A Landmark Year

In 2010, the Alpha-1 Foundation received two of the most generous donations for research in our history. It was also the year we created The Alpha-1 Project, whose goal is to speed development of new therapies, drugs and cures for Alpha-1. As always, Alphas, their families and friends across the country had a great time raising awareness and funds. See page 3.
This Fiscal Year 2009-2010 marks the 15th Anniversary of the Alpha-1 Foundation and we have been so involved with our expanding activities that we neglected to recognize the anniversary with any celebration. We think it appropriate to mention highlights from early Annual Reports that put things in perspective regarding “then and now”.

- In our first fiscal year of operation, 1995-96, the Foundation reported a net deficit of $42,661 in the combined financial statements of the Foundation and AlphaNet. (The Foundation has never run a deficit since.)
- AlphaNet, based on the model of “Alphas serving Alphas,” was providing consolidated health services to Alphas across the country. “The cost of augmentation therapy has been reduced by as much as 30%,” said the annual report for fiscal year 1996-1997.

We have come a long way from reporting a net deficit and just beginning our fundraising for research. Looking back a decade at our 10th anniversary — recognized by our 10 Year Retrospective —we see progress on several fronts, including these snapshots from the annual report for FY 2000:

- The Alpha-1 Foundation Research Registry had a new site directed by Charlie Strange, M.D., at the Medical University of South Carolina, and was nearing 1,000 individuals registered. (We now have over 3,500.)
- Leo and Marilina Fernandez contributed $1 million from the family foundation, which, along with matching grants, made possible our first liver research initiative and the Alpha-1 DNA and Tissue Bank.

We enjoyed this brief walk down “memory lane” and are proud to be able to celebrate our 15th anniversary in this annual report by recognizing our primary accomplishment: funding $42 million of research grants and related research programs at 89 institutions in North America and Europe.

We have had numerous accomplishments over the past year.

In November, 2009, we incorporated The Alpha-1 Project (TAP), a for-profit, wholly owned subsidiary of the Alpha-1 Foundation. This is the Foundation’s venture philanthropy company aimed at direct investment in promising new Alpha-1 therapies developed by biotechnology companies. This would not be possible without the success of our research program and researchers identifying new therapeutic targets.

In 2010 we launched It’s All in the Family, our program to help Alphas and Alpha-1 carriers encourage their families to consider testing for Alpha-1. The program significantly increased free and confidential testing, funded by the Foundation, through the Alpha-1 Coded Testing (ACT) Study. This confidential testing program is a safe haven for individuals to be tested without risking genetic discrimination. Although we will continue this program, our successful advocacy efforts with the passing of the Genetic Information Nondiscrimination Act (GINA) offer some protections at long last.

The Foundation reached $1 million in revenue from fundraising activities, achieving the goal for the Million Dollar Match grant contributed by Talecris Biotherapeutics; followed by the announcement by board member Gordon Cadwgan, Jr. and his wife Ruth, that the Cadwgan family, together with Gordon’s father, Gordon Sr., had just made their own $1 million donation for Alpha-1 research.

The Foundation ended its 2010 fiscal year in a strong and liquid financial position. Included in its June 30, 2010 financials, assets were $8.1 million in marketable securities, compared to $5.8 million at the end of fiscal year 2009, and $8.3 million in total net assets. Total revenues for the fiscal year amounted to $7.1 million, of which $6.5 million represented contributions and grant income. Nearly 80% of the year’s expenses supported research and related programs.

These 15 years have brought tremendous progress that has positioned us to “finish the job”. We thank you for your support and emphasize the importance of your continued commitment and dedication to help us provide the resources to reach our goal to cure Alpha-1.

John W. Walsh
President & CEO

Albert W. “Ab” Rees
Chairman of the Board
The Alpha-1 Project: Investing in new therapies

Incorporated in November, 2009, The Alpha-1 Project is the Alpha-1 Foundation’s venture philanthropy company whose goal is to invest in promising new Alpha-1 therapies developed by biotechnology companies.

