

## NOMID Alliance 2010 Annual Report

The NOMID Alliance is a 501 (c)(3) non-profit public charity founded in 2006 that is dedicated to promoting awareness, proper diagnosis and treatment, and improved care for people with CAPS (Cryopyrin-Associated Periodic Syndromes) and other autoinflammatory diseases.

CAPS is caused by a rare mutation of the *NLRP3(CIAS1)* gene in the cryopyrin inflammasome. These CAPS syndromes include: Neonatal-Onset Multisystem Inflammatory Disease (NOMID)-also known as Chronic, Infantile, Neurological, Cutaneous and Articular Syndrome (CINCA), Muckle-Wells (MWS), and Familial Cold Autoinflammatory Syndrome (FCAS)-also known as Familial Cold Urticaria (FCU).

There are many other autoinflammatory diseases, and we have been working on expanding our information, useful links and website content to address the needs of these patients, in addition to the new conditions that are being discovered. This year, we have been working on a redesign of our current website and a restructuring of the system to make it more user-friendly, and easier to navigate. We are also having the site translated into French and Spanish, (and other languages in the future) to be a resource for more patients worldwide that need information about autoinflammatory diseases in their native language.

The NOMID Alliance wrote letters to seek state proclamations so that Rare Disease Day would be recognized throughout the United States on February 28<sup>th</sup> 2010, and is a Rare Disease Day Partner with NORD and EURODIS. More information about this day is at: <http://www.rarediseaseday.org/> Angela Rudd of Arkansas, and Janelle Radney of Nebraska were successful in obtaining proclamations for Rare Disease Day in honor of The NOMID Alliance and all rare diseases. We had many other s writing letters for other states, but not all were able to obtain proclamations. The good news was that due to the efforts of many rare disease organizations, proclamations were obtained in most states across the nation.



ODDS OF A GENETIC MUTATION CAUSING A CRYOPYRIN-ASSOCIATED PERIODIC SYNDROME (CAPS)

**NOMID**  
**ALLIANCE**  
nomidalliance.net



Rare Disease Day<sup>®</sup>  
Partner

In honor of this day, we launched a line of clothing and products to recognize the uniqueness of patients with CAPS, and also the rarity of the condition with our "One in a Million" design. (see above) T-shirts, water

bottles, sweatshirts and much more are available at our online shop at [www.printfection.com/nomidalliance](http://www.printfection.com/nomidalliance) Many people have enjoyed these items, and it has been a successful fundraiser for our organization. People with these diseases are “One in a Million” in many ways!

In September 2010, Colleen Paduani, one of our board members, represented The NOMID Alliance at Autoinflammation 2010 in Amsterdam, the Netherlands. We had been working closely with the organizers of this important conference for many months prior to this event and helped to attract other organizations to attend the Patients Program that was held on September 4, 2010 in conjunction with the medical conference. Colleen gave a speech about our organization, and ran our information booth at the event. She was pleased to meet our friends from EURODIS, Denis Costello and Rob Pleticha that run the wonderful online [www.rarediseasecommunities.org](http://www.rarediseasecommunities.org) that features some patient communities for autoinflammatory diseases, such as CAPS, Familial Mediterranean Fever (FMF), and Behçets. In addition, it was a pleasure for Colleen to meet Paul Rivere from the French CAPS patient organization, AMWS-CINCA ([www.amws-cinca.eu](http://www.amws-cinca.eu)) and other representatives from many other autoinflammatory disease organizations from around the world. She also got to meet a number of patients with these diseases from Europe, and helped to increase awareness about our organization to the hundreds of doctors that were attending this conference. EURODIS was very generous to offer a stipend for some of Colleen’s travel expenses, and Autoinflammation 2010 gave our organization free access for the Patient’s Program, and a greatly reduced admission fee for the medical conference. We are so thankful for this wonderful opportunity!

Our board member, Dorelia Rivera presented and helped with a very special fundraiser hosted by Rene and Lizette Anaya in early 2010. They chose The NOMID Alliance as the charity to benefit from the celebration of the birth and baptism of their daughter Ameliz Anaya. Almost \$1300 was raised thanks to their efforts! The donors include: Dorelia Rivera, Victor & Maria Carrera, Luz Herrera, Edith Diaz, Guadalupe & Modesto Gonzalez Jr, Raul & Elvia Herrera, Michael & Iridia Niewinski, Kimberley & Jorge Rivera, Nereida & Alicia Pereda, Veronica & Sergio Lopez, Jaime & Lucila Cano, Enrique & Ninfa Nevarez, Maria Sanchez, Maribel Sanchez, Caridad & Jesus Rivota, Jose Rivera, Luvia Montenegro, Nancy & Andres Chaidez, Fares & Noelia Ghanimah, and Irene Favela. Thanks so much for your support!



