

Cystinosis Research Network Family Conference

July 19 - 21, 2007

The Hotel Contessa, San Antonio, Texas

“Searching for a Cure.....Deep in the Heart of Texas”

CRN Board of Directors Biographies



Mr. Jose T. Morales is currently serving his second term as the President of The Cystinosis Research Network and is a senior partner of Accenture's Supply Chain — Business Consulting Practice. He started with Accenture in January 2004 and has focused his energies in extending the firm's capabilities in the area of Sourcing and Procurement. Mr. Morales has extensive business management experiences in a broad array of industries: automotive, financial services, professional services, transportation, utilities, food and beverage industries. Prior to joining Accenture, Mr. Morales worked for the business-consulting firm of A.T. Kearney for 15 years. During his tenure at A.T. Kearney, he focused on Operations (manufacturing, networking, logistics, and procurement) and counted many Fortune 300 companies (revenue in excess of \$3 billion) as clients. Consulting services rendered to these clients were focused on setting strategy direction, leading reengineering initiatives, improving asset productivity, delivering cost reduction programs/benefits. Mr. Morales received his Master of Science degree from the University of Southern California and his Bachelor of Science degree from the United States Military Academy at West Point. He is proficient in English, Spanish and Portuguese. Although based out of the Dallas, Texas office, Mr. Morales resides in Greenwich, Connecticut with his wife, Velyna and 2 children, Christian (age 12) and Alexandra (age 11). When away from the office, Mr. Morales enjoys spending time with his family, reading, skiing and hunting.



Christy Greeley graduated from the University of Michigan with a Bachelor of Science in Psychology and a Master of Public Health in Public Health Policy and Administration. She has worked in both laboratory and clinical research at the University of Michigan Medical Center in the departments of Rheumatology, Pathology, and Psychiatry. She also worked for 9 years in pharmaceutical research at Parke-Davis Pharmaceutical Research as a Clinical Research Associate and Clinical Scientist, managing clinical trials for a variety of central nervous system drugs. She currently serves as Executive Director and Vice President of Research for the Cystinosis Research Network. She and her husband Dave have been married for 15 years and have two children, Alex, age 10, and Jack, age 7 with cystinosis.



John Shepperd is currently serving as Vice-President of Development for the Cystinosis Research Network. He is also the Chief Financial Officer and part owner of Lone Star Medical Equipment. John co-founded the company over six years ago, and has helped it grow into one of the nation's premier suppliers of medical equipment to the outpatient surgery market. Prior to that, John worked for the Texas Senate as a Policy Analyst on the Senate Natural Resources Committee. He graduated from the University of Texas in 1991 with a BA in American Studies. John and his wife, Kim, are natives of San Antonio, Texas. They currently reside three blocks from their old high school, along with their two children, John Ben (six), and Ava (two). Both children have cystinosis.



Marybeth Krummenacker graduated from State University of New York at Farmingdale with an Associates Degree in Business and for many years worked in the health insurance industry. She has worked for the last 10 years full time as the Administrative Assistant to the Public Information Officer of her local township and prior to that worked part time for her local school district. Among the many organizations Marybeth has volunteered her time to over the last 18 years she credits her ability to advocate with being involved in P.T.A. Marybeth held various positions throughout her tenure from Cupcake Mom to Council President. She often compares being President of a P.T.A. unit like being the CEO of a small corporation – ultimately being responsible for budgets and programs but always being held accountable to the membership or the administrators of the schools. Marybeth has stated that the best part of being involved was learning how to be an advocate not only her own children but for ALL children. She credits her P.T.A. experience for giving her the confidence to speak in front of large and small groups of people which taught her the “art” of advocating on topics such as budgets, curriculum and children’s safety issues. She has represented her school district and visited her state representatives in her state capital of Albany, New York as well as visited with her elected officials in Washington D.C. to address issues relating to children’s health and education. But Marybeth is most proud when she speaks about her two greatest accomplishments.....her children, Brian and Laura. Brian 24, is a graduate of Marist College, who is presently a middle school baseball coach, a part-time teaching assistant and contemplating returning to school for his education degree and Laura 21, who is busy working as a receptionist at a real estate dealer and as a teacher’s helper at a summer camp and finishing up Nassau Community College where she is pursuing a career in early childhood education.



Pamela K. Woodward was born, raised and currently resides in Utah. She always enjoyed working with numbers and figures so it was only natural to pursue a career in banking. After graduating from The Walker-Jacobs Private Banking Academy, she landed her dream job. Unfortunately, a short 8 months later she was needed at the family business, a long haul temperature controlled trucking company that her grandfather founded in 1934. She is presently the Secretary/Treasurer of that Company “Ned Kofford Trucking, Inc.” She has worked for the company on and off for over 39 years with the last 28 years at her current position. She helped her grandfather and along with some other local businesses formed the “Utah Technical College Professional Driver Placement Committee” they worked with the College in placing its graduates with local trucking companies and getting them started in their driving careers. After her grandfathers passing, she volunteered her time and served for over 5 years on the committee. She is currently serving on the Cystinosis Research Network Board as the Vice President of Family Support. She and her husband Rock have been married for 26 years. They have 2 daughters Utahna “Tahnje” who is 23 and has Cystinosis and Sierra without (May 28, 1990-March 28, 2006) who’s memory will live on forever.



