

THE LEGACY OF ANGELS FOUNDATION

2017 ANNUAL REPORT



Following Our Passion...
a Heart for Hope



The Legacy of Angels
FOUNDATION

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About TLOAF

BOARD OF DIRECTORS

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JARED DUFAULT
Tax Accountant

OUR MISSION

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

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; benefiting children with increased probability of early identification and effective access to treatment.

From the Co-Founder

In time of distress and despair, one reaches for hope and confidence. Countless patients and caregivers, impacted by a rare disease, become quickly familiar with these feelings as they confront unique challenges. Many encounter challenges in acquiring an accurate diagnosis, accessing experts for optimal care and treatment as well as, maintaining adequate insurance coverage amidst the turmoil.

Fortunately, The Legacy of Angels Foundation maintains a strong commitment to advancing scientific research for Krabbe disease and Cystic Fibrosis for the families facing these burdensome challenges. In 2017, our board approved \$1.26 million in research grants, championing advances in treatment for Krabbe disease and fine-tuning the diagnostic testing for Cystic Fibrosis. At the end of each grant cycle I find myself taking a moment to reflect on our accomplishments, to remember all the patients and caregivers affected by these two rare diseases, and to reminisce about my granddaughter, Makayla, who inevitable lost her battle to Krabbe disease, just as many others do.

Over the past several years, TLOAF's funding efforts have made advances in science, built strong commitments from researchers, and effectively addressed the importance of collaboration. We're thrilled to be at a pivotal time for Krabbe disease as the opportunity for a human clinical trial is closer than ever. It's the passion of both TLOAF Co-Founders and the Board of Directors, that every step brings our hearts hope that a vital treatment or a cure is near.

CONTINUING OUR PASSION.....A HEART FOR HOPE

As I sit here, challenged by endometrial cancer, I wonder when scientific advances will change the outcome for cancer patients. Yet, I don't dwell on what's happened or my inability to control the aftermath of my disease, instead I focus my thoughts and energy on guiding change. Presently, TLOAF is guiding change by inspiring researchers to collaborate, share resources, and reveal solutions. Our board members believe advocating for synergy will truly accelerate the discovery of new or improved treatments.

Looking forward, our foundation will stay committed to our three initiatives: Krabbe disease, Cystic Fibrosis and Newborn Screening. It's taken a decade of work and commitment, growing from lessons learned and adjusting our growth accordingly. As TLOAF continues it's mission, we will work diligently to improve collaboration further among researchers and develop new partnership with organizations who share our passion. This philanthropic venture my husband and I embarked upon is a legacy I hope will carry on until an effective treatment or cure reaches the bedside of each patient.

A Heart for Hope-



Sue Rosenau
Co-Founder and Chief Operating Officer
The Legacy of Angels Foundation



Financial Focus

THE LEGACY OF ANGELS FOUNDATION FUNDING COMMITMENT

At a time when there's several meaningful grant applications, knowing which one will make the greatest impact can be daunting. Yet, for The Legacy of Angels Foundation, the approach is simple—we utilize the expertise of our scientific advisory board to aid in selecting projects that will advance research, move us closer to clinical trials, and bring enhanced treatments or a cure to the bedside.

