

**Texas Health and Human Services Commission
Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council (PANSAC)
FINAL DRAFT Meeting Minutes
Friday, November 13, 2020
9:00 a.m.**

Microsoft Office Teams Live

Agenda Item 1: Welcome, introductions, and opening remarks

The Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council (PANSAC) meeting was called to order at 9:01 a.m. by John Chacón, HHSC, Facilitator. Mr. Chacón welcomed committee members and members of the public. Mr. Chacón stated that this was the first meeting of the PANSAC. Mr. Chacón announced the meeting was being conducted in accordance with the Texas Open Meetings Act, conducted roll call and asked each member to briefly introduce themselves including PANS experience and reason for serving on Council. Mr. Chacón announced that a quorum was present for the meeting.

Mr. Joe Perez, Health, Developmental, and Independence Services Interim Deputy Executive Commissioner, welcomed council members and members of the public who were in attendance and offered opening remarks.

Table 1: The Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council member attendance at the Friday, November 13, 2020 meeting.

MEMBER NAME	YES	NO	MEMBER NAME	YES	NO
Dr. Joel B. "Brandon Brock D.N.P.	X		Dr. Qazi U. Javed M.D.	X	
Honorable Senator Dawn Buckingham	X		Dr. Paula J. Kruppstadt M.D.	X	
Ms. Kara S. Chasteen	X		Ms. Sharon G. Lemons	X	
Dr. Anne Esquivel Ph.D.	X		Dr. Larry Lewellyn M.D.	X	
Ms. Lisa M. Formby	X		Dr. Amy L. Offutt M.D.	X	
Dr. Daniel V. "Dan" Freeland D.O.		X	Honorable Senator Beverly Powell		X
Ms. Sarah Rosen Garrett	X		Mr. Nathan Pullen	X	
Dr. Suzanne K. Gazda M.D.	X		Honorable Scott Sanford	X	
Ms. Lisa C. Hardy	X		Honorable Terry Wilson	X	
Dr. Anthony J. Infante M.D., Ph.D.	X				

Yes: Indicates attended the meeting

No: Indicates did not attend the meeting

Agenda Item 2: Agency and program overviews

- a. **Health and Human Services** - Interim DEC Joe Perez provided an overview of the Health and Human Services and referenced slide 2 from combined PowerPoint entitled "Agency and Program Overviews". Highlights of overview included:
 - Mr. Perez reviewed the HHS organizational chart. Advised members the HHS Executive Commissioner is Cecile Young and is appointed by the Governor of Texas.
 - The Medical and Social Services Office (MSS) is led by Michelle Alletto. Health Developmental and Independence Services (HDIS) is part of MSS and Joe Perez is the Interim Deputy Executive Commissioner of HDIS.

- HDIS administers approximately 40 different programs that serve as a safety net for Texans providing critical health care, nutrition and support services.
- b. **Rehabilitative and Independence Services** – Ms. Keisha Rowe, Office of Independent Services (OIS), HHSC, provided an overview of the Rehabilitative and Independence Services and referenced slide 3 from combined PowerPoint entitled “Agency and Program Overviews”. Highlights of overview included:
- Ms. Rowe provided an overview of Rehabilitative and Independence Services:
 1. The Office of Deaf and Hard of Hearing
 2. Office of Guardianship Services
- c. **Office of Independence Services** - Ms. Keisha Rowe, Office of Independent Services (OIS), HHSC, provided an overview of OIS and referenced slide 4 from combined PowerPoint entitled “Agency and Program Overviews”. Highlights of overview included:
- The Office of Independence Services (OIS) serves Texans to achieve and maintain their independence through service delivery, planning, and partnering with other programs to coordinate services. Ms. Rowe is the director of OIS.
 - There are 6 programs within OIS.
 1. Blind Children’s Vocational and Development Program (BCP)
 2. Blindness, Education, Screening and Treatment (BEST)
 3. Independent Living Services
 4. Office of Disability Prevention for Children
 5. Brain Injury Programs; Comprehensive Rehabilitation Services and Office of Acquired Brain Injury
- d. **Blind Children’s Vocational Discovery and Development Program** - Ms. Lauren Cox, Blind Children’s Program (BCP), HHSC, provided an overview of the Blind Children’s Vocational Discovery and Development Program and referenced slides 5 -18 from combined PowerPoint entitled “Agency and Program Overviews”. Highlights of overview included:
- Ms. Lauren Cox is the program manager of the Blind Children’s Vocational Discovery and Development Program (BCP).
 - BCP assists eligible children who are blind or visually impaired to reach independence in the home or community through communication, mobility, and activities of daily living.
 - BCP services over 3,250 children and their families annually throughout Texas.
 - BCP is committed to ensuring that Texas children who are blind or visually impaired have the same opportunities as other children, reach their full potential based on their individual capacities, live as independently as possible and lead productive lives in the community they choose.
 - Children eligible for BCP services must have a documented visual impairment, be 21 or younger, if older than 18, must be registered in school, and be a Texas resident.
 - BCP services include case management, parent education and direct skills training and specialized deafblind services to address a child’s individual needs.
 - Anyone can refer children to the BCP via email at BlindChildrensProgram@hhs.Texas.gov or by contacting the HHS Office of the Ombudsman at 1-877-787-8999 option 3.
- e. **Office of Disability Prevention for Children** – Mr. Jay Smith, Office of Disability Prevention for Children (ODPC), HHSC, provided an overview of the ODPC and referenced slides 19 -31 from combined PowerPoint entitled “Agency and Program Overviews”. Highlights of overview included:
- Mr. Jay Smith is the Office of Disability Prevention for Children (ODPC) Project Manager.

