Our top priority: providing access to pediatric palliative care
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Tao and Ophélya, a member of the activities team at the Lighthouse/Cover page: Alamah and Ghyslaine, a volunteer at the Lighthouse
Thanks to the generosity of our many donors and volunteers, The Lighthouse Children and Families is continuing its mission to provide first-rate palliative care to children and families from Montreal, but also Outaouais, Mauricie, and even as far afield as Abitibi-Témiscamingue and Saguenay.

The stories of Maélie and Loïc show the impact of The Lighthouse on the lives of so many families. We pool all our resources to provide the best possible services free of charge in both French and English.

To maintain the quality of care and services we are so well known for, we had to step up efforts this year to find new sources of funding. We received more revenue from our cocktail reception than ever before, and the Ministry of Health and Social Services renewed the grant that it has generously provided The Lighthouse for years now.

Universal access to pediatric palliative care, both in the community and at home, is the cornerstone of our 2016-2021 strategic plan. Our top priority is to continue efforts to maintain excellence of care at The Lighthouse while also expanding our range of services in the community. Our hope is to share the benefit of our expertise with more children, families, volunteers, and even palliative homecare teams.

However, this goal can only be reached with the cooperation and participation of parents, which explains our new “parent-partner” approach and changes to our rules of governance to encourage greater parent participation.

This past year—the first of our strategic plan—has seen inspiring progress through a series of actions designed to equip The Lighthouse to fully play its multiplier role in the community: share its expertise and knowledge and provide clinical support for families, volunteers, and caregivers.

We’re proud of what we’ve accomplished:

• We have stepped up our professional training for employees, so that they in turn are equipped to provide training to others in pediatric palliative care.
• We have been successfully recertified as a palliative care facility by the Quebec health ministry.
• We have ratified collaborative agreements with key partners: the Jeremy Rill Centre, the provincial authority on sudden infant death syndrome; Fédération du Mouvement Albatros du Québec, to provide professional training in pediatric palliative care; and Centre universitaire intégré de santé et des services sociaux de l’Est-de-l’Île-de-Montréal, to work together for ongoing improvements in the quality and coordination of care.
• We’re working hard to create digital resources for families, volunteers, and caregivers, to provide them with information and distance training.
• We’ve introduced a new, enriched workshop model to help families with decision making.

The management team has seen the arrival of energetic and highly talented new members: Céline Laberge, Director of Fundraising and Communications; Ginette Leduc, Director of Human Resources; and Dr. Jacques Ramsay, Medical Director. These compassionate and experienced professionals have joined a strong team that has delivered great results this year and makes us feel confident and optimistic about the future. We commend the entire Lighthouse team for their unstinting commitment to the children and their families and offer them our sincerest gratitude.

In closing, allow us to express our deep gratitude to the families who honor us with their trust at the most difficult times of their lives. We are here for and because of you. To be at your side will always be a special privilege.
Karine Tells the Story of Her Daughter Maélie

As vulnerable, delicate, and small as a porcelain doll, Maélie has lived under the constant threat of viruses that her fragile system struggles to fight. Maélie was a second child, one that her mother, Karine Beaurivage, dearly longed for after a return to school and a career change. She was born on July 22, 2013, after a complication-free pregnancy and labor. However, Karine quickly noticed the differences between Maélie’s development and that of her oldest son. Despite trying to reassure herself by repeating that each child is unique, Karine felt powerless hearing Maélie’s tears and seeing her difficulty eating. She became increasingly worried by Maélie’s lack of response to stimuli and by the fact that her first smile, long desired, never came.

A few months after Maélie’s birth, her parents finally learned that what they had thought were repeated blinks were in fact severe epileptic seizures. The doctors’ prognosis was bleak and brutal, and Karine learned that the lives of her daughter and her entire family would be far different from what they had pictured. For many months, Karine wore herself out searching for a medication or treatment that would improve her daughter’s state. However, her hopes amounted to nothing, and after Maélie’s first year of life, her daughter’s situation had barely changed. That’s when a neurologist from Sainte-Justine mentioned The Lighthouse to Karine and her spouse.

