



Our Mission: To improve the quality of life for those affected by lupus through advocacy, education, awareness, empowerment, and research.

Lupus Communiqué

Lupus Foundation of Mid and Northern New York, Inc.

Volume 5, No. 3, Spring/Summer 2006

Volunteer of the Year Philip Teague

The 2006 Lupus Foundation of Mid and Northern New York's Volunteer of the Year Award was presented to Philip Teague for his many years of support and dedication to both our organization and the lupus cause. Phil and his wife Kathy, a lupus patient and former Board Member, and their sons Andrew and Matthew, prepare and mail the quarterly newsletter. Phil is owner of Teague Accounting Experts in Chittenango and the entire family is very active with Boy Scout Troop 23 in Oneida. Congratulations Phil!



Calling All Golfers

The 6th Annual Lupus Charity Golf Classic is scheduled for Friday, August 18th, 2006 at Shenendoah Golf Club. Corporate Sponsor forms and Golfer packets are now available. The event is limited to 32 foursomes or 128 golfers and there are only a few spots still open for registration. Contact the office for more information or visit the website at www.nolupus.org to download forms.



The Lupus Communiqué

*Is published four times a year by
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Northern New York, Inc.*

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DISCLAIMER

It is the policy of Lupus Foundation of Mid and Northern New York, Inc. to publish articles on Lupus and related diseases that have been written by physicians, nurses, and other healthcare providers and medical professionals. The opinions and statements expressed by the authors or contributors to this publication do not necessarily reflect the opinions or positions of The Lupus Communiqué, or Lupus Foundation of Mid and Northern New York, Inc.

The material published herein is provided for informational purposes only and does not imply endorsement of any specific treatment, product, clinical trial, company or organization. We oppose self-diagnosis and self-treatment and urge readers to discuss any concerns they may have regarding diagnosis and treatment with their physicians. All rights reserved. No material in this issue may be copied or published without the express written consent of Lupus Foundation of Mid and Northern New York, Inc. Thank you.

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Please consider Memorial and Tribute contributions to our organization. It is a wonderful way to honor or remember someone special in your life while also supporting the lupus cause. If you belong to a Service or Fraternal organization, or participate in a workplace-giving program such as: CFC, SEFA, UNITED WAY, IBM or other campaign, please remember to designate our organization.

Lupus Foundation of Mid and Northern New York, Inc. is a tax-exempt charitable organization eligible to receive tax-deductible contributions under IRS Code Section 501(c)(3). Our federal tax identification number is 16-1083229 and a copy of our latest annual report may be obtained upon request from us or The NYS Attorney General's Charities Bureau at 120 Broadway, NY, NY 10271.

EDITOR'S NOTE

Suggestions or comments on the newsletter are always welcome. Please contact us with any address changes or other corrections to ensure accuracy in the database. If an address is incorrect the Post Office will not deliver under their revised policies and the mail piece will be returned and we will be charged a fee. Please notify us immediately of any changes to avoid extra postal fees. As Technical Director I also invite your input and assistance in improving our organization's operations, especially in maintaining our new website. Thank you.

Dave Arntsen

President's Message

On Saturday, May 6th, 2006 the Lupus Foundation of Mid and Northern New York held "Hope is on the Horizon" its Second Annual Education Symposium and Luncheon at Turning Stone Resort and Conference Center in Verona, NY. The event was well attended and well supported by patients, family members, medical professionals, industry, academia, and other voluntary health agencies. Thank you to all who helped to make our event a success, your support is appreciated. Because Clinical Research Trials are so important in developing new and better treatments we thought it would be more beneficial to include my patient perspective remarks from the Symposium regarding Participation in Trials instead of my usual message.

When our Education Committee met to plan this year's Symposium we decided that our theme should focus on the currently available lupus treatments, or rather lack thereof. Here are the facts: there hasn't been a drug approved by the FDA for treating lupus in nearly 40 years, and there has never been a drug specifically developed for lupus EVER!!! I don't know about you but as a lupus patient that has suffered devastating side effects from the therapies I have endured, this makes me very angry. Pick up any newspaper or listen to the television and you will hear about new treatments for many other diseases. There are presently only 3 drugs that are FDA approved for treating lupus: corticosteroids, anti-malarials, and aspirin. Therefore, most of the drugs being used today are considered off-label and borrowed from other diseases like Cancer. Well, I am sick of hand me down drugs aren't you?

