Canadian FOP Network Newsletter

Join us for our Annual General Meeting!
Date: **November 15, 2026, at 7 PM Eastern time** via Zoom videoconferencing.

Join us on Zoom videoconferencing for a Drug Development Update by Dr. Angela Cheung! This exciting event will occur on **November 26, 2026, at 8 PM Eastern time**. Link to the event coming soon.

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Edited and compiled by Kathleen Degenhardt

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Meet the Board

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Our Mission: Dedicated to raising awareness and research funds for a rare bone disease called Fibrodysplasia Ossificans Progressiva (FOP).

What's New

Toronto was the site of the International FOP Association's biennial Drug Development Forum from August 28-30, 2026! Read about it below.

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IFOPA Drug Development Forum

by Karen Munro

The International FOP Association (IFOPA) recently hosted the biennial Drug Development Forum (DDF) in Toronto. This year the DDF took place from August 28 to 30, 2026. The event is an important conference for researchers, scientist, and doctors working on FOP. Most specifically, the goal is for FOP drug development experts to learn about each others' work, to collaborate, and to forge new ideas.

Previous DDFs have alternated between a European and an American location. The last DDF, held in 2024, took place in Stockholm, Sweden, so it was an exciting surprise that this year's event was announced for Toronto!

Although the DDF is targeted at scientists, the event takes place in conjunction with a day-long meeting of the International Presidents' Council (IPC), and so I was invited to attend both events. The IPC is a group of the leaders of all the international FOP organizations. Present at this year's meeting, which took place on August 27, 2026, just before the DDF, were the representatives of FOP groups from Canada (me!), the UK, the Netherlands, Greece, Poland, China, Germany, pan-Africa, Colombia, Argentina, Malaysia, and several other countries via Zoom link. We had important presentations from pharmaceutical representatives on the process of drug development and approval, and we discussed our priorities for the future. In particular, we talked about the importance of treatments for FOP being affordable and available to FOP patients world-wide.

A formal dinner opening the DDF took place on the evening of August 27. The IFOPA graciously invited some local FOP families to attend, and so I was delighted to spend time with Valerie Herce and her aunt, Elsa and Richard Wallace (parents of the late Marin Wallace), Kim Wilson (mother of Trent Biro), and Jaxon Hamilton and his mother, Lara Theoret! The IFOPA's gene discovery video series, which was presented earlier this year in several parts, was shown pieced-together in a combined presentation. The video was exceptionally well-done and very moving – I expect there were no dry eyes in the room. (NOTE – if you want to see the constituent videos yourself, go to YouTube and search for IFOPA, then scroll down to the "Journey to Discovery" videos).

The DDF itself took place over the next 2.5 days, and it included presentations on such varied topics as:

- The fundamentals of FOP biology (and yes, they are still learning new things about this important subject);
- Identification of potentially effective therapeutic substances;
- Pre-clinical experiments;
- Clinical testing;
- The drug approval process;
- Real world patient experiences with FOP drugs;
- Hearing loss in FOP;
- Combining drugs for FOP treatment;
- Selecting the right candidates for future surgeries on FOP patients;
- Ultra-rare FOP variant patients;
- The future of FOP treatments, including gene therapy;

And a great deal more. It was an absolute whirlwind! Not being a scientist, I didn't understand a lot of it, but it was incredible to see the amount of interest in treatments and a cure for FOP.

It was also exciting to see Canadian researchers present their work. The following people from Canada participated in the DDF:

- Representatives from Dr. Toshi Yokota's University of Alberta lab shared their progress on gapmers to suppress FOP; these folks have been previous expert speakers at our FOP Family Meetings in 2017 and 2025.
- Christinne Falguera, a graduate student working with Dr. Peter Kannu at the University of Alberta, presented her poster titled "Exploring the experiences of Canadian patients and their families impacted by FOP" (many thanks to everyone who contributed to Ms. Falguera's important work).
- Ella Liu, a medical student working with Dr. Angela Cheung at the University of Toronto, presented a talk about an FOP patient in Canada with an ultra-rare type of FOP variant.
- Dr. Angela Cheung of Toronto General Hospital showed her poster describing experiences with FOP patients using the FOP medication Sohonos.

