

Guide to Getting Media Coverage

National Niemann-Pick Disease Foundation
Revised Spring 2009

Sections of this guide for the National Niemann-Pick Disease Foundation were adapted from a media guide published by the Michigan Public Policy Initiative, and use material provided by the League of Women Voters of the United States. The National Niemann-Pick Disease Foundation appreciates their generosity in sharing this information.

Table of Contents

Introduction

Why is it important to get NPD and the NNPDF into the media?

Getting Media Coverage

Start with a Plan

Writing an Effective Press Release

Sample Press Release #1

Sample Press Release #2

Putting Together an Effective Press List

Sample Press List

Writing and Submitting a Letter to the Editor

Sample Letter to the Editor

Using Cable Television

Producing and Airing a PSA

Checklist for Press Kits

Developing Relationships with the Media

Requesting a Proclamation

Sample Summary and Proclamation

Contacting a United States Senator or Representative

Fact Sheet on Niemann-Pick Disease

Introduction

One of the major goals of the National Niemann-Pick Disease Foundation is to raise awareness of Niemann-Pick Disease among the public and medical community. This guide is meant to assist supporters of the Foundation in carrying out local awareness campaigns.

Sections of this document were adapted from a media guide published by the Michigan Public Policy Initiative, and use materials provided by the League of Women Voters of the United States. The following Introduction is from the original publication:

Published by the Michigan Public Policy Initiative - a joint venture of the Michigan Nonprofit Association and the Council of Michigan Foundations, this guide is designed for nonprofit leaders - people with a lot to accomplish in little time. Each section gives the key information you need to get media coverage of nonprofit issues, projects and other activities. For those who are new to media work, the guide provides the basics for getting started. For those who are more experienced, each part of the guide can serve as a checklist for your ongoing efforts to keep the public informed through media.

Each section of this guide stands alone. The how-to tips in the guide were provided by the League of Women Voters of the United States. Please feel free to separate the sections and share them with others. If you duplicate the how-to tips, please credit the League of Women Voters of the United States and the Michigan Public Policy Initiative.

Working with the media is an integral part of accomplishing an organization's mission by informing the public and influencing public policy. The simple steps in this guide provide the basics for effective work with the media.

The National Niemann-Pick Disease Foundation appreciates the generosity of the Michigan Public Policy Initiative in sharing this document.

Why is it important to get NPD and the NNPDF into the media?

Create Awareness and Champion the Cause --Keeping the name and mission of the NNPDF at the forefront increases public support.

Gather Support for the Families Affected by NPD – Informing the local community about the challenges a family affected by NPD faces will help bring support for the family.

Promote Specific Events – Fundraising and Awareness events will be better attended if they have been publicized by the media.

Recognition of Donors, Sponsors, Volunteers, etc.—Those who support NPD families and the NNPDF through donations, sponsorships, volunteerism, etc, should be recognized in their communities for their contributions. This recognition will, in turn, encourage others to show their support, as well.

Getting Media Coverage

Start with a Plan

1. Identify all obvious publicity opportunities – Awareness and education events, fundraisers, Family Conference, a specific achievement of an NPD family member (dance recital, kindergarten graduation, First Communion, etc.), community activities/events in honor of an NPD family or the Foundation, specific acts of kindness that would make a good feature story, the election of a local person to the Foundation board, etc.
2. Prepare a Media Kit, including the following, as appropriate for the item/event/issue you are publicizing: (Note: Not every press release requires a full press kit. You may include fewer items, perhaps even just the press release, especially if your media contact is already familiar with NPD and the NNPDF.)

Cover letter

Facts and figures about the NPD family and the NNPDF

Clips of past activities

Board member names, contact information, and biographies if applicable

Specific news items and feature articles

Writing an Effective Press Release

Press releases are often used to get publicity for a fundraising or awareness event. They can also be used to get a reporter interested in doing a more in-depth story about your family and Niemann-Pick Disease. It may take several attempts before anything gets published – newspapers receive hundreds of press releases.

