

Virtual Conference



LEAN
ON ME
2021 soft

Find out more information about our events at
[trisomy.org!](https://www.trisomy.org)

Virtual Conference General Sessions

Monday July 19, 2021

4:30pm CST [Aquatic Therapy](#)

Briana DeMars OTA

7:00pm CST [Welcome to Conference](#)

Including The Parade of Stars!

Join us for an evening of fun! We will be kicking off our 2nd Virtual Conference "Lean on Me" hearing from our SOFT Founder - Kris Holladay and SOFT President - Barb VanHerreweghe. We will also be showing off our beautiful kids in the Parade of Stars! This is an event you do not want to miss - we may have some fun and surprises!

Tuesday July 20, 2021

11:00am CST [Fitting, Adjusting and Modifying Mobility Equipment](#)

Michael J. Workman PT C/NDT

Michael J. Workman PT C/NDT has been a physical therapist for the past 27 years with a primary focus on the clinical treatment of children with neuromotor impairments. In addition to being the co-owner of the private practice Professional Therapies, Michael is also the primary developer/co-owner of The Bamboo Brace, a dynamic elbow brace for children and adults with special needs as well as the Equipment Placement Director for the charity Ability Found.

3:00pm CST

Trisomy 13/18 - The Basics

John C. Carey, MD, MPH, FAAP, FACMGG

Throughout his career, Dr. Carey has been interested in birth defect syndromes and the care of children with these conditions. Dr. Carey graduated from Villanova University in 1968 with an A.B. and obtained his M.D. from Georgetown University School of Medicine in 1972. He trained in pediatrics and genetics; dysmorphology as a resident and fellow at the University of California San Francisco, 1972-1979. Dr. Carey obtained an M.P.H. from the University of California at Berkeley in 1976 in between his residency and fellowship years. Dr. Carey joined the faculty at University of Utah Health Sciences Center in 1979. He became Chief of the Division of Medical Genetics in 1985 and remained in that leadership position until 1999 when he stepped down to assume the role as Editor-in-Chief of the American Journal of Medical Genetics. He held that editorial position from 2001-2016 and is now Editor in chief Emeritus and Associate Editor of the Journal. Dr. Carey established the Medical Genetics Fellowship Program at the University of Utah in 1985 and was the Program Director until he stepped down in 2014 but continues as a mentor and teacher in the Program. Dr. Carey's research focus has been in congenital malformations, neurofibromatosis, and syndrome delineation. He has authored or co-authored over 300 papers, chapters, invited articles, and editorials for scientific journals. He also co-authored the textbook, "Medical Genetics," by Jorde, Carey, Bamshad, now in its 5th edition. The book is a widely used text in schools of medicine throughout North America, South America, and Europe. Dr. Carey has served as medical advisor and "Founding Professional" for the Support Organization for Trisomy 18, 13 and Related Disorders (SOFT) since 1980. The medical and ethical aspects of care of infants and children with these conditions (and related disorders) is currently a major academic interest.

Wednesday July 21, 2021

10:00am CST

[Face the Sun - Art Session](#)

Holly Garces - Art Therapist, MS, ATR

I was blessed and lucky to grow up in beautiful Petoskey, Michigan. My lifelong love of art and desire to work with others, led me to receive a Masters of Art Therapy in 2007 from Mount Mary University, Milwaukee. After graduation I worked for ten years at a senior care facility in Milwaukee. While there I developed an intergenerational art therapy program to bring older adults and children together through art making.

I moved to St. Joseph 7 years ago to be closer to my family and the Great Lakes I so dearly love. I currently work with the Krasl Art Center, as their "Art Angel". In this position I bring art making to the patients at Lakeland hospital, on the pediatric unit as well as into the infusion center at Marie Yeager Cancer Center. I also provide art therapy to the public as part of the counseling team at Thrive Psychology in St. Joseph.

When it's time to play I love taking advantage of all the beauty of Michigan, gardening and sharing in laughter, music, food and fun with my husband, son, dog and family. If any of you want to learn more about art therapy or the work I do please don't hesitate to reach out. Art Therapy is my passion and I am always excited to share it with others. I can be reached at Thrive Psychology 269.408.8474 or kern.holly@yahoo.com

Educational Background:

M.S., Art Therapy, Mount Mary University, Milwaukee, WI.

Professional Affiliations:

Registered Art Therapist, Art Therapy Credentials Board, Inc. (ATCB)

Member, American Art Therapy Association (AATA)

Member, Michigan Association of Art Therapy (MAAT)

1:00pm CST

[Lean on Us: An Overview and Review of TRIS](#)

Project Activities

Deborah A. Bruns PhD

Deborah A. Bruns is Professor and Off-campus program coordinator for the Special Education program in the School of Education at Southern Illinois University Carbondale. She teaches coursework in collaborating with families with children with disabilities as well as early childhood special education assessment and curriculum methods. Prior to this position, Dr. Bruns worked as an educational therapist at the New York Foundling Hospital. Several of the young children she worked with there were diagnosed with trisomy 18. Since its launch in 2007, Dr. Bruns has been the Principal Investigator of the Tracking Rare Incidence Syndromes ([TRIS](#)) project.

