Funding Research...
Providing Hope
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OUR MISSION

Is to improve the lives of children by working to promote the expansion of newborn screening, and to further education, awareness and research of Krabbe Disease and Cystic Fibrosis to provide a better treatment and a cure.

OUR VISION

Is to direct, fund and promote research to develop and enhance treatments and cures for Krabbe Disease and Cystic Fibrosis.

TLOAF will promote through education and awareness the expansion of Newborn Screening, Krabbe Disease and Cystic Fibrosis; benefitting children with the increased probability of early identification and effective access to treatment.
CO-FOUNDER’S LETTER
2016 Reflections.

FUNDING RESEARCH - PROVIDING HOPE

2016 proved to be a challenging year for both TLOAF and me personally. Health challenges forced me to take a break from a leadership role with The Legacy of Angels Foundation to letting others take the reins. We faced challenges ranging from business leadership to making potential life changing decisions through our grant funding.

This year The Legacy of Angels Foundation funded over 3.5 million in research grants supporting all three of the Foundation’s initiatives: Krabbe Disease, Cystic Fibrosis and Newborn Screening. It is extremely gratifying to support research that will “make a difference” in the lives of those with Cystic Fibrosis and Krabbe Disease.

Each year the requests for funding increase. 2016 was no exception, as we received the largest amount of grant requests coming into TLOAF since inception. With continued cuts in federal funding for rare diseases, researchers are reaching out to all possible avenues with hope to secure funding for their projects. So the challenge continues for TLOAF to identify the biggest need that follows both our mission and passion and to prioritize where our grant dollars will make the largest impact, including opportunities for partnership.

The challenges were vast but with great challenges come great opportunities and the opportunity of providing HOPE. Personally, I continue to have HOPE that my health will remain stable. For TLOAF, the opportunity to support research that shows great potential in the treatment of Krabbe Disease and for better diagnosis of Cystic Fibrosis is exciting. It is the HOPE of both TLOAF Co-Founders and the Board of Directors, that every step we take for better treatments and a cure for both Krabbe and Cystic Fibrosis, provides increased HOPE for those fighting both of these diseases and for their families.

TLOAF DEVELOPMENT AND FUTURE

As The Legacy of Angels Foundation grows, so does the work that needs to be accomplished in preparation for the future. My husband Paul and I have been operating the Foundation since inception. Passion has been our driving force! In December of 2016, a “paid” working staff was developed. Along with being Co-Founder and Vice President of The Legacy of Angels Foundation Board of Directors, I am now “on staff” as Chief Operating Officer. We also had the privilege to hire our daughter, Stacy Pike as Director of Operations and Administration. Stacy brings a great deal of experience and knowledge to the foundation and will be a tremendous asset as we move forward. We welcome her help and expertise as we grow and move forward.

In review, even amongst our challenges, 2016 proved to be another great year! The Legacy of Angels Foundation is excited about the research we supported and the new additions to TLOAF. Our strategic grantmaking, supporting all three of the TLOAF initiatives, will continue to move better treatments and diagnosis forward that in the end will increase HOPE to all affected by Krabbe Disease and Cystic Fibrosis. We look forward to 2017 and embracing new challenges to maximize our impact in support of our mission.

Warm Regards,

Sue Rosenau
Co-Founder and Chief Operating Officer
The Legacy of Angels Foundation
In the United States, **KRABBE DISEASE** affects about 1 in **100,000** individuals.

— HTTPS://GHR.NLM.NIH.GOV/

**KRABBE DISEASE** is an inherited disorder that destroys the protective coating (myelin) of nerve cells in the brain and throughout the nervous system.

— WWW.MAYOCLINIC.ORG

Scientists estimate that about **12 MILLION** Americans are currently a carrier for **CYSTIC FIBROSIS**

— KIDSHEALTH.ORG

**CYSTIC FIBROSIS** is an inherited disorder that causes severe damage to the lungs, digestive system and other organs in the body (mayoclinic.org)

— WWW.MAYOCLINIC.ORG
In 2016 the largest amount of grant dollars was awarded since inception. We continue to look for opportunities to partner with other institutions and agencies to maximize our funding support. As we look forward to the future in our grant funding, TLOAF financial advisors are positioning the foundation’s assets to be able to sustain market volatility. We look forward to supporting research that follows both our mission and passion.
2016 FUNDED GRANTS

The Foundation funded $3,631,146 in grants for the following:

