

10-14-15

**HOUSE AD HOC COMMITTEE ON  
PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC DISORDER**

Report of Interim Meeting  
Thursday, October 8, 2015  
House Hearing Room 1 -- 10:00 a.m.

**Convened** 10:03 a.m.

**Recessed**

**Reconvened**

**Adjourned** 11:18 a.m.

**Members Present**

Representative Heather Carter, Chair  
Representative Randall Friese  
Dr. Melanie Alarcio  
Shelly Avila  
Kate Fleck  
Kari Kling  
Molly Ochoa  
Dr. Sydney Rice  
Dr. Mark Ross  
Paul Ryan  
Dan Twibell

**Members Absent**

Representative Vince Leach  
Charles Bassett\*  
Tess Burleson  
Dr. Jay Cook  
Dr. Cari Christ\*  
Dr. Michael Daines  
Dr. Fayez Ghishan  
Lee Miller  
Dr. Suraj A. Muley  
Dr. Susan Swedo

\*Chairman accepted comments from Colby Bower on behalf of Dr. Cara Christ, Arizona Department of Health Services, and Kathi Beranek on behalf of Charles Bassett, Blue Cross/Blue Shield.

**Agenda**

Attachment 1

**Request to Speak**

None

**Presentations**

<b><u>Name</u></b>	<b><u>Organization</u></b>	<b><u>Attachments (Handouts)</u></b>
Mr. Paul Ryan	Citizen	2, 3

  
Sandy Kelley, Chairman Assistant  
October 8, 2015

(Original attachments on file in the Office of the Chief Clerk; video archives available at <http://www.azleg.gov>)

## ARIZONA HOUSE OF REPRESENTATIVES

### INTERIM MEETING NOTICE OPEN TO THE PUBLIC

#### HOUSE AD HOC COMMITTEE ON PEDIATRIC AUTOIMMUNE NEUROPSYCHIATRIC DISORDER

**Date:** Thursday, October 8, 2015

**Time:** 10:00 A.M.

**Place:** HHR 1

#### AGENDA

1. Call to Order
2. Opening Remarks
3. Introduction of Members
4. Review of a Standard of Care
5. Communicating a Standard of Care
6. Review of a Center of Excellence
7. Funding Options for a Center of Excellence
8. Public Testimony
9. Adjourn

#### Members:

Representative Heather Carter, Chair  
Representative Randall Friese  
Representative Vince Leach  
Dr. Melanie Alarcio  
Shelly Avila  
Charles Bassett  
Tess Burleson  
Dr. Cara Christ  
Dr. Jay Cook  
Dr. Michael Daines  
Kate Fleck

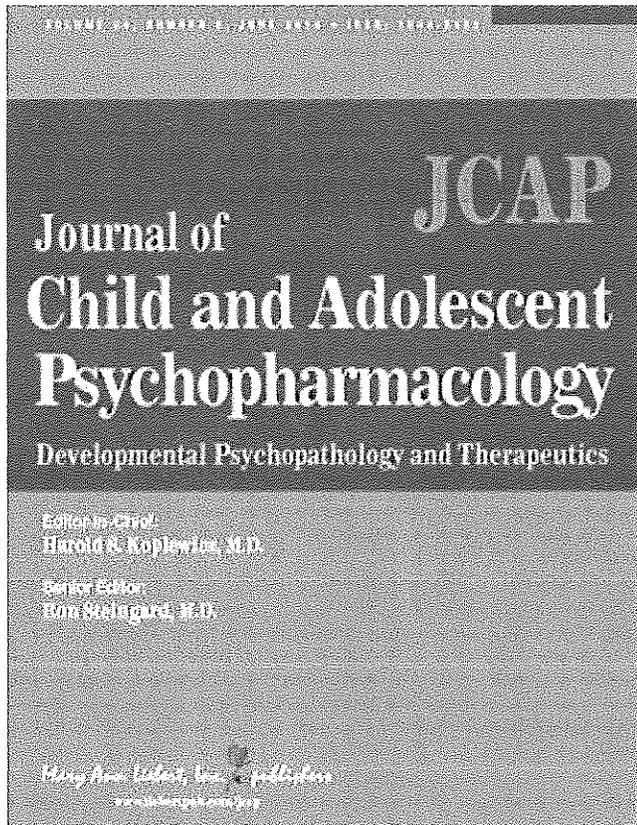
Dr. Fayez Ghishan  
Kari Kling  
Lee Miller  
Dr. Suraj A. Muley  
Molly Ochoa  
Dr. Sydney Rice  
Dr. Mark Ross  
Paul Ryan  
Dr. Susan Swedo  
Dan Twibell

