

### Notice 1382

(Rev. October 2013)

### **Changes for Form 1023**

- Mailing address
- Parts IX, X, and XI

## Reminder: Do Not Include Social Security Numbers on Publicly Disclosed Forms

Because the IRS is required to disclose approved exemption applications and information returns, exempt organizations should not include Social Security numbers on these forms. Documents subject to disclosure include supporting documents filed with the form, and correspondence with the IRS about the filing.

# Changes for Form 1023, Application for Recognition of Exemption Under Section 501(c)(3) of the Internal Revenue Code

### **Change of Mailing Address**

The mailing address shown on Form 1023 Checklist, page 28, the first address under the last checkbox; and in the Instructions for Form 1023, page 4 under *Where To File*, has been changed to:

Internal Revenue Service P.O. Box 12192 Covington, KY 41012-0192

To file using a private delivery service, mail to:

201 West Rivercenter Blvd. Attn: Extracting Stop 312 Covington, KY 41011

### Changes for Parts IX and X

Changes to Parts IX and X are necessary to comply with new regulations that eliminated the advance ruling process. Until Form 1023 is revised to reflect this change, please follow the directions on this notice when completing Part IX and Part X of Form 1023. For more information about the elimination of the advance ruling process, visit us at IRS.gov. In the top right "Search" box, type "Elimination of the Advance Ruling Process" (exactly as written) and select "Search."

#### Part IX. Financial Data

The instructions at the top of Part IX on page 9 of Form 1023 are now as follows. For purposes of this schedule, years in existence refer to completed tax years.

- 1. If in existence less than 5 years, complete the statement for each year in existence and provide projections of your likely revenues and expenses based on a reasonable and good faith estimate of your future finances for a total of:
  - a. Three years of financial information if you have not completed one tax year, or
  - b. Four years of financial information if you have completed one tax year.

(Continued)

2. If in existence 5 or more years, complete the schedule for the most recent 5 tax years. You will need to provide a separate statement that includes information about the most recent 5 tax years because the data table in Part IX has not been updated to provide for a 5th year.

### Part X. Public Charity Status

**Do not complete** line 6a on page 11 of Form 1023, and do not sign the form under the heading "Consent Fixing Period of Limitations Upon Assessment of Tax Under Section 4940 of the Internal Revenue Code."

Only complete line 6b and line 7 on page 11 of Form 1023, if in existence 5 or more tax years.

#### Part XI. Increase in User Fees

User fee increases are effective for all applications postmarked after January 3, 2010.

- 1. \$400 for organizations whose gross receipts do not exceed \$10,000 or less annually over a 4-year period.
- 2. \$850 for organizations whose gross receipts exceed \$10,000 annually over a 4-year period.

For the current user fee amounts, go to IRS.gov and in the "Search" box at the top right of the page, enter "Exempt Organizations User Fees." You can also call 1-877-829-5500.

**Application for reinstatement and retroactive reinstatement.** An organization must apply to have its tax-exempt status reinstated if it was automatically revoked for failure to file a return or notice for three consecutive years. The organization must:

- (1) Complete and file Form 1023 if applying under section 501(c)(3) or Form 1024 if applying under a different Code section;
- (2) Pay the appropriate user fee and enclose it with the application;
- (3) Write "Automatically Revoked" at the top of the application and mailing envelope; and
- (4) Submit a written statement supporting its request if applying for retroactive reinstatement.

If the application is approved, the date of reinstatement generally will be the postmark date of the application, unless the organization qualifies for retroactive reinstatement. Alternate submissions and standards apply for retroactive reinstatement back to the date of automatic revocation. See Notice 2011-44, 2011-25 I.R.B. 883, at <a href="http://www.irs.gov/irb/2011-25\_IRB/ar10.html">http://www.irs.gov/irb/2011-25\_IRB/ar10.html</a>, for details.

### **Changes for the Instructions for Form 1023**

- Change to Part III. Required Provisions in Your Organizing Documents
- Clarification to Appendix A. Sample Conflict of Interest Policy

(Continued)

### Changes to Instructions for Form 1023, Application for Recognition of Exemption Under Section 501(c)(3) of the Internal Revenue Code (Rev. June 2006)

### Part III. Required Provisions in Your Organizing Document

Applicable to organizations in the state of New York. Changes are necessary to comply with Rev. Proc. 82-2, 1982-1 C.B. 367, to incorporate the state of New York as a jurisdiction that complies with the *cy pres* doctrine to keep a charitable testamentary trust from failing the requirement for a dissolution clause under Regulations section 1.501(c)(3)-1(b)(4), when the language of the trust instrument demonstrates a general intent to benefit charity. Therefore, the instructions on page 8, line 2c, after the third paragraph now include the state of New York in the state listing as an authorized state. Since the state of New York allows testamentary charitable trusts formed in that state and the language in the trust instruments provides for a general intent to benefit charity, you do not need a specific provision in your trust agreement or declaration of trust providing for the distribution of assets upon dissolution.

### Appendix A. Sample Conflict of Interest Policy

Appendix A, Sample Conflict of Interest Policy, is only intended to provide an example of a conflict of interest policy for organizations. The sample conflict of interest policy does not prescribe any specific requirements. Therefore, organizations should use a conflict of interest policy that best fits their organization.

P.O. Box 192 Covington, KY 41012-0192	
If you are using express mail or a delivery service, send Form 1023, user fee payment, and attachments	to:
Internal Revenue Service 201 West Rivercenter Blvd. Attn: Extracting Stop 312 Covington, KY 41011	
WELLS FARGO BANK 6003	
DRIPPING SPRINGS 401 W MERCER ST DRIPPING, SPRINGS, TX 78620  DATE 8/30/16 37-65/1119	
EIGHT HUNDRED FIFTY DOLLARS & NO/100 DOLLARS	
EIGHT HUNDRED FIFTY DOLLARS & NO/100 DOLLARS	
UR OUR HOPE MARY ELIZABETH PARKER PO BOX 50152 AUSTIN TX 78763-0152	
The Portsyntone Foundation	

::111900659::7866414340\*6003

An exact copy of your complete articles of organization (creating document). Absence of the proper purpose and dissolution clauses is the number one reason for delays in the issuance of determination letters.

Location of Purpose Clause from Part III, line 1 (Page, Article and Paragraph Number) Art of Inc, Art 2
 Location of Dissolution Clause from Part III, line 2b or 2c (Page, Article and Paragraph Number) or by operation of state law of Inc, Art 8, Exhibit A

Signature of an officer, director, trustee, or other official who is authorized to sign the application.

Your name on the application must be the same as your legal name as it appears in your articles of

Send completed Form 1023, user fee payment, and all other required information, to:

Signature at Part XI of Form 1023.

Internal Revenue Service

### Form 1023 Checklist

### (Revised December 2013)

Application for Recognition of Exemption under Section 501(c)(3) of the Internal Revenue Code

Note. Retain a copy of the completed Form 1023 in your permanent records. Refer to the General Instructions regarding Public Inspection of approved applications.

Check each box to finish your application (Form 1023). Send this completed Checklist with your filled-in application. If you have not answered all the items below, your application may be returned to you as incomplete.



Assemble the application and materials in this order:

- Form 1023 Checklist
- Form 2848, Power of Attorney and Declaration of Representative (if filing)
- Form 8821, Tax Information Authorization (if filing)
- Expedite request (if requesting)
- Application (Form 1023 and Schedules A through H, as required)
- Articles of organization
- Amendments to articles of organization in chronological order
- Bylaws or other rules of operation and amendments
- Documentation of nondiscriminatory policy for schools, as required by Schedule B
- Form 5768. Election/Revocation of Election by an Eligible Section 501(c)(3) Organization To Make Expenditures To Influence Legislation (if filing)
- All other attachments, including explanations, financial data, and printed materials or publications. Label each page with name and EIN.
- User fee payment placed in envelope on top of checklist. DO NOT STAPLE or otherwise attach your check or money order to your application. Instead, just place it in the envelope.
- Employer Identification Number (EIN)
- Completed Parts I through XI of the application, including any requested information and any required Schedules A through H.
  - You must provide specific details about your past, present, and planned activities.
  - Generalizations or failure to answer questions in the Form 1023 application will prevent us from recognizing you as tax exempt.
  - Describe your purposes and proposed activities in specific easily understood terms.
  - Financial information should correspond with proposed activities.
- Schedules. Submit only those schedules that apply to you and check either "Yes" or "No" below.

Schedule A	Yes No <u>*</u>	Schedule E	Yes No <u>*</u>
Schedule B	Yes No <u>✔</u>	Schedule F	Yes No 🕊
Schedule C	Yes No 🛫	Schedule G	Yes No_
Schedule D	Yes No <u></u> ✓	Schedule H	Yes No <u></u>

## Form **1023**

(Rev. December 2013)
Department of the Treasury
Internal Revenue Service

## **Application for Recognition of Exemption Under Section 501(c)(3) of the Internal Revenue Code**

() se with the June 2006 revision of the Instructions for Form 1023 and the current Notice 1382)

(00) OMB No. 1545-0056

**Note:** If exempt status is approved, this application will be open for public inspection.

Use the instructions to complete this application and for a definition of all **bold** items. For additional help, call IRS Exempt Organizations Customer Account Services toll-free at 1-877-829-5500. Visit our website at **www.irs.gov** for forms and publications. If the required information and documents are not submitted with payment of the appropriate user fee, the application may be returned to you.

Attach additional sheets to this application if you need more space to answer fully. Put your name and EIN on each sheet and identify each answer by Part and line number. Complete Parts I - XI of Form 1023 and submit only those Schedules (A through H) that apply to you.

