The Legacy of Angels Foundation is a private family 501 (c) (3) organization co-founded by Paul and Sue Rosenau in 2008.

To find out more about The Legacy of Angels Foundation go to: http://www.tloaf.org/
Welcome

From the Co-founders

As we reflect on 2012, we are grateful for the opportunities The Legacy of Angels Foundation has experienced. We are still newcomers to this work, grateful to be in a position to share with others some of what we have been given, and committed to making a difference in the lives of those afflicted with krabbes and cystic fibrosis diseases.

We continue to educate ourselves more about the scientific research that fits our mission and funding opportunities of interest to the foundation. Our philanthropy continues to look for collaborative efforts that can leverage our grant funds.

In the Spring of 2012, The Legacy of Angels Foundation convened the 2nd Annual Krabbe Translational Research Network meeting, an invited group of about 30 top researchers of krabbes disease. The 2 ½ day meeting brought lots of excitement among researchers and projects that appear promising for more effective treatments of krabbes.

Our on-going effort is to grow in our foundation work and to stay focused on aligning our passions, values and highest philanthropic priorities with our mission.

We look forward to 2013 to continue our passion in improving 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 cure.

Paul and Sue Rosenau
**Board of Directors**

**Paul Rosenau**  
President and Co-founder

**Sue Rosenau**  
Vice President and Co-founder

**Stacy Pike/Brett Rosenau**  
Secretary

**Heather Techmeier**  
Treasurer

**Dale DeRaad**  
Board Member

**Maureen Gartzke**  
Research Consultant

**John Priebe**  
Financial Advisor

**Jared Dufault**

**Mission**

The mission of *The Legacy of Angels Foundation*, a 501C3 private giving family foundation established in 2008, is to improve the lives of children by working to promote the expansion of newborn screening, and to further education, awareness and research of Krabbes disease and Cystic Fibrosis to provide a better treatment and cure.

**Vision**

To accomplish our mission, *The Legacy of Angels Foundation will*:

Direct, fund and promote research to develop/enhance treatments and cures for Krabbes and Cystic Fibrosis.

Promote through education and awareness the expansion of Newborn Screening, Krabbes disease, and Cystic Fibrosis benefiting children.
Interested applicants must submit a Letter of Inquiry (LOI). Letters of Inquiry for the current funding year must be received by March 1.

Consideration will only be given to projects that:
1. Conduct research to develop and enhance treatments and cures for Krabbe disease and Cystic Fibrosis, and
2. Promote through education and awareness the expansion of Newborn Screening, Krabbe disease, and Cystic Fibrosis; benefiting children with the increased probability of early identification and effective access to treatment.

**Please note:** No more than 5% of grant funds can be used for administrative purposes.

Letters of Inquiry will be evaluated on subject matter eligibility and the potential practical benefit of the proposed research. Projects of interest that follow the criteria will be invited to complete an Application for Funding. The Foundation does not accept unsolicited proposals.

The following additional attachments are required to accompany the Application for Funding:
- Copy of IRS letter certifying your 501(c)(3) tax-exempt status
- Letters of support
- Submit CV (Curriculum Vitae)
- IRB
- Listing of current funders for this project
- Any collaborative or partnership proposals must include letters of agreement from all parties involved.

Application for Funding and all supporting documentation must be received by June 1st. No exceptions.

Bi-annual progress reports are required for all funded projects. Due dates are June 1st and November 1st.