The Alpha-1 Project (TAP) is a for-profit, wholly owned subsidiary of the Alpha-1 Foundation. TAP allows us, for the first time, to invest directly in drug development. TAP is designed to accelerate the discovery, development and commercialization of drugs, therapies and cures for those with Alpha-1.

For well over a decade, the Foundation has been funding research that has generated much vital information about Alpha-1. So far, however, these research discoveries have not resulted in new treatments.

“Our researchers have advanced the science needed to produce new therapies, but they were never supposed to find new drugs — only drug targets. And they have done that,” says Marcia Ritchie, vice president and chief operating officer of the Foundation.

“TAP is based on exciting recent research that demonstrates how the lung and liver disease of Alpha-1 come about, and on the biotechnology community’s growing interest in Alpha-1 and its treatment,” said Adam Wanner, Foundation scientific director. He said that basic Alpha-1 deficiency research has been extremely successful, and the Foundation’s basic research programs will continue, with TAP a vital but separate endeavor.

“Some of our researchers have identified therapeutic targets that may ultimately result in a therapeutic cure, or cures, for Alpha-1,” said John Walsh, Foundation president and CEO. “The only way we are going to get the job done is if we can directly fund translational research — the drug development process.”

On our Cover: Moments to Remember

TOP, The Cadwgan family, Ruth, Gordon Sr., center, and Gordon Jr. donated $1 million to our research programs. Ruth and Gordon Cadwgan announced the gift at the national conference of the Alpha-1 Association in Orlando, FL.

LEFT, Lawrence Stern, Chairman and CEO of Talecris Biotherapeutics, speaks at the Foundation’s annual Celebration of Life about Talecris’s matching grant of $1 million to the Foundation, which was doubled by our Million Dollar Match program.

BOTTOM, FROM LEFT: Mykayla O’Brien rides with Team Alpha-1 during the annual October “Escape to the Cape” bike trek on Cape Cod, Massachusetts. ● Peg Iverson and Tom Corron enjoy the “Get the Scoop on Alpha-1” fundraiser in Des Moines, IA. ● A group called “The Plastic Instruments” performs in the “Rock on for a Cure” band competition and fundraiser in Miami, FL.
Financial Statements

Statement of Financial Position
YEAR ENDED JUNE 30, 2010

Assets

Current Assets
- Cash (includes $130,214 and $127,129, respectively, which has been restricted by the donor) $451,385 $739,228
- Marketable securities 4,546,573 3,551,522
- Accounts receivable 374,667 698,806
- Due from COPD Foundation 44,371 25,695
- Due from TAP 13,985
- Other assets 10,042 75,811
Total current assets 5,441,023 5,091,062

- Marketable securities – non-current 3,565,779 2,284,961
- Investment in TAP 250,000
- Property and equipment, net 46,851 55,327
- Other assets 19,521 19,495
Total assets $9,323,174 $7,450,845

Liabilities and Net Assets

Current Liabilities
- Accounts payable and accrued expenses $954,700 $1,134,051
- Deferred revenue 45,248 7,906
Total current liabilities 999,948 1,141,957

Net Assets
- Unrestricted 5,365,256 2,839,184
- Temporarily restricted 2,957,970 3,469,704
Total net assets 8,323,226 6,308,888

Total liabilities and net assets $9,323,174 $7,450,845

Gross Revenues by Classification
FOR THE FISCAL YEAR ENDED JUNE 30, 2010

Unrestricted Contributions $1,516,704 13%
Restricted Contributions $1,878,795 26%
Other Income $975,051 13%
AlphaNet $2,830,000 40%
TOTAL: $7,182,550

Functional Expenses
FOR THE FISCAL YEAR ENDED JUNE 30, 2010

Research & Detection $3,386,838 66%
Advocacy $174,375 3%
Other Programs $487,205 9%
Administration $443,824 9%
Fund Raising $675,970 13%
TOTAL: $5,168,212
## Statement of Activities and Changes in Net Assets