Karine called The Lighthouse straightaway. Her family and her spouse’s were in Quebec City, too far away to help, and exhaustion was setting in from all the care Maélie required. Today Maélie is three and a half, and she does not walk or communicate. She is fed by a tube and frequently suffers from fluid buildup in her respiratory system. Her state requires around-the-clock surveillance and care.
It was under these difficult circumstances that The Lighthouse came into Maélie’s life. The sudden ability to take breaks from caring for Maélie changed Karine’s life. She was able to think of herself again and pick back up certain activities that helped her to manage her stress, such as exercise and painting.

But for Karine, The Lighthouse’s support goes far beyond just the skilled care and all the affection and attention that Maélie receives during her stays. She is truly touched by how accessible and available the entire Lighthouse team is, and how attentive and caring they are.

Karine is amazed at the breadth of services available from The Lighthouse and how easy it is to discuss her and her daughter’s needs with the team. And she is especially grateful for how sincere and humane everybody is. She says that each time Maélie is admitted for a stay feels very therapeutic for her, as well. People are available to talk, and they listen to what Karine has to say about Maélie’s condition and progress from her unique perspective as a mother.

Karine also acknowledges that The Lighthouse has helped her tremendously in her own personal development and how she sees her daughter’s illness and future. She is now much less preoccupied with fighting the disease and more focused on appreciating and living in the present moment. Instead of grappling for progress or a cure, Karine is now centered on reassuring and comforting Maélie, and savoring the times they share together.

In December 2016, Maélie’s condition worsened during a stay at The Lighthouse, the only place Karine could conceive of saying goodbye to her daughter. But Maélie held on and survived, and continues to be surrounded by the love of her mother, who, thanks to The Lighthouse, has learned to value every moment that life has to offer.
On August 31, 2009, Julie Grenier became the happy mother of Loïc, a handsome, healthy baby boy who developed normally. However, when he was five years old, the calm and smiling Loïc became excited and agitated. He underwent many medical consultations in their hometown of Mont-Laurier, but this led only to suspicions of behavioral trouble and to a long waiting list to meet with a pediatric psychiatrist.

Nevertheless, Julie’s maternal instinct kept telling her that only extreme physical discomfort could explain Loïc’s behavior. After many weeks of worry and uncertainty, the doctors diagnosed a urinary tract infection and transferred Loïc to Sainte-Justine for further testing. On May 22, 2015, the cruel results came back: Stage 4 cancer of the muscles and muscular tissue, metastasized to the lungs, with a 30% chance of survival.

Alone to face the cruel truth, Julie felt as though the ground was slipping out from under her feet and she was being sucked into a bottomless pit. The next two months were spent at the department of oncology at Saint-Justine, where Loïc undertook intensive chemotherapy and radiation treatments. Their return home to Mont-Laurier in July was brutally hard. Weakened by weeks of bedrest, Loïc had to relearn how to walk. And traumatized by the long hospitalization and aggressive treatments, he developed an acute phobia of the hospital, and even the idea of returning there sent him into a deep state of distress and panic.

Loïc and his mother Julie, swimming in the heated pool at The Lighthouse
However, Loïc had to return. To lessen her son’s anxiety and limit the number and length of his hospital stays, Julie made frequent roundtrips between Mont-Laurier and Montreal. But five months of constant travel drained Julie’s mental and physical energy, so when the doctors told her in January 2016 that Loïc had to enter palliative care, she broke down. They explained the palliative care services at The Lighthouse, but Julie would hear nothing of it—she was determined to bring Loïc home to live out his days in Mont-Laurier. Julie was angry, explosive, and hostile. Still, she let her friends convince her to give The Lighthouse a try. She arrived guarded and mistrustful, but was finally won over by the team, who through their professional and personal interaction provided small moments of calm in the whirlwind of her suffering.

Since palliative radiation and chemotherapy treatments were necessary several times a week, distance became a major obstacle. The Lighthouse offered Julie and Loïc lodging at Maison André-Gratton, its pediatric palliative care home, where they would benefit from constant surveillance and attention from the nursing staff. They settled in, making a little nest for themselves and forging ties of affection and friendship with the entire team.

In summer 2016 after a stay in Mont-Laurier, they came back to Montreal to continue the palliative chemotherapy treatments and try to keep the cancer from spreading further. They received a warm welcome from the staff at The Lighthouse, and both felt like they were coming home.

