



# Starlight Children's Foundation Canada Great Escapes Study

March 2016



# Great Escapes (GE) Study Overview

## GE Study Design

- Custom-designed 3-part surveys
  - Part 1, Part 2, Part 3
  - French version
  - English version
- What is the impact of the Great Escapes program for participants and their families?

## Survey Outcome Measures

- **Key outcome measures:**
  - **Parents, participants, and overall family**
  - Financial indicators
    - Direct healthcare costs
    - Additional parental costs
    - Family work hours lost
  - **Well-being**
    - Quality of Life
    - Emotional well-being
  - **Perceived value of program**
    - Willingness to pay for program

## Surveys Completed

- Administered via Survey Monkey link provided by Starlight to parents of children who participated
- 51 parents survey 1
- 61 parents survey 2
- 73 parents survey 3
- **35 parents completed all 3 surveys**



# Summary of main findings: Baseline measures

**What are the impacts of living with & caring for a chronically ill child for parents' lives, and for society?**  
(based on assessment done prior to Great Escapes event):

- Heavy impact on the emotional well-being of **parents**
- Poor overall quality of life & emotional well-being for chronically ill **child**
- Very high estimated **societal costs** (i.e. direct medical, parent out-of-pocket & productivity costs)



# Summary of main findings: Study Outcomes

## What is the impact of the Great Escapes event for:

- **Parents**

- very high levels of satisfaction with GE event
  - 90% parents: event had positive impact on child's emotional health
  - Parental willingness-to-pay (WTP) for the event ("value" parents attached to impact of the event for their child) was high:
    - mean WTP = \$362.32

- **Children living with a chronic illness**

- positive impact on child's quality of life & emotional well-being

- **Society**

- Societal costs decreased substantially after the event
- suggests a positive impact on overall healthcare costs
- **Social Return on Investment (SROI) for the event = 3.49**



# Survey Components - Review

## Survey 1

- **Pre-event survey**
  - 1 month prior to GE event
- Key Demographics
- Quality of life & emotional well-being prior to the event
- Resource utilization

## Survey 2

- **Post-event survey**
  - Immediately following GE event
- Qualitative component to assess satisfaction with the GE event itself
- Quality of life & emotional well being

## Survey 3

- **Post-event survey**
  - 1 month following the GE event
- Quality of life & emotional well-being following the event
- Resource utilization
- Willingness to pay



# Analysis

## **Two analyses were carried out:**

- Analysis on all participants who completed each survey
- Analysis on participants who completed all three surveys (n=35)

**Results were similar for both analyses - most of the results presented are for the all participant analysis**

## **Costing analysis:**

- Direct medical resources were costed using Quebec sources (e.g., RAMQ)
- Time lost from work was costed using average daily wage in Canada
- Costs were updated to 2015 using the Consumer Price Index



# GE participants: Parents

Variable	N	Survey 1
<b>Parents</b>		
<b>Gender (N (%))</b>	51	
Female		46 (90.2%)
Male		5 (9.8%)
<b>Age (Years)</b>	51	
Mean age $\pm$ SD		42.1 $\pm$ 7.6
Min-Max		31.0 - 67.0
<b>Marital status (N(%))</b>	45	
Married		28 (62.2%)
Common law		12 (26.7%)
Single		5 (11.1%)
<b>Employment status (N(%))</b>		
<b>Major caregiver</b>	50	
Full time		20 (40.0%)
Part-time		13 (26.0%)
Unemployed		13 (26.0%)
Other		4 (8.0%)
<b>Spouse/partner</b>	42	
Full time		34 (81.0%)
Part-time		3 (7.1%)
Unemployed		1 (2.4%)
Other		4 (9.5%)



# GE participants: Children

## Based on responses at Survey 1:

- Mean age of children with chronic conditions:
  - $11.5 \pm 5.3$
  - [Range: 3 – 22] (n=51)
- 82.4% of families had additional children
  - [Mean = 1.65 children per family - range 0-4] (n=51)





