

Families of Spinal Muscular Atrophy Announces Major Breakthrough in Development of Drug Candidate for Currently Untreatable Disease

The First Novel Clinical Candidate for Spinal Muscular Atrophy is Selected

June 22, 2007, Libertyville, IL --Families of Spinal Muscular Atrophy (FSMA) is pleased to announce the selection of a Clinical Candidate for Spinal Muscular Atrophy through its program being conducted at deCODE chemistry. At the same time FSMA is now extending its contract with deCODE to continue work towards an Investigational New Drug (IND) application with the Food and Drug Administration. If successful, this would be the first novel drug designed specifically to treat Spinal Muscular Atrophy (SMA).

SMA is a genetic disorder with no current treatment that is the leading killer of children under two years of age. SMA is typically marked by the degeneration of voluntary muscle movement including the muscles that control crawling, walking, swallowing or breathing. This is an important step in the development of a small molecule therapeutic for this debilitating and normally fatal disease.

The lead compounds have shown the ability to extend survival in a mouse model of SMA. Due to this successful result the organizations have now been able to select a Clinical Candidate. This is the first time a novel compound specifically designed to treat SMA has reached this stage in drug development. Families of SMA has been funding and directing this particular program for the last 7 years. The total investment to date in this program alone is over \$10M.

"Selecting a Clinical Candidate means that we are now preparing to run the safety tests required to apply to the FDA to begin clinical trials. This work will require funding of \$2.5M and take almost 12 months to complete," said Kenneth Hobby, Executive Director of Families of SMA. "If we are successful in this stage we would then look to start phase I clinical trials."

"Excitingly, the program has identified drug-like compounds that act on SMA patient cells in culture to increase SMN2 gene activity and thereby the amount of functional SMN protein. The same compounds also have therapeutic benefit in a mouse model of a severe form of SMA. We are very pleased to see the project come this far," said Mark Gurney, Senior Vice President, deCODE genetics and deCODE chemistry.

"To our knowledge this is the first novel program for SMA that has reached this stage," said Dr. Jill Jarecki, FSMA Research Director. "The goal of the deCODE collaboration was to generate a final optimized compound with the required properties of an effective SMA drug, called a "Clinical Candidate". Now in May of 2007 this goal has been met. As will be reported at the upcoming FSMA-sponsored 11th Annual International SMA Group Meeting in June, our compounds prolong survival in mouse models of SMA and are very effective at crossing the blood brain barrier to reach motor neurons in the spinal cord. We are very optimistic about the potential of moving this drug to IND within the next year, and the lessons we are learning will help strengthen the SMA drug pipeline."

About Families of Spinal Muscular Atrophy

FSMA is dedicated to eradicating SMA by promoting and supporting research, helping families cope through informational programs and support, and educating the public and the medical community about SMA. The organization, originally founded in 1984 by a small group of parents, has grown to more than 32 chapters and affiliates worldwide and more than 5,000 member families. FSMA receives the majority of its funding through volunteer efforts, funding over \$30 million to date, and continues to increase its funding commitments each year with \$15 million in new research planned over the next three years. In addition, Families of SMA has funded more than \$3 million in patient support efforts.

Since its founding, FSMA-sponsored research has made significant contributions to better understanding SMA and advancing new therapies towards human clinical testing. These accomplishments include:

- Identification of a mutation in the SMN1 gene as the cause of the disease. A second copy of the gene called SMN2 produces reduced amounts of SMN protein due to a defect in splicing.
- The funding of two leading-edge drug discovery programs designed to increase functional protein production from the SMN2 gene to compensate for the loss of the SMN1 gene.
- The establishment of Project CURE SMA, a 7 center clinical trial network, which is currently testing two medications for their possible impact on treating SMA patients. This network will also serve as the conduit for future human drug trial

About deCODE chemistry, Inc.

deCODE chemistry, Inc. is a wholly-owned subsidiary of deCODE genetics (NASDAQ: DCGN) providing research services to world-class pharmaceutical companies, biotechnology companies, academic institutions, and government facilities. deCODE chemistry, along with deCODE biostructures, conducts collaborative drug discovery and development for pharmaceutical and biotechnology companies using an integrated platform of structural biology and chemistry technologies. Our services are designed to help our clients develop small molecule therapeutics with the greatest promise of efficacy, selectivity, and safety in the clinic.

For more information about FSMA visit the website www.curesma.org or call 1-800-886-1762. Media Contact: Lenna Scott, 847-975-4171