OBAMA-BIDEN TRANSITION PROJECT

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To: Alta Charo, Francis Collins, Greg Simon, and Harold Varmus
Members, NIH Obama Transition Team

From: NASPGHAN (The North American Society of Pediatric Gastroenterology, Hepatology, and Nutrition) and CDHNF (Children's Digestive Health and Nutrition Foundation)

Date: January 5, 2009

Thank you very much for your email of December 30, 2008 ("NIH Transition Team invites your perspective") soliciting our input as to "specific NIH issues that you think we should know about, and that are not captured by these summaries" (e.g. recommendations from FASEB, AAU, Research America, PhRMA and the Ad-Hoc Group for Medical Research.) We are in strong agreement with all of these documents but we are concerned that not a single one emphasized the importance of research with a pediatric focus. Our organization, which was founded in 1973, represents ~1500 pediatric gastroenterologists in North America. Thus we have the perspective of one of the oldest, largest, and most proactive of the pediatric subspecialty organizations. We believe that there are three major issues unique to the health and welfare of children where the NIH could and should play a major role:

1) One of the major issues faced by all physicians who care for patients < 18 years of age is the dearth of properly done, randomized controlled pediatric trials for many of the drugs we give children every day - this is despite the various congressional rulings providing incentives to pharmaceutical companies to test drugs in children. In general, pharmaceutical organizations have "gotten around" congressional mandates to test new drugs in children by doing small scale uncontrolled, short term trials in pediatric subjects. NIH funding is the only mechanism for doing proper trials comparing drugs manufactured by two different pharmaceutical industries and performing the long-term follow up studies so crucial in young subjects.

2) The second issue is inadequate funding for support of research in diseases which either present uniquely in childhood or which affect children disproportionately. The following specific research areas were presented by our Society to the Digestive Diseases Interagency Coordinating Committee in December 2001, and funding for them is still urgently needed: These priorities include: animal models, preventive and therapeutic interventions, tools for diagnostic and population screening, developmental physiology and pathophysiology, relationship of nutrient intake and development, secretion and diarrhea, mechanisms of cellular differentiation, proliferation, restitution, and repair; acid peptic disease, transplantation, obesity and nutrition, impact of childhood malnutrition, microbial flora, immune system, allergy and immunology

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3). The third issue, closely related to the above two issues is the critical shortage of pediatric clinician scientists - both in our own subspecialty and in other pediatric subspecialties as well. For example, although there are ~ 1000 board-certified pediatric gastroenterologists and ~70% of these hold full-time academic appointments, only 12 percent of pediatric gastroenterology time is spent in research. Approximately 12 percent of gastroenterologists receive some Federal funding for research, which on the average supports only 22% of salary needs. Only 10 percent of pediatric gastroenterologists spend more than half their time in research and a mere 3 percent spend more than three-quarters of their time in research. Improving funding for scientifically valid research could have a major positive impact on increasing the numbers of talented individuals who choose to become pediatric clinician scientists.

A review article published last month in Pediatric Research nicely summarizes the problem of the negligible proportion of the NIH budget devoted to the pediatric research portfolio. (Pediatr Res. 2008 Nov; 64(5):462-9.) According to the abstract: "This review article examines the National Institutes of Health's (NIH) overall budget and its pediatric research funding across three time periods: predoubling [fiscal year (FY) 1992-1997]; doubling (FY 1998-2003); and postdoubling (FY2004-2009). The average annual NIH appropriations increased by 5.4%, 13.4%, and 1.3% in each period, respectively. The average annual pediatric research funding (actual grants, contracts, intramural research, and other mechanisms of support) increased much less, by 4.7%, 11.5%, and 0.3% in each period, respectively. Between FY 2004 and FY 2007, the average NIH budget increase has nearly flattened, to only 1.96%. During this period, average pediatric research funding has dropped markedly lower, to 0.57%; estimated FY 2008 pediatric funding is at negative 0.5%."

We firmly believe that the opportunity for productive years of life saved in children is far greater than in adults. In the post genomic era, pediatric populations offer an especially powerful advantage in the study of genetic and multigenic determinants of disease because they are typically early in the course of disease, relatively free of treatment effects, relatively free of accumulated environmental factors, and have fewer co-morbidities. We very much appreciate the opportunity to present our concerns for consideration by the NIH Obama Transition Team and we look forward to a climate of improved NIH support for research to benefit the health and welfare of children.