10/6/15  
JY

**People with disabilities may request reasonable accommodations such as interpreters, alternative formats, or assistance with physical accessibility. If you require accommodations, please contact the Chief Clerk's Office at (602) 926-3032, TDD (602) 926-3241.**

# Expert recommendations for diagnosing pediatric acute onset neuropsychiatric syndrome

22 October 2014



Credit: Mary Ann Liebert, Inc., publishers

A panel of leading clinicians and researchers across various general and specialty pediatric fields developed a consensus statement recommending how to evaluate youngsters in whom neuropsychiatric symptoms suddenly develop, including the abrupt, dramatic onset of obsessive-compulsive disorder (OCD). This difficult diagnosis is typically made by pediatricians or other primary care clinicians and child psychiatrists, who will benefit from the guidance provided in the recommendations published in *Journal of Child and Adolescent Psychopharmacology*.

Representing the PANS Collaborative Consortium, Kiki Chang, MD, Stanford University School of Medicine (Stanford, CA) and coauthors describe the goals of the First PANS Consensus Conference, from which the expert panel derived its recommendations: to clarify the diagnostic boundaries of PANS, to develop systematic strategies for evaluation of suspected PANS cases, and to set forth the most urgently needed studies in the field. Most cases of PANS appear to be triggered by an infection, and most often an upper respiratory infection.

In the article "[Clinical Evaluation of Youth with Pediatric Acute Onset Neuropsychiatric Syndrome \(PANS\): Recommendations from the 2013 PANS Consensus Conference](#)," the authors detail the core components of a thorough diagnostic evaluation, including family history, medical history, physical examination, psychiatric and mental status exam, laboratory studies, and an infectious disease evaluation.

"This is a watershed moment in our thinking about PANS," says Harold S. Koplewicz, MD, Editor-in-Chief of the *Journal of Child and Adolescent Psychopharmacology* and President of the Child Mind Institute in New York. "For too long confusion and a lack of understanding concerning this syndrome have left severely impaired children with few, if any, treatment options. This effort promises an improvement in the quality of care and we are grateful to be able support it and to publish our special issue on the topic."

**More information:** The article, part of a forthcoming special issue on PANS/PANDAS, is available free on the [Journal of Child and](#)

## Pediatric Autoimmune Neurological Center of Excellence at the University of Arizona

### Opportunity:

To establish and fund the nation's (the world's) first pediatric neurological autoimmune disease Center of Excellence. The Pediatric Autoimmune Center of Excellence (PACE) would diagnose and treat affected children, conduct clinical research on pediatric neurological diseases and provide world class medical school training for the pediatric specialists of the future.

### Estimated Costs:

The following chart summarizes the estimated annual costs to accommodate the projected increase in diagnosis and treatment demand for pediatric autoimmune disease in Arizona.

### **PEDIATRIC NEUROIMMUNOLOGY CENTER at The University of Arizona**

**Requesting \$1 Million each year for five years**

FTE	Description	Assistant Prof at a 1.0 FTE	Assistant Prof pro-rated for project effort
FTE 0.7	Rheumatologist	\$236,300.00	\$165,410.00
FTE 0.7	Allergy Immunologist	\$229,500.00	\$160,650.00
FTE 0.7	Neurologist	\$266,900.00	\$186,830.00
FTE 0.7	Developmentalist	\$238,000.00	\$166,600.00
FTE 0.7	RN Coordinator	\$76,965.00	\$53,875.50
Min of 52 Clinics/ Yr	Clinic Annual Expense	\$118,329.80	\$118,329.80
FTE 1.0	Pediatric Nurse Practitioner	\$132,106.00	\$132,106.00
FTE 1.0	Social Worker	\$75,639.00	\$75,639.00
<b>Total Estimated Cost</b>		<b>\$1,373,739.80</b>	<b>\$1,059,440.30</b>