

## **The NOMID Alliance 2007 Annual Report**

The NOMID Alliance is dedicated to increasing awareness, proper diagnosis, treatment and improved care for all people with Cryopyrin-Associated Periodic Syndromes (CAPS), which include: Familial Cold Autoinflammatory Syndrome (FCAS), Muckle-Wells Syndrome (MWS) and Neonatal-Onset Multisystem Inflammatory Disorder (NOMID); and other autoinflammatory diseases.

Our non-profit organization was pleased to have obtained IRS 501 (c)(3) tax-exempt status in 2007 to cover from the date of our incorporation in California on May 1, 2006. The State of California also granted tax-exempt status to our non-profit, starting at the date of incorporation. All donations to The NOMID Alliance are fully tax-deductible.

A grant was offered to The NOMID Alliance by Regeneron Pharmaceuticals in 2007 to help fund the creation, printing and distribution of a brochure about CAPS disorders. This CAPS brochure will be the main part of our FCAS-MWS -NOMID Awareness Campaign that will officially launch in 2008 to help more people become informed about CAPS. In addition, targeted mailings and distribution of the CAPS brochure at medical conferences worldwide in 2008 will help more doctors to learn about these very rare syndromes.

Our hope is that with increased awareness of CAPS, that more patients will be able to get diagnosed and treated sooner for CAPS, which could greatly improve their quality of life. CAPS patients have symptoms of fevers, rashes, pain and other complications starting at birth, or in early infancy. Due to a current lack of awareness about these rare syndromes, most patients suffer for years, often even into adulthood before obtaining a proper diagnosis and treatment for their condition.

We created our informative brochure about CAPS in 2007, and worked with our medical advisory committee to edit the text prior to printing. This process took longer than we originally planned, so the brochure was not ready to print until early 2008, but the funds collected for the project in 2007 were used to print 8,000 copies of the CAPS brochure, which are being distributed to patients and doctors worldwide.

We would like to thank all our generous donors, friends and volunteers that have worked hard in the past year to help fundraise for The NOMID Alliance. Every donation is greatly appreciated, and goes directly into funding our various programs. At this time, all of us involved with The NOMID Alliance are unpaid volunteers in order to dedicate as much of our donation money as possible to further our cause.

The Griffin Family of Cape Girardeau, Missouri held a family fundraiser for their children's birthday that raised over \$500 for The NOMID Alliance in 2007! This wonderful and thoughtful fundraising event also helped to increase awareness about CAPS, and we are very thankful for their efforts. So many people have been very generous in the past

year to help our organization grow and reach more people, and we are very grateful.

We are also thankful for the unrestricted grant from Regeneron Pharmaceuticals, Inc of Tarrytown, NY that was donated to help fund the printing and development of our CAPS brochure. We truly appreciate this grant, and all donations to The NOMID Alliance. In 2008, The Liberty Group of Bowling Green, Kentucky also donated a large amount of printing services to also help us to be able to print the CAPS brochure, which allowed us to dedicate more funds to distributing the brochure to patients and doctors worldwide. These donations have been instrumental in helping many people with CAPS.

In 2008, we have launched our awareness efforts with the distribution of the CAPS brochure. It was first given out to families with CAPS, to help them to increase awareness in their own communities and with doctors in targeted areas. Their response was incredible, and we had to do a second printing to keep up with the demand! We hope that we can translate the CAPS brochure into other languages, especially Spanish, since there is so little in print or online at this time about these syndromes in other languages besides English. We also plan to improve our website and have it in other languages next year.

Many patients have contacted us with gratitude for finally having a booklet about their syndrome to share with doctors, teachers, and others. One 58 year old patient with FCAS said,

“My family and I were brought to tears of joy when we had this brochure in our hands. After so many years, we finally feel that our condition is going to be seen as a valid disorder when we go to see doctors. The brochures came right before Mother’s Day, and it was the best present our mother could have ever had!” (This family has many suffering from FCAS, including the mom.)

