



## FOOD ALLERGY CANADA

# Helping Canadians live safely and confidently with food allergy

We are a national charity and the country's leading patient organization committed to educating, supporting, and advocating for the more than 3 million Canadians impacted by food allergy. We focus on improving daily quality of life by providing education and support needed to effectively navigate this medical condition, building informed and supportive communities, and acting as the national voice on key patient issues.



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# FOOD ALLERGY CANADA





Empowering those impacted to live well

We are the trusted provider of education and support for managing food allergy safely and confidently. Through our educational programming, support services, and medically-reviewed resources, we help individuals and families living with the condition through life stages and events, while raising awareness of food allergy and educating the broader community.



**ADVOCACY** 

The national voice for key patient issues

As the national voice for the millions of Canadians affected by food allergy, we take actions to improve daily living. We elevate the food allergy condition and engage key stakeholders nationally and globally within government, industry, and other sectors to make meaningful changes for the food allergy community.



RESEARCH

Keeping a focus on patient-centred research that can be translated into action

A research agenda that is rooted in patient engagement and focused on improving quality of life for Canadians with food allergy is critical. We ensure the patient voice is an integral part of the research process, and we translate the knowledge and insights gained from research into practical programming, resources, and tools.



### WHAT IS FOOD ALLERGY?

When the immune system mistakenly treats the protein (most often) in a particular food as harmful. The body responds by having an allergic reaction.

#### How common is it?

More than 3 million Canadians, including almost 500,000 children, are affected by food allergy. 1-in-2 Canadian households are impacted by it.



### What if an anaphylactic reaction occurs?

Anaphylaxis is a medical emergency requiring immediate treatment with epinephrine.





#### How serious is it?

Someone diagnosed with food allergy is at risk for anaphlyaxis, a potentially life-threatening allergic reaction.



#### Is there a cure?

No. Avoiding the allergenic food is required to prevent a reaction.



# A MESSAGE FROM OUR EXECUTIVE DIRECTOR



It's an exciting time for the field of food allergy with more research insights today than ever before. Research on prevention, treatment and cure provides hope for the future, yet the reality is, we can't ignore the "now", what it takes to live safely and confidently with food allergy today.

This is where Food Allergy Canada fits – providing evidence-based and medically-reviewed education and support while advocating for a better future.

Much has been achieved, but our work is far from done when you consider:

- Food allergy is not consistently understood as a serious medical condition that has no cure and requires avoidance to prevent potentially life-threatening allergic reactions
- Epinephrine is underutilized in the treatment of anaphylaxis and there is confusion on the role of antihistamines
- The rate of anaphylaxis among those with a known food allergy implies challenges with managing avoidance

- Individuals and families report a high level of anxiety around their food allergies
- 1-in-3 children with food allergy report being bullied, specifically because of their food allergy

As a parent of twin boys who manage multiple food allergies, making food allergy a priority is personal. Our family understands the lived experience of managing this condition, and we have seen through the eyes of our boys, the challenges of living confidently with it.

I'm honoured to be leading a dedicated and passionate team focused on changing the current food allergy picture. You can count on Food Allergy Canada to:

 Be at the table as your advocate – whether with government, the food industry, or the education sector, we ensure our voice is heard on issues that matter to you.

- Provide medically-reviewed and evidence-based information and educational programming. In today's environment of misinformation, knowing who to trust for credible information is paramount. We work closely with our Healthcare Advisory Board to ensure we deliver on this commitment.
- Share meaningful advancements in the research on prevention, diagnosis, and treatment possibilities.
- Educate the broader community on food allergy and what it takes to support you.

As you read through this report, I hope you are inspired to help us **#MakeFoodAllergyCount**. With your support, we can continue tackling the issues and make real and lasting impact.

Jennifer Gerdts



# A MESSAGE FROM THE BOARD CHAIR



Since joining the board over two years ago, I am consistently amazed at how much this organization has achieved and continues to drive forward. I am inspired by Food Allergy Canada's commitment to improving the quality of life for the millions impacted by food allergy, and the ability to deliver above and beyond on the mission every year.