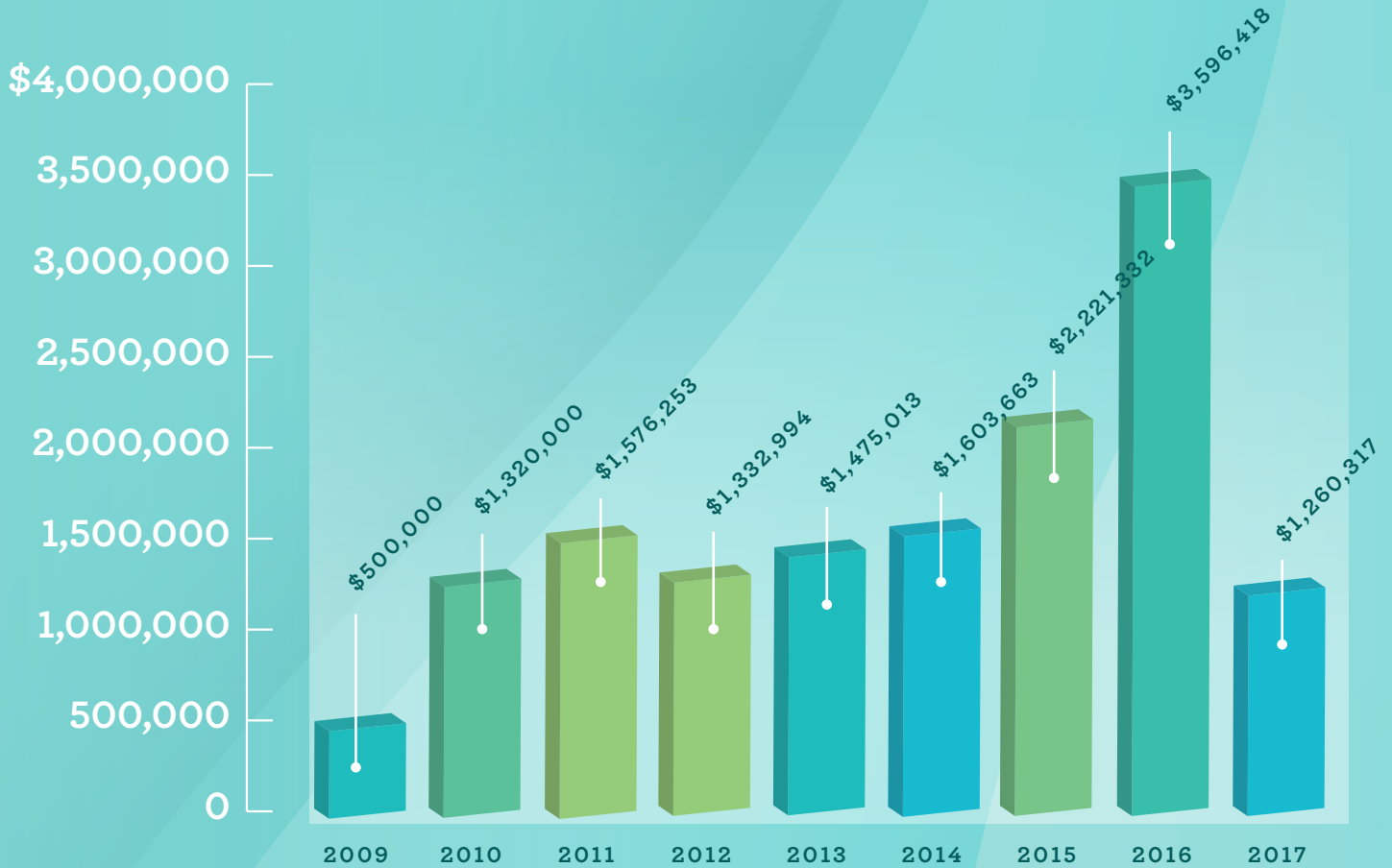
As we enter the next few years, we will begin to require partnership funding to maximize our dollars. As an organization, we need to do better by using our philanthropic funds to compliment and extend the impact on research. Working in conjunction with funding mechanisms, such as patient advocacy groups (PAGs), the National Institute of Health (NIH), and institutions, we can reshape rare disease research and the healthcare system to create shared values, build collaboration, and foster sustainability for all involved.

We have a portfolio we're proud of—TLOAF has funded 74 grants totaling nearly **\$15 million** since inception. Yet, from a financial perspective it's important we re-evaluate our goals and ensure we continue to fund for impact, keeping a close watch on our sustainability. We must be ready for difficult years where the market is weak and returns on investments are modest at best.

Statement of Financial Position

As of December 31st, 2017	ASSETS	
	Current Assets	\$3,643,682.58
	Other Assets	\$31,013,985.53
	TOTAL ASSETS	\$34,657,668.11
	LIABILITIES AND EQUITY	
	Liabilities	
	Current Liabilities	\$546.48
	TOTAL LIABILITIES	\$546.48
	Equity	
	Retained Earnings	\$31,736,930.33
	Net Income	\$2,920,191.30
	Total Equity	\$34,657,121.63
	TOTAL LIABILITIES AND EQUITY	
	TOTAL ASSETS	\$34,657,668.11

Grant Funding: 2009-2017



**TLOAF HAS AWARDED
NEARLY \$15 MILLION
IN GRANTS OVER THE
PAST 9 YEARS.**

**SINCE INCEPTION,
TLOAF HAS GROWN
FROM ASSETS OF \$31
MILLION TO A PORTFOLIO
TOTALING \$34.6 MILLION
ON DECEMBER 31, 2017.**

Rare Disease Information and Facts

Did you know that there's a law called, "Right-to-Try?" The law permits terminally ill patients the opportunity to try experimental therapies once Phase 1 testing is achieved even though FDA approval is absent. Colorado was the first to implement the law in 2014 with 40 other states following suit shortly after. Yet, the law is under much scrutiny as current changes underway could permit dying patients the opportunity to access experimental treatments without an FDA or a Compassionate Care application. President Trump is in favor of the new law.

