

Cystinosis Research Network Family Conference

July 13-15, 2017

Snowbird Ski and Summer Resort

Snowbird, Utah

AGENDA



Draft 5-7-17

Wednesday, July 12		Room
3:00 pm – 8:00 pm	CRN Board of Directors Meeting <i>Closed Session</i>	Seven Summits, Snowbird Center
Thursday, July 13		Room
12:00 pm – 5:00 pm	Registration/Information Desk	Cottonwood Lobby, Snowbird Center
12:00 pm – 5:00 pm	Snow City Arts <i>The CRN 2017 conference has designated the theme “Soaring to New Heights,” that has informed the design of a group art project. The idea is to have individuals create representations of themselves as birds in mixed media sculpture forms. Each bird will be uniquely designed. These individual sculptures will then be suspended together to create a collaborative time based hanging art installation of birds flying in a flock in an upward spiral. The upward spiral form was chosen to signify how those impacted by Cystinosis can reach new heights working as one community. The installation will only exist for one night on July 15th in Snowbird, Utah. The art project I’ve designed is to reflect this: when individuals with shared goals come together and connect in a meaningful way, they are stronger, they are able to fly higher.</i>	Alpine A, Snowbird Center

2:00 pm – 4:00 pm	CRN Scientific Review Board Meeting <i>Closed Session</i>	Seven Summits, Snowbird Center
5:00 pm – 7:00 pm	CRN Welcome Reception <i>Complimentary</i> <i>Hosts: CRN Board of Directors, Future by Design</i> <i>Please join us for a Carnival fun complete with entertainment, drinks and appetizers and an opportunity to meet the families and physicians attending the conference.</i>	Cottonwood Lobby, Snowbird Center
7:00 pm – 10:00 pm	Family Introductions/Networking <i>Host: Clinton Moore, VP Family Support</i> <i>Please join us with your entire family for introductions, a welcome video, and an appearance by “Team Cysteamine Live”.</i>	Cottonwood, Snowbird Center
Friday, July 14		Room
7:00 am – 8:30 am	Breakfast <i>Complimentary</i>	Cottonwood Lobby, Snowbird Center
8:00 am – 5:30 pm	Registration/Information	Cottonwood Lobby, Snowbird Center
8:00 am – 5:30 pm	Snow City Arts <i>The CRN 2017 conference has designated the theme “Soaring to New Heights,” that has informed the design of a group art project. The idea is to have individuals create representations of themselves as birds in mixed media sculpture forms. Each bird will be uniquely designed. These individual sculptures will then be suspended together to create a collaborative time based hanging art installation of birds flying in a flock in an upward spiral. The upward spiral form was chosen to signify how those impacted by Cystinosis can reach new heights working as one community. The installation will only exist for one night on July 15th in Snowbird, Utah. The art project I’ve designed is to reflect this: when individuals with shared goals come together and connect in a meaningful way, they are stronger, they able to fly higher.</i>	Alpine A, Snowbird Center
8:00 am – 5:30 pm	Camp CRN Children’s Group Tweens with cystinosis (ages 8-12) Teens with cystinosis (ages 13-18) Sibling Tweens (ages 8-12) Sibling Teens (ages 13-18)	Alpine B Alpine C Aspen Willow Studio Room
8:30 am – 9:00 am	Welcome and Opening Remarks Cystinosis Research Network Overview <i>Jeff Larimore, CRN President</i>	Cottonwood, Snowbird Center

