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)

2007

Open to Public Inspection

Department of the Treasury Internal Revenue Service(77

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

Α	Fort	he 2007 calen	dar year,	or tax year beginning Jul :	1 , 2007,	and o	ending	Jun 3			2008	
В	Check										tification Number	
	A	ddress change	ress change Please use THE NATIONAL HEMOPHILIA FOUNDATION 13									
	N	ame change	or print or type.	Number and street (or P.O. box if r	nail is not delivered to street ad	ldr) F	toom/suite	•	E Tele	phone nun	nber	
	Ir	nitial return	See specific	116 WEST 32ND STRE	ET		11TH	FLOOR		(212) 328-3700		
	Termination Instructions. City, town or country State ZIP code + 4 F Acc					F Acce	ounting lod:	Cash X	Accrual			
	А	mended return		NEW YORK	NY	1 10	001-	3212		Other (spe	ecify)	_
	A	pplication pending	• Secti	on 501(c)(3) organizations and	I 4947(a)(1) nonexempt		H and I a	re not applic			organizations.	•
			chari	table trùsts must attach a con n 990 or 990-EZ).	pleted Schedule A			s this a grou f 'Yes,' enter			? [_] Yes ▶	X No
G	Web	site: ► WWW.	HEMOPE	HILIA.ORG			H (c) /	Are all affilia	ites includ	ed?	Yes	No
J	Orga (che	nization type ck only one) .		X 501(c) 3 ◀ (insert no	o.) 4947(a)(1) or	527	H (d)	(if 'No,' allac s this a sepa	arate retur	n filed by a	in .	
ĸ	Check here if the organization is not a 509(a)(3) supporting organization and its organization covered									y a group r	uling? X Yes	No
	gros	s receipts are	normally	not more than \$25,000. A return a return, be sure to file a com	rn is not required, but if	the					r ► 1248	
_											tion is not requir	
L	Gros	s receipts: Ad	d lines 6b	, 8b, 9b, and 10b to line 12 ≥ 1	11,233,308.						990-EZ, or 990-I	~r).
Pa	irt I			nses, and Changes in Ne		Salar	ices (See the	: instru	ıctıons	.)	
	1			ants, and similar amounts rece		1	ı					
				advised funds								
				not included on line 1a)				5,284,				
				(not included on line 1a)					006.			
		Government	contribution	ons (grants) (not included on li	ne 1a)	10		1,627,		*		
	١ ١	1a through 1d) (d	cash 🖇	7,010,643. noncash	\$0	<u>) •</u>)		<i>.</i>		1 e	7,010	
	2 Program service revenue including government fees and contracts (from Part VII, line 93)									2		<u>,157.</u>
	3	•								3	75	<u>,345.</u>
	4		-	d temporary cash investments								
	5			from securities		1	1			5	279	<u>,383.</u>
	b Less: rental expenses											
	c Net rental income or (loss). Subtract line 6b from line 6a									6c		
Ŗ	7 Other investment income (describe)								7			
お と と と ひ し 色	88	Gross amour	nt from sa	les of assets other	(A) Securities		ļ	(B) Othe	r			
Ň		than inventor	ry		2,527,256.	8 a	1		.			
Ĕ	t	Less: cost or	other bas	sis and sales expenses	2,844,770.	86	·····					
	(Gain or (loss) (a	ittach schedu	ıle)	-317,514.	80	•			u \$2.5\$		
				nbine fine 8c, columns (A) and						8d	-317	,514.
	9	Special even	its and act	tivities (attach schedule). If any studing \$	amount is from gamin O. of contributions	g, cne	eck ner	e , -	J			
	•			iduling \$		9 a	.1	305	001.	11,2%		
	۱,			other than fundraising expense					260.			
				om special events. Subtract lin			•			9с	126	,741.
				ry, less returns and allowances		1		IN 1 D1 1 IN	cia ci i i	NEW S		
				ld								
				ales of inventory (attach schedule). Sub						10 c		
	11	. ,	•	art VII, line 103)						11	1,011,	523.
	12			es 1e, 2, 3, 4, 5, 6c, 7, 8d, 9c,						12	8,210	
	13			n line 44, column (B))						13	7,993	
X	14									14		428.
EXPENSES	Management and general (from line 44, column (C)) 15 Fundraising (from line 44, column (D)) 16 Payments to affiliates (attach schedule)							15		709.		
N S								16	555			
E	5 17 Total expenses. Add lines 16 and 44, column (A)								17	9,322,	766.	
_	18									18	-1,112,	
N S	19			or the year. Subtract line 17 from line 12alances at beginning of year (from line 73, column (A))							7,730,	
A S S E T S	20									20	1,130,	
' T S	21			ances at end of year. Combine							6,617,	627
		. 101 433013 01		anious at sina or your confidence	10, 10, 0110 00 111							· · · ·

Form 990 (2007) THE NATIONAL HEMOPHILIA FOUNDATION 13-5641857 Page Part II Statement of Functional Expenses All organizations must complete column (A). Columns (B), (C), and (D) are required for scatter 501(5)(3) and (d) are required for sc

	for Section 501(c)(3) and (4) organ	IZALIOI	is and section 4947(a)(1)	nonexempt charitable	irusis but optional for oti	leis. (See iristruct.)			
	o not include amounts reported on line 6b, 8b, 9b, 10b, or 16 of Part I.	62 lig	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising			
22 a	Grants paid from donor advised								
	funds (attach sch)								
	(cash \$								
	non-cash \$)								
	If this amount includes foreign grants, check here	22 a							
22 b	Other grants and allocations (att sch)					Swiggishs (#15 C/C)			
	(cash \$ 1,611,189.								
	non-cash \$)								
	If this amount includes				etio per na fil				
	foreign grants, check here	22b	1,611,189.	1,611,189.					
23	Specific assistance to individuals								
	(attach schedule)	23							
24	Benefits paid to or for members								
	(attach schedule)	24							
25 a	Compensation of current officers,								
	directors, key employees, etc. listed in Part V-ASee .L-25a.Stmt	25 a	256,699.	86,756.	144,273.	25,670.			
h	Compensation of former officers.				,				
	directors, key employees, etc. listed		}						
	in Part V-BSee L-25b. S.tmt	25 b	178,650.	0.	160,786.	17,864.			
C	Compensation and other distributions, not included above, to disqualified persons (as								
	defined under section 4958(f)(1)) and persons								
	described in section 4958(c)(3)(B)	25 c			' I				
26	Salaries and wages of employees not included on lines 25a, b, and c	26	2,602,148.	2,163,776.	192,584.	245,788.			
07									
27	Pension plan contributions not included on lines 25a, b, and c	27	212,215.	170,142.	19,413.	22,660.			
00			322,023						
28	Employee benefits not included on lines 25a - 27	28	304,777.	265,753.	17,978.	21,046.			
29	Payroll taxes	29	199,065.	165,529.	14,733.	18,803.			
30	Professional fundraising fees	30	73,750.	0.	0.	73,750.			
31	Accounting fees		43,936.	32,525.	8,199.	3,212.			
32	Legal fees	-	15,227.	9,871.	5,356.	0.			
33	Supplies		75,624.	52,545.	11,181.	11,898.			
34	Telephone		45,335.	26,429.	15,437.	3,469.			
35	Postage and shipping	-	124,255.	103,292.	4,897.	16,066.			
36	Occupancy	36	327,248.	222,746.	93,035.	11,467.			
37	Equipment rental and maintenance	37	256,083.	224,684.	23,392.	8,007.			
38	Printing and publications	38	271,525.	246,832.	1,045.	23,648.			
39	Travel	39			•	• • • • • • • • • • • • • • • • • • • •			
40	Conferences, conventions, and meetings	40	1,475,40%.	1,424,078.	28,551.	22,778.			
41	Interest	41			•				
42	Depreciation, depletion, etc (attach schedule)	42	29,810°.	20,872.	6,634.	2,304.			
43	Other expenses not covered above (itemize):								
a	INSURANCE	43a	27,471.	13,692.	12,769.	1,010.			
b	MEMBERSHIP DUES	43 b	29,707.	11,811.	3,229.	14,667.			
c	CONSULTING	43 c	1,104,073.	1,099,343.	245.	4,485.			
d	EMPLOYMENT RECRUITING	43 d	1,586.	540.	46.	1,000.			
е	IN-KIND EXPENSES	43 e	5,450.	1,950.	3,500.	0.			
f	MISC	43f	23,736.	19,808.	1,960.	1,968.			
g	BANKING and INVESTMENTS FEES	43 g	27,800.	19,466.	6,185.	2,149.			
44	Total functional expenses. Add lines 22a								
• •	Total functional expenses. Add lines 22a through 43g. (Organizations completing columns (B) - (D), carry these totals to lines 13 - 15)	44	9,322,766.	7,993,629.	775,428.	553,709.			
	Costs. Check . If you are following			7,555,025.	110717011	333,109.			
	Are any joint costs from a combined educational campaign and fundraising solicitation reported in (B) Program services? Yes X No								
	If 'Yes,' enter (i) the aggregate amount of these joint costs \$; (ii) the amount allocated to Program services :								
\$			to Management and ger		; and (iv) the				
	indraising \$		g_nanag_nana and got		,				

Part III Statement of Program Service Accomplishments (See the instructions.)

Form 990 is available for	public inspection and, for som	ne people, serves as t	he primary or sole source	of information about a particular	_
organization. How the nu	iblic nerceives an organization.	in such cases may be	e determined by the inform	ation presented on its return. The	retore,
please make sure the ref	turn is complete and accurate	and fully describes, in	Part III, the organization's	programs and accomplishments.	

please make sure the return is complete and accurate and fully describes, in Fart III, the organization's programs and accurate	ompilarimenta.
What is the organization's primary exempt purpose? Incorporated in the State of N.Y. in 1948. The Foundation is 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) organizations and 4947(a)(1) nonexempt charitable trusts must also enter the amount of grants and allocations to others.)	Program Service Expenses (Required for 501(c)(3) and (4) organizations and 4947(a)(1) trusts; but optional for others.)
a Health Education Training	
SEE ADDITIONAL INFORMATION ATTACHED "SUMMARY REPORT OF	
THE NATIONAL HEMOPHILIA FOUNDATION'S ACCOMPLISHMENTS	
IN 2008"	
(Grants and allocations \$ 179,023.) If this amount includes foreign grants, check here ▶	3,676,702.
b Community Services	
SEE ADDITIONAL INFORMATION ATTACHED "SUMMARY REPORT OF	
THE NATIONAL HEMOPHILIA FOUNDATION'S ACCOMPLISHMENTS	
IN 2008"	
(Grants and allocations \$ 790.) If this amount includes foreign grants, check here ▶	2,057,070.
c Research	
SEE ADDITIONAL INFORMATION ATTACHED "SUMMARY REPORT OF	
THE NATIONAL HEMOPHILIA FOUNDATION'S ACCOMPLISHMENTS	
IN 2008"	
(Grants and allocations \$ 1,431,376.) If this amount includes foreign grants, check here ▶	1,942,314.
d	
(Grants and allocations \$) If this amount includes foreign grants, check here ▶	
e Other program services	
(Grants and allocations \$) If this amount includes foreign grants, check here ▶	
f Total of Program Service Expenses (should equal line 44, column (B), Program services)	7,676,086.

