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Congress of the United States
House of Representatives
Washington, DC 20515-0914

September 10, 2015

The Honorable Sylvia Burwell
Secretary
U.S. Department of Health and Human Services
200 Independence Ave, SW
Washington, DC 20201

RE: Request Rigorous Oversight and Action regarding federal court finding State of Florida denial of children's health services and access to care under Medicaid

Dear Secretary Burwell:

I am writing to follow-up on my January 8, 2015 letter regarding United States District Court's ruling in December 2014 that determined that the State of Florida is in violation of federal law for systemic denial of health services to children under the Medicaid and Social Security laws. The court challenge was brought by the Florida Chapter of the American Academy of Pediatrics and the Florida Academy of Pediatric Dentistry. The court's findings of fact and conclusions of law revealed an outrageous and miserable history by the State of Florida of systematically and purposely ignoring its duty to provide adequate care for children and meet its legal and moral responsibilities. I respectfully request that you and the U.S. Department of Health and Human Services ("HHS") exercise your oversight and enforcement authority to ensure Florida children receive the care required under the law.

Despite the fact that eight months have passed since the ruling, the state has done nothing to address the shortcomings in medical services to children as the court directed. In fact, the State has exacerbated the problems and continues to ratchet back on required children's health programs. Last week, numerous medical directors and assistant medical directors of the state's Children's Medical Services ("FLCMS"), the Title V program in Florida, which provides services for children with special needs, signed a letter expressing their serious concerns with the lack of access to care for the children served by FLCMS. The letter is attached.

The medical directors included a detailed list of the concerns they have seen firsthand as FLCMS providers. The directors explain that FLCMS has placed a moratorium on new enrollees and that current child enrollees (60,000) are having their eligibility reevaluated unnecessarily. Additionally, the medical directors state that the reevaluation process is "flawed" and has led to

“almost one-fourth of eligible CMS children being screened out”. After they are “screened out,” children must then enroll in a Medicaid managed care plan. FLCMS, like the State Children’s Health Insurance Plan and the Early Periodic Screening, Diagnostic and Treatment benefit in Medicaid, is designed to provide services to children, specifically children with special health needs. It is highly questionable that the managed care plans will provide the necessary and qualified providers and services these children need. Instead, knowledgeable medical directors advise that the children should remain with current health providers who know the children, their families and complex special needs.

It is unconscionable that even after a U.S. District Court ruling, the State of Florida and Governor Scott continue to evade their legal responsibilities to ensure access to care for children as required by law. I urge HHS to exercise your oversight and enforcement authority now to address the matter. I strongly advise that you work with medical directors at FLCMS, pediatricians, dentists and advocates to hold Florida officials’ feet to the fire to ensure pediatric providers receive the reimbursement they are entitled to and most importantly, that children receive the care they deserve. If you have any questions or comments, please do not hesitate to contact me or my Legislative Director, Elizabeth Brown, at 202-225-3376.

Sincerely,

A handwritten signature in blue ink that reads "Kathy Castor". The signature is written in a cursive style with a large, stylized "K" and "C".

Kathy Castor
U.S. Representative
Florida – District 14

cc: Andy Slavitt, Acting CMS Administrator
Victoria Wachino Director for the Center for Medicaid and CHIP Services

August 20, 2015

Celeste Philip, MD, MPH
Deputy Secretary for Health
Deputy State Health Officer for CMS
Florida Department of Health

Jordan L. Rutledge, MPH
Accreditation Specialist, Health Plans
Accreditation Association for Ambulatory Health Plans
5250 Old Orchard Road, Suite 200, Skokie, IL 60077

Dear Dr. Philip and Ms. Rutledge:

We are writing to provide input about the Florida Children's Medical Services (CMS) upcoming accreditation site visit. Pediatricians and pediatric specialists who have spent years caring for Florida's children with special health care needs through CMS are alarmed at the vast changes that have taken place since CMS has set out to operate as a specialty Medicaid Managed Assistance (MMA) plan. These changes have resulted in a significant decrease in access to care for these vulnerable children. In reviewing the Accreditation Association for Ambulatory Health Care (AAAHC) web site we found the following statement: "Whether you're anticipating a surgical procedure, selecting a pediatrician for your newborn, or something in-between, you expect safe, high-quality care. The AAAHC certificate of accreditation is a sign that a health care organization meets or exceeds nationally-recognized Standards." We are concerned that Florida CMS no longer provides the high quality care that it once did; and that the granting of accreditation may be misleading to parents of children with special health care needs.

