

ALPHA-1 *News*

The Official Newsletter of the Alpha-1 Association



A Message from The Chair

Jan Petersen

Greetings to Alphas, families and friends!

This issue of Alpha-1 News is an annual report edition that summarizes our activities and accomplishments in 2006 and articulates our vision and plans for 2007. I am pleased to report that the Association has made significant progress over this past year.

Thanks in great part to AlphaNet and its fiscal management over the past several years, we have stabilized our financial position. We are pleased to publish our audited financial statements for Fiscal Year Ending June 30, 2006 in this issue rather than wait until the Town Hall meeting at the Annual Conference. In June 2006, we centralized our financial and day-to-day operations in Miami, FL under the leadership of Marlene Erven, Executive Director. In conjunction with the new administration, an assessment of Association programs and services has been undertaken and is ongoing.

During this past year, our Support Group Network, now comprised of 70 Support Groups, has been instrumental in connecting Alphas with other Alphas, providing educational opportunities, creating awareness of Alpha-1 in communities across the country, as well as tackling important health policy issues. We are grateful to the Support Group Leaders for the gifts of support, kindness, caring and sharing they have given so freely to the Alpha-1 Community.

An active and engaged Support Group Leadership Advisory Committee works with Support Group Leaders to identify and address their needs. As a result of their hard work this past year, a new comprehensive Support Group Leader Training Manual and Resource Guide is being released this month. Our National Education Conference brought together more than 350 Alphas and family members in June 2006 in San Diego, our largest attendance in our history!

We co-sponsored a record 12 education days with the Alpha-1 Foundation that provided educational programs to Alphas and family members in a wide range of regions throughout the US. Through our partnership with Alpha-1 Kids, a not-for-profit organization, there is a specialized program for parents of Alpha-1 infants, children and adolescents.

A joint Public Policy Working Group, comprised of members of the Board of Directors of the Association and Foundation, was organized this year and has set specific priorities and strategies for next year. I encourage you to read about them in this issue and get involved!

Without the generosity of all who support the Association, we could not maintain our programs and services. Your support—whether the resources you provide are in the form of time, talent or finances—is what drives our success. With your help we will continue to expand our programs and services while maintaining our efficient use of the monies we raise.

I am proud to be a part of this organization and serve as your chair. To those who know me and have already given your support, I offer my thanks. To those of you whom I have yet to meet, we need your help as well. I implore each of you to consider how you can contribute to the betterment of other Alphas, how you can get involved in some way to make a difference. Please call the Alpha-1 Association and let us know how you would like to help!

Sincerely, Jan Petersen, Esq.

S u p p o r t , E d u c a t i o n a n d A d v o c a c y

Vol. 18 Issue 4
ANNUAL REPORT
January 2007

Inside:

What is Alpha-1?
page 2

Resources
page 2

**Message from
Executive Director**
page 3

Financials
page 4 & 5

In Memory & Honor
page 6

Save the Date!
page 6

Making a Difference
page 7

Advocacy Report
page 8

Medigap Benefit
page 9

**Peter Smith
Scholarship Fund**
page 9

Education Day Series
page 10

Support Groups
page 11

Calendar of Events
page 12

Alpha-1 Antitrypsin Deficiency

Alpha-1 Antitrypsin Deficiency (Alpha-1) is a genetic/hereditary condition that leads to decreased circulating levels of alpha-1 antitrypsin (AAT) in the blood and significantly increases the risk of serious lung disease in adults and liver disease in infants, children and adults. Rarely, Alpha-1 can cause a skin condition call panniculitis. Individuals with Alpha-1 may remain healthy throughout their lives.

It is estimated that as many as 1 in every 2,500 Americans have two defective AAT genes and have the severe form of Alpha-1. An estimated 20 million individuals have one normal and one defective AAT gene (carriers). There is evidence for some increased risk of lung and liver disease in carriers.

Early diagnosis and avoidance of risk factors, such as cigarette smoking, can help prevent Alpha-1 from causing lung disease. Alpha-1 is severely under diagnosed. It is estimated that less than 10% of those living with Alpha-1 have been diagnosed.

For more information on Alpha-1 and how you can help spread awareness in your local community, please visit the Alpha-1 Association at www.alpha1.org or call 1-800-521-3025.

Alpha-1 Association Resources

The Association offers a number of resources to individuals affected by Alpha-1 and their families.

