Greetings from the New ULF President

Greetings to all the members of the ULF. I am looking forward to serving you as the new president of the ULF. I have been elected to replace Dr. William Kintner since he has had some health issues this year. You can read his letter to you in this publication. I want to thank him for all he has done for the ULF over the last 30 + years and for his continued support as a member of the board of directors.

Our summer conference in Baltimore, Maryland was a resounding success. We were able to collaborate with ALD Connect to host a joint meeting and find ways to interact with the population relating to ALD. Inside you will find the summaries of the scientific symposium. We are looking forward to our next conference July 15-19, 2015 in Omaha Nebraska. We are adding 2 days to the meeting so we will have the opportunity to meet the needs of many different leukodystrophy families.

We are looking to help you get fundraising activities going to help raise money for the ULF. Please contact us at the office for more information. We are also going to concentrate on a large fundraising effort to raise money for our two endowment funds which support research and program services. We are excited that we were able to facilitate grant funding of $60,000.00 for leukodystrophy research this year. Our hope is to be able to increase that amount for next year. Your support can make that happen.

We are very excited about the future of the ULF. You as members are the key to the success of our organization. Whether you are new or a long time member, your participation and financial support are needed to continue the great work of the ULF. We depend solely on your support to keep the ULF moving forward. As the Holiday season approaches a special gift in memory or honor of a loved one will help the ULF continue our mission to serve individuals and families affected by leukodystrophy by exchanging information and promoting progress on research, treatment and prevention. Our goal is to one day cure all leukodystrophies. Thank you for your support, love, and generosity. You are not alone, we are here to serve you.

Peace and Joy to you in the coming year!

Robert Rauner
ULF President
Dear Members:

I need to inform you that the stroke I underwent on February 23, has left me significantly compromised with my cognitive functions and memory. I am working on retraining my brain to overcome the deficits of the stroke. As I announced at the last board meeting on June 6th, I cannot continue as president of the ULF. Therefore, I am resigning as your President, effective at the end of the business day on June, 30, 2014.

I consider it an honor and privilege to have served as the ULF President during this tumultuous time this past 2 1/2 years. I know that Bob Rauner and the new slate of officers will continue the good work as we move the ULF forward. For now, Colleen and I will remain as members of the board of directors until our term expires, July 1, 2015. I am making myself available to Bob Rauner for information and consultation anytime. I am pleased with the progress we have made together and look forward to seeing a bright and robust future for the ULF. I regret also having to miss the summer conference this year in Baltimore. It is the responsibility of members of the board of directors and members of the medical & scientific advisory board to attend the annual summer meeting. I believe this can be a great team building experience when we get behind it.

Thanks for the memories!

Sincerely,

William Kintner

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Feel free to contact any of our officers or directors by email at office@ulf.org or by phone (800) 728-5483
The 2014 ULF Scientific Meeting this year was organized in collaboration with ALD Connect and took place in Baltimore, Maryland one day prior to the yearly Family conference. The venue for the scientific meeting was a grand ballroom in the restored Embassy Suites hotel in downtown Baltimore. Approximately 60 participants contributed to a very successful meeting that involved 16 speakers from 5 countries (U.S., Austria, Canada, The Netherlands and Germany). The close proximity to the Kennedy Krieger Institute and John Hopkins University stimulated attendance by young neurologists and scientists in training. For the first time, family members of the ULF and ALD Connect were also invited to listen to the scientific talks. The speakers presented the latest results of their leukodystrophy research and all of the participants contributed to the scientific meeting through questions and informal interactions. The research covered a variety of different leukodystrophies. The morning session was devoted to X-linked ALD, whereas the afternoon session covered other leukodystrophies including Krabbe disease, Canavan disease, Pelizaeus-Merzbacher disease, Zellweger spectrum disorders, Alexander disease, Pol-III-related leukodystrophies, amino acid tRNA synthetase defects and undiagnosed leukodystrophies. This was a particularly exciting meeting because it covered a wide range of topics from newborn screening for X-ALD and Krabbe disease to reports of new leukodystrophies and the latest efforts on gene therapy. The talks underscored the rapid pace of advances that are taking place in the leukodystrophies and the hope that it brings to families for developing effective therapies.

Michele Caggana, Sc.D., FACMG (Newborn Screening Program, Albany, NY) presented the latest results on newborn screening for leukodystrophies in New York. NY is the first state to initiate population-based screening for Krabbe disease and X-ALD. More than 2 million infants have been screened for Krabbe disease since 2006 and 14 were identified as high risk for developing infantile Krabbe disease. Five of these infants have received a bone marrow transplant with variable outcomes. On January 1 this year, NY began screening for X-ALD using the test developed by Ann and Hugo Moser and Walter Hubbard. Among the first 181,000 newborn infants screened, 6 infants were identified; all were confirmed to carry mutations in the \textit{ABCD1} gene. These infants will be closely monitored for development of adrenal insufficiency and/or white matter disease. In addition, 4 other infants were detected with probable peroxisome biogenesis disorder. It is expected that newborn screening for these leukodystrophies will expand to other states in the near future, which will allow earlier therapy and improved outcomes for the affected infants.

