MDA summer camp
- > Annual physical, occupational, respiratory and speech therapy consultations
- Educational seminars that provide information about neuromuscular diseases and offer a forum to discuss subjects of importance to families living with these disorders
- Support groups to assist families and individuals in dealing with the special problems imposed by neuromuscular diseases

## **MDA Clinics**

MDA maintains a network of over 235 hospital-affiliated neuromuscular clinics located at prestigious medical institutions and university-based facilities across the United States. At MDA clinics people with neuromuscular diseases have access to the nation's top specialists in this group of diseases. These clinics are essential to the medical management of neuromuscular diseases but are also key to the development of new therapies.

Each year MDA provides tens of thousands of medical visits through its clinic program. Individuals affected by any of the disorders in MDA's purview have access to these hospital-affiliated and university-based clinics staffed by top health professionals using a multidisciplinary team approach. These experts advise about all aspects of medical management of neuromuscular disease, including respiratory care and physical therapy. Anyone whose physician suspects a neuromuscular disorder, upon referral by the person's physician, would be eligible for a diagnostic evaluation at an MDA clinic. Should the diagnosis indicate a disease other than one included in MDA's program, the Association will then refer the individual to an appropriate community resource.

Also, MDA clinics are essential to the advancement of neuromuscular disease research. They serve as the key centers for ongoing clinical trials for the development of a wide range of potential therapies. The Association's research priority is the support of projects that focus on the development of therapies. MDA clinics are the focal points for the clinical application of scientific advances designed to treat neuromuscular diseases.

## MDA/ALS Clinical Research Centers

The Association has established 34 regional amyotrophic lateral sclerosis (ALS) research and clinical centers across the country to focus attention on a very rapidly progressive debilitating neuromuscular disorder that strikes adults in the prime of life.

## They are:

- The Eleanor and Lou Gehrig MDA/ALS Research Center at Columbia University Medical Center in New York:
- Forbes Norris MDA/ALS Research Center at California Pacific Medical Center in San Francisco:
- Jerry Lewis MDA/ALS Clinical and Research Center at the University of Southern California in Los Angeles;
- MDA/ALS Clinical Research Center at the University of Wisconsin in Madison;
- The Vicki Appel MDA/ALS Center at Methodist Hospital in Houston;
- MDA/ALS Center at Massachusetts General Hospital in Boston;
- MDA/ALS Research Center at the University of Chicago Hospitals in Chicago;
- MDA/ALS Center at UCLA in Los Angeles;
- MDA/ALS Center at the University of Colorado in Denver;
- MDA/ALS Center at Yale University in New Haven, Connecticut;
- MDA/ALS Center at Emory University School of Medicine in Atlanta;
- MDA/ALS Center at Johns Hopkins University in Baltimore;
- MDA/ALS Center at Washington University School of Medicine in St. Louis;
- MDA/ALS Center at Duke University in Durham, N.C.;
- MDA/ALS Center at the University of Texas in Dallas;
- Kessenich Family MDA/ALS Center at the University of Miami;
- MDA/ALS Center at the University of Utah in Salt Lake City;

- MDA/ALS Center at Carolinas Medical Center in Charlotte;
- MDA/ALS Center at SUNY Health Sciences Center Syracuse;
- MDA/ALS Center at the University of Kansas Medical Center in Kansas City, Kansas;
- MDA/ALS Center at Mt. Sinai Hospital and Medical Center in New York;
- MDA/ALS Center of Hope at Drexel University College of Medicine in Philadelphia;
- MDA/ALS Center at St. Joseph's Hospital and Medical Center in Phoenix, AZ;
- MDA/ALS Center at the University of Arizona Health Sciences Center in Tucson, AZ;
- MDA/ALS Center at the University of New Mexico Health Sciences Center in Albuquerque;
- MDA/ALS Center at the University of California, Irvine in California;
- MDA/ALS Center through the University of Texas Health Science Center at San Antonio, TX;
- MDA/ALS Center at the University of Washington Medical Center, Seattle, WA;
- MDA/ALS Center at Vanderbilt University Medical Center, Nashville, TN;
- MDA/ALS Center at Ohio State University, Columbus, OH;
- MDA/ALS Center at the University of Rochester Medical Center in Rochester, NY;
- MDA/ALS Center at the University of Arkansas for Medical Sciences in Little Rock;
- MDA/ALS Center at the University of Pittsburgh Medical Center in Pittsburgh;
- MDA/ ALS Center at the University of Massachusetts Medical Center in Worcester.

MDA's services program is administered through its network of some 230 field offices located in the United States and Puerto Rico. MDA Health Care Service Coordinators knowledgeable about federal, state and local community resources also assist hundreds of thousands of people with disabilities and their families by advising them about other services for which they may be eligible.

Thousands of people benefit each year from MDA's assistance with durable medical equipment. For example, in fiscal 2005 MDA assisted with the purchase of wheelchairs, leg braces and communication devices. The Association also augmented payment for wheelchair and leg brace repairs. In addition, thousands of adaptive devices were provided to individuals through MDA's local equipment loan closet programs -- including, but not limited to, walkers, canes, bath equipment, wheelchairs, hydraulic lifts and hospital beds.

In fiscal 2005 some 4,100 young people enjoyed a week of fun and friendship through MDA summer camps which offer activities geared to the special needs and abilities of those with neuromuscular disease. Thousands of individuals and their families received support through MDA's nationwide network of 290 support groups, as well as through MDA-sponsored educational seminars, referral services and online chat sessions at <a href="https://www.mdausa.org/chat/calendar.html">www.mdausa.org/chat/calendar.html</a>.