**Grant Structure Timeline and Progress Reporting**

<table>
<thead>
<tr>
<th>Event</th>
<th>Date</th>
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<tbody>
<tr>
<td>Letter of Inquiry Due</td>
<td>March 1</td>
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<tr>
<td>Review of Letter of Inquiry Done</td>
<td>April 1</td>
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<tr>
<td>Grants Due</td>
<td>June 1</td>
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<tr>
<td>Mid-year Progress Reports Due</td>
<td>June 1</td>
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<tr>
<td>Announcement of Grants Awarded</td>
<td>September 1</td>
</tr>
<tr>
<td>Year End Progress Reports Due</td>
<td>November 1</td>
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<tr>
<td>Grant Funds Dispersed</td>
<td>September 30</td>
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**Scientists and Clinicians Unite to Fight Rare Childhood Disorder**

*The 2nd Krabbe Translational Research Network Program for*

*The Study of Neurodevelopment in Rare Disorders*
Pittsburgh, PA – for two and one half days the leading scientists researching the rare childhood disease, Krabbe met with practitioners and other experts to bring the latest research into the clinic where it can improve the outcome for children with Krabbe Disease.

Paul and Sue Rosenau, who created The Legacy of Angels Foundation after their family experienced the tragic death of a grandchild due to Krabbe, sponsored the program. The Rosenau’s have stated, “we wanted to focus our philanthropy on the education and awareness of this disease and help fund research for better treatments and ultimately a cure for Krabbe disease.”

Krabbe disease is a rare, inherited degenerative disorder of the central and peripheral nervous systems. It is characterized by the presence of globoid cells (cells that have more than one nucleus), the breakdown of the nerve’s protective myelin coating, and destruction of brain cells. The early-infantile form of this disease affects infants, with onset before age 6 months. Without early diagnosis and treatment Infantile Krabbe disease is generally fatal before age 2

As part of their effort to fight this disease The Legacy of Angels Foundation sponsored the 2nd annual Krabbe Translational Research Network meeting, held March 12- 14 at the Hilton Garden Inn in Pittsburgh, PA.

Maria L. Escolar, M.D. who directs The Program for the Study of Neurodevelopment in Rare Disorders (NDRD) at the University of Pittsburgh Medical Center and has created a Virtual Medical Home and Clinic for Children with Krabbe Disease located on the web at: http://ndrdvirtualmed.com/index.shtml hosted the meeting. More than twenty doctors, researchers, clinicians, and family members participated.


Dr. Maria L. Escolar summed up the outcome of the meeting as, “we have identified new projects that have potential to improve therapy; and developed teams of translational researchers that will collaborate towards our goals.”

The MRI The Legacy of Angels Foundation provided partnership funding for was installed in 2012. Below are photos of the first patients being scanned through.
Paul and Sue Rosenau, co-founders of *The Legacy of Angels Foundation* received the Cystic Fibrosis Angela Warner Friend of the Foundation Award at the annual CF Breath of Life Gala that was held on November 17, 2012 in Minneapolis. The Friend of the Foundation Award is presented to an individual(s) who brings the fight for a cure for cystic fibrosis to a greater level. In 2003, The Friend of the Foundation Award was named after Angela Warner, who lost her lifelong battle of 21 years to cystic fibrosis.
2012 Grants Approved for Funding

Maria Luisa Escolar, M.D. – University of Pittsburgh Medical Center, Pittsburgh, PA
MRI for Neurodevelopment For Rare Diseases Program

Maria Luisa Escolar, M.D. – University of Pittsburgh Medical Center, Pittsburgh, PA
Krabbe Translational Research Network Collaborative Lab Grant

Maria Luisa Escolar, M.D. – University of Pittsburgh Medical Center, Pittsburgh, PA
Krabbe Transitional Research Network (KTRN) Meeting

David Wenger, Ph.D. - Thomas Jefferson University, Philadelphia, PA
Intracerebroventricular and Intravenous Injections of AAVrh10-CGALC into the Dog Model of Krabbe Disease

Michael Farrell, M.D. - Medical College of Wisconsin, Milwaukee, Wisconsin
Quality Improvement in Cystic Fibrosis Newborn Screening: Improving Follow-up and Outcomes with Tools for Facilitative Interactive Communication

Mei Baker, M.D. - University of Wisconsin, Madison, Wisconsin
Improving IRT/DNA Newborn Screening for Cystic Fibrosis to Reduce False Positives by a New Molecular Strategy

Total dollars of approved grants - $1,332,994.00