



**STATE OF ARIZONA**  
**Department of Health Services**

**NOTICE OF REQUEST FOR INFORMATION  
(RFI)**

**ARIZONA DEPARTMENT  
OF HEALTH SERVICES**

1740 West Adams Street  
Phoenix, Arizona 85007  
(602) 542-1040  
(602) 542-1741 Fax

**REQUEST NUMBER:**

**HF671002**

**REQUEST DUE DATE/TIME:**

**June 23, 2016 at 3:00 p.m. Local Arizona Time**

**SUBMITTAL LOCATION:**

**Submit via email to the Procurement Officer indicated below**

**DESCRIPTION:**

**Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS)**

In accordance with A.R.S. § 41-2555, the Arizona Department of Health Services (ADHS) is issuing a Request for Information (RFI) for the behavioral health-related services specified herein. It is the responsibility of the Respondent to routinely check the ADHS Procurement website for any changes to this request <http://www.azdhs.gov/procurement/index.htm>

Additional instructions for preparing the information are included in this RFI.

With seventy-two (72) hours prior notice, persons with disabilities may request special accommodations such as interpreters, alternative formats, or assistance with physical accessibility. Such requests are to be addressed to the RFI contact person named below.

**RESPONDENTS ARE STRONGLY ENCOURAGED TO CAREFULLY READ THE ENTIRE REQUEST FOR INFORMATION (RFI) BEFORE RESPONDING.**

**Contact Person:**

Jacqueline S. Ortega-Avila, Procurement Officer

Arizona Department of Health Services

(602) 542-5188

E-mail: [Jacqueline.Ortega-Avila@azdhs.gov](mailto:Jacqueline.Ortega-Avila@azdhs.gov)

# REQUEST FOR INFORMATION

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### 1. Requirements / Instructions

- 1.1 Submit your response via email to the Procurement Officer listed on page one (1), as an Attachment of no more than ten (10) written pages, single spaced, 12-point font size. The ten (10) page limit is inclusive of any and all information, attachments, pictures, etc.
- 1.2 Responses should be organized to correspond to the numbering convention indicated in this RFI.
- 1.3 Responses should Include Organization name, address and telephone number on a cover page. In addition, provide the name, title, telephone number and e-mail address of your organization's designated contact person for questions or clarification related to your response.
- 1.4 The Arizona Department of Health Services (ADHS) will not provide any reimbursement for the cost of developing a response to this RFI.
- 1.5 A copy of this RFI can be found at <http://azdhs.gov/operations/financial-services/procurement/index.php#rfi>

### 2. RFI Opening

- 2.1 Information received by the requested due date and time will be reviewed. The name of each Responder will be publicly available. Pursuant to A.A.C. R2-7-G301.2, to the extent allowed by law, information contained in a response may be considered confidential until the procurement process is concluded or two (2) years, whichever occurs first. Responses to an RFI are not offers and cannot be accepted to form a binding contract. A.A.C. R2-7-G301.1.

### 3. Questions

- 3.1 All questions related to this RFI shall be submitted by email to the Procurement Officer named on page one (1) of this document no later than **5:00 PM on June 16, 2016.**

### 4. Funding Source

- 4.1 Funding source for this Grant is the Disease Control Research Fund.

### 5. Available Funds

- 5.1 Up to \$250,000.00 is available for all awards. Maximum award per application is two hundred and fifty thousand dollars (\$250,000.00) maximum project duration is up to one (1) year from the award date.
- 5.2 ABRC reserves the right to award one or multiple grants up to the total amount available.

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### Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) and

### Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS)

#### 1. Background

- 1.1. The Arizona Biomedical Research Commission is seeking information related to opportunities to enhance and improve health services for patients and families struggling with Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) / Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS).
- 1.2. ABRC is seeking information from interested parties that would participate in the creation and development of new opportunities to allow for the creation of a future Arizona Center of PANS/PANDAS Excellence to better serve Arizona residents in providing state of the art comprehensive health care.

#### 2. History

- 2.1 The mission of the ABRC is to identify and support innovative biomedical research to improve the health of all Arizonans. ABRC is focused on leveraging existing resources, maximizing partnerships, cultivating communication, and promoting innovation. ABRC manages multiple initiatives which are guided by input from leaders and professionals from Arizona's universities, nonprofit research institutions, hospitals, medical centers, and patient advocacy groups. ABRC's initiatives have evolved into four (4) distinct programs: Research Grants, Arizona Public Cord Blood Program, Arizona Biospecimen Locator, and Research Education;
- 2.2 During the 2016 legislative session, Arizona House Bill 2640 was passed appropriating \$250,000.00 of ABRC funds to provide grants on a competitive basis for the research of PANS/PANDAS;
- 2.3 The goal of this funding opportunity is to accelerate promising research toward clinical testing and breakthroughs designed to improve the health of patients with PANS/PANDAS. ABRC is seeking innovative projects that leverage Arizona's resources and strengthen collaboration. This award is established to fund multi-disciplinary center(s) that conduct multidisciplinary and collaborative research and provide care to patients and their families battling PANS/PANDAS. Collaboration among investigators could include: within an institution, across institutions, or across disciplines; and
- 2.4 The following is taken from the National Institute of Mental Health (NIMH) website ([www.nimh.nih.gov/labs-at-nimh/research-areas/clinics-and-labs/pdnb/web.shtml](http://www.nimh.nih.gov/labs-at-nimh/research-areas/clinics-and-labs/pdnb/web.shtml)),
  - 2.4.1. PANDAS Infections is a term used to describe a subset of children and adolescents who have Obsessive Compulsive Disorder (OCD) and/or tic disorder, and in whom symptoms worsen following strep infections. PANS is a newer term used to describe all cases of abrupt onset OCD, not just those associated with streptococcal infections.
  - 2.4.2. In the early 1990's, investigators at the National Institute of Mental Health (Drs. Susan Swedo, Henrietta Leonard, and Judith Rapoport) were doing studies of childhood-onset OCD and observed that some of the children had an unusually abrupt onset of symptoms. The OCD and tic symptoms were accompanied by a variety of other neuropsychiatric symptoms, including separation anxiety, "anxiety attacks," irritability, extreme mood swings, temper tantrums, and immature behaviors (like talking "baby talk"), hyperactivity, problems with attention and concentration, handwriting changes, and problems with math, reading and other school subjects. All of these ancillary symptoms were new (or much worse than baseline difficulties) and started at the same time as the OCD or tics, or very shortly thereafter.
  - 2.4.3. The diagnosis of PANDAS is a clinical diagnosis, which means that it depends on a carefully taken history and a physical examination, rather than on laboratory tests. The history must reveal an abrupt onset of OCD and/or tics (or sudden, dramatic worsening if the child had mild OCD or tics previously). The physical examination must rule out other issues requiring different treatments. Laboratory tests can

