

July 9, 2002

Dear Friend,

I wish to thank you for your request to participate in the International Spinal Muscular Atrophy (SMA) Patient Registry. This registry is coordinated by the Department of Medical and Molecular Genetics Department at Indiana University and is fully funded by Families of SMA.

The purpose of the International Spinal Muscular Atrophy Patient Registry is to provide a resource by which individuals and families affected by SMA and researchers interested in studying SMA can come into contact with one another. Investigators who are interested in SMA research need access to information concerning SMA patients and families. It is important to establish a system whereby scientists and families with SMA can get in touch with each other. The International SMA Patient Registry makes this happen.

By registering information with the International SMA Patient Registry you are in no way committing yourself to participate in any research project. Your information simply allows us to notify you of any research projects which you or a family member may qualify to participate in, should you choose to do so. Under **NO** circumstances will your name be released to a researcher without your permission. Should a researcher wish to contact a family such as yours, we would first inform you of the study and then if we receive your permission to release your name to the researcher, we will do so. It is also important to note that research studies often have multiple criteria that an individual must meet in order to participate. Therefore, you may receive letters describing research studies for which you are not eligible.

Even if you do not participate in an actual research study, the information you provide, by completing the patient questionnaire, will be coded so that it can be entered into a secured computer database and pooled with information from other individuals and families with SMA. We are then able to provide researchers with important statistical data without using names.

If you wish to participate in the International Spinal Muscular Atrophy Patient Registry, please read and sign the informed consent statement and then complete the enclosed Spinal Muscular Atrophy Patient Questionnaire and return to us by using the enclosed business reply envelope. If you have any questions or would like more information please call Connie Garland at Indiana University at (317) 274-5745 and/or Audrey Lewis at Families of SMA at (800) 886-1762. Thank you in advance for your help in this important matter.

Sincerely,
P. Michael Conneally, Ph.D.
Distinguished Professor
Department of Medical and Molecular Genetics

Please send your forms to:
SMA Patient Registry – attn. Connie Garland
Indiana University School of Medicine
Dept of Medical and Molecular Genetics
975 West Walnut St
Indianapolis, IN 46202-5251