MDA makes available many informational videos that address the special medical needs of those with neuromuscular diseases. For those whose breathing is compromised, a 25-minute video on respiratory assistance is available at no cost. Also available for newly-diagnosed families is a 15-minute video entitled "The MDA Support Group and You," which is designed to dispel doubts and highlight benefits of attending support groups. For parents of boys affected by Duchenne muscular dystrophy (DMD), a 39-minute video titled "Standing and Walking are Gifts: A Guide to Heel Cord Tenotomy" provides an overview of the surgical procedure often recommended for prolonging walking in boys affected by the disorder.

A vast array of publications are also available that address a variety of medical concerns such as nutrition, mobility and problems relating to chewing and swallowing. Materials are also available to help parents and caregivers of those affected by neuromuscular disease. Specialists in the various medical disciplines addressed by these materials served as editorial advisors and contributing editors.

Additional information about MDA's Health Care and Community Services Program is available through MDA's Web site at www.mdausa.org/clinics/.

## MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 PROFESSIONAL AND PUBLIC HEALTH EDUCATION FOR THE FISCAL YEAR ENDING MARCH 31, 2005

In the fiscal year ended March 31, 2005, the Muscular Dystrophy Association (MDA) expended \$20.8 million on its professional and public health education program. MDA's public information and health education program seeks to meet the needs of the medical profession, the scientific community, the general public and people with neuromuscular diseases by providing timely and thorough information about MDA's programs and the diseases they cover.

MDA produced, updated and distributed dozens of publications to millions of people describing the Association's comprehensive services, its extensive research program and the more than 40 neuromuscular disorders that MDA covers, and providing advice to families affected by neuromuscular diseases. The Public Information Department produced six issues of MDA's award-winning bimonthly national magazine, Quest, offering a readership of more than 350,000 a stimulating mix of articles. These articles touched on a range of diseases in MDA's program, and highlighted progress being made by MDA-supported researchers, MDA services, health care information, and assistance with disability-related issues affecting individuals and families. In addition, MDA's TV Production Department produced and distributed educational videos on various topics for families affected by neuromuscular diseases.

MDA also produced its monthly ALS Newsmagazine for those affected by Lou Gehrig's disease. MDA created several new brochures in its "Facts About" series providing basic information about individual diseases in MDA's program, geared toward people newly diagnosed, and revised and reprinted several other disease-specific publications for those affected and their families. The Association also developed a new publication for families living with ALS titled Everyday Life With ALS: A Practical Guide.

Tens of thousands of print public services advertisements carried the MDA message in newspapers and other periodicals across the country, with circulation in the tens of millions. Many millions more saw television public service announcements on local and national broadcast networks of all types, including cable channels. News about MDA activities and research advances was carried by major wire services, on television news programs and in thousands of newspaper and magazine articles.

The Association made its complete range of literature available electronically on its three main Web sites: <a href="https://www.mdausa.org">www.mdausa.org</a>, <a href="https://www.mdausa.or

www als mdausa org. The Web sites offered a constant stream of updated information about MDA's programs. Internationally recognized as a key source of information about neuromuscular diseases, the main site attracted visitors from dozens of countries around the world. Total visits to the site amounted to more than 5.4 million for the year.

The Association conducted more than 100 sessions per month of its popular online chats. Visitors to the MDA sites also had the opportunity to ask questions about diseases, research and services and many other topics.

Health professionals obtained the latest information about neuromuscular disease through the Association's library of print materials and its expansive Web site – which includes an "Ask the Experts" feature where questions are answered by researchers and clinicians who specialize in neuromuscular disease. Additional information was offered to the medical community through educational videos and community-based seminars offering updates on neuromuscular disease research. Secure online areas were also available for MDA scientific investigators and clinicians to exchange information and ideas.

MDA's e-mail newsletter, MDA e-update, delivered news about research breakthroughs and other pertinent information to friends of the Association. The online newsletter is distributed on a monthly basis to keep readers current on rapid research progress and other news from the Association.

# MUSCULAR DYSTROPHY ASSOCIATION, INC. OFFICERS (\*) AND MEMBERS OF THE BOARD OF DIRECTORS

July 9, 2004

National Office 3300 East Sunrise Drive Tucson, Arizona 85718-3208

Stanley H. Appel, M.D.

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# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 STATEMENTS ABOUT ACTIVITIES FOR THE FISCAL YEAR ENDED MARCH 31, 2005

The Association awards research grants each year to physicians and scientists in the United States and abroad where research is directed toward developing effective treatments for the neuromuscular disorders covered by the Association's programs.

The determination for the award of research grants is based on a review of formal proposals submitted by applicants. These proposals include detailed descriptions of the program to be funded and supporting documents detailing the credentials and professional accomplishments of the applicant.

This information is reviewed by members of one of the following:

- 1. Scientific Advisory Committee
- 2. Medical Advisory Committee

The determination is made based on scientific merit and relevance to stated purposes of the Association. Awards are authorized by the Board of Directors for a period of one to three years. The Association records the initial year's liability and related expense for these grants after they have been recommended for approval by the Association's Scientific or Medical Advisory Committees and approved by the Board of Directors. Funding of the remaining committed future amounts of grants is contingent upon satisfactory scientific and medical review and the availability of funds. Research grant funds are generally transmitted to the appropriate financial officer of the grantee institution.

