



## Family Day 2018

A family gathering for  
juvenile arthritis + other  
rheumatic diseases

Saturday, October 13, 2018  
Delta Hotels by Marriott | Burnaby



## Family Day 2018 Camp Director's Welcome



2



### Welcome to our 10<sup>th</sup> Annual BC Family Day Conference in Burnaby, BC!

Thank you for being a part of this year's event and what we hope will be an unforgettable day of learning, connection and fun.

Over the past ten years, Cassie and Friends has brought together hundreds of families, just like yours, to share stories, learn from each other, hear from experts and to know, without a doubt – you are not alone.

Our vision for what it means to transform lives in the Juvenile Arthritis and rheumatic disease community has never been stronger. In 2018/19, we are excited to push our commitment to kids and families even further as we work to bring more support, research, advocacy and education to families and centres across Canada.

Most importantly, we remain steadfastly focused on what matters most – the kids! We want every child and sibling affected by JA to know that arthritis is a condition, but will never define who they are or what they can be.

PS: Be sure to visit our photobooth to get your family photo taken, and share it with us + others via social media using our conference hashtag: **#JAwontstopme**. Thank you for being a part of this year's event.

**Jennifer Wilson**  
Executive Director  
Cassie and Friends Society

## Family Day 2018 Camp Program Leader



3



### Over the past ten years, my family has made more memories and friendships at Cassie and Friends' Family Days than we could ever count.

And every year, we leave feeling stronger than ever to face the challenges and unknowns of Juvenile Arthritis together.

Our committee chose the theme "Camp Cassie and Friends" with just that feeling in mind. We want Family Day to be a place where you come with your family and CONNECT with each other. Where you can lean on friends – old and new – and learn and have fun.

I sincerely hope you will enjoy our program today – from our fireside chat with Olympian, Spencer O'Brien to educational sessions designed to help you learn more about how to support your child and family through the many challenges that can accompany life with chronic disease.

Take a break from stress and worry, make new connections and leave knowing you have incredible support in both each other and Cassie and Friends. I sincerely hope you have an amazing camp experience and that you, too, will be inspired to join our community and give back!

**Debbie Setton**  
Chair, Family Day Committee  
Cassie and Friends Society

Family Day 2018

## Greeting from our Healthcare Partner

4



### BC Children's Hospital Division of Pediatric Rheumatology

#### Message from Dr. Lori Tucker, Pediatric Rheumatologist & Board Member, Cassie and Friends

Juvenile Idiopathic Arthritis (JIA) affects more than 24,000 children and youth in Canada, that's every 3 in 1000 kids in BC (about the same number of children as type 1 diabetes, and about twice as many as cystic fibrosis). Other rheumatic diseases in children, such as systemic lupus erythematosus (SLE), dermatomyositis, vasculitis, and periodic fever disorders are less common, but all together, there are a large number of children in BC with these conditions.

Our entire pediatric rheumatology team at BC Children's Hospital is very proud to be a part of this special community of kids, parents, health care providers and other friends. From educational events like Family Day to the annual Cassie and Friends run, we find great inspiration in working alongside each of you to raise much-needed support and awareness for all kids living with rheumatic conditions and to keep pursuing the answers and outcomes your children deserve.

Family Day 2018

## Greeting from our Major Sponsors

5



### Ally for Life: BMO

BMO Canada offer its very best wishes for a successful Family Day! BMO is honoured to support this important day so that children living with Juvenile Arthritis, and their families, can build lifelong bonds as they grow and progress with their condition. We are pleased to work alongside an organization like Cassie & Friends that truly makes a difference in the lives of children and families facing challenging times.



### Champion for Kids – Travel Sponsor: The Arthritis Society of BC & Yukon

#### Message from Christine Basque, Executive Director

The Arthritis Society, BC & Yukon is pleased to be a part of this meaningful day with you and your family, and to help those in need attend Family Day through special travel bursaries. We are excited to collaborate in this meaningful partnership with Cassie & Friends which helps to support the Juvenile Arthritis community. We believe there are many such collaborative opportunities for The Arthritis Society and Cassie & Friends as we step forward into the future together!