Pa	Identification of Applicant						
1	Full name of organization (exactly as it appears in your organizing	ng document)	2 c/o Name (if	applicab	ole)		
The	ne PURA Syndrome Foundation						
3	Mailing address (Number and street) (see instructions)	Room/Suite	4 Employer Identifi	cation Nur	mber (EIN)		
3 Li	ttle Harbor Rd			81-2235	5818		
	City or town, state or country, and ZIP + 4		5 Month the annua	ıl accountii	ng period end	ds (01 – 1	2)
Ber	wick, ME 03901		December (12)				
6	Primary contact (officer, director, trustee, or authorized repraga Name: Heather Bowie	resentative)	<b>b</b> Phone:	207	7-698-5986	6	
			c Fax: (optional	)			
8	provide the authorized representative's name, and the name representative's firm. Include a completed Form 2848, Power Representative, with your application if you would like us to a way a person who is not one of your officers, directors, trust representative listed in line 7, paid, or promised payment, to the structure or activities of your organization, or about your provide the person's name, the name and address of the per	r of Attorney and communicate wit tees, employees, help plan, manag financial or tax m	Declaration of h your representa or an authorized ge, or advise you natters? If "Yes,"		<b>☑</b> Yes		No
	promised to be paid, and describe that person's role.						
	Organization's website: www.purasyndrome.org						
b	Organization's email: (optional) h.bowie@pura-syndrome.org	g 					
10	Certain organizations are not required to file an information rare granted tax-exemption, are you claiming to be excused f "Yes," explain. See the instructions for a description of organ Form 990-EZ.	rom filing Form 9	90 or Form 990-	EZ? If	☐ Yes		No
11	Date incorporated if a corporation, or formed, if other than a	corporation. (N	/IM/DD/YYYY)	03 /	02 /	2016	
12	Were you formed under the laws of a <b>foreign country?</b> If "Yes," state the country.				☐ Yes		No
							—

ame: The PURA Syndrome Foundation	EIN:	81 _2235818
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Par	Uli Organizational Stru	icture					
You (See	must be a corporation (includi instructions.) <b>DO NOT file thi</b>	ng a limited liability company), an u	nincorporated association, or a trust on lines 1, 2, 3, or 4.	to be	tax ex	empt.	
1		state agency. Include copies of any	f incorporation showing <b>certification</b> amendments to your articles and		Yes		No
2	certification of filing with the ap a copy. Include copies of any a	ity company (LLC)? If "Yes," attach a copy of your articles of organization showing the the appropriate state agency. Also, if you adopted an operating agreement, attach of any amendments to your articles and be sure they show state filing certification. It is for circumstances when an LLC should not file its own exemption application.					No
3	Are you an <b>unincorporated association</b> ? If "Yes," attach a copy of your articles of association, constitution, or other similar organizing document that is dated and includes at least two signatures. Include signed and dated copies of any amendments.				Yes		No
	and dated copies of any ame				Yes		No
b	Have you been funded? If "No,	" explain how you are formed without	anything of value placed in trust.		Yes		No
5	how your officers, directors, dir	or trustees are selected.	ng date of adoption. If "No," explain	<b>V</b>	Yes		No
		s in Your Organizing Documer					
to me does	eet the organizational test under a not meet the organizational test.	section 501(c)(3). Unless you can check DO NOT file this application until you	ation, your organizing document contain the boxes in both lines 1 and 2, your o u have amended your organizing docu if you are a corporation or an LLC) with	rganizi <b>ıment</b> .	ng doci Submi	ument t your	
1	religious, educational, and/or meets this requirement. Desc	scientific purposes. Check the box ribe specifically where your organizi	our exempt purpose(s), such as charito confirm that your organizing docuing document meets this requirement cument. Refer to the instructions for d Paragraph):  Articles of Inc, Articles	ment t, sucl	n as ipt <b>ond</b>		
2a	for exempt purposes, such as confirm that your organizing do	charitable, religious, educational, and/ocument meets this requirement by ex	your remaining assets must be used e or scientific purposes. Check the box opress provision for the distribution of a not check the box on line 2a and go to	on line ssets	2a to upon		
2b	If you checked the box on lin Do not complete line 2c if yo	e 2a, specify the location of your di u checked box 2a. Article of Inco	ssolution clause (Page, Article, and F poration, Article Eighth and Exhibit	aragr f A	aph).		
	you rely on operation of state	law for your dissolution provision a	aw in your particular state. Check th nd indicate the state:	is box	if 		
Par	t IV Narrative Descripti	on of Your Activities					
this in applic detail	nformation in response to other position for supporting details. You is to this narrative. Remember the	parts of this application, you may summ may also attach representative copies at if this application is approved, it will l	narrative. If you believe that you have a arize that information here and refer to to for newsletters, brochures, or similar do be open for public inspection. Therefore the strong for information that must be included.	he specument, your	ecific pa ts for su narrativ	arts of upport e	the ing
Par		Other Financial Arrangements dependent Contractors	With Your Officers, Directors,	Trus	tees,		
1a	total annual <b>compensation</b> , or other position. Use actual figure	proposed compensation, for all service	rectors, and trustees. For each person es to the organization, whether as an epensation is or will be paid. If addition what to include as compensation.	officer	, emplo	yee, c	
Name		Title	Mailing address		ensation al actual		
See	attached						
		1	1				

## Part V Compensation and Other Financial Arrangements With Your Officers, Directors, Trustees, Employees, and Independent Contractors (Continued)

	Employees, and me	iependent Contractors (C	onunueu)			
b	receive compensation of more	than \$50,000 per year. Use	ur five highest compensated employees whethe actual figure, if available. Refer to the include officers, directors, or trustees listed in	nstruc	ctions f	
Name	3	Title	Mailing address		ensation al actual	
N/A				•		
С		npensation of more than \$50,	es of your five highest compensated <b>indep</b> 000 per year. Use the actual figure, if avai ation.			rs
Name	;	Title	Mailing address		ensation al actual	
N/A						
			ed relationships, transactions, or agreements we be a state of independent contractors listed in line			
2a	Are any of your officers, direct relationships? If "Yes," identif		ch other through <b>family</b> or <b>business</b> the relationship.		Yes	No
b		fficer, director, or trustee? If "	rs, directors, or trustees other than Yes," identify the individuals and describe rs, or trustees.		Yes	No
С		ident contractors listed on line	ur highest compensated employees or es 1b or 1c through family or business he relationship.		Yes	No
3a		ntractors listed on lines 1a, 1	ensated employees, and highest b, or 1c, attach a list showing their name,			
b	other organizations, whether t	ntractors listed on lines 1a, 1l ax exempt or taxable, that are individuals, explain the relation	nsated employees, and highest b, or 1c receive compensation from any e related to you through <b>common</b> onship between you and the other		Yes	No
4	employees, and highest comp	ensated independent contract mended, although they are no	s, trustees, highest compensated tors listed on lines 1a, 1b, and 1c, the of required to obtain exemption. Answer			
b	Do you or will you approve co	empensation arrangements in	gements follow a conflict of interest policy? advance of paying compensation? of approved compensation arrangements?		Yes Yes Yes	No No No

orm	1023 (Rev. 12-2013) (00) Name: The PURA Syndrome Foundation EIN: 81 _ 22	35818	Page 4
Pai	Compensation and Other Financial Arrangements With Your Officers, Directors, Employees, and Independent Contractors (Continued)	Trustees,	
d	Do you or will you record in writing the decision made by each individual who decided or voted on compensation arrangements?	✓ Yes	☐ No
е	Do you or will you approve compensation arrangements based on information about compensation paid by <b>similarly situated</b> taxable or tax-exempt organizations for similar services, current compensation surveys compiled by independent firms, or actual written offers from similarly situated organizations? Refer to the instructions for Part V, lines 1a, 1b, and 1c, for information on what to include as compensation.	✓ Yes	□ No
f	Do you or will you record in writing both the information on which you relied to base your decision and its source?	✓ Yes	☐ No
g	If you answered "No" to any item on lines 4a through 4f, describe how you set compensation that is <b>reasonable</b> for your officers, directors, trustees, highest compensated employees, and highest compensated independent contractors listed in Part V, lines 1a, 1b, and 1c.		
5a	Have you adopted a <b>conflict of interest policy</b> consistent with the sample conflict of interest policy in Appendix A to the instructions? If "Yes," provide a copy of the policy and explain how the policy has been adopted, such as by resolution of your governing board. If "No," answer lines 5b and 5c.	✓ Yes	□ No
b	What procedures will you follow to assure that persons who have a conflict of interest will not have influence over you for setting their own compensation?		
С	What procedures will you follow to assure that persons who have a conflict of interest will not have influence over you regarding business deals with themselves?		
	<b>Note:</b> A conflict of interest policy is recommended though it is not required to obtain exemption. Hospitals, see Schedule C, Section I, line 14.		
6a	Do you or will you compensate any of your officers, directors, trustees, highest compensated employees, and highest compensated independent contractors listed in lines 1a, 1b, or 1c through <b>non-fixed payments</b> , such as discretionary bonuses or revenue-based payments? If "Yes," describe all non-fixed compensation arrangements, including how the amounts are determined, who is eligible for such arrangements, whether you place a limitation on total compensation, and how you determine or will determine that you pay no more than reasonable compensation for services. Refer to the instructions for Part V, lines 1a, 1b, and 1c, for information on what to include as compensation.	☐ Yes	<b>∠</b> No
b	Do you or will you compensate any of your employees, other than your officers, directors, trustees, or your five highest compensated employees who receive or will receive compensation of more than \$50,000 per year, through non-fixed payments, such as discretionary bonuses or revenue-based payments? If "Yes," describe all non-fixed compensation arrangements, including how the amounts are or will be determined, who is or will be eligible for such arrangements, whether you place or will place a limitation on total compensation, and how you determine or will determine that you pay no more than reasonable compensation for services. Refer to the instructions for Part V, lines 1a, 1b, and 1c, for information on what to include as compensation.	☐ Yes	<b>∠</b> No
7a	Do you or will you purchase any goods, services, or assets from any of your officers, directors, trustees, highest compensated employees, or highest compensated independent contractors listed in lines 1a, 1b, or 1c? If "Yes," describe any such purchase that you made or intend to make, from whom you make or will make such purchases, how the terms are or will be negotiated at arm's length, and explain how you determine or will determine that you pay no more than fair market value. Attach copies of any written contracts or other agreements relating to such purchases.	☐ Yes	<b>∠</b> No
b	Do you or will you sell any goods, services, or assets to any of your officers, directors, trustees, highest compensated employees, or highest compensated independent contractors listed in lines 1a, 1b, or 1c? If "Yes," describe any such sales that you made or intend to make, to whom you make or will make such sales, how the terms are or will be negotiated at arm's length, and explain how you determine or will determine you are or will be paid at least fair market value. Attach copies of any written contracts or other agreements relating to such sales.	☐ Yes	<b>∠</b> No
8a	Do you or will you have any leases, contracts, loans, or other agreements with your officers, directors, trustees, highest compensated employees, or highest compensated independent contractors listed in lines 1a, 1b, or 1c? If "Yes," provide the information requested in lines 8b through 8f.	☐ Yes	<b>∠</b> No
c d e	Describe any written or oral arrangements that you made or intend to make.  Identify with whom you have or will have such arrangements.  Explain how the terms are or will be negotiated at arm's length.  Explain how you determine you pay no more than fair market value or you are paid at least fair market value.  Attach copies of any signed leases, contracts, loans, or other agreements relating to such arrangements.		
9a	Do you or will you have any leases, contracts, loans, or other agreements with any organization in which any of your officers, directors, or trustees are also officers, directors, or trustees, or in which any individual officer, director, or trustee owns more than a 35% interest? If "Yes," provide the information requested in lines 9b through 9f.	☐ Yes	<b>☑</b> No

(00) Name: The PURA Syndrome Foundation EIN: 81 \_ 2235818

#### Compensation and Other Financial Arrangements With Your Officers, Directors, Trustees, Part V **Employees, and Independent Contractors** (Continued)

- **b** Describe any written or oral arrangements you made or intend to make.
- **c** Identify with whom you have or will have such arrangements.
- d Explain how the terms are or will be negotiated at arm's length.
- e Explain how you determine or will determine you pay no more than fair market value or that you are paid at least fair market value.