**YEAR ENDED JUNE 30, 2010**

### Changes in Unrestricted Net Assets

#### Unrestricted Support and Revenue

<table>
<thead>
<tr>
<th>Description</th>
<th>2010</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>$3,333,504</td>
<td>$3,676,773</td>
</tr>
<tr>
<td>Donated Shares</td>
<td>1,013,200</td>
<td></td>
</tr>
<tr>
<td>Fund raising revenues</td>
<td>352,017</td>
<td>368,151</td>
</tr>
<tr>
<td>Investment income (loss)</td>
<td>350,430</td>
<td>(373,823)</td>
</tr>
<tr>
<td>Other income</td>
<td>254,604</td>
<td>264,310</td>
</tr>
<tr>
<td>Net assets released from restriction — satisfaction of program restrictions</td>
<td>2,390,529</td>
<td>2,309,655</td>
</tr>
<tr>
<td><strong>Total unrestricted support and revenue</strong></td>
<td><strong>7,694,284</strong></td>
<td><strong>6,245,066</strong></td>
</tr>
</tbody>
</table>

### Unrestricted Expenses

<table>
<thead>
<tr>
<th>Program services</th>
<th>2010</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Alpha-1 Research Network</strong></td>
<td>2,511,150</td>
<td>2,471,802</td>
</tr>
<tr>
<td><strong>Florida Detection Program</strong></td>
<td>333,168</td>
<td>333,684</td>
</tr>
<tr>
<td><strong>Alpha-1 Registry and ACT Trial</strong></td>
<td>247,265</td>
<td>286,765</td>
</tr>
<tr>
<td><strong>PFT Study</strong></td>
<td>230,000</td>
<td>562,374</td>
</tr>
<tr>
<td><strong>Alpha-1 Advocacy</strong></td>
<td>174,375</td>
<td>191,038</td>
</tr>
<tr>
<td><strong>Other Alpha-1 Services</strong></td>
<td>552,460</td>
<td>643,267</td>
</tr>
<tr>
<td><strong>Total program services</strong></td>
<td><strong>4,048,418</strong></td>
<td><strong>4,488,930</strong></td>
</tr>
<tr>
<td><strong>Supporting services</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Administration and general</td>
<td>443,824</td>
<td>515,538</td>
</tr>
<tr>
<td>Fund raising</td>
<td>675,970</td>
<td>637,130</td>
</tr>
<tr>
<td><strong>Total supporting services</strong></td>
<td><strong>1,119,794</strong></td>
<td><strong>1,152,668</strong></td>
</tr>
<tr>
<td><strong>Total unrestricted expenses</strong></td>
<td><strong>5,168,212</strong></td>
<td><strong>5,641,598</strong></td>
</tr>
<tr>
<td><strong>Increase in unrestricted net assets</strong></td>
<td><strong>2,526,072</strong></td>
<td><strong>603,468</strong></td>
</tr>
</tbody>
</table>

### Changes in Temporarily Restricted Net Assets

<table>
<thead>
<tr>
<th>Description</th>
<th>2010</th>
<th>2009</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contributions, bequests and grant revenues</td>
<td>1,878,795</td>
<td>3,222,802</td>
</tr>
<tr>
<td>Net assets released from restriction</td>
<td>(2,390,529)</td>
<td>(2,309,655)</td>
</tr>
<tr>
<td><strong>(Decrease) increase in temporarily restricted net assets</strong></td>
<td>(511,734)</td>
<td>913,147</td>
</tr>
<tr>
<td><strong>Increase in net assets</strong></td>
<td>2,014,338</td>
<td>1,516,615</td>
</tr>
<tr>
<td><strong>Net assets, beginning of year</strong></td>
<td>6,308,888</td>
<td>4,792,273</td>
</tr>
<tr>
<td><strong>Net assets, end of year</strong></td>
<td><strong>$ 8,323,226</strong></td>
<td><strong>$ 6,308,888</strong></td>
</tr>
</tbody>
</table>
The Alpha-1 Foundation’s Grants and Awards Program continues to expand the scope, number and types of awards provided to qualified researchers.