Troy Lund, M.D., Ph.D. (University of Minnesota, Minneapolis) discussed the importance of biomarkers for evaluating the response to clinical treatment of X-ALD. Biomarkers are a measureable indicator of a disease’s existence and/or its progression. In X-ALD, abnormally elevated plasma fatty acids (i.e. C26) are an excellent biomarker for diagnosis but not for disease progression. In contrast, the brain MRI Loes score represents a valid biomarker that correlates with neurologic function. There is a desperate need for other easily measured biomarkers using, for example, a blood test or CSF sample. Often, the efficacy of a drug or other therapy is heralded by a favorable change in the biomarker before a clinical response is seen. Dr. Lund has used mass spectrometry to look for blood proteins in 18 children with cerebral ALD and identified several brain-related proteins that are increased or decreased. With further study, these proteins may turn out to be valid biomarkers for the demyelination in X-ALD.
John Fink, M.D. (University of Michigan, Ann Arbor, MI) discussed the pathophysiology of the axonopathy in adrenomyeloneuropathy (AMN). He emphasized the importance of peroxisomes in axonal function and drew a parallel between the axonopathy seen in AMN and other hereditary spastic paraplegias. He hypothesized that peroxisomal metabolism in oligodendroglia and Schwann cells help support axonal function and survival through still unidentified mechanisms. For example, certain key metabolites may be shuttling back and forth between the axons and oligodendrogial cells. These mechanisms are likely to be identified through the use of animal transgenic models that isolate contributions of each cell type to axonal survival.

Kathy Zackowski, Ph.D., O.T. (Kennedy Krieger Institute, Baltimore, MD) gave an overview of gait abnormalities in AMN. The first neurologic symptom in AMN males and symptomatic female X-ALD carriers typically develops between 20-29 years of age and is usually related to walking and climbing stairs. Dr. Zackowski found that hip strength is an independent predictor of walking velocity and is readily detected using simple testing, such as get-up-and-go and step width. In 142 men and women with AMN, weakness was the most prevalent feature affecting movement performance. In a study involving 15 women with AMN, a 24-week exercise-conditioning program resulted in increased strength and faster walking velocity, which translated into better overall gait function. The changes also correlated with spinal cord mean diffusivity detected with DTI/MRI. Based on these results, she is developing exercise guidelines for people to do at home.

Peter Barker, Ph.D. (Johns Hopkins University, Baltimore, MD) discussed the value of magnetic resonance spectroscopy (MRS) in diagnosing and monitoring leukodystrophies. MRS has proven useful in evaluating several of the leukodystrophies, although it is still not routinely requested in most centers. As compared with the conventional single-voxel MRS method, which is limited to collecting signals from one area of the brain, MRS imaging (MRSI) permits measurement of many areas and provides a display of spatial patterns of metabolites. The patterns differ in hypomyelinating disorders compared to demyelinating leukodystrophies. In childhood ALD, a pattern of increased choline, decreased NAA and increased lactate is seen in myelin. These changes may even appear before the onset of MRI-detectable white matter disease. After hematopoietic stem cell transplantation in one boy, an increase in NAA was observed, suggesting MRSI may detect a new biomarker for childhood ALD. As more powerful magnets are developed for MRS and software becomes more sophisticated, it should be possible to detect an increasing number of minor brain metabolites in the leukodystrophies, which will be useful for understanding the mechanisms of brain disease and monitoring therapy.