Global Correction of Krabbe Disease Via Combined Cell, Gene and Neuroprotective Therapies
Ernesto Bongarzone, Ph.D. -- University of Illinois

Generation and Validation of New Humanized Krabbe Disease Mouse and Induced Pluripotent Stem Cell Models
Ernesto Bongarzone, Ph.D. -- University of Illinois

Lentiviral-mediated Hematopoietic Stem Cell Gene Therapy for Canine Globoid Cell Leukodystrophy
Allison Bradbury, Ph.D. -- University of Pennsylvania

Krabbe Disease Patient Care and Research (NDRD)
Maria Escolar, M.D. -- Children’s Hospital of Pittsburgh

Development Program for the Treatment of Krabbe Disease Using Intravenous Adeno-associated Virus Gene Therapy
Maria Escolar, M.D. -- Children's Hospital of Pittsburgh

Treatment of Krabbe Disease Using Gene Therapy: Rat Toxicology Studies and Preclinical Drug Production
Maria Escolar, M.D. -- Children’s Hospital of Pittsburgh

A Pilot Engraftment Study in Immunosuppressed Rats
Maria Escolar, M.D. -- Children’s Hospital of Pittsburgh

High Accuracy Galactosylceramidase (GALC) Enzyme Assay for Second Tier Screening of Krabbe Disease
Michael Gelb, Ph.D. -- University of Washington

Comparison of Intrathecal AAV9, AAVrh10 and AAV-Oligo001 in Combination with Bone Marrow Transplant
Steven Gray, Ph.D. -- University of North Carolina at Chapel Hill

GeneThink: A Revolutionary Educational Website/Application Providing Increased Access to Accurate and updated Natural History, Diagnosis, and Treatment Information About Genetic Disorders
Dawn Laney, MS, CGC -- Emory University

The Paul M. Fernhoff Memorial Lecture Series
Dawn Laney, MS, CGC -- Emory University
TLOAF APPOINTS DIRECTOR OF PROGRAMS AND ADMINISTRATION

Stacy Pike, daughter of Co-Founders Paul and Sue Rosenau, joined The Legacy of Angels Foundation as the Director of Programs and Administration on December 1, 2016. Stacy comes with more than 10 years of experience in the medical and pharmaceutical industry. In her prior position at Novo Nordisk she was responsible for increasing patient awareness and maximizing growth opportunities for hemophilia products, support offerings, and services in MN, ND, SD, NE, and WI. She cultivated strong relationships with patients/caregivers, hemophilia organizations, and state/local advocacy groups. Her experience working with national and local non-profit organizations, her understanding for marketing biotech specialty products and services, and her involvement in patient advocacy and outreach will be valuable to TLOAF’s mission.

Along with Stacy’s work credentials, she brings a great deal of passion to TLOAF’s mission with the loss of her daughter, Makayla Lynn Pike in May of 2003 to Krabbe Disease. She has been an active board member since the foundation was formed and is ready to be a part of the day-to-day projects and programs of the foundation. Stacy states, “there’s no greater honor then working for an organization that was created, in part, as a legacy for my daughter and others diagnosed with Krabbe Disease. I’m excited for the future of TLOAF and applaud my parents for all the work they have done over the past 8 years to assist in education, advocacy, and funding research for newborn screening, Cystic Fibrosis, and Krabbe Disease.”

Stacy received her two-year associates of science degree from Riverland Community College. She went on to study sociology and criminal law at the University of Minnesota and received her Bachelor of Arts degree in 2005. Stacy currently resides in Farmington with her two daughters; Allyson (8) and Ava (6). Ms. Pike was recently engaged and they plan to marry in early 2018. In her free time Stacy can often be found at the local gym attending a group fitness class. She also enjoys being outdoors, cooking, playing cards, and most of all spending time with family and friends.

5 BABIES out of 2.3 million IN 10 YEARS have received a diagnosis of Krabbe Disease confirming the rare incidence rate of this disease.

—ACCORDING TO THE NEW YORK STATE DEPARTMENT OF HEALTH
OUR FOCUS AREAS

The Legacy of Angels Foundation has three initiatives; Cystic Fibrosis, Krabbe Disease, and Newborn Screening. We support organizations and programs that further education, conduct research for better treatments, or provide a scientific discovery for a cure.

KRABBE DISEASE

Krabbe Disease, also known as globoid cell leukodystrophy or galactosylceramide lipidosis, is a rare and often fatal degenerative disorder that affects the myelin sheath of the nervous system. It is an autosomal recessive inherited disease that causes a mutation of the GALK gene. With hematopoietic stem cell transplant, currently the only treatment available, TLOAF works to promote education and support scientific research that advances survival and quality of life for those affected.