- **For newly diagnosed individuals or to obtain educational materials, call:**
Patient Information Hotline: (800) 245-6809
- **For Referral to a Peer Guide**
Toll-Free (877) 346-3212
- **For Referral to a Support Group**
Toll-Free (877) 346-3212
- **For Private Answers to Questions—**
Email to info@alpha.org
 - Alpha-1 in Childhood
 - Liver Affected
 - Lung Affected
 - Panniculitis
- **Visit our Bulletin Board at www.alpha1.org for discussions groups on Alpha-1 topics of:**
 - Alpha-1 in Childhood
 - Liver Affected
 - Lung affected
 - Panniculitis

Alpha-1 Association

Executive Committee

- Jan Petersen, Chair
- Ed Brailey, Vice Chair
- Jen Bauernfeind, Secretary
- Robert Haggerty, Treasurer
- John Morton, Past Board Chair

Board Members

- Robert J. Fallat, MD
- Bettina Irvine
- Janet Henderson
- Don Rabush
- Dennis Pollock
- Allen Russell

How To Contact Us

Alpha-1 Association
 2937 SW 27 Avenue, Suite 106
 Miami, FL 33133
 Toll-Free (800) 521-3025 or
 Local (305) 648-0088
 Fax number (305) 648-0089

Marlene Erven
 Executive Director
 Toll-Free (800) 521-3025
mservern@alpha1.org

Cathey Horsak
 Director of Community Programs
 and Outreach
chorsak@alpha1.org
 Toll-Free (877) 346-3212

Miriam O'Day
 Sr. Director of Public Policy
moday@alpha1.org
 Local (410) 216-6916
 (877) 829-8488

To Contact the Editor

To contact the editor with ideas and suggestions (or even complaints!) for the newsletter, write to:
 Ann Dassing—Front-Page Promotions, Inc.
 14 Hatfield Street Caldwell, NJ 07006
 Phone: (973) 403-0032 • Fax: (973) 403-9174
 E-mail: anndassing@comcast.net

Editorial Board

- Noreen James
- Mark Rabush
- Bettina Irvine
- Allen Russell

Photographs by staff and Rick Brady.

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A Message from Executive Director

Marlene Erven

Dear Friends,

As I complete my first six months as Executive Director of the Alpha-1 Association, I continue to be impressed with the dedication and collaborative spirit of our staff as well as the passion, energy and commitment of our Board of Directors and volunteers. When I made the decision to join the Alpha-1 Association, I knew that I was joining an organization committed to improving the day-to-day lives of individuals living with Alpha-1. I have had the pleasure of working with many talented and passionate individuals who have worked tirelessly toward this goal.

I have worked hard to improve on the success of the Association and to further our mission by bringing greater focus and structure to the organization. Our goals for 2007 are designed to directly support the mission of the Association: to identify those affected by Alpha-1 and to improve the quality of their lives through support, education, advocacy, and research. My daily goal is to help us stay on track and make sure that all day-to-day activities of the Association directly support these goals. I am optimistic about the future and the goals that we have set for 2007.

We will focus on expanding and enhancing our Support Group Network as a vital resource for Alphas and family members and as a means of creating awareness and outreach. By providing specialized training and access to greater resources we will empower Support Group Leaders to make a difference in their support groups and within their communities. Creating awareness and early detection are a critical part of our goals in this area.

We also intend to develop and implement a new service that will provide specialized genetic counseling and information on Alpha-1 to both the lay and medical communities. This service will expand our Patient Information Hotline and you will hear more about this service as it develops and becomes available.

Our 2007 National Education Conference will be held June 8-10th in Alexandria, Virginia. The theme for this meeting is "Mind and Body: Control Your Own Destiny". We expect this conference to attract the greatest number of people in our history and hope to provide some of the best programming for all Alphas and their family members.

The Association has assumed a leadership role in planning and coordinating the 2007 National Education Series that are co-sponsored with the Alpha-1 Foundation. The Series will encompass six Education Days and six Regional Support Group Meetings. The Series provides medical information and resources to Alphas, their families, and caregivers throughout the country.

Thanks in great part to our new Editorial Board for Alpha-1 News, you will see an expanded range of articles and features beginning in the next issue to provide even more information and education for our members.

We will continue to expand and enhance our Web site both as a resource for the Alpha-1 Community and as an interactive area where you can expand your involvement with the work of the Alpha-1 Association.

Our Public Policy Working Group has set an aggressive agenda for this year which is outlined in this issue. I encourage you to become involved as an Alpha-1 Advocate by monitoring current issues as disseminated through our Action Alerts! and by taking action to influence these important legislative and regulatory issues.

As a patient-focused and patient-driven organization, we need the ongoing involvement of our membership as volunteers, advocates, spokespersons, and active participants. We rely upon you to bring issues forward and help identify areas that need to be addressed. Our membership base strengthens community ownership of our national mission and programs and helps unify the voices of all Alphas. By embracing the passion of our volunteers and staff and aligning both through our goals and objectives, we can make an impact for individuals and their families affected by Alpha-1.

