

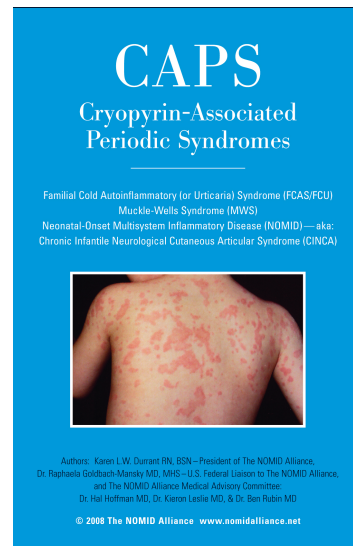


NOMID Alliance 2008 Annual Report

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). 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).

This year was one of great growth and increased awareness about Cryopyrin-Associated Periodic Syndromes (CAPS) worldwide. The NOMID Alliance was pleased to be able to print and distribute the CAPS medical guidebook starting in March 2008 to patients, doctors and researchers worldwide. The first printing of 5,000 copies of the CAPS guidebook was distributed by July of 2008, and a second printing was done in August 2008 due to great demand. The booklet is also available online as a downloadable pdf on our website at:

http://www.nomidalliance.net/downloads/finalCAPSbrochure_web.pdf



The NOMID Alliance had the opportunity to have a poster presentation with the distribution of the CAPS guidebook at the FMFSAID2008 Congress in Rome, Italy in April 2008. This is the leading conference for doctors and specialists studying periodic fever syndromes and other autoinflammatory disorders in the world. One of our board members, Dorelia Rivera was able to attend to represent The NOMID Alliance, and kindly used some of her United Airlines employee vouchers to cover the travel costs. Dori did a wonderful job introducing our non-profit to the leading researchers in the world that deal with CAPS, and was able to share our CAPS guidebook with them at this important conference.

In the spring of 2008, the Griffin family from Missouri held a fundraiser on their children's birthday to benefit The NOMID Alliance, and raised over \$500, and also had an informative

poster display to teach people about CAPS. This family also had a fundraiser in 2007, and have collected over \$1000 for The NOMID Alliance in the past two years! A special thanks to Keiran and Chloe Griffin and their family for their support and generosity to choose to benefit The NOMID Alliance on their birthday. Seth Durrant of San Francisco was inspired to have a similar fundraiser at his 9th birthday in September of 2008 to benefit The NOMID Alliance, and raised over \$200. Jan da Prato also had a fundraiser in honor of her son, Zach that raised \$155 and both Jan and the Griffin family helped raise CAPS awareness in Missouri.

There were a few very special family fundraisers benefitting The NOMID Alliance this year in honor of loved ones that had passed away in 2008. The family of James W. Smith of Alvaton, KY chose The NOMID Alliance as one of the charities that friends and loved ones could donate to in honor of this wonderful man. The family of Anne Marie Mallais (nee Vienneau) of Dalhousie, New Brunswick, Canada also chose The NOMID Alliance to receive donations in the honor of Anne Marie, a patient with FCAS (a form of CAPS) that had championed awareness efforts in Canada for many years. We cannot thank these families enough for their caring during a time of great sadness and loss of such wonderful loved ones.

In October 2008, our organization had a booth at the American College of Rheumatology Conference in San Francisco, CA to increase awareness about CAPS, and about our organization to Rheumatologists from all around the world. We made a lot of contacts with doctors, and hundreds of doctors visited our booth each day, and many had little or no knowledge about CAPS.



Benefiting The
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Hosted By:
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In November of 2008, Earnhart + Friends in Bowling Green, KY sponsored an amazing fundraiser benefitting The NOMID Alliance, orchestrated by board member Jennifer Earnhart and her family. They collected artwork from artists from all over the country, and art pieces made by CAPS patients for the auction, and raised over \$5000! It was a very lovely evening, and the Earnhart's did an incredible job educating the public about CAPS, and also fundraising for our non-profit.