Food Allergy Canada has taken the leadership role in advancing the food allergy conversation among government and other key partners, they consistently deliver on educating and supporting the impacted community through transformative programming, and they champion the patient voice in food allergy research.

As you read through this report, I encourage you to learn more about the impact this organization has made and how they are poised to **#MakeFoodAllergyCount** going forward. You'll also get a chance to read stories from parents and others, sharing how this organization has changed their lives.

Together with your support, Food Allergy Canada can continue to be trailblazers and keep the momentum for change going.



Bob Ellis

### **KEY MILESTONES ACHIEVED**

#### 2005



Ushered in Sabrina's Law, ground-breaking legislation to protect students at risk of anaphylaxis

#### 2014-2016



Helped to make schools safer by launching <u>AllergyAware.ca</u> to provide online anaphylaxis education to school personnel, with new courses added to educate child care staff and the public

#### 2015



Significantly improved quality of life, knowledge, and confidence in managing food allergy for parents and individuals through our newly diagnosed handbook, as substantiated by research

#### 2019



Launched the National Food Allergy Action Plan to prioritize food allergy with key stakeholders, including the federal government

#### 2011-2019



Advocated for over a decade to improve allergen labelling regulations that require manufacturers to provide easier access to ingredient information

#### 2014-2017



Increased support and empowered youth to manage their food allergy more confidently through the launch of our Allergy Pals/Allies mentorship program and monthly programs

#### 2017-2020



Accelerated the opportunity for the prevention of food allergy by increasing awareness and knowledge of evidence-based guidance on the early introduction of allergens through resources like Eat Early. Eat Often.

#### 2018-2020



Led the effort to secure a temporary second supplier of epinephrine auto-injectors during a crucial shortage period and to get permanent suppliers in Canada (ALLERJECT®, Emerade™)



# **MAKING A REAL IMPACT**

# Allergy Pals/Allies



Newly Diagnosed Program



Our son Ryan is 11, an age where management of his food allergies needed to start to become more of 'his' thing. Allergy Pals provided him with a perfect opportunity to gain some independence and participate on his own. During the session, he felt like everyone was helping each other because all the kids completely understood what it's like living with food allergy – he generally doesn't have this type of understanding or support from his peers.

Ryan feels more empowered to speak up about his food allergies and he has the confidence to manage them on his own, all because of the program. It had such a positive impact on his life.

- Melissa J., parent of child with multiple food allergies

It was overwhelming and stressful when we discovered my daughter had a food allergy, we were at a loss at how to manage this condition. Luckily, a health professional recommended Food Allergy Canada's site and we participated in a newly diagnosed webinar within days of my daughter's diagnosis. That was a game changer for us. We feel much more confident managing food allergy with the tools we learned in the session and the support we received.

This program provided us with the critical knowledge we need and information we can trust. It absolutely changed our lives and helped us tremendously.

- Gerardo C., parent of child with multiple food allergies



# **MAKING A REAL IMPACT**

**Advocacy** 



I've been involved with several advocacy initiatives as a part of the great work that Food Allergy Canada has done for the food allergy community. I have spoken in support of allergen management changes for foodservice and stock epinephrine in restaurants to help make dining experiences safer. I've hosted a community meeting with my MP to raise the profile of food allergy within government and appeared in a video for the National Food Allergy Action Plan to share my perspective on living with food allergy. I'm also aware of the organization's advocacy to improve access to epinephrine auto-injectors and there are now three suppliers in Canada! All of these efforts are so important for improving the quality of life of those living with food allergy. It's because of Food Allergy Canada and their ongoing advocacy work that these issues are getting attention, they are creating positive change in the food allergy space!