# Family Day 2018

## Camper Information

6



**We hope you have a meaningful and fun day at Camp Cassie and Friends. We've gathered some information below to assist you and your campers at the event.**

### EMERGENCIES

Call 911. If possible, please also notify a Cassie & Friends' volunteer.

### NETWORKING

Campers can choose to identify the type of rheumatic disease that affects them with a corresponding bead placed on their lanyard. Please visit the Beads Station on Level 2 to learn more.

### PARENT CABIN

If you are a returning parent and/or wish to enjoy a more informal opportunity to connect during the day, please feel free to visit our Parent Cabin (Maranello Room on Level 3).

### INFO DESK

Questions, suggestions, general help? The Cassie & Friends information booth is located at the top of the main escalator on Level 2.

### PHOTOS

Photos taken during the event may be used for Cassie & Friends publications and promotional materials. Photos will be posted on our website ([www.cassieandfriends.ca](http://www.cassieandfriends.ca)) as they become available.



7



### SOCIAL MEDIA

Connect with other families – and share your experience with those who could not attend – using social media. Keep your tweets relevant and searchable by using the hashtag **#JAwontstopme**.

Follow Cassie & Friends on twitter at **@CAFSociety** or Instagram at **@cafsociety\_yvr**

### EVALUATION

An evaluation survey asking for your feedback will be sent to you by email in the week following Family Day. Please take a few minutes to fill it out. Your suggestions will help us improve our next event.



# Family Day 2018

## Parent Program

8



| TIME/VENUE   | EVENT   |
|--|---|
| <b>7:45AM – 8:30AM</b><br>2 <sup>nd</sup> floor lobby<br>and Grand Villa 3 | <b>Registration and Morning Expo</b>  |
| <b>8:15AM</b><br>Veranda/Portico   | <b>Toddler Program Drop-Off (Ages 0 to 4)</b>   |
| <b>8:30AM</b><br>Grand Villa 3   | <b>BMO Family Camp Kick-Off with special welcome by Wildflower Women of Turtle Island Drum Group</b>  |
| <b>8:45AM</b><br>Grand Villa 3   | <b>Free to Soar – a Fireside chat with Olympian, Spencer O'Brien</b><br><br>Born in Alert Bay, BC, Spencer O'Brien, has made a name for herself as a professional snowboarder, 2016 X Games Gold Medalist, two times World Champion, Olympian and proud Haida Kwakwakw'wakw First Nation. But in 2013, she was a young woman battling extreme, unexplainable pain, mysterious illnesses and depression. |
| <b>9:25AM</b><br>Depart from Grand Villa 3                                 | <b>Kid (5 to 8), Youth (9 to 12) and Teen (13+) Programs Begin</b>  |
| <b>9:30AM – 10:00AM</b><br>Grand Villa 3                                   | <b>Morning Expo and Parents' Break</b>  |