With sincerest wishes for a wonderful year ahead,

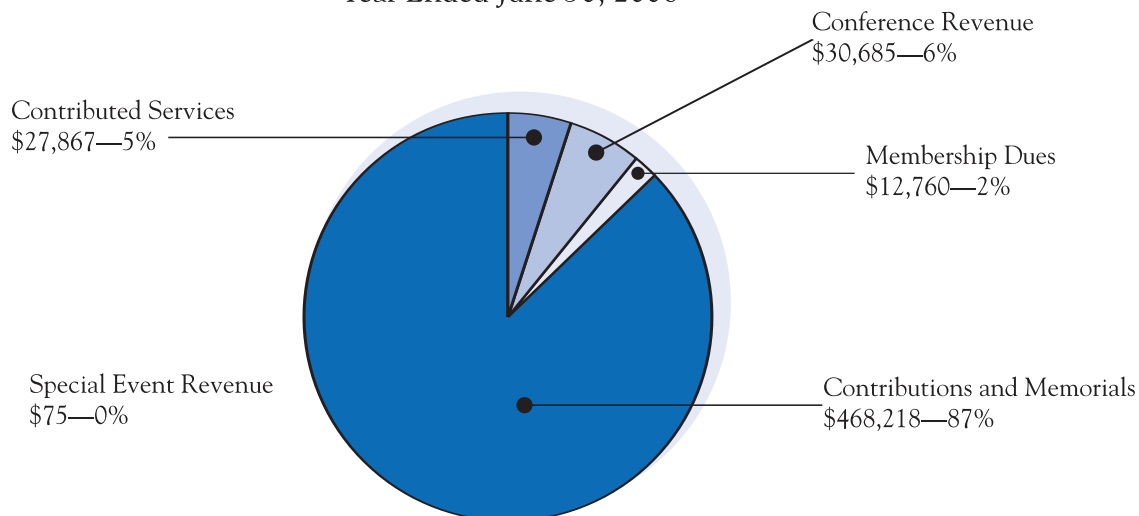
Marlene S. Erven
Executive Director

Statement of *Financial Position*

For The Year Ended in June 30, 2006—With Comparative Totals For The Year Ended June 30, 2005

	Totals	
	2006	2005
Assets:		
Cash and cash equivalents	207,072	157,516
Accounts and grants receivable	46,800	14,213
Prepaid expenses	2,154	-
Security deposits	5,331	5,331
Subtotal	261,363	177,060
Fixed Assets:		
Computer and office equipment	12,972	8,822
Less-accumulated depreciation	(4,048)	(2,348)
Net fixed assets	8,924	6,474
Total assets		270,287
183,534		
Liabilities and Net Assets		
Liabilities:		
Accounts payable	92,922	2,940
Accrued expenses	4,923	10,666
Accrued liabilities-leased employees	1,474	2,820
Total Liabilities	99,319	16,426
Net Assets:		
Unrestricted	79,768	80,108
Temporarily restricted	91,200	87,000
Total net assets	\$170,968	167,108
Total liabilities and net assets	\$270,287	\$183,534

GROSS REVENUES BY CLASSIFICATION
Year Ended June 30, 2006



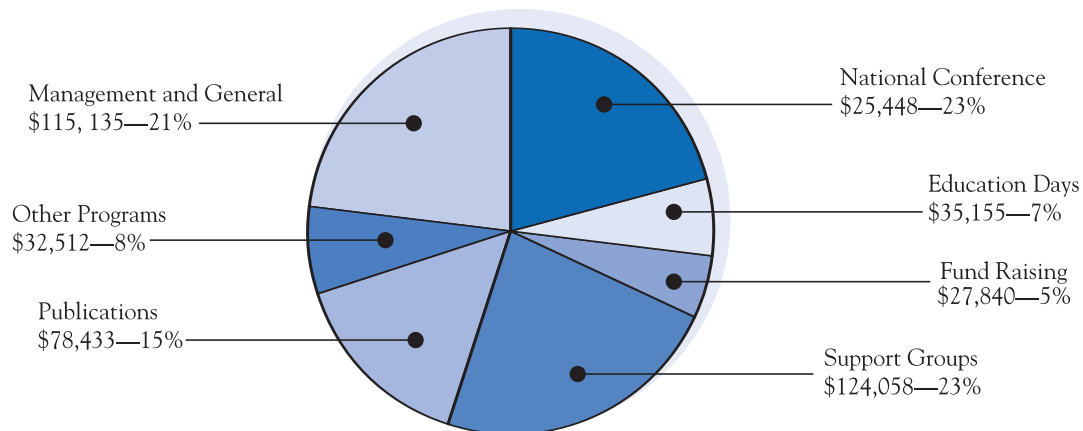
A full and complete copy of the Audited Financial Statements for Fiscal Year Ending June 30, 2006 are located on the Alpha-1 Association's Website at: www.alpha1.org

Statement of *Activities*

For The Year Ended in June 30, 2006—With Comparative Totals For The Year Ended June 30, 2005

	Totals	
	2006	2005
Revenue:		
Membership Dues	12,760	\$18,880
Contributions and Memorials	468,218	\$454,809
Contributed Services	27,867	30,000
Conference Revenue	30,685	21,585
Special Event Revenue,	75	3,609
Other Income		418
Investment Income:		
Interest and Dividends	2,836	321
Total Revenue	\$542,441	\$529,622
Expenses and Losses:		
Functional Expenses:		
Support Group	124,058	145,294
Publications	78,433	57,808
Education Days	35,155	38,453
National Conference	125,448	152,225
Other Programs	32,512	17,814
Management and General	115,135	73,956
Fundraising	27,840	29,108
	\$538,581	\$514,658
Increase (decrease) in net assets before reclassification	3,860	14,964
Net Assets	—	—
Increase (decrease) in net assets	3,860	14,964
Net Assets—Beginning of Year	167,108	152,144
Net Assets—End of Year	\$170,968	\$167,108

FUNCTIONAL EXPENSES
Year Ended June 30, 2006



A full and complete copy of the Audited Financial Statements for Fiscal Year Ending June 30, 2006 are located on the Alpha-1 Association's Website at: www.alpha1.org

In Memory

We gratefully acknowledge the following individuals who have made Memorial and Honor gifts to the Alpha-1 Association during 2006.