9:00 am – 10:00 am	Living, Breathing, and Succeeding with CF <i>Keynote Speaker – Jerry Cahill</i> Advocate. Cystic fibrosis. Hero. Leader. Relentless. Hopeful. All of these words have one thing in common; they can be used to describe Jerry Cahill, a man who lives and succeeds in spite of his medical limitations. At 60 years old, Jerry Cahill has overcome	Cottonwood, Snowbird Center
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	<p>remarkable odds and has become living, breathing proof that cystic fibrosis patients can have a normal life through firm commitment to exercise and medical compliance. Currently a CF Ambassador at the Boomer Esiason Foundation, Cahill leads its scholarship and grants division and is the founder of <i>Team Boomer</i> – the athletic arm of BEF dedicated to encouraging exercise among CF patients while simultaneously raising money for scholarships. He has also started the program <i>You Cannot Fail</i>, which includes apparel, a website, an autobiographical coffee table book, and two children’s books. In February 2016, Jerry created <i>60:60</i> and set a goal to complete 60 activities on his “living list” – an alternative to a bucket list – as a way to inspire others with CF to live their lives to the fullest. He also records educational podcasts and videos and encourages other people with CF to share their stories on <i>Club CF</i>. On top of all of this, Jerry invited a camera crew to follow him over the past five years, giving a unique insight into his life as a cystic fibrosis patient, pole vault coach, and advocate. The documentary <i>Up for Air</i> followed his journey through training, treatments, and a double lung transplant – showing a new phase of living with CF. Jerry, a strong advocate of exercise, credits pole vault and physical fitness with his success; he believes that “exercise is the single most important thing in my life that keeps me healthy with CF.” For more information on these programs, please visit:</p> <p>www.cfwindsprints.com www.jerrycahill.com www.clubcysticfibrosis.com www.youcannotfail.com www.teamboomer.org</p>	
10:00 am – 10:15 am	Break	Cottonwood Lobby, Snowbird Center
10:15 am – 11:15 am	Cystinosis Overview/State of the World of Cystinosis	Cottonwood, Snowbird Center
11:15 am – 12:00 pm	Advocacy presentation	Cottonwood, Snowbird Center
12:00 pm – 1:00 pm	Lunch <i>Complimentary</i>	Cottonwood Lobby, Snowbird Center
Panel Sessions 1, 2 & 3 <i>Panel Sessions are targeted towards different stages of the cystinosis journey, divided into tracks by age. They will be smaller group sessions with a panel of experts presenting information, guiding discussion and fielding questions. Attendees should feel free to attend sessions of most interest to them. Please note the Adults section of Panel Session 3 is a closed sessions for cystinosis adults only.</i>		
1:00 pm – 2:00 pm	<p>Panel Session 1 Caregiver/Infant & Child (0-10): Cystinosis 101 Panelists: Teenager (11-17): Cystinosis 201 Panelists: Adult (18+): Cystinosis 301 Panelists:</p>	<p>Cottonwood A</p> <p>Cottonwood B</p> <p>Cottonwood C</p>

2:00 pm – 3:00 pm	Panel Session 2 Caregiver/Infant & Child (0-10): Physician Q & A Panelists: Teenager (11-17): social relationships, gaining independence Panelists: Adult (18+): healthcare expectations and self-management/medication adherence, public awareness campaign/advocacy (closed session) Panelists:	Cottonwood A Cottonwood B Cottonwood C
3:00 pm – 4:00 pm	Panel Session 3 Caregiver/Infant & Child (0-10): Education/IEP/504, child life/SCA Panelists: Teenager (11-17): Transplant and Dialysis Panelists: Adult (18+): fertility and sexuality, forum on depression and mental health (closed session) Panelists:	Cottonwood A Cottonwood B Cottonwood C
4:00 pm – 4:15 pm	Break	Cottonwood Lobby, Snowbird Center
4:15 pm – 5:30 pm	Medical Panel <i>Host: William A. Gahl, M.D., Ph.D.</i> <i>Please join the entire group for the unique and informative opportunity to have your questions and concerns addressed by the leading physicians and researchers in cystinosis. All of the doctors who have presented at the Family Conference, all attending Medical Advisory Board and Scientific Review Board members, as well as other health care professionals involved in treating and researching cystinosis are scheduled to participate. Questions for the panel will be collected during the proceedings today.</i>	Cottonwood, Snowbird Center
5:30 pm	Group Photograph	Cottonwood, Snowbird Center
6:30 pm	Meet & Greet Family Buffet Dinner <i>Hosts: Future By Design</i> <i>Complimentary</i>	Cottonwood & Cottonwood Lobby, Snowbird Center
7:00 pm	Speaker/VIP Dinner <i>Closed Session</i> <i>Hosts: CRN Board of Directors</i>	The Aerie Restaurant, Cliff Lodge, 10 th floor
Saturday, July, 15		Room
7:00 am – 8:30 am	Breakfast <i>Complimentary</i>	Cottonwood Lobby, Snowbird Center
8:00 am – 4:00 pm	Registration/Information	Cottonwood Lobby, Snowbird Center

