

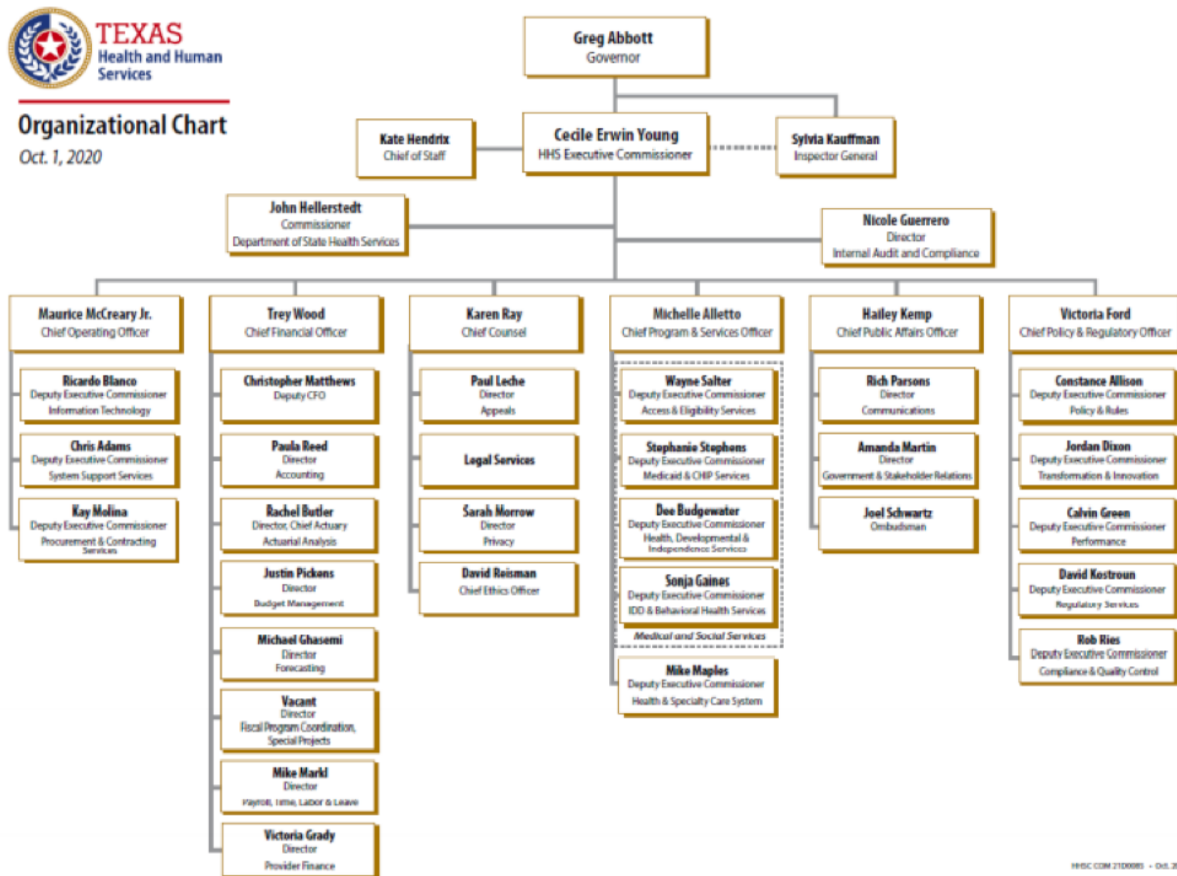


HHSC: Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Committee, November 13th, 2020

Welcome, introductions, and opening remarks. The first meeting of this council was convened by John Chacon, HHSC.

Agency and program overviews

Health and Human Services.