The NOMID Alliance is thankful for the unrestricted grant from Regeneron Pharmaceuticals in 2007 to help fund the first printing and production of the CAPS guidebook. In addition, Earnhart + Friends and Liberty Group donated services and printing ink to for the first printing of the CAPS booklet, which helped us to have enough money to have a larger printing of the guidebook than originally planned.

The NOMID Alliance has been contacted by many patients since the CAPS guidebook was first distributed. These patients have found it very helpful, and it has validated their condition and allowed them to have a way to teach others about their rare condition. A few patients have found the website and booklet online, shared the information with their doctor and have since been diagnosed with CAPS after years of misdiagnosis for their symptoms.

We have also seen an increase in earlier diagnosis of pediatric patients in the past year due to more awareness of CAPS by doctors, but also through our website and CAPS booklet. Many families with CAPS requested the booklet to distribute to hospitals in their area, and Karen Atkinson and her family in Canada sent copies of the booklet to all the pediatric hospitals in Canada, and shared it with the Canadian Organization of Rare Disorders (CORD.) This has helped more patients in Canada, and their efforts are an inspiration to us all.

Thank you to our generous donors that have contributed to The NOMID Alliance in 2008, which include:

Regeneron Pharmaceuticals, Mike & Michelle Griffin and their children Kieran and Chloe for their annual fundraiser raising over \$515, Karen Bangert & Family, Rodney & Pam Arnold & Family, Cliff & Theresa Peda & Family, Shari Stroup & Family, Jan Farrar & Family, Bob Janota & Family, Mark & Wendy Diamond & Family, Jimmy Bowen & Family, Lisa Limbaugh & Family, Alan & Dana Branson & Family, Don Gentle & Amelia Essman & Family, Lynn Goeckler & Family, Mike Deimund & Family, Anonymous, Frances Day, Joseph Adlon, Aisling Mc Niffe, Christer & Anne Lewenhaupt, Dr. Luis & Kathy Folan, Gary Siegel & Michele Jones, Carol LeMaitre & Joe Cunningham, George Dzul & Lena Kaufman, Dr. & Mrs. Rand, Matt and Dr. Jeana Hoyt, Gail Hope, Ashley Hofman, Michelle Vincent, Samuel & Colleen Paduani, Lisa Rappa, Rick & Theresa Wilson, Nathan & Karen Durrant.

A special thanks to Regeneron Pharmaceuticals in 2007 for their unrestricted grant to the NOMID Alliance to help fund the production and distribution of the CAPS brochure in 2008. We also are very thankful for the donation of printing and final production of the CAPS brochure by Earnhart + Friends and The Liberty Group of Bowling Green, Kentucky. We cannot thank you enough for your support!

We are thankful for the dedication and amazing fundraising effort by Tim & Jennifer Earnhart, Earnhart+Friends, Liberty Group and many others that made the Evening of Art fundraiser so special. Also to the many artists and families that donated art for the auction, your efforts are incredible! Thanks to the sponsors for making this event possible: Earnhart + Friends, Liberty Group, Southern Foods, Minit Mart, Girkin Development, LLC, Harned Bachert & Denton LLP, Kirby & Kirby Certified Public Accountants, and Van Meter Insurance Group.

Thanks to all the donors at the event: David & Melanie Coffey, Alan & Sherry Scarboro, Randy & Natalie Scarboro, Scott Bachert, Dee Dee Murphy, David and Miki Wiseman, Kyle & Courtney Wise, Stephen & Hannah Ogden, Jeff & Lisa Lancaster, Stephanie Mc Ghehee-Shacklette, Derek & Michelle Hull, Bob Zeller, Warren & Amy Guyer, Pat Smith, Steve & Betsy Stinson, Joe & Cheri Natcher, Darrin Stiles, Sandra Abell, Dr August Mayfield, Mr & Mrs Mark McElroy, Mr & Mrs Bret Smith, Mr Tim Earnhart, Mr & Mrs Tim Earnhart, Mr & Mrs