Part IV Balance Sheets (See the instructions.) (B) End of year (A) Beginning of year Note: Where required, attached schedules and amounts within the description column should be for end-of-year amounts only. Cash - non-interest-bearing 2,331,839. 45 2,829,278. 46 Savings and temporary cash investments...... 46 47 a Accounts receivable 47 a 869,143. **b** Less: allowance for doubtful accounts...... 47 b 22,503 1,391,241. 47 c 846,640. 48a Pledges receivable 48 a **b** Less: allowance for doubtful accounts...... 48b 480 49 Grants receivable..... 49 346,607 150,185. 50 a Receivables from current and former officers, directors, trustees, and key employees (attach schedule) 50 a b Receivables from other disqualified persons (as defined under section 4958(f)(1)) and persons described in section 4958(c)(3)(B) (attach schedule)..... 50 b 51 a Other notes and loans receivable (attach schedule)..... 51 a **b** Less: allowance for doubtful accounts..... 51 c 52 Inventories for sale or use..... 52 53 Prepaid expenses and deferred charges..... 138,832 53 211,025. Cost X FMV 5,756,188. 54 a 5,615,946. b Investments — other securities (attach sch) ▶ Cost FM∨ 54b 55a Investments - land, buildings, & equipment: basis... 55 a b Less: accumulated depreciation (attach schedule)..... 55 b 55 c 56 57 a 1,320,991. b Less: accumulated depreciation 57 b 57 c 1,318,694 32,107 2,297. Other assets, including program-related investments (describe ► 58 Total assets (must equal line 74). Add lines 45 through 58 9,996,814. 59 9,655,371. Accounts payable and accrued expenses..... 969,896. 60 1,170,157. 61 Grants payable 112,148. 61 11,686. 62 1,184,655 62 1,855,901. Loans from officers, directors, trustees, and key employees (attach schedule) 63 64 a b Mortgages and other notes payable (attach schedule) 64 b Other liabilities (describe - . . _ _ _ 65 Total liabilities. Add lines 60 through 65...... 2,266,699. 66 3,037,744. Organizations that follow SFAS 117, check here X and complete lines 67 through 69 and lines 73 and 74. 67 67 1,804,765 2,172,647. Temporarily restricted.... 68 5,925,350. 68 4,444,980. 69 Organizations that do not follow SFAS 117, check here ► | and complete lines Q 70 through 74. Capital stock, trust principal, or current funds..... 70 Paid-in or capital surplus, or land, building, and equipment fund 71 72 Retained earnings, endowment, accumulated income, or other funds...... 72 Total net assets or fund balances. Add lines 67 through 69 or lines 70 through 72. (Column (A) must equal line 19 and column (B) must equal line 21)...... 7,730,115. 73 6,617,627.

BAA Form 990 (2007)

Total liabilities and net assets/fund balances. Add lines 66 and 73

9,996,814.

74

9,655,371.

	rm 990 (2007) THE NATIONAL HEM art IV-A Reconciliation of Revenu instructions.)				with I		3-564 Retur i		Page
	iristi dettoris.)								
а	Total revenue, gains, and other support	per audited finar	ncial stateme	nts			a		
b	Amounts included on line a but not on F	3					12 to 2013		
	1Net unrealized gains on investments				b1				
	2Donated services and use of facilities			F-	b2				
	3Recoveries of prior year grants				b3		<u> </u>		
	4Other (specify):								
	Add tippe bit through bit				b4				
С	Add lines b1 through b4						C		_
ď	Amounts included on Part I, line 12, but						<u>.</u>		
_	1Investment expenses not included on Pa				d1				
	2Other (specify):								
					d2		10.00 10.00		
	Add lines d1 and d2				<i></i>		d		
е	Total revenue (Part I, line 12). Add line art IV-B Reconciliation of Expens	s c and d					- ► e		
P	art IV-B Reconciliation of Expens	es per Audite	<u>d Financia</u>	I Statement	s with	Expenses po	er Reti	urn	
	· · · · · · · · · · · · · · · · · · ·								
a	Total expenses and losses per audited t		nts				a		
b	Amounts included on line a but not on F 1 Donated services and use of facilities	•		1	h1				
	2Prior year adjustments reported on Part			F					
	3Losses reported on Part I, line 20			<u> </u>	b3				
	4Other (specify):							÷	
				I	b4		37.45 37.45		
	Add lines b1 through b4						b		
c	Subtract line b from line a	<i>.</i>			<i></i> .		с		
d	Amounts included on Part I, line 17, but								
	1 Investment expenses not included on Pa				d1	,. <u>.</u>	_ *		
	2Other (specify):				1		55.7		
					d2				
_	Add lines d1 and d2						d ▶ e		
e	Total expenses (Part I, line 17). Add lin	······································					<u> </u>		
QUAÇE	Current Officers, Director or key employee at any time du	iring the year eve	n if they wer	e not compens	ated.) (See the instructi	ons.)		
	(A) Name and address	(B) Title and av	levoted	(C) Compens (if not pa	id,	(D) Contribution employee be	nefit	(E) Expe	d other
	.,	to posit	lion	enter -0	-)	plans and def compensation		allowand	Jes
Va	al Bias								····
C/	O NHF116 W 32 ST. NY NY 10001]				·- a			
Ef	fective 5/19/08 NY10001	CHIEF EXECUTIVE C	off 43.00	29	,808.		0.	10	,000
St	ephen Bender					•			
_C/	ONHF 116 w32st ny ny 1001								
	NY 10001	Director	10.00		0.		0.	· · · · · · · · · · · · · · · · · · ·	0
	Y STANHOPE								
<u>C/</u>	O NHF116 W 32 ST. NY NY 10001	-	00.00		•				^
-		Chair of the Boa	rd 20.00		0.		0.		0
	ITA GONZALES					l	İ		
<u></u>	O NHF116 W 32 ST. NY NY 10001 NY 10001	DIRECTOR	10.00		0.		0.		0
M i	ichael Luettgen	DIRECTOR	10.00		<u> </u>		٠.		
	: 	-1	I			1	I		

10.00

NY 10001 Director

0.

C/O NHF116 W 32 ST. NY NY 10001

See List of Officers, Directors, Trustees, & Key Emptoyees Statement

0.

0.

Form 990 (2007) THE NATIONAL HEMOPHIL		Coontinus	13-5641		P Yes	age 6			
Part V-A Current Officers, Directors, Trustees, and Key Employees (continued) 75 a Enter the total number of officers, directors, and trustees permitted to vote on organization business at board meetings . ▶ 15									
b Are any officers, directors, trustees, or key employees listed in Form 990, Part V-A, or highest compensated employees listed in Schedule A, Part I, or highest compensated professional and other independent contractors listed in Schedule A, Part II-A or II-B, related to each other through family or business relationships? If "Yes," attach a statement that identifies the individuals and explains the relationship(s).									
c Do any officers, directors, trustees, or key employees listed in form 990, Part V-A, or highest compensated employees listed in Schedule A, Part I, or highest compensated professional and other independent contractors listed in Schedule A, Part II-A or II-B, receive compensation from any other organizations, whether tax exempt or taxable, that are related to the organization? See the instructions for the definition of 'related organization'.									
If 'Yes,' attach a statement that includes the in				546 546 48	3.73%	: 8 : W			
d Does the organization have a written conflict of interest policy? 75 Part V-B Former Officers, Directors, Trustees, and Key Employees That Received Compensation or Otl									
Benefits (If any former officer, director during the year, list that person below a the instructions.)	or, trustee, or key empl	ovee received compens	ation or other benefits of	described b	elow) >			
					pense ind ot inces				
Alan Kinniburgh PHD c/o NHf 116w 32nd st ny ny 1001 period 7/1/07-8/1/07	0.	148,224.	30,426.			0.			
Part VI Other Information (See the instr	uctions)			·····	Vac	Ala			
76 Did the organization make a change in its activ	vities or methods of con	nducting activities?			Yes				
If 'Yes,' attach a detailed statement of each ch 77 Were any changes made in the organizing or g If 'Yes,' attach a conformed copy of the change 78a Did the organization have unrelated business g b If 'Yes,' has it filed a tax return on Form 990-T	overning documents be es. ross income of \$1,000	ut not reported to the IF or more during the yea	r covered by this return	77 ? 78a	X	X			
79 Was there a liquidation, dissolution, termination year? If 'Yes,' attach a statement	n, or substantial contra	ction during the	· · · · &	79		<u>x</u> _			
80 a Is the organization related (other than by associatembership, governing bodies, trustees, office	rs, etc, to any other ex	empt or nonexempt org	ition) through common janization?			X			
b If 'Yes,' enter the name of the organization ►	and ch	eck whether it is Pev	empt or Ingneyer	MARIE					
81 a Enter direct and indirect political expenditures.	(See line 81 instructio	ns.)	81 a	Ψ·.					
b Did the organization file Form 1120-POL for thi		· ·		81 b		Х			
ВАА				Form 9	90 (2007)			

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Part	VI Other Information (continued)		· 	Yes	No					
82 a E	Did the organization receive donated services or the use of materials, equipment, or facilities substantially less than fair rental value?	s at no charge or at	82 a	स्याप्त स्थान	Х					
b l r	f 'Yes,' you may indicate the value of these items here. Do not include this amount as evenue in Part I or as an expense in Part II. (See instructions in Part III.)	82 b								
83 a E	Did the organization comply with the public inspection requirements for returns and exemption	on applications?	83 a	Х	ļ					
	Did the organization comply with the disclosure requirements relating to <i>quid pro quo</i> contrib		83b	Х						
84 a [Did the organization solicit any contributions or gifts that were not tax deductible?	,,.,	84 a	. 1.730.75	X					
b I	If 'Yes,' did the organization include with every solicitation an express statement that such c	ontributions or gifts were	84 b		V.38.78					
85 a 501(c)(4), (5), or (6). Were substantially all dues nondeductible by members?										
b Did the organization make only in-house lobbying expenditures of \$2,000 or less?										
ļ V	If 'Yes' was answered to either 85a or 85b, do not complete 85c through 85h below unless t waiver for proxy tax owed for the prior year.									
	Dues, assessments, and similar amounts from members									
	Section 162(e) lobbying and political expenditures				100					
	Aggregate nondeductible amount of section 6033(e)(1)(A) dues notices									
	Taxable amount of lobbying and political expenditures (line 85d less 85e)			36.50	West.					
g (Does the organization elect to pay the section 6033(e) tax on the amount on line 85f?	.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	85 g	N//	A Verson					
h f	f section 6033(e)(1)(A) dues notices were sent, does the organization agree to add the amount on line85f to its reason fues allocable to nondeductible lobbying and political expenditures for the following tax year?	nable estimate of	85 h	N/A	A A					
86 5	501(c)(7) organizations. Enter: a Initiation fees and capital contributions included on		ANS.							
	ine 12	86a N/A								
b (Gross receipts, included on line 12, for public use of club facilities	86 b N/A			Ŕ					
87 5	501(c)(12) organizations. Enter: a Gross income from members or shareholders	87a N/A			2.85°C: 2.86°C:					
6	Gross income from other sources. (Do not net amounts due or paid to other sources against amounts due or received from them.)	87b N/A			#57 (5) 34 (2)					
88 a /	At any time during the year, did the organization own a 50% or greater interest in a taxable or an entity disregarded as separate from the organization under Regulations sections 301.7 if 'Yes,' complete Part IX	corporation or partnership, 701-2 and 301.7701-3?	88 a		X					
b A	At any time during the year, did the organization, directly or indirectly, own a controlled entit section 512(b)(13)? If 'Yes,' complete Part XI	y within the meaning of	88 b		Х					
89 a 5	501(c)(3) organizations. Enter: Amount of tax imposed on the organization during the year u	nder:								
5	section 4911 ► none ; section 4912 ► none ; section 4	955►none			730 1 h					
b	501(c)(3) and 501(c)(4) organizations. Did the organization engage in any section 4958 exceduring the year or did it become aware of an excess benefit transaction from a prior year? If explaining each transaction	ss benefit transaction 'Yes,' attach a statement	89b		X					
c E	Enter: Amount of tax imposed on the organization managers or disqualified persons during t year under sections 4912, 4955, and 4958	he ▶ 0.		in Casa in Sana as and sa						
d E	Enter: Amount of tax on line 89c, above, reimbursed by the organization				基 差					
e /	All organizations. At any time during the tax year, was the organization a party to a prohibite	ed tax shelter transaction?	89 e		Х					
f /	All organizations. Did the organization acquire a direct or indirect interest in any applicable i	nsurance contract?	891		Х					
g /	For supporting organizations and sponsoring organizations maintaining donor advised funds organization, or a fund maintained by a sponsoring organization, have excess business hold the year?	Did the supporting ings at any time during	89 g		X					
90 a l	_ist the states with which a copy of this return is filed ► See States Filed In									
(Number of employees employed in the pay period that includes March 12, 2007 (See instructions.)		90 b		38					
91 a 3	The books are in care of ► THE ORGANIZATION Telephone nu									
ι	Located at ► 116 WEST 32ND STREET 11TH FLOOR NEW YORK N	NY_ ZIP + 4 - 1000	L <u>-32</u>							
b A	At any time during the calendar year, did the organization have an interest in or a signature financial account in a foreign country (such as a bank account, securities account, or other f	or other authority over a inancial account)?	91 b	Yes	No X					
- 1	f 'Yes,' enter the name of the foreign country▶		SMOS SMOS		FLF:					
5	See the instructions for exceptions and filing requirements for Form TD F 90-22.1, Report of inancial Accounts.									
BAA			Form	990 ((2007					

