

CDH International



www.cdhconference.org



2021 GLOBAL CONGENITAL DIAPHRAGMATIC CONFERENCE

APRIL 28 - 30, 2021
WWW.CDHCONFERENCE.ORG



BECAUSE OUR CONFERENCES ARE CONFIDENTIAL TO MAINTAIN PRIVACY AND ALLOW PARENTS TO TALK FREELY ABOUT THEIR JOURNEYS WITH CDH, WE ONLY ALLOW MEMBERS OF CDH INTERNATIONAL TO ATTEND. THIS IS ALSO TO KEEP OUR MEMBERS SAFE AND MEDICAL INFORMATION PRIVATE.

THIS YEAR, BECAUSE OUR CONFERENCE IS VIRTUAL, ALL WHO FILL OUT THE CONFERENCE REGISTRATION WILL BECOME AUTOMATIC OFFICIAL MEMBERS OF THE CHARITY. AS ALSO, MEMBERSHIP IS FREE AT CDH INTERNATIONAL AND THIS YEAR, OUR CONFERENCE IS AS WELL.

WHILE WE ARE TRYING TO HARD TO STAY TRUE TO OUR NORMAL CONFERENCE AGENDAS, WE ARE ADAPTING AS MUCH AS THE REST OF THE WORLD IS DURING THIS PANDEMIC. IT IS OUR HOPE THAT BY HOPING OUR CONFERENCE VIRTUALLY, WE CAN INCLUDE MANY MORE FAMILIES WHO OTHERWISE WOULD NOT BE ABLE TO ATTEND IF IT WERE A NORMAL EVENT IN PERSON.

WE ALSO WELCOME RESEARCHERS AND ACDHO CHARITIES.

TO REGISTER FOR THE 2021 CDH CONFERENCE, PLEASE GO TO WWW.CDHCONFERENCE.ORG

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ABOUT THE CDH CONFERENCE:

- EXPECT TO LEARN A LOT ABOUT CONGENITAL DIAPHRAGMATIC HERNIA!
- OUR GUEST SPEAKERS ARE ALWAYS THE BEST IN THEIR FIELDS, BRINGING US NEW INFORMATION EVERY YEAR
- ALL CDH FAMILIES ARE WELCOME TO ATTEND! THIS INCLUDES FAMILIES OF SURVIVORS, GRIEVING FAMILIES AND EXPECTANT FAMILIES.
- OUR CONFERENCES INCLUDE FAMILY INTRODUCTIONS, ROUND-TABLE DISCUSSIONS, RESEARCH GUEST LECTURES, Q&A SESSIONS AND MUCH MORE!
- EACH CONFERENCE USUALLY RUNS FOR 3 HALF-DAYS; CDH RESEARCH DAY, CDH AWARENESS DAY AND CDH SUPPORT DAY BUT WILL BE ADJUSTED THIS YEAR
- CHERUBS CONFERENCES ARE PLANNED TO BE EDUCATIONAL, SUPPORTIVE AND AFFORDABLE
- MEET NEW FRIENDS, SEE OLD FRIENDS AND PARTICIPATE IN RESEARCH FOR VARIOUS HOSPITALS
- WE TAKE PHOTOS, WE VIDEOTAPE INTROS AND LECTURES BUT WE ALWAYS RESPECT MEMBER CONFIDENTIALITY AND PRIVACY
- WE HAVE A PARADE OF CHERUBS AT EVERY CONFERENCE AND WILL NOT BE ABLE TO DO SO THIS YEAR VIRTUALLY BUT IF YOU HAVE WINGS, WEAR THEM!
- NO BALLOON RELEASE THIS YEAR BUT IF YOU HAVE THEM, USE THEM!
- WE HAVE A PIZZA PARTY ON THE FIRST NIGHT OF EVERY CONFERENCE. - THIS YEAR IS IT VIRTUAL
- KID'S GET A CHANCE TO LEARN THE CDH KIDS SONG AND PERFORM ON THE LAST DAY OF THE CONFERENCE. • CHERUBS DOES NOT CHARGE A CONFERENCE FEE. •
- FOR SAFETY AND PRIVACY OF OUR MEMBERS, YOU MUST BE A MEMBER OF CDHI TO ATTEND.

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WEDNESDAY, APRIL 28



The Virtual Pizza Party!

6:00 pm EST

Welcome and Opening Remarks –
Dawn Ireland, CDH President

6:15 pm EST

Family Introductions

- Those who purchased Conference boxes will have pizza kits mailed to them. Everyone else, please provide your own pizza
- The whole family can join in!
- We will ask everyone to introduce yourselves and share your story – but it is not required that you do so if you don't feel comfortable
- Each Introduction must be less than 5 minutes to give everyone a turn
- ALL families are welcome!
- Make sure to have tissue handy as we do cry sometimes... but we laugh too!
- Wear your conference shirt if you have them!