CYSTIC FIBROSIS

Cystic Fibrosis is a life-threatening genetic disorder that causes the accumulation of thick sticky mucus and secretions generating issues for the lungs, pancreas, and digestive system. This disorder is caused by a mutation of the Cystic Fibrosis Transmembrane Conductance Regulator Gene (CFTR) and is considered rare, despite it’s one of the most common widespread genetic disorders. There’s been significant progress in treating the disease, but Cystic Fibrosis patients still live a shortened life. TLOAF supports education and scientific research to create new treatments and find a cure.

NEWBORN SCREENING

Newborn screening is a vital public health program that’s utilized internationally to identify disorders in infants. The core of TLOAF’s mission is to strengthen and improve testing for Cystic Fibrosis and Krabbe Disease. TLOAF supports scientific leaders fine-tuning the diagnostic technology to prevent false-positive results and ensure appropriate diagnosis for Cystic Fibrosis and Krabbe Disease.

MARIA LUISA ESCRIVAR

TLOAF grant recipient, Maria Luisa Escolar, a native of Colombia, has become a household name for patients with Krabbe Disease. Maria began her journey in medicine at the Escuela Colombiana de Medicina in Bogota, Colombia. In 1988 she went on to receive a Master’s in Science and Human Nutrition at Columbia University College of Physicians and Surgeons, New York, NY. She then trained at the Cornell Medical Center at the New York hospital in Child Development and Behavioral Pediatrics.

After her education and training in New York, Maria accepted a job as a clinical associate at Duke University Medical Center, overseeing residents in child development. It is here where she received a referral from Dr. Joanne Kurtzberg for a neurodevelopmental evaluation on a baby girl with Krabbe Disease. The referral was to assess if the child should receive an unrelated umbilical cord blood transplantation. It was this patient case that sparked Maria’s interest in rare diseases and earned her several other self-referred families with lysosomal storage disorders (LSDs).

With the increase in referrals, Maria began to pursue a program that would focus on rare neurodegenerative diseases that could offer comprehensive care for patients, awareness and support to physicians with little experience with them. While at Duke, Dr. Escolar worked diligently with the state of North Carolina to conduct an early intervention program with the hope of using this infrastructure to continue to provide care for patients with rare diseases. Dr. Escolar soon found an opportunity to expand the program to 2 days a week at the University of North Carolina-Chapel Hill (UNC) where she cultivated a program of specialized care for children with LSDs. In 2000, Dr. Escolar established the Program of Neurodevelopmental Function in Rare Disorders (NFRD) at UNC for children affected with many LSDs affecting the brain where she begun conducting natural history studies and evaluating treatment outcomes. The NFRD program allotted her national and international recognition as a researcher specialized in pediatric neurodevelopmental disabilities.

In 2011, Dr. Escolar moved the program to the University of Pittsburgh Medical Center where her husband, Paul Szabolcs, was scouted for Chief of Pediatric Bone Marrow Transplantation and Cellular Therapies. Dr. Escolar renamed the program The Study of Neurodevelopment in Rare Disorders (NDRD). This clinic offers comprehensive neurodevelopmental assessments that span several disciplines, ranging from ophthalmology to physical therapy and palliative care, for those affected with a rare fatal neurological disease. The families and patients that need to consult with Dr. Escolar or those unable to travel to the clinic can receive care through the NDRD Virtual Medical Home.

Maria continues to focus her research and natural history studies on Krabbe Disease at NDRD. To keep the momentum moving, Dr. Escolar formed the Krabbe Translational Research Network (KTRN) in 2010, to assist in moving the continuum of scientific and pathologic breakthroughs for better treatments to those with Krabbe Disease. The KTRN has successfully brought together many individuals, from a range of disciplines and institutions across the
country, to collaborate and share data to accelerate new developments in Krabbe. The funding for this network has been solely provided by The Legacy of Angels Foundation and completed its sixth meeting in February of 2016.

