### Form 990

# FURM 8868 ATTACHED 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

2004

Department of the Treasury Internal Revenue Service

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

Open to Public Inspection

Α	For	the 2004 calend	lar year, c	or tax year beginning	, 2004	, and	ending			,	
В	Chec	k if applicable:					9	D Emp	oloyer Id	entification Number	
		Address change	Please use IRS label	Ars Therapy Develo	pment Foundation	on,	Inc.	04	1-346	52719	
		Vame change	or print or type.	215 First Street	•			E Tele	phone n	umber	
		nitial return	See specific	Cambridge, MA 0214	2			61	7-44	11-7200	
		Final return	instruc- tions.					F Acc	ounting hod:	Cash X	Accrual
		Amended return				OT	1		1	specify)	7
		Application pending	Section	on 501(c)(3) organizations and	4947(a)(1) nonexempt	UI	H and I are not applie	cable to s			
			charit	able trusts must attach a com	pleted Schedule A		H (a) Is this a grou	p return f	or affiliat	tes? Yes	X No
0	Mak	site: ► N/A	(FOIII	990 or 990-EZ).			H (b) If 'Yes,' enter	number of	affiliates	▶	
G							H (c) Are all affilia	tes includ	ed?	Yes	No
J	Org	anization type ck only one)		☑		1	(If 'No,' attac	h a list. S	ee instru	uctions.)	
-	-					527	H (d) Is this a sepa	rate retur	n filed by	y an	
N				nization's gross receipts are no eed not file a return with the IR		_	organization				X No
	rece	eived a Form 99	0 Package	e in the mail, it should file a re	turn without financial da	ata.	I Group Exe	emption	Numb		
	Son	ne states require	e a compl	ete return.			M Check ►	if the	e organiz	zation is not require	ed
L	Gros	s receipts: Add	lines 6b,	8b, 9b, and 10b to line 12 ▶ 5	5,253,825.		to attach Sch	edule B (	Form 99	0, 990-EZ, or 990-P	F).
2	rtil	Revenue	, Expen	ses, and Changes in Ne	t Assets or Fund I	Balar	nces (See Instri	uctions)			-
	1	Contributions,	gifts, gra	nts, and similar amounts recei	ved:					147	
	a	a Direct public s	support			1a	1,662,	941.			
	ı	Indirect public	support.			1b	156,	236.			
		Government c	ontributio	ns (grants)		1 c					
	(	Total (add lines la through 1c) (car	sh \$	1,641,296. noncash	\$ 177,881	)			1d	1,819,	177.
	2	d Total (add lines 1a through 1c) (cash \$ 1,641,296. noncash \$ 177,881.)							2		
	3			assessments					3		
	4			temporary cash investments.					4		
	5	Dividends and	interest f	rom securities					5		
	E	Less: rental ex	xpenses.			6b					
	C			ss) (subtract line 6b from line					6c		
R	7	Other investme	ent incom	e (describe		Se	e Statemen		7	2,	320.
REVENUE	8a	Gross amount	from sale	es of assets other	(A) Securities		(B) Other				
Ň						8a					
Ē	b	Less: cost or c	other basis	s and sales expenses	1,121,645.	8b					
				e)Statement2		8c					
	10			oine line 8c, columns (A) and (I	**			:	8d	-5,	219.
	9	Special events	and activ	vities (attach schedule). If any	amount is from gaming	, chec	k here ►[	_			
	а			uding \$			0 015	000			
						9a	2,315,				
				ther than fundraising expenses		9 b				1 601	605
				m special events (subtract line				nt3	9c	1,631,	685.
				, less returns and allowances.		10a					
						10b			10		
				es of inventory (attach schedule) (subtr				-	10 c		
	11 12			rt VII, line 103)					11	2 447	0.63
$\neg$	13			1d, 2, 3, 4, 5, 6c, 7, 8d, 9c, 10 line 44, column (B))					12	3,447,	
E	14			al (from line 44, column (C))				-		3,033,	
P	15		_					-	14	301,	
EXPERSES	16			4, column (D))					15	461,	421.
E	17			es 16 and 44, column (A))					17	3 70F	021
	18			e year (subtract line 17 from lin					18	3,795,	
ASSET	19			T				-		<del>-347,</del>	
ES	20			ices at beginning of year (from sets or fund balances (attach e					20	1,041,	013.
TS	21			sets or fund balances (attach e ices at end of year (combine lii				_	21	604	012
DA	41	ivet assets of it	unu balan	ices at end of year (combine III	les 18, 19, and 20)				21	694,	UIZ.

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.