- Dr. Michael Underhill of the University of British Columbia presented his work on the mechanics of bone formation (not direct FOP research, but a related topic).
- Dr. Tracie Pennimpede of Queen's University talked about her lab's work on a substance that seems to target ossification in FOP without toxicity to developing growth plates.

I didn't previously know about the work of Drs. Underhill and Pennimpede, so these speakers came as pleasant surprises.

In addition to the scientists and researchers, speakers from Canadian families living with FOP participated in patient panels. These panels were absolutely vital to helping the scientists and physicians understand how FOP affects patients on a day-to-day basis. The Canadians who generously gave of their time were Kim Wilson, mother of Trent Biro of Ontario, and Lara Theoret and her son Jaxon Hamilton, also of Ontario. I was very proud of our Canadian participants, who spoke meaningfully of their experiences.

This was my second Drug Development Forum, and I found it to be incredibly valuable. I give my most profound thanks to the International FOP Association for organizing and hosting the event, and in particular, for holding it in Canada.

Lara Theoret, Michelle Davis of the IFOPA, Jaxon Hamilton

Kim Wilson, Karen Munro, Lara Theoret, Christinne Falguera, Jaxon Hamilton

Christinne Falguera's Presentation at the Drug Development Forum, printed here with her permission

Exploring the Experiences of Canadian Individuals and Their Families Impacted by FOP

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Introduction

- Fibrodysplasia ossificans progressiva (FOP) is a rare genetic disorder caused by a missense variant in the *ACVR1* gene disrupting the bone morphogenic pathway.
- Leads to heterotopic ossification (HO)—the abnormal formation of bone in soft tissues.
- Causes progressive loss of mobility and impairs cardiorespiratory function over time.
- Only ~20 known individuals with FOP in Canada.
- FOP flare-ups are unpredictable, cause severe pain, and can accelerate HO progression.
- By adulthood: increasing disability, psychological distress, and emotional strain for families.

Figure 1. Progression of HO in 3 Individuals with FOP. Kannu and Levy (2021) The Journal of Pediatrics.

RATIONALE

Most FOP experience research has been conducted internationally, with the majority of participants based in the U.S. Existing studies rely largely on burden-focused surveys and diagnostic statistics. These findings do not fully capture lived experiences, challenges, and strengths.

RESEARCH QUESTION AND AIMS

What are the lived experiences of Canadian families with FOP?

Three Key Aspects of the FOP Experience:

1. Diagnostic Journey
2. Transition From Pediatric to Adult Care
3. Resiliency and Coping Strategies

Methodology

CONCEPTUAL FRAMEWORK

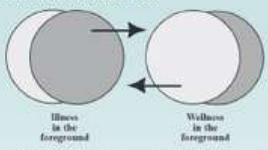

Figure 2. The Shifting Perspectives Model of Chronic Illness Paterson (2001) Journal of Nursing Scholarship.

- Shifting Perspectives Model: Describes how individuals with chronic illness shift between states of illness and wellness. Applying this model helps us understand how individuals with FOP adapt over time.

STUDY DESIGN AND PARTICIPANT SAMPLE

- Focused ethnography: Examines a specific topic within a small group of people with shared experiences over a shorter timeframe.
- This approach allows us to explore participants' experiences from their perspective (emic view), while also incorporating my interpretation (etic view).

Figure 3. Participants

- Individuals with FOP and parents were recruited locally and through the CFOPN society. Clinicians with FOP experience were recruited by my supervisor.
- Twenty semi-structured interviews and three focus groups.
- Interviews were audio and video recorded, then transcribed verbatim and anonymized. Transcripts were analyzed using qualitative content analysis.

Results

Figure 4. Three Themes and Associated Participant Quotes

Conclusion

- Through collaboration with CFOPN, this study amplifies patient and parent voices to identify system-level barriers, including diagnostic delays, fragmented care, and gaps in transition planning.
- Using FOP as a case example, these findings may inform more responsive, patient centered care pathways for other rare genetic disorders and people living with permanent mobility loss.
- Centering lived experience gives participants a meaningful opportunity to reflect on and share perspectives that ay otherwise be overlooked in research and care.

Limitations

- English speakers, individuals within CFOPN, and individuals who have access to a computer or phone.
- All individuals with FOP seen within a public healthcare system.
- Study sample may have been subject to self-selection bias.