At the beginning of October, Loïc’s trip to Bagotville Military Base provided by Children’s Wish had to be cut short due to a sudden worsening of his state. When he got back to The Lighthouse, Loïc asked to see everyone he loved. They came in one by one, their hearts breaking and their throats choked with grief, to say goodbye to this unique and beloved boy.

Lying beside Julie, Loïc, seeing tears roll down her cheeks, whispered in his weakened voice not to worry, that everything would be fine since he was going to see his grandpa. This is how Julie recalled her little boy’s final moments: “When Loïc was born, they put him on my stomach, where he cried for the very first time. I wanted his final moments on Earth to be like his first—in my arms, curled up in the warmth of maternal love.” On October 24, 2016, Loïc passed peacefully away at The Lighthouse, cradled in his mother’s arms. Julie will never forget her son’s death, and remains ever grateful to the team at The Lighthouse, who succeeded, with humanity and sensitivity, in softening this painful time and wrapping her in such warm, loving care that she will be eternally marked by the memory of it all.
Access to pediatric palliative care is a top priority of The Lighthouse. Every child in need of palliative care, and every child’s family, deserves comprehensive, quality services whenever they need them, wherever they live, whatever language they speak, whatever their culture or financial situation, and however much care or supervision they require. And the goal must always be to create an environment that fosters normal and complete development of the child, provides a safe and secure setting—and this is essential—allows the child to play and enjoy life right until the end!

Sharing our expertise and knowledge is one of the pillars of our 2016–2021 strategic plan. A digital learning platform will be launched in the next year with the support of our new senior training advisor to improve access to information and remote training for families, volunteers, and caregivers.

Improving training is one of the ways to make good on our ambitious plan to offer universal access to pediatric palliative care, so no child in need goes without. Information is a priority, so we have joined with partners to create training modules for the people who actually visit the homes and bedsides of children in communities across Quebec. It’s our way of sharing our expertise in pediatric palliative care with families, caregivers, volunteers, and the general public. What’s more, we’ve reached an agreement with FMAQ (Fédération du Mouvement Albatros du Québec) to use its volunteers to meet the home respite care needs of families in rural Quebec. A new partnership with the University of Quebec in Abitibi-Témiscamingue will be used to train Albatross volunteers.

With the strategic plan now in place for a year, we’re seeing a significant increase in demand for pediatric palliative care training from the community, both in terms of basic training and professional development. The Lighthouse has thus welcomed students from every field of study directly or indirectly related to its mission: medicine, nursing, auxiliary nursing, home care, social work, art therapy and special education, architecture, management, and more. Interns have come from France (Poitou-Charentes, Nord-Pas-de-Calais, Provence) and Luxembourg, as well as from Quebec universities (Montreal, Concordia, UQAM) and colleges (Vieux-Montréal, Champlain).

Care and service quality—the very essence of our mission—mobilized our entire team during the year. No effort was spared to make sure only best practices were used. And these efforts led to concrete results, including palliative care facility certification through 2021 for The Lighthouse from the Quebec Ministry of Health and Social Services in recognition of the quality of care we provide, Canadian palliative care certification for our nursing advisor, and the holding of The Lighthouse’s first-ever “Science Day” on pediatric palliative care in collaboration with a variety of clinical experts. In fact, we plan to make this latter activity an annual event open to all of our partners.
The Care and Services Department stepped up collaboration with its main partner: families. We invited families to take an active part in strategic planning, in developing a survey to gauge the “patient experience,” and in vetting and improving the action plans stemming from the strategic plan and the results of the “patient experience” survey. Results were presented to the Care and Services Committee (which is chaired by a parent member of the Board) for analysis and follow-up.

A workshop on “complex decision making” was also offered to parents. Parents have hard decisions to make about their children’s care, and the consequences can affect the entire family. Two and a half days in length, the workshop was led by our social worker and a professor from the University of Québec in Outaouais.

A special partnership to provide specialized bereavement counseling services was concluded with the Montreal Children’s Hospital’s Jeremy Rill Centre. The Lighthouse’s bereavement team now offers its services to families that have unexpectantly lost a child under the age of two.

