

NOMID Alliance 2009 Annual Report

The NOMID Alliance is a 501 (c)(3) non-profit public charity founded in 2006 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 *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).



Colleen Paduani, one of our board members held a very successful and entertaining fundraising event in honor of Quinn, her daughter that has NOMID. The "Walk in the Park-Hope for Quinn" event on July 25, 2009 in Newburgh, New York was a walk, with a barbeque and birthday party for Quinn after the event. There were many fun prizes for the winners, and it was attended by a number of members from the Fire Department of New York City (FDNY) and many people in the community. This event raised over \$4000 for The NOMID Alliance, and helped raise awareness for these rare diseases. Thanks Colleen, Quinn and the Paduani Family! We are so impressed with your efforts.

Thanks so much to all the amazing sponsors and volunteers that did so much to make this special day possible: Fusion Graphix, The Orlando Family, Benmarl Winery, The Hot Dog Hut, Ray Catena Lexus, Superior Auto Body & Collision, Stop and Shop, Inspired Creations by Lisa Rappa, Adams Fairacre Farms, Staffing Symphony, Members of the FDNY and many more. There are so many attendees that are anonymous on our

list, but we want to thank you all for coming out in support of Quinn and The NOMID Alliance. Donors include: Sam and Colleen Paduani, Lisa Rappa, Abby Kohut, Pamela Abner, Maria Carmela Desantis, Rachael & Lucas Ferrara, William & Cheandra Jones, Kerri Condon-Dehmer, Karen Durrant, Jennifer Earnhart, Amanda Buck, Richard Delgado, Anonymous, Alexa Perez.



Quinn, her brother Declan & their grandparents



Colleen Paduani (l) and other volunteers



Colleen (Right) and Sam Paduani (Left) presenting awards at A Walk in the Park

Thanks to our 2009 Donors: Anonymous (many), Novartis Pharmaceuticals USA, Mike Oisten, Joan Struck, Colleen Paduani, Bob & Colleen Whichello, R. Harvey Johnston & Sarah Johnston, Camille Leiffers and many that donated through Network for Good. Thank you!

We are pleased to announce that in the late fall of 2009, Novartis Pharmaceuticals has given The NOMID Alliance an \$8000 unrestricted grant to help fund the redesign and programming of a new website, and translation of the site into Spanish and French so it will be easier for patients to learn more about these rare diseases. This new website and translation will be developed in 2010.



Birthday girl Quinn!

Our CAPS guidebook has become the leading medical guidebook on CAPS worldwide, and it is in its second printing. Many patients have been able to access the booklet online on our website at: http://www.nomidalliance.net/downloads/finalCAPSbrochure_web.pdf and have taken it to their doctors to seek a diagnosis for autoinflammatory diseases. The center spread of the booklet has a helpful comparative chart of some of the periodic fever syndromes that are often considered when trying to diagnose patients with these diseases.

We were also able to help a number of patients get into clinical trials for CAPS and other diseases to receive needed treatment for their conditions in the past few years. In addition, we have started to collaborate with AMWS-CINCA, a French organization for patients with CAPS, EURODIS (Rare Disease Europe) and NORD (National Organization of Rare Disorders) on the development of a wonderful new online community for patients with CAPS, and other rare diseases at: <http://www.rarediseasecommunities.org/en/community/caps>

The NOMID Alliance is becoming more involved in honoring Rare Disease Day on February 28th 2010, and have become a Rare Disease Day Partner with NORD and EURODIS. More information about this day is at: <http://www.rarediseaseday.org/>



Sincerely,

Karen deW Durrant

Karen Durrant RN, BSN—President and Founder of The NOMID Alliance,
and The NOMID Alliance Board of Directors for 2009:

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

2009 Financial Statement for The NOMID Alliance

Donations

\$ 6113.35 Total donations received in 2009
\$ 8000.00 Grant money (from Novartis Pharmaceuticals to use in 2010)
\$14,113.35 Total funds received in 2009

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

\$ 22.95 (already deducted from donations total listed above)

Expenses

\$ 628.53 Program Expenses (software, reference materials, etc)
\$ 566.25 Promotion Expenses (t-shirts for Walk in the Park)
\$ 149.16 Office Supplies
\$ 6250.00 Payment towards Website design/creation (Earnhart+Friends)
\$ 720.86 Net Wages paid (rate \$10/hr for certain work-mostly volunteer work)
\$ 197.01 Total payroll taxes paid out (IRS, State taxes)
\$ 0 Phone (home line used at no cost to non-profit)
\$ 65.55 Internet: Web hosting, domain name, etc.
\$ 267.41 Postal fees, PO Box (92.00) shipping, stamps
\$ 45.26 Fed-Ex
\$ 0.00 Printing fees
\$ 0.00 Copies/faxes
\$ 0.00 Transportation/travel
\$ 0.00 Parking fees while doing business, & event parking
\$ 0.00 Government filing fees: IRS, State, City
\$ 250.00 Business/event insurance
\$ 9140.03 Total Expenses in 2009

\$ 6113.35 Total money donations in 2009
\$ 8000.00 Grant money received in 2009
\$ 6166.26 2008 funds carried over into 2009
\$ 20,279.61 Total funds available in 2009

\$20,279.61 Total funds available in 2009
- \$9140.03 Total expenses in 2009
\$11,139.58 Funds to carry over to 2010*

* These funds are going to be used to pay for website programming, language translation for the website and our CAPS guidebook, and for 2010 operating expenses.