- Pauline O., parent of children with multiple food allergies

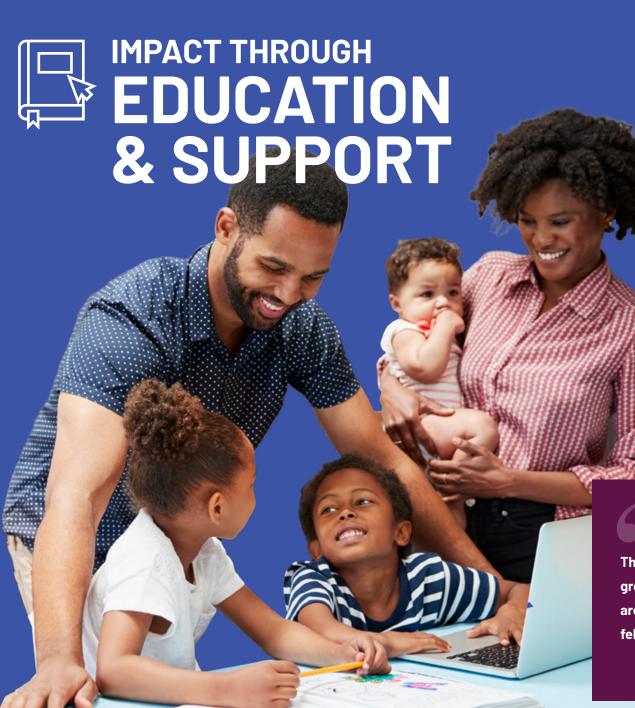
Credibility



As a part of Food Allergy Canada's Healthcare Advisory Board, I can attest to the organization being a trustworthy and credible source of information. Those with food allergy can turn to Food Allergy Canada for educational materials that are medically vetted and relevant, whether they are dealing with a new diagnosis or another point in the food allergy journey. Additionally, the organization stays current with developments in areas such as prevention and treatment, to keep the community well-informed. There is also an underlying philosophy of shared responsibility for allergen management, one which empowers patients and their caregivers to take steps to self-protect while educating and encouraging others to provide support and help to reduce risks, which is notable. Food Allergy Canada helps families live well with this condition.

- Julia Upton, MD, FRCPC, MPH





#### Program for the Newly Diagnosed

Education and support for parents and individuals

🏅 foodallergycanada.ca/newlydiagnosed

A food allergy diagnosis is life-changing, it can cause uncertainty and anxiety. Through our transformational program, individuals receive credible information and support through our comprehensive handbook and small-group webinars. 100% of participants noted they better understand how to manage food allergy after a session, and handbook users noted a significant improvement in quality of life, knowledge, and confidence in managing food allergy.

The entire presentation was helpful, invaluable and grounding. The benefits to my child and my family are endless and the positive ripple effects will be felt for quite a while. Thank you so much!

# Allergy Pals & Allies

Empowering youth through online mentorship

#### \* foodallergycanada.ca/allergypals

This free online mentorship program for ages 7-15 connects youth with food allergy and empowers them to build the skills and confidence needed to manage their condition. Almost 1,000 youth have been mentored, making a significant positive impact on their quality of life.







# National Education Series

Educating the impacted community

☆ foodallergycanada.ca/webinars

Our national education series is delivered through webinars and focuses on educating families, youth and adults with food allergy, healthcare professionals, educators, and others. Through presentations by leading allergists and experts, thousands have been educated about this medical condition and how to live well with it. Participants consistently express having a better understanding of the content after a webinar.

From our Creating a better future webinar series: This was an excellent webinar and provides so much hope for a safer future for my son.

### **Allergy Aware**

Educating the educators and broader community

☆ allergyaware.ca

AllergyAware.ca online courses are accessible, medically reviewed and provide continuity in the education on food allergy and anaphylaxis for school/child care staff and the public. The courses have been taken over 100,000 times with reports of greater confidence in preventing and treating reactions, which helps keep children at risk safe at school.



Excellent course to build capacity within a school setting.



#### **Awareness Campaigns**

Shining a light on food allergy

\* foodallergycanada.ca/faam foodallergycanada.ca/ShineATealLight

Our public campaigns during Food Allergy Awareness Month (every May) and Halloween raise the profile of food allergy amongst the broader community.

With views in the hundreds of millions, these campaigns have communicated the seriousness of food allergy, how to treat life-threatening reactions, and how to support those impacted.

66

From a family who participated in our #ShineATealLight
Halloween campaign: This campaign had a chain effect of
one voice becoming many. If you say something to one person
and make a difference, hopefully that person continues to
spread the word to amplify our voice. I found that people
in my community who were not impacted by food allergy
personally started to become more aware and joined the
#ShineATealLight movement to spread allergy awareness too.