Rehabilitative and Independence Services

- Office for Deaf and Hard of Hearing Services
- Office of Guardianship Services
- Office of Independence Services
 - Blind Children's Vocational Discovery and Development Program (BCP)—
- We assist eligible children who are blind or visually impaired to reach independence in the home or community through communication, mobility, and activities of daily living.
 - Serve 3,250 children and their families annually
 - Staff in all regions/areas of 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.
 - 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
 - Be a Texas resident
- BCP provides services designed to help children and families meet these program outcomes:
 - Children and families will have access and/or have the skills to access needed services.
 - Parents will actively engage in their child's development, educational system, medical system, and social system.
 - Children will actively engage in their community and daily living skills to their unique capacity.
- These outcomes are met by providing the following services to address a child's individual needs:
 - Case Management— Case management services help the child and family access appropriate resources and services to achieve maximum independence and self-sufficiency.
 - Parent Education— Parent education services are provided to a parent or guardian to provide instruction and learning on a specific topic or skill.
 - Direct Skills Training— Direct skills training is hands-on services provided by the BCS to help children learn, master, maintain or improve their level of functioning and independence.

- Specialized Services— Deafblind Specialist Deafblind services are provided to children who have a combined vision and hearing loss. Services included but are not limited to:
 - Specialized consultation services
 - Technical assistance and resources to families
- Email the Blind Children’s Program at BlindChildrensProgram@hhs.Texas.gov. Call the HHS Office of the Ombudsman a. 1-877-787-8999, select a language, and then select Option 3.
 - **Blindness Education Screening and Treatment (BEST)**
 - **Independent Living Services (ILS)**
 - **Office of Disability Prevention for Children (ODPC)**—is the successor to the former Texas Office for the Prevention of Developmental Disabilities. Senate Bill 200 abolished the former office and its executive committee and transferred the duties to the Health and Human Services Commission (HHSC) effective Sept. 1, 2017. The Office of Disability Prevention for Children (ODPC) was created in response to this legislatively mandated transfer to ensure the prevention of developmental disabilities remains a focus in Texas.
- 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.
 - 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.
 - Collaborating with healthcare providers, stakeholders and other state agencies.

Areas of Focus

- Prevention of disabilities caused by maternal health issues during pregnancy.
- Prevention of injuries in children.
- Early identification and diagnosis of disabilities to ensure early intervention and services.
- Address co-occurring intellectual and developmental disabilities (IDD) and mental health (MH) conditions.

PANS & ODPC— Through education and community collaboration efforts, ODPC is committed to promoting:

- early identification and diagnosis; and
- mental health wellness in children diagnosed with PANS.

Ongoing Initiatives

- Social media and website presence

- Public awareness efforts
- Speaking engagements
- Developing partnerships within and outside of HHSC
- Support and promote existing prevention efforts
- Councils, workgroups, and stakeholder meetings

Collaboration Efforts

<ul style="list-style-type: none"> • Early Childhood Intervention (ECI) Office of Mental Health Coordination (OMHC) • Maternal Child Health (MCH) • Women Infant and Children Program (WIC) • Medicaid and CHIP Services – Person Centered Practices • UT Center for Disability Studies 	<ul style="list-style-type: none"> • Hogg Foundation for Mental Health • Safe Kids – Dell Children’s Hospital • Kids Living Well – Austin-Travis County Mental Health Authority • Travis County Underage Drinking Taskforce • <u>LifeSteps</u> of Central Texas • Safe Alliance
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See: https://hhs.texas.gov/about-hhs/process-improvement/improving-services-texans/office-disability-prevention-children?utm_source=pcd-domain&utm_medium=vanity-url&utm_campaign=website

Road to Recovery Trainings

- Supporting Children with IDD’s who have experienced trauma.
- Developed by the National Traumatic Stress Network.
- Collaboration with the UT Center for Disabilities Study and the Hogg Foundation for Mental Health.

Future Program Planning

- ODPC website update project
- Educational mailout initiative
- ODPC Conference in March
- ODPC webinars
- Road to Recovery trainings
- Statewide media campaign in collaboration with ECI
- Presenting and exhibiting at conferences

Brain Injury Programs

Office of Independence Services

Blind Children’s Vocational Discovery and Development Program

Office of Disability Prevention for Children

Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council

Overview of the council and membership—

- Enacted by HB 2783 (86R)—Authored by legislative Council member, Representative Terry Wilson
- Established to advise HHSC and the legislature on research, diagnosis, treatment, and education of PANS/PANDAS

19 members

- 2 members of the Texas Senate
- 2 members of the Texas House of Representatives
- 15 members representing various fields in science, education, social work, advocacy, and a parent
- Members serve two-year terms and may be re-appointed to serve.

