

July 7, 2009

The Honorable Nydia M. Velazquez  
Chair,  
House Committee on Small Business  
2361 Rayburn House Office Building  
U.S. House of Representatives  
Washington DC 20515

The Honorable Sam Graves  
Ranking Member,  
House Committee on Small Business  
B-363 Rayburn House Office Building  
U.S. House of Representatives  
Washington DC 20515

Dear Chairman Velazquez and Ranking Member Graves:

The undersigned organizations write to express their support for the inclusion of rare disease research as an area of research that is deserving of “special consideration” in the Small Business Innovation Research (SBIR) program reauthorization. We applaud your efforts to develop a strong measure to reauthorize and enhance SBIR, making it responsive to research opportunities in the 21<sup>st</sup> century.

Some important research and development efforts undertaken by small businesses and focused on rare diseases have been supported by SBIR. Small research enterprises may be attracted to research that focuses on rare diseases, but they experience difficulties in obtaining support for their research and development programs. Economic difficulties coupled with the already significant financial hurdle that many small biotechnology companies face in drug development can put rare disease research at risk, however special attention from SBIR grants can help to foster significant progress in the search for treatments for these conditions.

While increased attention on rare disease research from SBIR grants stands to most benefit small biotechnology companies, the true benefit is to the patients that we represent. These individuals depend on the research and development pipeline for new therapies to extend and improve their lives, and we applaud your legislation that will create a favorable environment for support of rare disease research.

Sincerely,

Alpha-1 Association  
Alpha-1 Foundation  
ALS Association  
American Association for Respiratory Care  
American Sleep Apnea Association  
ARPKD/CHF Alliance  
AVI Biopharma  
Beyond Batten Disease Foundation  
BVVL International  
Caring Voice Coalition  
Colorado COPD Connection  
Congenital Adrenal Hyperplasia Research Education and Support (CARES) Foundation

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Costello Syndrome Family Network  
Cutaneous Lymphoma Foundation  
Cystic Fibrosis Foundation  
ECD Global Alliance  
EFFORTS (Emphysema Foundation For Our Right To Survive)  
FasterCures  
Foundation for Prader-Willi Research  
Friedreich's Ataxia Research Alliance (FARA)  
Gene Logic  
Genetic Alliance  
Hannah's Hope for Giant Axonal Neuropathy, Inc.  
Hemophilia Foundation of America  
HHT Foundation International  
Hide & Seek Foundation  
HumanGeneticDisorders.com  
Huntington's Disease Society of America  
International Myeloma Foundation  
Lymphatic Research Foundation  
MHE Research Foundation  
MLD Foundation  
Muscular Dystrophy Association  
National Alopecia Areata Foundation  
National Foundation for Ectodermal Dysplasias  
National Health Council  
National Niemann-Pick Disease Foundation, Inc.  
National Organization Against Rare Cancers  
National Organization for Rare Disorders  
National PKU Alliance  
National Tay-Sachs & Allied Diseases Association, Inc.  
NBIA Disorders Association  
Ocimum Biosciences  
OpenHelix LLC  
Pachyonychia Congenita Project  
Pediatric Adolescent Gastroesophageal Reflux Association  
Platelet Disorder Support Association  
PTC Therapeutics, Inc.  
Pull-thru Network, Inc.  
PXE International  
Sarcoma Foundation of America  
Shire HGT  
Shwachman Diamond Syndrome Foundation  
Sudden Arrhythmia Death Syndromes (SADS)  
Tesserae Genetics  
The Project: The Children's Rare Disease Network  
TransDerm, Inc.  
Trisomy 18 Foundation  
Tuberous Sclerosis Alliance  
UNICConnect LC