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		
22 Grants and allocations (att sch) See Stm 4	1						
(cash \$ <u>334,324.</u>							
non-cash \$)	22	334,324.	334,324.				
23 Specific assistance to individuals (att sch)	23						
<ul><li>Benefits paid to or for members (att sch)</li><li>Compensation of officers, directors, etc</li></ul>	25	110,577.	80,058.	10,947.	19,572.		
26 Other salaries and wages	26	894,269.	647,838.	88,369.	158,062.		
27 Pension plan contributions	27				200,002.		
28 Other employee benefits	28	97,260.	70,812.	9,262.	17,186.		
29 Payroll taxes	29	103,235.	74,308.	10,665.	18,262.		
30 Professional fundraising fees	30						
31 Accounting fees	31	17,467.		17,467.			
<b>32</b> Legal fees	32	8,020.	8,020.				
<b>33</b> Supplies	33	42,791.	27,506.	4,839.	10,446.		
34 Telephone	34	24,224.	19,082.	2,011.	3,131.		
35 Postage and shipping	35	33,148.	17,588.	3,268.	12,292.		
<b>36</b> Occupancy	36	354,835.	324,087.	10,674.	20,074.		
37 Equipment rental and maintenance	37	5,527.	5,077.	282.	168.		
38 Printing and publications	38						
<b>39</b> Travel	39	106,261.	48,568.	6,287.	51,406.		
40 Conferences, conventions, and meetings	40	30,258.	27,406.	988.	1,864.		
41 Interest	41						
42 Depreciation, depletion, etc (attach schedule)	42	43,560.	31,411.	4,445.	7,704.		
43 Other expenses not covered above (itemize):		1 500 000	1 01 5 000	404 540			
a See Statement 5	43 a	1,590,068.	1,317,298.	131,510.	141,260.		
<b>b</b>	43b 43c			<del></del>			
c	43 c						
de	43 u		-		· · · · · · · · · · · · · · · · · · ·		
Total functional expenses (add lines 22 - 43). Organizations completing columns (B) - (D), carry these totals to lines 13 - 15		2 705 024	2 022 202	201 014	461 407		
	44	3,795,824.	3,033,383.	301,014.	461,427.		
oint Costs. Check . Lif you are following					<b>.</b> □		
are any joint costs from a combined educational f 'Yes,' enter (i) the aggregate amount of these				ogram services? nount allocated to Progr			
\$; (iii) the amount all	•	W		; and (iv) the			
Fundraising \$	ocutca	to management and gorr		, and (10) an	s umount unocated		
Part III Statement of Program Serv	rice A	ccomplishments					
What is the organization's primary exempt purp	ose? ►	See Statemer	nt 6		Program Service Expenses		
Il organizations must describe their exempt pu	rpose a	achievements in a clear a	and concise manner, Sta	te the number of	(Required for 501(c)(3) and (4) organizations and 4947(a)(1) trusts; but optional for others.)		
of organizations must describe their exempt pu lients served, publications issued, etc. Discuss ations and 4947(a)(1) nonexempt charitable tr	usts m	ust also enter the amoun	surable. (Section 501(c)( It of grants & allocations	to others.)	4947(a)(1) trusts; but optional for others.)		
a See Statement 7							
		(Grants and	allocations \$	334,324.)	3,033,383.		
<b>b</b>	<u>_</u>						
	· ·	<u></u>					
		(Grants and	allocations \$	)	*.		
c							
(Grants and allocations \$ )							
d							
,			allocations \$				
e Other program services.  f Total of Program Service Expenses (sho		<del></del>	allocations \$	<u> </u>	3.033.383.		

### Part IV Balance Sheets (See Instructions)

Not	e:	Who	ere required, attached schedules and amounts within umn should be for end-of-year amounts only.	the de	scription	(A) Beginning of year		(B) End of year
	4	45	Cash non-interest-bearing			375,845.	45	806,467.
			Savings and temporary cash investments		Ţ		46	
			, , , , , , , , , , , , , , , , , , , ,		Ī			
	4	47 a	Accounts receivable	47 a				
			Less; allowance for doubtful accounts	47 b			47 c	
	4	48 a	Pledges receivable		20,000.			
			Less: allowance for doubtful accounts			1,100,000.	48 c	20,000.
	4	49	Grants receivable				49	
AS	£	50	Receivables from officers, directors, trustees, and ke employees (attach schedule)	;у 			50	
ASSETS	Ę		Other notes & loans receivable (attach sch)		ļ			
T			Less: allowance for doubtful accounts			•	51 c	
ĺ	Ę		Inventories for sale or use				52	
	ŗ	53	Prepaid expenses and deferred charges		, ,	19,235.	53	14,708.
			Investments - securities (attach schedule) See .				54	59,503.
			Investments - land, buildings, & equipment: basis.	55 a				
		þ	Less: accumulated depreciation (attach schedule)	55 b			55 c	
	Ę		Investments — other (attach schedule)				56	
İ		5 <b>7</b> a	Land, buildings, and equipment: basis		238,692.			
		b	Less: accumulated depreciation (attach schedule)Statement.9	57 b	187,743.	75,126.	57 c	50,949.
	5	88	Other assets (describe - See Statement 1	)	).	99,651.	58	90,943.
	£	59	Total assets (add lines 45 through 58) (must equal lines	ne 74).		1,669,857.	59	1,042,570.
	6	50	Accounts payable and accrued expenses			558,566.	60	253,387.
Ļ	6	51	Grants payable				61	
LIABILITIES	6	52	Deferred revenue				62	
1	6	3	Loans from officers, directors, trustees, and key employees (attach	schedule	)		63	
1	6	34 a	Tax-exempt bond liabilities (attach schedule)		. , , , ,		64 a	
į			Mortgages and other notes payable (attach schedule)				64 b	
š			Other liabilities (describe 🛌 See Statement			69,418.	65	95,171.
			Total liabilities (add lines 60 through 65)			627,984.	66	348,558.
N	Org		zations that follow SFAS 117, check here 🕨 🔃 🗓 an	id com	olete lines 67			
N E			through 69 and lines 73 and 74.			4 041 073		604 020
Ą	6		Unrestricted		P	1,041,873.	67	694,012.
<b>₹</b> SONEET-S			Temporarily restricted		The state of the s		68	
š			Permanently restricted	C	Ć.		69	
g '	Org		zations that do not follow SFAS 117, check here	L J a	nd complete lines			
	_		70 through 74.				~~~	
E UND			Capital stock, trust principal, or current funds		70			
B	_		Paid-in or capital surplus, or land, building, and equip		71	······		
Ĺ			Retained earnings, endowment, accumulated income				72	
BALAZCES			Total net assets or fund balances (add lines 67 throu 72; column (A) must equal line 19; column (B) must	equal I	ne 21)	1,041,873.	73	694,012.
	7	4	Total liabilities and net assets/fund balances (add lin	es 66 a	ind 73)	1,669,857.	74	1,042,570.