Form 990 (2007) THE NATIONAL HEMO	PHILIA FO	UND	ATION		13-5641	857	Р	age 8
Part VI Other Information (continu	ıed)						Yes	
c At any time during the calendar year, d	lid the organiza	ition m	naintain an office	outside of the U	nited States?	91 c		X
If 'Yes,' enter the name of the foreign of								
92 Section 4947(a)(1) nonexempt charitab							'	► 📙
and enter the amount of tax-exempt in	terest received	or acc	crued during the t	ax year				
Part VII Analysis of Income-Produ								
	Unrelate	d busi	ness income	Excluded by se	ction 512, 513, or 514	(E	3	
Note: Enter gross amounts unless otherwise indicated.	(A) Business code	 	(B) Amount	(C) Exclusion code	(D) Amount	Related o function	r exei	mpt ne
93 Program service revenue: a PUBLICATIONS				:		,	24,1	L57.
*								
c		ļ						
d								
е								
f Medicare/Medicaid payments								
g Fees & contracts from government agencies								
94 Membership dues and assessments.							75 , 3	345.
95 Interest on savings & temporary cash invmnts								
96 Dividends & interest from securities .				14	279,383.		-	
97 Net rental income or (loss) from real estate:	(etc.) (c.) (c.)							
a debt-financed property								
b not debt-financed property								
98 Net rental income or (loss) from pers prop								
99 Other investment income								···-
100 Gain or (loss) from sales of assets other than inventory				18	-317,514.	i		
101 Net income or (loss) from special events				1	126,741.			
102 Gross profit or (foss) from sales of inventory								
103 Other revenue: a		1						
b ADV. IN EDUC PUB	541800	1	1,011,523.					
С								
d								
e								
Subtotal (add columns (B), (D), and (E))			1,011,523.		88,610.			502.
105 Total (add line 104, columns (B), (D)	, and (E))				, -	1,1	99,6	<u>635.</u>
Note: Line 105 plus line 1e, Part I, should e								
Part VIII Relationship of Activities	to the Acco	mpli:	shment of Exc	empt Purpos	es (See the instruc	:tions.)		
Line No. Explain how each activity for who of the organization's exempt pur	ich income is r poses (other th	eporte nan by	ed in column (E) or providing funds	of Part VII contri for such purpose	buted importantly to thes).	e accomplis	hmen	ıt
93a Sale of health educa	tional pu	blic	cations rel	ated to li	ving with		•	
bleeding and clottin	g disorde	rs a	and awarene	SS				
94 all membership fees	received	are	used for m	ission pur	pose of educat	ion adv	oca	су
and research								
Part IX Information Regarding Ta	xable Subsi	diari	es and Disreg	arded Entitie	s (See the instruc	tions.)	<u>N</u>	A/I
(A)	(B)		(0	5)	(D)	(£	Ε)	
Name, address, and EIN of corporation,	Percentag	e of	Nature of	activities	Total	End-o		ır
partnership, or disregarded entity	ownership in	iterest			income	ass	sets	
		8						
**************************************		<u></u> 8						
		<u>ક</u>						
		8	l Analos (M. 5	and Day Co	Dandinasta (Caritta	inoteriati	000.	
Part X Information Regarding Tr								
a Did the organization, during the year, receive any						Yes		No No
b Did the organization, during the year,				n a personal ber	ieнt contract	[] Yes	Δ	No
Note: If 'Yes' to (b), file Form 8870 and	-orm 4/∠U (See	: IIISŢſ	ucuons).		TEEA0108 12/27/	o7 Form	990	(2007

aiii	l'	d in question 107 above? perjury, I declare that I have examined this return, incomplete. Deplaration of preparer (other than officer) is	luding accompanying schedules and statemer based on all information of which preparer h	nts, and to the best of m has any knowledge.	y knowledge and belief, it is		
Please	► -@	h/ll	2/10/08				
Sign Here	Signature of o	was BACSAM	000	Date	e		
Paid Pre-	Preparer's signature		Date	Check if self-employed	Preparer's SSN or PTIN (See General Instruction X)		
parer's Use Only	Firm's name (or yours if self- employed), address, and	NATIONAL HEMOPHILIA FOUN 116 W 32ND ST		EIN ►			
BAA	ZIP + 4	NEW YORK	NY 10001-3212	Phone no.	Form 990 (2007		

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 4947(a)(1) Nonexempt Charitable Trust

Supplementary Information — (See separate instructions.)

2007

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 THE NATIONAL HEMOPHILIA FOUNDATION 13-5641857 Part 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 (d) Contributions to employee benefit plans and deferred (b) Title and average (c) Compensation (e) Expense employee paid more than \$50,000 hours per week count and other devoted to position allowances compensation GLENN MONES _____C/O NHF 116 W32ND ST.NY NY 10001 VP PUBLIC POLICY 43.00 180,458 0. 26,465 JOHN INDENCE _C/O NHF 116 W32ND ST.NY NY 10001 VP MARKETING /COMMUNICA 43.00 117,380. 10,190 0. ANN-MARIE NAZZARO _C/O NHF_116_W32ND ST.NYNY 10001 VP EDUCATION 43.00 148,025 23,007 0. MARY ANN LUDWIG C/O NHF 116 W32ND ST.NY NY 10001 VP DEVELOPMENT 43.00 186,532 0. 27,146 NEIL FRICK C/O NHF 116 W32ND ST.NY NY 10001 VP MEDICAL RESEARCH 43.00 110,798 17,127 0. Total number of other employees paid over \$50,000 Part II = A 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 MARC ASSOCIATES INC. 1101 17TH ST. NW, 20036 WASHINGTON DC GOVERNMENT RELATIONS 144,020. Macro International 11785 beltsville drive cal MD 20705 program peer review 71,376. Corporate Kids Events 18414 alexandra way grass valley CA 95949 Child care 67,360. THE MAGAZINE GROUP 1707 L ST. NW WASHINGTON 20036 DCPUBLICATIONS 172,880. THE McCORMICK GROUP 448 TARPON BLVD FRIPP IS. SC 29920 ORGANIZATIONAL STRUCTURE CONSULTING 90,000. Total number of others receiving over \$50,000 for professional services. Part II - B Compensation of the Five Highest Paid Independent Contractors for Other Services (List each contractor who performed services other than professional services, whether individuals or firms. If there are none, enter 'None.' See instructions.) (a) Name and address of each independent contractor paid more than \$50,000 (b) Type of service (c) Compensation INTEGRATED PUBLISHING SALES 280 Manor Brook Drive, Chagrin Falls QН 44022 SALES 173,177. Total number of other contractors receiving

over \$50,000 for other services ...

Part	Statements About Activities (See instructions.)		Yes	No
1	During the year, has the organization attempted to influence national, state, or local legislation, including any attempt to influence public opinion on a legislative matter or referendum? If 'Yes,' enter the total expenses paid			
	or incurred in connection with the lobbying activities ▶ \$ 153,978. (Must equal amounts on line 38, Part VI-A, or line i of Part VI-B.)			
	(Must equal amounts on line 38, Part VI-A, or line i of Part VI-B.)	_1	X	
	Organizations that made an election under section 501(h) by filing Form 5768 must complete Part VI-A. Other organizations checking 'Yes' must complete Part VI-B AND attach a statement giving a detailed description of the lobbying activities.			
	During the year, has the organization, either directly or indirectly, engaged in any of the following acts with any substantial contributors, trustees, directors, officers, creators, key employees, or members of their families, or with any taxable organization with which any such person is affiliated as an officer, director, trustee, majority owner, or principal beneficiary? (If the answer to any question is 'Yes,' attach a detailed statement explaining the transactions.)			
а	Sale, exchange, or leasing of property?	2 a		Х
b	Lending of money or other extension of credit?	_2b		Х
С	Furnishing of goods, services, or facilities?	2 c		X
	See Part V, Form 990			ŀ
d	Payment of compensation (or payment or reimbursement of expenses if more than \$1,000)?	2 d	Х	
е	Transfer of any part of its income or assets?	2 e		Х
3 a	Did the organization make grants for scholarships, fellowships, student loans, etc? (If 'Yes,' attach an explanation of how the organization determines that recipients qualify to receive payments.)	3 a	Х	
þ	Did the organization have a section 403(b) annuity plan for its employees?	3 b	Х	
c	Did the organization receive or hold an easement for conservation purposes, including easements to preserve open space, the environment, historic land areas or historic structures? If 'Yes,' attach a detailed statement	3c		Х
d	Did the organization provide credit counseling, debt management, credit repair, or debt negotiation services?	3 d		X
4a	Did the organization maintain any donor advised funds? If 'Yes,' complete lines 4b through 4g. If 'No,' complete lines 4f and 4g	4a		Х
b	Did the organization make any taxable distributions under section 4966?	4b		
С	Did the organization make a distribution to a donor, donor advisor, or related person?	4c		
	Enter the total number of donor advised funds owned at the end of the tax year			

0.

f Enter the total number of separate funds or accounts owned at the end of the tax year (excluding donor advised funds included on line 4d) where donors have the right to provide advice on the distribution or investment of amounts in such funds or accounts

g Enter the aggregate value of assets held in all funds or accounts included on line 4f at the end of the tax year... 🟲

Schedule A (Form 990 or 990-EZ) 2007

Page 3

Par	t IV Reason for Non-Priv	ate Foundation Status (S	See instructions.)							
l cert	ify that the organization is not a pr	ivate foundation because it is:	(Please check only ONE ap	plicable box	(.)					
5	A church, convention of church	hes, or association of churches	. Section 170(b)(1)(A)(i).							
6	A school. Section 170(b)(1)(A))(ii). (Also complete Part V.)								
7	7 A hospital or a cooperative hospital service organization. Section 170(b)(1)(A)(iii).									
8	8 A federal, state, or local government or governmental unit. Section 170(b)(1)(A)(v).									
9	9 A medical research organization operated in conjunction with a hospital. Section 170(b)(1)(A)(iii). Enter the hospital's name, city, and state									
10	An organization operated for t (Also complete the Support S	he benefit of a college or unive chedule in Part IV-A.)	rsity owned or operated by	a governme	ental unit, Se	ction 170(b)(1)(A)(iv).				
11 a	11 a X An organization that normally receives a substantial part of its support from a governmental unit or from the general public. Section 170(b)(1)(A)(vi). (Also complete the Support Schedule in Part IV·A.)									
11 b	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 33-1/3% of its support from contributions, membership fees, and gross receipts from activities related to its charitable, etc, functions — subject to certain exceptions, and (2) no more than 33-1/3% of its support from gross investment income and unrelated business taxable income (less section 511 tax) from businesses acquired by the organization after June 30, 1975. See section 509(a)(2). (Also complete the Support Schedule in Part IV-A.)									
13										
	Type I Type II			Type III						
	(a) Name(s) of supported organization(s)	(b) Employer identification number (EIN)	(c)	lizations. (See instruction (d) Is the supported organization listed in the supporting organization's governing documents?		(e) Amount of support				
				Yes	No					
	1									
			,							
	•									
Total			***********							
14	An organization organized and	d operated to test for public safe	ety. Section 509(a)(4). (Se	e instruction	ns.)					