In memory of Francis Roloff

E. O. McMorrow

In memory of Harvin Giedd

Karin M. Olson

Phillips & Temro Industries (Sonia
Homer, Ann Nowak, Jessica Schossow)

In memory of James Faircloth

Philip & Emmie Edenfield

C. Danny Cumbee

Donald & Donna Kumiski

James & Kent Rigsby

In memory of Joanne R. Contessa

Matt L. Contessa

Rudy & Patty Didonato

In memory of Nancy Longua Henkel

Michael Longua

Lawrence J. Longua

In memory of John E. Kudhner

Larry Kamenoff

In memory of Bill Young

John R. Schubert

In memory of Kenneth P. Teske

Jerald & June Hoekstra

Gertrude Teske

St. Pauls Lutheran Church

In memory of Larence Ingleston

Irene Tanner

In memory of Lori Chestnut

S.G. Leftwich

In memory of Lyle Quackenbush

Karrie Gooding

In memory of Lysbeth Ann Maly

Tom & Ruth Harkin

In memory of Monica Winter

L.C. Winter

In memory of Paul Anderson

Stewart & Evelyn Windham

In memory of Phyllis Bond

Kenneth & Judith Williams

In memory of Chad Brailey

William & Joanne Zipadelli

In memory of Larry J. Shambre

Patti J. Osgar

In memory of Randy Harwell

Sandra K. Likes

In memory of William S. Kirk

Ruth L. Kirk

In memory of: Porter Grant, Harry

Hotchkiss, Jay McLaughlin, Rita Edwards,

Robert Johnson, Robert Elliott, Dottie Mathews, Ann West, Harrol Popham, Wanda Diggers, Sara Jane Knoll, Jay Durham, Billie Harness, Diane Padgett, Charlotte Elliott, Loreena Masters, Lila Nevergold, Paul Hughes, Gail Lyons, Claude Baker, Paul Anderson, Nancy Harte, Howard Wilkes, Randy Harwell, Diane Stowers

In memory of Judith Crowell Bakula

Robert C. Crowell

In Honor

In honor of Kathy Haduck

Shirley Yarnall

In honor of Robert A. Sandhaus, MD PhD

Tom and Joan Young

Save The Date

MIND AND BODY: CONTROL YOUR OWN DESTINY

MAKE YOUR HOTEL RESERVATIONS EARLY!

ALPHA-1 ASSOCIATION 16TH ANNUAL EDUCATION CONFERENCE

ALEXANDRIA, VA • JUNE 8-10, 2007

Hilton Alexandria Mark Center, 5000 Seminary Road, Alexandria, VA. 22311

If you are planning to attend the Conference, please make your hotel reservations as soon as possible. A block of rooms has been reserved for the Alpha-1 Association at the special rate of \$125 per night plus tax. For room reservations please call: 703-845-1010 or toll free at 877-783-8258 and request the A1A Meeting, DC Area (code AOA) group rate. *Please note that check in time will be 3:00 pm and check out time will be noon.*

Printed Conference Registration forms will be available and mailed in early March. You will be able to register for the Conference on line at that time with a credit card. You may find the latest information on the Conference by visiting our website at: <http://www.alpha1.org/home/index.asp>.



Ab Rees

Making A Difference

By Ann Dassing

I caught up to Ab Rees recently and we chatted about his role as Board Member for both the Alpha-1 Foundation and Alpha-Net Inc. Mr. Rees feels that his service on both boards has given him a unique opportunity to see, firsthand, how each group addresses Alphas' quality of life and the search for a cure. He also has worked closely with Marlene Erven, new Executive Director of Alpha-1 Association, during her tenure with the Alpha-1 Foundation, and he is confident the three organizations will work together to the greatest benefit of Alphas across the country.

Shortly after being diagnosed with Alpha-1, Mr. Rees found himself reaching out to the Alpha-1 community for support and information. At the suggestion of his wife, Lynne, he attended an Alpha-1 Association National Education Conference in Washington, D. C. with hundreds of other Alphas. It was there that he met John Walsh and Bob Barrett. Impressed by their leadership and the amount of materials generated for Alphas, he agreed to join the AlphaNet Board of Directors in 2003. Currently, he serves as Chairman of the AlphaNet Board and when asked by John Walsh to serve as Treasurer and Board member of the Alpha-1 Foundation Board, he readily agreed. He is serving his first three-year term in that role.

