

Part II Balance Sheets Attached schedules and amounts in the description column should be for end-of-year amounts only. (See instructions.)		Beginning of year	End of year	
		(a) Book Value	(b) Book Value	(c) Fair Market Value
Assets	1 Cash—non-interest-bearing	78,231	77,113	77,113
	2 Savings and temporary cash investments			
	3 Accounts receivable ▶ _____ Less: allowance for doubtful accounts ▶ _____			
	4 Pledges receivable ▶ _____ Less: allowance for doubtful accounts ▶ _____			
	5 Grants receivable			
	6 Receivables due from officers, directors, trustees, and other disqualified persons (attach schedule) (see instructions)			
	7 Other notes and loans receivable (attach schedule) ▶ _____ Less: allowance for doubtful accounts ▶ _____			
	8 Inventories for sale or use			
	9 Prepaid expenses and deferred charges			
	10a Investments—U.S. and state government obligations (attach schedule)			
	b Investments—corporate stock (attach schedule)			
	c Investments—corporate bonds (attach schedule)			
	11 Investments—land, buildings, and equipment: basis ▶ _____ Less: accumulated depreciation (attach schedule) ▶ _____			
	12 Investments—mortgage loans			
	13 Investments—other (attach schedule)			
	14 Land, buildings, and equipment: basis ▶ _____ Less: accumulated depreciation (attach schedule) ▶ _____			
15 Other assets (describe ▶ _____)				
16 Total assets (to be completed by all filers—see the instructions. Also, see page 1, item I)	78,231	77,113	77,113	
Liabilities	17 Accounts payable and accrued expenses			
	18 Grants payable			
	19 Deferred revenue			
	20 Loans from officers, directors, trustees, and other disqualified persons			
	21 Mortgages and other notes payable (attach schedule)			
	22 Other liabilities (describe ▶ _____)			
	23 Total liabilities (add lines 17 through 22)	0	0	
Net Assets or Fund Balances	Foundations that follow FASB ASC 958, check here ▶ ☐ and complete lines 24, 25, 29 and 30.			
	24 Net assets without donor restrictions			
	25 Net assets with donor restrictions			
	Foundations that do not follow FASB ASC 958, check here ▶ ☒ and complete lines 26 through 30.			
	26 Capital stock, trust principal, or current funds	0	0	
	27 Paid-in or capital surplus, or land, bldg., and equipment fund	0	0	
	28 Retained earnings, accumulated income, endowment, or other funds	78,231	77,113	
	29 Total net assets or fund balances (see instructions)	78,231	77,113	
30 Total liabilities and net assets/fund balances (see instructions) .	78,231	77,113		

Part III Analysis of Changes in Net Assets or Fund Balances		
1 Total net assets or fund balances at beginning of year—Part II, column (a), line 29 (must agree with end-of-year figure reported on prior year's return)	1	78,231
2 Enter amount from Part I, line 27a	2	-1,118
3 Other increases not included in line 2 (itemize) ▶ _____	3	0
4 Add lines 1, 2, and 3	4	77,113
5 Decreases not included in line 2 (itemize) ▶ _____	5	0
6 Total net assets or fund balances at end of year (line 4 minus line 5)—Part II, column (b), line 29 .	6	77,113

Part IV Capital Gains and Losses for Tax on Investment Income

(a) List and describe the kind(s) of property sold (e.g., real estate, 2-story brick warehouse; or common stock, 200 shs. MLC Co.)	(b) How acquired P—Purchase D—Donation	(c) Date acquired (mo., day, yr.)	(d) Date sold (mo., day, yr.)
1a			

(e) Gross sales price	(f) Depreciation allowed (or allowable)	(g) Cost or other basis plus expense of sale	(h) Gain or (loss) (e) plus (f) minus (g)
a			
b			
c			
d			
e			

Complete only for assets showing gain in column (h) and owned by the foundation on 12/31/69			(l) Gains (Col. (h) gain minus col. (k), but not less than -0-) or Losses (from col.(h))
(i) F.M.V. as of 12/31/69	(j) Adjusted basis as of 12/31/69	(k) Excess of col. (i) over col. (j), if any	
a			
b			
c			
d			
e			

2 Capital gain net income or (net capital loss) $\left\{ \begin{array}{l} \text{If gain, also enter in Part I, line 7} \\ \text{If (loss), enter -0- in Part I, line 7} \end{array} \right\}$	2	
	3	
3 Net short-term capital gain or (loss) as defined in sections 1222(5) and (6): If gain, also enter in Part I, line 8, column (c) (see instructions). If (loss), enter -0- in Part I, line 8		

Part V Qualification Under Section 4940(e) for Reduced Tax on Net Investment Income**SECTION 4940(e) REPEALED ON DECEMBER 20, 2019 - DO NOT COMPLETE**

1 Reserved			
(a) Reserved	(b) Reserved	(c) Reserved	(d) Reserved
2 Reserved			2
3 Reserved.			3
4 Reserved			4
5 Reserved			5
6 Reserved			6
7 Reserved			7
8 Reserved ,			8

Part VI Excise Tax Based on Investment Income (Section 4940(a), 4940(b), 4940(e), or 4948—see instructions)