# Key findings: 4 dimensions

Physical Well-Being

Emotional Well-Being/QoL

Economic Well-Being

Program value & satisfaction



# Physical Well-Being: nature of conditions

- Most children have **very serious, chronic diseases**
- Some of which can be classified as *rare* diseases
- Most common conditions were cerebral palsy (17.5%) and genetic/chromosomal abnormalities (17.5%)
- Overall burden is high in terms of the everyday experiences and associated costs of these conditions



# Emotional Well-Being: parental stress/anxiety

- **Q: During an average week how much does your child's stress or anxiety cause distress for you or interfere with your daily activities?**
  - % of parents rating the impact as “Very much” decreases from 35.5% at S1 to 20.8% at S3;
  - Suggests Great Escape event may have some beneficial lasting impact on parental distress/daily activities
- **Q: In the past week how much does your child's level of stress or anxiety interfere with your everyday life in the following areas?**
  - 42% & 46% of parents reported impact as very much/great deal on their activities & stress/anxiety at S1
  - Impact decreased marginally to 37.7% and 34.7%, at S3



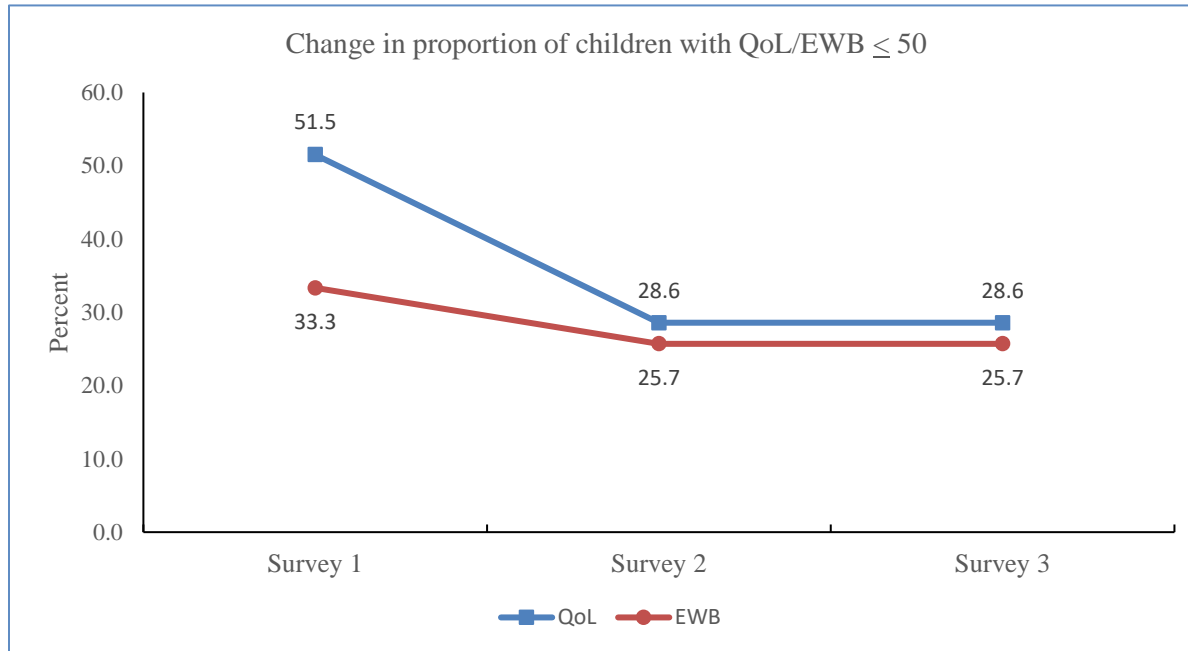
# QoL and Emotional Well-Being: child outcomes

Variable	S1	S2	S3
QoL			
Mean score	58.1	59.8	58.8
% with QoL $\leq$ 50	42.9%	31.0%	36.1%
EWB			
Mean score	60.7	66.7	59.2
% with EWB $\leq$ 50	34.7	26.7	31.9

QoL and emotional well being were assessed on a 0 – 100 scale where 100 reflects perfect QoL (or no emotional problems) and 0 reflects the poorest possible QoL (or poorest emotional well being).



