

Nutrition is a critically important variable in the well-being of [spinal muscular atrophy \(SMA\)](#) patients, and there are many complex issues to be considered in the dietary management of an individual SMA patient. While as a community, we have made much ground toward a consensus on best practices for management of respiratory care issues, nutrition is still a relatively uninvestigated, and controversial, subject. This is an extremely important issue, particularly with regard to type I children, who are extremely fragile, and often require special attention and management of dietary issues.



ANGELS CHARITY, INC.

With support from [SMA Angels Charity](#), the Pediatric Motor Disorders Research Program at the University of Utah has launched a new website, [www.smaandnutrition.org](http://www.smaandnutrition.org) to help SMA families provide SMA researchers with information that will help them investigate the impact of nutrition on the disease and to help SMA families evaluate their current nutritional regimen. From now until June 14, we'd like to especially ask all families with [Type 1 SMA](#) patients to complete the SMA Type I Nutritional Survey, whether or not your child is on any special kind of special diet. This on-line survey should take approxi-

mately 15 minutes. The survey includes questions about feeding regimens and methods; select medications, equipment, and medical interventions; specific type of formulas regularly given to the patient; and how the diet is determined and adjusted. The short-term goal is to gather data on the frequency of use of special diets for type I children and to better identify the similarities and differences of types of special diets currently prescribed. We hope to gather information from as many possible families before June 14, and hope to present preliminary results at the FSMA meeting in June.

**\*\*Please Note:** Ideally, we'd like all participating families to fill out a detailed dietary record when they submit answers to the nutritional survey. The ultimate goal of this website is to serve as a tool to help provide feedback to families about their child's diet, resulting in a report about possible nutritional deficiencies and recommendations that you can share with your local dietician and care providers. However, depending on how many responses we get to this initial request, dietary record analysis may be delayed. During this initial launch period, we hope to assess how useful a tool this may be by assessing the interest of the community in this project. Ultimately, this project will only be successful if we get a majority of the community participating. Your participation is greatly appreciated!



We have provided a link on this site to our [nutritional guidelines for SMA patients](#) on the University of Utah School of Medicine research website. These guidelines need to be refined by real data from SMA patients. Participation in the survey requires a login and password. In order to receive login information for the website, SMA patients must be enrolled in our IRB approved research study "Clinical and Genetic Studies in SMA" which allows us to collect data about you or your child's experiences and medical issues in living with SMA. Participants or their parent/guardian must sign a consent form to allow us to contact you to ask additional questions about you or your child's medical history. It is not necessary to participate in the full study; you may elect to participate just for the nutritional part.

**To obtain a login, email [smadiet@gmail.com](mailto:smadiet@gmail.com)  
or contact the Pediatric Motor Disorders Program research office  
for more information at 801-585-9717**