1a	Exempt operating foundations described in section 4940(d)(2), check here ☐ and enter "N/A" on line 1. Date of ruling or determination letter: _____ (attach copy of letter if necessary—see instructions)		
b	Reserved.	1	0
c	All other domestic foundations enter 1.39% of line 27b. Exempt foreign organizations enter 4% of Part I, line 12, col. (b)		
2	Tax under section 511 (domestic section 4947(a)(1) trusts and taxable foundations only. Others enter -0-)	2	0
3	Add lines 1 and 2.	3	0
4	Subtitle A (income) tax (domestic section 4947(a)(1) trusts and taxable foundations only. Others enter -0-)	4	0
5	Tax based on investment income. Subtract line 4 from line 3. If zero or less, enter -0-.	5	0
6	Credits/Payments:		
a	2020 estimated tax payments and 2019 overpayment credited to 2020	6a	0
b	Exempt foreign organizations—tax withheld at source	6b	0
c	Tax paid with application for extension of time to file (Form 8868)	6c	0
d	Backup withholding erroneously withheld	6d	0
7	Total credits and payments. Add lines 6a through 6d.	7	0
8	Enter any penalty for underpayment of estimated tax. Check here ☐ if Form 2220 is attached.	8	0
9	Tax due. If the total of lines 5 and 8 is more than line 7, enter amount owed .	9	0
10	Overpayment. If line 7 is more than the total of lines 5 and 8, enter the amount overpaid .	10	
11	Enter the amount of line 10 to be: Credited to 2021 estimated tax ☐ Refunded ☐	11	

Part VII-A Statements Regarding Activities

	Yes	No
1a During the tax year, did the foundation attempt to influence any national, state, or local legislation or did it participate or intervene in any political campaign?	1a	No
b Did it spend more than \$100 during the year (either directly or indirectly) for political purposes? (see Instructions for definition). <i>If the answer is "Yes" to 1a or 1b, attach a detailed description of the activities and copies of any materials published or distributed by the foundation in connection with the activities.</i>	1b	No
c Did the foundation file Form 1120-POL for this year?	1c	No
d Enter the amount (if any) of tax on political expenditures (section 4955) imposed during the year: (1) On the foundation. \$ <u>0</u> (2) On foundation managers. \$ <u>0</u>		
e Enter the reimbursement (if any) paid by the foundation during the year for political expenditure tax imposed on foundation managers. \$ <u>0</u>		
2 Has the foundation engaged in any activities that have not previously been reported to the IRS? <i>If "Yes," attach a detailed description of the activities.</i>	2	No
3 Has the foundation made any changes, not previously reported to the IRS, in its governing instrument, articles of incorporation, or bylaws, or other similar instruments? <i>If "Yes," attach a conformed copy of the changes</i>	3	No
4a Did the foundation have unrelated business gross income of \$1,000 or more during the year?	4a	No
b If "Yes," has it filed a tax return on Form 990-T for this year?	4b	
5 Was there a liquidation, termination, dissolution, or substantial contraction during the year? <i>If "Yes," attach the statement required by General Instruction T.</i>	5	No
6 Are the requirements of section 508(e) (relating to sections 4941 through 4945) satisfied either: • By language in the governing instrument, or • By state legislation that effectively amends the governing instrument so that no mandatory directions that conflict with the state law remain in the governing instrument?	6	Yes
7 Did the foundation have at least \$5,000 in assets at any time during the year? <i>If "Yes," complete Part II, col. (c), and Part XV.</i>	7	Yes
8a Enter the states to which the foundation reports or with which it is registered (see instructions) 		
b If the answer is "Yes" to line 7, has the foundation furnished a copy of Form 990-PF to the Attorney General (or designate) of each state as required by General Instruction G? <i>If "No," attach explanation.</i>	8b	Yes
9 Is the foundation claiming status as a private operating foundation within the meaning of section 4942(j)(3) or 4942(j)(5) for calendar year 2020 or the taxable year beginning in 2020? See the instructions for Part XIV. <i>If "Yes," complete Part XIV</i>	9	Yes
10 Did any persons become substantial contributors during the tax year? <i>If "Yes," attach a schedule listing their names and addresses.</i>	10	No

Part VII-A Statements Regarding Activities (continued)

11	At any time during the year, did the foundation, directly or indirectly, own a controlled entity within the meaning of section 512(b)(13)? If "Yes," attach schedule. See instructions.	11		No
12	Did the foundation make a distribution to a donor advised fund over which the foundation or a disqualified person had advisory privileges? If "Yes," attach statement. See instructions	12		No
13	Did the foundation comply with the public inspection requirements for its annual returns and exemption application? Website address ▶ <u>N/A</u>	13	Yes	
14	The books are in care of ▶ <u>ERIC ROGERS</u> Telephone no. ▶ <u>(475) 230-2596</u>			

Located at ▶ 121 SEAPORT BLVD BOSTON MAZIP+4 ▶ 02210

15	Section 4947(a)(1) nonexempt charitable trusts filing Form 990-PF in lieu of Form 1041 —check here ▶ ☐			
	and enter the amount of tax-exempt interest received or accrued during the year ▶ 15			
16	At any time during calendar year 2020, did the foundation have an interest in or a signature or other authority over a bank, securities, or other financial account in a foreign country?	16	Yes	No
	See the instructions for exceptions and filing requirements for FinCEN Form 114. If "Yes", enter the name of the foreign country ▶			

