

ARIZONA STATE LEGISLATURE
Fifty-first Legislature – Second Regular Session

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

Minutes of Interim Meeting
Tuesday, October 14, 2014
House Hearing Room 1 -- 10:00 a.m.

Chairman Ugenti called the meeting to order at 10:15 a.m. and attendance was noted by the secretary.

Members Present

Representative Michelle Ugenti, Chair	Kate Fleck
Representative Heather Carter	Kari Kling
Dr. Melanie Alarcio	Lee Miller
Shelly Avila	Molly Ochoa
Kathi Berank (for Charles Bassett)	Dr. Sydney Rice
Cara Christ (for Will Humble)	Paul Ryan
Dr. Jay Cook	Cori Zdebel
Dr. Michael Daines	

Members Absent

Representative Victoria Steele	Dr. Suraj A. Muley
Tess Burleson	Dr. Mark Ross
Dr. Fayez Ghishan	Dr. Susan Swedo

INTRODUCTION OF MEMBERS

Chairman Ugenti asked members to introduce themselves and give their area of expertise.

OPENING REMARKS

Chairman Ugenti stated that this is such a broad, multi-faceted topic that she is proposing subcommittees be established to handle specific areas. She referred to a handout prepared by Mr. Ryan listing the proposed subcommittees and asked for members' opinion as to relevance (Attachment 1). She said she would like to fine tune the issues to be studied, so that members' expertise can be maximized and redundancy minimized. She asked Mr. Ryan to elaborate on his goals and vision for this subject.

Mr. Ryan stated that pediatric autoimmune diseases are a huge, complex problem involving new medicine, new types of diseases and encompass a very broad area in the field of neurology.

These diseases affect children who are normal one day and the next day, they are not. He reviewed the proposed subcommittee objectives spelled out in the attachment:

- Medical Standard of Care and Awareness
 - Develop a medical standard of care
 - Issue the standard of care to first responders
 - Raise public awareness
- Pediatric Autoimmune Center of Excellence
 - Establish a definition for a Pediatric Autoimmune Center of Excellence and a network of facilities, extensive research capabilities and a medical educational degree program
- Insurance
 - Define guidelines to address rejected insurance claims
 - Establish partnerships that encourage insurance companies, centers of excellence and research facilities to combine resources to study pediatric diseases
- Funding
 - Recommend legislative and budgetary allocations
 - Investigate state, federal and private grants

Discussion ensued on the above issues.

Dr. Daines said that since these are autoimmune neuropsychiatric disorders, treatment is targeted toward trying to suppress the immune response, so the immune system is not attacking the brain of the child, causing the problems associated with this disorder. Initial treatment is to use antibiotics to get rid of the bacteria that originally trigger the disorder and then follow up with steroids to try to suppress the immune response. Because of the side effects of steroids, their use is limited. Study has shown that intravenous immunoglobulin (IVIG) is beneficial; however, IVIG is a more expensive treatment than steroids and is frequently denied as a treatment for these children.

Dr. Alarcio stated that it is very difficult to target which organism triggers the disease; however, in most instances, it is strep.

In response to Chairman Ugenti, Dr. Alarcio answered that perhaps half of the cases can be diagnosed through strep. Chairman Ugenti asked whether members think a medical standard of care would be helpful to pediatricians and/or families. Dr. Daines said it will be fairly easy to develop a standard of care for most of the patients; however, he pointed out that there are exceptions.

Ms. Fleck said she believes that part of the standard of care needs to include that the first question is not whether the condition is psychiatric but whether there is infection. Currently, children are given antipsychotic medications and put in a psychiatric ward. She pointed out that infections are generally not diagnosed by the treating physicians.

Dr. Cook told members about a child who had seven documented strep infections where the parents were told it was psychological. He gave the child gamma-globulin infusion and said the child slept for the first time in his life. He stated that this condition is treatable; however, some colleagues disagree and some parents do not trust the diagnosis because they have been told many different things.

Ms. Zdebel said that doctors are not aware that they can do the antibody tests and parents are not aware that all the tests can be run, not just the strep test. The strep test is the most common, the least expensive and is covered by insurance companies.

Discussion ensued on diagnosis and treatment. Dr. Cook advised that treating a child with steroids costs hundreds of dollars while gamma-globulin therapy costs thousands of dollars. He noted that the cost to treat with plasma exchange is \$20,000 to \$40,000.

Mr. Ryan spoke of the benefit of having a Pediatric Autoimmune Center of Excellence which will provide a full range of pediatric clinical services, extensive research capabilities and an in-house medical educational degree program.

Chairman Ugenti advised that insurance issues are a relevant part of this discussion but she questioned the need for an insurance subcommittee.

Ms. Berank related that the reason some infectious tests are not covered is because they are experimental. She maintained that medical research is absolutely essential and spoke of the need for literature that shows that the tests are effective and not experimental. She advised that the test for strep is covered; however, IVIG is not.

Mr. Ryan explained that the reason for recommending the insurance subcommittee is to discuss what is being denied by the insurance industry.

