

REACHING OUT

SPRING 2021

Palliative Care Benefits

COVID-19 Vaccine
and Individuals
with CdLS



CdLS Foundation
Cornelia de Lange Syndrome Foundation, Inc.

Director's Message

Welcome to our first edition of *Reaching Out* of the new year - a year that is filled with the hope of possibilities. Together with you, we intend to do great things. The last twelve months have been a testament to the strength, resilience, and love of our amazing CdLS community. Thank you for standing together with us to pull through a very challenging year.

Your incredible support has allowed us to continue to provide life-enhancing services to individuals with CdLS as well as their families. THANK YOU for being there for us - and for each other!

As we look forward the future - it looks bright.

We are gearing back up for a combination of in-person and virtual events. We are planning our first virtual family gatherings and enhancing our upcoming virtual clinics in various locations. Raising awareness is never far from our hearts as we look forward to championing awareness with all of you in May of this year. No matter how you show up, your voice matters.

In this issue, we seek to raise awareness of the broad range of care options - both standard and palliative care. We bring you the story from a grandfather with a grandchild who has special needs that wrote an open letter to his children. We also have a few virtual FUNraisers for you to help support us while having fun. We hope you find the pages inspirational - from the lighthearted to the more serious topics. We will be there with you every step of the way.

Together - let's face 2021. Together - we are #CdLSStrong.

Warmly,



Bonnie Royster, CdLS Foundation
Executive Director

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FINANCE MANAGER

Slivia Goldman

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email: info@CdLSusa.org

www.CdLSusa.org

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VIRTUAL SYMPOSIUM UPDATE



Antonie D. Kline, M.D., CdLS
Foundation Medical Director

Two thousand twenty was the year of “firsts”. Latest in the world of the CdLS Foundation was our first virtual multidisciplinary clinic for adolescents and adults. Because of COVID-19, we had to cancel the November aging clinic in Baltimore, MD, and we decided to trial a virtual format.

This clinic is usually held twice a year at Greater Baltimore Medical Center. Usually about eight to nine families attend, each individual with CdLS and their family meet with about twelve or thirteen medical professionals. These specialists are extremely knowledgeable about CdLS, most have attended this clinic for nearly ten years or more. In addition to the medical aspect of the clinic, the families typically meet after lunch as a group, and discuss transition and support with a family service coordinator.

For the virtual clinic, each of the medical professionals who agreed to participate gave a 10 to 15 minute presentation via Zoom of more typical findings with aging in each of their fields. Some questions from families were received ahead of time, and were covered in these talks. Topics discussed included: genetic counseling related to gene mutations and the cause of CdLS and unlikely risk for siblings to carry a mutation; eye findings seen in CdLS with aging; GI issues in CdLS; gynecologic implications for teens and women with CdLS; behavioral issues and management and medications in CdLS; communication possibilities during aging; and a brief overview of other specialties.

After each talk there was opportunity for questions read from the chat. Although nearly 20 families had signed up, unfortunately not all families were able to attend. Two of the family service coordinators helped facilitate the clinic. After a break following the medical presentations, there was a group discussion with the remaining families, covering topics such as state and federal services, guardianship as well as programs their children participate in and what it may look like as they age and potentially finding alternative living arrangements.

Families gave feedback that they enjoyed the virtual format and appreciated not having to travel away from their home. At times, adults with CdLS can resist travelling or have difficulties with behaviors. Of course, the mutual gathering and connections were missed, but some virtual connections were made. Due to limiting the number of families who can attend, we would ask that families try and notify us if they cannot participate, so others on the waiting list could have the opportunity. We will likely use this format in the future, and would welcome your suggestions.

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How Palliative Care Can Benefit Families and Children with Complex Care Needs

By Shih-Ning Liaw, MD, and Marsha Joselow, MSW, LICSW

One of the biggest misconceptions of pediatric palliative care is that it is only for dying children. Health care providers often talk about palliative care as an alternative pathway to standard care, and the choice presented to patients and families is sometimes framed as an either-or conundrum: EITHER you choose standard care to prolong life OR you choose palliative care to prioritize comfort.

“Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness.” (Mayo Clinic, 2017)

But what if this is the wrong question to ask? What if this is a false dichotomy, and palliative care represents a way to pursue treatment that supports a balance of both goals – of living as WELL as possible for as LONG as possible? In a landmark study published in the New England Journal of Medicine in 2010*, a team of researchers looked at the impact of palliative care services introduced early in the course of treatment among patients with a serious type of lung cancer. Not only did they find that those who received palliative care reported better quality of life and emotional well-being, they also found that those who received early palliative care survived longer. This study fundamentally changed the conversation around palliative care and what it represents. It should no longer be thought of as an alternative to standard care, but as a standard component of care to be provided alongside disease-directed therapy.

Palliative care specializes in serious and complex illness. Unlike other specialties that focus on organ systems and specific diseases, palliative care focuses on the whole person and the experience of living with serious illness. It

represents a philosophy of care that honors what is most important to the patient, and in pediatrics, this care extends to the family caring for the child with complex care needs. Palliative care recognizes that addressing the multitude of challenges that come with complex illness requires the collaborative expertise of an interdisciplinary team, which may consist of physicians, nurses, social workers, child life specialists, and chaplains. Palliative care provides expert symptom management to minimize suffering from distressing symptoms.

Palliative care acknowledges that communication in a complex healthcare environment can be difficult and seeks to facilitate collaboration within a fragmented system. Palliative care strives to ensure that treatment plans are aligned with the patient and family’s goals, hopes, and values. Palliative care promises to walk alongside patients and families as they experience the ups and downs of living with serious illness. Palliative care recognizes that families caring for children with medical complexity may face enormous disruptions in work and may lead to financial insecurity. To address this, palliative care ensures that each family has information and access to all programs including local and federal ones that might benefit them. Palliative care provides supportive presence, a listening ear, and non-judgmental space to reflect, process, and think about anything and everything...the big and the small, the joys and the sorrows, the celebrations and the grief...that come with caring for a child with complex care needs.

*Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010 Aug 19;363(8):733-42. doi: 10.1056/NEJMoa1000678. PMID: 20818875.

CLOSER LOOK: PALLIATIVE CARE

By Kathy Wagner

When a pediatric nurse practitioner friend of mine suggested we investigate Palliative Care for our Molly, I was a bit confused and more than a little defensive quite honestly. Molly had a life long history of bowel issues. She recently had a volvulus (twisted bowel), and had nearly died. After weeks in the ICU and many complications, she was home and seemed to be ever so slowly recovering from this horrible experience. It is an understatement to say this was a really challenging period. She had so many new care giving needs. We felt completely overwhelmed, but why would we need Palliative Care? Palliative care is hospice care, right? Molly wasn't dying. We had hope for her future. An inner voice told me to find out more. We needed help. At times I felt like we were drowning in her ever-increasing medical needs.

My friend told me that Palliative Care was becoming part of the standard of care for medically complex kids, and was not just for those with a terminal diagnosis. I still felt like we weren't candidates for this service, but we were pretty desperate at this point to improve Molly's quality of life. Just asking her surgeon for the referral felt really uncomfortable. I listened to my gut. Why not see what they have to offer?

Once we met the Palliative Care Team at Boston Children's, we learned that they followed medically complex kids for decades sometimes. We told the team about Molly and our family, her medical journey thus far, and our concerns for her future. We felt an enormous sense of relief after meeting with the team for just an hour or so. It felt hopeful, not like we were giving up on our daughter. We finally had found partners to help us through the medical gauntlet.

My heart sank a bit as I realized how much Molly could have benefitted from Palliative Care so much earlier. A team to manage her pain and anxiety? Help us communicate our wishes for Molly with specialists? Improve coordination of her care? Help us find the language needed to articulate

what was most important to us for Molly's quality of life? How had we missed out on this all these years? Sadly, in Molly's case, our experience with Palliative Care would be very short, but also provided us with the tools we would sorely need very shortly.

In our case, Molly would need the hospice services that are also a part of Palliative Care. We didn't know when we met with the Palliative Care Team that Molly's small bowel was now failing. We were back at Boston Children's in just a few weeks after she experienced yet another obstruction. We were faced with the hardest decisions of our life.

It's difficult to find the words to explain what having this team of caring, compassionate, understanding, and talented professionals by our side meant to us in our time of much desperation and angst. Their collective experience and wisdom helped us in so many ways. The team made multiple visits to Molly's bedside to discuss options and concerns, and to hold our hands, acknowledging gravity of the situation we were facing.

After Molly's small bowel ceased to function yet again, before even implementing the procedures we had chosen to try and help her, our heartbreaking choice became clear. The Palliative Care Team helped us articulate our thoughts to her other doctors. We transitioned Molly to comfort measures only. Palliative Care was heavily involved in setting this up, controlling her pain and providing emotional support to our family. Molly died peacefully six days later.