Part VII-B Statements Regarding Activities for Which Form 4720 May Be Required**File Form 4720 if any item is checked in the "Yes" column, unless an exception applies.**

		Yes	No
1a	During the year did the foundation (either directly or indirectly):		
	(1) Engage in the sale or exchange, or leasing of property with a disqualified person? ☐ Yes ☒ No		
	(2) Borrow money from, lend money to, or otherwise extend credit to (or accept it from) a disqualified person? ☐ Yes ☒ No		
	(3) Furnish goods, services, or facilities to (or accept them from) a disqualified person? ☐ Yes ☒ No		
	(4) Pay compensation to, or pay or reimburse the expenses of, a disqualified person? ☐ Yes ☒ No		
	(5) Transfer any income or assets to a disqualified person (or make any of either available for the benefit or use of a disqualified person)? ☐ Yes ☒ No		
	(6) Agree to pay money or property to a government official? (Exception. Check "No" if the foundation agreed to make a grant to or to employ the official for a period after termination of government service, if terminating within 90 days.) ☐ Yes ☒ No		
b	If any answer is "Yes" to 1a(1)–(6), did any of the acts fail to qualify under the exceptions described in Regulations section 53.4941(d)-3 or in a current notice regarding disaster assistance? See instructions ☐	1b	
c	Did the foundation engage in a prior year in any of the acts described in 1a, other than excepted acts, that were not corrected before the first day of the tax year beginning in 2020?	1c	No
2	Taxes on failure to distribute income (section 4942) (does not apply for years the foundation was a private operating foundation defined in section 4942(j)(3) or 4942(j)(5)):		
a	At the end of tax year 2020, did the foundation have any undistributed income (lines 6d and 6e, Part XIII) for tax year(s) beginning before 2020? ☐ Yes ☒ No If "Yes," list the years ▶ 20____, 20____, 20____, 20____		
b	Are there any years listed in 2a for which the foundation is not applying the provisions of section 4942(a)(2) (relating to incorrect valuation of assets) to the year's undistributed income? (If applying section 4942(a)(2) to all years listed, answer "No" and attach statement—see instructions.)	2b	
c	If the provisions of section 4942(a)(2) are being applied to any of the years listed in 2a, list the years here. ▶ 20____, 20____, 20____, 20____		
3a	Did the foundation hold more than a 2% direct or indirect interest in any business enterprise at any time during the year? ☐ Yes ☒ No		
b	If "Yes," did it have excess business holdings in 2020 as a result of (1) any purchase by the foundation or disqualified persons after May 26, 1969; (2) the lapse of the 5-year period (or longer period approved by the Commissioner under section 4943(c)(7)) to dispose of holdings acquired by gift or bequest; or (3) the lapse of the 10-, 15-, or 20-year first phase holding period? (Use Schedule C, Form 4720, to determine if the foundation had excess business holdings in 2020.)	3b	
4a	Did the foundation invest during the year any amount in a manner that would jeopardize its charitable purposes?	4a	No
b	Did the foundation make any investment in a prior year (but after December 31, 1969) that could jeopardize its charitable purpose that had not been removed from jeopardy before the first day of the tax year beginning in 2020?	4b	No

Part VII-B Statements Regarding Activities for Which Form 4720 May Be Required (continued)

		Yes	No
5a	During the year did the foundation pay or incur any amount to:		
(1)	Carry on propaganda, or otherwise attempt to influence legislation (section 4945(e))?	☐ Yes ☒ No	
(2)	Influence the outcome of any specific public election (see section 4955); or to carry on, directly or indirectly, any voter registration drive?	☐ Yes ☒ No	
(3)	Provide a grant to an individual for travel, study, or other similar purposes?	☐ Yes ☒ No	
(4)	Provide a grant to an organization other than a charitable, etc., organization described in section 4945(d)(4)(A)? See instructions.	☐ Yes ☒ No	
(5)	Provide for any purpose other than religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals?	☐ Yes ☒ No	
b	If any answer is "Yes" to 5a(1)–(5), did any of the transactions fail to qualify under the exceptions described in Regulations section 53.4945 or in a current notice regarding disaster assistance? See instructions		5b No
c	If the answer is "Yes" to question 5a(4), does the foundation claim exemption from the tax because it maintained expenditure responsibility for the grant? If "Yes," attach the statement required by Regulations section 53.4945–5(d).	☐ Yes ☐ No	
6a	Did the foundation, during the year, receive any funds, directly or indirectly, to pay premiums on a personal benefit contract?	☐ Yes ☒ No	
b	Did the foundation, during the year, pay premiums, directly or indirectly, on a personal benefit contract? If "Yes" to 6b, file Form 8870.		6b No
7a	At any time during the tax year, was the foundation a party to a prohibited tax shelter transaction?	☐ Yes ☒ No	
b	If "Yes", did the foundation receive any proceeds or have any net income attributable to the transaction?		7b
8	Is the foundation subject to the section 4960 tax on payment(s) of more than \$1,000,000 in remuneration or excess parachute payment during the year?	☐ Yes ☒ No	

Part VIII Information About Officers, Directors, Trustees, Foundation Managers, Highly Paid Employees, and Contractors

