



**2007 Annual Report
of the
National Meningitis Association Inc.**

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1 Introduction

The National Meningitis Association (NMA) initially was founded in February 2001 as the Meningitis Prevention and Awareness Children’s Trust, Inc. in Lexington Park, Maryland. The organization received initial approval from the Internal Revenue Service to operate as a 501(c) (3) public charity in August 2001. In August 2002, the name was changed to the National Meningitis Association, Inc. to underscore the national focus of the organization as reflected by its founders, its volunteer board members and the nature of the programs established to promote national awareness of meningococcal disease and prevention approaches.

2 National Meningitis Association Mission Statement and Goals

The primary purpose of the National Meningitis Association is to spread the message of “Vaccination – Education – Protection” regarding bacterial meningitis and meningococcal disease in particular. Our mission statement is:

- To help educate families, medical professionals, and others about the dangers of bacterial meningitis and prevention approaches to the disease

Until meningococcal meningitis is completely eradicated, we are dedicated to increasing awareness, promoting prevention, supporting families and survivors who are stricken by this deadly disease, and searching for new ways to reduce the incidence of meningitis in our country.

3 Operations

NMA operates as a volunteer-based public charity with a national focus. Funds to support the organization are raised primarily through unrestricted educational grants, individual donations, and fund-raising events. The organization is comprised of an executive director and four deputy directors. Day-to-day activities are conducted primarily through email, toll-free telephone services, a Web site (www.nmaus.org), and other written correspondence. The organization also has a large volunteer corps around the country that assist in responding to telephone queries regarding the disease. NMA receives approximately 350 telephone calls and more than 9,000 Web site visits per month from individuals across the United States, as well as several other countries.

The Web site (www.nmaus.org) is maintained and updated on a daily or weekly basis depending on need, driven by news of meningitis cases or updates on public health policy and legislation. Housed on the Web site is recent news surrounding meningococcal meningitis, downloadable



educational materials, information on meningococcal meningitis legislation in the United States, and links to other online resources.

Board members are elected for two years and may serve consecutive terms. Formal 2007 board meetings included the following:

- February 9, 2007 – Manhattan, NY
- July 14 2007 – Alpharetta, GA
- November 3, 2007 – Phoenix, AZ

The board members are:

Lynn Bozof	Executive Director	Georgia
Tama Lee	Treasurer	Georgia
Candice Benn	Secretary	California
Nancy Springer	Director	New York
Leslie Maier	Director	Arizona

In addition, a volunteer-based, non-voting advisory board, established in 2005, continues to support NMA.

4 2007 NMA Programs

The major focus for NMA in 2007 was to further raise awareness levels of meningococcal disease and available prevention measures across the country, with an emphasis on reaching adolescents, young adults, and their parents, as well as members of the media, educational institutions, public policy officials, and the medical community. The availability of conjugate meningococcal vaccine called Menactra® enabled NMA begin shifting the focus of its efforts to include younger children, including 11-12 year olds and high school students, in addition to college students. NMA’s success implementation of these programs was underscored by the numerous telephone and Web responses received from across the country, as well as positive feedback from television and radio markets regarding our public service announcements.

4.1 Direct-to-Parent Mailing

NMA received an unrestricted educational grant to distribute informational postcards to parents of 11-12 year olds and college bound freshman in all 50 states following the Centers for Disease Control and Prevention’s decision to expand the meningococcal immunization recommendations to include all adolescents 11 – 18 years of age. Through this mailing NMA reached approximately 4.6 million households with meningococcal disease awareness and prevention messages. NMA has received a very positive response to date with more than 3,000 inquiries to the NMA hotline and Web site requesting additional information about the recommendations and

where to locate the vaccine. Additionally, traffic to NMA's Web site increased by several thousand visitors in the months following the distribution.