BAA

Part IV-A Support Schedule (Complete only if you checked a box on line 10, 11, or 12.) Use cash method of accounting.

Note: Y	ou may use the worksneet in ti	ne instructions for cor	iverting from the acci	ual to the cash meth	ou or accounting.	
beginni	ar year (or fiscal year ing in)►	(a) 2006	(b) 2005	(c) 2004	(d) 2003	(e) Total
15 G re ur	iffs, grants, and contributions eceived. (Do not include nusual grants. See line 28.)	6,215,238.	8,015,334.	6,585,825.	6,448,443.	27,264,840.
	lembership fees received	58,468.	80,155.	66,025.	78,845.	283,493.
17 Gr mo or th	ross receipts from admissions, erchandise sold or services performed, furnishing of facilities in any activity at is related to the organization's haritable, etc, purpose	26,372.	31,104.			112,818.
an lo: in: ur se	ross income from interest, dividends, ints rec'd from payments on securities ans (sec. 512(a)(5)), rents, royalties, come from similar sources, and inclated business taxable income (less ec. 511 taxes) from businesses acquired the organzation after June 30, 1975	283,579.	265,015.	179,136.	145,860.	873,590.
19 No	et income from unrelated business ctivities not included in line 18					
oi ei oi	ax revenues levied for the rganization's benefit and ither paid to it or expended n its behalf					
fa or ur in fa	he value of services or acilities furnished to the rganization by a governmental nit without charge. Do not noclude the value of services or acilities generally furnished to be public without charge.					
SC	Other income, Attach a chedule. Do not include ain or (loss) from sale of apital assets	1,146,462.	1,112,211.	934,006.	1 417 982	4,610,661.
	otal of lines 15 through 22					
	ine 23 minus line 17					
	nter 1% of line 23					33,032,304.
-	Organizations described on line	 		olumn (e), line 24		660,652.
h Pr	repare a list for your records to show the apported organization) whose total gifts eturn. Enter the total of all these excess	e name of and amount contr	ributed by each person (oth	er than a governmental uni	t or publicly	
	otal support for section 509(a)(33,032,584.
	dd: Amounts from column (e) fo		873,590. 4,610,661.	19		Zago Saga Cayyan A
					26d	
e P	ublic support (line 26c minus lin	ne 26d total)			▶ <u>26e</u>	27,548,333.
	ublic support percentage (line		led by line 26c (deno	minator))	▶ 26f	83.40 %
a Fe na St	organizations described on line or amounts included in lines 15 ame of, and total amounts rece uch amounts for each year:	, 16, and 17 that were lived in each year fron				
	2006)					
to \$! A	or any amount included in line of show the name of, and amour 5,000. (Include in the list organ after computing the difference by ifferences (the excess amounts 2006) add: Amounts from column (e) for the column of the column	it received for each ye izations described in l etween the amount re o for each year:	ear, that was more th lines 5 through 11b, a ceived and the larger	an the larger of (1) these well as individuals. Tamount described in	ne amount on line 25) Do not file this list in the second or (2), enter the second or (2), ent	for the year or (2) with your return, sum of these
c A	dd: Amounts from column (e) fo	or lines: 15		16	_	
	17	20		21	► 27c	
d A	dd: Line 27a total	ar	nd line 27b total		► 27 d	
eР	ublic support (fine 27c total min	ius line 27d total)			▶ 27e	 चर्चा वस्तात सा इस्तार राजा
f T	Public support (line 27c total mirrotal support for section 509(a)(2) test: Enter amount	from line 23, column	(e) ► 27f		
gP	ublic support percentage (line	27e (numerator) divid	led by line 27f (denoi	minator))	F 27g	*
h Ir	nvestment income percentage (line 18, column (e) (n	umerator) divided by	/ line 2/f (denominate	or))► 27h	8

²⁸ Unusual Grants: For an organization described in line 10, 11, or 12 that received any unusual grants during 2003 through 2006, 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.

13-5641857

Private School Questionnaire (See instructions.) (To be completed ONLY by schools that checked the box on line 6 in Part IV) N/A Yes 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? 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.) Does the organization maintain the following: a Records indicating the racial composition of the student body, faculty, and administrative staff?.. 32 a b Records documenting that scholarships and other financial assistance are awarded on a racially 32 b nondiscriminatory basis? c Copies of all catalogues, brochures, announcements, and other written communications to the public dealing with student admissions, programs, and scholarships?.... 32 c 32 d d Copies of all material used by the organization or 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.) 33 Does the organization discriminate by race in any way with respect to: 33 a a Students' rights or privileges?..... 33 b c Employment of faculty or administrative staff?..... 33 c 33 đ d Scholarships or other financial assistance?..... e Educational policies?..... 33 e 33 f f Use of facilities? 33 a 33 h h Other extracurricular activities? If you answered 'Yes' to any of the above, please explain. (If you need more space, attach a separate statement.) 34 a Does the organization receive any financial aid or assistance from a governmental agency?..... 34 a b Has the organization's right to such aid ever been revoked or suspended?..... 34 b If you answered 'Yes' to either 34a or b, please explain using an attached statement. 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.

13-5641857 Schedule A (Form 990 or 990-EZ) 2007 THE NATIONAL HEMOPHILIA FOUNDATION Page 6 Part VI-A Lobbying Expenditures by Electing Public Charities (See instructions.) (To be completed ONLY by an eligible organization that filed Form 5768) N/A if the organization belongs to an affiliated group. Check ► b if you checked 'a' and 'limited control' provisions apply. Check ► a (a) Affiliated group Limits on Lobbying Expenditures To be completed totals for all electing (The term 'expenditures' means amounts paid or incurred.) organizations 36 Total lobbying expenditures to influence public opinion (grassroots lobbying) 36 37 Total lobbying expenditures to influence a legislative body (direct lobbying)..... 37 38 Total lobbying expenditures (add lines 36 and 37)..... 38 39 Other exempt purpose expenditures 39 Total exempt purpose expenditures (add lines 38 and 39)..... 40 40 Lobbying nontaxable amount. Enter the amount from the following table — If the amount on line 40 is -The lobbying nontaxable amount is -Over \$500,000 but not over \$1,000,000 \$100,000 plus 15% of the excess over \$500,000 41 Over \$1,000,000 but not over \$1,500,000 \$175,000 plus 10% of the excess over \$1,000,000 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 \$1,000,000 42 Grassroots nontaxable amount (enter 25% of line 41)....... 42 Subtract line 42 from line 36. Enter -0- if line 42 is more than line 36...... 43 Subtract line 41 from line 38. Enter -0- if line 41 is more than line 38.......... 44 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 (a) (b) (c) (d) (e) (or fiscal year 2007 2006 2005 2004 Total beginning in) > Lobbying nontaxable amount ... Lobbying ceiling amount (150% of line 45(e)) . Total lobbying expenditures 48 Grassroots nontaxable amount Grassroots ceiling amount (150% of line 48(e)) ... 50 Grassroots lobbying expenditures Part VI-B Lobbying Activity by Nonelecting Public Charities (For reporting only by organizations that did not complete Part VI-A) (See instructions.) During the year, did the organization attempt to influence national, state or local legislation, including any Yes No Amount attempt to influence public opinion on a legislative matter or referendum, through the use of: Х b Paid staff or management (Include compensation in expenses reported on lines c through h.). X c Media advertisements...... Х d Mailings to members, legislators, or the public e Publications, or published or broadcast statements..... Х X f Grants to other organizations for lobbying purposes

If 'Yes' to any of the above, also attach a statement giving a detailed description of the lobbying activities

g Direct contact with legislators, their staffs, government officials, or a legislative body......

h Rallies, demonstrations, seminars, conventions, speeches, lectures, or any other means ...

i Total lobbying expenditures (add lines c through h.).....

Х

Х

153,978.

153,978.

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

51 Did the	e reporting organization of Code (other than section	directly or in	directly engage in any of the followin	ig with any other organization describing to political organizations?	ed in secti	on 50	1(c)
			o a noncharitable exempt organizatio			Yes	No
					51 a (i)		X
(ii)Ot	her assets			.,	a (ii)		X
b Other	transactions:						
(i)Sa	les or exchanges of asse	ets with a no	oncharitable exempt organization		b (i)		Χ
(ii)Pu	rchases of assets from a	a noncharita	ble exempt organization		b (ii)		X
(iii)Re	ntal of facilities, equipme	ent, or other	r assets		b (iii)		<u>X</u>
(iv)Re	imbursement arrangeme	nts			b (iv)		<u>X</u>
							_X
, ,			•				Χ_
c Sharin	g of facilities, equipment	t, mailing lis	ts, other assets, or paid employees		<u> </u>		<u>X</u>
d If the a the go any tra	answer to any of the abo ods, other assets, or ser ansaction or sharing arra	ve is 'Yes,' vices given ngement, sl	complete the following schedule. Coll by the reporting organization, If the c now in column (d) the value of the go	umn (b) should always show the fair r organization received less than fair ma ods, other assets, or services receive	market val arket value d:	e in	
(a)	(b) Amount involved		(c) noncharitable exempt organization	(d) Description of transfers, transactions, and			te
Line no.	Amount involved	name or	Honoriantable exempt organization	Description of transfers, transactions, and	Sharing arra	ngenien	
	····						
						-	
							
		······································					
							
-					,		
····							
			iliated with, or related to, one or more ther than section 501(c)(3)) or in sect	e tax-exempt organizations lion 527?	► Ye	s X	No
····	,' complete the following	schedule:	(b)	(c)			
	(a) Name of organization		(b) Type of organization	(c) Description of relatio	nship		
	_						
						·	
·			٩				
···· · · · · · · -							
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· U L 							
					<u></u>	·-··	
					000	00.75	
BAA				 Schedule A (Formalis) 	n 990 or 9	90-E.Z	<i>)</i> 2007

Schedule B (Form 990, 990-EZ, or 990-PF)

Department of the Treasury Internal Revenue Service

Schedule of Contributors

Supplementary Information for line 1 of Form 990, 990-EZ and 990-PF (see instructions)

OMB No. 1545-0047

2007

Name of organization		amproyer ractionation frames.
THE NATIONAL HEMOPHIL	13-5641857	
Organization type (check one):		
Filers of:	Section:	
Form 990 or 990-EZ	X 501(c)(3) (enter number) organ	nization
	4947(a)(1) nonexempt charitable tru	st not treated as a private foundation
	527 political organization	
Form 990-PF	501(c)(3) exempt private foundation	
	4947(a)(1) nonexempt charitable tru	st treated as a private foundation
	501(c)(3) taxable private foundation	
Check if your organization is cover boxes for both the General Rule as	red by the General Rule or a Special Rule. (Note: <i>Onl</i> nd a Special Rule — see instructions.)	ly a section 501(c)(7), (8), or (10) organization can check
General Rule —	200 000 F7 - 200 PF Had was included the case	
contributor. (Complete Parts)	990, 990-EZ, or 990-PF that received, during the year, and II.)	\$5,000 of filore (in money or property) from any one
Special Rules —		
For a section 501(c)(3) organiz 509(a)(1)/170(b)(1)(A)(vi) and amount on line 1 of these form	zation filing Form 990, or Form 990-EZ, that met the 3 received from any one contributor, during the year, a ns. (Complete Parts I and II.)	3-1/3% support test of the regulations under sections contribution of the greater of \$5,000 or 2% of the
For a section 501(c)(7), (8), or aggregate contributions or beq purposes, or the prevention of	(10) organization filing Form 990, or Form 990-EZ, th luests of more than \$1,000 for use <i>exclusively</i> for relig cruelty to children or animals. (Complete Parts I, II, a	at received from any one contributor, during the year, jious, charitable, scientific, literary, or educational and III.)
\$1,000. (If this box is checked, etc, purpose. Do not complete	any of the Parts unless the General Rule applies to the	ese contributions did not aggregate to more than during the year for an <i>exclusively</i> religious, charitable, his organization because it received nonexclusively
religious, charitable, etc, contr	ibutions of \$5,000 or more during the year.)	
990-PF) but they must check the b	ot covered by the General Rule and/or the Special Rule box in the heading of their Form 990, Form 990-EZ, or if Schedule B (Form 990, 990-EZ, or 990-PF).	es do not file Schedule B (Form 990, 990-EZ, or on line 2 of their Form 990-PF, to certify that they do
BAA For Paperwork Reduction A for Form 990, Form 990-EZ, and F	ct Notice, see the Instructions orm 990-PF.	Schedule B (Form 990, 990-EZ, or 990-PF) (2007)

Compensation of Current Officers, Directors, Key Employees, Etc.