1. Make certain that the press release includes who, what, when, and where in the first paragraph. Why and how may also appear in the press release. Make the verbs active and the subject concrete. Avoid the use of clichés, jargon and fancy phrases. Cover the most important facts first and follow with details.
2. A news release should begin with a lead that attracts the reader's attention and encourages them to read on. The lead is the most important part of a news story. It must be clear, concise, and make that all-important first impression.
3. Don't forget to include a brief family story and personal quotes. Quotations add life to any story and should be used whenever possible. Sentences in quotes should be short and to the point, e.g., "I couldn't stand by doing nothing. I had to fight back!" Be sure to attribute the quote to the correct speaker.
4. Include the name of the National Niemann-Pick Disease Foundation and refer readers to the website at <http://www.nnpdf.org> for more information. Use the Foundation's full name followed by the abbreviation in parentheses on the first usage (ex. The National Niemann-Pick Disease Foundation (NNPDF)). You may then use just the abbreviation (NNPDF) in later references.
5. Try to limit your press release to one page. Reporters are generally pressed for time and can't wade through long documents.
6. Try to find out in advance what the preferred format is – print, email, or fax. If a preference is not known, try to email the press release, as the media can "copy and paste" rather than re-type the full release.
7. Avoid preaching or editorializing. Stick to facts rather than opinions, unless the opinion is directly attributed to a particular speaker or source. Do not write, for example, that "The presentation was

fascinating.” Rather, you could write, “Audience member Jane Doe said, ‘I found the presentation fascinating. The speaker opened my eyes to a profoundly new angle on the issue.’” Keep opinions and judgments within quotes.

8. Give your press release a catchy title, e.g., **Local Family Fights Back**. Check headlines and lead sentences in published articles to get a feel for the style your paper uses.

9. Proof everything at least twice, and have someone else proofread it, as well. If your press release is disorganized or poorly written, the reader may be unfavorably impressed; the nonprofit’s image may suffer and opportunities for publicity may be lost.

10. If you expect legislative action on an issue or know of an upcoming event that you will want to respond to, write a press release in advance and make updates or fill in details after the event. This will allow you to respond more quickly following an event and you will get more coverage.

11. Style Points:

Write **FOR IMMEDIATE RELEASE** and the date near the top of the page.

Include a contact name and telephone number near the top.

Use a standard, easy-to-read font such as Times New Roman 12 point.

At the bottom of the first page write “more” if the release continues onto a second page. Write “End” or use the symbol “###” or “30” to indicate the end.

12. A picture is worth a thousand words. Include a photograph if possible with your news release, including a complete and accurate caption. Close-ups are better than wide or long shots. People want to see kids and families in action! Avoid, if possible, shots of people just standing around. If the photo was taken in a private setting, make sure you have permission from those pictured in it to submit the photo for publication. If the photo was taken at a public event (ex., a picture of participants in a Fun Run), permission is not always required, as the person, by their presence in a public place, has in essence, given their permission to “be seen.” Err on the side of caution; be sensitive to the feelings of those appearing in photos and get their permission if in doubt, especially when minors are in the photo.

13. After sending your release, make follow-up calls to reporters to make sure they received it. Offer to re-send the release if necessary. Thank them for their attention to your article/event/issue.

Sample Press Release #1

National Niemann-Pick Disease Foundation

Contact: (Your name, phone number and email address)

News Release
For Immediate Release

October Declared 7th Annual Niemann-Pick Disease Awareness Month Local Child Diagnosed with Rare Disease

Frederick, MD <September 17, 2008> -- Darrile and Mark Papier of Frederick had never heard of Niemann-Pick Disease (NPD). What could this cruel disease be, that doctors had just told them would rob them of their energetic little boy, Dillon?