**Peer Reviewed Research Portfolio for 2010**

Our 2010 Peer Reviewed Principal Investigators are:

**Tracy Adair-Kirk, Ph.D.**
- Effects of Oxidative Modifications on Elastic Fibers

**Jeffrey Atkinson, M.D.**
- Adverse Lung Consequences of the Human PiZ Protein

**Anna Blumental-Perry, Ph.D.**
- Cigarette smoke induced Endoplasmic Reticulum stress response in the pathogenesis of COPD

**Stephen Bottomley, Ph.D.**
- Small Molecule Inhibition of Z-Antitrypsin Polymerysation — A Potential Therapeutic Approach

**Michael Campos, M.D.**
- Improving COPD Diagnosis and AATD Testing in Primary Care

**Marilyn Coors, Ph.D.**
- Alpha-1 Genetic Testing at Risk Children and Adolescents

**N. Tony Eissa, M.D.**
- Interplay of Innate Immunity and Autophagy in Hepatocytes Expressing ZZ alpha-1 Mutant

**Symma Finn, Ph.D.**
- Quantifying Empowerment in Alpha-1 Antitrypsin Deficiency

**Terrence Flotte, M.D.**
- Gene Therapy for AAT Liver Disease Using RNAi
- 13th Annual Meeting of the American Society of Gene Therapy

**Marilyn Foreman, M.D.**
- Genetic Determinants of COPD in African Americans

**Maria Gaczynska, Ph.D.**
- Investigation of the Structure of Alpha-1 PI Polymers by AFM

**Cristy Gelling, Ph.D.**
- Alpha-1 Antitrypsin Z-Variant Degradation in Saccharomyces Cerevisiae

**Anne Gershenson, Ph.D.**
- Alpha-1 Antitrypsin Polymer Structure and Local Mobility

**Thomas Gildea, M.D.**
- Post Lung Transplant FEV1 Change in AAT Deficiency

**Catherine Greene, Ph.D.**
- Autoantibodies in Alpha-1 Antitrypsin Deficiency

**Nedim Hadzic, M.D.**
- Alpha-1 Foundation/Alpha-1 Awareness UK Research Award

**Craig Hersh, M.D.**
- Fine Mapping of a COPD Locus on Chromosome 19q

**Kristen Holm, Ph.D.**
- Illness Perceptions, the Social Environment, and AATD-Associated COPD

**Jeong Soo Hong, Ph.D.**
- Rhinovirus Mediated Immune Responses in Experimental COPD

**Anil Jain, M.D.**
- Using an EMR to Screen for and Diagnose AAT Deficiency

**Beena Krishnan, Ph.D.**
- Folding/Misfolding Landscape of Alpha-1 Antitrypsin

**Chen Liu, M.D., Ph.D.**
- Therapeutic Small Molecules for Alpha-1 Antitrypsin Deficiency

**Angelia Lockett, Ph.D.**
- ATS Travel Grant 2010 to present the abstract, “Effects of Alpha-1 antitrypsin (A1AT) on Pulmonary Endothelial Cell Responses of pro-inflammatory cytokines”

**Noel G. McElvaney, MB, BCh, BAO**
- Alpha-1 Antitrypsin Modulates Neutrophil Activity

**Gillian McNab, Ph.D.**
- ATS Travel Grant 2010 to present the abstract, “Prevention of polymerisation of murine “Z” α-1 Antitrypsin by Small Peptides”