Chair and Vice-chair are elected from the legislative members. Meetings times and location are determined by the Chair and council with no specific parameters on frequency

Tasks include:

- Develop an annual report by September 1 of each year
- Report is submitted to the
- Governor
- Legislature
- HHSC

Recommendations focus on:

- Practice guidelines for the diagnosis and treatment
- Mechanisms to increase clinical awareness and education
- Strategies for outreach to educators and parents to increase awareness
- Developing a network of volunteer experts on the diagnosis and treatment

Texas Health and Safety Code Subtitle E, Title 2, Chapter 119A

Texas Government

Code Chapter 551 – Open Meetings

Chapter 2110 – Advisory Committees

Texas Administrative Code Section 351.801

Advisory Committees Bylaws will be discussed in next meeting, including:

- Member expectations
- Frequency of meetings
- Committees
- Protocols

Required Training:



[Public Information Act \(PIA\) Training](#)— Texas Government Code Section 552.012 requires elected or appointed public officials to complete open records training.

- PIA training located at this webpage.

[Open Meetings Act \(OMA\) Training](#)— Texas Government Code Section 551.005 requires elected or appointed officials who participate in meetings are subject to OMA. OMA training located at this webpage. After completion, print and send certificates of completion to the PANS Council Liaison email

Upcoming meetings— Proposed meeting dates:

- February 26, 2021 9a-12p
- May 21, 2021 9a-12p
- July 16, 2021 9a-12p
- Additional meetings may be added as needed by the Chair

Expense reimbursement— Members are not subject to compensation or reimbursement for expenses incurred in performing advisory council duties.

Legislative report—The Council must develop an annual report by September 1 of each year that is submitted to the

- Governor
- Legislature
- HHSC

Advisory Committee Coordination Office overview. The Office was the result of the Sunset Review to create a standardized process for all advisory committees. The processes are uniform across all advisory committees. This office directs the webcasting of all meetings. The meetings may be real time or slightly delayed because of the bandwidth of the viewer's device. It is important to speak into the microphone and state their name in advance of speaking. Bylaws will be developed based on standard components. The Office has a director, associate director and staff. The office facilitates meetings to make successful decisions. They have many resources and tools available to committees and councils, including Roberts Rules of Order (used as a guiding tool). Circular C-022 can provide more information and provides guidance to Advisory Committees and Councils.

As a result 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).

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 or live-streaming the Advisory Committee/Council meetings. With this said, moving forward all the Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council (PANSAC) meetings will be webcasted or livestreamed to provide this stakeholder experience as well as to comply with HHS Policy.

While the public attendee link 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 20 seconds due to the bandwidth capability of the device. For this reason, we ask council members to attend physically whenever possible but due to the pandemic, we are asking members to join via the Teams Live Events meeting invite. In some cases, if a member does not have the authentication for the Teams Live Events platform, they will join via the web anonymously to establish video and call in to a dedicated call in number and ID to establish audio.

At the beginning of each meeting, as part of our logistical announcements, we will remind the council members and staff presenting to speak into their microphones so that people on the webcast or 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 of your device.

HHS advisory committees have several resources that are used as guiding factors. All committees/councils will have their bylaws that will provide specific guidance for that committee/council. In addition to that, there are a few additional resources that you may or may not be familiar with.

ACCO currently has six facilitators. Same facilitator assigned as possible and a back-up is assigned. ACCO Staff:

- Cassandra Marx, Director
- John Chacon, Associate Director
- Francesca Kupper, Facilitator/Project Manager
- Sallie Allen, Facilitator/Project Manager
- Kayla Cates-Brown, Facilitator/Project Manager
- Gilbert Chavez, Facilitator/Project Manager
- Susanna Sparkman, Facilitator/Project Manager
- Eric Owens, Facilitator/Project Manager

Work closely as a team with program area staff, specifically with the program area council liaison which for PANSAC is Jay Smith, Project Manager, Office of Disability Prevention for Children (ODPC) PANS Liaison, Office (512) 206-5100, jay.smith@hhs.texas.gov

An ACCO Facilitator contributes structure and guidance to interactions to enable committees/councils to function effectively, comply with the OMA and make productive or successful decisions.