We miss our girl so much, but we are at peace with our choice to cease further treatment for Molly's long history of intractable bowel issues. By sharing our story, we hope to educate CdLS families about the benefits of Palliative Care for children and adults with complex medical needs. Our only regret is that we didn't access these services sooner.



Jupiter Gunter

LIVING MOMENT TO MOMENT

When a child is born with CdLS, parents often reach out to the CdLS Foundation seeking advice. In 2019, when Jupiter Gunter was born, he was immediately diagnosed with CdLS. His parents, Shaunita and Christian laid in the hospital bed and knew they could not just be defeated. Shaunita looked up “help me understand Cornelia de Lange Syndrome” and the Foundation was the first thing that came up. They reached out to the CdLS Foundation the day their son was born. That very night, both parents made a commitment to educate themselves and their family about what the road ahead might be for their precious son.



The young parents had to quickly adapt to a “new normal” that included the challenges of not being able to hold their baby for weeks at a time and enduring the pain of watching him go through multiple surgeries. The CdLS Foundation offered emotional support to Shaunita when Jupiter was going through those surgeries. Family Service was there for her when she needed guidance and help navigating the intense medical arena.

Shaunita and Christian also came to rely on support from the CdLS Foundation and believe it significantly helped lighten their load and hearts. For instance, when their doctors insisted that Jupiter needed a tracheotomy, they turned to the Foundation for advice. Whitney from the Foundation’s Family Service provided a referral to a CdLS specialist that helped Shaunita and Christian make a more informed decision with which they were all comfortable.



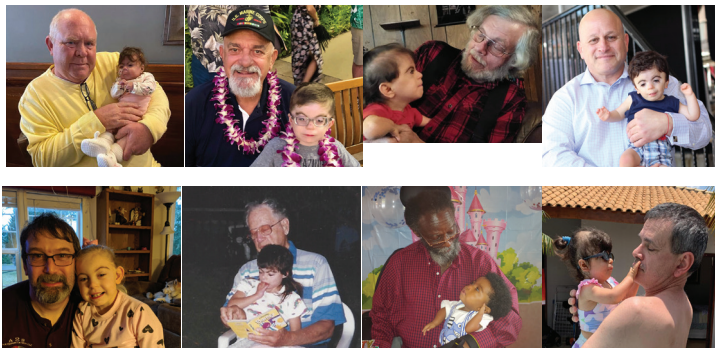
Shaunita confirms that, “Without the Foundation so many families would be lost. Having someone with more in-depth insight on what Jupiter needs helps us pass along information [to our son’s doctors] so that our son receives the best care.” Above all, Shaunita and Christian believe, “The CdLS Foundation has shown us the definition of unconditional love and that our babies are simply perfect.”

An Open Letter from A Grandfather of Special Needs Kids to Their Parents

Dear Parents,

As a grandfather, I accept my "special needs" grandchildren may never live a "typical" life, whatever that is. I accept these children for who they are. They are unique and made in the image of God. He loves them and I can do no less.

I am so proud of your children when they reach a milestone they struggled for. They are young warriors not knowing the meaning of giving up. For instance, other people may not understand the thrill of knowing your child can now poop in the toilet. They don't have to understand but I celebrate with you.



Before I go any farther, I must make mention of an important part of your family. Other children, typical children who are part of a "special needs family," may inadvertently be almost forgotten. If your family includes children who are "typical," please monitor them and make sure they are doing well. Life can be lonely for such children. Give them some golden time just for them.

Believe me as a grandfather, I notice things. I can tell when a child is feeling left out. That's where I can come into action. I can take the child out for lunch or to a movie or other fun things to do. The point is giving this child some time where he or she is spoiled for a while.

I have to admit I become somewhat angry when people exclude your children from things like birthday parties. Even if your child or children aren't able to attend at least they can be invited. This includes family as well as friend type gatherings. There is no reason to not include children with special needs unless it is a health or safety issue. Even then an option may come up so they are not left out.



I see your world and now mine through the lens of a grandfather. Through this lens I see I have taken on a greater love for life. I see life is fragile and even enigmatic. As I look through my grandfather filter, I see not all of life is black and white, right or wrong, good or bad. Life just is and it includes mystery!