8:00 am – 4:00 pm	<p>Snow City Arts</p> <p><i>The CRN 2017 conference has designated the theme “Soaring to New Heights,” that has informed the design of a group art project. The idea is to have individuals create representations of themselves as birds in mixed media sculpture forms. Each bird will be uniquely designed. These individual sculptures will then be suspended together to create a collaborative time based hanging art installation of birds flying in a flock in an upward spiral. The upward spiral form was chosen to signify how those impacted by Cystinosis can reach new heights working as one community. The installation will only exist for one night on July 15th in Snowbird, Utah. The art project I’ve designed is to reflect this: when individuals with shared goals come together and connect in a meaningful way, they are stronger, they are able to fly higher.</i></p>	Alpine A, Snowbird Center
8:00 am – 4:00 pm	<p>Camp CRN</p> <p>Children’s Group Tweens with cystinosis (ages 8-12) Teens with cystinosis (ages 13-18) Sibling Tweens (ages 8-12) Sibling Teens (ages 13-18)</p>	Alpine B Alpine C Aspen Willow Studio Room
8:30 am – 8:45 am	<p>Opening Comments</p> <p><i>Jeff Larimore, CRN President</i></p>	Cottonwood, Snowbird Center
8:45 am – 9:15 am	Leadiant Biosciences/Walgreen’s	Cottonwood, Snowbird Center
9:15 am – 9:45 am	Horizon/Accredo	Cottonwood, Snowbird Center
9:45 am – 10:00 am	Break	Cottonwood Lobby, Snowbird Center
10:00 am – 12:00 pm	Research Updates	Cottonwood, Snowbird Center
12:00 pm – 1:00 pm	<p>Lunch</p> <p><i>Complimentary</i></p>	Cottonwood Lobby, Snowbird Center
1:00 pm – 2:00 pm	<p>Poster Session</p> <p><i>This session will showcase a mix of science, medicine, industry, advocacy group and patient experiences to provide an interactive experience for both family and professional attendees. Researchers, clinicians, industry, advocacy representatives, students, patients, and caregivers will be invited to exhibit their latest research findings, treatment breakthroughs, advocacy group updates and real patient and family experiences. This will be an interactive session where exhibitors will be available to discuss their work or experiences with those attending. We invite you to browse the posters and take this opportunity to ask the authors and presenters questions.</i></p>	Cottonwood A, Snowbird Center
2:00 pm- 3:00 pm	<p>Parents of Children and Adults with Cystinosis Panel</p> <p><i>Moderator: Maya Doyle</i></p> <p><i>Panelists:</i></p>	Cottonwood, Snowbird Center

	<p><i>Panel presentation during which parents of children and adults with cystinosis will answer prepared questions and address topics related to the use of coping mechanisms through the ups and downs that cystinosis brings related to not only developmental and transitional issues of daily life but also medical issues. Parents of individuals at every stage of the disease will be featured and will share how they have managed the variety of challenges they have faced. Audience participation will be encouraged.</i></p>	
<p>3:00 pm – 4:00 pm</p>	<p>Future by Design Adult Panel Moderator: Aimee Adelman Panelists: <i>Panel presentation during which individuals living with cystinosis will answer prepared questions and address topics related to the use of coping mechanisms through the ups and downs that cystinosis brings related to not only developmental and transitional issues of daily life but also medical issues. Adults living with cystinosis will be featured and will share how they have recognized and lived to their full potential given the challenges they have faced. Audience participation will be encouraged.</i></p>	<p>Cottonwood, Snowbird Center</p>
<p>6:00 pm – 10:00 pm</p>	<p>Farewell Dinner Dance Complimentary <i>Please join all conference attendees for dinner, dancing, photo booth and fun for all ages to celebrate our cystinosis community.</i></p>	<p>Cottonwood & Cottonwood Lobby, Snowbird Center</p>