Activities and Education is another area of activity. It refers to all the various activities organized for the children as well as our support workshops for parents and siblings. This year, noted artists graciously joined with us to work with the children on pieces of art, generously sharing their talent and experience to help the children develop to their full potential. We also added a new service that combined two complementary approaches into one—massage therapy and music therapy. Numerous benefits were observed, notably with regard to relaxation and relief.

The role of volunteers, who contribute so much to the quality and breadth of care at The Lighthouse, was also revisited and expanded into new areas. The caregiving team now has volunteers who work with the children in the pool. Training was also provided in safe patient handling techniques (SPHT).

Lastly, the Care and Services Department—The Lighthouse’s veritable nerve center—is constantly updating the care and services it provides by concluding new partnerships and creating new opportunities to show its commitment to the children and their families!

We were also excited to welcome our new medical director, Dr. Jacques Ramsay. His long commitment to care quality and safety are sure to be a boon to the culture of quality we seek to nurture.
SERVICES AVAILABLE AT THE LIGHTHOUSE’S MAISON ANDRÉ-GRATTON

PATIENT PROFILE

3,852 overnight stays by children
88% occupancy rate*
*Given the current occupancy rate, the Lighthouse can take in children at any time, whether because of an emergency or at end of life.

4.7 nights (average length of stay)

814 total stays

679 admissions since Maison André-Gratton opened in June 2007, including 35 this year

By age group
- 0-2 years: 6.25%
- 3-5 years: 25.44%
- 6-12 years: 45.53%
- 13-18 years: 22.88%

By referral = 224 children
- Public social health sector: 82.88%
  - Teaching hospitals: 46.88%
  - Other health institutions: 35.71%
- Other sector: 15.62%
  - Lighthouse Children and Families: 13.83%
  - Not-for-profit organizations: 1%
  - Clinics: 0.45%
  - Agencies: 0.45%
- Education sector: 1.79%
  - Specialized schools: 1.79%

Par région
- Montréal: 35.71%
- Montérégie: 28.13%
- Lanaudière: 12.5%
- Laval: 8.04%
- Estrie: 4.02%
- Laurentides: 4.02%
- Capitale-Nationale: 1.34%
- Mauricie et Centre-du-Québec: 1.34%
- Abitibi-Témiscamingue, Chaudière-Appalaches, Côte-Nord, Nord-du-Québec: 1.34%
- Saguenay-Lac-Saint-Jean: 1%
- Outaouais: 1%
24/7 medical team

65 employees (care and services, activities and education, kitchen, maintenance, fundraising, communications, and administration)

1,568 training hours provided to employees

14,589 volunteer hours

932,5 training hours (basic and ongoing) provided to volunteers

5,593 people made a donation to the Lighthouse

2,214,286$ collected through fundraising

1,130,708$ received in goods and services donations

755,000$ collected at the cocktail dinner party, a new record!

442 new birthday participants following our My Birthday as a Gift fundraising campaign

69 activities organized by third parties for the UNITED for the Lighthouse fundraising campaign
The Lighthouse Children and Families wishes to salute the commitment and dedication of the many board and committee members who give so generously of their time and expertise. Thanks to these volunteers from all walks of life, the Lighthouse can uphold the highest quality standards. THANK YOU for supporting the Lighthouse’s cause with such conviction.

**Boards and Committees:**

**Because They Care!**

The Lighthouse Children and Families wishes to salute the commitment and dedication of the many board and committee members who give so generously of their time and expertise. Thanks to these volunteers from all walks of life, the Lighthouse can uphold the highest quality standards. THANK YOU for supporting the Lighthouse’s cause with such conviction.

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Senior Advisor Champlain Financial Corporation

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Maxime Vandal
President Les Ensembliers

Michèle Viau-Chagnon
Founder The Lighthouse Children and Families

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Chair, 2010-2015 Fundraising Campaign
The Lighthouse Children and Families

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Founder The Lighthouse Children and Families

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Chair and Co-Chief Executive Officer Power Corporation du Canada

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Senior Advisor, Business Continuity National Bank of Canada

Maxime Vandal
President Les Ensembliers

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Care and Services Director

Annick Gervais
Family Coordinator

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Ethicist, Psychologist, and Nurse
McGill University, Montreal Children's Hospital

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Dentons Canada LLP

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Groupe conseil StratEXEC Inc.