| TIME/VENUE  | EVENT   |
|---|---|
| <b>10:00AM – 11:00AM</b>                                | <b>Parent/Caregiver Concurrent Sessions #1</b><br><a href="#">See pages 16 – 17 for session descriptions and locations</a>  |
| <b>11:00AM – 11:15AM</b>                                | <b>Break</b>  |
| <b>11:15AM – 12:15PM</b>                                | <b>Parent/Caregiver Concurrent Sessions #2</b><br><a href="#">See pages 18 for session descriptions and locations</a>   |
| <b>12:15PM – 1:30PM</b><br>Grand Villa 3                | <b>Parent/Caregiver Roundtable Lunch</b><br>(You will be seated with families whose children share a similar diagnosis and/or age)  |
| <b>12:15PM – 1:30PM</b><br>Villa Bistro<br><b>AMGEN</b> | <b>Health Care Professionals Appreciation and Education Lunch with Guest Speaker, Dr. Lavro Lamot.</b> This activity has been made possible through a grant provided by Amgen.  |
| <b>1:45PM – 2:45PM</b>                                  | <b>Parent/Caregiver Concurrent Sessions #3</b><br><a href="#">See pages 19 for session descriptions and locations</a>   |
| <b>3:00PM – 4:00PM</b><br>Villa 1 + 2                   | <b>Put on Your Own Oxygen Mask First: A Parent Panel on Self-Care and Family Resilience</b> Moderated by Dr. Penny Sneddon, Registered Psychologist, Cornerstone Child and Family Psychology Clinic, BC Children's Hospital Medical Psychology<br><br>We can't provide effective care of our children if we don't take care of ourselves first. In this session, we'll share life stories of JA parents who have learned ways of engaging in self-care in the context of taking care of a child and family affected by rheumatic disease. |
| <b>4:00PM – 4:15PM</b><br>Veranda/Portico               | <b>Toddler Pick-up</b>  |
| <b>4:15PM – 5:00PM</b><br>Grand Villa 3                 | <b>Family Camp Closing Ceremony + Special Surprise from the Kids!</b>   |