Colleen Paduani at our Autoinflammation 2010 booth, and presenting at the Patients Program in Amsterdam

Thanks to a good friend, Jenny Willmore of Logan, Utah we have found a very dedicated and excellent translator, Jorge E Torres of Colima, Mexico to help with the translation of the CAPS booklet, and also our website that is being redesigned this year. Thanks so much Jenny, Jorge and to all our generous donors! So many people need information about these rare diseases in other languages, especially Spanish. We are also very thankful for Romain Thibaux, a friend that is working on reviewing the French website translations for the new website. We are so thankful for all our volunteers that have helped us so much in the past year.

The NOMID Alliance developed a business card sized information card about CAPS for doctors, patients and family members to share with anyone interested in learning more about this rare disease. These were first distributed at the Autoinflammation 2010 Conference in Amsterdam, and are available for anyone interested. (see the next page for an example) Please contact us if you would like some! We have been sharing them with patients with our annual giving campaign letters that were mailed out in the late fall of 2010. We hope to develop more info cards about other autoinflammatory diseases in the next year, if we see an interest in having them. So far, many patients have found these very handy, and helpful, in addition to our CAPS guidebook.

Dedicated to improving awareness, care and treatment for patients with Cryopyrin-Associated Periodic Syndromes (CAPS), such as: NOMID/CINCA, Muckle-Wells, FCAS, and other autoinflammatory disorders.

Please visit us online to learn more about CAPS and the latest treatment options, find ways to connect with other patients, or to download the CAPS guidebook. Contact us if you need help finding a CAPS specialist.

1-415-831-8782

Cryopyrin-Associated Periodic Syndromes (CAPS) are rare autoinflammatory diseases caused by a mutation in the *CIAS1* gene. These include: Familial Cold Autoinflammatory Syndrome (FCAS), Muckle-Wells Syndrome (MWS), & Neonatal-Onset Multisystem Inflammatory Disease (NOMID, also known as CINCA).

**COMMON CAPS SYMPTOMS:**

- Rash from infancy
- Periodic Fevers
- Conjunctivitis
- Joint Pain
- Headaches
- Fatigue & Malaise

Some patients' symptoms are triggered by cold or cooling temperatures (FCAS or MWS). They can also have progressive hearing loss from childhood onwards. In some cases, they have relatives with the same symptoms for many generations.

More severe cases of CAPS (NOMID/CINCA) may develop chronic inflammation in the brain (aseptic meningitis), pressure in the eye at the optic nerve (papilledema), joint damage, and cognitive and/or mental delays.

CAPS info cards: Pocket sized to share with anyone!

Here is a sneak peek at the website that is being redesigned for our organization, thanks to an unrestricted grant from Novartis Pharmaceuticals, the generosity of our donors, plus the efforts of Workshop in Bowling Green, Kentucky and design suggestions from Nate Durrant, our Secretary/treasurer /board member who is also an Art Director. Nate has helped to design our "One in a Million" logo, all the identity for The NOMID Alliance, and many other things as an unpaid volunteer for our organization. We are very thankful for Workshop for offering to do some of their services for us at a reduced cost, with some donated services too. Thanks also to Tammy Burages, a dear friend that has taken over the website programming for us, when the original programmer could not complete the job. Thanks so much. We couldn't do this without all of you!

The website will be launched in the summer of 2011. In 2010, there were a number of unforeseen delays in this project, but those have been resolved and the site is being programmed in 2011. In addition, Karen Durrant, the President of The NOMID Alliance who also oversees the day-to-day running of the organization, and all the website content and management was on medical leave for part of 2010 due to a few breast cancer surgeries and chemotherapy. Some of our other board members had health issues last year, but have done a great job helping our organization despite temporary challenges. Despite this setback, The NOMID Alliance kept functioning, and we kept working to help further this website project, and many other ongoing efforts to help patients, and further awareness about autoinflammatory diseases.

**NOMID ALLIANCE**

EN | FR | SP | GN Search  GO

Increasing Awareness, Care and Treatment for CAPS: NOMID/CINCA, MWS, FCAS and other autoinflammatory diseases

HOME ABOUT US CONTACT US View the CAPS Guidebook Donate & Support

**Welcome!**  
We are here to help people with autoinflammatory diseases

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[Click Here to find out more.](#)

*"I am free. I am no longer a prisoner of pain."* -MWS patient  
Artwork by a 10 yr. old CAPS patient

**Learn** **Connect** **Support** **News**

Rare Disease Communities | EURORDIS | NORD

In 2010, our board members helped lead some excellent fundraisers and worked to do more outreach and awareness efforts in the United States and overseas. Dorelia did a great job with her fundraiser, and was hard at work with advocacy and interactions with our government leaders.