Name as Shown on Return

THE NATIONAL HEMOPHILIA FOUNDATION

13-5641857

Compensation

Name	Chk if a Bus	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
Val Bias Stephen Bender RAY STANHOPE RITA GONZALES See Compensation		29,808. 0. 0.	0.	26,827.	2,981.
Total Compensation Received		219,808.	76,000.	121,827.	21,981.

Contributions to Employee Benefit Plans & Deferred Compensation Plans

Name	Chk if a Bus	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
Val Bias Stephen Bender RAY STANHOPE RITA GONZALES See Employee Benefit Plans & Total Contributions to Employee Benefit Plans & Deferred Compensation	. Defe	0. 0. 0. 0. rred Compensation	on Plans		
Plans		26,891.	10,756.	13,446.	2,689.

Expense Account and Other Allowances

[^] Name	Chk if a Bus	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
Val Bias Stephen Bender RAY STANHOPE RITA GONZALES		10,000. 0. 0.		9,000.	1,000.
See Expense Account and Oth Total Expense Account and	ier All			0.000	1,000.
Other Allowances Total to Part II, Line 25a		10,000. 256,699.	86,756.	9,000. 144,273.	25,670.

17,864.

160,786.

0.

178,650.

Name as Shown on Return	Employer Identification No.
THE NATIONAL HEMOPHILIA FOUNDATION	13-5641857

Loans and Advances (D) (C) (A) (B) Fundraising Management Program Total Name and general services Total Loans & Advances Compensation (D) (C) (A) (B) Fundraising Management Total Program Name and general services 14,822. 148,224. 0. 133,402. Alan Kinniburgh PHD **Total Compensation** 14,822. 0. 133,402. Received 148,224. Contributions to Employee Benefit Plans & Deferred Compensation Plans (D) (A) (B) (C) Fundraising Total Program Management Name and general services 0. 27,384. 3,042. 30,426. Alan Kinniburgh PHD Total Contributions to Employee Benefit Plans & **Deferred Compensation** 27,384. • 3,042. 30,426. 0. Plans **Expense Account and Other Allowances** (C) (D) (A) (B) Fundraising Management Total Program Name and general services Total Expense Account and

Other Allowances

Total to Part II, Line 25b ►

Form 990, Page 5, Part V-A List of Officers, Directors, Trustees, & Key Employees Statement

(A) Name and address	(B) Title and average hours per week devoted to position	(C) Compensation (if not paid, enter -0-)	(D) Contributions to employee benefit plans and deferred compensation	(E) Expense account and other allowances
Business X Person Rachel Miller				
C/O NHF116 W 32 ST. NY NY 10001	DIRECTOR			
- NY 10001	10.00	0.	0.	0.
Business X Person				
Thomas Truncale				•
C/O NHF116 W 32 ST. NY NY 10001	DIRECTOR		•	_
- NY 10001 Business X Person	10.00	0.	0.	<u> </u>
Business X Person Adam Wilmers				
C/O NHF116 W 32 ST. NY NY 10001	DIRECTOR			
- NY 10001	10.00	0.	0.	0.
Business X Person				
MICHAEL J. BORNHORST				
C/O NHF116 W 32 ST. NY NY 10001	DIRECTOR	_	_	_
- NY 10001	20.00	0.	0.	0.
Business X Person PHILLIP KUCAB				
C/O NHF116 W 32 ST. NY NY 10001	DIRECTOR			
- NY 10001	10.00	0.	0.	0.
Business X Person				
KENNETH G. MANN PHD				
C/O NHF116 W 32 ST. NY NY 10001	DIRECTOR			
- NY 10001	10.00	0.	0.	0.
Business X Person				
MICHAEL O'CONNOR C/O NHF116 W 32 ST. NY NY 10001	Vice Chair of the Bo		٠.	
- NY 10001	20.00	0.	0.	0.
Business X Person				
CLIFFORD COHEN				
C/O NHF116 W 32 ST. NY NY 10001	DIRECTOR			`*
- NY 10001	<u>15.00</u>	<u> </u>	0.	.0.
Business X Person				•
EILEEN BOSTWICK PHD C/O NHF116 W 32 ST. NY NY 10001	Director			
- NY 10001	15.00	0.	0.	0.
Business X Person	10.00			
Craig Kessler				
C/O NHF116 W 32 ST. NY NY 10001	MASAC Chair			
- NY 10001	20.00	0.	0.	0.
Business X Person				
STEVEN P. FAUST	DIBECTOR			
C/O NHF116 W 32 ST. NY NY 10001 - NY 10001	DIRECTOR 10.00	0.	0.	0.
Business X Person				
Philip Blomquist				
C/O NHF116 W 32 ST. NY NY 10001	Director			
<u>- NY 10001</u>	10.00	0.	0.	0.

Form 990, Page 5, Part V-A List of Officers, Directors, Trustees, & Key Employees Statement Continued

(A) Name and address	(B) Title and average hours per week devoted to position	(C) Compensation (if not paid, enter -0-)	(D) Contributions to employee benefit plans and deferred compensation	(E) Expense account and other allowances
Business X Person Howard Balsam C/O NHF116 W 32 ST. NY NY 10001 period 8/6/07~5/18/08 NY 10001	interim ceo 43.00	190,000.	26,891.	0.

Form 990. Part VI, Page 7, Line 90a

States Filed In

NEW YORK

Form 990, Page 1, Part I, Line 9

Special Events and Activities Statement

List of Three Largest Events and Type and Number of Others	Gross Receipts	Less Contributions	Gross Revenue	Less Direct Expenses	Net Income (Loss)
andretti luncheon	37,084.	0.	37,084.	17,623.	19,461.
Team Hemophilia	3,895.	0.	3,895.	5,389.	-1,494.
walkathon	253,432.	0.	253,432.	140,766.	112,666.
other	10,590.	0.	10,590.	14,482.	-3,892.
Total	305,001.	0.	305,001.	178,260.	126,741.

Compensation

Foirm 990, Part II. Line 25a

Compensation

Name	Chk if a Bus	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising	
Michael Luettgen Rachel Miller Thomas Truncale Adam Wilmers MICHAEL J. BORNHORST PHILLIP KUCAB KENNETH G. MANN PHD MICHAEL O'CONNOR CLIFFORD COHEN EILEEN BOSTWICK PHD Craig Kessler STEVEN P. FAUST Philip Blomquist		0. 0. 0. 0. 0. 0. 0. 0. 0.				
Howard Balsam		190,000.	76,000.	95,000.	19,000.	

Foirm 990, Part II. Line 25a

Compensation

Continued

	Name	Chk if a Bus	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
Total		- I I	190,000.	76,000.	95,000.	19,000.

Form 990, Part II, Line 25a

Employee Benefit Plans & Deferred Compensation Plans

Contributions to Employee Benefit Plans & Deferred Compensation Plans

Name	Chk if a Bus	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
Michael Luettgen Rachel Miller Thomas Truncale Adam Wilmers MICHAEL J. BORNHORST PHILLIP KUCAB KENNETH G. MANN PHD MICHAEL O'CONNOR CLIFFORD COHEN EILEEN BOSTWICK PHD Craig Kessler STEVEN P. FAUST Philip Blomquist Howard Balsam		0. 0. 0. 0. 0. 0. 0. 0. 0. 0.	10,756.	13,446.	2,689.
Total	·	26,891.	10,756.	13,446.	2,689.

Form 990, Part II. Line 25a

Expense Account and Other Allowances

Expense Account and Other Allowances

Name	Chk if a	(A) Total	(B) Program	(C) Management	(D) Fundraising
Name	Bus	Total	services	and general	T difdraioing
Michael Luettgen		0.			
Rachel Miller		0.		_	
Thomas Truncale		0.		.	
Adam Wilmers		0.			
MICHAEL J. BORNHORST				.	
PHILLIP KUCAB	<u> </u>	0.			
KENNETH G. MANN PHD		0.			
MICHAEL O'CONNOR	IIII	. 0.			
CLIFFORD COHEN	II	0.			
EILEEN BOSTWICK PHD	_	0.			
Craig Kessler		0.			

Form 990, Part II. Line 25a
Expense Account and Other Allowances

Continued

Expense Account and Other Allowances

Name	Chk if a Bus	(A) Total	(B) Program services	(C) Management and general	(D) Fundraising
STEVEN P. FAUST Philip Blomquist Howard Balsam		0.			

Total

0.

Form 990, Page 4, Part IV, Lines 57a & 57b Land, Buildings and Equipment Statement

	(a) Cost/Other Basis	(b) Accumulated Depreciation	(c) Book Value
furniture fixturers & equipment	185,234.	185,234.	0.
computers	984,775.	982,478.	2,297.
leasehold improvements	150,982.	150,982.	0.

Total

1,320,991.

1,318,694.

2,297.

Supporting Statement of:

Form 990 p 4/Line 60, column (A)

Description	Amount
accounts payable	470,681.
accrued expenses	281,490.
accrued payroll vacation	217,725.
Total	969,896.

Supporting Statement of:

Form 990 p 4/Line 60, column (B)

Description	Amount
Accounts Payable	423,203.
Accrued Expenses	501,329.
Accrued payroll and accrued vacation	245,625.
Total	1,170,157.



Summary Report of the National Hemophilia Foundation's Accomplishments in 2008

Introduction

The National Hemophilia Foundation (NHF), founded in 1948, has a history of service through education, research and advocacy for individuals and families living with and affected by hemophilia and, later, other bleeding disorders. Now as a well-established organization in its 60th year, responsiveness is the hallmark of the successful evolution of NHF services. The organization has evolved to meet new, emerging and evidence-based needs as they have arisen. NHF has grown to encompass a network of 48 community-based chapters nationwide; independent organizations of varying capacity. Along with about 15 independent associations,* and collaboration with 140 hemophilia treatment centers (HTCs),* the chapters are instrumental in implementing NHF's health promotion programs. These programs are developed and run in conjunction with partners at the Centers for Disease Control and Prevention (CDC) and its Division of Blood Disorders.

The programmatic activities conducted in FY 2008 aimed to prevent secondary conditions in people with bleeding disorders by improving their access to public health programs and implementing effective health promotion and wellness programs. NHF's overall objective is to increase the percentage of people with bleeding disorders who: 1) know about and have access to HTC-based comprehensive care services and local chapter/NHF services; 2) recognize and know strategies to prevent typical and emerging secondary conditions; 3) are aware of and understand emergency preparedness initiatives; and 4) are aware, have knowledge of and participate in safe physical activities and healthy eating.

The variation in disease impact and needs in different subgroups of the bleeding disorders population demands a life stages approach to NHF's work plan objectives and activities. The CDC recognize the validity of this approach, as mentioned in one of its Health Protection Goals, "Healthy people in every stage of life," and in Healthy People 2010's focus on the "unique health issues and risk behaviors that affect the quality of health in every stage of life." The NHF strategies are tailored and targeted for all life stages, from early childhood—by reaching new parents/families, through teens and young adults, to adults. Gender and race/ethnicity are also important subgroup focus areas.

^{*}For purposes of this report, all chapters and independent associations are referred to as "chapters." Chapters pay membership dues to NHF, associations do not. Both work in collaboration with NHF. Membership in NHF is not required to receive NHF services and materials.

[•] Hemophilia treatment centers (HTCs) are federally funded and provide state-of-the-art medical and psychosocial services, and research through a team of bleeding and clotting disorder specialists.