- ODPC strives to prevent developmental disabilities, including those that manifest in utero and during birth, in children ages 0-12, minimize the losses caused by preventable disabilities and coordinate a unified, comprehensive prevention effort in Texas.
- ODPC's duties include educating the public, promoting sound public policy, identifying, collecting and disseminating information and data and collaborating with healthcare providers, stakeholders and other state agencies.
- There are four areas of focus:
 1. Prevention of disabilities caused by maternal health issues during pregnancy.
 2. Prevention of injuries in children.
 3. Early identification and diagnosis of disabilities to ensure early intervention and services.
 4. Address co-occurring intellectual and developmental disabilities (IDD) and mental health (MH) conditions.
- Ongoing initiatives include social media and website presence, public awareness efforts, speaking engagements and trainings, developing partnerships within and outside of HHSC support and promote existing prevention efforts and participate in councils, workgroups, and stakeholder meetings.

Agenda Item 3: Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council

- Overview of the council and membership**
- Rules and bylaws and roles and responsibilities of council members**
- Upcoming meetings**
- Expense reimbursement**
- Legislative report**

Mr. Jay Smith, Office of Disability Preventions for Children, Project Manager, provided an overview of the PANS Council, rules and bylaws, roles and responsibilities of council members, upcoming meetings, expense reimbursement and legislative report and referenced a PowerPoint entitled "Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council". Highlights of overview included:

- The Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council (PANS) was enacted by HB2783 and established to advise HHSC and the legislature on research, diagnosis, treatment, and education of PANS/PANDAS.
- The PANS membership is comprised of 19 members serving two-year terms with the option for reappointment.
- PANS council tasks include the development of an annual report due by September 1 of each year and submitted to the Governor, Legislature and HHSC.
- Recommendations focus on practice guidelines for diagnosis and treatment, mechanisms to increase clinical awareness and education strategies for outreach to educators and parents to increase awareness and developing a network of volunteer experts on diagnosis and treatment.
- Members are required to complete the Public Information Act and Open Meetings Act trainings and email certificates of completion to Jay Smith, PANS Council liaison at jay.smith@hhs.texas.gov.
- Future meeting dates are:
 - February 26, 2021, 9a -12p
 - May 21, 2021, 9a - 12p

- July 16, 2021, 9a - 12p
- Members are not subject to compensation or reimbursement for expenses incurred in performing advisory council duties.

Agenda Item 4: Advisory Committee Coordination Office (ACCO) overview

Mr. John Chacón, HHSC, ACCO Facilitator, reviewed the support functions relating to how ACCO supports the council, webcasting/virtual live streaming protocol, and guiding factors and referenced a handout entitled "Advisory Committee Coordination Office". Highlights of the overview of ACCO support functions included:

- Mr. Chacón stated that because of the Sunset Review in 2014-2015, HHSC established the Advisory Committee Coordination Office to create standardized processes for all HHS advisory committees. In addition to helping staff support HHS advisory committees in a consistent manner, it also increased transparency and established processes for tasks such as electing officers and soliciting new members. These processes are used across all Health and Human Services Commission (HHSC) committees and many at the Department of State Health Services (DSHS).
- Mr. Chacón stated that one of the ways the Health and Human Services (HHS) would like for stakeholders across the state to be informed of the happenings in the state is by webcasting/live streaming the Advisory Committee/Council meetings. With this said, moving forward all the PANSA Council meetings will be webcasted/virtually live streamed to provide this stakeholder experience as well as to comply with HHS Policy.
- Mr. Chacón stated that while webcasting/Teams Live Events is live stream of an actual meeting, it's not real time because it's dependent on the device being utilized to view the meeting so it may be delayed from 5 seconds to 45 seconds due to the bandwidth capability of the device. For this reason, we ask council members that are not able to attend physically to call in to a dedicated conference call in number and for those unable to join via the Teams Live Events link to call in on the dedicated number, so they can establish audio via the presenters' platform.
- Mr. Chacón stated that at the beginning of each meeting, as part of our logistical announcements, an ACCO facilitator we will remind the council members and staff presenting to use their microphones on their devices so that people on the webcast/Teams Live Events live stream can hear. We will also remind council members and presenters to please state your name each time before speaking and to speak directly into the microphones.
- Mr. Chacón stated that HHS advisory committees have several resources that are used as guiding factors. He stated that all committees/councils will have their bylaws that will provide specific guidance for that committee/council. He stated that there are a few additional resources that members may or may not be familiar with i.e., Roberts Rules of Order as a guide, Circular C-022: Health and Human Services Enterprise Policy for Advisory Committees, and the Advisory Committee Handbook.
- Mr. Chacón stated that members of the council should not communicate by email on matters of the council. Doing so could lead to a violation of the Open Meetings Act.