Through an online feedback form housed on the NMA Web site, we also were able to gauge the visitor's awareness of meningococcal disease prior to receiving the postcard through a brief survey. Survey results indicate that before receiving the DTP postcard:

- Only 30 percent of respondents were aware of meningococcal disease
- More than 70 percent of respondents were unaware the disease was vaccine-preventable
- Nearly 20 percent of those who had heard of the disease were not aware of the severe nature of meningococcal disease or its symptoms

4.2 “Getting It ... A Disease, A Vaccine” Educational Video DVD and Resource Kit

NMA produced an educational video in 2006 called “*Getting It...A Disease, A Vaccine,*” narrated by Glenn Close and featuring the stories of meningococcal disease survivors and families affected by the disease. The video was made possible in part by funding from the B.O.C.E.S. in Wyoming, due to the efforts of one of our “Moms on Meningitis” (M.O.M.s) in Wyoming, Laurie Hartwig. Doug Myers, an Emmy-award winning producer and NMA advisory board member, donated his time to produce the video. Dr. Nancy Snyderman, also an NMA advisory board member, participated on-screen in the video, provided her medical expertise, and arranged for NMA to complimentary use of the Johnson & Johnson state-of-the-art editing facility. The video has received international recognition, including the very prestigious Telly Award and the 2007 Platinum Best of Show Aurora Award.

To help educate school communities and parents about the dangers of meningococcal disease and the importance of prevention, NMA also developed a corresponding educator's guide containing resource materials for use in the classroom. The educator guide and video were distributed to 15,000 members of National Association of School Nurses with the August 2007 issue of the *Journal of School Nursing*, as well as to various regional school districts and public health departments across the country.

4.3 Moms on Meningitis (M.O.M.s) Program

The M.O.M.s program is a coalition comprised of nearly 40 mothers whose children were personally affected by meningococcal disease. The mothers are volunteers who receive training to effectively communicate their personal experiences with the disease to members of their local communities through regional awareness and media efforts. In 2007, NMA hosted a two-day M.O.M.s Mission *Possible!* training session in Orlando, Florida, where it provided training on the following:

- Initiating “seasonal” media outreach efforts
- Promoting the “Getting It: A Disease...A Vaccine” educational video and resource guide
- Fundraising and grant funding

Following the meeting, the MOMs committed to conducting more than 80 activities to further NMA’s mission, including hosting screenings of the “*Getting It: A Disease...A Vaccine*” educational video, giving presentations on meningococcal disease prevention, distributing educational materials to members of their local communities, hosting booths at local meetings/health fairs, conducting fundraising events and participating in media interviews.

Regional radio public service announcements (PSAs) featuring the M.O.M.s and highlighting the importance of immunization also were distributed in local media outlets. Preliminary results include:

Moms On Meningitis” Radio PSA Summary

- Audience reach: Nearly 41 million
- Confirmed usage: More than 6,700 airings on 86 stations (AM and FM)
- Estimated advertising value: \$423,297

4.4 Together Educating About Meningitis (T.E.A.M.) Program

Our incredible young survivors involved in the T.E.A.M. program continued to help raise awareness about meningitis through participation in various media interviews and presentations on meningococcal disease prevention. The T.E.A.M. members include survivors from New York, Iowa, Pennsylvania, Massachusetts, and Texas. In addition, video footage of one of the T.E.A.M. survivors was featured on the Today Show.

4.5 Television and Radio Public Service Announcements (PSAs)

“Parents Against Meningitis: What Happened Shouldn’t Happen” Television and Radio PSA Summary

The radio and televisions PSAs (10-, 15-, 30-, and 60-second announcements) entitled “Parents Against Meningitis: What Happened Shouldn’t Happen,” produced in 2005, have been very successful. The PSAs were re-distributed to thousands of radio and TV stations nationwide in September 2007. According to the Nielsen Ratings reports, this campaign is currently among the top 17 percent of campaigns in U.S. distribution. Usage of the PSAs to date, includes:

- Reached more than 215 million viewers/listeners in 200 markets across the country
- Nearly 28,000 airings on 151 television stations and 159 radio stations (AM and FM)
- Estimated advertising value: \$1,703,195

Regional Meningococcal Disease Public Service Announcements

In addition, two regional PSAs created in 2005, are still receiving being aired regularly. The two PSAs, which feature Bobby Cox, manager of the Atlanta Braves, and Mike Scoscia, manager of the Los Angeles Angels, were shown on the Jumbo-tron during each of the team's home games, reaching more than 50,000 fans each game.