Education Department/HANDI

Successful Information Forums—Mechanisms for disseminating bleeding disorders information and conducting education sessions: NHF has identified two successful information forums that help achieve the objectives delineated in this report: Annual Meeting and HANDI. Through outreach, education and networking at Annual Meeting and through the services offered by HANDI, NHF's information resource center, NHF reaches all subpopulations or life stages.

HANDI

HANDI is NHF's information resource hotline and library for consumers (people with bleeding disorders), their families and healthcare providers who are seeking more information about bleeding and clotting disorders. Information specialists are available 40 hours a week, via an 800 phone line, and through e-mail. In 2008 they answered more than 2,220 requests in 33 subject areas, distributing approximately 12,000 publications that have addressed each of the subpopulations or life stages.

In collaboration with NHF's Education Department, HANDI exhibited bleeding disorders information at NHF's 10th Anniversary Women's Conference, the American College of Obstetricians and Gynecologists (ACOG) Clinical Meeting in May 2008 and the World Federation of Hemophilia's 28th World Congress in Turkey in June 2008.

HANDI also works with NHF's Education Department to update brochures for Project Red Flag (PRF), the women with bleeding disorders awareness campaign, and for the National Prevention Program. To accommodate a burgeoning Spanish audience, it created a Spanish translation of NHF's general fact sheet on bleeding disorders.

HANDI and NHF's Education Department have begun preparations to be available 24 hours a day, 7 days a week to ensure that information dissemination and referrals for vital resources are maintained for the bleeding disorders community in an emergency. Staff members in the Education and Communications Departments have been trained by HANDI staff on proper procedures and resources available in a disaster emergency. Certain requirements have been set up for these additional staff such as the length of a shift, the ability to have Internet and phone access, a USB drive containing essential referral information and laptop computers. Education and HANDI are currently working on developing protocols for gathering information, creating an emergency services e-mail and means for remotely accessing the NHF database.

NHF National Prevention Program (NPP)

The National Prevention Program is NHF's primary education initiative collaborating with the Centers for Disease Control and Prevention (CDC), chapters, HTCs and consumers to help individuals make informed decisions to prevent or reduce the complications of bleeding disorders. NPP's theme is *Do the 5!*, five strategies for living a longer and healthier life. NHF conducts annual trainings, develops materials, and provides grants to chapters to get individuals to *Do the 5!* The campaign messages are featured prominently at the NHF Annual Meeting.

The Do the 51 messages are:

- 1. Get an annual comprehensive checkup at a hemophilia treatment center
- 2. Get vaccinated Hepatitis A and B are preventable
- 3. Treat bleeds early and adequately
- 4. Exercise and maintain a healthy weight to protect your joints
- 5. Get tested regularly for blood-borne infections

Annual Meeting

The NHF Annual Meeting is the national education event of the year for the combined audiences of people with bleeding disorders and their families (± 60%); healthcare providers (±20%) and industry representatives (approximately 20%). Unique among annual meetings of national voluntary health agencies, NHF brings together, at one conference, these varied but connected constituencies. The Annual Meeting is one of the methods NHF uses to deliver prevention education messages to the bleeding disorders community.

Reaching and Educating Individuals and Families with Bleeding Disorders:

In this report period, NHF conducted its Annual Meeting in November of 2007 in Orlando, Florida. Of the total 2762 attendees, 1,447 or 52% were consumers—with persons with bleeding disorders comprising 33% of consumer-attendees and family members/significant others 50%. Others in the consumer category describe themselves as "friends" or "supporters."

Youth at the 59th Annual Meeting in Orlando, FL, totaled 413. This is typical for the location, which attracts the largest number of youth and children. Of these youth, 25 were the young adult members of the NHF National Youth Leadership Institute (NYLI), who receive training at the Annual Meeting.

Among consumers 75% report their race/ethnicity as Caucasian; 22% as a racial-ethnic minority: African-American (9%), Latino (8%), Asian (4%) and Native American (1%); 3% declare "other" or give no reply. Concerning specific bleeding disorders, the highest number of attendees is affected by hemophilia—613 reporting hemophilia as their personal/family disease; and 143 reporting von Willebrand disease (VWD).

The special character of the NHF meeting, bringing together the key, interacting constituencies in one location allows NHF to train and educate consumers (patients and families). simultaneously with their healthcare providers—delivering best practices and the same uniform, consistent messages across groups, and amplifying the efficacy and the learning impact. HANDI staff disseminated more than 100 discrete resources and patient education materials throughout the Annual Meeting.

Education Sessions and the National Prevention Program (NPP) Messages:

Education Sessions are the centerpiece of the NHF Annual Meeting. They extend and enhance the core prevention messages stressed in NHF's National Prevention Program (NPP) and help reach underserved populations and women with bleeding disorders. Sessions at the Annual

¹ Of almost 550 bleeding/clotting disorder healthcare providers: 35% were RNs, 19% MDs, 16% SWs and 8% PTs.

Meeting cover exercise and nutrition, proper treatment of bleeds; hepatitis and blood-borne infections; the value of HTC comprehensive care—all synchronizing with the *Do the 5!* prevention messages. And every annual meeting since 1998 has included sessions for women with bleeding disorders. Each of the education sessions is evaluated on a 4.0 scale, where 4 = excellent. Of the 43 Education Sessions offered to consumers (non-MD sessions) in 2007, 26 (60%) received scores equal or greater than 3.6. Examples of sessions with their ratings in 2007 include:

- ABCs of Bleeding Disorders (3.88)
- Building Resiliency (3.40)
- Hepatitis C: What You Need to Know (3.83)
- Evaluating Your Hepatitis C via Biopsy (3.46)
- Blood and Product Safety (3.41)
- Preparedness: A Refresher (3.87)
- NPP Chapter Grant Initiatives (3.79)
- Do the 5!—Fit Adults, Fit Kids (Lifestyles for a long and healthy life) (3.68)
- Workshop on VWD Basics: Women and Men (3.80)
- Managing and Living with VWD (3.50)
- Ask the Experts: Women (3.85)

NHF also recognized oustanding chapter programs with Awards of Distinction for health education, outreach and communications. Winning chapters received a \$1,000 incentive to enhance their program. NHF gave 16 Awards of Excellence to outstanding individuals in such areas as nursing, social work, research, physical therapy, genetic counseling, volunteering and advocacy. Physician and humanitarian of the year awards were also conferred.

Education in Thrombosis and Thrombophilia

Education in thrombosis and thromobophilia has been developed by NHF specifically for the providers within the Hemophilia Treatment Center (HTC) network. For example, at the 59th Annual Meeting of NHF, sessions that were specialty-specific were conducted, i.e., for Nurses, Social Workers and Physicians.

In developing our provider sessions in the area of clotting, we work with the National Alliance for Thrombosis and Thrombophilia to acquire the top faculty and for the appropriate support materials.

Through HANDI, NHF's information resource center, an average of five requests are received per month, from both patients and providers in the area of clotting disorders. NHF disseminates state-of-the-art treatment articles and refers patients to both NATT and to HTCs in their local area.

Annual Meeting Planning for 2008 - Denver, Colorado

In January 2008, HTC, chapter and consumer representatives, CDC partners and NHF staff met in Denver, Colorado, to plan the education sessions for the 60th Annual Meeting November 13-15, 2008. Using recent literature as well as evaluations of prior meetings as guidelines, the Annual Meeting Working Group developed more than 40 education sessions for constituents and 15 medical education sessions.

Meeting the Needs of Patients and Families

Parents of newly diagnosed children consistently report a high level of learning through Annual Meeting education sessions, both in evaluation grades and in their comments. "The sessions provide a good mix of technical information and everyday good advice," wrote one parent. The written feedback on evaluation forms also provides suggestions to improve education offerings. Concerning the Emergency Preparedness session in 2007, participants asked for a template to guide them in creating their own emergency plan and a more hands-on learning approach to the session. Our Annual Meeting planning team for 2008 incorporated these elements, including a table-top practice exercise, for the next Annual Meeting. The context of the NHF Annual Meeting as a teaching/learning environment offers the singular opportunity to tackle substantive, poignant topics and issues openly and thoroughly. For example, several comments on the "Managing and Living with VWD" session are captured in this participant's response: "I really appreciate the emphasis on problems and answers about life issues, (such as) intimacy and communication with your partner."

Objectives and Activities

 Newly diagnosed families, in 10 First Step-trained communities, will improve their knowledge, attitudes and behaviors concerning their bleeding disorder.

NHF provides education, mentoring and social networking for parents/guardians and families with newly diagnosed children through its First Step Program. In this project period we have enhanced NHF's First Step program with new education modules and activities including sections on inhibitors, physical activity/nutrition and ethics in the bleeding disorders community; monitored the First Step discussion board and online web services; funded 7 chapters to conduct First Step programs;² conducted 2 mentor training sessions; convened the First Step Task Force for program and strategic planning; conducted education and networking sessions at our Annual Meeting in 2007; conducted focus groups to explore topics of interest to families of children up to age 12; and trained veteran parents to become mentor parents; and distributed more than 300 First Step brochures and welcome kits to families with newly diagnosed children.

As of May 2008, of the 7 funded chapters, 6 had completed their programs. These chapters conducted education sessions at local First Step meetings and parent dinners, hosted support and networking groups, trained veteran parents as mentors and coordinated social outings with educational components. Each chapter conducted at least 3 First Step meetings and, on average, approximately 20-25 parents attended an event or meeting. According to pre- and post-tests distributed at the First Step meetings, knowledge, attitudes and behaviors related to the prevention messages increased by at least 10% among the families of newly diagnosed children.

In April 2008, 7 new First Step grants were awarded (including 3 chapters that had never had a previous First Step program). A workshop to guide chapters on implementing First Step (Refresher Course) will be conducted September 9, 2008.

 Improve self-efficacy and leadership skills of youth and young adults who participate in NHF events

² Through a public-private partnership education grant

NHF's National Youth Leadership Institute (NYLI) fosters the development of youth leaders to help NHF chapters and associations across the country build strong youth programs. 25 NYLI members attended the Annual Meeting in November 2007, where they received leadership training in the following areas: presentation/public speaking skills, conflict of interest and marketing practices within the bleeding disorders community. NYLI also attended general education sessions on bleeding disorders to further their understanding of prevention behaviors. Several members presented their local project, which allow them to work with their local chapter. Some of the local projects included writing a children's book on bleeding disorders and siblings, preventive health education for youth attending summer camp, and creating a new camp for children with bleeding disorders in Mexico. Ninety-two percent (92%) of NYLI members in attendance found the sessions at Annual Meeting to be useful in helping them implement programs on the local level.

NYLI members also planned and implemented the first NHF Winter Youth Retreat., Forty-seven (47) teenagers from 26 states, Guam and Mexico attended the Youth Retreat at Camp-for-All in Burton, TX, in February 2008, and participated in activities that encouraged critical thinking, leadership and physical activity. Along with NYLI and NHF staff, collaboration from the medical staff of Gulf States Hemophilia and Thrombophilia Center, Youth Development Specialist Pat Torrey and the staff at Camp-for-All ensured the success of the retreat. The overall feedback from the retreat was positive. One camper said, "I learned new ways in which you can be a leader. I also learned that you don't have to be an expert at something to teach it to someone else."

Since the retreat, NHF has received many calls requesting further information about NYLI, how people can get involved and how younger youth, not yet old enough for NYLI, can get involved as well. Anne Henningfeld, Director, Camp Bold Eagle in Michigan, stated, "I have gotten calls now from kids out of state that attended the retreat and friends of those who attended the retreat asking to take part in our youth programs here. There has been a huge ripple effect from your retreat," One NYLI member chronicled his participation as a counselor at the Youth Retreat in the May/June 2008 issue of *HemAware*, NHF's bi-monthly magazine.

NYLI members attended NHF's Washington Days in March 2008, where they learned about the legislative process; how a bill becomes law, state vs. federal advocacy and how to share their stories with legislators. Additionally they sat in on a hearing on the Hill where Dr. Julie Gerberding, Director of the CDC, presented, "Health Issues and Opportunities."

