

Results of the 2nd JMML Foundation Family Survey, May 2007

Executive Summary

A 2nd JMML Foundation Family Survey was solicited online in May 2007 for 2 weeks. 48 people from 9 countries and 18 U.S. states completed the survey. 60% were mothers of children with JMML and 21% were fathers. 77% of the responders had a relationship with a child who was post-transplant and recovering from JMML.

24 questions were asked pertaining to educational and emotional support issues for families. Of these, the ones families rated high in both importance (>4.5 out of 5) and their experiences with them (>4 out of 5), termed “Best Practices,” were the JMML knowledge of their transplant physicians, hematologist/oncologist physicians, and nurses, as well as their ability to communicate with other families with children with JMML. The ones families rated highest in importance (>4.5) but lowest in their experiences with them (>3), noted as “Focus Areas,” were the ease in finding information about JMML and the completeness of that information, existing support for siblings and parents of deceased JMML children, and their ability to communicate with their own family.

Comparisons with 2005: Respondents in 2007 felt that nurse knowledge of JMML was significantly greater this year (4.04 vs. 3.64 in 2005) and more important (4.72 vs. 4.27 in 2005). They found it easier to find information about JMML this year than in 2005 (2.41 vs. 1.9 in 2005) and rated the completeness of information higher as well (2.77 vs. 2.33 in 2005). Support ratings for siblings of deceased children were raised this year (2.42 vs. 1.89 in 2005), as were marks for existing support for parents of deceased JMML children (2.58 vs. 2.36 in 2005). The top four focus areas were the same this year as last year. There is no information as to why there would be a marked change in the ratings of nurse knowledge, though the expansion of the Foundation website and the development of the JMML Rainbows support group may explain the other increased ratings.

10 questions were asked pertaining to financial concerns for JMML families. Respondents noted paying the highest average dollar amount for JMML children for stem cell transplants (avg \$8,313), other (\$5,347), and lodging during transplants (\$4,483). The items they noted having had to spend the greatest percentages out-of-pocket were for travel to/from medical care (60%) and supplies/toys during hospital stays (48%). The categories for which respondents reported paying the lowest average dollar amount were for respite care (avg \$183/respondent) and counseling (\$932). Spending averages could not be compared to 2005 survey results as dollar amount choices were added to this year’s survey. Noting that the “other” category was so large, the descriptions of these expenses in the comments section should be added to this question in next year’s survey. *Comparisons with 2005:* In 2005, 42% of respondents mentioned that they paid 75-100% of their total costs for travel to/from medical appointments. This agreed with the greatest percentage of out-of-pocket expenses measured this year. Overall, measurements from 2005 were not directly comparable with those of this year due to the addition of dollar amounts to this year’s survey.

In the open-ended comment section of this survey, all the same categories of comments from the 2005 survey arose with the exception of international country support, which no one commented on this time. One additional category of comment

arose pertaining to positive feedback for the Foundation. *Comparisons with 2005:* Of the 55 total comments in 2007, two-thirds of the comments fell into 3 categories: the need for more, easy-to-find, updated information (18); positive feedback to the Foundation regarding the sharing of information, website, and the support group (11); and clarifications or requests regarding financial concerns. These comments suggest that the survey is focusing on the areas that are important to families, as 5 questions pertain to information and 10 questions pertain to finances. In 2005, 71% of comments noted fell into three categories: accurate, easy-to-find, easy-to-understand, and updated information (19); physician education and connection with families (10); and financial concerns (8).

Background

The JMML Foundation Family Survey was created to support the Foundation's Strategic Plan objectives involving education and charity to the families and caregivers of children with JMML. This 2nd JMML Foundation Family Survey served two purposes:

1. To assess the Foundation's progress towards meeting the needs and desires of the people the Foundation serves; and
2. To focus the Foundation's efforts on the areas that JMML families find most important.