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.

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Form 990 (2004)

Forr	990 (2004) ALS Therapy Development Foundation, Inc.	04-34627	L9	Page 5
P	nt VI Other Information (See instructions.)			Yes No
	Did the organization engage in any activity not previously reported to the IRS? If 'Yes,'		Ţ	
,,	attach a detailed description of each activity	.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	76	X
77	Were any changes made in the organizing or governing documents but not reported to the IF	ks?	77	X
	If 'Yes,' attach a conformed copy of the changes.		Ì	
78:	Did the organization have unrelated business gross income of \$1,000 or more during the year	r covered by this return?	78 a	X_
1	olf 'Yes,' has it filed a tax return on Form 990-T for this year?		78 b	N/A
79	Was there a liquidation, dissolution, termination, or substantial contraction during the			
,,,	year? If 'Yes,' attach a statement	* * * * * * * * * * * * * * * * * * * *	79	X
80:	Is the organization related (other than by association with a statewide or nationwide organiza	tion) through common		
001	membership, governing bodies, trustees, officers, etc, to any other exempt or nonexempt organization	janization?	80 a	X
I	If 'Yes,' enter the name of the organization $ ightharpoonup N/A$			
	and check whether it is e	xempt or nonexempt.		
81 a	Enter direct and indirect political expenditures. See line 81 instructions	81a 0.		
	Did the organization file Form 1120-POL for this year?		81 b	X
82	Did the organization receive donated services or the use of materials, equipment, or facilities	at no charge or at		
02.	substantially less than fair rental value?		82a	X
,	e if IVac than may indicate the value of these items here. Do not include this amount as			
	off 'Yes,' you may indicate the value of these items here. Do not include this amount as revenue in Part I or as an expense in Part II. (See instructions in Part III.)	82ь N/Л	7	
	Did the organization comply with the public inspection requirements for returns and exemptio		83 a	X
ŀ	Did the organization comply with the disclosure requirements relating to quid pro quo contribu	utions?	83 b	X
84 a	Did the organization solicit any contributions or gifts that were not tax deductible?	· · · · · · · · · · · · · · · · · · ·	84a	X
1	If 'Yes,' did the organization include with every solicitation an express statement that such co	ntributions or nifts were		
•	not tax deductible?		84 b	<del> </del>
85	501(c)(4), (5), or (6) organizations. a Were substantially all dues nondeductible by members?		85 a	
ŧ	Did the organization make only in-house lobbying expenditures of \$2,000 or less?		85 b	N/A
	If 'Yes' was answered to either 85a or 85b, do not complete 85c through 85h below unless th	e organization received a		
	waiver for proxy tax owed for the prior year.	( )	l	
	Dues, assessments, and similar amounts from members	85c N/A	7	
c	Section 162(e) lobbying and political expenditures		<b></b> ⊀	
	Aggregate nondeductible amount of section 6033(e)(1)(A) dues notices		<b>⊣</b>	
f	Taxable amount of lobbying and political expenditures (line 85d less 85e)	85f N/A	4	
ç	Does the organization elect to pay the section 6033(e) tax on the amount on line 85f?		85 g	N/A
ŀ	If section 6033(e)(1)(A) dues notices were sent, does the organization agree to add the amount on line 85f to its reason	able estimate of		
	dues allocable to nondeductible lobbying and political expenditures for the following tax year?		85 h	N/A
86	501(c)(7) organizations. Enter: a Initiation fees and capital contributions included on	1 1		
ŀ	Gross receipts, included on line 12, for public use of club facilities		₹	
87	501(c)(12) organizations. Enter: a Gross income from members or shareholders	87a N/A	4	
ŧ	Gross income from other sources. (Do not net amounts due or paid to other sources	37/7		
	against amounts due or received from them.)		4	
88	At any time during the year, did the organization own a 50% or greater interest in a taxable c or an entity disregarded as separate from the organization under Regulations sections 301.77	orporation or partnership,		
	or an entity disregarded as separate from the organization under Regulations Sections 301.77 If 'Yes,' complete Part IX	01-2 and 301./701-3:	88	X
89 a	501(c)(3) organizations. Enter: Amount of tax imposed on the organization during the year un			
	section 4911 ► 0.; section 4912 ► 0.; section 4912	1955 ► 0.		
E				
	501(c)(3) and 501(c)(4) organizations. Did the organization engage in any section 4958 excess during the year of did it become aware of an excess benefit transaction from a prior year? If	'Yes,' attach a statement	89b	Х
	explaining each transaction		( 03 n	
c	Enter: Amount of tax imposed on the organization managers or disqualified persons during th year under sections 4912, 4955, and 4958	ıe . ▶		0.
	year under sections 4912, 4955, and 4958			0.
000	Enter: Amount of tax on line 89c, above, reimbursed by the organization	. , . , ,		<u> </u>
90 a	List the states with which a copy of this return is filed Massachusetts		90 b	r <del>0</del>
	Number of employees employed in the pay period that includes March 12, 2004 (See instructi		$\overline{}$	
91	The books are in care of F Insource Services, Inc. Telephone nu	Tipler (/ol) 435	±4.7∪	
00	Located at ► 148 Linden Street, Wellesley, MA  Section 4947(a)(1) nonexempt charitable trusts filing Form 990 in lieu of Form 1041 — Check I	ZIF + 4 F UZ48	<u>د</u>	A ► [ ]
92	Section 4947(a)(1) nonexempt charitable trusts filing Form 990 in lieu of Form 1047 — Check I and enter the amount of tax-exempt interest received or accrued during the tax year	nere	13/.	A P
	and enter the amount of tax-exempt interest received or accrued during the tax year			1A\ \ta