Proponents of the Right-to-Try law are enthusiastic about the new bill as it gives authority to the terminally ill, with guidance from a licensed medical practitioner, to utilize unapproved therapies for another chance at life. Yet, some rare disease organizations, physicians, and patient advocacy groups raise concerns about safety, efficacy, lack of coverage for experimental treatments, and a possible ticket to false hope. As a rare disease research foundation, The Legacy of Angels Foundation believes it's important and sensible for patients to be knowledgeable about options for treatment and care. Many patients affected by a rare disease face the possibility of death and find themselves intensely searching for the next opportunity for treatment. To learn more about this law, the pros and cons, visit https://en.wikipedia.org/wiki/Right-to-try_law.

**APPROXIMATELY
7,000 RARE DISEASES
HAVE BEEN IDENTIFIED**

(SOURCE: US FDA)

**1 IN EVERY 10
AMERICANS ARE
AFFECTED BY A RARE
DISEASE**

(SOURCE: GLOBAL GENES)

**95% OF RARE
DISEASES DO NOT
HAVE AN APPROVED
TREATMENT**

(SOURCE: PHARMA, MEDICINES
IN DEVELOPMENT 2016)

Our Grant Program

The Legacy of Angels Foundation's grant program is vital to our mission. Our foundation works to identify a wide range of the most promising projects in Cystic Fibrosis, Krabbe disease and Newborn Screening, with the help of our scientific advisory board. The studies we've invested in have enabled advances in the areas of diagnosis, genetics, treatments, newborn screening, and education. Our funded projects for 2017 total **\$1,260,317** and were awarded to the following recipients:

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

Assessing the Added Value of Whole Genome Sequencing in Cystic Fibrosis Newborn Screening

Philip Farrell, M.D., Ph.D. –
University of Wisconsin, Madison

High Accuracy Galactosylceramidase (GALC) Enzyme Assay for Second Tier Screening of Krabbe Disease

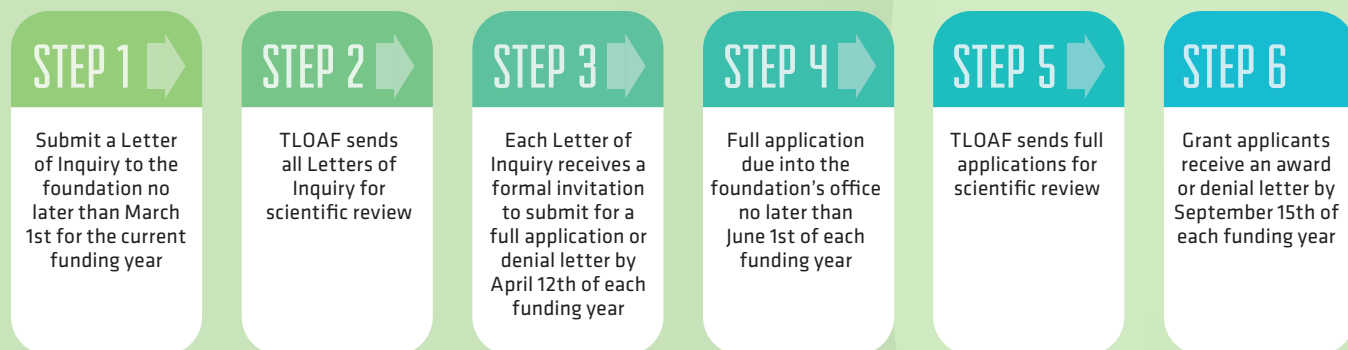
Michael Gelb, Ph.D. –
University of Washington

The Paul M. Fernhoff Memorial Lecture Series

Dawn Laney, MS, CGC –
Emory University

Our Grant Process

For people living with Cystic Fibrosis or Krabbe disease, every discovery offers new hope. Our grant process is structured to meet the needs of the field and supports our scientific efforts to conquer both complex diseases and advance Newborn Screening.



