



The JMML Foundation News

A quarterly newsletter to connect families, supporters, healthcare providers, and friends of kids with juvenile myelomonocytic leukemia (JMML)

OCTOBER 2005

VOLUME 1, NUMBER 1

The full-text printable version of this newsletter is available at our website: www.jmmlfoundation.org -- click on "Downloads," then "Newsletter Archive"

FOUNDATION MILESTONES

17 November 2004

Foundation incorporated in CA, USA

May 2005

Registered with CA Attorney General

July 2005

Received California tax-exempt status letter

August 2005

1st JMML Foundation Family Survey open

30 August 2005

www.jmmlfoundation.org is launched

24 September 2005

1st Family Survey results are posted to website

3 October 2005

Received IRS 501(c)(3) tax-exempt status letter

October 2005

1st JMML Foundation newsletter

FUTURE EVENTS

9 December 2005

1st JMML International Symposium

Spring 2006

1st JMML Foundation Golf Tournament/Auction in San Diego, CA, USA

The 1st JMML International Symposium – Families are Invited!



Atlanta, Georgia, site of the 1st JMML International

The 1st JMML International Symposium will be held in Atlanta, Georgia, USA on December 9, 2005 at the Omni Hotel at CNN Center. The goal of the conference will be to establish an international scientific forum, driven simply by a focus on the JMML disease and not by country or institutional goals, that combines clinical, basic, and translational research in order to improve survivability among JMML patients.

All families of JMML children are cordially invited to observe the conference. To let us know if you're interested in attending, please go to our website, click on "Contact Us," and let us know your name, contact information, and a brief explanation of your child's condition, no later than November 15, 2005. Though the Foundation has limited funding to cover family attendance this year, we will see to coverage for all meals served during the conference for attendees who can pay for travel and lodging on their own.

For more information, visit our website and click on "Symposium."

Ways to Give

Currently, you can make donations to The JMML Foundation in the following ways:

- By check through the mail
- By check or credit card via PayPal on our website in the form of one-time donations or recurring donations
- Online recurring donations allow donors to designate a child the donation is made "in honor of," to have the child's family notified of the donation, or to remain anonymous. Donors may be recognized for their contributions on our website and through our newsletters.

All unrestricted gifts allow the Foundation to apply funds to areas in which we can make the most difference to our families and children with JMML. For more information, go to www.jmmlfoundation.org – click on "Make a Donation."

WEBSITE TIP



Did you know that you can rate all links and downloads on the Foundation website? Just click on "Rate this Site" under each link or download. You can help parents more quickly find the resources that helped you the most!

VOLUNTEERS NEEDED!



If you can offer some time to help us in the following areas, please email fdini@jmmlfoundation.org:

- Newsletter editor or writers
- Translators (especially Spanish or Japanese)
- Country-specific support information
- Fundraising events in your area (from garage sales to golf tournaments...)

A full list of areas in which we need your help is listed at www.jmmlfoundation.org – click on "Volunteer."

CONTACT US

If you would like to receive more information about JMML or the Foundation, volunteer, contribute to future newsletters, or just talk, please contact us through any of the following means:

- By phone: 1-858-243-4651
- By email: admins@jmmlfoundation.org
- By mail: The JMML Foundation, 7825 Highlands Village Place #292, San Diego, CA 92129-5182

Through our website: www.jmmlfoundation.org; click on "Contact Us."

Note from the Foundation

Thank you for your support for children with Juvenile Myelomonocytic Leukemia (JMML). As the father of a 3-year old girl now 8 months post-transplant for JMML, I've seen personally what a child has to suffer and pass through during treatment for this rare disease. I also understand what it feels like for a parent to look upon their child through it all, fearful for their future and your own, sensitive to every slightest change in their health, frustrated with the uncertainty, and sad or lonely at times, but above all thankful for every single day they're with us. With time, these feelings aren't even held just for your own child – they pour out for every other kid with JMML you come to know and love.

Please continue to support families dealing with JMML. Follow these kids where you can and never forget their families, because they will never forget what they're passing through. And if you can, please support us with a donation, so we can continue to press for a cure and ease some of the burden each family incurs because of JMML. The only place these families should have to focus their energy is on their kids. Their beautiful, wonderful kids.