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 FOR THE FISCAL YEAR ENDED MARCH 31, 2005

	Aggregate Charges	Third Party Reimbursements	Net	
Clinic program	\$7,059,768	\$0	\$7,059,768	
Orthopedic equipment & repairs	7,505,845	(1,535,506)	5,970,339	
Summer camp program	2,611,226	0	2,611,226	
Other	848,746	(10,274)	838,472	
Specific assistance	\$18,025,585	(\$1,545,780)	\$16,479,805	Part II Line 23
Other Patient & Community Services related expenses			62,751,320	
			\$79,231,125	Part IIIb

# Directory of MDA Clinics

(\*MDA/ALS Center Directors) (Effective as of June 2005)

Exhibit L Form 990 Page 1 of 6 (Reference See Exh. H Part III b Page 1)

#### **ALABAMA**

#### **BIRMINGHAM**

The Children's Hospital Director. Charles R Law, M D

University of Alabama Hospital Codirectors Shin J Oh, M.D. Gwendolyn C. Claussen, M D

#### HUNTSVILLE

Huntsville Hospital Codirectors: Tejanand G. Mulpur, M D. Anjaneyulu Alapati, M D

#### **MOBILE**

Rotary Rehabilitation Hospital John G Yager, M.D., Ph.D.

#### **MONTGOMERY**

Baptist Medical Center Joseph Leuschke, M.D Leah O Sanchez, M.D.

#### **ALASKA**

#### **ANCHORAGE**

Alaska Regional Hospital Director: Michel Gevaert, MD

## **ARIZONA**

#### **PHOENIX**

St Joseph's Hospital and Medical Center Codirectors: John Bodensteiner, M.D. Richard Stanley Burns, M D\*

#### **TUCSON**

The Mucio F. Delgado Clinic for Neuromuscular Disorders, University of Arizona Health Sciences Center Director: Lawrence Z. Stern, MD\*

#### **ARKANSAS FORT SMITH**

Cooper Clinic Codirectors: James H. Buie, M D. William A Knubley, M.D.

#### LITTLE ROCK

University of Arkansas for Medical Sciences Ambulatory Care Center Director: Stacy A. Rudnicki, M.D.\*

#### **CALIFORNIA BAKERSFIELD**

Mercy Hospital

#### **DOWNEY**

Rancho Los Amigos National Rehabilitation Center Director. Irene S Gilgoff, M D.

#### **FRESNO**

MD Medical Group Director: Abbas Mehdi, M D

#### LOMA LINDA

Loma Linda University Medical Center Codirectors Stephen Ashwal, M.D. James E Shook, M.D. Laura Dawn Hen Nist, M.D.

#### LOS ANGELES

University of California at Los Angeles Codirectors. Thomas L Anderson, M D Michael C Graves, MD\*

The Hospital of the Good Samaritan/ University of Southern California Neuromuscular Center Codirectors: Valerie Askanas, M.D W. King Engel, M D\*

#### **MADERA**

Valley Children's Hospital Director Amanda N Fernandez

Children's Hospital of Orange County Director:

Samuel R. Rosenfeld, M.D.

University of California, Irvine Medical Center Codirectors: Tahseen Mozaffar, M.D.\* John Weiss, MD\*

#### SACRAMENTO

University of California at Davis Medical Center Director Craig McDonald, M.D.

#### SAN DIEGO

Children's Hospital Director Paul Schultz, M D

#### SAN FRANCISCO

California Pacific Medical Center Deborah F. Gelinas, M D Robert G. Miller, M D\*

University of California at San Francisco Medical Center/UCSF Children's Hospital Director Jonathan B. Strober, M D.

#### SANTA BARBARA

Santa Barbara Cottage Hospital Director David Frecker, M D

#### **STANFORD**

Stanford University Codirectors. Ching H. Wang, M.D., Ph.D. Yuen Tat So, M.D.

#### **COLORADO**

#### DENYER

The Children's Hospital Director: Dennis J Matthews, M D

University of Colorado

Codirectors: Hans E. Neville, M.D.\* Steven P. Ringel, M D.\*

## CONNECTICUT

#### **FARMINGTON**

University of Connecticut Health Center Director Kevin J Felice, DO.

#### **HARTFORD**

Connecticut Children's Medical Center Codirectors<sup>\*</sup> Carol R Leicher, M D. Brian G Smith, M.D

#### **NEW HAVEN**

Yale University Director jonathan M Goldstein, M D\*

# **DELAWARE**

#### WILMINGTON

Alfred I DuPont Hospital for Children Codirectors: Mena Scavina, DO. Laura S Inselman, M.D. William G. Mackenzie, M D.

Christiana Care Health Services Director. Charles Bean, M D

#### DISTRICT OF COLUMBIA WASHINGTON

Children's Hospital National Medical Center Codirectors. Sarah H, Evans, M.D. Diana Escolar, M D

Georgetown University Hospital Michael Sirdofsky, M.D.

#### **FLORIDA**

#### FT. LAUDERDALE

Broward General Medical Center Director. Harish D. Thaker, M.D.

#### FT. MYERS

Lee Memorial Hospital Director: Harris L. Bonnette, M.D.

#### GAINESVILLE

University of Florida Clinic in the UF Health Sciences Center at Shands Hospital Director: Edward Valenstein, M D

#### **JACKSONVILLE**

Mayo Clinic Jacksonville Director: Kevin B. Boylan, M D

Nemours Children's Clinic at Jacksonville Director David N Hammond, M.D.