In Ab Rees, the Alpha-1 community is fortunate to have a Board Member with 39 years of management experience in executive positions of Fortune 500 companies. Most recently, Ab was Chairman and CEO of Railworks Corporation, a railroad construction, products and services company with \$500 million in revenue. Mr. Rees has broad experience, both here and abroad, with major achievements in productivity, cost reductions, restructurings, mergers and acquisition, business growth and customer service in Senior Management of 4 large Railroads. He holds a degree in Business from the University of Central Arkansas and graduated from the Program for Management Development from Harvard Business School. In addition to his Board roles for the Alpha-1 community, Mr. Rees has served as a member of numerous industry joint ventures and in-house Boards of Directors.

A skeptic by nature, Mr. Rees has proven to himself that all three organizations are delivering services, addressing quality of life issues and working for a cure for the Alphas they serve.

"I have proven to myself that these three organizations are working together better than ever before, to find a cure for Alpha-1 antitrypsin deficiency, and in addition, these organizations are supporting the Alpha-1 community, wherever they live- from big cities, to rural farms, and whatever the occupation. We are reaching more individuals who have been diagnosed with Alpha-1 Antitrypsin Deficiency and we are advocating for them on a local, regional and national level," stated Mr. Rees.

Mr. Rees explains to many Alphas around the country that although the role of each of the three groups is different, together they provide a total package of coverage. The AlphaNet organization is the funding mechanism for the Foundation and the Association. Each year, it generates millions of dollars for research, education, advocacy and communication. AlphaNet Inc. has funded more than \$18 million since 1997 in research for the Foundation and \$1.5 million for the Alpha-1 Association. So, in essence, Alphas have three organizations working for them, to address the quality of life and to find a cure. In addition, these three groups have different programs for education, early detection, along with a network of hospitals and doctors, and other health care professionals, for the benefit of Alphas and their families.

Mr. Rees has six children, and has also been blessed with seven grandchildren. He and his wife, Lynne, reside in Kansas City, Missouri, with their two youngest children, Taylor, age, 11, and Jack, age 8.

In closing, Mr. Rees pointed out that, "the people who come to the Education Day meetings come from cities, they come from farms, some are from small communities, some are from very densely populated areas, and they may not be aware of what the Alpha-1 organizations are doing for them. However, when they leave an Education Day, they not only feel better about what is going on in the world for them but they know their quality of life is being addressed as well as the effort to find a cure."

Working Together for the Alpha-1 Community

The Alpha-1 Association is dedicated to identifying those affected by Alpha-1 Antitrypsin Deficiency and to improve the quality of their lives through support, education advocacy, and research.

AlphaNet's mission is to improve the lives of those affected with Alpha-1 Antitrypsin Deficiency by creating and disseminating a wide range of expert disease management services, while providing significant contributions toward research for a cure.

The Alpha-1 Foundation is dedicated to providing the leadership and resources that will result in increased research, improved health, worldwide detection and a cure for Alpha-1 Antitrypsin Deficiency.



Advocacy Report

By Miriam O'Day

As you know, living with a chronic condition can create great needs for the individual and their family members. The Association's advocacy program targets ways to improve access and remove barriers to care for those who require expensive medication and services and often become disabled as a result of illness. This sometimes translates into advocating for a health policy that benefits the neediest among us because it is well understood that private carriers follow reimbursement trends set by Medicare and Medicaid. So as we reflect on the accomplishments of 2006 and set goals for 2007; the best story of the year is our successful advocacy on behalf of dual eligible Medicare and Medicaid Alphas. The Association was able to work directly with the Centers for Medicare and Medicaid Services on behalf of individuals who lost benefits as a result of state and federal government disputes over providing services to dual eligible Alphas who were automatically enrolled in the new federal drug benefit. The success of our advocacy was based on collaboration with the Alpha-1 Foundation, AlphaNet and the Alpha-1 Community.

Also in 2006:

Congress introduced legislation that would mandate Medigap policies for

individuals who are qualified for Medicare due to disability and not because of age;

An Alpha testified before Congress highlighting the need for additional public health resources to enhance research and understanding of Chronic Obstructive Pulmonary Disease (COPD);

Several pieces of legislation were introduced to extend Medicare benefits that would be advantageous for Alphas. This included a bill to define pulmonary rehabilitation as a distinct set of benefits and a bill to provide home health visits to home bound individuals by respiratory therapists. Another bill was introduced to repeal the 2006 law that ceded ownership of oxygen equipment after 36 months to the beneficiary. None of these bills passed the 109th Congress although the sponsors remain committed to reintroduction in 2007;

Congress recognized Alpha-1 and the need for enhanced research and targeted detection giving Alpha-1 an opportunity to leverage this support with federal agencies such as the National Institutes of Health and Centers for Disease Control and Prevention;

The Association joined the newly formed Airline Oxygen Council of America to lend our voice in the collective effort to ease air travel with supplemental oxygen;

The Public Policy Working Group was

reinvigorated to harness the leadership and wisdom of volunteers from the Association and Foundation Board of Directors.

