

March of Dimes Foundation

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Jim Mayhew
Office of Consumer Information and Insurance Oversight
US Department of Health and Human Services
Hubert H. Humphrey Building, Room 445-G
200 Independence Avenue, SW
Washington, DC 20201

Attention: OCIO-9994-IFC

August 11, 2010

Dear Mr. Mayhew,

The March of Dimes Foundation submits the following comments in response to the Interim Final Rule (IFR) regarding “Patient Protection and Affordable Care Act: Preexisting Condition Exclusions, Lifetime and Annual Limits, Rescissions and Patient Protections,” published by the Internal Revenue Service, Department of the Treasury; Employee Benefits Security Administration, Department of Labor; and Office of Consumer Information and Insurance Oversight, Department of Health and Human Services. The March of Dimes Foundation is a unique collaboration of scientists, clinicians, parents, members of the business community, and other volunteers affiliated with 51 chapters in every state, the District of Columbia and Puerto Rico. The Foundation’s mission is to improve the health of women of childbearing age, infants and children by preventing preterm birth, birth defects and infant mortality. The March of Dimes is pleased to express support for the insurance reforms in this rule, and to identify specific components of the rule that could be strengthened to ensure better health coverage is available to women of childbearing age, infants and children.

Pre-existing Condition Exclusions

The March of Dimes has long opposed the practice of pre-existing condition exclusions and is particularly pleased that children are the first population to benefit from the new prohibition of this practice. The Foundation supports the policy put forth in the rule that prohibits not just an exclusion of coverage of specific benefits associated with a preexisting condition, but also prohibits a complete exclusion from a plan or coverage based on a preexisting condition. This policy will help make health insurance more accessible to children with special healthcare needs, such as those born preterm or with a birth defect, who have previously been shut out of the private insurance market. However, the Foundation is concerned that the rule may still permit an insurer to impose an excessively long waiting period on a child with a preexisting condition. For

an infant or child who needs prompt medical care, an unreasonably long waiting period for coverage could be tantamount to an outright denial of coverage. The March of Dimes urges the agencies to modify the rule to address this potential problem.

Annual Limits

As an organization whose volunteer base includes many families whose children have complex and ongoing medical needs, often resulting from preterm birth or birth defects, the March of Dimes has long had serious concerns with the practice of imposing annual dollar limits on coverage. The Foundation understands that due to concerns of market disruption and steep premium increases, Congress chose to phase out annual limits rather than prohibit them immediately. However, we have serious concerns that the first year annual limit restriction set forth in the regulation, \$750,000, is too low for families whose children have serious medical needs, such as those resulting from preterm birth, birth defect, or other complications requiring a lengthy stay in a neonatal intensive care unit (NICU), surgeries or other costly treatments. The following examples from March of Dimes volunteer families illustrate the need for the annual limit restriction to begin at a higher threshold than \$750,000. The first set of examples are families whose child reached medical costs above that limit during just a NICU stay:

- In Texas, Kelly's twin boys were born at just 24 weeks gestation weighing 1 pound 9 ounces each. They spent almost 5 months in the NICU and each surpassed \$750,000 within the first few months of their stay
- Natalie was born in Dallas, Texas at 25 weeks, weighing 17 ounces. She was in the NICU for 104 days during which time she required services to breath, eat and maintain 'normal' body functions like stable blood pressure. The costs incurred during that period exceeded \$1 million.
- Katelyn, from Leesburg, Virginia, was born at 25 weeks and weight less than one pound. During her 5 month stay in the NICU she underwent heart surgery, along with treatment for infections and lung problems. Her medical costs for her hospital stay were over \$1 million.
- In Texas, Haley was born at 26 weeks and weighed only 2 pounds 8 ounces. She had to stay in the NICU for several months, receiving treatment for respiratory problems and a brain bleed. Her medical costs for her NICU stay were over \$1 million.