**For more information about our grant process or how to submit a Letter of Inquiry, please visit TLOAF.org. **

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.



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 being one of the most common wide spread 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.



Krabbe Disease

Krabbe disease, also known as globoid cell leukodystrophy or galactosylceramide lipidosi, is a rare and often fatal degenerative disorder that affects the myelin sheath of the nervous system. The disease is inherited in an autosomal recessive manner, causing a mutation of the GALC gene. With a 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.



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.

Researcher Spotlight

Dr. Michael Gelb



Michael Gelb from the University of Washington. Stacy Pike, Director of Programs and Administration, had the pleasure of interviewing Dr. Gelb and sharing his story of success.

Q: WHERE DID YOU GROW UP?

Dr. Gelb, who prefers to be called Mike, grew up in the urban valley of Los Angeles known as San Fernando Valley. Mike comes from a family of 3 siblings with him being the first child welcomed by his parents. Mike attended public school, enjoyed hanging out with friends, and had a thrill for science.

Q: WERE YOU DRAWN TO SCIENCE EARLY ON?

Mike took a liking to science in high school thus, to no surprise to his parents, he enrolled at the University of California-Davis, as a chemistry and biochemistry major. His original career vision was to attend medical school yet, after a year of college, he decided to be a scientist.

After receiving his undergraduate degree, he decided it was time to cut ties with the west coast, landing at Yale University for graduate school. With cousins nearby and the beach just a few miles away from campus, Mike quickly settled into his new space in Connecticut. Here Gelb studied under the direction of Stephen G. Sligar for his Ph.D. on aspects of the catalytic mechanism of cytochrome P450; in laymen's terms, he studied enzymes and how they worked. He joined the faculty at the University of Washington Seattle in 1985 and started his own research lab.

Each year, The Legacy of Angels Foundation selects an individual to recognize in our annual report. No resumes are submitted, no required application to complete, and no award is provided; we simply focus on the dedication and passion of an individual who has made a positive impact on our mission. During my interview, over lunch in sunny San Diego, two hours accelerated by as I intently listened to a biochemist reveal his story of success. This year, TLOAF selected Dr.

Q: WHAT SPARKED YOUR INTERESTS IN NEWBORN SCREENING?

Newborn screening sparked Mike's interests when his wife, Heidi, became pregnant with their first child at the age of 40. Due to Heidi's age, the couple participated in additional medical assessments to stay well informed about the health of their baby. In addition, Gelb stumbled upon the movie Lorenzo's Oil, strengthening his interests in newborn screening. Mike's thoughts during the movie were, "we should be able to figure out how to measure all these enzymes."

Mike's interests in testing many enzymes continued to grow, and he even thought of a way to do it. Still, he needed a connection to the medical world of newborn screening to get started. Mike found a local expert, Dr. C. Ronald Scott, a pediatrician in the Department of Medicine at the University of Washington. Dr. Gelb's and Dr. Scott's weekly "side-talks" about newborn screening and measuring enzymes grew into a 15-year working relationship that continues today. Dr. Gelb and Dr. Scott enlisted the knowledge of Professor Frank Turecek, a mass spectrometry leader, to assist in their enzyme work. It was this wise biochemistry team that developed the multiplex tandem mass spectrometry for newborn screening of enzyme deficiency diseases.

Q: WALK US THROUGH A TYPICAL DAY IN THE GELB LAB

The lab includes student researchers studying enzymology. Mike's lab purifies enzymes, prepares enzyme inhibitors and proteomic reagents, analyzes enzymatic process in animal cultures, works on the use of mass spectrometry of proteins, enzymes, and lipids, and performs several other clinical chemistry techniques. Although Mike enjoys being in his lab, much of his lab time is spent educating and mentoring graduate students or post-doctorates. In addition to managing all aspects of the lab, Mike teaches organic chemistry, chemical biology, and enzymology 3-4 hours a week.

Q: WHAT'S YOUR GREATEST ACCOMPLISHMENT?

Dr. Michael Gelb is the recipient of many awards and has a long list of scientific accomplishments, yet the success of his multiplex tandem mass spectrometry was rated at the top. The initially developed tool allows for the detection of 6 different lysosomal storage disorders; Pompe, Fabry, MPS I, Krabbe, Gaucher, and Niemann Pick A/B. This scientific breakthrough has advanced methods for analyzing lysosomal storage diseases in newborn screening centers around the world. This method is currently utilized to screen for Krabbe disease in 7 states; Ohio, Pennsylvania, Tennessee, New York, Kentucky, Missouri and most recently, Illinois.

