

Liam's Land

for Lymphatic Malformation Research



Liam's Land Annual Newsletter

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June 2012

Vascular Anomalies Medical Expert Receives Debut Liam's Land Grant for Lymphatic Malformation Research

LITTLE ROCK, AR. (May 4, 2012)/SAVANNAH, GA (May 30, 2012) - A vascular anomalies expert at the Arkansas Children's Hospital Research Institute (ACHRI) and the University of Arkansas for Medical Sciences (UAMS) is the inaugural recipient of a medical grant from Liam's Land, a non-profit founded in Savannah, Georgia that champions research into lymphatic malformations.

Gresham Richter, MD, a surgeon and researcher on the ACH campus, will receive the \$20,000 Kathryn Barton Hobbs Medical Grant funded by Liam's Land each of the next two years to continue his investigations into the causes of lymphatic malformations; research geared to finding treatment options and prevention strategies. Dr. Richter is also an associate professor of Pediatric Otolaryngology at the UAMS.

"Children with lymphatic malformations deserve more answers and a cure," Richter said. "We are excited to have Liam's Land as a resource to help kids affected by this disorder."

Lymphatic malformations are clusters of channels and cysts that fill with a type of fluid that is difficult for the vascular system to process, resulting in intense swelling. They typically develop in the neck or underarm areas, though they may affect any part of the body. Researchers have yet to find a cause of lymphatic malformations, though there is evidence they begin during fetal development. More than 1 in 4,000 children are born with lymphatic malformations, and they usually undergo dozens of surgeries before adulthood and can suffer breathing and eating impairments as well as levels of deformity.

The program where Richter works at ACHRI is one of only a few in the world dedicated to identifying a cure for lymphatic malformations and other vascular anomalies affecting children.

"Identifying what drives lymphatic malformation growth is vital information. If Dr. Richter and his lab can identify what promotes this development, there is great hope for finding an antidote to stop growth and cure this challenging disease," said Janet Steffen, RN, founder and Executive Director of Liam's Land Organization (501c3). The Steffens' son, Liam, was born with lymphatic

malformation in 2010. Just over 2 years old, Liam has already endured multiple surgeries and MRIs. The organization's first grant is named in honor of Kathryn Barton Hobbs, who lost her life to lymphatic malformation more than 10 years ago.

In addition, Steffen has launched an international LM registry to track the incidence and prevalence of LM as well as examining medical, environmental, and workplace exposures to parents while pregnant. The registry will also help track outcomes in order to insure proper medical treatment and care. Steffen reports that many physicians may see LM once in their career and not be fully experienced in treatment. Unfortunately this can lead to poor outcomes. Steffen stresses that parents ultimately seek physicians and institutions that care for many LM cases. It is her hope that Liam's Land will be a resource for prestigious multi-institutional children hospitals in their work developing "stands of care and best practice" to encourage proper treatment and procedures for lymphatic malformation patients everywhere.

"We are excited about funding ACHRI and UAMS's research. Dr. Richter's initial success is already a beacon of hope for those with lymphatic malformation," stated Steffen. Arkansas Children's Hospital is the only pediatric medical center in Arkansas and one of the largest in the United States serving children from birth to age 21. The campus is celebrating 100 years of providing Care, Love and Hope in 2012. The private, nonprofit healthcare facility boasts an internationally renowned reputation for medical breakthroughs and intensive treatments, unique surgical procedures and forward-thinking medical research - all dedicated to fulfilling our mission of enhancing, sustaining and restoring children's health and development.

For more information about lymphatic malformation and the work Liam's Land is providing to find the cause, treatment, and cure, go to www.liamsland.org.



Dr. Gresham Richter,
Principal Investigator and Associate Professor of Pediatric
Otolaryngology at UAMS and ACH

TEAM LM ROCKS THE INAGUARAL SAVANNAH ROCK AND ROLL MARATHON!!!



From across the pond in England, Team LM has a supporter. Three year old, Lloyd, impacted by lymphatic malformation in his face, neck, and tongue, cheers for the 22 runners that graced the streets of Savannah, Georgia on a chilly November 5, 2011 morning to run 26.1 and 13.1 miles in the Savannah Rock N' Roll Marathon while raising awareness and money for lymphatic malformation research. Executive Director and trainer for Team LM, Jason Sapp, stated, "I have never been more proud of a group of runners as our FIRST Team LM. Each of them worked so hard raising awareness for everyone affected by LM. It inspired them to train, run, eat healthy, and help fund LM research. Because of Team LM, Liam's Land has been able to fund an amazing amount of money for research. And we will push for more runners and more success for the 2012 Team LM." The inaugural TEAM LM raised over \$17,000! Running for the children...Running for the cure!

For more information about how you can support Team LM or become a member, go to our website www.liamsland.org or contact jasonsapp@liamsland.org



Words from the Executive Director

Dear friends, family, and supporters,

What a first year! Liam's Land is proud of our milestones in the first year of our non-profit. Here are just a few of our milestones:

- March 2011 – Officially became a 501c3
- May 2011 – Launched website
- May 2011 – Held our first Executive Committee meeting
- June 2011 – Held our first Board of Director's meeting
- July 2011 – Announced our Medical Advisory Board
- July 2011 – Started Team LM recruitment
- November 2011 – Hosted a pre-race pasta dinner serving over 550 individuals
- November 2011 – Inaugural Team LM ran the Savannah Rock N' Roll Marathon
- January 2012 – Launched an International LM Registry
- March 2012 – Received our first grant applications
- May 2012 – Announced a two year grant agreement funding \$20,000 each year to Arkansas Children's Hospital and the University of Arkansas Medical Sciences.

It is due to hard work and commitment from so many donors that have allowed Liam's Land for lymphatic malformation to be so successful.

Lymphatic malformation is a rare disease. Therefore, funding for research is limited. We will strive to push for more awareness in order to gain more funding. Your continued support will help us achieve our goals to seek better treatments and find a cure. We thank you in advance for your support.

Sincerely,

Janet E. Steffen
Founder and Executive Director

www.liamsland.org

For the Children.....For the Cure