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RESEARCH DAY



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We are excited to include many researchers at this year's event. Please note the following rules:

These speeches are for informational purposes only and may or may not pertain to your child's medical experiences. Please know that whatever the researchers say, what info that they give is not to sway anyone's choices, guilt anyone for making different choices or make you question anything other current research. We do the best we can with the knowledge we have at any given time in both research and parenting. We are all learning.

Please wait to ask questions until the end of each speech.

The doctors cannot answer personal medical questions or give you medical advice unless they are your doctor's surgeon. You may ask in general questions, but not for medical advice for your child. They do not have your child's full medical history or chart and it would be unethical to give you advice of any medical nature in a public forum without proper information.

All contact information for research will be available for you if you would like to participate in any research. Please, join them all!

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THURSDAY, APRIL 29



11:00 am EST	Welcome and Opening Remarks
11:15 am EST	Dr. Matt Harting – University of Texas, Houston Dr Tim Jancelewicz – Le Bonheur Children's Hospital CDH Study Group
12:00 pm EST	Dr. Mahmaud El Fiky Cairo University Global Initiative for Children's Surgery The World Federation of Associations of Pediatric Surgeons
12:30 pm EST	Dawn Ireland, President Jason Miller, CDH Registry Administrator CDH International
1:00 pm EST	Dr. Roya Farhadi MD Mazandaran University of Medical Sciences, Sari, Iran
1:30 pm EST	Dr. Augusto Zani, Lina Antounians and Zani Lab University of Toronto, Sick Kids Hospital
2:15 pm EST	Julia Wynn, MS CARE for Kids / DHREAMS
3:00 pm EST	Dr Francis High Massachusetts General Hospital Boston Children's Hospital
3:30 pm EST	Dr Daryl Scott, Dr. Yoel Gofin, Tiana Scott Baylor Medical Center
4:00 pm EST	Dr. Gabrielle Kardon University of Utah
4:30 pm EST	Kristin Aigner, RN, BSN OSF St. Francis Medical Center
5:00 pm EST	Dr. Richard Keijzer University of Manitoba
5:30 pm EST	Live Q&A Closing Remarks



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SUPPORT AND AWARENESS DAY



The journey of Congenital Diaphragmatic Hernia is hard on every family. It's overwhelming, terrifying, heart breaking and so confusing. It's understandable how many develop PTSD because of CDH and at CDH International, we take a whole family approach to support.

Today, as we discuss both CDH Awareness and Support, we will discuss ways to work together and also we will talk about coping with CDH.

The Round Tables are a favorite at our Conferences. To many, it's the best part of the event as they can confidentially and openly share experiences in a non-judgmental environment.

We have just one rule today at the CDH Conference....

What is said at the CDHi Conference, stays at the CDHi Conference.

Please do not share anything said in confidence at the Round Tables.

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FRIDAY, APRIL 30



11:00 am EST

Opening Remarks
Dawn Ireland

11:10 am EST

Congenital Diaphragmatic Hernia Awareness
Mellissa Reaves

11:30 am EST

The Importance of Advocating Together
Nadia Bodkin, Rare Advocacy Movement

12:00 pm EST

Volunteering at CDH International
Tracy Meats

12:20 pm EST

Fundraising at CDH International
Nicolle Colvin

12:40 pm EST

Congenital Diaphragmatic Hernia Support
Tracy Meats

1:00 pm EST

Round Table Session 1

- Feeding and GI Issues
- Dealing with Family and Friends
- How Do We Pick Up the Pieces? (grieving families only)
- Survivors Only Group (13 and older)

2:30 pm EST

Round Table Session 2

- PTSD
- Behavioral and IEP Issues
- Self Advocating
- Ways to Honor our Children (grieving families)

3:30 pm EST

Round Table Session 3

- Marriage and Relationship Issues
- Behavioral Issues
- Can we ever put CDH behind us?
- What CDH has taught us personally

4:30 pm EST

Socializing

5:00 pm EST

Closing Remarks

6:00 pm EST

CDH Concert (on our Facebook page)



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VENDOR HALL



ALLIANCE OF CONGENITAL DIAPHRAGMATIC HERNIA ORGANIZATIONS

CDH International is a proud founding member of ACDHO, a chartered group of Congenital Diaphragmatic Hernia charities founded in 2012 to work together, support patient families, raise global awareness, participate in research and promote a positive, non-competitive CDH community.

Each member organization of ACDHO provides different services and projects that complement the CDH community and all organizations fully support each other.

As such, we invited all members of ACDHO to promote their organizations to attend this conference, open it up to their members and promote their organizations in our Vendor Hall.

If you would like to learn more about the Association of Congenital Diaphragmatic Hernia Organizations, please visit:

www.acdho.org



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2021 CDH CONCERT



Jason Adamo Duo
Suzanne Simone (CDH survivor!)
Anthony Rogowski
Chris Hendricks



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