f	Attach a copy of any signed leases, contracts, loans, or other agreements relating to such arrangements.				
Pai	rt VI Your Members and Other Individuals and Organizations That Receive Benefits Fr	om	You		
The of yo	following "Yes" or "No" questions relate to goods, services, and funds you provide to individuals and or activities. Your answers should pertain to past, present, and planned activities. (See instructions.)	ganiz	zations	as pa	art
1a	In carrying out your exempt purposes, do you provide goods, services, or funds to individuals? If "Yes," describe each program that provides goods, services, or funds to individuals.		Yes		No
b	In carrying out your exempt purposes, do you provide goods, services, or funds to organizations? If "Yes," describe each program that provides goods, services, or funds to organizations.		Yes		No
2	Do any of your programs limit the provision of goods, services, or funds to a specific individual or group of specific individuals? For example, answer "Yes," if goods, services, or funds are provided only for a particular individual, your members, individuals who work for a particular employer, or graduates of a particular school. If "Yes," explain the limitation and how recipients are selected for each program.		Yes		No
3	Do any individuals who receive goods, services, or funds through your programs have a family or business relationship with any officer, director, trustee, or with any of your highest compensated employees or highest compensated independent contractors listed in Part V, lines 1a, 1b, and 1c? If "Yes," explain how these related individuals are eligible for goods, services, or funds.		Yes		No
Pai	rt VII Your History				
	following "Yes" or "No" questions relate to your history. (See instructions.)				
1	Are you a <b>successor</b> to another organization? Answer "Yes," if you have taken or will take over the activities of another organization; you took over 25% or more of the fair market value of the net assets of another organization; or you were established upon the conversion of an organization from for-profit to non-profit status. If "Yes," complete Schedule G.		Yes		No
2	Are you submitting this application more than 27 months after the end of the month in which you were legally formed? If "Yes," complete Schedule E.		Yes		No
Pa	rt VIII Your Specific Activities				
	following "Yes" or "No" questions relate to specific activities that you may conduct. Check the appropri vers should pertain to past, present, and planned activities. (See instructions.)	ate b	ox. Yo	our	
1	Do you support or oppose candidates in <b>political campaigns</b> in any way? If "Yes," explain.		Yes		No
2a	Do you attempt to <b>influence legislation</b> ? If "Yes," explain how you attempt to influence legislation and complete line 2b. If "No," go to line 3a.		Yes		No
b	Have you made or are you making an <b>election</b> to have your legislative activities measured by expenditures by filing Form 5768? If "Yes," attach a copy of the Form 5768 that was already filed or attach a completed Form 5768 that you are filing with this application. If "No," describe whether your attempts to influence legislation are a substantial part of your activities. Include the time and money spent on your attempts to influence legislation as compared to your total activities.		Yes		No
3a	Do you or will you operate bingo or <b>gaming</b> activities? If "Yes," describe who conducts them, and list all revenue received or expected to be received and expenses paid or expected to be paid in operating these activities. <b>Revenue and expenses</b> should be provided for the time periods specified in Part IX, Financial Data.		Yes		No
b	Do you or will you enter into contracts or other agreements with individuals or organizations to conduct bingo or gaming for you? If "Yes," describe any written or oral arrangements that you made or intend to make, identify with whom you have or will have such arrangements, explain how the terms are or will be negotiated at arm's length, and explain how you determine or will determine you pay no more than fair market value or you will be paid at least fair market value. Attach copies or any written contracts or other agreements relating to such arrangements.		Yes		No
С	List the states and local jurisdictions, including Indian Reservations, in which you conduct or will conduct gaming or bingo.				

scientific discoveries, or other intellectual property? If "Yes," explain. Describe who owns or will own any copyrights, patents, or trademarks, whether fees are or will be charged, how the fees are

determined, and how any items are or will be produced, distributed, and marketed.

**b** Provide the name of each foreign organization, the country and regions within a country in which each foreign organization operates, and describe any relationship you have with each foreign organization.

c Does any foreign organization listed in line 14b accept contributions earmarked for a specific country or specific organization? If "Yes," list all earmarked organizations or countries.

d Do your contributors know that you have ultimate authority to use contributions made to you at your discretion for purposes consistent with your exempt purposes? If "Yes," describe how you relay this information to contributors.

e Do you or will you make pre-grant inquiries about the recipient organization? If "Yes," describe these inquiries, including whether you inquire about the recipient's financial status, its tax-exempt status under the Internal Revenue Code, its ability to accomplish the purpose for which the resources are provided, and other relevant information.

f Do you or will you use any additional procedures to ensure that your distributions to foreign organizations are used in furtherance of your exempt purposes? If "Yes," describe these procedures, including site visits by your employees or compliance checks by impartial experts, to verify that grant funds are being used appropriately.

Yes

Yes

Yes

Yes

✓ No

□ No

■ No

✓ No

Form	1 1023 (Rev. 12-2013) (00) Name: The PURA Syndrome Foundation EIN: 81 _ 22	235818	Page	8
Pa	rt VIII Your Specific Activities (Continued)			_
15	Do you have a close connection with any organizations? If "Yes," explain.	☐ Yes	✓ No	D
16	Are you applying for exemption as a <b>cooperative hospital service organization</b> under section 501(e)? If "Yes," explain.	☐ Yes	✓ No	O
17	Are you applying for exemption as a <b>cooperative service organization of operating educational organizations</b> under section 501(f)? If "Yes," explain.	☐ Yes	✓ No	O
18	Are you applying for exemption as a charitable risk pool under section 501(n)? If "Yes," explain.	☐ Yes	✓ No	0
19	Do you or will you operate a <b>school</b> ? If "Yes," complete Schedule B. Answer "Yes," whether you operate a school as your main function or as a secondary activity.	☐ Yes	✓ No	O
20	Is your main function to provide hospital or medical care? If "Yes," complete Schedule C.	☐ Yes	✓ No	<b>D</b>
21	Do you or will you provide <b>low-income housing</b> or housing for the <b>elderly</b> or <b>handicapped</b> ? If "Yes," complete Schedule F.	☐ Yes	✓ No	D
22	Do you or will you provide scholarships, fellowships, educational loans, or other educational grants to individuals, including grants for travel, study, or other similar purposes? If "Yes," complete Schedule H.	☐ Yes	<b>∠</b> No	D
	Note: Private foundations may use Schedule H to request advance approval of individual grant			

procedures.

### Part IX Financial Data

For purposes of this schedule, years in existence refer to completed tax years. If in existence 4 or more years, complete the schedule for the most recent 4 tax years. If in existence more than 1 year but less than 4 years, complete the statements for each year in existence and provide projections of your likely revenues and expenses based on a reasonable and good faith estimate of your future finances for a total of 3 years of financial information. If in existence less than 1 year, provide projections of your likely revenues and expenses for the current year and the 2 following years, based on a reasonable and good faith estimate of your future finances for a total of 3 years of financial information. (See instructions.)

			A. Statement of	of Revenues and	Expenses		
		Type of revenue or expense	Current tax year	3 prior tax	years or 2 succeedin	g tax years	
			(a) From 1/1/16	(b) From 1/17	(c) From 1/18	(d) From	(e) Provide Total for
			To 12/16	To 12/17	To 12/18	To	(a) through (d)
	1	Gifts, grants, and					
	<b>'</b>	contributions received (do not					
		include unusual grants)	20,000	20,000	25,000		
	2	Membership fees received					
	3	Gross investment income					
	4	Net unrelated business					
		income					
	5	Taxes levied for your benefit					
	6	Value of services or facilities					
		furnished by a governmental					
S		unit without charge (not including the value of services					
ne		generally furnished to the					
Revenues		public without charge)					
Re	7	,					
		listed above or in lines 9–12					
		below (attach an itemized list)	20,000	20,000	25,000		
	8		20,000	20,000	25,000		
	9	Gross receipts from admissions, merchandise sold or services					
		performed, or furnishing of					
		facilities in any activity that is					
		related to your exempt purposes (attach itemized list)					
	10	Total of lines 8 and 9	20,000	20,000	25,000		
	11	Net gain or loss on sale of	,	,	,		
	١.,	capital assets (attach					
		schedule and see instructions)					
	12	Unusual grants					
	13	Total Revenue					
		Add lines 10 through 12	20,000	20,000	25,000		
	14	Fundraising expenses					
	15	Contributions, gifts, grants,					
		and similar amounts paid out (attach an itemized list)	0	15,000	10,000		
		,	0	13,000	10,000		
	16	Disbursements to or for the					
		benefit of members (attach an itemized list)					
	47	•					
es	17	Compensation of officers, directors, and trustees					
Expenses	18	Other salaries and wages					
dx	19	Interest expense					
Ш	20	Occupancy (rent, utilities, etc.)					
	21	Depreciation and depletion					
	22	Professional fees	1,000				
	23	Any expense not otherwise					
		classified, such as program					
		services (attach itemized list)	1,850	17,400	17,400		
	24	Total Expenses					
		Add lines 14 through 23	2850	32,400	27,400		

	1023 (Rev. 12-2013) (00) Name: The PURA Syndrome Foundation  It IX Financial Data (Continued)	V.		22358			Pa	ge <b>1</b> (
Га	B. Balance Sheet (for your most recently completed tax year)				Τ,	Year En	d: N	I/A
	Assets					(Who		lars)
1	Cash			1		,		,
2	Accounts receivable, net			2	T			-
3	Inventories			3				
4	Bonds and notes receivable (attach an itemized list)			4				
5	Corporate stocks (attach an itemized list)			5				
6	Loans receivable (attach an itemized list)			6				
7	Other investments (attach an itemized list)			7				
8	Depreciable and depletable assets (attach an itemized list)			8				
9	Land			9				
10	Other assets (attach an itemized list)			10				
11	Total Assets (add lines 1 through 10)			11				
12	Accounts payable			12				
13	Contributions, gifts, grants, etc. payable			13	T			
14	Mortgages and notes payable (attach an itemized list)			14	T			
15	Other liabilities (attach an itemized list)			15	T			
16	Total Liabilities (add lines 12 through 15)			16	T			
	Fund Balances or Net Assets	•						
17	Total fund balances or net assets			17				
18	Total Liabilities and Fund Balances or Net Assets (add lines 16 and 17)			18				
19	Have there been any substantial changes in your assets or liabilities since the end of the shown above? If "Yes," explain.	ре	riod			Yes	<b>V</b>	No
Pai	rt X Public Charity Status							
is a	X is designed to classify you as an organization that is either a <b>private foundation</b> or a <b>pul</b> more favorable tax status than private foundation status. If you are a private foundation, Paremine whether you are a <b>private operating foundation</b> . (See instructions.)							tatus
1a	Are you a private foundation? If "Yes," go to line 1b. If "No," go to line 5 and proceed as ir If you are unsure, see the instructions.	nstr	ucted	d. [		Yes	<b>V</b>	No
b	As a private foundation, section 508(e) requires special provisions in your organizing document addition to those that apply to all organizations described in section 501(c)(3). Check the beconfirm that your organizing document meets this requirement, whether by express provision reliance on operation of state law. Attach a statement that describes specifically where you organizing document meets this requirement, such as a reference to a particular article or your organizing document or by operation of state law. See the instructions, including Apple for information about the special provisions that need to be contained in your organizing do to line 2.	ox on ir sec end	to or by tion i lix B,	n				
2	Are you a private operating foundation? To be a private operating foundation you must end directly in the active conduct of charitable, religious, educational, and similar activities, as a to indirectly carrying out these activities by providing grants to individuals or other organizatives," go to line 3. If "No," go to the signature section of Part XI.	opp	osed	l		Yes		] No
3	Have you existed for one or more years? If "Yes," attach financial information showing that you are operating foundation; go to the signature section of Part XI. If "No," continue to line 4.	e a	priva	te [		Yes		No
4	Have you attached either (1) an affidavit or opinion of counsel, (including a written affidavit from a certified public accountant or accounting firm with expertise regarding this tax law rethat sets forth facts concerning your operations and support to demonstrate that you are listatisfy the requirements to be classified as a private operating foundation; or (2) a statemed describing your proposed operations as a private operating foundation?	mat kely	ter),	on [		Yes		No
5	If you answered "No" to line 1a, indicate the type of public charity status you are requesting by You may check only one box.	che	cking	one o	ft	he cho	ices b	oelow
a b c	The organization is not a private foundation because it is: 509(a)(1) and 170(b)(1)(A)(i)—a church or a convention or association of churches. Complete are 509(a)(1) and 170(b)(1)(A)(ii)—a <b>school</b> . Complete and attach Schedule B. 509(a)(1) and 170(b)(1)(A)(iii)—a <b>hospital</b> , a cooperative hospital service organization, or a notation of the complete and attach schedule are convenient.					le A.		] ] ]
-	organization operated in conjunction with a hospital. Complete and attach Schedule C.	_						