Brittney LeBeau currently resides in Aurora, Illinois with her husband Brett and 2 children, Alexis 6 and Evan 3 years old, both have cystinosis. Prior to having children, she worked in the banking industry for 6 years and graduated from the College of DuPage with an A.A. degree in business and then went on to complete her B.A. at North Central College in Naperville, Illinois in business management. After college she worked for Spiegel Corp. as a senior forecast analyst. Since having children she has worked in various volunteer positions mainly through her church and currently serves on the counting team where weekly offering is processed. In October she enthusiastically accepted the challenge to take over the Treasurer's position.



Frankie McGinnis graduated from the University of South Carolina with a Bachelor of Arts degree in secondary education/history. She currently works as an office manager for A Better Way Chiropractic. She worked as a personal assistant for 7 years. She has served on the Parent Advisory Board for the Center for Developmental Services in Greenville, SC where she developed fundraising ideas and served as liaison between center and parents. She has represented Greenville Hospital Systems as a parent advocate at a national conference on disabilities. She currently serves as Secretary for the Cystinosis Research Network. She is married to JT and has two children, Chris age 19, who serves in the Air Force, and Laura, age 11 with cystinosis.



Paula Shal graduated from the University of Wisconsin-Madison with a degree in Education and minors in math, science, and language arts and completed her student teaching in Peterborough, England. She has her Master's degree in Adult Education and Distance Learning through the University of Phoenix Online. Paula is the Operations Training and Resource Supervisor for American Girl, Inc., an independent subsidiary of Mattel, where she oversees the technical training and resources needs of seasonal and permanent employees. She also has her own E-bay business. Paula has been married seven years to her husband, Jim. They live in Madison, Wisconsin with their three Yorkshire terriers, Xena, Buzz, and Keeper. Paula serves on the CRN board as Web site and newsletter editor. She is an adult with late onset cystinosis and was born 12/8/70. Paula was not diagnosed until after her first kidney transplant at age 17, which she received from her mother. Due to rejection episodes, Paula also received a kidney from her brother in 1991 and her husband in 2002. Paula's hobbies and interests include gardening, exercising, antiques, traveling, web site design, digital media, and watching the Chicago Cubs.



Sandy Glaize has a Bachelors degree in Psychology from the University of South Florida and a Masters degree in School Counseling from the University of Central Florida. During her thirty-five years of professional service, she has worked as a social worker for the State of Florida, a school social worker, and is currently employed as an elementary school guidance counselor. She as also taught courses in Life Career Planning and College Success at the community college level. Throughout her career, she has worked extensively with Exceptional Education planning and testing, conducting small group and individual counseling sessions, crisis intervention, consulting with parents regarding their children's academic, social, behavioral and emotional concerns, and teaching parent education classes. She serves on the Cystinosis Research Network Board of Directors as Education Chair. Sandy and her husband, David, have been married for 35 years and have two daughters, Whitney, who is a speech therapist employed by the school system, and Leslie, who is an accountant. They live in Orlando, Florida.



Karen Gledhill is an adult with cystinosis from Rochester, NY. She is the one of the oldest with late onset cystinosis. She learned her kidneys were failing at age 20. At that time, her sister, Debra, was also checked and diagnosed with kidney problems. Her sister's blood lab was familiar with Dr. Schneider at UCSD, and that is how Karen and Deb were diagnosed. Both had been told throughout their lives that they had "strange crystals" in their eyes. Karen spent 2 1/2 years on dialysis and received a transplant at age 32 from a cadaver and has just celebrated 25 YEAS POST TRANSPLANT! Karen works in the advertising field and has volunteered her time for well over 25 years. The organizations she has held leadership positions in are the local National Kidney Foundation and TAO (Transplant Awareness Organization). She is also involved with the Rochester Eye and Tissue Bank and has been a transplant athlete since 1992.



Dave Greeley has spent his professional career in the sports and entertainment marketing business. He started his career for the hockey division of the Compuware Corporation and the Detroit Jr. Red Wings, the first-ever American-based team in the Ontario Hockey League (OHL), a feeder to the National Hockey League. The Detroit-area native then went on to work for Palace Sports & Entertainment, which owns the NBA Detroit Pistons, The Palace of Auburn Hills, and Pine Knob Music Theatre. After three years with the Palace, Greeley went to work for the Portland Trailblazers and The Rose Garden. In addition to corporate sponsorship activities, Greeley became involved with several emerging sports and entertainment businesses, including the Seattle Seahawks (and their new stadium) and Action Sports Media, a college sports marketing representation company. Greeley later served as the chief marketing officer of the Chicago Bears and ran the team's sales and marketing business. He played a key role in the development of the new stadium at Soldier Field. Presently, Greeley serves as executive vice president/general manager of KemperSports Marketing & Communications, a Chicago-based sports marketing, events, and public relations agency. Married to Christy with two children, Alexandra (ten years old) and Jack (seven year old with cystinosis), Greeley holds a Bachelor of Arts degree and a Master of Business Administration from the University of Michigan. He lives in the Chicago area with his family and is currently on the CRN's Board of Directors.