9

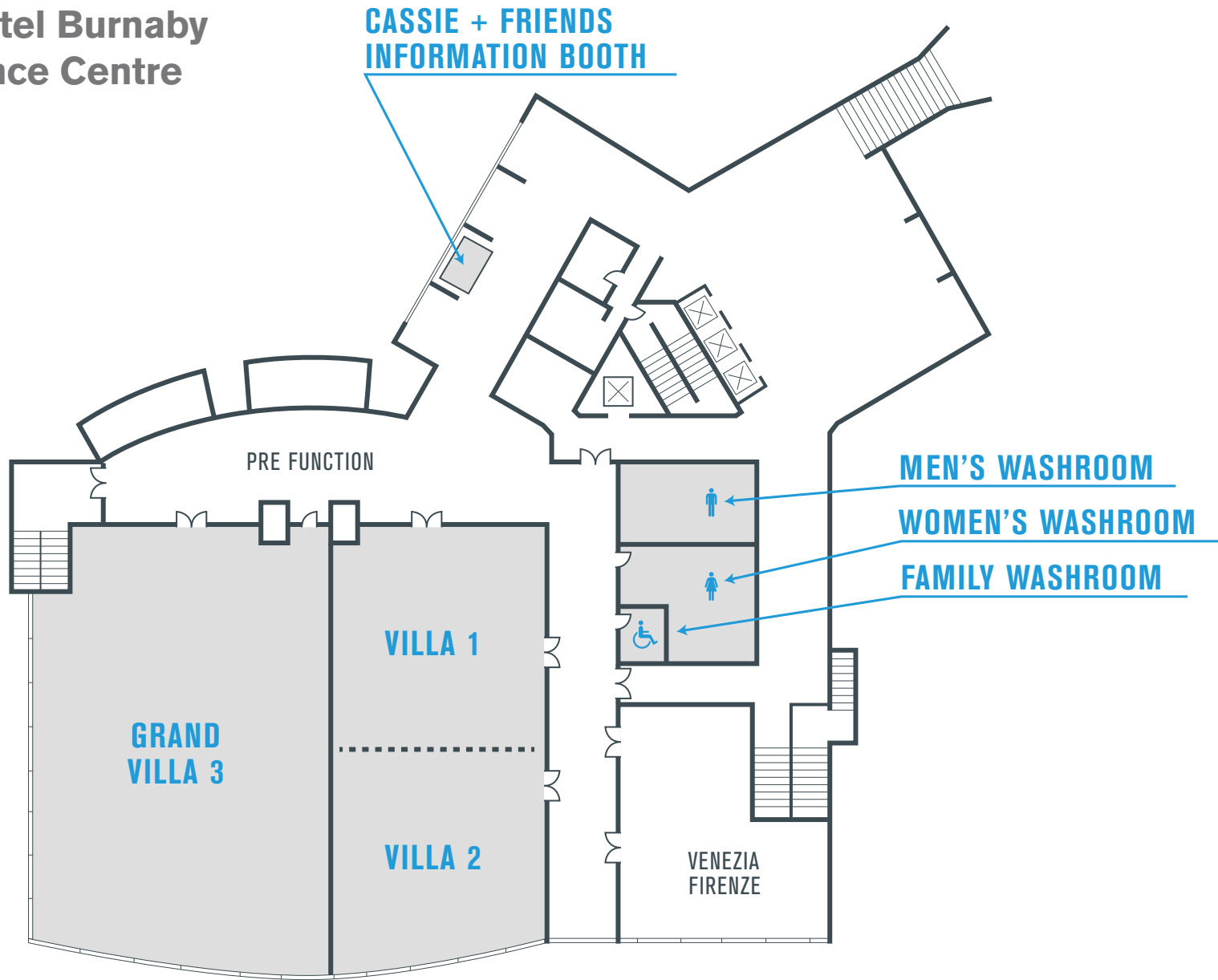


Family Day 2018

**Delta Hotel Burnaby  
Conference Centre**

**Level 2**

10  
≡



11  
≡

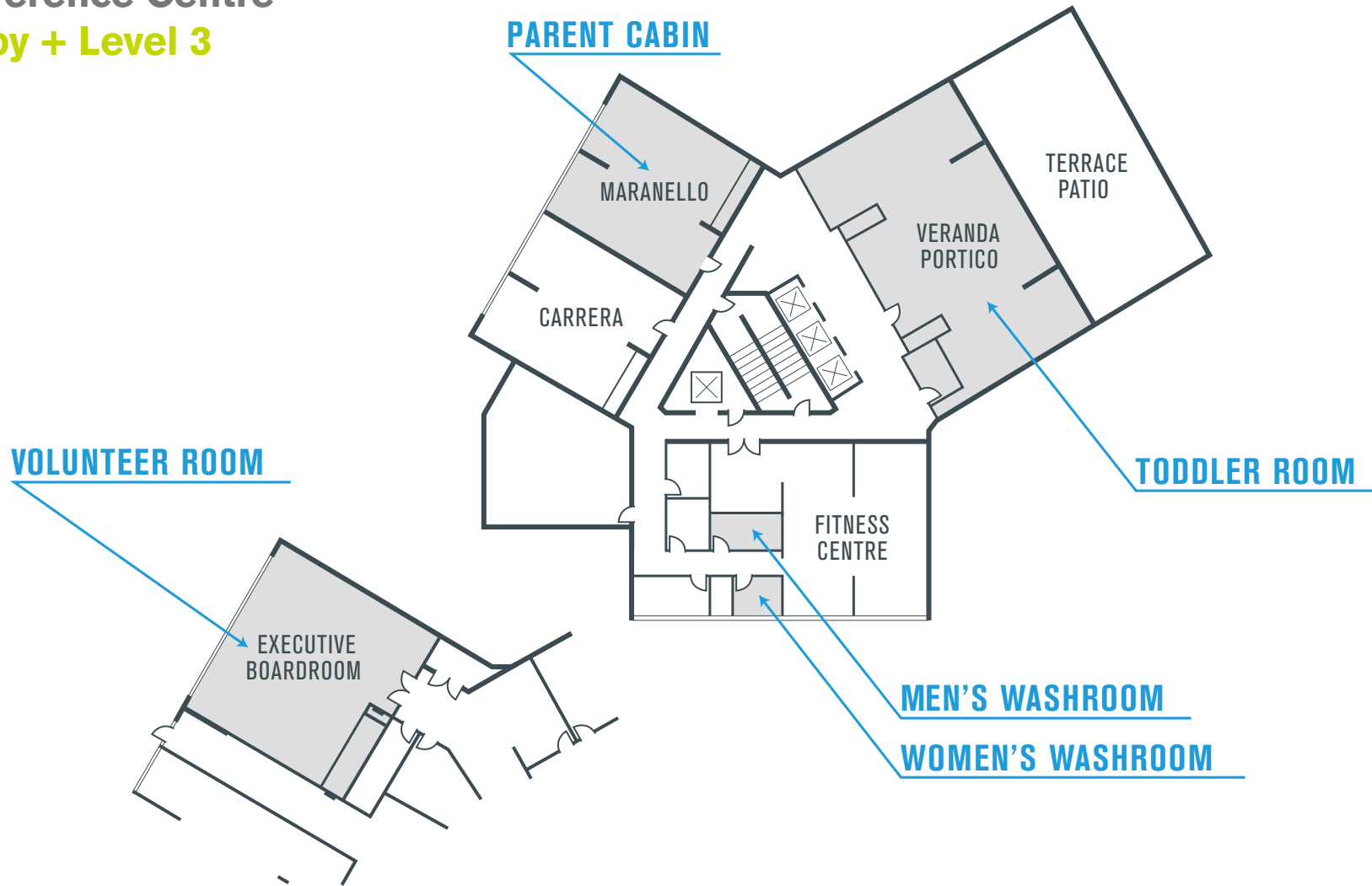


Family Day 2018

**Delta Hotel Burnaby  
Conference Centre**

**Lobby + Level 3**

12  
≡



13  
≡



## Family Day 2018

### Keynote Address

## Free to Soar – a Fireside Chat with Olympic Snowboarder, Spencer O'Brien



14



#### TIME/VENUE

8:45AM – 9:20AM  
Grand Villa 3

#### EVENT

BMO Family Camp Kick-Off



15



Considered to be one of the world's most progressive Slopestyle snowboarders, O'Brien first learned to snowboard at age 11 from her father. She first started out in Halfpipe and then quickly made the transition to Slopestyle when her local mountain announced that they wouldn't build and maintain a pipe at the station anymore. At 17 she moved to Whistler with all her savings, which was just enough to do a whole season just snowboarding.

O'Brien has competed primarily on the World Snowboard Tour, the world's largest series of freestyle snowboarding events, which has made her a Four-Time Winter X Games Medalist and winner of the the 2012 World Snowboarding Championships. In 2013, Spencer won gold at the FIS World Championships, helping her qualify for the 2014 Sochi Winter Olympics. Just a few weeks before her Olympic debut, O'Brien was diagnosed with rheumatoid arthritis.