**d** 509(a)(3)—an organization supporting either one or more organizations described in line 5a through c, f, g, or h or a publicly supported section 501(c)(4), (5), or (6) organization. Complete and attach Schedule D.

Reminder: Send the completed Form 1023 Checklist with your filled-in-application.

### Part XI User Fee Information

You must include a user fee payment with this application. It will not be processed without your paid user fee. If your average annual gross receipts have exceeded or will exceed \$10,000 annually over a 4-year period, you must submit payment of \$850. If your gross receipts have not exceeded or will not exceed \$10,000 annually over a 4-year period, the required user fee payment is \$400. See instructions for Part XI, for a definition of gross receipts over a 4-year period. Your check or money order must be made payable to the United States Treasury. User fees are subject to change. Check our website at www.irs.gov and type "User Fee" in the keyword box, or call Customer Account Services at 1-877-829-5500 for current information.

1 00	and the hely word box, or can odd to the Account Cervices at 1-077-025-000	70 for current importations.	
1	Have your annual gross receipts averaged or are they expected to average in ff "Yes," check the box on line 2 and enclose a user fee payment of \$400 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$850 (Stiff "No," check the box on line 3 and enclose a user fee payment of \$8	ubject to change—see above).	s 🗹 No
2	Check the box if you have enclosed the reduced user fee payment of \$400 (		
3	Check the box if you have enclosed the user fee payment of \$850 (Subject t	to change).	
appli	re (Signature of Officer, Director, Trustee, or other authorized official)  (Type or print name authorized official)	nowledge it is true, correct, and complete.  Boule 9/12 ne of signer) (Date)	
Rei	minder: Send the completed Form 1023 Checklist with your	filled-in-application. Form, 102	3 <sub>1</sub> (Rev. 12-2013)

Form	1023 (Rev. 12-2013) (00) Name: The PURA Syndrome Foundation EIN: 81 _	2235818	Page 13
	Schedule A. Churches		-
1a	Do you have a written creed, statement of faith, or summary of beliefs? If "Yes," attach copies of relevant documents.	☐ Yes	☐ No
b	Do you have a form of worship? If "Yes," describe your form of worship.	☐ Yes	☐ No
2a	Do you have a formal code of doctrine and discipline? If "Yes," describe your code of doctrine and discipline.	☐ Yes	☐ No
b	Do you have a distinct religious history? If "Yes," describe your religious history.	☐ Yes	☐ No
С	Do you have a literature of your own? If "Yes," describe your literature.	☐ Yes	☐ No
3	Describe the organization's religious hierarchy or ecclesiastical government.		
4a	Do you have regularly scheduled religious services? If "Yes," describe the nature of the services an provide representative copies of relevant literature such as church bulletins.	d 🗌 Yes	☐ No
b	What is the average attendance at your regularly scheduled religious services?		
5a	Do you have an established place of worship? If "Yes," refer to the instructions for the information required.	☐ Yes	☐ No
b	Do you own the property where you have an established place of worship?	☐ Yes	☐ No
6	Do you have an established congregation or other regular membership group? If "No," refer to the instructions.	☐ Yes	☐ No
7	How many members do you have?		
8a	Do you have a process by which an individual becomes a member? If "Yes," describe the process	☐ Yes	☐ No
b	and complete lines 8b–8d, below.  If you have members, do your members have voting rights, rights to participate in religious function or other rights? If "Yes," describe the rights your members have.	s, 🗌 <b>Yes</b>	☐ No
С	May your members be associated with another denomination or church?	☐ Yes	☐ No
d	Are all of your members part of the same <b>family</b> ?	☐ Yes	☐ No
9	Do you conduct baptisms, weddings, funerals, etc.?	☐ Yes	□ No
10	Do you have a school for the religious instruction of the young?	☐ Yes	☐ No
11a	Do you have a minister or religious leader? If "Yes," describe this person's role and explain whether the minister or religious leader was ordained, commissioned, or licensed after a prescribed course or study.	☐ Yes	□ No
b	Do you have schools for the preparation of your ordained ministers or religious leaders?	☐ Yes	☐ No
12	Is your minister or religious leader also one of your officers, directors, or trustees?	☐ Yes	☐ No
13	Do you ordain, commission, or license ministers or religious leaders? If "Yes," describe the requirements for ordination, commission, or licensure.	☐ Yes	☐ No
14	Are you part of a group of churches with similar beliefs and structures? If "Yes," explain. Include the name of the group of churches.	e 🗌 <b>Yes</b>	☐ No
15	Do you issue church charters? If "Yes," describe the requirements for issuing a charter.	☐ Yes	□ No
16	Did you pay a fee for a church charter? If "Yes," attach a copy of the charter.	☐ Yes	☐ No
17	Do you have other information you believe should be considered regarding your status as a church If "Yes," explain.	?	☐ No

Does or will the organization (or any department or division within it) discriminate in any way on the

basis of race with respect to admissions; use of facilities or exercise of student privileges; faculty or administrative staff; or scholarship or loan programs? If "Yes," for any of the above, explain fully.

"No," explain.

☐ No

Yes

### Schedule B. Schools, Colleges, and Universities (Continued)

5	Complete the table below to show the racial composition for the current academic year and projected for the next
	academic year, of: (a) the student body, (b) the faculty, and (c) the administrative staff. Provide actual numbers rather than
	percentages for each racial category.

If you are not operational, submit an estimate based on the best information available (such as the racial composition of the community served).

Racial Category	(a) Student Body		egory (a) Student Body (b) Faculty		(c) Administrative Staff		
	Current Year	Next Year	Current Year	Next Year	Current Year	Next Year	
Total							

6 In the table below, provide the number and amount of loans and scholarships awarded to students enrolled by racial categories.

Racial Category	Number of Loans		Category Number of Loans Amount of Loans		Number of Scholarships		Amount of Scholarships	
	Current Year	Next Year	Current Year	Next Year	Current Year	Next Year	Current Year	Next Year
Total								

7a	Attach a list of your incorporators, founders, board members, and donors of land or buildings, whether individuals or organizations.		
b	Do any of these individuals or organizations have an objective to maintain segregated public or private school education? If "Yes," explain.	☐ Yes	☐ No
8	Will you maintain records according to the non-discrimination provisions contained in Revenue Procedure 75-50? If "No," explain. (See instructions.)	☐ Yes	□ No

Form 1023 (Rev. 12-2013)

Form	1023 (Rev. 12-2013) (00) Name:	2200010	Page 1
	Schedule C. Hospitals and Medical Research Organizations (Continue	ed)	
Se	ction I Hospitals (Continued)		
10	Do you or will you manage your activities or facilities through your own employees or volunteers? I "No," attach a statement describing the activities that will be managed by others, the names of the persons or organizations that manage or will manage your activities or facilities, and how these managers were or will be selected. Also, submit copies of any contracts, proposed contracts, or other agreements regarding the provision of management services for your activities or facilities. Explain how the terms of any contracts or other agreements were or will be negotiated, and explain how you determine you will pay no more than fair market value for services.  Note. Answer "Yes" if you do manage or intend to manage your programs through your own employees or by using volunteers. Answer "No" if you engage or intend to engage a separate organization or independent contractor. Make sure your answer is consistent with the information provided in Part VIII, line 7b.	•	□ No
11	Do you or will you offer recruitment incentives to physicians? If "Yes," describe your recruitment incentives and attach copies of all written recruitment incentive policies.	☐ Yes	☐ No
12	Do you or will you lease equipment, assets, or office space from physicians who have a financial or professional relationship with you? If "Yes," explain how you establish a fair market value for the lease.	r 🗌 <b>Yes</b>	□ No
13	Have you purchased medical practices, ambulatory surgery centers, or other business assets from physicians or other persons with whom you have a business relationship, aside from the purchase "Yes," submit a copy of each purchase and sales contract and describe how you arrived at fair market value, including copies of appraisals.		□ No
14	Have you adopted a <b>conflict of interest policy</b> consistent with the sample health care organization conflict of interest policy in Appendix A of the instructions? If "Yes," submit a copy of the policy are explain how the policy has been adopted, such as by resolution of your governing board. If "No," explain how you will avoid any conflicts of interest in your business dealings.		□ No
Se	ction II Medical Research Organizations		
1	Name the hospitals with which you have a relationship and describe the relationship. Attach copies of written agreements with each hospital that demonstrate continuing relationships between you are the hospital(s).		
2	Attach a schedule describing your present and proposed activities for the direct conduct of medicaresearch; describe the nature of the activities, and the amount of money that has been or will be spent in carrying them out.	al	
3	Attach a schedule of assets showing their fair market value and the portion of your assets directly devoted to medical research.		

