

# **TASTE OF CHICAGO**

**5P- SOCIETY CONFERENCE**

~~**JULY 23<sup>RD</sup> - 26<sup>TH</sup> 2020**~~

**JULY 15-18 2021**



# Welcome to the Taste of Chicago!

Welcome to the 5p– Society’s 35th family conference. We are heading back to one of the first conference locations. Chicago, with its charm, history, warmth, food, sports and wind! It’s been 21 years since we’ve last visited Chicago,. We’ve actually visited Chicago the most with conferences in 1987, 1988 and 1999.

This year’s conference will be held at the Eaglewood Resort & Spa, an exceptional Midwest resort located in Itasca. The Prairie Style architecture of the resort is legendary work of Frank Lloyd Wright throughout the Chicagoland area. The resort also has a fantastic recreation and entertainment area with a bowling alley, fitness rooms, pool, and a full service wellness Spa.

The host families have been working hard to bring you a Taste of Chicago by fundraising, planning and preparing for a fantastic event. Speakers are lined up with topics of interest to our 5p minus community. Find out more about the sibling and family outings in the Conference Information session on pages 4 & 5.

We are also very excited to announce that the 5p– Society has been asked to host the first International meeting for Planet 5p, a global Cri du Chat community, who’s goal is to bring more collaboration between the international support organizations and help countries develop their own support organizations. The meeting will take place on Wednesday before the conference begins.

Chicago has a lot to offer! We hope you plan on spending some extra time here to explore this exciting city!!

Your host families:

Nick & Christina Cutrara

Michelle Trusk

Chris & Megan Jones

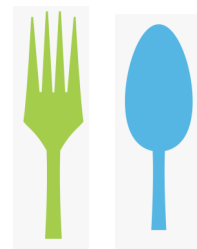
Jason & Gina Burke

Matthew & Jacquelyn Winders

And the Conference committee helpers



# Taste of Chicago Event Schedule



## Thursday, July 15, 2021

5:00 PM—10:00 PM	Registration
5:00 PM—7:00 PM	Welcome Reception
7:00 PM—9:00 PM	New Family Orientation—Kent Nicholls, Founder 5p— Society
7:00 PM—9:00 PM	Sibling Mixer
7:00 PM—11:00 PM	AmySue's Place Open (Hospitality Suite)

## Friday, July 16, 2021

7:30 AM—12:00 PM	Kid Camp Rooms 1-5 open
8:15 AM—9:00 AM	Opening Session
9:00 AM—10:20 AM	Parent Panels (By Age)
9:00 AM—11:30 AM	Sibling Workshop
10:30 AM—11:50 AM	Mom's Workshop
	Dad's Workshop
12:00 PM—4:00 PM	Family Outing—onsite (lunch provided)
4:00 PM—6:00 PM	Grandparents Workshop
7:00 PM—11:00 PM	AmySue's Place Open
8:00 PM—11: PM	Board of Directors Meeting

## Saturday, July 17, 2021

7:30 AM—12:00 PM	Kid Camp Rooms 1-5 open
8:30 AM-9:00 AM	Opening Session
9:00 AM—10:20 AM	Break Out Sessions
10:30 AM—11:50 AM	Break Out Sessions
12:00 PM—2:00 PM	Lunch on your own
12:00 PM—2:00 PM	Professional Advisory Board Lunch/Volunteer Lunch
2:00 PM—5:00 PM	Kid Camp Rooms 1-5 Open
2:00 PM—3:20 PM	Break Out Sessions
3:30 PM—4:50 PM	Break Out Sessions
5:30 PM—6:30 PM	Picture Session
6:30 PM—10:00 PM	Banquet and Family Dance and Raffles
9:00 PM—11:00 PM	AmySue's Place Open

## Sunday, July 18, 2021

9:00 AM—12:00 PM	Closing session
	Special Speakers
	Picture Session
	Charlotte, North Carolina 2022