With hardwork and perseverance, O'Brien went on to see her lifelong dream finally happen when she took home her first ever X Games gold medal. In 2017, she placed 2<sup>nd</sup> in Slopestyle in the FIS World Cup in Czech Republic and in 2018 she competed for Team Canada once again in the Pyeongchang, Korea Olympics.

Outside of snowboarding, Spencer enjoys cooking, baking, fashion and hiking. Giving back is important to Spencer. She is involved with the Alliance for Climate Education, Nike S7 program that promotes health and wellness in Aboriginal communities and has donated equipment to the First Nations Snowboard Team.





# Family Day 2018

## Concurrent Sessions

### Parent/Caregiver Sessions – Block #1



16



#### TIME/VENUE

#### EVENT

10:00AM – 11:00AM  
Grand Villa 3

**Juvenile Idiopathic Arthritis (JIA) – Insights and Outcomes**

**Dr. Tommy Gerschman**, Pediatric Rheumatologist with Special Interest in Pediatric Sport & Exercise Medicine, Fortius Sport and Health, Burnaby, BC

What might you expect during a month in the life of a child living with juvenile idiopathic arthritis (JIA)? What can you know about their future? In this session, you'll hear about some of the common experiences a child with arthritis and their family might go through (i.e. ever wonder what we mean by a 'flare' and how that might be different from pain?). You'll also learn how JIA is diagnosed and what the different "subtypes" mean and gain new insights into the tools doctors use to help predict a child's outcome. Bring your questions!