	M Analysis of income-Produc					
Note: Ent	er gross amounts unless		Isiness income		ction 512, 513, or 514	(E) Related or exempt
otherwise	indicated.	(A) Business code	<b>(B)</b> Amount	(C) Exclusion code	<b>(D)</b> Amount	function income
	ogram service revenue:		:			
a h						
						***************************************
	edicare/Medicaid payments					
-	es & contracts from government agencies					
	embership dues and assessments					
	erest on savings & temporary cash invmnts   vidends & interest from securities		,,			
	t rental income or (loss) from real estate:					
	bt-financed property					
	t debt-financed property					
	t rental income or (loss) from pers prop					
	her investment income [			3	2,320.	······
	ain or (loss) from sales of assets ner than inventory					-5,219.
<b>101</b> Net	t income or (loss) from special events					1,631,685.
	oss profit or (loss) from sales of inventory					
	her revenue: a					
D						
я́.						·····
<b>104</b> Sul	btotal (add columns (B), (D), and (E))				2,320.	1,626,466.
105 To	ital (add line 104, columns (B), (D), ai	nd (E))			· · · · · · · · · · · · · · · · · · ·	1,628,786.
	e 105 plus line 1d, Part I, should equa				· · · · · · · · · · · · · · · · · · ·	
	Relationship of Activities to	***************************************				
Line No.	Explain how each activity for which of the organization's exempt purpor	income is report	ed in column (E) of	Part VII contribu	ited importantly to the	accomplishment
.,	of the organization's exempt purpo.	ses (other than b	y providing idinas io	- such purposes	). 	
N/A						
			·····			
						***************************************
Part IX	Information Regarding Tax	able Subsidia	aries and Disrec	arded Entition	es (See instructions.)	
*********************	(A)	(B)	(C)		(D)	(E)
Nama	, address, and EIN of corporation,	Percentage of			Total	End-of-year
	rtnership, or disregarded entity	ownership interes	Nature of a	activities	income	assets
N/A			हैं ।			
			8			
			8			
	81 / P P P P		)	I D (4 )	<u> </u>	
******	Information Regarding Tra	~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~~				
	ne organization, during the year, receive any fun	-				<del></del>
	the organization, during the year, pay	•		a personai benei	it contract	. Yes X No
Note:	If 'Yes' to (b), file Form 8870 and Form			echadulas and states	nents and to the hest of my	convedes and helief it is
	Under penalties of perjury, I declare that I hav true, correct, and complete. Declaration of pre	eparer (other than offic	er) is based on all information	ation of which prepare	r has any knowledge.	
Please	<b>▶</b>					
Sign	Signature of officer				Date	
Here	▶					
	Type or print name and title.					
Paid	Preparer's			Date		reparer's SSN or PTIN (See eneral Instruction W)
Pre-	signature Marvey G Gre				employed ► F	00121174
parer's	Firm's name (or Cohen, Green yours if self-	~~~~~~				
Use	lemployed). > IZIZ BOVISTO		·····			010080
Only	address, and Chestnut Hil	I, MA 0246	/-2109		Phone no. ► 617	-227-5300

#### SCHEDULE A (Form 990 or 990-EZ)

## 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.)

2004

OMB No. 1545-0047

Department of the Treasury Internal Revenue Service

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

Name of the organization Employer identification number 04-3462719 ALS Therapy Development Foundation, Inc. Compensation of the Five Highest Paid Employees Other Than Officers, Directors, and Trustees (See instructions, List each one, If there are none, enter 'None.') (a) Name and address of each (b) Title and average (c) Compensation (d) Contributions (e) Expense employee paid more than \$50,000 hours per week devoted to position to employee benefit plans and deferred account and other allowances compensation Dir of Operatns Lawler Carraher-Kang 62,659 1,000 40 0. 15 Lincoln Ave, Manchester, MA 01944 SE Region Dir Lou Kobbs 40 67,948 0 0. 320 Sherrybrook Dr. Myrtle Beach, SC Dir of Pharmaco Gwendolyn Wong 3,956. 85,000 0. 6 Cedarwood Terr, Lexington, MA 40 Dir of Initiaty Tyson Goodridge 0. 66,046. 1,352. 26 Arbor Street, Wenham, MA 01984 40 Sr Mai Gift Off Anya Goodridge 1.336 26 Arbor Street, Wenham, MA 01984 40 56,316 0. Total number of other employees paid over \$50,000 Part II Compensation of the Five Highest Paid Independent Contractors for Professional Services (See 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 Insource Services, Inc. 148 Linden Street Wellesley, MA 02482 Bkkpg/Techn/HR/Oprtn 297,448. <u> Mirage Media \_ \_ \_</u> 1301 Post St, #101 San Francisco, CA 94109 R&D & Clinic Consult 208,000. Capitol Partners, Inc 601 Pennsylvania Ave, Washington, DC 20014 Lobbyist &consultant 31,625. Jeff Cole 51 Hyde St, Newton, MA 02461 Software Consulting 30,725. GCMP, Inc. RN/Patient Services 42,310. 14 Dunlin Square Greensboro, NC 27455 Total number of others receiving over \$50,000 for professional services . . . .