Methodology

A 10 question survey was created and posted to the www.surveymonkey.com website. This website was selected because of its free service, professional look, ease of use, multitude of tools, and easy accessibility for survey takers. Six of the 10 questions asked were multiple-part questions (34 subquestions total) covering the topics of educational, emotional support, and financial concerns. For each of these questions, responses were measured on a scale of one to five (five being the highest rating); importance of each measure to the individual was also measured for each question on a scale of one to five (five being most important). Three demographics questions were posed at the beginning. The final question was open-ended and asked for participants' comments on how the Foundation could best serve their needs; it also allowed people to include personal contact information if they wanted to receive have a follow-up from the Foundation. The full text of each question and summaries of all responses received are included in Appendix A of this document.

Results

Demographics Question Results

Demographic responses presented the following information regarding the people currently served/reached by the Foundation:

Geographically

- 48 people participated (34 in 2005)
 - o 2007 results:
 - o 2005 results: 29% of the number of members (116) of the JMML Support Group on Yahoo in August 2005
- Participants from 9 countries responded (6 in 2005)
 - o 2007 results: (in order of representation): 67% from US (32), 8% from UK (4), 6% from Australia (3), 6% from Canada (3), 4% from New Zealand (2), and 2% (1 each) from Belgium, Ireland, Netherlands, and Sweden.
 - o 2005 results: (in order of representation): 71% from US (24), 12% from UK (4), 9% from Sweden (3), 6% from Canada (2), and 3% from Italy (1)
- US participants came from 18 states (14 in 2005)
 - o 2007 results: California (8), Michigan (3), Florida (2), Iowa (2), North Carolina (2), Ohio (2), Texas (2), Alabama (1), Washington DC (1),

- Georgia (1), Kentucky (1), Minnesota (1), Nebraska (1), New Jersey (1), New York (1), Pennsylvania (1), Washington (1), and Wisconsin (1).
- 2005 results: California (4), Pennsylvania (3), Arkansas (2), Florida (1), Georgia (1), Illinois (1), Iowa (1), Michigan (1), Nebraska (1), New York (1), North Carolina (1), Ohio (1), Tennessee (1), and Virginia (1) (4 did not specify their state)

Relationship to children

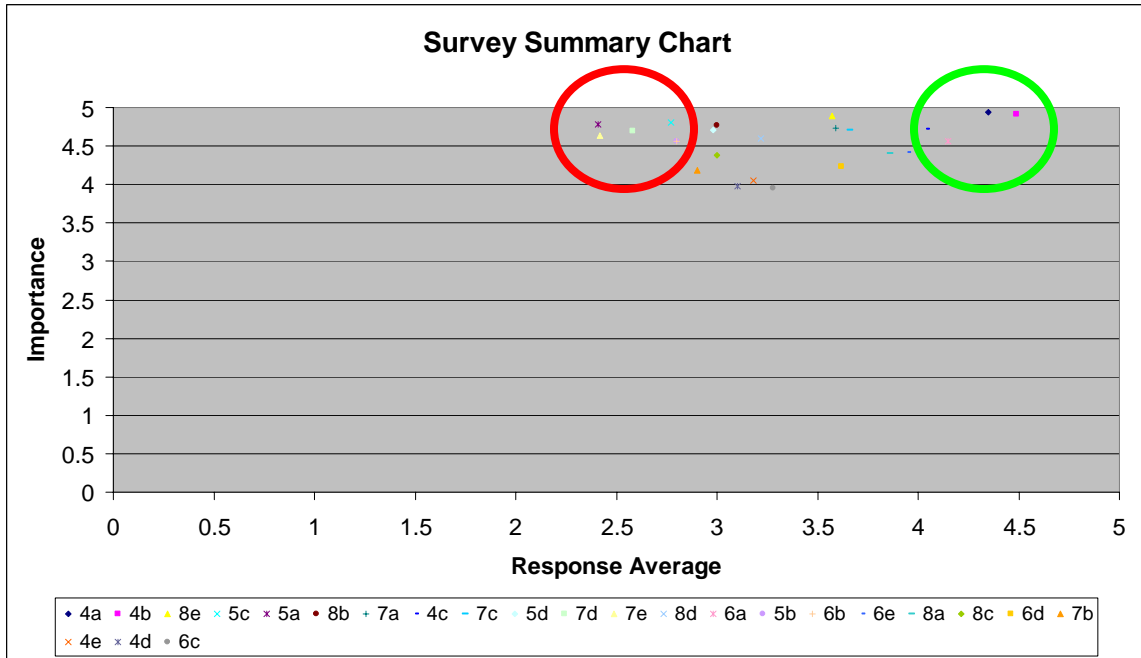
- 60% (29) percent of respondents were mothers (68% in 2005)
- 21% (10) were fathers (15% in 2005)
- 8% (4) were family friends (12% in 2005)
- 8% (4) were grandparents (6% in 2005)
- 4% (2) were aunts/uncles (0% in 2005)
- 2% (1) specified "other" (0% in 2005)
- 0% (0) were siblings (0% in 2005)

