

N F C A <sup>®</sup>

*Celebrating 15 years!*



National Family Caregivers Association

Fiscal 2009 Annual Report

July 2008 – June 2009

# Table of Contents

1	Letter From the Chairman of the Board
2	Board of Directors
3	Honorary Board and Staff
4	Fifteenth Anniversary
5	Report on Programs
6	Education
8	Building Community
10	Advocacy
11	NFC Month
12	Growth and Change at NFCA
15	Financials for 2009

# Letter From the Chairman of the Board



As the National Family Caregivers Association (NFCA) completes its 15th year of operation, we're energized by the amount of success we have achieved — as well as by the challenges and opportunities that lie ahead.

Over the relatively brief span of time that NFCA has been in existence, the topic of family caregiving has gone from obscurity to a topic of national significance in public policy, medical practice, employment, and social services. It's no exaggeration to say that NFCA played a significant role in helping to raise this level of awareness.

Because of the dual nature of our mission, we've worked on parallel tracks toward meeting it. On the one hand, we've helped family caregivers to recognize the unique role they play in healthcare and society, to overcome the challenges of caregiving, and to appreciate caregiving's rewards. At the same time, we've worked continuously to build awareness among the general public and lawmakers about the urgent, and still largely unmet, needs of this vast and unpaid workforce.

Our success has been made possible by the nearly boundless energy, insight, commitment, and creativity of our members, volunteers, and staff. On the attached pages, we report briefly on our activities and achievements during the past fiscal year.

We hope you will find inspiration and encouragement in these accomplishments, and that you will join with us in carrying on with our mission.

A handwritten signature in black ink, appearing to read "Jim Paglia". The signature is written in a cursive, flowing style.

Jim Paglia

# NFCA Board of Directors

## OFFICERS

**Jim Paglia, Chairperson**

CEO/President (Owner)

In's & Out's, Inc.

Chesterton, IN

**Andrea Cohen, Secretary**

Co-Founder and CEO

HouseWorks

Boston, MA

**Jonathan (Jon) Shanfield, Treasurer**

Vice President

Chevy Chase Bank, FSB

Bethesda, MD

## DIRECTORS

**Eric Berger, Director**

Senior Vice President, Public Policy and Communications

DaVita, Inc.

Washington, DC

**Hal Chapel, Director**

CEO and Co-Founder

Lotsa Helping Hands

Sudbury, MA

**Suzanne Mintz, President and Co-Founder**

**Elizabeth Pearson**

President, Managing Attorney

Pearson & Bernard PSC

Covington, KY

**Eve Stern**

Co-CEO and President

SNAPforSeniors

Seattle, WA

Click here for additional information about the members of NFCA's Board:

[http://www.thefamilycaregiver.org/about\\_nfca/board\\_and\\_staff.cfm](http://www.thefamilycaregiver.org/about_nfca/board_and_staff.cfm)

# Honorary Board and Staff

## HONORARY BOARD MEMBERS

In addition to our voting board, NFCA's honorary board includes:

**John Breaux** – Retired, U.S. Senate (D-LA)

**Senator Charles Grassley** (R-IA)

**Senator Barbara Mikulski** (D-MD)

**Irene Pollin, MSW** – Founder/Chairman  
Sister to Sister: The Women's Heart Health Foundation

**Senator Olympia Snowe** (R-ME)

**Judy Woodruff** – Senior Correspondent for “The NewsHour with Jim Lehrer”

**Dana Reeve** – (Deceased) Honorary Board Member 2000 - 2006

## SPECIAL ADVISOR

**Cynthia (Cindy) Fowler**, NFCA Co-Founder  
Vice President, Graves Fowler Creative  
Sacramento, CA

## FULL-TIME STAFF

**Suzanne Mintz**, President and Co-Founder

**Christal Willingham**, Director of Finance and Program Administration

**David Schulbaum**, Director of Marketing and Development

**Elizabeth Fernandez**, Administrative Specialist

**Judy Barlas**, Member Relations Specialist

## PART-TIME STAFF

**Deborah Halpern**, Director of Communications

**Stephen McMahon**, Grant Writer and Director of Programs

**Sandy Rogers**, Newsletter Managing Editor

**Brooks Kenny**, Strategic Advisor, Corporate Relations



# Fifteenth Anniversary

NFCA held a reception during National Family Caregivers Month to celebrate this important turning point in the organization's history and produced a graphic timeline that captured the significant events from each year. Among them were:

- The launch in 1995 of an annual celebration to support family caregivers, now known across the country as National Family Caregivers Month
- First testimony before Congress in 1997
- Establishment of the Caregiver Community Action Network volunteer program in 1999
- The naming in 2001 of NFCA's educational program, *Communicating Effectively with Healthcare Professionals*, as a Program of National Significance by the U.S. Administration on Aging
- The first-ever National Town Hall Meeting on Family Caregiving on Capitol Hill in 2004
- The awarding in 2006 of a Purpose Prize to NFCA's president and co-founder, who was recognized as one of the top 60 and older social entrepreneurs in the country



Jim Paglia, NFCA board chair and CEO of In's and Out's, talks with Marilyne Coblenz (center), marketing program manager of Intel's Digital Health Group, and Melissa Vayra, manager, health practice, Burson-Marsteller.



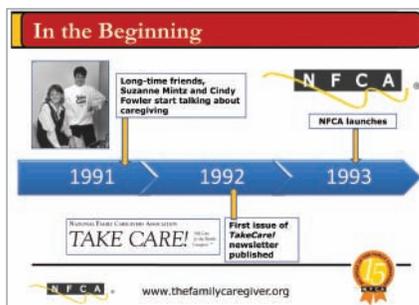
Phyllis Hegstrom, secretary of industry affairs, and Paul Hogan, CEO, both of Home Instead Senior Care, flank NFCA President and Co-founder Suzanne Mintz.



Courtney Lang (left), senior director, Advocacy and Professional Affairs, and Gaylon Morris (right), AVP Alliance Development, both of Wyeth Pharmaceuticals, join NFCA Co-founder Cindy Fowler.



Featured speaker Susan Dentzer (center), editor in chief of *Health Affairs*, talks with Howard Gleckman, senior research associate at The Urban Institute, and Myrl Weinberg, president of the National Health Council.



[Click here to see a detailed timeline.](#)

# Fiscal 2009 Accomplishments

## **NFCA's mission is to:**

*Empower family caregivers to act on behalf of their loved ones and remove barriers to health and well-being.*

To meet our mission, we organize our programs under three broad umbrellas. Some of our initiatives don't fit neatly under just one. A prime example of this is National Family Caregivers Month, which by its very nature defies categorization. NFCA's programming focus during fiscal 2009 was:

- **Education**
- **Building Community**
- **Advocacy**
- **NFCA Month**

NFCA changed a great deal during fiscal 2009. We added members to the board, increased our staff, grew our membership base, and expanded our reach.

On the following pages we detail our programming accomplishments and report on the changes at NFCA.

# Education

*Communicating Effectively with Healthcare Professionals* (CE), NFCA's signature education program, was delivered to a larger audience than ever before in fiscal 2009 and NFCA received funding to expand the program even further in fiscal 2010.

**A free two-part teleconference/webinar for family caregivers** was held in November as the signature event of National Family Caregivers Month 2008. This was NFCA's first foray into teaching the program to a national audience and it proved very successful. More than 1,260 people registered for both sessions and 50 percent participated. This high conversion rate, especially for a free program, is a testament to both the need for the specific information CE conveys and the hunger of family caregivers for practical "How To" information they can use to improve the health and well-being of their loved ones and themselves.

Pre- and post-test evaluations showed a statistically significant increase in participants' understanding and their self-perceived knowledge in preparing for and coping with their family members' healthcare encounters.

A portion of the family caregiver attendees also participated in a longitudinal evaluation effort to determine if information learned was put into practice within the three-month period following the program. Again, the results showed statistical significance and indicate that participation in the *Communicating Effectively* Web-based program increased caregivers' tendencies to be better organized and prepared for doctors' office visits.

The program was made possible by grants from the Medtronic Foundation, Novartis Pharmaceuticals and Forest Pharmaceuticals, Inc. Additional support was provided by: AGIS, Intel Digital Health, Eisai Inc., Evercare, and the MetLife Foundation.

