**PANS/PANDAS Advisory Councils**

Lessons learned from the Illinois PANS/PANDAS Advisory Council

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**History**

* During the 99th session of the Illinois General Assembly (2015), a bill became law that created an advisory committee on two conditions called PANDAS and PANS (P.A. 99-0320). The first meeting of this newly constituted Advisory Council was held in March of 2016.
* This was done in preparation for work on a PANS/PANDAS insurance mandate. It was felt that we needed to educate the General Assembly on the conditions, and the need for better, faster, easier access to care. The insurance mandate bill was introduced at the same time the Council work started.
* Members included: An immunologist, a health care provider with experience with PANDAS and autism, a representative of PANDAS/PANS Advocacy & Support, an osteopathic physician, a medical researcher, a certified dietitian-nutritionist, a school psychologist, a child psychiatrist, a school nurse, a pediatrician, a representative of an organization focused on autism, a parent, a social worker, a representative of the special education service in the state BOE, the Director of Public Health, or his or her designee, and four members of the ILGA.

**Picture of women posing for a picture, in front of a Illinois Department of Public Health sign.**

**Goals were determined by the statute**

* Not later than January 1, 2017, and annually thereafter, the advisory council shall issue a report to the General Assembly with recommendations concerning:
* (1) practice guidelines for the diagnosis and treatment of the disorder and syndrome;
* (2) mechanisms to increase clinical awareness and education regarding the disorder and syndrome among physicians, including pediatricians, school-based health centers, and providers of mental health services;
* (3) outreach to educators and parents to increase awareness of the disorder and syndrome; and
* (4) development of a network of volunteer experts on the diagnosis and treatment of the disorder and syndrome to assist in education and outreach.

**Activities to reach our goals**

* The yearly report would detail the practice guidelines for diagnosis and treatment of IL residents. These guidelines were basically developed by the PANDAS/PANS Clinical Research Consortium and aligned with the PANDAS Physicians Network, with input from IL physicians practicing in the field.
* To increase awareness amongst pediatricians, the educational system, and mental health providers:
1. we made ourselves “regulars” at AAP Chapter conferences, educational meetings, and mental health conferences
2. We offered to present to private mental health providers and at school in-services, focusing on special educators, social workers, and school psychologists
3. We offered a free yearly Summit meeting, bringing in knowledgeable speakers, as well as ascertaining needs amongst the community
4. We created content to disseminate post cards, dx chart, treatment options, etc
* We provided regular information to the State Board of Ed for dissemination to all school nursing staff
* We agreed to become a free Speakers Bureau, and answered all calls for more information
* Development of an IDPH webpage dedicated to PANDAS

**A picture of a table set up at a conference with PANDA/PANS information.**

**A picture of a PANDAS/PANS flyer explaining the syndrome.**

**A picture of a PANDAS/PANS Summit flyer.**

**Funding**

* No funding through Illinois
* Used local non-profit money for supplies and conference fees
* Got sponsorships from specialty pharmacy for yearly summit
* VERY LIMITED

**Successes**

* Acceptance and an expectation from the AAP that our group would always be present at chapter conferences
* Positive relationship development with the ILGA, major hospital systems, private physicians and mental health providers, and schools
* Increased physician awareness and some new providers
* Yearly increased attendance at the Summits
* Access to legislators and new bill development
* Very trustful group process

**Barriers to Success**

* Lack of Funding
* Diminished interest
* Loss of key members
* COVID-19 Pandemic

**Ways to do it better**

* Obtain funding
* Change legislation to allow for alteration of goals based on present need
* Focus on education and recruitment
1. Med schools
2. Psychology and social work programs
3. Teacher education
* Alter co-chairs yearly for fresh perspectives and to avoid burnout
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