1 List all officers, directors, trustees, foundation managers and their compensation. See instructions				
(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, other allowances
DOUGLAS BARRY 121 SEAPORT BOULEVARD BOSTON, MA 02210	DIRECTOR 0.50	0	0	0
CHRISTOPHE HOTERMANS 121 SEAPORT BOULEVARD BOSTON, MA 02210	DIRECTOR 0.50	0	0	0
RANA STRELLIS 121 SEAPORT BOULEVARD BOSTON, MA 02210	DIRECTOR 0.50	0	0	0
2 Compensation of five highest-paid employees (other than those included on line 1—see instructions). If none, enter "NONE."				
(a) Name and address of each employee paid more than \$50,000	(b) Title, and average hours per week devoted to position	(c) Compensation	(d) Contributions to employee benefit plans and deferred compensation	(e) Expense account, other allowances
NONE				
Total number of other employees paid over \$50,000.				0

Part VIII Information About Officers, Directors, Trustees, Foundation Managers, Highly Paid Employees, and Contractors (continued)
3 Five highest-paid independent contractors for professional services (see instructions). If none, enter "NONE".

(a) Name and address of each person paid more than \$50,000	(b) Type of service	(c) Compensation
NONE		
Total number of others receiving over \$50,000 for professional services.		0

Part IX-A Summary of Direct Charitable Activities

List the foundation's four largest direct charitable activities during the tax year. Include relevant statistical information such as the number of organizations and other beneficiaries served, conferences convened, research papers produced, etc.	Expenses
1 PROVIDES PRESCRIPTION DRUGS FOR THE TREATMENT OF PAROXYSMAL NOCTURNAL HEMOGLOBINURIA(PNH), ATYPICAL HEMOLYTIC UREMIC SYNDROME(AHUS), REFRACTORY GENERALIZED MYASTHENIA GRAVIS(GMG), PERINATAL/INFANTILE AND JUVENILE-ONSET HYPOPHOSPHATASIA(HPP), AND LYSOSOMAL ACID LIPASE DEFICIENCY(LAL-D) TO QUALIFYING ILL PATIENTS	41,253,378
2	
3	
4	

Part IX-B Summary of Program-Related Investments (see instructions)

Describe the two largest program-related investments made by the foundation during the tax year on lines 1 and 2.	Amount
1	
2	
All other program-related investments. See instructions.	
3	
Total. Add lines 1 through 3	0

Part X Minimum Investment Return (All domestic foundations must complete this part. Foreign foundations, see instructions.)

1	Fair market value of assets not used (or held for use) directly in carrying out charitable, etc., purposes:		
a	Average monthly fair market value of securities.	1a	0
b	Average of monthly cash balances.	1b	77,700
c	Fair market value of all other assets (see instructions).	1c	0
d	Total (add lines 1a, b, and c).	1d	77,700
e	Reduction claimed for blockage or other factors reported on lines 1a and 1c (attach detailed explanation).	1e	0
2	Acquisition indebtedness applicable to line 1 assets.	2	0
3	Subtract line 2 from line 1d.	3	77,700
4	Cash deemed held for charitable activities. Enter 1 1/2% of line 3 (for greater amount, see instructions).	4	1,166
5	Net value of noncharitable-use assets. Subtract line 4 from line 3. Enter here and on Part V, line 4	5	76,534
6	Minimum investment return. Enter 5% of line 5.	6	3,827

Part XI Distributable Amount (see instructions) (Section 4942(j)(3) and (j)(5) private operating foundations and certain foreign organizations check here ☒ and do not complete this part.)

1	Minimum investment return from Part X, line 6.	1	
2a	Tax on investment income for 2020 from Part VI, line 5.	2a	
b	Income tax for 2020. (This does not include the tax from Part VI.).	2b	
c	Add lines 2a and 2b.	2c	
3	Distributable amount before adjustments. Subtract line 2c from line 1.	3	
4	Recoveries of amounts treated as qualifying distributions.	4	
5	Add lines 3 and 4.	5	
6	Deduction from distributable amount (see instructions).	6	
7	Distributable amount as adjusted. Subtract line 6 from line 5. Enter here and on Part XIII, line 1.	7	

Part XII Qualifying Distributions (see instructions)

1	Amounts paid (including administrative expenses) to accomplish charitable, etc., purposes:		
a	Expenses, contributions, gifts, etc.—total from Part I, column (d), line 26.	1a	41,254,496
b	Program-related investments—total from Part IX-B.	1b	0
2	Amounts paid to acquire assets used (or held for use) directly in carrying out charitable, etc., purposes.	2	
3	Amounts set aside for specific charitable projects that satisfy the:		
a	Suitability test (prior IRS approval required).	3a	
b	Cash distribution test (attach the required schedule).	3b	
4	Qualifying distributions. Add lines 1a through 3b. Enter here and on Part V, line 8, and Part XIII, line 4	4	41,254,496
5	Foundations that qualify under section 4940(e) for the reduced rate of tax on net investment income. Enter 1% of Part I, line 27b. See instructions.	5	0
6	Adjusted qualifying distributions. Subtract line 5 from line 4.	6	41,254,496

Note: The amount on line 6 will be used in Part V, column (b), in subsequent years when calculating whether the foundation qualifies for the section 4940(e) reduction of tax in those years.