# Education *continued*

**Bringing the *Communicating Effectively* program to family caregivers at their work sites** is being made possible by a two-year grant from the Jacob and Valeria Langeloth Foundation. The CE Workplace initiative, which will officially begin in fiscal 2010, is designed to help both family caregivers and their employers. Surveys show that 70 percent of family caregivers are employed and that businesses lose between \$17 billion and \$34 billion annually due to employees' caregiving responsibilities. Focusing on teaching family caregivers the information they need to function more effectively in healthcare settings builds their capabilities and confidence, thereby reducing stress and helping remove one of the impediments to their being fully present while at work. Bringing the CE program to them electronically, so they can watch it at their desktops, makes participation easy.

**A comparative and cost evaluation study** by The Stratton VA Center in Albany, New York, during fiscal 2009 analyzed the effectiveness of the CE workshop as compared to a newly created self-paced DVD and workbook model. Crystal Moore, PhD, NFCA's master trainer for the CE program, was a co-investigator on the project. The study, which is to be completed in the first quarter of fiscal 2010, will also determine whether there is any correlation with reduced healthcare costs because of this caregiver training.

# Building Community

NFCA's community offers our members the opportunity to share their stories through the Family Caregiver Story Project portal on the Web site as well as the opportunity to find a pen pal. NFCA's popular forums got a big boost in fiscal 2009 with support from Intel Health. The forums are by far the most popular destination on our Web site, proving how much family caregivers want to connect with and learn from their peers.

## Story Project Excerpt

*I'm 80 and my wife is 63. She has Alzheimer's. The only help I've received has been from my daughter, who has a brain tumor. My wife is steadily losing more of her memory and capabilities. I love her so ... I never felt this alone before. My love for her and her love for me is still strong and keeps me going. ... She clings to me and cries, "I don't want to lose you!" I cry with her and reply, "You will never lose me." So life goes on. I have no other choices at this time. These are my golden years. I think I can still make it golden. I have to get rid of hurt, anger, resentment and disappointment. That's my diary for today. Thanks for listening.*

## Forum Excerpt

*My 16-year-old daughter was diagnosed with a rare brain cancer in May. I was wondering if anyone has dealt with a child with brain cancer. I am at odds. I have been going through a great amount of depression and panic attacks, while not letting her see that as much as possible ...*

Note: The woman who posted this query received 22 replies within two days.

## Caregiver Community Action Network

Among the tens of thousands of family caregivers who make up our community, there is a very special, highly dedicated group of volunteers who participate in the Caregiver Community Action Network (CCAN). CCAN volunteers go through a rigorous vetting process and there is a great deal of diversity within the group, but one thing they all have in common is the fact they are all either current or former caregivers. Their authenticity is what separates NFCA's volunteers from other support programs for family caregivers.

# Building Community *continued*

CCAN volunteers provide resource information, peer support, community education, media relations, and advocacy. In the past year, with the support of a grant from the MetLife Foundation, we made significant expansions and enhancements to CCAN. Among other accomplishments, NFCA:

- Piloted an enriched state program in Michigan with an enhanced recruitment effort, more integration of volunteers' activities, an e-community, and opportunities for volunteers to meet in person. This focused attention on Michigan taught us the value of having a central administrative office (either virtual or actual) in the states to coordinate efforts. Future plans call for replication of the enriched state model in other states.
- Increased membership in the program by one-third and added three new states. (See chart.)

June 30, 2008	June 30, 2009	Percentage Change
85 members	113 members	33%
37 states	40 states – Wyoming, Alaska and Louisiana were added	12.3%

Accomplishments by individual volunteers included:



With 18 CCAN volunteers, Michigan has the most of any state. A few of Michigan's CCAN representatives are shown above.

- Distributed 25,000 educational gift bags to family caregivers during National Family Caregivers Month. For more detail, see NFC Month write-up on page 11.
- In Arizona, a CCAN volunteer was a critical player in the development, passage, and funding of legislation to create a Lifespan Respite Care Network in that state, making Arizona only the fourth state in the country to have such a program legislated.
- In Massachusetts, NFCA's reach grew exponentially with the advent of a cable show dedicated to family caregiving.

Hosted by a CCAN volunteer, the show airs one original program per week with three repeats per week, reaching 5,000 viewers each. Forty original shows aired between July 1, 2008, and June 30, 2009.

- In Florida, CCAN volunteers participated in numerous activities, including an expo in celebration of NFC Month 2008 that attracted more than 150 people; organized an interfaith service in Boca Raton; and made presentations on caregiver self-identification and self-care to hundreds of family caregivers in Miami.