Johannes Berger, Ph.D. (Medical University of Vienna, Vienna, Austria) reported studies on pharmacologic induction of ABCD2 as a possible therapeutic approach in X-ALD. The ABCD2 protein is structurally similar to ABCD1, which is mutated in X-ALD, and has the ability to take over its function (gene redundancy). For example, overexpression of ABCD2 lowers very long chain fatty acids (C26) in cultured X-ALD cells and prevents the myelin abnormality in ALD knockout mice. However, levels of ABCD2 tend to be low in cells that have high expression of ABCD1 and therefore does not replace its function in X-ALD cells. In an attempt to increase ABCD2 expression, Dr. Berger has focused on bone marrow derived cells, including CD34 stem cells that are potentially important for treating X-ALD. He found that 13-cis-retinoic acid, a retinoid drug that is typically used for skin disease, can increase ABCD2 expression in some cells, but not in CD34-derived monocytes that differentiate into macrophages. Studies are ongoing to identify other potential drugs that induce ABCD2 in the cells that are key players in X-ALD. This pharmacologic approach holds promise for using gene redundancy as a novel way to treat some leukodystrophies.
Florian Eichler, M.D. (Massachusetts General Hospital, Harvard Medical School, Boston, MA) gave an update on disease modification and gene therapy in a mouse model of X-ALD. The defective Abcd1 gene is expressed in a variety of cells in the mouse brain including oligodendrocytes, astrocytes, microglia and neurons. Microvascular endothelial cells also express the gene and are important for maintaining the blood-brain barrier, which is disrupted in boys with cerebral X-ALD. The inflammatory demyelination is associated with abnormalities in tight junctions between cells and a reduction in claudin-5 and ICAM-1. Dr. Eichler investigated the efficiency of gene therapy of Abcd1 knockout mice by direct intraventricular injection into the brain and compared it to a more generalized systemic delivery by intravenous injection. Although direct intraventricular injection was able to deliver the normal human gene into astrocytes and microglia cells, it did not get into oligodendrocytes and endothelial cells. In contrast, intravenous gene delivery was more effective in delivering the gene into all of the cells. This led to a reduction in C26 fatty acid in the brain and spinal cord within 2-4 months, reduction in oxidative markers and improvement in behavior. The systemic intravenous injection approach was not only better at treating the brain, but also had the benefit of delivering the gene into the adrenal gland. As in vivo gene therapy is investigated in X-ALD, it will be important to evaluate different methods of gene delivery and see what works best.

Marjo van der Knaap, M.D., Ph.D. (VU University Medical Center, Amsterdam, The Netherlands) reported on a new class of leukodystrophies that arise from defects in mitochondrial and cytoplasmic tRNA synthetase enzymes. The diseases constitute a family of leukoencephalopathies with an unusually wide range in clinical onset, severity and progression. Some patients are affected at birth with a profound neurologic impairment and succumb within 2 years of age, whereas others have a slowly progressive disease that has onset in adulthood. The diseases include 1) Leukoencephalopathy with Brain stem and Spinal cord involvement and Lactate elevation (abbreviated LBSL) with DARS2-related genetic defects in mitochondrial aspartyl-tRNA synthetase; 2) Leukoencephalopathy with Thalamus and Brain stem abnormalities and Lactate elevation (LTBL) with EARS2-related deficiency of mitochondrial glutamyl-tRNA synthetase; 3) Hypomyelination with Brain stem and Spinal cord involvement and Leg spasticity (HBSL) caused by DARS-related deficiency of cytoplasmic aspartyl-tRNA synthetase. The MRI tends to have a mitochondrial appearance and MRS is useful for detecting lactate accumulation. Some patients with HBSL have a gait impairment that responds to steroid therapy. LBSL is caused by a common splicing mutation in 94% of patients and high-throughput drug screening has identified several candidate drugs that improve splicing efficiency, but they unfortunately have toxic side effects. This group of diseases will undoubtedly expand in number as more tRNA synthetase enzymes are known. The genetic diagnosis is critical for potential therapy, especially for HBSL.

Ian Duncan, BVMS, Ph.D. (University of Wisconsin, Madison, WI) proposed that studies in animal models of Pelizaeus-Merzbacher disease (PMD) can provide insights into the natural history of this human leukodystrophy. Several animal species have been found with mutations in the gene for myelin proteolipid protein (PLP1), which causes PMD. Dr. Duncan has investigated the Welsh springer spaniel dog (shaking pup) model, which is caused by a H36P mutation in PLP1. Affected pups develop gross tremor early in life that worsens over time. Animals exhibit spasticity, clonus and hypertonia. Brain MRI shows hypomyelination with preservation of axons, similar to that seen in children with PMD. In the brain, oligodendrocytes undergo apoptosis and begin dying as early as 6 weeks of age. The brain atrophies and has decreased weight by 1-2 years of age. Interestingly, myelin in the spinal cord, but not in brain, paradoxically increases over time. Studies in boys with PMD have not yet been done to examine whether spinal cord myelin increases with age. How this occurs and why the spinal cord myelin reverts to a more normal state is not yet known, but has implications for designing a therapeutic strategy for treating PMD, perhaps by promoting oligodendrocyte division and differentiation in the brain.
Mel Feany, M.D., Ph.D. (Harvard Medical School, Boston, MA) reported on how a Drosophila model of Alexander disease is uncovering new information about the pathogenic mechanisms of this leukodystrophy. Alexander disease is caused by dominant mutations in glial fibrillary acidic protein (GFAP). Dr. Feany has genetically engineered fruit flies with identical mutations in GFAP as seen in human patients. As in humans, the Alexander fly exhibits symptoms of seizures and neurologic dysfunction along with loss of myelin, axons and neurons. The mutant GFAP forms toxic aggregates in glial cells resembling Rosenthal fibers, the pathologic hallmark of Alexander disease. To identify modifier genes for Alexander disease, she systematically knocked down the expression of 2300 different genes and monitored the flies for functional changes. These experiments identified 6 signaling pathways with clinical effects, including the nitric oxide pathway. Knockdown of this pathway caused an increase in seizures and cell death that was mediated by reduced nitric oxide synthetase and increased cGMP levels. These results were confirmed in a mouse model of Alexander disease. Using high-throughput screening of 2000 potential drug compounds, she identified 4 muscarinic compounds that reduced GFAP toxicity and seizures in the flies. These studies in the tiny fruit fly are providing insights into the disease mechanisms of Alexander disease that promise to open new avenues for therapy.