# Taste of Chicago Conference Information



**Dates:** July 23-26, 2020

**Location:** Eaglewood Resort & Spa, 1401 Nordic Rd, Itasca, IL 60143 630.773.1400

**Hotel website:** [www.eaglewoodresort.com/illinois\\_resort](http://www.eaglewoodresort.com/illinois_resort)

**Room rate:** \$149.00 per night; to guarantee adjoining rooms there will be a \$20.00 per night increase to the room rate. To make your room reservation you can call the resort at 877.285.6150 and let them know you are with the 5p– Society conference, or you can make your reservations online at: <https://nam01.safelinks.protection.outlook.com/?url=http%3A%2F%2Fbookings.ihotelier.com%2Fbookings.jsp%3FgroupID%3D2279963%26hotelID%3D15450&data=02%7C01%7Cahejduk%40eaglewoodresort.com%7Ccdd6a3e87f6742cfec5808d715dad0f1%7Ce21f0bb58a67410e86e6f6990e7f99b1%7C0%7C0%7C637001901860580675&sdata=XS10%2FVd7PC0jflflaWnfgZyDplwgACvf9Kk0uwp6eJC8%3D&reserved=0>



**Parking & Transportation:** There is free ample parking at the resort. Please visit the hotel website for directions at [https://www.eaglewoodresort.com/how\\_to\\_get\\_to\\_eaglewood/](https://www.eaglewoodresort.com/how_to_get_to_eaglewood/) There is not a shuttle from either of the airports to the Eaglewood.



**Conference registration:** Please note that hotel reservations and conference registration are separate. Please register online for the conference. The online links can be found on our website at: <https://fivepminus.org/event/2021-5p-society-conference-chicago-illinois/> Registration links are now open.



This is the easiest way to make reservations. If you would like a paper registration form to send in a check, please send an email to [director@fivepminus.org](mailto:director@fivepminus.org) and request one.



**Cost: 5p– Society Members** - Individual registrants only \$100.00 (\$150 after July 1); Family registration for up to 4 individuals \$200.00; each additional registrant \$50.00 (\$250 after July 1st) **Non-members** - Individual registrants only \$150.00 (\$200 after July 1); Family registration for up to 4 individuals \$250.00; each additional registrant \$50.00 (\$300 after July 1st).



**Family Fun Event:** There will be an additional \$3.00 per person cost for families to attend the Family Fun Event. This will be an onsite event with food trucks, fun and games.

# Taste of Chicago Conference Information



**Scholarships:** We will offer five scholarships. The scholarships will pay for hotel room for three nights and registration fee for 4 individuals in the same family. Link for scholarship Guidelines and Application can be found at: <https://forms.gle/89A3ScbWvzxoyLgd9>



**Sibling Events:** Our siblings will have three events to participate in: 1) On Thursday evening they can join other siblings for a sibling mixer; 2) On Friday morning they can join other siblings to learn more about having a brother or sister with a disability, learn coping skills and engage in interactive conversations; 3) On Saturday the siblings will head over to Urban Air Adventure Park in Bloomingdale, Illinois. Siblings will be able to participate in the following: Sky Rider, Ropes Courses, Climbing Walls, Warrior Obstacle Course, Battle Beam, Tubes Playgroup, ProZone Performance Trampolines and Basic Trampolines.



Lunch will also be provided. This will be for ages 6 and up.

**Kid's Club:** We will once again offer free child care for the children and adults of all ages with the syndrome and their siblings. Children will be placed into one of five rooms divided by age group. Adults with the syndrome (ages 13 and up) will have one room dedicated just for them. Siblings that are to attend the sibling events will need to be checked in and out of Kid's Club. We will be once again using the KidCheck system to monitor the children and adults.



**Welcome Reception:** Please make sure you join us for the Welcome Reception on Thursday evening from 5:00-7:00PM. Your host families are eager to meet you!