Roberts Rules of Order

- Serves as a guide for advisory committee meetings and decision making, but procedural matters can also be determined by consensus (discussion and vote)

Circular C-022: Health and Human Services Enterprise Policy for Advisory Committees

- Issued in July 31, 2007 to establish guidelines that cover staff responsibilities, communication of activities, and internal appointment requirements for appointment members to advisory committees.
- Revised July 19, 2010 and recently in September of 2018.
- Establishes system-wide guidelines regarding HHS agency advisory committees • Latest revision in 2018 included a new Advisory Committee Handbook to assist all programs at HHSC and some at DSHS in supporting advisory committees.
- Also created a new appointment process for all advisory committee members appointed by the HHS Executive Commissioner.
- The circular notes that advisory committees are responsible for following all applicable laws and agency rules including the Texas Open Meetings Act and the Texas Public Information Act as well as guidance from the HHS Ethics Office. You will be hearing from Kym Oltrogge on the Texas Open Meetings Act and Public Information Act. You will also be hearing from Mr. David Reisman, the Chief Ethics Officer for HHS regarding the HHS Ethics Office.
- Circular 22 also directs staff to allow for the opportunity for public comment at advisory committee meetings. Policies Affecting Services: Advisory Council Letters and Reports
- Some statutes or rules governing HHSC and DSHS councils require council members to write a report, while other statutes or rules require the reports to be written by agency staff.
- For reports written by council members, council support staff may need to provide information as requested by council members.
- Staff may provide their input as a subject matter expert but should not edit or revise the council's report.
- There are guidelines for writing the reports and your council liaison can provide you that information along with the approved report template you need to use.

Subcommittee Operations Unless otherwise noted in statute, rule, or bylaw, the council chair, with approval of agency staff, may establish subcommittees for purposes of studying and making recommendations on issues the council determines appropriate to the charge

of the council. I know Kym Oltrogge will talk about the Open Meetings Act, but there are a few things we get a lot of questions on, so I want to stress them as a meeting facilitator:

1) Only the items that are on the agenda can be discussed at a meeting. So, if someone talks about something not on the agenda, a facilitator will politely let you know that we need to add the topic to a future agenda.

2) Agenda items have to be specific enough so that the public knows what will be discussed and can attend to provide comment, so we can't put a broad category on the agenda.

3) To ensure that all business can be conducted in the timeframes allowed and that everyone who wants to comment can, public comment is commonly limited to three minutes per person. While we do limit the time for each person, this does not mean we will cut them off at exactly 3 minutes.

4) Communication - Members of the council should not communicate by email on matters of the council. Therefore, we ask that all communication to council members be sent via Blind Carbon Copy (Bcc) to prevent a quorum email chain of the council. Doing so could lead to a violation of the Open Meetings Act.

DEFINITIONS:

Council Liaison:

- An HHS or DSHS staff member assigned to an advisory committee to perform organizational tasks that support committee meetings and activities.
- Jay Smith, Project Manager, Office of Disability Prevention for Children (ODPC) PANS Liaison, Office (512) 206-5100, jay.smith@hhs.texas.gov is the Pediatric Acute-Onset Neuropsychiatric Syndrome Advisory Council liaison.

Presiding Officers:

- The chair and or vice-chair of a committee who provide guidance and leadership in accordance with statute, rule and policy.
- Officers may be elected by members of the committee or appointed by the HHS Executive Commissioner or Governor as determined by statute or rule.
- Webcast/Virtual Livestream:
 - An audio and video broadcast over the Internet using streaming media technology to distribute a single content source (i.e., advisory committee meeting) to many simultaneous listeners or viewers.
- Click on <https://hhs.texas.gov/about-hhs/communications-events> to view live or archived meetings.