The doctors told the Papiers that Dillon, now six-years-old, will likely not live past his teens. He will never drive, never date, never go to college, and his parents will be left to wonder how Dillon's life might have turned out, had he not gotten the diagnosis of Niemann-Pick Type C (NPC). The average lifespan of a child with NPC is 10 years, so time is not on young Dillon's side.

October marks the 7th Annual Niemann-Pick Disease Awareness Month – a time when families affected by Niemann-Pick, together with their relatives, friends, and the National Niemann-Pick Disease Foundation (NNPDF), work to raise awareness of this rare disease that robs parents of their children, and children of their lives, and to raise funds for research into treatments and a cure.

To that end, the Papier family and their team of friends, neighbors and co-workers are planning a NNPDF awareness campaign and all-city "Rake-a-Thon" on Saturday, October 19th, 2008. Individuals who would like their yards raked or who would like to volunteer for this event should contact Darille Papier at 123-456-7890. Raking by the team of volunteers is offered free of charge; however, tax-deductible donations to the NNPDF will be gratefully accepted. The Papier team is challenging local businesses, school and civic groups to support this event via a sponsorship or through volunteer service.

A backyard cookout sponsored by Bob's Burger Corner and an educational presentation at Riverfront Park will wrap up the day's events. Rake-a-Thon volunteers are invited to eat at the cookout free-of-charge. All others are asked to make a freewill donation which will further benefit the NNPDF. Bob will be serving burgers, brats and hot dogs, along with chips, watermelon, soda, and ice cream.

Niemann-Pick is a disease that strikes children through accumulation of excess lipids in key cells in the organs. The cells malfunction, leading to failure in basic motor skills, including gait and mobility impairments, eventually requiring a wheelchair and hospital bed. As the disease progresses, other debilitating symptoms develop, such as the loss of the ability to speak and swallow, and seizure disorders. The health of a child with Niemann-Pick Type C (NPC) declines until ultimately, the disease claims his or her life.

Today, there is no cure for Niemann-Pick, but research is making progress. The National Niemann-Pick Disease Foundation works to fund research and to support families in their day-to-day care of children with NPD. Established in 1992, the NNPDF is an international, voluntary, non-profit organization comprised of parents, relatives and friends committed to finding a cure. www.nnpdf.org

--- End ---

Sample Press Release #2

National Niemann-Pick Disease Foundation

Contact: Janet Pease Work (504) 555 3489 Home (504) 555 8920

FOR RELEASE ON OR AFTER NOON, SUNDAY, JANUARY 6, 2002

Local Family Has High Hopes for FOX NFL “NPD Sunday”

James Brown, the FOX NFL Sunday anchorman who has become a patron celebrity supporter of the National Niemann-Pick Disease Foundation, has taken his support to a higher level and that's good news for a Metairie family. During today's FOX NFL Sunday pre-game show (January 6, 2002), Brown and the entire FOX NFL Sunday anchor crew wore special NPD lapel pins to show their support of the National Niemann-Pick Disease Foundation. Brown also acknowledged the lapel pins on the air and made a special plea to the FOX network audience to join him and the other FOX NFL anchors in their support of the NPD cause.

The complete FOX NFL anchor team includes Brown, Hall-of-Famers Terry Bradshaw and Howie Long, and Chris Collinsworth. All four broadcasters wore the pins and joined in the message of support. The FOX network also provided a link from their <foxsports.com> website to the NPD website <nnpdf.org> and encouraged viewers to visit there for more information.

James Brown's commitment to the NPD cause is also important to a local family. Jim and Missy Ward and their child Amanda are also battling Niemann-Pick Disease and the FOX network support has given them good reason to celebrate. The Ward family held a tailgate-style, football party for supporters at their home Sunday afternoon, to celebrate the support of the FOX team and inspire further support for the NPD cause.

NPD families all around the country were encouraged to hold their own celebrations and invite their key supporters and local news media. Lapel pins were distributed to the families who participated. This collective event became known as “NPD Sunday”. The gathering at the Ward home was one of 21 (twenty-one) NPD Sunday events held in 13 (thirteen) states.

