

**FOD SURVEY RESULTS:
1999 FOD COST BENEFIT ANALYSIS RESULTS**

52 FOD Families responded to the Survey for 63 FOD Children:

2 GA2	42 MCAD
1 HMG	2 SCAD
2 LCAD	1 TPD
7 LCHAD	6 VLCAD

24 States were represented:

18 Children from the Northeast
14 Children from the South
20 Children from the Midwest
11 Children from the West/Southwest

Age at Diagnosis:

13 children at birth to 2 weeks (had the **LOWEST Total Costs and LEAST Complications** ~ unless they had an early severe episode)
18 children before 1 year old
21 children between 1 year old and 7½ years old
10 children (5 MCAD) diagnosed 3 weeks to 7 years **AFTER DEATH**
Death ~ between the ages of 4 days and 21 months old

Costs Before Diagnosis:

2 children \$400,000- \$790,000 (It took 2½ to 3 years to be diagnosed once the search for a diagnosis began/incurred major complications)
11 children \$100,000- \$399,999
6 children \$50,000- \$99,999
20 children \$10,000- \$49,999
16 children \$0 -\$9,999

Complications:

DEATH/ cardiac and liver problems/ seizures/ cerebral palsy/ coma/ motor and speech delays/ brain damage/ kidney failure/ quadriplegia/ feeding problems/ hypoglycemia/ numerous hospitalizations
(Complications occurred from a **DELAY in DIAGNOSIS** and/or from having 1 or several severe episodes ~ See Complications Data Sheet below)

Cost of Complications:

2 children	\$500,000 (Diagnosis made 19 months to 5 years AFTER birth)
2 children	\$100,000- \$200,000
6 children	\$50,000- \$99,999
5 children	\$10,000- \$49,000
13 children	\$0 -\$9,999

Insurance Coverage:

60 Children had coverage

3 Children had no coverage

2 Children were later terminated because of the FOD (An Insurance company was going to terminate one Family because the parents were FALSELY accused of child abuse because their child was sick all the time!)

(Most companies covered most of the Costs, however several families still had large out-of-pocket costs)

Summary:

EARLY DIAGNOSIS AT BIRTH NOT ONLY SAVES LIVES AND MONEY BUT IT WOULD ALSO PREVENT DEBILITATING COMPLICATIONS AND DEATH!

[Be aware that some respondents did not answer every question for various reasons]

BENEFITS of NEWBORN SCREENING for FODs

Our FOD Cost Benefit Analysis Survey results are not the first to suggest that Newborn Screening for FODs would be beneficial for families across our country, but I believe it is the first to involve over 50 FOD Families. It not only details data for MCAD, which is the most common FOD, with an incidence of approximately 1/20,000 (1 in 80 of northern European ancestry are carriers), but it also includes data for 7 of the more rare FODs.

As you can see above and in the following tables, the results STRONGLY suggest that EARLY detection and treatment as a newborn (as compared to after a child has already experienced one or several severe episodes) can save lives, prevent medical complications, and save on medical expenses.

For the most part, those **children diagnosed through Newborn Screening had LOWER COSTS and FEWER COMPLICATIONS. Overall, the infants/children diagnosed months to years AFTER birth (nearly one-half of the MCAD children and almost ALL of the children with LCHAD, VLCAD, SCAD, etc.,) incurred the GREATEST MEDICAL COSTS and COMPLICATIONS.**

Our survey results demonstrated the physical and economical costs of late detection, but one thing that could not be measured was the **EMOTIONAL COST** that many of these families have needlessly endured ~ **a cost that most likely could have been prevented if their child/children were DIAGNOSED and TREATED at BIRTH!** Instead, families are having to deal with deaths and/or an array of ongoing medical complications.

The more information on the benefits and necessity of NEWBORN SCREENING for FODs (and many other metabolic disorders) we can provide to families, physicians, insurance and hospital administrators, and other professionals involved in the well-being of children AND families, the better!

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••• **NOTE:** In the data below, the 'Total Medical Cost' = the Sum of Costs Before Diagnosis and the Cost of Complications

Also, those children diagnosed from birth to 2 weeks of age were considered under the 'Newborn Screened' category