Part XIII Undistributed Income (see instructions)

	(a) Corpus	(b) Years prior to 2019	(c) 2019	(d) 2020
1 Distributable amount for 2020 from Part XI, line 7				
2 Undistributed income, if any, as of the end of 2020:				
a Enter amount for 2019 only.				
b Total for prior years: 20____, 20____, 20____				
3 Excess distributions carryover, if any, to 2020:				
a From 2015.				
b From 2016.				
c From 2017.				
d From 2018.				
e From 2019.				
f Total of lines 3a through e.				
4 Qualifying distributions for 2020 from Part XII, line 4: ► \$ _____				
a Applied to 2019, but not more than line 2a				
b Applied to undistributed income of prior years (Election required—see instructions).				
c Treated as distributions out of corpus (Election required—see instructions).				
d Applied to 2020 distributable amount.				
e Remaining amount distributed out of corpus				
5 Excess distributions carryover applied to 2020. (If an amount appears in column (d), the same amount must be shown in column (a).)				
6 Enter the net total of each column as indicated below:				
a Corpus. Add lines 3f, 4c, and 4e. Subtract line 5				
b Prior years' undistributed income. Subtract line 4b from line 2b.				
c Enter the amount of prior years' undistributed income for which a notice of deficiency has been issued, or on which the section 4942(a) tax has been previously assessed.				
d Subtract line 6c from line 6b. Taxable amount—see instructions.				
e Undistributed income for 2019. Subtract line 4a from line 2a. Taxable amount—see instructions.				
f Undistributed income for 2021. Subtract lines 4d and 5 from line 1. This amount must be distributed in 2020.				
7 Amounts treated as distributions out of corpus to satisfy requirements imposed by section 170(b)(1)(F) or 4942(g)(3) (Election may be required - see instructions).				
8 Excess distributions carryover from 2015 not applied on line 5 or line 7 (see instructions).				
9 Excess distributions carryover to 2021. Subtract lines 7 and 8 from line 6a.				
10 Analysis of line 9:				
a Excess from 2016.				
b Excess from 2017.				
c Excess from 2018.				
d Excess from 2019.				
e Excess from 2020.				

Part XIV Private Operating Foundations (see instructions and Part VII-A, question 9)

1a If the foundation has received a ruling or determination letter that it is a private operating foundation, and the ruling is effective for 2020, enter the date of the ruling. **2007-03-16**

b Check box to indicate whether the organization is a private operating foundation described in section ☒ 4942(j)(3) or ☐ 4942(j)(5)

	Tax year	Prior 3 years			(e) Total
	(a) 2020	(b) 2019	(c) 2018	(d) 2017	
2a Enter the lesser of the adjusted net income from Part I or the minimum investment return from Part X for each year listed	0	0	0	0	0
b 85% of line 2a	0	0	0	0	0
c Qualifying distributions from Part XII, line 4 for each year listed	41,254,496	32,999,289	22,827,788	24,750,090	121,831,663
d Amounts included in line 2c not used directly for active conduct of exempt activities	0	0	0	0	0
e Qualifying distributions made directly for active conduct of exempt activities. Subtract line 2d from line 2c	41,254,496	32,999,289	22,827,788	24,750,090	121,831,663
3 Complete 3a, b, or c for the alternative test relied upon:					
a "Assets" alternative test—enter:					
(1) Value of all assets	77,113	78,231	84,552	88,583	328,479
(2) Value of assets qualifying under section 4942(j)(3)(B)(i)					0
b "Endowment" alternative test— enter 2/3 of minimum investment return shown in Part X, line 6 for each year listed.	2,551	2,736	2,881	2,985	11,153
c "Support" alternative test—enter:					
(1) Total support other than gross investment income (interest, dividends, rents, payments on securities loans (section 512(a)(5)), or royalties)					0
(2) Support from general public and 5 or more exempt organizations as provided in section 4942(j)(3)(B)(iii).					0
(3) Largest amount of support from an exempt organization					0
(4) Gross investment income					0

Part XV Supplementary Information (Complete this part only if the foundation had \$5,000 or more in assets at any time during the year—see instructions.)

1 Information Regarding Foundation Managers:

a List any managers of the foundation who have contributed more than 2% of the total contributions received by the foundation before the close of any tax year (but only if they have contributed more than \$5,000). (See section 507(d)(2).)

b List any managers of the foundation who own 10% or more of the stock of a corporation (or an equally large portion of the ownership of a partnership or other entity) of which the foundation has a 10% or greater interest.

2 Information Regarding Contribution, Grant, Gift, Loan, Scholarship, etc., Programs:

Check here ☐ if the foundation only makes contributions to preselected charitable organizations and does not accept unsolicited requests for funds. If the foundation makes gifts, grants, etc. to individuals or organizations under other conditions, complete items 2a, b, c, and d. See instructions

a The name, address, and telephone number or e-mail address of the person to whom applications should be addressed:

ALEXION ACCESS FOUNDATION
100 COLLEGE STREET
NEW HAVEN, CT 06510
(203) 272-2596
GLOBALACCESS@ALEXION.COM

b The form in which applications should be submitted and information and materials they should include:

APPLICATION FORM

c Any submission deadlines:

NONE

d Any restrictions or limitations on awards, such as by geographical areas, charitable fields, kinds of institutions, or other factors:

ELIGIBLE PARTICIPANTS IN THE ALEXION ACCESS FOUNDATION PROGRAM ARE GENERALLY REQUIRED TO MEET, AMONG OTHER THINGS, MEDICAL, INSURANCE AND FINANCIAL CRITERIA TO BE ELIGIBLE FOR SUPPORT.

