



JACOB'S CURE
a fight against Canavan Disease



The Jacob's Cure Research Summit & Family Conference
June 3-5, 2011
Renaissance Marriott, Harrison, NY

Organization Overview

Jacob's Cure, a non-profit organization that raises funds for the treatment and cure of Canavan and other white matter brain diseases, was founded by Jordana Holovach in 2000 to save her son, Jacob, who was diagnosed with Canavan Disease at six months of age. Children with Canavan cannot sit, crawl, walk or say a single word. They develop seizures, lose their ability to see and swallow, and die within the first decade of life. Since its inception, research funded by Jacob's Cure has slowed or halted the progression of the disease in most of the Canavan children. This research includes gene-therapy and pharmacological interventions. While there is currently no cure for Canavan Disease, Jacob's Cure is funding a stem cell trial that aims to further treat and ultimately cure the disease. Jacob's Cure and our team of scientists have partnered with Geron Corp. (a stem cell biotech) to expedite this revolutionary research that will lead the way to treatments for other "white matter" neurological diseases, such as Parkinson's, MS and ALS.

Additionally, Jacob's Cure gives families devastated with the diagnosis of Canavan Disease a place to turn for help and information with regard to the daily care of their child and advocacy issues, and often most importantly, it gives them the opportunity to speak with another parent who has been through the journey of a Canavan family. Today, Canavan families are directed to Jacob's Cure and our team of doctors and researchers for evaluation, pharmacological intervention and support. They no longer have to feel hopeless and alone.

For more information about Jacob's Cure and Canavan, please visit www.jacobscure.org



Conference Overview

The first Jacob's Cure Research Summit in 2008 was organized in an effort to bring together scientists and physicians from around the world who are currently working on defining the molecular, biochemical, pharmacological, developmental, and clinical correlates of white matter diseases, including Canavan Disease. The bringing together of individuals from diverse scientific backgrounds was intended to foster the sharing of information and collaborative efforts that will contribute to the identification of avenues of therapeutic intervention. Because of the success of the first summit, Jacob's Cure will continue to proudly promote the advancement of life saving research by hosting its 2nd annual white matter disease research summit that will unite world-renowned scientists who specialize in this area of brain disease research. The Research Summit intends to further the collaborations which began in 2008, to share recent findings and to continue to identify new avenues for treatment for Canavan and other white matter disorders.

This year, we will also include the Canavan children and their immediate families in the conference. We see this as an opportunity to advance science by uniting the research community with the patients they aim to cure. Families will be invited to sit in and listen to presentations and will be encouraged to partake in a Q & A session that will invite researchers and families to ask questions of each other for a united brainstorm. Additionally, the Canavan families have never had an opportunity to meet each other, share stories and gain the support that can only come from others experiencing the same day-to-day trials and tribulations of life with a Canavan child. Since this conference was announced, the response from the families has been overwhelmingly positive. We expect at least 30 families to attend the conference from all over the US and other countries including Israel, Norway, Ireland, Turkey and the Phillipines. We will also set up video conferencing for those families who are unable to travel to the conference. Because the cost of care for a Canavan child can be overwhelming, our goal is to be able to cover the cost of the rooms and meals for the families. However, due to our funding limitations and our 501c3 guidelines, we cannot support travel expenses for the families and are seeking grants to support this effort.



Sponsorship Information:

The Research Summit & Family Conference provides corporate and foundation partners with the opportunity to be recognized for their contributions to and support of white matter disease research. When you sponsor Jacob's Cure, you are partnering with an organization that is recognized for its dedication to finding treatments and cures and for supporting research that brings results to patients in their lifetimes.

The 2011 Canavan Research Summit & Family Conference gives corporate and foundation partners the opportunity to demonstrate their philanthropic efforts to an enthusiastic audience of parents, researchers, doctors and other non-profit leaders.

Sponsorship Opportunities:

Platinum Sponsor: - \$25,000

- ❖ Category exclusivity
- ❖ Product display opportunities (customized to sponsor's needs)
- ❖ Statement of partnership on Jacob's Cure website and conference web banner with your corporate/institutional logo and link to your homepage
- ❖ Listing on conference website
- ❖ Full-page ad on back cover of meeting agenda (provided to each conference attendee)
- ❖ Signage near registration table and throughout conference with your statement of partnership and logo/name
- ❖ Logo/name on invitation and all conference materials
- ❖ Logo/name displayed on screens in all conference rooms
- ❖ 4 tickets to Saturday night dinner with families and researchers
- ❖ Recognition in conference eblast and social media blast (over 6,000 recipients)
- ❖ Recognition in conference press release