Carol Hughes was born and raised in Pittsford, NY. In 1969, her family moved to Vero Beach, Florida. Garry, her high school sweetheart and she married in 1978. They have been blessed with two daughters, Jennell, born in 1983 and Heidi, born in 1985. They are also members of First Church of God. Once the girls were born, Carol chose to be a stay at home mom, devoting time to her family and community. She has served on the board of numerous organizations including; several levels of PTA, Girl Scout Councils, Trop Leadership, Indian River County Fire District Auxiliary, Band Parents and Cheerleading Associations, serving in the interest of the children of their community. Carol has been a member on the CRN Board of Directors since its inception in 1996. Heidi was diagnosed at 12 months of age with cystinosis and underwent a successful kidney transplant on December 17, 2002 at NIH, in Bethesda, Maryland, with her dad, Garry being the donor.



Danial Julian has been serving on the board of directors for the Cystinosis Research Network for a little over 1 year. He graduated from Purdue University with a Bachelor's in Industrial Design. He spent 7 years in the Air Force as a Civil Engineering Technician with the Illinois Air National Guard. Upon graduation, he worked at Compression Incorporated, a full-service product development company in Indianapolis, IN for 5 years. He then took a position with Sunrise Medical, a mobility products company in Boulder, CO before starting his own company Peak Product Design in 1999. He has won several design awards in recent years in the medical and juvenile product categories. He also has approximately 40 patents in a broad range of products, such as: exercise equipment, juvenile products, dental care, and medical products. He and his wife Jan, who grew up together moved back to their home state of Illinois in 2002, have been married for 13 years and have two children, Taylee, age 6, and Kenadee, age 4 with cystinosis.



Mack Maxwell graduated from the University of Texas at Arlington with a Bachelor of Science in Information Systems. He has been in the Information Systems industry since 1986 and is currently a lead programmer analyst for Tarrant County College. His work is in business applications and he is currently working on HR projects. Mack is 43 years old. He was born on April 9, 1964 and diagnosed with nephropathic cystinosis around the age of 7. He had his kidney transplant on June 10, 1975 at age 11. He began going to the NIH to receive treatment for cystinosis in 1999, at age 35. This was his first time to take Cystagon and cysteamine eye-drops. His eyes were completely crystal free after one year on cysteamine eye-drops. Mack is in excellent health. Mack is on the Board of Directors for the Cystinosis Research Network. He serves on the Education and Awareness Committee and helps maintain the CRN website. One of his objectives is emphasizing the importance of physical fitness, especially for people with cystinosis. His hobbies and interests include working out, sports, and travel with his favorite destinations being Vegas, Brazil, and Europe.



Elva Smith is a 71-year-old grand mom and a native of Georgia, having been born in Savannah and raised in Atlanta. She attended Wesleyan College in Macon, GA and received her laboratory training at Georgia Baptist Medical Center in Atlanta. She is an ASCP registered medical technologist, and has worked, off and on, for almost 50 years in various clinical laboratory settings (from a Physician's Office Lab to an Endocrine Research Laboratory) in several locations throughout the eastern United States. Her last employment was with the Centers for Disease Control and Prevention in Atlanta where she was involved with CDC's role in establishing the standards for implementation of the Clinical Laboratory Improvement Amendments of 1988 (CLIA). Elva is retired, a widow with 4 children, and 5 grandchildren, and currently lives in Decatur, GA. Her grandson, Mitchell Smith, was diagnosed with cystinosis in November 2004 at age 17 months and is now 4 years old. Elva is thankful that Mitchell has responded well to his medications and is a typical little boy full of energy and mischief. He lives in Lawrenceville, GA with his 5-year-old sister Rachel and parents, Eric and Lorna Smith.



Lynn Thomas has lived in Orchard Park, NY for 14 years. Currently she is serving on the Family Support committee. She is a single working mother who has a Bachelor of Science in Management Information Systems, a Bachelor of Science in Business Administration and a Bachelor of Science in Business Administration in Accounting. As a Consultant to M & T Bank in the Project Management Office she is involved with the reporting of all Information Technology projects within the bank. Her job also involves encouraging the use of corporate standards and procedures and teaching the use of industry accepted Project Management practices. What gives her the most pride in life is her son Garrett who has cystinosis and is 11 years old. This drives her passion to find a cure for cystinosis.