Q: WHAT DO YOU WANT READERS TO KNOW ABOUT YOU?

Throughout the interview, it's evident that Mike has a passion for chemistry and enzymology, however, you would be amazed at his level of experience in surfing. He truly craves being on the ocean with his surfboard in hand. Mike enjoys a two-week surfing vacation yearly to remote areas such as Bali or Mentawai's Island.

Another interesting hobby of Mike's is playing classical guitar. He chuckled a bit when talking about a nearby bar that hosts open mic nights for guitar enthusiasts. "I play a few songs well but if you ask me next year about my guitar playing, I likely still play those same few songs well."

On a personal side, Mike met his wife in graduate school; they're both scientists. His wife, Heidi, has her Ph.D. in molecular biology. Mike has a son, Max, who currently works at Google and a daughter, Anna, who runs a "farm-to-table" event company from her apartment in New York City.

Dr. Michael Gelb is a TLOAF grant recipient and a lead chemist in advancing newborn screening for lysosomal storage disorders. If you want to learn more about Dr. Michael Gelb's work, his laboratory, or his program, please visit <http://faculty.washington.edu/gelb/>.



**The Legacy of Angels
FOUNDATION**



2017 WorldSymposium

The bright and carefree city of San Diego hosted the 13th annual WorldSymposium conference February 13th-17th. This international conference highlighted the basic science, the translational research, and the most recent results of clinical studies in lysosomal storage diseases (LSDs). Today, researchers have identified approximately 50 different inheritable LSDs and this conference reports on the unique challenge of these rare diseases.

A fundamental feature of this conference is the COPA workshop, designated as the Council of Patient Advocates, to encourage collaboration between researchers and patient advocacy groups. This year, the workshop focused on the phases of translational research. Translational research relates to the course that developing therapies move through, from a basic laboratory discovery to a clinical trial, and into patients. Many patient advocacy groups (PAGs) work to pursue partnerships at the COPA workshop with lead disease-specific researchers, to aid in building a patient population, start a natural history study, and promote funding for advancements that are relative to their organization's mission.

As the conference moved through days 2 through 4, each segment required focused concentration and comprehensive documentation as scientific language can be difficult to grasp at times. TLOAF grant recipient, Dawn Laney, presented on the role of the genetic counselor in long-term follow-ups. Presently, it's the role of the genetic counselor to provide useful resources and be the "tour guide," as well as the "translator," for disease progress and management. Rare diseases require a trained expert to be a good resource to families, mitigate guilt, and provide a safe space for questions to be addressed.

Other interesting and valuable presentations occurred on the topics of pharmacological chaperones, adeno-associated virus vectors, and enzyme replacement therapy for treatment of lysosomal storage disorders. One of the highlights that came out of this meeting is the need for an LSD brain bank, necessary for natural history studies and therapeutic research on human tissue samples. Thankfully, through the University of Pittsburgh Medical Center, 9 brains affected by Krabbe disease are currently available for tissue samples. Tissue collections and samples are coordinated through Partners for Krabbe Research, a 501 (c) (3) organization created to provide awareness and support research for Krabbe disease.

In closing, the conference wouldn't be complete without the FDA's perspective on rare disease drug development. This year, Richard Moscicki discussed the importance of "patient-focused" drug development, common issues, and lessons learned in orphan diseases. A summary of the FDA's perspective can be seen in the colored bubbles below.