# Advocacy

With the election of Barack Obama to the presidency and his focus on healthcare reform, there was a great deal of activity in Washington, DC, and NFCA was in the thick of it.

NFCA's advocacy activities during this time focused on the following:

- Educating our members, policy makers, and the public about how our current healthcare system is failing those with chronic conditions and their family caregivers. We did this through articles, letters to the editor, media interviews, and blogs.
- Providing legislative updates on our Web site on relevant proposed bills. Rather than just a listing of bills and where they stood in the legislative process, NFCA provided a short explanation of how the bill would help family caregivers and their loved ones, translating complicated language into information family caregivers could easily understand and use. Click on [http://www.thefamilycaregiver.org/caregiver\\_advocacy/current\\_legislation\\_issues.cfm](http://www.thefamilycaregiver.org/caregiver_advocacy/current_legislation_issues.cfm)
- Promoting system delivery reform directly and through coalition relationships, to

advocate the need for thorough care coordination and seamless transitions for those with a chronic illness or condition as a means of improving the health and well-being of family caregivers and their loved ones, and as the best way to cut Medicare costs

- Testifying before the Veterans Affairs Committee Subcommittee on Health
- Helping to craft patient- and family centered principles and legislative language for specific pieces of the healthcare reform bills
- Working with the home office of Congressman John Dingell (D-MI) to host a Family Caregiving Town Hall meeting in May that attracted more than 50 family caregivers



**Town Hall Meeting**

May 28, 2009  
3:30 p.m.—5:00 p.m.

Brownstown Township Hall  
Township Board Chambers  
21313 Telegraph Rd.  
Brownstown, MI



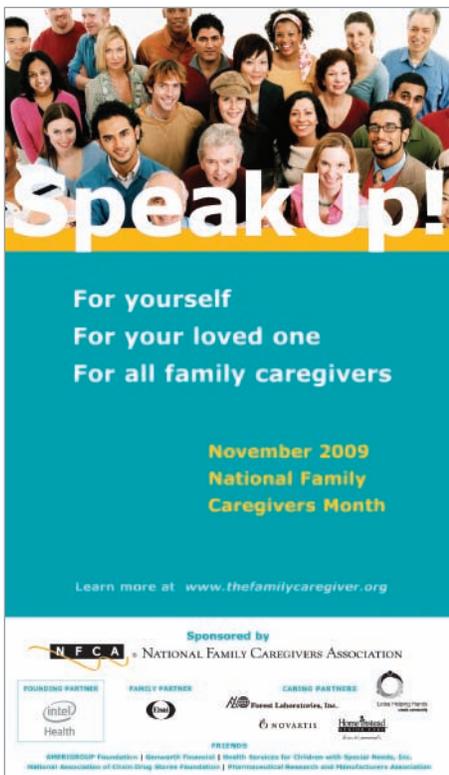
Office of Congressman John D. Dingell (MI-15)  
Phone: (313) 278-2936

JOIN CONGRESSMAN JOHN DINGELL  
AND LOCAL FAMILY CAREGIVERS  
ON THURSDAY, MAY 28, 2009  
3:30 P.M.—5:00 P.M.  
BROWNSTOWN TOWNSHIP HALL  
TOWNSHIP BOARD CHAMBERS  
21313 TELEGRAPH RD.  
BROWNSTOWN, MI

LISTEN TO FAMILY CAREGIVERS  
SPEAK UP  
ON BEHALF OF  
UNIVERSAL HEALTH CARE.  
AN ISSUE OF UTMOST IMPORTANCE TO FAMILY  
CAREGIVERS IN NEED OF  
HEALTH CARE INSURANCE TODAY.



