

Pediatric Neuromuscular Clinical Research Network for SMA Trials

Darryl De Vivo, MD, Director Petra Kaufmann, MD, MSc, Investigator Ira Messer, Administrative Coordinator

The SMA Clinical Research Center is part of the Pediatric Neuromuscular Disease Program at Columbia University Medical Center and a partner of the Motor Neuron Center. Fundraising is in progress to support the activities of a newly established clinic *dedicated* to the care and medical management of children living with SMA, a disease that causes the degeneration of motor neurons in the spinal cord.

Your support is critical to the continued success of the SMA Clinic

SMA is the leading genetic cause of infantile death. The range of severity is distinguished by three levels of disease. SMA Type I is the most severe and children are never able to sit independently. Their life expectancy is extremely compromised, often less than four years. Children with SMA Type II are able to sit unassisted at some point in their lives but they suffer a myriad of complications and remain weak throughout life. SMA Type III is the least severe and children with this form are able to walk but still suffer weakness and distress. The SMA Clinical Research Center offers expertise, education, resources, and guidance to all families affected by SMA.

Our mission is to:

- Provide comprehensive patient care
- Support research into the cause and cure for SMA
- Educate health care professionals
- Raise the profile and understanding of SMA to better educate everyone

Our efforts are community based and rely on support from the community, like you. Ongoing financial contributions are a vital tool that keeps our multi-disciplinary clinic and research initiative forging ahead to achieve our mission. Insurance reimbursement for our medical services is simply inadequate to sustain this comprehensive effort.

Please consider sponsoring our clinic and its endeavors.

\$5000 + Platinum supporters \$2500+ Gold supporters \$1000+ Silver supporter

\$other Friends

We acknowledge all contributions in our Spinal Muscular Atrophy Clinical Research Center Newsletter and throughout the year at meetings and events. The newsletter is available to all families involved in the SMA Clinical Research Center and the Pediatric Neuromuscular Clinic, as well as those who visit our website.

Every dollar raised will go directly towards clinical care and research advances .

Please make checks payable to Columbia University's Motor Neuron Center with 'SMA Clinic' in the memo line and send to: Ira Messer

Harkness Pavilion HP519 180 Fort Washington ave NY, NY 10032

Please include your name and number if you interested in a receipt for tax purposes.

Thank you in advance for your time and consideration for this important cause. Please feel free to contact us with any questions or for more information. To review our website, visit www.columbiasma.org. We look forward to working with you as you have now joined the commitment towards the survival and ultimate cure of

Sincerely,

children with SMA.

Darryl C. De Vivo, MD Ira Messer (212) 305-1812

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