This set of examples shows families who reached total one year medical costs above \$750,000 in the first year of a child's life, including NICU stay and other costs:

- In Houston, TX, Mason was born at 37 weeks gestation and with Pfeiffer's syndrome--characterized by the premature fusion of certain bones of the skull, which prevents further growth of the skull and affects the shape of the head and face. He was in the NICU for 37 days and required numerous surgeries. In his first year of life, his medical bills were well over \$1 million.
- Twins Jake and Josh, also in Texas, were born preterm and had to stay in the NICU for 200 days, at a cost of \$2000 per boy, per day. With additional costs for surgeries and transfusions, their medical costs for their first year of life were over \$1 million each.
- Devra's twin boys, Sam and Eli, were born at 24 weeks, 6 days, weighing in at 1 pound 7 ounces and 1 pound 9 ounces. Sam, the more medically compromised of the two, was in

the NICU for 9 months and required 7 surgeries. He came home on oxygen and required 80 hours a week of nursing care. Medical costs for his first year of life were over \$2 million.

- In Virginia, Heather's son Christian was born preterm and required extensive NICU care. His total medical costs for his first year of life were \$1.8 million.
- In Maryland, Justin was born at 25 weeks with Downs Syndrome, required medivac transportation to a children's hospital and stayed in the NICU for 90 days. His NICU stay alone cost \$950,000, and his first year medical costs (including specialists' visits, lab work, radiology, etc.) totaled \$1 million.
- A Florida volunteer delivered her baby at 28 weeks. The infant had to stay in the NICU for just over 8 weeks, and that stay alone cost \$800,000. Bills from the neonatologist, ophthalmologist, pathologist, radiologist and other specialty services cost an additional \$160,000.
- Another Florida family delivered twin boys at 28 weeks. The boys had to stay in the NICU for 9 weeks, and both required surgeries. Their total medical expenses for their first year of life were \$1 million each.

Most of these children are now healthy and thriving, thanks to the medical care they received. However, if these families faced an insurance policy with an annual dollar limit on benefits of \$750,000, they would have struggled to afford the care their children required. For families in these situations, they may face the impossible choice of bankruptcy or being unable to afford life-saving care for their children. The March of Dimes recognizes that it is rare for a family to face such extremely high medical costs for the care of a child. However, for a child born very prematurely, this costly medical treatment is not that unusual. In these situations, the care is necessary and far too expensive for a family to shoulder without insurance coverage. The Foundation urges the Departments to revise the regulation on annual limits to accommodate the needs of families like these.

The March of Dimes recognizes that even with a revision to accommodate many more families whose children require costly medical care, some families may still reach their annual limit. In these situations, Medicaid is often the "payer of last resort" and the only place for a family to turn for help in accessing needed health care services for their child. The Foundation recommends that the regulation be revised to require that families be notified that they are approaching their annual limit and that they also be informed that their child may be eligible for Medicaid and provided information on how to apply.

Choice of Health Care Professional

The March of Dimes recognizes that children have health care needs that differ from those of adults, and as such the Foundation supports the policy requiring insurance plans to permit the designation of a pediatrician as a child's primary care provider. However, for children with significant medical needs, a traditional pediatrician may not be the most appropriate designee. For example, a child with significant respiratory problems may see his pediatric pulmonologist more regularly than his general pediatrician, and his pediatric pulmonologist may in fact become the provider who regularly coordinates his care. In such a situation, the child's family, in consultation with their providers, should be able to select as the primary care physician the

provider who most often interacts with their child and whose expertise is most appropriate for the ongoing care that the child requires. The March of Dimes suggests that the regulation be modified to clarify that in the instance of child with special health care needs, a plan must allow a family to designate a pediatrician, pediatric sub-specialist, or other specialist handling the child's care as the child's primary care provider.

Once again, the March of Dimes thanks you for working quickly to implement these new provisions which take significant steps forward in helping children and their families access needed health care. We hope the Departments will find our comments useful as you work to further refine the regulation. All of us at the Foundation look forward to continuing to work with you on ongoing efforts to implement the Patient Protection and Affordable Care Act.

Sincerely,



Marina L. Weiss, Ph.D.
Senior Vice President, Public Policy
and Government Affairs