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be useful in documenting that the child currently has a strep infection or that they have had one recently. However, the laboratory tests cannot make a diagnosis.

2.4.4. Since PANS is newly described, there have been no treatment trials performed to demonstrate which interventions will be effective. If the diagnostic work-up of PANS reveals an infectious trigger, treatment of the infection may be useful in reducing symptom severity of the OCD and other neuropsychiatric symptoms.

### 3. Current State of Care in Arizona

- 3.1. Dr. Swedo, with the NIH, estimates kids with PANS/PANDAS “may make up as much as 25 percent of children diagnosed with OCD and tic disorders, such as Tourette syndrome.” (<http://www.scientificamerican.com/article/from-throat-to-mind/>);
- 3.2. The Center for Disease Control and Prevention (CDC) estimates that more than 1 in 360 (or 138,000) children and teens in the US have Tourette Syndrome (<http://www.cdc.gov/ncbddd/tourette/data.html>);
- 3.3. The International OCD Foundation estimates that 1 in 200 (or 500,000) children and teens in the US have OCD (<https://iocdf.org/about-ocd/who-gets-ocd/>);
- 3.4. The number of children and teens in Arizona with OCD, Tourette Syndrome or PANS/PANDAS is unknown;
- 3.5. Although the NIH, several universities, and many physicians and researchers recognize PANS/PANDAS, lack of general knowledge around the diagnoses remains; and
- 3.6. The Journal of Child and Adolescent Psychopharmacology published a consensus statement in 2015 after a group of clinicians and researchers from diverse fields: general and developmental pediatrics, infectious diseases, immunology, rheumatology, neurology, and child psychiatry convened in May 2013. The consensus statement is a collective medical voice acknowledging PANS and offers physicians clinical evaluation consensus recommendations to assist in the evaluation of children with suspected PANS.

### 4. Future Vision

- 4.1. The ABRC vision is to help support the development of an Arizona Center of PANS/PANDAS Excellence that would provide a continuum of services to those with PANS/PANDAS. Possible ideas include but are not limited to:
  - 4.1.1. Increase PANS/PANDAS research;
  - 4.1.2. Increase physician and medical professional education and awareness;
  - 4.1.3. Increase support services to families; and
  - 4.1.4. Increase access to care.

### 5. Purpose of the RFI

- 5.1. ABRC is determining the interest, potential partners, types of services that would support the vision of creating the Arizona Center of PANS/PANDAS Excellence to create and expand PANS/PANDAS research and services; and
- 5.2. ABRC is seeking appropriate expertise, knowledge and input from potential partners who share the same vision.

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**6. Eligibility**

- 6.1. Any individual(s) with the skills, knowledge, and resources necessary to carry out the proposed research as the Program Director(s)/Principal Investigator(s) are eligible to apply for this Grant;
- 6.2. The Principal Investigator (PI) shall reside in Arizona; and
- 6.3. The lead institution shall originate in Arizona and shall be a multi-disciplinary research and medical center specializing in pediatric neurological disorders.

**7. RFI Instructions and Documentation**

ABRC request a response to the following below. Please submit an email and attachments detailing your interest and response to the questions listed below:

- 7.1. Tell us about your organization/collaboration and how it would be an ideal partner for ABRC.
- 7.2. How do the plans or goals of your organization/collaboration complement the ABRC's vision for the Arizona Center of PANS/PANDAS Excellence?
- 7.3. What services could your organization/collaboration add to the Arizona Center of PANS/PANDAS Excellence? Are there any special qualities, talents, or resources within your organization that will enhance the vision to realize the Arizona Center of PANS/PANDAS Excellence?
- 7.4. Identify your proposed timeline and key milestones for partnering with ABRC.
- 7.5. What other partnerships of this nature have you been involved in or are currently involved in, and provide details?

**8. Additional Information**

- 8.1. For more information on ADHS and ABRC, visit our website at [www.azdhs.gov](http://www.azdhs.gov) and [www.azdhs.gov/BIOMEDICAL](http://www.azdhs.gov/BIOMEDICAL).

**9. Respondent Contact Information to be included in the Response:**

- 9.1. Organization Name: \_\_\_\_\_  
Attention: \_\_\_\_\_  
Address: \_\_\_\_\_  
Address: \_\_\_\_\_  
City, State, ZIP: \_\_\_\_\_  
Phone: \_\_\_\_\_  
Email: \_\_\_\_\_  
Website: \_\_\_\_\_