Form 1023 (Rev. 12-2013)

Schedule D. Section 509(a)(3) Supporting Organizations

Sec	ction I Identifying Information About the	Supported Organization(s)				
1	State the names, addresses, and EINs of the suppsheet.	ported organizations. If additional space is needed, att	tach	a sepa	ırate	
	Name	Address		EIN	1	
				-		
				-		
2	Are all supported organizations listed in line 1 pub go to Section II. If "No," go to line 3.	olic charities under section 509(a)(1) or (2)? If "Yes,"		Yes		No
3	Do the supported organizations have tax-exempt 501(c)(6)?	status under section 501(c)(4), 501(c)(5), or		Yes		No
	If "Yes," for each $501(c)(4)$ , (5), or (6) organization information:	supported, provide the following financial				
	<ul> <li>Part IX-A. Statement of Revenues and Expenses</li> <li>Part X, lines 6b(ii)(a), 6b(ii)(b), and 7.</li> </ul>	s, lines 1–13 and				
	If "No," attach a statement describing how each of section 509(a)(1) or (2).	organization you support is a public charity under				
Sec	ction II Relationship with Supported Orga	anization(s)—Three Tests				
To b	be classified as a supporting organization, an organ Test 1: "Operated, supervised, or controlled by" on Test 2: "Supervised or controlled in connection with Test 3: "Operated in connection with" one or more	ne or more publicly supported organizations, or ith one or more publicly supported organizations, or				
1	Information to establish the "operated, supervised Is a majority of your governing board or officers el organization(s)? If "Yes," describe the process by elected; go to Section III. If "No," continue to line	lected or appointed by the supported which your governing board is appointed and		Yes		No
2	Information to establish the "supervised or control Does a majority of your governing board consist of board of the supported organization(s)? If "Yes," of board is appointed and elected; go to Section III.	of individuals who also serve on the governing describe the process by which your governing		Yes		No
3	Information to establish the "operated in connection	on with" responsiveness test (Test 3)				
	Are you a trust from which the named supported accounting under state law? If "Yes," explain whe writing of these rights and provide a copy of the v Section II, line 5. If "No," go to line 4a.	organization(s) can enforce and compel an ther you advised the supported organization(s) in		Yes		No
4 a	Information to establish the alternative "operated in Do the officers, directors, trustees, or members of or more of your officers, directors, or trustees? If "line 4d, below. If "No," go to line 4b.	f the supported organization(s) elect or appoint one		Yes		No
b	Do one or more members of the governing body of officers, directors, or trustees or hold other import and provide documentation; go to line 4d, below.	tant offices with respect to you? If "Yes," explain		Yes		No
С	Do your officers, directors, or trustees maintain a officers, directors, or trustees of the supported org documentation.	close and continuous working relationship with the ganization(s)? If "Yes," explain and provide		Yes		No
d	Do the supported organization(s) have a significan and timing of grants, and in otherwise directing th and provide documentation.	nt voice in your investment policies, in the making se use of your income or assets? If "Yes," explain		Yes		No
е	Describe and provide copies of written communic organization(s) aware of your supporting activities.					

orm	1023 (Rev. 12-2013) (00) Name: The PURA Syndrome Foundation EIN: 81 _ 22	235818	Page <b>19</b>
	Schedule D. Section 509(a)(3) Supporting Organizations (Continued)		rage re
Sec	ction II Relationship with Supported Organization(s)—Three Tests (Continued)		
5	Information to establish the "operated in connection with" integral part test (Test 3)		
	Do you conduct activities that would otherwise be carried out by the supported organization(s)? If "Yes," explain and go to Section III. If "No," continue to line 6a.	☐ Yes	☐ No
6	Information to establish the alternative "operated in connection with" integral part test (Test 3)		
а	Do you distribute at least 85% of your annual <b>net income</b> to the supported organization(s)? If "Yes," go to line 6b. (See instructions.)	☐ Yes	☐ No
	If "No," state the percentage of your income that you distribute to each supported organization. Also explain how you ensure that the supported organization(s) are attentive to your operations.		
	How much do you contribute annually to each supported organization? Attach a schedule.		
С	What is the total annual revenue of each supported organization? If you need additional space, attach a list.	_	
d	Do you or the supported organization(s) <b>earmark</b> your funds for support of a particular program or activity? If "Yes," explain.	☐ Yes	☐ No
7a	Does your organizing document specify the supported organization(s) by name? If "Yes," state the	☐ Yes	☐ No
b	article and paragraph number and go to Section III. If "No," answer line 7b.  Attach a statement describing whether there has been an historic and continuing relationship		
	between you and the supported organization(s).		
Sec	ction III Organizational Test		
1a	If you met relationship Test 1 or Test 2 in Section II, your organizing document must specify the supported organization(s) by name, or by naming a similar purpose or charitable class of beneficiaries. If your organizing document complies with this requirement, answer "Yes." If your organizing document does not comply with this requirement, answer "No," and see the instructions.	☐ Yes	☐ No
b	If you met relationship Test 3 in Section II, your organizing document must generally specify the supported organization(s) by name. If your organizing document complies with this requirement, answer "Yes," and go to Section IV. If your organizing document does not comply with this requirement, answer "No," and see the instructions.	☐ Yes	□ No
Sec	ction IV Disqualified Person Test		
as c	do not qualify as a supporting organization if you are <b>controlled</b> directly or indirectly by one or more defined in section 4946) other than <b>foundation managers</b> or one or more organizations that you supposes who are also disqualified persons for another reason are disqualified persons with respect to you	ort. Foundation	
1a	Do any persons who are disqualified persons with respect to you, (except individuals who are disqualified persons only because they are foundation managers), appoint any of your foundation managers? If "Yes," (1) describe the process by which disqualified persons appoint any of your foundation managers, (2) provide the names of these disqualified persons and the foundation managers they appoint, and (3) explain how control is vested over your operations (including assets and activities) by persons other than disqualified persons.	☐ Yes	□ No
b	Do any persons who have a family or business relationship with any disqualified persons with respect to you, (except individuals who are disqualified persons only because they are foundation managers), appoint any of your foundation managers? If "Yes," (1) describe the process by which individuals with a family or business relationship with disqualified persons appoint any of your foundation managers, (2) provide the names of these disqualified persons, the individuals with a family or business relationship with disqualified persons, and the foundation managers appointed, and (3) explain how control is vested over your operations (including assets and activities) in	☐ Yes	□ No

c Do any persons who are disqualified persons, (except individuals who are disqualified persons only because they are foundation managers), have any influence regarding your operations, including your assets or activities? If "Yes," (1) provide the names of these disqualified persons, (2) explain how influence is exerted over your operations (including assets and activities), and (3) explain how control is vested over your operations (including assets and activities) by individuals other than disqualified

individuals other than disqualified persons.

persons.

□ No

☐ Yes

81 \_ 2235818

### Schedule E. Organizations Not Filing Form 1023 Within 27 Months of Formation

Schedule E is intended to determine whether you are eligible for tax exemption under section 501(c)(3) from the postmark date of your application or from your date of incorporation or formation, whichever is earlier. If you are not eligible for tax exemption under section 501(c)(3) from your date of incorporation or formation, Schedule E is also intended to determine whether you are eligible for tax exemption under section 501(c)(4) for the period between your date of incorporation or formation and the postmark date of your application.

1	Are you a church, association of churches, or integrated auxiliary of a church? If "Yes," complete Schedule A and stop here. Do not complete the remainder of Schedule E.	☐ Yes	□ No
2a	Are you a public charity with annual <b>gross receipts</b> that are normally \$5,000 or less? If "Yes," stop here. Answer "No" if you are a private foundation, regardless of your gross receipts.	☐ Yes	☐ No
b	If your gross receipts were normally more than \$5,000, are you filing this application within 90 days from the end of the tax year in which your gross receipts were normally more than \$5,000? If "Yes," stop here.	☐ Yes	☐ No
За	Were you included as a subordinate in a group exemption application or letter? If "No," go to line 4.	☐ Yes	☐ No
b	If you were included as a subordinate in a group exemption letter, are you filing this application within 27 months from the date you were notified by the organization holding the group exemption letter or the Internal Revenue Service that you cease to be covered by the group exemption letter? If "Yes," stop here.	☐ Yes	□ No
С	If you were included as a subordinate in a timely filed group exemption request that was denied, are you filing this application within 27 months from the postmark date of the Internal Revenue Service final adverse ruling letter? If "Yes," stop here.	☐ Yes	□ No
4	Were you created on or before October 9, 1969? If "Yes," stop here. Do not complete the remainder of this schedule.	☐ Yes	☐ No
5	If you answered "No" to lines 1 through 4, we cannot recognize you as tax exempt from your date of formation unless you qualify for an extension of time to apply for exemption. Do you wish to request an extension of time to apply to be recognized as exempt from the date you were formed? If "Yes," attach a statement explaining why you did not file this application within the 27-month period. Do not answer lines 6, 7, or 8. If "No," go to line 6a.	☐ Yes	□ No
6a	If you answered "No" to line 5, you can only be exempt under section 501(c)(3) from the postmark date of this application. Therefore, do you want us to treat this application as a request for tax exemption from the postmark date? If "Yes," you are eligible for an advance ruling. Complete Part X, line 6a. If "No," you will be treated as a private foundation.	☐ Yes	□ No
b	<b>Note.</b> Be sure your ruling eligibility agrees with your answer to Part X, line 6. Do you anticipate significant changes in your sources of support in the future? If "Yes," complete line 7 below.	☐ Yes	☐ No

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### Schedule E. Organizations Not Filing Form 1023 Within 27 Months of Formation (Continued)

7 Complete this item only if you answered "Yes" to line 6b. Include projected revenue for the first two full years following the current tax year.

	Type of Revenue	Projected revenu	ue for 2 years following	g current tax year
		(a) From To	( <b>b)</b> From	(c) Total
1	Gifts, grants, and contributions received (do not include unusual grants)	10	10	
2	Membership fees received			
3	Gross investment income			
4	Net unrelated business income			
5	Taxes levied for your benefit			
6	Value of services or facilities furnished by a governmental unit without charge (not including the value of services generally furnished to the public without charge)			
7	Any revenue not otherwise listed above or in lines 9–12 below (attach an itemized list)			
8	Total of lines 1 through 7			
9	Gross receipts from admissions, merchandise sold, or services performed, or furnishing of facilities in any activity that is related to your exempt purposes (attach itemized list)			
10	Total of lines 8 and 9			
11	Net gain or loss on sale of capital assets (attach an itemized list)			
12	Unusual grants			
13	Total revenue. Add lines 10 through 12			
post 501 sect cont requ	ording to your answers, you are only eligible for tax track date of your application. However, you may (c)(4) from your date of formation to the postmark of the following stributions under Code section 170. Check the box usest for exemption under 501(c)(4) from your date of a completed Page 1 of Form 1024. Application	be eligible for tax exendate of the Form 1023. tax, but generally not at right if you want us of formation to the pos	nption under section Tax exemption under deductibility of to treat this as a tmark date.	▶ □
	ch a completed Page 1 of Form 1024, Application (a), to this application.	TOT NECOGNITION OF EXE	inplion under Section	