#### TIME/VENUE

#### EVENT

10:00AM – 11:00AM  
Venezia and Firenze

**Group Session for Parents of Children with Autoinflammatory Disease**

**Dr. Lori Tucker**, Pediatric Rheumatologist, British Columbia Children's Hospital

**Jenny Tekano**, Pediatric Rheumatology Nurse, BC Children's Hospital

**Dr. Kelly Brown**, Investigator, BC Children's Hospital Research Institute

Is your child diagnosed or suspected to have PFAPA, Familial Mediterranean Fever, TRAPS, Mevalonate Kinase Deficiency Disorder, CAPS, CRMO or another rare disease, usually with regular fever episodes and other body symptoms? In this session, you will meet other families affected by these conditions and have the chance to ask questions to a pediatric rheumatologist, pediatric rheumatology nurse and researcher.

17



#### TIME/VENUE

#### EVENT

10:00AM – 11:00AM  
Maranello

**Parent Connect Cabin**

Hosted by **David Porte**, Founder and Board Chair, Cassie and Friends Society

Every camp has its own traditions but one thing is the same...it's a time to reunite with old friends and make new ones! If you are a returning or experienced parent, or are looking for a more casual session to start your day, please feel free to join David Porte, along with other members of Cassie and Friends, at our Parents' Cabin. Share your story, learn more about our commitment to transform lives and meet some of our dedicated volunteers.



## Family Day 2018

### Concurrent Sessions

#### Parent/Caregiver Sessions – Block #2

18



##### TIME/VENUE

##### EVENT

11:15AM – 12:15PM  
Villa 1

**School Solutions and Educational Rights Panel**

**Heather Best**, Occupational Therapist, BC Children's Hospital

**Dr. Kristin Houghton**, Pediatric Rheumatologist, BC Children's Hospital

**Kelsey Chomistek**, Young Adult living with Juvenile Arthritis and Graduate Student, University of Alberta

**Colleen Castonguay**, JIA Parent and Vice-Principal, School District #43

Get expert advice and recommendations from an occupational therapist, parent, school administrator and other 'experts' on issues related to effective communication with educators, school accommodations and your child's overall educational rights. There will be lots of time for questions and an overview of some of the most common school challenges and tips for how to address them.

##### TIME/VENUE

##### EVENT

11:15AM – 12:15PM  
Villa 2

**Complementary and Alternative Therapies for Arthritis Symptoms**

**Dr. Cora Breuner**, Adolescent Medicine, Orthopedics, Sports Medicine, Seattle Children's Hospital

Rheumatic disease symptoms can be a huge burden on both children and families. Learn about non-pharmaceutical ways to manage when pain breaks through or becomes chronic, when morning stiffness slows you down and when fatigue drains your energy.

## Family Day 2018

### Concurrent Sessions

#### Parent/Caregiver Sessions – Block #3

19



##### TIME/VENUE

##### EVENT

1:45PM – 2:45PM  
Villa 1 and 2

**Choosing the Right Treatment for Your Child**

**Dr. Jaime Guzman**, Pediatric Rheumatologist, British Columbia Children's Hospital

This session will explore the trade-offs that parents and doctors should consider when deciding which treatments(s) to use in a child with rheumatic disease. Dr. Guzman will also review the most recent data on the tapering and stopping of medications.

##### TIME/VENUE

##### EVENT

1:45PM – 2:45PM  
Venezia and Firenze

**Risky Behaviour and Teen Transition**

**Dr. Cora Breuner**, Adolescent Medicine, Orthopedics, Sports Medicine, Seattle Children's Hospital

**Dr. Mercedes Chan**, Pediatric Rheumatologist, British Columbia Children's Hospital

For younger kids, "risky" behaviours might be refusal to go to sleep or picky eating. But for pre-teens and teens, risky behaviours and peer pressure can have far worse and far-reaching effects. In this session, you'll learn about common behaviours that put your teen at risk (and their medical effects) and learn how you can help your teen be prepared and confident to care for their rheumatic disease on their own as they move into adulthood.

