

CoRDS Registry

Coordination of Rare Diseases
at Sanford



While rare diseases rank low on the everyday list of worries for the average American, 1 in 10 have been diagnosed with a rare disease, which is a staggering 30 million people. Over 50% of rare disease diagnoses affect children. In healthcare, the lack of access to information on rare diseases is one of the largest hurdles we face as a nation. On average, it takes 7.6 years to diagnose a rare disease. During this time, a patient may see eight or more physicians and receive 2-3 different diagnoses (Rare Disease Impact Report, 2013). This cycle creates a significant impact associated with an increase in cost to patients, healthcare institutions, insurance providers, and tax payers.

Our goal at the Coordination of Rare Diseases at Sanford (CoRDS) is three-fold: (1) Assemble contact registries, (2) generate standardized datasets through common data elements (CDEs), and (3) curate disease-specific databases on rare diseases. We offer the only cost-free rare disease patient registry service. We provide comprehensive database support from the build, maintenance, management and regulation in order to create a registry unique to each rare disease. Additionally, we collect and maintain basic CDEs and contact information for anyone with a rare disease. We are regulated through the CoRDS Scientific Advisory Board (SAB) and Sanford Health's Institutional Review Board (IRB).

The CoRDS Registry spans 292 rare diseases and is comprised of 20 rare disease patient advocacy groups (PAGs), most of which represent ultra-rare diseases and participants in all 50 states. These PAGs are typically established by parents and family members of individuals with a rare disease who have very limited resources and time. Whenever we engage potential partners we are received with a fair amount of skepticism. We commonly hear "this is too good to be true," or are asked "what's in it for you?"

This public service is much more than a tool to increase society's knowledge and understanding of rare diseases. We offer our participants and their families hope. The CoRDS Registry acts as a safety net to support those who may have been recently misdiagnosed or who remain undiagnosed. The hope is that CoRDS is able to reduce the sense of isolation and hopelessness that many of these patients experience. Our Patient Enrollment System (PES) has already shown the potential to serve as a resource for physicians and researchers. Meeting the aims of the CoRDS Registry is increasing our knowledge of rare diseases.

With your continued support of legislation that increases the amount of available federal funding for research institutes like Sanford Research, we can begin to overcome this hurdle. Sanford Research studies nearly 100 rare diseases and has doubled the amount of Federal funding received for research activities since 2010 (\$6.1 million to \$13.4 million, see Fig. This research has a significant impact on the local and national biomedical industries. With additional resources, this success could be replicated through CoRDS. CoRDS currently receives the majority of its funding internally, limiting its growth potential.

With increased research into rare diseases, there has been a steady increase in the number of medications developed to treat rare diseases. "Orphan drug sales will make up 19% of the total share of prescription drug sales by 2020, totaling \$176 billion and they'll grow at an annual rate of nearly 11% per year through the end of the decade, compared with about 4% for drugs treating larger populations." (EvaluatePharma's Orphan Drug Report 2014).

CoRDS hopes to bridge the gap between pharma, research, and rare disease patients. The missing pieces of the puzzle include: the need to increase awareness of our registry's resources, provide funding to researchers, and to collaborate with commercial entities. CoRDS acts as the buffer between these three polarizing entities with a strong commitment to accelerating research for pharmaceutical, biomedical, and healthcare industries, always keeping the best interests of the participants first.

The CoRDS Registry has already contributed to this trend. Supporting legislation which supports and advances our private healthcare systems' ability to serve their patients will no doubt be a significant contributor to our nation's economy for decades, even generations, to come.

You hold a piece to the puzzle. Thank you.

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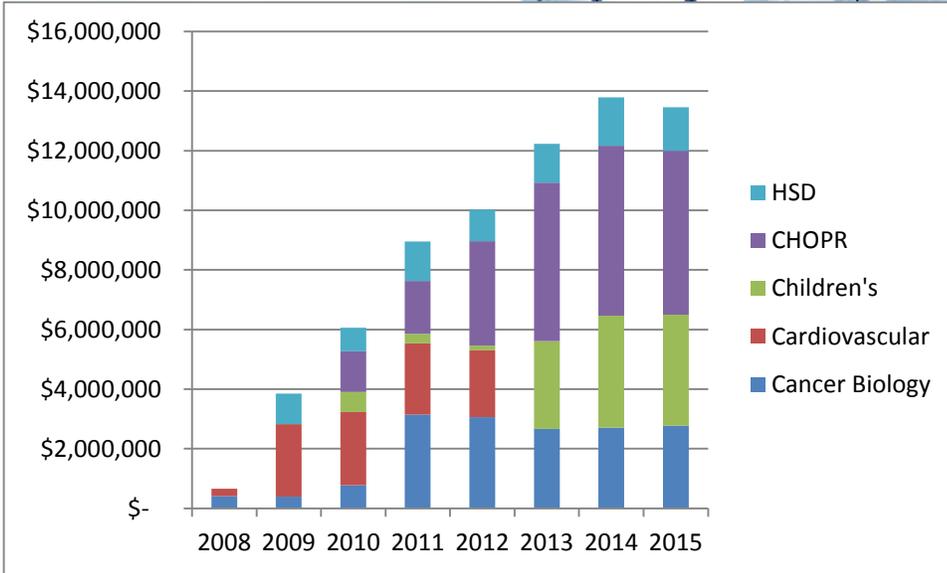


Figure 1 Total Federal Grant Funding for Sanford Research