Part XV **Supplementary Information** (continued)**3 Grants and Contributions Paid During the Year or Approved for Future Payment**

Recipient	If recipient is an individual, show any relationship to any foundation manager or substantial contributor	Foundation status of recipient	Purpose of grant or contribution	Amount
Name and address (home or business)				
a <i>Paid during the year</i> See Additional Data Table				
Total			▶ 3a	41,253,378
b <i>Approved for future payment</i>				
Total			▶ 3b	0

Enter gross amounts unless otherwise indicated.

	(a) Business code	(b) Amount	(c) Exclusion code	(d) Amount	(e) (See instructions.)
1 Program service revenue:					
a _____					
b _____					
c _____					
d _____					
e _____					
f _____					
g Fees and contracts from government agencies					
2 Membership dues and assessments. . . .					
3 Interest on savings and temporary cash investments					
4 Dividends and interest from securities. . . .					
5 Net rental income or (loss) from real estate:					
a Debt-financed property.					
b Not debt-financed property.					
6 Net rental income or (loss) from personal property					
7 Other investment income.					
8 Gain or (loss) from sales of assets other than inventory					
9 Net income or (loss) from special events:					
10 Gross profit or (loss) from sales of inventory					
11 Other revenue: a _____					
b _____					
c _____					
d _____					
e _____					
12 Subtotal. Add columns (b), (d), and (e). . .		0		0	0
13 Total. Add line 12, columns (b), (d), and (e). (See worksheet in line 13 instructions to verify calculations.)			13		0

[illegible]

Information Regarding Transfers To and Transactions and Relationships With Noncharitable Exempt Organizations

	Yes	No
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--	--	--

1a(1)		No
1a(2)		No

--	--	--

1b(1)	No
--------------	-----------

1b(2)		No
--------------	--	-----------

1b(3)		No
--------------	--	-----------

1b(4)		No
--------------	--	-----------

1b(5)		No
--------------	--	-----------

1b(6)		No
--------------	--	-----------

1c		No
----	--	----

value
ue

[illegible]

described in section 501(c) (other than section 501(c)(3)) or in section 527? ☐ Yes ☒ No

b If "Yes," complete the following schedule.

(a) Name of organization	(b) Type of organization	(c) Description of relationship

Under penalties of perjury, I declare that I have examined this return, including accompanying schedules and statements, and to the best of my knowledge and belief, it is true, correct, and complete. Declaration of preparer (other than taxpayer) is based on all information of which preparer has any knowledge.
--

**Sign
Here**

2022-06-30

Signature of officer or trustee

Date _____

Title

May the IRS discuss this
return
with the preparer shown
below

(see instr.) ☒ Yes ☐ No

**Paid
Preparer
Use Only**

Print/Type preparer's name LAURA J KENNEY	Preparer's Signature	Date 2022-06-30	Check if self-employed ☐	PTIN P00202198
Firm's name ▶ CLIFTONLARSONALLEN LLP				Firm's EIN ▶ 41-0746749
Firm's address ▶ TWO INTERNATIONAL PLACE 22ND FLOOR BOSTON, MA 02110				Phone no. (617) 717-0831

Form 990PF Part XV Line 3 - Grants and Contributions Paid During the Year or Approved for Future Payment				
Recipient	If recipient is an individual, show any relationship to any foundation manager or substantial contributor	Foundation status of recipient	Purpose of grant or contribution	Amount
Name and address (home or business)				
a <i>Paid during the year</i>				
VIALS OF KANUMA WERE DISTRIBUTED TO VARIOUS VARIOUS OC	NONE	I	FOR CHRONICALLY INDIGENT, TEMPORARILY UNINSURED, OR FINANCIALLY STRESSED PATIENTS.	333,384
VIALS OF SOLIRIS WERE DISTRIBUTED T VARIOUS VARIOUS OC	NONE	I	FOR CHRONICALLY INDIGENT, TEMPORARILY UNINSURED, OR FINANCIALLY STRESSED PATIENTS.	21,819,783
VIALS OF STRENSIQ WERE DISTRIBUTED VARIOUS VARIOUS OC	NONE	I	FOR CHRONICALLY INDIGENT, TEMPORARILY UNINSURED, OR FINANCIALLY STRESSED PATIENTS.	5,082,480
Total ► 3a				41,253,378

Form 990PF Part XV Line 3 - Grants and Contributions Paid During the Year or Approved for Future Payment				
Recipient	If recipient is an individual, show any relationship to any foundation manager or substantial contributor	Foundation status of recipient	Purpose of grant or contribution	Amount
Name and address (home or business)				
a <i>Paid during the year</i>				
VIALS OF ULTOMIRIS WERE DISTRIBUTED VARIOUS VARIOUS OC	NONE	I	FOR CHRONICALLY INDIGENT, TEMPORARILY UNINSURED, OR FINANCIALLY STRESSED PATIENTS.	14,017,731
Total ▶ 3a				41,253,378

TY 2020 General Explanation Attachment**Name:** ALEXION ACCESS FOUNDATION**EIN:** 20-8963321**General Explanation Attachment**

Identifier	Return Reference	Explanation	
1		SCHEDULE B, PART II, LINE 1(B)	VIALS OF SOLIRIS, TO TREAT PAROXYSMAL NOCTURNAL HEMOGLOBINURIA (PNH), ATYPICAL HEMOLYTIC UREMIC SYNDROME (AHUS) AND REFRACTORY GENERALIZED MYASTHENIA GRAVIS (GMG).