Open Meetings Act overview. Tex. Health & Safety Code § 119A.002: The . . . Advisory Council is established to advise the commission and the legislature on research, diagnosis, treatment, and education related to pediatric acute-onset neuropsychiatric syndrome.

Type of entity	Criminal prosecution possible under OMA?	Handguns prohibited?
Advisory committee est'd by a statute that does not mention the OMA; subject to OMA by HHS policy	No	No

What is a meeting?

1. Quorum + deliberation + governmental body's public business
- OR
2. Quorum + governmental body conducts meeting/is responsible for meeting + governmental body called meeting + public business

Public Notice Requirements

1. Date
2. Hour
3. Location
4. Subjects to be discussed

Open Meetings Act (OMA), Tex. Gov't Code ch. 551: The OMA requires a governmental body to hold all meetings in public, in an accessible location.

- 1 Training requirements:
2. HHS requires all committee members to comply with the OMA training requirements. 2. Training must last between one to two hours.
3. Training must include:
 - a. General background of the legal requirements
 - b. Applicability of the OMA to governmental bodies
 - c. Procedures and requirements regarding quorums, notice, and recordkeeping requirements
 - d. Procedures and requirements for holding an open meeting and a closed meeting
 - e. Penalties and other consequences for failing to comply with the OMA.

4. HHS requires the completion certificate to be kept in your files.

5. HHS requires all committee members to be trained every five years. Why is the Advisory Council subject to the OMA? 1. OMA defines “governmental body” as a board or similar entity within the executive or legislative branch directed by one or more elected or appointed members.

More detailed information can be found by following the link above.

Ethics overview

Official Representation— 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.

Representation— 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.

Disclosure— Advisory committee 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 similarly engaged in a profession, trade, or occupation, or if the member merely provides a personal experience, with no personal or private interest, in giving feedback on the subject matter.

Honoraria Prohibition— Advisory committee members may not accept payment for services that are requested because of the members’ title or position on the committee.

Conflicts of Interest— Advisory committee members should not be in a position to derive personal benefit from actions or decisions made in their official capacity.

Bribery— Advisory committee 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.

Confidential Information— Advisory committee 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.

Includes all information protected by the Health Insurance Portability and Accountability Act (HIPAA), information that has commercial value or use, such as trade secrets, and information communicated in confidence by the HHS System.

Misuse of Government Property— Advisory committee members shall not use state government time, property, facilities or equipment for purposes other than official business.

Prohibition on Lobbying— Advisory committees, or its members, may not expend state appropriations to advocate for or against any bill or measure.

Public Servants— As public servants, advisory committee members are subject to ethics laws contained in the chapters 36 & 39 of the state penal code and elsewhere in state statutes.

David A. Reisman Chief Ethics Officer
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Cell: (512) 940-9221
Anonymous Helpline: (512) 424-6639
david.reisman@hhsc.state.tx.us

Public comment. No public comment was offered.

Action items and topics for staff or member follow-up.

- Newborn screening and DNA testing for PANS
- Practice Guidelines Discussion
- Mechanisms for increasing clinical awareness
- Subcommittee discussion and a process for moving forward
- Education and collaboration
- Services available for people with PANS
- Stigma around diagnosis
- Cognitive Interventions and emotional trauma
- Election of Officers

Adjourn. There being no further business, the meeting was adjourned.

This summary contains supplemental information from third-party sources where that information provides clarity to the issues being discussed. Not every comment or statement from the speakers in these summaries is an exact transcription. For the purpose of brevity, their statements are often paraphrased. These documents should not be viewed as a word-for-word account of every meeting or hearing, but a summary. Every effort has been made to ensure the accuracy of these summaries. The information contained in this publication is the property of the organization and is considered confidential and may contain proprietary information. It is meant solely for the intended recipient. Access to this published information by anyone else is unauthorized unless the organization grants permission. If you are not the intended recipient, any disclosure, copying, distribution or any action taken or omitted in reliance on this is prohibited. The views expressed in this publication are, unless otherwise stated, those of the author and not those of the organization or its management.