Acknowledgements

UNIVERSITY OF ALBERTA
IPSEN
Shriners Hospitals for Children

References

References are available upon request. Please contact Christinne Falguera at Falguera@ualberta.ca

The Marin Elizabeth Wallace Independent Living Award

The Marin Elizabeth Wallace Independent Living Award has been established in loving memory of Marin Elizabeth Wallace, who passed away in 2020. Marin Elizabeth Wallace was a Canadian who lived with FOP and an alumnus of York University receiving her BA in English in 2005. Marin Elizabeth Wallace was a committed York University student and graduate who also wrote and edited for Excalibur.

Further to Marin's degree from York, she moved on to obtain her Masters in Publishing from Oxford Brooks University in Oxford which she completed in person in 2009/2010. She worked in editing and writing for various publications over many years. The donation for the bursary was mostly money she herself had made from her writing.

The Marin Elizabeth Wallace Independent Living Award will be awarded annually to an entering or continuing full-time student enrolled in a program in the Faculty of Liberal Arts and Professional Studies who is also receiving support from a registered disability pension such as; ODSP, ADSP etc.

To apply, please complete your **FAAS profile**.

For more information, head to **this link: https://www.yorku.ca/laps/student-award/the-marin-elizabeth-wallace-Independent-living-award/**

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Girl Guides Scholarship

Miranda Lena Munro Friz was a Canadian who lived with FOP between 2005 and 2020. During her lifetime, Miranda was a committed member of the Girl Guides of Canada. Miranda went though each level of Guiding, and she loved it all. During the last year of her life, she was both a Pathfinder (girls aged 12-14) and a junior leader of a unit of Brownies (girls aged 7 and 8, now called Embers).

When Miranda unexpectedly passed away at age 15, her parents created a scholarship through Girl Guides of Canada in her memory. The Miranda Friz Memorial National Scholarship is available to a member of Girl Guides of Canada who is pursuing post-secondary studies in social sciences or gender studies.

To learn about some of the worthy Guides who have been awarded this scholarship or to apply, go to the **Girl Guides of Canada website** at the following link:

https://www.girlguides.ca/WEB/GGC/Volunteers/Membership_Opportunities/Scholarships/2025_Scholarship_Recipients.aspx

Prevalence of FOP in Canada

by Karen Munro

How many people worldwide live with FOP? What about in Canada? And why does it matter? Let's dive into this subject! In fact, every FOP diagnosis is vitally important for multiple reasons.

Arguably the number one concern is that people with FOP need the correct diagnosis to avoid harm. When FOP is not properly diagnosed, FOP is often mistaken for other medical conditions and patients may receive improper medical treatment that provokes FOP flare-ups (eg, amputations, biopsies, chemotherapy, manual limb manipulation, etc). Some of these unnecessary interventions have permanent and disabling effects.

Another major issue is research into treatments. Having a correct calculation of the number of FOP patients may affect whether pharmaceutical companies decide to put money into drug research. On a related note, when a company is making the effort to carry out a drug trial, the more potential participants there are, the better – if we diagnose more people, there are more possible trial subjects.

Still another reason is simply giving people certainty about their medical status. Anyone with an undiagnosed issue will tell you that it is EXTREMELY stressful. In past decades, there have been many cases of people experiencing FOP for long periods of time and not knowing what was happening. In my family's own case, we knew for 9 months that our daughter, Miranda, had a medical concern, and I spent many a sleepless night worrying about her. 9 months is nothing, though, compared to over 20 years, which is the undiagnosed period experienced by a Ukrainian family that attended our CFOPN family meeting in 2009!

When our family got Miranda's diagnosis in 2007, we were told that 1 in 2 million people have FOP. If I recall correctly, this number was determined based on a prevalence study some years previously. I remember thinking that since the world population was (at that time) about 7.5 billion, this means there were likely 3,750 people with FOP, though at the time only about 800 were known to the International FOP Association (IFOPA).

Based on the believed prevalence, Canada wasn't doing badly at identifying patients.

When the Canadian FOP Network (CFOPN) was founded in 2009, Canada's population at that time was about 33.7 million, and so we should have had about 17 people living with FOP.