NATIONAL FAMILY CAREGIVERS ASSOCIATION  
[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)



# National Family Caregivers Month

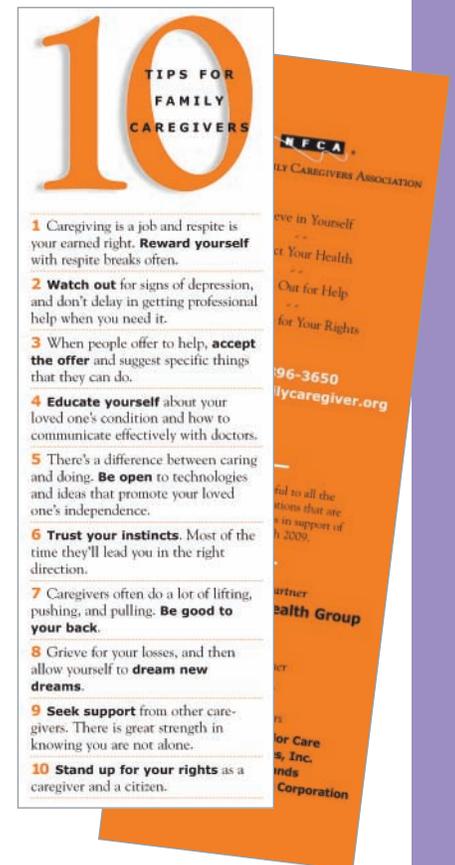
The theme of NFC Month 2008 was, appropriately, Speak Up! and this was fostered in a variety of ways, from encouraging our members to let their voices be heard by voting for the presidential candidate of their choice to the *Communicating Effectively* national teleclass/webinar.

A major activity of the CCAN volunteers during National Family Caregivers Month (NFC Month) is the distribution of educational gift bags, made

possible through the generosity of corporate partner Eisai.

Eisai has supported the Ambassadors' Program since 2006, initially with a grant that permitted the distribution of 10,000 gift bags to individual family caregivers as well as organizations working with family caregivers. During both NFC Month 2007 and 2008, 25,000 gift bags were distributed. With the growth of the CCAN program each year, the Ambassador gift bags are distributed to an ever-growing list of communities and states. The NFC Month 2008 gift bags included a diverse group of "How To" educational pieces, including the ever-popular "10 Tips for Family Caregivers."

More than 50 national non-profit organizations endorsed NFC Month and helped spread the word. Many put on activities in their local communities, while the press highlighted the month with numerous stories. The president issued a proclamation, as did some governors and mayors, adding to the recognition.



# Changes and Growth at NFCA

## BOARD

During fiscal 2009, both Linda Jones, RN, and Eric Fig, CPA, completed their second three-year term and left the board. For many years Ms. Jones served as the volunteer director of the Caregiver Community Action Network. Much of the growth of the program is attributable to her efforts. Eric Fig served as treasurer, chairperson of the finance committee, and chairperson of the board. Their services will be sorely missed.

While the board lost representatives from the medical profession and accounting field, we gained public policy and legal expertise:

**Eric Berger**, Senior Vice President, Public Policy and Communications  
**DaVita, Inc.**, Washington, DC

and

**Elizabeth Pearson**, President, Managing Attorney  
**Pearson & Bernard PSC**, Covington, KY

## STAFF

David Schulbaum joined the staff in June as director of marketing and development, with overall responsibility for the CE Workplace program as well as growing our list of corporate contributors and developing new markets. Mr. Schulbaum has a broad background in non-profit marketing and extensive experience in the professional publications market.

At the same time, NFCA began a search for a chief operating officer so we would have the capacity to respond to the growing demand for family caregiver services and expertise. In the final days of the fiscal year, an offer was tendered to Lisa Winstel with a start date of July 1, 2009. Ms. Winstel brings 18 years of non-profit experience to this new position.

## Medtronic Mentoring Grant

NFCA participates in the Medtronic Foundation's Patient Link Program, a select group of non-profits committed to making a difference in patients' lives. The Foundation provides funding for projects and identifies some Patient Link

# Changes and Growth *continued*

members to assist in non-financial ways. In fiscal 2009, NFCA was selected to participate in the Foundation's Mentor Project, which is designed to help organizations build their operational capacity. This year-long grant will continue into fiscal 2010.

## Reaching a Broader Audience and Raising the Profile of NFCA

During fiscal 2009, NFCA saw a significant increase in traffic to our Web site, with an average of 74,000 visitors per month (up 16 percent since 2008), including 21,000 *new* visitors per month (up 18 percent). This continues the annual increase in NFCA's reach since the organization began tracking these numbers in 2005.