**T-shirts:** To order your t-shirt, please add them to your registration form. Shirts sizes Youth XS to Adult XL will be \$10.00 each and shirts Adult 2XL and above will be \$12.00 each. If you are not attending the conference and would like to order a t-shirt (s), please send an email to [director@fivepminus.org](mailto:director@fivepminus.org) for a paper t-shirt order form.



**Banquet & Family Dance:** We will have our annual banquet and family dance on Saturday night. Dress is casual, although a lot of families like to get dressed up and that is okay too!! There will be a photographer available to take family photos. Get ready to dance the night away and have fun!



**Hall of Fame Awards:** To honor that special parent(s), sibling(s), grandparent(s) or special volunteer with our annual awards, please fill out and return the attached form. Nominees should be someone who has gone above and beyond the call of duty for the 5p- Society. Nominations will be accepted until June 15, 2021.

# Taste of Chicago Speakers & Presentations



## **Kent Nicholls—New Family Orientation**

Kent is the founder of the 5p– Society and a parent to Kellie, a young adult with 5p– Syndrome. Kent currently on the Board of Directors and is chairperson of the Strategic Planning committee. If this is your first time attending a conference you will not want to miss his session.



## **Dennis Campbell, Ph.D.—Cri du Chat 101**

Dennis is the Chair of the Professional Advisory Committee and well as dad to Amy, a young adult with 5p– Syndrome. Dennis has recently retired from his position as a professor of Special Education at the University of South Alabama. He and his wife Shari, along with Amy have recently relocated to Auburn, Alabama.



## **AmySue Reilly, Ph.D.— Effective Behavior Modifications**

AmySue has been speaking with the families of the 5p– Society since 2003. She along with Dennis Campbell is on the Professional Advisory Board for the 5p– Society. AmySue has recently retired from Auburn University as a professor of Special Education, Rehabilitation and Counseling. We are honored to have her continue to assist us with behavioral issues that our children face. Make sure to visit the hospitality suite in the evenings, renamed AmySue's Place in her honor.



## **Colleen Frayn, RN, BS, CEIM, HTCP—Infant Massage**

Colleen Frayn, RN, BS, CEIM has been working in Maternal Child Health care for most of her nursing career and has been teaching Infant Massage for 30 years. Infant Massage provides a time to deepen your relationship with your baby. The benefits are many and are categorized into 4 areas: Relaxation, Relief, Stimulation, and Interaction. Stress hormones decrease and relaxation hormones increase as babies are massaged. One of the major benefits for Cri du Chat infants is decreasing or eliminating constipation. Come and join us for this informative and fun class. Bring a pillow and blanket for baby to lay on. Colleen is also an aunt to a young man with 5p– Syndrome, Kenny.







### **Hollie Brookman, RDH—Improved Dental Checkups Begin at Home**

Hollie Brookman received her Bachelor of Science in Dental Hygiene from the University of Louisville in 2014. In 2013, she was chosen from among her peers to receive a student scholarship for infection control and prevention. In 2014, she represented the University of Louisville Dental Hygiene Program at the American Dental Hygiene Association Annual Conference in the student table clinic research presentations. Hollie Brookman has been a registered dental hygienist in the state of Kentucky since 2014. Her main experience is in general, clinical dentistry with a diverse patient population, including pediatric, geriatric, and special needs patients. Hollie resides in Louisville, KY with her husband, Robert, and two children, Hannah and Clara. Hannah is four years old and was diagnosed with Cri du Chat Syndrome at birth. As a special needs mom, Hollie has learned (and is still learning!) the importance of advocating for her child and others with disabilities. Dental health is an often overlooked aspect of total health. In this session, she will discuss steps you can implement at home in order to help your loved one achieve better dental health. She will also discuss ways you can advocate for your loved one during dental visits and create a team approach to their professional dental care.