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Management Consultant

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Groupe conseil StratEXEC Inc.

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Lucie Gérin
Director of Human Resources
Moisson Montréal

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(April 2016 to February 2017)
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Raymond Chabot Grant Thornton

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Ginette Leduc
(since September 2016)
Human Resources Coordinator

Ombudswoman

Nadine Mailloux
Ombudswoman, City of Laval

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Isabelle Desmarais
Parent
Investigations Coordinator
Chambre de la Sécurité Financière

The Lighthouse Children and Families Representatives

Johanne Desrochers
Chief Executive Officer
Financial Results 2016-2017

A Shared Effort to Improve Access to Pediatric Palliative Care

Thanks to the trust and generosity of our donors and funders, The Lighthouse Children and Families ended fiscal 2016-2017 with total revenue of over $4.5 million, excluding in-kind donations of goods and services. This revenue once again served to deliver high quality services to children in need of palliative care, as well as respite and support for their families.

In all, The Lighthouse received 5,593 donations in 2016-2017 from foundations, businesses, and members of the general public. This provided over $2.2 million in financial support to ensure that seriously ill children enjoy life right to their very last day.

Expense Breakdown

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<th>Percentage</th>
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<td>Child and family services</td>
<td>69%</td>
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<tr>
<td>Administration</td>
<td>13%</td>
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<tr>
<td>Fundraising and communications</td>
<td>18%</td>
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Source of Funding

<table>
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<th>Source</th>
<th>Percentage</th>
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<td>MSSS grant</td>
<td>47%</td>
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<tr>
<td>Donations from the general public</td>
<td>20%</td>
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<tr>
<td>Corporate donations and foundations</td>
<td>32%</td>
</tr>
<tr>
<td>Other</td>
<td>1%</td>
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Corporate Donations and Foundations

Over $1.3 million was collected in 2016-2017 from corporate donors and foundations. This vital support brings happiness into the too-short lives of children at The Lighthouse and soothes families in their daily struggle with illness.

Dons mensuels

Monthly donors offer the valuable gift of a stable source of revenue. The impact of their giving is felt throughout the year.

In 2016-2017 the number of monthly donors rose 41%, a giant step forward that pays dividends every month in the form of care for more families.

Over time, these donations add up to a huge contribution to our organization.
Testamentary Giving

Leaving a gift to The Lighthouse in your will is a legacy for tomorrow. Our sincerest thanks to all those who have chosen to open their hearts and provide such essential support for the future.

UNIS pour le Phare

UNITED for the Lighthouse is a campaign where the community helps organize Lighthouse fundraising activities. This year, we raised $130,293 thanks to 69 activities organized by third parties, such as individuals, groups, or companies.

unispourlephare.com

The Lighthouse Grandparents’ Circle

The Lighthouse Grandparents’ Circle was new in 2016-2017. Its goal is to introduce The Lighthouse to people 55 and over so that they too can help by donating money, donating time, or simply telling others about The Lighthouse. To date, “Discover The Lighthouse” activities have provided a first-hand look at our facility to 52 new people.

A warm ‘thank you’ to the members of the Grandparents’ Circle Committee for their dedication to the cause and for inviting their many friends and neighbors to learn more about us!

The Donor with a Big Heart

For nearly a decade Michel Poirier has been taking part in fundraising drives and events for The Lighthouse. He knows just how valuable The Lighthouse is for gravely ill children and their families.

Recently Michel began to wonder how he could do more for those he would leave behind after his death. So when he drew up his last wishes, he included a testamentary gift to The Lighthouse. He has great faith in the organization and is committed to its mission, and he knew in his heart that the money would be spent in the best interests of the children and their families.

Michel’s message to others is that testamentary giving is not just for rich people. Any gift, however big or small, is important to The Lighthouse and brings hope to children and families. As he points out, our goods and possessions will not follow us into the afterlife, so Michel urges all those who share his love of The Lighthouse to consider how they too can leave a legacy.
Cocktail annuel

The Lighthouse broke another record this year, collecting $755,000 at its 16th annual cocktail reception under the co-presidents of honor Sophie Desmarais, Bernard Poliquin (senior vice president, Ivanhoé Cambridge), and Martin Thibodeau (president, Quebec Division, RBC Royal Bank), supported by a team of 27 patrons of honor.