Stage of treatment of the child with JMML

- 77% (37) percent of responders had a relationship with a child who was post-transplant and recovering from JMML (68% in 2005)
- 17% (8) had a relationship with a child who passed away due to JMML (24% in 2005)
- 8% (4) had a relationship with a child who had not yet gone into transplant (15% in 2005)

Educational and Emotional Support Question Results

The scatter diagram below displays the average responses to each part of question numbers 4 through 8:



The green circle on the chart identifies the question areas with a combination of the highest importance and the highest average responses; these are termed “Best Practices” and are broken out in rank as follow:

Highest Importance & Highest Response (Best Practices)

Rank	Question	Question #	Response Avg	Importance
1	How knowledgeable about JMML were your child's transplant physicians?	4b	4.49	4.91
2	How knowledgeable about JMML was your child's hematologist/oncologist?	4a	4.35	4.94
3	How do you rate your ability to communicate with other families of JMML patients about JMML?	6a	4.15	4.56
4	How knowledgeable about JMML were your child's nurses?	4c	4.04	4.72

The red circle on the chart identifies the question areas with a combination of the highest importance and the lowest average responses; these are termed “Focus Areas” and are broken out in rank as follow:

Highest Importance & Lowest Response (Focus Areas)

Rank	Question	Question #	Response Avg	Importance
1	What were your experiences in terms of the ease of finding information about JMML?	5a	2.41	4.78
2	How would you rate existing support for siblings of deceased JMML children?	7e	2.42	4.63
3	How would you rate existing support for parents of deceased JMML children?	7d	2.58	4.7
4	What were your experiences in terms of the completeness of information you found about JMML?	5c	2.77	4.81
5	How do you rate your ability to communicate with your family?	6b	2.8	4.56

For informational purposes, the next two tables show the questions with the highest response averages and those with the greatest importance to survey participants:

Top Response Averages

Rank	Question	Question #	Response Avg	Importance
1	How knowledgeable about JMML were your child's transplant physicians?	4b	4.49	4.91
2	How knowledgeable about JMML was your child's hematologist/oncologist?	4a	4.35	4.94
3	How do you rate your ability to communicate with other families of JMML patients about JMML?	6a	4.15	4.56
4	How knowledgeable about JMML were your child's nurses?	4c	4.04	4.72

