



December 15, 2015

Mustafa K. Khokha, M.D.  
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Dear Dr. Khokha:

Thank you for writing to Dr. Francis Collins and Institute and Center Directors at the National Institutes of Health (NIH) to share your group's white paper outlining the importance of birth defects research and children's health. As the Acting Director of the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD), which led the Trans-NIH Structural Birth Defects Working Group, I was asked to respond to your message.

Fifteen years ago, the NICHD created the Birth Defects Initiative to foster interactions between basic scientists and clinicians who have a common interest in birth defects. Since interest in birth defects research involves many Institutes and Centers (ICs) at the NIH, a Trans-NIH Structural Birth Defects Working Group was established to better coordinate efforts among ICs. When the Gabriella Miller Kids First Common Fund Working Group was created to implement the funds appropriated by Congress to carry out the Gabriella Miller Kids First legislation, it made sense for the trans-NIH group to become the core of the new effort. The Kids First Data Resource will enhance the tools available for the structural birth defects research community and will be helpful in developing an ongoing resource upon which additional initiatives can be built. Your white paper has been sent to all the members of this group, who will provide the point of entry at NIH for researchers interested in additional initiatives in the area of birth defects research.

The NIH will host a workshop in April, 2016, to seek community input specifically on the development of the Kids First Data Resource. The goal is to seek advice and guidance from across the structural birth defects and pediatric cancer communities as to potential uses for the data that will become available. Bioinformatics and data specialists also will participate to provide practical input on how best to accomplish these goals.

In addition, the 11<sup>th</sup> Structural Birth Defects Meeting is being organized for April 3-5, 2017, by a steering committee composed of researchers who span the spectrum from basic to clinical science, with input from community leaders who recognize the need for research on birth defects. With these important planning efforts underway, the timing of your white paper was excellent, and I hope we can continue to call upon you and others in the research community as we move forward on this important area.

Thank you again for writing to the NIH, and for sharing your thoughts with us. Please share this with your colleagues that signed the letter.

Sincerely,

/s/

Catherine Y. Spong  
Acting Director, NICHD