Colleen Paduani had a very nice "Teddy Bear Tea" fundraiser in July of 2010 in honor of her daughter, Quinn's birthday. This was a very successful and fun event! In September, Seth- the middle son of Nate and Karen Durrant had a birthday fundraiser that benefitted The NOMID Alliance. The family had also had a spring fundraising letter campaign to help raise funds for our organization.

Novartis Pharmaceuticals Canada donated money to our organization in early 2010, and helped to share our CAPS guidebook in Canada with doctors and patients. They shared the booklet to inform others about our organization, and about CAPS. It was not used to promote any specific treatments or medications.

We would like to thank the Jean Okazaki and her family for choosing The NOMID Alliance as a charity to receive donations in honor of the life and memory of Harry Okazaki. We were deeply touched and honored to receive a very generous \$1000 from this family in honor of Harry Okazaki, and are sorry for this wonderful man's passing last year.

Thanks to all our other donors in 2010:

Novartis Pharmaceuticals Canada, Robert & Susan Fry, Steve & Françoise Durrant, Joan Struck, Mrs. Geraldine Dennis, Don and Daniele Nisewanger, HDR Engineering of Omaha, NE, Sarah Ogilvie, Dorelia Rivera, Diane & Robert Wheeler, and Jean Okazaki, in the memory of Harry Okazaki.

Thanks for all that donated at Seth's birthday: Gary Siegel & Michele Jones, Peter Tran & Jennie Ho, Edna & Clifford Lee, Victoria & James Sutton, Dr Luis & Kathy Folan, Dr Tim and Alexis Rand, and Nate & Karen Durrant,

Thanks to all that donated to The NOMID Alliance at the "Teddy Bear Picnic" in Newburgh, NY in July 2010 in honor of Quinn: Anonymous, Colleen & Samuel Paduani, Maria Sanchez & Robert Arneman, Rachael & Lucas Ferrara, Margaret Gaydos, Dennis & Jill Sarlo Jr, Anne Mahoney & Eric Rodriguez, Lisa Rappa, Scott & Janice Gunnells, Christian & Angela Kelly, and Yuh-Hwey Shek.

Sincerely,



Karen Durrant RN, BSN—President and Founder of The NOMID Alliance, and

The NOMID Alliance Board of Directors for 2010:

Nathan Durrant, Colleen Paduani, Jennifer Earnhart, Dorelia Rivera, and Brad Miles

# 2010 Financial Statement for The NOMID Alliance

## Donations

\$ 7122.30 Total donations received in 2010  
\$ 187.00 Revenue from [www.printfection.com/nomidalliance](http://www.printfection.com/nomidalliance)  
("One in a Million" t shirts, products benefitting The NOMID Alliance)  
\$ 7309.30 Total funds received in 2010

## Fees for online donation services (Paypal, Network for Good: causes.com)

\$ 1.70 (already deducted from donations total listed above)

## Expenses

\$ 30.31 Program Expenses (purchased CAPS informational DVD)  
\$ 271.50 Promotion Expenses (t-shirts and items for Autoinflammation 2010)  
\$ 176.01 Office Supplies (paper, printer ink, etc)  
\$ 2809.10 Transution.com website translation system, CAPS booklet translation  
\$ 2984.12 Net Wages paid ( \$10/hr special projects-mostly volunteer work)  
\$ 650.76 Total payroll taxes paid out (IRS, State taxes)  
\$ 3.99 Filetaxes.com services for W-2  
\$ 9.13 International calls ( Phone \$0-home line used at no cost to non-profit)  
\$ 65.55 Internet: Web hosting, domain name, etc.  
\$ 615.47 Postal fees, PO Box (92.00) shipping event items, stamps  
\$ 101.96 Printing-CAPS info business cards  
\$ 0.00 Copies/faxes  
\$ 1452.37 Transportation/travel (Autoinflammation 2010 conference)  
\$ 256.08 Conference fees (Autoinflammation 2010)  
\$ 0.00 Parking fees while doing business, & event parking  
\$ 20.00 Government filing fees: IRS, State, City  
\$ 250.00 Business/event insurance  
\$ 9696.35 =Total Expenses in 2010

\$ 7122.30 Total donations received in 2010  
+\$ 187.00 Revenue from items at [www.printfection.com/nomidalliance](http://www.printfection.com/nomidalliance)  
+\$ 9710.20 2009 funds carried over into 2010  
\$ 17,019.50 =Total funds available in 2010

\$ 17,019.50 Total funds available in 2010  
- \$ 9696.35 Total expenses in 2010  
\$ 7323.15 Funds to carry over to 2011\*

\* These funds are going to be used to pay for website programming, translation, printing and 2011 operating expenses.