# Family Day 2018

## Toddler, Kid, Youth + Teen Camp Programs



20



While you attend breakout sessions, your kids and teens will be in age-based program groups enjoying an adventure-filled day with new friends. Here's what they'll be up to over the course of Family Day.



### Day Trippers

**Toddler Program (0 to 4)**

Veranda/Portico

**Group Leader: Fernanda 778.829.5819**

**Activities** Bouncy Castle + Play Zone, Music + Story Time, Critter Show, Face Painting



### Scouts

**Kid Program (5 to 8)**

Hive Climbing Gym

**Madison Wallinger 604.992.9373**

**Activities** Bouldering, Brix for Kids Lego, Puppet Workshop, Slime Making, Lunch provided by Stong's Community Market



### Campers

**Youth Program (9 to 12)**

Fortius Sport & Health Centre

**Madison Wallinger 604.992.9373**

**Activities** Camp Games, Lunch at Foritus, Slime Making



### Cabin Hoppers

**Teen Program (13+)**

Various Locations

**Madison Wallinger 604.992.9373**

**Activities** Escape Room, Lunch at Wing's, Teen-Only Youth Panel at Keystone Environmental Head Office

21



**NOTE:** If you need to reach your child at any time today, please call the Group Leader listed below or visit the Cassie and Friends Information Table located at the top of the escalator on Level Two.



Family Day 2018

## About Cassie + Friends Society

22



Our mission is to transform the lives of kids and families affected by Juvenile Arthritis and other rheumatic diseases. Since 2007, we've raised over \$2 million for research, pediatric rheumatology programs, equipment, child and family support, advocacy and educational events.

### Your Support Helps us Transform Lives

#### PARENT EMERGENCY FUND

We support hundred of parents and caregivers each year with urgent need costs like hospital parking, prescriptions, meals, equipment and other burdens.

#### EQUIPMENT CUPBOARD

We make thousands of dollars in life-enhancing medical aids, such as forearm crutches, pencil grips, mindfulness resources and numbing creams for painful injections, readily available to parents and children at no-cost each year.

#### PARENT-TO-PARENT SUPPORT PROGRAM

We created Canada's first program offering parents of children with rheumatic diseases the opportunity to be matched with a more "experienced" parent during times of new diagnosis or during challenging flares.



23



#### KIDS ON THE BLOCK SCHOOL PERFORMANCE PROGRAM

Our school program for Grades K to 4 raises awareness of Juvenile Arthritis in schools and spreads an important message of inclusion, friendship and that kids with JA can do anything!

#### FAMILY DAY CONFERENCE

These annual events bring together parents, children, siblings, doctors, nurses, researchers and other experts for a day of fun, education and connection.

#### YOUTH LEADER NETWORK

New! A network of teens and young adults living with rheumatic diseases whose mission is to connect and empower other affected youth, especially as they transition into post-secondary education, first jobs/early careers, relationships and adult life.

#### RESEARCH

We support research that directly addresses the day-to-day challenges and fears facing kids and families living with rheumatic conditions, while never losing sight of our greatest hope – a cure.

To learn more, sign up for our e-news or DONATE today to transform lives, please visit: [www.cassieandfriends.ca](http://www.cassieandfriends.ca)



# Family Day 2018

ALLY FOR LIFE

## Thank you to our **sponsors**

# BMO



CHAMPIONS FOR KIDS



CHAMPIONS FOR KIDS – TRAVEL SPONSOR



BEST FRIENDS



FRIENDS



#100 – 33 East 8<sup>th</sup> Ave.  
Vancouver, BC V5T 1R5  
T 604.617.1382  
E [info@cassieandfriends.ca](mailto:info@cassieandfriends.ca)

To learn more, sign up for our e-news or DONATE today  
to transform lives, please visit: [www.cassieandfriends.ca](http://www.cassieandfriends.ca)

cassie+  
friends