MIAMI

University of Miami School of Medicine Director

Walter G Bradley, DM, FR C.P.\*

**ORLANDO** 

Orlando Regional Lucerne Hospital Director Michael | Creamer, D.O

Nemours Children's Clinic at Orlando Director Michael Pollack, M D

PANAMA CITY

HealthSouth Lisenby Clinic Director Jack B Shumate, M D

SARASOTA

HealthSouth Outpatient Rehabilitation & Sports Medicine Center Director J. Terry Petrella, M D

ST. PETERSBURG

St. Petersburg Neurology Clinic Director: Allan S Weiss, M D

**TALLAHASSEE** 

Tallahassee Neurological Clinic Codirectors. Ricardo Ayala, M D Winston R. Ortiz, M.D.

**TAMPA** 

Tampa Children's Hospital at St. Joseph's Director Raymond J Fernandez, M D

**WEST PALM BEACH** 

St. Mary's Hospital Director. S. Russell Wilson, M D

GEORGIA ATLANTA

Emory University Center for Rehabilitation Medicine Codirectors. Linton Cooke Hopkins, M D Michael Benatar, M.D., Ph D. Jonathan D Glass, M D\*

Children's Health Care of Atlanta Codirectors. Edward Goldstein, M D Joanne Janas, M D

**AUGUSTA** 

Medical College of Georgia Director. Jerry Ned Pruitt II, M.D

WARM SPRINGS

Roosevelt Institute for Rehabilitation

HAWAIL

KAILUA

Castle Medical Center Codirectors Ronald Yamaoka, M D Kevin G Kimata, M D **IDAHO** 

**BOISE** 

Idaho Elks Rehabilitation Hospital Director Robert H. Friedman, M.D.

ILLINOIS CHICAGO

Northwestern Memorial Hospital Codirectors

Teepu Siddique, M D Robert Sufit, M.D

Rush University Medical Center Codirectors Peter Thomas Heydemann, M D Irwin M Siegel, M.D

University of Chicago Hospitals Codirectors E Chelmicka-Schorr, M D Raymond Roos, M.D.\* Betty C. Soliven, M D

University of Illinois at Chicago Director Julie Rowin, M.D.

EAST MOLINE

Trinity Outpatient Rehabilitation Center Codirectors. Kazi Imran Majeed, M D. Vardges Vandian, D O Miguel A. Sanguino, M D

**EVANSTON** 

Evanston Hospital Director: David Randall, DO

HINSDALE

Hinsdale Hospital Director Thomas D Sullivan, M D

PEORIA

OSF Saint Francis Medical Group Center Codirectors Jai Kumar, M D Greg Blume, M.D. Christopher M. Zallek, M.D.

**SPRINGFIELD** 

Memorial Medical Center Director. Michael R Pranzatelli, M.D.

Saint John Rehabilitation Director Rodger J Elble, M.D., Ph.D.

**URBANA** 

Carle Clinic Association Director. Robert Cranston, M.D.

INDIANA ELKHART

Elkhart Clinic, LLC Director Thomas R.Vidic, M.D.

**EVANSVILLE** 

St. Mary's Medical Center Director Raymond Nicholson Jr., M.D

**FORT WAYNE** 

Lutheran Hospital

Codirectors<sup>1</sup>
Jerry L Mackel, M.D.
C.J Ottinger, M.D.

**INDIANAPOLIS** 

Indiana University Hospital Director<sup>1</sup> Robert Pascuzzi, M D Exhibit L Form 990 Page 2 of 6

(Reference

See Exh. H

Part III b

Page 1)

Methodist Hospital of Indiana Director. James Pappas, M D

<u>IOWA</u>

**DES MOINES** 

Younker Memorial Rehabilitation Center Director Calvin Jay Hansen, M D

IOWA CITY

University of Iowa Hospitals and Clinics Director Katherine Mathews, M.D.

KANSAS CITY

University of Kansas Medical Center

Codirectors: John B Redford, M D. Arthur Dick, M D\*

WICHITA

Via Christi Medical Center — St. Francis Campus Director Dilawer H. Abbas, M.D.

**KENTUCKY** 

LEXINGTON

University of Kentucky Medical Center Director

Arman Sabet, M.D

LOUISVILLE
Baptist Hospital East
Director:
Gregory L. Pittman, M.D.

**LOUISIANA** 

ALEXANDRIA

Rapides Regional Medical Center Director: Charles Ugokwe, M.D., MPHTM

**BATON ROUGE** 

The NeuroMedical Center Director. Oscar Leslie Rogers III, M D , Ph D

The Baton Rouge Clinic, AMC Director.
Barbara Jean Golden, M.D.

LAFAYETTE

Our Lady of Lourdes Hospital

MONROE

St. Francis Medical Center Codirectors: Aristoteles Pena-Miches, M.D. Arun Kalra, M.D.

**NEW ORLEANS** 

Louisiana State University Medical Center Director -Amparo Gutierrez, M.D.

Children's Hospital Codirectors.

Ann Henderson Tilton, M.D. loaguin Wong, M.D. Maria Weimer, M.D.

**SHREVEPORT** 

Louisiana State University Health Science Center Director

Robert N. Schwendimann, M.D.

MAINE **BANGOR** 

Eastern Maine Medical Center Codirectors R Stephen S. Amato, M.D., Ph D Peter Keebier, M.D.

**PORTLAND** 

Maine Medical Center Director Stephen D Rioux, M D.

MARYLAND

**BALTIMORE** Johns Hopkins University

Codirectors. Daniel B Drachman, M D Jeffrey D Rothstein, M D, Ph D\* Thomas O Crawford M.D Kathryn Wagner, Ph.D.

Maryland General Hospital Director Neil C. Porter, M.D.

**MASSACHUSETTS BOSTON** 

Brigham and Women's Hospital Director: Anthony A. Amato, M.D.

Children's Hospital Corporation Codirectors: Fred Shapiro, M.D. Basil Darras, M.D.