We actually had a membership of 10-12, but over the next few years we gained 3 or 4 more FOP members. By 2015, we were close to the expected figure of 1 in 2 million. But... Just a few years ago, FOP scientists decided to carry out more up-to-date prevalence studies. What they learned came as a surprise – in parts of Europe and the Americas, the prevalence of FOP was revealed to be closer to 1 per million!

To be more specific, the range was between 0.61 and 1.43 per million*, with the United States figure at 0.88 per million**.

Overnight, the expected prevalence increased significantly. There is no reason to think that the numbers aren't typical throughout the world, meaning that with our current world population of about 8.3 billion, there could be over 8,000 people with FOP. Only about 1,000 are currently known to the IFOPA, which suggests that around 7,000 people with FOP may be undiagnosed (some may be correctly diagnosed though not connected to the IFOPA).

Identifying new people living with FOP is the mission of the Tin Soldiers organization. Tin Soldiers has been instrumental in finding FOP patients in areas such as Africa and India where the number of diagnosed people was very low. You can read all about Tin Soldiers and its mission in the CFOPN's February 2026 newsletter.

Now let's turn back to Canada. With the newly understood higher prevalence, do we still think we know of most folks living here with FOP? There are currently 41.3 million people in Canada, and if we use the American prevalence figure of 0.88 in 1 million, we ought to have about 36 persons living with FOP. However, I spoke to renowned FOP expert Dr. Fred Kaplan recently, and he told me he thinks the worldwide prevalence is closer to 0.71 per million. If Dr. Kaplan's rate is correct, then we ought to have about 29 persons with FOP. I suggested to Dr. Kaplan that the range in Canada is likely between 29 and 36 persons, and he agreed.

As it happens, the CFOPN has only 24 FOP members. Of course, not all diagnosed FOP patients are members of our group, and we as an organization are aware of 4 additional non-CFOPN-member Canadian persons.

The total population of FOP patients in Canada known to the CFOPN is thus 28.

However – a total population of only 41.3 million is quite small. If even a few people with FOP died at unexpectedly young ages, then that skews the demographics significantly.

Therefore, I consider that we should add in 6 people who died early and who, if alive today, would be under age 50 - after all, the universe doesn't know to create a brand-new FOP person just because someone passed away young.

If we add in those 6 extra people (of whom 3 would be under age 30), then our total comes to 34.

How does this look per region of Canada? Here are the numbers:

Province/Region:	Population:	Expected FOP:	Actual FOP:
Alberta	5 million	3-5	4 (3 living)
Atlantic provinces	2.6 million	2	2
British Columbia	5.7 million	4-5	3 (2 living)
Manitoba	1.5 million	1	0
Ontario	16.2 million	12-14	18 (15 living)
Québec	9.1 million	6-8	5 (4 living)
Saskatchewan	1.3 million	1	1
Territories	0.134 million	0	0
Other (born here but left)	N/A	0	1
TOTAL:	41.3 million	29-36	34 (28 living)

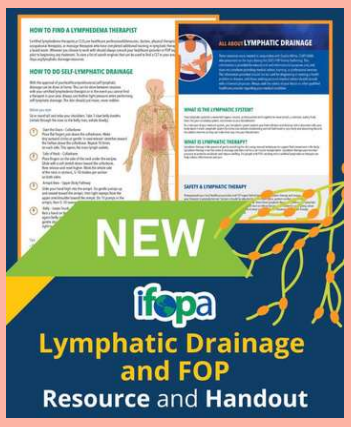
Given these numbers, we are within the expected range of 29-36 FOP patients. Even if we consider only those still living, at 28 we are just about at the low end of the range. Therefore, I think it's fair to guess that we've identified close to everyone in Canada (or born in Canada) with FOP. Of course, we would still like to know any that we might have missed, but overall, Canada has done well at identifying FOP patients.