The Association plans to attend several meetings, which are planned to introduce new members of Congress to priorities within the chronic disease community. There are tremendous opportunities for Alphas to identify new allies as the mid-term elections produced 51 new House members (3 currently undecided) and 10 new Senate members.

The Working Group set the following priorities for 2007 and the new 110th Congress:

- Seek a home Health Infusion benefit specifically for Alpha-1 Medicare beneficiaries;
- Support legislation to require Medigap parity in all 50 States;
- Support and endorse legislation to codify pulmonary rehabilitation as a Medicare benefit;
- Support home visits by Respiratory Therapists for Medicare beneficiaries;
- Advocate on behalf of Organ Transplantation;
- Stimulate Congressional support and awareness of Alpha-1 through briefings, public testimony and individual meetings.

In 2007 the Alpha-1 Association will join other plasma consumers and industry in urging Congress to pass legislation that will ensure a national standard and guarantee Medigap policies for the disabled. Currently all age qualified Medicare beneficiaries are eligible for Medigap policies however, at present only 24 states have such requirements for the disabled and 26 states do not. Legislation co-sponsored in the 109th Congress by Phil English (R-PA) and Bobby Rush (D-IL) is expected to be reintroduced in the new 110th Congress, which begins in January 2007. This legislation will serve to assist in the payment of the Medicare Part B 20% patient co-payment responsibility, which can be financially burdensome to those who are disabled and have a chronic condition such as Alpha-1. Expanded Medigap access will not result in increased government spending, as beneficiaries will be responsible for premium and deductible payments. In fact the Association has learned that experts believe this legislation will cost the federal government nothing as it will be incumbent upon the states to have their providers extend this benefit to the disabled.

To join our E-Advocate mailing list and receive Alpha-1 Association ActionAlerts! on pending legislation and regulatory issues, please email awolf@alpha1.org

The very latest information: *Medigap*

Insurance coverage by State

The states that do require insurance providers to offer Medigap to the disabled are: California; Colorado; Connecticut; Kansas; Louisiana; Maine; Maryland; Massachusetts; Michigan; Minnesota; Mississippi; Missouri; New Hampshire; New Jersey; New York; North Carolina; Oklahoma; Oregon; Pennsylvania; South Dakota; Texas; Vermont; Washington; and Wisconsin.

For the 110th Congress, we have a commitment from Rep. Bobby Rush (D-IL) to introduce the legislation and support once again from Rep. Phil English (R-PA) who would be the lead Republican.

A Testimonial from a Pennsylvania Alpha:

“It is important for everyone to remember that Medigap coverage is not welfare. It is a supplemental policy offered to disabled people, regardless of their age,” informed Terry M. of Pennsylvania, one State which provides the Medigap coverage for its residents. For 15 years, Terry suffered with symptoms that mirrored exercise-induced asthma, and

was told this slowing down was part of the natural aging process. But Terry was only turning 50, and didn't feel that his age was the only contributing factor to his declining health. He questioned those he knew who had exercise-induced asthma and he found he had none of the same symptoms. He moved his records and continued to be tested. In the winter of 2001, he contracted pneumonia and after 2 sets of x-rays, he was seen by a pulmonologist, who noticed his lungs were larger at the bottom. Fearing that cancer was present, he went to the University of Pennsylvania for a consultation. That was where he tested positive for Alpha-1, and began treatment of augmentation therapy. It was at this time that he began to look for a supplemental insurance policy to cover that \$400-\$500 a month medication bills. His insurance agent suggested Medigap and that has worked for him since that time. He has brought his monthly expense down to \$145, enabling him to stay on his regime of augmentation therapy without dramatically increasing his monthly charges.

Terry wants to encourage all who might be faced with mounting medication bills to consult with their insurance agent or the Alpha-1 Association for help in applying for Medigap insurance. He offered that in his case, he had previous experience helping his Dad apply for medical insurance, and so was a bit familiar with the process. He indicated that his insurance agent was very helpful in the process and recommended this as an option for others.

If your State does not currently offer this extra policy, it is time that they considered it. Please write to your Congress representatives and let them know you need this coverage to help you manage your future medication costs. The Alpha-1 Association can also help you identify your representative and where to send your correspondence. It is vital they hear from as many Alphas as possible to help them effect a positive change for all by passing the Medigap legislation for their residents.

The *Peter Smith* Scholarship Fund

The Peter Smith Scholarship Fund application deadline is April 10, 2007!

The Peter Smith Scholarship Fund is available for post high-school education individuals with Alpha-1 Antitrypsin Deficiency, their spouses, and their children.

This scholarship honors the memory of Peter Smith, who believed that knowledge is power. He demonstrated this by writing, editing and publishing Alpha-1 News from 1989 until 1992. By October of that year, he had spread the word to over 1,200 households. His efforts encouraged, enlightened and inspired those with Alpha-1 to reach out to one another—and to learn. The intent of The Peter Smith Scholarship is to continue the tradition of inspiring and assisting by helping those with Alpha-1 and their families learn and achieve. The program is currently administered by the Alpha-1 Association, located in Miami, FL.