To add to the special spirit of the event and demonstrate the unity of NPD families, at 12:30pm EST, just following the on-air acknowledgment from James Brown, those attending the NPD Sunday events joined in a prayer of thanks for the support offered by Brown and the Fox network, and a prayer for an eventual cure or treatment for NPD. The time was adjusted for each time zone so that all attendees were literally praying together at the same time – all over the nation. The Ward family and their guests joined in that prayer.

James Brown became involved with the NPD Foundation after meeting Hunter Ozmer, a young woman with NPD from Roanoke, Virginia. James was introduced to Hunter at a restaurant in Bethesda, Maryland, where James makes his home. The Ozmer family was in town visiting the National Institutes of Health as part of a clinical research study. After hearing her story, James volunteered his help as a supporter of the NPD cause.

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Putting Together an Effective Press List

1. Include all major newspapers in your area and major weeklies, as well as ethnic, African-American, Latino and women's publications.
2. Get a list of state/local specialty publications/magazines that might be interested in your project. Include all relevant publications. Check newsstands for local publications
3. Include television and radio stations with news and current event talk shows. For broadcast news shows, send a release to the specific reporter covering your issue, or to the senior producer or news director for smaller stations. For talk shows, send to the producer. Target drive time early morning shows or late afternoon/rush-hour shows.
4. Include college, university and community newspapers, church bulletins, and women's and minority organizations' newsletters.
5. Include organizations (service organizations, health organizations, hospitals, clinics, etc.) that might be interested in hearing about or participating in your campaign or project.
6. Send notice of all events to newspaper and radio "community calendars." Nonprofits get free listings.
7. Identify a contact person at each newspaper, radio station, cable public access station, etc. Check web sites for staff directories, or make phone calls or send emails to inquire. Contact names are sometimes on page 2 or on the editorial page. Your public library may be able to help with resources. Keep an updated list of reporters and columnists covering nonprofit, health, and feature (human interest) stories. Find out what their preferred format is for receiving press releases (email, print, fax).
8. Verify that you have proper contact names and titles (e.g., assignment editor, health care reporter, community/lifestyle reporter and editorial writer). Obtain correct spelling of names, telephone numbers, fax numbers, email addresses and mailing addresses. Look for bylines and add them to your press list. Update your press list on a regular basis.
9. Include popular local web sites in your list, such as web sites for the Chamber of Commerce, tourism sites, current events, etc.

Sample Press List

Publication	Mailing Address / Phone	Reporter / Specialty	Telephone	Email Address
Times-Picayune	1010 Howard Ave New Orleans, LA 70114	Keith O'Brian – family life, features	111-555-3487	kobrian@tp.com
La. Technology Journal www.latech.com	1515 Poydras St New Orleans, LA 70112	Joe Grace –web master	222-555-8925	jgrace@LATJ.com
City Business	825 Baronne St New Orleans, LA 70112	Bill Smith – health/medical	111-555-7634	bsmith@citybiz.com
WWL-TV	315 Royal St New Orleans, LA 70115	Andrea Mitchell - health	111-555-4867	amitchell@wwltv.com

Writing and Submitting a Letter to the Editor

The letters-to-the-editor section is one of the most widely read sections of any newspaper. While letters to the editor are usually written in response to an article or editorial published earlier in the newspaper, they can also be used to raise subjects not normally covered by the newspaper.