Gustavo Maegawa, M.D., Ph.D. (Johns Hopkins University, Baltimore, MD) has been using high-throughput screening assays for discovery of therapeutic small molecules for Krabbe disease. He is exploring two different methods. In one, he has generated a SV-40 transformed brain cell line from the Twitcher mouse that grows continuously and is deficient in the GALC enzyme that is missing in Krabbe disease. As seen in Krabbe disease, the cells accumulate psychosine. After treating the cells in 96-well format with a library of potential drug compounds, he is searching for compounds that reduce psychosine levels using mass spectrometry. An alternative method relies on measuring GALC enzyme activity directly in transformed fibroblasts from a Krabbe patient. The ability to screen up to 400,000 chemical compounds in this way is a powerful approach for drug discovery that will hopefully identify clinically useful drugs.

Nancy Braverman, M.S., M.D. (McGill University, Montreal, Canada) also applied methods of high throughput screening to identify drugs that correct peroxisome import in patients with peroxisome biogenesis disorders (PBD). Her method relied on using a genetically engineered cell line from a patient with PBD carrying a specific PEX1 mutation (G843D) that possesses a small amount of residual function. She found that betaine, an FDA approved drug, acts as a chemical chaperone to improve peroxisome protein import and reverse biochemical abnormalities. These results formed the rationale for recently initiating a clinical trial of betaine in PBD patients. The results of the trial are pending. Other drug candidates identified include the flavonoid diosmetin, which is much more powerful than betaine in correcting peroxisomal import. It is expected that diosmetin will soon be tested in PBD patients for its ability to improve peroxisome function.

Genevieve Bernard, M.D., MSc, FRCPC (McGill University, Montreal, Canada) gave a research update on PolIII-related leukodystrophies. These diseases are caused by mutations in POLR3A and POLR3B that code for subunits of Polymerase-III, which is responsible for transcription of small RNAs, such as tRNAs and ribosomal RNAs. They include 4H syndrome (Hypomyelination, Hypodontia, Hypogonadotropic Hypogonadism), ADDH (Ataxia, Delayed Dentition, Hypomyelination), TACH (Tremor-Ataxia with Central Hypomyelination), Leukodystrophy with oligodontia, and HCAHC (Hypomyelination with Cerebellar Atrophy and Hypoplasia of the Corpus Callosum). The diseases have phenotypic overlap with characteristic hypomyelination and dental abnormalities in most patients. In reviewing 105 cases of 4H syndrome, Dr. Bernard found that children typically developed symptoms before age 6 years with motor delay or regression.
In contrast, 10% of cases had onset after 10 years with cognitive delay and learning disability, but motor symptoms were typically absent. Dental abnormalities were seen in 87% of cases and 67-81% had delayed puberty. In general, \textit{POLR3A} patients had a more severe disease course; \textit{POLR3B} patients had earlier onset of disease with a common c.1568T>A mutation predicting a milder course. MRI shows hypomyelination of optic radiations, corticospinal tracts and ventrolateral thalamus and dentate nucleus with thinning of the corpus callosum. Molecular studies indicate no general decrease in small RNA species, so hypomyelination may be due to reduced transcription of certain key RNAs needed for myelin formation.

\textbf{Adeline Vanderver, M.D.} (Children’s Hospital National Medical Center, Washington DC) emphasized the utility of using whole exome DNA sequencing to search for undiagnosed leukodystrophies. She has focused on a large group of leukodystrophy patients enrolled in a myelin disorders registry. Among these patients, it took an average of 8 years to arrive at a correct diagnosis. Seventy-four patients were identified who had no definitive diagnosis. Whole exome DNA testing was performed on the patients and their parents. DNA testing solved 40% of the cases, but 44 cases still remained undiagnosed. Of the diagnosed patients, some had atypical clinical features for the identified gene, but the MRI pattern was generally consistent with the identified gene defect. The majority of patients (57%) were also found to carry DNA sequence variants in genes that were not considered leukodystrophy genes. She concluded that this whole exome sequencing approach must be validated in a completely prospective patient cohort before standard testing can be recommended. Further, comparisons must be made between whole exome sequencing, whole genome sequencing and next generation sequencing panels to determine the best and most cost-efficient method for diagnosing leukodystrophy patients.