There is mystery in the reality of special needs as it pertains to life. How is it one child or even two or three children in one family may have special needs? How does this happen? This is such a mystery. Perhaps the best thing to do, the most human thing I can do is accept these children. Accept them by seeing beyond their "special needs" and see them for who they are.



You see, in accepting children and other people with "special needs," I may see my own needs. I may then see acceptance means love. As a grandfather I do not merely accept my grandchildren I love them. They are part of me.

I am getting older by the day. I look back over my life and I see there are more days behind me than in front of me. I know I may miss out on certain years of my grandchildren. I may be taken ill and no longer able to make a trip to see them. If this happens, I trust they will always know how much I love them. This will never end.

All my love,

Papa.

HIGHLIGHTED EVENTS

RUNNING IN MEMORY OF JASON - MEET THE BROCKSTEINS



Did you know that the distance of a full marathon is 26.2 miles? That number is what prompted the Brockstein family to create their own Team CdLS virtual Chicago Marathon in October of 2020.



The family says they had always wanted to do a fundraiser in memory of son, Jason - who was born in August 1994, and sadly passed away just 15-months later in November 1995. It was sister Hannah who suggested the idea of running a marathon for what would have been Jason's 26.2-year birthday in 2020.

The timing was perfect for the Bank of America Chicago Marathon! Even though the race in Chicago was cancelled due to COVID-19, the Brocksteins carried on and created their own virtual marathon. It was a success in more ways than one.

"I've run the Chicago Marathon two times prior - in 1994 with Jason at the finish line, and 1998 with a small photo of Jason with me, pushing me through the pain to the finish," commented dad, Bruce. "But this event was local, with friends and family at the ten water stops and the finish line. It made the whole day a true celebration of Jason's life

and our friendships - the best by far of the three marathons that I've run - despite being 20 years older and much more painful."

Together with the help of friends and family, the Brocksteins raised over \$12,000 for the CdLS Foundation.

"As a physician, I have a need for data and objective information. In 1994 there wasn't a huge amount in the medical literature, but the CdLS Foundation was a great source for current information for me," recalls Bruce.

"Attending a CdLS Foundation event on Jason's fifth day of life was probably the most helpful thing for me," commented mom, Heidi. "At a time when we were mourning the idea of who our child would be and what our family would look like, we were able to observe all of these happy families. We knew that although our path was not what we had imagined, it was still beautiful. It was just going to be different."

According to Heidi, when Jason was alive, "he had the unique ability to bring people together. His beautiful hair, his contagious smile and laughter captured the attention of anybody who saw him."

Now more than twenty years after his passing, Jason is still bringing people together, thanks to his loving family, who runs in his memory, raising funds to enable others with CdLS and their families to receive the important support that they need.

GENERATIONS OF GIVING BACK - THE POMFRET ONE LOVE ONE HEART 5K



Since 2005 friends, family and community members in Decatur, GA, have looked forward to the One Love One Heart 5k. The event was created by Jennifer and James Pomfret in honor of their daughter Maya.

Born in 2003, Maya is the Pomfret's first child. "We really struggled emotionally as we were navigating a new life with a child with special needs," commented Jennifer. "One night in 2005 we were having our close friends, the Czech's, over, and they suggested that we do a 5k fundraiser to move the negative emotions toward a positive one. It worked!" That was the inception of the Pomfret One Heart One Love 5K.

"Maya is the number one reason this event took place," Jennifer explained. "We were not sure that she was ever going to walk, but of course she DID with the help of her teachers when she was around 8 years old. Her teachers made it a goal to have Maya walk the entire 5k. Every year she tries to walk the race."



After 13 years of organizing this labor-intensive event, Jennifer and James decided that they needed a break. So, the 5K fundraiser was halted after 2018. That was until Hannah, Maya's younger sister, and close friend Kira Czech, both decided to take on the event as their sophomore year project.

"We love Maya so much, and it makes us happy to do

something that supports her and everyone else who has CdLS," explained Hannah.

Kira went on to say, "We have been a part of this race since we were very little, and we knew if we continued it, the event would be successful since we have a lot of people to support and help us accomplish our goal."

Due to the uncertainty of COVID-19 during the planning of the event, the girls decided to host the 5K as a "virtual" event.

The baton has been handed over from one generation to another, and the One Love One Heart 5K runs on as a tribute to Maya and others who have CdLS.