1. Newspapers often cover nonprofit issues. If you see an article or opinion piece that presents a position opposite your group's, write a letter to the editor respectfully disagreeing with the article and stating your organization's position. If you don't disagree but have a different perspective, that too can be the basis of a letter to the editor.
2. If there is no article to use as a starting point, write an opinion letter. Keep the letter simple by focusing on one or two points. The letter should express a definite opinion on the subject.
3. Call the newspaper and ask to speak to the letters-to-the-editor department. Ask how long the letter should be. Find out the name, fax number, email address, and mailing address of the person you should send it to. Many newspapers allow email submission of letters to the editor. Others require a signed hard copy. Many newspapers will include this information on the editorial page or elsewhere in the newspaper itself.
4. In the first paragraph of your letter, refer promptly to the article or position that you are writing about. Name the reporter who wrote the article (or the author of the letter to the editor) and the date and the title of the article. Then respectfully state why you disagree and proceed to give your position on that particular issue. Short and pitchy is better than long and rambling.
5. Send with a cover letter addressed to the appropriate editor. Attach your business card. Be sure to sign the letter with your name, title, the name of your organization and your contact information.

Sample Letter to the Editor

April 13, 2009

Address

Dear Editor:

Mayor James Johnson has proclaimed next week, April 19-25, as a citywide Niemann-Pick Disease Awareness Week. We thank Mayor Johnson for helping raise awareness of this rare but deadly disease which robs parents of their children, and children of their lives.

Niemann-Pick Disease (NPD) is a rare, genetic disorder – one of several lysosomal storage diseases – which results in neurological deterioration and ultimately, death.

We know about Niemann-Pick Disease because our six-year-old daughter, Hannah, has Niemann-Pick Type C. Although we can't fully accept this, the doctors tell us that unless treatments and therapies are found, Hannah will eventually lose her ability to walk, her ability to talk, her ability to swallow, and she will eventually struggle for every breath she takes. Her future care may include the insertion of a feeding tube and the administration of oxygen, until finally, NPD steals our baby from us.

Our family, with the support of many wonderful friends and the community, are working to raise funds for essential research to find treatments and a cure for NPD.

Please join us this Saturday, April 25, at our Third Annual Hannah's Hope Chest Fundraiser. The event will be held at the Central Park Community Building and Grounds, from 4 p.m. until 10 p.m. Attractions will include a pork barbecue dinner catered by Smokey's Ranch Saloon, raffles, door prizes, bingo, and live music. Also, for the younger set, there will be pony rides, a magician, face painting, games, etc.

Channel 4 tv anchors Melissa Montieth and Jack Williams will share duties as Masters of Ceremonies, with a special surprise guest scheduled to make an appearance. (Hint: Bring your favorite football to be autographed!)

Hope to see you this Saturday at the Hannah's Hope Chest Fundraiser at Central Park, beginning at 4:00 p.m.

Sincerely,

Name

Title

Organization

Contact Information

Using Cable Television

1. Seventy-five percent of all Americans have access to cable TV. Surveys show that about 50% of all cable subscribers watch their community public access channels on a regular basis. More and more Americans are tuning in to cable.
2. Because of their activities and interests, community television viewers are an ideal target for nonprofit messages and nonprofit programming.
3. Cable access will allow you to control your program content, air it during prime time and repeat it frequently.
4. There are different kinds of cable stations. About two-thirds of communities with cable TV have at least one "public access" channel (non-commercial use by the public), and some larger cities also have "local origination" channels (similar to local commercial stations with paid advertisements), which are sometimes available for local programming.
5. Public access stations have less funding, fewer staff and fewer restrictions. Local origination channels have more money, more staff and more controls over content of programs.
6. Many public access and local origination stations offer production training at low cost. Once you are trained, these stations often allow you to use their production facilities. You also can use the cable access channel to publicize specific events.
7. Find out what channels you have in your area. Request a copy of their guidelines or regulations. In many cities, the cable system has a special office that helps community groups get access, find producers and publicize their programs.
8. Your nonprofit could air educational videos, public service announcements and other programs to publicize projects and campaigns. Ask your cable stations if you can start your own monthly "Nonprofit Talk" public affairs show.
9. Find out if you have an origination channel in your area and monitor its programming. If it is airing programs with viewpoints that you oppose, you should have a good chance of getting your own program aired.