So, we decided to make our theme "Hope is on the Horizon" to inform all of you about the treatments in the pipeline for lupus and related diseases that have not been approved yet. We also felt that it would be beneficial to all of you to learn about the process in which treatments are brought to market and to learn about clinical trials. We will not have new lupus treatments until the FDA is satisfied with the data from the lupus clinical trials and that has not yet happened. Lupus is a disease that should qualify for accelerated drug approval under "unmet treatment need" and is listed as an example in the US Congressional Record as such and yet, some drug companies who filed under these criteria for lupus drug approval are still waiting.

Sandi Frear and I recently attended a National Autoimmune Disease Conference and saw the following presentation given by Dr. Andrew Wiseman from La Jolla Pharmaceutical Company. We were given permission to share it with you today as we think it clearly shows where Lupus and autoimmune diseases are in the overall picture of drug development and what it takes to get from "Bench to Bedside," or from the research laboratory to the patient.

Pretty amazing, isn't it! Autoimmune diseases are the 4th leading cause of disability, and one of the top 10 causes of death among women, and presently affect 24 million Americans; about twice as much as Cancer and yet, the majority of research funding in this nation is NOT directed towards autoimmune conditions. Here is the bottom line: we will not get lupus or autoimmune drugs approved until we get the data from the trials and we will not get that data until we get patients into the clinical trials.

Please listen--We are by no means telling you to participate in a clinical trial. We are merely informing you of the present dilemma in getting new treatments approved for autoimmune diseases like lupus. We are asking you to listen to today's program, and to ask questions, and to process that information as it applies to you personally. And, if you think you may be a candidate to participate in a clinical trial, then consider taking that information back to your loved ones and personal physician and have a very serious conversation. Making the choice to participate in a clinical trial is not only huge, but a very, very personal decision that should be based on discussions with family members and treating physicians familiar with the patient's history. We cannot emphasize this strongly enough.

We are very excited to be offering this program to you and it is our hope that all of you leave here today with a better understanding of the topics and that if you have lupus or a related disease or love someone with lupus that you use this information to take control and enhance your quality of life. Education and empowerment are the keys to surviving chronic disease and we are here for you as you continue on that trek. Thank you very much.

Stay cool and don't forget the sunscreen, be well—Kathleen

Memorials, Tributes, and Donations

Memorials

In Loving Memory of...

*Lou Smith-
James & Patricia Mitchell
David & Kathleen Arntsen*

*Dorothy J. Kitchen-
Jim & Elaine Coleman,
Sam & Esther Kitchen,
Charles & Sharon McFadden,
Ruth Kelley, Denise Kitchen,
Elizabeth McFadden, Linda Crowe
David & Diane Mead,
Edward & Catherine Crosby,
Uncle Lymen Yager, Thelma Kitchen,
Harry & Barbara Cresswell
Milburn & Theresa McFadden
Frank & Jane Kitchen, Linda Albertine,
Kenneth & Shirley Carey*

*Joseph F. Puleo-
Dominick & Marie Oriolo*

*Ann Sweet-
Dominick & Marie Oriolo*

*Duane Szwarcop and
Claudine Szwarcop-
The Obleman Family
Gloria, Cheryl, Melody, Tim & Penny*

Donations

Campaign Donors

IBM, SEFA, CFC, United Way, Merrill Lynch

Education Symposium Grants

La Jolla Pharmaceutical Co.

Pfizer, Inc.

Aspreva Pharmaceuticals, Inc.

Daiichi Pharmaceuticals, Inc.

Genentech, Inc.

Encysive Pharmaceuticals, Inc.

Eye Eco, Inc.

Tributes

In Honor of...