4.6 Meningitis Case Response Program

As part of NMA's efforts to educate families across the U.S. about meningococcal disease prevention, the organization contacts local media outlets reporting on a case to offer accurate information about the disease and encourage the inclusion of prevention information in the stories they are developing. Additionally, NMA volunteers provide outreach to those families who want or need support as they deal with the impact of disease on their families. In 2007, NMA also provided packages of brochures and NMA disease awareness bracelets to schools who experienced a case of the disease in an effort to help educate other students and parents about meningococcal meningitis and available prevention methods.

In 2007, NMA responded to more than 75 cases among adolescents and college students in the following states : FL, IL, CA, MO, NJ, PA, NY, TX, TN, NH, WV, VA, OH, LA, WI, KY, OK, TX, GA, VA, AZ. In addition, NMA participated in more than 45 media interviews surrounding these cases.

4.7 Medical Organization Collaboration and Support

NMA continued its collaboration with the National Foundation for Infectious Diseases (NFID) in development and maintenance of "S.T.O.P. (Share. Teach. Outreach. Protect) Meningitis," which is a collaboration of all the major medical organizations with an interest in meningococcal disease prevention. NMA was the only parent advocacy non-profit organization involved in this project. The goal of the initiative is to provide clinicians and other health care providers with resources and tools to help them educate their patients' parents about meningococcal disease prevention. A link to the program is maintained on the NMA Web site.

In addition, NMA participated in several major health-service conventions to help raise meningitis awareness and support efforts.

2007 Medical Meetings

- American Academy of Pediatrics
- American Academy of Family Physicians
- National Association of Pediatric Nurse Practitioners
- Arizona Adolescent and Adult Vaccine Symposium
- California Coalition of Childhood Immunization
- California Binational Health Week
- Immunize Georgia
- American Camp Association

4.8 Centers for Disease Control and Prevention (CDC) and Department of Health and Human Services (HHS) Meetings

NMA members attended the CDC's Advisory Committee on Immunization Practices (ACIP) meetings in Atlanta whenever meningococcal disease discussions were on the agenda. It is important to reinforce the human toll of this disease to ACIP members. NMA has been asked to partner with the CDC to help on educational initiatives.

4.9 Parent Teacher Awareness (P.T.A.) for PTAs Program

We have continued our PTA program, trying to target states with weak or no meningitis legislation. The program was developed to target PTAs, since they provide a strong platform for NMA to educate parents, school officials, pre-adolescents and adolescents. It reaches parent influencers through parent-to-parent communications and encourages education regarding the disease and prevention among parents, educators, and school officials. Our PTA program toolkits are designed to help PTAs educate parents of middle school children in particular about the disease and the vaccine for pre-adolescents and adolescents. The informational kits can be downloaded directly from the NMA Web site and are distributed in hard copy during PTA conferences and conventions attended by NMA. There were more than 3,200 downloads of PTA materials in August, September, and October.

2007 PTA Meetings

PTA Conventions

- National
- New Hampshire
- Minnesota
- Missouri
- Nevada
- New England (*Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island and Vermont*)

4.10 Web Site Development and Support

The Web site was re-designed and updated in 2007. This "shell" format was designed specifically to help streamline the vast amount of information housed on the NMA site as well as ensure easy user accessibility. This design accommodates the addition of new programs, such as the Marketplace, M.O.M.s map and educational video, enhanced T.E.A.M. program, as well as others NMA may wish to add in the future. The Web site is consistently ranked near the top of major search engines and includes the M.O.M.s and T.E.A.M. Web pages

4.11 Meningitis Awareness Wristbands

Youth and adult sizes are available and can be ordered through the NMA Web site. The wristbands are available for use by other organizations to help raise funds and awareness about



meningitis. The wristbands were also made available at medical meetings, PTA conventions, and sent out as part of our case response package to schools nationwide.

4.12 Brochure Development

The NMA brochures are routinely requested by many high schools, colleges, and other parent and educational groups. Both the English and Spanish language brochures may be downloaded from the NMA Web site or ordered directly from the organization.

4.13 Legislative Efforts

NMA continues to work to educate legislators about the need for immunization and education. To date, almost 40 states have legislation requiring meningitis education or vaccination for college students, and two states have implemented legislation requiring the meningitis vaccine for adolescents. NMA volunteers and families have been actively involved in testifying and/or providing educational information for many of the states that have passed legislation. Our volunteers also continue to encourage legislation on a national scale.