Massachusetts General Hospital Director Robert H Brown, M D, Ph.D\*

New England Medical Center Hospital Director Harry C Webster, M D

**BURLINGTON** 

Lahey Clinic Foundation Codirectors. H Royden Jones, M D. James A. Russell, D.O.

**SPRINGFIELD** 

Baystate Medical Center Director George Baquis, M D.

WORCESTER

University of Massachusetts Medical Center David Chad, M.D.\*

**MICHIGAN** 

**DETROIT** 

Children's Hospital of Michigan Codirectors: Michael A. Nigro, DO. A Edward Dabrowski, M D Gyula Acsadı, M.D., Ph.D.

Wayne State University Physician Group Adult MDA Clinic at Harper University Hospital Codirectors Michael Shy, M D

Richard A Lewis, M.D. **EAST LANSING** 

Michigan State University Clinical Center Director: David Simpson, DO

**FARMINGTON HILLS** Michigan Institute for Neurological Disorders Codirectors Michael A. Nigro, DO Louis Rentz, D.O David A. Simpson, D.O.

**FLINT** 

McLaren Regional Medical Center Codirectors Ronald Hunt, M D David A Green, M D

**GRAND RAPIDS** 

Mary Free Bed Hospital Director John F Butzer, M.D.

KALAMAZOO

Kalamazoo Center for Medical Studies at Michigan State University Codirectors: Daniel Fain, M D Michelle Crooks, MD

**MARQUETTE** 

Marquette General Hospital Director. Frederick Maynard Ir, M.D.

MIDLAND

MidMichigan Medical Center Director Kamal Sadjadpour, M D

**MINNESOTA** 

**DULUTH** 

The Duluth Clinic Director Wolcott S Holt, M D.

**MINNEAPOLIS** 

Fairview University Medical Center Director John West Day, M.D., Ph.D.

**ROCHESTER** 

Mayo Clinic Director. Eric J Sorenson, M D

**MISSISSIPPI** 

JACKSON

University of Mississippi Medical Center S H. Subramony, M.D

**OCEAN SPRINGS** 

Gulf Coast Neurology Center Codirectors: Lennon E. Bowen IV. M D. William Evans, M.D. Michael Winkelmann, M.D.

**MISSOURI** 

CAPE GIRARDEAU

Southeast Outpatient Rehabilitation Director Paul I Guidos, M D

**COLUMBIA** 

University Hospital/ Rusk Rehabilitation Center Director Upinder K Dhand, M.D.

JOPLIN

St. John's Regional Medical Center Director. Wagar Waheed, M.D.

**SPRINGFIELD** 

St. John's Regional Health Center Codirectors: Michael Luzecky, M D Rodney Quinn, M D. George F. Wong III, M D Steven M Otto, M.D.

ST. LOUIS

Washington University School of Medicine Director. Alan Pestronk, M D\*

**MONTANA** 

BILLINGS

Deaconess Billings Clinic Codirectors. Mary Gaddy, M.D. Bill S. Rosen, M.D.

**GREAT FALLS** 

Benefis Therapy Center Director William E Henning, DO

MISSOULA

Community Medical Center Director William E Henning, DO.

**NEBRASKA** 

**OMAHA** 

University of Nebraska Medical Center Codirectors. Gary Pattee, M D. Wayne Stuberg, Ph D, PT

**NEVADA** 

LAS VEGAS

UMC Enterprise Quick Care Codirectors: Donald William Johns, M.D. David L. Ginsburg, M.D.

**RENO** 

Washoe Medical Center — South Meadows Director Timothy Louie, M.D.

**NEW HAMPSHIRE** LEBANON

Mary Hitchcock Memorial Hospital Codirectors: Nancy Bagley, M.D. Brian D Kossak, M.D.

**NEW JERSEY EDISON** 

John F Kennedy Medical Center Director: Thomas E. Strax, M.D.

Exhibit L Form 990 Page 3 of 6 (Reference See Exh. H Part III b Page 1)

**ENGLEWOOD** 

Englewood Hospital Codirectors Stanley J Myers, M D Joseph H. Willner, M D. Harvey R. Gross, M D.

**NEWARK** 

UMDNJ — University Hospital Codirectors: Jennifer Michaels, M D John Bach, M D

**STRATFORD** 

Kennedy Memorial Hospital Director: Donald A. Barone, D.O

**TINTON FALLS** 

MDA Clinic and Neuromuscular Center at HealthSouth Rehabilitation Hospital of Tinton Falls Codirectors: Christos P. Anayiotos, M.D. Judith F Topilow, M.D.

**TRENTON** 

St. Francis Medical Center Director Albert Tahmoush, M D

**NEW MEXICO** 

**ALBUQUERQUE** 

University of New Mexico Health Science Center Director: John E Chapin, M D\*

University of New Mexico Carrie Tingley Hospital Director: Leslie Morrison, M.D.

NEW YORK

ALBANY

Albany Medical Center Hospital Director Neil Lava, M.D

**AMHERST** 

Dent Neurologic Institute Director Tomas Holmlund, M D

**BRONX** 

Montefiore Medical Center Director, Alfred J Spiro, M.D

**BROOKLYN** 

Long Island College Hospital Director Gary Sclar, M.D., Ph D

**BUFFALO** 

Erie County Medical Center Director Richard B T Cowan, M D

**EAST MEADOW** 

Nassau University Medical Center Codirectors: Imran Wahedna, M D. Satish Kadakia, M D

**NEW YORK** 

Hospital for Joint Diseases and Medical Center Codirectors:

Alfred D. Grant, M D Mary Lynn Chu, M.D

Institute of Rehabilitation Medicine, New York University Medical Center Codirectors Jeffrey M. Cohen, M.D Mary Lynn Chu, M.D

Mount Sinai Hospital and Medical Center Codirectors. Mark Sivak, M D C. Warren Olanow, M.D., F.R.C.P.\* Dale J. Lange, M D \*

Columbia University Medical Center Codirectors. Hiroshi Mitsumoto, M D\* Paul H. Gordon, M.D.\* Michio Hirano, M D. Darryl DeVivo, M D Petra Kaufmann, M D

**PORT JEFFERSON** 

St. Charles Hospital and Rehabilitation Center Director Scott McWilliams, M.D.