\textbf{Matthias Eckhardt, Ph.D.} (Rheinische Friedrich-Wilhelms University, Bonn, Germany) described his studies on a new mouse model of Canavan disease. Canavan disease is caused by genetic deficiency of ASPA, an enzyme that breaks down N-acetylaspartate (NAA) to acetate and aspartate. Canavan patients accumulate NAA and have severe myelin abnormalities. It is thought that ASPA deficiency prevents the formation of acetate from NAA in Canavan disease. Acetate deficiency in turn prevents the normal synthesis of myelin lipids and acetylated proteins, which results in the brain pathology. To investigate this mechanism, Dr. Eckhardt genetically engineered a mouse with deficient NAA synthetase activity (strain Nat8L) that could not make NAA. Surprisingly, the Nat8L mice made normal myelin lipids and proteins, proving that NAA itself or its breakdown metabolites are not essential for myelin synthesis. ASPA knockout mice accumulate NAA and die at 20-30 days of age with neurologic symptoms, but the double knockout mice (Nat8L/ASPA) have about one-half of the amount of NAA seen in ASPA knockout mice, develop no myelin abnormalities, remain active and have normal survival. ASPA knockout mice that are heterozygous for the Nat8L mutation show a partial neurologic phenotype and have a much longer survival beyond 30 days. These studies point to NAA accumulation itself as the culprit in Canavan disease. Furthermore, lowering NAA accumulation by inhibiting its synthesis may be a rational strategy for treating children with Canavan disease. Identification of inhibitors of NAA synthetase should now be explored as possible drugs for treatment of Canavan disease.

\textbf{Reuben Matalon, M.D., Ph.D.} (University of Texas Medical School, Galveston, TX) and (\textbf{Guangping Gao, Ph.D.}) (University of Massachusetts Medical School, Worcester, MA) described the latest advances in gene therapy for Canavan disease. Adeno-associated virus (AAV) is the viral vector of choice for gene therapy because of its low immunogenicity, excellent safety and efficacy. The first generation approach to gene therapy used AAV2 viral vectors for delivering the normal ASPA gene into the brain of Canavan patients by direct injection.
Dr. Gao subsequently found that AAV9 vectors are better than AAV2 for targeting brain cells. When injected intravenously into Canavan mice, the AAV9-ASPA vector crosses the blood-brain barrier and infects all of the cells in a more extensive pattern compared to direct brain injection. Intraventricular administration of the AAV-ASPA vector also worked. Studies have shown efficient delivery of the gene using both mice and monkeys. In Canavan mice, intravenously administered AAV9-ASPA vector reduced CNS vacuolation, restored myelination, improved motor function and decreased urinary NAA excretion. Treatment of mice one week before expected death rescued the animals, but earlier treatment was better. Survival extended from <4 weeks in untreated mice to >24 months after gene therapy. Other AAV serotypes work as well if not better than AAV9 in gene delivery, including AAV8 and AAV10. As optimization of gene delivery improves, the possibility for effective treatment of Canavan disease will become more of a reality.

Dr. Sakkubai Naidu (center) accepting her ULF award from Dr. William Rizzo (left), Chair of the ULF Medical & Scientific Advisory Board and Robert Rauner (right), ULF President, which honored her for outstanding commitment & dedication to patients with leukodystrophies and for advances in diagnosis and discovery of new leukodystrophies at our summer conference in Baltimore, Maryland.

A bird’s eye view of the awesome ULF/ALD Connect Scientific Meeting at the Embassy Suites, Inner Harbor.

All meeting photos taken by our Director, Joseph Changle, thanks for great pictures and memories!
Networking at lunch at the scientific meeting.

Bob Rauner socializing with families over lunch.

Family networking and socializing over dinner.

Professional and family networking.

Just a few of the kids in our formal childcare allowing their parents to focus on the meeting knowing their kids were in good hands.
Some attendees of the family meeting.

Some of the informal youth group attendees.

A couple of the informal group sessions in progress.

All aboard, the Saturday night Baltimore Inner Harbor cruise ship ready for departure!
IN MEMORY OF...