Read the full story











BEFORE Allergen Labelling Changes

#### **Nutrition Facts** Serving Size 1 cookie (60 g) Servings Per Container **Amount Per Serving** Calories 300 Calories from Fat 140 % Daily Value\* **Total Fat** 16g 25% Saturated Fat 10g 50% Trans Fat 0q Cholestrol 35mg 12% Sodium 350ma 15% ess is a little, 15% or more is a lot Ingredients: Apples, Shortening, Liquid albumen (egg), Salt, Sugar, Flour (wheat), Lemon juice, Casein (milk), Cinnamon. Contains: Wheat, Egg, Milk. May contain pecans.

AFTER Allergen Labelling Changes

# Food Allergen Labelling

Ensuring every Canadian knows what's in their food

#### \* foodallergycanada.ca/advocacy

Knowing what's in your food is critical in preventing allergic reactions. Through our ongoing advocacy with Health Canada for more than a decade, we helped to make food labels easier to understand. Our efforts have contributed to significant changes, including:

- Updated food allergen labelling regulations in 2011 to make it mandatory for priority food allergens to be listed in plain, simple language (e.g., "milk" vs. "casein")
- Guidance on the use of one precautionary allergen statement ("may contain") to indicate potential risk of cross-contamination with a priority food allergen in 2012
- New requirements in 2016 on the legibility of ingredient labels
- The declaration of priority food allergens in beer products in 2019

Our advocacy has enabled safer food choices.

# Overcoming a Shortage of Life-Saving Medicine

#### Increasing access to epinephrine

#### \* foodallergycanada.ca/advocacy

Anaphylactic reactions can happen despite preventive measures. Being prepared with epinephrine auto-injectors is paramount, yet there have been challenges with consistent access to these devices. In 2018, our advocacy with Health Canada, the provinces and territories, pharmaceuticals, and other key stakeholders helped to secure a temporary alternate supply during a time of EpiPen® supply interruptions, the only device offered in Canada at the time. More recently in 2020, our advocacy initiatives helped to bring additional epinephrine auto-injector suppliers to Canada (ALLERJECT®, Emerade™). Now, Canada is no longer a single-source market and has a minimum of two device options, providing greater access to epinephrine, which can ultimately save lives.



# Health Minister announces access to a U.S.-approved epinephrine auto-injector

- Health Canada press release - August 2018



I'm pleased that we have been able to secure a supply of epinephrine auto-injectors for Canadians with lifethreatening allergies and their loved ones, particularly as families across the country are currently preparing for the start of the school year. We will continue to work with partners and stakeholders on long-term solutions to make sure life-saving auto-injectors remain available.

**The Honourable Ginette Petitpas Taylor**Former Minister of Health

We commend Health Canada for leading the effort to secure an interim solution to the shortage of epinephrine auto-injectors, a necessary step to ensuring that Canadians have access to this life-saving medication. As one of the key stakeholders involved in this effort, we will continue to work with Health Canada and others towards a longer-term plan that focuses on having a minimum of two suppliers in Canada. Our immediate next step is to help ensure that patients receive clear information on when and how they can access this new supply.

**Jennifer Gerdts, Executive Director**Food Allergy Canada

# Helping to #MakeFoodAllergyCount

#### Driving the National Food Allergy Action Plan

#### \* foodallergycanada.ca/nationalplan

Canadians with food allergy know the importance of individual responsibility when managing their medical condition, yet they are dependent on a societal apparatus of awareness and empathy, policies, and processes to help keep them safe.

The challenges faced by the more than 3 million Canadians affected by food allergy can lead to enormous psychological, physical, and social burdens. Almost half of respondents from a patient survey described their anxiety level as 8 out of 10 or higher. 1-in-3 children with food allergy report being bullied because of their food allergy. In Canada, the estimated annual individual cost of having food allergy is \$1.26 billion.

Food allergy is also a health equity issue. Access to an allergist is critical to getting an accurate diagnosis yet many lack this access. Canadians with food allergy are reliant on accurate ingredient information from food providers to avoid what they are allergic to and minimize having a potentially life-threatening allergic reaction. Compounding this is the inconsistent understanding by the public that food allergy is a serious medical condition.



