On May 7, 2009 cardiac AL Amyloidosis was recognized by the Secretary of Veterans Affairs as having a “positive association between exposure to herbicide agents” this allowed cardiac AL amyloidosis to be established as a presumptive disease associated with 2,3,7,8-tetrachlorodibenzo-p-dioxin (TCDD) exposure. Below is a brief introduction to Agent Orange exposure and information on how Veterans may enroll to receive the benefits that they have earned.

* * * * * * *

Introduction

Between the years of 1962 and 1971 the United States Government dredged various parts of Vietnam, Cambodia, Laos, and South Korea with several herbicides intentioned to defoliate the countries' vegetation. By killing the plant life, the United States military was able to minimize guerrilla acts and deprive opposing forces of food. However, not enough testing was done on the potential negative effects of these herbicides and the scope of their deadly impact is still being unveiled today.

The most notorious of these herbicides is nicknamed, "Agent Orange" and was also the most widely used. The specific combination of the chemicals in Agent Orange produced an unforeseen by-product called 2,3,7,8-tetrachlorodibenzop-dioxin (TCDD). Dioxin TCDD is a pollutant and exposure to high levels of it has been linked to serious health conditions in many animal studies. As concerns about the harmful effects of Agent Orange began to arise, the United States Congress passed Public Law (PL) 102-4, The Agent Orange Act of 1991 in an effort to garner information on the health effects of the herbicides sprayed during the Vietnam War. The Law required that a comprehensive evaluation of scientific and medical research regarding Dioxin TCDD and Agent Orange exposure be completed every two years, with the findings updated and published every two years. It was not until 2006 that the committee charged with reviewing the scientific and medical publications on Agent Orange exposure, recognized an...
2013 Senior Research Grant Recipient
Ping Zhou, MD, PhD - Tufts Medical Center

**Off the shelf Lambda Light Chain Knockdown Therapy** - Despite the advances of stem-cell transplant and proteasome inhibitor therapy, systemic AL amyloidosis (AL) remains a lethal disease for patients who die of AL within 3 to 4 years of diagnosis, representing about half of newly diagnosed patients. We need to develop targeted therapies that directly and rapidly eliminate production of toxic amyloid-forming light chains in order to improve patient outcomes and survival. We will extend our work developing an off-the-shelf lambda light chain specific gene silencing agent that interferes directly, specifically and promptly with production of the protein that causes 80% of cases of AL - the lambda light chain protein. We have shown in plasma cells from patients with AL lambda type, that our agent markedly and rapidly reduces lambda light chain production. This grant will allow us to extend our pre-clinical study of this agent in an additional 20 patient specimens and in a mouse model.

2013 Junior Research Grant Recipient
Jennifer Ward, PhD - Boston Medical Center

**Tetracycline Analogs for Treatment of Amyloidosis** - Primary systemic AL (amyloid light chain) amyloidosis is caused by the light chain (LC) of an antibody that misfolds, aggregates and forms amyloid fibrils that deposit throughout the body. Targeting the plasma cells which produce antibodies with chemotherapy has been successful at stopping progression of disease but there still remains no approved therapy against the amyloid fibrils that remain in tissues. We have built upon studies with other amyloidogenic proteins to demonstrate that the tetracycline antibiotic doxycycline can disrupt light chain AL amyloidosis fibrils isolated from human tissue. We propose to treat transgenic mice with doxycycline to determine if doxycycline can break up the amyloid deposits and we will determine the time and dose needed. We will test if doxycycline treated fibrils are toxic to cardiac and renal cells. We believe that successful treatment of AL amyloidosis will be achieved using a combination of therapies targeting both the plasma cell and the fibrils themselves.
President’s Corner

For some 2012 has been a trying year: the loss of a loved one, a new diagnosis, or the reemergence of amyloidosis. Whatever your experience has been with the disease, I hope the Amyloidosis Foundation was able to provide you with the resources and support you needed.

2013 holds lots of promising developments for the amyloid community. Drugs for amyloidosis are in various stages of clinical trials, the Foundation awarded two new research grants, and our awareness and educational programs are rapidly expanding. Please know that none of these programs would be in existence without your generous help.

On behalf of all us here at the Amyloidosis Foundation I’d like to wish you and your family a happy new year!

Mary E. O’Donnell
President

Make Your Resolution!

Make your New Years resolution with the Amyloidosis Foundation! Now is the perfect time to incorporate the Foundation into your yearly planning and as a part of your life! Whether it be volunteering at a Foundation event, donating a silent auction item, joining a committee, participating in our involvement program or even “liking” our Facebook page and providing newsletter feedback - We value our community and want to stay in touch with you!