*Patricia A. Mitchell for Mother's Day-
David & Kathleen Arntsen*

*James E. Mitchell, Jr. for Father's Day-
David & Kathleen Arntsen*

*Danielle Turner-
Hannaford Lupus Initiative*

*Sandi Frear-
Carnival Foundation*

*Cathy Walseman-
Beta Sigma Phi Sorority*

*Geri Lemke-
Diane Wright, Donald & Joan Dorn*

Partner Memberships

*Danielle Turner-
Carl & Pat Scavello*

*Julie Mikitin-
Harold & Marlene Cross*

Donations

Fred & Jeanne Castronovo

*Victorian Tea Party
Peter Rogers, Carol Walker
Patrick Lucas, Bill & Sandi Frear
David & Kathleen Arntsen
James & Patricia Mitchell
Dick & Helen Lenart*

*Mr. & Mrs. Chester Trzepacz
Jacqueline Sperry, Don & Joan Gloo
The Flint Family in honor of Cathy Walseman
Bob & Cathy Walseman, Isabel Woolshlager
Larry & Kathy Scharf, Doris Walseman
Martha Boshart & Cathy Roshan Khan
Frank, Mary & Carl Della Posta
Leonardo & Laura Mangiaracina
Eleanor Canell, Sarah Eastup & Family*

Education



On Tuesday, April 4, 2006 Dr. Alan Smiley, Rheumatologist from Slocum-Dickson Medical Group spoke at the General Education Meeting at Faxton-St. Luke's Healthcare Anderson Auditorium. Dr. Smiley spoke on "Lupus Treatments" and gave an overview of present lupus drugs and treatments in the pipeline. Following his presentation he conducted an informal question and answer period with the audience. We thank Dr. Smiley for his informative presentation and his efforts on behalf of local lupus patients.

Support Group Information

Utica Area Facilitator-Helen Lenart

lupusmidny@aol.com

The Utica Area Support Group usually meets monthly on the third Thursday at Faxton-St. Luke's Healthcare Regional Cancer Center in Utica in Weaver Lounge, 2nd floor. Due to busy summer schedules, family vacations, and our August Golf Classic and NY State Fair Lupus Booth; we will not meet during the months of July and August. The next meeting will be at 7:00pm on September 14, 2006.

Lewis County & Boonville Area, Jefferson County & St. Lawrence County

We are in the process of scheduling our Annual Autumn Luncheon. Details will be forthcoming.



LUPUS RESEARCH INSTITUTE

*National
Coalition*

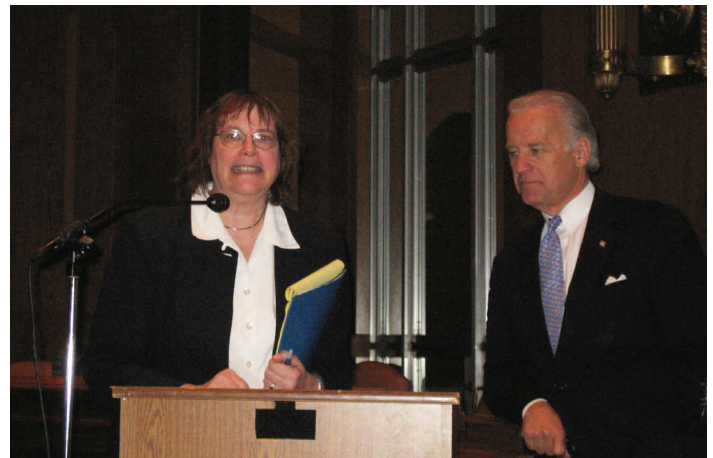
The Patient Voice for Lupus Research

Lupus Foundation of Mid and Northern New York is proud to support the Lupus Research Institute and honored to be a member of the Lupus Research Institute National Coalition.



Advocacy

Patient Advocates Sandi Frear and Kathleen Arntsen traveled to Washington in late March to attend the National Coalition of Autoimmune Patient Groups Advocacy Event. They visited seven Key Congressional Offices to discuss current Autoimmune Disease Legislative Issues. Pictured above are Sandi and Kathleen with Congressman Sherwood Boehlert who is retiring in January. Above right they met with US House Appropriations Staff Director Frank Cushing on the Capitol Veranda. Pictured to the right is Kathy Hammitt, NCAPG Advocacy Committee Member presenting Senator Joseph Biden with an appreciation plaque for his efforts on behalf of patient healthcare issues. Kathleen Arntsen was asked to present during the Advocacy Training Session to help motivate advocates on their legislative visits.