Ramon Abanilla  
Ligaya Pollosco

Thomas Andre  
David & Gail Andre

Jacob Ayers  
David & Martha Seals

Robby Backenson  
Kay O’Keefe

Mary Margaret Sheppard

Charles Bamberger  
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Oleh & Roxolana Saciuk

Zenovia Bihun  
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Vincent Knod  
Leo & Jackie Knode

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Lauran E. Lancaster  
Todd & Tiffany Lancaster

Anthony Dean LaPorte  
Paklab

Peter MacDonald  
Myles MacDonald

Meg Shatilla

Kyle Mach  
Stephen & Ruthie Duenner

Stephen Mach  
Stephen & Ruthie Duenner
Memorials

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Amantha Massey-McLaughlin
Paul Masur
Lynelle Schwedhelm
Arlene J. May
Alisa May
Kelsey Rae McDonald
Alice Miller
Jay McKinley
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Wanda Muzik
Anthony Steckling
Wanda Muzik
Christopher Stewart
Lynelle Schwedhelm
Alyssa Stramel
Tom & Stephanie Garrity
David Christopher Strock
Terri Scott
Matthew Sundstrom
Robert & Anna Sundstrom
Mitchell Sundstrom
Robert & Anna Sundstrom
Steven Tchernoff
Norman & Linda Tchernoff
Jordan H. Teraoka
Glen & Joyce Teraoka
Nathaniel K. Thomas
Kim Thomas
Dane Duncan Tolmie
Dr. & Mrs. John Tolmie
Garrett C. Wagner
Brett & Maria Anders
John & Pamela Andrews
Brian & Teresa Bajor
Dawn Bakie
Timothy Bechtold
Robert & Jeanette Bekebrede
Jeffrey & Jill Bell
Timothy & Laurie Berry
Michael & Carla Boster
Christian & Stephanie Boyce
Kenneth & Teresa Boyer
Sharon Brucker
David & Michelle Burski
Diana Carbonell
Lorraine Clemente
Luke & Susan De Sadeleer
Silvio & Joy Dellapina
Ronald & Janet Fouche
Keith & Karen George
Jeffrey & Shirley Graue
William & Michele Helbling
Brad Herschbach
William & Elizabeth Hill
Kelly & Kaye Hodges
Gordon & Diane Holdiman
Evan & Andrea Hyde
Jackson Hewitt Tax Svc
Barbara Jordan
Patricia Karol
Thomas & Lora Kehoe
Joseph & Deborah Kuster
Timothy & Laurie Lowery
Don & Vickie McShane
Mr. & Mrs. Robert O’Connor
Vaughn & Tricia Paddock
Daniel & Sandra Peters
David Prokupek
Margaret Risk
M. Patricia Schulze
James & Cathy Semanski
James & Angelia Stamatis
Kerry Stengel
Melanie Taube
Valerie Terry
Glenn & Julie Thomas
Kurt & Kathy Wagner
Gary Weinstein
Daniel & Jo-Anne Willetts
Chelsea Wilson
Steven & Kathleen Wilson
Jeremy Wyatt
R. Renee Young
David Warren
Mrs. Rosalind Allen
Tyler Watkins
Pat Oman
Katy Welch
Mary Tackett
Coleton Wright
Dan & Gena Ryan
Elliott Wynn
John & Debra Mercier
Albert & Esther Wynn
Robert Wynn
John & Debra Mercier
Albert & Esther Wynn
Suzanne Yamnitz
Larry & Dolores Yamnitz
Clint Yarbrough
Arlene Friedheim
Brad Yotti
Jim & Sue Bowersett
Lance Yotti
Jim & Sue Bowersett
IN HONOR OF...

