

Marshall L. Summar, MD, Chief, Genetics and Metabolism Margaret O'Malley Professor of Genetic Medicine Children's National Medical Center

Dr. Summar is internationally known for his pioneering work in caring for children diagnosed with rare diseases. He joined Children's National in 2010 from Vanderbilt University. At Children's National he leads the Division of Genetics and Metabolism, currently the largest clinical division in the world seeing over 7000 patients a year with rare diseases. He also directs the Clinical Research Center and is Vice-Chair of Special Projects. Dr. Summar's laboratory works on both devices and treatments for patients with genetic diseases and adapting knowledge from rare diseases to mainstream medicine. His work has resulted in new drugs in FDA trials for patients with congenital heart disease and premature birth. His laboratory is best known for its work in the rare diseases affecting nitrogen and ammonia metabolism. Dr. Summar has also organized and led a large number of international work groups to develop standards of care and treatment for rare diseases resulting in significant improvements in outcomes. Dr. Summar developed a program with NIH where very young children can benefit from NIH research programs at Children's National. Dr. Summar is board-certified in Pediatrics, Clinical Genetics, and Biochemical Genetics and has been listed with Best Doctor's in America since 2004. He serves on the board of directors of the National Organization of Rare Diseases and the Society of Inherited Metabolic Diseases. He directs the National Organization of Rare Diseases Scientific Advisory Committee and is spearheading an effort to develop national standards for families to collect information about poorly understood rare diseases affecting 25 million Americans. He is very active in newborn screening issues developing testing and followup systems.

## **Committee on Energy and Commerce**

U.S. House of Representatives Witness Disclosure Requirement - "Truth in Testimony" Required by House Rule XI, Clause 2(g)

1.	Your Name: Marshall Lynn Summar				
2.	Are you testifying on behalf of the Federal, or a State or local government entity?		Yes	No x	
3.			Yes x	No	
4.	Other than yourself, please list which entity or entities you are representing: National Organization of Rare Diseases (NORD)				
5.	. Please list any Federal grants or contracts (including subgrants or subcontracts) that you or the entity you represent have received on or after October 1, 2011: none				
6.	If your answer to the question in item 3 in this form is "yes," please describe your position or representational capacity with the entity or entities you are representing: Board of Directors Member, Scientific Advisory Committee Chair				
7.	If your answer to the question in item 3 is "yes," do any of the entit disclosed in item 4 have parent organizations, subsidiaries, or partnerships that you are not representing in your testimony?	ies	Yes	No x	
8.	contracts (including subgrants or subcontracts) that were received by the entities listed under the question in item 4 on or after October 1, 2011, that exceed 10 percent of the revenue of the entities in the year received, including the source and amount of each grant or contract to be listed: none				
9. Please attach your curriculum vitae to your completed disclosure form.					
Signature:Date:_7/7/2014					