**ROCHESTER** 

University of Rochester Medical Center/ Strong Memorial Hospital Codirectors: Charles A Thornton, M.D\* Rabi Tawil, M.D

**SYRACUSE** 

SUNY Upstate Medical University Codirectors: Carl J Crosley, M.D. Jeremy M Shefner, M.D., Ph D.\*

UTICA

St Luke's Memorial Hospital Center Director Carl J. Crosley, M D

WATERTOWN

Mercy of Northern New York Director: Carl J Crosley, M.D.

**WEST HAVERSTRAW** 

Helen Hayes Hospital Director Inocencia Carrano, MD

WHITE PLAINS

White Plains Hospital and Medical Center Director. Stanley B Holstein, M D

NORTH CAROLINA ASHEVILLE

Mission Hospital OccuMed Codirectors

Codirectors Duff A Rardin, M.D. Michael H.Young, M.D.

**CHAPEL HILL** 

University of North Carolina Hospitals Codirectors. Colin D Hall, M D James F Howard Jr., M D.

**CHARLOTTE** 

Carolinas Medical Center Director: Jeffrey Rosenfeld, Ph D , M.D.\* **DURHAM** 

Duke University Medical Center Codirectors Donald B. Sanders, M.D. E Wayne Massey, M.D. Richard S. Bedlack Jr., M.D.\* Exhibit L Form 990

Page 4 of 6

(Reference

See Exh. H

Part III b

Page 1)

WILMINGTON

Wilmington Health Associates Medical Clinic, PLLC Director S Susan Torres, M D

WINSTON-SALEM

Wake Forest University School of Medicine Director lames B Caress, M.D

**NORTH DAKOTA** 

**FARGO** 

MeritCare Hospital Codirectors. Richard Craig Bailly, M.D. Karen Reinke Garnaas, M.D. Samira H. El-Zind, M.D.

OHIO

CINCINNATI

University of Cincinnati Medical Center Director: John Quinlan, M D

Children's Hospital Medical Center Director. Brenda Wong, M.D., M.R.C.P

**CLEVELAND** 

MetroHealth Medical Center Codirectors Irwin B Jacobs, M D. Marc David Winkelman, M D

**COLUMBUS** 

Ohio State University Hospital Codirectors. Jerry Mendell, M D John T. Kissel, M D\* Steven Nash, M D.\*

Children's Hospital Outpatient Care Center Codirectors: Jerry Mendell, M.D. John T. Kissel, M.D.

**TOLEDO** 

Center for Health Services Director: James A. Auberle, M.D

YOUNGSTOWN

Dean Martin Neuromuscular Clinic/ St. Elizabeth Medical Center Codirectors Donald J. Tamulonis Jr., M D John R. Becker, M.D.

OKLAHOMA CIT

OKLAHOMA CITY
Integris Southwest Medical Center
Codirectors
Brent Beson, M D.
Julie Parke, M D.

**TULSA** 

Children's Medical Center Director: G. Steve Miller, M.D

#### **OREGON**

**EUGENE** 

Sacred Heart Hospital Director: Steven Goins, M D

**MEDFORD** 

Providence Medford Medical Center Codirectors. Larry Maukonen, M D Cornelia Byers, M D

**PORTLAND** 

Oregon Health Sciences University Codirectors Barry S. Russman, M.D. Jau-Shin Lou, M.D., Ph.D.

Shriners Hospital for Children Codirectors<sup>1</sup> Barry S Russman, M D Michael D Sussman, M D

## **PENNSYLVANIA**

ALLENTOWN

Good Shepherd Rehabilitation Hospital Director Terry D. Heiman-Patterson, M.D.

DANVILLE

Geisinger Medical Center Director<sup>1</sup> Scott Mitchell Friedenberg, M.D.

**DUBOIS** 

DuBois Regional Medical Center Director Ruediger Kratz, M D

ERIE

Northshore Clinical Associates Director Jeffrey J. Esper, D.O.

**HERSHEY** 

Hershey Medical Center Director Zachary Simmons, M D

**PHILADELPHIA** 

Children's Hospital of Philadelphia Codirectors Richard S Finkel, M D Gihan Tennekoon, M D

Hospital of the University of Pennsylvania Director:
Shawn j Bird, M D.

Drexel University College of Medicine Codirectors Terry Heiman-Patterson, M D\* Anahita Deboo, M D

**PITTSBURGH** 

Children's Hospital of Pittsburgh Director: Henry B Wessel, M.D.

University of Pittsburgh Medical Center Falk Clinic Director<sup>1</sup> David Lacomis, M.D.\*

**SAYRE** 

Guthrie Clinic Director. Paul Buckthal, M.D. **WILKES-BARRE** 

Geisinger Wyoming Valley Medical Center Director. Scott Mitchell Friedenberg, M D

**WILLIAMSPORT** 

Williamsport Hospital Director: Young W. Park, M D.