Sources:
* Pignolo et al. The natural history of fibrodysplasia ossificans progressiva: A prospective, global, 36-month study. Genetics in Medicine. 2022; 24, 2422-2433
** Pignolo et al. Prevalence of fibrodysplasia ossificans progressiva (FOP) in the United States: estimate from three treatment centers and a patient organization. Orphanet J Rare Dis. 2021; 16:350

Resources to Know About

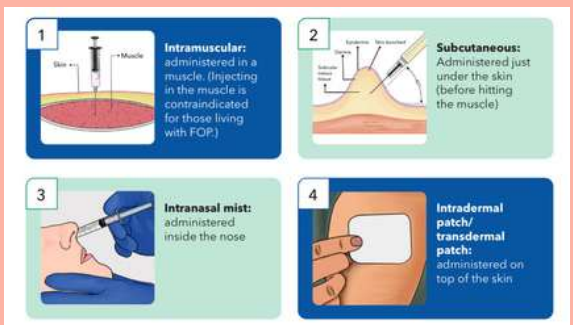
Lymphatic Drainage

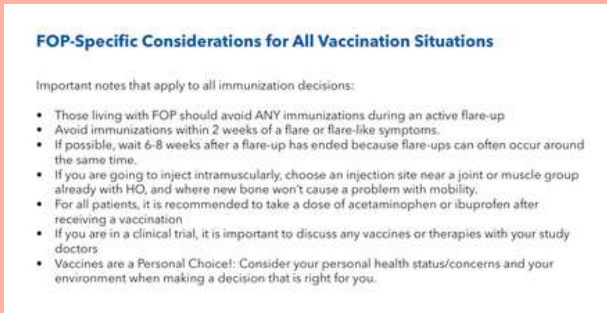
Lymphatic drainage may help clear fluid for FOP patients. The IFOPA has put together this **wonderful guideline of information.**



Vaccines

As we get into the fall and vaccines, **here is a guideline** for FOPers and their families on how to choose if a vaccine is right for you.





FOP-Specific Considerations for All Vaccination Situations

Important notes that apply to all immunization decisions:

- Those living with FOP should avoid ANY immunizations during an active flare-up
- Avoid immunizations within 2 weeks of a flare or flare-like symptoms.
- If possible, wait 6-8 weeks after a flare-up has ended because flare-ups can often occur around the same time.
- If you are going to inject intramuscularly, choose an injection site near a joint or muscle group already with HO, and where new bone won't cause a problem with mobility.
- For all patients, it is recommended to take a dose of acetaminophen or ibuprofen after receiving a vaccination
- If you are in a clinical trial, it is important to discuss any vaccines or therapies with your study doctors
- Vaccines are a Personal Choice!: Consider your personal health status/concerns and your environment when making a decision that is right for you.

Impacts of FOP on Hearing, Speech, and Swallowing

Here are some new resources on the **impacts of FOP on hearing, speech, and swallowing**. Thank you to the IFOPA for creating this resource.

THE IMPACTS OF FOP ON
HEARING, SPEECH AND SWALLOWING

Some individuals living with FOP share that complications from new bone growth and swelling in or around the ear, jaw and tongue are among the most significant challenges they face as FOP progresses. These changes can affect the individual's ability to swallow, speak clearly and hear. Understanding how FOP impacts these areas and taking proactive steps with specialists such as audiologists, laryngologists and speech-language pathologists can help individuals manage symptoms and improve quality of life.

HEARING AND FOP

The reported prevalence of hearing loss among individuals with FOP varies across studies. One study reported a prevalence of 5% in individuals under 18 years of age (She et al., 2020), while another found that 52% of survey respondents with a mean age of 25 years experienced hearing loss (Levy et al., 1999).

Cause of Hearing Loss

- Hearing loss is most likely to occur due to ossification of the middle ear structures.
- Conductive hearing loss, like that experienced in FOP, should improve with external amplification (such as hearing aids).

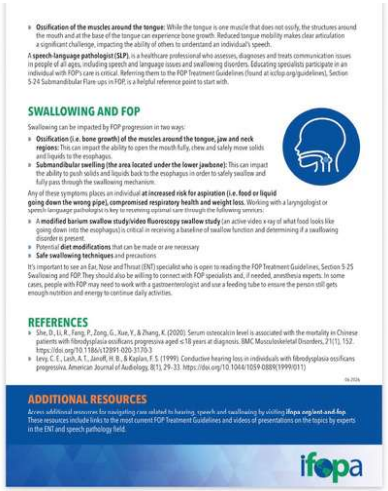
What Steps Should be Taken

- **Regular hearing evaluations should be done by an audiologist at least once a year.** If any hearing loss is detected, frequency of screenings should be increased based on conversations with an evaluating audiologist.
  - School screenings and primary care office checks are not sensitive enough as they only measure hearing on a simple pass/fail scale. These tests can miss the gradual, progressive hearing loss common in FOP. Regular evaluations by an audiologist are essential, as they provide detailed measurements that can detect even small changes over time.