**Shujuan Pan, Ph.D.**
- A miRNA-Binding Site SNP Associated with Early Onset of End Stage Liver Disease in ZZ Patients

**Anne-Karina Perl, Ph.D.**
- Role of EGF Receptor in Regenerating Airway Epithelium and Airway Thickening

**Robert M. Reed, M.D.**
- Cardio MRI in Screening for Pulmonary HTN Complicating COPD

**John G. Ryan, Dr.P.H.**
- Alpha-1 in Primary Care: Education and Screening in Community Practices

**Richard Sifers, Ph.D.**
- PI Z Polymer-Induced Re-Assignment of Degradation Route

**Eric Sjoberg, Ph.D.**
- Pharmacological Chaperones for AAT Deficiency

**Sihong Song, Ph.D.**
- Development of AAT Deficient Mouse Models

**Clifford Taggart, Ph.D.**
- Elastase Inactivation of SLPI in AAT Deficiency

**Jeffrey Teckman, M.D.**
- Analysis of Conformational Therapy In Vivo

**Rubin Tuder, M.D.**
- Pathogenetic role of the stress response gene RTP-801 in cigarette smoke induced alveolar inflammation and emphysema

**Shivraj S. Tyagi, Ph.D.**
- The Role of Bronchio-Alveolar Stem Cells in Cigarette Smoke-Related Emphysema

**Daniel J. Weiss, M.D., Ph.D.**
- Stem Cells and Cellular Therapies in Lung Biology and Lung Diseases Workshop

Our 2010 Program Grants Principal Investigators are:

**Mark Brantly, M.D.**
- Alpha-1 Coded Testing Study
- Alpha-1 DNA and Tissue Bank
- Alpha-1 State of Florida Detection Program

**Tony Eissa, M.D.**
- The Alpha-1 Research Program

**Dawn McGee, M.S.**
- Family Health History Project

**Robert Sandhaus, M.D., Ph.D.**
- Director, Alpha-1 Program, National Jewish Health

**Ronald Sokol, M.D.**
- Promoting Research of A1AT Deficiency Liver Disease through the Cholestatic Liver Disease Consortium (CLiC)

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- Alpha-1 Coded Testing Study
- Alpha-1 Research Registry
- Travel Monies for the Quantum-1 Study

**Adam Wanner, M.D.**
- Scientific Director, Alpha-1 Foundation
Needed: More Alphas for research studies

Many Alphas believe they are enrolled in the Research Registry — and they’re mistaken.

How can Alpha-1 be cured? How do scientists find new treatments or a cure for any disease? Sooner or later, they need patients — like people with Alpha-1 lung or liver disease. Scientists doing research on Alpha-1 need help from more Alphas. A lot more.

“The studies planned for the future will require many more Alpha-1 patients than we know are diagnosed in the United States,” says Charlie Strange, M.D., director of the Alpha-1 Foundation Research Registry. “The race toward a cure must involve us all.”

Without the active participation of Alphas, much of the research needed to develop new treatments and finally a cure for Alpha-1 will be impossible, Strange points out. The Research Registry is a confidential database of Alphas and Alpha-1 carriers. If a researcher needs volunteers with Alpha-1 to participate in clinical trials, surveys, or other scientific projects, the Registry is a vital resource. That’s why the Alpha-1 Foundation created the Registry and funds it.

How to Help with Alpha-1 Research

The Registry is maintained at the Medical University of South Carolina. For more information about the Registry program, visit the website, www.alphaoneregistry.org, email alphaone@musc.edu or call toll free at 1-877-886-2383.

Or if you feel comfortable that you know enough about the Registry and you’re ready to help with Alpha-1 research, you can enroll now at www.tinyurl.com/a1registry. By the way, many Alphas believe they are already enrolled in the Research Registry — and many of them are mistaken. You can find out with one quick call to the Registry at 1-877-886-2383.

After you’re enrolled, the Registry may well contact you about a research study that you might qualify for. The Registry never reveals your name or any personal information about you. It’s always your choice if you want to take part in a study or not.