Agenda Item 5: Open Meetings Act (OMA) overview

Ms. Kym Oltrogge, Attorney, Legal Services Division, HHSC, provided an overview of the Open Meetings Act (OMA) and referenced a PowerPoint and handout entitled "OMA PANSA Council- Open Meetings Act, Tex. Gov't Code ch. 551". Highlights of the overview included:

- Guidance on requirements for open meetings, using video conference, and resources.
- Kym Oltrogge reviewed the OMA and advised members all meetings must be held publicly and accessible.
- The OMA training focuses on how to apply the OMA to the committee. Members must retake the OMA every 5 years as required by HHSC.
- The OMA applies to all governmental bodies with elected officers. An advisory committee is not a governmental body, but the OMA applies to all advisory committees by policy not by law.
- If the OMA is followed members will not be subject to criminal prosecution.
- The definition of a meeting is a quorum + deliberation + governmental body's public business; Or a quorum + governmental body conducts meeting/is responsible for meeting + governmental body called meeting + public business.
- Other platforms could be considered as conducting a meeting such as a Facebook page, email correspondence, other electronic apps if there is a quorum of members.
- Public notices require the date, hour, location and subjects to be discussed and must be posted for 8 days prior to the meeting. All notices are reviewed by the legal department.
- If an item is not on the agenda it cannot be discussed.
- All HHS councils must be broadcasted live, and archives of the meetings must be kept on the HHS website for a minimum of two years.

Agenda Item 6: Ethics overview

Mr. David Reisman, Chief Ethics Officer, provided an overview of the HHS Ethics Policy and referenced a PowerPoint entitled "Ethics Advisory Committee Talking Points". Highlights of the overview included:

- Guidance on HHS ethics policy as it relates to HHS Advisory Committees.
- Advisory committee members may not claim or appear to represent HHSC or the committee in any legislative or advocacy activity without approval from the committee's presiding officer and the HHS Ethics Office in coordination with the HHSC Government and Stakeholder Relations Office.
- Committee members are not prohibited from discussing a report that has been formally adopted by the specific committee they represent, or from representing themselves or other non-state agency entity in the legislative or advocacy process.
- Members shall disclose all direct personal or financial interests in a motion under consideration and recuse themselves from any deliberations or decisions on that matter.
- Personal or private interest does not include the member's engagement in a profession, trade, or occupation when the member's interest is the same as all others.
- Members may not accept payment for services that are requested because of the members' title or position on the committee.
- Members should not be in a position to derive personal benefit from actions or decisions made in their official capacity.
- Members should not knowingly solicit, accept, or agree to accept any benefit for having exercised the member's official powers or duties in favor of another person.
- Members may not disclose confidential information and all agency generated information, including information in draft form, acquired through his or her

committee membership, until such time as the information or document is released and made public, the HHS Executive Commissioner has approved the release in writing, or the HHS Ethics Policy permits release. Also includes all information protected by the Health Insurance Portability and Accountability Act (HIPAA).

- Members shall not use state government time, property, facilities or equipment for purposes other than official business nor expend state appropriations to advocate for or against any bill or measure.

Agenda Item 7: Public comment

No written or oral public comment was offered

Agenda Item 8: Action items and topics for staff or member follow-up

Highlights of the action items and agenda topics for next meeting and council member discussion included:

- Next meeting is scheduled for Friday, February 26, 2021 at 9:00 am.
- Newborn screening and DNA testing for PANS
- Practice Guidelines Discussion
- Mechanisms for increasing clinical awareness
- Outreach strategies and awareness
- Sensitivity and specificity of testing parameters
- Subcommittee discussion and a process for moving forward
- Education and collaboration
- Services available for people with PANS and resources
- Stigma around diagnosis
- Cognitive interventions, accommodations and cross generational emotional trauma
- Election of Officers

Agenda Item 9: Adjourn

Mr. John Chacón, HHSC Facilitator, thanked council members, staff, and members of the public and adjourned the meeting at 11:12 a.m.

Below is the link to the archived video of the November 13, 2020 Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council (PANSAC) meeting that will be available for viewing approx. two years from date of meeting.

[Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Committee Agenda](#)