Our advocacy efforts in NYS finally paid off in late June when the NYS Legislature restored \$500 million in Medicaid cuts including the 3 initiatives that we fought so hard to get for the past 2 years--

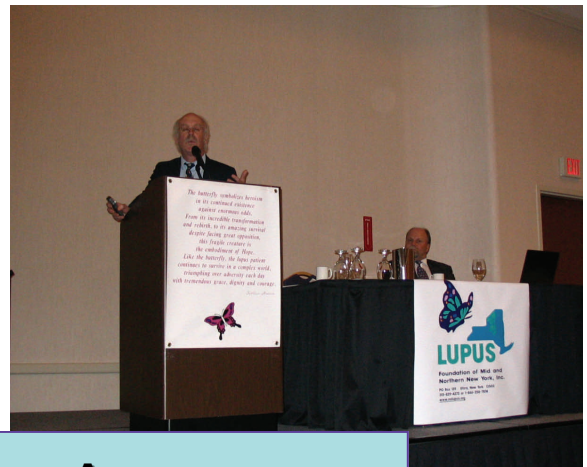
- ◆ The 'physician prevails' (sometimes called 'physician override') consumer protection in the state's new Medicaid Preferred Drug Program that will assure the doctors can ensure that their Medicaid Patients get access to the drugs they need, even when they are not on the state's Preferred Drug list.
- ◆ The Medicaid wraparound protection that assures that those dually eligible for Medicaid and Medicare can continue to receive drugs not covered by the new Medicare Part D program will now be extended beyond this July to January 1, 2007.
- ◆ Cost can not be considered a factor in excluding Medicaid drugs under the state's new Clinical Drug Program.

Thank you to all who were part of this statewide effort.

2nd Annual Education Symposium and Luncheon



Empowerment



Awareness



“Hope is on the Horizon”



Dr. R. John Looney (far right) from University of Rochester presented on “Clinical Trial Participation “ and is pictured below with Trial Coordinator Emily Walsh (center) and Trial Participant Christine Dobson (left).



Board Member David Arntsen welcomes Dr. Beth Biggee, a Rheumatologist from Bassett Healthcare as the first presenter at the Symposium who spoke on “Connective Tissue Disease Treatment Updates.”

Education



Symposium organizers Sandi Frear and Kathleen Arntsen with Dr. Ann Parke (center) Keynote Speaker from University of Connecticut who spoke on “Phospholipid Syndrome.”

Research



President Arntsen thanking Dr. Raquel Rosen, Nephrologist from Bassett Healthcare for her presentation on “Updates in Lupus Nephritis.”

But They LOOK So Good!

-The Paradox of Looking Good, but Feeling Bad-

Surprisingly, more than 125 million Americans have at least one chronic condition. and nearly half have more than one (Partnership for Solutions). An illness or injury is considered chronic, when it lasts a year or longer, limits activity and may require ongoing care.

Not everyone with a chronic condition has the same symptoms or degree of symptoms. Some have mild complications and with a little adjustment in their diets or schedules, they can lead a pretty “normal” life. Some have to make bigger changes, sacrificing various activities or their work situations in order to contend with their conditions. Others become so ill they are unable to work at all and struggle just to meet life’s daily needs.

Just about every one of us has experienced being so sick we had to stay home from work or school, because we were too sick to go. We hate being sick, because the time ticks by, the work piles up and we cannot do anything about it. We gripe and moan that we “don’t have time to be sick!” even for just a day. It is just plain miserable to be sick, in pain and debilitated - *nobody* enjoys it.

Often when we come across someone who says they have been sick and in pain for a long time, we might think they are either *exaggerating* or they are not *doing* something about it. After all, when we got sick, we got some rest, took some medication and were soon back on our feet. Moreover, when we were sick, we were pale and droopy, but they often look “perfectly normal.”

The truth is, most chronic conditions cannot be seen with the naked eye, but nevertheless are persistently keeping the person from enjoying life the way they once knew. For instance, a person can battle *extreme* fatigue and/or cognitive impairments on the inside, even though they may appear *healthy* and *well* on the outside. Just the same, a person can have *horrible* pain and/or dizziness, despite the fact that to the onlooker they may look *strong* and *able*.

The biggest grievance those with chronic conditions have is that their loved ones often do not *believe* what they are going through is *real*, because to others they “*look good*.” Sadly, this makes the person feel as if they are being called a *liar* or a *wimp*. This can cause great strains on relationships between friends, family members and spouses.