Florida statutes have mandated that the State's CMS become an MMA, and we recognize and support the need for accreditation, to continue to meet both the needs of our medically complex children and national quality measures. Unfortunately, the knowledge and experience on how to do so are being discarded.

We question the wisdom of granting the Florida CMS accreditation without an open and frank discussion of these and other issues with physicians and other healthcare professionals who have the knowledge, expertise, and experience required to serve these most vulnerable children and maintain a system of care to do so.

We are seeking the opportunity to enter into substantive discussion with the leadership of Florida CMS and the AAAHC site visit team to ensure the future of an excellent system of care for medically complex children and youth. We also seek reinstatement of the statewide network of Primary Care Programs, Medical Homes, and meaningful programmatic involvement of all CMS Regional Medical Directors.

Thank you in advance for your consideration. We seek the opportunity to advance the commitment to medically vulnerable children, the highest quality of care, and continued innovation that has been the established history of CMS over the past 40 years. A detailed list of our concerns is attached.

Sincerely,

(Signatures begin on Page 2, in alphabetical order.)

Page 2 August 20, 2015 letter to Celeste Philip, MD, MPH and Jordan Rutledge, MPH

Patricia Blanco, M.D.
Medical Director, Southwest Florida Region, Sarasota

Susan M. Cross, M.D.
Medical Director, Tallahassee Big Bend Region

Donald Fillipps, M.D.
Primary Care Medical Director, North Central Florida Region, Gainesville

Jeffrey Goldhagen, M.D.
Primary Care Medical Director, North Central Florida Region, Jacksonville

Timothy C. Gompf, M.D.
Assistant Medical Director, Tampa Bay Region

Lynn M. Keefe, M.D.
CPT Medical Director, Northwest Florida Region, Niceville

William Knappenberger, M.D.
Assistant Medical Director, Central Florida Region, Viera

Rex Northup, M.D.
Northwest Florida Regional Medical Director, Pensacola

Ayodeji Otegbeye, M.D.
Medical Director, Central Florida Region, Orlando

John Ritrosky, Jr., M.D.
Medical Director, Southwest Florida Region, Ft. Myers

Barbara Rumberger, M.D.
Medical Director, Southwest Florida Region, CMS Medical Foster Care Statewide Consultant, CPT
Medical Director, Collier County

Mary E. Seay, M.D.
Assistant Medical Director, Tallahassee Big Bend Region

Julia R. St. Petery, M.D.
Assistant Medical Director, MFC Medical Director, Tallahassee Big Bend Region

Jennifer Takagishi, M.D.
Assistant Medical Director, Tampa Bay Region

(Time constraints precluded the inclusion of additional signatures.)

(Electronic copies of all original signatures are available.)

Detailed Concerns Regarding The Accreditation of Florida Children's Medical Services

1. There is currently a moratorium on new admissions to CMS. This is especially concerning for those children for whom CMS provides the only available comprehensive system of care able to handle these children's unique problems. For example, newborns born to HIV positive mothers need immediate treatment if they are to have any hope of not developing a fatal disease. CMS has the only comprehensive program for these children, yet these vulnerable children are refused admission to CMS during this moratorium.

2. All of the approximately 60,000 current CMS children are undergoing a re-screening process in which their eligibility is being reevaluated. That re-screening process began in May of this year, and is slated to continue through the end of this month and is reported as the reason for the current moratorium on new admissions to CMS. No clinically significant reason has been provided for the need to re-screen all children over such a short time frame, which in turn has resulted in an inappropriate hold on new admissions, and has needlessly delayed the enrollment of many new and deserving CMS children and has placed many of these children at significant risk.