General Explanation Attachment

Identifier	Return Reference	Explanation	
2		SCHEDULE B, PART II, LINE 2(B)	VIALS OF ULTOMIRIS, TO TREAT PAROXYSMAL NOCTURNAL HEMOGLOBINURIA (PNH), ATYPICAL HEMOLYTIC UREMIC SYNDROME (AHUS) AND REFRACTORY GENERALIZED MYASTHENIA GRAVIS (GMG).

General Explanation Attachment

Identifier	Return Reference	Explanation	
3	REASONABLE CAUSE STATEMENT ABOUT LATE ELECTRONIC FILING	990-PF	ALEXION ACCESS FOUNDATION (THE FOUNDATION), EIN# 20-8963321, FORMERLY KNOWN AS THE ALEXION COMPLEMENT FOUNDATION, IS PROVIDING THIS REASONABLE CAUSE EXPLANATION FOR WHY THE FOUNDATION'S 2020 FORM 990-PF WAS NOT SUBMITTED ELECTRONICALLY ORIGINALLY, AND REQUESTING THAT NO PENALTIES BE CHARGED BECAUSE OF THE FOUNDATION'S INABILITY TO SUBMIT ELECTRONICALLY. ON JUNE 7, 2022, THE FOUNDATION RECEIVED A LETTER FROM THE IRS INDICATING THE FOUNDATION'S 2020 FORM 990-PF WAS BEING RETURNED BECAUSE IT WAS NOT FILED ELECTRONICALLY, AS REQUIRED BY THE TAXPAYER FIRST ACT. THE IRS LETTER IS DATED APRIL 20, 2022. DUE TO COVID, MAIL DELAYS, AND THE FOUNDATION'S SHORT-HANDEDNESS OF LABOR, THE LETTER WAS NOT DELIVERED TO FOUNDATION MANAGEMENT UNTIL JUNE 7, 2022. THE FOUNDATION IMMEDIATELY CONFERRED WITH ITS TAX ADVISORS TO TRY TO UNDERSTAND WHAT HAPPENED. THE REASON THE RETURN WAS NOT FILED ELECTRONICALLY IS THAT THE FOUNDATION'S NAME CHANGE HAD NOT BEEN UPDATED IN IRS COMPUTER SYSTEMS. ALTHOUGH FOUNDATION MANAGEMENT HAD FAXED A LETTER TO THE IRS ON NOVEMBER 4, 2021 TO REQUEST THE NAME CHANGE, THE NAME CHANGE WAS NOT GIVEN EFFECT IN THE COMPUTER SYSTEMS OF THE IRS. THIS LEFT THE FOUNDATION WITH NO OPTION OTHER THAN TO MAIL THE RETURN. THE IRS HOSTS A WEB PAGE STATING THAT EXEMPT ORGANIZATIONS THAT BECOME UNABLE TO ELECTRONICALLY FILE THEIR FORMS BECAUSE OF NAME CHANGES SHOULD MAIL THEIR FORMS INSTEAD. HERE IS THE ADDRESS OF THIS WEB PAGE HTTPS://WWW.IRS.GOV/CHARITIES-NON-PROFITS/EXEMPT-ORGANIZATIONS-E-FILE-NAME-CHANGEAFTER WAITING A WEEK TO SEE IF THE SYSTEMS AT THE IRS WOULD BE UPDATED, FOUNDATION MANAGEMENT SUBMITTED THE FOUNDATION'S 2020 FORM 990-PF VIA CERTIFIED MAIL ON NOVEMBER 11, 2021. THE FOUNDATION IS NOW MAKING A NEW ATTEMPT TO ELECTRONICALLY FILE ITS 2020 FORM 990-PF BECAUSE THE FOUNDATION WAS NOT ABLE TO FILE ELECTRONICALLY LAST YEAR, AND BECAUSE OF COVID-RELATED INTERNAL DISRUPTIONS TO ITS WORKFLOW, THE FOUNDATION RESPECTFULLY REQUESTS THAT THE IRS NOT ASSESS PENALTIES BASED ON THESE REASONABLE CAUSE EXPLANATIONS.