Dr. Escolar and The Legacy of Angels Foundation (TLOAF) have partnered on several projects that relate to their mission; to provide further education, awareness and research for Krabbe Disease, Cystic Fibrosis and Newborn Screening. Dr. Escolar was full of hope and vigor when TLOAF partnered with Children’s Hospital of Pittsburgh Foundation on the purchase of a 3T Siemens MRI unit to support research and clinical efforts of the NDRD. The MRI is used in conjunction with diffusion tensor imaging (DTI) to produce computerized automated images of the brain tracts to assist in making decisions about treatments. Dr. Escolar’s NDRD program has thrived due to the tremendous financial support of TLOAF as she stated, “I am forever grateful for The Legacy of Angels Foundation. They value research, comprehensive care, and better treatment for those with Krabbe Disease. I am hopeful I can accomplish these things.” Dr. Escolar has received funding on several grant applications from TLOAF which you can read more about at www.tloaf.org.

Dr. Escolar has been involved in many rare disease projects and over sixty publications related to lysosomal storage disorders. She has also been at the forefront of developing clinical tools to assist in detecting neurodegenerative disease. With the assistance of many of her trainees, she developed the Protocol for the Assessment of Neurodevelopmental Function in Early Infancy (PANDI). This tool assists physicians and parents with valuable knowledge on early development, behavior and options for early intervention when there are delays. Dr. Escolar has also transformed the NDRD clinic into a training facility for many students and physicians in several educational platforms; occupational therapy, psychology, genetic counseling, audiology, physical therapy, neurology, nursing and many others. It is her hope that more physicians and other sectors of medicine will become more knowledgeable in rare neurodevelopmental disorders.

On a more personal note, when Dr. Escolar is not busy coordinating, or consulting patient care in 48 US states and 34 countries, she is enjoying time with her husband, Paul Szabolcs. The couple currently lives in Pittsburgh. The successful physicians enjoy the company of their two adult children Isabella (24) and Julianna (22). When their careers are not dictating their schedule, Paul and Maria enjoy going back to their native countries, of Hungary and Colombia, to visit family and friends.

“I am forever grateful for The Legacy of Angels Foundation. They value research, comprehensive care, and better treatment for those with Krabbe Disease. I am hopeful I can accomplish these things.”
The Legacy of Angels Foundation research consultant, Micki Gartzke, attended the 2016 American College of Medical Genetics meeting. The opportunities for networking provided great value to TLOAF, as the foundation was amid the review of a significant gene therapy grant for Krabbe Disease. A first in its field!

This meeting, of scientists and doctors in the field of genetics, gathers annually to share the latest research and create unique communication avenues for entities looking to advance genetic treatments. The knowledge gained at this conference will help support TLOAF’s future work in several areas: (1) expanding its Scientific Advisory Board, (2) advancing the foundation’s interests, (3) providing insights on pharmaceutical interests in genetics, and (4) learning from other rare disease organizations.

American College of Genetics officials, as well as Dr. Rodney Howell, the Founding Chairman of the U.S. congressionally mandated Secretary of Health’s Advisory Committee on Heritable Disorders and Genetic Disease in Newborns and Children, were in attendance.

This conference assists TLOAF’s efforts in utilizing the highest level of efficiency in grant funding. We look forward to fostering the relationships we initiated at this venue and will utilize the information gained to assist in moving the field of medicine forward in Cystic Fibrosis and Krabbe Disease.

Mutations in the GALC GENE cause Krabbe Disease. These mutations cause a deficiency of the enzyme galactosylceramidase. This deficiency leads to a progressive loss of myelin that covers many nerves. Without myelin, nerves in the brain and other parts of the body cannot function properly, leading to the signs and symptoms of Krabbe Disease.

— HTTPS://GHR.NLM.NIH.GOV/
The Legacy of Angels Foundation Co-Founders, Paul and Sue Rosenau participated in an amazing night of fund raising for the Cystic Fibrosis Foundation at their annual Minnesota Breath of Life Gala on Saturday, November 19, 2016. They were joined by TLOAF Board member Bob Hoffman and his wife Judy; TLOAF Accountant Jared Dufault and his wife Stacy; former TLOAF Board member Dale DeRaad; and TLOAF Financial Advisor John Priebe and his wife Jenny. The event brought together nearly 700 supporters to raise funds in support of a cure for Cystic Fibrosis. The evening began with a silent auction featuring hundreds of items, while guests enjoyed cocktails and hors d’oeurves. Dinner followed with a program including testimony from a Cystic Fibrosis family describing life with CF, award presentations including the prestigious Angela J Warner Friend of the Foundation Award, live auction items and the infamous “Bid for a Cure”! As the tally of the fund raising grew, and the million-dollar mark was within reach, excitement flourished and guests opened their hearts and wallets to reach an evening total of $1,006,500! It was inspiring to feel the passion and energy in the room as everyone joined in their support of “finding a cure” for Cystic Fibrosis.
The 6th annual KTRN meeting, sponsored by The Legacy of Angels Foundation’s signature grant, was held at the historic ‘Tween Waters Inn Island Resort and Spa of Captiva Island, Florida March 2nd-5th. This meeting had a somber start as Sue Rosenau, Co-Founder of TLOAF, was unable to attend. Sue stayed home to rest and stay strong to beat the ovarian and uterine cancer she was diagnosed with in late October, 2015. Paul Rosenau, Co-Founder, commenced the conference with a touching and emotional speech written by Sue. She was missed dearly, but as she stated in her speech to the scientists that filled the room, “Let’s remember why we are here......It’s all about the kids. Don’t you worry about me because as Arnold Schwarzenegger says, I’ll be back.”