The review committee will announce scholarship winners on May 15, 2007.

Download one of the following applications at www.alpha1.org, located under Support, or call Anna Wolf at 800-521-3025.

The Alpha-1 Education Day Series

By: Cathey Horsak, Director of Community Programs & Outreach

This Fall offered many opportunities for Alphas to come together in their local area and learn more about Alpha-1. The Alpha-1

Association and the Alpha-1 Foundation collaborate to provide regional educational programs for Alphas and their family members, as well as the local medical community. Alpha-1 Education days address issues and topics specific to Alpha-1. The COPD/Alpha-1 Days are geared to both populations, with an emphasis on increased awareness on the importance of testing for Alpha-1.

September –Sacramento, California

Dr. Bob Fallat, Alpha-1 Association Board member, served as our host physician for this Education Day held on September 30th. He enlisted the assistance of Dr. Carroll Cross and Dr. Mark Zern from the Alpha-1 Foundation's Clinical Resource Center at the University of California, Davis Medical Center. Alphas from California, Oregon, and Nevada were in attendance and a patient panel shared experiences on living with Alpha-1.

October – Charleston, South Carolina & Ormond Beach, Florida

Both of these Education Days were part of the COPD Education Day Series. Dr. Charlie Strange was the host physician at Charleston on October 14th. He and his staff planned the agenda and provide the education forum for Alphas and COPD patients from South Carolina, North Carolina and Georgia. Approximately eighty-five percent of the attendees were Alphas.

Dr. Mark Brantly and Dr. Robert Sandhaus represented the Alpha-1 Community at Ormond Beach, Florida held on October 25th. The program was hosted by the Alpha-1 Association, Alpha-1 Foundation, COPD Foundation and the Florida Hospital Memorial System. There were over 230 attendees with the group consisting primarily of COPD patients and medical professionals. The Alpha-1 DNA & Tissue Bank collected 30 samples of blood (DNA) from attendees. The Bank serves as a resource for DNA and tissue samples that are studied by researchers investigating Alpha-1 and other diseases.

November—Boston, MA; Cranberry, PA; and Oakbrook, IL.

The Boston Education Day was hosted by the Alpha-1 Association, Alpha-1 Foundation, COPD Foundation and Harvard Medical School, Brigham & Women's Hospital. The program was held on November 4th and Dr. Ed Silverman was the Alpha-1 host physician. Approximately ninety percent of the attendees were Alphas.

The Pennsylvania Education Day was hosted by The Alpha-1 Association, Alpha-1 Foundation, COPD Foundation and the University of Pittsburgh Medical Center on November 6th. Dr. Charlie Strange from the Medical University of South Carolina provided the Alpha-1 update while Dr. Frank Sciurba from the University of Pittsburgh provided the COPD update. Fifty percent of the attendees were COPD patients and the DNA & Tissue Bank obtained 30 blood draws at this Education Day.

The Alpha-1 Education Day Program concluded its 2006 schedule in Oakbrook, Illinois on November 11. Dr. Mark Brantly was the host physician and he was joined by Dr. Kyle Hogarth and Dr. Nancy Reau both from the University of Chicago, an Alpha-1 Foundation Clinical Resource Center. After attending an Alpha-1 fund raiser on Friday evening, the spirit of giving continued at the Education Day. Ab Rees, Board Member for the Alpha-1 Foundation and AlphaNet, explained how our three organizations are working closely together to unite the Alpha-1 community. Ab encouraged all attendees to get involved, to make a difference and he challenged each attendee to start by contributing to the fundraiser for research. He pledged to match every dollar raised during the Saturday Education Day program. A total of \$5,000 was raised for research on Saturday alone, due to Ab Rees' commitment to the Alpha-1 community and determination to find a cure for Alpha-1. What a fantastic way to conclude our 2006 Education Day program!



Robert Fallat, M.D. receives recognition award from John W. Walsh



Lucille (Cindy) Karns, California Alpha; Barbee Bennington, SGL, Arizona; Jerry Killens, SGL, Oregon



Sacramento Ed Day – Carroll Cross, M.D. and Sandy and John Dorf



Support Group Network-2006

By Cathey Horsak

At the end of each year, we reflect back on our accomplishments as we plan for the coming year. Our goal for 2007 is to establish a support group in every state and to expand our support group network to reach as many Alphas as we possibly can.

The Alpha-1 Association support group network has experienced both growth and change in 2006. We welcome these new groups and sincerely thank those who have volunteered to lead these groups.