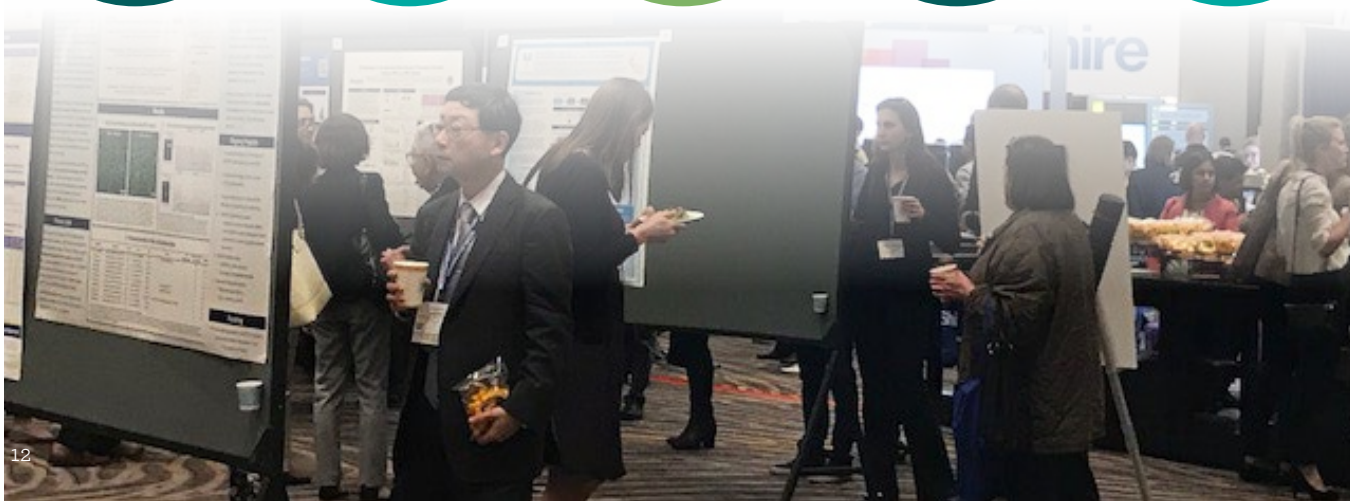
Many therapies for Orphan diseases were approved in 2015; a strong trend continues

Patient center drug development is important in orphan diseases

FDA is willing to be very flexible in its approach to serious rare diseases with unmet needs

Recent experiences have taught us very valuable lessons regarding natural history studies, early robust assay development, and randomization from the beginning of clinical studies

There's increased level of global collaboration on rare diseases



2017 APHL Newborn Screening and Genetic Testing Symposium



Dr. Dietrich Matern

The Association of Public Health Laboratories (APHL) selected New Orleans, better known as the “Big Easy,” to bring key leaders together to present on programs and advancements in newborn screening and genetic testing. Leaders from around the world presented on laboratory

updates, molecular advances, pilot studies to improve newborn screening, the importance of standardizing data collections, policy issues, and so much more. TLOAF Co-Founders, Paul and Sue Rosenau, along with Stacy Pike, Director of Programs and Administration, attended the conference to enhance the foundation’s knowledge on emerging laboratory trends and genetics in NBS.

Dr. Dietrich Matern, a TLOAF grant recipient, presented on, “Impact of Post-Analytical Interpretive Tools on Newborn Screening for Three Lysosomal Disorders: First Year Prospective Experience in Kentucky.” The state of Kentucky recruited Mayo Clinic’s Biochemical Genetics lab to provide NBS for Krabbe disease, Pompe disease, and MPS. From February 16th, 2016 to August 27th, 2017, 83,870 Kentucky newborns were screened. Of those screened, 1 Krabbe, 4 Pompe, and 1 MPS were detected. Dr. Dietrich Matern believes NBS for these rare diseases can be efficient and effective when free bioinformatics tools are applied in combination with biochemical genetic second-tier tests.

“We want every baby to have the same opportunity at life no matter when or where they are born.”

Ashley Comer

State Hygienic Laboratory at the University of Iowa

Another significant take away from the symposium was the increasing need to improve advocacy and timeliness. As Ashley Comer from the State Hygienic Laboratory at the University of



Iowa states, “We want every baby to have the same opportunity at life no matter when or where they are born.” For example, in 2011, New Jersey reported that only 86% of the newborn blood spots were getting to the public health laboratory within 3 days of the baby being born. This is unacceptable according to the public health NBS guidelines because in some conditions, each hour counts.

Lastly, after 2 days of informative presentations on national and international newborn screening (NBS), genetic testing, and policy issues, there’s a need to improve the education around newborn screening to expectant mothers. Are you aware of when your child was screened in the hospital for this mandated test? Was the NBS test explained to you, prior to the birth of your child? Did your pediatrician provide you with your child’s NBS test results at their 2-week check-up? There’s no time like the present to accelerate education to expectant moms and dads about the NBS process as presenters, researchers, and industry constituents echoed the same message throughout the symposium, every newborn baby deserves a healthy start! For more information or to download presentations from this symposium; please visit <http://uwtv.org/series/faculty-lectures/>.