Sincerely, Fred Dini, October 2005

Spotlight on a JMML Researcher: Dr. Mignon Loh



Dr. Mignon Loh

Dr. Mignon Loh, MD, is an Assistant Professor of Clinical Pediatrics at the University of California at San Francisco.

She became interested and involved in JMML research while working under Dr. Kevin Shannon at UCSF. Given Dr. Shannon's interests in focusing on the development of mouse models in JMML and Dr. Loh's interests in conducting patient oriented laboratory research, they have been able to form a productive collaboration in which they can better "divide and conquer" the illness.

Currently, Dr. Loh's research focuses on two areas. Her first interest lies in developing lab tests to better describe how children with JMML are responding to treatment. Current indications of response, such as watching for decreased spleen size (pretty crude) or testing for GM-CSF hypersensitivity (very time and labor intensive) are challenges in present day management. Her hope is to create tests based on genetic tests that identify low levels of leukemia. If successful, relapses could be anticipated earlier and possibly allow for more effective and timely treatment of relapsed children.

Her second research interest involves making use of a new technology called "multi-parameter flow cytometry" to gain a more refined view of JMML. Currently, a "Western blot" technique is used to look at phosphorylated protein levels across a spectrum of all cells in a sample. This new technology should allow researchers as never before to see how specific subsets of cells activate proteins in the different genetic mutations that are found in JMML. Over time, this project may help in developing targeted therapies for new JMML patients.

Dr. Loh is married to an orthopedic surgeon and has two children, a 5-year old boy and a 2-year old girl. In her free time, she likes to spend time reading to her children, running to the beach with her family, hiking, and cooking all kinds of cuisine but especially Italian.

Dr. Loh was selected as our first spotlighted researcher due to her special commitment to our families. She has graciously agreed to join our Foundation's Board of Directors through June 2009.

Remember These Kids



We deeply value the power of positive thoughts or prayers for healing and recovery. The parents of these kids with JMML have asked that you please keep their children on your mind and in your heart as they approach treatment or work hard to recover:

- Brian D.
- Chiara D.
- Fynn M.
- Nathan V.
- Rosa V.
- Samantha R.
- Shanna L.

Just as importantly, please never forget these children who lost their battle with JMML but forever touched the lives of everyone they came in contact:

- Conor F.
- Jordan G.

These are the children whose stories are on, or will soon be on, our website. If you would like us to list your child with JMML in future newsletters and share their story with others, please email us a photo of your child and a short story about them to admins@jmmlfoundation.org.

First Steps for Parents of Newly-Diagnosed Kids

Based on the experiences of parents of children with JMML, the Foundation recommends the following first steps for parents of newly-diagnosed children:

- Join the [Yahoo JMML Support Group](http://health.groups.yahoo.com/group/jmml_support/?yguid=202561467) at http://health.groups.yahoo.com/group/jmml_support/?yguid=202561467. This link will connect you with other families who are experiencing or have lived through the same disease as you and who can offer strength, compassion, sanity checks, and their own experiences....
- Contact us as JMML family members and join our own registry so we can better serve you....
- Educate yourself. Use our website as a starting ground for learning about JMML, and use the Yahoo Support Group and website forums to learn more about other individual experiences....
- You are your child's best advocate. Push to make sure your healthcare providers explain everything you want to know to you, and if something doesn't make sense, press the issue....
- Help us get the word out about JMML. Please send us a short story about your child with JMML and a picture of them by email to admins@jmmlfoundation.org....

The full text of these steps are available online – go to our website and click on “First Steps.” If you would like to comment on this list of first steps, please contact us as fdini@jmmlfoundation.org.

1st Annual Report posted to JMML Foundation website

The JMML Foundation's 1st Annual Report has been posted to our website. The annual report is based on the Foundation's accomplishments during our first fiscal year, from 11/17/2005 through 6/30/2005. To view the full report, go to www.jmmlfoundation.org -- click on "Financials."

Results of the 1st Family Survey

The results of the 1st JMML Foundation Family Survey from August 2005 have been compiled. In total, 34 people responded to this survey, sharing their insights and experiences with educational, emotional, and financial support resources for JMML families.