Sche	dul	e A (Form 990 or 990-EZ) 2004 ALS Therapy Development Foundation, Inc. 04-346271	.9	F	2 age 2
Pai	1 11	Statements About Activities (See instructions.)		Yes	No
1	to or	iring the year, has the organization attempted to influence national, state, or local legislation, including any attempt influence public opinion on a legislative matter or referendum? If 'Yes,' enter the total expenses paid incurred in connection with the lobbying activities			
	-	ust equal amounts on line 38, Part VI-A, or line i of Part VI-B.)	1	X	
	Or- org lob	ganizations that made an election under section 501(h) by filing Form 5768 must complete Part VI-A. Other ganizations checking 'Yes' must complete Part VI-B AND attach a statement giving a detailed description of the obying activities.			
	sul tax be	ring the year, has the organization, either directly or indirectly, engaged in any of the following acts with any bstantial contributors, trustees, directors, officers, creators, key employees, or members of their families, or with any cable organization with which any such person is affiliated as an officer, director, trustee, majority owner, or principal neficiary? (If the answer to any question is 'Yes,' attach a detailed statement explaining the transactions.)			
а	Sa	le, exchange, or leasing of property?	2a		<u>X</u>
t	Lei	nding of money or other extension of credit?	2b		X
c	Fu	rnishing of goods, services, or facilities?	2c		X
d	! Pa	yment of compensation (or payment or reimbursement of expenses if more than \$1,000)?	2d		X
e	Tra	ansfer of any part of its income or assets?	2e		X
3a	Do	you make grants for scholarships, fellowships, student loans, etc? (If 'Yes,' attach an			**
ŀ	,	planation of how you determine that recipients qualify to receive payments.)  you have a section 403(b) annuity plan for your employees?	************		<u>X</u>
		l you maintain any separate account for participating donors where donors have the right to provide advice the use or distribution of funds?			X
b	Do	you provide credit counseling, debt management, credit repair, or debt negotiation services?	4b		X
Par	ŧ IV	Reason for Non-Private Foundation Status (See instructions.)			
5 6 7 8 9	orga	A church, convention of churches, or association of churches. Section 170(b)(1)(A)(i).  A school. Section 170(b)(1)(A)(ii). (Also complete Part V.)  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).  A medical research organization operated in conjunction with a hospital. Section 170(b)(1)(A)(iii). Enter the hospital's rand state			
10	L_	An organization operated for the benefit of a college or university owned or operated by a governmental unit. Section (Also complete the <b>Support Schedule</b> in Part IV-A.)	, , ,	1)(A)(	iv).
11 a	X	An organization that normally receives a substantial part of its support from a governmental unit or from the general pushed Section 170(b)(1)(A)(vi). (Also complete the <b>Support Schedule</b> in Part IV-A.)	ublic.		
11 b		A community trust. Section 170(b)(1)(A)(vi). (Also complete the <b>Support Schedule</b> in Part IV-A.)			
12		An organization that normally receives: (1) more than 33-1/3% of its support from contributions, membership fees, and from activities related to its charitable, etc, functions — subject to certain exceptions, and (2) no more than 33-1/3% of from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired organization after June 30, 1975. See section 509(a)(2). (Also complete the Support Schedule in Part IV-A.)	its suo	port i	its
13		An organization that is not controlled by any disqualified persons (other than foundation managers) and supports organ described in: (1) lines 5 through 12 above; or (2) section 501(c)(4), (5), or (6), if they meet the test of section 509(a)(2), section 509(a)(3).)	nizatior . (See	is	
		Provide the following information about the supported organizations. (See instructions.)			
		(a) Name(s) of supported organization(s)	(b) Lin from	e nun abov	
				<del></del> ,	
			····		
14		An organization organized and operated to test for public safety. Section 509(a)(4). (See instructions.)	<del></del>		2004

Schedule A (Form 990 or 990-EZ) 2004 ALS Therapy Development Foundation, I 04-3462719 Part IV-A Support Schedule (Complete only if you checked a box on line 10, 11, or 12.) Use cash method of accounting. Note: You may use the worksheet in the instructions for converting from the accrual to the cash method of accounting. Calendar year (or fiscal year **(e)** Total beginning in)..... Gifts, grants, and contributions received. (Do not include unusual grants. See line 28.). 2,724,705 2,900,961 3,943,096 1,557,621. 11,126,383. 16 Membership fees received 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 . . 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 7,571 19,616 12,545 17,242 56,974. Net income from unrelated business activities not included in line 18. Tax revenues levied for the organization's benefit and either paid to it or expended on its behalf..... 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. Other income. Attach a schedule. Do not include gain or (loss) from sale of capital assets. 2,732,276 2,920,577. 3,955,641. 1,574,863. 11,183,357. Total of lines 15 through 22 1,574,863 2.732.276 2,920,577 3,955,641 11,183,357 Line 23 minus line 17, 15,749 27,323 29,206. 39,556. Enter 1% of line 23. 26 a 223,667 Organizations described on lines 10 or 11: a Enter 2% of amount in column (e), line 24..... b Prepare a list for your records to show the name of and amount contributed by each person (other than a governmental unit or publicly supported organization) whose total gifts for 2000 through 2003 exceeded the amount shown in line 26a. Do not file this list with your 26 b c Total support for section 509(a)(1) test: Enter line 24, column (e)...... 11,183,357 26 c d Add: Amounts from column (e) for lines: 18 56,974. 19 56,974. 26 b 26 d 22 e Public support (line 26c minus line 26d total)...... 26 e 11.126,383. 26 f 99.49 % f Public support percentage (line 26e (numerator) divided by line 26c (denominator)). . . Organizations described on line 12: N/A a For amounts included in lines 15, 16, and 17 that were received from a 'disqualified person,' prepare a list for your records to show the name of, and total amounts received in each year from, each 'disqualified person.' Do not file this list with your return. Enter the sum of such amounts for each year: (2003)(2000)(2001)bFor any amount included in line 17 that was received from each person (other than 'disqualified persons'), prepare a list for your records to

show the name of, and amount received for each year, that was more than the larger of (1) the amount on line 25 for the year or (2) \$5,000. (Include in the list organizations described in lines 5 through 11, as well as individuals.) Do not file this list with your return. After computing the difference between the amount received and the larger amount described in (1) or (2), enter the sum of these differences (the excess amounts) for each year:

(2003) (2002)		(2001) (2000)	<b>.</b>		
c Add: Amounts from column (e) for lines:	15	16			
17	_ 20	21		27 c	
d Add: Line 27a total		and line 27b total		27 d	
e Public support (line 27c total minus line 27d	<b>&gt;</b>	27 e			
f Total support for section 509(a)(2) test: Enter	amou	nt from line 23, column (e) ▶ 27 f			
g Public support percentage (line 27e (numera	▶	27 g	ે ક		
h Investment income percentage (line 18, colu	nn (e)	(numerator) divided by line 27f (denominator))	>	27 h	%

**Unusual Grants:** For an organization described in line 10, 11, or 12 that received any unusual grants during 2000 through 2003, prepare a list for your records to show, for each year, the name of the contributor, the date and amount of the grant, and a brief description of the nature of the grant. **Do not file this list with your return.** Do not include these grants in line 15.

Page 4

Private School Questionnaire (See instructions.) (To be completed ONLY by schools that checked the box on line 6 in Part IV) N/AYes No Does the organization have a racially nondiscriminatory policy toward students by statement in its charter, bylaws, 29 other governing instrument, or in a resolution of its governing body?..... 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, 30 and scholarships?.... 31 If 'Yes,' please describe; if 'No,' please explain. (If you need more space, attach a separate statement.) 32 Does the organization maintain the following: 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 32b nondiscriminatory basis?... c Copies of all catalogues, brochures, announcements, and other written communications to the public dealing 32 c with student admissions, programs, and scholarships?..... d Copies of all material used by the organization or on its behalf to solicit contributions? . . . . . . . 32d If you answered 'No' to any of the above, please explain. (If you need more space, attach a separate statement.) 33 Does the organization discriminate by race in any way with respect to: 33 a a Students' rights or privileges?..... 33 b **b** Admissions policies?..... 33 c c Employment of faculty or administrative staff?..... 33 d d Scholarships or other financial assistance?..... 33 e e Educational policies?.... 33 f g Athletic programs?.... 33 q 33h h Other extracurricular activities?..... 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 Has the organization's right to such aid ever been revoked or suspended?..... If you answered 'Yes' to either 34a or b, please explain using an attached statement. 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.

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Part VI-A Lobbying Expenditures by Electing Public Charities (See instructions.)
(To be completed ONLY by an eligible organization that filed Form 5768)

Che	ck ► a  if the organization belongs to an affiliated group. Check ► b  if you	ı check	ed 'a' and 'limited contr	ol' provisions apply.
	Limits on Lobbying Expenditures		(a) Affiliated group totals	<b>(b)</b> To be completed for ALL electing
	(The term 'expenditures' means amounts paid or incurred.)	т	•	organizations
36	Total lobbying expenditures to influence public opinion (grassroots lobbying)	36		*****
37	Total lobbying expenditures to influence a legislative body (direct lobbying)	37		7,500.
38	Total lobbying expenditures (add lines 36 and 37)	38	0.	7,500.
39	Other exempt purpose expenditures	39		
40	Total exempt purpose expenditures (add lines 38 and 39)	40	0.	7,500.
41	Lobbying nontaxable amount, Enter the amount from the following table —			
	If the amount on line 40 is — The lobbying nontaxable amount is —			
	Not over \$500,000			
	Over \$500,000 but not over \$1,000,000 \$100,000 plus 15% of the excess over \$500,000			
	Over \$1,000,000 but not over \$1,500,000 \$175,000 plus 10% of the excess over \$1,000,000	41		1,500.
	Over \$1,500,000 but not over \$17,000,000 \$225,000 plus 5% of the excess over \$1,500,000			
	Over \$17,000,000			
42	Grassroots nontaxable amount (enter 25% of line 41)	42		375.
43	Subtract line 42 from line 36. Enter -0- if line 42 is more than line 36	43	0.	0.
44	Subtract line 41 from line 38. Enter -0- if line 41 is more than line 38	44	0.	6,000.
	Caution: If there is an amount on either line 43 or line 44, you must file Form 4720.			

4 -Year Averaging Period Under Section 501(h) (Some organizations that made a section 501(h) election do not have to complete all of the five columns below. See the instructions for lines 45 through 50.)

Lobbying Expenditures During 4-Year Averaging Period

	Calendar year (or fiscal year beginning in) ►	<b>(a)</b> 2004	<b>(b)</b> 2003	<b>(c)</b> 2002	(d) 2001		• • • • •		, ,	
45	Lobbying nontaxable amount	1,500.						1,500.		
46	Lobbying ceiling amount (150% of line 45(e))							2,250.		
47	Total lobbying expenditures	7,500.						7,500.		
48	Grassroots non- taxable amount	375.						375.		
49	Grassroots ceiling amount (150% of line 48(e))							563.		
50	Grassroots lobbying expenditures							0.		
Par	Part VI-B Lobbying Activity by Nonelecting Public Charities (For reporting only by organizations that did not complete Part VI-A) (See instructions.)  N/A									
Durir atter	ig the year, did the orgar npt to influence public op	nization attempt to influe inion on a legislative ma	ence national, state or latter or referendum, thr	ocal legislation, includir ough the use of:	ng any	Yes	No	Amount		
ā	Volunteers			,.,						
Ł	Paid staff or manageme	nt (Include compensatio	on in expenses reported	f on lines <b>c</b> through <b>h.</b> ).						
C	Media advertisements									
c	Mailings to members, le	gislators, or the public.								
e	e Publications, or published or broadcast statements									
f	f Grants to other organizations for lobbying purposes									
ç	g Direct contact with legislators, their staffs, government officials, or a legislative body									
ł	h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any other means									
i	i Total lobbying expenditures (add lines c through h.)									
	If 'Yes' to any of the above, also attach a statement giving a detailed description of the lobbying activities.									