The Paul Fernhoff Lecture Series

Since 2014, The Legacy of Angels Foundation has found tremendous value in the Paul Fernhoff Memorial Lecture Series. This yearly event, established by Dr. Paul Fernhoff's colleagues at Emory University, began after his tragic death, to honor his legacy and work in newborn screening. The following lectures, in chronological order, have received TLOAF grant support, aligning closely with our mission and focus areas:

2014–CDC Newborn Screening Translational Research Initiative

2015–Dr. Philip M. Farrell-A Miraculous New Era for Cystic Fibrosis: Impact of Molecular Screening and Therapy

2016–Dr. David Wenger-Krabbe Disease, 100 Years from Bedside to Bench and Back to the Bedside

2017–Dr. Maria Escolar-Krabbe Disease: Reflections of 17 years and 150 patients

This year, Dr. Maria Escolar was selected as the keynote speaker to present on 17 years of clinical experience with Krabbe disease. On September 19th, in the Health and Sciences Research Building at Emory University, Dr. Escolar began by reflecting on her very first meeting with a Krabbe patient. The patient was a baby girl, fragile yet precious, who could no longer hold her head, produce baby sounds, or visually track objects. It was this patient that sparked her interest in rare diseases, earning her several other self-referred families with lysosomal storage disorders (LSDs). Her drive and determination to provide care for patients with rare diseases influenced the development of her world-renowned clinic at the University of Pittsburgh Medical Center known as, The Study of Neurodevelopment in Rare Disorders (NDRD).

Dr. Maria Escolar continued on with the remainder of her presentation by discussing the symptoms and biomarkers of the disease, the motor delays, and the long-term results of 18 neonatal transplants. Each part of her presentation portrayed the ongoing complexities of this rare neurological disease. The late Deborah Fernhoff and family, Emory University faculty members, beloved colleagues of Dr. Paul Fernhoff, rare disease advocates, and TLOAF staff were among the audience. As Co-Founder, Sue Rosenau noted, "it's a great educational event that brings the community together to learn about advancements in infant and child health, something Paul Fernhoff was passionate about."



The Legacy of Angels Foundation: *Championing Programs that Support Our Mission*



Raising Awareness!



February 28th: Rare Disease Day

April 7th: World Health Day

May: Cystic Fibrosis Awareness Month

September: Newborn Screening and Leukodystrophy Awareness Month

Camden's Concert

July 11th, 2017



An evening dedicated to music and raising money to further research in Cystic Fibrosis. This event, now in its seventh year, provided outstanding entertainment by the Wright Brothers. The Wright Brothers performed songs from the 1920s to the present day, covering an array of genres.

Co-Founders, Paul and Sue Rosenau, along with TLOAF board member Bob Hoffman and his wife Judy attended this festive and meaningful event at the Hopkins Center for the Arts in Hopkins, MN. Over the past seven years, Camden's Concert has raised a total of \$500,000 for CF research!

Breath of Life Gala

November 18th, 2017



Nearly 700 individuals attended the black-tie premier Breath of Life Gala, benefiting the Cystic Fibrosis Foundation's mission. The Legacy of Angels Foundation supported this event and Co-Founders, Paul and Sue Rosenau, filled their table with board members and supporters of TLOAF.

This year nearly 1 million dollars was raised! Don Shelby emceed the event which included an inspirational story from Missy Bass, a vibrant 36-year-old Cystic Fibrosis mom and wife. Missy was diagnosed at 2 months of age and given a life expectancy of just 16 years old. Missy is dedicated to her pill regimen and treatments which she believes are due to her good health today.

TLOAF will continue to support events such as this that raise money for better treatments and ultimately a cure for Cystic Fibrosis. For more information on this event and others, visit cff.org/Minnesota/.

NORD Luncheon

November 9th, 2017



Co-Founder, Sue Rosenau and Director of Programs and Administration, Stacy Pike, attended an advocacy training workshop organized by the National Organization for Rare Diseases (NORD) at the Westin in Minneapolis. Kristen Angell, Associate Director of Membership, presented on the Rare

Action Network (RAN). RAN is the nation's leading advocacy network working to improve the lives of the 30 million Americans living with a rare disease.

RAN serves to work with patients, families, caregivers, physicians, academia, and industry, at the state level, to act on issues affecting those living with a rare disease. To learn more or join this network, please visit rareaction.org.



PAUL AND SUE ROSENAU, TLOAF CO-FOUNDERS

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