Ironically, those with chronic conditions would like nothing more than to gain complete control of their lives and not have to adjust to any limitations at all! Nonetheless, their bodies do not always cooperate with their *desires*, no matter how much they *want* it to.

Regrettably, a *travesty* occurs when the person not only has to contend with no longer being able to do what they *love* to do, but also has to *battle* for their loved one's *belief*, *respect* and *understanding*. While the person with the illness/pain is *mourning* their loss of *ability* and *freedom*, others often *accuse* them of just being *lazy* or *malingering*.

We must resist the temptation to make a *visual diagnosis* by coming to the conclusion that our loved one must be *embellishing* their situation or trying to *pull the wool over our eyes*, because to us they "*look fine*." After all, when we rebut what they are telling us with, "But you *LOOK* good," our friend really hears, "But, I don't *believe* you, because I can't see it."

Frankly, it is *impossible* for us to be compassionate, until we have *acknowledged* there is a situation for which to *be* compassionate! In other words, how can we say, "I am sorry you are sick," when we are always saying, "I do not *believe* you are sick, because you don't *look* sick?"

People living with chronic conditions do not want to give up! They make efforts to laugh, smile, look their best and enjoy life, even though they know they will pay dearly for it. Because of this, we should not confuse their endeavors to *live life* and *be positive*, with assuming they are *feeling well* or *doing better*. Instead, let us commend them for their incredible *courage*, *perseverance* and *persistence* that make their illnesses and injuries *seem* invisible to us.

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"But They LOOK So Good!" is an excerpt from the 52 page booklet, *But You LOOK Good: A Guide to Understanding and Encouraging People Living with Chronic Illness and Pain!* Copyright © 2005 *The Invisible Disabilities Advocate*: www.MyIDA.org. Visit IDA's website for links, articles, support and to order IDA's booklet. No internet? Send a SASE to: IDA, P.O. Box 4067, Parker, CO 80134 to request a mail order form.

Visible? Invisible? What's the Difference?

All too often, a person with a visible impairment is *presumed* to be *unable* to complete a task or participate in an activity. This is quite aggravating and hurtful to that person, when they are perfectly *able* to contribute and partake in the deed.

Accordingly, it is just as insidious when a person explains their debilitating illness, yet people refuse to *believe* them, because they *look* fine on the outside. The disease or injury may have eaten away or damaged the brain, bones, spine, muscles and/or nerves on the inside. Nevertheless, because others cannot see the damage for themselves, they *reject* the validity of the person's limitations.

Therefore, do not assume that someone using a wheelchair *cannot* do something or that someone not using a wheelchair *can*. Much of the time, it is not the wheelchair that keeps people from working and enjoying activities. Instead, it is often the "invisible" symptoms like pain, extreme fatigue and neurological damage that limit them.

Below, is a chart of some **general* similarities and dis-similarities between living with a disability that is visible on the outside and one that is not visible from the outside. The purpose is to create a better understanding of the frustrations, concerns and desires of people living with a disability that is visible and/or invisible.

	Visible Disabilities	Invisible Disabilities
General Description	Person's obstacle is <u>visible</u> : use of wheel-chair, prosthesis, walker, crutches, oxygen, etc. or they may have loss of limb(s) or sight. Limitations may be minor to totally disabling.	Person's obstacles are <u>invisible</u> from outside: debilitating fatigue, pain, cognitive impairments, neurological damage, heart problems, etc. Limitations may be minor to totally disabling.
	Note: An individual may have both visible and invisible disabilities.	
Differing Assumptions	Although the person may <u>LOOK</u> <u>unable</u> to complete a task, they are often <u>able</u> to participate, with or without limitations. People <u>PRESUME</u> they <u>cannot</u> do something, even when they say they <u>can</u> .	Although the person may <u>LOOK</u> <u>able</u> to complete a task, they may have limitations or may even be totally <u>unable</u> to participate at all. People <u>PRESUME</u> they <u>can</u> do anything, even when they say they <u>cannot</u> .
Similar Assumptions	People <u>PRESUME</u> they know what their abilities are by looking at them. People <u>DO NOT BELIEVE THEM</u> when they say they <u>can</u> do something.	People <u>PRESUME</u> they know what their abilities are by looking at them. People <u>DO NOT BELIEVE THEM</u> when they say they <u>cannot</u> do something.
Differing Goals	To convince others that even though they may LOOK disabled, they are dis- <u>ABLED</u> , because they are <u>ABLE</u> to participate in work or an activity.	To convince others that even though they may NOT look disabled, they may be <u>UN-able</u> to participate in work or an activity.
Common Goals	<u>STRIVE</u> for Respect, Credibility, Admiration and Belief. Do not want to be <u>PREJUDGED</u> by <u>Outer Appearance</u> . Desire <u>ACCESSIBILITY</u> : Right to enjoy a store, restaurant, recreational area, etc., just like everyone else.	<u>STRIVE</u> for Respect, Credibility, Admiration and Belief. Do not want to be <u>PREJUDGED</u> by <u>Outer Appearance</u> . Desire <u>ACCESSIBILITY</u> : Right to enjoy a store, restaurant, recreational area, etc., just like everyone else.