# Change in QoL/EWB



- For parents who completed all **3 surveys**
- **90.2%** of the parents thought that the event had a positive impact on the emotional health of their ill children



# Economic Well-Being : health care costs

## Decrease in all costs between Surveys 1 and 3

Variable	Survey 1	Survey 3	Difference
Direct medical costs	\$2,252.40	\$1,115.67	-\$1,136.73
Parental costs	\$372.24	\$303.38	-\$68.86
Productivity losses	\$701.15	\$536.87	-\$164.28
Total costs per month	\$3,325.79	\$1,955.92	-\$1,369.87*
Projected annual cost of care	\$39,909.50	\$23,471.08	\$16,438.42

\*Change in costs is not statistically significant  
(Costs are expressed as \$/patient/month)



# Economic Well-Being : direct health care costs

- **Hospitalization is the major cost driver**
  - contributes 81% of total cost at Survey 1
- **Dramatic decrease in costs between Surveys 1 and 3**
  - **50% decrease** in costs between the two surveys
- **Decrease in all direct medical components between S1 & S3**
  - except for physician consultations
- Data suggests that:
  - **Great Escape event led to direct medical cost savings of \$1,137 per patient per month**



# Economic Well-Being: parental/family costs

- **Initial parental/family costs are substantial:**
  - Survey 1 parental costs = \$372 per family per month
  - Caregiver costs are largest cost driver
    - 42% of costs at Survey 1
- **Decrease in costs between Surveys 1 & 3**
  - 18% decrease in costs between S1 & S3
  - Cost savings between Surveys 1 & 3 of \$69 per patient per month
  - Decrease suggests that the event led to a reduction in parental costs





# Economic Well-Being: productivity loss

- **Substantial productivity losses by family members**
  - \$701 per family per month at Survey 1
- 23.4% cost reduction in productivity loss between S1 & S3
- **Dramatic reduction in proportion of main caregivers reporting productivity losses between S1 & S3**
  - 50.9% vs. 39.7% from Survey 1 to Survey 3



# Economic Well-Being

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Data suggest: **GE event led to reduction in all treatment-related costs**



# Willingness to pay

- WTP assessment: parents were asked to attach a value to the Great Escape event
- parents were offered values of \$0, \$100, \$250, \$500, \$750, \$1000 or other
- **Willingness to pay (Mean  $\pm$  SD): \$362.32  $\pm$  \$295.23 (N=69)**
- **Willingness to pay (Median): \$250**
- **Minimum and maximum values: \$0.00 - \$1000.00**
- **Proportion of patients WTP  $\geq$  \$500 = 39.1%**



# Parent Quotes about the WTP question

- *C'est le montant que nous serions prêts à déboursier si nous avions les moyens financiers. Malheureusement, notre situation financière est très précaire depuis la naissance de notre enfant handicapé.*
- *Priceless, if I could afford it priceless.*
- *Inestimable, si j'avais les moyens ça n'a pas de prix.*
- *Unfortunately I have not the means to pay for activities like this. Starlight without it would not be possible.*
- *Ca na pas vraiment de prix!*
- *Super bien nous a permis de se rapprocher et de passer du temps sans penser trop au traitement. .de plus c était une bonne période pour Alexis au la douleur était beaucoup moins présente merci à toute l équipe pour cêtre belle organisation.*



# Social return on investment (SROI)

SROI components:

## Societal impact of the Great Escape event:

1. Societal cost savings generated (direct medical costs + parent costs + productivity losses)
  - Survey 3 costs – Survey 1 costs =  
\$1,369.87/patient/month
2. WTP – reflects the “value” parents place on the event and the impact on their chronically ill child: \$362.32

**Event input (cost of event to Starlight): \$36,251.15**



# SROI

<b>Input parameters</b>	<b>Cost savings</b>
Medical + parent + productivity (\$/patient/month)	\$1,369.87
Willingness to pay (\$/per patient)	\$362.32
Total/patient/month	<b>\$1,732.19</b>
Total number of families	73
Total cost savings	<b>\$126,449.70</b>
Starlight costs for event	\$36,251.15
<b>SROI</b>	<b>3.49</b>