TY 2020 Other Expenses Schedule**Name:** ALEXION ACCESS FOUNDATION**EIN:** 20-8963321**Other Expenses Schedule**

Description	Revenue and Expenses per Books	Net Investment Income	Adjusted Net Income	Disbursements for Charitable Purposes
BANKING FEES	1,118	0	0	1,118

efile GRAPHIC print - DO NOT PROCESS		As Filed Data -		DLN: 93491181014102	
Schedule B (Form 990, 990-EZ, or 990-PF) Department of the Treasury Internal Revenue Service		Schedule of Contributors ▶ Attach to Form 990, 990-EZ, or 990-PF. ▶ Go to www.irs.gov/Form990 for the latest information.			OMB No. 1545-0047
					2020
Name of the organization ALEXION ACCESS FOUNDATION				Employer identification number 20-8963321	

Organization type (check one):

Filers of:	Section:
Form 990 or 990-EZ	☐ 501(c)() (enter number) organization
	☐ 4947(a)(1) nonexempt charitable trust not treated as a private foundation
	☐ 527 political organization
Form 990-PF	☒ 501(c)(3) exempt private foundation
	☐ 4947(a)(1) nonexempt charitable trust treated as a private foundation
	☐ 501(c)(3) taxable private foundation

Check if your organization is covered by the **General Rule** or a **Special Rule**.
Note: Only a section 501(c)(7), (8), or (10) organization can check boxes for both the General Rule and a Special Rule. See instructions.

General Rule

- ☒ For an organization filing Form 990, 990-EZ, or 990-PF that received, during the year, contributions totaling \$5,000 or more (in money or other property) from any one contributor. Complete Parts I and II. See instructions for determining a contributor's total contributions.

Special Rules

- ☐ For an organization described in section 501(c)(3) filing Form 990 or 990-EZ that met the 33¹/₃% support test of the regulations under sections 509(a)(1) and 170(b)(1)(A)(vi), that checked Schedule A (Form 990 or 990-EZ), Part II, line 13, 16a, or 16b, and that received from any one contributor, during the year, total contributions of the greater of **(1)** \$5,000 or **(2)** 2% of the amount on (i) Form 990, Part VIII, line 1h, or (ii) Form 990-EZ, line 1. Complete Parts I and II.
- ☐ For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, total contributions of more than \$1,000 *exclusively* for religious, charitable, scientific, literary, or educational purposes, or for the prevention of cruelty to children or animals. Complete Parts I, II, and III.
- ☐ For an organization described in section 501(c)(7), (8), or (10) filing Form 990 or 990-EZ that received from any one contributor, during the year, contributions *exclusively* for religious, charitable, etc., purposes, but no such contributions totaled more than \$1,000. If this box is checked, enter here the total contributions that were received during the year for an *exclusively* religious, charitable, etc., purpose. Don't complete any of the parts unless the **General Rule** applies to this organization because it received *nonexclusively* religious, charitable, etc., contributions totaling \$5,000 or more during the year ▶ \$ _____

Caution: An organization that isn't covered by the General Rule and/or the Special Rules doesn't file Schedule B (Form 990, 990-EZ, or 990-PF), but it **must** answer "No" on Part IV, line 2, of its Form 990; or check the box on line H of its Form 990-EZ or on its Form 990PF, Part I, line 2, to certify that it doesn't meet the filing requirements of Schedule B (Form 990, 990-EZ, or 990-PF).

Name of organization
ALEXION ACCESS FOUNDATION

Employer identification number
20-8963321

Part I

Contributors (see instructions). Use duplicate copies of Part I if additional space is needed.

(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
1	ALEXION PHARMACEUTICALS INC 100 COLLEGE STREET NEW HAVEN, CT 06510	\$ 41,253,378	☐ Person ☐ Payroll ☒ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)
(a) No.	(b) Name, address, and ZIP + 4	(c) Total contributions	(d) Type of contribution
		\$	☐ Person ☐ Payroll ☐ Noncash (Complete Part II for noncash contributions.)

Name of organization ALEXION ACCESS FOUNDATION	Employer identification number 20-8963321
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Part II Noncash Property			
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
1	SEE SUPPLEMENTAL INFORMATION	\$ 21,819,783	2020-12-31
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
1	SEE SUPPLEMENTAL INFORMATION	\$ 14,017,731	2020-12-31
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
1	VIALS OF STRENSIQ, TO TREAT PERINATAL/INFANTILE AND JUVENILE-ONSET HYPOPHOSPHATASIA(HPP).	\$ 5,082,480	2020-12-31
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
1	VIALS OF KANUMA WERE DISTRIBUTED TO PATIENTS SUFFERING FROM LYSOSOMAL ACID LIPASE DEFICIENCY(LAL-D).	\$ 333,384	2020-12-31
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-		\$	
(a) No. from Part I	(b) Description of noncash property given	(c) FMV (or estimate) (See instructions)	(d) Date received
-		\$	

Name of organization ALEXION ACCESS FOUNDATION	Employer identification number 20-8963321
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Part III

Exclusively religious, charitable, etc., contributions to organizations described in section 501(c)(7), (8), or (10) that total more than \$1,000 for the year from any one contributor. Complete columns (a) through (e) and the following line entry. For organizations completing Part III, enter the total of *exclusively* religious, charitable, etc., contributions of **\$1,000 or less for the year. (Enter this information once. See instructions.) ► \$ _____**

Use duplicate copies of Part III if additional space is needed.

(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	(e) Transfer of gift		
	Transferee's name, address, and ZIP 4		Relationship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	(e) Transfer of gift		
	Transferee's name, address, and ZIP 4		Relationship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	(e) Transfer of gift		
	Transferee's name, address, and ZIP 4		Relationship of transferor to transferee
(a) No. from Part I	(b) Purpose of gift	(c) Use of gift	(d) Description of how gift is held
	(e) Transfer of gift		
	Transferee's name, address, and ZIP 4		Relationship of transferor to transferee