Gold Sponsor: - \$10,000

- ❖ Product display opportunities (customized to sponsor's needs)
- ❖ Statement of partnership on Jacob's Cure website and conference web banner with your corporate/institutional logo and link to your homepage
- ❖ Listing on conference website
- ❖ Full-page ad in meeting agenda (provided to each conference attendee)
- ❖ Signage near registration table and throughout conference with your statement of partnership and logo/name
- ❖ Logo/name displayed on screens in all conference rooms
- ❖ 2 tickets to Saturday night dinner with families and researchers
- ❖ Recognition in conference eblast and social media blast (over 6,000 recipients)
- ❖ Recognition in conference press release



Saturday Night Reception Sponsor - \$7,500

- ❖ Statement of partnership on Jacob's Cure website and conference web banner with your corporate/institutional logo and link to your homepage
- ❖ Full-page ad in meeting agenda (provided to each conference attendee)
- ❖ Logo/name displayed on banner or screen during dinner (families, researchers and donors)
- ❖ 2 tickets to Saturday night dinner with families and researchers
- ❖ Recognition in conference eblast and social media blast (over 6,000 recipients)
- ❖ Recognition in conference press release

Welcome Reception Sponsor - \$5,000 - NO LONGER AVAILABLE

- ❖ Full page ad in meeting agenda (provided to each conference attendee)
- ❖ Listing on conference webpage
- ❖ Signage at reception room entrance with your statement of partnership and logo/name
- ❖ Recognition in conference eblast and social media blast (over 6,000 recipients)
- ❖ Recognition in conference press release

Lunch Sponsor - \$5,000 (two available)

- ❖ Full page ad in meeting agenda (provided to each conference attendee)
- ❖ Listing on conference webpage
- ❖ Signage on lunch buffet tables with your statement of partnership and logo/name
- ❖ Recognition in conference eblast and social media blast (over 6,000 recipients)
- ❖ Recognition in conference press release

Breakfast Sponsor - \$3,000 (two available)

- ❖ Full page ad in meeting agenda (provided to each conference attendee)
- ❖ Listing on conference webpage
- ❖ Signage on breakfast buffet tables with your statement of partnership and logo/name
- ❖ Recognition in conference eblast and social media blast (over 6,000 recipients)
- ❖ Recognition in conference press release

Children's Entertainment Sponsor - \$3,000

- ❖ Full page ad in meeting agenda (provided to each conference attendee)
- ❖ Listing on conference webpage
- ❖ Signage near registration table and in front of entertainment room with your statement of partnership and logo/name
- ❖ Recognition in conference eblast and social media blast (over 6,000 recipients)
- ❖ Recognition in conference press release

Break Sponsor - \$1,500 (two available)

- ❖ Full page ad in meeting agenda (provided to each conference attendee)
- ❖ Listing on conference webpage
- ❖ Signage on break tables with your statement of partnership and logo/name
- ❖ Recognition in conference eblast and social media blast (over 6,000 recipients)
- ❖ Recognition in conference press release



Sponsorship Opportunities (Cont'd):

Travel Sponsors

We are looking for a total of \$50,000 in funding to provide travel stipends for the families since our core mission and 501c3 status do not allow us to cover patient travel. If you would like to specify your funding for this purpose, you will receive additional recognition as a travel sponsor in our press release and online blasts and a special listing in the meeting agenda, in addition to the category recognition as specified above.

In-Kind Contributions

We welcome all kinds of door prize donations for both the families and the researchers. Please contact sarah@jacobscure.org for additional information.

Visibility Plan:

To increase visibility for the conference and our sponsors, we intend to work with a PR firm on a press release to attract parenting, health, and lifestyle press interested in the family and/or rare disease aspects of the conference. We currently have secured an organizational spotlight in Exceptional Parent Magazine, and we are working with them on the possibility of an additional article specifically about the conference. We are also promoting the conference through banners on our website and blog, which receive between 3,000 and 10,000 page views each month. We will send out eblasts to our mailing list of 4,000, including 400+ media contacts, and our Twitter and Facebook communities of over 2,200 supporters. We will also encourage the families to contact their local press for additional publicity for the conference and our sponsors. At the last conference, we had 30 researchers from around the world attend, and we anticipate that number increasing as word of our organization has spread in the past two years and we have formed additional partnerships. As you can see from our press page, Jacob's Cure has already been successful at obtaining high quality press, and we intend to use all of our efforts around this conference to help raise visibility for Canavan disease, the conference and our sponsors. Please see our past press at <http://jacobscure.org/press-room.php>.