Producing and Airing a PSA

1. Radio and television stations commit a portion of their air time to free public service spots on behalf of nonprofit organizations. Free Speech Messages (FSMs) are statements of opinion, while Public Service Announcements (PSAs) are announcements or reminders of events or services.
2. Call your radio or TV station and ask to speak to the Public Service Director. Find out what kind of spots they run, what rules apply, what their time limits and formats are and to whom and by when should they be submitted.
3. Most stations will not accept any political messages in PSAs. However, if you can succeed in convincing the station that it has given a political issue unbalanced treatment, it may let you air an FSM.
4. Nonpartisan PSAs focusing on getting out the vote, citizen education or citizen activism have a good chance of being aired. Submit your TV or radio PSA script to the station for approval before you go into production. This can save you time and money.
5. Your nonprofit's name should be heard and seen twice during a PSA. Some stations are very particular about identifying 501(c)(3) status. Check on this in advance. A phone number, web site address or address should also be given.
6. Beta SP or one-inch tape are the best choices for TV PSAs. Thirty-second (80 words) PSAs are aired often; 15-second and 20-second PSAs are also in demand. Every station has different preferences. Check first. Leave three to five seconds at the end of your PSA for your logo (tagging).
7. TV PSAs can easily be made into radio PSAs. Most radio stations accept 7-1/2 inch reel or CD. Develop 15-second, 30-second and 60-second hard copy PSAs for local radio stations.
8. Submit your PSA at least one to two months before a specific event. Write a "kill date" (date on which PSA must be taken off the air) on your PSA. This is very important, as accidentally running a PSA for an event which has already passed makes a station look disorganized, and then they may not be as cooperative the next time around.
9. Be sure to make follow-up calls.
10. If the station doesn't seem receptive to your PSA, suggest that you work together on developing one to encourage citizen participation in government or in important community events. Involve the station in your outreach effort—it might be more receptive.
11. If a station airs your PSA, ask if it is possible to get feedback on when or how many times it aired.

Checklist for Press Kits

(Note: Not every press release requires a full press kit. You may include fewer items, perhaps even just the press release, especially if your media contact is already familiar with NPD and the NNPDF.)

- Cover memo or press release with contact name and phone number
- Fact sheet(s) on the issue
- History of the issue
- Quotes or comments by experts
- Selected press clippings
- State-by-state or city-by-city analysis
- Speeches or statements on the issue
- Charts, visuals or photographs
- Background biography on spokesperson
- Annual report
- Typeset copies of speeches or public testimony
- Standard one-page description of your organization

Developing Relationships with the Media

Get to know your media representatives. Call the editors and tell them who you are, and that you will be sending them information about NPD and that you will be in touch with an occasional story idea or news release. Follow up after you have sent something to make sure it got to the right place and to answer any questions.

The ideal situation is that you and your family will become the source that reporters call for information and comments on all developing stories related to the Foundation or NPD. Let them know that you are knowledgeable and resourceful, and that you can help them find accurate answers to their questions.

Requesting a Proclamation

1. A proclamation declaring Niemann-Pick Awareness Month can be used as the basis for press releases and other awareness events.
2. Call the Governor's Office to identify who handles proclamations and where to send your request. The Governor's Office is often listed in the phone book or can be found online. You would contact your state representative or state senator to obtain a Legislative Proclamation. You may also wish to request proclamations from the Mayor in towns where events are being held.
3. Write a simple cover letter requesting the proclamation. The cover letter should state the name of the requesting organization (The National Niemann-Pick Disease Foundation), the date for the proclamation (October), and contact information for yourself.
4. Include a summary page that briefly describes Niemann-Pick Disease, the Foundation's awareness efforts, and your personal story. Add one to three small pictures to the summary to make it stand out (the Governor's Office may receive dozens of these requests).
5. Send in your request at least two months before the proclamation is desired, if possible.

Sample Summary and Proclamation

Sample Summary

Niemann-Pick Disease is a devastating metabolic disease which primarily affects children. Niemann-Pick Disease type C results in a deterioration of the brain, central nervous system, liver, lungs, and other organs. The disease is usually fatal by the late teens.