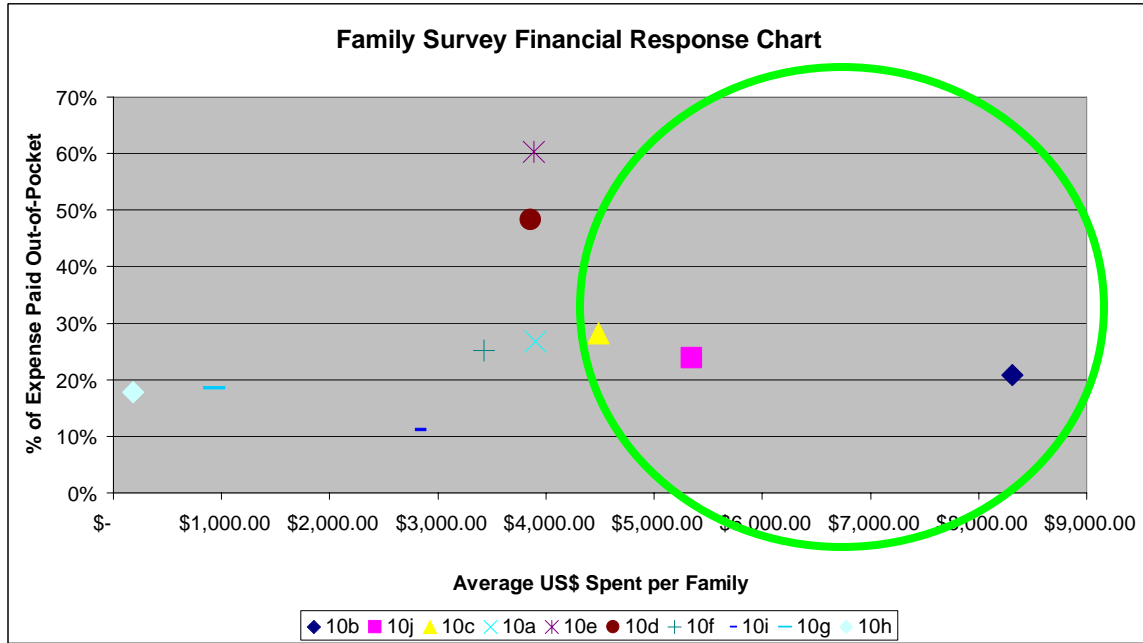
Most Important Topics

Rank	Question	Question #	Response Avg	Importance
1	How knowledgeable about JMML was your child's hematologist/oncologist?	4a	4.35	4.94
2	How knowledgeable about JMML were your child's transplant physicians?	4b	4.49	4.91
3	If you received counseling for your family, how helpful was counseling for the child with JMML?	8e	3.57	4.89
4	What were your experiences in terms of the completeness of information you found about JMML?	5c	2.77	4.81
5	What were your experiences in terms of the ease of finding information about JMML?	5a	2.41	4.78

Financial Support Question Results

Following a recommendation from the 2005 Family Survey, separate lines were added to question 9 under each cost category where families could check off the range of US dollars spent on each.

The question 9 results regarding family financial commitments show the following:



Financial Focus Areas:

A. The categories for which respondents reported paying the highest average dollar amount, in rank order, were the following:

Rank	Cost Category	Average \$ Amount Spent
1	Stem cell transplants	\$8,313
2	Other	\$5,347
3	Lodging during transplants	\$4,483

B. The categories for which respondents reported paying the highest average percentages out-of-pocket, in rank order, were the following:

Rank	Cost Category	Percentage of Costs Paid Out-of-Pocket
1	Travel to/from Medical Care	60%
2	Supplies/toys during hospital stays	48%

For informational purposes, the categories for which respondents reported paying the lowest average dollar amount, in rank order, were the following:

Rank	Cost Category	Average \$ Amount Spent
1	Respite	\$183
2	Counseling	\$932

Open-Ended Discussion Results

The recommendations and concerns described in the open-ended conclusion responses fell into the following categories:

- JMML information
- Physician education/liaison/connection
- Financial support
- Research/cure
- Family connection/support network
- Emotional support/counseling
- Other areas for the Foundation to focus on
- Positive feedback to the Foundation

Specific recommendations described under each of these categories are listed in Appendix A.

Overall Survey Recommendations for the 3rd JMML Foundation Family Survey:

1. In order to better assess JMML family members' current opinions on Educational and Emotional Support issues, questions #4-8 should be re-written to specify that the answers should reflect the state of information, counseling, and professional knowledge as observed during the previous year only.
2. In order to better assess the JMML Foundation's impact on the lives of the families and children it serves, questions should be added that address opinions about the efficacy of specific Foundation programs and the public's knowledge of specific programs.

Actions

1. A Foundation officer will contact all persons who left contact information in their response to Question 10 by 31 October 2007.
2. Survey results will be posted on the Foundation website in August 2007 and noted in the first newsletter following this date.
3. The Foundation will act upon the “Focus Areas” identified in Questions 4-9 by:
 - a. Searching for existing resources that can support these areas and be relayed to families through the Foundation website; and/or
 - b. Conducting market research and obtaining quotes for services during the fiscal year running from July 1, 2005 to June 30, 2006.
4. Comments collected through Question 10 will be taken into account when:
 - a. Planning out actions for all “Focus Areas;”
 - b. Forming and executing Foundation programs prior to the issuance of next year’s survey; and
 - c. Refining next year’s survey questions.
5. Where possible, the data collected regarding the “Focus Areas” will be used in creating the Foundation budget for the fiscal year 2008, which runs from July 1, 2007 to June 30, 2008.
6. The next JMML Foundation Family Survey will be administered in May 2008. Metrics will compare Aug 2006 results with those of the Aug 2005 survey in order to determine the Foundation’s progress regarding family satisfaction with research, educational and support resources.