NATIONAL CdLS AWARENESS DAY

MAY 8, 2021

Each year the Foundation encourages families and volunteers to host a variety of awareness raising initiatives throughout the United States to educate and inform others about CdLS. Some different ways you can participate include, requesting a proclamation from your local government official, go live on your social media page to share facts about the syndrome or do a virtual presentation for your class.

If you are interested in learning more about hosting an Awareness Day event or have questions, please email Gabrielle at gnadeau@CdLSusa.org or visit www.cdlsusa.org/raise-awareness.

CALENDAR

February 12

CdLS Remembrance Day

February 28

Rare Disease Day

March 10

CdLS Clinic at
Shriner's Hospital
Salt Lake City, UT

April 10

Virtual Multidisciplinary
Clinic for Adolescents
and Adults

May 8

National CdLS
Awareness Day

May 21

New England Golf
to Benefit the CdLS
Foundation
Ipswich, MA

October 9

Baltimore Running Festival
Baltimore, MD

October 10

Bank of America
Chicago Marathon
Chicago, IL

October 11

Amber Gaines Memorial
Golf Classic
St. Louis, MO

November 7

TCS New York City
Marathon
New York, NY

FUNDRAISING

Strategies for 2021

One of the things that 2020 has taught us is to think out of the box when it comes to special events. Many of our fundraisers last year were determined to go on with their fundraising efforts when their group event was cancelled, by hosting their own “virtual” events.

A great example is the Feehan Family’s Backyard Obstacle Course. When the Down & Dirty Mud Run was cancelled in Pennsylvania due to COVID, Mike Feehan decided to create his own obstacle course in his backyard. The great thing about it was that his 12-year-old son Connor, who has CdLS, could participate. Also, there were no entry fees to pay, and no travel or hotel expenses.



Feehan Back Yard Obstacle Course 2020

Running his backyard obstacle course with the kids and a couple of relatives, Mike raised close to \$35,000 for the Foundation!

Here are some of Mike’s strategies to inspire you in your own fundraising endeavors for the CdLS Foundation:

1 PICK AN EVENT TO USE AS A REASON TO RAISE MONEY

- Low-cost events are easier: a walk, a run, an obstacle course
- Auctions, golf outings, etc. require more coordination, but can be more intriguing to certain people

2 CREATE YOUR ONLINE FUNDRAISING CAMPAIGN (USING THE CdLS FOUNDATION’S DONATION LINK)

- This is where you tell your event’s story (why, where, when, etc.). Make it personal, but concise
- Use fun photos to engage your donors
- You would send the link to this campaign to your potential donors
- You donors can make their online donations here

3 IDENTIFY YOUR POTENTIAL DONOR NETWORK

- Send the link to your fundraising campaign to family, friends, co-workers, neighbors and those in your contact list, asking them to support your efforts and the CdLS Foundation.
- Follow-up – keep your event top of mind
- Send an initial email to your contacts two-months before your event, including the link to your fundraising page
- Send a reminder email two-weeks before the event including the link
- Send an email with photos/videos of the event a week afterwards, and let them know they can still donate

4 SAY THANK YOU!

- Send a thank you email within a few days following the event to all of your donors. You will be able to keep track of who donated through your fundraising campaign page

If you have questions about getting started on your own event, or if you need help creating your online fundraising campaign, please contact Annette Scheidecker at 800-753-2357 or ascheidecker@cdlsusa.org.

2020

Fundraising Recap

While the year of COVID certainly had an impact on many of our special events and third-party fundraisers, you, our wonderful families and supporters did not let us down. Your love and continued support of the Foundation continues to overwhelm us.

Here are just some of the highlights of your fundraising efforts for 2020:

- Amber Gaines Memorial Golf Classic in St. Louis, MO, raised \$74,000.
- Six Team CdLS Captains ran the cancelled Bank of America Chicago Marathon virtually - collectively raising \$63,000.
- The Feehan family turned their backyard in Pennsylvania into an obstacle course for their virtual 2020 Backyard Mud Run raising \$35,000!
- In May we sent out a special Spring Appeal to help offset the losses from several events that were cancelled, and thanks to your generosity we raised \$22,000.
- Captains for the cancelled Baltimore Running Festival also ran on their own raising another \$10,000.
- The Feighan-Kurth family held their annual Walk for Will & Hope virtually in Michigan and raised close to \$5,000.
- The Rissland's held a very clever virtual version of their annual Brew & BBQ in Alpharetta, GA raising both \$4,000 and awareness.
- With the help of our Giving Tuesday Ambassadors, we raised over \$20,000 on December 1st, more than we have ever raised before!