Mick Bain
Pamela Atwood
Matthew Barry
Jennifer Barry
Kellie Scally
Michael Barry
Alexandra Fisher
Dawn Marie Bjornsen
Robert & Sandra Bjornsen
Olivia Borodychuk
Jim & Peg Beuschel
Chad & Lisa Borodychuk
Eric & Kelley Borodychuk
Gary & Patty Bugh
Diaz School of Piano
Anthony & Linda Kusnier
James & Virginia Pearce
Plante Moran
Paul & Kristy Pollatz
Jack & Barb Rau
Emily Shaver
Richard & Cecilia Tombelli
Gregory Brown
David Culberson
Aaron Leinemann
Evangeline Muratore
Ray Muratore
Frank & Marilyn Nemzer
Jason Tuscano
Greg Van Nest
Noah Buniger
Sayde Hazan
Michael Thomas Burke
Gene & LouAnn Rizer
Ethan Chang
Hamilton Chang
Morgan Chang
Tom & Ann Marie Chang
Robert Penberth
Ian Cornell
Reed Andrews
Olivia Delgado
Michelle Becker
Del Amo Fashion Wigs
Samuel & Deanne Pittman
Skyler DiPalma
Linda Savana
Christine Dominski
Robert & Patricia Pierce
Joshua Isaiah Flores
Veronica El Shami
Carlos Flores
Stephanie Juarez
Alvin Rigor
Louden Frank
Betty Frank
Laila Gracie
Kiyō Baird
Lissette Guth
Judi Guth
John Halter
Dave Zech
Logan Hensley
Mark & Janie Hammons
Alexandra Hiles
James Fowler
Janet Smith
Daniel Hughes
Active Network
Ivonne Benevides
Christopher & Holly Clark
Catherine Daily
Mary Dilts
Alba Dobladó
Michael & Deanne Duckett
David & Mellisa Flohre
Venissa Garcia
Nick & Michelle Gibson
Jodie J. Huet
Bobby & Kim Jones
Sharon R. Jones
JustGive
Robert & Jennifer Ketler
Kimberly Oliver
Margaret E. Smith
Mr. & Mrs. Brian Stahl
Mrs. Mai Yin Thigpen
Stan Zieg
Kylan Hunter
Sue Garvey
Tara Hunter
Colleen Kreager
Leaigha R. Keiser
Cheryl Ewers
Nora Kieffer
Mrs. LaVerne Raimer
Sean Kulzer
Terry & Sharla Taylor
Jaxon D. LaBorde
Steve & April Wagner
Isaac Levin
Sophie-Shifra Gold
Patricia Mach
Stephen & Ruthie Dunner
Ryan Marbut
Emogene Richardson
Jackson Henry Miller
Robert & Kathleen Miller
Ryan Miller
Robert & Marsha Jones
William Pozna
Janet Mills
Joy McFarland
Latavia Moore
Edwin & Lisa Lovvorn
William Nusser
Robert & Nancy Nusser
Danny Perrine
Anthony & Maria Cerminara
Jason & Sherry Ciganik
James & Paula Finello
Cheryl Hartshorne
Don & Betty Hartshorne
Earl & Helen McKinley
Eileen McKinley
Bradley & Melissa Miller
Mary Moschella
Timothy & Laura Mullen
Steve & Lisa Perrine
James & S. J. Reich
Steve & Colleen Sarosi
James & Kathleen Walter
Kelsey Perry
Jessica Hall
Bob Rauner
Jay & Michelle Bachman
Larry & Rodene Brchan
Rick & Sue Brockhoff
Andrew & Cheryl Casad
Al & Brenda Chambers
Ray & Betty Clayton
Carroll & Jenna Crist
Doug & Lorele Dittoe
Spencer & Tammy Doak
Jean Frazer
George & Jo Hill
Craig Himmelberg
Doug & Tammie Holle
Larry & Althea Holle
Allen & Carmen Jambor
Mike & Traci Larsen
Dennis Long
Gregg & Ellen Lund
Diane Mohrhoff
Karen Nichols
Kirby & Amber Novacek
Cheryl Ober
Dan Oppegard
Ken & Shelley Ostronic
Bart Peters
Gary & Deb Pool
Rose Rauner
Yvonne Rauner
Lynette Reinke
Bob & Sandy Schindler
Timothy & Julie Shaw
Randy & Jill Sigler
Gary & Sharon Spier
Ken & Nancy Vogel
Joe & Joy Warner
John & Lynn Willey
Bradley Rausch
Chris & Holly Rausch
Matthew Rausch
Chris & Holly Rausch
John W. Sanborn
Erica & Katherine Sanborn
Dane Sinnott
Pat & Debbie Sinnott
Jacquelyn Tomson
Martha Tomson
Ryan Tong
Patricia Cooper
Shannon Pipes
Karen Vasquez
Cheri Gomez
Hamilton R. Young
Jennifer Clements


Albert Dave Barton: March 26, 2014, loving father of Jeri Steckling, Cedar Springs, MI.

Ty P. Cambra: August 23, 2014, loving son of Rick and Lynnette Cambra, Manhattan Beach, CA.

Hope Betti Pleyl Coburn: December 11, 2013, loving wife of Horace Coburn and loving mother of Lynn L. Coburn, Carol A. Coburn (John Welch), James H. Coburn and Marilyn Gonzales (Frank), Las Cruces, NM.

Emily Irene Cyr: 13 years old, March 31, 2014, loving daughter of Richard r. Cyr and Corenne (Innie) Holguin, loving sister of David Cyr, Alexander Cyr and Nina Cyr, Londonderry, NH.

John Garland Gibbs: July 1, 2014, loving husband of Donna (Summers) Gibbs and loving father of Paul Stephen Gibbs, Mark Eric Gibbs and Brian David Gibbs, Denton, TX.

Jay Harp: 39 years old, March 23, 2014, loving son of Karen A. Harp and loving brother of Mike (Lucy) Machowek, Hoquiam, WA.

Michael Hirschbeck: April 8, 2014, loving son of John and Denise Hirschbeck, Poland, OH.