In support of TLOAF and the KTRN meeting, board members Bob Hoffman, Stacy Pike and consultant Micki Gartzke were in attendance. Maria Escolar led the conference that attracted nearly two dozen scientists from around the world. The collaborative group presented lots of exciting information about new science and pathology of Krabbe Disease.

A few of the highlights were:

- **REDUCED INTENSITY CONDITIONING (RIC)** in a single unit umbilical cord transplant has shown to be safe and reduce the side effects of the transplant significantly.
- **NEW BRAIN IMAGING** highlighted biomarkers that may be useful in newborn screening.
- **NEW KNOWLEDGE IN PATHOLOGY** thanks to the recently developed Krabbe Brain Bank at the University of Pittsburgh.
- **UPDATED STATISTICS** from the NY State Department of Health referencing 5 babies out of 2.3 million in 10 years have received a
diagnosis of Krabbe Disease confirming the rare incidence rate of this disease.

- NOTABLE RESULTS FROM DR. DAVID WENGER’S presentation showed an increased lifespan and function of the Twitcher mouse he treated with bone marrow transplant and gene therapy.

Before concluding the 2½ day conference, the group had the pleasure of hearing from Christian Yianopolos, a child diagnosed with Krabbe Disease at the age of 7. This amazing young boy, nearly 10 at the time of the conference, underwent a traditional cord blood transplant. Christian completed his transplant course in approximately 8 months with 6 readmissions. Some of the complications he endured during his course of therapy were GVHD, BK hemorrhagic cystitis, 16 NG tubes due to emetics, central line and PICC line infections. This well-spoken and bright child currently battles low bone density, flat feet, gross motor delay, mild kidney disease, and pediatric stress disorder. Through his presentation, Christian brought perspective to the group of scientists that additional research and pathology is needed to prevent the pre/post-transplant issues.

TLOAF appreciates everyone’s participation and passion to develop a better treatment and hope of a cure for this horrible and devastating disease. The foundation looks forward to holding the next KTRN conference in 2018, but until then, we wish all those contributing to the mission and vision of TLOAF best of luck with their research.
Almost 1,400 different MUTATIONS of the CF gene can lead to CYSTIC FIBROSIS
—KIDSHEALTH.ORG
This prestigious event, now in its fourth-year, selected David Wenger, a Professor of Neurology at the Sidney Kimmel Medical College at Thomas Jefferson University, as the keynote speaker. David has over forty years of experience in lysosomal storage disorders, with an emphasis on Krabbe Disease. He established the Lysosomal Disease Testing Laboratory in 1973, and this renowned testing facility has diagnosed over 4500 patients with an LSD, 672 of those have been Krabbe or Globoid Cell Leukodystrophy. The Co-founder of TLOAF, Paul Rosenau, had the pleasure of introducing Dr. David Wenger and his lecture on Krabbe Disease.

Dr. David Wenger began with acknowledging Dr. Knud H. Krabbe who put a name to the disease originally referred to as diffuse brain sclerosis. He continued his lecture by noting the milestones of the disease, most importantly the defect that causes Krabbe Disease (deficiency of galactocerebrosidase or GALC), purification of the protein, and the cloning of the gene. Currently 150 mutations have been identified, contributing to the complexity in treating Krabbe Disease. Today’s treatment, for pre-symptomatic patients, is a cord blood transplant, but additional research is needed to help these patients 5-10 years’ post-transplant, due to decline in the peripheral and central nervous systems. David and his team at Thomas Jefferson are currently working on a project to get adequate GALC enzyme into the PNS and CNS.