A very successful evening in the company at the talented Patrick Langlois as emcee and actor Guylaine Tremblay, who very generously and tenderly shared stories about the children at The Lighthouse.

In a first this year, artwork created by children at The Lighthouse in collaboration with such noted artists as Bernard Séguin Poirier, Armand Vaillancourt, and Jean-Daniel Rohrer was included in the silent and live auctions, to the delight of the art lovers in attendance.

cocktailduphare.com

Young Donors’ Circle

For a second consecutive year, our Young Donors’ Circle contributed directly to the visibility and fundraising success of The Lighthouse Children and Families. This committee of engaged and energetic young business leaders attracted the attention and financial support of a new generation of donors by organizing fundraising events, including a Summer Cocktail Party at Marché Jean-Talon. The committee raised a total of $30,986 for The Lighthouse in 2016–2017.

Young Donors’ Circle Committee:

- Elisa Clavier (McCarthy Tétrault)
- Nicolas Archambault (Director and Content Producer)
- Olivier Coche (National Bank Financial)
- Tifanie Brazier (TELUS)
- Évelyne Brunet (National Bank of Canada)
- Claudia Deschamps (SNC-Lavalin Inc.)
- Marc-Antoine Saroli (TELUS)
- Eve-Marie Cormier (National Bank of Canada)

Santa’s Calling Campaign

The Santa’s Calling campaign had a record year with $34,765 in donations received. Over 300 children experienced the joy of getting a call from Santa or had the privilege of a VIP invitation to meet famous Old Saint Nick in person.

leperenoelmapelle.com
My Birthday as a Gift

My Birthday as a Gift, the general public fundraising campaign of The Lighthouse Children and Families, met with great success in 2016-2017 with **442 celebrants**, **3,540 donors**, and a total of **$187,835** raised during the year.

When you give your birthday as a gift, you ask friends, family, and colleagues to donate to The Lighthouse in honor of your birthday—a much more significant way to celebrate this annual event. Thank you to all our celebrants who gave their birthdays as gifts of joy to the sick children at The Lighthouse.

Thank you too to all the personalities who, in addition to collecting donations for the children, used their star power to draw attention to The Lighthouse.

mafeteencadeau.com

I raised money for The Lighthouse, but in reality they were the ones who helped me, because doing something for such an important cause gives you an incredible feeling of self-worth, like you’re really doing good."

- Simon-Olivier Fecteau

"I was really very touched by my visit to the facility, especially the chance to meet the children. You could just feel all the life and energy in the staff and the whole place."

- Philippe Bond

"Just because the future is dark doesn’t mean the present can’t be bright. Quite the opposite, you have to treasure every moment. That’s what they do at The Lighthouse."

- Stéphane Laporte

Donors of Goods and Services

In addition to cash donations, The Lighthouse received numerous gifts of goods and services from partners, substantially reducing its operating costs.

In advertising, such help is vital to ensuring The Lighthouse gets the broad exposure it needs. Once again this year, The Lighthouse’s TV and radio commercials were broadcast free on the major networks.

The value of this advertising amounted to over **$1.1 million** over the year.
Thank You to Our Donors

The Lighthouse wishes to express its heartfelt and unending gratitude to each of its donors, sponsors, and partners. Thank you for choosing The Lighthouse, for believing in The Lighthouse, and for carrying the cause like a bright and luminous torch for all to see. Your trust in The Lighthouse is what permits us to move forward, to create, and to build.

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Thank You to Our Donors

This is a list of donors from the last fiscal year, April 1, 2016, to March 31, 2017. It includes those who donated goods and services as well as 2016-2017 payments from multiyear donations. Much effort has been made to ensure accuracy. However if your name or your company's name has been omitted or misspelled, please accept our apologies and let us know so that we can update our files accordingly.


In memoriam donations

Merci à ceux et celles qui ont choisi d’honorer la mémoire d’un être cher en faisant un don au Phare Enfants et Familles.
Alexia during a stay at The Lighthouse