



MIAAP Office

106 W. Allegan
Suite 310
Lansing MI 48933
(517) 484-3013
Fax: (517) 575-6285

Contact: Sarah Ombry
Phone: (616) 550-1634
E-mail: sarah@reschstrategies.com

President

Teresa Holtrop, MD, FAAP
Wayne Children's Health
Access Program (WCHAP)
3013 W. Grand Blvd. #650
Detroit, Michigan 48202
(313) 832- 8269
tholtrop.wchap@gmail.com

FOR IMMEDIATE RELEASE

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Repeal of Affordable Care Act is Bad Medicine for Children with Life Threatening Diseases

*Members of the Michigan Chapter of the American Academy of
Pediatrics Ask Congress to Defend Patients' Access to Care*

President-Elect

Sharon Swindell, MD, MPH, FAAP
Ypsilanti Pediatrics
200 Arnet, Suite 200
Ypsilanti, MI 48198
(734) 649-1325
sswindell8286@gmail.com

Lansing, Mich. – As debate and votes are expected to continue in Washington, D.C. this week, Michigan patients, physicians and members of the Michigan Chapter of the American Academy of Pediatrics (MIAAP) on Monday met to urge members of Congress to vote against legislation repealing the Affordable Care Act (ACA).

Executive Director

Denise Sloan
106 W. Allegan
Suite 310
Lansing MI 48933
(517) 484-3013
Fax: (517) 575-6285
dsloan9@gmail.com

“Children in Michigan are among our state’s most vulnerable populations, and pediatricians work every day to protect their health and well-being,” said MIAAP President-Elect Sharon Swindell, MD, a general pediatrician practicing in Ypsilanti, MI. “The Affordable Care Act has given many children and families opportunities for more comprehensive and child-centered coverage than previously available.”

One Michigan family that benefitted from the ACA is Amanda and Thomas Ruddy of Hudsonville. Their son was diagnosed with a brain tumor, DIPG, which typically affects children. As a clinical research nurse, Amanda explored all of her options and came to the harsh realization that the only hope for her son was a clinical research trial. The ACA mandates insurance coverage for patients entering clinical trials making it possible to pursue the option. Unfortunately the tumor claimed his life in November 2016, just prior to his planned enrollment.

“The Affordable Care Act allowed us to hope for a cure because access to a clinical research trial was the only chance our son would have at survival. When our son became gravely ill, it was because of the concurrent care provision in the Affordable Care Act that we were able to put him on hospice without giving up on any other possible treatment plans,” Amanda Ruddy said. “Without clinical

(MORE)

research trials, there will never be a cure. I would hate to see another family have to endure a similar situation without the access to care we had through the ACA.”

Said MIAAP member David Dickens, MD, of Grand Rapids: “There are several provisions built into the Patient Protection and Affordable Care Act that are critically important to caring for pediatric cancer patients. At risk is access to existing care, progress towards better cures and dignified care if cure is not possible. We urge Congress to thoughtfully deliberate the unintentional negative impact that a repeal would have on our most vulnerable patients.”

Karen McEwen is another Michigan parent whose daughter, Elana, was diagnosed with a rare, incurable disease called Primary Ciliary Dyskinesia (PCD). Her most prominent fear is that as Elana ages, she won’t have access to health insurance due to her pre-existing condition.

“As a parent of a child with PCD, something that will be a lifelong battle for her, I’m worried about the future of our healthcare system,” McEwen said. “Denying coverage for pre-existing conditions or putting medical limits on people with chronic illnesses will financially ruin us and families like ours.”

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The Michigan Chapter of the American Academy of Pediatrics promotes the health, safety and well-being of children and adolescents so they may reach their full potential. The Michigan AAP accomplishes this by addressing the needs of children, their families, and their communities, and by supporting Chapter members through advocacy, education, research, service, and improving the systems through which they deliver pediatric care.