# Part VII Information Regarding Transfers To and Transactions and Relationships With Noncharitable Exempt Organizations (See instructions)

51 Did th	e reporting organization of	directly or in	ndirectly engage in any of the follorganizations) or in section 527, r	owing with any other organization describe	d in section	n 501 (d	c)
			to a noncharitable exempt organi	• •		Yes	No
	. *	•			51 a (i)		Х
(ii) O	ther assets				a (ii)		X
<b>b</b> Other	transactions:						
(i)S	ales or exchanges of ass	ets with a n	oncharitable exempt organizatior		. <u>b (i)</u>		Χ
(ii)P	urchases of assets from a	a noncharita	able exempt organization		b (ii)		Χ
(iii)R	ental of facilities, equipme	ent, or othe	r assets		b (iii)		Χ
(iv)R	eimbursement arrangeme	ents		. , , , , , , , , , , , , , , , , , , ,	b (iv)		Χ
<b>(v)</b> Lo	oans or Ioan guarantees.				b (v)		Χ
(vi)P	erformance of services or	membersh	ip or fundraising solicitations		b (vi)		Χ
c Sharir	ng of facilities, equipment	, mailing lis	ts, other assets, or paid employe	es	с		Χ
d If the the go any tr	answer to any of the abo oods, other assets, or ser ansaction or sharing arra	ve is 'Yes,' vices given ngement. si	complete the following schedule. by the reporting organization. If how in column (d) the value of th	Column (b) should always show the fair me he organization received less than fair ma e goods, other assets, or services received	iarket value rket value d:	of n	
(a) Line no.	(b) Amount involved		(c) noncharitable exempt organizati	(d)			9
	Althount involved	11441110 01	Thomas and the complete control or garried to	postription of Kanstors, transactions, and		igomone	
N/A		<del></del>					
					······································	<del>~~~~~</del>	
	<del></del>						····
· · · · · · · · · · · · · · · · · · ·							
					.,		
			-				
							-
						-	
					***************************************		
descri	bed in section 501(c) of t	he Code (ot	liated with, or related to, one or in the than section 501(c)(3)) or in	nore tax-exempt organizations ection 527?	► ☐ Ye	s X	No
Dif Yes	s,' complete the following	schedule:	(6)	(a)			
	(a) Name of organization		(b) Type of organization	(c) Description of relatio	nship		
N/A			1				
IV/ A	***************************************				~~~~		
					<del></del>		
	***************************************						
					***************************************	·····	
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		***************************************					

**Federal Statements** 2004 Page 1 04-3462719 ALS Therapy Development Foundation, Inc. Statement 1 Form 990, Part I, Line 7 Other Investment Income Dividend Income \$ 478. .842. Interest Income Total \$ Statement 2 Form 990, Part I, Line 8 Net Gain (Loss) from Noninventory Sales Publicly Traded Securities Gross Sales Price: 1,116,426. Cost or Other Basis: 1,121,645. Total Gain (Loss) Publicly Traded Securities \$ -5,219. Total Net Gain (Loss) From Noninventory Sales \$ Statement 3 Form 990, Part I, Line 9 Net Income (Loss) from Special Events Less Less Net Gross Contri-Direct Income Gross Special Events Receipts butions Revenue Expenses (Loss) 

 0.
 2,315,902.
 684,217.
 1,631,685.

 0.
 \$ 2315902.
 \$ 684,217.
 \$ 1,631,685.

 SPECIAL EVENTS Statement 4 Form 990, Part II, Line 22 **Grants and Allocations** Cash Grants and Allocations Class of Activity: NEUROLOGY RESEARCH Donee's Name: Relationship of Donee: UNIVERSITY OF CALIFORNIA NONE Amount Given: 60,000. Class of Activity: RESEARCH

Class of Activity: RESEARCH

Donee's Name: ALS ASSOCIATION NAT'L OFFICE

NONE

Relationship of Donee: NONE

Donee's Name:

Amount Given:

Relationship of Donee:

Amount Given: 15,000.

ALS RESEARCH - FRAN DELANEY

24,824.

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#### **Federal Statements**

Page 2

ALS Therapy Development Foundation, Inc.

04-3462719

10,000.

Statement 4 (continued) Form 990, Part II, Line 22 **Grants and Allocations** 

Cash Grants and Allocations

Class of Activity: Donee's Name:

Relationship of Donee:

Amount Given:

Class of Activity: Donee's Name: Relationship of Donee:

Amount Given:

Class of Activity:

Donee's Name:

Relationship of Donee: Amount Given:

Class of Activity:

Donee's Name:

Relationship of Donee:

Amount Given:

RESEARCH

UNIVERSITY OF PITTSBURGH

NONE

RESEARCH

ALSGEN

NONE

150,000.

RESEARCH

UNIVERSITY OF IOWA

NONE

10,000.

RESEARCH

MAYO FOUNDATION

NONE

64,500.