PUERTO RICO

HATO REY

Hospital Auxilio Mutuo Director: Edward Ramos, M D

**MAYAGUEZ** 

Hospital Universitario Ramon Emeterio Betances Director. Alfredo Perez Canabal, M.D

**PONCE** 

Ponce School of Medicine Director. Carlos Otero, M D

SAN JUAN

University of Puerto Rico Medical Sciences School of Medicine Director: Jose R. Carlo, M.D.

**RHODE ISLAND** 

**PROVIDENCE** 

Rhode Island Hospital Director James Gilchrist, M.D

**SOUTH CAROLINA** 

CHARLESTON

Medical University of South Carolina Director: Timothy D Carter, M D.

**COLUMBIA** 

Palmetto Richland Memorial Hospital Director. Miroslav Cuturic, M D

**SPARTANBURG** 

Spartanburg Neurological Services Codirectors Robert A. Ringel, M D Bogdan P Gheorghiu, M D

**SOUTH DAKOTA** 

RAPID CITY

Black Hills Rehabilitation Hospital Codirectors: K Alan Kelts, M.D Matthew E. Simmons, M D

SIOUX FALLS

Neurology Associates Director. K Gene Koob, M.D.

TENNESSEE CHATTANOOGA

Chattanooga Neurology Associates Director. Hytham A. Kadrie, M.D., F.R.C.P.

**JOHNSON CITY** 

Northside Hospital Director Stephen L.Wayne, M.D. KNOXVILLE

St. Mary's East Towne Codirectors Randall G Trudell, M.D Kendrick K Henderson, M.D. Exhibit L Form 990

Page 5 of 6

(Reference

See Exh. H

Part III b

Page 1)

**MEMPHIS** 

Baptist Memorial Hospital Director. Tulio Bertorini, M.D.

**NASHVILLE** 

Vanderbilt University Medical Center Codirectors. Gerald M. Fenichel, M.D.\* Jane E. Howard, M.D.\*

**TEXAS** 

**AMARILLO** 

Baptist St. Anthony's Health System Codirectors: Michael G. Ryan, M.D. Rush A. Snyder Jr., M.D.

**ARLINGTON** 

Neurology Associates of Arlington Director Robert E McMichael, M D

BEAUMONT

HealthSouth Rehabilitation Center Director: Itzel S. Solis, M D

**CORPUS CHRISTI** 

Spohn Hospital Director David A McFarling, M.D.

DALLAS

University of Texas Health/Southwestern Medical Center Codirectors. Sharon Nations, M.D. Jeffrey L. Elliott, M.D.\* Gil I Wolfe, M.D. Susan lannaconne, M.D.

Neurological Clinic of Texas Director Susan E. Hotz, M D

Texas Neurology, P.A. Director. Daragh Heitzman, M.D.

DENISON

Texoma Neurology Associates Director<sup>\*</sup> Easwar M Sundaram Jr., M D

**EL PASO** 

Border Children's Health Center Director Johanan Levine, M D

FT. WORTH

Cook Children's Medical Center Director Warren A. Marks, M.D

HARLINGEN

Valley Baptist Medical Center Director. Cynthia Anna Garcia, M.D

HOUSTON

Texas Children's Hospital Codirectors.

Timothy Lotze, M.D. Robert Cruse, D.O.

Texas Institute for Rehabilitation and Research Director: Itzel Solis, M.D.

The Vicki Appel MDA Neuromuscular Clinic The Methodist Hospital Codirectors. Stanley H.Appel, M.D.\* Ericka P Simpson, M.D

#### LAREDO

Doctors Hospital of Laredo Codirectors: David A. McFarling, M.D Ellen I Leonard, M.D.

#### LUBBOCK

Covenant Health System Codirectors: Bachar Al-Alami, M.D., P.A. Roger Wolcott, M.D.

#### MIDLAND

Midland Memorial Hospital Director John W Foster Jr., M.D.

#### **ROUND ROCK**

Round Rock Medical Center Director Adam D. Horvit, M.D.

#### SAN ANGELO

Shannon Medical Center Director Christopher W Vanderzant, D.O.

#### **SAN ANTONIO**

University of Texas Health Science Center Director: Carlayne Jackson, M.D.\*

#### **TYLER**

University of Texas Health Center at Tyler Codirectors: Angelita D Tangco, M.D Mark C. Race, M.D.

#### WACO

Providence Health Center Director: George Mark Schwartze, M.D

## WICHITA FALLS

Clinics of North Texas Director Stephen Farmer, D.O

#### **UTAH**

SALT LAKE CITY

University of Utah Medical Center Director Mark B. Bromberg, M.D., Ph.D.\*

## **VERMONT**

### BURLINGTON

Fletcher Allen Health Care Center Director<sup>1</sup> Rup Tandan, M D.

#### **VIRGINIA**

## CHARLOTTESVILLE

Kluge Children's Rehabilitation Center Director Christine M. Houlihan, M.D.

University of Virginia Hospital Codirectors: Lawrence H Phillips II, M D. Vern Charles Juel, M D. Ted M. Burns, M.D.

#### **NORFOLK**

Sentara-Norfolk General Hospital Director: L. Matthew Frank, M D

#### RICHMOND

Children's Hospital Director. Eugenio A. Monasterio, M.D.

Medical College of Virginia Codirectors<sup>1</sup> Hernan T Gatuslao Jr., M D Zakia D Bell, M D.

#### ROANOKE

Roanoke Neurological Center Director: Bashir K. Ahmad, M D

## WASHINGTON

#### **OLYMPIA**

Providence/St. Peter's Hospital Director Greg Carter, M.D.