	Schedule F. Homes for the Elderly of Handicapped and Low-income Housi	iig	
Sec	ction I General Information About Your Housing		
1	Describe the type of housing you provide.		
2	Provide copies of any application forms you use for admission.		
3	Explain how the public is made aware of your facility.		
b c	Provide a description of each facility.  What is the total number of residents each facility can accommodate?  What is your current number of residents in each facility?  Describe each facility in terms of whether residents rent or purchase housing from you.		
5	Attach a sample copy of your residency or homeownership contract or agreement.		
6	Do you participate in any joint ventures? If "Yes," state your ownership percentage in each joint venture, list your investment in each joint venture, describe the tax status of other participants in each joint venture (including whether they are section 501(c)(3) organizations), describe the activities of each joint venture, describe how you exercise control over the activities of each joint venture, and describe how each joint venture furthers your exempt purposes. Also, submit copies of all joint venture agreements.	☐ Yes	□ No
	Note. Make sure your answer is consistent with the information provided in Part VIII, line 8.		
7	Do you or will you contract with another organization to develop, build, market, or finance your housing? If "Yes," explain how that entity is selected, explain how the terms of any contract(s) are negotiated at arm's length, and explain how you determine you will pay no more than fair market value for services.	☐ Yes	□ No
	Note. Make sure your answer is consistent with the information provided in Part VIII, line 7a.		
8	Do you or will you manage your activities or facilities through your own employees or volunteers? If "No," attach a statement describing the activities that will be managed by others, the names of the persons or organizations that manage or will manage your activities or facilities, and how these managers were or will be selected. Also, submit copies of any contracts, proposed contracts, or other agreements regarding the provision of management services for your activities or facilities. Explain how the terms of any contracts or other agreements were or will be negotiated, and explain how you determine you will pay no more than fair market value for services.  Note. Answer "Yes" if you do manage or intend to manage your programs through your own employees or by using volunteers. Answer "No" if you engage or intend to engage a separate organization or independent contractor. Make sure your answer is consistent with the information provided in Part VIII, line 7b.	☐ Yes	□ No
9	Do you participate in any government housing programs? If "Yes," describe these programs.	☐ Yes	☐ No
	Do you own the facility? If "No," describe any enforceable rights you possess to purchase the facility in the future; go to line 10c. If "Yes," answer line 10b.  How did you acquire the facility? For example, did you develop it yourself, purchase a project, etc. Attach all contracts, transfer agreements, or other documents connected with the acquisition of the	☐ Yes	□ No
С	facility.  Do you lease the facility or the land on which it is located? If "Yes," describe the parties to the lease(s) and provide copies of all leases.	☐ Yes	□ No

b Do you impose any restrictions to make sure that your housing remains affordable to low-income

Do you provide social services to residents? If "Yes," describe these services.

for the area.)

residents? If "Yes," describe these restrictions.

☐ No

■ No

Yes

Yes

value of the property or equipment was determined.

Form 1023 (Rev. 12-2013)

Schedule H. Organizations Providing Scholarships, Fellowships, Educational Loans, or Other Educational

	nts to Individuals and Private Foundations Requesting Advance Approval of Individual Grant Procedures
Sec	Names of individual recipients are not required to be listed in Schedule H.  Public charities and private foundations complete lines 1a through 7 of this section. See the instructions to Part X if you are not sure whether you are a public charity or a private foundation.
	Describe the types of educational grants you provide to individuals, such as scholarships, fellowships, loans, etc.
b	Describe the purpose and amount of your scholarships, fellowships, and other educational grants and loans that you award.
	If you award educational loans, explain the terms of the loans (interest rate, length, forgiveness, etc.).
е	Specify how your program is publicized.  Provide copies of any solicitation or announcement materials.  Provide a sample copy of the application used.
2	Do you maintain case histories showing recipients of your scholarships, fellowships, educational loans, or other educational grants, including names, addresses, purposes of awards, amount of each grant, manner of selection, and relationship (if any) to officers, trustees, or donors of funds to you? If "No," refer to the instructions.
3	Describe the specific criteria you use to determine who is eligible for your program. (For example, eligibility selection criteria could consist of graduating high school students from a particular high school who will attend college, writers of scholarly works about American history, etc.)
4a	Describe the specific criteria you use to select recipients. (For example, specific selection criteria could consist of prior academic performance, financial need, etc.)
b	Describe how you determine the number of grants that will be made annually.
С	Describe how you determine the amount of each of your grants.
d	Describe any requirement or condition that you impose on recipients to obtain, maintain, or qualify for renewal of a grant. (For example, specific requirements or conditions could consist of attendance at a four-year college, maintaining a certain grade point average, teaching in public school after graduation from college, etc.)
5	Describe your procedures for supervising the scholarships, fellowships, educational loans, or other educational grants. Describe whether you obtain reports and grade transcripts from recipients, or you pay grants directly to a school under an arrangement whereby the school will apply the grant funds only for enrolled students who are in good standing. Also, describe your procedures for taking action if the terms of the award are violated.
6	Who is on the selection committee for the awards made under your program, including names of current committee members, criteria for committee membership, and the method of replacing committee members?
7	Are relatives of members of the selection committee, or of your officers, directors, or <b>substantial Yes No contributors</b> eligible for awards made under your program? If "Yes," what measures are taken to ensure unbiased selections?
	<b>Note.</b> If you are a private foundation, you are not permitted to provide educational grants to <b>disqualified persons</b> . Disqualified persons include your substantial contributors and foundation managers and certain family members of disqualified persons.
Sec	Private foundations complete lines 1a through 4f of this section. Public charities do not complete this section.
1a	If we determine that you are a private foundation, do you want this application to be considered as a request for advance approval of grant making procedures?
b	For which section(s) do you wish to be considered?
	• 4945(g)(1)—Scholarship or fellowship grant to an individual for study at an educational institution
	<ul> <li>4945(g)(3)—Other grants, including loans, to an individual for travel, study, or other similar purposes, to enhance a particular skill of the grantee or to produce a specific product</li> </ul>
2	Do you represent that you will (1) arrange to receive and review grantee reports annually and upon completion of the purpose for which the grant was awarded, (2) investigate diversions of funds from their intended purposes, and (3) take all reasonable and appropriate steps to recover diverted funds, ensure other grant funds held by a grantee are used for their intended purposes, and withhold further payments to grantees until you obtain grantees' assurances that future diversions will not occur and that grantees will take extraordinary precautions to prevent future diversions from occurring?

Do you represent that you will maintain all records relating to individual grants, including

information obtained to evaluate grantees, identify whether a grantee is a disqualified person, establish the amount and purpose of each grant, and establish that you undertook the supervision and investigation of grants described in line 2?

☐ No

☐ Yes

EIN: 81 \_ 2235818 Schedule H. Organizations Providing Scholarships, Fellowships, Educational Loans, or Other Educational Grants to Individuals and Private Foundations Requesting Advance Approval of Individual Grant Procedures (Continued)

Sec	ction II	Private foundations complete lines 1a through 4f of this section. Pul complete this section. (Continued)	olic	chari	ties do not	
4a	education	will you award scholarships, fellowships, and educational loans to attend an all institution based on the status of an individual being an employee of a employer? If "Yes," complete lines 4b through 4f.		Yes	□ No	
b	circumsta education 80-39, 19 requireme	omply with the seven conditions and either the percentage tests or facts and noces test for scholarships, fellowships, and educational loans to attend an all institution as set forth in Revenue Procedures 76-47, 1976-2 C.B. 670, and 80-2 C.B. 772, which apply to inducement, selection committee, eligibility nts, objective basis of selection, employment, course of study, and other? (See lines 4c, 4d, and 4e, regarding the percentage tests.)		Yes	□ No	
С		will you provide scholarships, fellowships, or educational loans to attend an al institution to employees of a particular employer?		Yes	☐ No	□ N/A
	actually c	vill you award grants to 10% or fewer of the eligible applicants who were onsidered by the selection committee in selecting recipients of grants in that ovided by Revenue Procedures 76-47 and 80-39?		Yes	□ No	
d		ovide scholarships, fellowships, or educational loans to attend an educational to children of employees of a particular employer?		Yes	☐ No	□ N/A
	actually c	vill you award grants to 25% or fewer of the eligible applicants who were onsidered by the selection committee in selecting recipients of grants in that ovided by Revenue Procedures 76-47 and 80-39? If "No," go to line 4e.		Yes	□ No	
е	institution or fewer of (whether of	vide scholarships, fellowships, or educational loans to attend an educational to children of employees of a particular employer, will you award grants to 10% of the number of employees' children who can be shown to be eligible for grants or not they submitted an application) in that year, as provided by Revenue as 76-47 and 80-39?		Yes	□ No	□ N/A
	without su information	lescribe how you will determine who can be shown to be eligible for grants abmitting an application, such as by obtaining written statements or other n about the expectations of employees' children to attend an educational lf "No," go to line 4f.				
		tistical or sampling techniques are not acceptable. See Revenue Procedure 85-2 C.B. 717, for additional information.				
f	institution 25% limits award gra be consid significant circumsta nor a sign	vide scholarships, fellowships, or educational loans to attend an educational to <i>children of employees of a particular employer</i> without regard to either the ation described in line 4d, or the 10% limitation described in line 4e, will you nts based on facts and circumstances that demonstrate that the grants will not ered compensation for past, present, or future services or otherwise provide a benefit to the particular employer? If "Yes," describe the facts and noces that you believe will demonstrate that the grants are neither compensatory ificant benefit to the particular employer. In your explanation, describe why you tisfy either the 25% test described in line 4d or the 10% test described in line 4e		Yes	□ No	

# **The PURA Syndrome Foundation Form 1023 Application Attachments**

## Identification of Applicant Part 1 Question 8

Steven Whiting, Attorney Whiting Law Firm, PA 75 Pearl St., Suite 207 Portland, ME 04101 \$1,000

Articles of Incorporation and Bylaws
Part II Question 1 and 5

### DOMESTIC NONPROFIT CORPORATION

STATE OF MAINE

of disparcin shall be

### ARTICLES OF INCORPORATION

	Deputy Secretary of State						
Pursuant to 13-E	3 MRSA §403, the undersigned incorporator(s) execute(s) and deliver(s) the following Articles of Incorporation:						
FIRST:	The name of the corporation is The PURA Syndrone Foundation						
SECOND:	("X" one box only. Attach additional pago(s) if necessary.)  The corporation is organized as a public benefit corporation for the following purpose or purposes:  Exclusively for charitable and educational purposes under \$501(c)(3) of the U.S.						
Incorporators	Internal Revenue Code,						
	The corporation is organized as a mutual benefit corporation for all purposes permitted under Title 13-B or, if not for all such purposes, then for the following purpose or purposes:						
	than C. Whiting Parthaut Me 04101						
THIRD:	The Registered Agent is a: (select either a Commercial or Noncommercial Registered Agent)						
	Commercial Registered Agent CRA Public Number:						
	(name of commercial registered agent)						
	Noncommercial Registered Agent  Stephen C. Whiting  (name of noncommercial registered agent)						
	75 Pearl St., Suite 207, Portland, ME 04/01 (physical location, not P.O. Box - street, city, state and zip code)						
	(mailing address if different from above)						
FOURTH:	Pursuant to 5 MRSA §108.3, the new commercial registered agent as listed above has consented to serve as the registered agent for this nonprofit corporation.						