In May, two women from NYLI and one alumnus facilitated "Things I wish my mother had told me..." a session at the NHF national women's conference., It provided young adults' perspective on living with a bleeding disorder for chapters, providers and consumers from across the country. The NYLI also takes advantage of opportunities that might arise where they can meet with and bring leadership training to youth in local chapters.³

· Increase the knowledge of women's bleeding disorders and strategies for preventing

³ NYLI took part in planning and implementing Team Hemophilia on Tour, a public awareness initiative with Andretti Green Racing and Bayer Healthcare. NYLI members boarded the tour bus and headed to different Indy Car Race sites during the summer. stopping at chapters and summer camps along the way to facilitate youth programs on leadership, self-efficacy and prevention education.

secondary conditions, among national women's conference attendees

At the NHF Annual Meeting in 2007 a pre-conference symposium for consumers, "Focus on von Willebrand disease (VWD)," was attended by 60 consumers and received an overall evaluation of 3.8 of a possible 4.0. Expert speakers included Roshni Kulkarni, MD; Andra James, MD; Thomas Abshire, MD, and Edward Kuebler, LMSW-ACP. The session, "Ask the Experts: Women," received an overall evaluation of 3.8 of a possible 4.0. Drs. Barbara Konkle and Andra James addressed hematologic as well as gynecologic concerns of women patients.

The Women with Bleeding Disorders Task Force and NHF staff planned a curriculum for a national women's conference⁴, May 16-17, 2008, in Durham, North Carolina, to address compelling issues for women in the bleeding disorders community and to mark the 10^h anniversary of NHF's women's initiative – Project Red Flag (PRF). The conference focused on:

- reducing secondary complications for women with bleeding disorders and carriers
- reducing unnecessary medical procedures within the same population
- reducing obesity (within the same population)
- addressing areas of misinformation about bleeding disorders in women
- providing strategies to maximize the use of evidence-based medical guidelines published by the NHLBI on diagnosis and treatment of VWD
- addressing unmet needs identified by younger women with bleeding disorders

An expert faculty was recruited; approximately 150 people attended. Highlights of this 10th anniversary celebration along with an historical perspective on the success of Project Red Flag are presented in the May/June 2008 issue of *HemAware*.

In this project period, with CDC input, we have updated and redesigned all PRF brochures to reflect the NHLBI Guidelines on diagnosis and treatment of VWD. Two \$2500 Project Red Flag Scholarships have been awarded to women with bleeding disorders pursuing college degrees. Competitive applications were reviewed for best practice model programs at local organizations and 10 grants were awarded, totaling more than \$72,000. These grants provide much needed funds for local chapters to educate women and provide information on women's bleeding disorders. At ACOG in May 2008, Education and HANDI staff disseminated PRF materials and the NHLBI guidelines as well as hosted a symposium for 60 obstetricians and gynecologists, presented by Dr. Andra James (former chair of the Women with Bleeding Disorders Task Force), to raise awareness and improve the diagnosis and treatment of women with bleeding disorders.

• Increase access to language-appropriate information and prevention strategies among minority populations

The NHF Multicultural Task Force attended the NHF Annual Meeting in November 2007 to review and comment on the English version of NHF's "Fast Facts," summarizing general information on bleeding disorders, von Willebrand disease, clotting disorders and NHF programs. Three of the task force members translated the "Fast Facts" into Spanish for distribution to all federally funded HTCs and all chapters/associations. Translation of the Fast Facts sheets into Vietnamese began in September 2008.

For NHF's 59th Annual Meeting, the 5th Annual Travel Grant Program for first-time attendees

⁴ Through public-private partnership education grant

was implemented. NHF provided assistance to individuals and/or families with bleeding disorders who would be unable to attend due to financial constraints and had never attended an NHF Annual Meeting. Forty-three individuals, from 12 families affected by bleeding disorders, were awarded travel grant scholarships to attend. The families represented predominantly Latinos, Asian/Pacific Islanders, African-Americans and a small number of Caucasians. Registration data show that this program increased by approximately 10% the number of minority families who have attended the Annual Meeting in 2007. The families were very appreciative of the opportunity to meet other families with bleeding disorders. NHF will provide a six-month follow-up report from the awardees about what they learned at Annual Meeting and their use of this information.

• Increase awareness and knowledge of the importance of physical activity/nutrition for preventing secondary conditions among attendees at NHF national meetings

The core activity for this objective is the Physical Activity and Nutrition Initiative NHF partners with the YMCA and CDC. We have developed draft program guidelines for chapters and local YMCAs to participate in a pilot physical activity/nutrition initiative and identified 6 local chapters (collaborating with an HTC) to participate in the initiative. NHF has been organizing and planning for this initiative for the first 6 months of this agreement – solidifying YMCA relations, developing program materials and canvassing and identifying 6 pilot chapters and corresponding local YMCA branches. In addition to this initiative, NHF conducted wellness education sessions at the 2007 Annual Meeting and planned wellness education sessions at the May national women's conference to further encourage the importance of physical activity/nutrition for people with bleeding disorders.

NHF has worked toward meeting its objective of increasing awareness and knowledge of physical activity/nutrition at NHF national meetings through educational and fitness sessions. At the 2007 Annual Meeting, "Doing the 5--Fit Adults, Fit Kids: Lifestyles for a Long and Healthy Life" was attended by more than 100 individuals and received a score of 92.3% out of 100%. To take an active approach, NHF's Education staff teamed up with the Physical Therapy Working Group to host a "Fit n' Run/Walk" for all conference attendees. The Annual Meeting Working Group met in January 2008 in Denver, Colorado, to help plan wellness sessions for the 2008 Annual Meeting taking place in November 2008.

On May 17, 2008, at our national women's conference we conducted a session on reducing obesity rates in women with bleeding disorders presented by our CDC partners. As the NHF/YMCA physical activity/nutrition initiative is in the planning phase, the creation and dissemination of educational materials has not yet taken place. In the meantime, HANDI continues to disseminate brochures to promote awareness and increase knowledge of participating in physical activity. Once the program officially begins, then we will be able to monitor the progress of individuals participating in it and measure intention to incorporate regular physical activity into their lifestyle in an ongoing manner, and adherence to regular physical activity for the project year as outcomes.

 Increase knowledge, attitude and behavior toward emergency preparedness among families with bleeding disorders in 5 local areas

This year we have worked with both our chapters and the NHF Disaster Preparedness Task Force to meet this objective. As mentioned above, based on feedback we have received from

consumers at chapter preparedness meetings and at the NHF Annual Meeting, we have charged the Task Force with compiling a very detailed check list of preparedness activities for both consumers and chapters. This check list will act as a template for a preparedness plan ensuring that consumers and chapters have detailed instructions for how to prepare for possible emergencies in their areas. It was available at NHF's Annual Meeting in Denver, Colorado, rolled out in an interactive session run by the Task Force members and our CDC partner, so that those attending gained exposure to the type of questions that need to be answered to put their plans together.

At the NHF Annual Meeting in 2007 the session, *Preparedness: a Refresher*, was co-presented by Sally Owens of the CDC and Gregory Thomas, MS, then with Columbia University's National Center for Disaster Preparedness. The objective of this session was to lead families and individuals with bleeding disorders and chapter and HTC representatives through best practices in essential preparedness planning. (This session received an overall average rating of 3.87.) This education session complemented the information presented in the September/October 2007 issue of *HemAware* -- "Preparing for Disaster." This feature article included precautionary information for people with bleeding disorders and provided important links for additional emergency preparedness resources. And as stated, feedback from this session was integral to planning an interactive 2008 Annual Meeting preparedness training session.

We have also worked with chapters and are starting 3 pilot site programs in Preparedness. Specifically, the Nebraska Chapter of the NHF is working on patient education seminars throughout the state so that all their members have the important information they need in an emergency; Hemophilia Foundation of Michigan is developing preparedness plans for its off-site meetings and summer camping programs, and the Hemophilia Foundation of Hawaii chapter is working on an inter-island communication plan in case of a disaster. All pilot programs will receive a supply of NHF Emergency Go-Bags and emergency contact cards, or "NHF Readiness Cards," to distribute to their constituents.

As NHF and CDC have identified HANDI as the primary information center during an emergency in the community, NHF is currently implementing its 24/7 HANDI phone line andhas trained the staff who will implement the plan.

• Increase knowledge of HTC Social Workers on Insurance and Reimbursement Issues
Recognizing the central role of social workers in increasing the patients' and families'
understanding of insurance coverage, NHF inaugurated a special training workshop for social
workers on this important topic. In April 2008, NHF conducted its third
Insurance/Reimbursement workshop, Access to Insurance at Every Life Stage, for 36 social
workers from across the country. The one-and-a half-day workshop received an overall rating of
3.9 on a 4.0 (4=Excellent) scale; continuing education units (CEUs) were provided for the
participants. In the program's 3 years, NHF has trained a total of 111 social workers.

Research and Medical Information Department

Awarded a Clinical Fellowship to:

 Mindy Grunzke, MD, University of Colorado at Denver and Health Science Center Mountain States Regional Hemophilia and Thrombosis Center

Awarded Career Development Awards to:

- Qizhen Shi, MD, PhD, Medical College of Wisconsin for her project, "Immune Response in Platelet-Derived FVIII Gene Therapy of Murine Hemophilia A."
- Alisa Wolberg, PhD, University of North Carolina at Chapel Hill, for her project, "Recombinant Factor VIIa and RL Platelets as a Hemophilia Therapy."

Awarded Judith Graham Pool Postdoctoral Research Fellowships to:

- Jyoti Mathur, PhD, Stanford University, for her project, "AAV Vectors for the Treatment of Hemophilia B."
- Ruijin Su, MD, PhD, Puget Sound Blood Cente,r for her project, "Targeting Dendritic Cells to Induce Immune Tolerance to Factor VIII."
- Jun-Jiang Sun, MD, University of North Carolina at Chapel Hill, for his project, "Hemophilia Arthropathy: Gene Delivery Vectors for Determining Mechanisms and Therapy."

Awarded a Nursing Excellence Fellowship to:

• Judith Kauffman, RN, BSN, MS, CPNP, and Kacie Kaufman, RN, MSN, BC-APN, The Children's Mercy Hospital, Kansas City, MO, for their joint project, "The Effects of an Educational Intervention on Joint Health in Children with Hemophilia."

Awarded a Physical Therapy Excellence Fellowship to:

• Jenny Robison, PT, Vanderbilt University Medical Center, Nashville, TN, for her project, "The Effect of Inframalleolar Orthotics on Temporal Gait Characteristics and Foot Pressures in Children with Hemophilia."

Held in conjunction with Baxter BioScience the first meeting of all current and graduated NHF Clinical Fellows

Held NHF's 9th Novel Technologies and Gene Transfer for Hemophilia Workshop, February 22-23, 2008, at the Children's Hospital of Philadelphia

Exhibited NHF materials, answered questions and received requests for information at the American College of Obstetricians and Gynecologists Annual Meeting in New Orleans, LA, World Federation of Hemophilia Congress in Istanbul, Turkey, and the International Society on Thrombosis and Haemostasis Congress in Geneva, Switzerland.

Produced a new consumer publication, "Nosebleeds."

Through NHF's resource center, HANDI, specialists answered approximately 4,500 requests for information and distributed more than 30,000 publications.

In conjunction with volunteers, HANDI staff assisted in developing all educational tracks for the providers--physicians, nurses, social workers and physical therapists-- who attended NHF's Annual Meeting in Orlando, FL.

Public Policy Department

In 2008, the highlight NHF's public policy work was the introduction of the Health Insurance Coverage Protection Act (S. 2706/H.R.6528), introduced by Senator Byron Dorgan (D-ND) and Representatives Anna Eshoo (CA), Betty Sutton (OH), Jason Altmire (PA) and James Langevin (RI) in the House. The legislation would ultimately set the minimum lifetime caps on private insurance plans at \$10 million with an annual inflationary index.