Support Group Spotlight

Tennessee Support Group
Date & Time: February 20, 2013 from 3:00pm to 5:30pm
Location: Vanderbilt Clinic of The Vanderbilt University Medical Center
Room: 2703
The Tennessee support group meets monthly in The Vanderbilt Clinic on both Wednesdays and Saturdays
Coordinator: Charlotte Haffner
For more information email: info@amyloidosis.org

Support Group Spotlight

Northern California Support Group
Date & Time: February 2, 2013 from 10am to 2pm
Location: Kaiser, Walnut Creek 1425 South Main Street
Room: Oak 1 & Oak 2
Speaker: The Binding Site has updated information on FLCs and may be able to join us.
Coordinator: Dena Heath
For more information email: info@amyloidosis.org

Providing our patients and their families with the support they need is very important to the Foundation. The expansion of our support group program is one of the ways that we are working to meet this need. Please contact the Foundation to learn more about our support groups or express interest in coordinating the formation of a new one.

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Mary E. O’Donnell
President
Agent Orange

association with AL amyloidosis and the pollutant.

**Association**

The Department of Veteran Affairs considers AL amyloidosis to be a presumptive condition associated with Agent Orange exposure. When a disease is considered to be presumptive that means that it was expected to develop under normal conditions. As it applies to the VA: there are certain diseases that are accepted as to have resulted from a veteran’s service - should they meet the time and location criteria.

The *Veterans and Agent Orange: Update 2010* lists AL amyloidosis as a non-neoplastic health condition and places it in the same chapter as multiple myeloma due to the commonalities between the two diseases. The Update 2010 states that both conditions, "share several biological features, most notably clonal hyperproliferation of B-cell-derived plasma cells and production of abnormal amounts of immunoglobulins" (*Institute of Medicine*, p.409). It is through these commonalities - and the difficult to explain statistic that 10% to 15% of multiple myeloma patients also have AL amyloidosis; though there is currently little research to pinpoint exactly what the specific correlation is - that has allowed veterans who suffer from AL amyloidosis to receive benefits and compensation. This presumptive consideration allows for a Veteran not to have to prove an explicit connection between their AL amyloidosis and military service. Due to the presumptive service connection, the VA assumes that a relationship between AL amyloidosis and Agent Orange exposure exists based on other qualifying criteria such as dates of service and location.

**Compensation & Benefits**

Although AL amyloidosis is presumptive, a Veteran must still submit a claim to receive consideration for disability compensation. Eligible veterans may receive the following benefits:

1. **Agent Orange Registry Health Exam** - is free and voluntary to Veterans who have been exposed to Agent Orange.
2. **Health Care Benefits** - encompassing a full range of services (must first enroll in VA's healthcare system)
3. **Disability Compensation** - monthly payments for service-connected or service-related conditions.
4. **Dependents’ Benefits** - children of Vietnam Veteran’s who have suffered birth defects may be eligible for healthcare, monetary compensation or vocational training.

3. **Survivors’ Benefits** - spouses, children and dependent parents may be eligible to receive benefits following the death of a Veteran.

It is important to note that each claim is assessed individually and there are many factors that are considered when providing Veterans with the benefits and services that they have earned.

**How to Submit a Claim**

The VA has now streamlined the process of submitting claims by allowing for their processing to be done online. This new approach has allowed for the VA to dramatically decrease its turn-around time and award compensation in a more efficient manner. The following page lists a detailed account of helpful resources and contact information for veterans interested in filing a claim to receive the benefits and services earned in selfless service to the United States.
Open Clinical Trials

The list of clinical trials that are currently accepting patients is not limited to the ones listed, in fact there are over twenty open clinical trials for amyloidosis around the world. The Foundation does not support one clinical trial over another but does adamantly advocate for patient participation in clinical trials. A sustained and enhanced clinical research effort is what will be behind any medical progress in amyloidosis. More information on other clinical trials and their locations can be provided by contacting the Foundation or visiting www.clinicaltrials.gov.

Drug or Name of Study: Bendamustine and Dexamethasone in Patients With Relapsed AL Amyloidosis; Phase II
Sponsor: Columbia University
Collaborator: Cephalon
Principal Investigator: Suzanne Lentzsch, MD
Location: Columbia University (more locations will open soon)

Drug or Name of Study: Study of Oral MLN9708 in Adult Patients With Relapsed or Refractory Light Chain Amyloidosis
Sponsor: Millennium Pharmaceuticals, Inc.
Location: Various locations within the United States and Internationally

*Coming Soon*
Drug or Name of Study: Carfilzomib
Principal Investigator: Adam Cohen, MD
Location: Fox Chase Cancer Center, Philadelphia, PA (more locations to come)
Reflections on the 6th Annual New York Benefit  By Charlotte Haffner