Form No. MNPCA-6 (1 of 3)

FIFTH:	The number of directors	(not less than 3) constit	uting the initial b	ooard of directors of	the corporation, if the number has
	been designated or if the	initial directors have been	en chosen, is		
	The minimum number of directors shall be	directors (not less than	3) shall be	3	and the maximum number
SIXTH:	Members: ("X" one box	only.)			
	There shall be n	o members.	embers and the is	nformation required	by 13-B MRSA §402 is attached.
SEVENTH:	(Optional)	(Check if this article i	s to apply.)		
	\$	the Corporation shall no	ot participate in c	or intervene in (inclu	aganda, or otherwise attempting to ding the publication or distribution
EIGHTH:	(Optional)	(Check if this article i	s to apply.)		
		dissolution or final liq	uidation and the	e requirements of th	nternal affairs of the corporation, ne Internal Revenue Code section
Incorporators	,		Dated	2/29/1	6
A	C, WA	1	Street 7	5 Pear	1 Str. Suite 20 sidence address)
Ste	ohan C, h	Miting	/	Portland (city, stat	1 Str. Suite 20 sidence addryds) 1 ME 04101 wand zip code)
	(signature)		Street	(see	sidence address)
	(-gammy			<b>V</b>	
	(type or print name)			(city, stat	te and zip code)
	is an incorporator (1%8 to) ic corporation. The article		Street		orinted said righted on as betintf by of the appropriate ordinar of the
ergeraton, ac ediserand to do	(signature)	nee, maliying the de	assum assum	(PC	sidence address)
Seale month you	(type or print name)	or Maurie Secretary of t	ante.	(city, stat	e and zip code)
sulomit complet	el form to Secreta Divista			Messa	,

Corporate Incorporators*		
me of Corporate Incorporator		
у	Street	
(signature of officer)		(principal business location)
(type or print name and capacity)	n or the termination of its act	(city, state and zip code)
ame of Corporate Incorporator	the regardent of all its imbilities	e or all the charterman
	Street	
(signature of officer)	oli Cu	(principal business location)
encessing as chall their result		evenini rations under session
(type or print name and capacity)	enne Code af 1986 as amenda	(city, state and zip code)
Revise Statues, as amonded		
He part of the net ear		
* 25 mars - 10 mars - 627 mars		
	of the Corporation, or any priv	
	y be paid for services rendered	
	3 200 30000 200 000 0000 0000 0000	

### \*Articles are to be executed as follows:

If a corporation is an incorporator (13-B MRSA §401), the name of the corporation should be typed or printed and signed on its behalf by an officer of the corporation. The articles of incorporation must be accompanied by a certificate of an appropriate officer of the corporation, not the person signing the articles, certifying that the person executing the articles on behalf of the corporation was duly authorized to do so.

Please remit your payment made payable to the Maine Secretary of State.

Submit completed form to:

Secretary of State

Division of Corporations, UCC and Commissions

101 State House Station Augusta, ME 04333-0101

Telephone Inquiries: (207) 624-7752

Email Inquiries: CEC, Corporations@Mainc.gov

### THE PURA SYNDROME FOUNDATION

Attachment to Articles of Incorporation, for Section 8

As required by section 501(c)(3) of the U.S. Internal Revenue Code, upon dissolution of the Corporation or the termination of its activities, the assets of the Corporation remaining after the payment of all its liabilities shall be distributed exclusively to one or more organizations organized and operated exclusively for such purposes as shall then qualify as an exempt organization or organizations under section 501(c)(3) of the Internal Revenue Code of 1986 as amended, and as a charitable, benevolent or educational corporation within the meaning of Title 13-B of the Maine Revise Statues, as amended.

No part of the net earnings of the Corporation shall inure to the benefit of any member, director, or officer of the Corporation, or any private individual (except that reasonable compensation may be paid for services rendered to or for the Corporation in carrying out one or more of its purposes), and no member, director, or officer of the Corporation, or any private individual, shall be entitled to share in the distribution of any of the corporate assets on dissolution of the Corporation.

(mailing address if different from above)

### By-Laws of The PURA Syndrome Foundation

#### PURPOSE:

The PURA Syndrome Foundation is a non-profit, public benefit organization incorporated under the laws of the State of Maine to provide charitable and educational services within the meaning of §501(c)(3) of the Internal Revenue Code of the United States. In particular, the mission of the organization is to serve, educate, and fund research for families coping with the effects of PURA Syndrome.

### 2. BOARD OF DIRECTORS:

Sole Governing Body: The Board of Directors shall be the sole governing body of the corporation.

Qualifications: Any individual may be elected to the Board of Directors.

However, no more than forty-nine percent (49%) of the individuals on the Board may be "financially interested persons"... meaning that the individual, his spouse, brother, sister, parent, or child has received any compensation from the corporation for personal services rendered to the corporation within the previous twelve (12) months, whether as an employee, independent contractor or consultant.

Number of Board Members: There shall be at least three (3) Board members and at most fifteen (15) Board members at all times. At least two thirds (2/3) of the Board members shall be from families who have or have had a family member with PURA Syndrome.

<u>Election of Board Members</u>: Board members shall be elected by the existing Board at the first Board meeting each year.

If a seat on the Board becomes vacant before the expiration of that Board member's term, the Board may elect a new Board member to complete that Board member's term.

Initially, people will be elected to the Board for a one year, two year, or three year term. Thereafter, all Board terms shall be three years. This way one third of the Board members will be completing their terms each year, while at least two thirds of the Board will remain, to ensure continuity.

Individuals may serve on the Board a maximum of two consecutive terms.

Removal of Board Members: A Board member can be removed or suspended

from the Board only by a two thirds (2/3) vote of all other members on the Board.

A Board member shall be automatically removed after three (3) unexcused absences from three (3) consecutive Board meetings.

<u>Powers:</u> The Board of Directors has all of the powers of the corporation. While the Board may delegate some powers and responsibilities to the officers, the officers are, at all times, subject to the direction and control of the Board of Directors.

Duties: Each Director has a duty to act:

- (a) in good faith;
- (b) with ordinary prudent care; and
- (c) in the best interest of the corporation.

Committees: The Board of Directors may, from time to time, establish advisory committees to research and make proposals to the Board on various issues. At least one Board member must serve on each such committee, and the chairman must be a Board member. The chairman will keep minutes of all committee meetings, and shall report all findings and advice of the committee to the Board. The committees shall be advisory only, and shall have no power to make decisions on behalf of the corporation or to make any legal obligations on behalf of the corporation.

#### CHAIRMAN OF THE BOARD:

The President of the corporation shall also be the Chairman of the Board. The Chairman shall run all Board meetings. If the Chairman is absent from a meeting of the Board, the Vice President shall serve as the Chairman; and if neither the President nor the Vice President can attend a meeting, then the Board shall elect a temporary Chairman for the purpose of presiding over that meeting.

#### 4. MEETINGS OF THE BOARD OF DIRECTORS:

Meetings of the Board of Directors may be called at any time by the chairman or by two or more other directors. Notice stating the time, place and manner of the meeting of the Board of Directors must be given to each director, by any means reasonably calculated to apprise the directors, at least three (3) days in advance of the meeting. Notice may be waived by a director at any time, either before or after a meeting of the Board of Directors. Regular meetings of the Board shall be held at least quarterly.

Meetings of the Board may be held by telephone conference call, so long as all

Board members can hear each other.

### VOTES OF THE BOARD OF DIRECTORS:

Quorum of Directors: At least fifty one percent (51%) of the Board members must be present to constitute a quorum. No business shall be conducted at a meeting of the Board of Directors unless a quorum of the directors is present.

<u>Board Votes:</u> No action of the Board of Directors shall be of any legal force or effect unless at least two thirds (2/3) of the directors present at a valid meeting of the Board of Directors votes in favor of the action. No proxies or absentee ballots will be allowed.

Conflict of Interest: In any matter involving a director or officer, a family member of a director or officer, or any matter in which a director or officer has a direct or indirect financial interest, that director or officer will have to leave the room during any discussion by the Board on that matter and during the vote by the Board on that matter, and may not participate in any discussions or votes on that matter. However, before leaving the room, the Board member or officer with the conflict must fully disclose his conflict to the Board. Thereafter, the board may vote in a way that would benefit the absent director or officer only if the measure would be fair and equitable to the corporation and would be in the best interest of the corporation.

No Board member or Officer, or members of their immediate families, may receive funds or services from the corporation over and above the services that the corporation makes available to the public at large. For a Board member or Officer, or any member of their immediate family, to receive funds or services from the corporation over and above the services that the corporation makes available to the public at large, that Board member or Officer must first resign from the Board or as an Officer.

#### OFFICERS:

The Board of Directors shall appoint a president, secretary, treasurer, and as many vice presidents as the Board deems necessary and appropriate. An individual may hold more than one office. All officers shall be appointed annually, at the first meeting of the Board each year, unless an officer resigns or is removed by the Board prior to the next date scheduled for the appointment of officers.

All officers are required to act:

- (a) in good faith;
- (b) with ordinary, prudent care; and
- (c) in the best interest of the corporation.

### POWERS OF THE OFFICERS:

The officers shall have any and all ministerial powers which the Board of Directors delegates to the officers. In addition to any powers expressly delegated to the officers by the Board of Directors, the officers shall have the following powers and duties.

<u>President</u>: The president shall have any and all powers and responsibilities to manage the daily affairs of the corporation. He will be responsible for signing all legal documents on behalf of the corporation.

<u>Vice President(s)</u>: A vice president shall have only those powers and responsibilities which are expressly delegated to him by the Board of Directors or which are expressly delegated to the vice president by the president. The vice presidents, acting jointly, are also empowered to exercise any and all powers of the president when the president is ill, on vacation, resigns, or is otherwise unavailable to tend to the affairs of the corporation.

<u>Treasurer:</u> The treasurer shall be empowered and have the responsibility to manage the financial affairs of the corporation. He shall keep and maintain, or cause to keep and maintain, in good order all financial records of the corporation.

In addition, the treasurer will file the corporation's 990, 990-EZ, 990-N, or 990-PF return, and its 990-T and 1120-ME returns, as necessary, by May 1 of each year.

Finally, the treasurer shall be responsible for sending to donors, or for making sure that donors are sent, written acknowledgments of their donations, as set forth in section 11 of these By-laws.

<u>Secretary</u>: The secretary shall be responsible for keeping records of Board actions, including overseeing the taking of minutes at all Board meetings and distributing copies of minutes and the agenda to all Board members. He or she shall count all votes at the meetings of the Board of Directors. He or she shall notify the Directors prior to meetings of the Board of Directors.

All officers shall send a written report to the President concerning the activities within their departments prior to each Board meeting.

#### CLERK:

The Board of Directors shall also appoint a clerk for the corporation. The clerk shall remain in office until he resigns or is removed from the office by the Board of Directors. The clerk shall be empowered and have the responsibility to file the annual report of the corporation with the Secretary of State, pursuant to Title 13-B M.R.S.A. § 1301, on or before June 1.

#### COMPENSATION:

No Board members, officers or volunteers shall be compensated for their services. However, the Board may vote to reimburse anyone who performs services for the corporation for his/her out-of-pocket expenses. Board members shall receive reimbursement for travel expenses to organization-sponsored events and/or when travel is deemed necessary to support organizational objectives.

Employees of the corporation shall be compensated at salaries or wage rates to be set by the Board of Directors.

### INDEMNIFICATION OF BOARD MEMBERS, OFFICERS AND VOLUNTEERS:

The Board of Directors may vote to defend, indemnify and hold harmless any board member, officer, employee, or volunteer from liability for anything done within the scope of their duties, to the fullest extent permitted by law, if the corporation or that individual does not have adequate insurance to cover those costs.