Michael Barron, Mr & Mrs Nathan Durrant, Mr & Mrs Thomas Donnelly, Mr & Mrs Brian Goff, Bill Borders, Mr & Mrs Cecil Whitehead, Mrs Marilyn Allen, Mr & Mrs Freeman Dorris, Mr & Mrs Mark Cochran, Sarah Mayfield, Mr & Mrs Jim Ward, Ellen Griffin, Mr & Mrs Paul Cook, Jane Safford, Mr & Mrs Dennis Okeefe, Mr & Mrs John Inman, Mr & Mrs Darrel Mason, Mr & Mrs Steve Scott, Mr & Mrs Scott Gary, Dena Mullinax

A special thanks to all that have donated to The NOMID Alliance in 2008 in memory of the late James W. Smith of Alvaton, Kentucky. Also, thanks to his family for choosing The NOMID Alliance for contributions in his memory. Donors include: Sandy Stahl, Emily and William Selig, Dr and Mrs Nicholas Kafoglis, Meridith Johnson, Harriette Johnson, Stockland Investors, Inc., Richard and Karan Keaster, Rita and Roy Parks, Minit Mart of Bowling Green Kentucky, Mr. and Mrs. Jerry Goff, R. Harvey and Sarah Johnson, Hitcents.com, Creative Quilters of Southern Kentucky, Wilson and Judith Lowe, Mr. and Mrs. James Harris, Eileen Hepp, Mr. Wayne Orscheln, Kerrick, Stivers, Coyle and Van Zant, PLC, and Susan Cook.

Heartfelt thanks to the 2008 donors that honored the life and memory of Mrs. Anne Mallais (née Vienneau) of Dalhousie, New Brunswick, Canada. She was dedicated to increasing awareness about CAPS disorders, in the hope that others would not have to endure a lifetime of suffering with these conditions. These generous donors include: Biomérieux Canada, Denise & Colette Boulay, Cathie & Pat Brown, Arsene & Loraine Depres, Laurie & Denise Desroches, Rachael & Jim Doherty, Jeanette Dupuis, Marie & Leo Hachey, Gaele & Mike Lemay, Anne-Marie Mallais, Lucas & Krista Michaud, Thea Puttock, Paul & Simone Vienneau.

Sincerely,

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

and The NOMID Alliance Board of Directors for 2008:

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

2008 Financial Statement for The NOMID Alliance

Donations

\$ 6509.08 Total donations received in 2008
\$ 2840.61 Non-cash gifts/ donated services (pro-bono printing services)

Expenses

\$ 322.77 Total Fundraising costs
\$ 0 Program Expenses (reference books, training, etc)
\$ 820.69 Promotion Expenses (conferences, exhibits)
\$ 102.84 Office Supplies
\$ 0 Wages, payroll taxes, etc. (none-all volunteers 2006-2008)
\$ 0 Phone (home line used at no cost to non-profit)
\$ 51.65 Internet: Web hosting, domain name, etc.
\$ 841.53 Postal fees, P.O.Box, shipping, stamps
\$ 3574.29 Printing fees (CAPS guidebook, signage for events)
\$ 40.38 Copies/faxes
\$ 1087.37 Transportation/travel (Rome conference expenses)
\$ 83.00 Parking fees while doing business, & event parking
\$ 20.00 Government filing fees: IRS, State, City
\$ 250.00 Business/event insurance
\$ 7194.52 Total Expenses in 2008

\$ 6509.08 Total money donations in 2008
\$ 18.92 Paypal donation in 2007 not noted until 2008
\$ 5403.40 2007 funds carried over into 2008 (includes Regeneron \$5000 grant)
\$11931.40 Total funds available in 2008

\$11931.40 Total funds available in 2008
-\$7194.52 Total expenses in 2008
\$ 4736.88 Funds to carry over to 2009*

* The Evening of Art Fundraiser was held on November 11, 2008 and raised over \$5000. This money came in at the end of 2008, so most was carried into 2009.