We had first time meetings held in 2006 in the following new areas:

Ft. Collins, Colorado

Co-leaders Glen Perkins and Barb Pusey

Jacksonville, Florida

Leader Susan Kelbaugh

Dunnellon, Florida

Leader Lloyd Herlocker

Frankfort, Kentucky

Leader Libby Wilson

Springfield, Missouri

Leader Ruth Johns

Wilmington, North Carolina

Co-leaders Larry Tipper and Gayle Allison

McLean, Virginia

Elsa Anders

Scott Depot, West Virginia

Leader Valerie Guthrie

Frederic, Wisconsin

Leader Judy Parker

Other new leaders to the Association include:

Louisville, Kentucky

Leader Erika Garloch

St. Louis, Missouri

Leader Jim Swift

Annapolis, Maryland

Leader Lynn Lothian

Houston, Texas

Co-leader Andy Carle

We are searching for volunteers to lead support groups in several states. If you live in one of these states and are interested in starting a new group, please give me a call. The states where we do not currently have an Alpha-1 Association Support Group are: Alaska, Delaware, Hawaii, Louisiana, New Mexico, North Dakota, Rhode Island and Utah. Additionally, if you are in an area where there is no support group close by and you are interested in forming a new group, please give me a call. The Support Group Leader Advisory Committee member for your geographical area and I are anxiously awaiting and willing to assist volunteers in forming a new group.

The Alpha-1 Association appreciates and commends those support group leaders who have served the Alpha community this past year. Nick Senzee served as a leader in both Maryland and Delaware. Nick's career path is leading him in a new direction this year and he and his wife are expecting their first baby the end of December. Congratulations Nick and thanks for your service. Diana Patterson in Louisiana is embarking on a new adventure. She and her husband are

moving to Saudi Arabia. Diana has not only been a support group leader in Louisiana but she has also served as the AlphaNet coordinator for Louisiana, Arkansas, Mississippi and Alabama. And while we wish her well, we will all miss her enthusiasm and positive attitude. Diana, have a great time touring the world and know that all your Alpha friends anxiously await your return in a couple of years. We pay special tribute to and honor the memory of three special Alpha angels—Kathy Walters, California; Karalee Karp, California; and Joe Alford, Missouri. Their dedication to the Alpha-1 community was immeasurable, and they will live forever in our hearts.

In closing, the Alpha-1 Association is honored to have committed, dedicated volunteers. You, as a support group leader, make a difference in someone's life each and every day by your service to the Alpha-1 community. We thank you for your dedication and hard work. Ralph Waldo Emerson says it best, "To know that even one life has breathed easier because you have lived . . . this is to have succeeded." Support Group Leaders-- Thank You for 2006 and we look forward to a Healthy, Successful 2007!

If you are interested in forming a new support group, please contact Cathey Horsak, Director of Community Programs & Outreach, Alpha-1 Association, 877-346-3212.

HOW DO YOU FIND A LOCAL SUPPORT GROUP?

Go to the Alpha-1 Association's home page at www.alpha1.org. At the top of the page is a section called "Find a Support Group" with a box to "Select a State". Simply select your state and hit submit. **It is just that easy!**

If you do not have access to a computer or you have additional questions, please call Cathey Horsak, Director of Community Programs & Outreach, at 877-346-3212.

DATE	HOSTING ORGANIZATION	LOCATION
April 14	COPD/Alpha-1 Education Day Chronic Lung Disease: An Educational and Health Awareness Day Co-Sponsors: Alpha-1 Association, Alpha-1 Foundation, COPD Foundation, Community Health Resource Center, California Pacific Medical Center, American Lung Association East Bay, and Breathe California	San Francisco, CA
April 28	Alpha-1 Education Day Co-Sponsors: Alpha-1 Association, Alpha-1 Foundation, St. Luke's-Roosevelt Hospital	New York, NY
May 12	COPD & Alpha-1 Education Day Co-Sponsors: University of Minnesota, Alpha-1 Association, Alpha-1 Foundation, COPD Foundation	Minneapolis, MN
August 11	COPD/Alpha-1 Education Day Co-Sponsors: National Jewish Medical & Research Center, Colorado COPD Connection, COPD Foundation, Alpha-1 Association, Alpha-1 Foundation	Denver, CO
October 6	Alpha-1 and Liver Education Day Co-Sponsors: Alpha-1 Association, Alpha-1 Foundation, Washington University, and St. Louis University	St. Louis, MO
November	COPD & Alpha-1 Education Day Co-Sponsors: Brigham & Women's Hospital, Alpha-1 Association, Alpha-1 Foundation and COPD Foundation	Boston, MA

Alpha-1 Association Regional Support Group Meeting

DATE	LOCATION
TBA	Cincinnati, OH
March 24	Tulsa, OK
May 6	Portland, OR
July 14	Statesville, NC
August 4	Sioux Falls, SD
Fall	Orlando, FL

The Alpha-1 Association recognizes the generosity of following companies who have provided unrestricted educational grants to support the 2007 National Education Series: AlphaNet, Centric Health Resources, and Talecris Blotherapeutics.

Please visit the Alpha-1 Association Website at www.alpha1.org for more information on Alpha-1 Association and Support Group Meetings and Conferences.

For more information on supporting or exhibiting at an Education Program or the National Health Conference, please contact Marlene Erven at 1-800-521-3025 or email at mservern@alpha1.org



2937 SW 27th Avenue
Suite 106
Miami, FL 33133

We apologize if you have received more than one copy of this newsletter, and encourage you to share it with your healthcare providers, family members and friends.