

A MILLION DREAMS

Gala

Join us online
for our virtual gala
SATURDAY
OCTOBER 10, 2020



KrabbeConnect
CONNECTING PATIENTS & RESEARCH

Our Mission: To be the source of comprehensive information and access to resources for patients with Krabbe disease. The foundation will drive state-of-the-art research by bridging the gap between science and patient knowledge.

Thank You TO OUR SPONSORS

#CUREKRABBE CHAMPION

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Welcome

TO OUR VIRTUAL *Gala*

We are so happy you could join us on this very special occasion. An evening where we gather online and across the globe, to share KrabbeConnect successes, highlight patients stories, embrace the generosity of our corporate sponsors, and fundraise to the max to reach a day in which each patient can live a life free of Krabbe disease. As we gather safely from our homes, we want our community to know we are working harder than ever to unify work to #curekrabbe disease. KrabbeConnect cannot make this happen alone. We need the Krabbe disease experts, clinicians, researchers, family warriors, friends of the foundation, and our very important corporate sponsors to help change the lives of those born with this neurological disease.

This evening, KrabbeConnect gives thanks to each and every person watching this evening. Without you, we cannot meet the needs of our community and advance the necessary research to bring new therapeutic choices to the bedside of patients. Please, sit back, relax, and enjoy the program. Our goal for this evening is to leave you feeling inspired, altruistic, and eager to follow our journey to success—A CURE!

Warmly,

KrabbeConnect Board of Directors and Gala Committee



Evening Schedule

Reception

5:00 pm-6:45 pm CST

This year, we won't be together in person, but we can still be together online. We encourage you to show our community's strength by sending us pictures of your small and safely organized watch party. Email them to us at info@krabbeconnect.org We just might use your photo during our live online broadcast.

Program

7:00 PM- 8:00 PM CST

WELCOME

- Jen Burleigh-Bentz, "A Million Dreams"

HOSTS

- Cory Hepola, Evening Emcee
- Karen Sorbo, Evening Auctioneer
- James Detmar, Gala Moderator/Announcer

PROGRAM

- Stacy Pike-Langefeld and Anne Rugari, Co-founders of KrabbeConnect
- Game Show: Money Well Spent
- Video-Transplant Alone is Not a Cure
- Fund-A-Need Video: Nikola's Krabbe disease story
- Krabbe disease Tribute: Marc Gunn

We want to extend our appreciation to all the technicians at A/V For You and staff at Stagetime Productions.

So much work went into this program behind the scenes and we thank you for the remarkable, and impactful work you've done.



Our Emcee CORY HEPOLA

Cory Hepola is the Host of “Hey, it’s Cory Hepola” from 9-Noon on WCCO Radio in Minneapolis. He’s a two-time Emmy Winner for Outstanding TV Anchor and has been called a “Game Changer” in local media, landing on the cover of “Twin Cities Business” magazine.



Before WCCO, Cory was a News Anchor and Reporter at KARE 11 in Minneapolis. In October 2018, he was presented with his 2nd Emmy Award in 3 years for Outstanding Anchor, this time for his work surrounding Super Bowl LII in Minneapolis. All total, in his 3 years at KARE, Cory was nominated for 5 Emmys, including another win for Best Talent – Anchor in 2016. In 2017, he was featured in a cover article by “Twin Cities Business” detailing how the news media continues to evolve and was also awarded a “Hairry Award” for Best TV Hair in Minnesota.

Our Auctioneer KAREN SORBO

As a leading benefit auctioneer, Karen Sorbo’s dedication, effusive energy, commanding yet elegant stage presence and precision techniques have engaged audiences across the country. Karen has raised over 800 million dollars conducting over 2,800 auctions since graduating from both the Missouri Auctioneer School and World Wide College of Auctioneering in 1993. Karen achieved national recognition as an auctioneer and spokesperson for important and humanitarian causes. Highly regarded for her knowledge and expertise as a fundraiser Karen has been featured in local and national media. In 2011, she was selected as part of the 2011 “Women of Influence” Speaker Series by Minnesota Monthly Magazine. In January 2012, Karen’s performing, humanitarian efforts and 27 successful years as a leading benefit auctioneer were showcased on Access to Experts TV.



Tonight's Entertainment MARC GUNN

Marc Gunn plays Sci F'Irish music. He fuses his love of science fiction, fantasy, and comedy with his Scots-Irish heritage. You will laugh and smile to songs inspired from Firefly to hobbits, dragons to cats, to traditional Irish drinking songs. He has topped the charts on iTunes and Amazon and won numerous awards. He is a leading innovator on his musical weapon of choice, the autoharp.