To address these issues, we partnered with the Canadian Society of Allergy and Clinical Immunology (CSACI) to develop a comprehensive National Food Allergy Action Plan. Launched in 2019, this plan is intended to spur government leadership and fill voids in policy ideas, public understanding, industry practices, and research commitments in food allergy.

Once the plan is fully funded and implemented, we can help to save lives, reduce food allergy prevalence, lower healthcare costs, reduce the economic impact, and improve the quality of life for Canadians affected by this medical condition.

#### National Food Allergy Action Plan

#### **Mission**

To help Canadians with food allergy live safely & confidently, & advance the prevention, diagnosis & treatment of food allergy.

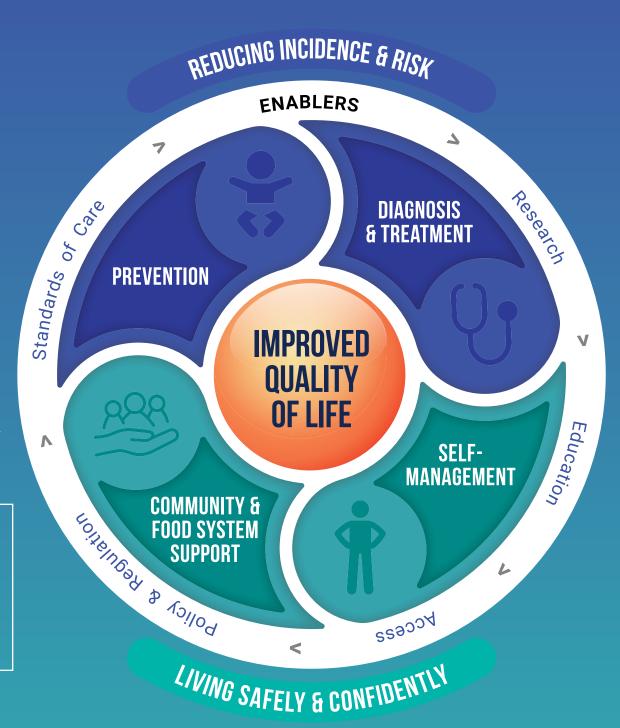
#### **Framework**

The National Food Allergy Action Plan requires a comprehensive approach to reduce the impact of food allergy and improve the quality of life of Canadians living with this condition. The framework of the plan focuses on reducing allergy incidence and risk and on helping Canadians with food allergy live safely and confidently.

Get involved and advocate for the **National Food Allergy Action Plan**.

Learn how you can #MakeFoodAllergyCount

foodallergycanada.ca/nationalplan





## **LOOKING FORWARD**

Over the next five years, we will continue to focus on our core mission of educating and supporting the impacted community and advocating on their behalf to make life better.

#### **EDUCATION AND SUPPORT**

### Newly diagnosed programming



Self-management programming



Public and school programming



**CURRENTLY:** When parents first learn their child has a food allergy, it is a whole new world of uncertainty, anxiety, hopelessness, and fear.

**CURRENTLY:** There are delays or failure to treat anaphylactic reactions because individuals at risk are unsure about the symptoms of reactions and when to use epinephrine.

**CURRENTLY:** The seriousness of food allergy is not consistently recognized by the public, and there is confusion between food allergy and food intolerance.

**GOAL:** Empower individuals who are recently diagnosed to manage with confidence.

**GOAL:** Empower individuals with food allergy to manage with greater confidence.

**GOAL:** Educating the next generation and the public on the seriousness of food allergy.

**STRATEGIES:** Continue to invest in the newly diagnosed to ensure they are getting the support and credible information they need at the critical point in time when they receive this life-changing diagnosis.

strategies: Develop and execute national education programs on signs and symptoms and how to treat allergic reactions for youth, parents, individuals, and healthcare professionals. These programs are essential to improving the quality of life for impacted Canadians.

**STRATEGIES:** Develop and execute public campaigns and school programming to educate the next generation and increase the awareness and understanding of food allergy, while also increasing empathy and support for those living with this condition.