Appendix A: Questions and Responses

Demographics

1. Country (or state if within USA)

Country Breakdown		%
US	32	67%
UK	4	8%
Australia	3	6%
Canada	3	6%
New Zealand	2	4%
Belgium	1	2%
Ireland	1	2%
Netherlands	1	2%
Sweden	1	2%
Total	48	100%

US State Breakdown		%
California	8	25%
Michigan	3	9%
Florida	2	6%
Iowa	2	6%
North Carolina	2	6%
Ohio	2	6%
Texas	2	6%
Alabama	1	3%
DC	1	3%
Georgia	1	3%
Kentucky	1	3%
Minnesota	1	3%
Nebraska	1	3%
New Jersey	1	3%
New York	1	3%
Pennsylvania	1	3%
Washington	1	3%
Wisconsin	1	3%
Total	32	100%

2. Relationship to a child with JMML

Relationship	Response Percent	Response Count
Mother	60.40%	29
Father	20.8%	10
Sibling	0.0%	0
Aunt/Uncle	4.2%	2
Grandparent	8.3%	4
Family Friend	8.3%	4
Other (please specify)	2.1%	1

3. Stage of treatment of the child with JMML

	Response Percent	Response Total
Before transplant	14.70%	5
After transplant - recovering	61.80%	21
Child passed away	23.50%	8
Total Respondents		34

JMML Education Concerns

4. How knowledgeable about JMML are/were your healthcare providers?

	1	2	3	4	5	N/A or Don't Know	Rating Average	Response Count
a. Knowledge Level of child's hematologist/oncologist(1=Poor, 5=Outstanding)	0.0% (0)	8.5% (4)	10.6% (5)	17.0% (8)	61.7% (29)	2.1% (1)	4.35	47
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	0.0% (0)	6.4% (3)	93.6% (44)	0.0% (0)	4.94	47
b. Knowledge Level of child's transplant physicians(1=Poor, 5=Outstanding)	0.0% (0)	6.4% (3)	4.3% (2)	19.1% (9)	61.7% (29)	8.5% (4)	4.49	47
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	2.2% (1)	4.3% (2)	93.5% (43)	0.0% (0)	4.91	46
c. Knowledge Level of child's nurses (1=Poor, 5=Outstanding)	6.4% (3)	6.4% (3)	8.5% (4)	31.9% (15)	44.7% (21)	2.1% (1)	4.04	47
Importance of this to me (1=Not important, 5=Very important)	2.2% (1)	0.0% (0)	6.5% (3)	6.5% (3)	84.8% (39)	0.0% (0)	4.72	46
d. Knowledge Level of child's social workers (1=Poor, 5=Outstanding)	17.4% (8)	15.2% (7)	19.6% (9)	19.6% (9)	19.6% (9)	8.7% (4)	3.10	46
Importance of this to me (1=Not important, 5=Very important)	2.2% (1)	4.3% (2)	26.1% (12)	21.7% (10)	39.1% (18)	6.5% (3)	3.98	46
e. Knowledge Level of counselors who have helped my family (1=Poor, 5=Outstanding)	15.6% (7)	8.9% (4)	15.6% (7)	17.8% (8)	17.8% (8)	24.4% (11)	3.18	45
Importance of this to me (1=Not important, 5=Very important)	4.4% (2)	2.2% (1)	15.6% (7)	22.2% (10)	37.8% (17)	17.8% (8)	4.05	45