Those are just some of the ways that you have helped to sustain the CdLS Foundation during a very difficult year. Thank you for your dedication to your CdLS Foundation.

WELCOME

New Families

California

Minako and Dan and son Daniel, born July 10, 2019

Colorado

Allison and daughter Emory, born December 16, 2019

Georgia

Amelia and son Wilson, born November 19, 2020

Illinois

Corrine and Dominick and son Geno, born September 4, 2020

Wisconsin

Abriana and Sean and daughter Kennedy, born April 11, 2020

VINCENT HACKENBERG

By, Gabrielle Hackenberg

Vincent is one of the happiest and most laid-back kids you will meet. From day one when we met him in the NICU he has brought us absolute joy and happiness.

He turned 2 in October and currently loves Mickey Mouse, Sesame Street and all things music and lights. Food is Vincent's number one motivator, he can eat more than any other 15lb child could/should, and he will eat any food you give him. Vincent is the light of our lives and everyone that he meets, and he loves being around people.



Vincent was suspected of having CdLS at birth and was officially diagnosed around 4 months from the CdLS team at CHOP and then confirmed with genetics tests at about 8 months. He has a very mild form, with only one amino acid change on a single chain of the *NIPBL-1* gene.

CdLS does not affect our day-to-day life in my opinion. It is just part of our lives. Vincent currently receives early intervention services for speech, occupational and physical therapy, which can be quite time consuming each week.

He also has developmental delays related to CdLS/his prematurity, but has made significant gains over the last 8 months or so and is on target with all milestones according to the CdLS milestone chart.

Vincent loves to play with other kids at "school" (aka daycare), loves to eat, listen to music and explore everywhere, now that he is crawling and pulling to stand.

Vincent had a rough first year. He was born at 32 weeks weighing only 2lbs 10oz. He experienced medical complications from his size and prematurity that kept him in the NICU for 8 weeks. We, Tyler and I [Gabrielle], were matched to adopt Vincent when he was around 7.5 weeks old and flew out to LA to meet him on his due date, taking him home from the NICU five days later. Vincent has significant reflux issues that made feeding a challenge for a long time, finally getting it under control with medication around 16 months old. At 8 months old Vincent contracted adenovirus which caused him to get severe pneumonia and kept him in the hospital for a month, being intubated and getting a central line. Due to his size, related to his diagnosis of CdLS, Vincent has very small ear canals so he needed to have tubes placed in his ears at 16 months old.

The Foundation has been a wonderful resource of information, but more importantly of people who know about this diagnosis, the challenges that can be faced from it and the connections needed to keep you grounded. It is amazing to see all the individuals across the lifespan to see what Vincent can achieve and who he can become.

Embrace the unexpected and don't let the diagnosis ever stop you or your child from reaching for the stars. A diagnosis, and maybe a unibrow, can't define you and shouldn't stop anyone from doing anything they want to do. Vincent has beaten all the odds and become so much more than anyone expected, and every child has that potential.

COVID-19 VACCINE AND INDIVIDUALS WITH CdLS

Statement from Dr. Kline and Dr. Jyonouchi

The Pfizer-BioNTech COVID-19 vaccine and the Moderna vaccine have been approved for an Emergency Use Authorization (EUA) by the Food and Drug Administration (FDA) and were about 95% effective at reducing the risk of COVID-19 infection. These are mRNA vaccines, not live virus vaccines, so there is no danger of getting COVID-19 from them.

These ground-breaking vaccines have the potential to end this pandemic in the coming year. We will be recommending these vaccines to individuals with CdLS when they become available. Both vaccines are currently NOT approved for use in children (studies in children are currently underway).

The Pfizer-BioNTech vaccine is approved for use in 16 years of age and older.

There have been concerns raised about the new Pfizer COVID-19 vaccine and allergic reactions after two reactions occurred in healthcare workers in the UK. Until more information is available in agreement with the CDC, we agree that all patients with history of anaphylaxis to other vaccines do not get the Pfizer-BioNTech vaccine.

Individuals with common allergies to medications, foods, inhalants, insects, and latex are no more likely than the public to have an allergic reaction to the Pfizer-BioNTech COVID-19 vaccine.

The Moderna vaccine will be for use in 18 years of age and older. No allergic reactions have been reported with this vaccine.