Representative Carter said she would like to hear from the Department of Health about how it is interacting with the public. Ms. Christ related that the Department works with the Medical Board to get information to providers; it does not interact with the public. Representative Carter stated reluctance about proposing legislation because of the early stage of the discussion; however, she wants to ensure that there is public awareness and said she is committed to increasing the level of awareness.

Ms. Fleck shared information that the Journal of Child and Adolescent Psychopharmacology (JCAP) is releasing online articles in its October issue relating to autoimmune diseases, specifically looking at Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) and Pediatric Acute Onset Neuropsychiatric Syndrome (PANS). The articles are a collection of papers written by national and international experts and hopefully will help stop some of the controversy surrounding this issue. She maintained that clinical trials over the years have yielded much information and said that people now have to be convinced about it.

Representative Carter said she would like to encourage members to get their constituents involved. As Chairman of the House Health Committee, she said that anything her Committee can do to increase the level of awareness is a step in the positive direction. She stated that not

every problem requires a legislative solution, but Legislators work with other agencies and can bring this issue to the forefront.

Mr. Ryan discussed funding. He brought up existing state programs, the shortage of doctors and specialists, applying for small grants, state and federal grants that already exist, and promotion of job growth and economic development in the state that benefit projects and programs identified by this Committee.

Chairman Ugenti asked about grants in the private sector. Mr. Ryan answered that is one area that is being worked on. Private sector grants generally involve research and that should be encouraged. Chairman Ugenti said that in order to justify funding, the community needs to get organized and specific about its intent and goals.

Dr. Daines pointed out that the state is already paying for these children since they are in special needs schools and behavioral programs and he opined that these programs are not helping the children get any better. He said he believes that appropriate treatment will result in a dramatic improvement in their behavior, resulting in decreased costs.

Representative Carter brought up the limited resources in the school systems to address children whose diagnoses has not been identified or have been misidentified, and agreed that treatment has not addressed the root problem. She said there is a huge gap in information; both groups involved need to be brought together so that the highest use of state resources can be made. This Committee can be used to bring the various groups to the table.

Chairman Ugenti concurred with Representative Carter, adding that it will help leverage available dollars if the Committee tackles some of these issues. The focus should be on awareness, making parents mindful that other tests are available, as well as educating the medical community about this disorder. Establishing a groundswell in the community will hopefully manifest itself into some funding in the future. She said she believes these other steps need to be addressed before a dedicated subcommittee on funding is established.

Mr. Ryan advised that his idea for the subcommittee on funding is to ensure that the tools are available.

Dr. Rice commented that funding needs to be a huge part of this because there will not be a Center of Excellence until there is funding. In order to do research and to have a standard of care, a lot of work is required which cannot be done unless there is funding. In addition, a track record on research is needed to qualify for some of the big national grants. To do the research, outcomes research is needed and the children need to be studied very closely over a period of time, requiring three or four qualified PhDs who must be paid for their time and efforts.

Mr. Ryan said that the University of Arizona has estimated that five or six more specialists are needed at \$1 million a year to do additional treatment of children and research. Giving budgetary constraints, he is asking for smaller steps to show the state's interest. One small step is to incentivize students to become doctors, etc., pointing out the lack of medical providers in rural Arizona.

Chairman Ugenti prioritized the Committee's goal: establish a Medical Standard of Care and Awareness subcommittee and the Pediatric Autoimmune Center of Excellence subcommittee. She stated that members can contact her by email if they want to sit on either subcommittee. Instead of establishing subcommittees on insurance and funding, the insurance industry can participate in those two subcommittees. She related that she, Representative Carter and staff will look into available grants that will facilitate the Committee's goals.

Representative Carter said she is committed to using one of the House Health Committee meetings to raise the level of awareness on this subject, defining the problem and describing what is happening in Arizona. That public forum can be used on the social media network to share information with the medical profession and parents. She advised that Legislators are constantly fighting for limited resources to do important things. If it can be shown that there is an actual cost savings, it will be a big step toward achieving state resources.

Mr. Ryan recommended limiting discussion to the pediatric autoimmune neurological field.

Chairman Ugenti suggested a PANDAS Awareness Day at the Capitol. She said the focus should be on what the goal is and how the Legislature can help with the solution.

Ms. Fleck, as a parent with a PANDAS child, expressed her goal: when a parent notices that the child behaves differently, whether overnight or over time, the first doctor the child sees should automatically test the child for infection to identify the disease, put the child on antibiotics, if necessary, and be aware of what the treatment is until the child can see a specialist.

Chairman Ugenti commended Ms. Fleck for expressing her goal, which is also the goal of this Committee. She hopes to get more Legislators involved in order to have a bipartisan effort and advised that follow-up meetings will be held. She thanked members for their participation.

Without objection, the meeting adjourned at 11:42 a.m.

Joanne Bell, Committee Secretary
October 27, 2014

(Original minutes, attachments and audio on file in the Chief Clerk's Office; video archives available at <http://www.azleg.gov>)