NOMID Alliance 2006 Annual Report

The NOMID Alliance was officially incorporated in California on May 1, 2006. This is our first annual report, and we have accomplished a lot in the past few months. In January 2006, the NOMID Alliance first started with a website created by Karen Durrant in San Francisco, CA at http:www.nomidalliance.net to increase awareness and be a resource for current information about the rare syndromes of Neonatal Onset Multisystem Inflammatory Disorder (NOMID), Muckle-Wells (MWS) and Familial Cold Autoinflammatory Syndrome (FCAS). The goals for this newly formed non-profit are:

Goal 1: To develop and launch an awareness campaign targeted at doctors and nurses working with newborn infants and young children, which may help to improve the rate of earlier diagnosis and treatment of these rare syndromes. This could significantly improve the quality of life of these children. In NOMID, FCAS and Muckle-Wells syndromes, there are specific signs and symptoms that are present at birth, or in early infancy, such as characteristic rashes, fevers, abnormal lab findings, and other symptoms. We want to create an informative brochure, to be distributed to: Neonatologists, Newborn Intensive Care Nurse Practitioners, Rheumatologists, Dermatologists, Neurologists and Allergists.

Goal 2: Act as a united voice worldwide, encouraging collaboration between global health professionals dealing with NOMID/CINCA, Familial Cold Autoinflammatory Syndrome (FCAS/FCU) and Muckle-Wells Syndrome (MWS), so that all people suffering from these rare conditions can have improved access to necessary care and treatment for their conditions. One of the long range goals would be to develop an advocacy program, to assist any families with struggles with their health care system. Unfortunately, this is an ongoing, common issue for all that suffer from these conditions.

Goal 3: To serve as a resource for individuals, families, and friends who are dealing with these syndromes, and other periodic fevers. A long range goal would be to gather enough resources and support for a family gathering/convention in the future.

Goal 4: We want to encourage medical and pharmaceutical groups to continue researching treatments for these syndromes, and other periodic fevers. Due to the rare nature of these syndromes, it is essential that we encourage the medical community to develop and fund further research and treatment options.

Soon after establishing our goals, we started the process of applying to be a non-profit and incorporate in California, and recruited some fine people to join the NOMID Alliance as members of the Board of Directors for the NOMID Alliance. The founding board members are: Brad Miles, Dorelia Rivera-Martinez, Jennifer Earnhart, Nathan Durrant and Karen Durrant. We worked hard as a board last year on establishing the non-profit's bylaws, conflict of interest statement, organizing documents, and started the detailed applications for the IRS and State of California's tax-exempt status, which will be filed in early March 2007.

The NOMID Alliance was a finalist in the Legal Zoom Non-Profit of the Year $5000 grant competition this summer. We did not win, but the experience and the honor of being in the final rounds of selection for a Non-Profit of the Year Award was energizing to us all. We feel that once we have established our tax-exempt status with the IRS and the state of California this year, that we will have a better chance at obtaining other grants to help our cause.

Our major goals for 2007 are:

1. Obtaining IRS and California tax-exempt status: Filing forms in March of 2007.
2. Increase fundraising efforts and grant proposal submissions.
3. Launch the NOMID-FCAS-MWS Awareness Campaign by the summer of 2007, with the development of an informative brochure about these syndromes being mailed to specific doctors throughout America, and eventually to other doctors around the world.
4. Expand the website to offer information in other languages, especially Spanish, to increase awareness in under-served populations. The addition of other languages may occur at a later date.
5. Further develop our advocacy efforts for people with these syndromes.

We were very busy establishing this non-profit this year, which was a huge learning experience for all of us, but were also able to do some general public. We had planned on having some larger fundraising events last year, but due to some unforeseen circumstances (namely some health complications in various families on the board) we had to scale back our large fundraising attempts in 2006. We had to prioritize accomplishing the organizing documents over fundraising this past year, but were still able to raise $1269.00 in donations to run our non-profit. This funding was enough to cover all the expenses for 2006, including the costs of creating the legal documents and fees for applications, etc.

In 2007, we are planning to more actively fundraise, especially after we have filed for IRS and California tax-exempt status in March of 2007.. Many people are creating various fundraising activities to raise funds for the printing and mailing of the soon-to-be-created brochure for the NOMID-FCAS-MWS Awareness Campaign. All members of the Board for the NOMID Alliance are unpaid volunteers, and we are keeping our costs low so we can dedicate all the donated funds to this awareness campaign. Hopefully, we can also attend some medical conferences this year to distribute literature and speak to various specialty doctors about these syndromes to increase awareness as well. We are also in the initial phases of grant proposals for funds for the awareness campaign at this time.

We look forward to increasing awareness about NOMID, MWS and FCAS through our awareness campaign, and hope that earlier diagnosis will lead to the proper treatment and care of patients at a younger age, which could help prevent severe damage from inflammation in the body. Your support for the NOMID Alliance is vital to continue helping many people worldwide with these syndromes, and those yet undiagnosed get the necessary help and treatment for these syndromes. Thanks you for your generous support!

Financial Statement of the NOMID Alliance for 2006

$1269.00 Total donated funds in 2006 for the NOMID Alliance

$15.66	Total fundraising expenses (fees from Paypal for online donations)
	Other expenses:
$ 54.24	Program expenses (textbooks on non-profits)
$ 0	Promotion expenses
$ 17.40	Office Supplies
$ 0	Phone (We are using a home line at no cost to the NOMID Alliance)
$134.97	Internet start up fees, 2006 fees for the site, set-up, domain fees, etc.)
$116.77	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
$ 20.00	Permits, licenses, fees
$829.00	Legal fees to to create 1023 IRS forms,file Articles of Incorporation and EIN
$1197.89	**Total operating expenses in 2006 for the NOMID Alliance**

$1269.00	**Donated funds**
-$1197.89	**Total expenses**
$ 71.11	**Left over for 2007**

Donors in 2006:

Karen Atkinson
Stephen Durrant and Françoise Calin
Joycelyn Gardner
Nathan and Karen Durrant
Jennifer Earnhart
Louise Keatley

Thank you for your support!

Karen Durrant, President of the NOMID Alliance

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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