There is no known problem with getting the vaccines with a history of any known medical issues (e.g. seizures, congenital heart disease, etc.). If you are concerned, please discuss with your child's doctor. Many individuals with CdLS as adults are still the size of a young or small child. When considering if your adult child should get the vaccine, it is recommended to talk with your child's PCP to review any past reactions to vaccines and medical history to help determine if they should get the vaccine when they are eligible.

WELCOME NEW BOARD MEMBERS

We would like to introduce the newest members of the CdLS Foundation Board of Directors.



MARY ANNE ELHERT

is the President and Founder of Protected Tomorrows, an advocacy firm that enhances the lives of people with special needs through a comprehensive life planning process. She is a financial professional and sister to an individual with disabilities.



YVONNE ALSTON

is a DEI (Diversity, Equity & Inclusion) strategist and advocate. Yvonne has combined her tremendous passion for DEI and her lived experiences with 20+ years in corporate marketing and communications to offer organizations critical DEI, brand, and communication strategies.

NICK JACKSON is the sibling of an individual with CdLS, Maddy. He is an attorney at the Disability Law Center in Salt Lake City, where his practice is focused on preventing the abuse and neglect of people with disabilities in Utah institutions, as well as addressing individual and systemic housing discrimination.



TRICIA WISE has broad business experience in retail, healthcare, non-profit and financial services. She is a mother to two children who had significant medical issues when they were younger, which is one of the reasons she is so passionate about helping others - especially children. Tricia also understands importance of giving back.



PAUL VILLANI is an accomplished technology leader, executive partner, and transformation catalyst with broad industry experience across healthcare, pharmaceuticals, industrials, aerospace, and defense. He is passionate about developing technology leadership and leveraging the power of people.

We also want to thank Board Members who have served on our board with distinction. We will be losing two amazing members this year -- Pat Lyons and Lynne Kerr. Both have been key members in helping the Foundation innovate, raise awareness and ensure that we continue to help those who need it. We thank you for sharing your time, talent and treasure with the CdLS Foundation.

In Honor/ Celebration

Logan Fowler
Sarah and Douglas Fleming

Charlie Donald
John Price

Hannah Boehman
Sara and Michael Boehman

Hannah E. Moore
Patricia and Brian Moore

Jonathan Swanson
Theodore Weidenbach
Suzanne and Jess Soltess

Molly Wagner
Cynthia Strout

Norm Winnerman
Marla and Mark Cahn
Anne Cahn

Shaylin H. Cubeta
Alice Hoke

Siena M. Renteria
Francie Barber and
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Alex R. Boneberg
Kathleen Glenn

Bradley Winter
Elaine Reed

Brady Kelton
Mary and Mark Kelton

Charles Schulte
Neil Boehman
Victoria and Rick Boehman

Chase J. Duff
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Christian Thomas
Jacqueline Hudson

Connor Willey
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Dane Curalli
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Devin Miller
Helen Miller

Dominick Curalli
Pauline and Byron Anderson

Emelynn Ottinger
Coleen and Charles Coakley

Frederick E. Hasecke
Nancy and Charles Kaelber

Gracy Mann
Maria Llewellyn

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Liam Brundage
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Nancy and Charles Kaelber

Lindsay Franco
Joanne and Jim Franco

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Lynne and Carl Hovey

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Jenna and Brian Lee-Elrod

Tyler Macy
Barbara and Timothy Macy

Zachary Markowitz
Susan and Arthur Markowitz

In Memory Of

Adam Hasecke
Nancy and Charles Kaelber

Allison Tryba
Susan and Lyle Tryba

Amber N. Gaines
June Drum

Charles J. Keithley
Paula Bechtold
Mary Ann Moramarco

Charles Schulte
Kenneth Schnell
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John Stevenson

Frank Colosi
Robyn Rothman and
John Stevenson

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CdLS Foundation

Cornelia de Lange Syndrome Foundation, Inc.

30 Tower Lane, #400
Avon, Connecticut, USA 06001
800.753.2357
www.CdLSusa.org

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EDUCATION HANDBOOK

NOW AVAILABLE

We are excited to announce that we have updated our Education Handbook. The refreshed guide offers updated information on education, therapies and additional supports. In the guide, you will learn about IEPs, how to successfully transition from different grade levels, different types of therapies and so much more. To receive your copy, contact Family Service at familyservice@CdLSusa.org or call 800.753.2357.

