ACCO SURVEY
990 RESPONSES

Respondents:

• 79.1% biological mother of the child/adolescent diagnosed with cancer
• 6.8 biological father of the child/adolescent diagnosed with cancer
• 2.6% Survivor
• 5% Grandparent or legal guardian
• 5% other (adoptive parent, other relative)
DEMOGRAPHICS
ETHNICITY

- Caucasian: 79.9%
- Hispanic/Latino: 6.4%
- Mixed Ethnicity: 5.4%
- Black/AA: 2.5%
- Asian, Pacific Isl.: 1.3%
- No response: 3.7%

Percent
ANNUAL FAMILY INCOME

- No response 6.4%
- > $125K 11.5%
- $90K - $125K 14.0%
- $65K - $90K 18.5$
- $40K - $65K 24.3%
- $20K - $40K 17.1%
- < 20K 7.9%

Percent
HOUSEHOLD DEPENDENTS

- One
- Two
- Three
- Four
- Five
- Six

Percent
HOUSEHOLD MAKEUP

- Bio mom/dad 76.1%
- Bio mom/step-dad 4.9%
- Bio dad/step-mom 0.3%
- Single Bio mom 10.9%
- Single Bio dad 0.3%
- Other 6.1%

Percent
NUMBER CHILDREN IN FAMILY DIAGNOSED

- 94.7% one child
- 1.3% two children
- Other (deceased, survivor taking survey)
OTHER FAMILY MEMBERS DIAGNOSED WITH CANCER

- 3.9% Biological mother
- 2.7% Biological father
- 0% Step-mother or step-father
AGE CHILD DIAGNOSED

- < 1 year
- 1 - 4 years
- 5 - 9 years
- 10 - 14 years
- 15 - 19 years

Percent
**DIAGNOSES**

- ALL: 38%
- AML: 3.8%
- Brain: 23.3%
- Neuroblastoma: 8.6%
- Wilms: 5.1%
- Rhabdo: 4.4%
- Osteo: 3.3%
- NHL: 2.8%
- Ewings: 2.5%
- Hepatoblastoma: 2.1%
- Other: 6.1%
REferred to...

- Local Community Hospital: 21%
- Other - VA, Non-teaching: 13.4%
- Children’s Teaching Hospital: 64.2%
CURRENT STAGE OF TREATMENT

- On Treatment: 36.6%
- Treatment Completed: 39.6%
- Relapsed: 3.2%
- Treatment Terminated: 1.6%
- Deceased: 14.4%
- Other: 3.4%
TYPES OF TREATMENT

- Chemotherapy: 95.1%
- Surgery: 57.5%
- Radiation: 40.9%
- Stem Cell Transplant: 13.3%
- Other (vaccines, antibody etc): 8%
- Alternative Medicine: 6.5%
DURATION OF TREATMENT

- Range was 4 months to 10 years (3 occurrences)
- Average 2.5 to 3 years
TREATMENT DENIED OR RESCINDED

- Yes: 15.5%
- No: 78.0%

Reasons:
- Experimental Therapy (20.6%)
- Recommended by Doctor but not warranted by insurance (31.2%)
- Not covered under plan – example transplant (6.2%)
- Clinical Trial - only covers standard of care (8.7%)
- Capped insurance coverage (11.2%)
- Other (out of network, drug not FDA approved for pediatric use etc. 23.1%)
OFFERED TO PARTICIPATE IN CLINICAL TRIAL

Percent

NO: 36%

YES: 62.8%
ENTERED INTO CLINICAL TRIAL

- Yes: 47%
- No: 44.2%
- Don't Know: 8%
SOURCE OF INFORMATION FAMILIES TURNED TO

- Listservs/Blogs: 25.9%
- Other CC: 45.7%
- CC Websites: 59.9%
- CC Providers: 94.5%

Percent
IMPACT OF DIAGNOSIS ON EMPLOYMENT

Stopped Work or cut back on work 75.7%
No impact 20.7%
PARENTAL WORK REDUCTION

1 stopped: 35.2%
1 adult < 50%: 10.5%
2 adults stopped: 3.0%
2 adults < 25%: 2.6%
2 adults < 50%: 2.1%
Other 75%: 12.9%
TIME SPENT PROVIDING CARE OF CHILD WITH CANCER

- Less 1 hr. 1.6%
- 1 - 4 hrs: 8.9%
- 5-10 hrs. 15.8%
- 11-20 hrs. 19.9%
- 21-40 hrs. 23%
- > 40 hrs. 28.8%
ANNUAL OUT-OF-POCKET EXPENDITURES FOR CARE OF CHILDREN WITH CANCER

- Less than $250: 17.2%
- $250 - $500: 6.8%
- $500 - $1,000: 8.7%
- $1,000 - $2,500: 15.3%
- $2,500 - $5,000: 19.5%
- $5,000 - $10,000: 17.4%
- Greater than $10,000: 11.9%
EXPENDITURES

• **Co-pays (meds, appointments, treatments, example $250 for each LP, out of network)
• **High deductible (example first $5,000 annually)
• Medications
• Supplies, equipment (wheelchair, support shoes,
• Travel to treatment (transportation, lodging)
FINANCIAL PROBLEMS: 83.5%

- Severe: 15.4%
- Considerable: 30.3%
- Manageable: 37.8%
- No Impact: 15.0%
SOURCE OF FINANCIAL HELP

- Family/Friends: 50.0%
- Savings/Retire: 33.1%
- CC Non-profit: 30.4%
- Public Agency: 20.7%
- Credit Card: 15.9%
- Employer: 9.8%
- Bank Loan: 6.4%
CC FAMILIES NEEDING SUPPORT SERVICES

Family Counseling 38.6%
- Needed, NOT Received: 14.0%
- Needed & Received: 24.6%

Respite 25.6%
- Needed, NOT received: 13.2%
- Needed & Received: 10.4%
SUMMARY

Childhood cancer is devastating to the family with the impact felt financially and emotionally for a very long time.

There is a significant opportunity and responsibility to support families with information, financial assistance, emotional support, as well as respite care.

“I am of the opinion that my life belongs to the whole community and as long as I live, it is my privilege to do for it whatever I can. I want to be thoroughly used up when I die, for the harder I work the more I live.”

~George Bernard Shaw