5. What were your experiences in learning about JMML?

	1	2	3	4	5	N/A or Don't Know	Rating Average	Response Count
a. Ease of finding information about JMML (1=Not easy, 5=Very easy)	26.1% (12)	28.3% (13)	28.3% (13)	13.0% (6)	4.3% (2)	0.0% (0)	2.41	46
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	2.2% (1)	17.4% (8)	78.3% (36)	2.2% (1)	4.78	46
b. Recentness of information you found about JMML (1=Out of date, 5=Very recent)	17.4% (8)	23.9% (11)	26.1% (12)	21.7% (10)	8.7% (4)	2.2% (1)	2.80	46
Importance of this to me (1=Not important, 5=Very important)	2.2% (1)	0.0% (0)	4.4% (2)	26.7% (12)	66.7% (30)	0.0% (0)	4.56	45
c. Completeness of information you found about JMML (1=Many holes, 5=Very complete)	10.9% (5)	28.3% (13)	32.6% (15)	15.2% (7)	6.5% (3)	6.5% (3)	2.77	46
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	2.3% (1)	13.6% (6)	81.8% (36)	2.3% (1)	4.81	44
d. Understandability of information you found about JMML (1=Hard to understand, 5=Easy to understand)	6.5% (3)	26.1% (12)	37.0% (17)	23.9% (11)	6.5% (3)	0.0% (0)	2.98	46
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	6.7% (3)	15.6% (7)	77.8% (35)	0.0% (0)	4.71	45

Emotional Concerns

6. How do you rate your ability to communicate with other people about JMML?

	1	2	3	4	5	N/A or Don't Know	Rating Average	Response Count
a. With other families of JMML patients (1=Poor, 5=Outstanding)	4.7% (2)	2.3% (1)	18.6% (8)	18.6% (8)	51.2% (22)	4.7% (2)	4.15	43
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	9.5% (4)	23.8% (10)	64.3% (27)	2.4% (1)	4.56	42
b. With your family (1=Poor, 5=Outstanding)	4.7% (2)	4.7% (2)	25.6% (11)	30.2% (13)	34.9% (15)	0.0% (0)	3.86	43
Importance of this to me (1=Not important, 5=Very important)	2.4% (1)	0.0% (0)	9.5% (4)	21.4% (9)	66.7% (28)	0.0% (0)	4.50	42
c. With your friends/coworkers (1=Poor, 5=Outstanding)	9.3% (4)	16.3% (7)	30.2% (13)	25.6% (11)	18.6% (8)	0.0% (0)	3.28	43
Importance of this to me (1=Not important, 5=Very important)	2.4% (1)	2.4% (1)	33.3% (14)	21.4% (9)	40.5% (17)	0.0% (0)	3.95	42
d. With your employer (1=Poor, 5=Outstanding)	4.7% (2)	7.0% (3)	16.3% (7)	11.6% (5)	20.9% (9)	39.5% (17)	3.62	43
Importance of this to me (1=Not important, 5=Very important)	4.8% (2)	0.0% (0)	7.1% (3)	14.3% (6)	35.7% (15)	38.1% (16)	4.23	42
e. With your healthcare providers (1=Poor, 5=Outstanding)	4.7% (2)	7.0% (3)	16.3% (7)	27.9% (12)	39.5% (17)	4.7% (2)	3.95	43
Importance of this to me (1=Not important, 5=Very important)	4.9% (2)	0.0% (0)	12.2% (5)	12.2% (5)	65.9% (27)	4.9% (2)	4.41	41