[Describe the form of Niemann-Pick that affects your family or summarize all three forms of the disease]

Type B Niemann-Pick is caused by the deficiency of a specific enzyme activity, acid sphingomyelinase (ASM). This enzyme is ordinarily found in special compartments within cells called lysosomes and is required to metabolize a special lipid, called sphingomyelin. If ASM is absent or not functioning properly, this lipid cannot be metabolized properly and is accumulated within the cell, eventually causing cell death and the malfunction of major organ systems. Type B has variable symptoms. Abdominal enlargement, particularly an enlarged liver or spleen, may be detected in early childhood. Progressive pulmonary (lung) problems are common, with symptoms often appearing in the teen years. Cardiac problems may also develop as a secondary effect of the enlarged organs and pulmonary problems. While Type B patients can live into adulthood, it is a serious progressive and ultimately debilitating disease that leads to early death.

At present, there is no treatment or cure for any form of Niemann-Pick Disease. The disease is difficult to diagnose and can lead to years of uncertainty for parents and family members. The National Niemann-Pick Disease Foundation has been working since 1992 to heighten public awareness of this disease, improve diagnosis, and fund research into a cure. After years of work, there is some hope in sight but more awareness and research is needed to defeat this disease.



[Your personal story here]

We ask for your immediate attention to this matter. Children's lives are at stake, and time is of the essence.



Sample Proclamation

Whereas, Niemann-Pick Disease is a devastating metabolic disease that affects children and adults, and

Whereas, Niemann-Pick Disease is a rare genetic illness that is difficult to diagnose, and

Whereas, Niemann-Pick Disease has no known cure or treatment, and

Whereas, families in this state and throughout the United States are known to be affected by this disease, and

Whereas, promoting awareness of the disease will aid in finding a cure and improving diagnosis,

Therefore, it is proclaimed that [month year] is Niemann-Pick Disease Awareness Month.

Contacting Your United States Senator or Representative

Email and letters are the preferred methods of contacting Congress on most issues. Phone calls may also be appropriate, but you cannot be sure that a written record of your call will be made.

1. Stick to one subject and be brief.
2. Include the bill number and title (i.e. S. 1379, The Rare Diseases Act of 2001).
3. Describe how the legislation impacts you personally. Include key information, using examples to support your position. "This legislation will expand funding for rare diseases that affect 1.2 million Americans".
4. Ask for specific action. "Please vote for S. 1379"
5. When writing your own Congressmen, state that you are a constituent. When writing other Congressmen, explain why you are writing. "As Chairman of the Finance Committee, please vote in favor of S. 1379".
6. To obtain addresses for Congressmen, call the League of Women Voters or use the Internet websites:
<http://www.house.gov>
<http://www.senate.gov>

Fact Sheet

Niemann-Pick Disease. There are three types of Niemann-Pick Disease. (You should use the statistics most appropriate to your message.)

1. Estimates of the number of Niemann-Pick cases vary widely.
 - Type A –There is no estimate of the number of cases
 - Type B – about 1,000 cases worldwide are known
 - Type C - 500 cases worldwide are known; approximately 200 cases in the United States
2. Life expectancy is
 - Type A - 1 to 3 years
 - Type B – extremely variable from childhood to late adulthood
 - Type C –typically childhood to late teens, although some live into adulthood.

Lysosomal Storage Diseases. Niemann-Pick is a Lysosomal storage disease.

1. There are at least 46 Lysosomal diseases. While each specific disease is rare, as a group they affect 1 in 7,700 births.
 - Other Lysosomal diseases include Tay-Sachs, Gaucher, Fabry, and Mucopolysaccharides
2. The average life expectancy for a person with a Lysosomal disease is 15 years.
3. Most Lysosomal diseases are rare.

Additional information about Niemann-Pick Disease and the Foundation can be found at www.nnpdf.org. You may copy or paraphrase text from the website pages to help develop your media packets.