Dolores Kreher (nee Neubauer): 80 years old, July 8, 2014, loving mother of Barbara (Ted) Neitzke, Sandra (Joe) Girten, Debra (William) Wright, Laura Gillotte and Dolores Easton and loving brother of Robert (Judith) Neubauer, Frankfort, IL.

Veronica Elizabeth Mijan: August 5, 2014, loving mother of Barbara Peterson, the late Patricia Mijan, Michael (Mary Kay) Mijan and Kathleen Cornell, Arlington Heights, IL.

Wyatt Hunter Riggs: 15 years old, April 29, 2014, loving son of Jeff Riggs and Amanda (John) Chumley, Hillsboro, IL.

Joseph C. Scott: 82 years old, August 27, 2014, loving father of Pam (Tom) Phalin, Joe (Jane) Scott, Janet (Bruce) Jupena and Suzanne (Scott) Kalna, Trafford, PA.


Coleton Christopher Wright: 15 years old, July 1, 2014, loving son of Chris and Joy Wright and loving brother of Morghan Wright, Edinburgh, IN.
Annual Benefit Drawing:
Our annual benefit drawing is in full swing and all tickets must be received by our office by Monday, December 22, 2014 in order to enter! If you did not receive your tickets via mail and would like to enter to win a great prize, please visit our website at www.ulf.org and click on Programs, Events & Fundraisers and then Fundraisers. We sincerely appreciate all of your support!

Our winners last year were Gloria LeDesma from Arizona who won the queen size, handmade quilt by Anita Lewis, Donna Arnold from Michigan who won the one week stay at Christmas Mountain Village in the Wisconsin Dells, Wisconsin and Mary Knapp from New Jersey who won the one week stay at Orange Lake Resorts/Disney in Kissimmee, Florida.

Mary gave her stay at Disney to her Goddaughter and her family. They recently sent us a thank you card with the following note addressed to everyone at the ULF:

*My family and I wanted to let you know what an amazing time we had at the Orange Lake resort in Orlando this October. Last Christmas, my very generous Godmother, Mary Knapp entered the ULF raffle & was lucky enough to win the first place prize! Knowing that we (me, my husband & my tow sons, Elijah who is 10 years and Avery who is almost 9 years) had never gone on a family vacation, Mary very generously gifts us the 1 week stay at the timeshare. I will be forever grateful to my Godmother and to the United Leukodystrophy Foundation for making this perfect family vacation possible!*

*We truly had a perfect vacation - much better than I every could have hoped for. The Orange Lake Resort is absolutely beautiful - it's a perfect place for a vacation. The resort is so big & has so much to offer that you could stay in the resort for the whole week & still not do it all! The timeshare was perfect - the boys loved sharing a room & each having a full queen size bed all to themselves! The boys also loved the “Hippo” slide (giant 3 story inflatable slide) - my husband even went down the slid a few times!*

*My favorite things were the washer & dryer in the timeshare (so great coming home with lots of clean laundry)! And I also loved the fact that the resort was only 3 miles from Disney World! Thank you for sharing your amazing timeshare with us! We made so many wonderful memories all thanks to the ULF! Sincerely, Jeremy, Rebekah, Elijah and Avery.*

Some different ways to raise funds and increase your donations:

Anytime you shop Amazon you can help support the ULF by using the Amazon Smiles program. This program supports the ULF anytime you shop. Simply click on the Amazon Smiles link on our home page or type http://smile.amazon.com/ch/35-1557361 from your web browser and a percentage of your purchase benefits the programs of the ULF.

If you need flowers for any occasion, simply visit our website at www.ulf.org, click on Programs, Events & Fundraisers and then click Support the ULF when you send flowers and a percentage of every purchase benefits the ULF. You can also directly access the link by typing ulf.flowerpetal.com.

Your employer may match all or part of your donation. Many employers offer matching gift programs and some employers will even match 100% of your donations! Please contact your HR (Human Resources) department to see if they have a matching gift program available and if they need any additional information they can contact the ULF directly by calling (800) 728-5483 or emailing our office at office@ulf.org. We will gladly supply them with any information they need to fulfill your request.
Help the ULF save mailing costs in this stressful economy by contacting our office at Office@ulf.org to receive your newsletter by e-mail.

SAVE THE DATE AND SAVE MONEY

Make your travel arrangements early for our 2015 Annual Scientific Meeting and Family Conference held at the Embassy Suites Downtown Old Market in Omaha, Nebraska.

Please plan your travel to arrive on Tuesday, July 14th and depart on Sunday, July 19th.

The meeting will kick off on Wednesday morning, July 15th and run through Saturday, July 18th.

Agendas and registration details will be emailed and posted online when available.