This lecture series began in 2012 to honor the renowned Lysosomal Storage Disease geneticist, Paul Fernhoff. In 2009, The Legacy of Angels Foundation had the privilege of collaborating with Paul and the Center for Disease and Prevention, with regards to newborn screening, an important initiative of TLOAF. Paul’s legacy continues to live on through the patients and families he touched as well as through this devoted lecture series, a key feature of the CDC Foundation’s Newborn Screening Translational Research Institute. Paul utilized Dr. David Wenger’s LSD testing laboratory in 33 cases to assist with diagnosis.

TLOAF sponsored this event through their Research Grant Program because it promotes its mission of education to a broad spectrum of key medical associates and institutions. Those in attendance, on behalf of TLOAF, included Co-Founders Paul and Sue Rosenau, board member Stacy Pike, and research consultant Micki Gartzke.
Micki Gartzke, TLOAF research consultant, attended the WORLD Symposium held in San Diego, CA, February 29 – March 4, 2016. The WORLD Symposium, attended by thousands of professionals around the world is a major educational and unifying activity in the field of lysosomal work, and has evolved into a highly interactive research activity. Much like The Legacy of Angels Foundation’s KTRN meeting, the underlying theme of this meeting is “transitioning molecular biology to human therapies.” In addition, it is clarifying challenges across the spectrum and shedding light on the needs and successes—in bringing bench discoveries into effective clinical therapies.

TLOAF has been regularly attending this annual meeting for its cross-platform research and advocacy values. Its beneficial features help the foundation in its key efforts towards improving outcomes for Krabbe Disease, a Lysosomal disorder.

Once again, participating in the Council of Patient Advocates luncheon meeting was insightful. The emerging therapies are starting to increase in this scientific and medical field. This unique opportunity also helps to expand the foundation’s contacts with others that have similar interests in related disorders.

Amongst the hundreds of presentations given on lysosomal disorders, emerging trends is always an important feature for the foundation’s education and awareness to continue its efforts in effective grant making.

A highlight of the meeting was the presentation of the “Young Investigator” award. TLOAF grant recipient, Allison Bradbury, from the University of Pennsylvania in Philadelphia, received this prestigious award for her innovative gene therapy project for Krabbe Disease in dogs.

The 2017 WORLD Symposium conference will be held at the Manchester Hyatt in San Diego.

Cystic Fibrosis (CF) is the SECOND MOST COMMON LIFE-SHORTENING, childhood-onset INHERITED DISORDER in the United States.

—CDC.GOV
In August, the Co-Founders of The Legacy of Angels Foundation, Paul and Sue Rosenau, were selected as one of the finalists for Minnesota Business magazine’s 5th annual Leaders in Health Care Awards. Friends of the organization, Brenda Bernhardt and John Priebe, nominated Paul and Sue. A celebration for all the finalists took place on Thursday, October 27th at the InterContinental Saint Paul Riverfront in downtown St. Paul. In celebration of the event, TLOAF sponsored a table and filled it with board member Bob Hoffman and his wife Judy; board member Stacy Pike and guest Josh Langenfeld; TLOAF Financial Advisor John Priebe; and friends Brenda and Kevin Bernhardt.

The evening started with a hosted cocktail reception, followed by a three-course dinner and an awards program. The awards program honored a leader or a company that made a difference in 2015 in the health care industry. A total of twelve awards were up for grabs for the Leaders of Heath Care in MN. Paul and Sue were nominated for the Champion Award along with Dr. Donna Block, a physician and President and Chief Executive Officer of Clinic Sofia and Glaffira Marcon, a board member and Lead Organizer of Healthcare.MN. The Champion Award is presented to an individual who has focused his or her efforts to elevate the profile/status of the state’s health care industry. Although Dr. Donna Block was presented with the Champion Award that evening, it was truly an honor for Paul and Sue to be one of the finalists for this prestigious award. The event provided TLOAF great media exposure to health care industries in Minnesota and to those who subscribe to the magazine. Please see dialog box for a segment of the Q and A printed in the Minnesota Business magazine’s November 2016 issue.

**QUESTION:**
**DOMINANT TREND FOR HEALTH CARE IN 2017**

A: The trend in the field of rare diseases is gene therapy and stem cell treatments. Both are evolving and will continue as optimal treatment for many rare diseases. Secondly, virtual medical care. It does not replace seeing a doctor, but it does help alleviate numerous office trips by answering patient questions virtually. Two projects we have supported are “Virtual Medical Home” and “Gene Think”.

** excerpt taken from MN Business Magazine, Nov. 2016**
GRANT FUNDING TOTAL
Since Inception

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