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Dear Sir/Madam,

I am writing to invite you and/or your child to participate in a new initiative here at the Sanford Children's Health Research Center (SCHRC) which is part of Sanford Health in Sioux Falls, SD. The newly established SCHRC shares a unique partnership with the Sanford-Burnham Institute for Medical Research (La Jolla, CA), as well as national and international research relationships through Sanford Children's Hospital. The mission of the SCHRC is to develop translational research for rare diseases to drive the development of new therapies from discoveries made in research labs by integrating basic science with clinical practice, a so-called "bench-to-bedside" approach.

Many new developments in the diagnosis and treatment of human disease are the result of research that involves the collection and analysis of medical records of patients with a certain disease or condition. Unfortunately, one major limitation for research on rare diseases is the relatively small number of patients from which study participants can be recruited. As you may be aware, a rare disease is considered to affect less than 200,000 individuals in the US, although many rare diseases number in the low thousands, hundreds, or even only a handful. The small number of patients can cause problems in identifying common themes in disease, and presents challenges in the identification of individuals eligible and interested in participation in clinical trials.

In an effort to achieving the aforementioned new development and further understanding of rare disease we have established the **Coordination of Rare Diseases at Sanford (CoRDS)** registry. The purpose of the CoRDS registry is to facilitate research on rare diseases by providing a resource through which researchers can screen for prospective study participants. Any researcher in the United States who is actively engaged in research on a rare disease would have access to this registry following consultation with a CoRDS advisory panel. This will help accelerate rare disease research by providing a readily available registry of patients who may be eligible for participation in future clinical trials.

To begin the enrollment process, please complete the attached postcard and email to [cords@sanfordhealth.org](mailto:cords@sanfordhealth.org) For more information, please visit our sites: [www.sanfordresearch.org/CoRDS](http://www.sanfordresearch.org/CoRDS) and 'Sanford CoRDS' on Facebook and Twitter

Sincerely,

A handwritten signature in black ink that reads "DA Pearce".

David A Pearce

**Dedicated to the  
Work of Health  
and Healing**