Thursday July 22, 2021

10:00am CST

[Kangaroo Kids](#)

Michelle Pikel

Kangaroo Kids came about after Ellie, Emery, and Bodey's cousin, Olivia, was diagnosed with Down syndrome at 12 weeks into her mom's pregnancy. Ellie, Emery, and Bodey wanted to do something to support their aunt and uncle with Olivia's impending care. With hundreds of miles separating them from their soon-to-be cousin, they decided, with their mom's assistance, to create a medical notebook for Olivia's parents, so they could keep all of her medical information in one place.

1:00pm CST

Supplemental Needs Trust

Daniel A. Kautz

Daniel A. Kautz is a Registered Investment Representative with investment experience since 1999. Building and maintaining client relationships is Dan's top priority.

Due to personal life experience, Dan focuses a portion of his practice on funding and managing Supplemental Needs Trusts and works closely with others in the field.

5:00pm CST

Finding Solutions:

Managing Photosensitive Seizures, Light Sensitivity and Ocular Health

Dr. Steven Cantrell OD

Dr. Steven Cantrell is an Optometrist from St. Louis and member of the SOFT Medical Advisory board. Dr. Cantrell received his training from the University of Illinois College of Optometry in Chicago, IL. He and his wife Peggy have two children Ryan (T-18 angel) and Lauren.

7:00pm CST

State Representatives (Chapter Chair) Meeting

Current and prospective State Representatives are invited to join us to hear about changes to the program and collaborate to better serve our communities.

Friday July 23, 2021

10:00am CST

[Finding Words for Our Grief](#)

Cora Welsh, M.A., CCLS

Cora Welsh works as the team manager of a dynamic interdisciplinary pediatric palliative care team at Johns Hopkins Children's Center in Baltimore, Maryland. In her role, Cora has the honor of helping babies, children, adolescents, young adults and their families find and celebrate joys and cope with tremendous difficulties. The central aspects of Cora's work are providing psychosocial support for families cared for by the palliative care team, and follow up care for bereaved families after the death of their child. Cora earned her Bachelor's Degree in Child Life and Literature from Wheelock College in Boston, Massachusetts and Master's Degree in Pastoral and Spiritual Care from Loyola University in Baltimore, Maryland.

Rev. Matt Norvell, DMin., M.S., B.C.C. Pediatric Chaplain

Rev. Matt Norvell is a Pediatric Chaplain and the Clinical Director in the Department of Spiritual Care at the Johns Hopkins Hospital. He is endorsed and ordained in the Alliance of Baptists denomination. He currently serves on the pediatric palliative care team, leads the Children's Center Annual Tribute Service, serves on the hospital Diversity Council, and is the education chair for the Johns Hopkins Hospital ethics committee. He provides leadership support for the Johns Hopkins Hospital RISE (Resilience In Stressful Events) Team which provides trained peer support for employees who encounter stressful, patient related events. Matt is one of the co-developers and presenters of the Caring for the Caregiver curriculum which assists other health care institutions to establish their own peer support programs.

7:00pm CST

[SOFT Friends Video Premier](#)

Join us for the Premiere of the Annual Kari Holladay "SOFT Friends" Video and "SOFT Quilt" Auction.

Saturday July 24, 2021

12:00pm CST

[Moms Only Group](#)

Led by Barb VanHerreweghe, Kelly Hernandez & Terre Krotzer. The moms only group is a place to connect with other moms and have deeper discussions in a completely safe, judgement free environment. This session **will not** be recorded for later viewing.

3:00pm CST

[Dads Only Group](#)

Led by Jamie Lint and Josh Bradley. The dads only group is a place to connect with other dads and have deeper discussions in a completely safe, judgement free environment. This session **will not** be recorded for later viewing.

7:00pm CST

[SOFT Angel Candle Lighting Ceremony](#)

We welcome everyone to join us for the Candle Lighting Ceremony in memory of our SOFT Angels. Submit your angel's name and photo by July 10th to be included in the ceremony. If submitting your angel's name you must also register for the webinar to be able to access the live Zoom event.

Sunday July 25, 2021

1:00pm CST

[SOFT Virtual Conference Closing Remarks](#)

Led by Josh Bradley. Join us for our conference wrap up event. We will come together one last time to share and enjoy eachothers company. We will also announce the winners for the SOFT Run, Walk or Roll event.