7. How would you rate existing support services for the following members of your family?

	1	2	3	4	5	N/A or Don't Know	Rating Average	Response Count
a. Support for parents of JMML children (1=Poor, 5=Outstanding)	11.6% (5)	4.7% (2)	23.3% (10)	27.9% (12)	27.9% (12)	4.7% (2)	3.59	43
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	7.1% (3)	11.9% (5)	76.2% (32)	4.8% (2)	4.73	42
b. Support for siblings of JMML children (1=Poor, 5=Outstanding)	14.0% (6)	9.3% (4)	27.9% (12)	11.6% (5)	9.3% (4)	27.9% (12)	2.90	43
Importance of this to me (1=Not important, 5=Very important)	2.4% (1)	4.8% (2)	11.9% (5)	14.3% (6)	42.9% (18)	23.8% (10)	4.19	42
c. Support for JMML children themselves (1=Poor, 5=Outstanding)	7.0% (3)	11.6% (5)	18.6% (8)	18.6% (8)	32.6% (14)	11.6% (5)	3.66	43
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	7.1% (3)	11.9% (5)	71.4% (30)	9.5% (4)	4.71	42
d. Support for parents of deceased JMML children (1=Poor, 5=Outstanding)	9.3% (4)	4.7% (2)	7.0% (3)	2.3% (1)	4.7% (2)	72.1% (31)	2.58	43
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	4.8% (2)	4.8% (2)	38.1% (16)	52.4% (22)	4.70	42
e. Support for siblings of deceased JMML children (1=Poor, 5=Outstanding)	9.3% (4)	4.7% (2)	9.3% (4)	2.3% (1)	2.3% (1)	72.1% (31)	2.42	43
Importance of this to me (1=Not important, 5=Very important)	2.4% (1)	0.0% (0)	2.4% (1)	2.4% (1)	39.0% (16)	53.7% (22)	4.63	41

8. If you have received counseling for anyone in your family, how helpful was it?

	1	2	3	4	5	N/A or Don't Know	Rating Average	Response Count
a. Helpfulness of family counseling (1=Not at all, 5=Very helpful)	2.6% (1)	2.6% (1)	7.7% (3)	7.7% (3)	15.4% (6)	64.1% (25)	3.86	39
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	7.9% (3)	7.9% (3)	23.7% (9)	60.5% (23)	4.40	38
b. Helpfulness of marriage counseling (1=Not at all, 5=Very helpful)	7.7% (3)	2.6% (1)	7.7% (3)	2.6% (1)	7.7% (3)	71.8% (28)	3.00	39
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	0.0% (0)	7.9% (3)	26.3% (10)	65.8% (25)	4.77	38
c. Helpfulness of counseling for self (1=Not at all, 5=Very helpful)	12.8% (5)	0.0% (0)	5.1% (2)	5.1% (2)	10.3% (4)	66.7% (26)	3.00	39
Importance of this to me (1=Not important, 5=Very important)	2.6% (1)	0.0% (0)	2.6% (1)	10.5% (4)	26.3% (10)	57.9% (22)	4.38	38
d. Helpfulness of sibling counseling (1=Not at all, 5=Very helpful)	0.0% (0)	5.1% (2)	7.7% (3)	10.3% (4)	0.0% (0)	76.9% (30)	3.22	39
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	5.3% (2)	5.3% (2)	28.9% (11)	60.5% (23)	4.60	38
e. Helpfulness of counseling for the child with JMML(1=Not at all, 5=Very helpful)	2.6% (1)	2.6% (1)	2.6% (1)	2.6% (1)	7.9% (3)	81.6% (31)	3.57	38
Importance of this to me (1=Not important, 5=Very important)	0.0% (0)	0.0% (0)	0.0% (0)	2.6% (1)	21.1% (8)	76.3% (29)	4.89	38

Financial Concerns

9. How much of the following expenses have you had to pay from your own pocket related to your child's treatment for JMML?