#### 11. CHARITABLE CONTRIBUTIONS:

This corporation may be required to register under the Charitable Solicitations Act, Title 9 M.R.S.A. §5003(1).

The Treasurer will send to donors, or cause to be sent to donors, written acknowledgments of donations of \$250.00 or more, and of all the donations of \$75.00 or more for which the corporation gives the donor something of value in return, as required by IRS regulations, so that the donors may take tax deductions for those donations.

The Treasurer will also send to donors, or cause to be sent to donors, written

acknowledgment of receipt of non-cash gifts worth \$500.00 or more, and will also provide donors of non-cash gifts worth more than \$5,000.00 with a written appraisal by a qualified appraiser, so donors can take tax deductions for those gifts on 8283 forms.

### 12. CONVEYANCES OF PROPERTY:

The corporation may give away real or personal property only in furtherance of its charitable and/or educational purpose, or to one or more other exempt organizations under §501(c)(3) of the Internal Revenue Code. No real or personal property of the corporation may be given away to any directors or officers of the corporation, or to any member of their immediate families.

Real and personal property of the corporation may be sold only for its full fair market value.

Under no circumstances may the corporation loan any monies to any directors or officers of this corporation.

#### 13. DISSOLUTION:

Upon the dissolution of the corporation or the termination of its activities, the assets of the corporation remaining after the payment of all its liabilities shall be distributed exclusively to one or more organizations organized and operated exclusively for such purposes as shall then qualify as an exempt organization or organizations under §501(c)(3) of the Internal Revenue Code of 1986, as amended, and as a charitable and/or educational corporation within the meaning of Title 13-B of the Maine Revised Statutes, as amended.

No part of the net earnings of the corporation shall inure to the benefit of any member, director or officer of the corporation, or any private individual (except that these by-laws may be amended in the future to provide that reasonable compensation may be paid for services rendered to or for the corporation in carrying out one or more of its purposes), and no member, director, or officer of the corporation, or any private individual, shall be entitled to share in the distribution of any of the corporate assets on dissolution of the corporation.

#### 14. AMENDMENTS:

These By-Laws may be amended at any time by a vote of at least two-thirds (2/3)

of the directors on the Board.

Dated: 3/30/16

WD - Heather Dowie

60 No. ANDY DOOS

Smal Anderson

Helida Ad Helida Andorson

DAMON FISHER

Cecrel van Hoeckel

### Narrative Description Part IV

PURA Syndrome was first described in medical literature in 2014. It is a rare genetic disorder resulting from a de novo, or new, mutation in the PURA gene. The PURA gene is particularly important in brain development which is why problems with the PURA gene are primarily associated with a neurodevelopment disorder and include seizures and low muscle tone. Parents have come together to form this foundation with the purpose of increasing the quality of life for our children with PURA Syndrome by supporting each other and furthering research on this disorder.

#### **Past Activities:**

Prior to the incorporation of The PURA Syndrome Foundation, a group of families affected by PURA managed to achieve the following:

- start a private Facebook group for parent support and a public Facebook page to raise awareness (https://www.facebook.com/Friends-of-PURA-Syndrome-887378417969823/)
- find 50+ patients with PURA Syndrome worldwide and connect them with doctors and researchers and each other
- host an informal gathering of families affected by PURA and two medical researchers
- gather and coordinate with a medical advisory team
- build a website with medical information, research papers, and family bios (http://www.purasyndrome.org)
- create and make available an educational brochure

#### **Present Activities:**

The PURA Syndrome Foundation was incorporated in the State of Maine on 3/2/2016 for educational and charitable purposes. Its mission is to serve, educate, and fund research for families coping with the effects of PURA Syndrome. To that end the organization is:

- Planning international conference of families, doctors, and researchers in Philadelphia in 2017. This event will provide information about current best practices regarding PURA Syndrome and allow researchers to collaborate to better understand this syndrome.
- Assisting families in fundraising events for the organization by providing administrative support and space on website to tell patient stories.
- Growing the patient population and reaching out to researchers with a patient cohort and providing pertinent information about how PURA Syndrome affects the quality of peoples' lives.

#### **Future Activities:**

- In keeping with the organization's mission to serve families, The PURA Syndrome Foundation will continue to find new patients, provide information about participating in research, create and distribute an information packet, and plan and host yearly conferences.
- In keeping with the organization's mission to educate others about PURA Syndrome, The PURA Syndrome Foundation will maintain a website, seek opportunities to educate physicians, invite researchers and medical professionals to the yearly conferences.
- In keeping with the organization's mission to fund research, The PURA Syndrome Foundation will collaborate with our medical advisory team to offer appropriate grants to further understanding of and potential treatments for PURA Syndrome.

### List of Officers and Directors Part V Question 1a

Information on file.

Please submit request through purasyndrome.org

## List of Officer and Directors Part V Question 3



# Description of How Conflict of Interest Policy was Adopted Part V Question 5a

The PURA Syndrome Foundation Conflict of Interest Policy was adopted by unanimous vote of the Board of Directors in a meeting held on April 16, 2016.

**Conflict of Interest:** In any matter involving a director or officer, a family member of a director or officer, or any matter in which a director or officer has a direct or indirect financial interest, that director or officer will have to leave the room during any discussion by the Board on that matter and during the vote by the Board on that matter, and may

not participate in any discussions or votes on that matter. However, before leaving the room, the Board member or officer with the conflict must fully disclose his conflict to the Board. Thereafter, the board may vote in a way that would benefit the absent director or officer only if the measure would be fair and equitable to the corporation and would be in the best interest of the corporation.

No Board member or Officer, or members of their immediate families, may receive funds or services from the corporation over and above the services that the corporation makes available to the public at large. For a Board member or Officer, or any member of their immediate family, to receive funds or services from the corporation over and above the services that the corporation makes available to the public at large, that Board member or Officer must first resign from the Board or as an Officer.

### Fundraising Part VIII Question 4a

- 1. Mail solicitation— Direct mail campaigns directed to individuals and organizations that have expressed an interest in the organization either through previous donations or other means.
- Email solicitation- Email campaigns to individuals and organizations that have expressed an interest in supporting the organization through previous donations or other means. Email campaigns may also include solicitations through social media or other forms of internet communications.
- 3. Personal solicitations- The PURA Syndrome Foundation's directors and officers may appeal directly to friends, family, colleagues, foundations and other entities for donations.
- 4. Foundation grant solicitations The PURA Syndrome Foundation will respond to funding opportunities offered by other foundations related to the organization's charitable mission.

- 5. Accept donations on your website— The PURA Syndrome Foundation will accept donations on its website through a donate tab.
- 6. Government grant solicitations— The PURA Syndrome Foundation will respond to funding opportunities offered by the Federal, State, and local governments related to the organization's charitable mission.
- 7. Other–Other forms of fundraising may include hosting events such as galas or sporting tournaments.

### Fundraising Part VIII Question 4d

Fundraising will be conducted by The PURA Syndrome Foundation primarily online. Solicitations may reach donors throughout the United States and internationally. Proceeds will be used exclusively for The PURA Syndrome Foundation.

### Grant, Loans or Other Distributions to Organizations Part VIII Questions 13a and b

The PURA Syndrome Foundation will make grants to other organizations, such as universities and other research facilities, to carry out its mission to fund research that may lead to understanding, treatments and cures for PURA Syndrome. Research grants will be provided with restrictions, determined by the Board of Directors of The PURA Syndrome Foundation to ensure the funds are used to further its mission. The amount of the grants will be based on reasonable and negotiated budgets that restrict the use of funds from any other purpose other than the restricted purpose.

The PURA Syndrome Foundation will not offer loans to any organization or individual.

### Grants, Loans or other Distributions to Organizations Part VIII Question 13d

Grants will be issued to organizations such as universities conducting research in PURA Syndrome. This may include but is not limited to University of Rochester Medical Center, Rochester, NY where one of our medical advisors is currently employed and Temple University, Philadelphia, where research on PURA has been conducted.

### Grants, Loans or other Distributions to Organizations Part VIII Question 13e

Records for grants may include but are not limited to:

- a grant proposal
- · list of principle researchers and their responsibilities
- · research milestones including timelines
- · deliverables and reporting requirements
- budget and schedule of payments
- · publications resulting from the research
- minutes from Board of Directors' meeting approving funding and evaluating use of funds, periodic reports and final reports, and Grant Committee recommendations

### Grants, Loans or other Distributions to Organizations Part VIII Question 13f

The grant proposal will specify:

- The name of the organization, Principle Investigator along with biographical sketch
- Statement on how the research applies to The PURA Syndrome Foundation's mission

- Description of grantor's responsibility.
- Description of grantee's responsibility and statement obligating grantee to use funds only for purposes for which grant was made
- Statement providing for periodic written reports including final written report to account for how grant funds were used
- Statement acknowledging The PURA Syndrome Foundation's authority to withhold and/or recover funds in case such funds are or appear to be misused.

# Grants, Loans or other Distributions to Organizations Part VIII Question 13g

Grant proposals will be reviewed by a Grant Committee which will include a Board member and peer scientists for research viability and its relation to The PURA Syndrome Foundation's mission. Approval will be based upon the availability of funds, the relationship of the research with The PURA Syndrome Foundation's charitable purpose, the viability of the research, the credibility of the researchers, and research protocols. Periodic written reports including final written report will be required. Information obtained from the research must be made available to the public.

### Grants, Loans or other Distributions to Organizations Part VIII Question 14b

Research grants will be made available globally. Specifically, members of the PURA Medical Advisory Team are connected to medical centers in the United States, United Kingdom, Holland, and Australia. It is anticipated that The PURA Syndrome Foundation will put out a call for grant submissions in part through these connections. Only grant proposals from medical and research facilities in countries not on the terrorist watch list will be accepted.

### Grants, Loans or other Distributions to Organizations Part VIII Question 14d

The PURA Syndrome Foundation EIN: 81-2235818

The PURA Syndrome Foundation website states that contributions will help with raising awareness, helping families, and funding much needed research to assist with better treatments for patients.

### Grants, Loans or other Distributions to Organizations Part VIII Question 14e

Foreign organizations that apply for grants will go through the same grant process as described in Part VIII Question 13 and there will be representatives from foreign countries on the Grant Committee. Before being awarded a grant, organizations will be required to provide information about the relationship of the research to The PURA Syndrome Foundation's charitable purpose, the viability of the research, the recipient's financial status, the credibility of the researchers, and research protocols.

# Grants, Loans or other Distributions to Organizations Part VIII Question 14f

Foreign organizations that apply for grants will go through the same rigorous procedure as described in Part VIII Question 13.

# Financial Data Part IX Statement of Revenues and Expenses Line 15

	1/16 - 12/16	1/17 - 12/17	1/18 - 12/18
Research Grants	0	15,000	10,000

# Financial Data Part IX Statement of Revenues and Expenses Line 23

	1/16 - 12/16	1/17 - 12/17	1/18-12/18
website + google admin	400	400	400
1023 filing fees	850		
conference expenses	0	15,000	15,000
online donation system	600	2000	2000
total	1850	17,400	17,400