KrabbeConnect dedicates this page to Stagetime Productions, a full-service event management and production company. We are so thankful for the wonderful individuals at Stagetime Productions for the creative and artistic components of our gala program this evening. Tonight, would not have been possible without the following marvelous people:

Stagetime
Productions



SHANNON PIERCE

Owner / Producer

Shannon is an incredible event planner and entertainment producer. She is a highly sought expert in the Twin Cities area due to her vast experience and knowledge in writing and producing. Some of the high-profile projects she has produced and/or directed are as follows: 2004 Winter Carnival Ice Palace, 2008 MN Sesquicentennial Statehood Weekend, 2015 National Senior Game Celebration of Athletes at CHS Field, 2018 Super Bowl Live Event, and the 2019 One Minnesota Inaugural Party at the Minneapolis Convention Center. We invite you to review her full biography at Stagetimeproductions.com



JAMES DETMAR

Creative Director

James is a seasoned creative director, writer, veteran actor, improviser, and corporate event host. James is well-suited to navigate and host any event with his charismatic personality, creative writing, and exquisite ability to personalize an event. James biography comes with a long list of accomplishments with his most recent work serving as a freelance creative director for Cargill Animal Nutrition, The Minnesota Twins, Factory Motor Parts, Greater Twin Cities United Way, The University of Minnesota Foundation, Minnesota Public Radio, The Charles Schwab Corporation and Children's Hospital. To learn more about James, we invite you to visit Stagetimeproductions.com



JEN BURLEIGH-BENTZ

Actor / Singer

Jen Burleigh-Bentz is an actor/singer based in the Minneapolis/St. Paul market. Although Jen has toured internationally, she loves living in River Falls, WI where she and her singer/songwriter husband own and operate a full-line music store, Brickhouse Music [brickhousemusic.com]. Crazy as it may sound for a music retail store owner and operator, Jen has been blessed with having years of employment on Broadway stages as well as having performed in many shows in amazingly small and intimate theatres throughout the country. For more information on this beautifully talented artist, visit jenburleigh-bentz.com





Krabbe Connect Accomplishments

2019-2020

- Poster on “Disease Burden and Treatment Considerations in Krabbe disease: A Caregiver Perspective”. Presented at the Feb 2020 WorldSymposia and at the October 2019 National Organization for Rare Disorders Rare Disease Summit.
- Two resource maps released September 2020: The Krabbe Disease Patient Journey and Patient Care Support Resources. The resources are meant to give our newly diagnosed families and those working in the medical community the ability to comprehend their treatment options and quickly navigate support resources in a short amount of time.
- The release of KrabbeCURES, September 2020: a community engagement study utilizing the National Organization for Rare Disorders I am RARE platform to unite the Krabbe disease community through shared knowledge. This online study platform for the Krabbe disease community will allow participants to easily complete IRB-approved surveys about their disease burden journey and allow participants to learn about other participants’ experiences by viewing aggregated survey data. This participant-driven resource works to quickly fill gaps in research to expedite research efforts need to #curekrabbe.
- Externally-Led Patient Focused Drug Development meeting with the FDA: This meeting is considered one of the most important initiatives for our Krabbe disease community. This initiative came to fruition due to KrabbeConnect’s commitment to utilize the funds from the 2019 Fund-A-Need portion of the A Million Dreams gala. The purpose of this meeting is to ensure the FDA and important stakeholders have a robust understanding of patients’ and caregivers’ experiences with Krabbe disease. This also includes understanding of how individuals with Krabbe disease view their quality of life (with transplant and without), what aspects of the disease are most problematic for them, and what actions patients’ and caregivers’ utilize to treat or cope with the disease. The information from this meeting will allow FDA and drug developers great insights into what patients live through and can help shape the development of therapies for Krabbe disease.

Please note: The above list of accomplishments is a result of your contributions to our foundation. Kudos to each of YOU for making this happen.
Together We CAN #CUREKRABBE.



KrabbeConnect Board of Directors

Stacy Pike-Langenfeld-President

Anne Rugari-Vice President

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Kyra Wells-Financial Advisor (NEW)

Pat Roberts-International Liaison (NEW)

Wendy Zielen-Board Secretary

Kevin Cushman-Outreach Coordinator (NEW)

David Cooper-Director

Dr. Hina Malik-Director

Carol Ogg-Director

KrabbeConnect Gala Committee

Matt Laughlin, Co-Chair

Anna Zappetillo, Co-Chair

Stacy Pike-Langenfeld

Anne Rugari

Heidi Squire

Eric Toppo

Josh Langenfeld

Kevin Cushman

Vision:: A day in which each patient receives an early diagnosis, has access to state-of-the-art care, and lives a life free of Krabbe disease.

Volunteers

Our foundation is so grateful to our board of directors and to each and every volunteer whose assisted us since inception. Thank you for your time, your commitment, and your generosity. You are the backbone to KrabbeConnect and we wouldn't be here today if it weren't for you.

Willing to share your small gala gathering to #curekrabbe.
Email us your pictures at info@krabbeconnect.org