Looking for an Alpha-1 drug around the world

Researchers from across the United States, and even opposite sides of the globe, are using Foundation grants to study small molecules, tiny compounds that could ultimately treat or even prevent both Alpha-1 lung and liver disease. Another researcher is testing whether Alpha-1 might be partly an autoimmune disease.

Stephen P. Bottomley, Ph.D., of Monash University, Australia, is studying small compounds that can bind to misfolded Alpha-1 “Z” proteins and prevent them from polymerizing, or linking together in long chains. The misfolded chains of Z protein get stuck in the liver cell where they are created, and cannot pass normally into the bloodstream. This is believed to be the underlying cause of both lung and liver disease in Alphas. Bottomley hopes to convert these small compounds into a potential drug for the treatment of Alpha-1.

Chen Liu, M.D., Ph.D., of the University of Florida is also using a Foundation grant to study different small molecules as a possible treatment.

Catherine M. Greene, Ph.D., of the Royal College of Surgeons in Ireland, suspects that Alpha-1 lung disease has an autoimmune component — in which the body attacks its own tissues. The lack of alpha-1 protein in the lungs allows neutrophils, the body’s own white blood cells, to damage lung proteins. These damaged proteins can lead the body to produce “autoantibodies,” which attack the damaged proteins as if they were foreign invaders. Greene is studying up to 16,000 autoantibodies to see how they affect the severity of Alpha-1 lung disease.
Honor Gallery

The Alpha-1 Foundation’s Honor Gallery salutes the individuals, corporations and foundations that share our commitment to advancing research, improving health, worldwide detection, and finding a cure for Alpha-1. The Foundation gratefully welcomes a number of new members who have supported our mission for the first time through their generous contributions.

The Foundation acknowledges the continued support of the many long-time donors who have invested in our mission through contributions, events and workplace giving. It is with sincere gratitude and appreciation that we recognize our Honor Gallery. The following is a list of donors who contributed $500 or more between July 1, 2009 and June 30, 2010.

$1 Million or More
AlphaNet, Inc.
Tulare County Medical Society
Robin Armstrong

$100,000-$999,999
Baxter Healthcare Corporation
Compuquip Technologies, Inc.

$20,000-$99,999
Firstgiving, Inc., USA – online giving website

$5,000-$19,999
Alpha-1 Association
Alpha Oties
American Express Company Matching Gifts Program

$1,000-$4,999
Ampogen Foundation
Amicus Therapeutics, Inc.
A.G. Andrikopoulos
AT&T

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$500-$999
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$100,000-$999,999
Baxter Healthcare Corporation
Compuquip Technologies, Inc.
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United Way of Greater Triangle
Joel C. Wolkott
Jo Ann and Michael L. Walker
Doris and Adam Wanner, M.D.
Frances L. Wiles
The Alpha-1 Foundation received donations in honor of the following individuals between July 1, 2009 and June 30, 2010.

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AlphaNet Coordinators
Alphas for Building Friends for a Cure
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Robin Ashmore
Charlotte S. and Robert C. Barrett
Michelle Heffey and John Barnby
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Jennifer Bauernfeind
Willma Mae and Bud Behner
Carole Benson
Kenneth E. Benson
Pam and Forrest Bird
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Beverly and Richard “Dick” Bueker
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Adriana Pereira, M.D. and Michael Campos, M.D.
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Alyce Yout
Wendy, Bill and Chelsea Zabel
Gene Zareck
Cindy and Joseph “Joe” Ziebar

**In Memory Of**

The Alpha-1 Foundation received donations in memory of the following individuals between July 1, 2009 and June 30, 2010.

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John Arthur Anderson
Fred Ashmore
Arlinda Baber
A. Edward Bain
Judith Crowell Bakula
Megan Ball
Carole Baumbrick
Susan “Suzie” Barbee
Carmen R. Barber
Amy E. Barrett

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Alpha-1 Foundation's programs focus on research, detection

The central goal of the Alpha-1 Foundation is research to improve the health of those with Alpha-1 Antitrypsin Deficiency and ultimately find a cure for Alpha-1. In addition, worldwide detection has always been a major part of our mission.