## **LOOKING FORWARD**

#### **ADVOCACY**

#### Access to accurate ingredient information



#### **National Food Allergy Action Plan**



**CURRENTLY:** Food labelling issues and inconsistencies in allergen management practices within the food industry have resulted in severe allergic reactions, limited safe food options, and a lack of confidence in being able to assess the true risk of cross-contamination.

**GOAL:** Ensuring every Canadian knows what is in their food.

**GOAL:** To have a fully funded plan that once executed will reduce the impact of food allergy and improve the quality of life for impacted Canadians.

STRATEGIES: Continue to drive this issue forward and collaborate with the food industry, government, and other key stakeholders. Canadians managing food allergy need a safe eating strategy and easy-to-access ingredient information to make informed and safe food choices. Access to accurate ingredient information, particularly outside pre-packaged foods, and within the foodservice industry, will help Canadians navigate safe choices and live more confidently.

STRATEGIES: Continue to engage with the government, industry, and other key stakeholders to fund and initiate the key elements of the plan which includes prevention, management, treatment and broad-based community and food system support.

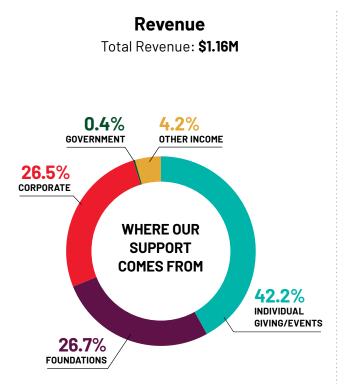
**CURRENTLY:** With no cure for food allergy and gaps in policy,

a national plan is necessary, yet it remains unfunded.

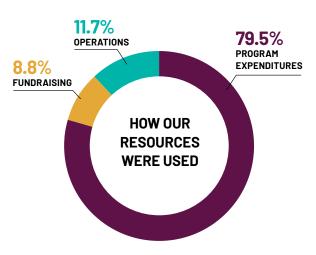
industry practices, research commitments, and public understanding,

### **DOLLARS DRIVING IMPACT**

**OUR FINANCES: 2019** 







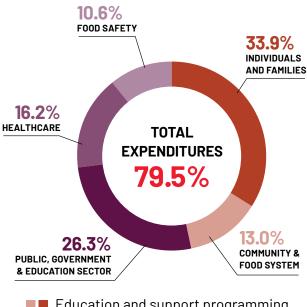
NOTE: Third party event with a directed donation to research is excluded from 2019 revenue and expenditures.

#### **Programs Expenditure Ratio**

Food Allergy Canada is committed to keeping administrative costs low and educational and support programming along with key stakeholder engagement high, enabling us to advocate effectively. The costs of fundraising and operations are at an average of 20 cents of each dollar raised, with the remaining 80 cents of every dollar going towards programming and awareness/engagement initiatives benefitting over 3 million Canadians affected by food allergy and their families.

#### **Program Expenditures**

Areas of work this funding supported:



- Education and support programming
- ■■■ Awareness and engagement initiatives

#### **Download**

- \* Registered Charity Information **Return - 2019**
- \* Food Allergy Canada Detailed Financial Statements - 2019

### **THANK YOU: 2019 SUPPORTERS**

#### TRANSFORMATIVE SUPPORTERS

Walter and Maria
Schroeder Foundation

Family and Friends of Sean Delaney

#### **FOUNDATION SUPPORTERS**

The Charles Norcliff Baker
& Thelma Scott Baker Foundation

Tagliani Foundation

Williams Wilson Sherport Foundation

#### INDIVIDUAL SUPPORTERS

Thank you to the more than 760 individuals and families who supported Food Allergy Canada in 2019.

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Aimmune Therapeutics

Captivate Network

Dare Foods

Heller Productions Inc.

kaléo / ALLERJECT®

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# **CONTACT US**

#### **Food Allergy Canada**

505 Consumers Road, Suite 507 Toronto, ON M2J 4V8

#### foodallergycanada.ca

1866 785-5660

info@foodallergycanada.ca











Learn more and help to #MakeFoodAllergyCount at **foodallergycanada.ca** or call **1866 785-5660** 

