

A study is being conducted at the Children's Hospital of Philadelphia to determine the costs and outcomes for metabolic disorders with initial focus on Medium-Chain Acyl CoA Dehydrogenase (MCAD) deficiency. Your participation in this cost survey (**no matter which metabolic disorder your family is affected by**) would be *extremely* helpful in establishing whether more contemporary methods and policies for newborn screening for metabolic disorders are cost-effective. This survey involves answering questions about medical costs incurred because of your or your child's metabolic disorder both pre- and post-diagnosis. Even if you or your child did not incur any medical expenses, it is important to record that information. We want to collect data on the costs incurred in the most recent full year. If more than one child has been affected in your family, we would appreciate your filling out one survey per child per year. All data collected is confidential. Please send all completed surveys **ASAP** to:

Dr. Charles Venditti
University of Pennsylvania
CRB Rm 505
415 Curie Blvd
Philadelphia PA 19104

-OR- return by fax at Dr. Venditti's attention (215) 590-3298
-OR- email: venditti@ix.netcom.com (*preferred method*)

*****SURVEY*****

Q #1	With what metabolic disorder has the affected individual been diagnosed?	(for example, MCAD, VLCAD, etc.)
Q #2	What was the affected individual's age at diagnosis?	mos/yr
Q #3	What is the affected individual's current age?	mos/yr
Q #4	Was the affected individual's disorder diagnosed by the newborn screen?	(Yes/No/Unknown)

***If the affected individual was diagnosed by the newborn screen –OR– has been diagnosed with a metabolic disorder for the entire most recent full year, please ONLY answer the POST-DX part of each question. Otherwise, if the affected individual was not diagnosed for at least some period of time during the last full year, please fill out BOTH the PRE-DX and POST-DX sections and indicate the number of months in the PRE-DX period and the number of months in the POST-DX period. For example, if your child was diagnosed with MCAD in June 2000, then you would fill out both sections when answering each question, attributing the costs of the first 6 months of 2000 to the PRE-DX category, and the costs of the last 6 months of 2000 to the POST-DX category.**

Q #5 INPATIENT HOSPITALIZATIONS • please place an answer in each applicable box

Data is for 1/00-12/00 (if child died, please indicate last full year for which data is available)	Total # inpatient hospitalizations for this year	Average # nights per hospital stay in this year (or list # days per stay for each stay)	Total out-of-pocket costs (\$) family incurred for inpatient hospitalizations in this year (including transportation/parking/lodging - if known or can be estimated)	Total amount paid (\$) by insurance for inpatient hospitalizations in this year (if known)
PRE-DX				
POST-DX				

Q #6 EMERGENCY ROOM VISITS • please place an answer in each applicable box			
Data is for 1/00-12/00 (if child died, please indicate last full year for which data is available)	Total # ER visits for this year	Total out-of-pocket costs (\$) family incurred for ER visits in this year (including transportation and parking - if known or can be estimated)	Total amount paid (\$) by insurance company for ER visits in this year (if known)
PRE-DX			
POST-DX			
Q #7 OUTPATIENT/CLINIC VISITS • please place an answer in each applicable box			
Data is for 1/00-12/00 (if child died, please indicate last full year for which data is available)	Total # outpatient/clinic visits for this year	Total out-of-pocket costs (\$) family incurred for outpatient/clinic visits in this year (including copay/transportation/parking - if known or can be estimated)	Total amount paid (\$) by insurance company for outpatient/clinic visits in this year (if known)
PRE-DX			
POST-DX			
Q #8 MEDICATIONS • please place an answer in each applicable box			
Data is for 1/00-12/00 (if child died, please indicate last full year for which data is available)	Is the affected child taking medications or supplements? If Yes, please indicate medication names.	Total out-of-pocket costs (\$) family incurred for medications in this year (including copay)	Total amount paid (\$) by insurance company for medications in this year (if known)
PRE-DX	Y/N		
POST-DX	Y/N		
Q #9 SPECIAL MEDICAL EQUIPMENT (SME) • please place an answer in each applicable box			
Data is for 1/00-12/00 (if child died, please indicate last full year for which data is available)	Does the affected child use a glucometer? If Yes, please indicate frequency.	Total out-of-pocket costs (\$) family incurred for SME in this year (if known or can be estimated)	Total amount paid (\$) by insurance company for SME in this year (if known)
PRE-DX	Y/N		
POST-DX	Y/N		
Q #10 PARENT TIME COSTS • please place an answer in each applicable box			
Data is for 1/00-12/00 (if child died, please indicate last full year for which data is available)	Total parent time devoted to accompanying child to hospital, outpatient/ clinic visits, picking up medications and SME in terms of total <u>days</u> for this year (if known or can be estimated)	Proportion of this time that was time <u>off of work</u> (for example, 10%, 50%, 100%)	
PRE-DX			
POST-DX			

THANK YOU VERY MUCH FOR YOUR PARTICIPATION!