Those priorities are reflected in the two major new programs we unveiled in fiscal year 2010: The Alpha-1 Project (TAP) and It’s All in the Family.

The goal of TAP is to invest directly in promising new Alpha-1 therapies developed by biotechnology companies. (See page 3.)

It’s All in the Family is our program to help Alphas and Alpha-1 carriers encourage their families to consider testing for Alpha-1. With an easy-to-read brochure and web page, we’ve made it easy to talk about Alpha-1 and to get free and confidential testing through our Alpha-1 Coded Testing study.

These new programs were made possible by the research infrastructure built and funded by the Foundation:

The Alpha-1 Coded Testing (ACT) study provides free, confidential testing, administered through a research study that evaluates perceived risks and benefits of genetic testing. The study allows anyone at risk to learn their alpha-1 genotype. The ACT Study is conducted under the direction of Charlie Strange, M.D., at the Medical University of South Carolina. Anyone may apply online for testing at tiny.cc/actform. For information, call 1-877-886-2383.

The Alpha-1 Research Registry, also directed by Charlie Strange at the Medical University of South Carolina, is a confidential database of nearly 3,500 Alphas and Alpha-1 carriers. It is a resource for investigators seeking individuals with Alpha-1 to participate in clinical trials, surveys, and other scientific and medical activities.

The Alpha-1 Foundation DNA & Tissue Repository at the University of Florida has completed its enrollment. This is the central storage site for DNA and tissue samples from Alphas and others. Established in 2002, the repository has more than 2,300 members enrolled and is available for researchers worldwide to request medical information (the names of donors are not revealed) and samples for research projects.

The Targeted Detection Program promotes worldwide awareness among medical professionals, the media and public and the identification of Alphas in at-risk population groups. An important part of the Targeted Detection Program is the State of Florida Detection Program. This is collaboration between the State of Florida Department of Health and Human Services, the Alpha-1 Foundation and the University of Florida College of Medicine.

The Alpha-1 Clinical Resource Center Network has nearly 70 centers throughout North America that specialize in patient care and education for those with Alpha-1. Alphas and their physicians are encouraged to contact their regional Clinical Resource Center for information and guidance.

Scientific Meetings and Conferences — The Alpha-1 Foundation, Food and Drug Administration and the Department of Health and Human Services co-sponsored a workshop, “Improving Endpoints, Improving Care: Alpha-1 Antitrypsin Augmentation Therapy and Clinical Trials,” in 2009. The goal was to improve design of future clinical trials intended to establish clinical efficacy of Alpha-1 therapy. The workshop was part of the Foundation’s ongoing sponsorship of scientific meetings and conferences.

Publications — The lead story in the Fall, 2009 issue of Alpha-1, the Foundation’s magazine, told why the Foundation picked up the cost of the Quantum-1 Study after the National Heart, Lung and Blood Institute dropped funding. The study was designed to show that a CT scan is the best tool for measuring the progression of lung disease. The story noted that the Foundation’s decade of leadership on CT scan research had recently brought a victory: the Food and Drug Administration’s Blood Plasma Advisory Committee recommended the use of quantitative CT scans for future clinical trials.

Other Foundation publications include the Research Registry Update newsletter and educational brochures for Alphas, their families and healthcare providers.

Building Friends for a Cure — The goal of Building Friends for a Cure is to increase awareness and raise funds for research programs, ultimately leading to a cure for Alpha-1. Volunteers can help with special event planning, letter writing campaigns, and assisting in local, national and international social and sporting events. (See our cover and page 3.)

For a free subscription to Alpha-1 or information on any program, contact the Foundation toll-free at 1-888-825-7421 or visit www.alpha-1foundation.org.
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