Media coverage was extensive in fiscal 2009, with quotes and commentary in national and regional publications as well as on the Internet, radio and TV. Total readership of publications in which NFCA was quoted, had a letter to the editor published, etc. was 27 million. When we add in the Internet and local publications picking up stories or events involving volunteers, the numbers are even higher. (To see NFCA President Suzanne Mitz's letter to the editor in *The New York Times* click on [http://www.nytimes.com/2009/02/06/opinion/106care.html?\\_r=1&ref=opinion.](http://www.nytimes.com/2009/02/06/opinion/106care.html?_r=1&ref=opinion))



NFCA's president and co-founder, Suzanne Mintz, raised the profile of NFCA through her leadership position on numerous boards and committees, including:

- National Health Council Board of Directors
- National Transitions of Care Coalition Advisory Task Force
- National Patient Safety Foundation Governing Board
- Partnership to Fight Chronic Disease Advisory Board
- Joint Commission Patient and Family Committee

# Summary

Fiscal 2009 was a very significant year in the life of NFCA. Not only was it the organization's 15th anniversary, a milestone in its own right, but it marked the beginning of a new phase in the organization's growth with the:

- Addition of a new senior staff member and the search for another
- Launch of a free annual webinar on important healthcare topics, open to family caregivers and professionals alike across the nation
- Recognition by policy makers of the role that family caregivers play in the provision of chronic illness care in America and NFCA's role in shaping public policy on behalf of all family caregivers.

The staff and board of the National Family Caregivers Association wish to thank all of the individuals, companies, organizations, and foundations that enabled us to help so many family caregivers during fiscal 2009. We are pleased that so many family caregivers reached out to NFCA and gave us the opportunity to help them help themselves.

# Financials – FY 2009

## ASSETS

### Current Assets

Cash and Cash Equivalents	\$ 338,417
Investments	\$ 32,393
Accounts Receivable	\$ 204
Prepaid Expenses	\$ 4,892
<b>Total Current Assets</b>	<b>\$ 375,906</b>

Property and Equipment	\$ 68,003
Less accumulated depreciation	\$ (49,591)
<b>Net Property and Equipment</b>	<b>\$ 18,412</b>

### Other Assets

Deposits	\$ 4,786
----------	----------

<b>Total Assets</b>	<b>\$ 399,104</b>
---------------------	-------------------

## LIABILITIES

### Current Liabilities

Line of Credit	\$ 75,000
Accounts Payable	\$ 18,463
Accrued Vacation	\$ 12,297
Deferred Revenue	\$ 240,549
<b>Total Current Liabilities</b>	<b>\$ 346,309</b>

### Net Assets

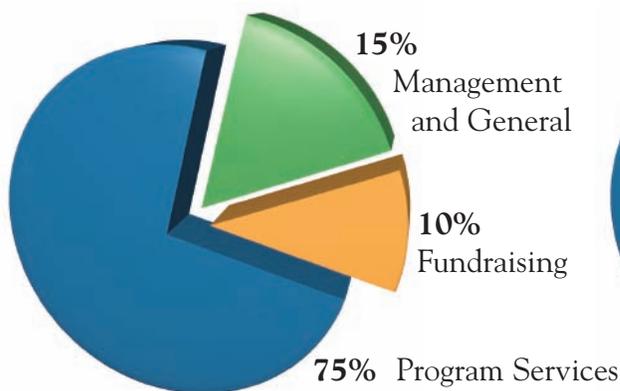
Unrestricted	\$ 15,545
Temporarily Restricted	\$ 37,250

<b>Total Liabilities and Net Assets</b>	<b>\$ 399,104</b>
---	-------------------

## Funders List Corporations and Foundations

**Abbott Laboratories**  
**AGIS**  
**American Medical Identification**  
**Appel Family Foundation**  
**AstraZeneca**  
**Blue Cross Blue Shield – Illinois**  
**Dreyfus Family Foundation**  
**Eisai Inc.**  
**Elan Pharmaceuticals**  
**Evercare/Ovations**  
**Forest Pharmaceuticals, Inc.**  
**Health Central Network**  
**Home Instead Senior Care**  
**Intel Digital Health**  
**Medtronic Foundation**  
**MetLife Foundation**  
**National Association of Chain Drug Stores**  
**Novartis Pharmaceuticals**  
**Pfizer**  
**Principle Business Enterprises, Inc.**  
**Purdue Pharma**  
**Right at Home**  
**Songbird Hearing, Inc.**  
**Teva Neuroscience**  
**Wyeth**

Expenses



Revenues and Gains