334,324. Total Grants and Allocations \$

Statement 5 Form 990, Part II, Line 43 Other Expenses

		(A)Total	(B) Program Services	(C) Management & General	(D) Fundraising
Bank Fees Communications Computer Expenses Facility Maintenance Insurance Internet Licenses & Permits Mailing House Costs Membership Dues Miscellaneous Expenses Office Expense Outside Labor Printing & Design Recruiting Research and Development Staff Development & Traini Utilities Web Hosting Fee	ing Total	11,474. 24,468. 5,126. 72,595. 6,427. 14,709. 5,013. 8,780. 865. 8,126. 1,701. 666,386. 110,608. 3,271. 510,965. 2,982. 115,366. 21,206.	6,047. 3,338. 54,680. 3,747. 10,235. 1,510. 3,297. 680. 605. 667. 544,081. 76,877. 314. 510,965. 214. 84,781. 15,260. \$ 1,317,298.	11,474. 10,206. 856. 7,063. 1,679. 2,149. 2,853. 185. 1,125. 294. 74,189. 3,773. 2,890.	8,215. 932. 10,852. 1,001. 2,325. 650. 5,483. 6,396. 740. 48,116. 29,958. 67. 2,768. 19,937. 3,820. \$ 141,260.

ALS Therapy Development Foundation, Inc.

04-3462719

Statement 6 Form 990 , Part III Organization's Primary Exempt Purpose

ALS TDF is an independent non-profit biotechnology research center which is among the world's leading translational research programs in ALS, screening drugs in a mouse model of the disease. Our mission is to identify viable targets for therapy development and expeditiously manage the creation of those treatments that will arrest the suffering of today's ALS patients.

Statement 7
Form 990, Part III, Line a
Statement of Program Service Accomplishments

Description

Program Service Expenses

Grants and

Allocations

2004 marked the completed testing of most currently proposed ALS therapies, almost ten thousand mice, more than all other ALS labs combined, and our results are both challenging and invigorating. We overcame the barrier of administering drugs directly into the spinal cord. We refined our method of testing, improved quality and confirmed that the mouse model still accurately predicts the results of clinical trials. These results are critical because they set provide a new standard for data quality in to the ALS research

Our research discovered important new therapeutic target areas including protein confirmation, inflammation, the proteasome and cell cycle. ALS TDF is building programs to identify new therapies in each of these areas.

334,324. 3,033,383.

334,324. \$3,033,383.

Statement 8 Form 990, Part IV, Line 54 Investments - Securities

Corporate Stocks	Valuation <u>Method</u>		Amount	
CORPORATE STOCK	Market	Value	\$	59,503.
		m - 4 7		<u> </u>

Total \$ 59,503.

Total Investments - Securities \$ 59,503.

2004	Federal Statements	Page 4
	ALS Therapy Development Foundation, Inc.	04-346271
Statement 9 Form 990, Part IV, Line 57 Land, Buildings, and Equipme	ent	
Categor	Accum. y Basis Deprec.	Book Value
Furniture and Fixtures Machinery and Equipment Improvements Miscellaneous	\$ 5,443. \$ 4,187. \$ 213,248. 163,555. 11,389. 11,389. 8,612. 8,612. \$ 8,612. \$ 187,743. \$	1,256. 49,693. 0. 0. 50,949.
Statement 10 Form 990, Part IV, Line 58 Other Assets		
Rounding	\$ Total \$	88,742. 1. 2,200. 90,943.
		····
	rs\$ Total \$	88,780. 6,391. 95,171.
Form 990, Part IV, Line 65 Other Liabilities  ACCRUED PAYROLL & BENEFIT	Total \$\overline{\stees}, and Key Employees  Title and Contri- Average Hours Compen- bution to	6,391. 95,171. Expense Account/
Form 990, Part IV, Line 65 Other Liabilities  ACCRUED PAYROLL & BENEFIT ACCRUED PAYROLL TAXES  Statement 12 Form 990, Part V List of Officers, Directors, Trus	Total \$\overline{\stees}, and Key Employees  Title and Contri- Average Hours Compen- bution to	Expense Account/ Other
Form 990, Part IV, Line 65 Other Liabilities  ACCRUED PAYROLL & BENEFIT ACCRUED PAYROLL TAXES  Statement 12 Form 990, Part V List of Officers, Directors, Trus  Name and Address  James Heywood 215 First Street	Total \$\frac{\frac{1}{5}}{5}\$  Stees, and Key Employees  Title and Contri- Average Hours Compen- bution to Per Week Devoted sation EBP & DC  President & CEO \$ 110,577. \$ 9,326.	Expense Account/ Other

### **Federal Statements**

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ALS Therapy Development Foundation, Inc.

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Statement 12 (continued) Form 990, Part V List of Officers, Directors, Trustees, and Key Employees

Name and Address	Title and Average Hour Per Week Devot		Contri- bution to EBP & DC	Expense Account/ Other
Jennifer Huntington 20 Berkshire Road Newtonville, MA 02460	Director Part-time	\$ 0.	\$ 0.	\$ 0.
John Heywood Room 3-340, MIT / 77 Mass Ave Cambridge, MA 02139	Director Part-time	0.	0.	0.
Dr. David Searls 1244 Turnbury Lane North Wales, PA 19454	Director Part-time	0.	0.	0.
Steve Fowler 4420 Morella Avenue Studio City, CA 91607	Director Part-time	0.	0.	0.
Keith Melanson 34 Page Farm Road Sherborn, MA 01770	Treasurer Part-time	0.	0.	0.
Spiros Jamas, Sc.D. 67 Mt. Vernon Street-Unit One Boston, MA 02108	Director Part-time	0.	0.	0.
	To-	tal <u>\$ 110,577.</u>	\$ 9,326.	\$ 0.