case #	diagnosis	year sought	year diagnosed	age diagnosed	diagnosis before/after death	total medical cost	estimated/actual	complications detail
29	MCAD	1982	1988	N/A	after (6 year)	N/A	N/A	DEATH
41	MCAD	1993	1996	5 years	before	\$ 1,200,000	estimated	autism/MR/PDD/asthma/speech&behavioral problems/E seizures/enuresis/Gtsurg
42	MCAD	1995	1995	19 months	before	600,000	estimated	cerebral palsy/seizure disorder/Gtube
53	MCAD	1986	1989	4 years	before	200,000	estimated	anoxia/cerebral palsy/quadruplegia/severe disabilities
51	MCAD	1993	1994	8 months	before	123,324	estimated	coma/cerebral palsy/hypoglycemia
27	MCAD	1987	1988	18 months	before	76,263	actual	seizure disorder/speech, mental development delays/frequent illness/hypogly
44	MCAD	1998	1998	2 weeks	before	75,000	estimated	cardiomy/eni liver/seizure/brain damage/almost lost kidney function
52	MCAD	1997	1997	27 months	before	75,000	estimated	4xICU/2 mos hospitalization/brain damage/coma/seizures/aphas/aprax/leg br/tgu
28	MCAD	1997	1997	6 months	before	65,000	estimated	hypoglycemic/cardia arrest/hospitalization
39	MCAD	1998	1998	6 months	before	65,000	estimated	hospitalization
18	MCAD	1992	1993	19 months	before	63,000	estimated	coma for 1 week before diagnosis
38	MCAD	1997	1997	15 months	before	57,000	estimated	brain damage/cerebral palsy/learning disabilities
40	MCAD	1997	1997	6 months	before	56,941	actual	2 seizures/week/long coma/multilorgan failure
19	MCAD	1997	1997	13 months	before	50,000	estimated	crisis episode/hospitalization/seizure disorder/PT
54	MCAD	1994	1994	10 months	before	45,000	estimated	coma/speech and phy coord problems
43	MCAD	1995	1995	2 weeks	before	36,233	actual	none
48	MCAD	1995	1995	11 months	before	35,000	estimated	hospitalization
16	MCAD	1995	1995	2 years	before	30,000	estimated	none
33	MCAD	1996	1996	1 year	before	30,000	estimated	fluctuating sugars/lethargy/coma reactions
17	MCAD	1995	1995	22 months	before	25,000	estimated	none
15	MCAD	1992	1992	8 months	before	22,440	estimated	none
36	MCAD	1993	1993	2 years	before	20,000	estimated	none
30	MCAD	1996	1996	N/A	after	17,500	estimated	DEATH
35	MCAD	1998	1998	2 years	before	15,250	estimated	none
23	MCAD	1996	1996	2 weeks	before	15,000	estimated	none
25	MCAD	1985	1986	N/A	after (1 year)	15,000	estimated	DEATH
49	MCAD	1990	1990	2 years	before	10,000	estimated	none
26	MCAD	1985	1988	4 years	before	6,000	estimated	coma/hospitalization/seizures
13	MCAD	1994			before	5,000	estimated	none
14	MCAD	1993			before	5,000	estimated	none
24	MCAD	1986	1986	2 weeks	before	4,100	estimated	2 hospitalizations
37	MCAD	1995	1995	2 days	before	3,020	estimated	hospitalization with rotovirus
47	MCAD	1992	1992	1 week	before	3,000	estimated	none
20	MCAD	1992	1992	1 week	before	2,300	actual	2 hospitalizations
46	MCAD	1991			after	2,000	estimated	DEATH
32	MCAD	1997	1997	11 months	before	1,200	estimated	none
34	MCAD	1998	1998	10 days	before	18	estimated	none
45	MCAD	1998	1998	1 week	before	18	estimated	none
50	MCAD	1994	1994	birth	before	18	estimated	none
21	MCAD	1996	1996	1 year	before	-	actual	none
22	MCAD	1996	1996	1 week	before	-	actual	none
31	MCAD	1995	1997	N/A	after	-	actual	DEATH
total MCAD						<u>\$ 3,054,624</u>		
average - MCAD						\$ 80,385		

case #	diagnosis	year sought	year diagnosed	age diagnosed	diagnosis before/after death	total medical cost	estimated/actual	complications detail
5	LCAD	1990	1992	2.5 years	before	800,000	estimated	8 mos in ICU/128 ER admits in 4 years/c.mycopathy/respiratory arrest/seizures
62	VLCAD	1998	1998	5 months	before	500,000	estimated	cardiomyopathy/trach/Gtube/respiratory arrest/hypoglycemia/developmental delays
9	LCHAD	1991	1991	6 months	before	370,000	estimated	cardiac: arrest / fatty liver
10	LCHAD	1988	1995	7 years	before	275,000	estimated	brain damage/seizures/incontinent/re/frequent hospitalizations/hypotonia
57	TPD	1991	1998	7.5 years	before	240,000	estimated	feeding problems/muscle weakness/orthotics/wheelch/speech & developmental delays
12	LCHAD	1994	1994	10 months	before	200,000	estimated	no
59	VLCAD	1992	1992	4 months	before	150,000	estimated	collapsed lung
63	VLCAD	1989	1997	N/A	after (7 year)	131,211	estimated	DEATH
8	LCHAD	1994	1995	N/A	after (1 year)	130,000	estimated	DEATH - pneumonia, heart failure
6	LCHAD	1991	1991	7 months	before	120,000	estimated	comatose/fat infiltration of muscle, heart, liver
55	SCAD	1995	1996	8 months	before	101,887	actual	only because began Tx AT BIRTH for SCAD
56	SCAD	1995	1987	3.5 years	before	90,000	estimated	delayed muscle growth/gross & fine motor skills delay
4	LCAD	1994	1994	17 months	before	60,000	estimated	extensive hospitalizations/ICU
2	GA II	1993	1993	4 years	before	39,121	actual	no
11	LCHAD	1995	1995	6 months	before	33,000	estimated	hospitalization
7	LCHAD	1991	1995	N/A	after (4 year)	24,000	estimated	DEATH - heart and liver failure
60	VLCAD	1997	1998	8 months	after	6,000	actual	DEATH
3	HMG	1992	1994	15 months	before	5,000	estimated	metabolic crisis/acidosis/hypoglycemia
61	VLCAD	1993	1993	2 weeks	before	500	estimated	no complications but 3-month-old sibling died in 1987 - undiagnosed
1	GA II	1996	1996	birth	before	18	estimated	no
58	VLCAD	1999	1999	N/A	after (3 week)	-	actual	DEATH! 3 days before death - enlarged heart/liver/motor development delay
total other FOD's						<u>\$ 3,275,737</u>		
average - other FOD's						\$ 155,987		
total all FOD's						\$ 6,330,360		
average - all FOD's						\$ 137,617		