*This chart is a "generalization" and not meant to be a description of all cases and situations!

Neither types of disabilities are worse than the other. Each person's degree of limitations are varied, despite their outer appearance. Furthermore, some people fall under both categories, because they may have a visible impairment as well as an invisible one. For some it is the visible disabilities that hinder them, for others it is the invisible ones and for some it is both.

Whether we have a *visible* or an *invisible* disability, we are all striving for respect, understanding, accessibility and most of all... *belief*. We do not want others to pre-judge us and be unwilling to hear the truth. Instead, we want people to listen and treat us like *valuable*, contributing people with *integrity*, *courage* and *strength* despite our disability.

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Sixth Annual LUPUS Charity Golf Classic Raffle

Drawing to be held August 18, 2006 at Shenendoah Golf Club

1st Prize – 1 Week Lake Tahoe Condo

2nd Prize – Set of PING Irons or \$500.00 Cash

3rd Prize – Shenendoah Windshirt

All proceeds benefit:

Lupus Foundation of Mid and Northern New York, Inc.

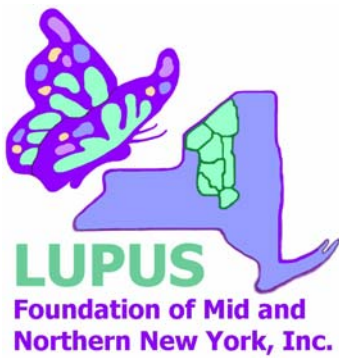
** Need not be present to win*

Donation \$5.00 each or 3 for \$10.00

Please contact us at 315-829-4272 or e-mail lupusmidny@aol.com if you want to sell or purchase tickets. Thank you.

LUPUS FOUNDATION OF MID AND NORTHERN NEW YORK MEMBERSHIP APPLICATION & ORDER FORM

Name:	Date:										
Address:	Phone #:										
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E-mail address:	Fax #:										
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**SIXTH ANNUAL
LUPUS CHARITY GOLF CLASSIC**
AUGUST 18, 2006
Shenendoah Golf Club
Turning Stone Casino Resort



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- Other Donation** – Please list _____

*All foursomes include 18 holes of golf w/cart, dinner, gift, and prizes for four

For additional information call: 315-829-4272 or 1-866-2-LUPUS-4 E-mail lupusmidny@aol.com

Please make checks payable to: ***The Lupus Foundation***
P.O. Box 139
Utica, NY 13503

Thank You!

2006 Appreciation Awards

Sandi Frear Education

Helen Lenart Awareness



Vice President Helen Lenart (left) receives the Public Awareness Award from Board Chairman Michael Jones.



Secretary Sandi Frear (far right) receives the Patient Education Award from Treasurer Sarah Eastup (left) and President Kathleen Arntsen (center).

Danielle Turner Fundraising

Pfizer, Inc. Corporate



Stephanie Darwak (left) and Anna Maria Maritato (right) from Pfizer, Inc. receive the Corporate Award from President Arntsen (center) for their continuing support of our programs.



Volunteer Danielle Turner (right) receives the Fundraising Award from President/CEO Kathleen Arntsen.

Congratulations and Thank You to our Award Recipients !