4.14 Confederation of Meningitis Organisations

NMA was invited to join the Confederation of Meningitis Organisations (COMO) in 2006. NMA participated in the 2007 COMO annual meeting, with members from several other countries. COMO is dedicated to assisting member organizations to be sustainable, identifiable, and influential sources of information and support services for those people affected by meningitis in their regions/countries. COMO is committed to the elimination of meningitis and septicemia.

4.15 NMA Marketplace

The NMA Marketplace page was initiated this year. The purpose of this Web page is to feature products developed for or made by NMA volunteers, which are available for a donation. The first item on the NMA Marketplace is a cookbook featuring Cajun recipes developed by one of the NMA M.O.M.s.

5 Fundraising

This year NMA re-registered in every state requiring fundraising registration to maintain our ability to conduct national fundraising campaigns. Fundraising efforts have included grant development, acceptance and participation in the federal government's Combined Federal Campaign, participation in several fundraising events across the country, as well as online donation access on our Web site. We continued to receive unrestricted educational grants from sanofi pasteur. In 2007, NMA was the beneficiary of a fundraising event held by the non-profit theatre group, Cause Celebre. Several of the M.O.M.s have also conducted successful fundraiser/awareness events including softball tournaments, golf tournaments, and a silent auction.

6 Other Administrative Costs/Financial

Since NMA is an all-volunteer organization, administrative costs include such items as board meeting travel, telephone, web site, office supplies, and shipping and postage expenses. Administrative and fundraising costs are currently approximately 3% of the annual budget.

7 Audits and IRS 990 Filings

In accordance with government regulations, NMA has submitted to an independent audit and has made all required federal filings.

8 Plans for 2008

The National Meningitis Association looks forward to continuing to expand our meningitis education efforts focused on saving lives in conjunction with CDC recommendations for the meningitis vaccine. The meningitis vaccine, Menactra, is approved for 11 year olds and older. The FDA also has licensed the vaccine for 2-10 year olds. We are very encouraged with the potential for improved immunization protection and are working closely with the Centers for Disease Control and Prevention on a pilot educational program in Arizona. Arizona is the first state to require the meningitis vaccine for adolescents.

One of our major goals this year is to disseminate, as much as possible, our educational DVD and resource guide. It is such a powerful tool and will have a great impact on raising awareness and encouraging vaccination. Our challenge is find the best ways to get the DVDs distributed and to find funding to be able to produce as many DVD kits as needed.

This year we plan to continue collaboration with various organizations including the National Foundation for Infectious Diseases (NFID), National Association of School Nurses (NASN), Immunization Action Coalition (IAC), Children's Hospital of Philadelphia (CHOP), American College Health Association (ACHA), Parents of Kids with Infectious Diseases (PKIDS) and others to ensure that all facets of our society are presented with clear, concise information on meningitis prevention and awareness.

We are excited about the involvement of the advisory board and are extremely grateful for all the volunteers who work so hard to support our efforts. We continue to work to significantly increase our outreach and hope to expand our fundraising activities this next year to meet the needs of all our program goals. Some of our other 2008 plans include:

- Continuation of the PTA program into states with little or no meningitis legislation
- Continuation of our case response program
- Educational efforts reaching parents and adolescents that receive their health care via public health sector
- Development of an enhanced T.E.A.M. program to include parents, survivors, siblings, friends, and other relatives who wish to work with NMA
- Development and distribution of an updated radio and television PSA campaign
- Implementation of a third M.O.M.s education and support workshop
- Continued, ongoing outreach through our established programs



- Outreach to diversity populations

Out goals are to:

- Establish the need for year-round meningococcal immunization
- Reinforce NMA as a credible and valuable resource for parents, medical professionals and media regarding information on the disease and prevention
- Encourage parents to be proactive in child's health and not wait for back-to-school physicals or school vaccination requirements to immunize their children. This also will help to maximize the available vaccine supply while protecting those at greatest risk for the disease

Significant challenges still exist to ensuring every child is protected from meningitis through immunization as well as education.