#### **PASCO**

Physicians Health Center Director Donald G Dicken, M.D., PC

#### **SEATTLE**

Children's Hospital Medical Center Director. Kenneth Jaffe, M.D.

University of Washington Medical Center Codirectors George H Kraft, M D Thomas Bird, M.D. Gregory Carter, M.D.\* Michael Weiss, M.D.\*

#### **SPOKANE**

St. Luke's Rehabilitation Institute
Director
Vivian M Moise, M.D.

## **WEST VIRGINIA**

## CHARLESTON

Charleston Area Medical Center Codirectors' Kenneth C Wright, M D Sasidharan Tarayath, M.D.

#### **MORGANTOWN**

West Virginia University Hospital Codirectors. Margaret E Jaynes, M.D Laurie Gutmann, M.D.

#### WHEELING

Ohio Valley Medical Center Codirectors Srini Govindan, M D Henry L. Kettler, M.D.

## WISCONSIN

#### **GREEN BAY**

St. Vincent Hospital Director. Terence S. Edgar, M.D.

#### MADISON

University of Wisconsin Hospitals and Clinics Codirectors: Benjamin R. Brooks, M.D.\* Barend P. Lotz, M.D. Andrew J Waclawik, M.D.

#### MARSHFIELD

Marshfield Clinic Director: Rodney Sorensen, D.O.

#### MILWAUKEE

Children's Hospital of Wisconsin Medical College of Wisconsin Director Richard D Jacobson, M.D., Ph.D.

Froedtert Memorial Lutheran/Medical College of Wisconsin Codirectors. Wendy L. Peltier, M.D Alexandru C. Barboi, M.D Exhibit L Form 990 Page 6 of 6 (Reference See Exh. H Part III b Page 1)

## MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 RELATED PARTY TRANSACTION FOR THE FISCAL YEAR ENDED MARCH 31, 2005

Stanley H. Appel, M.D. at Baylor College of Medicine serves as a member of the Association's Board of Directors. For the year ended March 31, 2005, Dr. Appel was awarded research grants in the amount of \$110,000 for ALS research. He also was a recipient of an earmark gift in the amount of \$22,973 for ALS research. By policy, Mr. Appel excuses himself for discussions and voting on consideration of his grant.

# MUSCULAR DYSTROPHY ASSOCIATION, INC. #13-1665552 OTHER CHANGES IN NET ASSETS OR FUND BALANCES FOR THE FISCAL YEAR ENDED MARCH 31, 2005

Minimum Pension Liability Net Unrealized Losses on Investments	\$ 9,032,962 3,507,631
	\$ 12,540,593

# Form **8868**

(Rev December 2004)

Department of the Treasury Internal Revenue Service

Application for Extension of Time To File an Exempt Organization Return

► File a separate application for each return

OMB No 1545-1709

<ul><li>If you are</li></ul>	filing for an Automatic 3-Month Extension, complete only Part I and check this box	< ▶ ☑	
	filing for an Additional (not automatic) 3-Month Extension, complete only Part II (c		
	polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted an automatic 3-month extension on a polete Part II unless you have already been granted and a polete II unless you have a polete I		
Part I	Automatic 3-Month Extension of Time—Only submit original (no copies need	eaea)	
Form 990-1	corporations requesting an automatic 6-month extension—check this box and comp	lete Part I only ▶ □	
	porations (including Form 990-C filers) must use Form 7004 to request an extension of s, REMICs, and trusts must use Form 8736 to request an extension of time to file Form		
returns note (not automa	Filing (e-file). Form 8868 can be filed electronically if you want a 3-month automatic exided below (6 months for corporate Form 990-T filers). However, you cannot file it electronitic) 3-month extension, instead you must submit the fully completed signed page 2 (line electronic filing of this form, visit www.irs.gov/efile.	nically if you want the additional	
Type or	Name of Exempt Organization	Employer identification number	
print	Muscular Dystrophy Association, Inc.	13 : 1665552	
File by the due date for filing your	due date for 2200 Foot Supriso Drive		
return See instructions	City, town or post office, state, and ZIP code For a foreign address, see instructions.  Tucson, Arizona 85718-3299		
Check type	of return to be filed (file a separate application for each return):		
Form 99		☐ Form 4720	
☐ Form 99	0-BL	☐ Form 5227	
☐ Form 99	0-EZ	☐ Form 6069	
☐ Form 99	0-PF	☐ Form 8870	
	s are in the care of ▶ Daniel Bereck  No. ▶ ( 520 ) 529-5200		
	inization does <b>not</b> have an office or place of business in the United States, check this	box ▶ □	
• If this is f is for the w	or a <b>Group Return</b> , enter the organization's four digit Group Exemption Number (GEN hole group, check this box ▶ ☐. If it is for part of the group, check this box ▶ ☐ EINs of all members the extension will cover.	N) If this	
to file t ► □	st an automatic 3-month (6-months for a <b>Form 990-T corporation</b> ) extension of time un- he exempt organization return for the organization named above. The extension is for the calendar year 20 or tax year beginning		
2 If this	ax year is for less than 12 months, check reason:   Initial return   Final return	Change in accounting period	
	application is for Form 990-BL, 990-PF, 990-T, 4720, or 6069, enter the tentative ta undable credits. See instructions	x, less any	
	application is for Form 990-PF or 990-T, enter any refundable credits and estimated tax Include any prior year overpayment allowed as a credit	c payments <u>\$</u>	
with F instruc		stem). See <b>\$</b>	
	ou are going to make an electronic fund withdrawal with this Form 8868, see Form 845 instructions.	53-EO and Form 8879-EO	