3. The current re-screening process is flawed (see #4, below) and has thus resulted in almost one fourth of eligible CMS children being screened out. Those screened out are required to enroll in one of Florida's "regular" MMA plans. These "regular" MMA plans are ill-equipped to care for children with special health care needs. These "regular" MMA plans are deficient in nurse case managers with the expertise to case manage special needs children, and these plans are often deficient in primary and specialty care physician panels appropriate for special needs children.

4. The re-screening process is flawed (see #3, above) in that it uses a copyrighted nationwide screening tool (the Children with Special Health Care Needs (CSHCN) screener) designed to identify such children using a series of 5 questions which the child's parent answers. An extensive review of the CSHCN screener has been carried out, including a lengthy telephone discussion with Christina Bethell, PhD, MBA, MPH, one of the authors of the screener. As designed, a child "screens in" if the parent answers "yes" to any of the 5 questions. Additional information obtained from the child's medical team is used to validate that decision. Dr. Bethell pointed out that 1 of the 5 questions (question 3) was added in order to capture a very small number of children with special needs (1.9%) who would be missed if only the other 4 questions were used. However, Florida CMS requires that the parent answer yes to question 3 **and** at least one additional question. In addition, the child's medical team has no input into the final decision. Thus, it would appear that this inappropriate application of the CSHCM screener is actually designed to screen currently eligible children **out** of CMS. This flawed methodology has to date resulted in the loss of CMS sponsorship for approximately one quarter of currently eligible CMS children.

5. According to the accreditation application, the CMS Governing Body has neither a pediatrician nor a physician with knowledge of children with special health care needs. This is despite the fact that the CMS statute requires that there be a central office physician with expertise in children with special health care needs.

6. By Florida Statute, each local CMS region has a Medical Director, who is a pediatrician with extensive experience in dealing with children with special health care needs, and who is knowledgeable about the specific services available to CMS children in that geographic region. Prior to the establishment of the Governing Body, the CMS Medical Directors had quarterly meetings with the CMS central office staff.

Since the move to establish an MMA, CMS Medical Director meetings have been abolished. The narrative in Florida's Title V Annual Report for 2014 speaks to the Medical Directors meeting each quarter to discuss "program direction", "emerging issues facing children with special health care needs" and "health delivery systems". (See MCH Title V Block Grant 6/27/13, p 5) The 2015 Title V narrative reflects a striking decrease in the involvement of the CMS Medical Directors in CMS program direction. There is no discussion of Medical Directors or Medical Director meetings under public input. The only Medical Director participation was on 3 workgroups chaired by CMS Nursing Directors. (See MCH Title V Block Grant 7/28/15, pp 14-15 and pp 86-87).

7. The summary termination of all but 2 of the CMS Primary Care Programs with no discussion or explanation, effective September 30, 2015.

8. Preventing the CMS Cardiac Technical Advisory Panel from performing site visits that have historically assured standards of excellence for the pediatric cardiovascular programs in Florida.

9. Termination, without discussion, of the statewide leadership of the CMS Child Protection Team (CPT).

10. Underfunding of the CMS cleft lip / cleft palate multidisciplinary teams throughout the state, resulting in the closure of the majority of the teams.

11. The recent decision to eliminate from rule the standards for CMS cardiac centers that have been in place for 30 years, and that resulted in Florida CMS having a nationally recognized quality regionalized program for children with cardiac disease.

In summary, it would appear that the Governing Body is dismantling CMS with no input from the CMS Medical Directors. The CMS leadership has provided no information that this dismantling of CMS is happening:

- a) As a result of a negative evaluation of services and outcomes;
- b) In the context of a strategic plan to improve access to care and services;
- c) Due to budget constraints;
- d) Through an evidence-based quality improvement process;
- e) With the input of youth and families, and/or
- f) In consultation with professionals with expertise in the care of children with special health care needs