Report on Childhood Cancer
Survey of Patient Needs

Survey Period: April 18 – May 25, 2017

A joint initiative of the Children’s Cause for Cancer Advocacy & the Patient Advocate Foundation
SURVEY RESPONDENTS AT A GLANCE (343 total respondents)

- Caregiver to a child with cancer: 143 (42%)
- Teen or young adult with cancer (under the age of 18): 13 (4%)
- Teen or young adult who is a pediatric cancer survivor: 111 (32%)
- Adult who was treated for a pediatric cancer: 32 (9%)
- I am not a caregiver or a pediatric cancer patient/survivor: 44 (13%)

Anecdotally, we know that at least some of these “other” respondents are bereaved parents.
SURVIVOR Respondents:

- 66% female
- Median household income: $60,000
- 60% of survivor respondents were 19-21 years old.

PARENT/CAREGIVER Respondents:

- 60% of responding parents have a male child with cancer.
- Median household income: $70,000
- Among parent respondents, 85% of their children with cancer are 15-and-under
- 88% of responses came from moms.
GEOGRAPHIC REPRESENTATION
At least one person answered the survey from the 41 states shaded light blue.
INSURANCE OVERVIEW

Is the child/survivor currently insured? → 91% YES

TYPE OF COVERAGE:

Parent/Caregiver Response

Survivor Response

- Private Health Insurance through Employer
- Private Health Insurance (paid for by you or a family member)
- Medicaid
- CHIP
- State-sponsored health plan
- Other*

*Other: military health care; combination coverage (i.e. employer + Medicaid), etc.
DENIAL OF COVERAGE

Was treatment ever denied by your health insurance carrier?

- **Survivors**:
  - Yes: 15%
  - No: 63%
  - Unsure: 22%

- **Parents/Caregivers**:
  - Yes: 33%
  - No: 64%
  - Unsure: 3%
What was the reason given for **DENIAL OF COVERAGE**?
(‘select all that apply’)

- **41%** Care deemed “not medically necessary”
- **32%** Experimental therapy or clinical trial
- **32%** Therapy or test not covered
- **29%** Out-of-network physicians or facility
- **15%** Incorrect billing or coding
- **12%** Off-label indication for prescribed medication
- **10%** No reason given for denial
- **8%** Coverage caps reached

“We appealed successfully in each instance, but it took a great deal of effort and energy.”
- parent
In the last 12 months, have you experienced a **FINANCIAL HARDSHIP** due to the cost of your child’s medical care?

If yes, how severe was the hardship?

*This chart shows parent/caregiver responses only*

- **YES**
  - Extremely severe, unable to manage (36%)
  - Moderately severe (22%)
  - Somewhat severe but manageable (36%)
  - Not very severe (6%)

- **NO** 38%

- **UNSURE** 3%
Q: At any point in your child’s care, were you asked about any financial hardships your family may be experiencing related to food, energy or housing?

A: 56% answered NO.

Among parents/caregivers who self-identified with a FINANCIAL HARDSHIP, what are the top sources of their financial distress? (select all that apply)

- 57% Hospital bills
- 55% Prescription costs
- 50% Visits to medical providers or specialists
- 40% Laboratory services
- 36% Lodging
- 35% Surgery
- 52% Transportation costs
Q1: In the last 12 months, how much have you paid out of your own pocket towards your child's healthcare costs outside of your monthly health insurance premiums?

Q2: How much do you estimate you currently owe (loans, credit card debt etc.) or have in outstanding balances for your healthcare costs related to your child's cancer treatment?
In the past 12 months which specific costs would you say contributed the most to your overall out of pocket expenses for the child/survivor’s treatment or care?

The bigger the word, the more often it appeared in open-ended responses.
TREATMENT-RELATED FINANCIAL HARDSHIPS

Percentage of parents reporting difficulty with the following over the past year: (select all that apply)

- 87% - maintaining a regular work schedule
- 70% - family responsibilities
- 45% - transportation costs (gas, maintenance of vehicle)
- 37% - scheduling childcare or care for other family members

46% of parents report that one or two family members stopped working to care for the child, over the past 12 months.

One parent wrote: “Both of our cars were repossessed and we couldn’t buy Christmas gifts for the kids.”

Percentage of survivors reporting difficulty with the following over the past year: (select all that apply)

- 40% - maintaining a regular work schedule
- 35% - family responsibilities
- 27% - transportation costs (gas, maintenance of vehicle)

16% of survivors report needing to take unpaid time off for treatment or survivorship care over the past 12 months.

1-in-5 survivors stopped working or reduced work hours in the past year. Others reported missing college classes and taking time off from school.
HOURS PER WEEK that parents or other household members spend caring for a child's needs associated with their cancer treatment and care:

- <1 hour: 13%
- 1-5 hours: 18%
- 6-10 hours: 14%
- 11-20 hours: 11%
- More than 20 hours/week: 44%
TRANSPORTATION

- 95% of parents/caregivers report using their own car to get to/from medical appointments.

- Approximately 30% of all respondents (parents/caregivers and survivors) report traveling over 2 hours (one way) for the child/survivor’s cancer care.

- Over half of parents/caregivers reported difficulty in getting their child to and from appointments over the past year.

  - Top challenges: cost of transportation; vehicle problems; and securing care for other children.
  - Some reported that their appointments are not within driving distance.

  “My appointments take place over 1500 miles from my front door. My parents and I fly to every checkup, quarterly or semiannually.”
  – young adult survivor
1 in 4 parents/caregivers report that their child’s treatment was delayed or compromised because of a shortage of a drug or a drug was unavailable. 25% of those parents report that the physician was not able to get the drug from another source.

We waited for government subsidy to drug company to continue production.

I was unable to receive crucial maintenance for a month.

Treatment delay was resolved by many peer to peer conversations.

We couldn't change facilities to where the drug was available & continue care there.

There was a nationwide shortage of one of the chemo drugs used to treat my cancer. They used alternate drugs for the time that were effective for me in the short term, but I relapsed a few months later.

I was unable to undergo a portion of my treatment involving Cytarabine until the shortage ended.

We traveled to another facility, only to find out we would still have to wait an extra day.

How did the drug shortage you encountered impact your child’s care?

I needed methotrexate, when the drug company was going to stop making it. Luckily, the government stepped in before it was a problem.

The chemo drug was no longer available, and my daughter had a life threatening allergy to the only available alternative. We had no choice but to start the alternate drug in the ICU at a low rate in hopes of breaking through the sensitivities and reactions.
IMPACT ON EMPLOYMENT

Parental employment status in the month before diagnosis & now

- Employed Full-time
  - Before Diagnosis: 79
  - Currently: 39

- Employed Part-time
  - Before Diagnosis: 10
  - Currently: 19

- Unemployed
  - Before Diagnosis: 2
  - Currently: 29

- Homemaker/Other unpaid work
  - Before Diagnosis: 9
  - Currently: 14
SURVIVOR OUTLOOK

27% of the surveyed survivors are not currently receiving follow-up care from a survivorship clinic. Of those, just 15% cite cost as a factor in deciding not to receive follow-up care.

24% of survivors in this study report that the cost of their cancer-related medical care impacted their ability to pursue the higher education of their choice. 1 in 4 of the impacted students delayed college or university, while most others opted to attend school closer to home (community college or an in-state university).

30% of surveyed survivors said the cost of their medical care has impacted their career course or job choice.