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Innovation Hearing – Outside Witness Testimony
FullCommittee@appro.senate.gov
U.S. Senate Committee on Appropriations
FY15 Hearing: Driving Innovation through Federal Investments

Dear U.S. Senate Committee on Appropriations:

Thank you for considering our testimony for the hearing “Driving Innovation through Federal Investments.” Our non-profit helps patients with autoinflammatory diseases, which are rare genetic conditions that affect patients throughout their lives. Many of these syndromes have been recently classified, or their genetic cause found in the past 10-15 years. The National Institutes of Health (NIH) NIAMS and NGHRI divisions have led the way in helping to classify some of these diseases, find the genetic causes for a number of them, and provide clinical trials for medications to treat these diseases. They are exceptional researchers, and need more funding to do even more amazing work that can also help many other, more common diseases, in addition to these rare diseases.

I am not only the president of this organization for these diseases, but I am also a pediatric RN, and a parent of a child that has a rare, challenging autoinflammatory disease. The **Translational Autoinflammatory Disease Section of NIAMS at the NIH** has made a huge difference for not only my son, but many other patients, and they are in great need of more research funding and support. Without this research, my son, and many patients with these diseases from the US, and around the world would go untreated, and are at risk of dying without the care and treatment at the NIH for autoinflammatory diseases. It is often the only hope for these patients, especially for some conditions that this team at the NIH is the only center in the world doing clinical trials with medications.

The NIH overall needs more funding, but I wanted to draw special attention to the needs of **NIAMS, NGHRI** and especially the **Translational Autoinflammatory Disease Section of NIAMS**, because these diseases need more research attention in the US, and globally. NIH research funds are the best way to help find causes, and innovative treatments for these diseases, and this division at NIAMS is a leader.

Funding is tight. Limited funds greatly affect this division of NIAMS to start research for more diseases, do extensive genetic testing for more undiagnosed patients and diseases, to help train the next generation of researchers, and also take on new patients that are in desperate need of treatment at the NIH. They receive a very small portion of the research funds for the NIH, but they are still doing ground-breaking work that makes a huge difference. **Imagine what more funding could do!** We need to build a stronger program in the US for these diseases, and also more centers of reference with the NIH to treat patients across the country. The research for these diseases can greatly benefit the understanding of inflammation that affects more common diseases, such as heart disease, diabetes, and other conditions. Thank you.

Sincerely,

Karen Durrant RN, BSN-President and Founder of the Autoinflammatory Alliance