# SROI: Sensitivity analysis

<b>Input parameter variation</b>	<b>SROI</b>
Base case	3.49
Variation in WTP (\$500)	3.77
SROI based on WTP alone (\$362.32)	0.73
Only parent and productivity costs included	1.20
20% reduction in Starlight costs	4.36



# Program value and satisfaction

- **Based on responses from Survey 2:**
- **Parents were very satisfied with GE event:**
  - **Very high levels of child satisfaction with event**
    - 87.9% were very satisfied
  - **Parent satisfaction with event was very high**
    - 98.4% were very satisfied





# Program Value & Satisfaction: Specific Events & Future Participation

- All parents were **extremely happy** to allow their children to participate in future GE event
- Most popular activity: aquatic park and water-related activities
  - 54.2% of families rated water park as favorite activity
- Second favorite activity: fireworks
  - 22.0% of families rated this as their second most favorite activity



# Program Value & Satisfaction: Overall Feedback

- Parents were overwhelmingly positive about the event and its impact on their lives, their family life, and the life of their child with severe health challenges
- **Feedback focused on:**
  - Positive impact for the family (able to spend quality time with each other - a rare opportunity)
  - Positive impact for the parents (reduced stress, increased support)
  - Positive impact for child (empowered, reduced stress, fun)



# Program Value & Satisfaction: Overall Feedback (Examples of Quotes from Parents)

- *[She] haven't moved much in quite a while swing her move swim enjoy herself was my greatest gift she was so excited they're are no words to describe she so overly excited thank you so much for inviting us she always looks forward to the next event thank you :)*
- *It gave us uninterrupted time together. We shared much laughter and fun. My daughter was "at her best" as described by her sisters. Extremely grateful*
- *Overall I think [he] feels less alone! Meeting other families with children with serious illness helps us all feel more connected and less alone. When [he] was born we were overwhelmed and nervous. Over the years we have adapted and grown as a family; and facing death several times has made us appreciate our time together and the little pleasures in life. These events have allowed us a little family fun with out having to worry about all the planning. We then only need to worry about getting there and having fun!*
- *Positive: Thank you all for the opportunity this weekend. We bonded as a family. Had tons of fun and [he] was particularly happy to go on a trip. We don't get to travel often as we don't have the funds. Thank you again!!!*



# Program Value & Satisfaction: Overall Feedback (Examples of Quotes from Parents)

- *Activité lui permettant de participer comme un enfant n'ayant aucune restriction physique. Endroit où il ne se sent pas différent, limité. Ça lui fait vivre une belle escapade, où il peut oublier les tracas du quotidien.*
- *Ma fille est traitée à chaque mois à l'hôpital, quand la date se rapproche, elle résiste va aller parce que elle a peur de gouttes, la seringue et l'anesthésie. Ces sorte d'événements son de beaucoup d'aide et nous aident à oublier un instant tout sa maladie et de profiter en famille et de rencontrer des autres familles de l'hôpital*
- *Nous avons réalisé que grâce aux Grandes évasions de Startlight, Brian est plus confiant et se permet d'essayé des choses (ex.: les glissades d'eau a Jay Peak). De plus, lors de ses sorties, il est plus souriant et profite de ses moments en famille. Il oublie ses problèmes de langage et/ou de santé. Les Grandes évasions de Startlight ont un impact TRÈS positif envers lui et envers sa famille.*
- *Quand les parents vivent moins de stress et surtout que tout était très bien organisé l'enfant le ressent, nous avons passé un séjour mémorable avec nos deux garçons merci a vous*



# Study Conclusions

- **child's chronic condition had heavy impacts on family**
  - Financial & emotional costs
- **QoL & emotional well-being of children were poor**
  - however, these measures *improved* after the GE event
- **Substantial societal costs associated with child's illness**
  - however, these costs *decreased* after the GE event
- **Parents & children had very high levels of satisfaction with event**
  - *all* parents would allow their child to participate in future events
- **WTP estimates provided by parents were high**
  - This demonstrates a *high value* attached to the GE event
- **SROI estimate for the event was *strongly positive* (3.49)**



**Thank you!**

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