	0-25%	25-50%	50-75%	75-100%	N/A	\$0	\$0-\$100	\$100-\$500	\$500-\$1,000	\$1,000-\$10,000	\$10,000-\$50,000	>\$50,000	
a. Routine medical appointments	42.9% (24)	0.0% (0)	1.8% (1)	1.8% (1)	5.4% (3)	19.6% (11)	7.1% (4)	3.6% (2)	7.1% (4)	8.9% (5)	0.0% (0)	1.8% (1)	
b. Stem cell transplants	39.6% (21)	0.0% (0)	0.0% (0)	1.9% (1)	15.1% (8)	24.5% (13)	3.8% (2)	0.0% (0)	1.9% (1)	7.5% (4)	3.8% (2)	1.9% (1)	
c. Lodging during transplants	31.5% (17)	1.9% (1)	0.0% (0)	7.4% (4)	16.7% (9)	20.4% (11)	1.9% (1)	7.4% (4)	1.9% (1)	9.3% (5)	1.9% (1)	0.0% (0)	
d. Supplies/toys during hospital stays	22.8% (13)	5.3% (3)	5.3% (3)	12.3% (7)	5.3% (3)	8.8% (5)	10.5% (6)	12.3% (7)	7.0% (4)	8.8% (5)	1.8% (1)	0.0% (0)	
e. Travel to/from medical care	15.5% (9)	5.2% (3)	1.7% (1)	22.4% (13)	5.2% (3)	5.2% (3)	3.4% (2)	19.0% (11)	12.1% (7)	8.6% (5)	1.7% (1)	0.0% (0)	
f. Prescriptions	32.7% (18)	7.3% (4)	0.0% (0)	1.8% (1)	5.5% (3)	16.4% (9)	5.5% (3)	10.9% (6)	10.9% (6)	7.3% (4)	1.8% (1)	0.0% (0)	
g. Counseling	30.8% (16)	3.8% (2)	0.0% (0)	0.0% (0)	17.3% (9)	30.8% (16)	5.8% (3)	3.8% (2)	3.8% (2)	3.8% (2)	0.0% (0)	0.0% (0)	
h. Respite	31.4% (16)	0.0% (0)	0.0% (0)	2.0% (1)	21.6% (11)	33.3% (17)	3.9% (2)	0.0% (0)	7.8% (4)	0.0% (0)	0.0% (0)	0.0% (0)	
i. Hospice	27.7% (13)	0.0% (0)	0.0% (0)	0.0% (0)	34.0% (16)	29.8% (14)	6.4% (3)	0.0% (0)	0.0% (0)	0.0% (0)	2.1% (1)	0.0% (0)	
j. Other significant costs (please explain in final comments block)	26.3% (10)	0.0% (0)	0.0% (0)	7.9% (3)	26.3% (10)	23.7% (9)	5.3% (2)	0.0% (0)	0.0% (0)	7.9% (3)	0.0% (0)	2.6% (1)	

Conclusion

10. Please tell us what you think is the best way The JMML Foundation can help your child and your family. If you would like us to follow-up with you, please also list your name and the best way to we can contact you.

Summary:

Categories of Concerns and Suggestions	Total
JMML information	18
Positive Feedback to Foundation	11
Financial support	8
Other areas for Foundation to Focus on	5
Research/cure	5
Emotional support/counseling	4
Family connection/support network	3
Physician education/liaison/connection	1
Grand Total	55

Individual Comments (in brief):

Categories of Concerns and Suggestions	Conclusion Concerns and Suggestions	Total
Emotional support/counseling	More help to siblings	1
	Free counseling	1
	Link to support group	1
	More care for families of deceased kids (grief info/books)	1
Emotional support/counseling Total		4
Family connection/support network	Support group for deceased children	1
	Other ways to get in touch with families	1
	Parent seminars	1
Family connection/support network Total		3
Financial support	Family grants	2
	Expenses: food, clothing, lodging, travel for out-of-state BMT	2
	Scholarships	1
	Expenses: childcare while mother in hospital, housekeeping while in hospital	1
	Expenses: loss of job, unpaid leave	1
	Costs of prepping home for post-BMT (eg. Hepa)	1
Financial support Total		8
JMML information	Updated info	5
	More info	2
	Updated info (protocol changes, new stats)	1
	Database of info	1

	Easy-to find info	1
	Easy-to-find info	1
	Info on Noonans/JMML	1
	Info on stable kids	1
	Informational materials at hospitals	1
	Current info (use dates)	1
	Specific info requested (vaccines/monoclonal antibodies)	1
	Specific info requested: Post transplant info	1
	Accept questions via email	1
JMML information Total		18
Other areas for Foundation to Focus on	Acknowledge stable kids	2
	Lobbying	1
	Advice resource	1
	Hospital care packages	1
Other areas for Foundation to Focus on Total		5
Physician education/liaison/connection	More communication between families and doctors	1
Physician education/liaison/connection Total		1
Positive Feedback to Foundation	Thanks!	2
	Great support group!	2
	Willing to help	1
	Great new homepage!	1
	Great job!	1
	Great website!	1
	Have everything I need	1
	Thanks for the information!	1
	Great information!	1
Positive Feedback to Foundation Total		11
Research/cure	More research	3
	Fundraising for research	2
Research/cure Total		5
Grand Total		55