### **Mary Ann Ehlert, Protected Tomorrows - Journey Through an Eight Step Special Needs Planning Program/ABLEact information**

Our founder, **Mary Anne Ehlert**, CFP, had a successful career in the financial industry when she decided to act on her lifelong desire to specialize in serving the families of the disabled. The source of her inspiration was very dear to her heart. Mary Anne herself had come from such a family. Her younger sister, Marcia, to whom she felt especially close, suffered severe mental handicaps due to cerebral palsy. Although their parents were naturally determined that Marcia should get the best possible care, they had also been understandably confused how best to plan and provide for her future.



### **James Chalmers—Living with Cri du Chat Syndrome**

James is a 48-year-old man with Cri du Chat Syndrome. Jim runs marathons, coaches and gives inspirational talks. He says that coaching has taught him more about himself than anything else he has done. He has worked for the Red Wing Shoe Company for almost 20 years.





### **Claire Conley, NeuroMovement for the Cri du Chat Child: The Amazing Anat Baniel Therapy Method**

Claire is a certified Feldenkrais® Practitioner (FGNA - 2003), Anat Baniel Method<sup>sm</sup> Practitioner 2003, with advanced certification for Infants & Children, High Performers and Vitality & Anti-Aging. Claire also has graduated with advanced certification from The Scoliosis Project 2008 in Zurich, Switzerland.



Today, Claire works with special needs infants and children, healthy infants and children as well as adults, seniors, athletes, musicians and artistic performers of all kinds to achieve enhanced performance. She also works with people who have chronic or situational pain issues including scoliosis, back, neck & shoulder pain.



### **Carly Lapin - Managing Challenging Behaviors and Toilet Training**

Carly Lapin is a Board Certified Behavior Analyst and a doctoral student in behavior analysis. Carly has been working with children with autism for over 10 years and has conducted research on building rapport between children with autism and their therapists. Carly is in the process of her dissertation research on toilet training children with autism. In addition, Carly's specialty area is in the assessment and treatment of challenging behaviors. Carly currently serves as the director of Outreach for The Place for Children with Autism. The Place provides ABA therapy to children with autism ages 2-6. They have 9 centers throughout Illinois and are expanding to other locations this year.



### **Briana Benetiz, Special Education Pool Instructor, COTA/L—Benefits of Aquatherapy**

This course will go through the physical and cognitive benefits of aquatic therapy for people with different abilities. We will go through positioning, adaptive equipment and the therapeutic use of water.



### **Laura Castillo, Executive Director, 5p– Society, Facilitator - Raising an Adult with Cri du Chat /5p– Syndrome: A parent discussion panel**

With the assistance of other parents with adults with the syndrome, we will discuss the different topics that every parent should know about raising an adult with the syndrome, from education, adult programs, housing, medical needs and behavioral issues.







An International Meeting will take place on Wednesday, July 14, 2021. Families from several countries around the world including Spain, Germany, Brazil, New Zealand, Cuba and Colombia will be joining us for a one-day meeting prior to the Chicago Conference, located at Eaglewood Resort & Spa, 1401 Nordic Rd, Itasca, IL 60143 630.773.1400.

If you are coming or would like to come from one of our International cohorts and would like to join us, please register separately here: <https://5psociety.regfox.com/planet-5p-international-meeting-registration>

There will be several scholarships available designated just for our international attendees. These scholarships will assist in paying for the Chicago conference and hotel fees for five nights. If interested please fill out the online form located here: <https://forms.gle/83wcH6SsanLpaTUE6>

Please note these scholarships are needs based.

Learn more about Planet 5p, it's mission and vision, along with future research.

Speaking at the International Meeting:

Carolina Nicolás—Planet 5p, Director of Communication

Cristina Bel—Planet 5p, Co-Founder

Janitza Montalvo-Ortiz, Assistant Professor Department of Psychiatry, Division of Human Genetics at Yale School of Medicine.

Round table discussions about plans for future collaboration between the countries.