September 26th 2012 my dear friend Beverly Murray and myself boarded a plane for New York City. We were going to help support the Amyloidosis Foundation at the 6th annual New York City Benefit for the Amyloidosis Foundation. Beverly had never been to New York before so I really wanted this trip to be a lot of fun for her. Shortly after we arrived I called Uria Espanoza, who is not only the chairwoman of the NYC Benefit but also the Secretary of the Amyloidosis Foundation's board of directors, to let her know that we had landed safely. Uria suggested that we meet downtown for dinner - she was just as nice as I thought she would be! Over dinner, she asked me to say a few words about my experience with amyloidosis and how it took so long to get the correct diagnosis. I expressed how thankful I was to have met Dr. Doug Sawyer, chief of the Division of Cardiovascular Medicine at Vanderbilt. Dr. Sawyer had just come to Vanderbilt from Boston where he had been involved in a 10 year study of amyloidosis. Things have really worked out well for me, but more often it does not. My goal now is to become an advocate for education and research for this terrible disease; of which there is no known cause and no known cure. We must all work together, patients and doctors. Amyloidosis is a terrible and personal disease that effects everyone in a different way. Education is the key to early diagnosis, improved treatments and a higher quality of life for amyloidosis patients. I would like to offer many thanks to the wonderful doctors I have, and to the wonderful ones I have met. You make a difference. AF
Joe LaGuardia will always be remembered as a passionately driven pioneer and dedicated community member who elevated the stature of the New York State Fair to unprecedented heights; known now as “The House that Joe Built”.

Please join us for our 1st Annual “Joe LaGuardia” Amyloidosis Foundation 5K Run/Walk to be held in Syracuse, New York at the Syracuse “Inner Harbor” on May 14, 2013. (the first anniversary of Joe’s passing from this dreaded disease). The purpose of this fundraising event is to raise awareness of this rare disease and to raise money for research so that a cure can be found.

Before Joe was diagnosed with Amyloidosis in November of 2011, he had retired as Executive Director of Lakefront Development Corporation. One of Joe’s responsibilities with Lakefront was to oversee the activities that took place at the “Inner Harbor”. Joe loved his position at Lakefront and was passionate about how this area would help in the growth and development of Syracuse and the community in which he lived and grew up. Joe was a respected leader in the New York State Fair and Entertainment Industry. Joe has earned honors and recognition by The Entertainment Buyers Association, The Academy of Country Music and The International Association of Fairs and Expositions where he received the highest honor in the industry when he became a Certified Fair Executive in 1994. Joe was very active and generously devoted his time to many community organizations such as, The Syracuse Sports Hall of Fame, The Syracuse Sports Corporation, The Central NY Arthritis Foundation, Elmcrest Childrens Center, The Syracuse Convention and Business Bureau, The Syracuse Chiefs and many others. The center of Joe’s universe was his family. Joe was the greatest husband, father, papa and friend. Again, this event will take place on May 14th, 2013 - the first anniversary of Joe’s death and will have a donation fee of $35. There will be a live band, activities, food and of course, fun. But most of all, you will be able to help raise awareness of AMYLOIDOSIS and the research efforts into this deadly disease. In the Syracuse area, there are a number of people fighting this disease as well as those who have fought bravely to survive and did not. So we ask all to walk, run, and support our efforts in the research of AMYLOIDOSIS. Information regarding the upcoming Run/Walk can be found www.josephlaguardia.com and also the Amyloidosis Foundation website. Please sign up there and educate yourself on this disease. We look forward to meeting new faces. AF

Date: May 14, 2013
Registration: 4:00pm
Race Start: 5:30pm
Location: Inner Harbor- Syracuse, New York
Website: www.josephlaguardia.com
Contact: joelaguardia-benefit@gmail.com

Joe reads with his grandchildren, Giada and Anthony
The Amyloidosis Foundation’s 2013 Metro-Detroit Spring Benefit

The Amyloidosis Foundation will be hosting a benefit for the amyloidosis community in the metro-Detroit area on May 2nd, 2013. Several physicians and prominent members of the amyloid community will be in attendance to support the first-ever Foundation benefit in the Detroit region. The benefit will include dinner, music, door prizes and silent auction. The theme will focus on the healing power of art. Many of the silent auction items will be pieces of artwork created by patient artists. If you would like to donate a piece of artwork or other silent auction item, participate on the benefit’s planning committee, or attend the event please contact the Foundation. As details of the benefit become finalized invitations will be circulated. We hope to see you there! AF

We Need Your Support!

“What individual commitment to a group effort — that is what makes a team work, a company work, a society work, a civilization work”, Vince Lombardi.

It is the individual commitment of our donors and supporters to the Amyloidosis Foundation that allows us to provide our many services: ranging from patient support to research grants to education of the medical community.

It is because of your generosity that we are able to continue to work towards finding a cure.

What Did You Think?

The Amyloidosis Foundation welcomes your feedback! We are always looking for letters, articles or any suggestions that you may have to make this publication better!

If you have something that you would like to share with the Amyloidosis Foundation community, please contact us at info@amyloidosis.org

We look forward to hearing from you!