Based on the topics that were rated lowest but ranked highest in importance to respondents, the following educational and emotional support resource focus areas were identified:

- Ease of finding information about JMML
- Support for siblings of deceased JMML children
- Completeness of information you found about JMML
- Support for parents of deceased JMML children
- Understandability of information you found about JMML
- Support for siblings of JMML children

Also, the following financial support focus areas were identified:

- Travel to/from medical care
- Lodging during transplants
- Counseling

To review the full survey report, go to www.jmmlfoundation.org – click on “Downloads,” then “Research and Programs.”

DONOR RECOGNITION



A very special thank you to all of our initial donors (July – October 2005):

Guardian Angel (\$1000+)*

Hero (\$750+)

Inspiration (\$500+)

Masten Family
Thomas Family

Hope (\$250+)

Supporter (\$100+)

Anonymous
R. Saydak

Friend (\$10+)

Anonymous
Anonymous
Dini Family
M. Valentine

*All giving levels are based on cumulative donations each fiscal year (July 1 – June 30).

To make an unrestricted financial contribution and help us find a cure for JMML and support our families, please go to www.jmmlfoundation.org and click on "Make a Donation."

WE WANT TO HEAR FROM YOU

For comments on our newsletter or article submissions, contact: fdini@jmmlfoundation.org

★ Volunteer of the Quarter: Mandy Valentine ★

This quarter, The JMML Foundation shines a spotlight on Mandy Valentine, our Website Administrator. Mandy is a single mom with two children: Jessica, 10, and Nathan, 2. She lives in Liverpool, United Kingdom, and works full-time as Corporate Services Manager responsible for admin, information technology, and performance management for her local government in Merseyside. Her interest in volunteering developed after her son Nathan was diagnosed with JMML in 2004.

Mandy volunteered in part to help improve the information available to her and other parents on JMML. "When Nathan was diagnosed a year ago," she says, "the first thing I wanted to do was find as much information as possible, but the hospital had no literature specific to JMML so I had to rely on the internet. It was very soul destroying when all I could find was brief comments saying prognosis remains poor or being confronted with research reports which I couldn't understand."

Developing the Foundation website has also helped her feel more active in the fight for her son's life as he awaits treatment. She explains, "Although it was good that Nathan remained stable and no treatment had to be planned for the immediate future, the waiting for something to happen made me feel so useless and unable to help him. Being given the opportunity to work on the foundation's website helped me feel more productive and gave me something positive to focus on at a time when I needed to do something, anything. I can't think of any other achievement in my professional life that I could be more proud of."

The parents of kids with JMML have offered many notes of appreciation for our new website, and the Foundation is forever indebted to Mandy for making it a reality. Her tireless efforts from December 2004 to August 2005, all the while as she struggled with caring for Nathan and attending to her family and job, resulted in a professional-looking site that allows for easy retrieval of useful information with plenty of room to grow, at virtually no cost to the Foundation. Thank you, Mandy!

Thanks also to our other volunteers this past quarter:

- Shannon Browne for her advice and donation of web hosting
- Nelleke Guequierre and Bart De Reu for their website contributions
- Ina Masten for arranging our free conference-call capability
- Fred and Mari Dini for donating all Foundation registration fees
- Larry Edwards for developing our Foundation logo

Research Update

Did you know that our website has a direct news feed from the National Institute of Health's PubMed website? That means any new research articles involving JMML show up automatically on our homepage. In the future, we hope to provide full text to all JMML research through our website. Click on these recent titles to view the article abstracts:

Date	Title	Authors
2005 Jul 26	Prolonged severe pancytopenia preceding the cutaneous lesions of juvenile xanthogranuloma.	Hara T , Ohga S , Hattori S , Hatano M , Kaku N , Nomura A , Takada H , Kokuba H , Ohshima K , Hara T .
2005 Jul 26	RAS-blocking bisphosphonate zoledronic acid inhibits the abnormal proliferation and differentiation of juvenile myelomonocytic leukemia cells in vitro.	Ohtsuka Y , Manabe A , Kawasaki H , Hasegawa D , Zaike Y , Watanabe S , Tanizawa T , Nakahata T , Tsuiji K .