The Senate version of the legislation was introduced during NHF Washington Days 2008, an annual event where members of the bleeding and clotting disorders communities from across the country converge on the Hill to learn about key issues and meet with legislators and staff. This year's event attracted a record of more than 250 participants representing 40 states. Since its introduction, the bill has attracted the interest of many legislators as well as the media and a broad coalition of organizations representing healthcare consumers and industry. The original sponsors have agreed to reintroduce the legislation in the new Congress. NHF is now working with the rest of the coalition to commission a study from Price Waterhouse documenting the impact of lifetime caps and the potential impact of this legislation.

Also on the federal level, NHF is proud to have been part of the effort that led to the passage of the Genetic Information Nondiscrimination Act (GINA). In the bleeding disorders community, GINA is of particular importance to women who are interested in determining whether they are carriers of the gene for hemophilia but may have avoided testing in the past for fear of discrimination by insurers or employers.

Another important highlight was the establishment of pharmacy standards for hemophilia as outlined in NHF's Medical and Scientific Advisory Council's (MASAC) Recommendation #188, "MASAC Recommendations Regarding Standards of Service for Pharmacy Providers of Clotting Factor Concentrates for Home Use to Patients with Bleeding Disorders." This document recognizes the contribution of specialty pharmacy to the health and well-being of people with bleeding disorders. It furthermore establishes minimum standards that must be adhered to by pharmacies serving the bleeding disorders

population. Establishing such standards had become increasingly necessary as large specialty pharmacies lacking requisite experience on bleeding disorders began to enter the marketplace, in some cases as the recipient of sole or limited source contracts with large payers. NHF continues to work to promulgate these standards with pharmacies and payers. In addition, NHF is promoting these standards as a model initially for other groups dependent on specialty pharmacies for plasma-derived products and their recombinant analogues.

NHF has also worked closely with our chapters in a number of states around the country to respond to a variety of threats to access to high-quality care. These threats have included attempts by payers to reduce reimbursement rates for clotting factor, to limit access to products by means of restrictive formularies or preferred drug lists, or to establish sole source provider contracts. In almost every case, NHF has been successful in either completely preventing or at least mitigating the effects of these harmful actions. NHF is also working to minimize or prevent such actions through the establishment of legislative standards of care in the states or the establishment of bleeding disorders advisory boards to advise state governments on what is appropriate care for people with bleeding disorders.

Chapter Services Department

Beginning in 2005, the NHF Board, Senior Management, and chapter leaders throughout the U.S. engaged in a collaborative process of exploring new structures and models for NHF, aimed at improving services to individuals with bleeding and clotting disorders nationwide.

The consensus was that NHF was not adequately structured to face present and future challenges. This effort culminated in a Chapter Development plan designed to create a more viable and sustainable chapter network in order to better serve NHF's owners (individuals and their families affected by bleeding and clotting disorders) throughout the country.

Options were provided to all chapters for how they will affiliate with NHF, and a set of Chapter Standards were developed to ensure a minimum level of program services, fundraising and operations throughout the chapter network. NHF established a new Chapter Services Department, with regional staff in place to help guide and assist chapters.

To fund the Chapter Development plan, the Campaign for Our Future was launched late in 2008. Proceeds from this effort will assist chapters with staffing and operational needs as they strive to meet Chapter Standards.

Form 990-

Exempt Organization Business Income Tax Return

(and proxy tax under section 6033(e))	
year 2007 or other tax year beginning Jul 1	, 2007,

20	10	7
	, ~	

401(a) trust

Department of the Treasury Internal Revenue Service (77)

408A

C

For calendar year 2007 or other tax year beginning Jul 1, 2008 and ending Jun 30

Other trust

OMB No. 1545-0687

Open to Public Inspection for 501(c)(3) Organizations Only See separate instructions. Check box if name changed and see instructions.) Employer identification number Name of organization (Check box if address changed (Employees' trust, see instructions for Block D.) THE NATIONAL HEMOPHILIA FOUNDATION Print Exempt under section Number, street, and room or suite number. If a P.O. box, see instructions. 13-5641857 or X 501(c)(3) Unrelated business activity codes (See instructions for Block E.) 116 WEST 32ND STREET Type 11TH FLOOR 408(e) 220(e) State ZIP code City or town 530(a) 10001-3212 511120 NEW YORK NY 529(a) Book value of all assets at end of year Group exemption number (See instructions for Block F.).

501(c) trust

ADVERTISING REVENUE FOR HEMAWARE PERIODICAL DISTRIBUTED TO BLEEDING AND CLOTTING COMMUNITY AND OTHERS . USED TO DISTRIBUTE EDUCATIONAL INFORM During the tax year, was the corporation a subsidiary in an affiliated group or a parent-subsidiary controlled group? . . . ▶ ☐ Yes If 'Yes,' enter the name and identifying number of the parent corporation... The books are in care of ► NATIONAL HEMOPHILIA FOUNDATION Telephone number► (212)328-3700

G Check organization type ► X 501(c) corporation

Describe the organization's primary unrelated business activity.

Par	Unrelated Trade or Business Income		(A) Income	(B) Expenses	(C) Net	
	Gross receipts or sales			walkana a sanata menana		
t	Less returns and allowancesc Balance 🟲	1c		860-11-24 P. 30 30 11-31		
	Cost of goods sold (Schedule A, line 7)					
3	Gross profit, Subtract line 2 from line 1c	1 1				
4 a	Capital gain net income (attach Schedule D)	4a				
	Net gain (loss) (Form 4797, Part II, line 17) (attach Form 4797)	I I				
	Capital loss deduction for trusts	4c		5. 李·传统的"克尔·克·克·克·克·克·克·克·克·克·克·克·克·克·克·克·克·克·克·		
5	Income (loss) from partnerships and S corporations (attach statement)					
6	Rent income (Schedule C)	6				
7	Unrelated debt-financed income (Schedule E)	7				
8	Interest, annuities, royalties, and rents from controlled organizations (Schedule F)	8				
9	Investment income of a section 501(c)(7), (9), or (17) organization (Sch G)	9				
10	Exploited exempt activity income (Schedule I)	10				
11	Advertising income (Schedule J)	11	1,011,523.	920,113.	91,410.	
12	Other income (See instructions; attach schedule.)			Ban 4 8 204 3 5 10		
	·	12		AND AND STATE		
13	Total. Combine lines 3 through 12	13	1,011,523.	920,113.	91,410.	

Deductions Not Taken Elsewhere (See instructions for limitations on deductions.)

	(Except for contributions, deductions must be directly connected with the unrelated business income.)							
14	Compensation of officers, directors, and trustees (Schedule K)	14	0.					
15	Salaries and wages	15						
16	Repairs and maintenance	16						
17	Bad debts	17						
18	Interest (attach schedule)	10						
19	Taxes and licenses	19						
20	Charitable contributions (See instructions for limitation rules.)	20						
21	Depreciation (attach Form 4562)							
22	Less depreciation claimed on Schedule A and elsewhere on return	22 b						
23	Depletion	23						
24	Contributions to deferred compensation plans	24						
25	Employee benefit programs							
26	Excess exempt expenses (Schedule I)	26						
27	Excess readership costs (Schedule J)	27	91,410.					
28	Other deductions (attach schedule)	28	01 410					
29	Total deductions. Add lines 14 through 28	29	91,410.					
30	Unrelated business taxable income before net operating loss deduction. Subtract line 29 from line 13	30	<u> </u>					
31	Net operating loss deduction (limited to the amount on line 30)		0.					
32	Unrelated business taxable income before specific deduction. Subtract line 31 from line 30		1,000.					
33	Specific deduction (Generally \$1,000, but see line 33 instructions for exceptions)	\ <u>~~</u>	1,000.					
34	Unrelated business taxable income. Subtract line 33 from line 32. If line 33 is greater than line 32, enter the smaller of zero or line 32.	34	0.					

Schedule C — Rent Inco					Leas	ed With Rea		erty) (see instructions)	
1 Description of property								······································	
(1)						······			
(2)					,				
(3)									
(4)	2 Rent received	l or occuped		.					
						3 Dedu	ictions d	firectly connected	
(a) From personal p (if the percentage of rent property is more than not more than 50	roperty for personal 10% but 0%)	(b) From r (if the personal if the rent is	eal and pe percentag property e based on	ersonal property le of rent for exceeds 50% or a profit or incon	y ne)	3 Deductions directly connected with the income in columns 2(a) and 2(b) (attach schedule)			
(1)									
(2)									
(3)					·				
(4)									
Total	To	otal							
Total income. Add totals of co here and on page1, Part I, line	lumns 2(a) and 2(b) e 6, column (A)	. Enter			Ī	Total deduction here and on poly line 6, colun	age 1, P	art art	
Schedule E - Unrelated	Debt-Financed	Income (see	instructio	ns)	,				
1 Description of o	debt-financed prope	rty	ora	s income from Illocable to	ļ	debt-	finance	ected with or allocable to d property	
			debt-fina	anced property	depre	(a) Straight line eciation (attach	sch)	(b) Other deductions (attach schedule)	
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(2)			ļ	·····	 				
(3)									
(4)	·····				ļ				
4 Amount of average acquisition debt on or allocable to debt-financed property (attach schedule) 5 Average adjust or allocable to de property (attach		debt-financed	6 Column 4 divided by column 5			7 Gross income reportable (column 2 x column 6)		8 Allocable deductions (column 6 x total of columns 3(a) and 3(b))	
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(3)				8	1		·		
(4)				ક					
Totals						here and on pa line 7, column	age 1, Ei i (A). Pa	nter here and on page 1 art I, line 7, column (B).	
Total dividends-received dedu	etions included in	caluma 0					►		
Schedule F — Interest, A								untions)	
Scriedule F — Interest, A	ilinuides, Royai	Exempt Cont			Orga	inzations (S	ee m <u>su</u> c	ictions)	
1 Name of Controlled Organization	2 Employer Identification Number	3 Net unr income (see instru	related (loss)	4 Total of sp	ecified nade	5 Part of c that is in- in the con organiza gross in	cluded trolling tion's	6 Deductions directly connected with incom in column 5	
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Nonexempt Controlled Organiz	rations					1		_!	
7 Taxable Income	8 Net unrelated	9 Total o	f specified	10 Part (of colum	nn 9 that is	11	Deductions directly	
7 Faxable income	income (loss) (see instructions	paymer	nts made	included	I in the	controlling oss income		nnected with income in column 10	
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Schedule G — Investment Inco					nization (se		3-564 uctions)		Page
1 Description of income	2 Amount of inc		3 direc	Deductions ctly connected ach schedule)	4 Set- (attach s	asides		5 Total set-as	deductions and ides (column 3 s column 4)
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Totals					•				
Schedule I — Exploited Exemp	t Activity Incom	ne, Otr	ier i ha		Income (se	e instru	ictions)		I
1 Description of exploited activity	2 Gross unrelated business income from trade or business	dire conr with pr of un bus	penses ectly nected roduction related iness come	4 Net income (loss) from unrelated trade or business (column 2 minus column 3). If a gain, compute columns 5 through 7.	5 Gross inc from activ that is no unrelate business income	ity d a	6 Expe attributa colum	ble to	7 Excess exempt expenses (column 6 minu column 5, but not more than column 4)
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Schedule J - Advertising Inco	me (See instruction	nns)		Lacison was engaged		OCUSER PROS	10,000,000	2000 11200	<u> </u>
Part I Income From Periodi			onsolid	ated Basis					
1 Name of periodical	2 Gross		Direct ertising osts	4 Advertising gain or (loss) (column 2 minus column 3). If a gain, compute columns 5 through 7.	5 Circulati income		6 Reade cost		7 Excess readership costs (column 6 minus column 5, but not more than column 4).
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(5) Totals from Part I						4.49		kinalo r	
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	► 1,011,523.), 113.	Estantica					<u> </u>
Schedule K — Compensation of	of Officers, Dire	ctors,	and in	ustees (see inst			T		
1 Name				2 Title	3 Percent of time devoted to business				ation attributable ated business
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