SPEECH AND FOP

Speech can be impacted by FOP progression in one of three ways:

- **Respiratory restrictions:** Lung health can significantly impact the volume of one's speech, making it more difficult to understand the individual. For further resources and steps to take to protect one's respiratory health, visit our **FOP and Lung Health** page at **ifopa.org/lung_health**
- **Ossification (i.e. bone growth) of jaw muscles:** Reduced mouth opening can impact the ability to use one's lips properly to form words and also results in decreased volume of speech, making it more difficult for others to hear or understand the individual.



- **Ossification of the muscles around the tongue:** While the tongue is one muscle that does not ossify, the structures around the mouth and at the base of the tongue can experience bone growth. Reduced tongue mobility makes clear articulation a significant challenge, impacting the ability of others to understand an individual's speech.

A **speech-language pathologist (SLP)**, is a healthcare professional who assesses, diagnoses and treats communication issues in people of all ages, including speech and language issues and swallowing disorders. Educating specialists participate in an individual with FOP's care is critical. Referring them to the FOP Treatment Guidelines (found at ectfop.org/guidelines), Section 5-24 Submandibular Flare-ups in FOP, is a helpful reference point to start with.

SWALLOWING AND FOP

Swallowing can be impacted by FOP progression in two ways:

- **Ossification (i.e. bone growth) of the muscles around the tongue, jaw and neck regions:** This can impact the ability to open the mouth fully, chew and safely move solids and liquids to the esophagus.
- **Submandibular swelling (the area located under the lower jawbone):** This can impact the ability to push solids and liquids back to the esophagus in order to safely swallow and fully pass through the swallowing mechanism.

Any of these symptoms places an individual at **increased risk for aspiration (i.e. food or liquid going down the wrong pipe), compromised respiratory health and weight loss.** Working with a laryngologist or speech-language pathologist is key to receiving optimal care through the following services:

- A **modified barium swallow study/video fluoroscopy swallow study** (an active video x-ray of what food looks like going down into the esophagus) is critical in receiving a baseline of swallow function and determining if a swallowing disorder is present.
- Potential **diet modifications** that can be made or are necessary
- **Safe swallowing techniques** and precautions

It's important to see an Ear, Nose and Throat (ENT) specialist who is open to reading the FOP Treatment Guidelines, Section 5-25 Swallowing and FOP. They should also be willing to connect with FOP specialists and, if needed, anesthesia experts. In some cases, people with FOP may need to work with a gastroenterologist and use a feeding tube to ensure the person still gets enough nutrition and energy to continue daily activities.

REFERENCES

- She, D., Li, R., Fang, P., Zong, G., Xue, Y., & Zhang, K. (2020). Serum osteocalcin level is associated with the mortality in Chinese patients with fibrodysplasia ossificans progressiva aged ≤18 years at diagnosis. BMC Musculoskeletal Disorders, 21(1), 152. https://doi.org/10.1186/s12891-020-3170-3
- Levy, C. E., Lash, A. T., Janoff, H. B., & Kaplan, F. S. (1999). Conductive hearing loss in individuals with fibrodysplasia ossificans progressiva. American Journal of Audiology, 8(1), 29–33. https://doi.org/10.1044/1059-0889/1999/011

ADDITIONAL RESOURCES

As we additional resources for navigating care related to hearing, speech and swallowing by visiting **ifopa.org/ent-and-fop**. These resources include links to the most current FOP Treatment Guidelines and videos of presentations on the topics by experts in the ENT and speech pathology field.

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FOP Members Doing Things They Enjoy

James fishing

Adamo walking his dog, Sparkie

Trent and his dad at the Toronto Blue Jays baseball game

Ian, his sister, and a friend shopping at Costco

Kathleen at the T-Rex Discovery Centre in front of Scotty.

Jaxon playing ping pong