The NOMID Alliance distributed the CAPS brochures in early April 2008 at the FMFSAID 2008 Congress in Rome, Italy. One of our board members, Dorelia Rivera-Martinez, represented The NOMID Alliance at this gathering of over 300 doctors that study autoinflammatory diseases (including CAPS), and presented our scientific poster about our awareness programs during the poster session on April 7th, 2008. These doctors were very pleased to have such current literature for their patients, and took many copies back with them to share with their patients worldwide.

Thank you for your support!

**Karen Durrant, President of the NOMID Alliance**

The NOMID Alliance  
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San Francisco, CA 94159  
415-831-8782  
www.nomidalliance.net

Karen Durrant, RN, BSN-President and Founder  
Nathan Durrant- Secretary and Treasurer  
Brad Miles-Board Member  
Jennifer Earnhart-Board Member  
Dorelia Rivera-Martinez- Board Member

## Upcoming Events in 2008

The NOMID Alliance will be at booth #1544 at the American College of Rheumatology Convention held right here in San Francisco at the Moscone Center. We were offered one of the few non-profit booths that were available, and are excited to have this great opportunity to increase awareness about CAPS to rheumatologists at this conference that come from all over the world. We hope to give our CAPS brochure to these doctors, and discuss with them about the new findings and treatments that are being researched and developed for patients with CAPS. There is more hope and options for patients with these syndromes than ever before. Yet, due to a lack of awareness about CAPS, delays in diagnosis are still prevalent, and many patients are still suffering.

On November 11, 2008 Earnhart + Friends in Bowling Green, Kentucky is hosting a wonderful art auction/fundraiser to benefit The NOMID Alliance called "An Evening of Art." Artists are donating many pieces of work for the auction, plus families with CAPS from all over the world have been sending in artwork from their local artists. We hope to also have some paintings created by children with CAPS for the auction as well. More information is available online at our website, [www.nomidalliance.net](http://www.nomidalliance.net) under the "News and Events" heading. Please contact us if you are interested in attending or donating artwork.

Thank you for your support!

Karen Durrant, President of the NOMID Alliance

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Brad Miles-Board Member  
Jennifer Earnhart-Board Member  
Dorelia Rivera-Martinez- Board Member

## A Special Thanks to all Our Donors in 2007

Karen Chapman  
Dr. Amy Chambliss  
Joseph & Brandy Davis  
Karen Durrant  
Stephen Durrant & Françoise Geffroy Durrant  
Darren & Angela Flieg  
Donald Gentle & Amelia Essman  
Kenneth & Alexa Griffin

Michael & Michelle Griffin  
William & Lynn Goeckeler  
Deanna & John Hayley  
James & Lori Laramore  
Tim Reed  
Darryl & Cynthia Scott  
Eric & Lori Scott  
Robert & Diane Wheeler

## 2007 Financial Statement for the NOMID Alliance

\$1030.07 Total donated contributions in 2007 to The NOMID Alliance

\$5000.00 Total Grant money received in 2007

**\$6030.07** Total funds received in 2007

\$ 1.08 Total fundraising expenses (fees from Paypal for online donations)

### Other expenses:

\$ 57.14 Program expenses (textbooks on non-profits)

\$ 0 Promotion expenses

\$ 72.40 Office Supplies

\$ 0 Phone (We are using a home line at no cost to the NOMID Alliance)

\$ 51.65 Internet 2007 fees for the site, domain fees, etc.)

\$109.55 Postal fees (\$112 P.O. Box for 2006, \$4.77 in postage fees)

\$ 0 Printing (no printed materials made- all done on a home computer in 2006)

\$ 9.85 Copies

\$ 0 Transportation

\$ 0 Parking

\$ 325.00 Permits, licenses, fees, include tax-exempt IRS and State tax form filing

\$ 0 Legal fees

**\$ 626.67** Total operating expenses in 2007 for The NOMID Alliance

**\$6030.07** Donated funds

-\$ 626.67 Total expenses

**\$ 5403.40** Left over for 2007\*

\*These funds were used for the printing of the CAPS brochure in early 2008

### Grants

Regeneron Pharmaceuticals, Inc.

### Donors

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Dr. Amy Chambliss

Joseph & Brandy Davis

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